

THEORY, TECHNOLOGY AND SOCIETY



Eventful Bodies

The Cosmopolitics of Illness

Michael Schillmeier



EVENTFUL BODIES

In the impressively scholarly and original Eventful Bodies, Michael Schillmeier brilliantly fashions a “cosmopolitics of illness”. Taking dementia, stroke and SARS as his case studies, Schillmeier not only reformulates our understandings of health and illness, but also interrogates the very foundations of social theory. This book is essential reading for anyone interested in the processuality, complexity and heterogeneity of contemporary society.

Mike Michael, University of Sydney, Australia

This is a beautiful book. It focuses on dementia, stroke and SARS and how they unbutton not just bodies and selves, but also social relations and the forms of order that underpin them. From this perspective of illness as a cosmopolitical event, Schillmeier offers us a profound new approach for theorizing and researching medicine, health and illness that keeps people centre stage. Drawing together the empirical, the political and the existential, Eventful Bodies also proposes a new, activist and caring sociology.

Joanna Latimer, Cardiff School of Social Sciences, UK

Bodies may indeed be everywhere in contemporary social theory, but rarely are they articulated with such feeling and conceptual rigour as in this beautiful and insightful book. The cosmopolitical approach to bodies under challenge that Schillmeier develops here looks certain to set the agenda for social approaches to embodiment for some time to come.

Steven D. Brown, University of Leicester, UK

If you ever wondered what cosmopolitical research would look like, you need to read this book. Michael Schillmeier carries out a brilliant exercise in making accessible and practical the thought of philosophers such as Heidegger, Whitehead, Deleuze or Stengers in order to offer a splendid and novel analysis of the societal issues of health and illness beyond the dominant deficit model.

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Eventful Bodies

The Cosmopolitics of Illness

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Contents

<i>Acknowledgements</i>	<i>vii</i>
Introduction	1
1 Forgetting Bodies	7
Enacting a ‘National Crisis’ – Twenty-first Century Biopolitics of Dementia	7
Symbolic Biopolitics	10
Technologies of Reason and Truth	11
Wise Communities – Extitutionalizing Health Care	13
The Collective Denial of Dementia and the History of Madness	15
Dementia and the Negativity of Reason	16
Disorganized Life and Madness	18
Traitement Moral	18
The Fiction of Common Sense	21
Inconsistent und Incoherent – The Trouble with Dementia	23
Linked but Divided – Biopolitics, Advocacy Groups and Social Sciences	25
Politics? What politics?	27
The Cosmopolitanism of Health	29
The Cosmopolitics of Dementia	35
Lacking Rationality, Lacking Reality?	37
Knowing and Not-knowing	38
Resisting Unwillingly and Dementia Publics	39
Power/Non-knowledge – The Agency of Not-knowing	40
Rethinking Common Sense	41
Conceptual Persona	43
Affective Relations and Experience as Assembling Feelings	44
Experience and Society: The Person as an On-going Collective Achievement	48
From Recognition to Re-cognition	53
Time Lost, Time Regained	55
Remembering as Presencing	57
‘The Day that got lost in a Handbag’	61
In Search for Anhaltspunkte – Having, Binding and Keeping	64

	Actor-Networks of Dementia	67
	‘What is at Hand’? The Presence of Absence	73
	Shackling and Un-shackling Relations	80
	Nothing but ‘Accomplished Facts’ – The Lure of Dementia	82
	Actor-Networks of Angst	84
	The Force of Silence – Conscience, Guilt and Care	89
	Situated Non-knowledge	93
	The Social: A Matter of Care	97
2	Stroked Bodies	103
	Making Partial Connections	103
	Incapacitating Connections	105
	Re/Generating Materials and Cosmopolitical Research	107
	Disruptions/Decisions	108
	Becoming a Half-sided Body	109
	Living away from Home	112
	Mornings in the Ward	114
	Lifters	115
	Normalization	116
	Rationalization	118
	Moralization	119
	Caring Relations	120
3	Infectious Bodies	125
	Emergency Situations	125
	The Cosmopolitical Epoch and the Precariousness of Living Societies	133
	Relational Becomings	139
	Experiencing the Unknown	142
	Fighting the Virulence of the Virtual Enemy – Enhanced Surveillance, Control and Isolation	145
	Networking Medical Practice	147
	Translating Networks of Risks	151
	Re-thinking Societies, Re-thinking Illness	156
	Conclusion: The Social as Event	161
	<i>References</i>	<i>165</i>
	<i>Index</i>	<i>185</i>

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For

Daniel, Jan and Jeff

Artists of Life

Introduction

Eventful Bodies tackles the general observation that in the course of life *events* may occur that unbutton the world taken as ‘normal’ and in consequence disrupt, question, endanger, and alter common and taken-for-granted social relations. In particular, this book is about incisive bodily occasions that unravel the manifold experiences of illness. Illness is an inextricable and thus ‘normal’ part in the course of our life. We may say that the risk of becoming ill is intrinsic to healthy bodies. Still, the experience of illness alters the various ways we are used and (are) expect(ed) to do things, how we feel, perceive, act and interact with others and our environment. Bodies affected by illness are not mere bio-medical facts of a disease, but *affect* the personal orderings of human beings as well as their social world (cf. Canguilhem 1991). The experiences of illness trouble the practices and relations of our embodied life, the more so if these illnesses are life threatening, infectious and/or resist to be curable. Bodily events as different as for instance a serious stroke, a severe viral infection or dementia thoroughly affect individuals and their life-world. In the event of life-threatening contagious diseases it is not only the experience of illness itself, but also the mere *risk* of a possible infection, which may dramatically change personal life and human organization on a global scale.

These bodily events may happen every day but they are not everyday events. Rather, they are unforeseen, exceptional and encroach on the course of everyday life practices. They can be understood as *cosmopolitical events* since the ‘cosmos’ of social realities before and after such bodily events differs significantly. By cutting into and questioning the commonality of the embodied human social being, these affected bodily relations draw attention to the different ways in which normalcy is remembered, maintained and expected. Hence, cosmopolitical events unbutton social normalcy *and* realize it not as naturally given, but as vulnerable to uncertainty, contingency and change (cf. Schillmeier 2011). These processes unfold the realities of eventful bodies enacted by *the cosmopolitics of illness*.

The *cosmopolitics of illness* introduce unsettlement, pain and suffering. However, these bodily events and their effects do not refer to merely deficient modes of life, but initiate and require *new* modes of embodied social existence. Ill bodies are not simply bodies deprived of normality, but irritate, upset, and trouble what is lived and thus experienced *as* normal. Hence, the *cosmopolitics of illness* makes us aware of the normativity of embodied social relations and alludes to the processes and practices that configure ‘normal bodies’. Consequently, the *cosmopolitics of illness* not only visualizes the unsettlement of embodied human life, but also offers insights into the complex and powerful practices of *normalizing* embodied human relations.

Since the ill person *does not* speak for the majority, the normal(ized), the taken-for-granted reality, s/he tackles issues of the excluded, of minorities, the endangered, the unexpected, and so on. The experience of illness troubles the plugged-in normalities and normativities of social consensus and fosters a *cosmopolitical ethos* that cares for difference and diversity. The onset of Alzheimer's Disease (AD), for instance, radically re-shapes selves, re-orders social relations, living experiences and the meaning that can be given to them. The effects of a severe stroke can also dramatically transform the lived social normalcy, its modes of articulation and interaction. Both events not only utterly question the sense of feeling at home with oneself and one's environment, but also require novel social relations between them. Dementing and stroked bodies introduce and require the re-ordering of social relations. We also know from the history of contagious diseases like for instance SARS (Severe and Acute Respiratory Syndrome) that it is not only the actual experience of illness, but already the risk posed by a possible global pandemic endangerment of human life, which dramatically reconfigures social interaction of everyday life, disrupts the different public health systems, affects national and transnational economies, provokes political conflicts and activism, challenges scientific knowledge and so on. In all three cases, what has been taken-for-granted is radically challenged by the onset of the effects of the event.

This book also challenges the bio-medical model of illness as a deficit and emphasizes instead the contingent and highly situated ways of how the cosmopolitics of eventful bodies *interrogate and change* social reality. In that sense, ill bodies are *political agents* in the diverse ways their orderings disrupt, question, alter and even endanger the normativities of 'healthy' bodies, their practices and relations. The case of infectious disease also highlights the agency of non-human others (virus, bacteria). These actors – human and non-human alike – gain agency by unknotting, questioning and altering 'the normal' as a highly normative construct of situated power relations, be they bio-molecular, inter-personal or between humans and non-humans.

The *cosmopolitics of illness*, so my argument claims, contests the modernist idea that politics is merely the affair of healthy and rational human beings. The experiences of illness complicate the understanding of classical politics, its eligible actors and recognized practices. Hence, this book outlines a novel empirical *agenda and conceptual space* for social research that not only includes those that have been excluded, marginalized, forgotten, ignored, or disfigured in the process of normalizing socio-political action, but also those ruled out by mainstream sociology as relevant (political) actors. Rethinking politics in this way aims to challenge the cognitive bias of the sociological discourse and opens the debate on politics by addressing the somatic, material and affective dimension and the diversity of relevant actors and agency formations. The *cosmopolitics of illness* is about controversies incited by eventful bodies and heterogeneous actors (human and non-human alike) and not about homogenizing and finalizing agency as the property of healthy and rational humans. Clearly, to give agency to seriously

ill people does not intend to romanticize their conditions, nor does the inclusion of non-human actors like viruses mean to anthropomorphize non-human entities. Rather, it intends to free them from the stigma of passivity and/or negativity.

* * *

This book documents my on-going and wider interest in analyzing cosmopolitical events and the social (Schillmeier 2009c, 2010, 2011, 2013a, 2013b). As a contribution to a *cosmopolitical* research agenda, the analysis of cosmopolitical events tries to trace as well as to resist the normal and taken-for-granted of social relations. A cosmopolitical research agenda addresses the issue that social research easily can ‘lack the resistance to the present [*Realität*]’ as Deleuze and Guattari have put it (Deleuze and Guattari 1994: 108). If social sciences lack to resist to the present, the analyzed reality becomes a *function of the experienced* [*fonction du vécu*] that treats the present as a stabilized and uncontested matter of fact. Sociologists know very well how difficult it is to trace the taken-for-granted of social reality and related practices. To make the latter visible, Harold Garfinkel argues, the researcher ‘must either be a stranger to the “life as usual” character of everyday scenes, or become estranged from them’ (Garfinkel 1967: 37). In other words, the researcher must be able to experience the differences introduced by the field of research, which apparently is a risky encounter, since the field of research and its actors may trouble the researcher’s ‘cosmos’ of questions, prejudices, ideas and concepts about them (Stengers 2000, 2010, 2011a,b). On the other hand, the conceptual rigour depends on how everyday practices do become visible and how the actors involved achieve them. Thus to accomplish both, social research needs a certain distance between researcher and researched in order to make a difference with social research. Only then, the highly situated empirical complexity becomes visible and the desire for conceptual rigour and adequate description can be achieved, reflecting on its own term the processes and doings that assemble the ‘normalcy’ of social situations.

Obviously, the proposed distance between researcher and researched should not be conflated with the idea of dis-interested, rationalized or standardized forms of collecting statistical, ‘representative’ data, for instance of disease patterns. Rather, the analysis of the *cosmopolitics of illness* offers a contrast to the discourse of representation and its methodical means of providing general knowledge about issues of health and illness. To do so, this book draws on the experiences and practices and thus *eventful* character of social orderings as they become visible when embodied human life significantly changes with either the actual experience of illness or the risk of becoming seriously ill. In such a reading, the experience of dementia, a serious stroke or a life-threatening infectious disease, and not its representation, *breaches* the general norms of health and related practices. It introduces novel norms of illness instead that have to be accounted for in a pragmatic sense – empirically and conceptually. Consequently, *Eventful Bodies* tries to relate rigorous empirical research on how social relations come into

being with the philosophical creation of ideas about it. *Eventful Bodies* outlines a non-representational reading of health and illness. It is precisely the analysis of *events* which emphasize the reality of processes and practices that unravel the possibilities of social orderings and not the theoretical representation or mere opinion of it (Garfinkel 1967: 36). Clearly, then, social research is not an innocent endeavour and is ‘always, and unavoidably, an intervention in the world in which all those (humans and nonhumans) enjoined in it can, and do, affect each other’ (Whatmore 2003: 90).

Eventful Bodies is nurtured and driven by the question concerning the possibility of an *ethos* of social scientific research that achieves the double bind of tracing and resisting the normal, the average, the *sens commun* as the good sense, and the normalcy of conventions. Moreover, *Eventful Bodies* is sought to contribute to a novel understanding of societal issues of health and illness beyond the hiatus of social and medical models that have been dominating the modern discourse, related practices and imaginaries.

* * *

Chapter 1, *Forgetting Bodies*, aims to offer a critical and contrasting reading of the modern history of a mere biopolitical and/or biomedical understanding of dementia and its governing basic principles of reason and rational thought. For the latter, dementia is not only understood as a severe cognitive deficiency with wide-spreading and primarily negative personal, inter-personal and societal effects, but also as a condition that defies human (political) agency due to the loss or lack of cognitive abilities and knowledge. In contrast to the cognitivist framing of human (political) agency, I outline – conceptually and empirically – the *cosmopolitical* power of dementia, which in the moment of uncertainty and not-knowing politicizes the cosmos of modern politics understood as the realm where human rational thought, reflection and expression meet. Dementia *affects* our taken-for-granted personal and social life. This is precisely why it is such an emotionally intensive and demanding experience. People living with dementia as well as their partners, families and caring others not only experience the emotional impact that is related to the loss of cognitive abilities. It is also brings to the fore the importance of affective relations. Consequently, the *cosmopolitics of dementia* draws upon fragile relations in the making that cannot be delegated to the mind, but emphasizes processes of affectivity in building social worlds. *Eventful Bodies* offers an in-depth socio-philosophical discussion of affective relations and the process of experience in order to rethink the empirical complexity of dementia as more than the negative effects of a cognitive impairment.

Obviously, there are many forms of dementia with diverse effects (cf. Alzheimer’s Society 2012b), which cannot be systematically discussed in this chapter. Accordingly, Chapter 1 only reflects upon some of the specificities of dementia and how it affects the social normalcy and our understanding of it. Focusing on Alzheimer’s Disease, I will explore the emerging effects when

the taken-for-granted modes of social and personal life are severely disrupted, changed and altered in the moment the process of forgetting is starting to replace the process of remembering. *Forgetting Bodies* addresses what it means to *live in* dementia as well as *to care about* the dementing person. This is done by an in-depth analysis of selected parts of Marion Kainz's ethnographic film '*The day that got lost in a handbag* [*Der Tag der in der Handtasche verschwand*]'. The film provides subtle as well as intensive insights into the life of Mrs M, an elderly woman with Alzheimer's who lives in a long-time care facility somewhere in Germany.

In Chapter 2, *Stroked Bodies*, I explore the relation between ageing bodies, illness, technologies and care. Drawing on ethnographic work, I retrace the story of a male person, Mr B, who has suffered two strokes in a period of ten years. *Stroked Bodies* explores how the *effects* of these bodily events thoroughly reshape Mr B's personal and social life and how he eventually moves from his home to a nursing home. Contrasting a mere deficit model of ageing and illness, I analyze how emerging relations of human bodies and things assemble the shifting situations of good and bad practices, i.e. situated collective achievements that create *extensions of care* to feel at home *in* or not. These achievements are collective since not only bodies are eventful entities in the ways they relate, but also technologies (Braun and Whatmore 2010). Challenging a deterministic model of technologies, Chapter 2 explores how assistive technologies contribute not only to the indeterminateness of good or bad practices in constant care, but also draw our attention on the situated and often conflicting requirements of caring as they emerge with eventful bodies and the cosmopolitics of illness. I argue that good caring practices demand meticulous attention to the emerging specificities that often enact *relations of hesitation* which put into question the requirements of good care in practice. Care practices can easily turn into non-caring relations when fixed and generalized packages of care are delivered, which necessarily exclude and/or are indifferent to the situated concerns that connect ill bodies with others in 'good health' in more or less fragile, risky and unforeseeable ways.

The concluding Chapter, *Infectious Bodies*, shifts the focus from bodies that have already experienced the event of a serious illness towards *the risk* of contracting a life-threatening illness and the cosmopolitics involved. By analyzing the infectious event of SARS, which emerged 2002 in South China as an atypical pneumonia and quickly migrated along international air-traffic, I will discuss how emerging *nonhuman* entities like a virus gain agency and contribute to the *cosmopolitics of eventful bodies*. I will argue that contagious diseases like SARS are social processes which link heterogeneous entities (human and nonhuman) and thereby create their very conditions of possibilities, which in the case of SARS involved the possibility of novel viral life as well as human illness and death.

Infectious Bodies re-traces the emergence of a virus which crossed the xenographic barrier from animals to humans and discusses its relevance for social research. The social and political world of humans met a radically new agent that did not fit the traditional outlook of a socio-political actor, who is supposed

to be a rational human being or likewise a social organization, but not in any case a disseminating virus. While SARS quickly became a global media event, the world encountered the daunting risk of a silent and invisible, but nevertheless extremely versatile and life-threatening agent. For a short but nevertheless dramatic period of time SARS delegated its power to the uncertainties of a thoroughly unknown contagious disease. Re-assorting global and local concerns, SARS enacted emergency situations governed by vague knowledge and knowledge practices. The emergence of SARS provoked existential anxieties, challenged public health care systems, unleashed global scientific networks and controversies, triggered off rigid practices of surveillance and control which in turn provoked social conflicts, ethical and legal concerns, blended local, national and transnational politics.

Concluding, I examine the relevance of a social understanding of illness for an ethos that is concerned with and cares for the differences and uncertainties of life as an on-going collective accomplishment.

Chapter 1

Forgetting Bodies

Enacting a ‘National Crisis’ – Twenty-first Century Biopolitics of Dementia

Where have I been? Where am I? Fair daylight?
I am mightily abused. I should ev’n die with pity,
To see another thus. I know not what to say.
I will not swear these are my hands: let’s see;
I feel this pinprick. Would I were assured
Of my condition.
[...]
I am a very foolish fond old man,
Fourscore and upward, not an hour more nor less;
And, to deal plainly,
I fear I am not in my perfect mind.
Methinks I should know you, and know this man;
Yet I am doubtful for I am mainly ignorant
What place this is; and all the skill I have
Remembers not these garments; nor I know not
Where I did lodge last night ... (...) Am I in France?

(King Lear in Shakespeare’s *King Lear* IV, Scene 7)

King Lear’s experience in Shakespeare’s tragedy tackles what should become a most challenging bodily event of twenty-first century aging societies: Dementia (cf. Alzheimer’s Society 2012a). Clearly, dementia is not a new phenomenon at all, but probably ‘as old as mankind itself’ (Boller and Forbes 1998: 125). Nevertheless, dementia not only remains poorly understood, but it continues to be an existential personal fear for many of us (Corner and Bond 2004) and is thought to be/come a substantial societal problem. In 2012, more than 400 years after Shakespeare’s *King Lear*, the British conservative Prime Minister David Cameron labelled dementia a ‘national crisis’ that demands ‘an all-out fight-back [...] that cuts across society’ (Cameron in Alzheimer’s Society 2012a). Dementia not only has a ‘devastating impact on the people who develop it, and the families who care for them’ as the former Secretary of State for Health, Alan Johnson (Labour Party) has put it, but – like a contagious disease – dementia troubles, infects and contaminates central societal institutions (Johnson in Department of Health 2009). Dementia, so Cameron says, as

[o]ne of the greatest challenges of our time is what I'd call the quiet crisis, one that steals lives and tears at the hearts of families, but that – relative to its impact – is hardly acknowledged. [...] [Dementia] is simply a terrible disease. And it is a scandal that we as a country haven't kept pace with it. [...] The level of diagnosis, the level of understanding and the level of awareness of dementia is shockingly low. It is as though we've been in a sort of collective denial. Already a quarter, one quarter of hospital beds are occupied by someone with dementia. Already the total cost of the disease is around £19 billion in England alone. That is higher than the cost of cancer, heart disease or stroke. And in less than ten years, as we all live longer lives, the number of people with dementia will reach a million (Alzheimer's Society 2012a). 'Dementia', he states elsewhere, 'we as a society simply cannot afford to ignore any longer'. (Department of Health 2012: 3)

For Politics,¹ dementia is both a personal and societal pathology of epidemic character. The collective denial has been fostering the contagious forces to spread its devastating effects unleashing thereby an on-going national crisis. To coat the belated political recognition of dementia as an *ignored societal* problem – and not a merely *personal and family tragedy* one has to cope with as a normal, that is natural part of getting older – Cameron's rhetoric comments on dementia as a 'quiet crisis'. Accordingly, dementia acts like an undetected thief who 'steals lives [...] at the hearts of families' (Alzheimer's Society 2012a). The progressive loss of cognitive abilities thoroughly questions, disrupts and alters the biographies of close and long lived socio-emotional bonds between partners, within families, relatives and with friends. Dementia, then, is not just 'simply a terrible disease' (ibid.), but a theft of close and highly affective social relationships. As a thief that steals social relations it progressively spreads malignant forces across society and future generations, whilst increasingly troubling our health care system and upsetting our economy. Dementia is the enemy of personal and social life. Thus, Cameron stresses, like other 'killer diseases' such as HIV and cancer, dementia needs to be 'cracked' (ibid.).

In many ways, Cameron's diagnosis articulates a late version of what Michel Foucault (2003a) called 'biopolitics'. For Foucault, biopolitics is an on-going complex development since the nineteenth century and refers to the 'acquisition of power over man insofar as man is a living being, that the biological came under State control. (...) It is the power to "make" life and "let" die' (ibid.: 239). It refers to

techniques that could be used to take control over bodies. Attempts were made to increase their productive force through exercise, drill, and so on. They were also techniques for rationalizing and strictly economizing on a power that had to be used in the least costly way possible, thanks to a whole system of surveillance,

1 Politics with a big 'P' refers to Politics of the State, its representatives and the realm of 'biopolitics'. Foucault (2003a).

hierarchies, inspections, book-keeping, and reports – all the technology that can be described as the disciplinary technology of labor. (Ibid.: 242)

Later on, this process of disciplining bodies has been accompanied and transformed by a new technology: the ‘biopolitics of the human race’ that treats humans not as individual bodies, but as a ‘global mass that is affected by overall processes characteristic of birth, death, production, illness, and so on’ (ibid.: 242). With the technologies of biopolitics, medicine became a matter of institutionalizing medical care, which goes hand in hand with ‘normalizing knowledge’ and ‘campaigns (...) to medicalize the population’ (ibid.: 244). Foucault’s analysis also stresses that these biopolitical technologies ‘incapacitate individuals, put them out of the circuit or neutralize them’ (ibid.), which is primarily the ‘problem of (...) old age, of individuals who, because of their age, fall out of the field of capacity, of activity’ (ibid.).

Following the Foucauldean analysis of nineteenth century biopolitics, it seems that the collective denial of dementia – as a problem of old age – is very much an effect of biopolitical neutralization of old age related problems.² Dementia, however, returned as an issue of twenty-first century *biopolitics* once it was not conceived primarily as a problem of old age, but as a problem of aging societies. In that sense, Cameron’s biopolitics diagnoses first of all a ‘terrible disease’ of an aging population. Obviously, his diagnosis of dementia as a disease relies heavily on genetics, neuropathological and molecular biology (cf. Bond 1992, Fox 1989, Lock 2005). Cameron’s political aim is precisely to generate a common understanding of dementia that does away with the idea that dementia is a natural part of becoming old. To do so, he requires a general symbol that advocates his understanding: *Dementia as disease*. The symbol holds since it is grounded in research, although the aetiologies of the different conditions and symptoms that make up dementia are highly unknown and those which are meant to be known remain contested.

Thus, dementia became a *biopolitical symbol* of a contemporary societal disease that refers to a complex and serious neuro-pathological problem, which needs to be diagnosed and treated, prevented and cured. Moreover, as a spreading and progressing illness of aging societies it not only has fatal and devastating effects on the personal and social life, it also produces enormous costs that threaten the economy. Hence, illnesses like dementia are issues of *common* interest since they affect the nation, as Cameron would say. Dementia, then, is a general and public issue as it refers to a bodily impairment with dramatic effects for personal and social life. It names an impairing process

in which there is progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out

2 For pre-nineteenth century understanding, disease, as a sign of loss of ‘vitality’, was a natural part of growing old, of senescence, see for example Haber (1983).

daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, which complicate care, and which can occur at any stage of the illness. The causes of these illnesses are not well understood to date but they all result in structural and chemical changes in the brain leading to the death of brain tissue. The main sub-types of dementia are: Alzheimer's disease, vascular dementia, mixtures of these two pathologies ('mixed dementia') and rarer types such as Lewy body dementia, dementia in Parkinson's disease and fronto-temporal dementia. The term 'Alzheimer's disease' is used sometimes as a shorthand term to cover all forms of dementia. The dementias all share the same devastating impact on those affected and their family carers. Dementias affect all in society irrespective of gender, ethnicity and class. They can affect adults of working age as well as older adults. People with learning disabilities are a group at particular risk. (Department of Health 2009: 15–16)

For the biomedical model, dementia is a non-curable illness circumscribing the deterioration of mental agility and capability, memory and intellectual power, a slowing down of thinking and processing thoughts which goes hand in hand with problems of the intake and reproduction of new mental content. These processes of prostration affect problems and losses of understanding, orientation, judgment, calculation, language and the self. People with dementia often show altered behaviour, depression, difficulties in controlling emotions and abrupt mood changes. As a consequence, independent and taken-for-granted everyday life activities become more or less impossible and consequently social relationships (personal and non-personal) are often severely disrupted and altered.

The loss of bodily functions has neuro-pathological effects, which generate symptoms that trouble personal and social life. Dementia is a brutal but democratic actor: Everybody may be affected by it with the same 'devastating impact on those affected'. Clearly, from such a perspective, it is the bio-medical impairment effects, and not the contingency of social markers, which manifest the *self-evidence* of a societal problem as one of *common* interest although the *causes* of the disease remain highly unknown and scientifically contested (cf. Alzheimer's Society 2012a).³

Symbolic Biopolitics

Clearly, Cameron's bio-medical spin is a half-baked one and highlights the *symbolic viz. representationalist* framing of contemporary biopolitics. From the current bio-medical point of view, dementia does not name a disease, but rather the symptoms of an *illness of illnesses syndrome*. The British National Health Service (NHS)

3 Obviously, the scientific controversies and the related heterogeneity of understanding dementia are part of what I call the cosmopolitics of illness. However, this study will have to be postponed in order to be analyzed in depth.

stresses that dementia is not a disease but a collection of symptoms that result from damage to the brain. These symptoms can be caused by a number of conditions. The most common cause of dementia is Alzheimer's Disease (National Health Service [no date]). Typical for symbolic biopolitics, the complexity of an issue needs simplification (cf. Scott 1999), a 'standardized package' (Star 1999), a catch phrase or a single word to address a problem as a compromised but 'common' one that effectively *symbolizes* or represents a problem of general interest that 'touches' everybody's concern without having to name the specificities attached to it. Late modern biopolitics is symbolic Politics, politics of representation.⁴ Evidently, then, the better a symbol travels the better it fits a generalized public of possible voters that will recognize and promote the general issue as a common one.

This is my point: Although extremely talkative about common concerns, symbolic Politics is about general representations and not about the specificities of the issue at stake. In Cameron's case, the rhetoric of 'dementia as a disease' leaves out the non-homogeneity and multiplicity of causes that lead to a complex and diverse set of symptoms that circumscribe 'dementia'. Rather, Cameron's simplified understanding of 'dementia' functions as an umbrella term that lumps together causes and symptoms. Clearly, it seems that Cameron mistakes the symptoms for its causes; by insisting that 'dementia' is a disease he is wrong. This, however, is not very problematic for current biopolitics, since what counts is the symbol that is meant to represent and perform a *general* concern, fully addressed by symbolic Politics.

Concomitantly, the symbolism of biopolitics defines how *we* should see dementia. *Dementia* that stands for Alzheimer's Disease and other illnesses refers to an already publicly widely used symbol for a personal and societal adverse event. 'Dementia' symbolizes a propagating problem of the mind that could affect all of us. Although one does not know exactly what it is, as a symbol of a potential and serious risk for human health it works efficiently precise since it travels well and thus acts as a perfect intermediary for communicating biopolitical interests. In that sense biopolitics instrumentalizes ignorance, uncertainty and insecurity in order to secure its own *particular* understanding of dementia along the rhetoric of *common* interest. Thus, in line with nineteenth century biopolitics, it is important to convey that the disease is a biomedical problem that inflates with the ageing of societies and is not just a naturally occurring problem of old age.

Technologies of Reason and Truth

Symbolic biopolitics aims to attempt a *common truth* about dementia as one of common interest. Typically for such rationalizing and globalizing rhetoric is

4 Politics itself becomes a mere symbol of a 'domain' that is meant to represent politics. Obviously, as I argue, symbolic Politics refers to a complex process of connecting diverse practices that are always more than politics seen as a purified action of a single domain (cf. Latour 2012).

the instrumentalization of statistical data. These *technologies of truth* give the diagnosis of a problem a scientific, mathematical and logical outlook. They serve a symbolic *economy of knowledge of self-evidence*, even then when the issue at stake – like dementia – is (scientifically) barely understood. General statistics and purified scientific research results such as rates, figures, numbers, maps, patterns, and estimations function as necessary *technologies* which by abstracting from their own process of production simplify and thus dramatize the symbolic value of a societal issue that is meant to demand biopolitical action. These biopolitical technologies translate – more or less vulpine and inventive – controversial, uncertain and complex knowledge and knowledge processes into easily accessible *matters of fact* that provide the relevant synoptic informational ploy to argue *as if* it is a matter of stable, given knowledge and undisputable truth.

Following James C. Scott, the ‘stylized facts’, as described above, ‘are a powerful form of state knowledge, making it possible for officials to intervene early in epidemics, to understand economics that greatly affect public welfare, to gauge whether their policies have the desired effect trends, and to make policy with many of the crucial facts at hand’ (1999: 77). We have seen that Cameron’s diagnosis unravels dementia as an alarming, epidemic situation for which the nation is not prepared.⁵ It is precisely the societal neglect of dementia which has co-fabricated the progressing crisis. Clearly, in the case of dementia, the stylized facts are ways to cope with a long-standing history of neglecting the personal, scientific, social, political and economic challenges posed by dementia.

The stylized technologies function as symbolic *techniques of self-assuring political reason and truth* in order to settle an issue as generally understandable and of societal importance. As techniques of simplification these symbolic technologies are meant to bridge the gap between expert reasoning (scientific and so on) and everyday life knowledge. These technologies, however, are not just neutral tools of *securing and simplifying knowledge* for democratic use. Scientific and mathematical techniques are used as technologies that are meant, as *good technologies*, to self-evidently symbolize secure knowledge by reflecting the capability and power of reasoning itself. Symptomatically for symbolic biopolitics, the experiences and concerns as they unfold with the everyday specificities of dementia dwindle to the talkative display of mere matter of facts of living with dementia. The latter function as highly standardized and normalized *symbols* for the problem recognized that underline and legitimate the general will (which is inherently good) to address it. Thereby, symbolic politics delivers a rhetoric that is designed to speak to and for everyone by appealing to *sanity and reason* in order to convey the issue at stake as one of *common interest*.

However, the strategies of biopolitics that aim to *represent* common interests face an on-going paradoxical situation: Although the symbolism of such biopolitics addresses and speaks for issues of common interest, biopolitics itself refers to

5 In Chapter 3 ‘Infecting Bodies’ we will see that the question of ‘preparedness’ plays a significant role as well.

a highly specialized and functionally differentiated perspective, next to many others, and not a *common* one. It is a feature of modern societies to lack a coherent and encompassing overview position of societal matters. Rather, modern societies differentiate into a multiplicity of different modes of observing, networking and enacting societal issues, which do not sum up into a coherent whole but produce their own realities (cf. Latour 2013; Luhmann 1995, 1997 and 1998). Thus, the attempt to act *as if* there is a bird's eye view from and with which we may address common societal issues constantly enforces a process 1) of de-complexifying the specific problem into a matter of common interest, and 2) of weakening the functional complexity of the specific mode of observation in order to establish common sense by consensus-oriented practices.⁶

What becomes visible is not the specific problem seen from a specific perspective, like for example, from biopolitics. It rather addresses a specific problem seen *as if* it is a common one *although* it is framed by the highly specific perspective of a conservative government (which only adds specificity and not generality to the problem addressed). Thus, symbolic biopolitics is being mangled by the need to see the specificity of the problem from a specific perspective. At the same time symbolic biopolitics intends and is forced to represent the specific problem as a matter of a general and common societal fact. It is not difficult to grasp why symbolic viz. representative State politics, irrespective of being conservative or otherwise, is not perceived as a trustworthy perspective! The more so, since its technologies of reason 'not merely describe, observe, and map; they strive to shape a people [...] that will fit their techniques of observation' (Scott 1999: 82).

Wise Communities – Extitutionalizing Health Care

According to Cameron, it is not enough 'to crack' the bio-medical challenge posed by dementia, but to address the social problem of dementia, that is the stigma that comes with it (cf. Blum 1991; Burgener and Berger 2008; Herskovits and Mitteness 1994; Mackenzie 2006; Shiflett and Blieszner 1988). The latter appears highly challenging, since dementia is not only a set of symptoms of a multiplicity of bodily disorders of highly unknown origins, but one that affects *cognitive* functions. The disease attacks the holy realm of modernity: the mind. Cameron, avoiding any direct link of dementia as a 'mental' (...) problem, points out that 'there is always more to the person than the disease they are suffering with' (Alzheimer's Society 2012a). Having said this, he acknowledges the difficulties that come with the split between a progressive biomedical, that is, a quickly spreading neuro-pathological *disease*, which needs to be fought back with the help of medical diagnosis, prevention and cure, and the person with dementia as a human and social being, who is more than just a body with a neuro-pathological problem. Since the experience of dementia is not only a biomedical and neuro-pathological

6 Cf. Scott (1999).

issue of individuals, but a challenge to social relations and a progressively costly burden for contemporary societies, it appears as a matter of common sense that we not only fight against dementia across society, but that we also become ‘dementia friendly communities’ (cf. Department of Health 2013) in order to strengthen the biopolitics of dementia.

‘The government for its part’, so Cameron states, ‘sees this as a huge challenge’ (Alzheimer’s Society 2012a). He suggests that we need 1) to ‘raise awareness’ and ‘build genuinely dementia friendly communities’, 2) to ensure ‘that our health services and our social services are fit for purpose and work for people suffering from dementia’, and 3) ‘to put research into cracking the problem of dementia, early identification, proper treatments, proper cures’ (ibid.). The idea of ‘dementia friendly communities’ is thought to improve ‘the inclusion and quality of life of people with dementia’:

It is envisaged that a dementia friendly community is one that shows a high level of public awareness and understanding so that people with dementia and their carers are encouraged to seek help and are supported by their community. Such communities are more inclusive of people with dementia, and improve their ability to remain independent and have choice and control over their lives (Alzheimer’s Society [no date]).

Dementia friendly communities are thought to be or become ‘wise’ (Goffman 1963: 40) communities: communities of ‘normals’ who are well-informed about people with dementia and help to *assist* a similarly ‘wise’ health care system to enable people with dementia to re/gain normalcy, that is independency, discretion and self-control, in order to increase their quality of life.⁷ Cameron tries to revitalize the eighteenth century idea of ‘assistance’ in a national fashion as ‘the foremost social duty, regardless of its recipient, as that is the basis on which societies are held together, the living bond between men, the link that is most personal and yet most universal as well’ (Foucault 2009: 413).

The politics of wise communities is the will to normalize a biopolitical understanding of dementia and to re-normalize the life of people with dementia. Whereas the former process of normalization defines dementia as a disease, that is a biomedical object, which needs to be better diagnosed, treated and eventually cured, the latter recognizes independency, discretion and self-control as the *ordinary* forms of normal human life which reflect the modernist requirements of the human being as the self-reigning subject. Cameron’s ‘national crisis’, then, is also a crisis of normalization in which dementia and people with dementia play a central role. As I have argued above, this crisis of normalization is a self-inflicted crisis of the very neutralization of the ‘problem’ of old age since the late nineteenth century; it became a biopolitical issue in the moment it is seen as a persisting and progressive fact of ageing societies.

7 On the ambiguities of community and home care see Knapman and White (1995).

The call for dementia friendly communities as wise communities redistributes the question of dementia care, so much so that dementia care is not simply the problem of institutionalized health care settings that seem more and more unable to deal with the costly dementia epidemic. Rather, the call for wise communities is less the effect of institutionalizing biopolitical technologies within traditional health care settings, than a sign of *extitutionalization* that draws attention to the limits of institutionalized practices (cf. Serres 2005; Domenech and Tirado 2013). Consequently, health care becomes a question of public awareness and knowledge that is able to assist and unburden the highly troubled institutionalized health care settings which are challenged by the requirements of dementia care.

The call for dementia friendly communities and the need for the extitutionalizing of health care also reflect the long history of institutionalizing, confining, disciplining and punishing mental illnesses. The collective denial of dementia is symptomatic for a mental problem that is meant to remain a private/family issue and not a public/societal one. However, with the diagnosis of ageing societies, the diverse biopolitical strategies from the seventeenth to the nineteenth century face a self-inflicted problem of disciplining bodies with troubled minds on one hand and neutralizing the ‘problem’ of old age on the other. Thus it is important to highlight the modern history of bodies with troubled minds, without which the collective denial of dementia remains misunderstood.

The Collective Denial of Dementia and the History of Madness

Cameron’s rhetoric of dementia as a ‘quiet crisis’, which has been collectively denied and has turned the unrecognized into a ‘national crisis’, can be read as the confession of failure of late modern biopolitics in dealing with the long echo of one its most radical rational triumphs: the silencing of madness as a matter of unreason and its social exclusion through the confinement of the ‘mad’ (cf. Foucault 1961, Doerner 1981). The history of dementia cannot be thought without the history of madness, precisely since dementia was closely linked to it.

Following Foucault, in the late seventeenth century, madness became visible as the ‘relationship between unreason as its final meaning and rationality as its form of truth’ (Foucault 1973: 255) and thereby its own being has been made invisible. Madness became a non-being, socially reamed between reason and its negation:

This gesture, which banished madness to a neutral and uniform world of exclusion, did not mark a halt in the evolution of medical techniques, nor in the process of humanitarian ideas. It assumed its precise meaning in this fact: that madness in the classical period ceased to be the sign of another world, and that it became the paradoxical manifestation of non-being. Ultimately, confinement did seek to suppress madness, to eliminate from the social order a figure, which did not find its place within it; the essence of confinement was not the exorcism of a danger. Confinement merely manifested what madness, in its essence, was:

a manifestation of non-being; and by providing this manifestation, confinement thereby suppressed it, since it restored to its truth as nothingness. Confinement is the practice, which corresponds most exactly to madness experienced as unreason, that is, as the empty negativity of reason; by confinement, madness is acknowledged to be *nothing*. (Foucault 1971: 115–16)

Madness was the blank presence of the most radical difference to anything rational, reasonable and socially acceptable. There was no societal way of dealing with it except through shutting it away and suppressing its detached Otherness. The societal space of madness was governed by reason's effort to secure the imprisonment of its presence. To remain absent from the social life of the reasonable man, the insane were facing a threefold possibility of confinement: 1) Behind the private gates of family ties, 2) within 'houses of correction' in which 'the suppression of the difference, or the fulfilment of this nothingness in death' (ibid.: 116), and within 3) hospitals and asylums for the mentally ill (cf. Weiner 2008).

With the age of reason, madness has been finally included into society in order to exclude it in more or less cruel ways from social and public life. Through *exclusion by inclusion* madness became a *being without being*, ontologically and socially. For early modern societies, to care for the mad meant to protect society from the insane. Moreover, the prison was not merely considered as the most effective mode of protection from madness, but was also seen as the place where madness was produced and from where it was feared (unreasonable as it may sound) to spread dangerously through the air, threatening social life like leprosy or any other deadly contagious disease (cf. Foucault 2009: 355). In effect, the moral ideal of confining madness was thought as 'an asylum which, while preserving its essential functions, would be so organized, that the evil could vegetate there [like a bacillus or virus, MS] without ever spreading; an asylum where unreason would be entirely contained and offered as a spectacle, without threatening the spectators; where it would have all the powers and non of the risks of contagion' (ibid.: 207).

Dementia and the Negativity of Reason

Until the middle of the eighteenth century the positivities of dementia remained too abstract and too negative to be conceptually ordered, modelled and traceable by science and medicine. This 'negativity of being' (...) that governed an early modern understanding of madness did not allow the fanning out of the varieties of madness and the differentiation between differently defined forms of it. However, it did establish variations of different proximities to the 'negativity of unreason' (cf. Foucault 2009).⁸ Dementia was one of these variations and was seen as most

⁸ Next to dementia, Foucault analyzes mania and melancholia, hysteria and hypochondria.

closely linked with the ‘negativity of unreason’ and thus appeared utterly vague and fragile. Only gradually dementia became known, though not so much by understanding what it is but by differentiating it from what it is not. According to Foucault (ibid. 253), for seventeenth century physicians, ‘dementia’ assembling *dementia*, *amentia*, *fatuita*, *stupiditas*, or *morosis* could be differentiated from other illnesses, but difficult to be described in its positive and concrete content: ‘Dementia, as a medical experience, does not crystallize’ (ibid.: 255).

In early modernity, the disorder of dementia did not have specific symptoms, but named *all the possible* symptoms *madness* could have. It summoned the abstract fulfilment of any form of unreason. According to Foucault (2009: 253, 256):

Dementia is close to madness conceived of in the full negativity of its disorder. Dementia is thus in the mind both pure chance and total determinism, where any effect can be produced because any cause can provoke it. There is no disorder in the organs of thought that cannot bring on one of the aspects of dementia. It has no symptoms of its own as such, but is rather the open possibility of all the possible symptoms of madness. [...] Dementia is anything unreasonable in the orderly mechanics of the fibres and spirits of a well-ordered brain.

After all, dementia is *stupiditas sive morosis*, a ‘defect of the intellect and judgement’ arising from a troubled mediation between body and the rational soul affected by the faulty forces of memory and imagination which darken the light of reason and intellect located in the brain and affect the functioning and physiology of its organs, that is its animating spirits [*Lebensgeister*] (ibid.). Due to the pathological changes of the function and physiology of the brain, its organs and fibres, the representation of things gets disturbed and the truth of things (that is the transformation of sense data) cannot be sufficiently intermediated anymore. The brain, its organs and fibres are thought to be/come too heavy, too wet, too dry, too cold, too sticky, too stiff, too slow or lack vibration performance, in order to correctly intermediate the sense impressions needed to be able to think and reason properly, that is, to act rational (ibid.: 256). Old age is one out of many reasons, be they congenital or acquired through lifetime, which may affect dementia. However, dementia may appear at every age and thus also children and very young people are affected by dementia – as for example in the case of *morosis*. To be defined as a specific illness, dementia is difficult since all too many causes can be traced without leading to a defined profile that would organize its symptoms:

Its truth consists in a juxtaposition, with on the one side the accumulation of possible causes, whose level, order and nature can be different as possible, and on the other a series of effects whose only common characteristic is that they demonstrate a lack or a defect in the functioning of the faculty of reason, which is unable to relate to the reality of things and the truth of ideas (Foucault 2009: 257).

Though differentiated from stupidity and seen less mechanistically and less spiritual, current twenty-first century bio-medical efforts try to deal with the disturbing effects of *stupiditas sive morosis* in ageing societies.

Disorganized Life and Madness

Commencing the second half of the eighteenth century the changing, ‘disorganized’ social life of modernity itself, the human social ‘milieu’ has evoked the risks of becoming mad (cf. Foucault 2009: 343). These risks are manifold and seem to capture the whole modern life: It is the enjoyment of man’s freedom or liberation from traditional bonds and the lack of secure and stable relations, the freedom and dependencies of life driven by economic interest, the experience of borderless religious beliefs which lack the organization of religious rituals and institutionalized authority, its related desires, worries and guilty pleasures. Moreover, the desire for scientific progress and its urge of unveiling given errors, the intensity of abstract and disembodied work of speculation about scientific ‘objects’ enforces a lifestyle that enjoys thinking but lacks physical exercises and the sensuous relations with others. The enjoyments of culture, like for instance theatre, literature, or music are considered as most problematic since they alert, mix up, disturb, excite, stimulate, shock, stir up and thrill our senses, fabricating illusionary, artificial and impassionate sceneries of life which produce a rift between what is and what is to be and thus alienate from any form of a *natural* sense and sensibility.

In effect, the human being finds himself in a self-created milieu of freedom that is prone to produce madness since it constantly enforces a sense of alienation from the taken-for-granted, the natural, the immediacy of the directly sensed, and so on. Madness becomes a historical event and with it the madman does not ‘lose *the* truth but *his* truth: he loses himself’ (Foucault 2009: 379). The modern social milieu enacts a constant change of human beings, establishing ‘the possibility of a counter-nature’ (ibid.: 373) affecting an on-going ‘degeneration’ from a natural state of ‘immediacy’ (ibid.: 372) and thus multiplies the possibilities of becoming mad and demented (ibid.: 374). Unsurprisingly, the moderns, disentangled by their social milieus from a natural state of being, cannot find madness with those seemingly closer to nature: be it the non-moderns, primitives or animals. According to American medical enquiries at the beginning of the nineteenth century, the Indians do not show any forms of dementia (ibid. 374). Dementia becomes the signature of the loss of the personal truth of the modern man.

Traitement Moral

In the late eighteenth century the confinement practices of madness made a significant reformatory shift towards a ‘traitement moral’ (Pinel), a humanitarian approach to madness. With Vincenzo Chiarugi in Florence/Italy, William Tuke in

the UK or Jean-Baptiste Pussin and Phillipe Pinel at Bicêtre in Paris, the insane were relieved from their chains and some of the most violent treatments have been dismissed. With new techniques that promised possible cures, science and medicine disassociated madness from the negativity of unreason, its non-being, and turned it into a positive object of a classifiable human neuro-pathology and mental disease (ibid.: 338; Gerard 1997; Mora 1959; Weiner 2008: 266). The madmen turned into a 'medical personage' (Foucault 2009: 503) and the physician became *the* central figure within the 'displaced and deformed' (ibid.: 504) space of confining madness:

Since the end of the eighteenth century, the medical certificate had been more or less obligatory for the confinement of the mad. But inside the asylum, the doctor took pride of place, since it was he who transformed the space into a medical institution. Despite that, and this was the key point, the intervention of the doctor was not done on the basis of some skill or medical power as such that he alone possessed, justified by a body of objective knowledge. It was not as a scientist that *homo medicus* gained authority in the asylum, but as a wise man. If the medical practitioners were required, then it was not for the knowledge that they brought, but rather as a moral and juridical guarantee of good faith. [...] If the medical character could circumscribe madness, it was not because he knew it, but because he mastered it. (ibid.: 504)

This means that unreason has not been 'declared innocent forever' (Foucault 2009: 503) linking the medico-scientific gaze with the moral treatment. Rather, madness is confined within a micro-cosmos of constant 'observation' and 'perpetual judgment' (ibid.: 500). With the physician being 'Father and Judge, Family and Law', such bourgeois cosmos of a '*surveillance paternelle*' (Gerard 1997: 393) was executing a 'trial where any error in life, by a virtue proper to life in the asylum, became a *social crime*, observed, sentenced and punished' (Foucault 2009: 503, accentuation MS; cf. Foucault 1977; also Gerard 1997). Foucault stresses:

The asylum of the positivist age, which Pinel is credited with having founded, is not a free domain of observation, diagnosis, and therapeutics; it is a judicial space where people are accused, judged, and sentenced, from which they can only be freed by [...] repentance. Madness was to be punished in the asylums, even if its innocence was proclaimed outside. For a long time to come, and at least until today, it was imprisoned in a moral world. (Foucault 2009: 503)

We can see that the *traitement moral* is a mixed blessing acting with a double-edged sword. On the one hand, it cuts off the chains of the mad, which for everybody who considers himself a rational, human/e being, must appear as a liberating act, freeing the mad from the brutal and inhuman past of physical confinement and violence. On the other hand, it cuts out a novel 'moral' space of confinement where the

‘medicine man’ is not so much the person with a specific expertise, but, quite on the contrary, he is the powerful representation of the most general, natural capability: that which *everybody knows and what everybody is supposed to recognize*.⁹

The medicine man becomes the icon of modernist complicity of common sense with good sense, of *sanity and reason* and good, reflective judgment. He represents what is required that everybody knows: Reason (thinking) and the willingness for the good. The madman, however, is in need of reason and good will, because he does not know what everybody knows precisely because he suffers from ‘une affection cérébrale (...) caractérisé par l’affaiblissement de la sensibilité, de l’intelligence et de la volonté [a cerebral disease characterized by an impairment of sensibility, intelligence and will]. The demented, as Jean Etienne Esquirol concludes, ‘est privé des biens dont il jouissait autrefois; c’est un riche devenu pauvre [a demented man has lost the goods he used to enjoy; he is a wealthy person turned poor]’ (Esquirol in Boller and Forbes 1998: 127). The demented person lacks the paraphernalia of common sense. He lacks articulate thought and does not care about thinking! This also means that he lacks good will, which, the medicine man insists, is a prerequisite, if he wants to know anything about himself and his troubled being.

So far, the modern history of the madman has been the history of being confined to his untimely character that has been negated, confined, punished, disciplined and so on. In the Dostoevskyan/Shestovian literature, the madman resembles the ‘idiot’ (cf. Deleuze 1994: 130), who is considered to have neither subjective, that is, natural pre-requisites to be able to think, nor does he have any objective pre-requisites of ‘the culture of the times’ (ibid.). The madman, the idiot or the demented person lack the ‘subjective’ and ‘objective’ pre-requisites in order to have a self-image. To idiocy there simply are no pre-requisites that would allow for the modern self-assurance of ‘I think and therefore I am’.

For the common sense understanding of madness as well as its sophisticated scientific and biomedical forms, both *moral* and striving for the good, it is vital to *overcome* the idiot as the figure of the ‘Untimely’ since he assembles nothing but negativity, the subjective and cultural forms of negation, negating the truth of being. For the common sense understanding, then, it is time to leave the chained times of the Untimely behind and with it the amoral practices of the past. The common sense of morality and the morality of common sense oblige to free the mad from their chains and negativity and turn madness into a *positive* phenomenon instead. Obviously, this means to establish and secure a common sense understanding of madness so that the mad is able to recognize his madness in the first place in order to confess his *deviation* from common sense! Drawing on the practices at Pinel’s Retreat, Foucault stresses:

In a single moment, the asylum, in the hands of Pinel, becomes an instrument of moral uniformity and social denunciation. The intention was to erect one form

9 Cf. Deleuze (1994: 224 and Chapter 3).

of morality as universal, which was to be imposed from within on other forms of morality that are foreign to it, and which contained the alienation that would inevitably affect people in the end. In the first case, the asylum was to act as an awakening and a reminder, invoking a forgotten nature; in the second, it was to act as social displacement, to uproot people from their condition. [...] What Pinel practised was relatively complex, as he tried to operate moral syntheses, assuring an ethical continuity between the worlds of madness and reason, but enacting a form of social segregation all the while that guaranteed bourgeois morality a de facto universality, enabling to impose itself as a law over all forms of alienation. (Foucault 2009: 495)

The mad is confined to a small but rigid empire of socialization with the medical personae as its moral authority and executive head. The *traitement moral* will confront the mad with his loss or lack of common sense, that is, his lack of reason, which hinders him from having any good will to change his socially conspicuous behaviour. However, to go back to normalcy the mad need to overcome the ascribed pathological findings. To do so, the specific pathologies must not only be observed in detail, but brought to the attention of the mad. Consequently, the mad becomes the object of control and the asylum the space of disciplining the mad and his misconduct, his misplaced emotions, his strangeness and abnormalities. However, since the mad is enclosed in a non-reflective and a-social world that makes him careless of the basic common sense principles of an ordinary thinking human subject, the mad is unable to reflect upon his deviations from the ordinary. Hence, the mad needs to feel and experience his pathologies *as deviant*. Once the mad realizes and confesses his deviant mode of action, he may learn from *his* misconduct and is supposed to be ready to be brought back on the right track of reason and social normalcy. Clearly, good will is needed; otherwise the mad remains unaware of his situation. The doctor acts as the authoritative stakeholder and the *inscription* of common sense becomes the goal of his medical *prescription*: the true representation of what is considered rational, good (willing) and normal. Obviously, the doctor is a wise man, precisely because he is rational and thus good (willing) and normal, and he is an ordinary person, since he is good (willing) and rational, and he is a rational person, because he is good (willing), normal and (sophisticated) ordinary. From a moral point of view, medical knowledge *is not* what makes him mastering the space of moral treatment. Rather, it is the voice of rationality, the good (will) and social normalcy of the ‘everyman’, which speaks to the madman and confronts him with what ‘everybody’ knows and according to which one should act.

The Fiction of Common Sense

Hence, the most general presupposition of the condition of possibility to enact a *moral treatment* is itself a moral matter of re-normalizing the power of common

sense that links rational thought, the good (will) and social normalcy. It is the imperative of common sense to bring the mad to terms [*zur Vernunft bringen*]:

Three alienated men, who each believed themselves to be sovereigns, and had all taken the role of Louis XVI, were arguing one day about their rights to royalty, which they were seeking to assert with slightly excessive enthusiasm. The *guard* approached one of them and took him to one side: 'Why', she said, 'are you bothering to argue with those people, who are obviously mad? Does not *everyone know* that you should clearly be *recognized* as Louis XVI?' The patient was flattered by this treatment, and withdrew, looking down his nose at the other two with considerable disdain. The same tactic worked with the second patient. And from that point on there were no more arguments. (Sémelaigne in Foucault 2009: 498, Accentuation MS)

Irrespective of who speaks for the 'everyman' – the doctor, the guard – it is the knowledge of the everyman that appears as the natural remedy to make the mad rethink their mad practices and even solve social conflicts that emerge from mental disorders. What is at play is a 'model of recognition' which makes the mad recognize themselves as normal once they retain and *recognize* the simplest things which everyone knows, even if it is nothing but the recognition of a fiction, an illusion provided by the representatives of sanity and reason. 'Recognition', as Deleuze has stressed (1994: 133), 'may be defined as the harmonious exercise of all the faculties [perception, memory, imagination, understanding] upon a supposed same object: the same object may be seen, touched, remembered, imagined or conceived' and consequently it is recognition that gives the object its identity. Thus, it is precisely the *sensorium commune* of the brain, which is thought to relate and translate the images transmitted by the senses and which allows for the practices of common sense and recognition. Once the mad is capable of exercising what is common sense and everybody knows and nobody can deny, the mad is capable of self-identity and is able to differentiate between his healthy reason and the mad imagination of others. The mad, then, imitates successfully 'the identity of the Self in the "I think", which grounds the harmony of all faculties and their agreement on the form of a supposed Same object' (ibid.). The mad becomes King Louis XVI due to the recognition of what everybody already knows, as *doxa*. It is the very identification with King Louis XVI as an undisputed fact which everyone recognizes as such, and which turns the power of common sense into a *good sense*. Deleuze stresses:

For while the common sense is the norm of identity from the point of view of the pure Self and the form of the unspecified object which corresponds to it, good sense is the norm of distribution from the point of view of the empirical selves and the objects qualified as this or that kind of thing [...]. Good sense determines the contribution of the faculties in each case, while common sense contributes to the form of the Same. (ibid.: 134)

The *traitement moral* of the asylum exercises the normative space of reconstituting sameness under conditions of difference. It enacts the moral principle of re-normalizing the mad whose faculties are disharmoniously assembled and where reason fails to unify, naturally as it were, the other faculties, and consequently is unable to know the simplest of things: common sense and good sense. The asylum, then, is not a shelter for difference, but the enforced sanctuary for difference from difference that needs to be overcome by the technologies and tactics of common sense. Difference is not only imprisoned by the *doxa* in its general and abstract form given by common sense as well as in its empirical manifestations. It is also the realm of *doxa* and its representatives that apply their different technologies of the general Same and the empirical Self to achieve the ‘mise en equivalence’ as the pre-condition for treatment and cure.

Inconsistent und Incoherent – The Trouble with Dementia

It is precisely the dis- or malfunctioning of the *sensorium commune* which hinders people with dementia to determine the contributions of the faculties. According to Pinel, ‘[i]n dementia, the essential functions of the mind think, but they think in a void, and consequently are extremely mercurial. Dementia is like a pure movement of the mind, devoid of any form of consistency, a perpetual flight that time cannot immobilise in the memory’ (Foucault 2009: 262). People with dementia simply lack the *sensorium commune* in order to think properly, which common sense thinks is the simplest of things to do. Still, the all-too-diverse symptoms of dementia make dementia resist to coherently qualifying and classifying as a single disease in medical and social contexts (cf. Hanson 1989).

As we have seen so far, the history of dementia is closely related to the history of madness. With the early moderns madness was mere negativity: Locked away in prison-spaces built for thieves and other delinquents or kept within the privacy of the family, madness, and with it dementia, was sealed off from public social life. With the age of reason the equivalence of madness with the negativity of unreason did have lasting and far-reaching effects on our understanding of and dealing with dementia as a deviance from the moral of normalcy. With the *traitement moral* and the formation of asylums, hospitals and correction houses some of the brutal technologies of confining madness changed. More subtle technologies of ‘discipline and punishment’ were employed to install the universal morality of reason in order to socialize and re-normalize the mad, which in effect allows reason (and thus the truth of human being) to return (cf. Doerner 1981). Through practices of confinement, unreason was separated from reason and medical intervention was missing. The medical gaze and the idea of diagnosing, treating and especially curing mental illnesses is more and more dominating the eighteenth and nineteenth century.

However, with the inconsistent and incoherent relations of possible causes and symptoms on the one hand, and the biopolitical neutralization of old age

in the nineteenth century, dementia remained ‘on the surface of experience’ (Foucault 2009: 262). The understanding of dementia remained too abstract and too general since it was too closely linked to the negativity, the non-being of reason, the Other of common sense. It was also disconnected from the will of biopolitical understanding since it was seen as a problem of the incapacitated old age. In effect, dementia continued to be a quiet crisis and remained hidden away. From such a perspective, the collective denial of dementia appears as a self-inflicted problem of modern biopolitics.

This may also explain why the findings of Alois Alzheimer’s detailed analysis of dementia at the end of the nineteenth century and beginning of twentieth century did not gain immediate biopolitical importance. The work of the German psychiatrist and neuropathologist *Alois Alzheimer* and many of his colleagues (Kraepelin, Nisch and others) were controversially discussing the different possible causes and forms of dementia. In his work, Alzheimer unravels the problem of classifying these different forms of dementia since the symptoms and their processes are too manifold and generate a series of ‘differential-diagnostic problems’ (Alzheimer 1898: 109). He speculates that dementia could be, next to vascular problems, the effect of a neural disease that comes with a loss of brain weight, deterioration of nerve fibres, altered cells as well as the visible accretion of ‘Corpora amylacea’, ‘clumpy pigment’, ‘black clods’ and so on (ibid.: 106), all of which did inform the subsequent debates on dementia until now. Alzheimer already speaks of the ‘silent form’ of dementia senilis, which ‘can be found in the family and in benefices and less in lunatic asylums’ (Alzheimer 1898: 103).¹⁰ Through his work on dementia he became attentive to Auguste Deter who has been developing symptoms such as time-space disorientation, general confusion, shifting moods and behavioural change (Alzheimer 1907). Deter died four and a half years after the symptoms had developed. These symptoms have been known in elderly people and were considered as a possible part of growing older and not as a specific disease. However, Deter was only 51 when she developed the old age symptoms.¹¹ After post-mortem analysis of her brain, Alzheimer speaks of a ‘peculiar disease of the cortex’ (ibid.). Deter was too young for an old age related illness and at the beginning of the twentieth century the group of over 65 of age was less than 5 percent of the population. Thus neither dementia nor old age was of biopolitical interest that was meant to speak for the whole population. Dementia and old age was of no interest to *common* interest. It will take the next 70 years for dementia to become an increasingly recognized problem of biomedical and biopolitical reasoning (Lock 2005). And it will take more than 100 years after Alzheimer’s analysis that dementia will turn into an existential illness of the modern self and a national crisis of ageing societies.

10 ‘The natural place for cure [...] is not the hospital, but a family’ (Foucault 2009: 416).

11 On the relationship between AD and ageing see Scodellaro and Pin (2013).

Linked but Divided – Biopolitics, Advocacy Groups and Social Sciences

Although there has been much work done to research the different forms of dementia, biopolitical technologies like statistical data and the inclusion of ‘mental disorders’ into the International Classification of Diseases (ICD) were needed to create the first ‘Diagnostic and Statistical Manual of Mental Disorders’ (DSM) in the 1940s (Boller and Forbes 1998; cf. Mast et al. 1995). The DSM neither did mention dementia nor AD, but the term ‘Organic Brain Syndrome’ was discussed, which although highly contested, continued to be in official use until the 1980s and even later to describe an irreversible syndrome (ibid.: 127). In the 1980’s and 1990’s dementia is defined as ‘a loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning’ (ibid.: cf. Fox 1989). Acknowledging the latter, dementia is not only a mental illness that affects the cognitive capability of individual bodies and leads to death, but also names an illness that disrupts our routine forms of social interaction, unleashing depression, mood change, language problems and so on. Dementia also endangers what holds capitalist society and its members alive: labour. From now on, dementia appears most daunting for societies that claim, in more or less abstract ways, to be modern. It interrogates modern reason and the modern self as the empirical effect of human life, work and language (Foucault 2001). Following from this, Cameron’s ‘national crisis’ names a crisis of human reason as well as the endangerment of its empirical forms (life, work, language) that configure the human as the self-reigning subject, the modern self.

The belated biopolitical perception of dementia as an overall societal crisis enforced political activism which led, for example, to a significant increase in research funding (cf. Fox et al. 1999; Lock 2005). Sciences across disciplines are launching a variety of research programmes which not only raise awareness of the complex and multifaceted bio-medical causes of dementia, but also try to seek knowledge of how dementia might be better understood, effectively treated or even be cured. The biopolitical perception of dementia goes hand in hand not only with a medicalization of dementia, but also with the emergence of social scientific research agendas on dementia that is highly critical of the former. Although dementia is framed as a societal crisis, and this is precisely what makes it a biopolitical issue in the first place, the relationship between biopolitics and social sciences is ambivalent, since the social models of dementia are primarily designed as an alternative to the hegemony of biopolitical and biomedical framings of dementia. Still, for current biopolitics, the social sciences are meant to add to the biomedical perspective the very ‘societal view’ or ‘social context’ of dementia in order a) to get the full picture of the crisis at stake, and/or b) to investigate and assess the human, that is, the psychosocial and social issues as well as the ethical aspects of dementia and dementia care. And this is precisely what the social studies of dementia are interested in. The editors of the journal *Dementia* stress:

That promotion and celebration of the social domain was always an underlying aim of the *Dementia* journal when it was first established 11 years ago, and it

remains just as important now. The human and lived experience is the primary epistemological lens through which the *Dementia* journal views the landscape of dementia, with all of its contours: twists, turns, valleys and hills. (Keady and Harris 2012: 3)

Hence, it is the highly ambivalent relationship between the social sciences that try to oppose the biopolitics of dementia and the flourishing development of social scientific research agendas that would not exist if dementia was not seen biopolitically as a 'societal problem'. At the same time, the engagement of a variety of patient associations and self-helping groups strengthened the perspective of dementia as a primarily societal issue; since the 1980s, advocacy groups of dementia brought into the public discourse issues of self-experiences of illness and the way these are dealt with. Consequently, dementia and ageing was a demanding policy issue of state politics directly linked to demands posed by patient advocacies. Thus, with the growing of biopolitical interest in dementia since the 1970s (Fox et al. 1999) and the powerful engagement of patient advocacy groups, the social studies of dementia have been growing rapidly as well. In effect, the formation of a variety of international journals was possible, which generated a vivid and controversial social scientific discourse on dementia, which is meant to analyze as well as to improve the social realities of people with dementia.¹²

Social studies of dementia contribute to the complex fact that becoming demented neither refers to a single and homogeneous process nor does dementia denote a uniform group of people with dementia. Rather, it comprizes heterogeneous and situated experiences of dementias with highly specific effects on individual bodies and their relations (Post 1994). As Tim Kitwood stressed, the practice-oriented engagement with people having dementia did not only question 'almost every cherished assumption' about the 'facts' attached to dementia, but 'men and women who have dementia have emerged from the places where they were hidden away' (Kitwood 1997: 133). Dementia is finally 'losing its terrifying associations with the raving lunatic in the old-time asylum' (ibid.). For Kitwood, such a historical event names the beginning of a 'process of humanization – or, more accurately, personalization', whereby wo/men with dementia are 'to be regarded as persons' (ibid.). Dementia is 'being perceived as an understandable

12 Unfortunately I am not able to do justice to all the different perspectives and objectives of social scientific research on dementia. On family and social relations, see for example Cecchin (2001), Gumbrium (1988a,b), Morgan and March (1992), Russell (2001); on issues of the (loss of the) Self, Identity or Personhood, see Basting (2003), (Berad 2004), Fontana and Smith (1989), Globermann (1994), Herskovits (1995), Kitwood (1990), Millett (2011), Nowell (2013), Sabat and Harré (1992), Surr (2006); On processes and relations of care, see Bohling (1991), Caron et al (2005), Wellin and Jaffe (2004). On moral issues see Orona (1989). For cross-cultural studies on dementia, see for example Ho et al. (2003). On non-verbal communication, see Hubbard (2002). On genetics, (Lock 2005) and on genetics, stress and dementia, see Anderson et al. (2004).

and human condition, and those who have been affected by it have begun to be recognized, welcomed, embraced and heard' (ibid.) as persons with specific and subjective experiences, feelings and specific ways of relating to themselves and their environments.

Dementia does not only sum up a process of brain defects, but articulates a fragile and highly situated *biographical* object that assembles the person's emotional bonds and social pathways and relations (cf. Bender 2003, Harding and Palfrey 1997). A person-centred approach is not only vital in understanding the psychosocial and interpersonal specificities of the person with dementia, but is also essential in improving to meet the particular requirements of related care practices. To do so, a person centred perspective of dementia 'looks far more to human than to medical solutions' (ibid. 2; cf. Wilkinson 2002). From a person-centred perspective, the medicalization of dementia has also proved to slow down an adequate understanding of the requirements of the specificities of care practices (Kitwood 1997).

Politics? What politics?

Other social scientific studies on dementia have shown that the perspective of care is not just the second step process that follows the truth of medical diagnosis nor should it be understood as the mere 'human' side of care that accompanies the 'medical' perspective of dementia which is independent of the different ways of the 'conduct of care' (cf. Latimer 2000). Rather, as Ingunn Moser (2008, 2010, 2011) has shown, it is the different ways of care practices themselves that shape not only our understanding of dementia and offer alternatives to the enactment of dementia by biomedical practices. Care practices also shape the medical diagnosis and practices of dementia. Moreover, the focus on improving everyday care practices 'offers wider possibilities for action in terms of care, patient agency, and subjectivity that somaticizing, biomedically based practices' (Moser 2011: 708; cf. Mol 2008):

In the relational ordering, dementia presents itself as a growing mismatch and problem with relations between the patient, the daily environment and fellow beings. It is not so much an objective and object like condition internal to the individual brain, as a problem with relation, interaction, and communication. This is not, however, to deny the reality of the problem (Moser 2010). Dementia is indeed something that confronts people in an objective way, but it is also something that can, within limits, be acted upon and shaped. (Moser 2011: 714–15)

Like Moser's relational account of dementia, person-centred perspectives highlight dementia as an under-conceptualized field of study. Rather than investigating the cognitive losses, lacks, deficiencies or subsequent disabilities

and the ways of coping with them, person-centred accounts try to ‘broaden the dementia debate’ by drawing particular attention to the capabilities of people with dementia. It is argued that research needs to address and support the agency of people with dementia and to give people with dementia a voice to ‘speak out’ and thus become active parts in understanding the life-courses of people with and shaping the experiences of dementia (cf. Bartlett and O’Connor 2010). Thereby, the person with dementia is not treated as a mere ‘passive care recipient’, but as a ‘citizen’, that is ‘an active social agent in the broad context of their lifestyle, lifecourse, social networks and community activities’ (ibid. 2010: 4). These inclusive accounts that are thought to give people with dementia a voice need to be endorsed in order to challenge the biopolitics of incapacitating people with dementia who are considered as ‘weak, and a burden’ (ibid.: 5) for their social environment and for a wider society.

The focus on the capabilities of people with dementia needs to be fully welcomed in order to resist and politicize the hegemony of a biomedical model of dementia that primarily sees the negativity of the disease and its devastating personal and societal effects. It also supports the different forms of ‘self-advocacy’ that articulate the concerns of people with dementia themselves. Moreover, it brings to light the experiences of and with malignant forms of dementia care and the different ways people with dementia are ‘shaped and constrained by’ their environment – be it through the families, the medical profession, care facilities as well as by societal perceptions and attitudes or other harmful practices and oppressing societal structures (ibid.).

However, there is a crucial difference in understanding politics and agency if we compare the relational model of Moser (2010, 2011) and the person centred model Bartlett and O’Connor (2010) advocate. For a relational account, care practices may improve the agency of dementia patients and allow them to do things they were not able to do without the improvement of care practices. The focal point of Bartlett and O’Connor is on ‘the person’ as an ‘active citizen’ who is called to speak out and is meant to be given a voice by social research. Thus, whereas for Moser, ‘agency’ is the *effect* of care processes, Bartlett and O’Connor *presuppose* an active citizen who is able and who wishes to speak out and take part in re/shaping the understanding of dementia and the conduct of care practices. As Fox (1989) has argued, contrary to the AIDS or disability movement, it was people *without* AD or other forms of dementia, who have been advocating the patient groups of AD and dementia. By highlighting the power of the principle of self-advocacy, Bartlett and O’Connor evoke the idea of ‘social citizenship’, which gives people with dementia political agency. However, as I will show in the next two chapters, the understanding of the person with dementia as an ‘active citizen’ follows a modernistic project of ‘politics’ that does not provide an alternative to the basic principles of modern biopolitics but shares them with biopolitics *although* they are meant to challenge the biopolitical effects of ‘silencing, marginalizing and discriminating’ people with dementia (Bartlett and O’Connor 2010).

The Cosmopolitanism of Health

It is often said that modern politics has been successful in achieving the translation of moral issues into political ones (cf. Rasch 2000). As Rasch, associating himself with Hannah Arendt and Chantal Mouffe, argues that in

Kantian terms, the political is the real not of determinative judgment but rather of *reflective* judgment. The political, as the realm of opinion, is distinguished from science and religion and morality. Therefore, if one opposes a political decision, one does not find oneself outside the political system because one opposes what is true or what is good; rather, one finds oneself in “opposition”, as a political legitimate “enemy” of the governing majority, an “enemy” who manipulates the power of those out of power to influence future decisions. (Rasch 2000: 163–4)

From my reading this is only half of the truth. I will argue that in order to translate moral issues (good life, health, well being) into symbols of politics, they are re-moralized as a matter of common sense [*Gemeinsinn*] pre-supposing and taking for granted sanity and reason [*gesunder Menschenverstand*] of the human being. This is precisely what links Politics with other modernist forms of politics (for example those that treat the person with dementia as an ‘active citizen’) which outline the political as a way of opposing consensus oriented and majority driven Politics.

As I have argued above, by appealing to everybody’s *will to act*, symbolic biopolitics, that tries to represent and structure public opinion, constantly evokes the re-entry of moral agency precisely by stylizing political issues as a matter of *common sense* that everybody is meant to understand and no one can deny. This appears as problematic since biopolitics is just one out of many perspectives on dementia and thus is neither able to represent society nor the issue at stake as a whole and thus is unable to articulate a general interest. However, to perform *as if* they were capable to do so, biopolitics advocates techniques of simplification and standardization which translate complex, disputed, uncertain, unsolved and often locally specific and situated *matters of concern* into the reality of present or future *matters of fact*. These matters of fact are seen as general symbols of good and truthful political concerns, which everybody with sanity and reason is meant to recognize as a *given* problem that needs to be solved (cf. Anstey et al. 2010; Alzheimer’s Society 2013). Statistics, numbers, estimates, probabilities and so on play a central role in shaping the public opinion and the understanding of dementia as well as it structures the politics of dealing with dementia along biopolitical means (cf. Comas-Herrera et al. 2007). However, the usage of these technologies is not restricted to symbolic biopolitics, but are global symbolic tools that *everybody* can use, including advocacy groups and social scientists, to address the pressing societal relevance of issues such as dementia (cf. Fox 1989, Moser 2008).

We have argued, that the idea of self-advocacy as outlined by person-centred approaches is meant to recognize people with dementia ‘as equal citizens, with the power to influence and bring about social change’ (Bartlett and O’Connor 2010: 3).

Thus, by a process of ‘equalization’, persons with dementia become political agents as well. Interestingly, then, the politics of equal citizens relies on *sanity and reason* in order ‘to speak out’ as much as symbolic biopolitics rests upon the same principle in order to convey the representation of common interests which everybody is meant to understand and which nobody can deny. Common sense and reflexive judgment are presupposed principles of setting biopolitical reasoning on one hand and self-advocated political action on the other that tries to resist the hegemonic biomedical and biopolitical discourse.

This is of outmost importance: By employing matter of facts as symbols of matters of concern biopolitics asks: Who, after having presented you the present and future facts about dementia, who will deny that it is not of common interest? Who will further neglect the reality of the disease and its devastating personal and societal effects? Such reasoning names a double process of stylization or equalization: It presents rationalized facts as cogitative [*vernunftbegabt*] agents. For symbolic biopolitics both facts and agents are politically valid only once they represent equalized measures. They symbolize consensus measures required for political action. Such convergence of consensus names the artificial starting point which translates matters of concern into fixed state of affairs in order to be/come true affairs of the State. This process requires consensus concerning who is considered a legitimate political actor and aims at consensus in the way the problem is tackled and finally solved. Presupposing the human reflexive citizen, ‘social citizenship’ concepts of person centred accounts share with biopolitics the idea of the legitimate political agent and the power of stylized facts. They add another political perspective by employing the same universal principle of sanity and reason. Following from that, it is an all too rash thought to argue that ‘the political’ of modern society ‘operates precisely because it finds itself without a determinate [moral, MS] ground’ (Rasch 2000: 163). The political does not operate without a determinate ground but requires symbolized (rationalized) facts and reflexive agents which serve ‘sanity and reason’ as the moral pre-condition of political action. Politics pre-supposes ‘healthy reason’ as its basic principle.

With the idea of *equal citizenship* the person with dementia becomes part of the legacy of enlightenment as it is developed in Immanuel Kant’s philosophy of reason and its related forms of *cosmopolitanism* (cf. Kant 1983, 1991, 1998). Kant’s critical philosophy as well as his anthropology is about ‘human understanding’ [*Menschenkenntnis*] and ‘cosmopolitan knowledge’ [*Weltkenntnis*] (cf. Kant 1983, 1991; Schillmeier 2012) and dismisses any form of direct experience of the empirical world (cf. Foucault 2010). For Kant, mind and body cannot be understood separately, but nevertheless serve their own means and refer to the executing principles of healthy reason (reflective mind) and sanity (animated body). However, what makes us understand and shape the relationship between mind and body is up to the use of healthy reasoning of our reflective mind and not that of the animated body. In that sense, anthropology and critical philosophy are always human politics, that is, politics of health applying the

principles of reason that enables a common language and marks the possibilities of humans to resist and transcend the given. It is precisely healthy reason which names the precondition of having (political) agency, of speaking out in the first place.

By applying ‘knowledge [*Erkenntnis*] of health’ (Foucault 2010: 108), Kant’s philosophy and anthropology explore the principles of human understanding and exemplify ‘the science(s) of the normal par excellence’ (ibid.). One may say that Kant’s critical philosophy and anthropology presuppose, analyze and enact the healthy human being by applying the principles of sanity and reason in order to map (the limits of) human existence and how it differs from the nonhuman, the apolitical and not to forget the mentally ill and their ‘afflictions of the power of understanding’ [*Gebrechen der Erkenntnißkraft*] (cf. Kant 1977[1764]). Only by applying the interchangeable and universal principle of healthy reason, humans are considered ‘equal’ and unfold the realm of what I like to call the ‘cosmopolitanism of health’. It denotes a form of politics that presupposes ‘healthy reason’ as its common and taken-for-granted principle. It defines the condition of possibility of human everyday political agency as well as that of current State Politics and the politics of social citizenship.

For my concerns, it is crucial to highlight the contrast between Kant’s ‘cosmopolitanism’ and the concept of ‘cosmopolitics’ as advocated here. Consequently, I will draw attention to the contrast between a *universal cosmopolitanism of health* and what I have called the *cosmopolitics of illness*. The cosmopolitanism of health refers to the *sensus communis* that is given by the realization of ‘the good’ as the compliance of the body, reason, rationality, knowledge, truth, morality and political action whereby the compliance is determined by the laws of one of them: healthy reason. Dementia, on the other, unravels the cosmopolitics of illness, which disrupts and questions such compliance and its determining principle.

If we not only want to understand why (political) agency is primarily understood as a sole *human* capacity, but also why and how (political) agency defines being human, we need to go back to Kant’s most influential project of enlightened humanism (cf. Schillmeier 2012, 2013). Kant’s ‘An Answer to the Question: What is Enlightenment’ (1784) suggests that with the use of ‘healthy reason’ we humans are capable of self-guidance and thereby express the moral principle of what it means to be human: as ‘independent and free beings’ (Kant 1995: 89) we humans are our ‘own final end’ (Kant 2006: 3). Only by applying the moral principle of reason we are able to progress as a human culture. Kant states:

All cultural progress, by means of which the human being advances his education, has the goal of applying this acquired knowledge and skill for the world’s use. But the most important object in the world to which he can apply them is the human beings: because the human being is his own final end. – Therefore to know the human being according to his species as an earthly being endowed with reason especially deserves to be called knowledge of the world, even though he constitutes only one part of the earth. (ibid.)

By employing our reason we acquire ‘knowledge of the world’ which enables us to become progressively independent and free from the ‘mechanisms of nature’ and its ‘technical-practical [...] laws’ (Kant 1995: 361). The use of our naturally given healthy reason enables reflective judgment, which ‘politicizes socially acknowledged forms of rationality and belief systems superimposed by technologies and experts for our soul and body’ (Schillmeier 2012: 37). Kant’s argument is radical as well as intriguing: reason is *the* principle, the formal self-limiting and incontestable rule. Applied, it defines human beings as free and autonomous beings. Proper thinking, that is the use of our healthy reason, means, as a matter of fact, the ability to resist the seemingly given, natural or normal reality – be it imposed by nonhuman nature or self-imposed. Kant’s normative philosophy of healthy reason employs the *principles of scientific reasoning* to outline the moral principle of human being: Rules are resisted by rules, laws by laws, principle by principle (cf. Kant 1998).¹³ Being the principle of principles of human being, *reason* is a moral law and it is our *duty* to stick to it as a universal law that guides our practices (Kant 1961). Kant stresses:

For the pure practical use of reason consists in the precepts of moral laws. They all lead, however, to the idea of the highest good possible in the world insofar as it is possible only through *freedom: morality*. (Kant 1995 [1786]: 199)

Practical reason, then, is a moral act. Morality is grounded in practical reason; reason is the general law. It is the general moral law that grants the capability of everybody’s understanding, a moral law that can be understood by everybody and which knows what is required in practice, and therefore it is good (cf. Kant 1961: 56). Hence, it is reason that allows for reflective judgment (rationality) and makes reason speak in political action. ‘Nature has willed’, so Kant claims, ‘that man, entirely by himself, produce everything that goes beyond the mechanical organization of his animal existence and partake in no other happiness or perfection than what he himself, independently of instinct, can secure through his own reason’ (Kant 1983: 20). Consequently, rational beings are free and capable *political* beings; morality is grounded in the very common and normal capacity of every sane and adult human being. It enables them to use their own understanding, their autonomous opinion in order to oppose to the seemingly naturally given realities. It is our duty, then, to follow the commands of the universal lawfulness of reason in political action so much so that our action can become a universal law, a formal principle (Kant’s Categorical Imperative) (Kant 1983: 132).

For Kant, as Martha C. Nussbaum has pointed out in ‘The Fragility of Goodness’, ‘[t]he internal harmony and self-respect of the morally good person,

¹³ Obviously for Kant this ‘principle of life’ is not based on ‘concepts of the sensory’ and ‘science’, because it ‘emanates from the extrasensory’ (cf. Kant 1995: 361). However, it symbolizes a self-referential universal principle, which for Kant grants the enduring symbolic power of scientific and mathematical reasoning (cf. Kant 1998; Schillmeier 2012).

the autonomous maker of his own law, cannot be affected by mere happenings in the world' (Nussbaum 2001: 49). This is precisely so because the morally good person fulfils 'the requirement of *healthy* reason' (Kant 1995 [1986]: 199) and his 'thinking for oneself' does not dispute the 'prerogative of reason which makes it the highest good on earth, the prerogative of being the final touchstone of truth' (ibid.: 206). This allows the ordinary man as well as the most speculative thinker to use 'their freedom lawfully and hence in a way which is conducive to what is best for the world' (ibid.: 207).

Moreover, it enables rational beings to employ their own understanding (reason) and form a self-educating public [*Publicum*] in order to morally grow and mature as civilizing beings that leave behind the 'guardianship of nature' [*Vormundschaft der Natur*] (Kant 1983 [1786]: 53). If we follow the moral duty of using our reason we also mature as *world citizens* [*Weltbürger*], who may finally become capable to resist and question our self-imposed institutionalized governance by means of 'one's understanding without guidance from another' (Kant 1983 [1784]: 41). Humans, then, become *cosmopolitan actors* [*Weltbürger*] of a *cosmopolitan society* [*Weltbürgergesellschaft*] (cf. Kant 1991). As cosmopolitan actors we humans speak for common 'world' interests, for the common good that goes beyond conflicting individual or nation-state interests and aims at a 'perpetual peace' of human socio-cultural life. The cosmos of man is the 'knowledge of the world' provided by and aimed for healthy beings naturally 'endowed with reason'. Clearly, the disturbance or lack of healthy reason refers to an utterly non-autonomous, non-free realm where no political and moral action is possible.

We can imagine that for Kant, Cameron's symbolic Politics and the instrumentalization of stylized facts of expert knowledge would have been a central issue for public opposition. And indeed, for Kant this would be the most legitimate (political) act, since it articulates 'the freedom to use reason publicly in all matters' (ibid.: 42). In political public action, reason speaks for itself. Reason reveals publicly what it means 'to orient oneself in thinking' (Kant 1995 [1786]: 192). However, Kant would quickly add that the public use of reason is 'the use that anyone as a *scholar* makes of reason before the entire *literate world*' (ibid.). Thus, the human being must be able to employ his naturally given, healthy reason in order to act as a citizen. It is precisely the public role as scholar that encourages the citizen to criticize the symbolic realms of representation and its mechanisms (for example Cameron's Politics). Kant's political actors – although in raw forms – are healthy and clever by nature. They need to be rational beings ('equal citizens') in order to become political actors in the first place.

Evidently, then, Kant's normative cosmopolitanism, which cultivates reason as the universal law of human (political) agency, is not universal at all. Clearly, it is only valid for the cognitively capable, healthy human being who has the capacity to become political, literate and educated in order to dwell within the moral realm of cosmopolitan society (cf. Kant 1961: 54; Schillmeier 2012: 37).

Both symbolic biopolitics and the politics of 'citizenship' rely on the normality of healthy reason as the pre-condition of political agency as well. Current

symbolic Politics appeals to the *good sense* and tries to mobilize sanity and reason to tackle the matter of fact at stake. Thus, with the help of statistics and scientific knowledge dementia is framed as a problem of population and is meant to raise common interest. Politics defines dementia as a problem, which although poorly understood, becomes apparent as a general problem in a way that nobody is thought to deny its public relevance, since it names a true biopolitical and biomedical fact. Statistical scientific facts do not only play the role of defining a common interest, scientific research on dementia is meant to reveal the biomedical and neurological nature of dementia in order to treat or cure it. Thus, next to Politics, it is modern science and the medical gaze through which the nature of dementia – as a disease and deficiency – speaks. With the help of science and bio-medicine ‘undeniable’ general facts about dementia are meant to appeal to the logic of healthy reason, the moral and good will of the ordinary man. It is precisely our common sense understanding that symbolic Politics and its alliances address. With the production of concerns of common interest everybody is thought to be concerned about dementia! Moreover, it seems consensual and natural to ‘fight against’ dementia by employing and improving our rational technologies of knowledge (science, medicine) which finally will ‘crack’ and cure dementia. We have seen that Cameron’s focus on dementia as a ‘terrible disease’ that affects the whole nation, does indeed present a strong political symbol of a crisis that is meant to *represent* a societal problem of *common* interest. Cameron’s spin on dementia as a ‘national crisis’ serves as a placeholder to emphasize a ‘general’ concern by equating the ‘national’ with a ‘global’ population. Dementia is communicated as an illness that affects ‘*all* in society irrespective of gender, ethnicity and class’ (Department of Health 2009: 16). In addition, symbolic Politics does not stop highlighting another ‘undeniable’ fact of dementia: Dementia produces enormous economic costs, which in turn endanger the overall national stability (cf. Robertson 1990, Comas-Herrera et al. 2007).

Against the background of a national crisis, it seems unquestionable, then, that symbolic Politics must be ‘determined to go further and faster on dementia – making life better for people with dementia and their carers, and supporting the research that will ultimately help us slow, stop and even prevent the condition’ (Cameron in Department of Health 2012: 3). Such formulaic phrasings are hard to resist, since they express a *moral* of common sense that strives for better life, good care and cure. To be sure, I am neither suggesting to dismiss the issue of dementia and related experiences, nor do I intend to devalue the idea of preventing or curing dementia. Evidently, though, I try to highlight that the biopolitical construction of dementia as a *common concern* is not a neutral endeavour although the rational technologies employed argue *as if* it is. This is my point: Symbolic Politics refers to the moral conduct of what I have called the *cosmopolitanism of health* inasmuch as its technologies of general truth appeal to the good nature of thought and the good will of the ordinary thinker who is capable to understand the problem at stake. Obviously, biopolitics remains a contestable position with respect to perspectives on dementia, which are not dominated by the biomedical, economic or national

gaze. Symbolic biopolitics is designed for generalists and thus is not very well equipped to draw upon and deal with the very specific and situated life-worlds of people with dementia.

The concept of ‘social citizenship’ on the other is meant to offer a critical alternative to the bio-medical gaze and does include the persons with dementia and their particular experiences. However, like symbolic politics, the political power attributed to persons with dementia does depend on the idea of healthy reason as the condition for the possibility of (political) agency in the first place. People with dementia are equal citizens if they are able to speak out in the public sphere.

Clearly, the *dementing* person, the one caught by the moment of dementia, the one who can’t remember, who doesn’t know, who is paralyzed by uncertainties and anxiety, who remains silent and can’t write, the one who cannot speak out and so on, does not get a political voice precisely because s/he does neither match the morality of symbolic viz. representative Politics, nor does s/he fit with the idea of ‘social citizenship’. The dementing person unwittingly resists and subverts the hegemony of healthy reason, political good will and the realm of sanity and reason. Unwittingly, the dementing person does not show good will to be ‘equal citizen’, it denies to be enrolled as a cosmopolitan actor of healthy reason. Rather, the dementing process and its effects unravel the cosmopolitics of dementia!

The Cosmopolitics of Dementia

The disturbance of reason is precisely what makes the event of dementia *cosmopolitical*: It interrogates the common moral law that grounds the cosmopolitanism of health by placing an interstice within the self-sufficiency of reason, its technologies and socio-political forms of rational(ized) interaction. The political good will, that provides the possibility of cultivating the scholarly, literate and educated cosmopolitan future faces its dis-appropriation and unfolds the *cosmopolitics of dementia*.

The point that I try to elaborate is not to equate the ‘person with dementia’ with his/her illness, but to discuss the *political* relevance of the *process of dementing* itself, that is the process of forgetting, of intensive feelings, of being affected by an unknown world, of confusing things, of feeling lost, of being misunderstood, of feeling displaced, of lacking a voice, of being different than expected, and so on. Following Isabelle Stengers (2005: 996), cosmopolitics is not a political ‘project’ similar to the various forms of the ‘cosmopolitanism of health’ (biopolitics, social citizenship), but has ‘far more to do with a passing fright that scares self-assurance, however justified’ (ibid.). The dementing person not only does not resemble or represent sanity and reason, nor does s/he enjoy his/her autonomy in the capability of using his/her healthy reason to act scholarly, literate, pragmatic, knowledgeable, that is ‘worldly’. Quite on the contrary, the dementing person transgresses the *world of knowledge* and lives in a world utterly *unknown* to sanity and reason. By the process of dementing, reason becomes ungovernable

by reason, reason does not translate in verbal or textual forms, every day practices are troubled and the non-cognitive viz. *affective* relations gain importance over the rationally acting mind.

Martha Nussbaum stresses the unruly implications introduced when affective relations govern human life and subsequently interrogate and transgress the self-governance of reason:

The activities associated with the bodily desires not only exemplify mutability and instability in their own internal structure; they also lead us and bind us to the world of perishable objects, and, in this way, to the risk of loss and the danger of conflict. The agent who ascribes value to activities connected with the appetites and emotions will *eo ipso* be depending on the external, upon resources and other persons, for his possibilities of on-going good activity. Furthermore, these 'irrational' attachments import, more than many others, a risk of practical conflict and so of contingent failure in virtue. And even when passional activities are not deemed in itself valuable, the passions can still figure as sources of disruption, disturbing the agent's rational planning as if from without and producing distortion of judgement, inconsistency or weakness in action. To nourish them at all is thus to expose oneself to a risk of disorder or 'madness'. (Nussbaum 2001: 7)

For lawful minds like Kant and his modern rationalist descendants, the governing power of affective relations disrupt any moral claim of a universal principle that secures the general duty of the ordinary human being 'to promote the well-being of others' (Nussbaum 2001: xxii). With the gradual loss of cognitive functions, human agency erodes and the binding ground and principle that grants autonomy (practical reason), our moral common sense ('good will') is fading as well and we are enacted by the unsettling power that questions the taken-for-grantedness of healthy reason. With the loss of practical reason personally and socially disruptive as well as unruly action is disclosed. Moreover, without practical reason we are unable to use our own understanding and thus become utterly dependent on others. Incapable of using our own understanding, we are enacted by uncontrollable forces that disorder our life. Following from that, sanity and reason tells the ordinary man that it is not only a terrible disease and a fundamental loss of independency and identity, but a most problematic a-normal condition that needs to be 'cared for' by the power/knowledge of the common sense of us 'normals'.

As we have seen above, one way of resisting such an understanding is

by revealing and exploring the myriad of ways in which people with dementia are maintaining and asserting personhood, forming coalitions, claiming rights, becoming politically active, exercising agency, taking control, risks and responsibilities, speaking up for themselves and others, and dealing with the demands of citizenship within the context of dementia. (Bartlett and O'Connor 2010: 5)

I very much endorse to broaden the cosmopolitan perspective to people with dementia and all the positive and changing effects it has by resisting the assumptions of a mere deficit model of dementia. However, the perspective of cosmopolitics that I try to explore is about the insistent questions that remain when the conditions of possibility of performing political agency as ‘equal citizens’ are interrogated by the dementing process itself.

Lacking Rationality, Lacking Reality?

From the Kantian perspective, all the disturbing effects emanate from the fact that the dementing person misses out the inner rules, which provide the capability to link and *unite* intuition/sensory perception [*Anschauung*] with thinking, which provides the conditions of the possibility of experience [*Erfahrung*]. Obviously, then, the very social orders that depend and are enacted by rationality and reason are troubled as well. Without the rational capability of linking and uniting the sensory/affective realm with thinking one remains incapable of translating things that affect us – human and nonhuman alike – into things *known*, that is into enduring and recognizable objects, into ‘concepts’ in the Kantian sense (cf. Kant 1781/87[1998]). The very social objects of our daily life – humans and nonhumans alike – and the different ways they are related (their forms of knowledge) are the effect of conceptual functioning. As social objects they are part of our everyday life, which can be represented, imitated, classified, stylized, simplified, remembered, related, distributed and so on. Things known (objects) become part of our normal life by normalizing them. Our relations with social objects and the different ways we think/conceptualize them constitute the social orders of everyday life practices. Obviously, the performance of practical reason does not mean that the application of the principles of reason unravels what things are by nature. Rather, things become constructed objects by the specificity of *human* understanding: things inchoate and unknown become ‘objectified’ as known concepts by applying the laws of reason to give them form in the first place.

Accordingly, if the rational power of linking things sensed with the process of thinking them fades, we lose the possibility to make objects known and we lack the capability to turn them into forms, concepts and social objects: we lack experience and experienced objects, we lack knowledge and thus cannot construct and contribute to the social order of known things. At the same time, the lack of knowledge has disturbing effects on the known orders, social relationships and its objects. It introduces non-knowledge, non-knowing practices and unknown things. However, and this is most important, within the Kantian legacy, for those who are able to know, these modes of non-knowledge do neither appear as realities of their own (as *known/thought* objects do) nor do they have the capability *to object* to the social orders in place as thought objects (concepts) would be able to. For those who understand, non-knowledge is always either *known* non-knowledge and

knowledge to come or it is nothing. There is no non-known non-knowledge and thus no agency enacted by non-knowledge.

What is crucial in understanding my point is not to deny the conceptual power in gaining knowledge, but to highlight 1) the disregard of non-knowledge, which comes with the Kantian tradition, and 2) the neglect of the different ways it plays in the process of construction as well as resisting social orders or given realities. The disregard of non-knowledge becomes most subtle, when it is reduced – like in Kant's case – to a mode of knowledge that is still to come. Non-knowledge is a formless mass of objects, which, only when sensed and thought, become constructed objects of subjective experience. From a Kantian view, non-knowledge grants no being in itself.

Knowing and Not-knowing

As I have outlined above, for Kant knowledge is a self-referential anthropological effect that is the consequence of a thinking human being, a healthy subject, who, by using his own understanding articulates his political power, his human knowledge, which is capable of resisting not only the necessities of nature that define what things are, but is also able to question the self-imposed orderings by other humans and their technologies of knowledge. This has crucial effects not only on the very relations between knowledge and non-knowledge, but also on the relationship between the 'normals' who are capable of understanding and those who have difficulties in understanding or even lack knowledge. From a perspective of *cosmopolitanism of health* only the use of (human) knowledge, as a matter of performing the principles of (practical) reason, is able to question and resist the given orders, be they imposed by nature or self-imposed. Thus, political agency is the use of knowledge (philosophical, medical, political, common sense) as a moral obligation that performs the human being and his social orders as his own final end.

The Kantian perspective does not ignore the sphere of non-knowing, that is, the non-cognitive realm (sensory perceptions, affects and affective relations, material objects) as a necessary pre-condition for gaining conceptual knowledge and having experience. But the 'objective content' of the non-cognitive realm is constructed exclusively as a mental process, a process of cognitive construction. Without this ability, one has no understanding and one is unable to make the *circle of freedom* that defines *thinking* as the founding act of reason. It outlines the condition of possibility of thinking which provides the capability of human freedom in the first place.

Human agency as well political agency depend merely on the thinker who is able to process cognitively the feelings, affections and the materiality of his environment (objects). The subject who cannot think (properly) and thus lacks understanding is consequently seen as deficient of human and political agency as well as being socially problematic. Such a perspective renders whatever is

not known or what is not analyzed by cognition as deficient – individually and socially, philosophically and anthropologically.

Hence, the Kantian ‘mise en equivalence’ that tries to pave the way to universal liberation along universal principles of the mind produces its ‘*victims*’ as Stengers would say (cf. Stengers 2005: 995). People with severe mental illnesses, cognitive disabilities, dementing minds and so on are all unable to contribute to the ‘universal’ self-assurance of rational communities that ground the equivalence of their members in the capability of reason.

Resisting Unwillingly and Dementia Publics

From a cosmopolitical perspective, people with cognitive disabilities, and in the case of dementia, their dementing practices, resist *unwillingly* such ‘mise en equivalence’. They insert a *cosmopolitical* dimension to the cosmopolitanism of health. It is the cosmopolitical dimension which is precisely the huge challenge and the demands of ‘dementia’ that (Cameron’s) Politics, the institutionalized delivery systems of care, medicine and science, economy as well as everyone living with dementia and with dementing people are facing in multiple and highly heterogeneous ways. Hence, on one hand, Cameron’s rhetoric of a ‘crisis’ acknowledges the ‘interstices’ (Stengers 2011) unleashed by the *cosmopolitics* of dementia – be it personal, social, epistemic, ontological, political, economical, and so on. The sensible [*vernünftig*] community and the general public but also the knowledgeable experts are called to care for the specificities of dementia and its disruptive effects. Although Cameron’s Politics reveals ‘dementia’ as a biomedical problem that needs to be ‘cracked’, his rhetoric of a ‘crisis’ leads to the very problems we are facing to conceptualize, define, perceive and consequently acknowledge the uncertain and often inadequate ways of dealing with dementia.

Our ‘collective denial’ of dementia, then, is not so much a denial of dementia as a problem that needs to be solved, but the denunciation of the cosmopolitical agency of dementia that introduces *differences*, interrogating the self-assuring rational/ized grounds of our everyday orderings and troubling common sense, the political good will, sanity and reason and its most elaborated forms such as the philosophy of reason, symbolic biopolitics, economy and science. What is feared and most problematic is precisely the possible loss of reason, which functions as the general, self-referential principle *a priori* that exemplifies and grants the autonomy, the morality, the good will of those living a modern life: Dementia politicizes the self-referential *cosmos* of modern principles of morality, thinking and acting. Consequently, the *cosmos* of the dementing process has been neglected and denied.

For us late moderns, dementia appears as such a thoroughly demanding issue since we have to admit along our own technologies of reason that dementia cannot be neglected and denied anymore while at the same time we fail to have proper knowledge about it. Thus, it creates diverse ‘publics’ (cf. Dewey 1927)

which assemble *concerned* actors ‘jointly affected by a problem for which no existing institution or community is currently providing a settlement’ (Marres and Rodgers 2005: 929). Dementia awes public concern since it seems to be brought forward, at least partially, by modern life itself (‘ageing societies’) *without* having adequate institutionalized forms of solving it. These publics are concerned with dementia as a most unsettling as well as democratic issue. Dementia is unsettling because it is democratic: It is of a general ‘public’ concern since *every single body*, while becoming older in an ‘ageing population’ is at undeniable risk of being affected by it. And it is democratic since a) *nobody* (no person, no group, no discipline, no organization, no institution and the less so the ‘nation-state’) can provide a settlement of the issue of ‘dementia’, and b) *nobody* is in a *privileged* position to speak for ‘dementia’. Following this line of thought, it is precisely dementia itself, the dementing process that has the power to politicize *everybody’s* ‘cosmos’ of how *every body* does and experiences things (human and nonhuman alike) and how *every body* relates with his/her body and other ‘bodies’ (human and nonhuman alike) in order to do and experience things.

Power/Non-knowledge – The Agency of Not-knowing

The agent of *cosmopolitics* is not the knowledgeable, mindful body (be it a single body or a body of many bodies), but the un- or non/knowing embodied relations with all their unsettling, ambiguous and uncertain effects. The inclusion of the dementing person, then, should not be conflated with the ‘political good will’ as part of a ‘politically correct’ programme of ‘civil rights’ granted to the dementing person once they comply with the rules of the rationality of the political.¹⁴ Rather, as argued above, it is precisely the ‘passing fright’ of the moment of dementia itself that opens up a time-space of *not knowing* of what is happening and not knowing what to do about it that is characterizing the unfolding of what I call the *cosmopolitics of dementia*. Thus, contrasting the Kantian understanding of ‘cosmopolitanism’, which argues that the culture of politics of practical reason will progress towards a ‘good common world’ [cosmos], the idea of cosmopolitics ‘is precisely to slow down the construction of this common world, to create a space for hesitation what it means to say “good”’ (Stengers 2005: 995). Following Stengers, the notion of ‘cosmos’ attached to ‘politics’ can be understood

as an operator of *mise en égalité*, equalization, provided that we strictly separate *mise en égalité* and *mise en equivalence*, for equivalence implies a common measure and thus interchangeability of positions’ (995). Here operating means

14 To emphasize, the complex processes that make up the diversities of the changing experiences of dementia forbid the exclusion of the politically active person with dementia as much as politics should not be completely absorbed by the principles of ‘healthy reason’ and the idea of the ‘equal citizen’.

creating, infusing the political voices with a concern that is not a reflexive or self-indicting one but a positive, to be added to and not to undermine the way they discuss a situation. It is a matter of imbuing political voices with the feeling that they do not master the situation they discuss, that the political arena is peopled with shadows of that which does not have a political voice, cannot have one or does not want to have one. This is a feeling that political good will can so easily obliterate when no answer is given to the demand: "Express yourself, express your objections, your proposals, your contribution to the common world we're building. (ibid.: 995–6)

One of these shadows is precisely the dementing person, who, if one follows the logic of judging reason [*urteilende Vernunft*] viz. reflective judgement, appears incapable of having a political voice, the more so when the dementing person resists unwittingly the talkative forms of symbolic Politics and the literate forms of social citizenship. The situation of the dementing person politicizes the politics of equivalent measures, its mobilized stylized facts and technologies of truth, which in the discourse of symbolic Politics function as the starting point for common sense claims and practices. Politics cannot mobilize a dementing person as a political actor, not even as someone who may show *good will* in recognizing the equally *good will* of Politics: s/he unwittingly resists to be/come part of symbolic politics, a possible voter, a stake holder, equal citizen, a representative of common sense and so on. For Politics the *common good*, both the stylized fact that alludes to the truth of matter of fact of common interest and the ordinary man that represents sanity and reason, authorizes political action. Hence, for the means of Politics, in order to mobilize dementia as an object of common sense political action, the dementing person is necessarily excluded from having political agency, since s/he misses a healthy, memorizing cognitive system and is often unable to articulate his thoughts in verbal or literate form.

Rethinking Common Sense

To be clear about it: Being concerned with the *cosmopolitics of dementia* is not to abandon common sense, but to question the philosophical idea that common sense (as sanity and reason, as opinion) is an 'anthropological static feature' (Stengers 2009: 38) which grants the pre-condition and starting point for authorizing political agency. The *cosmopolitics of dementia* can be understood as a 'test' (ibid.). It names a testing of stylized facts and common sense claims in the very moment the very commonalities of our thinking and doing, our remembrance of what has been and our expectations of what will come, are disrupted, questioned and altered. Thus, rather than being a philosophical symbol for a general and universal principle that enables human (political) agency, *common sense* draws our attention to 'the bewildering variety of what it means to be both in touch with and touched by 'reality' (ibid.). Dementia can be understood as a *cosmopolitical event*.

It introduces difference, uncertainties and insecurities, assembling an event that resists the technologies of symbolic Politics as well as its philosophical foundation.

Rather than naming its denial or destruction, cosmopolitics initiates a contrast to representative and consensus based/oriented symbolic Politics. The cosmopolitics of dementia resist the modern understanding of politics and the self-assuring philosophical thought that grounds political action as a matter of 'sanity and reason'. Consequently, it also resists the idea of the 'ideal citizen' possessing 'the natural capacity for thought' (Deleuze 1994: 130) as the defining anthropological grounds for political action. From a *cosmopolitical* point of view, the dementing person turns into a political actor precisely because s/he unwittingly resists to be mobilized as a stylized object, for example for rational forms of care delivery, as an 'equal citizen' and so on, and withstands to be taken for granted as the rational, politically mature subject of symbolic Politics. To grant political agency to the *dementing person* unravels the *politicization of the taken for granted cosmos of the Political and its legitimate representatives*. The *dementing person*, then, is also interrogating and resisting the 'Image of thought' (Deleuze 1994: 131) that delivers the philosophical foundation of such unquestioned universal legitimation.

The Image of thought refers to 'the natural exercise of a faculty, of a presupposition that there is a natural capacity for thought endowed with a talent for truth or an affinity with the true, under the double aspect of a *good will on the part of the thinker* and an *upright nature on the part of thought*' (ibid.). This is of utmost importance, since symbolic Politics, as the realm of common sense, cannot be understood without the very philosophical pre-supposition of 'common sense as *Cogitatio natura universalis*' (ibid.). Deleuze shows that the inherent Image of thought refers to the problem of a circular structure of philosophical thinking, which, like the Cartesian '*je pense, donc je suis*', is meant to avoid all the presuppositions that would betray philosophical thought, but at the same time carries 'subjective or implicit presuppositions contained in opinions rather than concepts' (ibid.: 129) with it. Consequently, the concept of 'the pure [and identical, MS] self of 'I think' (ibid.) is based on the taken-for-granted empirical self and thus is founded upon non-philosophical grounds.

Deleuze remarks that we have to carefully pay attention to the implicit morality¹⁵ of concepts that transport the unquestionability of what we all should be capable of, 'of what everybody knows and is presumed to know what it means to think' (Deleuze 1994: 131). Moreover, the circularity of such thinking undermines the creativity of philosophy itself, that is the creation of concepts which are meant to resist the 'functions of the lived' [*fonctions du vécu*] of the consensual and taken-for-granted perceptions and affections (cf. Deleuze and Guattari 1994). Deleuze stresses: 'For if it is a question of rediscovering at the end what was

15 'When Nietzsche questions the most general presuppositions of philosophy, he says that these are essentially moral, since Morality alone is capable of persuading us that thought has a good nature and thinker a good will, and that only the good can ground the supposed affinity between thought and the True' (Deleuze 1994: 312).

there in the beginning, it is a question of recognising, of bringing to light or into the conceptual or the explicit, what was simply known implicitly without concepts' disables philosophy to 'truly begin, or indeed authentically to repeat' (Deleuze 1994: 129). Consequently, it is important to withstand the temptation of an all too smooth circularity of philosophical thought that relies on 'pure and simple opinions' (ibid.).

Conceptual Persona

The dementing person can be seen as a 'conceptual persona' [*personage conceptuel*] (cf. Deleuze and Guattari 1994, Chapter 3) that resists such 'natural, [...] dogmatic, orthodox or moral' Image of thought (Deleuze 1994: 131). Hence, the *cosmopolitics of dementia* pays attention and is concerned with

[a] question of someone – if only one – with the necessary modesty not managing to know what everybody knows, and modestly denying what everybody is supposed to recognise. Someone who neither allows himself to be represented nor wishes to represent anything. Not an individual endowed with good will and a natural capacity for thought, but an individual full of ill will who does not manage to think, either naturally or conceptually'. Like 'an underground man who recognises himself no more in the subjective presuppositions of a natural capacity for thought than in the objective presuppositions of a culture of the times, and lacks the compass with which to make a circle. Such a one is the Untimely, neither temporal nor eternal. (Deleuze 1994: 130)

Drawing on Dostoevsky's and Shestov's work, Deleuze's conceptual personae of the Untimely is the 'idiot' whose being is meant to make the others slow down in their consensual understanding of common sense. The *dementing person* shares with the idiot that s/he unwittingly questions what everybody is meant to recognize as a matter of fact. S/he is indifferent to the morality that presupposes what everybody is meant to know and s/he troubles common sense assumptions. As a conceptual persona, s/he puts 'the powerlessness to think (...) into thought' (ibid.). Moreover, s/he puts the powerlessness of having a political voice into politics. It is the powerlessness to think or to think properly and the missing wor(l)ds of the dementing person, that make others think and rethink their position and their ways of thinking and doing things. Dementia politicizes the (reflective) doing and undoing of social relations.

As a political persona, then, s/he questions, disrupts and alters common and taken-for-granted modes of everyday life and their spatio-temporal orderings. His/her illness-effects politicize the most personal and private relations and his/her 'ill will' resists to be represented and recognized by the 'generalized other' (Mead 1934) and the way the relations with significant others were taken for granted, lived and known. Not recognizing the life long partner, the children and

close friends, resisting the ways these relations were lived – for good or bad – feeling uncanny with one's supposedly well known environment is an intense and uncanny experience. It requires the others to rethink what has been taken as normal and obliges them to pay attention to the differences dementia introduces. The demented/ing situation itself unfolds the fright of the uncanniness of being; it troubles the human social and its related and situated forms of normalcy and normalization. The dementing person does not speak in the name of the common world, in the name of knowledge, in the name of social normalcy. No, dementia troubles and alters the normal, the given and expected personal and social life.

To summarize: The dementing person is rather indifferent to the powerful politics of knowledge economies and related knowledge practices. As a cosmopolitical actor, then, the dementing person 'is the one who always slows the others down, who resists the consensual way in which a situation is presented and in which emergencies mobilize thought or action' (Stengers 2005: 994). Dementia politicizes the cosmos of politics understood as the space where human rational thought and reflection meet. It thus resists politics as understood in the Greek and Kantian sense of cosmopolitanism. Moreover, as a cosmopolitical actor, dementia challenges the well thought economies of knowledge democracy and the celebrated pluralization of expertise. The dementing person unwittingly resists the social and political arrangements of private and public space. Dementia enacts the *questionability* of the meaning of the normal, the given and expected, the good and the social. This is why dementia is thought of as an emergency situation or a crisis: it is a liminal experience that disrupts, questions and alters our personal bonds, our routine social practices and related institutional settings as well as the politics and expertise that come with it.

Affective Relations and Experience as Assembling Feelings

Dementia *affects* our taken-for-granted personal and social life. This is precisely why it is such an emotionally intensive and demanding experience. For people living with dementia as well as for their partners, families and caring others, the emotional impact that is related to the loss of cognitive abilities, brings to the fore the importance of affective relations and the significance of every day practices which are not governed by cognitive processes and related knowledge practices. Consequently, with dementia we not only become aware of the effects of the loss or lack of cognitive capabilities, but also that conceptual knowledge is not all that we can know and understand. It also discloses that *experience* is not a mere inner and singular process of a human thinker. Rather it refers to a variety of 'feelings' which are felt, 'but what is felt is not necessarily analysed' (Whitehead 1979: 153). It nevertheless dominates the everyday life of those experiencing the effects of dementing processes. Conceived in this way, experience refers to a 'process of feeling and [u]nderstanding is a special form of feeling' (ibid.).

Such a radical twist in understanding the process of experience avoids conceptualizing experience primarily as a process of cognitive understanding that turns unknown things, which are merely sensed objects, into known objects, which are concepts and everything we can know. It also avoids bifurcating between the realm of nonhuman objects (objects as datum, non-knowing) and the human sphere, which by subjective experience is perceived and understood. Experience, in the Kantian sense, is the ‘process from subjectivity to apparent objectivity’ (ibid.: 156). Following Whitehead, experience is inverted,

namely from the objectivity, whereby the external world is a datum, to the subjectivity, whereby there is one individual experience. Thus [...] in every act of experience, there are objects for knowledge, but apart from the inclusion of intellectual functioning in that act of experience, there is no knowledge. [...] Cognizance belongs to the genus of subjective forms which are admitted, or not admitted, to the function of absorbing the objective content into the subjectivity of satisfaction. Its importance is therefore no necessary element in the concrete actual entity. In the case of any one such entity, it may merely constitute an instance of what Locke terms ‘a capacity’. If we are considering the society of successive occasions in the historic route forming the life of an enduring object [the personal order of a human being, MS], some of the earlier actual occasions may be without knowledge, and some of the later may possess knowledge. In such a case, the unknowing man has become knowing. There is nothing surprising in this conclusion; it happens daily for most of us, when we sleep at night and wake in the morning. Every actual entity has the capacity for knowledge; but, in general, knowledge seems negligible apart from a peculiar complexity in the constitution of some actual occasions.

We –as enduring objects with personal order– objectify the occasions of our own past with peculiar completeness in our immediate present. We find in these occasions, as known from our present standpoint, a surprising variation in the range and intensity of our realized knowledge. We sleep, we are half-awake, we are aware of our perception, but are devoid of generalities in thought. [...] Also we can remember factors of our immediate past, which at the time we failed to notice. (ibid.: 158, 160–61)

For Whitehead all actual entities, human and nonhuman alike, have the capacity for knowledge. But we humans are especially good in moving in and out of knowledge. Consequently, Whitehead asks,

when we survey the chequered history of our capacity for knowledge, does common sense allow us to believe that the operations of judgment, operations which require definition in terms of conscious apprehension, are those operations which are foundational in existence either as an essential attribute for an actual

entity, or as the final culmination whereby unity of experience is attained?
(ibid.: 161)

Whitehead's answer is a clear 'no', since it is precisely our common sense experience, which alludes to the negation of consciousness as the foundational act of the human being, of having agency. Kant's enlightened philosophy of reason celebrates the very 'general case of conscious perception' which is 'negative perception': This is not my daughter; this is not the house I used to live in and so on. 'My daughter' or 'this house' articulates the 'ingression in its full character as a conceptual novelty which addresses an alternative'. 'Consciousness is the feeling of negation. [...] Thus the negative perception is the triumph of consciousness. It finally rises to the peak of imagination, in which the conceptual novelties search through a universe in which they are not datively exemplified' (ibid.).

As I have shown above, conceptual novelties are precisely the starting and end point of Kant's cosmopolitanism of health, whereas for Whitehead 'consciousness only arises in a late derivate phase of complex integrations'. Accordingly, for Whitehead, conceptual objects, that is 'those elements of our experience which stand out clearly and distinctively in our consciousness are not its basic facts; they are derivative modifications which arise in the process' (ibid.: 162). This also explains why through consciousness the felt sensory perceptions are much more vivid than the consciousness of felt embodied processes, since the former are 'late derivatives in the concrescence of an experient subject' (ibid.). The form of embodied (physical) experience is emotional. It shows 'sympathy', that is, 'feeling the feeling in another and feeling conformally with another' (ibid.), which in human and animal experience is 'emotion interpreted, integrated, and transformed into higher categories of feeling' (ibid.: 163) and points towards the transition from being vaguely and massively felt [physical feelings] to being felt clearly and distinctively [conceptual feelings].

Experience is a complex set of feelings that assembles the novel becoming [concrecence] of every actual entity.¹⁶ Whereas, for Kant, 'the world emerges from the subject', for Whitehead, 'the subject emerges from the world' (...). Accordingly, the process of feeling cannot be separated off from the feeler, since it is the feelings *aiming* at the feeler: 'Feelings aim at their subject' (ibid.: 222). With these ideas of Whitehead on experience, which I have been discussing all-too briefly, a multi-fold contrast to the Kantian understanding of experience becomes visible:

- a. No entity in the real world can be separated (as an external agent) from the feelings, from what is felt and from which feelings are promoted. By replacing the notion of matter, 'stuff' or 'things' with feeling, whereby

16 For a thorough analysis of feeling as a 'transition effecting a concrescence' see Whitehead (1978).

- feeling thereby refers to the ‘operation of passing from the objectivity of the data to the subjectivity of the actual entity’ (ibid.: 41).
- b. Objectification (physical pole which refers to potentiality, that is the possibility to be felt; the ‘object’ to be a component of feeling) and subjectification (mental pole which presupposes givenness; the subject as the entity ‘constituted by the process of feeling, and including this process’ (ibid.: 88)) are the two poles of experience for which neither consciousness, thought nor sense-perception are essential elements.
 - c. The experient cannot be reduced to the rational human being (characterized by essential qualities), since all actual entities – human and nonhuman alike – are experiential beings which/who in the way they experience become what they are.
 - d. Experience cannot be ‘segregated from nature into the subjective privacy of the mind. Mental and physical operations are incurably intertwined’ (ibid.: 317).
 - e. Thinker and thought are the final ends of a complex process of feelings (bodily feelings, sensory perception); thus consciousness is ‘the final crown [of experience, MS], only occasionally attained, not its necessary base’ (Ibid.: 267). Thus, ‘consciousness presupposes experience and not experience consciousness’ (ibid.: 53).

Along the Whiteheadian inversion of the Kantian model, I suggest to introduce a contrast to a mere cognitivist understanding of dementia by emphasizing the affective and emotional dimension of experience. This means shifting the view away from

the different ways of tackling a biomedical disease that is associated with the loss of cognitive abilities, and the ‘devastating effects’ that come with it, such as the loss of self and identity, psychological problems, lack of personal and social abilities, lack of agency and so on,

towards

the focus on the experiences that are dominated by affective and emotional relations which lack the ‘normalcy’ of cognitive abilities.

Such a contrast brings into the view the shift from the realm of a cosmopolitanism of health that presupposes and requires sanity and reason (as outlined above) towards the cosmopolitics of dementia which puts sanity and reason into question. To emphasize, the contrast introduced is not meant as an operator of confrontational opposition between the concepts of cosmopolitanism of health and cosmopolitics of illness. The cosmopolitics of illness is not a rivalling concept that tries to win over cosmopolitanism. Neither is it meant to romanticize illness as an alternative to health. Rather, it adds the matters of concern of dementia that interrogate

the self-assurance of healthy reason and its advocates. Hence, the contrast I try to outline does not intend to evoke either-or decisions in order to gain consent over an issue at stake, but produces and multiplies differences and possibilities of thinking otherwise. A contrast enacts new ways of existing. In our case, it draws attention to the political agency of dementia that politicizes the normative conditions and the experience of politics being exclusively a matter of the nature of healthy principles and the functions of the mind. The cosmopolitics of dementia affects, that is disrupts, questions and alters the normalcy of cognitively dominated experiences and related social modes of ordering. Consequently, the cosmopolitics of dementia accentuates the affective and emotional relations which cannot be relegated to the 'subjective privacy of the mind' that are meant to solely make objects knowledgeable, but draws attention to the processes of embodied feelings and the diverse ways objects are felt but not known. The focus then is not just the troubled mind and its lack of known objects and relations, but the importance of the different ways of how objects and relations are felt *without* being known.

Experience and Society: The Person as an On-going Collective Achievement

The dementing process names an event where the past, present and future 'cosmos' of the person and his/her relations with others and vice versa become a source of change, distress, vagueness, uncertainties and non-knowledge. People with dementia, their families, relatives and friends, carers, doctors, science and politics alike are all struggling with the unknowns dementia introduces. It is the cosmopolitics of dementia and the multiple unknowns that it introduces that bring to the fore that the cosmos of everyday day human life has no single representative that is able to speak in its name. Quite on the contrary, the analysis of the symbolic biopolitics of dementia has shown that the 'dementia crisis' and its unknowns enrol a myriad of heterogeneous actors and perspectives that are involved in the orderings of one's personal everyday life. These unknowns are too multiple to be addressed from a single perspective. Moreover, dementia demands that we slow down and interrogate how we do things and rethink what we consider normal, meaningful, true and good knowledge, common sense and so on.

Sociologically, the dementing process troubles *social* relations, that is, the relations of humans and things in time and space and how specific modes of everyday life practices are generated, perceived, felt, dealt with and made durable. What a human being perceives, feels and knows depends on the changing practices and relations of humans and things. Accordingly, what is considered as normal and taken-for-granted is not merely given by nature, neither is it enforced on us without our cooperation nor are they solely subjective constructions. This means that our daily lives cannot be understood adequately from either a merely 'objective' (nature), 'structural' (society) or 'subjective' (person) perspective. Consequently, normalcy is not a natural condition, neither is it enacted by structural coercion of society nor is it a neutral anthropological process that refers to a knower-known

relation governed by the principles of ‘healthy reason’ whereby the subject knows and the object is the known. Rather, what is considered ‘normal’ or ‘taken-for-granted’ in the history of our personal lives and in our relations with humans and things refer to complex biographical effects, made and in the making. The normalcy of social orderings then is not given, enforced, or governed by a general principle that provides the conditions of everyday life, but an on-going *collective achievement* of subjects and objects (human and nonhuman alike) that differs in space and time.

To treat humans as well as nonhumans as a collective of subjects *and* objects avoids from the very beginning to presuppose principles (‘reason’, ‘knowledge’, ‘social’, ‘natural’) that divide the reality of experience into separated realms of ‘society/culture’ and ‘nature’, the human and nonhuman, mind and matter and so on. Following a pragmatist perspective,

experience is *of* as well as *in* nature. It is not experiences that is experienced, but nature – stones, plants, animals, diseases, health, temperature, electricity, and so on. Things interacting in certain ways *are* experience; they are what is experienced. Linked in certain other ways with another natural object — the human organism — they are how things are experienced as well. Experience thus reaches down into nature; it has depth. It also has breadth and to an indefinitely elastic extent. It stretches. [...] “[e]xperience” is what James called a double-barrelled world. Like it congeners, life and history, it includes *what* men do and suffer, what they strive for, love, believe and endure, also how men act and are acted upon, the ways in which they do and suffer, desire and enjoy, see, believe, imagine—in short, processes of experiencing. [...] It is “double barrelled” in that it recognizes in its primary integrity no division between act and material, subject and object, but contains them both in an unanalysed totality. “Thing” and “thought”, as James says in the same connection, are single-barrelled; they refer to products discriminated by reflection out of primary experience. (Dewey 1971[1925]: 4, 10–11)

Dewey’s understanding of experience promotes the idea that the basis of experience is not conscious knowledge, but is emotional. Akin to Whitehead, ‘the basis fact is the rise of an affective tone originating from things whose relevance is given’ (Whitehead 1967: 176). A given thing is the ‘object’, a ‘thing received’ and neither a ‘mode of reception’ nor ‘a thing generated in that occasion. Thus the process of experiencing is constituted by the reception of objects into the unity of the complex occasion which is the process itself’ (ibid.: 178/9). From such a perspective, the normalcy of relations is not about the relation of a stable, presupposed and unaltered knower who by sense perception perceives objects as bare *sensa* and makes them known exclusively by rational thought following the principles of reason. Rather, experience unfolds a wider process where ‘[t]he occasion as subject has ‘concern’ for the object. And the ‘concern’ at once places the object as a component in the experience of the subject, with an affective tone drawn from

this object and directed towards it' (ibid.: 176). Thereby the relations between processes of subjectification and objectification describe an active process ('creativity' in Whitehead's parlance) that provides the 'passive objects which derive their activity from the creativity of the whole' relational process: 'The creativity is the actualization of potentiality, and the process of actualization is an occasion for experience. Thus viewed in abstract objects are passive, but viewed in conjunction they carry the creativity which drives the world' (ibid.: 179). It is precisely 'how the experience constitutes itself depends on its complex subjective forms' (ibid.: 177) that shape the process of objectification. In that sense, objects, subjects and the process that is shaping both in the way they relate are essential in understanding the 'occasion of experience' (ibid.: 179), its actual entities and how they shape social practices and its orderings. What is crucial about such an understanding of experience and related modes of social ordering is that subject and object do not belong to different ontological spheres, different realities that separate humans from nonhumans. Rather, 'subject and object are relative terms':

An occasion is a subject in respect to its special activity concerning an object; and anything is an object in respect to its provocation of some special activity [feeling] within the subject. (Whitehead 1967: 176)

If we follow the Whiteheadian and Deweyan understanding of experience, the idea of subjects/object distinction is not obsolete at all *if* we treat both subjects and objects *as* experience, rather than conceiving 'objects isolated from experience through which they are reached and in which they function' (Dewey 1972[1925]: 13). Subjects and objects, or better objects and the process of subjective formations, are most important for conceptual and empirical research *if* subjects and objects are seen as relative terms. In effect, the research on dementia can primarily be understood as the study of experience and its different forms, that is, the study of the different forms of subjectification and objectification. To deal with the loss or lack of cognitive abilities, then, is not merely about dealing with a neuro-pathological illness and the loss of identity. If we want to find out about the uncertain and unknown cosmos of dementia we need to sharpen our focus on the 'primary experience' of doing and suffering; the affective relations between humans and humans and things.

Experience is a collective achievement of actual entities, which, as a matter of subjective concerns are inclusive parts in shaping the subjective forms of experiencing. To speak of this complex process does *e/affect* the reality of actual entities, which, in order to cohere and endure, achieves a group of mutually felt actual entities. According to the way they relate *viz.* feel each other they form the specificities of a self-sustaining social order that configure a 'society' (ibid.: 203; Whitehead 1978: 89). Similar to Gabriel Tarde's sociology (cf. Debaise 2008, Latour 2005, Schillmeier 2009, Tarde 2009), for Whitehead and Dewey 'everything is a society, [...] every phenomenon is a social fact' (Tarde 2012[1893]: 28). This means that societies are not closed, isolated and fixed substances, but every

society 'requires a social background, of which it is itself part' and thus 'must be considered with its background of wider environment of actual entities, which also contribute their objectifications to which the members of the society must conform' (ibid.: 90). Societies, then, refer to the grouping of mutually related actual entities, *enduring* experiences as it were, which make up the 'stubborn facts' (Whitehead 1978: 129) in our lives: persons, animals, things, health, illness and so on. A society, as Whitehead (Whitehead 1967[1933]: 204) stresses,

must exhibit a peculiar quality of endurance. The real actual things that endure are all societies. They are not actual occasions. It is the mistake that has thwarted European metaphysics from the time of the Greeks, namely, to confuse societies with the complete real things which are the actual occasion. A society has an essential character, whereby it is the society that it is, and it has also accidental qualities which vary as circumstances alter. Thus a society, as a complete existence and as retaining the same metaphysical status, enjoys a history expressing its changing reactions to changing circumstances.

In that sense, all enduring experiences or actual entities are societies, human and nonhuman alike, due to the specific mutual modes of feeling and relating of actual entities which define the self-sustaining character of these emerging societies. However, such societies are *enduring* entities, which means that they are temporal collectives depending on an on-going process of mutual relating. As temporal collectives they are in process and thus cannot be fixed by relations of contemporary actual entities. The character of a society, then, is a) self-sustaining but nevertheless dependent on its environment, b) has a history since it is a processual, future-oriented entity unless it becomes an entity of the past, and it is c) a never fully completed entity and hence changes with the 'reactions of changing circumstances'.

What gains full reality in such an understanding is not the society but the social process of how actual entities and societies come into being and how the stubbornness as well as the 'changing reactions to changing circumstances' takes place. Thus, it is the way of how different forms of experiences and societies come into being, change or fail to maintain which needs to be analyzed. In such a reading the life of a human being can be understood as a collective achievement, a society with 'personal order'. Accordingly, s/he is 'the same enduring person from birth to death' (Whitehead 1978: 90). With a personal order a specific character is sustained; it is a society of personal order without the need to presuppose consciousness as the classical notion of 'person' suggests (cf. ibid.: 35). Thus '[a] man, defined as an enduring percipient', whose social order is 'temporal and continuous', is a 'personal' society, a person (Whitehead 1967[1933]: 205). Such a society with personal order is not a fixed entity or substance, but a *more or less* stable 'corpuscular society' composed of many relating 'enduring objects' (societies) and their defining characteristics which due to altering circumstances experience 'change throughout time and space' (Whitehead 1978: 35).

What we experience with dementia is precisely that many of the defining characteristics of the network of taken-for-granted enduring objects that configure the personal order lose importance, fade away and consequently introduce dramatic changes accompanied by a myriad of unknowns. These unknowns appear precisely when the dementing process and the objects of ordering fade away; the *ideas and related forms of social ordering* are getting lost. Obviously, human beings rely heavily on massively and vaguely felt primary feelings or affective relations being ‘interpreted, integrated, and transformed into higher categories of feeling’, that is into *conscious feelings* of clear and distinct relations of mental *ideas*. These *ideas of feeling* are not more complex than primary feelings. Rather, they *simplify* the latter. However, they not only *simplify* the massive and vague primary feelings but also make them prone to be understood differently or even misunderstood: they become contestable, contingent forms of experiences (Whitehead 1967[1933]: 213). Through the process of imitation and institutionalization by conscious and unconscious practices, or by language and so on, ideas become simplified again and turn into repeatable, sustaining, re-cognizable and communicable *forms* of remembering, of living and expecting things of enduring objects/societies. At the same time, as we saw above, these forms of simplification assemble objects and subjects as *relative terms*, as *eventful entities*. Enduring objects or societies are eventful collective achievements, eventful assemblages. Hence, the specificities of the forms, and related subjects and objects, change as well.

With the experience of dementia we are facing the changing of subjective forms and altered objects and relations. As an effect of troubled cognitive abilities, it is not ‘ideas’ but the affective relations which gain importance in the way social processes are experienced. Such a perspective not only draws our attention to the neuro-pathologies of the mind, but emphasizes how we affectively relate with humans and things in our everyday life *without* possessing the reliability of ideas and related orderings that we can build on, live and work with, create new and unexpected things and so on. Thus, the cosmopolitics of dementia requires that we care about these fragile affective relations. Following from what we have said above, to care about a person with dementia will require

- a. To analyze the history viz. biography of the specific personal order and related enduring objects, for example personal attachments, social relationships and so on.
- b. To focus on affective relations and related objects of concern.
- c. To create forms of interaction which are oriented along affective relations with humans and things in order to create reliable and trusting social relations.

From Recognition to Re-cognition

Such a process- and object-oriented account draws attention on the emerging, subjectively formed affective relations of ordinary everyday life and promotes a patient-centred perspective of dementia. It does so precisely because the complex experiences of the specificities of the person's dementia cannot be understood and adequately addressed without taking into consideration the 'objective' biographical situation and the emotional attachments and relations that are becoming real as an on-going *collective achievement* of affective mediations involving humans and things.

To care about dementia in such a way means to engage with a highly demanding situation, since the dementing process constantly erases the objectifications and subjective forms of affective relations and the possibility to re-live their meanings, imitate them, rely on them, build on them, get *an idea* of them, change them, and so on. The dementing process obliterates the specific meanings and ideas of *how* the person is affectively related to this or that human being, to this or that object. Thus, the dementing process eradicates the possibility to take humans and things for granted in the ways they became real in the first place. Such bewildering process requires that the collective achievements need to be constantly re-made, re-felt and re-practiced, that is re-achieved and *re-minded* outside the brain in the course of everyday life practices. Thus, the dementing situation demands the (assistive) externalization of the simplifications and orderings of conscious feelings of 'the mind' along the conduct of every day life inter-action with humans and things.

This is obviously a most challenging situation since it is precisely the taken-for-granted which we are at least consciously aware and where the 'focalization of meaning is absent' (Dewey 1971[1925]: 253). It requires practices, objects and forms of *re-cognition* which may enable a process of affective acquainting and re-acquainting with humans and things. To emphasize, re-cognition as understood here, should not be conflated with 'repeated cognition' or the imitation of the common sense of 'healthy reason' that outlines the 'mise en equivalence' of knowledgeable men. Rather, re-cognition is understood as a 'reminder of the meaning in which a former experience terminated, and which may be used as an acceptable tool in further activities. (...) Re-cognition is a nod, either of voluntary piety or of coerced respect, not a knowing' (ibid.: 267). These acceptable tools for re-cognition must be carefully tested out and designed by paying close attention to the history and biographies of the affective relations and enduring objects of the person with dementia. We humans do not think as much and often as we think we do, but we rely heavily on non-conscious practices and relations instead, which, although a complex on-going achievement of affective relations, grant the continuity of eventful bodies and eventful human social life.

The dementing process may also require that cognition be distributed between the caring persons and the persons of care. We become concerned of things around us precisely when they introduce uncertainties and unknowns with open consequences. Hence, in the moment of experiencing such an event we do not

deal with 'objects known' but with non-known objects. With the event, difference is introduced to the specific ways normalcy has been accomplished. Following from this, the reliable and taken-for-granted are not provided by principles of consciousness or healthy reason, but conscious attention is most alert and active in the moment where the reliable and taken-for-granted is disrupted, questioned and altered. 'The immediately precarious, the point of greatest immediate need, defines the apex of consciousness, its intense or focal mode. It draws attention to the re-direction, re-adaptation, re-organization' (ibid.: 254) and 're-enaction' (Whitehead 1978: 245) of the vague, massive and uncontrolled meanings of things into ideas of meaning, which in turn can be used to rely on, to build upon and to change. Once these ideas are taken-for-granted, the focalization of meaning is absent again. Our daily life is full of movements in and out of conscious perception; we constantly re-assemble our world. Hence, our common sense experience articulates not so much the principles of healthy reason, but the 'rhythmic waxing and waning' of the 'stream of consciousness':

Empirical confirmation of this conception of consciousness is found in the extreme instability of every perceived object; the impossibility of excluding rapid and subtle change, except at the cost of inducing hypnotic sleep; the passage from being wide awake, awake, drowsy, dreaming and fast asleep, according as an organism is actively partaking, or abstaining from partaking, in the course of events. (Dewey 1971[1925]: 254–5)

Through the dementing process the taken-for-granted becomes visible precisely because it cannot be used and built upon for the requirements of the on-going collective achievements of everyday life. Although the taken-for-granted becomes an issue of thought: the normal, the known, the beloved, the hated and so on do not appear as social orderings which belong to the history of his/her personal order. Rather, they appear utterly unknown, distressing, and uncanny; they become questionable. The *questionability* of social orderings cuts into the assemblages of personal life and make us hesitant, nervous, insecure, uneasy and deeply affected, alert and concerned by and for the non-known. In the course of unusual events, unexpected situations, full with unknown practices and things, our consciousness is most alert to reduce the complexity of the felt but uncontrolled meanings to ideas of these meanings.

However, people with dementia often have problems in simplifying and controlling the meanings felt and consequently need *others* to simplify with and for them. The dementing process is an event with 'double-barrelled' consequences: it requires that we *think* much more *with* others than we are used to be. Consequently our daily life depends much more on others precisely when the personal order of humans and things is disrupted, questioned and altered, as it is with dementia. On the other hand, dementia requires that we *feel* much more with others and draws attention to the diverse processes of feeling and being felt, to the affective relations which shape our personal experiences as an on-going *collective* achievement.

Dementia is not just an inert problem of those who lack cognitive capabilities and us healthy ‘normals’ who will diagnose, treat or even cure the deviance from normalcy by applying the principles of healthy reason. Rather, it is the *cosmopolitics of dementia* which questions the self-assuring cosmos of healthy reason and its taken-for-granted modes of ordering. The dementing process introduces the requirements of a ‘cosmos’ that is unknown but nevertheless felt. Dementia, then, is not merely an inert problem of ‘the mind’ and it is not a mere private problem of a person with cognitive impairments that needs to be kept private. Rather, it assembles a most intense *social* concern since it addresses the precarious relations between the known and the unknown, feeling and thought, objects and subjects and vice versa, humans and things, ‘the outer world’ and the ‘inner world’, the present, the past and the future, the private and the public, and so on. Following Whitehead:

There is nothing in the real world which is merely an inert fact. Every reality is there for feeling: it promotes feeling; and it is felt. Also, there is nothing which belongs merely to the privacy of feeling of one individual actuality. All origination is private. But what has been thus originated, publicly pervades the world. (Whitehead 1978: 310)

Time Lost, Time Regained¹⁷

How long is now?¹⁸

... my sleep was so heavy as completely to relax my consciousness: for then I lost all sense of the place in which I gone to sleep, and when I awoke at midnight, not knowing where I was, I could not be sure at first who I was; I had only the most rudimentary sense of existence, such as may lurk and flicker in the depths of an animal’s consciousness; I was more destitute of human qualities than the cave dweller; but then the memory, not yet of the place in which I was, but of various other places where I had lived, and might now very possible be, would come like a rope let down from heaven to draw me up out of the abyss of not-being, from which I could never have escaped by myself. In a flash I would traverse and surmount centuries of civilisation, and out of a half-visualised succession of oil-lamps, followed by shirts with turned-down collars, would put together by degrees, the component parts of my ego.

17 The following parts of this chapter are an altered version of Schillmeier, M. (2009) ‘Actor-Networks of Dementia’, in Schillmeier, M. and J. Latimer (Eds) *Un/knowning Bodies*. Oxford: Blackwell/Wiley, 140–60.

18 ‘How long is now?’ is an art project by Naomie Schneider which invites us to explore and experiment with the relation of time/film and the idiosyncrasies of perceiving the ‘now’ as a moment of three seconds (<http://howlongisnow-project.org/project>).

Perhaps the immobility of the things that surround us is forced upon them by our conviction that they are themselves, and not anything else, and by the immobility of our conceptions of them. For it always happened that when I awoke like this, and my mind struggled in an unsuccessful attempt to discover where I was, everything would be moving around me through the darkness: things, places, years. My body still too heavy with sleep to move, would make an effort to construe the form which its tiredness took as an orientation of its various members, so to induce from that where the wall lay and the furniture stood, to piece together and to give a name to the house in which it must be living. Its memory, the composite memory of its ribs, knees, and shoulder-blades offered it a whole series of rooms in which it had at one time or another slept; while the unseen walls kept changing, adapting themselves to the shape of each successive room that it remembered, whirling madly through the darkness. And even before my brain, lingering in consideration of when things had happened and of what they had looked like, had collected sufficient impressions to enable it to identify the room, it, my body, would recall from each room in succession what the bed was like, where the doors were, how daylight came in at the window, whether there was a passage outside, what I had had in my mind when I went to sleep, and I had found there when I awoke. (...) These shifting and confused guts of memory never lasted for more than a few seconds (...). (Proust 2006: 27–8)

Marcel Proust's *In Search of Lost Time* is a wonderful novel on the intertwining of space, time and remembering. It is very much about non-cognitive remembering where emotions, sensory practices, bodies and objects play a crucial role in human life. The above quote describes the liminal time-span of awakening from sleep; it is a moment where the alertness of conscious feeling is minimal and dominated by the hurly-burly of affective relations instead, massive and vague. It describes the process of getting to know the sense of being oneself, the relocating of one's personal order in the moment of sheer displacement where no social orders, neither of the body and the mind, nor of the environment are existent. The body is too immobile to feel and establish its sense of connectedness with its surroundings. The mind is too relaxed for clear and distinct feeling and the humans, things, thoughts and practices felt are too distant to be graspable, too fast to be slowed down, too mobile in order to tame the tyranny of their multiplicity, their vague locations and uncertain beings. In effect, not only the turbulent swarming of things is vaguely grasped, but also the very being dwells within the uncanny abyss of non-being.

What follows is an adventurous, scary and uncanny search of Proust's personal order. It is a search about *things past* as much as it is about a search of *lost time*, a 'search for truth', characterized by the involuntary (Deleuze 2008: 60–61). Proust's 'objects of memory', his body and his environment, are 'things past'; they scarcely stretch in time and they seem all gone and feel like being 'all dead' (Proust 2006: 60). In the abyss of non-being, Proust hardly feels any thing but a massive and vague scenario of entities that just come and go but are nevertheless

intensively felt. Without *knowing* what they are they rush throughout the time of centuries and crisscross spaces as only ideas of meaning can do. However, Proust's dead objects do not even assemble *ideas* of meanings. They are too fast and too displaced, too mobile, too ephemeral in order to become stable ideas of meanings. They do not assemble enduring and unifying relations that clearly and distinctively qualify these meanings and related feelings. Proust's experience of such a liminal situation only lasts a couple of seconds and the humans, things and practices experienced are scanty of time as well, they lack endurance.

It is the process of re-member-ing that enables him to escape the space of vague and massive feeling of temporal barrenness. It is a process whereby the bewildered multiplicity of mobile meanings gains temporality; the experiences turn into temporal beings again and promote feelings that are of specific concern. So much so that they can be turned into enduring and personal objects, 'societies' as it were, that re-configure and stabilize the collective achievements which sustain the possibilities of personal order. The process of re-member-ing, then, draws upon the *importance of things* as experiences that gather viz. collect people, spaces and times. *In Search of Lost Time* unfolds a marvellous narrative of remembering as the collective achievement of sounds, smells, looks, tastes, feelings, images and embodied practices which relate humans and things through space and time. To be sure, Proust's *In Search of Lost Time* draws our attention not so much to 'memory'¹⁹ as a cognitive ability of our faculties in the brain. Rather, it brings the process of *re-member-ing* to our attention which unfolds a mode of re-assembling the lived but veiled affective relations, their members, detached attachments and practices that are configuring his 'relations of the world'. Proust's narration shows that the embodied process of re-member-ing is a messy, massive, vague, turbulent, unwilling, uncontrolled and fearful process of tracing and creating possible 'members'; it is a process of tinkering, assembling, feeling and imaging the scattered bits and pieces of experiences through time and space. It is a complex process of social ordering which does not orient itself along clear and distinct thought and knowledge practices. Rather, it layaways along the traces of vagueness, possibilities and intensive flows of feelings in time and space before these experiences may become clear and distinct, enduring, extensive and re-cognizable members and belongings of his personal order.

Remembering as Presencing

Remembering, then, is about re-feeling and re-making the multiplicity of embodied and lived memberships and belongings, societies as it were, which are assembling and shaping the personal ordering of a human being. Like any other order and unified form, personal order is, to paraphrase Gabriel Tarde, 'simply

19 The literature on 'memory' is vast. For our concerns see for example Brown and Reavey (2013).

[a] mediating term[s], [an] alembic[s] in which elementary diversity is potently transfigured and, as it were, sublimated' (Tarde 2012: 43). Obviously, the personal order, being a specific order, requires a huge amount of simplifying, excluding and forgetting as well. As a process of positive²⁰ feeling and being felt, however, re-member-ing is re-gathering the relations, practices and bits and pieces, human and nonhuman alike, that configure *and enable* the personal social ordering of the human being. The present personal order enacts a multi-fold process of re-creation, or as Martin Heidegger has put it, of 'presencing'. Martin Heidegger remarks in *On Time and Being*:

The present in the sense of presence [*Anwesen*] differs so vastly from the present in the sense of the now that the present as presence can in no way be determined in terms of the present as the *now*. The reverse would rather seem possible. [...] Presence determines Being [*Sein*] in a unified way as presencing and allowing-to-presence, that is, as unconcealing. What matter are we thinking when we say presencing? To presence [*Anwesen*] means to last [*Wahren*]. But we are too quickly content to conceive lasting as mere duration [*Anwahren*], and to conceive duration in terms of the customary representation of time as a span of time from one now to a subsequent now. To talk of presencing, however, requires that we perceive biding and abiding in lasting as lasting in present being. What is present concerns us, the present [*Gegenwart*], that is: what, lasting, comes towards us, us human beings. (Heidegger 1972: 11)

Personal order can be understood as a mode of re-member-ing which is a form of 'presencing': 'Presencing [*Anwesen*], in relation to what is present [*Anwesende*], is always that in accordance with which what is present comes to presence' (Heidegger 1984: 48). Re-member-ing as presencing is not so much about memorizing the past into a now in order to gain a durable presence, but it is providing the possibilities to go on and to have the possibility to do things differently without breeching the personal order at the same time. The personal order that becomes present absents itself in its unconcealment. The presencing of the personal order gets absent in the present of personal order.

It is precisely this double-fold relation of presencing/presence and presencing/absence that allows for the unfoldedness, the uniqueness of the relation, of *being the same but not identical*. Presencing is unconcealment and presence is the absence of unconcealment, it is the process of 'presencing [...] in which the absencing (but not the absent thing) is present' (Heidegger 1998: 226). Thus, the presencing of personal order goes hand in hand with a process of making absent

20 Positive feelings that include and make things present cannot do without negative feelings that exclude others and make them absent. The same may be said about remembering which in order to remember requires forgetting many things. A process of selection is necessary. On positive feelings and negative feelings (prehensions) see Whitehead (1978: 23, 41).

the on-going collective achievements that make personal order present. This is why we often conflate personal order or the person with notions like identity or a self-reigning subject. We will see in the following chapters that the dementing process disrupts the social orderings and relations of the person and not so much the 'identity' of the person.

As we have seen in the previous chapters, the personal order does not necessarily have to include consciousness. Consciousness is not the basis and principle of personal order but a late-coming feeling of how we are affectively relating with humans and things as well as the conditions and circumstances that arise from these relations. However, it is the alertness of consciousness in situations of change and uncertainty and the ability to re-organize the changing flows of vague and massive feelings into the presencing of refined and more or less clear and distinct 'ideas of meaning', thought, spoken or written. It thereby *exculpates* the 'feeler' from the massiveness and vagueness of primary feelings and *simplifies* the way of an on-going personal ordering as a multiplicity of relating societies. It is a way of giving feelings endurance whilst mediated with other, re-refined means of feeling. Thus, although the circumstances may change, and with it the processes of feeling and being felt, the personal order is enabled to prolong: personal order remains the same without being identical. Re-member-ing, then, is a process of presencing, of re-collecting relations that are of one's concern, relations one cares for, which have shaped and will shape how one cares for them. This means that the personal order should also not be conflated with the person as the conscious human subject. Rather, it refers to an on-going caring relationship of social orderings which configure the continuities of the experience of personal life which do not involve consciousness as its basic reigning principle.

Let us consider again the quote at beginning of Proust's novel where we find the narrator in a moment of awakening from deep sleep. In this short but highly uncanny moment of utter detachment from the world, he finds himself in 'the abyss of not-being'. His *Da-sein* is enmeshed with the 'things, places and years' that have lost their references; he stumbles within ontological insecurity. Proust's character is caught in a moment of dementia; it is the process of re-member-ing the possible members and belongings from being scattered and ephemeral, from lacking time and being merely fleeting actualities, towards becoming enduring collective achievements that bring back slowly but surely the security of being that he could not have achieved by himself alone. Gilles Deleuze (2008) stresses that Proust's *In Search of Lost Time* is very much about time lost *and* time regained. It implicates a process of learning, of apprenticeship. It is the apprenticeship 'of a man of letters' who learns – in and as the work of art only – to decipher the secrecy of *signs* although they may appear problematic, vague and contingent in the first place:

What forces us to think is the sign. The sign is the object of an encounter, but it is precisely the contingency of the encounter that guarantees the necessity of what it leads us to think. The act of thinking does not proceed from a simple

natural possibility; on the contrary, it the only true creation. Creation is the genesis of the act of thinking within thought itself. This genesis implicates something that does violence to thought, which wrests it from its natural stupor and its merely abstract possibilities. To think is always to interpret – to explicate, to develop, to decipher, to translate a sign. (...) We seek the truth within time, constrained and forced. (...) One must be endowed for the signs, ready to encounter them, one must open oneself to their violence. The intelligence always comes after; it is good when it comes after. It is good only when it comes after. [...] To think is therefore to interpret, is therefore to translate. (Deleuze 2008: 62)

In Proust's narration everything begins and ends with the force of signs:²¹ signs of life and signs of art. It is through art and only through art, along a cascade of involuntary exercises, thought, memory and imagination, that we reveal the complexity and heterogeneity, the emergence and transition of signs and the ways we explicate related meanings. For Proust it is the artistic agency which, in the liminal state of non-being, in the state of becoming awake while the body and consciousness is still too relaxed to act, retains the time of signs that apparently have lost their rich temporality, their full temporal being. This means that Proust, dwelling in the abyss of non-being, experiences signs which are short of time; they only express a minimum of temporality which only art can enhance with time. Being in a nascent state, these 'signs of life' are nevertheless the 'beginning of art' and will 'prepare us for the fulfilment of aesthetic ideas' (ibid.: 35). Thereby, involuntary memory plays an important associative role inasmuch as it constitutes the specific human being as well as his/her surroundings as 'virtual beings': 'Real without being present, ideal without being abstract' (ibid.: 38–9). He and the objects around him are in a nascent state of temporality and time can only be regained by the work of art and its practices of spiritualizing substance and immaterializing physical surroundings (ibid.: 30–1). For Proust, then, 'to learn is to remember, but to remember is nothing more than to learn, to have a presentiment' (ibid.: 42) which may finally issue into art and the signs of art. The dementing situation, however, complicates this process precisely at that moment when the productive relation of remembering and learning cannot be taken for granted anymore. The disruptions introduced are not only intensively felt and force us to think. The signs of dementia require an *art of care* which takes care of a deeply unknown cosmos, which is governed by affective processes whereby the relation between remembering and learning cannot be taken for granted any more. Consequently, the idea of realities as a 'collective' or a 'collective achievement' gains central importance for the art of caring about dementia.

* * *

21 On sign and reference, see also Heidegger (1993: 76).

In the concluding parts of this chapter, I will draw attention to the intensities of situations governed by an unsettling, distressing and often unknown ‘cosmos’ of everyday life. Analyzing Marion Kainz’s sensitive video-ethnographic portrait of an elderly woman with AD who lives in a long-time care facility (Kainz 1999/2000), I will show how the pragmatics of remembering and its failures are complex *collective* matters of concern. Dementia, so my argument maintains, unfolds human modes of existence that cannot be described merely as the effect of biological and mental deficits. Rather, it names the social estrangement of feeling-at-home with oneself and one’s environment. However, dementia not only refers to a loss of social reality, but it addresses new modes of social reality that challenge the taken for granted normalcy of everyday practices as well as the institutionalized forms of care that try to deal with it. The following discussion brings to the fore that dementia requires an ethos of *situated care* which requires to be most attentive to the affective relations of everyday life – made and in the making.

‘The Day that got lost in a Handbag’

Mrs M is sitting on a bench in a hallway of a healthcare institution. Her voice is low and she sounds concerned. She speaks to the filmmaker Marion Kainz:

Mrs M: I had here ... in the bag ... someth ... (*Looking in her bag*) in there ... probably ... something ... what I did not ... what I haven’t had ... or how? What do I know ... I’m so unconfident with everything.

Kainz: In your bag. ... What is in your bag?

Mrs M: (*Looking and searching her bag*) Nothing. ... I am probably searching for the day of yesterday.²²

Mrs M, who has been diagnosed with dementia, lives in a nursing home and is the central figure of an ethnographic film by the German director and filmmaker Marion Kainz (Kainz 1999/2000). It has been Mrs M’s smart and lucid way of expressing and describing how she is, feels and thinks, her sadness and her humour, her charm and her hidden smiles, her mischievousness, her anxieties, her deep feeling of being lost, but also her hopes, her humanness, I should say, that brought me closer to the concerns of dementia. It is precisely those concerns and Mrs M’s social and philosophical being, her interrogations of ‘what is going on’ which, in the most uncertain and uncanny moments of her life, in the moment of a betraying reality, brings to the fore her intense feelings, her desire and her concernedness towards being with humans and things. It also reveals the limits and absences her relations bring about. Mrs M’s experiences challenged many of

22 Mrs M talks about her handbag, see Kainz (1999/2000): 9th scene: 10:32.

my pre-formed ideas about human social relations. Her *questionabilities* made me think about my own sociological questions!

Mrs M's situation made me remember and re-read Proust's '*À la Recherche du Temps Perdu*'. The quoted sequence above where the narrator plunges into the 'abyss of non-being' reminded me of Mrs M who, like Proust, is searching for *time lost*, which for Mrs M, unlike Proust, scarcely or only for a moment in time translates into *time regained*. Proust's demented moment also highlights that the forgetting of things is not just the effect of an illness, but a common part of our everyday life. Clearly, this does not mean that there are no differences between Proust's description and Mrs M's dementia. It is important to note the difference. Unlike Proust's narration, Mrs M's situation troubles the artful process of regaining time and its repetitions whenever time is irretrievably lost.

Mrs M is looking at her clothes in the wardrobe in her room²³

Mrs M: These I'll put on a hanger. ... Again I am a ... has-been. ... Look, now there's something hanging in the wardrobe again ... a little while ago there was nothing hanging there ... nothing was hanging. You saw that as well, haven't you? ... The jacket, this is not my jacket. I'm anxious. What if someone is coming in my room ... and is searching ... then I'm a thief.

Kainz: What is that someone supposed to look for in your room [Bei Ihnen]?

Mrs M: Yes, Yes, I do not know ... because the wardrobes usually are empty and only scattered for some part [...].

Kainz: I do not understand why you should be a thief?

Mrs M: Well, if you find property that is not yours [...] well, who could have had them? They'll turn to me, of course.

Kainz: Are these third party properties in your wardrobe?

Mrs M: Yes, precisely.

Kainz: But these are all your clothes!

Mrs M: Mine?

Kainz: Yes.

Mrs M: No.

23 Cf. Kainz (1999/2000): 26th scene: 35:34.

Kainz: Yes, they are.

Mrs M: The coat, yes.

Kainz: And the dresses, too.

Mrs M: Really?

Kainz: Yes.

Mrs M: Then I do not know ... oh God, oh God ... I can't put up with it anymore ... I can't take it anymore. ... Here, the days ... they are passing [...] I'm going insane.

This troublesome dementing event enacts a most distressing situation. Mrs M's clothes in the wardrobe become foreign since they are not remembered and kept real as her *achieved possessions* which are essential parts of holding together the personal order of Mrs M.²⁴ Once they are realized as not being parts of her havings, but as possessions of others, the endurance of her personal ordering is troubled. Moreover, the established difference between what belongs to Mrs M and what does not becomes questioned as well. Mrs M fears that her environment cannot trust her anymore since they will think that she is a thief by collecting/having the belongings of others. Thus, the havings of Mrs M that are remembered as hers would hold together her personal orderings and would enable clear boundaries of what belongs to whom in order to *have* trusting relations with others and their havings.²⁵ In her conversation with the filmmaker, some of her 'lost possessions' gain membership again while others don't; although Mrs M is told that they are hers. But how could they be hers if the wardrobe is normally almost empty? Mrs M asks Marion Kainz to confirm that the wardrobe is normally almost empty. Mrs M seems to trust her. Like a scientist who wants the findings of his experiments to be confirmed by others in order to gain truth, Mrs M looks for a reliable witness who proves that she is right, that she is not a liar, that she is a trustworthy person and that her practices are reliable as well. However, the situation remains ambivalent and alienating since the seemingly trustful filmmaker turns out to be no reliable witness at all. Quite the contrary: The filmmaker witnesses the opposite of what Mrs M says is true. The foreign clothes are not foreign but belong to Mrs M. Consequently Mrs M strongly feels that the situation is not a trustful one. Mrs M has no explanation for the uncanny situation; she is at a loss, she does not know anymore what is going on. She feels that she is unable to trust herself or

24 On existing as 'having' and 'holding together', see for example Debaise (2006), Latour (2013), Tarde (2009), Whitehead (1978).

25 On a philosophy of 'having' see Debaise (2011), Tarde (2012).

others. The situation is uncanny since the same strange situation seems to repeat itself without any clarification in sight. She feels she is going insane.

In Search for Anhaltspunkte – Having, Binding and Keeping

Mrs M is sitting in her room with Marion Kainz, the filmmaker²⁶

Kainz: Do you recognise it?

Mrs M: The room? ... Yes. That's my room, isn't it?

Kainz: You recognise it, don't you? (Pause).

Mrs M: Yes. ... Come, sit down. ... I do not know anymore what to do. ... What do you know about me? Or, where I can link with [einhaken]? (Pause)

Kainz: It's hard for me to put myself into your position, of how you feel.

Mrs M: Lost ... I'm completely lost when I can't remember anymore, it is over. ... I do not know how to go on ... I really do not how I should go on ... there's a dark wall in front of me. (Long Pause) Can't I just go somewhere and ask them if they know me, [...] so I have indications?

Kainz: You are known here, I know you ... mmh, Mrs N knows you as well.

Mrs M: Yes, but I cannot do anything with it [damit kann ich nichts anfangen], because everything somehow has been standing still as well ... It would need to be something disruptive [Durchschlagendes], [...] that could give me a hint.

Kainz: What could this be, for example?

Mrs M: Well, where have I been all this time? [...] What did I do? ... I do not know anything about it. Is my memory gone?

Kainz: (Pause) It's vanishing [...] yes [...] it's vanishing. You're becoming forgetful.

Mrs M: I'm becoming forgetful [...] Yes [...] and how can I stop it?

Mrs M plunges into darkness, she is insecure and feels lost. There is nothing to associate and to engage with. She friendly welcomes Marion Kainz to accompany

26 Cf. Kainz (1999, 2000): 28th scene: 38:50.

her. She asks the filmmaker to help her find a way of re-associating with herself and her surrounding. However, the filmmaker is at a loss too; she doesn't know how Mrs M feels. In the dementing moment, everything has lost its temporality and no time is regained to make things alive again and become part of her life. She and her life-world offer no signs to decipher, nothing to connect with. Her life and the world around her neither stretch into the past, nor does she know how things will move on into the future.

She asks herself and Marion Kainz 'Where have I been all the time?' ... 'What have I done (all the time)?'. To have a sense of place and of herself, Mrs M needs to know what she has been doing, what she has done and where. It is precisely the biographical practices, her biographical relations and objects and how she relates with them, which are missing. The strange objects and unfamiliar relations that Mrs M experiences do not even assemble a hint that brings her closer to the question *who* she is and *what* is going on. Hence, in the moment of dementia, there are no signs, no practices and no locations available to attach to. Nor are there re-member-ings, belongings, or located doings. There is nothing to hook in that would permit a process of deciphering the uncanny chaos. The dementing moment also keeps her separated from *learning* about her personal order and her surroundings. What is active and moving forwards is the process of forgetting, of becoming forgetful. The achieved belongings and members of Mrs M's personal ordering do not promote any feelings that can be positively felt, re-member-ed and finally thought, used, taken-for-granted, or changed. In effect, Mrs M is concerned that there is no/thing that gains concern for her except the uncanny, foreign, decayed/ing things she meets, including herself. Everything is too disassembled and too immobile in order to gain temporal length and hence to be decipherable in the first place. There is no time given or left which would allow associating the things with her personal ordering. Caught by the dementing process everything is intensively felt, but remains strange, vague or unknown, like facing a black wall. Mrs M is very precise in describing her situation. Something 'breaching' is necessary, she says. Something 'breaching' is necessary so Mrs M could change the situation. Something that breaks through the black wall into the open, something that gives time for the process of unconcealment; some/thing where time is regained to provide *Anhaltspunkte* to work with, to associate with and decipher the messy situation, which then would enact the presencing of things.

Mrs M does not look for facts, but for nods, clues, suggestions or hints that provide orientation, 'food for thought' along the open search of what has been lost, of how she and the things of her concerns came and could come into being again. Mrs M looks for *Anhaltspunkte*. The latter literally translates as 'points to hold on' or 'points where things make a stop'. *Anhaltspunkte* are not facts, but neither are they immaterial nor merely spiritual. Mrs M is looking for *points of reference*, *signposts as it were*, *signs* which help her to re-trace the social orderings of her life, which are meant to bring her closer to the members and belongings of her personal ordering. Something to link with, as she says. Mrs

M still feels that there is something ordered to be re-collectable, but she has lost the traces of the social processes and its objectifications. Mrs M looks for *Anhaltspunkte* in order to re-assemble the disassembled social processes of humans and things, practices and feelings. She feels, though, that she cannot do the process of re-assembling on her own, so she enrolls Marion as an *interlocutor* to re-assemble with her. This suggests that Mrs M knows that she does not live or has not lived in or as a void. Therefore, the people she asks for help are *Anhaltspunkte* for themselves as well. They are signposts; signposts which may suggest a possible, trustworthy trajectory which may translate into a recognizable trace of her personal social orderings.

The disruptive process of dementing and its distressing and displacing effects of uncertainty force Mrs M to think; she thinks about how she can re-trace her social orderings in order to gain confidence and certainty about herself and her surrounding. She does not know what is going on, but others may know. This is not only an existential *Anhaltspunkt* for Mrs M in order to possibly gain something breaching [*Durchschlagendes*] that clears the dark wall of uncertainty. It is also a crucial *Anhaltspunkt* for me as a researcher as well as for all those who may care about people with dementia. Through a process of concealment, the dementing situation suggests that 'existing' embraces the achievement of 'havings' and the achievements of relations which assemble actual entities that mutually hold together. This double process of having and binding configure the orderings that *keep* humans and things together as well as it provides a personal order with its related belongings and members. Hence, the process of keeping is very much the effect of achieved *assemblages of concern* which grant the signs, the *Anhaltspunkte*, which allow these assemblages to endure and hold together, as well as it provides traces of how these binding relations are experienced by those being assembled.²⁷

Thus, the process of keeping is very much about 'creating and reproducing worlds that bind' (Latimer and Munro 2009: 318). Rather than focusing merely on the lack of a mental capability, Mrs M's search for *Anhaltspunkte* draws attention to the importance of *how* we are 'living in extension' and how our affective, embodied and material relations come into being and how we live and keep them. As I have shown above, the process of re-member-ing assembles practices involving humans and things, which, once assembled in specific enduring ways, we, for most of our lives, take them for granted as binding. We neither need to think about them in order to make them bind nor do we need to constantly re-assemble the complex social process which made them present in the first place. It is the assemblage itself, which by being kept, does the re-minding, the re-member-ing. It needs something breaching [*Durchschlagendes*] in order to force us to think about what we normally *keep* as 'given' without any further reflection. Hence, the process of keeping makes the process of presencing absent and permits to forget about it. The fact that we all necessarily have to forget in order to re-member in

27 On the notion of 'keeping' see Latimer and Munro (2009), Strathern (2004).

the first place is a crucial feature of the networks of remembering.²⁸ These relations assemble what I like to call actor-networks: actor-networks of remembering and actor-networks of dementia.

Actor-Networks of Dementia

Generally speaking, the notion ‘actor-network’ tries to capture the idea that actors, human and nonhuman alike, their abilities or disabilities to do things like feeling, thinking, acting, or remembering, are the effects and affects of relating heterogeneous entities. Hence a network is an actor as much as an actor is a network.²⁹ The description of actor-networks, then, is not about the focus on relationships of entities as given sources like a person, subject or object. It rather tries to trace the processes of how actors come into being as the effect of associating heterogeneous forces of different elements, objects promoting feeling and shaping the subjective forms of being felt. This process of eventful association of feelings³⁰ can be called *translation*. Only through translation does the composite of our world come into individual being, endure and/or change. Thus, actors are translated translators. The elements involved may differ in the ways they work as associates: They can be either ‘intermediaries’ or ‘mediators’.³¹ Following Bruno Latour, an intermediary ‘transports meaning or force without transformation’ whereas mediators ‘transform, translate, distort, and modify the meaning or the elements they are supposed to carry’ (Latour 2005: 39ff).

Memory, as taken-for-granted, can be seen as the intermediary between mind and matter that links past, present and future events (cf. Bergson 1991). Such a process intermediates between the realities of the past and the possibilities opening up for the present and its futures. But memory is also very much an act of mediation inasmuch it ‘brings to the world (...) the possibility of unfolding, hesitation and uncertainty’ (Grosz 1999: 25). Hence, one can say that on the one hand it is the very pragmatic of remembering that realizes the (resembling) possibilities given by the (known) past, which, in its most perfected, pragmatic and also most convenient, unthematized way, refers to all the routines we do without having to think about them. Then, memory is the perfect intermediary; it translates the past into the present seemingly without transformation. In effect the process of re-member-ing is black-boxed, invisible, made absent. One of the most powerful intermediaries

28 See for example Casey (2000), Esposito (2002), Middleton and Brown (2005).

29 See for example Callon (1986, 1991, 1998), Latour (1988, 2005), Law (1994, 2002), Mol (2003) and Schillmeier (2006, 2007a,b).

30 In the Whiteheadian understanding, which I endorse here, feelings that link and include are ‘positive prehensions’, whereas negative prehensions exclude. Both processes are essential for experience. See Whitehead (1978).

31 See Callon (1991), Latour (2005), Schillmeier (2007a).

of remembering is our non-sensuous bodily perception.³² It refers to our vague and often unnoticed physiological experience whereby the immediate presence comes into being by conforming to the immediate past: it makes us remember our own self as well as our body. In such ‘intermediary’ mode, memory refers to the process of realization that moves between conformation to the past and limiting the possibilities given by the past. Non-sensuous bodily perception deciphers the ‘signs of life’ (cf. Deleuze 2008).

As Edward S. Casey (2000) shows, practices, objects and places also operate as crucial intermediaries – less vague but more ‘objectified’ – of actor-networks of remembering.³³ The analysis of Mrs M’s experience of dementia also suggests that actor-networks of remembering do not exhaust in mere mentalist forms of recollection and representation. Rather they visualize the importance of embodied and material relations, place, object and body re-member-ing. Casey (2000: xi, xix) stresses:

[C]oncrete places retain the past in a way that can be reanimated by our remembering them: a powerful but often neglected form of memory. Body memories are not just memories of the body but instances of remembering places, events, and people with and in the lived body. In commemoration, body and place memory conspire with co-participating others in ritualized scenes of co-remembering. [...] [T]here are few moments where we are not steeped in memory; and this immersion includes each step we take, each thought we think, each word we utter. Indeed, every fibre of our bodies, every cell of our brains, holds memories – as does every physical object outside bodies and brains, even those inanimate objects that bear the marks of their past histories upon them in mute profusion. What is memory-laden exceeds the scope of the human: memory takes us into the environing world as well as into our individual lives.

With Casey we can say that ‘in the case of memory, we are always already in the thick of things’ (Casey 2000: xix). We live in a manifold of extensions. As Arnold and Sheperd (2008: 47) have argued, memory is distributed, and in important ways, it resides in things, in relations between things, and relations between things and humans; by remembering we do live in extensions: bodies, places and things. And we live the heterogeneity of time: past, present and future. Remembering, then, configures the complexities of ‘time-spaces’³⁴ of *relations of things* we are living. Hence, as I am arguing throughout these pages, remembering is not a mere mental copy of the past, but an act of *re-collecting* of *re-member-ing* whereby the spatio-

32 See Whitehead (1978; 1955). See also from different angles Bermúdez et al. (1998), Grosz (1994), Leder (1990), Merleau-Ponty (1962; 1968).

33 Instead of many see Casey (2000).

34 Cf. Schillmeier (2008b).

temporalities of minds, bodies and things constantly *re-relate* with each other.³⁵ Following from that, re-member-ing not only works as an intermediary but it is also and always a *mediator* of realities; re-member-ing actualizes something new – opening up times and spaces for a contingent future.³⁶ Such a process genuinely assembles heterogeneous elements in time and space. And, in effect, innovation, creativity and difference but also individuality and ‘objectuality’ are achieved. It individualizes the social commonalities of intermediated memory (for example social and individual routines) and introduces heterogeneity and difference. Consequently, as an eventful process, it *mediates* social orderings.

Mrs M enters her room and sits on her bed.³⁷

Mrs M: Here, this, this here, door, that’s where we’ve been. And I thought it’s Sunday! Huh? What? Now, now she’s crept into here. Now where’s Gerd, Michael? What’s this? A nightgown or what?

Kainz: These are your roommate’s clothes.

Mrs M: My roommates clothes? Really? So what’s she been looking for in here? Oh, she’s been sleeping here, right?

Kainz: Yes.

Mrs M: Mhm! Yes, roommate, really [wie jetzt]? Which roommate?

Kainz: Here [...] It’s her.

Mrs M: Oh her.

Kainz: Mhm (*confirming*).

Mrs M: She can go to a residential home too.

Kainz: She already is.

Mrs M: Well, and then she gets here?

Kainz: This here is the residential home.

35 Intermediation and mediation then are not different processes but the very extremes of one process of translation.

36 See for example Bergson (2002: Ch. III); see also Deleuze (2002).

37 Kainz (1999/2000): 3rd scene: 02:45.

Mrs M: Is it?

Kainz: Yes.

Mrs M: Nursing home and home for the elderly?

Kainz: Mhm (*confirming*).

Mrs M: Oh [...] here, yes; so what will they do with us?

We can say that dementia occurs when Mrs M lacks memory as an intermediary and she and her world cannot be taken for granted anymore: the immediate present does not conform to the immediate past. This may either produce odd realities, unknown and strange humans and things, unknown practices and so on, or, as we have seen above, the realities vanish and there is nothing to mediate. It is a similar uncanny situation where everything becomes immobile and is lacking temporality. There is uncertainty as well as ignorance about how things (including herself) came into being, what they are and what will happen to them. Lacking memories or confusing them produces an intricate mess of odd mediators; it complicates the world inasmuch as it thins out the thickness of things: the living extensions become questionable. They lose their havings and bindings. At the same time, new, strange and unknown entities become present since they are not felt as *one's* havings and belongings.

Mrs M walking in the hallway of the nursing home

Mrs M: Well, I'm feeling quite strange right now. ... Where are we going to?³⁸

Kainz: You wanted to ask this woman.

Mrs M: Her, her? [...] What did I want to ask?

Mrs K: You wanted to ask this woman, something, didn't you?

Mrs M: Yes, but what? [...] (*To the woman*) May I ask you something?

Nurse: Yes? What do you like to ask [Was möchten Sie denn]?

Mrs M: I'm not sure if I will go home this evening.

Nurse: You're now living here, Mrs M, don't you?

38 Kainz (1999/2000): 5th scene: 05:33.

Mrs M: (To the woman) (Pause) Do I (Pause).

Nurse: You should stay here, Mrs M, ok? [Bleiben sie mal hier]

Mrs M: (To Kainz) Did you hear that?

Kainz: Mhm (*Confirming*).

Mrs M: I can go home. I can go home. [...] You'll rail against me as well, don't you?

Kainz: Who? Me? No.

Mrs M: I do not want to do you any harm.

Kainz: Me neither.

Mrs M: I know. [...] What am I going to do? What am I saying here? I'll only be refused here as well [Hier werde ich auch bloß abgewiesen] [...] I'm living here.

Mrs M: (Enters the lounge of the nursing home) These are [...] these are the people from the bowling ... and all sorts of people who hate me.

Mrs M: (To the nurse) I wanted to ask if you could help me.

Nurse: Later, Mrs M, later.

Mrs M: What do you mean by later? (*Following the nurse some steps*)

Nurse: Yes (Pause).

Mrs M: When is that going to be? (Pause, *turning to Kainz*) I really do not need this; I'm going home now.

In the moment of dementia Mrs M walks into nowhere. She feels displaced and is full of urging questions about her strange situation. She feels attached to a place, which at the same time repeatedly refuses and rejects her. Mrs M is not patient in the situation, nor is she passive, but she is insecure and uncertain. Even her questions become questionable since she forgets them in the next dementing moment. Mrs M frequently moves in and out of the dementing processes, obviously a highly demanding and affective situation. Consequently, with her urging questions, Mrs M is looking for some rest, for something to hold on to. Mrs M is longing for re-collecting some of her havings and belongings. Understandably, she

wants to go home, to a place she is used to and feels that she belongs to. She feels the need to leave the strange place behind; the place where she constantly feels displaced and where she meets people who are utterly unknown, with whom she cannot connect, people who make her feel distressed and people who seem very unfriendly and after all, do not have any time for her and her concerns. Even the most urgent question, the question concerning time: 'Later?' What do you mean by later? When is that going to be?' is left unanswered. Nobody seems to *have* time for her, no time for a constructive social relation, for listening and communicating. Moreover, she herself feels like a stranger, a person who probably is asking too much, has too many questions concerning things that everybody should know, a person who is turning into a nuisance and behaves improperly. Mrs M is worried that even people who do have time and are close and trustful company (like the filmmaker) do not appreciate how she acts. Still, Mrs M feels and knows that she does not want to do something bad or ask for something bad. She only wants things to become trustworthy and engage with people and things that agree with her and vice versa: people and things that *compose* reliable relations, people and things that relate positively and allow for social relations, people who are concerned about her, who feel and are open for her concerns and do not repudiate her and her concerns. She does not want to be 'demented'³⁹ [*dementiert werden*]; she does not want her truth to be denied by others. She wants to be positively re-membered and thus be a continuous part of positively felt social relations, which enact and support conditions of possibilities of her Being.

When Mrs M enters the dining room lounge she thinks that all people there hate her. Her fear seems to be about the threatening of her being and about those that threaten her 'potentiality of being', her 'being possible', her existence. Mrs M is puzzled by her *fear*, which – as Heidegger notes – is grounded in a forgetting (Heidegger 1993: 342). The *Befindlichkeit* [affectivity] of *fear* is about Mrs M's fear of others that are threatening her potentiality of being, without being able to do anything against it with *her* own means. It is the *Befindlichkeit* of fear that tells Mrs M about her forgetting, which makes her feel vulnerable to act improperly against those she fears, against her threatening environment; consequently her fear often turns into depression and/or confusion/bewilderment. Heidegger (1993: 342–2) notes:

The existential and temporal meaning of fear is constituted by a self-forgetting: the confused backing away from one's own factual potentiality-of-being, which is threatened being-in-the-world take care of what is at hand. Aristotle correctly defines fear as *lupe tis he tarake*, as depression or confusion. Depression forces Da-sein back to its thrownness, but in such a way that its thrownness is precisely closed off. Confusion is based upon forgetting. When one forgets and backs away from a factual, resolute potentiality-of-being, one keeps those possibilities

39 The German verb '*dementieren*' and the French '*démentir*' mean to deny, to repudiate, or to question the truth of something.

of self-preservation and evasion that have already been circumspectly discovered beforehand. Taking care of things which fears for itself leaps from one thing to the other, because it forgets itself and thus cannot grasp any definite possibility. All “possible” possibilities offer themselves, and that means impossible ones, too. He who fears for himself stops at none of these – the “surrounding world” does not disappear – but he encounters it in the mode of no longer knowing his way around in *it*. This confused making present of the nearest best thing belongs to the forgetting oneself in fear.

We have argued above that actor-networks of dementia are thinning out things. Metaphorically speaking, minds, bodies and things become too thin *to stand on their own* anymore; the collective achievement of self-ordering and self-sustaining reality becomes disrupted, questionable and altered. Demented objects, human and nonhuman alike, change their mode of existence from being positively felt, known and (often) taken-for-granted, being ‘factish’ [*Gegenständliches*]⁴⁰ and social beings, to negatively felt, unknown and strange facts, that is a-social beings. The mode of existence of a-social beings involves a thinning out of temporality. They become time-scanty: through demented objects, time does not stretch and protract long enough to permit enduring relations. They are not societies but felt as actual entities coming and going, living and perishing at the same time. With the moment of becoming present these actual but demented entities perish.

Demented objects have no past and no future, but an absence that is present. But clearly, demented objects are not absent things! Quite on the contrary, these tumbled, oddly present absent things are far from being a mere standing reserve. They circulate, as we have already seen in Proust’s narrative, as highly complicating mediators associating the actor-networks of the dementing moment. Actor-networks of dementia transform the intermediary and taken-for-granted pragmatics of actor-networks of re-member-ing. They turn into mediators, putting the achieved and positively felt relations of humans and non-nonhumans at risk. They politicize social orders: cosmopolitics of dementia. As mediators the actor-networks of dementia become conspicuous. As I will show in the following pages, they constantly leave traces of questionable objects and situations; ‘signs of dementia’ that require but often refuse to be deciphered.

‘What is at Hand’? The Presence of Absence

Mrs M in her night dress walking down the hallway and meeting the filmmaker

Mrs M: I am all over the place [Ich bin ganz ausser mir] – Good day! With whom do I have the pleasure?

40 The German word ‘*Gegenstand*’ (object) still incorporates the notion of ‘standing’; *Gegenstand* literally translates as ‘something that stands against’.

Kainz: It's me, Marion!

Mrs M: Marion, what is on hand (t)here [was liegt da vor]?

Marion: Whereabouts?

Mrs M: Here, with me and the surrounding [bei mir und der Umgebung]!

Marion: You are here at the [...] nursing home. It is a home for the elderly and a nursing home.

Mrs M: A home for the elderly and a nursing home? Why haven't they told me anything about that?

Marion: I am sure that you must have just forgotten it in this moment since you are nervous.

Mrs M does not remember that and why she has moved into the nursing home. In effect, she frequently is terribly upset finding herself in a place she does not know and she feels that she does not belong to: *she finds herself nowhere* – strange and uncanny. She is also upset that the people there seem to have no concern of telling her where she is and why she is there. She feels very badly treated. Mrs M may have been told hundreds of times that she has moved out of her home and is now living in the ward. However, it is especially her short-time memory that fails. Mrs M remembers the old days better, but sometimes she forgets about them and/or mixes them up as well. Most of the time she forgets about recent moments, about things recently used, the place she slept last night, people she has just met on the corridor, people she met at lunch or in her room, things she just did or intended to do and so on. In effect, she forgets about her new home and the people, objects and practices involved. Her new 'home' appears utterly unknown. Consequently, all Mrs M wants to do is to go home where things are fine. As we have witnessed above, she frequently gets very upset when she perceives people around her as rather impolite in the way they react to her most urging questions.

We have seen that Mrs M – like Proust – struggles with re-member-ing, although in a quite different fashion. Whereas Proust celebrates the artful process of deciphering even the most rudimentary signs as an intensive and complex but most productive process of remembering and learning, Mrs M is constantly disrupted by *signs of dementia* which resist to be deciphered. Still, in both cases, what is experienced as questionable is the very sense of 'being on hand', of *Da-sein*,⁴¹ of existing. Through dementia, Proust and Mrs M are caught in the 'abyss of not-being'. Mrs M's moments and places of dementia, the moments where she plunges into the 'abyss of not-being' multiply during day and night

41 Cf. Heidegger (1993).

and her struggle with memory becomes a persistent company of her life. Mrs M appears to be constantly awakening from the Proustian deep sleep with all its 'shifting and confused gusts of memory'⁴² and their apparent losses.

At the time the ethnographic film was made, Mrs M often reflects upon the very fact that something odd is going on. She struggles while noticing that she is forgetting and confusing things, situations, friends, practices, thoughts, words, intentions, plans and herself. It becomes difficult for her to put the experiences into practice. Some days or nights are better than others. She also remembers some things and some people better than others. Unlike Proust, though, Mrs M is starting to forget the very fact(s) of forgetting or remembering itself.

Disentangled from the temporalities and spatialities of her past and present life-world, Mrs M frequently feels displaced. *Ich bin ausser mir* ('I am all over the place'), she says, which literally translates as 'I am outside of myself'. Mrs M worries about what is happening to her, she does not feel at home with herself anymore. Outside of herself she becomes except. She asks Marion, the filmmaker, a very odd question: 'What is at hand (t)here [*was liegt da vor*] (. . .) with me and the surroundings [*bei mir und der Umgebung*]?' Mrs M is concerned about herself and her circumambience: her *Da-sein*, her existence and the existence of others. She is terrified that her embodied being and her environment is not hers anymore and appears unknown, detached, cut off and there is nothing but a body here and an environment there. Herself and the environment: two mere objects that by their present absence *object* to being part of Mrs M's actor-networks, her personal order, her life-world.

With Martin Heidegger⁴³ we may say that Mrs M's question concerning 'what is at hand' refers to two modes in which entities are typically encountered in everyday practices: ready-to-hand [*Zuhanden*] and present-at-hand [*Vorhanden*].⁴⁴ Mrs M's question articulates a crisis of attachment from those modes of existence. First of all, she feels detached from entities and practices 'ready-to-hand' like her body, her surrounding, her domestic environment, which are taken for granted to assemble the common ways of how she is doing and experiencing things. When we deal and engage with 'ready-to-hand' action/orderings (humans, things and practices) we do so without noticing their 'presence(s)-at-hand'. They withdraw from being cognitively present. Obviously, as we have already argued above, this cognitive absence does not mean 'absent things' or that they have no meaning. Quite on the contrary, their meanings are part and parcel of our everyday life's keeping and making of meanings. Becoming ready-to-hand, the specific processes that have been necessary to achieve the readiness-at-hand of things are absent as well; at the same time they keep up practices and orderings and we gain time and skills to act with and along them, that is to support the possibility of novel things

42 Proust (2006: 28).

43 For a similarly unorthodox reading of Heidegger, see Harman (2002). But see in particular Deleuze (1994, 2006).

44 Heidegger (1993).

and practices coming into existence. If 'things', human and nonhuman alike, are failing to be ready-at-hand, they become present-at-hand and they become visible as questionable things. The specificities of things and their meanings can be questioned, altered, differently used or dismissed. Their mode of existence has changed. With the dementing process, the readiness-to-hand of things becomes present-at-hand as questionable, inactive, standing still, detached. The signs they suggest are vanishing; they become unknown and uncanny feelings. This change from the readiness-to-hand of things to the presence-at-hand of things *dements* [negates, refuses, resists] the truth and the specificities of social orderings, which make their readiness-to-hand and their ability to be cognitively absent possible in the first place.

The readiness-to-hand of things refers to our relatedness, to our affective relating with others and how these others shape our concerns. Rather than being a relationship with a self-present, intentional 'subject' and somehow indiscriminate and neutral 'objects' which are merely *vorhanden*, present-at-hand, the everydayness of ready-to-hand things discloses human existence precisely as the way human beings dwell with or live through others. To exist means to live in extension; whenever humans, things and practices are taken for granted they withdraw from being visible as such. Being-in-the-world or living in extension refers to primordial relations of human existence: Being-with-others, human and nonhuman alike, through which these relations gain their own specificity and significance. And re-member-ing is precisely what keeps us re-collecting our collective existence, living and enduring in extensions, the feelings, intensities and practices, the humans and things involved. To be in the world is to re-member the affective attachments to others. It presupposes others to be attached, not in an abstract but 'thisly' way,⁴⁵ that is, in a way objects become of our concern and partake in the ways these concerns take up subjective forms. Such a reading suggests that all things – human and nonhuman alike – are societies: individuated and enduring, that is temporal entities, beings *and* becomings. They are the same but not identical, present and absent.

However, Mrs M's question that is concerned with 'What is at hand here?' is also a question about *spatiality*, about her living in *extension*. She feels displaced because the networks of remembering have temporarily fallen apart, they do not connect properly; they make her forget and confuse things. Mrs M lives in a constant care facility that hardly resembles her former everyday life practices.⁴⁶ Everything looks, smells and feels different, has different rhythms and spaces: Everything *is* different. Mrs M's troubled short-time memory engenders the very difficulties of feeling at home with herself and her environment. Contexts, routines, situations, people, and things she may still remember through her long-term memories do not match with what she is supposed to feel and be at home with now. At the ward, her long-term memories do not contribute to making her feel at

45 Heidegger (2001). Garfinkel (1967) calls it 'indexicality'.

46 On the conduct of care see Latimer (2000), Tackenberg and Abt-Zegelin (2000).

home. In the moment of dementia, the recent past that is forgotten makes her stuck in the mere presence-at-hand of things.

Mrs M is shackled between the *no longer* and the *not yet*. Mrs M is trapped within the vicious circle of the presence of suspicious facts, which do not provide ‘locations’, practices and relations of humans and nonhumans alike, which assemble, enable and provide a living space for dwelling and would make Mrs M feel at home.⁴⁷ Hence, the feeling of not-being at home is constantly at stake:

Mrs M approaching a nurse in the hallway of the ward

Mrs M: May I talk to you?

Nurse: Yes, what? What do you want?

Mrs M: I am not sure.

Nurse: Yes? What do you want [was möchten Sie denn]?

Mrs M: I’m not sure if I will go home this evening.

Nurse: You’re now living here, Mrs M, don’t you?

‘Old’ habits, significant and highly specific lived routines and experiences with their incorporated temporalities, spatialities and things are stubborn facts in the moment the new habits, routines and experiences cannot be remembered. Precisely in the moment of dementia, the spatio-temporal specificities of the ward’s everydayness are part of Mrs M’s crisis of existential orientation. In so far it seems as if these present objects put Mrs M’s being-in-the-world, her *Da-sein*, her existence at risk. The significance and specificities of her being with human and nonhuman others are lost, which makes her feel nervous, agitated, and anxious. And last but not least: Mrs M thinks that nobody told her that she moved to such an un-homely place –another incomprehensible matter of fact, Mrs M is confronted with. Her concerns are about going home, about re-assembling the locations, locations that make and give sense to her.

Mrs M is talking to a male member of staff (MoS) in the hallway⁴⁸

MoS: Good Morning, Mrs M.

Mrs M: Good morning, from where do you know me?

47 On the relation between ‘dwelling’, ‘location’ and ‘space’, see Heidegger (1971).

48 Kainz (1999/2000): 18th scene: 24:20.

MoS: Pardon?

Mrs M: Where from do you know me?

MoS: You do not know me?

Mrs M: No.

MoS: Of course you do.

Mrs M: No, I do not!

MoS: No? Well, then, you will get to know me!

Mrs M: That's fine, then.

MoS: Do you want me to accompany you [...] for a while? [...] Would you like to walk with me [...] or would you rather have some time on your own?

Mrs M: Well, what's better?

MoS: That's on you to decide, not on me.

Mrs M: Well [...] wherever I receive more information.

MoS: Information? About what?

Mrs M: About a lot of things.

MoS: A lot of things [...] well [...] you are asking questions (laughs). I cannot possibly answer those.

Mrs M: Okay, then you are of no use to me.

The dementing process evokes repetition, but it doesn't repeat what has been remembered. Rather, it enacts the repetition of *questionabilities*: the dementing process enforces an on-going questioning of the humans, things and related practices experienced. Mrs M lacks the orientation along and with them and constantly tries to enlarge her actor-network: She asks others to act as signposts, as points of reference in order to help the search for her losses. Her search aims at re-finding orientation along the route of possible traces given. The dementing process enforces a process of thinking which comes into being while questioning, asking, and wondering! Thinking is orienting towards what is *questionable* [fragwürdig]. This is not only about Mrs M's concern to bring her objects, relations

and practices back into existence/endurance, which makes her think. It is also what makes those who care about Mrs M think about the uncanny situation in place. Dementia enforces cosmopolitics!

The sequence also shows how difficult it is for others to decipher the signs provided by Mrs M. The member of staff, who is meant to know Mrs M very well, seems to be at a loss with Mrs M's urgent and most general questions. Mrs M is not asking for prepared knowledge nor would she be able to deal properly with matter of facts since they constantly appear as unknowns. This is precisely how the sequence begins: The member of staff, who happens to work with Mrs M on a daily basis, is not known by Mrs M. Although she does not know him, she is very happy to get to know him. She is fine with the possibility of getting to know him. She shows concern about being involved in a process where he becomes a matter of concern for her. What Mrs M requires though is not so much the exchange of information, understood as fixed packages of knowledge, but ways of becoming affected by and concerned for the other in the first place. What she requires are ways to become affectively related in order to achieve the possibilities, the grounding locations of getting to know him and all the other 'many things' she wants to get to know. If these feelings are not achieved, are not ready-to-hand and thus do not have a trustworthy and specific meaning, they do not assemble locations of positive feelings that compose extensions. Rather, they constantly decompose them.

The extension between Mrs M and the member of staff are cut. For Mrs M the latter appears, like any other thing in the moment of dementia, as merely present-at-hand and is part of the distressing and unknown situation that marks her uncanny dwelling in the nursing home, where social relations seem rather difficult. Moreover, the member of staff appears utterly useless for Mrs M since he is not able to engage with her most pressing questions concerning *many things*. Although the member of staff is most surprised by such unusual quest, I think it is not at all unusual. Quite on the contrary, it is a quest that all humans share, what makes us humans, as pupils, students, scholars, apprentices and practitioners engaging with and learning from humans and things. Obviously, Mrs M is not a 'young pupil' anymore but a 'mature student' if you will, someone who already has experienced many processes of apprenticeship. These experiences assembled a myriad of practices, humans and things, which in the case of dementia are losing their existence, their being, their temporality and thus their traceable membership. No wonder she asks to get information about a lot of things; she is used to knowing many things!

The following three sequences refer to randomly chosen but nevertheless highly significant situations that address Mrs M and her relations in the nursing home and her relation with Marion Kainz, the filmmaker.

Shackling and Un-shackling Relations

Mrs M leaves her room and meets Marion Kainz, the filmmaker⁴⁹

Mrs M: Look, the sun is rising! Good morning!

Kainz: Good morning.

Mrs M: I wish you a good day [...] all the best.

Kainz: So do I.

Mrs M: Good morning!

Kainz: Good morning as well.

Mrs M: They shackled me again.

Kainz: Shackled?

Mrs M: Not the word “shackled”, but [...] they wore me down, you know?

Kainz: How?

Mrs M: Well, that’s hard to say (Pause) I have to [...] my hands [...] They’re so greasy.

Mrs M is invited to watch a video with the male member of staff (MoS) we met in the sequence above as well as with other residents.⁵⁰

Mrs M: What am I supposed to watch?

MoS: A video!

Mrs M: No, I do not have time for videos.

MoS: Mrs K is coming too. We’re going to watch ‘Die Feuerzangenbowle’ with Heinz Rühmann.⁵¹

49 Kainz (1999/2000): 12th scene: 13:35.

50 Kainz (1999/2000): 23rd scene: 31:20.

51 *Die Feuerzangenbowle* (1944) with the famous German actor Heinz Rühmann, is the story of ‘a successful writer, home-schooled in his youth, masquerades as a student at a

Mrs M: No, I do not need that, I know it already.

MoS: You know it already! Well, then I'll go only with Mrs K.

Mrs M: (To Kainz) Let him go. (Mrs M leaves the room) Can you show me the way home?

MoS: (leaves the room as well) Don't you want to watch it with us anymore, Mrs M? (Pause) (He returns to the room)

MoS: Don't you want to watch anymore, Mrs M?

Mrs M: (Waving to Kainz) Come, let's go!

Mrs M is meant to take part in a singing group.⁵²

MoS (female): Would you like to come with me, Mrs M?

Mrs M: What for?

MoS: It's warmer over there, because of the sun shining through the windows, you see?

Mrs M: It's fine here. I'm not sitting alone.

MoS: Ah, you're sitting with Marion. [...] Well, I for my part would be happy if you join our round. Look, we still have one chair left [...] I'll sit down next to you.

Kainz: I'm coming with you, Mrs M.

Mrs M: Yes.

Mrs M often forgets about Marion Kainz and her camera. Yet, they become close allies in experiencing worlds that seem inaccessible for both. For Mrs M – she and her surrounding – turn more and more into unknown and uncanny realities. For Marion Kainz, the filmmaker, although she participates in Mrs M's everyday life, her experiences are also inaccessible and she feels unable to put herself in Mrs M's place. For the filmmaker, Mrs M's uncanny world remains concealed as does the world for Mrs M – at least if we take the perspective of knowledge and 'knowing

secondary school to experience all the fun and pranks he missed out on' (<http://www.imdb.com/title/tt0036818>).

52 Kainz (1999/2000): 22nd scene: 30:00.

things'. However, it seems that both have established an affective relation that can do without knowing each other perfectly well. Although their situation is obviously a highly different one, they both share the feeling of non-knowing and they explore the world together and how it feels without knowing it.

Moreover, the filmmaker has time to let Mrs M be as she is. This seems to allow them enough time to build a relation of affection and trust *without* knowing each other. For Mrs M the affective relation opens up possibilities to relate and not to be on her own without having the feeling of being shackled. She can experience a feeling of having a joyful and positive (unshackling, non-repellent) relation and not a suffering and negative (shackling, repellent) one. With Kainz Mrs M can share possibilities, she is mobile, the relationship opens up a future. The ward life, on the contrary, she often experiences as an odd, disciplining, punishing and strange place, where things are happening which are not of her concern and consequently for which she also has no time to relate to and engage with. Mrs M feels the ward once and again as a devastating place, where she experiences a 'fertig machen'. The German verb 'jemanden fertig machen' means to take all possibilities from someone, to destroy and ruin someone, to bring someone to his/her end. It literally means 'to make ready', to prepare someone to be ready for doing things, to finish. In relation to her experience of 'being shackled' the notion turns upside down and becomes the negative 'fertig machen', as described above. When Mrs M sees Marion Kainz, on the other hand, 'the sun is rising'; the filmmaker seems to lighten up the 'dark walls' of Mrs M's experience. With the filmmaker Mrs M also feels not alone, she feels fine. For Mrs M, Marion Kainz does not seem to belong to the decomposing and shackling relations of the ward. Quite on the contrary, the relation with Marion Kainz offers possibilities to relax, to possibly escape and re-compose her life. 'Can you show me the way home' ... 'Come, let's go', she says.

Nothing but 'Accomplished Facts' – The Lure of Dementia

Mrs M drained, anxious, and upset.

Mrs M: I do not know what to do. I am being confronted with accomplished facts and I should be happy with them? I cannot be happy with them! I have – do you hear – I have fulfilled all my duties that have been necessary.

Kainz: You did so.

Mrs M: Yes, and?

Kainz: Nobody wants to do you any harm.

Mrs M: And now [nun]? What is happening now [jetzt]?

Kainz: You can continue to live here!

Mrs M: Continue to live here? What does this mean?

Marion: You have already been here for a while.

Mrs M: Already for a while? And nobody has told me so! How is this possible?

Let us recall: Proust's 'rudimentary sense of being', the ungrounded 'abyss of not-being' as well as Mrs M's anxious question 'What is at hand here?' were analyzed as the lack of ready-to-hand relations, practices, humans and things. Mrs M is confronted with an odd loss of the safeguard of embodied and closely felt ready-to-hand locations. To be sure: In the moment of dementia she is still with a body, but not with *her* body. The same can be said about the surroundings: Mrs M happens to find herself in an environment very much present but full of humans and things utterly unknown. Experiencing dementia, Mrs M's body and *Umwelt* are becoming merely present-at-hand: They appear as simply given, detached bodies and objects, coming from and going to nowhere. 'Present-at-hand', they do not make up the ready-to-hand relations of human and nonhuman entities that support and assemble Mrs M's on-going social orderings. When merely present-at-hand, these relations turn into relationships of self-closed, isolated occurrences in space and time, inaccessible and unrelated subjects and objects, which nevertheless dominate her life-world: They happen to be 'accomplished facts', as Mrs M has put it very lucidly. And Mrs M makes it very explicit that she cannot be happy with accomplished facts. She cannot be satisfied with the fact that her social orderings become crowded and dominated with 'accomplished facts' which are not hers and which are not her matters of concern. Mrs M feels governed by given things, shackled by external references. There is nothing to learn for Mrs M, since there is nothing to be re-member-ed which re-assembles the collective achievements of her social orderings. Mrs M experiences her embodied being detached from knowing it and experiences her environment as mere encapsulated and ungraspable, as coercive occurrences in space and time.

At the same time, Mrs M does not know that she is starting to forget. When she does not know, she forgets her forgetting of remembering. In effect, anxiety creeps in. Following my argumentation above, it is not so much a question of a lack of cognitive knowing or a failing of volition. It is not a mere intra-psychic problem. Rather, it is a matter of non-knowing, of feeling, of mood, of affection, of *Befindlichkeit*⁵³ concerning a situation and the relations, practices, humans and things involved. *Befindlichkeit* is about feeling the feelings of embodied processes, the attachments and detachments that we live and experience. *Befindlichkeit* is about how one does feel about one's being, one's existence, of how the attachments

53 '*Befindlichkeit*' is one of three 'existentials' (and not categories) of human existence (next to understanding and speech), see Heidegger (1993: §29).

and detachments are felt. 'How do you feel today with your flu?' or 'How do you feel with this new situation? These are questions concerning the *Befindlichkeit* of someone's situated being, her/his situated living and existence. The general question concerning the *Befindlichkeit* of someone is always a question concerning a situation. *Befindlichkeit* is a situated, non-cognitive self-understanding.

Caught in the very presence of unknown things Mrs M feels and finds herself in a situation of displacement, alienation, of being 'out of tune' as well as being shackled by the 'tunes' of others without having the possibility to tune in. Living with the plain presence of bodies and things, she is cut off from the pragmatics of remembering that unravels the multiple extensions to the past, which support and provide the possibilities of going on, that is for the future. In her existential crisis Mrs M has no past and finds no future: She does not know what to do! She is acting (with)in a very real present-at-hand environment, which, precisely because it is merely present, means nothing to her. The present world happens to come from, to be and to lead into nothing and to nowhere. Her agitated *Befindlichkeit* is of a situation being utterly displaced and detaching with no signposts to hold on to, except for the filmmaker. In the moment of non-knowing her understanding of the situation is emotional, her existence is emotional. What is still re-membered though is another existential, another *Wesen* of human existence, as Heidegger would say: speech. So Mrs M holds on to language, which is ready-to-hand, she lives in language – at least in the situation of the sequence from above.

Bearing this in mind, Mrs M's questions are not only very precise, but assemble deeply human and social concerns: They enunciate the *Befindlichkeit* of and with herself as well as with her environment. Mrs M's question 'what is at hand (t)here?' is an existential question: Being in tune [*Stimmung*] with herself and with her environment is questioned, is out-of-tune [*verstimmt*]. It brings to the fore Mrs M's intimidated, affected and un-homely *Da-sein* [*Being-here*], her anxious and uncertain *Befindlichkeit* through which it happened that her social orderings, her collective existing, her extensions, her possibilities are becoming lost under 'the spell of uncertainty' (Proust 2006: 28).

Actor-Networks of Angst

Mrs M's *Befindlichkeit* paralyzes her. She is at a loss. In the moment where the pragmatics of re-member-ing fails to relate past and future, Mrs M finds herself highly affected, dispersed in an utterly uncanny circumambience. She does not feel at home at all with herself and her surroundings. In effect, Mrs M plunges into *ontological uncertainty*: She is afraid of (her) nothingness, of being nowhere. This is precisely the *Befindlichkeit* of 'anxiety' [*Angst*]. Being anxious is feeling an *uncanny* situation. Uncanniness [*Unheimlichkeit*] refers to experiencing not-being-at-home.⁵⁴ 'Uncanniness', as Heidegger stresses,

54 Heidegger (1993: § 40).

reveals itself authentically in the fundamental attunement [Befindlichkeit, MS] of Angst, and, as the most elemental disclosedness of thrown *Da-sein*, it confronts being-in-the world with the nothingness of the world about which it is anxious in the Angst about its own most potentiality-of-being. (Heidegger 1996: 255[276])

[...] [I]n the face of which one has Angst is not encountered as something definite to be taken care of; the threat does not come from something at hand [Zuhandenen, MS] and objectively present [Vorhandenen, MS], but rather from the fact that everything at hand and objectively present absolutely has nothing more to 'say' to us. Beings in the surrounded world are no longer relevant. The world in which I exist has sunk into insignificance, and the world thus disclosed can set free only beings that are not relevant. (Heidegger 1996: 315[343])

As the etymology of (un-)canny suggests (canny derives from 'can'), she 'can-not' do anything with herself and her environment. Mrs M is entangled in uncanny relations of unknown bodies, unknown objects and practices, which have lost their relevance and their specific concerns. It is the silence of her body and her surroundings, present and 'thinned out' objects that 'say' nothing to Mrs M and assemble her actor-networks of Angst. Thus, it is precisely the on-going collective accomplishments that assemble the personal order of Mrs M which sink into insignificance, into undecipherable 'signs of dementia'. It brings about a rupture of the 'ontological structure of the being that I myself always am is centred in the self-constancy of existence' (Heidegger 1993: 332). As we have argued so far, the personal order that is the same but not identical; the self-constancy of existence is temporal, it is an enduring ordering, a society. As a society, the self assembles and re-assembles the heterogeneities of time (past, present and future), but it also assembles and re-assembles heterogeneous 'matters of concern' which provide and support the self-consistency of existence. In such a reading, 'the self' cannot be conceived as a substance or a subject, but is rather grounded in existence' (ibid.). Existence, then, is not an abstract term, but refers to the way we live our everyday life. To do so, that is to exist, needs time, counts on time; existing is the consumption of time. In that way of giving, requiring, counting on and consuming time we encounter and thus are entangled in the temporalizing temporality of things ready-to-hand and present-to-hand: 'As being-in-the-world Dasein exists factically together with beings encountered within the world' (ibid.: 333).

What makes Mrs M's experience of dementia a cosmopolitical event is the very encountering of the world, its bodies and things, as being merely there, without providing positive feelings to be felt, without being/becoming of Mrs M's concerns of existence. In effect, Mrs M struggles to be able to trace and re-member the social orderings which bring herself and her environment into enduring, meaningful existence. The cosmopolitical event of dementia, then, also brings to the fore the requirements of Dasein as 'being-possible', which 'is not something ... which as an addition also possesses that it can be something;

rather, it is primarily being-possible' (ibid.: 143). It is precisely the existential of *Befindlichkeit*, of the feelings felt, the situatedness of feeling, the specificities of how feelings are felt, which brings us back to and makes us remember our existence as 'being-possible'. Thus, in the moment where the ready-to-hand and present-to-hand lose their taken-for-granted sign-character of Dasein's specific forms of existence and turn into other forms of existence, into undecipherable signs of dementia. It is the *Befindlichkeit* emerging from such a situation whereby the mode of existence *changes*, which enables 'Dasein resolutely to take over that being which it already is' (ibid.: 339):

Thus, Dasein's being becomes ontologically transparent in a comprehensive way [...] within the horizon in which the Being of entities other than Dasein—and this means [...] of those which are neither ready-to-hand nor present-at-hand but just 'subsist'. (ibid.: 333, Heidegger 1962)

Obviously, ontological transparency does not refer to clear and distinct ontic feelings and practices. Quite on the contrary, it is Mrs M's *Befindlichkeit* which, in the moment of dementia, tells her and us about the messy, vague, disassembling, displacing and thus most uncanny situation of her experience. It tells us about the questionability of the common sense, of the taken-for-granted. The dementing situation politicizes, that is, disrupts, questions and alters the cosmos of her common modes of social orderings and related individual preferences of doing things, which enact her ways of self-understanding and her concerns for others. Thereby, the 'potentiality-for-Being' out of which the concern for others, human and nonhuman alike, is understood and becomes troubled as well. 'Understanding as existing', Heidegger notes, 'in the potentiality-for-Being, however it may have been projected, is primarily futural. But it would not temporalize itself if it were not temporal – that is, determined with equal primordially by having been and by the Present' (ibid.: 337). *Befindlichkeit*, so Heidegger claims, 'temporalizes itself primarily in having *been* [Gewesenheit, MS]' and thus 'the character of moods lies in bringing one back to something' (ibid.), something we have been *having*. *Gewesenheit*, that is having been, is always having *been* and been *having*.

But how, one might intervene, can entities be called actors if they 'say' nothing, if they are utterly alien to, detached from and non-significant to Mrs M? It is precisely Mrs M's Angst that relates non-related and non-specific objects. Heidegger notes:

Angst is not only Angst about . . . , but is at the same time, as attunement [Befindlichkeit], Angst for . . . That for which Angst is anxious is not a definite kind of being and possibility of *Da-sein*. The threat itself is, after all, indefinite and thus cannot penetrate threateningly to this or that factually concrete potentiality of being. What Angst is anxious for is being-in-the-world itself. In Angst, the things at hand in the surrounding world sink away, and so do the innerworldly beings in general. The 'world' can offer nothing more, nor can the

Mitda-sein [being with other *Dasein*, MS] of others. Thus Angst takes away from *Da-sein* the possibility of understanding itself, falling prey, in terms of the 'world' and the public way of being interpreted. It throws *Dasein* back upon that for which it is anxious, its authentic [*eigentliches*, MS] potentiality-for-being-in-the-world. Angst individuates *Da-sein* to its ownmost being-in-the-world, which, as understanding, projects itself essentially upon possibilities. Thus along with that for which it is anxious, Angst discloses *Da-sein* as being-possible, and indeed as what can be individualized in individuation of its own accord. (Heidegger 1996: 187)

One can say that the specificity of actor-networks of Angst is that they cut⁵⁵ the common and taken-for-granted spatio-temporal networks into messy, fractious, stubborn and highly individualized configurations. So much so they do not promote any feelings, which are of Mrs M's concerns, except being non-decipherable and uncanny. When she is within the *Befindlichkeit* of Angst she is assembled by the present-absence of practices, bodies and things, which remain unknown and are foreign to her social orderings.

We saw that the dementing process enacts the loss of the temporality of things – human and nonhuman alike – so much so that things do not endure in order to be re-membered, to be decipherable and to learn from. In the moment of dementia *nothing* contributes to make Mrs M feel at home with herself and her environment. Her world is un-wonted, un-gewohnt,⁵⁶ non-lived, non-habitual, fearful and distressing [ängstigend]. Since there is nothing to positively relate, to dwell in and to build upon/from, since there is nothing to keep to and to be remembered by, Mrs M finds herself in the *Befindlichkeit* of Angst. The actor-networks of Angst remind us of our mortal being, that is of being empirically present-at-hand and it's falling into non-being, its decay, ruin and death. Interestingly enough this happens alongside a breakdown of relations as well as along a veiling of the things involved. Mrs M encounters a radical severing of the ready-to-hand relations of mind, bodies and things: they become mere present-at-hand objects. Ambiguously enough, these present-at-hand objects *object* being merely objects present-at-hand. They turn into risky and virtual ones, silent, ungraspable, veiled objects that refuse to be known at all but nevertheless enact the presence of things. It is precisely by being non-epistemic objects, that is non-knowing objects, that they affect us in the most radical and uncanny way and lure Mrs M into the pondering of *Angst*. The *Befindlichkeit* of *Angst* assembles the coming and going of the massive and vague, uncertain and un-known *affections* of being with others who became signs of dementia.

55 Heidegger (1996: 175[187]: 39). On 'cutting networks', see Strathern (1996).

56 The German adjective 'ungewohnt' literally translates as 'non-dwelled' or 'non-habitual' and also means nothing to build on/from. For the relation between dwelling and building ['wohnen' and 'bauen'] as human existing, see Heidegger's 'Building Dwelling Thinking' in Heidegger (1971).

It is precisely the *Befindlichkeit* of *Angst* as a specific mode of affection that arises from uncanny, cut-off relations and undecipherable signs, which bring to the fore her existence as a highly individualized and enduring effect of on-going social (collective) orderings. Due to the dementing process, the *on-going collective achievements* become visible as *individual non-related entities*. It is the *Befindlichkeit* of *Angst* through which Mrs M becomes visible as a *person* that desires to assemble complex individualized feelings and matter of concerns. Whenever the dementing situation relates Mrs M to humans and things being undecipherable signs of dementia, she becomes concerned about her *individual* being and how she relates and is affected by the individualities of her environment. Through the dementing process Mrs M becomes visible for others as different since she does not contribute to the taken-for-granted social orderings in place. She cannot be taken for granted since she constantly questions the taken-for-granted. Conversely, Mrs M also feels as not *belonging* to these specific social orderings. She appears being *on her own* and perceives herself as being alone and lost. She, as well as her environment, is felt as standing out from the taken-for-granted and the often hidden and implicit flux of social orderings. She misses the clear and distinct feelings for and of herself, she is forgetting herself. She feels strange and bewildered. Caught in dementia, Mrs M becomes socially conspicuous; she turns into an event that dwells in a self-closed form. Individualized by dementia, Mrs M becomes a case, a resident in a long-term care unit, a 'home-less' person, an object of the medial, medical and scientific gaze; an annoyance for some and pitied by others. She becomes a cosmopolitical actor that disrupts the taken-for-granted social orderings. Cut off from the social routines, she appears 'non-social', living in her own world, more or less unapproachable, acting peculiar, and asking existential questions. In effect she appears helpless, vulnerable, asking for too much and is in need to be cared for. However, we have also seen that Mrs M desires for *Anhaltspunkte*, signposts to search for her lost collective being. To retrace what has been forgotten, Mrs M is not looking for individual entities or accomplished facts. Rather she is engaged with re-member-ing her 'own' temporalities, her biographical trajectories, her specific affective relations and collective achievements, her locations, her actor-networks and so on, which *made and make up* her existence, her life and potentiality-of-being. Mrs M's feeling of uncanniness that temporalizes as the *Befindlichkeit* of *Angst* unravels Mrs M's human existence as potentiality-of-being. Following such a reading, the individualizing effect of *Angst* is not only a disturbing fact of broken and disassembling social ties, but at the same time, it invites Mrs M to open up and enables her resolute searching for novel possibilities to regain time to dwell in and build upon.

Her *Angst* forces her to fight against her forgetting and unleashes her search for re-member-ing. In effect, she becomes *curious*.⁵⁷ The process of dementia and her frequent feeling of being 'all over the place' enforce the repetition of her curiosity. Mrs M articulates her on-going curiosity by addressing others through speech:

57 On 'curiosity' as a tendency of existence, see Heidegger (1996: 346).

What is going on with the surrounding and me? Do you know me? Where can I get information? Where can I link in order to find that help tracing the signs to re-assemble, to dwell and build again? Mrs M's persistent curiosity grounds in the persistence of forgetting what was.

Moving in and out of the dementing moment, Mrs M's *Da-sein* jitters within a 'multiverse' (James 2003) of ready-to-hand relations and the uncanny presence of undecipherable signs, between attachments and detachments, between collective achievements and individual presences. Her times and spaces of everyday life flicker between detached, self-closed relations that have no past and no future, and moments where the past is felt and open to be translated into the future present. We also have seen that the filmmaker – although often non-remembered and forgotten as well – plays an important role in regaining time. With the filmmaker, Mrs M connects 'hope', hope to regain time to find signs that bring back what has been lost. Without knowing each other very well, their relation is not dominated by mere negativity and forlornness. The affective relation with the filmmaker is a positive one and not just one of fear and anxiety. With the filmmaker – the partner in uncanniness – she feels the possibility of gaining possibilities, that is the possibility of getting to know things, of changing things, of escaping the un-homely relations and having a signpost that shows her the way 'home', of putting things in place again in order to build on, to dwell, to live in extension, to exist.

The Force of Silence – Conscience, Guilt and Care

We have seen so far how the presence of absence makes Mrs M plunge into unrest and anxiety. She is faced with accomplished facts to which she has no positive relation: they are neither part of her own life-world nor a product of her own decisions. Mrs M feels enacted by accomplished facts that clearly do not make her feel at-home-with.

Mrs M walking through the ward (drained, anxious, upset):

Mrs M: I am being confronted with accomplished facts and I should be happy with them? I cannot be happy with them! I have – do you hear – fulfilled all my duties that have been necessary.

Obviously, living in a long-term care facility, Mrs M has to keep up with rules and routines. Since she forgets her situation, these appear as modes of punishment for having failed to comply with certain societal expectations. In his seminal study on Asylums, Goffman defines a 'total institution'

[...] as a place of residence and work where a large number of like-situated individuals, cut off from a wider society for an appreciable period of time, together lead an enclosed, formally administered round of life. Prisons serve as

a clear example, providing we appreciate that what is prison-like about prisons is found in institutions whose members have broken no laws. (Goffman 1961: 11).

We have seen how the mere presence of the absence of things imprison her being of (her-) self, so much so that she feels utterly displaced and closed off from the social orderings that make up her existence. Mrs M cannot escape the presence of absence of things, things that lost their endurance. They neither appear as ‘societies’ contributing to her personal order nor are the social orderings and related members and belongings traceable that brought them into existence. Consequently, Mrs M’s world is devoid of decipherable signs; present but meaningless, they assemble the actor-networks of anxiety. Clearly, Mrs M cannot be happy with those ‘accomplished facts’. They not only make her feel devastated but shackle her existence. This may explain why she feels forced to point out to Marion, the filmmaker, that she has fulfilled all her duties. Her conscience is calling, she feels guilty.

Marion, the filmmaker responds quickly and confirms ‘yes, you did fulfil your duties’ (we suspect that she may have had experienced the situation very often during filming). Still, it seems that it helps little to ease Mrs M’s situation.

Mrs M: And now [nun]? What is happening now [jetzt]?

Marion: You can continue to live here!

Mrs M: Continue to live here? What does this mean?

Marion: You have already been here for a while.

Mrs M: Already for a while? And nobody has told me so, how is this possible?

‘Yes, but?’ she asks and adds right away: ‘And now [nun]? What is happening now [jetzt]?’ Mrs M remains stuck in the presence of the absence of things. Marion’s answer that she ‘can continue to live here’ instantaneously brings Mrs M’s dilemma back: How is she supposed to continue to live here and dwell in a place that for her does not ‘exist’ and thus is utterly alien? Mrs M becomes even more suspicious when she hears that she has already been ‘here for a while’. Nobody has told her so, no person, no thing, no body. And how could they? All these mediators – persons, bodies and things – do not assemble the pragmatics of Mrs M’s re-member-ing any more. They have turned into thinned-out actor-networks that do not stretch and protract in time. They are in need of time. Utterly unknown and detached, they mediate Mrs M’s *Da-sein* into uncanniness and Angst instead.

Mrs M feels un-homely and is forced to live in an oppressive place. She feels forlorn in the ‘they’ [Man] where everything has been already fixed, decided upon, and chosen. They keep Mrs M from associating, from having a say in the way things come into present. It is an unknown place which promotes strange

feelings, a place where things and people are non-social, non-social in the literal sense of the word: they do not associate, they are not allies, they are not members of her collective orderings. Being confronted with 'accomplished facts' producing undecipherable signs, Mrs M does not find traces suggesting where things come from and go to. The crucial question for Mrs M is: 'What is happening now'? How can she go on like that without any signs, without any suggestions? How are endurance, existing and dwelling possible under such conditions: '*Continue to live here? What does this mean?*' she ponders. What must have gone wrong, she seems to ask? She has fulfilled all her duties; she did socialize, she was a good member and fulfilled all the requirements of the social orderings she has been involved in. She has done *her* contributions, but nobody is reciprocating adequately, but 'they' [Man] do things without her being participating. By highlighting that Mrs M has fulfilled all her duties it seems that she answers to the call of her conscience.

I cannot deny that these sequences not only puzzled me emotionally, but also in terms of sociological reflection. The scene is filled with vagueness (anxiety, the presence of absence of bodies and things), with objects that do not object, with actors that act due to their indifference to others, with affects, feelings, emotions, with 'inner voices' and so on. All in all, I was confronted with very obscure traces of even more incomprehensible mediators and vague actor-networks.

Mrs M's insistence (she wants to be heard!) that she has fulfilled all her duties seems to be more than just a way of reassuring that she lived a societal life where she has contributed to all the moral expectancies of her social membership. Rather, the actor-networks of *Angst* assemble the silent call of conscience as a way of *self-assurance*, an assurance of the very individuality of *her* being-in-the-world, her personal ordering, her 'potentiality-of-being-a-self' (Heidegger 1996: 274). Her conscience insinuates that *she* has done everything necessary; *she* fulfilled all her duties. The call of conscience is adamant as well as vague, indeterminate and thus open to different understandings: Yes(!), she has fulfilled all her duties (what duties?). The call of conscience does not convey what Mrs M did and how she acted and lived. Her environment will not get an answer for what she means by 'duties'. This remains indeterminate. Conscience calls for Mrs M's personal ordering in the midst of her forlornness. Tuned by *Angst*, the call of conscience takes part in summoning 'Da-sein into existence, to its own most potentiality-of-being-a-self' (Heidegger 1996: 271[294]). The silent call of conscience assembles the conditions of possibility of being able to be guilty in the first place. Through *Angst*, the call of conscience is mediated not so much as a form of cognitive knowledge but as an emotional, affective and utterly vague though rather intense desire of Mrs M 'wanting-to-have-a-conscience' (Heidegger 1996: 272 [296]). The call of conscience, then, is also about the possibility of being able *to feel guilt* in the first place. From such a reading, her resolute declaration that she has fulfilled all her duties can be understood as a way of addressing her potentiality-of-being precisely as a result of being and having been with others. In that sense, feeling guilty also relates to the fact that she owes her existing to the being and becoming with others.

Mrs M fulfilled all her duties within the actor-networks she is belonging to. She also fulfilled her duties towards those members who/which assemble her personal ordering. She was an *active* part of those networks, she seems to say, she was an actor in those networks, she was an actor who came into being by the networks. She herself, so she claims, *is* an actor-network. She owes as much to the networks as the networks of her life owe to her. Guilt is a question of owning, of property, of having and not of being. *Being is having the ability to feel guilt; it is a question of existing, which is always a being with others and makes being possible.* Mrs M is trying to regain her being, her being with others. This is, following such a reading, what Mrs M is telling us with her *Angst* and with giving the silent call of conscience a voice. And the ability of feeling guilt is enacted by ready-to-hand and present-at-hand actor-networks. If they turn present absent, the actor-network of *Angst* re-minds us of our potentiality-of-being and existing as an on-going collective achievement (Heidegger 1996: 297). Heidegger stresses:

Uncanniness is the fundamental kind of being-in-the-world, although it is covered over in everydayness. Da-sein itself calls as conscience from the ground of this being. The 'it calls me' is an eminent kind of discourse of Da-sein. The call attuned by *Angst* first makes possible for Da-sein its project upon its ownmost potentiality-of-being. [...] The statement that Da-sein is at the same time the caller and the one summoned has now lost its empty formal character and its obviousness. *Conscience reveals itself as the call of care:* [...] The call of conscience, that is, conscience itself, has its ontological possibility in the fact that Da-sein is care in the ground of its being. (Heidegger 1996: 279)

Angst's silent mediation of the call of conscience and guilt brings to the fore that Mrs M owes her 'being-here', that is her existence, to others – human and nonhuman alike. In the uncanny situation of the cosmopolitical event of dementia, the very *personal being* in the world summons the *potentiality for being a society*, or as Heidegger would say: 'The appeal to the they-self [Man-selbst] signifies summoning one's ownmost Self to its potentiality-for-Being, and of course as Dasein—that is, as concerned Being-in-the-World and being with others' (Heidegger 1996: 280). Thus, Mrs M's concerns can be understood as a concern for her personal ordering, which is very much a concern for being with others – human and nonhuman alike – because her personal being *is* being and becoming with others. Mrs M's very personal ordering, her self, is not brought into existence by herself but in being/feeling with others. Human existence, and this is precisely what Proust's experience of 'the abyss of non-being' and his search of lost time and Mrs M's experience of dementia reveal: it addresses human existence as an on-going 'matter of concern', an on-going 'matter of care': the care for human others and the care for assembling human/nonhuman relations since human existence is the effect, the on-going collective achievement of concerning relations.

Situated Non-knowledge

Mrs M is talking to Marion Kainz (at the hallway).⁵⁸

Mrs M: I have it here [...] Here, I have it (She is pointing to her forehead).
It won't come out ... and and. (Pause)

Mrs M: If you have so much [...] of one thing [...] to many, how does one call that?

Kainz: Collection.

Mrs M: Collection? [...] not exactly. If one sees a lot of people, together [aufeinander] [...] how does one call that?

Kainz: Gathering.

Mrs M: No, that's not it, either.

Kainz: Group.

Mrs M: No. (Pause)

Mrs M: It is so close to it [Es ist so nah dran].

Kainz: So what feeling do you have?

Mrs M: That it could rhyme together.

Kainz: What could rhyme together?

Mrs M: What I'm seeing in the shadows. ... Isn't it a mess? Oh God, oh God, oh oh God. [...] It's so close to it.

Following some of the traces of Mrs M's life with dementia we could see that the human world is not a representation of given things but an on-going event of '*membering*', *collecting*, *gathering* – constituted by as well as constructing and maintaining – *heterogeneous* entities. The process of being human, 'dwelling' as Heidegger calls it, gains specificity in appropriation of and to heterogeneity, which assembles and supports societies.⁵⁹ It was precisely the effects of the dementing process which unravelled the importance of social orderings of affective mediations

⁵⁸ Kainz (1999/2000): 21st scene: 28:30.

⁵⁹ cf. Heidegger (1971).

of human and nonhuman entities. Mrs M is experiencing what it means if the process of re-member-ing fails and when the social orderings – ready-to-hand and present-at-hand – become indecipherable ‘signs of dementia’, assembling the uncanniness of an utterly un-homely world. With the dementing process the common and taken-for-granted orderings become disrupted, questioned and altered since they do not assemble societal viz. collective relations to dwell with and to build on, but assemble fearful, distressing and unsociable ‘accomplished facts’. Experiencing the dementing process Mrs M’s world (including herself) becomes uncanny: Mrs M faces her uncanny existence, disassociated from the on-going social orderings, which assemble her personal order.

Hence, with the dementing process intensifies the experience of living in a total institution precisely since Mrs M not only feels ‘cut off from a wider society’ as Goffman described it. Rather, she feels/is disassociated from social processes, which could create the societal character of things (including herself) in the first place. Her world (including herself) becomes present as non-social and do not gain societal stability (endurance). No collection, no group, no gathering. Mrs M becomes individualized, that is, affected and concerned by her actor-networks of Angst and her silent call of conscience. However, it is precisely these uncanny as well as individualizing actor-networks which bring Mrs M’s existence into ‘factual action’ (Heidegger 1996: 294). Her actor-networks make her question the sheer individual presence of things. The questionability and indeterminateness of things become the vantage point of her search to possibly regain decipherable signs, points of references and suggestions, which – by becoming matters of her concern – may enable her to re-assemble enduring social relations. She is searching for and desiring social relations.

By questioning the strange facts-at-hand (‘of one thing to many’) Mrs M prospects for a linkage, a point of mediation which would possibly allow her to participate in social orderings and their re-member-ings in order to regain traces of her personal society, of her collective achievements and related possibilities. She desires to become a compositional being again, living in ready-to-hand extensions. She desires to make an enduring difference, to re-member her personal orderings and become an enduring self again, being the same but not identical. Mrs M feels that it could rhyme together. She feels that her feelings of things may gain rhythm and patterns may emerge, continuing processes that assemble societies. When things rhyme together they would make present what she sees in the shadows. Her feeling is that they could make sense, but they do not. Somehow – without knowing why – they refuse to. They remain present facts that do not fit, that do not make sense. The more Mrs M’s world is insignificantly present, the more she individuates, the more she does not fit the social orderings in place, the more she becomes unknown for others as well including those who know her best and who have lived with her for many years or those who live with her now. Dementia enacts mutual non-knowing. The social understanding is primarily dominated by affective relations, by *Befindlichkeiten* – massive and vague at the same time.

Following Mrs M's questionabilities, we could witness that the dementing process enacts not only the concealing of social orderings, but also reveals that existence is being with others – human and nonhuman alike. Existing is not a general affair, but material, affective, and situated. Existing, then, is being with others whose specific types of orders promote feelings to be felt (physical feelings), which in effect shape and are shaped by subjective concerns (conceptual feelings) into actual unified entities, promoting feelings for other becomings and relations. Thus, all actual entities form a process with a double character of activity: it is the process which forms the actual entity (self-formation) that passes into an activity which forms others (other-formation) (cf. Whitehead 1961). 'In that sense', Whitehead notes, that

the future is immanent in each present occasion [...] In the formation of each occasion of actuality the swing over from re-enaction to anticipation is due to the intervening touch of mentality. Whether the ideas thus introduced by the novel conceptual prehension [feeling, MS] be old or new, they have this decisive result, that the occasion arises as an effect facing its past and ends as a cause facing its future [...] the present bears in its own essence the relationships which it will have to the future. It thereby includes in its essence the necessities to which the future must conform. [...] Thus the future is to the present as an object for a subject. It has an objective existence in the present. [...] What is objective in the present is the necessity of a future of actual occasions [...]. (ibid. 193–4)

If this future-to-present and 'object-to-subject of human experience' (Whitehead 1961: 188), this stream of feeling and its actual occasions become re-member-ed, it forms a 'chain of coordinated occasion', that is an enduring relation: a society of experiences. Such social ordering assembles and holds together the different experiences, providing and supporting the process of collecting and re-collecting societies. As societal beings – human and nonhuman alike – 'the past has an objective existence in the present which lies in the future beyond itself' (ibid.: 191). Thus, not only has the past 'an objective existence in the present' but the 'future is something for the present': 'Cut away the future, and the present collapses, emptied of its proper content. Immediate existence requires the insertion of the future in the crannies of the present' (ibid.: 191). Mrs M desires the past and future in order to escape the dementing situation and become a societal being in the midst of other societies. As societal beings, things – persons, bodies, objects, technologies – become present as temporal, that is enduring beings of a variety of assembled and coordinated social relations (human and nonhuman alike) whereby the past stretches into the present and the present protracts into the future. Things as societies become enduring possibilities. Mrs M desires to re-gain the possibilities of societal beings.

We have also argued that present things make the process of coming into being absent. Obviously this process bears fragile and delicate sets of practices, which

in the case of dementia not only get disrupted and questioned, but make us aware of the importance of *caring* about social orderings in our everyday life that grant our societal being, our potentiality-of-being, our ability to make a difference. We have seen how the *Befindlichkeit* of Angst arises while experiencing nothing but demented objects. We have also argued that Angst reminds us that the potentiality-of-being depends on an on-going *collective* achievement and thus relies on the heterogeneity of things in order to gain stability as well as enable change. Demented objects are not absent things or unreal. Quite on the contrary, they are present-at-hand, they are real, but precisely because they 'resist' being actualized as on-going collective achievements that link the effects of the past with present that opens future possibilities. Demented objects are stuck in the present. Mrs M's *Befindlichkeit* articulates this situation of being stuck in the present where everything seems to be at a still-stand, with no past and no future. It is precisely her *Befindlichkeit* of Angst and her conscience, which reveal Mrs M's *situated non-knowledge* as the effect of being confronted with insignificant presences, with accomplished facts, with signs of dementia: 'The insignificance of the world, disclosed in anxiety, reveals the nullity of the things of our concerns, or in other words the impossibility of projecting oneself [*sichentwerfen*] on a can-be that is primarily founded in the things of our concerns' (Heidegger 1996: 343). At the same time, the actor-networks of her Angst and conscience call for the possibility of regaining the past and future of these demented objects, that is their agencies (including Mrs M's 'can-be'). Her Angst and her conscience force Mrs M to question what happens to be merely present-at-hand.

However, we have seen that the frequent occurrence of the dementing process disrupts and constantly defers her search for active societal being(s), her desire for assembling and being assembled by collective accomplishments. Obviously, the dementing process is also a most demanding situation for those who care for Mrs M, for those who are concerned about Mrs M's situation, for those who wish to tune in her situated non-knowing, get affected by and feel her situation and become *sympathetic* with Mrs M's own way of doing things, with her questions and uncertainties. Interestingly enough, we have witnessed that it is the affective relationship with the filmmaker Marion Kainz wherein she felt more at home with than in other extensions. Kainz shared her time and her non-knowledge with Mrs M. Kainz, so it seems, over and over again she became a meaningful *location* to hold on to, an *Anhaltspunkt* of some kind. Kainz became a close but non-intrusive companion in a world that often is utterly unknown, fearful and distressing. Kainz became a pillion following and preserving Mrs M's questionabilities and *Befindlichkeiten*. With Kainz, Mrs M seems to achieve a relationship that is not just present-at-hand, but 'ready-to-hand'. The relation with Kainz offers a contrast to the concealed, shackled and fixed realities Mrs M is also experiencing. Relating to Kainz, Mrs M feels the possibility that her closed-off world could open up again and that it's undecipherable members and belongings become re-traceable signs. It seems to me that Marion Kainz's Da-Sein, her simply being here, her being here with Mrs M, her non-shackling care for Mrs M's idiosyncratic ways

of engaging with an uncanny world, enabled a positive affective relationship that cares for the *situated non-knowledge* they both share despite the differences of the situations they live in. Kainz, like Mrs M, follows the massive but vague traces of an uncertain and unknown world, although with different means.

The Social: A Matter of Care

Mrs M is sitting in her room and talking to a female member of staff⁶⁰

MoS: Should I turn on the light in here?

Mrs M: Don't bother to. I know how it looks like in here [...] I will not become nicer with the light.

MoS: Well, it is quite nice, this room, it's quite comfortable, isn't it [...] the room [...] comfortable.

Mrs M: Comfortable!?! [...] That's what you say!

MoS: (*Sitting down next to her*) Well, it's nicely warm, it's cosy, it has a carpet in here and a comfortable armchair. What are you lacking in here?

Mrs M: Everything! [...] Love [...].

MoS: Hmh (Sighing) ... When you are alone in your flat in AB-Street, you have no love either; you're getting more love here.

Mrs M: Oh yes, I got love.

MoS: (*Showing incomprehension*) But from whom?

Mrs M: What, what do I have here?

MoS: But you lived alone there, didn't you?!

Mrs M: Alone?

MoS: In AB-Street you were alone, I believe (*Nicking*)!

Mrs M: No, I may have lived on my own, but I was never alone [...].

60 Kainz (1999/2000): 19th scene: 25:05.

MoS: (*Getting impatient*) So, who was with you, then?

Mrs M: Here is where I am alone.

MoS: (*Pressing*) So who was with you?

Mrs M: Many!

MoS: But here are also. (Pause)

Mrs M: (*Interrupting the MoS*) You're really making me mad!

MoS: No.

Mrs M: Are you crazy?

MoS: Well, I can't say.

MoS: Maybe a little bit.

Mrs M: Well, this is what I think, that you do not know this anymore.

Obviously, things meant in a caring way do not create caring relations. Furniture, which is thought as cosy does not necessarily create a cosy dwelling. Mrs M gets distressed by the good will of the member of staff who wants to make her feel comfortable with her situation although Mrs M is telling her that she does not feel comfortable at all. Mrs M cannot attach to the room's interiors. For her they are discomfoting objects filling a discomfoting room. Differently put: these interiors do not give space for feeling comfortable, they are detached and vacuous objects. Mrs M knows that, she does not need light to be reminded of their uncomfortable presence. She feels their non-cosy-ness and they do not become cosy when they are more visible. Clearly, the sequence is not just about uncomfortable furniture. It is about every/thing that is missing. There are no attachments what so ever. Mrs M feels depressed, she misses 'love', personal attachments, ready-to-hand things, relations of concern, relations that articulate mutual concern and feelings that are positively felt, it seems. She misses a life that would make her feel at home. The specificities of her concerns remain vague and unclear; it is a feeling after all, massive and vague. Still, it is a situated concern, a concern of a problematic situation. Her sad *Befindlichkeit* suggests that she does not feel comfortable where she is now, the more so since she had a home she felt comfortable with. In her current situation, she feels un-loved and she misses togetherness. Togetherness, however, does not necessarily mean to share a home with others since for Mrs M to be alone does not necessarily mean to be without love. Quite the contrary: In her former home Mrs M was living alone, but she was loved by 'many', she says.

For the member of staff, on the other hand, the situation seems to be very clear: Everything is in place and Mrs M is much better off in the nursing home than being on her own in her flat. When the member of staff compares Mrs M's old flat with the room in the nursing home and when she is trying to convince Mrs M that what she feels as homely and unhomely is wrong, Mrs M gets upset. She feels distressed, maddened. Mrs M feels what she feels; feelings – although massive and vague – cannot be wrong, they do not lie, they are agents of an intimate relational and situated truth. Obviously they vary and thus are either positively felt, negatively felt or they are mixed feelings, but still, they are what they are, feelings promoted by objects that shape and are shaped by subjective forms. Feelings cannot be conflated or exchanged with mere given 'stuff' as the member of staff seems to suggest. The member of staff appears to question the only thing it seems that Mrs M is still sure of: her feelings, her affections: *My particular feelings about this place are not comfortable ones, so how dare you say that it is not like this if this is how I feel*, she seems to say. According to Mrs M's affective understanding of her situation, the member of staff must be mad to act like this and to doubt her adamant feelings. According to Mrs M, the member of staff must be the one who is demented because she has forgotten about her own madness and lures Mrs M into madness as well.

It seems that the member of staff's concern about caring for Mrs M is not about the affective relations in which Mrs M finds herself and it is not about relations that make her feel utterly un-homely. It rather is about accomplished and fixed facts. The member of staff talks about 'objects' and not about 'objects felt'. She tries to convince Mrs M with given facts, clear and distinct *relations of judgements* that have already decided what is meant to be good for Mrs M and what has been bad for her: *Nobody can deny that, that Mrs M is much better cared for in the nursing home than her old home was able to do. If Mrs M would think about it she would agree, because everyone will agree upon it*. This seems to be what the member of staff is saying.

A clear and distinct decision was made that Mrs M must be wrong, that she confuses the truth of her being, living, feeling and social life. Whereas the only thing that Mrs M is sure about in that situation is precisely her sad and detached feelings which are telling her very intimately about her non-homely situation. To question that by employing 'facts' makes Mrs M *verrückt* [mad]. It is the member of staff, so Mrs M, who must have forgotten that she herself is obviously mad by *ultimately* rendering as untrue what she [Mrs M] *intimately* and truly feels. The German '*verrückt*' stems from '*verrücken*', which means 'to move to another place' and to be '*verrückt*' refers to a person's mind having moved somewhere else. Being '*verrückt*' also means to deviate from the norm, from normalcy, from common sense, from healthy reason. Mrs M's feeling of being maddened, of being *verrückt*, of being made non-normal by the member of staff seems to be a very precise description of how Mrs M must experience the situation. It is precisely the *dis-placing* [*verrücken*] of Mrs M from *her* feelings of being with uncomfortable things in a non-homely *situation*. It is about dis-placing her situated affections

with a general perspective of someone else ('Comfortable!?' [...] That's what you say!). It is *her* lived situation that makes Mrs M sad and depressed. The judgement of the member of staff who pretends to know it better without being in her situation is worsening Mrs M's situation. She gets upset! To question the most intimate *Befindlichkeit* of Mrs M's situation means the dis-placement and deferral of Mrs M's concerns and a *Verrücken*, a maddening of her self.

In effect, the relation between Mrs M and the member of staff is one of non-understanding, both cognitively *and* affectively. The initial concern of the member of staff shows no *sympathetic* affinity for Mrs M's situated affection. Quite the contrary, her concern is to talk Mrs M out of her *situated Befindlichkeit*. She is suspicious about Mrs M and denies her affective relations and Mrs M feels turned down. We have already seen that, with dementia, affective relations and the related *Befindlichkeiten* play a crucial role in the way Mrs M understands her situation, her situated self and her environment. What makes her feel uncanny is being confronted with accomplished facts that appear alien, suspicious, fearful and distressing. Hence, the last thing Mrs M seems to need is being confronted with even *more* accomplished facts, objective truths as it were, enforced on her by others, without Mrs M's partaking. The caring situation between the member of staff and Mrs M is doomed to fail.

To pay attention and to link in with Mrs M's affective relations and her *Befindlichkeiten*, then, seems to be of a prime concern in order to possibly search and retrace – together with Mrs M – some of those relations, which could make her feel at home again. Such concerning relations which acknowledge the differences of others seem to be crucial in understanding, dealing with and caring for people with dementia. As we have seen, the relationship with Marion Kainz, the filmmaker, was able to achieve such a concerning and positive relation, which primarily worked on an affective level of understanding despite the differences of Mrs M's and Marion Kainz's situation. To care for the differences in place, it is most important to care for the *social* ways of *how* we are affectively related, concerned with and about others, human and non human alike. Caring, then, is caring of our self as 'being-possible' in the ways we care about and for others, about and for the differences of others.

To exist is to care. Caring has a temporal structure and links past, present and future concerns. Following the Heideggerian parlance, human existence as 'caring' is 'dwelling' as much as it is 'building'; building as dwelling and dwelling as building are as much about building on and keeping things, as it is about enabling, making, doing and multiplying things. Caring for our self grounds in building on and keeping relations with different others. Caring is grounded in being affected by others as well as affecting others and making a difference. Caring as existing re-members and re-gathers difference and otherness. Caring, then, is not about applying general principles (e.g. healthy reason, rationality) as a matter of common sense that presupposes the inter-changeability of positions in order to achieve differences. Rather, caring as existing, is caring for differences, for the process of differing in the situation experienced. This fundamental relation is at the heart of understanding existence as a social matter of care. Gabriel Tarde notes:

To exist is to differ; difference is, in a sense, the truly substantial side of things; it is at once their ownmost possession and that which they hold most in common. This must be our starting point, and we must refrain from further explaining this principle, since all things come back to it – including identity, which is more usually, but mistakenly, taken as the point of departure. For identity is only the minimal degree of difference and hence a kind of difference, and an infinitely rare kind [...]. To begin from the primordial identity is to posit at the origin of things a prodigiously improbable singularity, an impossible coincidence of multiple beings, at once distinct from and similar to one another. (Tarde 2012: 40)

Existing is differing and so is dwelling. Human being as dwelling is ‘safeguarding’ the presencing of difference. Dwelling as saving difference means ‘to set something free into its own presencing’ (Heidegger 1971), its individual ordering, the person as society, the same but not identical and inextricable from its concern for and with others. Caring looks after the process of differing and preserves the differences by caring about *how the possibilities of keeping* things (societies) come into being. The common, the ordinary, the simple or the societal, then, is not a *mise en equivalence* but a bewildering process of a productive relation of situated differences. Tarde (2012: 41) stresses:

[E]very sufficiently prolonged process of evolution exhibits a succession and interlacing of phenomenal layers which are remarkable alternately for the regularity and the caprice, the permanence and the fugacity, of the relations they present to us. The example of societies⁶¹ is eminently well-suited to promote an awareness of this central fact, and at the same time to indicate its true significance, by showing that in this series where identity and difference, the indistinct and the well-characterized each reciprocally make use of the other over and over again, the initial and final term is always difference, the characteristic, the bizarre and inexplicable agitation at the basis of all things, which reappears more clearly and sharply after each successive effacement. (Tarde 2012: 41)

Through the actor-networks of Mrs M’s dementia, an ontological ethos of the social became visible: it is the desire of the self (*moi*) that cares for others in order to being-possible, since only through being with others (human and nonhuman) does it appropriate its own (human) being, its social forms of existing, its enduring, that is societal being, its situated difference. Caring for social relations is not about applying general principles or the taken-for-granted knowledge. Rather, the actor-networks of dementia ask for feeling and understanding of, that is, being concerned and caring about *how* differences come into being. Caring is situated; it depends on circumstances. It requires to ‘spare and protect the thing’s presence in the region from which it presences’ (Heidegger 1971: 181).

61 The English translation is ‘society’, but following the French original it should be ‘societies’. It is important to keep the plural, since for Tarde all things are ‘societies’.

Caring is always caring about the situation in which and through which the requirements of caring evolve. Caring is located. Caring is caring about the conditions of possibility that make a difference! It has been precisely the cosmopolitical event of dementia that brought about the most uncanny moments for Mrs M, who, assembled by networks of *Angst* and her conscience is deeply concerned about her shattered existence and she cares for the situation she finds herself in. She cares about all the detached and uncanny ‘signs of dementia’ and is deeply concerned about searching for *Anhaltspunkte* [signposts], for points of references in order to possibly re-trace social orderings that could rhyme together, gain stability and become enduring relations to dwell with and to build on. It has been the actor-networks of dementia that make us aware that the human social is as much about caring for oneself as it is about caring about being with others, human and nonhuman alike. Mrs M’s ‘homelessness’ reminds us of the importance of caring for the collective, temporal and situated conditions of the possibility of our being, of our being-possible. Being caught within and affected by the present absence of bodies and things, Mrs M feels detached from building/dwelling within her world. However, through the actor-network of *Angst*, Mrs M not only suffers from being attached to insignificant bodies and things. By engaging with the questionability of herself and her environment, she cares about her futile situation by caring for possibilities of re-member-ing(s) and re-conjoining(s) out of social orderings.

At the same time, Mrs M appears as a cosmopolitical actor who, through her questioning of common orderings, requires that we care for the differences and non-socialities⁶² introduced. The cosmopolitics introduced entail that we others need to slow down our own taken-for-granted practices and engage with her questioning and questionabilities, that we support and possibly become or create *Anhaltspunkte* for her concerns, signs for her search of her lost personal orderings. Her concerns are always about us as well. It is the situated but utterly unknown cosmos of Mrs M that we share and which makes us question and rethink our taken-for-granted orderings and relations. Consequently, the pragmatics of remembering and its failures bring to the fore the dynamics of *inclusive differences* by which the sociality of humans cannot be thought of without the caring for the other and the requirements their differences demand, human and nonhuman alike. Care as a human social matter of concern preserves the possibilities of difference as an on-going collective achievement.

No doubt, the work on dementia did affect my sociological thinking. It made me realize more than ever that ‘the social’ as taken-for-granted does not explain anything but has to be explained by the *questionability* enacted by the eventfulness of everyday life practices.

62 The ‘social’ – as argued throughout this book – is not ‘stuff’ or (taken-for-granted) ‘matter of fact’, but refers to a creative/productive process of assembling differences (cf. Latour 2005). Hence, it does not assemble just socialities but socialities and non-socialities. Mrs M’s situation makes us aware of the power of assembling social and non-social things (including herself).

Chapter 2

Stroked Bodies¹

Making Partial Connections

In the previous chapter we met Mrs M, the central figure of a documentary film by Marion Kainz. Kainz and her steady-cam have accompanied Mrs M in her everyday life in a nursing home. The ethnographic film assembles Mrs M's experiences living in an uncertain, unhomely and foreign world. Kainz's ethnographic film collates the affective relations and related practices which emerge from situations that are governed by the pressing question of 'what is going on?'.² Thereby Kainz and her steady-cam became pillars in Mrs M's forlornness and her struggle with and through the copice of a world bewildered by undecipherable signs of dementia. They became 'connected as different, exterior presences to one another' (Strathern 2004: 38), whereby it was not knowledge but non-knowledge that made the relation hold together. We have argued that Kainz and Mrs M established a positive affective relation. Mrs M seemed to be highly indifferent to Kainz's interest in making a documentary on dementia. However, for Mrs M, Kainz and her steady-cam became extensions into a lost world, *Anhaltspunkte* as it were, for her search for the time lost and its members and belongings. Kainz became an interlocutor for Mrs M's questions, thoughts and *Befindlichkeiten*. For Kainz, on the other, Mrs M's uncanny life in a nursing home opened the conditions of possibility to realize her own interests in making a documentary on dementia in the first place. At the same time Kainz's close but nonintrusive presence established time for Mrs M which, in turn, allowed her to positively relate. To paraphrase Strathern (2004: 39), Mrs M can make a conversation work for her as a tool works, as she can make herself work in sustaining the conversation. Still, Mrs M and Kainz are sharing an utterly unknown world, which for each of them – while relating – becomes present in different and idiosyncratic ways. Following Strathern, we can argue:

1 This chapter is an altered version of a collaborative work with Michael Heinlein, cf. Schillmeier, M. and M. Heinlein (2009), 'Moving Homes: From House to Nursing Home and the (Un-)Canniness of Being-at-Home', *Space & Culture* 12(2): 218–31. See also Heinlein (2003). My thanks go to Michael Heinlein.

2 Kainz's documentation rigorously focuses on Mrs M and necessarily excludes many actors, issues and situations which also assemble Mrs M's dementia: Doctors, diagnosis, medical records, medicines, family, relatives and friends, Mrs M's past and so forth. Kainz's, as well as my reading of it, focus on situated complexity and necessarily produce gaps; each account 'carries its own burden of specificity' (Strathern 2004: 47).

What each creates is an extension of a position, which could not be done without the instrument of the conversation but in the end is done from the position each occupies for herself. (...) 'Partial' captures the nature of the interlocution well, for not only is there no totality, each part also defines a partisan position. Ethnographic truths are similarly partial in being at once incomplete and committed. (Strathern 2004: 39)

Their relation also helps Mrs M and Kainz to endure in their emerging, partial ways. It is most important for our analysis to draw upon the very *prosthetic character of being* as it is revealed in these situations of attachment. Through their partial connection, Mrs M and Kainz became extensions of each other. The filming, observing, questioning, listening and conversing relations between Mrs M and Kainz can be understood as 'tools' by which Mrs M and Kainz gain presence. As much as for Kainz the steady-cam is a tool to document and thus make the encounters with Mrs M last, as much it is the filmmaker, who, for Mrs M becomes a 'tool' to re-gain enduring and 'canny' relations. Through partial connections

each extends the other, but only from the other's position. What the extensions yield are different capacities. In this view, there is no subject-object relation between a person and a tool, only an expanded or realized capability. (Stengers 2004: 38)

The same can be said about the relationship between the documentary film and me as part of an audience who is affected by it and whose concern is the understanding of the complexities of social relations. Mediated by the ethnographic film, Mrs M's world gains subjective presence. Mrs M's situation – as assembled by Kainz – made me aware that *her* questionabilities are also about myself being with others. It is about the fragility of our existing, the vulnerability of living in extension, of being with others. Mrs M's demented situations brought to the fore a deeply affected self, which, actualized by the actor-networks of *Angst* and her conscience, dwells within a most uncanny world. She is deeply concerned about the strangeness of her life and desires to regain meaningful and trustworthy relations. Consequently, Mrs M searches for traces of her personal life in order to become a *temporal being* again, having a past and future. She desires more than being present-at-hand, dwelling within uncanny experiences of cut-off relations, encounter nothing but insignificant signs and disturbing situations. Deeply affected by the assemblages of the present absence of humans and nonhuman alike, Mrs M's is concerned about her existence. Her questions and her search for traceable signs of her life reveal her desire to care for the past, present and future of her relations with others. It discloses her desire to live, her desire of 'being possible', her desire to enjoy relations with others.

However, the ethnographic material also suggests that Mrs M's questions often *remain* questionabilities. Gaps remain gaps. The presence-at-hand of her world remains present-at-hand. Her desire to overcome the demented situation cannot be

enjoyed. Mrs M is angry, frustrated, sad, disappointed, anxious and insecure since she remains caught within the presence-at-hand of an alienated and alienating world. Her pressing questions become quickly closed by 'accomplished facts' to which Mrs M feels no connection whatsoever or is troubled by them.

Incapacitating Connections

We have also witnessed that Mrs M's experience of dementia is situated and thus cannot be separated from Mrs M's move from her private home into a long-term nursing home. The nursing home and Mrs M's experiences of 'demented' realities are also partially connected. They affect each other without being wholly defined by Mrs M's dementia or the nursing home. From such a view, it seems obvious that the life in a nursing home is an ambivalent one, even more so when one cannot remember living in a nursing home. The life in a nursing home is frequently experienced as a dramatic rupture from previous ways of living. It expresses the loss of practices and attachments, nearness and distance, the ways of being able to do things, which kept the former personal life significant, specific and stable *without* being fixed. The situation becomes more complicated and more alienating in the moment the resident forgets that s/he is living in a nursing home.

Moving into a nursing home, then, not only denotes a movement in/through space but also enacts an uncertain and insecure process of being moved by emerging relations which question and disrupt the ways people are used to experience and do things. In care studies, such a situation has been interpreted as a 'loss of control'. Fisher stresses the following:

Residents lose some control simply by having to comply with rules and restrictions from above. Other less formalized aspects of the facility confront residents as a threat to their ability to control and predict their new social environment such as: environmental regimentation, group dining and finding a seat, proximity to others with disabilities, confronting one's own declining health and foreseeable death, and finding friends among a large group of others. All these factors combine to inhibit the residents from identifying the facility as their "home". (Fisher 1991: 95)

Moreover, the moving into a nursing home is often related to a loss of feeling at home as well:

It was very hard moving here. I didn't want to leave my home. It's not like home. I felt displaced. I missed my apartment, my kitchen. I missed all the homey things. (Woman, SIL, 91; Fisher 1991: 99)

It was tough at first, but you learn to accept it. It's not at all like home. It's not even like having an apartment. There's no place like home. When I've been

away and return, I've never been able to say "I'm coming home" and mean it. (Man, SIL, 91; Fisher 1991: 99)

Living in a long-term nursing home brings to the fore the very ambiguity of institutionalized care: On the one hand, long-term care is not practiced 'at home', while on the other, care tries to give people a new home, which, as social studies of care suggest, is not at all the place to make one feel 'at home'. The social relations, practices, alignments and locations of the *lived* past are lost and consequently are missing by the *given* relations and things. The latter are not part of people's biographies or personal orderings which are constitutive parts of the on-going collective achievement which are enabling and maintaining the personal belonging/s and having/s in the first place. As a result, the nursing home does not permit personal orderings but enforce a feeling of displacement from the locations and practices that did configure the things present-at-hand and ready-to-hand. The nursing home provides *given* present facts, which for the residents do not have lived attachments to them. The human and nonhuman environment not only does not stretch into and connect with one's past, but also provides no future for the lived past in order to enable enduring personal realities.³ Hence, without having a past and a future, there is no return to the presence of people, locations and things with whom/which to feel at home. In effect, the nursing home appears as a non-home, stubbornly detached from the histories of personal orderings. In the previous chapter we have seen how dementia intensifies the feeling of not being at home as well as the desire to go home and to bring things back with which one feels at home.

We suggest that to be 'at home' refers to the fragile and enduring accomplishment of affective attachments to and of humans and things (visible or not, 'present-at-hand' and/or 'ready-to-hand'). If these affective attachments cannot be established, one does not feel not at home and is displaced from the process of 'homing', of becoming at home (*in*).⁴ Such a process-oriented and performative reading of

3 Drawing on how care practices perform a crucial shift of social life worlds, Gröning (1997) – following Erving Goffman's (1961) concept of total institutions – argues that a freely expressed social identity outside the ward is being under destruction by restrictive care practices within the ward. In this vein, other studies are concerned with the institutional implications of bodily and mental neediness for the conduct of care (Gröning 1998, 2001; Peper 2000; Scheffel 2000). What these studies have in common is that they try to critically reveal the social aspect of care work as it goes hand in hand with a loss of personal independency, autonomy, self-esteem, and so on. On the effects of organizational change on care work and care relations, see Schweiger (2011).

4 Feeling, being, or having a(t) home, then, refers to socio-cultural and material practices of 'un/doing' home. Doing/Undoing is a common notion used by ethnomethodologists, interactionists and within gender studies. 'Doing' refers to situated practices that produce, reproduce, and change social order and its differences and distinctions. 'Undoing', as it is used here, refers to a process of re-producing the orderings, distinctions/differences in place by taking them for granted while using/living them and thereby erasing the situated

‘being at home’ endorses an understanding of *home* that is more than just a mere taken-for-granted relationship between spatial arrangements of given things, but a complex process of feelings being felt and related practices which gather enduring affective relations and provide locations that make a difference with which one feels at home *in*.

By retracing the process of moving from the private home to a nursing home, these following pages highlight the fragility, contingency and situatedness of what it means to ‘feel at home’. To do so, we will leave Mrs M’s world of dementia and we will meet Mr B and his cosmopolitical world after experiencing a series of strokes.⁵ However, before we do so, I will have to make some additional brief notes on the cosmopolitical research agenda.

Re/Generating Materials and Cosmopolitical Research

Following Law (2004), social research is not an innocent practice that discovers the real world out there in a fixed and certain way. Rather, it is part of the construction of reality itself. Not only do different research methods represent the world in different ways, they also enact the world differently. Research methods are practices, which – like Marion Kainz’s artful intervention or Mrs M’s questionabilities – complicate the world by making some things present and others absent. Thus, neither the previous stories of Mrs M nor the following stories of Mr B will make up a consistent and conclusive story representing their reality.

In this vein, cosmopolitical research is not about a mere collection of given data out there, but alludes to a process of generating reality. ‘Generating materials’, so Sarah Whatmore claims, is ‘always, and unavoidably, an intervention in the world in which all those (humans and nonhumans) enjoined in it can, and do, affect each other’ and consequently requires ‘working together with those whom we are researching’ (Whatmore 2003: 90). Marion Kainz’s ethnographic film of Mrs M is a good example of what it means to ‘generate materials’ and ‘work together’. Kainz’s artful documentation by no means represents Mrs M’s life with dementia or gives an encompassing representation of dementia. Rather, the generated materials bring to the fore the situated intensities of Mrs M’s ward life with dementia, *cut outs* of her life, which in turn affected my concerns and shaped my way of engaging, shaping, i.e. generating materials by discussing sociological questions. My work,

and normative process of their construction. On doing and undoing, see Garfinkel (1967), Goffman (1977, 1988).

5 The following chapters draw on qualitative empirical data, ethnographic material and interviews with nurses, residents, and organizations of nursing homes. The research was conducted from 2000 to 2003 in Germany and was part of a wider research project on ‘service as interaction’ (Anderson and Heinlein 2003; Dunkel and Voß 2004), funded by the German Research Foundation (DFG; No. Vo 775/1–1). We are grateful to Philip Anderson, who was part of the research group, for providing additional empirical data.

then, was engaging with these situated and emerging complexities, which shaped my understanding of them as much as the former is shaped by my idiosyncratic sociological framing. Following from that, to develop a cosmopolitical research agenda requires to address ‘the ways in which all manner of entities, nonhuman as well as human, assembled in the event of research affect its conduct, exceed their mobilization as compliant data and complicate taken-for-granted distinctions between’ researcher and researched alike (ibid.: 91). The dementing process of Mrs M as well as Mr B’s life after a series of strokes document not only central experiences of illness, but are also generating questions of how things come into being *without knowing* them viz. being uncertain about them.

The following pages result from the interest in everyday care practices in long-term facilities. The research approach has been ethnographic using non-participant observation and narrative interviews (residents and care staff alike). It is about a German male person (who was already introduced as Mr B and will be called so henceforth), who moved from his home into a nursing home. This single case unfolds a series of different *realities in the making* which unravel the multiple experiences and practices associated with Mr B moving home(s). Three different connected and disconnected stories of Mr B will be presented. These different stories are not stories *in time*, that is, one story following the other. Rather, they happened to become present at the same time by using different methods. The first story became present out of narrative interviews. Mr B told us about the process and his experiences of moving from his house into the nursing home. The second story is the result of ethnographic work that brings to the fore a typical set of everyday care practices involving Mr B. The third story is ethnographic as well. It is about the use of assistive technologies to support the conduct of everyday care.

Disruptions/Decisions

Mr B and his wife lived in a third-floor flat until 2000. In 1990 and 2000, he suffered two strokes. After his second stroke in 2000, he moved into a nursing home. We first met Mr B in his room on the first floor of his care unit.⁶ He sits at the edge of his bed and is expecting us. We asked if it is possible to record the interview, which he approved. During the interview, Mr B presented himself as a competent and discretionary person who gave us a quite complex and coherent account of the circumstances that made him move into the nursing home.

In 1980, due to health problems, Mr B (then 61 years old) retires from being head of department of an industrial company. The health problems at that time had nothing to do with the strokes that followed. Mr B stresses that his retirement was not a voluntary decision; it rather was what his doctor told him to do. Mr B was very unhappy with the doctors’ advice, and he felt that his retirement was much too early: He liked his job and he was meant to be head of department

6 Philip Anderson and Michael Heinlein conducted the interviews.

for 4 more years. After retirement, he spent the next 10 years revitalizing an old passion: beekeeping. He took courses, got in touch with other beekeepers, and was building up his own professional apiculture. He was very pleased with it because, as he tells us, he was used to being busy and bearing responsibility for most of his working life.

In 1990, Mr B suffered his first stroke. Two months in hospital and intense rehabilitation could ease its bad physiological effects. Nevertheless, Mr B had to give up his professional apiculture since he was no longer able to practice his passion properly due to bodily restrictions. At that time Mr B and his wife were living in a third-floor flat without an elevator. After his stroke he missed the services of an elevator and they moved into a ground floor, barrier-free flat. Equipped with a walking stick and undertaking day-to-day physical exercises, he lived a slower but contented life. He and his wife felt fine in their new home, he says. According to Mr B, the next 10 years turned out to be the happiest of his life. One reason why he was feeling fine was that he was still able to drive. Mr B and his wife regularly went on holidays by car, which they enjoyed a lot and from which they retained good memories.

On New Year's Eve in 2000, Mr B suffered a second stroke, immediately paralyzing the right half of his body. From that moment onwards things changed dramatically. As a consequence, Mr B was no longer able to drive or walk with his walking stick. Even with the help of an ambulatory nursing service, life at home became highly problematic. In his eyes, he turned into a burden for his wife. That was why he felt it is the right decision to move into a nursing home. His home was not able to make him feel at home any longer precisely because he was not able to make his wife feel at home anymore. Mr B and his wife were very fond of their barrier-free flat, but he had to leave the flat so that it would remain a comfortable home for his wife.

Becoming a Half-sided Body

What we have heard so far suggests that Mr B's estrangement from feeling at home stems from his disabled body not being able to feel at home in the very place that normally made up home. Truly, the brain damage inflicted by the second stroke made him unable to move his right arm and his right leg. He felt, and yes, he *is* rather disabled, when taking into consideration what he was able to do beforehand. Indeed, at first sight Mr B's decision to move into a nursing home seemed to be all about the direct effects produced by his individual damage of the body. Having an impaired physiological body leads to his social disablement. So much so that he was not able to adequately play his part being the social partner for his wife. Because of his impairment his social competences were so disabled that he was not able to offer his wife a comfortable home anymore, although they still shared the flat they loved so much. Such a reading has much in common with a medical and individualized interpretation of disabled bodies as being the direct

effect of bodily impairments.⁷ Mr B's story resonates very much with individual reasons for moving homes. It is the tragic story of a victim suffering from a stroke who – because of that – was forced to move home(s). But a further look will show that in the case of Mr B things were more complicated than that.

Mr B told us that his paralyzed body did not allow him to get up from bed on his own in the morning. Thus, every morning he was in need of his wife's care. She had to pull him to the side of the bed in order to help him on a chair that was positioned properly beside his bed. With her physiological help, Mrs B also tried to offer social support for him and his impaired body to feel at home, at least somehow. All in all it was quite a hard job for both of them. Both were struggling with the paralysis: To lift and move Mr B's body was challenging, physiologically as well as socially and psychologically. Not to forget: this everyday situation was physiologically exhausting because Mr B's body is not only impaired, but he and his wife were already over 80 years old. For them, hard physiological work was socially and psychologically stressful as well.

Mr B's disability became present every morning and he and his wife were experiencing feelings of being overburdened and, finally, not being able to manage the situation anymore on their own. As a result, Mr B and Mrs B decide to call an ambulatory nursing service to help Mr B moving out of his bed. However, because of organizational commitments the nursing service could provide only one carer. It turned out that the nurse, despite her professional knowledge and trained skills, also had problems in getting Mr B up and out of his bed. Mr B was simply too heavy for her. Again, only with the help of his wife the nurse was able to care for him adequately.

Eight weeks later Mrs B suffered a slipped disc. At this point Mr B, as he told us, decided to move into a nursing home. He preferred to know that his wife is at home, which is a comfortable home that for both of them is still considered

7 Cf. International Classification of Functioning, Disability and Health (World Health Organization 2001) which evaluate the different scales of individual disability and health issues. In the German context, for instance, the movement from a private house to a nursing home presupposes a medical evaluation of the person. Depending on his/her physical or mental condition, three different scales of neediness – so-called *Pflegestufen* (levels of care) – are applied. These scales determine the severity of neediness: Level I describes a considerable need of care [*erhebliche Pflegebedürftigkeit*], Level II characterizes a severe need of care [*schwere Pflegebedürftigkeit*], whereas Level III applies to individuals with the most severe need of care [*schwerste Pflegebedürftigkeit*] (cf. Klie, 2005; Schneekloth and Müller, 1999). Being assigned to one of these categories decides the specificities of care needed, that is, what has to be done by the nurse and how much time the nurse may spend on different care practices for each resident. Level I, for example, allows a minimum of 90 minutes of care per day, with a minimum of 45 minutes for basic care; Level II, 180 minutes with 120 minutes for basic care; and Level III, 300 minutes with 240 minutes for basic care. These most general differentiations are thought to help in implementing 'formal tools' (Berg 1998) that follow highly ordered and pre-given rules; routines that regulate the conduct of individual care.

to be their home, although Mr B will not live there anymore. He preferred that she enjoys their home and that she would come visit him two or three times a week. Mr B feared that his wife would become ill as well precisely because of *his* physiological impairment. Hence, Mr B knew that him staying at home for longer would be a nuisance and could be responsible for his wife's bad health. It was better to show social empathy, solicitude [*Fürsorge*] and psychological strength. Consequently, Mr B decides 'independently',⁸ so he said, to leave home. In effect, Mr B felt that he remained a good and strong husband as long as he could take care of his wife's wellbeing.

What the story shows so far is how Mr B and his body, Mrs B and her body, Mr and Mrs B's age, a nurse and her body, (limited) professional skills provided by a nursing service short of employees, a bed and a chair, affective relations, emotions, social roles, and expectations are all part and parcel in maintaining and achieving the feeling of being at home (or not) in his life-world. Mr B's estrangement from feeling at home and the process of no longer being an active part of it, led to the decision of moving into a nursing home. This is more than just the effect of Mr B's bodily condition. Feeling at home, then, can be understood as the association, distribution, and delegation of relations that link feelings, bodies and things in a way so that they can generate a canny and homey living.

Following Heidegger, 'canniness' refers to the very meaning of being at home as 'tranquillized self-assurance' of 'everyday familiarity' that generates and keeps 'the self-sufficiency of the everyday way of taking care of things' (Heidegger 1996: 189). It names 'a positive possibility of beings which are absorbed in a world, essentially taking care of this world' (ibid.: 176). Canniness becomes problematic in the moment the very association, distribution, and delegation of feelings, bodies and things estrange Mr B from being a crucial, effective and caring [*besorgend, fürsorgend*] part of such a collective achievement of being at home. Considering this, the practices that constitute the very feeling of being at home or not are fragile bodily, emotional, spatial, and temporal achievements. This becomes apparent when we follow some of the 'good passages' when all the relations are in place and work and bad passages' when things do not fit properly or do not fit at all, when relations become discomforting or fail and passages become impossible.⁹

After his first stroke, Mr B was still able to live in ways that he considered as vital practices that made him feel at home again. Six weeks of rehabilitation and, with the help of a cane, Mr B regained a fairly good amount of mobility. Nevertheless, he had to give up his apiculture, which had an unforeseeable and positive side effect: For the first time in his life, Mr B and his wife were able

8 On the construction and relation of dependence and independence, see Schillmeier (2008b).

9 On everyday life of disabled people as a assemblage of 'good passages' and 'bad passages' that configure enabling as well as disabling practices, see Moser and Law (1999), see also Schillmeier (2010).

to travel frequently by car. The second stroke, however, dramatically altered the newly experienced forms of feeling at home. Mr B is not able to drive his car any longer, to go on holidays with his wife independently, to climb stairs, to get in and out of his bed on his own and so forth. He feels rather depressed, needy, and helpless. He is confronted with the limits of his and his wife's bodily abilities as well as the nurse's limited abilities. None of these are able to make Mr B feel at home within his everyday life. Life after the second stroke is quite the opposite of what life was still about after the first stroke: Enjoying his (leisure) time and being mobile, assistive technologies such as the cane being able to support his mobility, being in control of almost all everyday life situations, enjoying the familiarity and self-sufficiency of his life-world and thus not having to think very much about daily routines, being an equal partner to his wife, being a good husband and a strong man, caring [*besorgend*] and concerned [*fürsorgend*].

Living away from Home

After his second stroke with all its complicating effects, living in his beloved flat became impossible and Mr B was forced to move into a nursing home. However, contrary to what we would expect from the previous discussion that highlighted the movement from the home to a nursing home as a negative and displacing experience, Mr B seems to tell the opposite. He quite easily and quickly adapts to his new life, because, as he says, he used to travel and move around a lot. Mr B not only gets along very well with the nurses, he coincidentally meets old friends he has not seen for 60 years, who now live in the ward too. They meet up twice a day exchanging reminiscences of their school days and their home village. Other people from his hometown come to visit frequently to meet both him and his friends. He is very proud that 30 members of his former male choir have come to visit. They sang some beloved songs together and both staff and residents keep on talking about that lovely event. It makes Mr B very happy and proud, since he feels that by his presence and through related activities he is caring for the ward as well. Caring, being cared for, and having the opportunity to see his friends on a regular basis without much effort, means he feels more settled and independent than he was in the previous, most burdening weeks at home. It seems that he is at home again. Not to forget that his wife is visiting him as often as possible. She also brings him good food, because he was not happy with the cuisine at the ward. His wife makes him feel at home whenever she brings her self-cooked meals, he says. Most importantly, he sees her lively and well, as she is not suffering from dealing with *his* sufferings. Professional others do that job for her.

It seems as if Mr B has regained the canniness of being at home. But what exactly has changed from his 'uncanny' and distressing living in the flat? Here is a list: Nurses are at hand to help – and they are always there when help is needed, day and night. There are professional therapists and (assistive) technologies ready-to-hand that work well to improve and stabilize his mobility. Together they help

move the joints of his paralyzed body, help eliminate the stiffness and make his movements more flexible. Doctors come to visit him regularly. They look after his health and prescribe the necessary medication, which additionally ease Mr B's condition. Everything is organized and focused to make him feel at home with his situation. The new home has a proper infrastructure designed and organized for people like Mr B. For example, he does not have to climb stairs to get to his room in the first floor of the ward. He can use an elevator. Using a wheelchair he can move around the ward easily. Every resident has his or her own wheelchair. Instead of stairs there are ramps, and Mr B becomes quite mobile again. And when he does not want to use his wheelchair and rather walk, he can hold on railings that are fixed on all walls of the corridors.

But the infrastructure of the ward does not only provide for more mobility. In his room, for instance, Mr B, his wife, or the nurses can easily adjust his bed to the most comfortable position, depending on his daily condition. Such a bed has always been too expensive for Mr B to buy. Mr B likes it because it is the most important and helpful tool when it comes to getting in and out of the bed every day. When Mr B wants to get up, he can also lift himself up by using a grip that hangs over his head or, alternatively, the head part of his bed can be raised. He does not even have to get up from bed when he has to go to the toilet since a toilet chair can be moved to the side of his bed. All the things he needs when he stays in bed, for instance, his radio, some fruit to eat, newspapers, and, of special importance, his honey, can be placed on a mobile bedside table. It is designed in such a way that he can reach all his things easily without having to get up from bed. The 'material arrangements and foldings' (Hetherington 1997: 187) enable Mr B to feel at home away from home.

In the ward, Mr B can live his life differently and – according to him – better than at home, 'and my wife comes visiting whenever she has time', he adds with a smile. In the ward, nurses, doctors, therapists, and friends care about him. He is assisted by technologies (elevators, ramps, railings, beds, and wheelchairs) that enable him to live in a much different and also more convenient way than in his flat full of obstacles, where he also became an unbearable burden for his wife and the nurse. In the ward he gained confidence, he can do more things and is able to move more freely without the help of others. The supportive and enabling infrastructure and the way care work is organized to help Mr B to manage his daily life well. In effect, Mr B feels less dependent, more autonomous, and less disabled than at home. He feels fine, he feels at home. Moreover, what makes his life in the nursing facility homey is that his wife and his friends bring his old home into the new home.

At least this is how Mr B expresses his feelings about his situation when he is talking to us. When talking to the nurses, doctors, and therapists, he, according to the nurses, draws a quite different picture than the one conjured up in our interviews. The members of staff tell completely different stories of Mr B's situation. Considering the description of most of the staff members, Mr B seems to have strongly palliated his situation. In the following parts of the chapter, we will show that Mr B's situation is much more ambivalent than he is willing to tell

us. After all, these ambivalences are important and add up to the contingencies and complexities of the conduct of care and the ways of feeling at home or not.

Mornings in the Ward

The second story refers to the ethnographic work that was done at the same time span when the interviews were conducted. Morning toilet: To wash Mr B's half-paralyzed body, every morning two care workers have to assist. Around 8 a.m. the caretakers (both female) enter the room. They open the curtains and wake him up. He tends to still sleep at that time. They ask how he feels and he responds that he had a bad dream. He seems to be a little bit confused. One nurse asks whether today his wife will visit him. Mr B smiles and confirms. The two nurses start washing his body, and when finished, they put body cream on his sore skin. After that, they help Mr B to get dressed. Everyday routine, as it were.

All in all, we encounter *good care in practice* for both the nurses and Mr B. The nurses are able to do their job properly and Mr B actively takes part in being ready for the day. Moreover, Mr B managed to make our ethnographic presence, witnessing a rather intimate situation, more convenient: while the nurses are taking care of Mr B's genital hygiene all of a sudden the room was filled with attentive and intense silence. At this point Mr B tells a joke and everybody laughed. Still laughing, the nurses continue cleaning his genital area and put on new diapers. Mr B seems happy with having solved the difficult and discomforting situation. With a smile on his face he says: 'It did work out fine today, didn't it?'

Apparently, only that day. Since a couple of weeks these routines have become more and more problematic and exhausting, for Mr B and the nurses. Turning his body around, sitting at the edge of the bed, and standing up on his shaky legs for a considerable period of time means a quite distressing act for Mr B and the nurses. We remember that the morning rituals in his flat have turned into *bad care in practice*, which made his wife suffer a slipped disc and forced Mr B to move into a long-term care facility. In the nursing home though, the morning procedures, as exhausting as they are, appear more or less unproblematic. With the help of a triangle over his bed, Mr B, conspicuously weakened, can still play an active part during his morning toilet. And not to forget he has the ability to make funny jokes when sociologists colonize intimate situations while being around.

Nonetheless, his paralysis has become worse and his whole physiological (and psychological) constitution is slowly but constantly deteriorating. During the morning procedures he is not able to stand on his own feet anymore. He is becoming too weak. This has become highly problematic since the two nurses cannot properly take care of Mr B's hygiene and sore skin any more. The good care in practice slowly turns into the risk of becoming bad care in practice. The heterogeneous relations which, according to Mr B, have made his life in his new home rather comfortable and autonomous start to lose their re-normalizing and enabling power that initially made him feel at home.

Lifters

Mr B's doctors, nurses and the rest of staff are discussing his deteriorating condition and the severe problems concerning the morning toilet procedures. They 'decide'¹⁰ to use an assistive technology specifically designed to ease his troublesome situation. The so-called lifter enters the scene. There are two different kinds of lifters. One design is thought to help people standing up from a sitting position, whereas the second design tries to help people with a more severe condition and directly lifts up weak people from a lying position.

Mr B seems to have not many problems with the first lifter and he is still able to contribute to the morning routines. Mr B sits at the edge of his bed and the lifter, which is nearly as tall as Mr B, is placed in front of him at short distance. The lifter mainly consists of a tall, slender metal construction and a belt attached to it. This belt is lashed to the upper part of Mr B's body while his feet are firmly placed within a basin-like anti-slip feature. Then a nurse pushes a button and the lifter automatically begins to pull Mr B slowly into a standing position. To do so, Mr B has to help and cling to the lifter, press his feet firmly into the anti-slip feature and create body tension. Only then can the lifter pull Mr B up from his bed into a standing position. This procedure takes some time, but it has the advantage that both Mr B and the nurses are less stressed than they were without the tool. With this lifter Mr B has no problems at all. But after some weeks he can only manage to stand on one leg. Because of this, the function of the lifter is restricted as the pressure that is needed for the lifter to work properly is only possible when Mr B stands with his two legs firmly on the ground. It turns out that the first lifter is not of much help any longer. The nurses are forced to use the second model.

The second lifter works quite differently. Mr B's body is not burdened and stressed as with the first lifter. Mr B lies in his bed and has to slightly roll on his left side. Then, the nurses place a closely meshed but cellular net underneath his back. Mr B rolls back on his back and onto the net. To each of the four corners of the square net metal rings are fixed. These rings have to be remounted into a construction of four metal arms that are part of the lower end of the lifter standing beside Mr B's bed. After Mr B is lying on the net, his arms and legs have to be put into plastic slings. These plastic slings ensure that he does not plunge from the net when he is lifted. Once he is lifted, Mr B can be easily moved. He does not have to do anything. Or to put it differently: with the second lifter there is nothing left for him to do.

How does the use of the second lifter affect Mr B's feeling at home? The lifter plays a decisive but ambivalent participant role in the very enactment of Mr B's situation. This becomes most apparent when we look at the use of the lifter and how its 'script', to use a notion from Akrich (1992) and Latour (1994), is enacted in concrete situations. Care work, and with it the use of the second lifter, can

10 If the care work turns out to endanger the health of the nurses, they are forced by law to use lifters.

be understood as a specific ‘program of action’ (Latour 1991: 107) or ‘mode of ordering’ (cf. Law 1994) that combines and relates heterogeneous elements such as bodies, artefacts, assistive technologies, humans, knowledge and so forth, in order to improve the conduct of care from *bad care in practice* into *good care in practice*. However, as it turns out, with the use of the second lifter quite different realities become present and the lifter is part of Mr B’s worsening condition. The proper use of the lifter comes to its limits for – as Dodier (1998: 53) has put it – the ‘technical object only becomes operative in an activity if all the connections are made to ensure its integration into a network’. Its use problematizes (a) the very process of renormalizing, (b) the very process of rationalizing and (c) the very process of moralizing care practices (cf. Heinlein 2003).

Normalization

When Mr B’s body is becoming weaker, his body turns into a central issue. It is his individual bodily condition, his inability to stand on his legs that causes the problems during the daily morning basic care procedures. The lifter is there to normalize the morning routines and ease Mr B’s bodily problems and pain. And not to forget, the lifter also is meant to protect the nurses from health problems while taking care of the residents. With the help of the lifter, the nurses want to ensure that Mr B can be moved out of his bed and easily transported. By focusing solely on the deteriorating impaired body the script of the lifter and related care practices perform the medical construction of disabilities that welcome technological innovation as a means of completion, rehabilitation and correction of a ‘non-normal’ bodily condition. Technological innovation acts on the impaired subject.

The scripts of those technologies of normalization are concentrating on the physiological deficits and limits of the persons (residents and nurses) involved. Besides that, the script of the first lifter is very successful because it allows Mr B to contribute actively in getting up. The relationship between Mr B and the lifter is prosthetic, where each extend the other, but only from the respective other. The prosthetic relation enacts different capabilities. From such a perspective, as Strathern (2004: 38) stresses, there is ‘no subject-object relation between a person and a tool, only an expanded or realized capability’. To be active and able to help means a lot for Mr B, who has never perceived himself as disabled. With the lifter in place, the nurses feel relieved as well and the morning toilet procedures became better than without it. The intervention with the lifter is a success in dealing with an emerging and situated issue of care. But the script of the second lifter excludes the possibility of Mr B to contribute. Its script works best if and when people remain inactive; it is designed for people being too weak or too impaired to contribute actively. Clearly, the second lifter like the first one is designed for good care in practice. It is meant to ease problematic care situations like e.g. the morning toilet. It is meant to adjust to requirements of the care situation properly without adding additional physiological stress by delegating care work to the

assistive technology. Mr B's bodily contribution has been absorbed by and replaced by the second lifter. With Heidegger, one could say that Mr B's body has 'fallen into the world. Fallenness into the 'world' means an absorption in 'Being-with-one-another' (Heidegger 1996: 175) which is an essential part of our daily life routines. Heidegger also stresses that 'fallenness' is an ambiguous situation since on the one hand it names a 'positive possibility' of 'Not-Being-its-self' in as much as 'in its essential concern, is absorbed in a world' (ibid.: 176). Differently put, Mr B's body is taken care of entirely by others who care [*Besorgnis*] for him – humans and nonhumans alike. Mr B's 'position' remains unaffected in the sense that he does not need to contribute and the script does not allow him to. His body tells him and the others as well that he is too weak to contribute and the carer and their technologies agree. Everything is in place: weak bodies, strong technologies, relieved carers, time schedules, safety issues and so forth. Still, as we know from Mr B, he is used to contributing and making things happen. He enjoyed being active and engaging and he was good at being the head of a team.

The nurses tell us that Mr B is worried about his situation and complains about how he is becoming more and more disabled. The fact that the second lifter has to be used every morning and that Mr B cannot contribute confirms Mr B's negative *Befindlichkeit*. Mr B starts to try to bring himself in an active position again and he looks for ways to regain agency. Mr B begins to work against the assistive technology, which seemed to have absorbed his active being. He fights against the use of the lifter. Every morning Mr B stiffens his body so that the nurses have problems in positioning him rightly onto the net. He cries and screams. He tells the nurses that he gets a rash from the tissue of the net. But despite Mr B's protests, the nurses go on using the lifter and the lifter does its work properly. The situation is distressing for everybody involved. The nurses not only *have* to use the lifter because its use is prescribed by ward regulations, but they also have to follow a tight schedule in order to have time for the caring procedures of the other residents. For Mr B, on the other hand, the care situation means a substantial loss of feeling at home, a feeling that has been part of his story of a successful move. Even his wife cannot cheer him up anymore. His attachments to the care facility and its welcomed partial connections slowly turn into a series of detachments.

What was intended to improve, compensate, stabilize and maintain, that is, to *normalize* the bodily condition of Mr B, then, fails dramatically, and it seems that the second lifter contributes to the ambiguity of the care situation. Still, Mr B's 'doomed to be passive' body ceases to be a problem when it comes to being moved in and out of bed, transported from here to there. The nurses – after a short period of fighting with Mr B's resistance – can care for Mr B's body quite quickly and even stick to their schedules. In this sense, the script of the second lifter works perfectly well in *re-normalizing* the conduct of care. But the attempt to enact a *good passage* of normalization is counteracted by Mr B's bodily deterioration, his resistance and his negative *Befindlichkeiten*, i.e. the ways he finds himself. The lifter-assisted situation of care enacts a *bad passage* that results from the expectation of a disabled body being the prioritized problem to be solved. Although

it functions very well as a technology of care, its power to ensure a functioning body becomes problematic. Mr B does not feel at home at all anymore, and the lifter fails to re-establish *good passages* to make him feel more comfortable. Its script does not allow for a translation of a deteriorating body into the ‘design’ and state of bodies that the lifter is helpful for – and this is not because the lifter does not work properly. Rather, the caring process intensifies Mr B’s worries concerning his increasing bodily inabilities. The very *prosthetic relation of care* that is meant to extend his capabilities is missing and it seems that Mr B feels enacted as incapable by the use of the second lifter.

Rationalization

This ambiguous process of re/normalizing the everyday routine is also about rationalizing the conduct of care. Not only is the lifter sought to compensate Mr B’s lack of mobility, but also to re-professionalize care work. It delegates the *bad passage* experienced by both the nurses and Mr B into a habitual, effective and efficient frame of action. We remember: the very reason why Mr B moved out of his home was to relieve his wife from the daily hard work of care. The availability of expensive assistive technologies plays a crucial role in rationalizing the process of leaving the private house and moving into a long-term care facility. As we have seen through the logic of normalization, it is not only the body that becomes central, but also the technologies and specified knowledge practices that reflect the experience of professional caretaking. When Mr B lost his ability to stand on his own feet, the professional support provided by the nurses was endangered. The professionalism of the conduct of care was at risk. The sore skin of Mr B’s back could not be treated as properly and thoroughly as it was while Mr B was able to stand on his own feet. The first lifter helped out perfectly well. Later, although the first lifter was in use, the weakness of Mr B resulted in the nurses having to use the second lifter. The second lifter, however, failed to perform the renormalizing as well as the rationalizing script. The second lifter worked for a while quite well to do the morning toilet. But Mr B’s resistance and his trouble with the second lifter became so intense that the nurses decided to stop using it since they became involved in even more time-consuming struggles with Mr B than they were without using the second lifter. In effect, the nurses re-introduced the first lifter again or tried to get Mr B out of bed on their own, without technological assistance. However, as it turned out, both alternatives failed because the use of the first lifter took too much time, and Mr B’s passive body was too heavy for the nurses, who, by lifting him without the lifter, also risked their health. For the nurses, leaving the lifters aside could easily cause tremendous problems¹¹ with the administration of the ward given their rationalizing script of handling the situation: Mr B’s problems unavoidably called for the use of the second lifter.

11 Ensuing insurance problems as well.

What we can see here is that alternative orders of care practices are employed in a kind of trial-and-error strategy enacting the very object of care in multiple ways. Finally, none of the strategies employed work satisfactorily any longer; so much so that the nurses and their professional tools become disabled, too: they cannot provide practices that help to re-normalize and rationalize Mr B's situation and make him feel at home with his body and his environment. Obviously, this shows how much the nurses act within a highly problematic and ambivalent situation. On the one hand, they have to be effective and efficient, on the other, they cannot risk that the conduct of care becomes insufficient and nonprofessional – with and/or without the use of assistive technologies.

Moralization

A third script can be found when we look at the moral implications of the conduct of care: Moralization. The latter is closely linked to normalization and rationalization. The script of moralization confirms that Mr B has turned into a person with special needs. The moral point is that professional care – regulated, scrutinized, organized, managed – offers publicly accessible and assessable practices that are meant to make a significant difference to nonprofessional dealings with people who need constant care.

It became apparent that the use and the script of the lifters are deeply entrenched in a moral dilemma. On the one hand, the use of assistive technologies is necessary (not to say unavoidable and obligatory) to guarantee and ensure professional care work. But this moralizing logic applies not only to the concrete situations of taking care of Mr B. The moralizing script is also central to the public testing of professional care and the different ways of how professional care implements and performs standardizing and rationalizing practices of care. In our story, the lifters act as formal tools and as approved assistive technologies that are publicly accessible and assessable by diverse actors: relatives of residents, medical services of health insurances that control the ward, the media and so forth, that is meant to ensure that care is conducted in a professional and appropriate way. Assistive technologies contribute to the standard of professional care. Lifters, then, can be seen as moral supplements that enrich the capacity of delivering good professional care. The morality of the lifter is the following: nobody has to worry about the residents in the ward for they are being professionally cared for! Thus, assistive technologies function as rationalized and standardized forms of professional care practices that are meant to ensure good care in practice.

However, as we have seen above, at the time the second lifter is in use, Mr B's general situation is getting worse: Mr B's bodily and psychological condition deteriorates while the second lifter is meant to contribute to good (or should we say best?) care in practice. Let's remember that the second lifter is employed to overcome Mr B's weakness, which makes his care problematic. Moreover, the nurses are obliged to use the second lifter, which precisely is meant to assist bodies

like Mr B's body, which are too weak to aid the care work of the nurses. The second lifter did its job, but at the same time rendered Mr B's body not only weak, but also entirely passive. As we have seen, although the working scripts of the second lifter did work, they also inflicted unintended side effects and contributed to Mr B's negative *Befindlichkeit*. The use of the second lifter intensified Mr B's feeling of not being at home with his body and his environment anymore. He did not like the procedures of the second lifter, and as we have seen, he expressed his discomfort quite vividly.

Although all scripts seemed to be perfectly well in place, the use of the second lifter brought to the fore the limits of technologically assisted, professional care practices: It created a thoroughly ambiguous and messy situation whereby good and bad passages appeared at the same time. Hence, the fact that the lifter turns out to be a highly ambiguous device also challenges and questions the moralizing script. The moral obligation of professional care – to operate with the relevant practices and appropriate assistive technologies – is seriously endangered. It easily may lead to juridical problems, too. The medical services of health insurances as well as relatives have a critical eye on the conduct of care so that nurses, staff managers, and respective associations can control the moral obligation on different levels. In addition, a lack of professionalism and 'morality' in the conduct of care may easily turn into scandals of care that provoke massive negative political discussions and enormously bad press.

Caring Relations

Our discussion of Mrs M's and Mr B's *eventful bodies* has been focusing on bodies that have undergone a significant ordeal and how their everyday life is shaped by these changing experiences as well as how everyday life is enacting the experience of significantly changed viz. changing bodies. Thus, this focus on *how* embodied relations are disrupted, questioned and altered by such *cosmopolitical events* intends to make a contrast to a mere 'deficit model' of ageing and illness, which primarily is informed by a bio-medical discourse and framed by modern biopolitics. The effects of bodily events, as different as Mrs M's dementia or Mr B's strokes, assemble what I have called the cosmopolitics of illness. The cosmopolitics of illness unfold embodied experiences and practices, good and/or bad, which emerge from conditions of uncertainty, indeterminateness and related affectivities that are introduced by these bodily events. The emerging realities unleash complex, intense and often messy processes of re/generating embodied social relations. The cosmopolitics of illness bring to the fore that ill bodies are not mere bio-medical facts that diverge from a given normality, but emerging relations that undermine, put at risk, endanger and modify taken-for-granted, embodied relations of everyday life. Ill bodies are *cosmopolitical actors* not only by troubling the orderings of embodied everyday life, but also by transgressing the principles of *sanity and reason* that govern modernist symbolic (bio-)politics,

science and philosophy (e.g. the Kantian ‘cosmopolitanism of health’). Moreover, by cutting into and questioning the embodied human social as taken for granted, these affected, troubled and unknown/ing bodily relations draw attention to the ways normalcy gains reality, that is, achieved, remembered, maintained and expected.

It is precisely the cosmopolitics of illness that bring to the fore the powerful embodied *normativity* of normality and the taken-for-granted. At the same time, though, the cosmopolitics of illness demands that we *care about* the differences introduced by eventful bodies that challenge the normativities of the normal. Such events address the limits of the modernist idea of *curative interventions* precisely since they reveal that there is no bio-medically induced return to the normal as a given or average reality of health. The cosmopolitics of illness unfold the requirements of *caring relations*. Mrs M’s and Mr B’s bodies are *cosmopolitical agents* in the way they require *caring relations*, which *modify* the ways we are used to do and expect things to be and consequently ‘adding new obligations, new artifices, new stakes’ (Stengers 2011: 510).

These caring relations do not aim to overcome dementia and the effects of a stroked body by intending a return to the compliance of sanity, health and normality. Rather, these caring relations can be understood as a mode of *healing*, which, unlike curing, engages with a ‘social transformation’ rather than the aim of a remedial return to a lost past that is meant to be the norm/al for every/body:

[H]ealing is never a “return to health”, but rather a “social transformation”, implying the event of an articulation of experience with beings that the person “in good health” can do without. (Stengers 2011: 511)

Caring relations can be understood as the experimental work on the possibilities of a future in the presence of the stubbornness of illness and the specific social transformations it induces. This commitment to the future necessarily includes an interest in learning from and with the ill body; it also means to modify the other, the person ‘in good health’, the carer, the relatives, the ‘they’ [*Man*], i.e. to be affected in a *benign* way by the presence of illness, which ‘causes them to think, feel, and hesitate’ (Stengers 2010: 14) in the ways they relate and care. We have seen with Mrs M and Mr B how difficult it is for others to engage with the requirements of such caring practices. Caring practices demand careful attention to the emerging specificities that enact *relations of hesitation* that interrogate what the requirements of care are. Caring practices require more than good intentions and do not work simply along the mere employment of the *common good*, accomplished facts and general rules, or the mere application of (professional) technologies of care. Care practices can easily turn into non-caring relations whenever the situated requirements are overseen and mere fixed and generalized packages of care are delivered. The latter are prone to exclude and are often highly indifferent to the situated concerns that *connect* ill bodies with others in good health in more or less fragile, risky and unforeseeable ways.

Consequently, my insistence on *relations* of care tries to underline the importance that needs to be given to the biographies and individualities of ill bodies and how these eventful bodies trouble any pre-given, stylized formats of care. Care formats which are dominated by a discourse of the common good, the normal and its equation with *sanity and reason* are prone to fail caring practices; they are not only sterile, but often inattentive and numb to the situated requirements of eventful, ill bodies. Formatted care *regulates* ill bodies, rather than caring for and consequently learning from them. Carers are often torn apart by the situated causes that make them ‘think, feel and hesitate’ on the one hand and the delivery system of care that ignores the time and space needed to engage with the emerging requirements of care (cf. Latimer 2000; Schweiger 2011). The effects are dramatic and susceptible to affect *malignant*¹² relations, harmful for everybody involved.

Caring relations need to give importance to the specific requirements that emerge from eventful bodies which disrupt, question and alter the compliance between the truth, the good, the normal, and the common enacted by the powerful *mise en equivalence* of *healthy reason* and *healthy bodies*. Eventful bodies and what I have called the cosmopolitics of illness unfold complex *passages* that enact the everyday irruptive experiences of embodied social life. These passages effect and are affected by heterogeneous materials (human and nonhuman alike), good and bad relations, attachments and detachments, presences and absences, enablements and disablements, enjoyable and distressing *Befindlichkeiten* and so forth (cf. Latimer and Schillmeier 2009).

We have also witnessed how these passages are far from being clear-cut. Quite on the contrary, it is the ambiguities and contingencies of eventful embodied relations, which enact the situated realities of illness as well as the situated, often conflicting, requirements and practices of caring relations that may significantly contribute to *feel at home* or not. We have seen how the presence of mere spatial matter of facts unleashes the experience of living in uncanny extensions enacting the *Befindlichkeit* of Angst and Mrs M’s desire to re-gain enduring, i.e. traceable relations. Thrown in the dementing world, Mrs M’s world is affected by the presence of absence, by ‘demented objects’ (herself as well as her human and nonhuman environment). Such a situation requires novel human and nonhuman relations that *care* about the *possibilities* of Mrs M’s ongoing *collective self*, which, enacted by the dementing process, got stuck within the sheer presence of individual facts that neither protracts into the past nor into the future.

The case of Mr B and the use of assistive technologies brought to the fore that caring relations are not only about eventful bodies, but include *eventful technologies* as well.¹³ Assistive technologies of care are not just given means of care that technologically fix the needs of care. Rather, they are an active part (good and bad) that co-configure the requirements of caring relations. As we have seen, assistive technologies also complicate the everyday practices of care and contribute

12 On ‘malignant’ forms of care, cf. Kitwood (1997).

13 On eventful technologies see Braun and Whatmore (2010), and Schillmeier (2010).

to the ambiguities, indeterminateness and thus eventfulness of caring relations. Hence, caring relations require taking care of the on-going (affective) relations they create. *Caring relations require caring about the conditions of possibility they enact.* The unfolding realities of illness underline that our embodied selves, as well as our personal orderings, are fragile, on-going collective achievements of humans and things that need caring relations in order to feel at home.

Relations of care, then, can be understood as a way of providing novel forms of affective extensions that are concerned about the differences introduced by embodied events. In the case of Mrs M's experience of dementia, this obviously means to care about the biographical specificities of Mrs M's affective relations with others and how these relations were and are lived (cf. Brooker 2006; Kitwood 1997). It also implies to care about *situated extensions*, which may enable Mrs M to feel at home within the present, in order to build on the future possibilities these extensions may provide. Situated extensions enact attachments (or detachments), which provide enduring relations (human *and* nonhuman alike) by linking passing occasions with coming possibilities. Through situated extensions the mere spatiality of demented things may *temporalize* again (if only for a short moment in time). As we have witnessed, extensions of care do not necessarily have to be relations of knowledge. Quite on the contrary! The process of dementing brought to the fore the importance of affective relations and how they enact the distressing as well as comforting *Befindlichkeiten* of Mrs M.

The shifting and multiple hi/stories of Mr B's life with a stroked/ing and altered/ing body also showed the importance of affective human and nonhuman relations and how these relations were enacting spatio-temporal situations that re/generated good and bad passages, abilities and disabilities, enjoyment and suffering, activity and passivity. The brief look at Mr B's life in a professional care institution not only revealed the importance of assistive technologies in creating novel forms of extension, but also unravelled the emerging ambiguities and dilemmas, by using assistive technologies in the conduct of caring about Mr B's stroked and weakening body. We have seen how eventful bodies enact eventful technologies and *vice versa*: for the good and the bad, unknowable in advance. Cosmopolitics, as it were.

By re/generating the hi/stories of the forgetting body of Mrs M and the stroked body of Mrs B, I also intended to draw attention to how we are moved by the differences of emerging embodied and affective relations involving humans *and* nonhumans. In Mrs M's dementing world, the present absence of the nonhuman environment played a crucial role in those situations where she felt lost and insecure, dwelling in an utterly uncanny world. The present absence of things draws attention on the importance of nonhuman materialities and locations in the life-course of personal ordering. It accentuates an understanding of the self as an on-going collective achievement of human and nonhuman relations. With the onset of the cosmopolitics of dementia, many forms of Mrs M's being in extension that have been taken-for-granted and in which Mrs M felt at home with became unknown, alienating, frightening and fearful. To be sure, living in

extension does not mean that there is a given human being, which in addition also has external linkages with human and nonhuman others. Our reading suggests instead ‘that we are always in extension. Indeed extension is all that we are ever ‘in’ (Munro 1996: 264), spatially *and* temporally. Moreover, extensions cannot be understood without intensities. Relations, then, are always affective connections, matters of concerns and not just mere matter of fact linked in space and time.

* * *

In the concluding chapter of this book, I would like to shift the focus from bodies that have already experienced the event of a serious illness towards *the risk* of becoming ill, i.e. to be exposed to the risk of contracting a life-threatening illness and the cosmopolitics involved. Ten years ago, in 2003, an unknown infectious disease appeared, which later became known as SARS (Severe and Acute Respiratory Syndrome), posing the risk of becoming a pandemic threat to human life. It is precisely the very *realities* of a *potentially* life threatening future event that gains *cosmopolitical* power in questioning, disrupting and altering our past and present life. The SARS events draw attention to the question of what it means to live with *bioinsecurities* and *biouncertainties* and how the indeterminateness of life enacts its on-going conditions of possibility.¹⁴ As Hinchliffe et al. (2013: 1) stress:

healthy life is not simply something that is threatened by incursions from the ‘outside’; in a world in which pathogens and life co-evolve, life itself is as likely to be threatened by its very own liveliness, as much as anything else.

What is striking about SARS or any other infectious diseases is that emerging *nonhuman* entities (bacteria, viruses and so on) gain *cosmopolitical agency* and contribute to the *cosmopolitics of eventful bodies*.

14 Cf. Hinchliffe et al. (2012), Bingham and Hinchliffe (2008).

Chapter 3

Infectious Bodies¹

Emergency Situations

On March 15, 2003 a plane from New York arrived at Frankfurt airport in Germany. On board were three suspect cases of SARS (Severe and Acute Respiratory Syndrome), a contagious and life-threatening illness for which the cause has not yet been determined: a doctor from Singapore, who has been participating at a congress in New York; he was accompanied by his wife and mother-in-law. Before travelling to New York, the doctor treated a patient in Singapore, who was suffering from a flu-like illness. While being in New York, the doctor got sick and was diagnosed with pneumonia. Since then, his illness did not respond to the therapy and he decided to go back to Singapore in order to cure his pneumonia. Before leaving New York, he informed his hospital in Singapore about his illness. At that time, the local offices of the WHO (World Health Organisation) were witnessing a series of reports, mainly through the Internet and SMS messages, concerning the onset of unusual respiratory illnesses in Chinese hospitals.

Earlier, on February 26, a businessman flying from Hong Kong to Hanoi, Vietnam arrived at the Hanoi French Hospital with symptoms of a bad flu. Like the Singaporean doctor in New York a couple of weeks later, he was diagnosed with an unusual pneumonia and the illness did not respond to the treatment. In the course of a couple of days, almost all members of the medical staff, many patients and visitors at the ward of the French Hospital (House A) were falling sick with flu like symptoms. Blood tests and x-rays of their lungs showed similar worrying effects as those of the businessman. The family of the latter, who witnessed the rapid deterioration of his condition decided to evacuate him to a hospital in Hong Kong.² On March 12, the ward of House A of Hanoi French Hospital was closed to new admissions except for ill workers of House A. From that day until May 2 the other main part of the hospital, House B, began with admissions of similar cases. At the same time, patients from House A were transferred to House B. The situation of House A, where the first patient was treated with flu-like symptoms, and that of House B, where later cases were treated, radically differed. Whereas in House A, the unknown disease spread throughout the ward with severe effects

1 This chapter is an altered version of Schillmeier, M. (2008) Globalizing Risks – The Cosmo-Politics of SARS and its Impact on Globalizing Sociology, *Mobilities* 3(2): 179–99.

2 In the culture of Vietnamese nursing, the family of the patients play an important and active role.

on the infected (40 people infected and seven deaths), House B did not experience internal infections and the patients seemed to be less ill³:

No nosocomial SARS-associated coronavirus (SARS-CoV) transmission was reported in hospital B, and none of its 117 healthcare workers (defined as all staff working in the hospital building during the SARS outbreak) became ill with a SARS-compatible illness. This situation occurred despite obvious challenges to infection control. When hospital B began admitting patients, visitors were not tightly restricted, the main elevator was out of service and families and workers often used the designated patient elevator. Researchers (K.C.L., H.Q.N.) and infection control advisors working daily on the hospital B wards reported variable infection control and patient isolation, particularly during the early weeks. On March 19, formal infection control training was organized and substantial technical support and supplies arrived from WHO, Medicines Sans Frontiers–Belgium, and the Japan International Cooperation Agency. Systems were established to restrict visitors and entry guards and Medicines Sans Frontiers’ advisors were tasked with distributing and monitoring personal protective equipment, such as N95 masks, gloves, gowns, and hand sanitizer. Two of the authors of this article (...), who worked daily on the wards, observed that infection control practices improved considerably after these interventions. (Ha et al. 2004: 265)

Emergency situations like the one at the Hanoi French Hospital bring to the fore how daily clinical practices do not merely follow a general conduct, which is universally applicable, but often are messy, unruly and locally specific. Studies of emergency situations also show that the information and knowledge gained *a posteriori* are often difficult to recall and do not provide a coherent and whole picture.⁴ Emergency situations are emotionally distressing; people experience these situations differently and also act differently. Emergency situations like the one in Hanoi are also about uncertainties – known unknowns as well as unknown unknowns – which nevertheless may have devastating effects for those who are affected by them.

The small study of the situation at the Hanoi French hospital revealed that House A and B perform rather different nursing styles: whereas nursing in House A was primarily a matter of hospital staff, in House B nursing practices were more shared between staff and family members of the patient. There is no secure knowledge about when and how infection control measures were used and who used them. Infection control measures were differing during the emergency situation: in the

3 The qualifier for ‘less ill’ was ‘less deaths’ (cf. Ha et al. 2004).

4 As Ha et al. (2004: 267) stress: ‘[O]ur survey is subject to recall and reporting bias, because not only was it difficult for respondents to recall behaviors during specific periods within the previous 2 months, but respondents may have been concerned that results could be used to evaluate their performance’.

early phase of dealing with the unknown disease, medical staff, relatives and visitors of House A were not constantly wearing masks. In House A, different medical technologies have been utilized to treat patients (e.g. invasive respiratory measurements, ventilation and intubation), whereas in House B only non-invasive technologies were used. The environmental conditions of House A and B differed as well. House A was a relatively modern building with small rooms and low ceilings, using individual air-conditioning systems for each room (in use at the early onset of the crisis). House B, on the other hand, was an old building with big rooms, high ceilings, high ceiling fans and big windows for cross-ventilation and so forth.

This brief selection of *situated differences* makes clear that the conditions of possible infection are the effect of situated practices, which are partly known but often remain messy and poorly understood. Thus, even after getting to know the unknown better when the atypical pneumonia was identified as SARS caused by a novel corona-virus (SARS-CoV) and the locations of infection (House A) and non-infection (House B) were identified, the understanding of it remained partial and incomplete.

The idea of a ‘superspreader’ or a ‘superspreading event’ provides a typical concept that functions as a marker or supplement for such partial and incomplete knowledge. Superspreaders, as Priscilla Wald has shown, are key figures in the histories of the ‘outbreak narrative’ of contagious events such as typhus, HIV or SARS (cf. Wald 2008). Ha and his colleagues did not find evidence of a nosocomial SARS-associated coronavirus (SARS-CoV) transmission in House B (Ha et al. 2004). They argued that it ‘may support the hypothesis that, in the absence of a superspreading patient or event, most SARS patients will not transmit the virus’ (ibid.: 267). This argument is intriguing since with the idea of the superspreader or superspreading event, evidence of high transmission is attributed to a situation or a person which/who remains poorly understood. Nevertheless, superspreaders or superspreading events are seen as key knots in the distribution of the infectious disease. What qualifies superspreaders as distinct is not a given property or disposition that makes a person more infectious than others. Rather, a superspreader is the effect of highly specific situations that allows for more (secondary) infections than other situations do. Superspreaders play an ambivalent role, since a person is not only treated as a victim of a contagious event, but is seen as a key actor in creating and intensifying the infectious event. Superspreaders create the problem and are key to solve them inasmuch as they are key actors in order to make the contagious event traceable and knowable. However, as we have seen above, the connections and practices that make these situations more infectious are multiple and often remain only partially understood. Obviously, the dual use of the superspreader, both as the symptom and cause of more contagion is prone to misuse, fix and simplify contagious events when the symptom gets conflated with its cause. Personalizing a superspreading situation, then, may have devastating social and psychosocial effects for the person (or related social groups) ‘identified’ as superspreader(s) (cf. Wald 2008).

On March 12, the WHO, for the first time in its history, issued a worldwide alert concerning an atypical form of pneumonia in Vietnam, Hong Kong, SAR and Canton. On the next day, the businessman died at the Hong Kong hospital. Realizing the global alert, the clinic in Singapore did inform the WHO that one of their members of staff, while being in New York, fell ill as well. The WHO, in turn, informed their local offices in New York and they tried to find out where he is, since they feared he might well infect many others on his flight back from New York. Arriving at the Frankfurt airport, he and the whole plane were immediately quarantined. The suspected cases were brought to a Frankfurt hospital, treated and survived. None of the remaining passengers were infected.

Already in November 2002, Foshan, a city of three million inhabitants and shortly afterwards, Heyuan, 200 kms away and the capital of the southern Chinese province Guangdong, witnessed first cases of an uncommon respiratory illness. Although many doctors did report in detail to the Chinese health department, the latter either ignored them or treated them as a state secret that was not meant to spread beyond Chinese borders. Hence, the disease did already disseminate in 2002 and the Chinese policy of hiding information was helping the disease to keep on disseminating. Only after three months, on February 11, 2003, the Chinese department of health reported 306 cases of an uncommon respiratory illness (including 5 deaths).⁵ Ten days later, a doctor from Mainland China went to Hong Kong by bus to attend a family celebration. Before travelling to Hong Kong he has been treating a patient in Guangdong suffering from pneumonia. Arriving at a hotel in Hong Kong, he met his brother-in-law and they went for a shopping tour. Back in the hotel, the doctor, already very ill, is meant to have infected 12 other national and international guests. As it turned out, one of the infected guests was the businessman who fell ill in Hanoi and later died in Hong Kong after being evacuated from Hanoi.⁶ On March 4, the medical professor from Guangdong died in a hospital in Hong Kong. His brother-in-law died shortly after him. Later tracings of the network routes of infection suggest that more than half of all registered SARS infections around the world are linked to the hotel in Hong Kong.

On the March 15, the WHO issued a global health alert after cases were identified in Singapore and Canada as well. Meanwhile, the mysterious atypical pneumonia was given a name: 'SARS' (Severe and Acute Respiratory Syndrome). The disease was rapidly spreading inside and outside of hospitals, inside and outside of Hong Kong, inside and outside of China, and there were clear signs that the disease may turn into a serious global issue. Still, the uncertainties and non-knowledge concerning the cause(s) of the infections and how it is transmitted remained unclear.

5 In late April (20.4.) China admits that are much more SARS cases as previously reported (e.g. in Beijing). On that day, Hong Kong reports 12 deaths related to SARS.

6 40 people from the Hanoi Hospital got infected and seven of them died.

On the morning of March 10, 11 health care workers of one ward at a big hospital in Hong Kong were reported to have fallen ill with flu like symptoms and were on sick leave. On the evening of the next day the number of infected health care workers increased to 50. In the next several days the ward was closed and re-opened.⁷ Patients without symptoms were discharged and new cases with atypical forms of pneumonia were admitted. The ward became a 'cohorting' place for suspect cases and many of the patients without symptoms were quickly discharged for their own protection. So was a patient who frequently visited the ward for medical treatment of a chronic illness. After receiving his routine treatment on March 15, he fell ill with fever. Since his symptoms were similar to the patients with atypical pneumonia, he was transferred to the ward where all related cases have been cohorted. During his stay at the ward he was diagnosed with influenza A. Astonishingly, his condition improved rather quick as well. Since March 17 he had not shown any feverish symptoms and was discharged on March 19. Being a case of influenza A, his name happened to disappear from the 'case list' concerning the atypical pneumonia; he also disappeared from the 'contact-tracking' list. The contact-tracking list is meant to trace possible contacts of infectious patients in order to possibly reduce the 'risk of secondary transmission through health surveillance or isolation of contacts' (Legislative Council Hong Kong 2004: 90).

Meanwhile the investigations seemed to have identified the so-called 'index case' patient who is thought to have been the first source of infection. Moreover, the use of nebulizers was considered to be a possible cause of spreading the disease within the ward. However, both findings remained contested (*ibid.*). When the patient, who was discharged on March 19, presented himself again on March 22 for his follow up routine medical treatment, he suffered from respiratory failure and was immediately transferred to the intensive care unit of the hospital. Due to his re-admittance and his respiratory failure he 're-appeared' on March 23 as a possible case of atypical pneumonia. After difficulties of getting in contact with his family, his father was finally interviewed on March 24, but he was not aware of any actual diseases within the family. But already the next day, the father reported that his son's brother fell ill with flu-like symptoms and has been admitted to another Hong Kong hospital. The father of the patient reported that his son used to stay overnight at his brother's place when he had to go to the Hong Kong hospital for his weekly routine medical treatment. The brother's flat is part of a densely populated private housing estate in Hong Kong.

During this time, fast-circulating rumours of a deadly infectious disease were communicated via SMS, telephone and Internet and produced deep anxieties and panic within the Hong Kong population. The Hong Kong media constantly reported new cases of atypical infections and related deaths outside of hospitals as well. The Hong Kong Government on the other hand downplayed the situation and denied an outbreak in the community of Hong Kong (cf. Roloff 2007; Shiu-Hing Lo 2009). On March 26, a hospital, located nearby the housing estate where the

7 The Accident and Emergency Department of the Hospital was closed on March 19.

brother of the patient from above lived, reported 15 suspicious cases of an atypical pneumonia. The patients all happened to live in the same housing estate where the brothers met. As successive investigations have shown, already more than 100 residents of the estate were infected and more than 300 will become infected. At the end of March, one block of the housing estate, which showed the highest number of infections (it was again the block where the brother lived) was isolated, the households were confined to their home and the families were not allowed to have visitors for a period of ten days. Such drastic governmental measures were possible by enforcing an old quarantine law ('Quarantine and Prevention of Disease Ordinance'), which has not been employed for almost a century (cf. SARS Expert Committee 2003: 45). As archaic as it was, the quarantine enforcement came quite late and was only semi-helpful, since already half of the people living in the isolated block have fled and were living either in hotels or staying with family and friends (Roloff 2006: 32). Moreover, the enforced isolation and confinement not only intensified the mistrust in governmental policy but also created lots of tension between the quarantined people who felt they were being left behind and trapped in a deadly space. As a consequence the remaining people have been eventually evacuated to a former holiday resort.

The tracing of the chain of infection revealed a direct link between the infections of the two brothers. The brother, who visited his sibling at the housing estate after having been treated at a Hong Kong hospital, was considered the 'index case' for the infectious chain at the estate. However there was no undisputed evidence for it (Legislative Council Hong Kong 2004: 93). Moreover, the investigations were faced with a puzzling situation: the affected households reported that they did not know each other, have not met and were not involved in common activities. At that time it became more unclear than clear how the disease is transmitted. It was thought that it spread primarily via droplets and fomites spread. Aerosol transmission was another possibility, but was considered as a low probability of transmission. The situation was getting worse, since people started to think that the causative agent may already have been mutating and consequently may be transmitted differently and may have become even more deadly. Scientists, who were working in provisory labs at the estate, were caught in controversial disputes about their lab-results. The controversy intensified when foreign scientists contested their results. For many locals the disease was also the revenge of homeless ghosts. Ghosts that lived in the area which once was a banana plantation. Due to extensive urbanization of the region and the building of the housing estate, the plantation was erased and their ghosts became homeless (Roloff 2006: 33).

The possible causes of the contagious disease were multiple, disputed and uncertain. Moreover, the relationship between the anxious and panicking community and the stubborn government, which has been neglecting any community spread of the disease so far, was already highly problematic and reigned by mistrust. Consequently the enforcement of rigid governmental and police action was seen with suspicion and neglect. With their self-created website, *sosick.org*, the citizens shared their concerns and their everyday experiences. The

webpage also was a fast and well-organized site that could show where and how people were moving, where possible risks occurred or might possibly occur and so forth. The website also forced the government to improve their communication practices of relevant information.

Intriguingly, the investigations at the housing estate showed that the affected households lived vertically to each other, below and above. It became visible that the relevant flats were connected by a plumbing system, which linked these households, but has been partly defect and out of regular use. Moreover, it turned out that many of the SARS patients were also suffering from diarrhoea, as was the patient who visited his brother and stayed overnight in his flat of the housing estate. The SARS Expert commission reported:

The vertical spread of SARS in Block E was attributed to a combination of dried up Utraps, contaminated sewage, and updraft in the lightwell that facilitated droplet spread. The findings were later corroborated by a report released on 16.5.03 by an expert environmental health team of WHO, who had carried out an independent investigation on the community outbreak. (...) The studies highlighted the following:

- At the time of the outbreak, the U-traps of the bathroom floor drains in most apartments had been dry for long periods, losing their sealing function to the soil stack. In the case of a running exhaust fan and a closed bathroom door, droplets would have been drawn from the soil stack into the bathroom through the dry U-trap, thus contaminating the bathroom.
- A break of a flush-water pipe serving all unit 8 apartments of Block E on 21.3.03 led to an overnight shutdown of the flush-water system. This event most likely decreased the flow, but increased the generation and movement of droplets, in the soil stack. In addition, bucket flushing would have increased the generation of droplets in the bathroom.
- The running exhaust fan served to transport contaminated droplets present or generated in the bathroom into the lightwell. Due to the natural current within the lightwell, these droplets had the tendency to move up and could enter an apartment several floors away from the source through an open window (SARS Expert Commission 2003: 52; McKinney et al. 2006).⁸

With these findings another unusual and complex factor was added to the multiple ways the disease may potentially spread and be transmitted between humans. At the end of March, scientific research found evidence that the infection may be caused by a new strain of the well-known corona-virus, which is responsible for common colds and respiratory illnesses. Later in April, the genome of the SARS-CoV was identified as the possible causative agent of the life-threatening disease. Its origin remains disputed, but it seems that the SARS virus had jumped from

⁸ The results of the investigation have been contested by other investigations (cf. SARS Expert Commission 2003: 52).

animals (bats, civet cats, raccoon dogs etc.) to humans. Lab tests confirmed that several wild animals were tested positive with viruses very similar to SARS.

In China, 'exotic' animals are offered as delicatessen at markets. Epidemiological research showed that the early cases of SARS were often related to animal traders or cooks who were in close and direct contact with these animals. Many of them are living in the Pearl River Delta in the South of China. Since the late 1970s Guangdong and the Pearl River Delta have experienced excessive transformations, unravelling extensive mixtures of industrial and agricultural, rural and urban activities (cf. Lin 2001). Due to these entangled processes and practices, hybrid spaces of human/nonhuman living were created, which are thought to be prone to zoonosis, i.e. the emergence of illnesses that are transmitted from humans to animals and from animals to humans. In the course of excessive modernization of rural and agricultural life, social changes were triggered off on the 'macro' as well 'micro'-level. As a consequence, not only the socio-cultural life was radically altered but micro-bacteriological differentiation has been fostered as well.

Not only does the mediation and migration of SARS provoke global vulnerabilities, the virus itself is also partly the effect of excessive transformation processes enacted by the pressure of globalization and related regimes of modernization. Through the cross-species mutation of a virus and the cross-border movement of more or less visibly ill, but apparently highly infectious bodies, multiple and simultaneous events of infections occurred, which has caused 8442 registered cases of infection with 775 casualties. In July 2003, the SARS epidemic declined and the WHO declared the global threat of the epidemic as contained. Still, cases of SARS have been reported in 2003 and 2004. Since 2012, a novel SARS-related life-threatening virus (MERS, Middle East Respiratory Syndrome) appeared in Saudi Arabia.

The brief splinters of emergency situations as described above only name a tiny part of how SARS disrupted, questioned, altered and endangered embodied life and social orderings. Since the disease had propagated rapidly along international air traffic routes, a global pandemic of SARS was feared (cf. Price-Smith and Huang 2009). Ali and Keil (2006) pointed out the close relationship between air travel and microbial traffic in a globalizing world (cf. Ali 2010; Fidler 2004; Naylor 2003). As air traffic speeds up people's access to highly distant places it may also accelerate and distribute the transmission of infectious diseases. Consequently, contagious events such as SARS are able to endanger individual lives as well as disrupt societal organization across continents. Since SARS did appear in different countries and on different continents it could not be treated as a mere trans-regionally spread disease, but was feared to become a daunting pandemic threat – a global epidemic.

We have seen that during the first months of its appearance the life-threatening infectious disease showed severe effects but remained mysterious, nameless and non-traceable. The longer one did not know what the disease was, the more one was exacerbating the risk that it turns into a deadly, dangerous 'global assemblage' (Ong 2004: 81), endangering millions of human lives,

harming (trans-)national economies, producing new socio-political conflicts and inequalities and so forth. It was the passing fright – justified or not – of a globally acting contagious and life-threatening unknown, indifferent to nation-state boundaries and their control and surveillance strategies, which made politicians, scientists and legal systems act, communicate, reflect upon and rethink their own practices and frameworks of action by re-configuring local, national and global scales of societal performance. Luckily, local and trans-local efforts have been successful in containing the ‘microbial traffic’ (cf. Mayer 2000) of SARS; SARS remained a global risk and did not develop into a pandemic. However, SARS and its mutations continue to be a latent risk (cf. WHO 2003a): as new life emerges so do novel pathogens and emerging diseases. ‘The most important lesson from the SARS experience’, so the concluding remarks of the SARS Expert Commission claim, ‘is that we must be prepared for new and emerging infectious diseases’ (2003: 85; cf. also White and Banda 2009).⁹

The Cosmopolitical Epoch and the Precariousness of Living Societies

What we may have learned from SARS is that we neither live in a human controlled cosmos, nor does the cosmos of life resemble the morality of nature as harmonious, a healthy cosmos as it were, that is breached by the nonhuman antipodes of life. Rather, we live in dense extensions of co-evolving human and nonhuman living entities ‘favouring each other, competing with each other’ (Whitehead 1978: 98).

When sharing a common form such as life, these human/nonhuman relations make up a *society* of living beings (ibid.). However, the notion of society, as employed throughout the book, should not be conflated with a bounded entity or a given and fixed state of being. On the contrary, it refers to relations in the making which, by the process of relating, consume heterogeneous entities and *produce* new forms of life. This eventful relation is always a specific form of consuming others and being consumed by others, as much as it produces specific others and alters (in new and often unexpected ways) the relations in place. Consumption is production (cf. Lee and Munro 2001). Following from that, life events do not copy the past but by inter-relating they enact the uncertainty of their effects. In that sense, life events exhibit ‘a certain social deficiency’ (Whitehead 1978: 105) unleashing *cosmopolitical* effects. Moreover, life events obviously do not include all forms of life, rather only specific ones and enact partial connections. As consuming/producing interventions, these partial connections do not necessarily expand the capacities of all its connected parts. In our case, it created a living society whereby 1) humans, who have been in touch with a specific strain of a

9 The discourse of ‘preparedness’ also fosters the ‘rise of surveillance medicine’ in order to globally ‘monitor precarious normality’ delineating ‘a new temporalized risk identity’ (Armstrong 1995: 403). On biopolitics beyond the ‘nation state’, see Bashford (2006).

corona-virus, the SARS-CoV, experience a life-endangering process of embodied decomposition, and 2) a virus securing its being by robbing valuable¹⁰ food from these affected human bodies. These *human/SARS-CoV-relations* enact a new living society affecting the possibility of human death. 'Life is robbery', as Whitehead (1978: 105) noted, it links 'order and destruction' (Stengers 2011: 312).

The SARS-affected human body enacts what I like to call a human-SARS-CoV-living society. Following A.N. Whitehead (1978: 99), the human-SARS-CoV-living society assembles a 'structured society' in as much as the relation of human bodies and the SARS-CoV show 'patterns of structural inter-relations' (ibid.): the social organizations of human bodies being vulnerable to become infected by SARS and the SARS-CoV being able to dangerously infect human bodies. In abstraction from the *human-SARS-CoV-living society*, humans and SARS viruses exist differently and they are of different concerns. SARS, for example, may spread between animals without any negative effects for them. Following from that, only when being inter-related, human bodies and the SARS-CoV gain *social* relevance by *altering* the related societies: The SARS virus proliferates and human bodies may become seriously ill or die.

A major characteristic of the cosmopolitics of SARS was the structured but unknown novelty or originality introduced by the human-SARS-CoV-living society. *Without knowing* people became affected by a novel agent and became novel agents of infection themselves. The cosmopolitics of SARS and its unforeseen dynamics of infection unfolded the experiences of unruly emergency situations, suffering and excitement, uncertainties and insecurities, existential fears¹¹ and anxieties. Following a Whiteheadian parlance, the *event* unleashed by the *human-SARS-CoV-living society* created an *interstice of experiential intensities*: 'There is intense experience without the shackle of reiteration of the past' (Whitehead 1978: 105). 'Life', so Whitehead concludes, 'is a characteristic of 'empty space' and not of space 'occupied' by any corpuscular society' (ibid.). In that sense, the devastating illness 'SARS' and the life-threatening robbery of the SARS-CoV refer to a cosmopolitical 'epoch' (ibid.: 106) wherein a novel nonhuman agent, in order to live, endangers and consumes embodied social orderings that are meant to keep human life alive. It brings to fore 'how one existent manifests itself in the very fabric of another' (Jones 1998: 3) and becomes regnant with the destructive novelty it introduces to the fabric of the other by feeding its own desire to live.¹² The human/nonhuman association brings into being a novel living society, with composing and decomposing effects. The emergence of SARS, then, is a social event through and though.

10 On food as 'biological value' and not a mere given 'biophysical reality', see Canguilhem (1991: 220).

11 Cheng and Tang (2004) discuss the social-psychology of SARS.

12 On desire and persuasion (*désir et croyance*) as nano- or microscopic agentic forces of connection and attachment/detachment, see Tarde (2012).

In effect of this event, life is threatened by its own lively and heterogeneous conditions of possibility. As we have argued, all living societies in order to continue living not only require 'a wider social environment' (Whitehead 1978: 100), but require 'the destruction of elaborate societies derived from the environment' (ibid.: 105). 'Life is robbery' as Whitehead pointed out, and '[i]t is at this point that, with life, morals become acute. The robber requires justification' (ibid.). And clearly, the history of the SARS-CoV becoming a destructive robber of its human environment cannot be understood without the history of human ways of consuming its environment, mediated by technologies of excessive modernization re-assembling human/nonhuman relations and forms of life. Hence, to consider the SARS-CoV robbery as a bad or amoral and thus unjustifiable event, one needs to critically rethink how we humans act as robbers and the ways we consume our nonhuman environment from which the SARS-CoV robbery emerged in the first place. To think of the SARS-CoV merely in terms of an unjustifiable attack on healthy and peaceful human social life is blind to the topology of its conditions of possibility and the human modes of consumption that brought the human-SARS-CoV-living society into being in the first place (cf. Haggett 1994; Mayer 2000; Wilson 2001).

Life as robbery is a boundary issue, a boundary effect of interstices between heterogeneous entities which enable empty spaces for intervention, gaps for re-assembling (Debaise 2013; Stengers 2011; Whitehead 1978). As interstitial spaces of intervention, these spaces are also spaces of moral concerns addressing the relationship between consumption and production of others and otherness. The SARS event brings to the fore the conflict between societies understood as corpuscular or occupied space and societies of a wider type that refer to their eventful becoming, of novel 'belongings' enacting new assemblages. Thus, within outbreak narratives of contagious diseases like SARS, both understandings of society shape the ways we deal with contagion. The SARS-CoV is seen as an enemy of life, an unjustifiable intrusion from outside the confined boundaries of healthy human social life. It consequently needs to be fought back with war-like strategies that clearly separate off the human space from the nonhuman enemy (cf. Huat 2006). Hereby, the nonhuman producers of the dangers and uncertainties of the non-social, chaotic and unruly situation are considered as unwelcome intruders of an occupied space of human bodies (and their life-world). These spaces are understood as 'corpuscular societies', given as bounded, objectified entities. However, in order to be able to trace the human-SARS-CoV-living society, the second understanding of society as a 'wider' type gains importance. It addresses the partial connections or becomings of living societies whereby the non-social, chaotic and unruly situation is part and parcel of life. Thus, to understand the non-social nexus of the SARS event and its consequences for human life means to *engage with* and *protect* the cosmopolitical force of SARS rather than excluding or eliminating it. The search for the causative agent of SARS and how it emerged can be understood as a way of socializing the non-social by means of techno-scientific interventions and related social environments in which the agent is able to survive without harming human life.

Spaces of life, then, are boundary relations which bring societal novelties into being. Heidegger notes:

A space is something that has been made room for, something that is cleared and free, namely within a boundary, Greek *peras*. A boundary is not that which something stops but, as the Greeks recognized, the boundary is that from which something begins its presencing. (Heidegger 1971: 154)

Hence, by crossing the boundaries and reaching out to the social environment, societies materialize, assembling the specific and thus always bounded conditions of possibility of being. These emerging societies are virtual realities in the sense that one does not know what the social relations, that bring them into being, are able to. Nevertheless, the social environment plays a crucial role in the ways things/ societies – human and non-human alike – might come into being and maintain: living societies depend on a social environment which supports the capability of their becoming. However, the supportive act comes with a price: it is consumable!

Narratives of contagion as *stories of life* are boundary stories: linking boundaries, crossing boundaries, deferring and building boundaries and so on. Stories of life connect as much as they separate, compose as they decompose, assembling ‘more life’ and ‘more than life’, form and non-form, the social and the non-social, knowledge and non-knowledge (cf. Simmel 2010; Schillmeier 2010). Life, as a boundary existence, has no boundaries; life is ‘self-transcending’ and includes its other (cf. Simmel 2010). Priscilla Wald has convincingly argued that a contagious event like SARS is

more than an epidemiological fact. It is also a foundational concept of religion and of society, with a long history of explaining how beliefs circulate in social interaction. (...) The interactions that make us sick also constitute us as a community. Disease emergence dramatizes the dilemma that inspires the most basic human narrative: the necessity and danger of human contact. (Wald 2008: 3; cf. also Baehr 2005; Huat 2006)

I agree with Wald that SARS is indeed more than an epidemiological fact and it is also more than a bounded human affair. For Wald (2008), SARS is also a prototype of an ‘outbreak narrative’ which identifies the emerging infection, traces its complex network and finally is able to contain the spreading invasion. Although the outbreak narrative does provide insights into the global interconnectedness of modern life, it remains as much a story of ‘human exceptionalism’ as it does remain within a classical biomedical model of illness and immunology that narrates a biopolitical war against the enemies of human life.¹³ Following Tony D. Sampson’s (2012) adaption of Deleuze and Guattari’s notion of ‘molar forces’,

13 On the biomedical and immunological discourse of ‘the body as nation state’ which is at war against intrusive enemies, see Martin (1990).

the discourse of contagion and the outbreak narrative focuses on the ambivalent effects of

the universal application of epidemic models of disease across a range of contagious phenomena. Molar virality is, (...), endemic to new biopolitical strategies of social power, that is, a discursive (and pre-discursive) means of organizing and exerting control via, for instance, the widespread imposition of generalized immunological defences, anomaly detection techniques, and the obligation of personal hygiene in network security. (Sampson 2012: 6)

My reading of the SARS events suggests that SARS was also a ‘molecular’¹⁴ event of life itself, which draws attention to the specificities of how social orderings are disrupted, questioned, endangered and altered by processes of affection and self-transcendence of complex structured human/nonhuman extensions – organic and inorganic. SARS not only has been exhibiting a boundary existence of human/nonhuman life, of life/death or of knowing/not-knowing. The dynamics of infectious relations were also hyper-complex in the sense that local transmission may have global effects and global movement multiplies local events of transmission. Hence, *living in* heterogeneous life relations is not about a normal, healthy, safely bounded human life which SARS has invaded representing life’s Other. As Hinchliffe and Allen (2012: 6) stress:

Being healthy may not simply mean being free from pathogens, but a matter of immunocompetence; that is, the ability to live with a variety of other organisms that are always in circulation. This, in contrast to an infectious model of disease, starts to open up a relational understanding, one that does not oppose a healthy to a diseased body. Life, on this view, becomes necessarily pathological (...). Disease, in this sense, becomes less about contamination and contagion, and is more concerned with its systemic and endemic co-generation.

SARS is the effect of the liveliness of the heterogeneity of life itself and the eventful relations of human bodies, environments, hosts and pathogens. Hence, it is the diverse ways of *how* we humans interact and thus consume our environment which has effects on *how* pathogens emerge and consume human environments and *vice versa*. The virulence of the disease also depends on *how* the SARS virus was able to interact with and consume their hosts; the development of the disease also depended on the body affected and also on *how* the affected body was treated by medical practices, and so on.¹⁵

14 On the contrast between ‘molar’ and ‘molecular’ see Deleuze and Guatarri (1988). On ‘molecular virality’ in contrast to ‘molar virality’, see Sampson (2012).

15 More or less invasive (medical, political etc.) interventions may also have more or less positive or negative effects on ill bodies or on bodies considered to be at risk of being infected and infecting others. Some individuals who were put into quarantine suffered

With the cosmopolitical event of SARS we were not only facing the questionability, disruption, alteration and endangerment of human life, but we were experiencing the *precariousness* and *intensities* of living in extension, the fragility of our relational existence. As a boundary experience, the cosmopolitical epoch involved boundary action: doing and undoing boundaries. Enforced control mechanism, isolation and quarantine tried to cut off human beings from being consumed by the SARS-CoV. This also meant a radical limitation of how humans consume and thus interact with others. The logic of isolation and quarantine exhibits the idea of dividing ‘dirty’ (i.e. infected) spaces from ‘clean’ (non-infected) spaces, so that within the dirty spaces the virus may spread but not beyond its boundaries.¹⁶ Systematic cleansing of nonhuman infectious agents is also part of the logic of cutting off relations. Thus, civet cats, bred, slaughtered and consumed as delicatessen, have turned, at least temporally, into hazardous becomings¹⁷ suspect of transmitting the SARS virus and many of them have been culled in order to contain the spreading disease.¹⁸

Obviously, the SARS case and its epidemiological tracing is highly intriguing for contemporary and future sociological research concerned with the processes and dynamics of ‘world risk society’ (cf. Beck 2000; 2007; Holzinger, May and Pohler 2010) since it addresses the complexities of trans-boundary phenomena in the making. The SARS event offers an emblematic example of how contemporary societies fabricate and deal with trans-local action, intensities, movement and

from depression while others who actually contracted SARS and were treated with steroids became seriously ill from the severe side effects caused by the treatment.

16 In Hong Kong, governmental initiatives such as the ‘Team Clean’ were formed to transform ‘dirty’ urban spaces into ‘clean’ and ‘shiny’ ones in order to improve Hong Kong’s hygiene, health and outlook, but also to promote a sense of belonging to and affective relationship with the city. By identifying ‘black spots’ and ‘grey areas’ the city was mapped into the geometry of ‘dirty’/ ‘insecure’ and ‘clean’ and ‘secure’ spaces (cf. Roloff 2007). However, as we have seen, the Hong Kong SARS events were not the effect of a ‘hygiene’ problem of urban space.

17 For an excellent reading of ‘becoming’ as an epidemic process see Deleuze and Guattari (1987). See also Grosz (1999).

18 ‘The civet has been through ups and downs since the first time it was identified last May as the likely SARS carrier from which the virus jumped to humans under the right, or rather wrong, circumstances, said researchers at the University of Hong Kong and Shenzhen CDC. The civet is traditionally consumed in Guangdong as a nutrient food. It was banned during last year’s SARS epidemic, but its fame as a culinary delicacy was reclaimed on August 12 when the State Forestry Bureau put it back on the list of acceptable commercial consumption. Public wariness was eased for a few months until yesterday’s announcement. According to Jiang Zhigang, president of the Animal Ecology and Conservation Institute under Chinese Academy of Sciences, there are about 600 civet breeding farms, with a total of 40,000 civets, on the Chinese mainland. Shaanxi alone accounts for a third of the total’ (English.people.com.cn 2004).

Recent research argues that horseshoe bats are natural reservoirs of SARS-CoV (Ge et al 2013).

change. Being a trans-boundary phenomenon, the SARS event did question concepts like ‘the local’ and ‘the global’ perceived as distinct territorial spaces.¹⁹ It highlights the topology of a contagious illness instead and how local practices may turn into global risks, how global risks question, disrupt and alter local practices.²⁰ The cosmopolitics of SARS shed light on how nano-scaled²¹ affective forces cannot be separated from human everyday practices and *vice versa*. It draws attention to the social as an on-going process of assembling and thereby affecting heterogeneous entities, orderings and practices at different scales that creates societies (affected human bodies, affected cells, viruses) which, by relating, affect novel relations and possible societies. Moreover, it turns our attention towards the virtuality of illness risks, whereby an anticipated future process, the ‘not yet’, induces complex ways of re-thinking and re-enacting practices in the present (cf. Beck 2000; 2007; van Loon 2002; Shields 2006).²² This process is steeped in unknown/ing, uncertain, insecure contested experiences unfolding the eventfulness of the social and the cosmopolitics involved (cf. Latour 2005; Schillmeier 2009a, 2010a).

Relational Becomings

The SARS case dramatically shows how a nonhuman agent acquired *cosmopolitical* power in disturbing, altering and endangering the social orderings of embodied and human life.²³ The SARS virus gained its *agencement social* precisely because of its mutability: it transgressed the nonhuman animal boundaries of affection so much so that it became a virus capable of endangering human life. The virus still remained a virus, but multiplied its ontological status

19 At the same time, though, the mobilization of the idea of ‘nation’ played a decisive role in fighting ‘the war against SARS’, as Huat (2006) shows by tracing the epidemic in Singapore. See also Enemark (2007), Hung (2004), Ku and Horng-Iuen (2004).

20 For a topological reading of the social relevance of SARS as a global risk, see Schillmeier and Pohler (2006). On the topology and contagious diseases, see Hinchliffe et al. (2012).

21 The size of the SARS-CoV is 80–160nm.

22 The notion of ‘risk’, as advocated here, should not be conflated within the modernist understanding of probabilities and calculable risks, see also Beck (1992, 1999).

23 The SARS-CoV should not be conflated with a ‘cosmopolitan’ entity of the medical discourse that classifies species of flora and fauna, diseases, bacteria and viruses etc., which are disseminated worldwide (cf. e.g. NCBI 1994). From a medical perspective SARS cannot be considered ‘cosmopolitan’ because it did not circulate and distribute globally. Rather, as I will argue, it is the potential of SARS to become a cosmopolitan phenomenon that imbued it with complexity and social relevance.

Since Oct 2012 the SARS-CoV is a ‘select agent’: ‘On October 5, 2012, the National Select Agent Registry Program published a final rule declaring SARS coronavirus a select agent. A select agent is a bacterium, virus or toxin that has the potential to pose a severe threat to public health and safety’ (CDC 2013).

(cf. Morse 1993) and was able to seriously trouble the embodied social life of humans and their social, scientific, political, economical, medical, juridical, private and public organization. Thus, by linking heterogeneous, non-affiliated entities (e.g. a nonhuman virus with human organisms, infected bodies with air traffic) SARS redrew not only the boundaries between humans and nonhumans, nature and culture, but questioned and altered the common, taken-for-granted individual and societal arrangements. Through its ontological transformation, SARS questioned and reassembled human societal configurations. A nonhuman entity became a highly relevant cosmopolitical actor circulating in a technoscientific mediated and globalizing world. The SARS events put the default practices of societal orderings and their social scientific modes of description at risk by illustrating that 'the social does not designate a thing among other things, [...] but a type of connection between things that are not themselves social' (Latour 2005: 5). Social connections are eventful assemblages of heterogeneous entities. The cosmopolitical epoch of SARS unravels the multiple and heterogeneous dimensions involved in the making and questioning typical of the transformation into a highly relevant societal issue. It made us aware of heterogeneous societal realities as emerging configurations (Hannigan 2006), i.e. relational becomings and not fixed beings.

To highlight the cosmopolitical epoch of SARS, I will briefly discuss some of its significant events that happened between March and July 2003 and how these events were experienced and dealt with. Including how SARS was experienced in Canada, the following pages aim to highlight the trans-local dimension of potential infectious diseases (cf. Haggett 1994; Lovejoy 1993; Mayer 2000). Toronto, the provincial capital of Ontario, was the region where SARS became most visible outside of South Asia (cf. Shiu-Hing Lo 2009). It emphasizes the importance of global cities not only as central agents in globalizing processes, but also as powerful centres of infection that may diffuse infectious diseases on a global scale (cf. Ali and Keil 2006; Murphy 2006; Roloff 2007). The empirical data of the peak SARS phase mainly stems from an Internet ethnography conducted between March and July 2003. Transcontinental e-based technologies proved to be a central public and professional platform to tackle and communicate about a globalizing risk such as SARS.²⁴ Those novel and global networks, net sources, e-articles, e-news, web blogs, SARS information sites etc., traced the complex networks of the cosmopolitics of SARS. They allowed relevant actors to act at a distance and on a day-to-day basis, which proved to be vital in the case of a rapidly disseminating and infectious disease. The global networks outlined and highlighted the complexity of a public actor by following it around the globe (cf. SARS Watch ORG). In the concluding pages, I will follow the SARS event by using these very sources in order to visualize the heterogeneous becomings and effects of the phenomenon.

24 Next to primary data, relevant secondary literature was also accessed. Qualitative interviews with German virologists were conducted and analyzed by Wiebke Pohler.

We have argued that the danger of SARS emerged when human bodies became hybrid receptacles of re-assorted human/nonhuman entities: from being a harmless animal virus, SARS turned harmful due to its transformation into a virus that can be transmitted human-to-human. This is important: due to the virus's *ontological* transformation of becoming-human, human bodies became human-SARS-bodies. Like all living beings, viruses cannot exist on their own. Although viruses do have their idiosyncratic (and diverse) genetic information, it requires living cells in order to replicate. To replicate, the virus connects to a host-cell with the help of receptors and exploits the construction and deconstruction of cell-structure for its own multiplication. In the process of reproducing itself, the cell incorporates the viral DNA. And out of the connected elements of the cell and the virus, a new virus (virion) is born (cf. Morse 1993).

In order to pass from host to host, from body to body and – in the case of SARS – to travel from continent to continent, the virus needs a particular means of transmission – a highly specific third element apart from the virus and the cell. In the case of SARS, this third element related to respiratory and faecal droplets, but as we have seen it may also be airborne and include other forms of transmission. The globalization of both transmission and dissemination was fostered by the extensive and dense transcontinental air travel, which in turn intensified the very risk of the infectious disease becoming a global threat. It was only then that the virus was able to reproduce, to disseminate and to gain individual and social relevance for virtually all human beings. Our modern technologies of living, travelling, working and communicating ensure not only highly mobile worlds, but also turn viruses like SARS into highly mobile risks.²⁵

As a potential and anonymous air traffic passenger, the SARS virus was able to radically question and alter the usual civic strategies that enable and regulate free travelling. The latter requires passports as important tracers of the identity and belonging of a travelling citizen. Passports are part of institutionalized mechanisms to regulate, control and monitor national borders and interests that travellers may cross or encounter. At airports an ID-card functions within a globally recognized rite of passage for personal travel by tracing the linkage between an individual and her/his gender, her/his national and racial belonging and some of her/his bodily characteristics (height, eye and skin colour, finger prints). Such *ma(r)kers* of identity work well since they are treated as rather stable and fixed: they are not considered as becomings. Instead, passports are meant to reflect one's specific being: one's name, size, eyes, nationality etc.

During the SARS event, these stable and institutionalized *ma(r)kers* were replaced by a rather temporal bodily symptom: the feverish temperature of human bodies (cf. Ong 2004). The measuring and registration of normal or high temperatures (99°F or 37.5°C and more) became vital in order to travel outside of Asian sites (cf. SARS Watch Org). Accordingly, it was the becoming of one's body that meant either approval or prohibition to travel and secured or

25 On 'risks and mobilities', see Urry (2004).

endangered related citizenship rights. The SARS migration highlighted what passports or citizenship render invisible: the emergence of embodied practices and temporary physiological conditions. Human beings with genuine passports (including visas) are citizens, independently of whether they have a fever and are considered as temporarily or permanently ill. However, contagious bodies, which happen to be indifferent to cultural achievements like citizenship rights, modify this situation.

Hence it was not travelling persons or citizens, but possible contagious bodies that became globally travelling risks and subsequently the object of social mechanisms of scrutiny, monitoring, regulation and surveillance. During the SARS event, the combination of a relatively unspecified bodily appearance (Asian) with unspecified physiological reactions (coughing, high temperature, etc.) turned into socio-cultural ma(r)kers of a high interactional risk. These markers framed socio-cultural differences, produced social marginalization, and brought about politically legitimated oppression (isolation, quarantine) (Ali 2003).²⁶ Moreover, these ma(r)kers disrupted urban economic and cultural life (cf. Roloff 2007). Civil inattention, symptomatic of the performance of urban social normalcy, as Erving Goffman (1963) showed so convincingly, was seen as a risky practice. Instead, fearful attention was given to both bodily appearance and bodies with flu-like symptoms unravelling stereotyping, marginalizing and homophobic effects.

Experiencing the Unknown

Given the possibility that a contagious illness of unknown cause, disease pattern and evolution might circulate on a global scale, thoroughly trouble and changing everyday life. The cosmopolitics of SARS enacted 'hot' situations of trans-local social interaction and relations. Following Michel Callon (1998), 'hot' phases are characterized by uncertainties, controversies, ignorance and a considerable lack of social regulation. With the hot phase of the SARS event we were witnessing the emergence of heterogeneous and multiple *becomings* that reassemble relations of human and nonhuman, private and public, local and global, past, present and future, actual and virtual.

One month after the multi-located appearance of SARS, David L. Heymann, Executive Director of the Communicable Disease Program of the WHO, outlined the particular seriousness of the SARS threat:

26 SARS patients lost their jobs and former SARS patients remained victims of social exclusion and marginalization. 'SARS led to the shunning of Asian travellers, restaurants, visible minorities, and the entire of the second largest country in the world, in which only one city experienced infections. It was such shunning that did the real economic damage and had social costs long after the physical challenge had been met' (Kirtan and Cooper 2009: 313).

SARS is emerging in ways that suggest great potential for rapid international spread under the favourable conditions created by a highly mobile, closely interconnected world. Anecdotal data indicate an incubation period of 2 to 10 days (average 2 to 7 days), allowing the infectious agent to be transported, unsuspected and undetected, in a symptomless air traveller from one city in the world to any other city having an international airport. Person-to-person transmission through close contact with respiratory secretions has been demonstrated. The initial symptoms are non-specific and common. The concentration of cases in previously healthy staff and the proportion of patients requiring intensive care are particularly alarming. The '21 century' disease could have other consequences as well. Should SARS continue to spread, the global economic consequences – already estimated at around US\$ 30 billion – could be great in a closely interconnected and interdependent world. (WHO 2003b: 5)

In February 2003, the World Health Organization declared 'SARS', which at the time was only known as a severe, atypical pneumonia with an unknown aetiology, a 'global threat to health'. This alert was issued and maintained because similar cases had been reported from the beginning of March in Canada, Singapore, Germany and, later that month, in Vietnam and Hong Kong. As we have seen above, the unknown disease posed great risks to health workers as well as family members and friends being in close contact with the patients. Conventional medical treatment with antibiotics and anti-virals proved highly ineffective and the conditions of many patients rapidly deteriorated, requiring intensive care (cf. Peng et al. 2003; Murphy 2006).

On March 12, 2003, the WHO issued its first global alert in order to warn patients and international travellers alike who might be showing respiratory symptoms and high fever (WHO 2003c). This alert has been maintained ever since and has even been strengthened, given the additional risks brought about by H5N1 avian flu. Until the end of March 2003, the 'SARS' disease was thought to be airborne and spread by human-to-human contact. As we have seen, this assumption became questionable with a series of infections, like that happening in a housing estate in Hong Kong where 213 cases of respiratory symptoms were reported without having met or having had direct contact. Hence, it became likely that the dissemination of the disease involved an environmental component (e.g. sewage or ventilation systems) (SARS Watch Org 2003). However, the actual forms of transmission remained unclear and contested.

In many Asian countries, the rules governing access to national territory were tightened or supplemented by travel advisories imposed by the WHO. Travel advisories obviously have enormous effects on the economic and socio-political life of the countries involved. The imposition of a travel advisory hit Canada as well and led to political conflicts over the different perception of risks between the discourses of national health and those of the WHO (Naylor 2003: 212). For example, the Domestic Travel Health Advice issued by the Public Health

Agency of Canada considered travel through Canada as safe. It deemed that travelling could be undertaken as usual as long as (a) there had been no prior contact with a SARS case and (b) there had been no recent visit to high-risk regions in Asia. The risk involved in travelling to the Greater Toronto Area (GTA) was considered low and people were advised to carry on with their personal and business travel while practicing good personal hygiene (Public Health Agency of Canada 2003).

The political conflicts over SARS mainly centred on the epidemic and contagious effects of the event that directly related local, regional, national and global risk perceptions and assessments while affecting the taken-for-granted regimes of embodied individual and social life. Through the migration of SARS, personal and public hygiene were directly connected with political conflicts, economical issues, tourism and so forth. Moreover, it enabled and strengthened authoritative governance and measures on a transcontinental scale. In Canada and Asia, government officials told people to change all those personalized and routine habits that might make SARS spread. In Asia, this included a prohibition against spitting in public (Indonesia) or attending confessions in catholic churches (Singapore) (SARS Watch Org 2003).

Meanwhile, for the clinical dealing with SARS patients, the use of N95 masks, gloves, gowns, and hand sanitizers was obligatory. However, in everyday life the necessity of wearing facemasks was unclear and contested. Still, more than a third of the Chinese population of Hong Kong was wearing a mask, although due to a variety of socio-cultural and symbolic reasons. Obviously masks did function as a protection measurement for one's own health, but also as a means of protection of courtesy, social responsibility and solidarity towards the other (cf. Baehr 2005). To become infected was feared because one may infect one's family, friends and colleagues. Still, the way masks were used was not always done in a clinically correct way. Rather, it was practiced according to the requirements of the situation: while smoking, during eating and using the phone, the masks were lifted or put aside. Nevertheless, the mask became a global symbol for a life-threatening situation, which disrupted altered and endangered human life (cf. Roloff 2007).

When talking about the risks of SARS becoming-global, one should not forget the role of global media networks and how they followed, documented, displayed and performed the drama of invasion and contagion (cf. Wald 2008).²⁷ Through 'SARS' the world became a space of emergency in which everyone might become involved. Through global media networks, 'SARS' enrolled the public into a mystery game that kept secret what the disease was all about, who the (mass-)murderer was, what weapons are used. Being defined as a global risk, 'SARS' performed the role of a most wanted nonhuman (bio-)terrorist provoking the fears and perils of late modern globalizing life, of invading well-protected (western) national boundaries and so on (ibid.). Through the 'medialization' of

27 On SARS and the UK media, see Wallis and Nerlich (2005).

‘SARS’, the actual cases of infection were linked with media-created *publics* imitating and propagating the concerns, fears and anxieties of the risk of becoming infected by SARS. The SARS events were not only communicated globally and in real time, but were travelling faster and wider than did the actually infected/ing SARS bodies. Obviously, the implicit fear was that along intercontinental lines of flight, the bodily infections might spread as much and as fast as the diverse e-publics of SARS are disseminating.

Fighting the Virulence of the Virtual Enemy – Enhanced Surveillance, Control and Isolation

During the Canadian peak phase of SARS – between March and June 2003 – practices and technologies of intensive monitoring, controlling and surveillance were tested, ruled out, implemented and enhanced (cf. Shiu-Hing Lo 2009). Contestable as they are and as they have been, all these enforced technologies of governance became routine ways to generate and manage infectious disease control practices. At Canadian airports, 7 million people were screened – without a single case of SARS being detected (Naylor 2003: 218), and more than 25,000 people in the Greater Toronto area were quarantined (cf. Bennett 2009). Obviously, these practices reveal the conflicts between civil rights, public health and contagious diseases. As T.M. Wilkinson stressed: ‘Put at its starkest, it seems you can have rights or public health, but not both’ (2009: 181).

After a series of SARS cases, on March 26, 2003, the Premier of Ontario declared SARS a provincial emergency and a reportable virulent communicable disease (Naylor 2003). From that moment, potentially infected people (classified as suspect or probable) could be placed in isolation, monitored, screened etc. by official health authorities (cf. Public Health Agency of Canada 2003). In Singapore, hundreds of people who might have been exposed to ‘SARS’ were quarantined in their houses for 10 days. The government considered the idea of installing webcams in people’s homes to enforce quarantines (cf. SARS Watch Org 2003). The quarantine practices were expanded and blogs like Wangjiangsshuo’s blog reported that in cities, like e.g. Nanjing, more than 10,000 people were isolated and quarantined (cf. Wangjiangsshuo’s Blog 2004).

The uncertainty of characterizing and understanding ‘SARS’ initiated science fiction-like practices and revived long forgotten scenarios redolent of fighting the Plague in the fourteenth century. The WHO stated:

So long as the aetiological agent remained unknown, specialists in infectious disease control would be forced to resort to control tools dating back to the ‘Middle Ages’ of microbiology: isolation and quarantine. (WHO 2003a: 8)

The monitoring of rather *non-specific* viral prodromes happened to be symptomatic of the initial wave of ‘SARS’ cases. These symptoms could be related to any kind of

viral infection. Nevertheless, it was the detection of these symptoms of vague and uncertain origin that triggered and framed massive monitoring, surveillance and control procedures, which in turn enabled the tackling of these very symptoms *as if* they were symptoms of the global threat embodied by 'SARS'. Even the autopsy of people who died of the disease iterated the virtual risk of 'SARS'. Autopsies did not provide evidence of 'SARS'. Rather, as a medical expert stated: '[...] the autopsy is more useful to rule out non-SARS causes of death rather than confirming SARS' (Medscape Medical News 2003: 8).

Ontarians with symptoms or concerns were instructed to call 'Telehealth Ontario' or were ordered to quarantine themselves at home (cf. Ministry of Health and Long-Term Care 2009). The risk of 'SARS' infections, so it was argued, will increase rapidly if potentially infected people are ignoring voluntary isolation.²⁸ Those people became high-risk menaces for public health since their 'uncivil' behaviour might entail both a wide and uncontrollably rapid dissemination of SARS. Again, it was the anticipated risk of being infected that produced huge virtual numbers of people who might have been in contact with a high-risk person. In turn, the circulation of virtual risks generated enormous numbers of potentially infected people that had to be isolated. During isolation they underwent physiological screening, lab tests and chest X-rays were made and so on. Isolated risk cases were sent to hospitals or told to monitor themselves by checking body temperature and other potential flu-like symptoms (cf. Groneberg et al. 2003).

Voluntary quarantine was an ambivalent situation and quite often subverted by default. Breaking voluntary isolation was mainly motivated by the need to avoid income losses since it was uncertain if and who would pay for the days spent in quarantine. Moreover, going to work was considered safer and healthier than going to a hospital for a check-up. Hospitals were perceived as high-risk locations of getting infected. Risk cases, which were eventually considered to be free from (potential) SARS symptoms, also had to undergo the ten-day quarantine. At the same time, China, in contrast to Canada, threatened to execute or impose a life sentence upon anyone breaking the quarantine and deliberately spreading the disease. Isolation and quarantine politics challenged religious practices as well. To celebrate Easter, Catholic worshipers were told to stay at home. If they did attend mass in a church, they were advised to accept communion wafers by hand and not mouth; they were also informed not to shake hands, but to smile instead (cf. Ali 2003).

National and transnational alert and surveillance systems for Severe Respiratory Illness (SRI) were launched for the post-outbreak period of SARS. In Canada, 'Surveillance for Severe or Emerging Respiratory Infection in the SARS Post-Outbreak Period' (WHO 2003d) provides national guidelines for enhanced public health management and control measures of unidentified respiratory illnesses. The WHO developed guidelines for the 'Alert, Verification

28 [T]he refusal of one healthcare worker to comply with a voluntary quarantine led to the infection of dozens in a Toronto religious community' (Kirton and Cooper 2009: 317).

and Public Health Management of Severe Acute Respiratory Syndrome (SARS)' in the post-outbreak period, which were recommended to individual (developed) countries (*ibid.*).

All these social, political, economic and legal procedures, measurements and regulations spelled dramatic disruptions of common societal orderings in order to contain the *risk* of uncontrolled dissemination of an infectious disease. They were thought to cool down the hot, that is, the virtual and virulent phase of contagious events, but caused radical intrusions into the private and public life of people as free moving citizens. It turned private life into a public concern and vice versa. The duality of a virtual and virulent risk of a global threat made bodies (infectious bodies, feverish bodies, insecure bodies, moving and interacting bodies) the centre of societal intervention. Trans-continentially moving bodies became risk-bodies undermining the very globalizing networks that had enabled the successful performance of globalization in the first place. Furthermore, they initiated trans-continental conflicts but also global responsibilities of enacted (world-)risk-communities.

The risk of a global SARS pandemic foreshadowed a cosmopolitan monster, equipped with all-too-democratic, all-too-present but invisible and undetectable contagious forces, blending and acting beyond the scales and scopes of common (geo-)political reasoning, practices and limits. The transnational migration of SARS entailed the risk of a self-destructive viral Leviathan: re-assorting and contracting²⁹ humans and nonhumans and thereby feeding and disseminating destructive societal forces, which put human life and social orderings at risk.

Networking Medical Practice

The possibility of a worldwide dissemination of SARS was strongly linked (a) to the 'unprecedented nature of SARS, and the limited knowledge about it in both the public and clinical communities in the earliest days of the epidemic' (Murphy 2006), and (b) to the different local habits and possibilities of clinical and isolation facilities and infection control (Groneberg et al. 2003; Peng et al. 2003).

As stated above, the uncontrolled propagation of SARS within health care settings (e.g. through the use of nebulizers for bronchodilators, being in close contact with patients or infected health care workers) became symptomatic of the specificity of the 'SARS' event (cf. Gopalakrishna et al. 2004; Lau et al. 2003; Naylor 2003; Yu et al. 2007). In Toronto, a series of 'SARS' events forced public health officials to close down two hospitals and public schools.³⁰ Hospitals

29 The verb 'to contract' refers to both meanings I try to highlight: to bind, to arrange heterogeneous entities into a new lasting entity and to catch, to develop a disease.

30 In Beijing, 1.7 million school children were forced to stay at home. Government officials organized classes on television and the Internet (cf. BBC News 2003).

turned into high-risk locations of becoming infected. Even to live in proximity to a hospital was thought to entail a high risk of contagion. Hospitals, like the prisons in the mid-eighteenth century (cf. Foucault 2009: 355), became the source of contagion rather than a place of medical remedy and cure. Randy Wax, education director and staff intensivist for the Critical Care Unit at Mt. Sinai Hospital in Toronto, stressed:

At the beginning of the outbreak, our biggest problem was our inability to recognize when a patient had SARS and our lack of understanding as to how SARS spread. This led to the spread of SARS throughout various hospitals. In particular, the transfer of unrecognized SARS patients between hospitals with resulting staff exposure was a major problem. [...] I think the problem initially was that it wasn't clear how far SARS had spread through the health care setting. [...] It was difficult to know at the time that the illness was not contained [...]. (Medscape Medical News 2003)

Moreover, the SARS Commission First Interim Report stated that hospitals are not self-contained, but heavily rely on other institutions. This created communication problems in dealing with an unknown infectious disease:

SARS demonstrated that hospitals and other health care facilities are not isolated institutions operating on their own. [...] Because SARS was such a difficult disease to diagnose, because there were no reliable lab tests, and because knowledge about the disease was rapidly evolving on a daily basis, there were disagreements from time to time between the reporting institution and public health officials as to whether a particular case was a case of SARS. It was critical that each SARS case be recognized and reported. It was equally vital that every non-SARS respiratory infection not be classified as SARS simply as a precaution. (Campbell 2004: 147)

Evidently, SARS revealed the poor state and the vulnerability of the health care system of a 'developed country' like Canada that was not prepared to adequately deal with contagious events like SARS (cf. Bennett 2009; Price-Smith and Huang 2009; Shiu-Hing Lo 2009). From a global perspective (WHO), it was the missing of standardized and universalized infection control practices, primarily in 'developing' countries, which were thought to increase the risk of global transmission. Through SARS, the WHO gained authoritative and regulative power within national and local contexts, which they did not have before and

which remain ambivalent and contestable (cf. Kamradt-Scott 2009).³¹ All over the world, local control mechanisms and practices were advised to comply with global standardized infection precautions and norms (SARS Watch Org 2003). However, the experiences with SARS also brought about the emergence of local techniques and technologies that did not fit universalized practice, but nevertheless did function locally. Epidemiologist and WHO-representative Cathryn Murphy stated:

Variation in pre-SARS infection control capacity between nations and regions of the world, the absence of universally accepted and applicable generic infection control guidelines, and differences in routinely available personal protective apparel during the outbreak limited the extent to which a standardized minimum global level of infection control could be guaranteed. In that environment, innovation was necessary [...] and unique local responses to the unprecedented infection control requirements were practiced (Murphy 2006: 11; cf. Groneberg et al. 2003).

Canada's experience with the SARS events provoked a series of re-configurations of health care recommendations, practices and regulations. One of its main social effects has been to rethink public health as a collective and trans-boundary effort – linking human practices as well as addressing the relations of human and animal life (Bennett 2009). Several committees and reports on national and transnational levels inquired into SARS and its medical effects, but also discussed the socio-political effects (cf. Fidler 2004; Kirton and Cooper 2009; White and Banda 2009). The SARS Commission First Interim Report stressed:

Viruses do not respect boundaries between municipal health units. The chain of provincial protection against the spread of infectious disease is only as strong as the weakest link in the 37 local public health units. A failure in one public health unit can spill into other public health units and impact the entire province and ultimately the entire country and the international community. When dealing with a travelling virus, concerns about local autonomy must yield to the need for effective central control. (Campbell 2004: 201)

31 Without prior invitation, the WHO did send staff to China and publicly criticized China for their non-transparent and non-communicative position and attitude (cf. Royal Society of New Zealand 2003). The practices of the WHO as an IO remained contested. It was argued 'that the WHO engaged in agency slack or independent power in containing SARS by taking unauthorised, unprecedented, and undesired actions. These claims (...) additionally suggest that the WHO exceeded its authority and mandate, affectively engaging in *ultra vires* that contravened the preferences of its member states' (Kamradt-Scott 2009: 64; cf. Fidler 2004).

Justice Archie Campbell's inquiry led to 53 recommendations followed by an independent expert panel on SARS that issued another 50 recommendations to improve public health through infectious disease prevention (cf. Campbell 2005). The focus on identification diagnosis, surveillance, control and containment as well as on a new cross-level communication network of health care providers and government appeared vital to the investigations of the different commissions and panels (cf. Naylor 2003; Walker 2004). According to the reports thus compiled, SARS not only 'showed that Ontario's public health system is broken and needs to be fixed [...] with the necessary resources, expertise and capabilities' (Campbell 2004: 8), but also that much can be learned 'from countries that do not really have a highly developed healthcare system, but where keeping people well is paramount to saving lives' (Bennett 2009: 57). The reports stressed the structural and practical limits in dealing with an emergency situation of contagion (Lindsay 2003; cf. also Bennett 2009). The Campbell Interim Report (2004) made it very clear that '(e)mergency powers', fostered by the uncertainties and risks of an unknown but contagious disease like 'SARS', were 'inherently dangerous' since they enact more or less uncontrolled communication and (inter-)action:

They carry the twin dangers of overreaction and underreaction. Every emergency power, once conferred, lies about like a loaded weapon ready for the hand of any authority that can bring forward a plausible claim of an urgent need. To a hammer, everything looks like a nail. To some emergency managers, every problem may look like an opportunity to invoke emergency powers. [...] In the face of a deadly new disease with an uncertain incubation period, ambiguous symptoms, no diagnostic tests, uncertainty as to its infectiveness and mechanisms of transmission, and no idea where in the province it may be simmering, decisive action may be necessary that turns out in hindsight to have been excessive. (Campbell 2004: 19)

Under contagious but uncertain conditions, decisions or their deferral appeared as highly risky over- and/or under-reactions; the more so if these mismatches may contribute to the risk of 'SARS' becoming a pandemic reality. The SARS case highlighted the importance of local health care practices in fighting SARS. Nevertheless, it was the trans-local mobility of the contagious virus that forced the Interim Report and its successors (e.g. Campbell 2004, 2005) to provide clear and strong advice for a global network headed by a single person (!) as the central authority on a national level:

Although this system maximizes the ordinary local autonomy of local medical officers of health, municipal autonomy is hardly a value of superordinate importance when dealing with viruses that cross municipal, provincial, federal, national, and international boundaries. And the complicated legal machinery necessary to trigger the imposition of central powers, unless made

infinitely more simple than the almost medieval system for provincial override of local public health boards, would deprive the provincial override of any practical value in a public health threat. (Campbell 2004: 204)

The network-character of SARS became vital during the SARS events. What defines networks is the complex connectivity of heterogeneous entities that remain local at every moment of networking. As seen above, this is primarily a question of movement and practices that fabricate more or less (un-)stable and precarious spatial and temporal relations. Networks, as Bruno Latour has stressed, are made durable and powerful due to local connections of heterogeneous entities (cf. Latour 1999b, 2005). The localness of networks is their big strength but also their weakest point. This was precisely the issue at stake of trying to contain 'SARS' (Naylor 2003: 22). The local complexity was considered particularly dangerous since it entailed the risk of becoming a global network of local infections, generating global catastrophic effects. Hence, the quality of a good global anti-SARS network crucially depended on its local strength of cutting the network of infection. Local strength however was believed to be effective only if the trans-local risk of SARS was taken seriously. Thus, local practices were thought to be in need to be globally organized and require remaining independent of local interests. Local practices were also thought to work properly only if global standards of practice were enacted. On the national Canadian level, in order to secure the 'gold standards' of decision to preventing viral transmission, the risk was taken to give a God-like figure the last decisive voice in regulating the complex intersection of heterogeneities (human/nonhuman, private/public, local/global, knowledge/non-knowledge etc.).

Translating Networks of Risks

As we all know, SARS did not become a global epidemic. Rather, the communication and interaction of risk provoked the assemblage of highly effective and successful networks which were able to contain the dissemination of SARS.³² These networks *imitated* the trans-continental circulation of the SARS virus by employing a complex set of connections between socio-technical, political, medical and economic dimensions to contain the circulation of the disease (cf. SARS Watch Org 2003). To emphasize, the process of imitating the circulation of SARS did not mean copying it; these networks followed a different script altogether.³³

32 We also know that this does not mean that SARS may not re-appear, as the known SARS-CoV or in different forms of re-combination.

33 On the social relevance of imitation as a productive form of repetition, see Sampson (2012), Schillmeier (2009a, 2012a), Tarde (1921, 2012).

SARS was translated³⁴ into new ways of making it locally and trans-locally visible in order to stop SARS becoming-global. These networks re-assembled the becomings of SARS in order to cool down its hot phase and make it traceable and knowledgeable.

A major step in that direction proved to be the identification of the SARS-CoV as the causative agent, as well as subsequent molecular assays for diagnosis.³⁵ It represented quite a remarkable achievement of day-to-day virtual collaborations and networks of laboratories co-ordinated by the WHO – including biomedical laboratories for expediting identification of the SARS causative agent, collaborative groups on epidemiology, clinical groups, online medical journals, etc. (cf. Ali 2003). In order to tackle and identify the SARS causative agent, these transnational networks employed

a secure web site to post electron microscopic pictures of candidate viruses, sequences of genetic material for virus identification and characterization, descriptions of experiments, and results. The well-guarded secret techniques that give each laboratory its competitive edge have been immediately and openly shared with others. Laboratories also quickly exchange various samples from patients and post-mortem tissues. These arrangements have allowed the analysis of samples from the same patient simultaneously in several laboratories specialized in different approaches, with the results shared in real time. This collaboration has resulted in the identification of the suspected causative agent, and the development of three diagnostic tests, with unprecedented speed. (WHO 2003b: 8)

The diagnostic testing for SARS remained quite challenging since various methods required different and always lengthy incubation times before showing any results. More seriously, the demands of testing displayed the limits of the virtual network since it required handling antibodies in serum or blood. Sometimes a living virus in cell culture was necessary in order to monitor and analyze SARS. This called for high-standard visualizing equipment (e.g. an immunofluorescence microscope), which limited these tests to reference laboratories (cf. SARS Watch Org 2003). However, if these tests showed positive results and confirmed a SARS infection, a negative result did not indicate that the person had not been infected. Moreover, tests could only be carried out if there

34 On the notion of translation, the most interesting approaches are those linked to Actor-Network-Theory. See for example Callon (1986, 1998), Berg and Mol (1998), Hetherington and Munro (1997), Latour (2005), Law (1991, 1994, 2002), Law and Hassard (1999), Law and Mol (2002), Mol (2002), Schillmeier (2007, 2009b, 2010a, 2011b, c).

35 On April 12, 2003, the Michael Smith Genome Sciences Centre in British Columbia/CA mapped the genome of the SARS-associated corona virus. Corona viruses are well known for inducing flu-like symptoms, but also for their ability to change. The current case of the MERS virus event is a typical example.

were reasons (i.e. bodily symptoms) to suspect infection. But there were cases of SARS that displayed no symptoms, but were nevertheless highly infectious. They thus escaped the crucial testing controls. Since they presented no evidence, these cases were all the more dangerous because they remained undetected.

Most interestingly, the lack of understanding the disease and the risk of its pandemic dissemination altered common scientific practice: resources were mobilized and shared, as well as insights that were collectively exchanged *before* being published; laboratory networks were founded and funded, new forms of diagnosis were established and practiced (cf. WHO 2003e). The SARS risk provoked new forms of scientific communication,³⁶ novel insights into the virus itself while preserving and creating scientific and other types of jobs. On a national level, Canadian medical sciences, for example, re-examined their practices including infection control measures or the prescription of infection control guidelines highlighting the yielding of local concerns (cf. Peng et al. 2003).

The emergence of transnational networks meant a major step in preventing a pandemic risk from turning into a global catastrophe. These emerging networks tried 'to betray' the uncontrollable risk of SARS becoming a global threat by *translating* it into a controllable risk. As John Law has argued, every translation is 'trahison', a betrayal:

To translate is to connect, to displace, to move, to shift from one place, one modality, one form, to another while retaining something. Only something. Not everything. While therefore losing something. Betraying whatever is not carried over. (Law 2002: 99; see also Law 1997)

Simply put, these transnational networks translated the 'SARS' threat into the SARS illness that could be identified, monitored, traced, tested, contained, and thus prevented the infectious disease from becoming a pandemic. As we saw, the SARS events escaped and thus questioned the calculations characterizing established and routine individual and social risk practices. Consequently, it was the main aim of these emerging networks to translate the hot situation of non-calculable uncertainties into cooled down networks of normal(ized), that is, individually and/or socially calculated/able, 'codified situations' (Callon et al. 2001: 20) of risks. This meant that under conditions of uncertainty, habitual networks and knowledge practices were questioned and novel networks and knowledge practices emerged, re-assembling the limits of the former.

The hot phase of the SARS events provoked a shift from the logic of codified/iable risks to the messiness of relations of uncertainty and non-knowledge (ibid.). Uncertainty relations defy the logic of calculable risks and become

36 SARS networks were not entirely new. They benefited for example from the existence and experiences of the WHO influenza-network. (cf. WHO, no date).

cosmopolitical. The more contested, unruly and questionable/ing these relations are, the more real they are.³⁷ Consequently, the ‘SARS’ events appeared:

- highly uncertain and complex as do their causal links
- highly unpredictable in terms of their evolution and future effects
- indifferent to local, regional or national boundaries and related institutionalized modes of social ordering
- as cosmopolitical forces that escape ‘normal’ everyday human perception
- as dependent on scientific expertise, which in hot phases is more contested than ever.

To summarize: With ‘SARS’ we have seen how the cosmopolitical forces of an unknown and uncertain reality endangered human life and re-assembled social relations. We have also witnessed how medical staff – unwillingly – became victims, ‘carriers’ and active sources in disseminating endangerment and uncertainty.

The cosmopolitical event of SARS and its uncertainty regimes unleashed the re-mapping of local/global, human/nonhuman and culture/nature relations. Through its ontological movement, SARS was able to threaten human life, to disrupt and confound social orderings of personal and societal collective relations, to question and alter related forms of interaction and (political) communication. The SARS events remind us that social practices are always in the making through the assembling and re-assembling of heterogeneous entities. As we have seen, these emerging relations reveal more or less diffuse and often poorly understood assemblages that connect often highly conflicting and non-related entities, rationalities, interests etc. These relations connected viruses, cells, bodies, technologies, institutionalized settings, politics, economics, law, religion, media, continents, and assembled emergent forms of spatial and temporal settings (*becomings* as it were) of cosmopolitical realities, actual and virtual.

Through circulation, SARS multiplied enormously and co-existed in very different guises: in human and nonhuman environments, in infected and infecting bodies, as an actual disease with epidemic characteristics and as a virtual pandemic risk, in private and public spaces, in human bodies, in the mind, in appearances, in attitudes, in blood and air, on airplanes, in water and sewage systems, on screens in labs, in the media, in different countries, on papers and agendas of social and political institutions, as a troublemaker for the tourist industries, as an instigator of quarantine, surveillance and laws promulgated ad hoc and so forth.

With the SARS-CoV, common politics met a radically new agent that did not fit the traditional appearance of a political actor who is meant to be a rational human

37 For a similar argument, but within the logic of modernization theory, see Beck (1999, 2000).

being or likewise a social organization, but in any case not a disseminating virus. Indeed, a political actor is meant to speak, to discuss and understand the power of symbols; s/he is meant to produce rationally controlled arguments. SARS's political danger seemed to lie in its all too democratic potential of becoming global, which paradoxically bypassed the requirements of human politics. Conventional political ideas and practices encountered a silent and invisible, but nevertheless extremely versatile actor that delegated its power to uncertainty, vague knowledge and knowledge practices, virtual realities and emergent, non-linear processes, provoking existential anxieties and transnational conflicts over the migration of contagious bodies and a life-threatening illness. Indeed, the cosmopolitics of SARS was epidemic and contagious. It linked virtual risks and endangered bodies,³⁸ re-assorted global and local concerns, assembled social and non-social agents, blended local, national and transnational politics, economies, legal systems, provoked ethical concerns and so on (cf. Gostin et al. 2003).

Once the regimes of uncertainty were translated into traceable and codified networks of risk, together with the fact that SARS had not yet disseminated too much within the human sphere, its circulation could be stopped and with it the risk of a pandemic. Obviously, this does neither mean that SARS became fully known nor that it has been fully contained. On the contrary: neither is SARS fully understood nor do we have any security that it will not re-assemble in the future. We cannot cut off its possibility of emergence once and for all and we may easily witness emerging mutations of the virus with a different contagious profile. Still, the SARS story of 2002/3 was as much about an extremely daunting and quickly propagating danger as it was about powerful ways to counter its early progression. Although every single local infection could virtually lead to a global series of infections and it already did disseminate across continents, the very centres of infection were precisely traceable; the length of the vectors of transmission was relatively short and thus the complexity of dissemination was rather low. For instance, all the Canadian cases of SARS were traceable to the first multiple infections of patients and members of staff in Scarborough Hospital, Grace Division emergency department (Toronto) where the first Canadian case of SARS, a 79-year-old woman, was treated after returning from a short visit to Hong Kong. In Hong Kong she stayed at the very same hotel (as discussed above) as did the doctor, who had just arrived from the province of Guangdong in South China where he has been treating – without knowing – early cases of SARS (Naylor 2003: 34ff). Hence, SARS coming from Guangdong and arriving in Hong Kong disseminated across 30 countries on five continents in ways that were re-traceable. Luckily, many of the emerging clusters of infection could be traced back to the group of people sharing that elevator with the ill doctor in Hong Kong. Another successful network was established when the causative agent was singled out by the WHO-led techno-scientific laboratory networks.

38 People infected with SARS do not necessarily have to show any or the same symptoms.

Re-thinking Societies, Re-thinking Illness

My reading of the cosmopolitics of SARS suggests that contagious illnesses are societal events through and through, whereby social processes of linking heterogeneous entities (human and nonhuman) create their very conditions of possibilities, which in the case of SARS involved the possibility of novel viral life as well as human illness and death. Following Canguilhem (1991), we are experiencing the 'normativity' of life as well as its endangerment (cf. Margree 2003). For Canguilhem, life as 'polarized movement' (Canguilhem 1991: 222) is an active engagement of an entity with the changing circumstances of its environment and thereby evaluating the positive or negative effects of the relation for its survival.³⁹ Through the engagement with its environment the living being re-creates the 'norms' of its' living, which in turn affect the related environment. Thus, the norms that configure the 'normality' of the life of a being is the effect of 'biological normativity' and are not naturally given; it is an on-going accomplishment, made and in the making. Canguilhem (ibid.: 227) stresses:

Types and functions can be qualified as normal with reference to the dynamic polarity of life. If biological norms exist it is because life, as not only subject to the environment but also as an institution of its own environment, thereby posits values not only in the environment but also in the organism itself. This is what we call biological normativity.

Healthy beings, so Canguilhem claims (ibid.: 201), are able to perform this three-folded normative activity: engaging with its environment, re-composing its 'vital norms' and affecting its environment.⁴⁰ Health, then, is an active, contingent and flexible process of becoming while being in extension. Consequently, healthy relations are situational, relational accomplishments, provisional and changeable. Such an understanding of health radically differs from the biopolitical statistics that construct health and normality as a constant that characterizes the average man. Illness, then, does not refer to a reality that deviates from the average, from the statistical normal that defines health. Rather, illness limits and narrows down the possibilities to engage actively with the changing circumstances of the environment. Following that point of view, illness does not exclude health, but the latter appears as a relational force that is able to deal with circumstances that may affect or have already created an illness. *To prevent from, re-cover from illness*

39 '[L]ife is this polarized activity of debate with the environment, which feels normal or not depending on whether it feels that it is in a normative position or not' (Canguilhem 1991: 226).

40 'The physiological state is the healthy state, much more than the normal state. It is the state which allows transition to new norms. Man is healthy insofar as he is normative relative to the fluctuations of his environment' (Canguilhem 1991: 228).

*or to live with illness are markers of life.*⁴¹ Symptoms that make us feel ill (like e.g. fever) may also function as a mode of health, and the experience of an illness like a viral infection helps a living body to strengthen its immune-, i.e. health-competence. The more options available to deal with changing life situations, the healthier living beings are.

Obviously, and Canguilhem is adamant about it, becoming ill changes our mode of existence; the ways we are used and expect(ed) to do and experience things may alter dramatically. When being ill, our health-competences are reduced and lack plasticity. Consequently, the ways of engaging with our environment are often significantly reduced. Still, illness enacts its own norms, orderings, practices as well as it requires a changing environment to live the newly acquired normality of illness.⁴² Illness, experienced as 'abnormal', then, 'is not such because of the absence of normality. There is no life whatsoever without norms of life, and the morbid state is always a certain mode of living' (ibid.: 228). For Canguilhem, illnesses not only bring into being 'new ways of life' (ibid.: 100), but also introduce an event through which we gain insights into the normativities of health and related normalities precisely in that moment when health is questioned, disrupted and altered. Illness points toward an understanding that we neither can take the body as taken for granted nor do we know what the body is able to endure/do. Without diseases there would be no interest in questions of health, nor would the life sciences exist. Disease, so Canguilhem stresses (ibid.: 101),

reveals normal functions to us at the precise moment when it deprives us of their exercise. Disease is the source of the speculative attention which life attaches to life by means of man. If health is life in the silence of the organs, then, strictly speaking, there is no science of health. Health is organic innocence. It must be lost, like all innocence, so that knowledge may be possible.

Canguilhem's understanding of disease tackles a central idea that I have tried to unfold throughout this book: the experience of illness not only disrupts the normativity of the normal of social relations. By questioning and altering the normativity of the taken-for-granted (e.g. health and related modes of existence), the social orderings of such normativity become traceable as well. Moreover, the requirements of novel forms of social relations become apparent and oblige us

41 Such a reading of the normal as normativity, made and in the making, also has effects on the understanding of cure. 'Cure', so Canguilhem states (1991: 228), 'is the reconquest of a state of stability of physiological norms. It is all the closer to health or disease as this stability is more or less open to eventual change. In any case no cure is a return to biological innocence. To be cured is to be given new norms of life, sometimes superior to the old ones. There is an irreversibility of biological normativity'. See also Stengers (2011: 509).

42 'The pathological state, on the other hand, expresses the reduction of the norms of life tolerated by the living being, the precariousness of the normal established by disease' (Canguilhem 1991: 228).

to rethink what has been considered as normal, good/bad, taken-for-granted and how it was kept so. Indeed, with the experience of illness, health as the taken-for-granted loses its innocence, as do the social relations that bring it into existence and maintain their normality. Thus health is not a given and universal condition that can be objectified as normal; neither are its deviances and deficiencies from an objective norm that frame the realm of illness. Rather, health and illness are intertwined signatures of life. Health cannot be understood without illness and the effects of illness depend on health-competences, which enact the intensities of illness.

With the emergence of SARS we have witnessed how different normativities of life have collided. The SARS-CoV enacts the normativity of life in so far as the virus achieves new norms for itself, consuming parts of its human social environment. In turn, the normativity of human bodies is reduced and endangered: human bodies become ill or die and the SARS-CoV turns into a pathogenic agent. The SARS infected body becomes a pathological body when its variability and plasticity, i.e. its health competences, are radically reduced or fail. If the latter happens to be the case, human life is unable (with or without medical assistance) to create new norms for its ability to socially organize its endurance and consequently people die. Parts of the social organization of human life are consumed by the norms of the desire of viral forms of life and human bodies ultimately become unable to sustain life. It was the disruption and endangerment of the normativities of human health, that is, the significant reduction or lack of the capabilities to engage with a changing environment in order to survive, which names the uncanny experience of the SARS events: people were fearing to lose their hold of life!

The SARS events showed how internal bodily environments and external environments are closely linked and interact. It brought to the fore that 'the form and functions of the human body are the expression not only of conditions imposed on life by the environment but also of socially adopted modes of living in the environment' (Canguilhem 1991: 269).⁴³ Indeed, the cosmopolitics of SARS interrogated the modernist bifurcation between the realities of nature or nonhumans on one hand and society or humans on the other. With conceptualizing all things – humans and non-humans alike – as societies, I emphasized that all things depend on *social* relations that assemble heterogeneous entities thereby affecting composing and decomposing effects. As composing effects, social relations configure enduring societies like human bodies, ideas, prejudices, perceptions, cells, viruses, animals, institutions, nation-states and so forth. As discomposing

43 Bio-molecular research on AD underlines Canguilhem's and my point. AD is not conceived as a mere 'cause-and-effect chain of events, but rather [as] a complex maze of pathways that may or may not be activated under a specific combination of as yet poorly understood conditions, among which both factors internal and external to the body may well be important. Although molecular geneticists' research is virtually limited to teasing apart the relationship among internalizing factors, they do not deny that social and environmental factors from the time of conception onward may be implicated' (Lock 2005: 208).

effects, social relations question the orderings, disrupt, alter or endanger them. With the emergence of the human SARS virus and how it affected human lives we experienced the fragility, precariousness, contingency and heterogeneity of interacting living societies.

The cosmopolitics of SARS also made us aware of the importance of situated action and local practices when we want to understand an emerging contagious disease as well as what it means to live with it. As we have seen, in order to engage with the cosmopolitics of contagious threats like SARS, the emergent realities of local social practices needed to be traced and understood. However, just as local practices provoked trans-local or global concerns, global concerns were inextricably bound to the situated and local practices, which ultimately meant that both dimensions shared the same complexity. With the prospect of SARS becoming a global threat, the inter-relations of local complexity and its variations and differences multiply. Thus, it is precisely these 'local' processes of change that need to be traced and cared for in order to understand the 'trans-local' effects of contagion in complex human-nonhuman societies. Contagion and emergency situations require a 'sociology of processual events' (Alliez 2004: 54) that adequately addresses the *cosmopolitics* introduced.

The SARS event also showed how nonhuman actors (like the SARS-CoV) multiply the possible diversity of cosmopolitical actors capable to set free processes that re-connect and re-configure local, regional, national and global concerns of human practices and relations. Nonhuman cosmopolitical actors *complexify* the concept of 'risk society' (cf. Beck 1992, 1999) and related processes of non-knowing that unbutton social normalcy. Nonhuman actors like the SARS-virus deeply affected the normativities of human life and its social orderings.

The intermingling of human and nonhuman entities, local and global processes, present catastrophes and future risks, knowledge and non-knowledge draws attention to the social as a contingent and precarious process of connecting, producing, as well as endangering heterogeneous entities. Hence, in order to draw attention to the social processes of the SARS event, we have to engage with the power of the non-social that complicates, renders uncertain, re-assembles and endangers taken-for-granted societal orderings.

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Conclusion:

The Social as Event

My discussion of the *Cosmopolitics of Illness* tackled the general observation that, in the course of life *events*, may occur that unbutton the world taken as normal and consequently disrupt, question, alter and endanger common and taken-for-granted social relations. We have argued that cosmopolitical events like dementia, a stroke or a contagious disease may happen every day, but they are not everyday events. Cosmopolitical events are exceptional and extraordinary, ‘they take us by surprise, they overtake us’ (Cloots 2009: 61; cf. Ulig 2008).¹ These events create something new and different, who/which has not been part of assembling the social relations prior to the event. At the same time, it is the exceptional and extraordinary nature of cosmopolitical events that make us aware of the *ordinary eventfulness* of social relations and practices. Through the event of the extraordinary we may tackle the ordinary and its limits, which is itself the effect of eventful processes.

Cosmopolitical events of illness bring to the fore that health as well as our taken-for-granted everyday life is an on-going, collective and situated accomplishment, vulnerable to uncertainty and change. In that sense, the cosmopolitics of illness draws attention to the *eventfulness of embodied human life*. Cosmopolitics, then, refers to the *multi-verse* of situated and collective accomplishments that turn into matters of concern: they become doubtful, are at risk and endangered; they evoke dispute and politicize the normative cosmos of these accomplishments.

As I have shown, the effects of cosmopolitical events – as different as dementia, a stroke or SARS – have wide-ranging effects on human life and the social relations involved. But we have also witnessed how the social relations enact the contingent processes and experiences, good and bad passages of such illnesses. Cosmopolitical events not only thoroughly affect individuals and their life-world. Being contagious they may also disseminate quickly and dangerously across individuals, neighbourhoods, cities, regions, nations, continents and the whole globe. The different experiences of these cosmopolitical events unfold their specific, locally situated complexities. Consequently, I have tried to show that irrespectively of the difference between the very intimate and personal experiences of Mrs M and Mr B on one hand, and the risk of a global migration of SARS on the other, the cosmopolitics of illness requires the same attention to the situated and processual complexities which emerge *in situ*.

1 On the event, see e.g. Deleuze (2006), Derrida (2003), Heidegger (1994), Mersch (2002), Müller-Schöll (2003), Romano (2009), Rölli (2004).

This addresses also a methodological point of analysis that I tried to emphasize. Analyzing the cosmopolitics of illness offers a contrast to a mere biopolitical framing of illness and its focus on ‘big’ statistical data of a population in order to convey an important general matter of concern. In contrast to the emphasis on the need of big statistical data to emphasize general concerns, I have been concentrating on ‘small’ data of situated experiences and the importance of local specificities in order to ask ‘big’ socio-philosophical questions concerning human existence, the relationship between health and illness, humans and nonhumans, knowledge and non-knowledge, time and space and so forth.

Moreover, to draw on the cosmopolitics of illness, I wish to convey a conceptual point in re-thinking the social. Following my reading, the social is not so much about a set of practices that try to highlight the difference of perspective between the realm of humans and nonhumans, or the difference between society and nature. Rather, I am concerned with a process-oriented reading of the social and consequently of how societies, human and non-human alike, come into being, maintain their orderings and change.

Let us first consider the question concerning scale. I agree with Strathern, who argues that

[a] “small” thing can thus be made to say as much as a “big” thing. (...) If one can ask “big” questions of “small” data, then the difference between big and small disappears. It is reinstated only with the reinstatement of perspective and levels, and a concomitant sense of the partial nature of description. (Strathern 2004 XIV–XX)

For sociological and modern (Western) reasoning, social complexity refers to the possibility to switch the position one can take up on things (Strathern 2004: XIV). It is precisely the relations of different positions that configure social phenomena. Social complexity emerges for instance if we would analyze the different realities of illness as they emerge from different perspectives, for example, from politics, economy, law, science and so forth (cf. Luhmann 1992, 1997). One may also change magnitude moving from singular cases to many cases, from local to national and transnational comparisons and so on. Obviously, through these scale-changes, one magnifies and multiplies relations and connections – no matter if it concerns a switch from ‘small’ to ‘big’ data and *vice versa*. At the same time though, Strathern (2004: XV) rightly points out that scale switch also enacts a loss of perspectives inasmuch as the presence of the one makes the presence of the other absent. This necessarily creates conflicts, disputes and controversies.

It is part of the cosmopolitics of illness that the conflicts between the different perspectives will not add up and generate a coherent and full picture. Thus, it is neither sufficient to say that this or that perspective, the ‘local’ or the ‘global’, generate the full picture nor the switching from one perspective to another. The problem of the full picture highlights the general limits of any analyst independent of the different scales employed. Consequently, it is important to address the

partial, situated and eventful complexity of illness. Its partiality may provoke others to think about their own taken-for-granted perspectives in order to possibly imagine and address what has been left out, marginalized and excluded. Partial and situated complexities multiply and complicate the realities (of illnesses).

I have also argued that illnesses are not mere individual deficiencies from or abnormalities of a given, natural, average and general condition of health. Rather, illness and its agents are general features of living societies that 'test' the situated normativities and unravel the possibilities of health. The cosmopolitics of illness introduce contrasts to the normativities of health and their social orderings. Cosmopolitical agents of illness, humans and nonhuman alike, *estrangle* health and the taken-for-granted social relations. The different ways in which health possibilities and illness interact do create the norms and orderings of illness. Illness as a *general* feature of living beings makes us aware that what we consider as an *individual* issue, i.e. an issue of a specific scale, is a *shared* issue of different scales involved. The cosmopolitics of illness brings to the fore that individual relations or situated issues are shared collective relations and issues that disrupt, question, alter and elude given scale facts. The latter alludes to my interest in a process-oriented sociology, which explicates a contrasting understanding of the social that is meant to comprise an explanatory space of human affairs given by the difference between societal/cultural relations and natural laws.

Following a process-oriented reading of sociological concerns, the social does neither *explain* human organization nor is it 'adding something social to the description' (Latour 2005: 107). Rather, the social has to be explained by the associations of heterogeneous entities involved. Hence, the social does not refer to an explanatory realm that explains the non-social. Rather, the social 'in nowhere in particular [...] but may circulate everywhere as a movement connecting non-social things' (ibid.). Thus, it is neither the perspective of society that differs from nature that interests me, nor is it a specific scale that is supposedly more complex than another scale. Marilyn Strathern argues that

the interesting feature about switching scale is not that one can forever classify into greater or lesser grouping but that at every level complexity replicates itself in scale of detail. (...) [T]he realization of the multiplier effect produced by innumerable perspectives extends to the substitutive effect of apprehending that no one perspective offers the totalizing vista it presupposes. *It ceases to be perspectival* (...) In a world composed of different perspectives, the very claim to a perspective is flattening (Strathern 2004: xvi and 31; highlighted by MS).

If we consider the world as social phenomena, the social is about the composition of different modes of perspectives. Consequently, to argue for a social perspective in order to analyze the social is a flattening endeavour as well. It becomes a project of human exceptionalism if the social is limited to the realm of human society. Rather, a cosmopolitical understanding of the social 'observes no scale', but refers to a 'circuit of connections that joins parts that cannot be compared

insofar as they are not isomorphic with one another' (ibid.: 54). Consequently, cosmopolitical research focuses on the processual, the becoming, that is the eventfulness of the social, tracing the dynamics of 'post-plural societies' (cf. Strathern 1992; 2004). It questions the pluralist concept of society, which conceives 'society' as a 'holistic entity' in at least a threefold way: 1) society as a different (though related) domain/reality of nature, 2) society as a whole where the individuals are part of, and 3) society as a delimited space that allows comparison between other delimited spaces/societies. From a cosmopolitical view, the plurality of perspectives does not suffice to make up a higher complexity of 'the social' or 'society' in comparison with the complexity of the reality of the individual or nature. Rather, it prioritizes the social as a matter of propagation or process over organization (without dismissing the latter). Thereby it addresses the constant assembling and re-assembling of non-comparable entities as 'collectives' (cf. Latour 2005), for instance biological processes, human (and nonhuman) inter-action in a technologically mediated environment.²

From a post-plural and process-oriented perspective, no common principle neither defines the cosmos, the *Weltbürgergesellschaft* (Kant's cosmopolitanism), as a separate domain from the one called nature, nor is agency a sole capacity of humans (Schillmeier 2012). Rather, as the cosmopolitics of illness unfolds, the 'cosmos' is a fragile and on-going collective human and nonhuman achievement, which, with the onset of serious embodied events, is disturbed, questioned, altered and even endangered. With the focus on illness, this book has tried to back Donna Haraway's insistence that (sociological) attention should be given 'to the agencies and knowledges crafted from the vantage point of non-standard positions' (Haraway 1997: 269). Cosmopolitical agents do not speak for the majority, the normal(ized), average or taken-for-granted reality, but tackle issues of minorities, the excluded, the endangered, the ill, the suffering, the disabled, the unexpected and uncertain, the amoral, the non-sensical, the nonhuman and unreasonable. Their practices and experiences trouble the plugged-in normative norms of the common 'mise en equivalence', foster the possibilities of difference and enact the requirements of multiple and changing modes of existence. The experience of cosmopolitical events, like dementia, a stroke or SARS, requires an ethos that is concerned with and cares for the differences and uncertainties of life as an on-going collective accomplishment. Eventful bodies and the *cosmopolitics of illness* make us aware of embodied and material practices that undermine normalcy performed in accordance with the mores. Ill bodies instigate modes of embodied existence that interrogate and change the taken-for-granted.

2 Gabriel Tarde's speculative sociology is an early account of the 'social' understood as propagation rather than organization, see e.g. Tarde (1921, 2009).

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Index

- Absence(s) 58, 61, 73, 75, 89–91, 102,
104, 122, 127, 157
cognitive 75
present 75, 87
- Actor-Networks 66–7, 74, 78, 91, 94, 151
of Angst 84–9, 91, 94, 102, 104
of dementia 55, 67, 72–5, 101
of remembering 66, 68
- Ageing 5, 14, 24, 26
deficit model of 120
societies 11, 14, 24, 40
- Agency 2, 4–5, 28, 42, 46–8, 117, 148, 164
artistic 60
cosmopolitical 39, 124
human (political) 4, 31, 33, 35–8, 41
moral 29
patient 27
of not-knowing 40
- Alzheimer, Alois 24
- Alzheimer's Disease 2, 10–11,
- Alzheimer's Society 13–4, 29
- Anhaltspunkte 64–6, 88, 101–103
- Beck, Ulrich 138–9, 153, 159
- Befindlichkeit 72, 83–8, 94–6, 98–100,
103, 117, 120, 122–123
- Bergson, Henri 67–8
- Biopolitics 8–9, 11–3, 15, 24–34, 120,
133
of dementia 7–10, 14, 26, 28, 48
symbolic 10–13, 29–30, 33, 35, 39, 48
- Braun, Bruce 5, 122
- Callon, Michel 67, 142, 151, 153
- Canguilhem, Georges 1, 134, 155–8
- Care 5, 10, 27, 61, 89, 92, 96, 102,
105–106, 108, 110, 119
art of 60
bad 114, 116
call of 92
conduct of 27, 76, 106, 114, 117–120
constant 5, 76, 119
dementia 15, 25, 28
extension(s) of 5, 123
formats of 122
good 5, 114, 116, 119
health 13–15, 61, 129, 147–150
institutionalized (forms of) 61, 106
intensive 129, 143
long term 88–9, 118
matter of 92, 100
medical 95
packages of 27, 121
persons of 53
practices of 5, 26–8, 106, 116–122
professional 118–119
processes 28
relational forms of 42
relations of 26, 106, 122–123
requirements of 121–122
situation 116–117
systems 6, 8, 14, 39
technologies of 118, 121–122
work 106, 113, 115, 118–20
- Casey, Edward S. 66, 68
- Common Sense 13–4, 20–24, 29–30, 34,
36, 38–9, 41–3, 45–6, 48, 53–4, 86,
99–100
- Communities
dementia friendly 14–5
wise 13–5
- Conscience 89–92, 94–6, 101, 104
- Cosmopolitanism 29–31, 40, 44, 47, 164
of health 29, 31, 34–5, 38–9, 46–7, 121
normative 33
- Debaise, Didier 50, 63, 135
- Deleuze, Gilles 20, 22, 42–3, 56, 59–60,
68, 75, 161
and Guattari, Felix 3, 42–43, 136–138

- Dementia 3–5, 7–18, 23–31, 34–37, 39–44,
47–7, 50–55, 59–61, 65–8, 70–4,
76–9, 82–3, 85–88, 92–96, 99–103,
105–107, 123, 161, 164
cosmopolitics of 4, 35–73, 123
signs of 60, 73–4, 85, 87, 93, 96, 101,
103
- Dewey, John 39, 49–50, 53–4
- Emergency
situation(s) 6, 44, 125–126, 132, 134,
150, 159
space of 144
- Ethos 4, 6, 164
cosmopolitical 2
of situated care 61
of the social 101
- Events
cosmopolitical 1, 3, 41, 85, 92, 101,
120, 138, 154, 161, 164
- Existence
mode of 1, 73, 75, 85, 157
- Experience 1–4, 12–13, 17, 21, 26–8, 30,
34, 37–8, 40, 46–54, 57, 59–61,
65, 67–8, 74, 77, 79, 81–3, 85–6,
90, 92–3, 95, 103–5, 108, 112,
120–124, 130, 134, 138, 156–158,
161–162, 164
- Facts
accomplished 82–3, 88–90, 93, 96, 99,
100, 105, 121
bio-medical 1, 120
- Feeling(s) 27, 35, 38, 41, 44, 46–48, 50–1,
54–9, 61, 65, 67, 70, 75–6, 79, 81,
84–8, 91–5, 98–9, 101, 105–7,
109–115, 117, 120
conceptual 94
conscious 52–3, 56
ideas of 52
negative 58, 67
physical 94
positive 58, 67, 79, 85
primary 52, 59
- Foucault, Michel 8–9, 14–25, 30–1, 148
- Garfinkel, Harold 3–4, 76, 107
- Goffman, Erving 14, 89, 93, 106–107, 142
- Grosz, Elisabeth 67, 138
- Guilt 89, 91–2
- Heidegger, Martin 58, 60, 72, 74–6, 83–88,
91–4, 96, 101–102, 111, 117, 136,
161
- Heinlein, Michael 103, 107–108, 116
- Hinchliffe, Steve 124, 137, 139
- Infection, viral 1, 146, 156
- James, William 49, 88
- Kainz, Marion 5, 60–5, 69–70, 77, 79–82,
92–3, 96, 100, 103–104, 107
- Kant, Immanuel 29–34, 36–40, 44–7, 121,
164
- Kitwood, Tim 26–7, 122–3
- Latimer, Joanna 27, 55, 66, 76, 122
- Latour, Bruno 11, 13, 50, 63, 67, 102,
115–6, 139–140, 151, 163–164
- Law, John 67, 107, 111, 116, 151, 153
- Luhmann, Niklas 13, 162
- Madness 15–21, 23, 36, 99
- Memory 9–10, 17, 22–3, 55–7, 60, 64,
67–70, 74, 76
- Mol, Annemarie 27, 67, 151
- Morality 20–21, 23, 29, 31–2, 35, 39, 42–3
- Moralization 119
- Moser, Ingunn 27–9, 111
- Munro, Rolland 66, 124, 133, 151
- Normalcy 1–4, 14, 44, 47–8, 53–4, 61, 99,
112, 164
moral of 23
of relations 49
social 21–2, 44, 49, 142, 159
- Normalization 14, 44, 116–119
- Normalizing 1–2, 9, 37
re-normalizing 21, 23, 114, 116–118
- Normativity 1, 121, 155–158
- Nussbaum, Martha 32–3, 36
- Person(a)
dementing 5, 35, 37, 40–44
conceptual 43

- political 43
- Power
 - cosmopolitical 4, 124, 139
- Presence 16, 58, 67, 73, 83, 87–8, 94, 96, 98, 101, 103–104, 106, 112, 121–2, 162
 - of absence 89–91, 122, 162
 - at-hand 75, 104–105
 - blank 16
- Presencing 55, 58–9, 65–6, 100–101, 136
- Process
 - dementing 35, 37, 39–40, 44, 48, 52–4, 65, 71, 75, 78, 87, 93–4, 96, 108, 122
- Proust, Marcel 55–7, 59–60, 62, 73–4, 82, 84, 92
- Rationality 15, 21, 31–2, 37, 40, 100
- Rationalization 118
- Ready-to-hand 75, 79, 82–5, 87–8, 91, 93–4, 96, 98, 106
- Re-cognition 52–3
- Reason 11–13, 15–7, 19–25, 31–37, 39, 46, 49
 - healthy 22, 30–39, 48–9, 53–4, 99, 100, 122
 - judging 41
 - political 12
 - practical 32, 36–7, 40
 - technologies of 11–13, 39
- Relations
 - affective 4, 36, 38, 44, 50, 52–4, 56–7, 61, 88, 94, 100, 103, 107, 111, 123, 138
 - caring 120
 - of hesitation 5, 121
- Re-member-ing 57–9, 65–8, 74, 76, 84, 88, 90, 94, 102
- Roloff, Evelyn Lu Yen 129–130, 138, 140, 143, 144
- Sampson, Tony D. 136–7, 151
- Sanity and Reason 12, 20, 29–32, 34–6, 39, 41–2, 47, 120, 122
- SARS 2, 5, 6, 124–161, 164
- Scott, James C. 11–13
- Serres, Michel 15
- Simmel, Georg 136
- Stengers, Isabelle 3, 35, 39, 40–1, 44, 104, 121, 134–135, 156
- Strathern, Marilyn 66, 86, 103–04, 116, 162–4
- Stroke 1–3, 5, 8, 107–112, 120, 121, 123, 161, 164
- Tarde, Gabriel 50, 57, 63, 100–101, 134, 151, 164
- Traitement moral 18–9, 21
- Translation 67–8, 118, 151, 153
- Truth 11–2, 15–8, 23, 27, 31, 33–4, 41–2, 46, 60, 63, 72, 75, 100, 122
 - of being 20, 23, 99
 - ethnographic 104
 - objective 100
 - personal 18
 - situated 98
 - technologies of 11–12, 41
- Unreason 15–7, 19, 23
- Wald, Priscilla 127, 136, 144
- Whatmore, Sarah 4–5, 107, 122
- Whitehead, Alfred N. 44–47, 49–52, 54–5, 58, 63, 67, 94–5, 133–135