

In search of quality of life for a practical centenarian and his artistic wife

Annie Stevenson

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Abstract

Purpose – *The purpose of this case study is to highlight the importance of empowering and meeting the “higher needs” of the very old, which prolong a fulfilling life. Frailty in old age need not be feared and abhorred if society would accept that all of us need to live our lives as we wish until the end, and value those who assist us to do this. With the right attitudes to ageing and death and with the appropriate investment for a seamless care system that listens to, and functions well for those who need it, old age should be as enriching as any other time in life.*

Design/methodology/approach – *Personal narrative of the author's parents ageing, this paper gives the background and personality of the frail older person and his wife, that contextualises the challenges they face in his very old age. The professional and personal experiences of the author as she tackles the obstacles to support them are drawn from her career in social care with memories from diaries written, as she accompanies her parents on their journey of physical and mental deterioration along with a quest for realising what they have and making the most of it.*

Findings – *Given how challenging this journey is for an informed family, the implications are that in 2013 our “civilised” society still misunderstands the special and complex needs of frail older people, devalues them, and writes them off with institutionalised, rigid attitudes and services instead of working creatively to improve their lives. The paper observes how deeply rooted this is in us all.*

Originality/value – *The combination of the author's background in social work and expertise in health and care with living so close to relatively unusually long-lived parents, offers a unique insight into why it is so challenging to achieve quality of life for very older people needing care and should be of interest to CCGs, social services departments, older people's care providers and carer and user organisations.*

Keywords Creativity, Quality of life, Social work, Ageism, Frailty, Institutionalised, Longevity, Older carer

Paper type Case study

My father's “story”

My father was born in February 1913 in Rawdon, near Leeds. He miraculously was with us to celebrate his “big” birthday in February this year and is still with us at times – and somewhere else at other times, usually at night. This paper is about how, so far, he's achieved his wish of living out his old age at home with my mother, and has unexpectedly gained an extra year and a bit to his life, in a society that appears neither to value older people, nor those who care for them.

Dad would say he has led a relatively uncomplicated life compared to some, but I know it has been peppered with some deep traumas which as a down-to-earth, quiet, North Country lad, I'm not sure he has articulated. The youngest of three children, he contracted polio at the age of two which mainly affected his right leg and foot and meant he underwent an operation and was confined to bed for his toddler years. I imagine this was a tough beginning being confined so young and experiencing much pain when medicine was still being developed and the First World War was still going on. His father got him a “Neracar”, a three-wheeled motorbike, so he could get to school. However, after some successful pioneering orthopaedic surgery at the age

of 21, he was left with a club foot, one leg shorter than the other and able to walk with a limp. Many others who had polio at this time didn't come off so lightly.

He had a good education and became an engineering apprentice at sixteen, qualifying through night school to become a chartered electrical engineer. This eventually led him to a career in management consultancy to enhance productivity in firms by creating mechanisms to improve production lines and their financial efficiency, etc. He married, fathered a son and was tragically widowed, as well as coincidentally losing his brother-in-law at the same time as his first wife, all in his 20s. He met my mother in his 30s and she was 23, taking on his young confused son and going on to have three girls, of which I am the youngest. There were miscarriages and a stillborn baby, not unusual but nevertheless significant losses that this generation seemed to take in their stride. My mother really came into her own after I left home, when she studied for a degree in Fine Arts in her 50s in the first cohort of mature students at St Albans College of Art. Having hated school and gaining no qualifications due to "number blindness", she is now a successful fine artist, historian and poet.

To say that my parents are like chalk and cheese is an understatement. She is as talkative and creative as he is silent and practical. While she struggles with numeracy and excels in language, reading widely, he excels in maths, finds it hard to express himself and his reading consisted of the *Financial Times* and *Which Magazine*. She is highly intuitive, rather disorganised and his mind functions within a realm of logic, rationality and determination. He is her rock and she is his life-blood.

He reached the age of 90, always busy fixing things, doing church work and golfing. She was 81, painting, working as a guide at Hatfield House and writing, without many problems relating to health and age. He has experienced transient-ischemic-attacks (small strokes) for 16 years but always recovered afterwards and with the help of a daily aspirin, this didn't disable him. He is nearly totally deaf, but otherwise his constitution is good. They both recognise and appreciate their good fortune and a key decision was wisely made ten years ago when my mother persuaded him to move out of the family house he had bought in 1945. Mum used to watch him in alarm in the old house climbing a long ladder aged 89 with rope round his waist (his "safety harness") to cut back the creeper covering the front of the house. She knew that he would just carry on the same lifestyle, not really adjusting for his age, carrying on with his limp becoming more pronounced and wear and tear on his joints. Having experienced a doctor prescribing him specially designed built-up shoes to equalise his leg length which turned out to be hopelessly uncomfortable, Dad quietly bought himself some rubber heels from the shoe repairer, filed one down and glued it on himself to match the height of the other heel. This worked beautifully and he didn't bother the doctor again.

The only way to help him adjust to his advancing years was to change the environment. Mum found another small, well-designed, modern house in the same village with much better access to shops, a smaller garden and no creeper to cut back. Gradually, his mobility became more affected as even his self-designed heels couldn't compensate enough, and his gait became more unstable. We were holding our breath, hoping that he wouldn't fall and fracture something. A stair-gate was fitted which he rather enjoyed operating (nice piece of engineering) allowing him to manage the stairs himself for around a year. An occupational therapist (OT) pointed out that his methodical mind probably helped him manage the risk of falling very well as he thinks through the problems, identifies the risks and adjusts his body accordingly while his placid temperament allows him to work every action out successfully, without getting distracted. This ability served him well as long as my mother could "keep house" and he could control his own body. The problems really started 16 months ago (he was 99) when his mobility and balance deteriorated which meant his legs were not responding to what he needed them to do. So my mother had to work harder to make up for his increasing incapacity.

When one of her sisters died, Mum needed to attend her funeral. This was the point that she felt Dad needed to "go somewhere to be looked after, it's all too much". She arranged for him to go for respite to a local residential home so she and the rest of the family could go to the funeral.

In the meantime, sensing the need to get a full assessment of Dad's needs and Mum's as carer, we agreed that social services and their GP needed to be alerted, with their involvement and

wishes being at the fore. This was done just in time, as, (with some difficulty), their surgery agreed that he needed an Advance Care Plan (ACP) (GP: “But he’s not terminally ill?” [...]) Me: “No but he’s frail and aged 99, isn’t this the time to make an ACP? I can’t see him finding the elixir of youth and reversing the ageing process, can you?”).

He wrote his ACP, with some assistance, while he was in the home. He was very clear that his preferred place of care and dying would be at home, second choice as a last resort in the care home (If Mum can’t cope, but how will she manage to run the house without me?) and absolutely not in hospital. I watched him struggle to make sense of the (caring) care home for five days, and I caught glimpses of him looking bewildered and lost, trying to assess the distances to walk with his frame, to teeter to the wash basin to do his teeth, to wait patiently alone in his room while the staff came round to him to tell him when meal times were. They forgot on one occasion and he missed the evening meal altogether.

He returned home and within a few days had a serious chest infection. No-one (including the GP) expected him to survive it, we insisted on him being treated at home and not being admitted to hospital [...] thinking that this was it [...] we could achieve a really good death for him at home, fulfilling his wishes. We arranged a full care package, he was in a dreadful state, delirious, unable to breathe, and all his grandchildren came to say goodbye. When he was calm, he took off his watch to give to one of them, whispered that we should call the funeral director and “cancel the papers” but worried that it was a Bank Holiday! When he muttered [...] with a trace of annoyance [...] that his cousin Graham (who had died at 101 a year previously) had beaten him, I wondered if maybe this might not be the end after all?

Having refused food and fluids, he suddenly asked for water in the small hours of the next morning when I was braced to “see him off”. He drank and drank [...] by the morning he demanded to see a newspaper and where was his watch?

This was the start of the next stage of a journey that none of us expected. He never walked again as he was not mobilised after he recovered from the chest infection, a disadvantage of being at home. A hospital bed was ordered and he was brought downstairs and because he had an ACP, we had a community matron who has since overseen our case. Thankfully there are enough of us in the family to work as an extraordinary team to fight to respect Dad’s wishes as a frail, dependant, very old man to live out his final time in this world in his own home. Also to support Mum as his older carer who has to cope with the same level of responsibility that NHS staff would have done in the days when long-stay wards were open (before the Community Care Act 1990) at the ripe old age of 89 when (as she would say) “I should be painting and putting my feet up”.

Not only do both have a right to life (Article 2 under the Human Rights Act) but they also have a right to “respect for one’s privacy and family life, one’s home and correspondence” (Article 8). Why does Article 8 suddenly not apply to so many older people as society pushes them towards institutional (whether in one’s own home or not) care, whether they agree to this or not?

To summarise the 16 months following Dad’s “near death” experience

- We successfully got him NHS Continuing Care so he could be cared for at home, due to the unpredictability of his frailty. He was totally bedbound, doubly incontinent and continued to have episodes of delirium (extremely challenging to manage) after the chest infection. This was not helped by the following:
- Waiting four months for a standing hoist. This is a classic disconnect between the NHS and Social Services, which led to the loss of the use of his legs, but he was able to maintain the strength to stand. When it finally arrived it meant that he was able to use the commode. For a man unable to show much emotion, he was ecstatic.
- Thankfully he had an old recliner chair that Mum had spotted in a second-hand shop a few months before he became ill. He didn’t want it at the time, preferring to struggle to get up and down on and off their sofa, she nearly let it go, but I persuaded her to get it, “just in case you need it in the future. You never know, and in the meantime you can enjoy it and get your feet up while you can”. When the hoist finally came, this chair enabled Dad to be transferred there (without having to fight to get one) during the day and was key to allowing him to regain some quality of life.

- They have had a total of five different care agencies providing two carers, three times a day. At night, Mum was sleeping in the lounge on a sofa bed coping with his night deliriums until recently when night care has been provided most of the time.
- He made it to his 100th birthday and his 65th wedding anniversary in the same month! He is closing in on Cousin Graham. An extract from my diary in February this year:
The birthday party plans are going swimmingly. 10 of their generation (including 3 of their bridesmaids!) and us “kids” (eldest is 74!) will be gathered with them round their dining room table in their house for lunch. Another 10 (sons-in-law and grandchildren) will have lunch in the local pub, as they can’t fit round the table. Then all will come together to sing Happy Birthday and he can attempt to blow out his candles. And it’s open house for all his carers who have asked to join in!

They had a full page spread in the local paper for the double celebration so Dad received two cards from the Queen in one month:

- As well as golf, he is a keen tennis fan. He saw Andy Murray win Wimbledon this year. He remembers Fred Perry very well. (A mere 77 years ago, Dad would have been 33 then).
- Along with the “Battle of the standing hoist” there has been a “Battle of the wheelchair and required ramps”. Months of wrangling has allowed for this vital additional equipment to give Dad a breath of fresh air and change of scene from being stuck in the lounge for 16 months. It was also critical to enabling him to finally go for a respite admission to a nursing home last week for Mum to have a well-earned break without relying on an increasingly stretched family to be the “glue” of care which she provides to keep the whole show on the road. She chose to use this week to go on a painting holiday, organised by her and travelling alone from Hertfordshire to Devon, whilst keeping her age top secret.

Some highlights and lowlights

Darkest comedy time other than when we thought he was dying last year: when he fell into a deep sleep into his lunch. Mum thought he’d died (again). The GP was called.

Best empowering quote from a professional on Mum’s admission that she mixed up his sleeping medication with an anti-biotic: “I can recognise a drug-induced coma when I see one. Your mother is an expert in caring for him; she’s just tired which is why she mixed it up. I prescribe her a rest”.

Most horrified look from a professional: the ambulance driver who isn’t trained to use a standing hoist to get him into the wheelchair to get him to the nursing home for respite. Having waited for three hours for him to arrive Mum announced: “Annie you use that hoist to get him in the wheelchair. Dad will tell you what to do and I’ll help”. Needless to say, between us we did.

Most rewarding sight: seeing Mum’s suitcase ready to go on her recent holiday, along with two plastic bags. One contained her art materials and the other contained a small folding stool for her to use when she gets “a bit tired”. She carried the lot by taxi and train to Devon and back. I’m still not sure how she did this as she forgot to book the return taxi home from Paddington. “I just got on with it”.

Most passionate quote from Dad on sitting amongst the residents in the nursing home during a sing-song: “I’ve never heard such a row in all my life!”

Reflection

This is the background to my father’s frailty. My professional life is spent supporting quality of life in care homes (I’m a Lead Transformation Associate for *My Home Life*) so I value this part of the care sector for those who are suited to residential care. My fight is to see that all care-workers, (wherever they work), and family carers are treated with the respect and dignity they deserve through good working conditions, fair pay and appropriate training to reflect the complexity of the clinical conditions that affect older people. When care-workers and family carers have this respect and greater status, we may start to see quality in care improve. Co-incidentally they happen to be mainly women, but that is not to say that men don’t suffer from being denigrated as carers too. However, there may be a feminist issue which relates to care being traditionally the domain of the woman, (which comes “naturally” to them of course) so requires a woman’s caring

instinct as opposed to proper training and not seen as economically productive. This might shed some light on the conundrum of how to tackle poor quality care.

Despite this, there are many excellent care homes, where I believe the managers should be treated as heroes/heroines for running such unpopular establishments. Many people are suited to care homes and some find a new lease of life after moving into one. Many, however, do not. My father is clearly one of these. He has always been certain that he needs to live in his house, he has been a home-owner since 1945, and would never consider living in any kind of “accommodation”. With no blame apportioned to anyone, he nearly died to prove that point.

He sees himself as very lucky and his case is unusual. He didn’t expect to see in the millennium, let alone reach the age of 100. What enabled him to enjoy that birthday at home and Mum to get away on her painting holiday? The reclining chair was a great help. However, writing the ACP was pivotal. My role as the “old-fashioned” former (Middlesex) hospital social worker for the team for the Elderly would have certainly played its part and proved its worth. For it was my insistence that his voice was heard and his wishes recorded that I believe made the difference. The “old-fashioned” role is: to listen deeply, allow space and time for reflection, (crucial for older people) connect emotionally, advocate, co-ordinate, work collaboratively. Which care professionals today are allowed to do this?

Yet even with all of this, on reflection, he hasn’t escaped “institutional” care. By this I don’t mean the building where he lives, but internalised rigid, ageist attitudes that run so deep within us all, it’s very hard to recognise. He was bedbound for four months as it took that long for the multi-disciplinary team, consisting of the community matron, physiotherapist, OT and me as the social worker, to get the right equipment for him to get up and sit in a chair. The delays in getting the standing hoist to give him a life out of bed and overriding his clinical need to be timely mobilised, were scandalous, but no-one questioned it. It may be that he accepted this so readily (he has never complained about his care) as he had already experienced long periods being confined to bed in infancy.

Once the standing hoist was in place, the next consideration for some quality of life for Dad was having a wheelchair. This was arranged (again after much hassle partly because it had to be self referred and Mum couldn’t see how it would benefit them), but it wasn’t much good without ramps as the house is small with limited options for sitting elsewhere. Going outdoors was a different issue. Despite all my awareness, knowledge and determination, we’ve only just succeeded in achieving this by getting the appropriate ramps [...] just at the end of the warmest summer we’ve had in years. But he has been out a few times and I saw him absorb the sight of each plant my mother has in their garden as if he had come out of prison.

Recently it was clear that with Dad’s increasing night confusion, Mum was getting desperate for a decent break and the family team found it harder and harder to provide cover for her to go off for a few days. She needed at least a week to get away from all things related to care. With the wheelchair and ramps, it meant Dad could go to a nursing home for a week (with mixed feelings, but knowing it would help Mum) and Mum went for her painting holiday. She organised it so it fulfilled her need to be immersed in art, with great weather, good food and company. Dad arrived back home a day after her; at the nursing home he loved the food, enjoyed a bath, but that was as far as it went. The smile on his face said it all when he was wheeled into their sunny lounge.

One of the care staff at the nursing home suggested that we use an adapted taxi service to take him out on short outings. I metaphorically clapped my hands to my head. Why hadn’t I thought of that? My institutionalised mind had convinced me that he needs an ambulance to transport him anywhere. The reality is the driver didn’t know how to hoist him, so why is an ambulance required?

Until I was forced to, (because the ambulance driver couldn’t) I was too scared to use the standing hoist myself. Plagued by the fear of “health and safety” and indoctrinated by the need “to be trained”, I was jumping around like a frustrated nervous cricket while we were scratching our heads trying to think how to get him to the nursing home. If Mum hadn’t pushed me to do it, the respite admission would have failed.

So, Mum and Dad have had an incredible year, but how much more it could have been with added outings which all of us take for granted as part of our lives? We had the equipment to do it, just not the imagination and knowledge.

Ageism and institutionalised thinking plays out across the whole health and social care system which is grossly underfunded, where it's acceptable to over-ride older people's human rights, and acceptable for them to be fed and watered (and even this is inconsistent in hospitals) without paying attention to their emotional, psychological and spiritual needs. Even with my background in social work, care provision and campaigning, I couldn't get it quite right for my own parents.

Longevity is relatively new. Sixty is the new 40 and it isn't that unusual to reach a 100. With my genes, there is every reason to believe I could make it to 110! This affects every one of us and those in power in 2013 are still wondering how to achieve decent quality in care, let alone quality of life. We have extended human life because we have the required resources, science and technology. We have the same ability to achieve happiness and fulfilment for the final years. Yet our prejudices, rigid thinking and fear of decline and death are the greatest barriers. They create an endless loop of dread of old age, avoidance, denial, a workforce that are blamed and controlled instead of valued and empowered and a system that is more and more out of tune with those it is there to support.

My parents' story should be an inspiration to us all. His age related condition is frailty with some strokes; it could have been any of the others. What have I learned from this experience? Quality of life is possible at one hundred with funding, knowledge, imagination, open hearts and minds and a shared responsibility between state, professionals and family. But what does it take to have all of these?

Annie's son Richard has made a film of his grandmother, Jean Atkinson's work which can be accessed at: www.youtube.com/watch?v=RsrWr3BA_vM&feature=youtube_gdata_player

About the author

Annie Stevenson offers a 360-degree perspective on all aspects of care. Her background is in social work and she has 30 years experience of all sectors and all user groups in care: social services, health, housing, voluntary as a care provider and campaigner and is now running her own consultancy called Integration in Care. This is connecting sectors in care to improve effectiveness and efficiency in organisations and enhance user and staff experience. She also supports her mother who is an older carer and frail father. Annie Stevenson can be contacted at: annie.stevenson@integrationincare.org.uk

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