INTERNATIONAL STANDARD

ISO 25552

First edition
2022-02

Ageing societies — Framework for dementia-inclusive communities

Vieillissement de la population — Collectivités inclusives à l'égard des personnes atteintes de démence

Reference number
ISO 25552:2022(E)

ISO copyright office
CP 401 • Ch. de Blandonnet 8
CH-1214 Vernier, Geneva
Phone: +41 22 749 01 11
Email: copyright@iso.org
Website: www.iso.org

Published in Switzerland

Contents

Page

Foreword

ISO (the International Organization for Standardization) is a worldwide federation of national standards bodies (ISO member bodies). The work of preparing International Standards is normally carried out through ISO technical committees. Each member body interested in a subject for which a technical committee has been established has the right to be represented on that committee. International organizations, governmental and non-governmental, in liaison with ISO, also take part in the work. ISO collaborates closely with the International Electrotechnical Commission (IEC) on all matters of electrotechnical standardization.

The procedures used to develop this document and those intended for its further maintenance are described in the ISO/IEC Directives, Part 1. In particular, the different approval criteria needed for the different types of ISO documents should be noted. This document was drafted in accordance with the editorial rules of the ISO/IEC Directives, Part 2 (see www.iso.org/directives).

Attention is drawn to the possibility that some of the elements of this document may be the subject of patent rights. ISO shall not be held responsible for identifying any or all such patent rights. Details of any patent rights identified during the development of the document will be in the Introduction and/or on the ISO list of patent declarations received (see www.iso.org/patents).

Any trade name used in this document is information given for the convenience of users and does not constitute an endorsement.

For an explanation of the voluntary nature of standards, the meaning of ISO specific terms and expressions related to conformity assessment, as well as information about ISO's adherence to the World Trade Organization (WTO) principles in the Technical Barriers to Trade (TBT), see www.iso.org/iso/foreword.html.

This document was prepared by Technical Committee ISO/TC 314, *Ageing societies*.

Any feedback or questions on this document should be directed to the user's national standards body. A complete listing of these bodies can be found at www.iso.org/members.html.

Introduction

0.1 Overview

This document was developed in response to a worldwide recognition that individuals, families, and communities need to be more inclusive concerning persons with dementia. One goal of this document is to engage and include persons with dementia and their families, and carers, in communities of all types, sizes, and locations.

A dementia-inclusive community is one that is committed to working together to promote a better understanding of dementia, reduce stigma, raise public awareness, and that facilitates social inclusion and participation. By fostering a dementia-inclusive environment, communities can support persons with dementia to be independent citizens, to be connected as much as they want to, to feel safe and comfortable, and to be able to maximise their abilities and opportunities to participate.

0.2 Challenges and solutions

The worldwide rise in the number of persons with dementia has led to a growing need to increase understanding of dementia in all societies. Stigmatisation and discrimination towards persons with dementia sometimes occur within their community, creating barriers to diagnosis, treatment, and care, which can significantly impact their quality of life. Many societies do not support persons with dementia adequately and discourage them from exerting maximum control over their own lives. Additional support to enable continued engagement for persons with dementia in daily activities and community life, or to enable participation in decision-making in life, is often provided too late or not at all.

There is a need for education to address knowledge about what a dementia diagnosis can mean for persons with dementia and those around them, including treatment and care options as key elements, which would support development of a dementia-inclusive community within an integrated care approach.

NOTE Integrated care can include primary care, all allied health professionals, e.g. occupational therapists, social workers, physiotherapists, and dementia advisers.

The creation of supportive, safe, and inclusive communities for persons with dementia and those who care for them is essential to maximizing everyone's quality of life.

This document provides a comprehensive and interdisciplinary framework to develop a dementia-inclusive community.

Moreover, this document recognizes that training, resources, experience, personnel availability, and existing organizational structures are constraints that can have a direct impact on how quickly and effectively a dementia-inclusive community can be planned and implemented. Therefore, this document provides guidance on how to identify these constraints and address them as part of the process of designing a dementia-inclusive community.

A person with dementia possibly experiences physical, sensory, cognitive, social, and communication challenges and these need to be considered as part of a dementia-inclusive community. ISO/IEC Guide 71 provides information on various human capabilities and characteristics relevant to this document.

0.3 Expected outcomes and users of this document

Some of the expected outcomes from the use of this document include the following:

— improvement of the quality of life for anyone with dementia in a community;

— development of quality services for persons with dementia;

— ability to obtain recognition for establishing a dementia-inclusive community;

— optimization of the resources needed to develop a dementia-inclusive community;

— creation of new opportunities for all stakeholders in a dementia-inclusive community;

— more inclusive communities generally, where the participation of everybody, including persons with dementia, is facilitated and encouraged.

This document is aimed towards, but not limited to, user categories such as the following:

— authorities having jurisdiction within communities;

— organizations, congregations, and community groups;

— individuals, carers, and families;

— persons of interest in education, research, and development;

— decision makers;

— planners, designers, and providers of products, services, the built environment, and the community infrastructures.

0.4 Other requirements

There can exist other requirements, including regulatory requirements that can affect aspects of a dementia-inclusive community as addressed in this document (e.g. revoking drivers' licenses, provisions, and regulations for the restriction of freedom and decision-making in later stages of dementia). Consequently, those developing a dementia-inclusive community should identify potential regulatory, health and other requirements that can be in conflict with a dementia-inclusive community and discuss how these conflicts can be resolved or mitigated.

0.5 Approach and structure of this document

The challenges and solutions outlined above set the subject matter and objectives for this document.

An integrated community network is built on the development and integration of the community sectors, referred to as action areas.

Clause 4 provides a process-based framework for the development, maintenance, and continuous improvement of dementia-inclusive communities. To transform into a dementia-inclusive community, a set of generic guiding principles is presented in Clause 5. Clause 6 provides a set of requirements for the design of a dementia-inclusive network, while Clause 7 provides information about the action areas and integration between them.

The annexes provide additional information on aspects such as possible considerations when implementing requirements (see Annexes A and B) stages of dementia (see Annex C), other frameworks available for consideration (see Annex D), and a compact implementation and progress evaluation checklist (see Annex E).

Ageing societies — Framework for dementia-inclusive communities

1 Scope

This document provides a framework for dementia-inclusive communities, including principles and the considerations of inclusion, quality of life, built environments, special needs groups, and stakeholder engagement. It also provides guidance on how to systematically leverage, improve, and interconnect their existing assets and structures and transform efficiently into a dementia-inclusive community.

This document does not provide any clinical standards.

2 Normative references

There are no normative references in this document.

3 Terms and definitions

For the purposes of this document, the following terms and definitions apply.

ISO and IEC maintain terminology databases for use in standardization at the following addresses:

— ISO Online browsing platform: available at https://www.iso.org/obp

— IEC Electropedia: available at https://www.electropedia.org/

3.1
dementia
set of symptoms affecting brain function that are caused by neurodegenerative and vascular diseases or injuries

Note 1 to entry: Dementia is characterized by a decline in cognitive abilities such as memory; awareness of person, place, and time; language, basic math skills; judgement; and planning. Dementia can also affect mood and behaviour. As a chronic and progressive condition, dementia can significantly interfere with the ability to maintain activities of daily living, such as eating, bathing, toileting, and dressing.

Note 2 to entry: Alzheimer's disease, vascular disease, and other types of illnesses all contribute to dementia. Other common types of dementia include Lewy body dementia, frontotemporal dementia, and mixed dementias. In rare instances, dementia can be linked to infectious diseases, including Creutzfeldt-Jakob disease.

3.2
dementia-inclusive
providing equal access to opportunities and resources for persons with *dementia* (3.1), including, but not limited to, a focus on stigma reduction, *accessibility* (3.9), individual tailored services, and participation

Note 1 to entry: In a dementia-inclusive community, people are educated about dementia, its progression, and know that a person with dementia can sometimes experience the world differently. Persons with dementia, their families, and their carers are empowered, supported, and included in the community. The rights and full potential of the person with dementia are recognized and understood by all communities.

Note 2 to entry: In a dementia-inclusive community, the community facilitates persons with dementia and carers to optimize their health and wellbeing; live as independently as possible; be understood and supported; safely navigate and access their local communities, and to maintain their social networks.

3.3
community
place or group of people with an arrangement of responsibilities, activities and relationships

Note 1 to entry: A location such as a city, town, neighbourhood, village, or rural area, but it can also include groups of people with shared interests or features, such as professional groups, religious organizations and businesses.

Note 2 to entry: In many, but not all, contexts, a community has a defined geographical boundary.

Note 3 to entry: The following are also considered as actors in the community:

— authorities having jurisdiction within the community;

— organizations, congregations, and community groups;

— individuals, carers, and families;

— persons of interest in education, research, and development;

— planners and providers of products, services, the built environment, and the community infrastructures.

[SOURCE: ISO/TS 37151:2015, 3.1, modified — "place or" has been added, Note 1 to entry has been modified, and Note 2 to entry and Note 3 to entry have been added.]

3.4
community-based services
community-based care
community-based programmes
health and social services integration provided to an individual or family at their place of residence or at other non-institutional locations within the *community* (3.3) for the purpose of promoting, maintaining, or restoring health, minimizing the effects of illness and disability, and supporting and facilitating *autonomy* (3.5) and self-care

Note 1 to entry: Services and programmes can include healthcare workers, befriending services, delivered meals, home care, community mental health, health education, screening, immunizations, family planning, sexual health, palliative care etc.

[SOURCE: ISO/IWA 18:2016, 2.2, modified — "health and social services integration provided to an individual or family at their place" has replaced "blend of health and social services provided to an individual or family in his/her place", "or at other non-institutional locations within the community" has been added, "on his/her normal lifestyle" has been removed, "and supporting and facilitating autonomy and self-care" has been added, Note 1 to entry has been removed, "community-based programmes" has been added as admitted term, and new Note 1 to entry has been added.]

3.5
autonomy
ability to control, cope with and make personal decisions about how one lives on a daily basis, according to one's own rules and preferences

3.6
independent living
living at home or in a *community* (3.3) without the need for continuous help from another person and with a degree of self-determination or control over one's activities

Note 1 to entry: Independent living can refer to a range of housing and community arrangements that maximize independence and self-determination.

[SOURCE: WHO Ageing and Health Technical Report, Vol.5 and U.S. National Library of Medicine]

3.7
participation
active involvement in a life/community situation

Note 1 to entry: Situation can also be understood to be the community.

[SOURCE: ICF 2001, WHO; ISO 9999:2016, 2.13, modified — "active" has been added, "life/community situation" has replaced "life situation", and Note 1 to entry has been added.]

3.8
engagement
involvement in, and contribution to, activities to achieve shared objectives

Note 1 to entry: This involves:

— active involvement of persons with dementia in activities (social, physical, mental) that have a positive influence on their health and wellbeing and eventually autonomy and independence;

— activities that strengthen their family life and relationships;

— active contributions to the community to enhance the persons with dementia feeling of being of value to their community.

3.9
accessibility
extent to which products, systems, services, environments and facilities can be used by people from a population with the widest range of user needs, characteristics and capabilities to achieve identified goals in identified contexts of use

Note 1 to entry: Context of use includes direct use or use supported by assistive technologies.

[SOURCE: ISO 9241-112:2017, 3.15]

3.10
meaningful life
construct having to do with the purpose, significance, fulfilment, *participation* (3.7), and satisfaction of life

Note 1 to entry: A meaningful life can signify many different things for different people depending on culture, age, etc.

Note 2 to entry: What is seen as a "meaningful life" varies between cultures.

[SOURCE: A Dementia Strategy for Canada, June 2019]

3.11
quality of life
product of the balance between social, spiritual, physical, and mental health, economic and environmental conditions that affect human and social development

Note 1 to entry: It is a broad-ranging concept, incorporating a person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to salient features in the environment.

[SOURCE: ISO/IWA 18:2016, 2.22, modified — "spiritual, physical, and mental" has been added.]

3.12
ethical aspect
aspect of organizational/community behaviour that is in accordance with a human rights-based approach with a focus on the values of honesty, equity, and integrity related to the creation, design/development, maintenance, and improvement of a *dementia-inclusive* (3.2) *community* (3.3)

3.13
prevention
action aimed at promoting, preserving, and restoring health when it is impaired and to minimize suffering and distress

Note 1 to entry: Prevention refers specifically to all aspects (medical, social, physical, cognitive, behavioural, etc.) potentially associated with having dementia.

Note 2 to entry: In public health, 'prevention' includes primary prevention, secondary prevention and tertiary prevention. Primary prevention refers to actions performed to prevent the development or delay the onset of diseases. Healthy lifestyle promotion and vaccinations are examples of primary prevention. Secondary prevention is the early detection of disease before the symptoms or signs of ill-health arise, to intervene and thereby prevent or delay their progress. Screening for chronic diseases and cancers fall under this category. Tertiary prevention aims to prevent a recurrence, complications, and further negative impact of the diseases after they have already occurred, to maximize longevity and quality of life. Examples of this include rehabilitation of a person who survives a stroke, and the environment enhancement for a person with dementia, etc.

[SOURCE: ISO/IWA 18:2016, 2.19, modified — Note 1 to entry, and Note 2 to entry have been added.]

3.14
care
provision of what is necessary for the health, welfare, maintenance, and protection of someone

3.15
carer
caregiver
person who provides *care* (3.14)

3.16
culturally appropriate care
consideration given to cultural background, personal experiences and norms in the context of providing any formal or informal services to a person with *dementia* (3.1)

[SOURCE: A Dementia Strategy for Canada, June 2019]

3.17
formal carer
formal caregiver
paid professional who provides regular *care* (3.14)

3.18
formal care
care (3.14) provided on a regular, paid basis by organizations or persons representing organizations or by other persons

Note 1 to entry: Organizations can be profit-making or non-profit-making, public or private. Persons typically exclude family, friends or neighbours.

3.19
informal carer
informal caregiver
generally unpaid person who provides *care* (3.14) from time to time

Note 1 to entry: This term does not include trained care providers affiliated with home care agencies when working with clients at those agencies.

Note 2 to entry: An informal carer is likely to be a family member, relative, close friend, neighbour or volunteer. Support provided by an informal carer may include assisting with the activities of daily living, and helping with advance care planning.

3.20
informal care
care (3.14) provided by family, friends, or neighbours

3.21
person-centred care
way of organising and conducting *care* (3.14) that promotes the provision of care centred on a specific person's needs and preferences, identity, and their *engagement* (3.8) in the care process

Note 1 to entry: Person-centred care usually relies on concepts such as individualisation, personalisation, autonomy, participation, and engagement to achieve its goals.

3.22
family
combination of two or more persons who are bound together over time by ties of mutual consent, birth and/or adoption or placement and who, together, assume responsibilities for various roles and functions

Note 1 to entry: This can include "chosen families," such as strong friendships and communities where unrelated persons provide care normally provided by nuclear family members.

3.23
integrated community network
network of human relationships that facilitates *autonomy* (3.5), integration, and *engagement* (3.8) of persons with *dementia* (3.1) and their *carers* (3.15) and provides *community-based services* (3.4)

Note 1 to entry: The activities of the integrated community network are based on taking measures, such as the strengthening of family life, design of an integrated and phased health and social care network, and the integration across community sectors and the continuous improvement of the dementia inclusiveness of these sectors.

3.24
guiding principle
generic and essential principle or design specificity that informs the design of the *dementia-inclusive* (3.2) *community* (3.3) as a whole at all stages of planning, design, operation, and improvement

Note 1 to entry: In particular, guiding principles inform the design of the integrated community network and the design of the action areas.

3.25
action area
community sector involved in developing an *integrated community network* (3.23) to establish a *dementia-inclusive* (3.2) *community* (3.3)

Note 1 to entry: An action area, for example, can include housing, infrastructure, leisure, etc.

3.26
active assisted living
AAL
concepts, products, services, and systems combining technologies and social environment with the aim of improving the quality of people's lives

[SOURCE: IEC 60050-871: 2018, 871-01-02]

3.27
active assisted living service
AAL service
action or function of an AAL system creating an added value for customers

EXAMPLE An AAL service could comprise, for example

— configuration and maintenance of AAL systems,

— assistant systems to support the home environment.

Note 1 to entry: An AAL service can consist of several individual services.

[SOURCE: IEC 60050-871: 2018, 871-01-04]

3.28
assistive technology
equipment, product system, hardware, software or service that is used to increase, maintain or improve capabilities and safety of individuals

Note 1 to entry: Assistive technology can include assistive services and professional services needed for assessment, recommendation, and provision.

[SOURCE: ISO/IEC Guide 71: 2014, 2.16, modified — "and safety" has been added, Note 1 to entry has been removed, Note 2 to entry has become Note 1 to entry.]

3.29
assistive product
product (including devices, equipment, instruments and software), especially produced or generally available, used by or for persons with disability

Note 1 to entry: An assistive product can be used

— for participation,

— to protect, support, train, measure or substitute for body functions/structures and activities, or

— to prevent impairments, activity limitations or participation restrictions.

[SOURCE: ISO 9999:2016, 2.3, modified — Note 1 to entry has been removed, bullet points from definition have been added as new Note 1 to entry.]

3.30
process
set of interrelated or interacting activities that use inputs to deliver an intended result

Note 1 to entry: Whether the "intended result" of a process is called, output, product, or service, depends on the context of the reference.

Note 2 to entry: Inputs to a process are generally the outputs of other processes and outputs of a process are generally the inputs to other processes.

Note 3 to entry: Two or more interrelated and interacting processes in series can also be referred to as a process.

[SOURCE: ISO 9000:2015, 3.4.1, modified — Notes 4, 5 and 6 to entry have been removed.]

3.31
elder abuse
single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person

[SOURCE: WHO Fact sheet elder abuse, 2021]

4 Development of a dementia-inclusive community

4.1 General

The development of a dementia-inclusive community is a continuous and dynamic process.

4.2 Systematic development process

4.2.1 General

A systematic, formalised, and phased process should be applied to properly conceive, plan, implement, assess, and improve a dementia-inclusive community.

4.2.2 Establish the general process

The community shall establish, document, and maintain a systematic process for setting up, adjusting and developing the dementia-inclusive community. This process should guide the implementation of the requirements and recommendations set out in Clauses 5 to 7.

The process approach should:

— be coupled with a structured and cyclic development methodology such as the "Plan-Do-Check-Act" (PDCA) cycle;

— incorporate analysing and addressing possible risks.

NOTE 1 The PDCA cycle refers to a four-part management method that provides guidance for continuous improvement. It is also referred to as the Deming cycle[36].

Where applicable and desired, the development process and the incorporation of the requirements and recommendations provided in this document can be implemented in line with, or as part of a formalised management or quality management process.

NOTE 2 Management or quality management processes in this case refer to management structures already existing in the community, a quality management process (e.g. according to ISO 9001 or any domain specific quality management process or standard), or a management system standard.

4.3 Process elements of a dementia-inclusive community

4.3.1 General

Requirements and recommendations in this clause are process and management-oriented and facilitate the efficient implementation of the function and object-oriented requirements and recommendations in Clauses 5 to 7.

4.3.2 Establish basic processes elements

When establishing a systematic development process, the following aspects should be considered:

— build on and improve existing structures in the community, ensuring in particular the development and retention of an inclusive community identity and an efficient and effective development process and use of resources;

— apply risk governance and management strategies to ensure that there is adequate risk-benefit assessment, and assurance that the benefits outweigh the risks when implementing elements of the dementia-inclusive community;

— communicate plans and progress to persons with dementia, families, carers, other key stakeholders and the public in clear, transparent, appropriate, accessible formats, and provide updates at regular, planned intervals;

— throughout all process phases and iteration cycles, systematically identify, incorporate and ensure cross-compatibility with other relevant standards that can have relevance regarding any stage or action of the process of creating a dementia-inclusive community;

NOTE 1 To make its development process over time more efficient, the community can develop its own tools and templates based on the requirements and recommendations set out in this document.

NOTE 2 To facilitate that a holistic community development approach is adopted, Annex D provides an overview of other frameworks available for consideration. The framework presented in this document is open and encourages community specific additions and adaptations.

NOTE 3 The Bibliography contains a comprehensive but non-exhaustive list of potentially relevant standards.

— understand dementia, types of dementia, epidemiological data about dementia in the community, and the progression of dementia;

— use supported decision-making to involve persons with dementia, and carers in the analysis process (e.g. through focus group meetings, community listening sessions);

— analyse the potential of involving or incorporating research and development;

— examine the possibilities of incorporating products and services considered under the umbrella term active assisted living;

— analyse physical, sensory and cognitive accessibility in the community, including built environment, transportation, technology, etc.;

— define vision and goals (including stages of the progression of dementia covered) for the dementia-inclusive community;

— define measures to improve data collection and analysis, and the use of active assisted living products and services;

— define a set of suitable and community-specific indicators that allow progress and performance evaluation.

To ensure continuity, sustainability, and accountability of dementia-inclusive communities over time, the communities should ensure the equitable allocation of resources.

A community that is dementia-inclusive, or aiming to become so, should analyse and assess the existing situation, while advocating and creating a climate for change. This will enable the community to build on and improve existing structures.

The community should establish a structure to oversee the development of the dementia-inclusive community. This can include a steering committee and an advisory committee. This structure should also include representatives of stakeholder organizations, persons with lived experience of dementia and those caring for persons with dementia, and other interested members of society. Cultural minorities should also be represented. An impact statement for the dementia-inclusive community should be written.

NOTE 4 Clause B.2 provides additional considerations regarding an extended person-centred and personalisation-oriented development of the community.

NOTE 5 Annex E provides an implementation and progress evaluation checklist.

5 Guiding principles: outcomes and enabling factors

5.1 General

To achieve real and sustainable change within communities, a change in societal culture about dementia is needed. A systematic, formalized, and phased process can support community actors involved in the dementia-inclusive community development.

Guiding principles are generic and inform the design of the integrated community network and the action areas. A dementia-inclusive community takes the applicable guiding principles into account at all stages of planning, design, operation, and evaluation. Integrated community networks and the action areas are addressed in Clauses 6 and 7.

These guiding principles address the lack of awareness and understanding of dementia that result in stigmatization and barriers to diagnosis and care. Quality of life for persons with dementia encompasses physical, psychological, social, ethical, and existential aspects. The stigma surrounding dementia informs stereotypes that are generally inaccurate as they focus on the symptoms of dementia rather than recognising the abilities and skills of the person with dementia. This can lead to mistreatment, exploitation, abuse, isolation, and poor mental health for persons with dementia.

Over time the enabling factors required to develop and sustain a dementia-inclusive community can lead to a reduction in stigma, and the elimination of residual stigmatization as the dementia-inclusive community is normalized. In addition, the impact of dementia on carers and families can be physical, psychological, social and economic.

As part of the implementation and continuous improvement process, some guiding principles can be selected according to their priority in specific communities. Those priorities may change over time, and some principles may be applied earlier than others.

The guiding principles are grouped into categories:

— universal outcomes for persons with dementia, and their carers, towards which the community shall work;

— universal elements for the creation of enabling factors (e.g. factors that enable the person with dementia, and carers) in dementia-inclusive communities.

5.2 Key outcomes for persons with dementia and their carers

5.2.1 General

In this clause, a set of requirements for working towards positive key outcomes for persons with dementia and their carers are provided.

Dementia-inclusive communities provide equality of access to opportunities and resources for persons with dementia and their carers, with a focus on respect and dignity. Protection of human rights ensures that people are enabled to maintain their dignity regardless of the stage of progression of dementia or life circumstances they are in, and irrespective of the type of care or protection or safety measures that are required to be provided.

NOTE The first article of the Universal Declaration of Human Rights states that “All human beings are born free and equal in dignity and rights”. The notion of dignity is defined as the inherent and inalienable worth of all human beings irrespective of social status such as race, gender, physical or mental state. Dignity is deeply embedded in international human rights instruments.

5.2.2 The individual right to choose and control

Persons with dementia and their carers inherently should have the right to live a meaningful and fulfilling life with choice and control, autonomy, self-determination, and empowerment. The dementia-inclusive community should be a place where persons with dementia and their carers are understood and respected.

NOTE In the case where choice and control become challenging for people with dementia and their carers, 'supported decision-making' outlined in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) is an appropriate option.

5.2.3 Accessibility and seamless integration

In order to work towards accessibility and seamless integration, a dementia-inclusive community should

— be a place where persons with dementia have access to the local indoor and outdoor facilities that they are familiar with or interested in accessing, and where they are safe,

— help maintaining the social networks of persons with dementia, where people are inclusive, and understanding, and

— support carers regarding the activities carried out to support the person with dementia and regarding their own personal life circumstances and the demands of the carer role.

In particular, the built environment, activities, and services should be accessible.

NOTE 1 Due to the importance of this recommendation, and the growing amount of guidance documents, and standards on accessibility, the Bibliography provides a series of accessibility related standards.

NOTE 2 Clause B.3 provides additional considerations regarding the utilisation of innovation and technology-based approaches.

5.2.4 Protection, safety, and safeguarding

Systems should be provided to improve security to prevent injuries to persons with dementia and their carers. On one level, this can reduce anxiety and prolong independence for persons with dementia, while on another level, this enhances the capacity of the carer. Safety measures should be designed to be understood by persons with dementia and their carers, and should not be complicated. Therefore, a balanced approach to risk assessment is necessary.

5.3 Enabling factors for a dementia-inclusive community

5.3.1 General

This clause provides a set of requirements and recommendations towards the development of enabling factors for a dementia-inclusive community. Key aspects covered include aspects such as accommodating the progression of dementia, considering prevention, acknowledging competencies and skills, sustainability, participation, engagement, orientation and safety, and cultural norms, that affect persons with dementia, and carers.

5.3.2 Responses to the life cycle of dementia

The community should take different approaches and measures in order to be inclusive to persons with dementia at all stages of dementia progression.

NOTE Dementia is commonly considered as progressing in stages although a linear progression will possibly not characterize an individual's experience; see also Annex C.

5.3.3 Promotion of prevention strategies

The community should promote approaches where preventative strategies are at the forefront.

Prevention strategies can be targeted at preventing decline related to the dementia as well as related potential health conditions.

5.3.4 Competence and skills

The community should operate in partnership with all stakeholders to identify the information required to develop and implement engagement in meaningful activities of daily living and related competency development.

Equal access to opportunities for skill development should be accessible to both formal and informal carers through training organizations with expertise in dementia support.

Engage with supports as appropriate for peer learning to ensure opportunities for skill development for persons with dementia and their carers.

Specific training needs of formal and informal carers should be assessed and reviewed regularly, as the needs of the person with dementia changes.

NOTE It is commonly considered as important to adequately train formal carers in health and social care, non-pharmacological interventions/care, safeguarding and dementia care so that they can complement and follow the advice of both care and social care specialists. For informal carers, areas including care skills, nutrition, positive communication, safeguarding, non-pharmacological interventions/care and self-care to enable them to complement and follow the advice of medical and dementia care specialists and continue in their role(s) and non-pharmacological care.

5.3.5 Sustainability

Sustainability of dementia-inclusive communities is central to this framework and the balance of the following four factors should be maintained as a means to realize a dementia-inclusive community:

— economic sustainability;

— environmental sustainability;

— social sustainability;

— accessibility.

NOTE Sustainability issues are influenced by a whole group of stakeholders both in the urban and rural communities.

5.3.6 Awareness

Awareness and understanding of dementia shall be raised among all members of the public across all sectors of the society. Communities shall use a variety of communication methods, including the use of traditional print media and social media and well-coordinated marketing campaigns and should provide basic dementia awareness, education, and training programmes.

5.3.7 Involvement, participation, and engagement

The community should enable and provide persons with dementia with the opportunity to be actively involved in planning, decision-making and evaluation processes about policies and programs, particularly those directly concerning them. Persons with dementia and their carers should also be engaged from the beginning in the development and delivery of training and education initiatives. Persons with dementia should be provided personal help if needed to be able to participate.

5.3.8 Orientation and safety

The community should support persons with dementia, as much as possible, to navigate and be safe. The community should have a wayfinding and accessibility strategy, which includes aspects, such as signage, landmarks, structural elements, e.g. ramps, as well as paving and obstacles to ensure a person with dementia can access their community safely.

5.3.9 Consideration of cultural norms

The components of a meaningful life differ according to cultural norms. Approaches that consider cultural norms should be applied at an individual, community and nation-wide level, to ensure provision of culturally appropriate care and support. Also, the implementation of requirements and recommendations provided by this document should consider cultural norms and language. Representatives of diverse cultural groups represented within a given community should be engaged in contributing to the development of implementation plans.

6 Integrated community: creating a dementia-inclusive network

6.1 General

The principle of inclusion informs all strategic activities (vision, goals, objectives, etc.) towards developing, maintaining, sustaining, and improving a dementia-inclusive community. Dementia-inclusive communities can enable persons with dementia, families, and carers to feel empowered, supported and included, understand their rights, and realize their potential. This can support control of health care costs and create opportunities for individuals, enterprises, and society, to develop, grow and fulfil their potential.

NOTE For more information and guidance on carer-inclusive organization, see ISO 25551.

6.2 Integration & community network

6.2.1 General

Inclusion is facilitated and created by an integrated community network, which is based on the close interaction with, support of, and inclusion of, the persons with dementia, families, and carers.

6.2.2 Develop statement of purpose

The community shall develop and publish a statement of purpose that reflects the dementia-inclusive vision of the community.

NOTE Existing charters such as The Global Dementia Charter "I can live well with dementia" developed by Alzheimer´s Disease International can be used to guide the development of the community's own charter.

6.2.3 Empower and support independent living

Requirements:

— Regardless of the progression of dementia, the dignity and autonomy of the person with dementia shall be supported by focusing on their ability to have a meaningful life.

— For autonomy, public places and spaces shall be easily accessible and approachable, accommodate the needs of persons with dementia and their carers. Easily understandable external and internal navigation aids and signage shall be installed.

— The person with dementia shall be empowered with meaningful information, explained to them clearly, using principles and practices of supported decision-making and obtaining consent before any care or other activities are rendered to the persons with dementia.

— Before deciding on any procedure, all care providers of persons in more advanced stages of dementia shall strive to know such persons thoroughly. This can include aspects such as their previously expressed decisions on care preferences, their values, family situation, religious and cultural beliefs, personal life history, occupation, hobbies, habits, and their social connections.

Recommendations for palliative care period:

— Even when a person is dying, the community should support them to live fully consistent with their expressed preference, for example, advance care planning, until death occurs.

6.2.4 Support family life

Requirements:

— The community shall support persons with dementia to live in a place of their choice as far as possible.

— In turn, family members shall be supported to manage and optimize their relationship with one another, especially with the person with dementia.

— Family members shall be provided with support and information such as education and training. This can help them to acquire skills in understanding and communicating with persons with dementia, providing emotional support and care to both family members and carer.

NOTE It is commonly acknowledged that it can take a longer time to adjust to a new physical environment for a person with dementia. Moving and changes in physical environment lower the person's ability to function.

— When persons with dementia are responsible for children, the needs of those children shall be considered.

— Family members shall be provided with essential respite and appropriate formal carer resources to enable them to be able to optimally engage with the person with dementia.

Recommendations:

— The living environment should be supportive of family relationships.

— The preferred lifestyle of the person with dementia should be respected. Taking into consideration the abilities of the persons with dementia, family members should offer the opportunity to participate in the choice and decision whether to live with their family, or near to their family, or independent of their family.

— Living arrangements can provide specialised care, but special precautions to address emergency situation such as pandemics, and natural disasters should be considered.

6.2.5 Strengthen the social network

Requirements:

— The community shall support friends, neighbours, and other social connections to continue their engagement with the persons with dementia. This ensures persons with dementia shall not be isolated from the social network they have cultivated and cherished throughout their lives.

— The community shall support persons with dementia to continue to live within the community of their choice, with accessibility to their social network, amenities, services and supports.

— The community shall also provide opportunities and support for the persons with dementia to develop new caring social connections and networks, especially if there is a change in living environment.

— The social network shall be actively engaged and be supported to access information on dementia and acquire knowledge and training to better understand and communicate with persons with dementia. Training and education are essential for the dementia-inclusive community. Communication systems such as smart devices and apps can play an important role and shall be accessible to persons with dementia, their family, and carers to stay connected.

— The social network shall be informed and empowered to deal with challenging areas such as social isolation, violence, abuse (whether physical, mental, or financial), neglect, and lack of emotional support.

— The social network shall, where appropriate, encourage an inclusive and calm dining experience. This aims to achieve inclusivity and optimise nutritional status, as eating with others has been associated with improved nutritional intake.

Recommendations:

— The physical environment of the community and places persons with dementia frequently visit should be accessible, supportive of social bonds and relationships and general health and well-being.

6.2.6 Create an integrated, comprehensive, and phased health and social care network

The health and social care authorities should commit to developing an integrated care ecosystem that supports an individual in a person-centred, seamless, timely, effective, inclusive, equitable and sustainable manner.

As far as possible, the community should develop and create its own network of care, weaving the informal and formal care systems into one connected whole.

Special consideration shall be given to person-centred approaches that can include care.

The approach to care and care planning for a person with dementia should be informed by the symptoms that the person with dementia is experiencing. Where input from the person with dementia is not possible, the approach to care should be person centred, holistic, and take into account any advanced care directives or expressed wishes of the person with dementia.

Large institutions where people with dementia are secluded from society should be avoided wherever possible. Dementia-inclusive communities should endeavour to have smaller facilities, based within the community, adapted to the requirements of persons with dementia and their carers.

The design of housing for persons with dementia should be of a scale that promotes independence, social inclusion, and smaller groupings of individuals.

Home-based health and social services, such as visiting health care professionals, should be available for persons with dementia, specifically when the latter experience excessive stress leaving their homes.

The community should have a policy on Safeguarding Vulnerable Persons at Risk of Abuse and should commit to creating and maintaining the safest possible environment/community for persons with dementia and their carers.

6.2.7 Facilitate the design of workplaces that foster inclusion of persons with dementia

The community should support persons with dementia to contribute to society, the community and family. Work is a central part of a person's perception of self-worth and meaning. As far as possible, a person with dementia should be supported to continue to work according to the progression of the dementia and the nature of the work. Assessing and improving accessibility in the workplace should be considered, analysing not only physical aspects but also cognitive requirements of the tasks the worker is expected to do.

In this context, the community should create awareness among employers and staff members across organizations. They should have a high level of awareness of the needs of workers, and there should be respect for workers with dementia by all members of the workplace. This awareness should also include dialogue between the employer and the person with dementia about their capacity to continue with the work and consider whether they need to step down / end the work career.

Organizations should also recognize the needs of workers who are balancing working with providing care to a person with dementia and provide supportive policies and programmes.

NOTE For more information and guidance, see ISO 25550 and ISO 25551.

The community should provide counselling and facilitate planning for retirement.

6.2.8 Emergency, safety, and protection

When developing policies and planning for measures to enhance safety for persons with dementia, the community should include and acknowledge that the principle of self-determination and the right to take reasonable risks is essential for dignity and self-esteem. Safety of driving a car and having a driver's licence should be considered and there should be a means for reporting if a person no longer seems to be able to safely drive a car or other vehicle.

Safety and safeguarding of other people, community, carers should be taken into account when assessing rights of a person with dementia (e.g. driver's licence).

Means should be provided to improve security in order to prevent injuries to persons with dementia. This can reduce the anxiety level of the person with dementia and prolong independence.

Safety measures should be designed to be understood by persons with dementia, and carers, and should not be overly complicated. Instructions should be provided in an appropriate format using a balanced approach achieved through risk assessment.

It is especially important to recognize and know who and where are those persons' who have dementia and who live alone.

Self-determination should be balanced with safety, assess the safety of person with dementia and others in terms of certain activities such as driving, e.g. driver's license.

Community organizations and services should develop a fire and emergency management plan and should raise awareness of this plan within the community. The emergency plan should be made known to all involved in providing care and the plan should be reviewed and practised at least on an annual basis.

NOTE 1 For more information and guidance see ISO 22395.

Advance care planning by the person with dementia, particularly, the guidance on proxy decision-making should be facilitated.

NOTE 2 Advance care planning in this context refers to a type of care planning that is done earlier and looks farther ahead than the usual care planning practice in the environment to which this document is applied.

Communities should develop a policy for people abuse and protection reflecting existing national and local people abuse and protection policies and guidance. The policy should be made aware of and provided to all involved in providing care.

The community should set up a people abuse prevention and adult protection system.

The community should raise awareness and take steps to prevent persons with dementia from being influenced by scams, fraud, and other crimes.

Means should be provided to improve safety and security when using internet and assistive technical devices.

Health, medical, care and social care and first responder professionals should be trained on engaging with persons with dementia with whom they must interact in relation to communication, treatment and behavioural conditions and issues. The health and social care networks should have a plan in place to find, search for and return persons with dementia who is lost or missing. The plan should also address the safety and protection of persons with dementia under emergency situations in the community.

Policies and procedures for finding missing persons should be developed (if new) or updated and expanded (if existing) by the community.

Policies and procedures related to rescue operations and (natural) disaster-relief and emergencies shall incorporate due consideration to persons with dementia.

Policies and guidelines for infectious disease containment and mitigation during an infectious disease outbreak, including consideration and implementation of measures to establish communication, should be developed with due consideration for the needs of persons with dementia and their carers. Instead of simply interrupting communication with carers, families or close people, measures to establish communication should be considered and implemented. In considering whether to set up a register of persons with dementia, the community should balance the need of the person with dementia for control over their personal data versus their need for safety and protection.

The public health lessons from pandemics such as the COVID-19 pandemic, should be available and used to review policies and procedures in relation to pandemic planning containment and mitigation in relation to persons with dementia and their carers.

NOTE 3 For more information and guidance on supporting vulnerable persons in an emergency, see ISO 22395.

NOTE 4 Clause B.4 provides additional considerations regarding legal aspects surrounding the care for persons with dementia.

6.2.9 Prevention of decline associated with dementia

The community shall aim at strengthening prevention (see 3.13, Note 2 to entry) along the care continuum guided by the best available evidence known to the scientific and health communities.

6.3 Persons with dementia and the informal care system

6.3.1 General

Inclusion can be created by an integrated community network, which is based on the close, integrated, and seamless interaction with, support of, and inclusion of the persons with dementia, families, and carers.

Special consideration is given to the situation and needs of persons with dementia and carers as well as their functioning and symbiotic relations with each other and within the community.

NOTE Due to the nature of dementia and the associated functional, cognitive, and emotional impairments, informal carers from within the family network or the closer network or relationships (relative, friends, etc.) - who can provide care as much as possible within the familiar environment in which the person with dementia is situated – are often considered the ideal carers for persons with dementia. It is understood that these types of carers are not always available and might not be able to provide their support over the whole dementia lifecycle. In this case, carers who are associated more with the formal carers' sector can take on that role. They can also complement the support of more informal carers. Both formal and informal carers face similar challenges, have needs, need breaks/respite from caring, and can also themselves require care.

6.3.2 Supporting the informal care system

In a dementia-inclusive community, the informal care system [including extended family or significant other(s)] shall be enabled and supported.

6.3.3 Assessment of the carers

Family members or friends who are identified by the person with dementia, or in some situations identify themselves, as carers, should be engaged and assessed for areas of need, both practical and emotional, such as their motivations, areas of concerns, moods, knowledge, skills, physical health, social support and financial needs.

Assessment of wellbeing for carers related to their roles as carers should be available. Support, help, and care to carers should be offered according to the assessment. Assessment should be ongoing as the roles change and the level of caring increases.

6.3.4 Carer education, training, and coaching

Depending on the stage of the progression of dementia and their specific roles, carers – both formal and informal – shall be educated, trained, and coached. The focus shall be on the motivation and empowerment of informal carers enabling them to understand their own needs and that of the person with dementia.

In this context, the carers shall have the following, basic information regarding:

— the diagnosis, the stage and trajectory of the progression;

— understanding and communicating with persons with dementia, for example responding to behaviours;

— meaningful activities to engage persons with dementia;

— physical caregiving skills, ranging from activities of daily living assistance to simple nursing technique and health monitoring;

— care resources and services available;

— options of available long-term care settings (such as home-based, centre-based and residential) as well as respite services;

— emergency and urgent support during health or care crises;

— local health and social care systems;

— information on assistive products, assistive technology and accessibility solutions;

— signs of burnout or emotional stress of carers.

In this context, they should have the following, extended information regarding:

— relevant technology;

— treatment and care plan by the formal care team;

— medications and their side effects;

— policies and necessary legal provisions such as those related to advance care planning, vulnerable adult protection and proxy decision-making;

— financial education and advice related to caregiving and long-term care;

— communal emergency plan taking into account unique processes and scenarios to safeguard persons with dementia and their carers;

— signs of abuse, including financial abuse or neglect.

6.3.5 Self-care of the informal carers

Requirements:

— All carers shall be supported to continue enjoying their familiar social support from their family members and friends, as well as hobbies and personal interest areas, and work experience.

NOTE 1 For more information and guidance on carer-inclusive organization, see ISO 25551.

Recommendations:

— carers should be actively engaged and guided to access the following:

  1) health and social care services and information on health promotion and prevention;

  2) counselling services or psycho-emotional support;

  3) education and training on self-care customized to their needs;

  4) respite services and/or a break from caregiving responsibilities;

  5) financial counselling and aids for their own future income and financial security;

  6) legal advice and services related to their rights as carers.

— for working carers, their caregiving roles should be supported by their employers, for example through flexible work arrangements, family-care leave;

NOTE 2 For more information and guidance on ageing workforce and carer-inclusive organization see ISO 25550 and ISO 25551.

— carers should also be guided on preparation for their own future in the event when the persons they care for no longer need their care. For this, apart from continuing familiar social relationship, hobbies and interest, carers should be guided and coached to access courses and skills training to enrich themselves and prepare for future employability and employment or retirement.

7 Action areas: community sectors working towards a dementia-inclusive community

7.1 General

To create a dementia-inclusive community, there are several community sectors where actions can be taken to meet the physical, psychological and social needs of persons with dementia. Actions to be taken can be inferred and specified by the community based on the requirements set out through the guiding principles (see Clause 5) and the integrated community network (see Clause 6). The process of associating these requirements with the action areas and systematically improving over time is provided in Clause 4.

Types of action areas:

— housing (see 7.4);

— public space (see 7.5);

— public transport (see 7.6);

— businesses, shops, financial institutions, products and services (see 7.7);

— infrastructure (7.8);

— leisure, recreation and social activities (see 7.9);

— health and social care networks (see 7.10);

— community, voluntary, faith groups and organizations (see 7.11);

— children, young people, and students (see 7.12);

— additional community sectors specific to the target community (see 7.13).

People, places, and processes are key elements of any service, system or community sector in any community. People lie at the heart of what it means to be dementia-inclusive. Dementia-inclusive communities can consider from the viewpoint of a person with dementia how ‘people’, ‘place’ and ‘process’ empower, include and support them.

— Regarding people, considerations include how we think about dementia, interact, communicate and support persons with dementia, their families and carers, and take actions to ensure they are respected and included in community life.

— Concerning place, considerations include how physical spaces are made easy to navigate and accessible for people with dementia, with due consideration to their neurocognitive functions. Attention is paid to aspects of an environment that can either help or create obstacles to persons with dementia so that good design of spaces, with adherence to universal design principles can be instituted to enable persons with dementia to stay connected and included in the community and enjoy a safe and meaningful interaction with community life.

— Processes, such as systems, organizations and infrastructures are essential to consider as these can help enable or can create barriers to ensuring people and places are successful in supporting persons with dementia.

People, place, and process can be different depending on the context, such as a rural compared to an urban community. In a rural community, its strengths can consist of a small network of people and fewer places to coordinate. In an urban community, there can be more resources available, however deciding where to begin and how many stakeholders to engage can be more involved. Regardless of the setting, each dementia-inclusive community is unique, and its aim is to support persons with dementia within its boundaries. Keeping the focus on persons with dementia as the primary drivers of where change needs to happen is the key to being a successful dementia-inclusive community.

Community planning processes are considered as the key to developing a dementia-inclusive society, and challenges related to cognitive impairment shall be considered in these processes. It is also a requisite to collaborate across sectors, where professionals with expertise in dementia are included in the planning processes.

Communities should connect with other inclusive community initiatives to pool resources and ensure strategies are complementary and sustainable and seek common ground to develop a universal approach to inclusion.

7.2 Action areas to address

In accordance with 4.2, communities shall associate the guiding principles in Clause 5 and the specifications of Clause 6 with the action areas delineated in this clause.

In this context the community in question shall:

a) select the types of action areas (housing, infrastructure, etc.) to be addressed when starting the process of developing a dementia-inclusive community;

NOTE 1 In order to maintain resource efficiency, the community can build on the existing strengths and assets and start with those action areas that already contain elements of dementia-inclusiveness as indicated in this document.

b) implement the applicable requirements set out in Clause 5 and Clause 6 in a community-specific manner regarding the selected action areas. Therefore, in 7.4 to 7.11, no additional requirements are provided, only a general description of the scope of the action area to be followed;

NOTE 2 A listing of possible considerations when implementing, the requirements set out in Clauses 6 and 7 in a community-specific manner against selected action areas, is provided in Annex A.

c) be able to clearly distinguish, define, and describe the selected action areas, such as their scope, organizations, and stakeholders.

NOTE 3 The community can review, evaluate, and refine the addressed action areas and/or add additional action areas after the completion of each run through the process phases defined in 4.2.

7.3 Integration between action areas

As cross-sectorial cooperation is important in creating dementia-inclusive communities, action areas shall not be treated as independent silos. An integrated community network shall be built based on the development and cross-integration of the applicable action areas. The community shall plan and implement actions that work towards this goal when addressing the requirements per action areas as specified in 4.2.

The community shall ensure continuous improvement with regard to the integration of cross action areas (services, mobility, information flows, accessibility, etc.).

7.4 Housing

This action area covers community sub-sectors such as privately owned or rented homes, mainstream social housing, specialist or supported accommodations, extra care housing and care homes. The overall aim is to enable a person with dementia to have independent, accessible, inclusive, and non-discriminatory housing.

NOTE Non-discriminatory in this context means that the fact that a person has dementia does not affect the person's ability to rent or buy housing or to live in environments that support their independence and emotional well-being, their communities and family ties, and which reduce safety risks. Necessary adaptations in homes and other buildings where persons with dementia live can be made with respect to the needs, dignity, autonomy, and other rights of persons with dementia.

7.5 Public space

This action area covers the key outdoor public areas within a community such as streets, squares, public parks, public roads, footpaths, cycle routes, and outdoor amenity areas. In a dementia-inclusive community, these spaces are accessible, safe and easy to navigate to ensure involvement, participation, and engagement for a person with dementia. They have wayfinding and accessibility strategies including signage, landmarks, barrier-free routes, and accessible structural elements (e.g. ramps, handrails) and sensory elements (e.g. visual and auditory characteristics) to ensure a person with dementia can access their community and engage safely. Accessible, safe, and inclusive public space will also enable families, and carers who can be accompanying persons with dementia.

7.6 Public transport

This action area covers the community sub-sectors such as public transport facilities, stations, and stops along with public transport vehicles including buses, trams, trains, boats, ferries, and taxis. Safe, accessible, and inclusive public transport enables people with dementia, especially those who do not drive, to travel and access their community. Public transport is important for independence, autonomy, involvement, participation, and engagement. Accessible, safe, and inclusive public transport will also enable families, and carers who can be accompanying persons with dementia.

7.7 Businesses, shops, financial institutions, products, and services

This action area covers community sub-sectors such as businesses, workplaces, shops, financial institutions (e.g. banks), and any area of the community that is involved in the development and provision of products and services. Design and accessibility of these sub-sectors is fundamental to creating a successful dementia-inclusive community.

In a dementia-inclusive community, businesses that provide services should refer to ISO 22458[1)] and should ensure the services are accessible and usable for persons with dementia.

7.8 Infrastructure

This action area covers community sub-sectors such as services, communications, and digital infrastructure. Infrastructure is a fundamental aspect of social engagement and independence for persons with dementia.

7.9 Leisure, recreation, and social activities

This action area covers community sub-sectors such as leisure, recreation and wellness, and social activities and services. In a dementia-inclusive community, significant and meaningful activity specifically intended for individuals and groups of persons with dementia are identified, developed, and maintained, with recognition of how other activities can be adjusted to support persons with dementia. Services such as libraries, museums, theatres, music, and dance halls provide opportunities

1) Under preparation. Stage at the time of publication: ISO/FDIS 22458:2021.

for persons with dementia who have either never visited before or lost the confidence to visit them. They offer ideas, support, and culture in a local venue.

7.10 Health and social care network

This action area covers community sub-sectors such as the health, medical, care, and social care network, facilities, people, and services where health issues beyond dementia can be actively evaluated. Persons with dementia need the same access to health services as the rest of the population.

7.11 Community, voluntary, faith groups and organizations

This action area covers interaction with all community sub-sectors including but not limited to community, voluntary, faith groups and organizations. The community can engage and enable persons with dementia to volunteer their skills, their time, and their voice to causes meaningful to them. In addition, there can be opportunities for persons with dementia to engage in lifelong learning to achieve their potential.

7.12 Children, young people, and students

This action area covers community sub-sectors related to areas such as children, young people, and students. To create a dementia-inclusive generation and encourage understanding and solidarity, nursery schools, schools, colleges, universities, and youth groups are encouraged to include dementia awareness in the classroom, lecture hall or through relevant activities. Active involvement between young people and persons with dementia will foster understanding, inclusion and can be beneficial to both. Children and young people -engaging with persons' with dementia should be monitored and supported by their local community, and should have access to an emergency call system, or similar, in case of urgent situations.

7.13 Additional community sectors specific to the target community

Users can apply the action areas approach to further, specific sub-sectors relevant to the target community that the community can distinguish and define clearly.

Annex A
(informative)

Action areas – Possible considerations when implementing requirements

A.1 General

The following considerations can guide the community regarding the implementation of the requirements (set out in Clauses 5 and 6) in the action areas.

A.2 Housing – possible considerations

— People; considerations can include:

  a) housing officers, scheme managers and support workers can support persons with dementia and their carers to live well and where appropriate, in coordination with health and social care providers and police, fire and rescue officers.

— Places; considerations can include:

  a) design of new housing schemes to be dementia-inclusive and meet general and cognitive accessibility and usability criteria for persons with dementia.

— Processes; considerations can include:

  a) adaptations, built environment and design; special consideration of fire-safety features;

  b) assistive technologies and products (including telecare) and active assisted living systems;

  c) training of all staff in the housing sector appropriate to the settings in which they work and their roles.

A.3 Business, financial institutions, shops, products, and services – possible considerations

— People; considerations can include:

  a) businesses, colleagues at work, shop owners, financial institutions, and service providers provide appropriate awareness and education to customer-facing staff. This can include but is not limited to:

    — information about how dementia affects people;

    — not accepting aggressive marketing and agreeing on responsibility issues for the person with dementia;

    — advice on customer service skills including offering understanding and reassurance, communicating clearly and being aware of the environment;

    — advice on how to help persons with dementia with practical support;

    — tips and suggestions to manage with a difficult situation.

— Places; considerations can include:

a) adaptations to the space to help aid the accessibility and independence of persons with dementia.

— Process; considerations can include:

a) the support of employees who are persons with dementia or carers, businesses, shop owners, financial institutions, and service providers to ensure they are recognized dementia-inclusive, carer-inclusive organizations;

b) the work environment can be adapted to support independent working of persons with dementia.

A.4 Infrastructure – possible considerations

— People; considerations can include:

a) customer-service employees are trained to be dementia-inclusive. Persons with dementia are encouraged to carry assistance cards, as well as identification and carer's emergency contact details;

b) emergency services staff receive familiarization and training to a level appropriate to their role, to ensure:

— appropriate communication with persons with dementia and their family carer;

— understanding of any risks which they can reduce or remove in conjunction with the individual, specific to their area of expertise for example, fire risk.

— Places; considerations can include:

a) signage is clearly visible, understandable and uses bright primary contrasting colours with recognisable pictures to reinforce location. Maps and guides are easy to read and navigate;

b) accessible alternatives to bus and train transport in all areas, including areas where public transport services do not exist, consider volunteers as drivers and services such as dementia-inclusive taxi services;

— Processes; considerations can include:

a) road infrastructure and community transport, which are fundamental aspects of social engagement and independence for persons with dementia;

b) infrastructure elements such as airports including persons with dementia in disability policies and consideration given to all sectors within an airport where knowledge of dementia can be useful such as information desks, security, airlines, baggage claim and retail.

A.5 Leisure – possible considerations

— People; considerations can include:

a) staff working in arts, culture, leisure and recreation services such as leisure centres, libraries, adult education, and contact centres are trained to be dementia-inclusive, are made aware of the range of services that are available and provide information about what help is available and how to access it;

b) services can be easily adapted and sports clubs such as bowls, tennis, swimming, golf, and cricket can be inclusive of persons with dementia to help people maintain an active lifestyle.

— Places, considerations can include:

a) arts, cultural education, peer support groups, art therapy and appreciation, and reminiscence and recreation are offered;

b) venues, wherever reasonably possible, remove or reduce physical, sensory, or attitudinal barriers so that all aspects of spaces and activities are as accessible as possible for all visitors including persons with dementia, families, and carers;

c) exercise and physical activity can bring many benefits for persons with dementia.

— Processes; considerations can include:

a) inclusion and participation by persons with dementia in the general community with and without their carers;

b) opportunities for carers to socialize with and without the person with dementia;

A.6 Health and social care network – possible considerations

— People; considerations can include:

a) leaders within this action area ensure the following:

— all health and social care staff, including but not limited to, general practitioners and medical specialists, nurses and health visitors, social workers, care workers, qualified healthcare professionals and support staff have training in dementia care, with more appropriate further training for staff working directly with persons with dementia;

— all health and social care staff provide support to family members and carers of persons with dementia;

— all health and social care staff liaise with appropriate sectors such as fire and police.

— Places; considerations can include:

a) leaders within health and social care services consider how the physical environment can be made more dementia-inclusive.

— Processes; considerations can include:

a) health promotion and disease prevention;

b) ensuring timely diagnosis of dementia, comorbidities, and health issues;

c) guiding, connecting, providing and directing persons with dementia and their carers to appropriate and available post-diagnosis support, including personalized information to help them understand and manage their condition;

d) dementia professionals educate, train, and guide general community, authorities, business and institutions about dementia.

A.7 Community, voluntary, faith groups and organizations – possible considerations

— People; considerations can include:

a) community, voluntary, and faith organizations consider raising awareness about dementia among their staff, users, volunteers, congregations, and members, with a focus on the active inclusion and participation of persons with dementia.

— Places; considerations can include:

a) community, voluntary, faith groups and organizations consider ways to make the physical environment where their activities take place as accessible and inclusive as possible for persons with dementia;

b) community, voluntary, and faith organizations consider having policies and practices that are inclusive of persons with dementia, and carers, such as:

   — reaching out to welcome persons with dementia and their carers in all activities;

   — activities that are sensitive to the needs of persons with dementia, such as participation without the over-stimulation of crowds, or other alternative opportunities where appropriate, that allow persons with dementia to participate in a quieter environment;

   — home visits to persons with dementia, where appropriate, so activities can be maintained;

   — the recognition of carer stress so that help and support can be provided;

   — referrals for supportive services.

— Processes; considerations can include:

a) community, voluntary, faith groups and organizations can consider ways of demonstrating:

   — seeing the person and not the dementia, recognizing the personhood, rights;

   — and citizenship of people first and foremost;

   — recognition of the person's sources of identity;

   — the meaningful involvement of persons with dementia in the governance, management and key decision-making processes of the organization, where people with other health conditions and disabilities are involved in these activities;

   — a raised awareness about dementia among their staff, users, volunteers, congregations and members, with a focus on the active inclusion and participation of people with dementia;

b) community, voluntary, faith groups and organizations consider providing services such as volunteer visitors, drivers, respite, and peer support programmes and dementia cafes for persons with dementia and their carers;

c) volunteer roles for persons with dementia can be provided and adapted to their needs and abilities.

A.8 Children, young people, and students – possible considerations

— People; considerations can include:

a) young people are encouraged to have a better understanding of dementia and how it affects a person. They are encouraged to get involved in supporting persons with dementia, through raising awareness for dementia in their community, interactions with persons with dementia in youth groups, school programmes, volunteering, and intergenerational projects.

— Places; considerations can include:

a) young people are made aware of how the environment affects persons with dementia and compensate by having conversations with persons with dementia in quiet places with few distractions and minimizing chaotic environments.

— Processes; considerations can include:

a) schools and colleges encourage teachers to include dementia within the curriculum.

Annex B
(informative)

Possible further considerations

B.1 General

The following considerations can guide the community regarding the implementation of aspects that go beyond the requirements and recommendations specified in Clauses 5, 6, and 7.

B.2 Personalisation and care in the dementia-inclusive community

Persons with dementia require person-centred engagement, support, and care. The aim of this document is to increase the autonomy and inclusion of persons with dementia in their community and in environments familiar to them. It is understood that measures need to be taken that ensure that person-centred care is achieved in a systematic and sustainable manner.

The community can analyse and determine:

— in what areas and with what means it achieves person and family-centred care for persons with dementia;

— in what areas and with what means it achieves systematisation and efficiency.

In this context, the community can:

— link up with and incorporate research and development;

— obtain, maintain, and increase data about the community, the persons with dementia, and their carers to use them as the basis for designing a system that can bridge the gap. Establish which data needs to be obtained, processed, and maintained in line with relevant data protection regulations and requirements;

— continuously analyse and assess the potential of assistive technology, assistive products, and active assisted living to help to bridge the gap;

NOTE CWA 17502[35] provides guidance on how to achieve balance between the risk of implementing an assistive product such as monitoring solutions versus potential benefits as part of decision-making and implementation processes.

— facilitate the use of technology to ensure safety and security for persons with dementia, and carers;

— facilitate the development and use of approaches, services, available technologies, supports and other measures for prevention and their consequences for persons with dementia, and carers;

— consider cost benefits and impact analysis.

B.3 Consider innovation- and technology-based approaches

In the context of providing enabling factors, dementia-inclusive communities can consider innovation and technology-based approaches such as active assisted living services, assistive products, and assistive technology.

NOTE Assistive products considered under the umbrella term active assisted living can, when well designed and integrated, facilitate autonomy, independence, and engagement of persons with dementia. In particular in the home and family environment, they can provide relief and support to the carers. Implemented in the right way, these systems can also help to bridge the gap between the need for person-centred approaches and the need for efficiency and standardisation. IEC System Committee for Active Assisted Living (IEC SyC AAL)[40] produces documents and International Standards that can provide guidance in this context.

B.4 Legal aspects surrounding the care for persons with dementia

Procedures for managing legal aspects surrounding the care for persons with dementia can be set up. Financial and legal issues are important, particularly before decision-making capacity is diminished to ensure that care and financial decisions are made by someone that the person with dementia trusts. Important legal documents can include:

— Power of attorney (or equivalent) which enables a trusted third party to manage the person with dementia's financial affairs and healthcare decisions;

— will;

— do not resuscitate order/advance care directive (or equivalent);

— final wishes that are important to the person with dementia shall also be recognized such as preferred living situation, long-term care plans, care for a pet and even funeral arrangements need to be made while the person with dementia still has decision-making capacity.

The rights to personal data and privacy can be protected.

A person with dementia's right to make their own decisions should be recognized and facilitated with support as necessary.

Annex C
(informative)

Stages of dementia and their implications on action areas of the dementia-inclusive community

A dementia-inclusive community recognizes and caters to the changing needs of a person with dementia as the neurodegenerative condition deteriorates over the years. It is essential to have a system describing such deterioration so that provisions can be made to support persons with dementia across the life cycle. There are many staging systems for dementia. One of the most used staging systems is the Global Deterioration Scale.[1] This scale differentiates dementia, particularly, Alzheimer's Disease, into seven detailed stages, as the condition progresses.

Table C.1 gives guidance on how the action areas can be associated with stages of the progression of dementia. Both classifications (stages, action areas) cannot always be determined accurately and can vary with persons. Table C.2 provides examples for action areas associated with stages of the progression of dementia.

Table C.1 — Template: Action areas relevant for persons at different stages of the progression of dementia

GDS - Global deterioration scale	Action areas							
	Housing	**Business, financial institutions, shops, products, and services**	**Infrastructure**	**Leisure**	**Health and social care network**	**Community, voluntary, faith groups and organizations**	**Children, young people, and students**	**...**
1 No cognitive impairment	Persons at GDS 1 and 2 do not have cognitive impairments evident in clinical interviews.							
2 Subjective cognitive impairment								

Table C.1 *(continued)*

GDS - Global deterioration scale	Action areas							
	Housing	**Business, financial institutions, shops, products, and services**	**Infrastructure**	**Leisure**	**Health and social care network**	**Community, voluntary, faith groups and organizations**	**Children, young people, and students**	**...**
3 Mild cognitive decline								
4 Mild dementia								
5 Moderate dementia								
6 Moderately severe dementia								
7 Severe dementia								

Table C.2 — Examples: Action areas relevant for persons at different stages of the progression of dementia

GDS - Global deterioration scale	Action areas							
	Housing	**Business, financial institutions, shops, products, and services**	**Infrastructure**	**Leisure**	**Health and social care network**	**Community, voluntary, faith groups and organizations**	**Children, young people, and students**	**...**
1 No cognitive impairment	Persons at GDS 1 and 2 do not have cognitive impairments evident in clinical interviews.							
2 Subjective cognitive impairment								

Table C.2 *(continued)*

GDS - Global deterioration scale	Action areas							
	Housing	**Business, financial institutions, shops, products, and services**	**Infrastructure**	**Leisure**	**Health and social care network**	**Community, voluntary, faith groups and organizations**	**Children, young people, and students**	**...**
3 Mild cognitive decline	Housing facilities and accompanying services should be inclusive not just for persons with mild dementia. They should also cater to the needs of carers (such as well-trained and supportive estate management staff) and persons with advanced dementia who are wheelchair or bed-bound.	The life course of dementia should be considered in business operations. For example, persons with milder stages of dementia can possibly be supported to work, while the needs of carers of persons with more advanced dementia should be catered for.	While outdoor infrastructures and related services are often designed with milder dementia in mind, they should be wheelchair accessible and carer-inclusive. The actions should also fit for the needs of persons with moderate to severe dementia and their carers.	Facilities and programmes for leisure, recreation and social activities should be accessible and inclusive according to the degree of cognitive and physical decline. In advanced stages, leisure activities will possibly need to be more sensory-stimulating than participatory, and be delivered to homes.	Services should be designed and delivered to persons across the whole life cycle of dementia. For example, milder stages can be expected to attend a dementia-inclusive ambulatory clinic or a day-centre, while severe stages require home-visits.	Facilities and programmes should cater to the range of needs across the dementia trajectory. While persons with GDS 3 and 4 can be engaged as volunteers, facilities should be accessible to those with more advanced dementia. For persons with severe dementia home-based programmes should be available.	Youths should be made aware of the needs of persons with dementia in different stages. They should be encouraged and trained to participate in inter-generational activities with persons with dementia in different stages. The information should be adapted to the specific abilities of the youths.	
4 Mild dementia								
5 Moderate dementia								
6 Moderately severe dementia								
7 Severe dementia								

Annex D
(informative)

Other frameworks available for consideration

This document focuses on high-level coordination tools. It does not provide examples, guidelines, and templates for lower-level implementation activities. Such tools, however, are very practical and can be useful in the context of developing, maintaining, and evolving a dementia-inclusive community. Examples of tools and toolkits listed below are for both methodologies and tools presented in this document as well as additional lower level, practical tools that complement the tools provided by this document.

Non-exhaustive example list of further useful tools and toolkits:

a. Dementia Friendly America ®; Community Toolkit; https://www.dfamerica.org/toolkit-getting-started

b. AARP Roadmap to Livability Collection; 6 workbooks with strategies and solutions that make a community great for people of all ages; https://www.aarp.org/livable-communities/tool-kits-resources/info-2017/roadmap-to-livability-collection.html

c. Creating Dementia-Friendly Communities: A toolkit for Local Governments; © 2016 Alzheimer's Australia Vic; ISBN 978-1-921570-76-6 (https://www.dementia.org.au/dementia-news/issue-11/dementia-friendly-communities)

d. REACH2020; Toolkit and resources for the integration of assistive technology into communities and care settings; https://cordis.europa.eu/project/rcn/200425/factsheet/en

e. The Alzheimer Café - A Guideline Manual for setting one up; original document entitled, 'Handleiding Alzheimer Café' by Bère Miesen and Marco Blom.

f. Canadian Academy of Health Sciences: Improving the quality of life and care of persons with dementia and their carers

g. Agenda of the Alliance for People with Dementia, Federal Ministry for Family Affairs and Federal Ministry of Health, Germany

h. National Plan to address Alzheimer's disease, U.S. Department of Health & Human Services

i. PAS 1365:2015; Code of practice for the recognition of dementia-friendly communities in England, UK

j. Five-Year Plan for promotion of Dementia Measures (Orange Plan), Japan

k. WHO World Health Organization Draft Global Action Plan on the Public Health Response to Dementia (A70/28, 03.04.2017)

l. Creating a Dementia-Friendly York (Joseph Rowntree Foundation) October 2012

m. Dementia Friendly Dwellings for People with Dementia, their Families and Carers: http://universaldesign.ie/Built-Environment/Housing/Dementia-Friendly-Dwellings/

Annex E
(informative)

Implementation and progress evaluation checklist

It is often useful to have a checklist that those leading and supporting a dementia-inclusive community can use as an aid. Table E.1 can be adopted to the particular plans of a dementia-inclusive community.

Table E.1 — Implementation and progress evaluation checklist

Action Areas utilizing the Plan Do Check Act (PDCA) cycle
Development of a dementia-inclusive Community
Recommendations
1. Build on and improve existing structures in the community, ensuring in particular the retention of community identity and an efficient and effective development process and use of resources. 2. Apply risk governance and management strategies to ensure that there is adequate risk-benefit assessment, and assurance that the benefits outweigh the risks when implementing elements of the dementia-inclusive community. 3. Communicate plans and progress to key stakeholders, persons with dementia, families, carers, and the public in a clear, transparent, and appropriate form, and provide updates at regular, planned intervals. 4. Identify, incorporate, and ensure cross-compatibility with other relevant standards that can have relevance regarding any stage or action of the process of creating a dementia-inclusive community. Do this systematically and throughout all process phases and iteration cycles. 5. Incorporate the understanding of dementia, types of dementia, epidemiological data about dementia in the community, and the progression of dementia into your process of development. 6. Use supported decision-making to involve persons with dementia and carers in the analysis process. 7. Analyse the potentials of involving or incorporating research and development. 8. Examine the possibilities of incorporating products and services considered under the umbrella term active assisted living. 9. Analyse physical, sensory and cognitive accessibility in the community, including built environment, transportation. 10. Define the vision and goals for the dementia-inclusive community. 11. Define measures to improve data and the use of active assisted living products and services. 12. Provide suitable and community-specific indicators that allow progress and performance evaluation. 13. Ensure continuity, sustainability and accountability of care and the equitable allocation of resources to sustain the development of the dementia-inclusive community over time. 14. Establish a structure to oversee the development of the dementia-inclusive community. This can include: a steering committee and an advisory committee; representatives of stakeholder organizations; persons with lived experience of dementia; persons caring for persons with dementia; cultural minorities. 15. Write an impact statement for the dementia-inclusive community.
Guiding principles: outcomes and enabling factors
Requirements
Awareness

Table E.1 *(continued)*

1. Raise the awareness and understanding of dementia among all members of the public across all sectors of the society. 2. Use a variety of communication methods, including the use of traditional and social media and well-coordinated marketing campaigns.
Recommendations
The Individual right to choose and control 1. Demonstrate efforts that can make persons with dementia feel included and involved. Accessibility and seamless integration 2. Make local facilities, particularly the built environment, activities, and services that persons with dementia are familiar with accessible and safe. 3. Make the social networks of persons with dementia accepting and understanding. Protection, safety, and safeguarding 4. Provide demonstrated means to improve security and prevent injuries to persons with dementia. 5. Provide safety instructions designed to be easily understood by persons with dementia. Lifecycle of dementia 6. Consider taking different approaches and measures in order to be inclusive to persons with dementia at all stages of dementia progression. Promotion of prevention strategies 7. Provide demonstrated efforts that preventative strategies are promoted at the forefront. Competence and skills 8. Establish an evidence base and identify the data required to develop and implement high-quality skills and competency development. 9. Make skill development opportunities accessible to both formal and informal carers through training organizations with expertise in dementia support. Sustainability 10. Provide demonstrated efforts to ensure sustainability of the dementia-inclusive community in all of the following terms economic sustainability, environmental sustainability, social sustainability. Involvement, participation, and engagement 11. Provide persons with dementia opportunities to be actively involved in decision-making processes about policies and programs, including those directly concerning them. 12. Engage persons with dementia or their carers in the development and delivery of training and education initiatives. Orientation and safety 13. Provide demonstrated efforts to facilitate persons with dementia finding their way around and be safe.
Integrated community: creating a dementia-inclusive network
Requirements
Develop statement of purpose 1. Develop a statement of purpose that reflects the dementia-inclusive vision of the community. Strengthen independent living by:

Table E.1 *(continued)*

2. Providing demonstrated efforts to support the dignity and autonomy of the person with dementia by focusing on their functional ability to support a meaningful life regardless of the progression of dementia.
3. Providing demonstrated efforts to ensure that public places and spaces are easily accessible and approachable, and accommodating to the needs of persons with dementia.
4. Empowering the person with dementia with meaningful information, explain it to them clearly, use principles and practices of supported decision-making and obtain consent before any care activities are rendered to the persons with dementia.
5. Before deciding on any procedure, care providers of persons in more advanced stages of the progression of dementia shall provide demonstrated efforts to know such persons thoroughly, such as their previously expressed decisions on care options, their values, family situation, religious and cultural beliefs, personal life history, occupation, hobbies, habits, and their social connections.
Strengthen family life by:
6. Supporting persons with dementia to live in a place of their choice as far as possible.
7. Supporting family members to manage and optimize their relationship with one another, especially with the person with dementia.
8. Providing family members with support and information such as education and training that help them acquire skills in understanding and communicating with persons with dementia.
Strengthen the social network by:
9. Supporting friends, neighbours, and other social connections to continue their engagement with the persons with dementia.
10. Supporting persons with dementia to continue to live within the community of their choice, with reasonable accessibility to their social network.
11. Providing opportunities and support for the persons with dementia to develop new caring social connections and networks, especially if there is a change in living environment.
12. Actively engage and support the social network to access information on dementia and acquire knowledge and training to better understand and communicate with persons with dementia.
13. Informing and empowering the social network to deal with problem areas such as social isolation, violence, abuse, neglect, and lack of emotional support.
Prevention
14. Develop a strategy that strengthens dementia prevention along the care continuum guided by the best available evidence known to the scientific and health communities.
Supporting the informal care system
15. Provide demonstrated efforts, such as policy and supportive schemes, to enable and support the informal care system including extended family or significant other(s).
Carer education, training, and coaching adjusted to the stage of progression of dementia
16. Enable carers both formal and informal – to get educated, trained, and coached.
17. In the education and training of carers, include the following information: the diagnosis, the stage and trajectory of the progression; understanding and communicating with persons with dementia, for example regarding managing behaviours; meaningful activities to engage persons with dementia; physical caregiving skills, ranging from activities of daily living assistance to simple nursing technique and health monitoring; care resources and services available; options of available long-term care settings (such as home-based, centre-based and residential) as well as respite services; emergency and urgent support during care crises; local healthcare system; information on assistive products, assistive technology and accessibility solutions; signs of burnout or emotional stress of carers.
18. Self-care of the informal carers by the development of policies and procedures to ensure that all carers are supported to continue enjoying their familiar social support from their family members and friends.
Recommendations
Strengthen independent living: for palliative care period

Table E.1 *(continued)*

1. Even when they are dying, support persons with dementia to live fully consistent with their expressed preference until death occurs.
Strengthen family life
2. The living environment should be supportive of family relationships.
3. The preferred lifestyle of persons with dementia should be respected such as decision whether to live with their family, or near to their family, or independent of their family.
4. The living arrangements can provide specialised care, but special precautions to address emergency situations such as pandemics, natural disasters should be considered.
Strengthen the social network
5. Make the physical environment of the community and places the persons with dementia frequently visit supportive of social bonds and relationships.
Create an integrated, comprehensive, and phased health and social care network
6. Make the health and social care authorities committed to develop an integrated care ecosystem that supports an individual in a person-centred, seamless, timely, effective, inclusive, equitable and sustainable manner.
7. Develop and create the community's own network of care, weaving the informal and formal care systems into one connected whole.
8. Make the care approaches person-centred.
9. Connect the care and care planning for a person with dementia to the stage of the progression of the condition.
10. Make efforts to avoid large institutions where people with dementia are secluded from society, and create smaller facilities, based within the community, adapted to the requirements of persons with dementia and their carers.
11. Promote both social inclusion and smaller groupings of individuals in the design of housing for persons with dementia.
12. Make home-based health and social services available for persons with dementia, specifically when the latter experience excessive stress leaving their homes.
13. Facilitate the design of workplaces that foster inclusion of persons with dementia.
14. Support persons with dementia to contribute to society, the community and family, such as being supported to continue to work according to the progression of the dementia and the nature of the work.
15. Make workplaces accessible, not only in the physical aspects, but also the cognitive requirements of the tasks the worker is expected to do.
16. Create awareness among employers and staff members across organizations of the needs of older workers and workers with dementia among all members of the workplace.
17. Inform and make organizations aware of the needs of workers who are balancing working with providing care to a person with dementia and provide supportive policies and programmes.
18. Provide counselling and facilitate planning for retirement.
Emergency, safety, and protection

Table E.1 *(continued)*

19. Include and acknowledge the principle of self-determination and the right to take reasonable risks as being essential for dignity and self-esteem when developing policies and planning for measures to enhance safety for persons with dementia.

20. Provide fire and emergency management planning, awareness, and practice in relation to persons with dementia, make the emergency plan familiar to all involved in providing care and review the plan on at least an annual basis.

21. Facilitate advance care planning by the person with dementia, in particularly the guidance on proxy decision-making.

22. Provide a policy for elder abuse and protection reflecting existing national and local elder abuse and protection policies and guidance that is made familiar to all involved in providing care.

23. Set up an elder abuse prevention and adult protection system.

24. Raise awareness and take steps to prevent persons with dementia from falling prey to scams, fraud and other crimes.

25. Train health, medical, care and social care and first responder professionals on dealing with persons with dementia.

26. Make a set of policies and procedures in place to find, search for and return persons with dementia who is lost or missing.

27. Address the safety and protection of persons with dementia under emergency situations in the community, including rescue operations and (natural) disaster-relief.

28. Create policies and guidelines for infectious disease containment and mitigation during an infectious disease outbreak, including consideration and implementation of measures to establish communication, developed with due consideration for the needs of persons with dementia and their carers.

29. Balance the need of the person with dementia for control over their personal data versus their need for safety and protection when considering whether to set up a register of persons with dementia.

Assessment of the carers

30. Engage and assess carers for areas of needs, both practical and emotional, such as their motivations, areas of concerns, moods, knowledge, skills, physical health, social support and financial needs.

31. Provide screening and assessment of the wellbeing for carers related to their roles as carer and support and help carers accordingly. Update it regularly as the roles change and the level of caring increases.

Carer education, training, and coaching

32. In the education and training of carers, include the following information:

    relevant technology; treatment and care plan by the formal care team; medications and their side effects; policies and necessary legal provisions such as those related to advance care planning, vulnerable adult protection and proxy decision-making; financial education and advice related to caregiving and long-term care; communal emergency plan taking into account unique processes and scenarios to safeguard persons with dementia and their carers; signs of abuse, including financial abuse or neglect.

Self-care of carers

33. Actively engage, guide, and provide carers access to the following:

    primary health care services and information on health promotion and prevention; counselling services or psycho-emotional support; education and training on self-care customized to their needs; respite services and/or a break from caregiving responsibilities; financial counselling and aids for their own future income and financial security; legal advice and services related to their rights as carers; for working carers, are their caregiving roles supported by their employers, for example through flexible work arrangements, family-care leave.

34. Guide carers on preparation for their own future in the event when the persons they care for no longer need their care. Apart from continuing familiar social relationship, hobbies and interest, guide and coach and provide carers access to courses and skills training to enrich themselves and prepare for future employability and employment or retirement.

Bibliography

General documents

[1] Reisberg B., Ferris S. H., de Leon M. J., Crook T., The Global Deterioration Scale for assessment of primary degenerative dementia, The American journal of psychiatry, pp. 1136 – 1139, 1982.

[2] Pollock A., Marshall M. Designing Outdoor Spaces for People with Dementia. *Dementia Services Development Centr*e, 2012.

[3] Delhanty T. Housing Learning & Improvement Network. Landscape design for dementia care. Factsheet 35. *Housing LIN*, 2013. https://www.housinglin.org.uk/_assets/Resources/Housing/Support_materials/Factsheets/HLIN_Factsheet35_Landscape.pdf

[4] Chalfont G., Walker A. Dementia Green Care Handbook of Therapeutic Design and Practice. *Chalfont Design*, 2013. https://www.housinglin.org.uk/_assets/Resources/Housing/OtherOrganisation/Dementia_Green_Care_Handbook.pdf

[5] Marquardt G., Schmieg P., Dementia-friendly architecture: environments that facilitate wayfinding in nursing homes, American Journal of Alzheimer's Disease & Other Dementias, 2009, **24**(4). https://journals.sagepub.com/doi/pdf/10.1177/1533317509334959

[6] Improving the design of housing to assist people with dementia, *Dementia Services Development Centre*, 2013. https://www.housinglin.org.uk/_assets/Resources/Housing/OtherOrganisation/DSDC_dementia_design.pdf

[7] Dietz B., Demenzsensible Architektur: Planen und Gestalten für alle Sinne. Fraunhofer IRB Verlag, 2018.

[8] Turpie S., Dementia Friendly Housing: an architect's perspective, 8 November 2017, retrieved 23 August 2019, https://dementia.stir.ac.uk/blogs/dementia-centred/2017-11-08/dementia-friendly-housing-architects-perspective (2019/01/07).

[9] Burton E., Mitchell L., Inclusive Urban Design. Streets For Life. 1st edition, Routledge, 2006.

[10] A toolkit for the provision of personalised health care (PHC), REACH2020 (Responsive Engagement of the elderly promoting Activity and Customised Health Care); this project has received funding from European Union's Horizon 2020 research and innovation programme under *grant agreement No 690425.*

[11] Jamil A., Sharjeel K., Reisberg B. et al. *Staging Dementia, Principles and Practice of Geriatric Psychiatry (3), pp. 162 – 169.*

[12] A Standards Roadmap for the Silver Industry, SPRING Singapore Standards Division, 2018.

[13] Five-Year Plan for promotion of Dementia Measures (Orange Plan), Japan, 2012.

[14] Alliance for People with Dementia, Report on the Implementation of the Agenda of the Alliance for People with Dementia 2014-2018; Federal Ministry for Family Affairs and Federal Ministry of Health, Germany, 2019. https://www.bmfsfj.de/resource/blob/132340/11d16360baefc5da0ecc737153162610/die-allianz-fuer-menschen-mit-demenz-kurzbericht-englisch-data.pdf

[15] Demenzstrategie B., (English: Bavarian State Dementia Strategy), Bavarian State Ministry for Health and Care, 2013. https://www.stmgp.bayern.de/wp-content/uploads/2015/10/demenzstrategie_langfassung_neu.pdf

[16] Blom M., Alzheimer Cafés in the Netherlands: Growth, support and structure; 'Alzheimer Café UK' conference, Ascot, 2010. http://www.alzheimercafe.co.uk/Media/ACUK_14May2010_MarcoBlom.pdf

[17] National Plan to address Alzheimer's disease: 2017 update, U.S. Department of Health & Human Services, ASPE. https://aspe.hhs.gov/system/files/pdf/257526/NatlPlan2017.pdf

[18] Dementia Friendly America ® (REGISTRANT) Dementia Friendly America c/o National Association of Area Agencies on Aging (n4a) UNINCORPORATED ASSOCIATION MINNESOTA 1730 Rhode Island Avenue, NW, Suite 120 Washington D.C. 20036; Community Toolkit. 2018, https://www.dfamerica.org/toolkit-getting-started (2019/01/07).

[19] Roadmap to Livability Collection, 6 workbooks with strategies and solutions that make a community great for people of all ages, AARP Livable Communities, 2018, https://www.aarp.org/livable-communities/tool-kits-resources/info-2017/roadmap-to-livability-collection.html. (2019/01/07).

[20] Creating Dementia-Friendly Communities, A toolkit for Local Governments. Alzheimer's Australia, 2016, https://www.dementia.org.au/files/NATIONAL/documents/Dementia-friendly-communities-toolkit-for-local-government.pdf (2019/01/07).

[21] Canadian Academy of Health Sciences, Improving the quality of life and care of persons living with dementia and their carers. Ottawa (ON): The Expert Panel on Dementia Care in Canada, CAHS, 2019. https://cahs-acss.ca/wp-content/uploads/2019/04/REPORT.pdf

[22] Spotlight on Ontario's carers. Report by The Change Foundation, Canada, 2018.

[23] A Profile of Family Carers, Report by The Change Foundation, Canada, 2018.

[24] PAS 1365:2015; *Code of practice for the recognition of dementia-friendly communities in England, UK, 2015*. [2)]

[25] Communities Dementia Friendly, Global developments, 2nd Edition, Alzheimer's Disease International, 2017. https://www.alzint.org/u/dfc-developments.pdf

[26] The Global Network for Age-friendly Cities and Communities, WHO, 2018.

[27] Measuring the age-friendliness of cities. A guide to using core indicators. WHO, 2015. https://apps.who.int/iris/bitstream/handle/10665/203830/9789241509695_eng.pdf;sequence=1

[28] World Report on Ageing and Health, WHO, 2015. https://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf?sequence=1&isAllowed=y

[29] Convention on the rights of Persons with Disabilities (CRPD), United Nations.

[30] Report on the Evolution of the Blueprint on Digital Transformation of Health and Care for the Ageing Society, 2018, https://ec.europa.eu/eip/ageing/sites/eipaha/files/news/we4aha_blueprint_update_publishable_version_december_2019.pdf

[31] ICF WHO, International Classification of Functioning. Disability and Health, Geneva, 2001.

[32] WHO News release: Dementia cases set to triple by 2050 but still largely ignored, 11 April 2012, https://www.who.int/news/item/11-04-2012-dementia-cases-set-to-triple-by-2050-but-still-largely-ignored (2019/01/07).

[33] A Dementia Strategy for Canada, Her Majesty the Queen in Right of Canada, as represented by the Minister of Health, 2019. https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html

[34] Global action plan on the public health response to dementia 2017 – 2025, World Health Organisation, 2015. https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf?sequence=1

2) https://shop.bsigroup.com/products/code-of-practice-for-the-recognition-of-dementia-friendly-communities-in-england/standard

[35] CWA 17502, *Privacy of monitoring technology — Guidelines for introducing ambient and wearable monitoring technologies balancing privacy protection against the need for oversight and care* [3)]

[36] Deming W.E., 1993.The New Economics. MIT Press. Cambridge, MA. page 135.

[37] ISO/IWA 18:2016, *Framework for integrated community-based life-long health and care services in aged societies*

[38] Alzheimer´s Disease International, Global Dementia Charter "I can live well with dementia", 2013.

[39] ACT ON DEMENTIA, EU funded project 2017 – 2020. Project goal: promote collaborative actions among EU Member States to improve the lives of people living with dementia and their carers. https://actondementia.eu

[40] IEC System Committee for Active Assisted Living (IEC SyC AAL), https://iectest.iec.ch/dyn/www/f?p=103:186:9421455892528::::FSP_ORG_ID:11827 (2020/11/04).

[41] ISO 9001:2015, *Quality management systems — Requirements*

[42] ISO 25550, *Ageing societies — Guidelines for an age-inclusive workforce*

[43] ISO 25551, *Ageing societies — General requirements and guidelines for carer-inclusive organizations*

[44] WHO Fact sheet elder abuse, 2021, https://www.who.int/news-room/fact-sheets/detail/elder-abuse

Assistive products

[45] ISO 9999:2016, *Assistive products for persons with disability — Classification and terminology*

[46] ISO 23599, *Assistive products for blind and vision-impaired persons — Tactile walking surface indicators*

[47] IEC 60050-871:2018, *International Electrotechnical Vocabulary (IEV) - Part 871: Active assisted living (AAL)*

[48] ISO 21802, *Assistive products — Guidelines on cognitive accessibility — Daily time management*

Consumer products

[49] ISO/IEC Guide 37, *Instructions for use of products by consumers*

[50] ISO/IEC Guide 76, *Development of service standards — Recommendations for addressing consumer issues*

[51] ISO/TS 20282-2, *Usability of consumer products and products for public use — Part 2: Summative test method*

[52] ISO 22458, *Consumer vulnerability — Requirements and guidelines for the design and delivery of inclusive service*

Enabling factors

[53] ISO/TS 37151:2015, *Smart community infrastructures — Principles and requirements for performance metrics*

[54] ISO 24508, *Ergonomics — Accessible design — Guidelines for designing tactile symbols and characters*

[55] ISO 21801-1, *Cognitive accessibility — Part 1: General guidelines*

3) https://www.cencenelec.eu/media/CEN-CENELEC/CWAs/RI/cwa17502_2020.pdf

[56] ISO 9241-125, *Ergonomics of human-system interaction — Part 125: Guidance on visual presentation of information*

[57] ISO 16817, *Building environment design — Indoor environment — Design process for the visual environment*

[58] ISO 22322, *Societal security — Emergency management — Guidelines for public warning*

[59] ISO 22324, *Societal security — Emergency management — Guidelines for colour-coded alerts*

[60] ISO 19029, *Accessible design — Auditory guiding signals in public facilities*

[61] ISO 19028, *Accessible design — Information contents, figuration and display methods of tactile guide maps*

[62] ISO 19026, *Accessible design — Shape and colour of a flushing button and a call button, and their arrangement with a paper dispenser installed on the wall in public restroom*

[63] ISO 8201, *Alarm systems — Audible emergency evacuation signal — Requirements*

[64] ISO 21542, *Building construction — Accessibility and usability of the built environment*

[65] EN 17210, *Accessibility and usability of the built environment — Functional requirements*

[66] CEN/TR 17622, *Accessibility and usability of the built environment — Technical performance criteria and specifications*

[67] EN 17161, *Design for All — Accessibility following a Design for All approach in products, goods and services — Extending the range of users*

[68] ISO 24504, *Ergonomics — Accessible design — Sound pressure levels of spoken announcements for products and public address systems*

[69] ISO 7731, *Ergonomics — Danger signals for public and work areas — Auditory danger signals*

[70] ISO 1503, *Spatial orientation and direction of movement — Ergonomic requirements*

[71] ISO 28802, *Ergonomics of the physical environment — Assessment of environments by means of an environmental survey involving physical measurements of the environment and subjective responses of people*

[72] ISO 11429, *Ergonomics — System of auditory and visual danger and information signals*

[73] ISO 17049, *Accessible design — Application of braille on signage, equipment and appliances*

[74] ISO 9386-2, *Power-operated lifting platforms for persons with impaired mobility — Rules for safety, dimensions and functional operation — Part 2: Powered stairlifts for seated, standing and wheelchair users moving in an inclined plane*

General topics

[75] ISO 9000:2015, *Quality management systems — Fundamentals and vocabulary*

[76] ISO/IEC/TR 29194, *Information Technology — Biometrics — Guide on designing accessible and inclusive biometric systems*

[77] ISO 9241-220, *Ergonomics of human-system interaction — Part 220: Processes for enabling, executing and assessing human-centred design within organizations*

[78] ISO 27501, *The human-centred organization — Guidance for managers*

[79] ISO/IEC Guide 71:2014, *Guide for addressing accessibility in standards*

[80] ISO/IEC 29138-1, *Information technology — User interface accessibility — Part 1: User accessibility needs*

[81] ISO/IEC/TR 29138-3, *Information technology — Accessibility considerations for people with disabilities — Part 3: Guidance on user needs mapping*

[82] ISO/TR 22411, *Ergonomics data for use in the application of ISO/IEC Guide 71:2014*

[83] ISO 24505, *Ergonomics — Accessible design — Method for creating colour combinations taking account of age-related changes in human colour vision*

[84] ISO 9921, *Ergonomics — Assessment of speech communication*

[85] ISO 28803, *Ergonomics of the physical environment — Application of International Standards to people with special requirements*

[86] ISO 26800, *Ergonomics — General approach, principles and concepts*

[87] ISO 7000, *Graphical symbols for use on equipment — Registered symbols*

[88] ISO 7001, *Graphical symbols — Public information symbols*

[89] ISO 7010, *Graphical symbols — Safety colours and safety signs — Registered safety signs*

Information and Communication Technology (ICT)

[90] ISO/IEC/TR 29138-2, *Information technology — Accessibility considerations for people with disabilities — Part 2: Standards inventory*

[91] ISO 9241-112:2017, *Ergonomics of human-system interaction — Part 112: Principles for the presentation of information*

[92] ISO 9241-940, *Ergonomics of human-system interaction — Part 940: Evaluation of tactile and haptic interactions*

[93] ISO/IEC 24751-1, *Information technology — Individualized adaptability and accessibility in e-learning, education and training — Part 1: Framework and reference model*

[94] ISO/IEC 10779, *Information technology — Office equipment — Accessibility guidelines for older persons and persons with disabilities*

[95] ISO/IEC 24751-3, *Information technology — Individualized adaptability and accessibility in e-learning, education and training — Part 3: "Access for all" digital resource description*

[96] ISO 9241-20, *Ergonomics of human-system interaction — Part 20: An ergonomic approach to accessibility within the ISO 9241 series*

[97] ISO 24502, *Ergonomics — Accessible design — Specification of age-related luminance contrast for coloured light*

[98] ISO/IEC 40500, *Information technology — W3C Web Content Accessibility Guidelines (WCAG) 2.0*

Transport

[99] ISO 19132, *Geographic information — Location-based services — Reference model*

Emergency management

[100] ISO 22395, *Security and resilience — Community resilience — Guidelines for supporting vulnerable persons in an emergency*

ICS 11.020.10

Price based on 41 pages