

Policy **brief**

Dignity and non-discrimination for persons with dementia

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2012 Vienna Ministerial Declaration — Ensuring a society for all ages: Promoting quality of life and active ageing. In fostering the implementation of MIPAA/RIS in its third implementation cycle (2013-2017), UNECE member States “are committed to raising awareness about and enhancing the potential of older persons for the benefit of our societies and to increasing their quality of life by enabling their personal fulfilment in later years, as well as their participation in social and economic development.” (targeted in goal III: Dignity, health and independence in older age).

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Challenging context

Dementia is becoming increasingly prevalent across the UNECE region. The disease entails a progressive loss of cognitive capacity and eventual disability, which can result in deterioration of quality of life. Dementia has high social and financial costs, affecting people with dementia and their caregivers. People living with dementia are often discriminated against: their dignity is challenged today by many factors including the retrenchment of welfare resources, and the changing structure of families. The issue of dignity and non-discrimination of people with dementia has often been overlooked, however, due to their limited representation in public debates and the stronger focus of research and policy on issues such as welfare sustainability and the well-being of caregivers.

Suggested strategies

Dignity and non-discrimination of people with dementia can only be successfully ensured with a comprehensive approach encompassing all policy levels. This must include the macro level of laws and regulations in all relevant policy domains. NGOs and the media can play an important role in influencing public perceptions. Discrimination can be minimized by the community, which in turn can be supported by service users’

the active involvement of people with dementia in the organizations and dementia-friendly environments.

Appropriate care is vital in ensuring the dignity of people with dementia, who have often been considered more as ‘patients’ than persons. There is a need for a care paradigm that puts the person and his or her needs at the centre. Crucially, dignity is best maintained not by immediately directing all possible services and provisions at persons diagnosed with dementia, but rather by targeting services carefully to correspond to actual need while explicitly recognizing, and capitalizing upon, the capacities and wishes of the individual.

Timeliness and sensitivity of diagnoses, coordination of care services, access to palliative care, training of professionals, and systematic assessment of quality of care must be key components of any strategy. Support to informal caregivers is also fundamental. Finally, people with dementia have tended to be considered as ‘subjects’ of research and interventions; there is a need, therefore, to hear their voices and engage them as active participants.

Expected results

Ensuring the dignity and non-discrimination of people with dementia must be a comprehensive endeavour employing a multilevel strategy to coordinate the efforts of all stakeholders. By providing a systematic framework of possible intervention strategies, this policy brief offers a reference for policymakers aiming to address this issue in the UNECE region and beyond.

With good practice examples from:

Austria, Canada, Germany, Ireland, Italy, Malta, Norway, Serbia, Slovakia, Spain, Switzerland, United States of America.



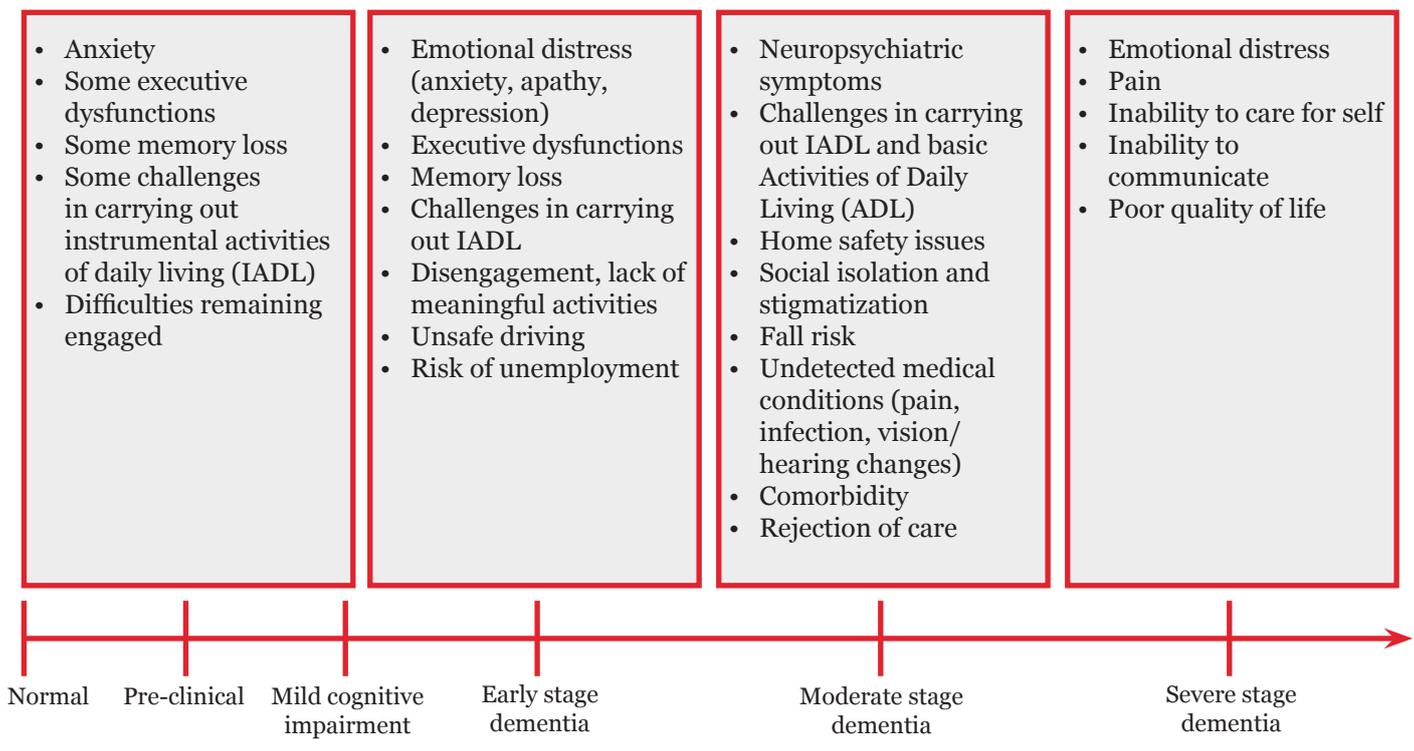
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Introduction

The global challenges of dementia

Dementia is a serious health condition, still without a cure, which by current estimates affects about 44 million people worldwide, with numbers of newly diagnosed cases on the rise. OECD evaluations suggest that 0.6 trillion US dollars are spent every year globally on dementia care.¹ Dementia affects not only those diagnosed with the disease but also their caregivers, who often have to reduce or stop their working activities and can themselves develop serious health conditions as consequence of care-related stress. Dementia is a long-lasting chronic condition. Persons with dementia can live 20 years or more after the diagnosis, experiencing gradual changes in their functional and clinical profile. Figure 1 illustrates the clinical course of dementia and how it can progressively affect individuals.

Figure 1
The stages and some possible consequences of dementia²



Ensuring the dignity of persons with dementia and their non-discrimination is an increasingly relevant policy issue. People with dementia are a growing population group who, as the disease progresses, may become strongly dependent on others and less autonomous in making their own choices. Dementia affects a person's ability to communicate with others and to express their needs, preferences and feelings. As a consequence of dementia, affected persons may change their own self-perception, leading to negative feelings, stigmatization, and even self-detrimental behaviours. The onset of behavioural disturbances and cognitive problems can lead to a deterioration of their social relations and role in the community. Nevertheless, depending on the stage of the disease and given a suitably supportive environment, people with

¹OECD, (2015).

²The figure is adapted from the work of Laura Gitlin and Nancy Hodgson, as illustrated in the course 'Living with Dementia: Impact on Individuals, Caregivers, Communities and Societies', available online at www.coursera.org. The term '**activities of daily living**' (ADL) refers to people's daily self-care activities such as functional mobility (moving from one place to another while performing activities), bathing and showering, dressing, self-feeding, personal hygiene and grooming (including brushing/combing/styling hair), toilet hygiene. '**Instrumental activities of daily living**' (IADL), in contrast, refers to those activities that are not necessary for fundamental functioning, but are needed to live independently in a community, such as housework; preparing meals, taking medications, managing money, shopping, use of telephone, using transport. 'Executive functions' is an umbrella term for cognitive processes which can be affected by the onset of dementia. These processes include working memory, reasoning, task flexibility, and problem-solving as well as planning and execution.

dementia may continue to exercise their remaining abilities and to participate in community life to the extent that their capacities permit. Yet in many countries, they are frequently denied this possibility, as well as their rights in general, as evidenced by the widespread use of physical and chemical restraints in home, institutional and hospital care settings.³

Defining dignity and discrimination

Coordination and effectiveness of strategies to safeguard dignity and avoid discrimination depend upon common and clear operational definitions to ensure shared understandings of the terms and to facilitate dissemination of good practices and knowledge transfer across countries.

Generally speaking, discrimination refers to the differential treatment (whether in favour of or against) of a person based on a group, class, or category to which she or he belongs. The concept of dignity, however, is a more complex construct, for which the appropriate definition is context-dependent. In this policy brief, dignity is defined as “*an inherent characteristic of being human, which can be felt as an attribute of the self, and is made manifest through behaviours that demonstrate respect for self and others*”.⁴ Dignity thus has an interpersonal nature, being built through relationships with others.⁵

Dignity is extremely pertinent to the topic of dementia, since the way in which affected people are treated by others influences their own experience of the disease. Maintaining dignity can sustain people with dementia through the challenges posed by the disease. Conversely, the denial of dignity can contribute to the decline of a person’s quality of life, autonomy, health and well-being. ‘Having dignity’ is a dynamic state⁶ – it is not something which one permanently has or does not have, but changes and is experienced to different degrees over time and across circumstances. This is especially true in cases of dementia since it is a progressive disease bringing continuous change in a person’s condition. Hence, ensuring the dignity of a person affected by dementia requires a comprehensive strategy with diverse measures and approaches depending on the stages of the disease, the living situation and the socioeconomic and health profile of a person.

Dignity violation, discrimination and risk of abuse

The issue of dignity and non-discrimination is closely tied to the topic of prevention of abuse of persons with dementia, be it physical, sexual, psychological, or financial or in the form of abandonment and neglect.⁷ UNECE policy brief No.14 ‘Abuse of Older Persons’⁸ focused on this issue, discussing how negative stereotypes about older people may provide the basis for abusive situations. Likewise, as in the case of abuse, the risk of dignity violation and discrimination of persons with dementia is higher when they are viewed as an ‘object’ rather than ‘subject’.⁹

Factors influencing dignity and non-discrimination of persons with dementia

The socioecological model (SEM)¹⁰ shown in Figure 2 provides a systematic lens through which to view measures and interventions to ensure dignity and non-discrimination of persons with dementia. The model describes factors at different levels influencing the causes and the effects of the violation of dignity and discrimination of persons with dementia in society. At the centre of the model is the person her/himself, who is interacting with the surrounding physical, socioeconomic and cultural environments.

³ The 2010 Annual Report of Alzheimer Europe revealed a dramatic number of restrictions of the freedom of movement of people with dementia, which are contained in the existing legal provisions of 32 European States. These relate for instance to involuntary internment, the use of coercive measures, and restrictions relating to driving licences. For further details see: <http://alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/Restrictions-of-freedom>

⁴ Jacelon and others, (2004).

⁵ Street and Kissane, (2001).

⁶ Jacelon, (2003).

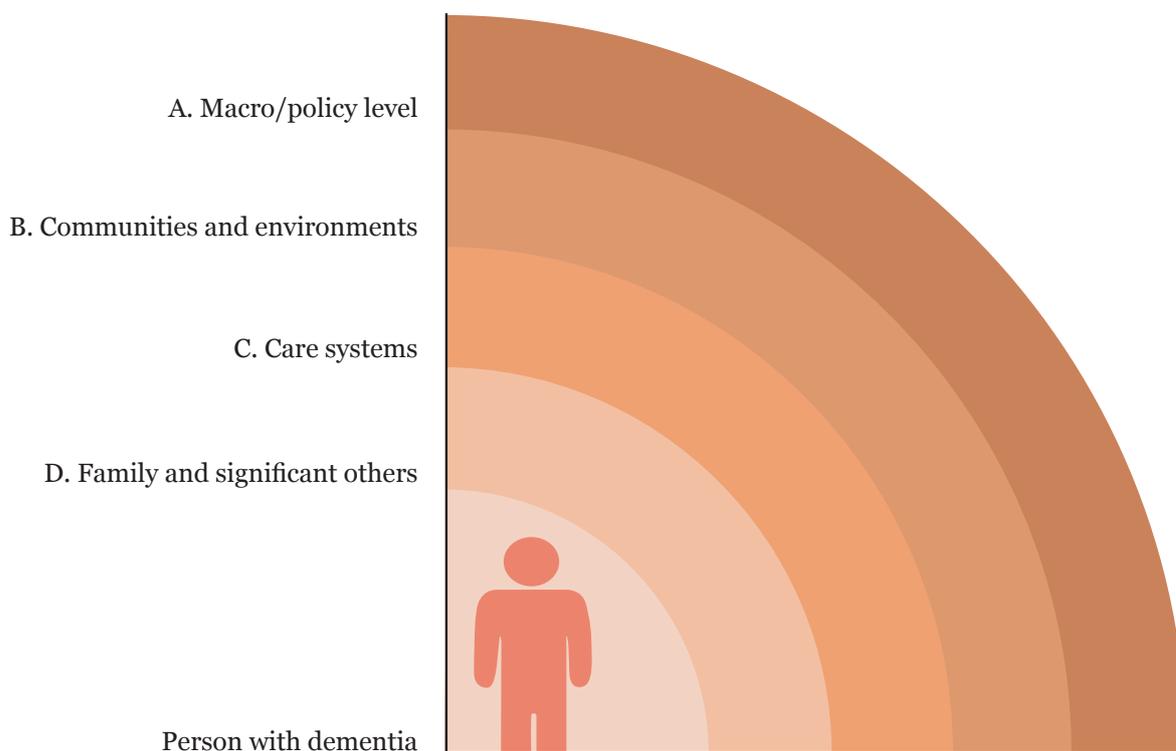
⁷ Melchiorre and others, (2013).

⁸ UNECE, (2013).

⁹ Applegate and Morse, (1994).

¹⁰ The model has been developed for the purpose of this policy brief but is inspired to a large extent by the experiences of health promotion policy, see for example <http://www.cdc.gov/cancer/crcp/sem.htm>

Figure 2
The socioecological model: levels of factors influencing dignity and non-discrimination of persons with dementia



The four levels identified by the SEM – (a) the macro/policy level, (b) the community and environment level, (c) the care systems and (d) the family and significant others – are interrelated. Indeed although they are represented as distinct levels for the sake of simplicity and to permit consideration of each level in this policy brief, it should be borne in mind that in reality they form a continuum with blurred boundaries and overlapping components.

A. Dignity and non-discrimination in all policies

Dignity and non-discrimination in policymaking

Ensuring the rights and dignity of persons with dementia should be a principle built into public laws and regulations in the full spectrum of policy sectors: not only health and social care, but also pension systems, transport, etc. However, cooperation among the different policy sectors is often difficult in many UNECE countries, as a result of a ‘silo mentality’, a mindset present in some institutions where single sectors concentrate only on their own objectives at the expense of broader societal and long-term outcomes. This mentality conflicts with the multidimensional effects of dementia, where savings in one policy area (e.g. reduced costs for home help services) can generate externalities, both positive and negative, in other policy domains (increased use of hospital emergency departments, for example).

Central, regional and local governments should support integration of policies that promote dignity and non-discrimination of people with dementia and their caregivers. As an example, regulatory and incentive frameworks in the public sector can be reformed to drive progress in dementia care. The complexity of dementia should be reflected in the way that care systems are organized and financed.¹¹ The financing of healthcare systems in the UNECE region is often based on systems that do not take into account the specificities of dementia.

Legal protection of people with reduced capacity

At the macro level, the clarity and effectiveness of legislation surrounding substitutive decision-making (that is, when someone other than the person with dementia is authorized to make decisions on their behalf), for instance through court-appointed

¹¹ As suggested by OECD’s recent report, OECD, (2015).

Norway, Switzerland, Austria and Italy — National and regional dementia strategies and plans

Addressing the challenges of dementia requires that comprehensive and cross-sectoral strategies are well defined at the national level. While national health and/or social care plans are common in the UNECE region, national strategic plans for dementia are relatively new in many countries and non-existent in others.

Examples of comprehensive dementia plans include those recently launched in Norway and Switzerland. The Norwegian Dementia Plan identifies five strategic areas for action: quality development, research and planning; boosting capacity and improving skills; improved coordination and medical follow-up; active care; and partnerships with families and local communities. Likewise, the Swiss National Dementia Strategy for 2014-2017 pursues nine goals in four action areas: health literacy, information and participation; needs-appropriate services; quality and professional skills; and data and knowledge transfer.

Other countries are currently committed to developing their own national dementia plans. For instance, in Austria the process of developing a strategy for dementia was jointly launched in an international conference by the Ministry of Health and the Ministry for Social Affairs in February 2015, following the completion of a 2014 National Dementia Report. Six working groups have been identified for the creation of the National Strategy: participation, removal of taboos and health support; research and data; professional care and support; coordination and cooperation; informal care and support services for living at home; and quality and expertise.

In countries where policy responsibilities are split among different administrative levels, it is important that national strategies consider regional-level factors and that they are tailored to the specific characteristics of local contexts. Italy's first national dementia strategy was developed by the Ministry of Health in close cooperation with the regions and the national patient and carer associations, and was approved in October 2014. It will be implemented at the regional level and monitored at the national level. Many regions, responding to their specific needs, have therefore developed regional plans for the implementation of the national strategy. For instance, the dementia plan of the Marche region focuses on the most relevant local issues such as reducing fragmentation of care, developing integrated care pathways and increasing community care services.

Sources: More about National Dementia Plans at <http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Plans>. For Austria, information was provided by the Austrian Ministry of Labour, Social Affairs and Consumer Protection.

guardians, should be ensured.¹² This means that the legal criteria determining when a person has the ability to make decisions that are fundamental to his or her own good should be clear and standardized. In addition, the procedures to appoint a substitutive decision maker should be timely and transparent. A person affected by dementia should be allowed to nominate in advance the persons they would like to be eligible for representing their interests when the disease compromises their cognitive functioning. These measures should be aimed at preventing potentially harmful situations at a time when the person is no longer able to care for her or his own personal needs. Examples of these negative situations include the misuse of the financial assets of persons with dementia, the disrespect of their preferences concerning advance care planning, or even the failure to adhere to terms of a will when a person is deceased.

Cooperation with the justice system

As mentioned above, dementia is a risk factor for abuse, neglect or abandonment. Although violations of someone's dignity and discrimination do not always represent an episode of abuse, when these take place they should be considered as markers of potential risks for the person with dementia. Indeed, the boundaries between the two phenomena are thin and, in this respect, collaboration between institutions of the justice system (e.g. police and magistrates) and those services and institutions which can more easily detect such situations (e.g. hospitals, home care services, NGOs) should be strengthened. In many countries there are considerable gaps in the legal provisions concerning protection of dignity for persons with dementia, e.g. in cases of inappropriate use of restraints or privacy violations. The intervention procedures in case of suspected financial, physical and/or verbal abuse are not always clear nor well-known by professionals in health and social care systems, or by NGOs and caregivers. The role of policy should be that of filling this gap and implementing more concrete measures to increase the collaboration between relevant stakeholders in this area.

¹² For an inventory of the legal provisions relating to 'proxy decision-making' (e.g. guardianship measures and continuing powers of attorney) and various forms of legal capacity (e.g. relating to marriage, making a will, making a contract, voting, civil liability and criminal responsibility) of people with dementia within the European Union, Iceland, Norway, Switzerland and Turkey see: <http://alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/Legal-capacity-and-proxy-decision-making>

Advocacy by NGOs and civil society

People with dementia may not be adequately represented in democratic voting systems. The protection of their rights therefore risks being overlooked in political agendas, in favour of groups with stronger lobbying power. Nevertheless, the goal of ensuring dignity and non-discrimination of people with dementia should be a common goal to which all political parties should actively commit. In this respect, the role of NGOs and other civil society organizations is crucial, as it is they who can most effectively advocate for the rights of people with dementia and their families. NGOs can take a leading role in promoting the respect, protection and fulfilment of all human rights of people with dementia and advocating for the adoption of a human rights-based approach to develop strategies, policies and programmes addressing their needs.

A positive initiative in this area is the recent Glasgow Declaration, an NGO-based commitment to fully promoting the rights, dignity and autonomy of people living with dementia, signed in 2014 by the members of Alzheimer Europe.¹³ The Declaration aims at stimulating the adoption of a European Dementia Strategy and national strategies in every country in Europe. It has been already effective in raising awareness among policymakers and, at the time of writing, 61 policymakers (including 52 MEPs) from 19 different European countries have signed the Declaration.

Serbia — 'Let's not forget those who forget'

The advocacy role of NGOs can be decisive in persuading policymakers to take action, even when evidence of the effectiveness of a policy or intervention is already well documented. An example of this can be found in Serbia, where the tendency to institutionalization of people with dementia is declining, but community services are still underdeveloped and not accessible for most in need. Here, people with dementia and their families are often isolated and receive almost no support from the formal care services.

In this context, the project 'Let's not forget those who forget', coordinated by the NGO 'Amity' and funded by the Trag Foundation, is an important example of advocating for the rights of people with dementia, and in particular for ensuring their right to live in the community. The initiative aimed specifically at influencing the members of the City Assembly of Belgrade to establish a day-care centre for persons with dementia.

During the first phase of this project, a survey was carried out to evaluate the needs of people with dementia and of their families. The survey showed that 60 per cent of them did not use any formal service, and the majority of respondents reported a strong desire to live in the community as long as possible. Over three quarters of the family caregivers indicated the need for counselling and training. 80 per cent of caregivers expressed the need for community-based support services, and were willing to contribute to their cost.

During the second phase of the project, an awareness-raising campaign was carried out, including meetings, press conferences, round tables and media involvement (111 media appearances in 2014 alone). Parallel to the campaign, an advocacy coalition of 17 civil society organizations in Belgrade was created and began lobbying for the establishment of day-care centres in the community. Decision makers demonstrated readiness and promised to include the realization of this service in the Social Welfare Development Strategy of the city, and then in the Decision on Social Welfare Rights and Services, and to pilot the service, prior to establishing permanent financing. Today the project is officially completed, but continues to advocate for the rights of people with dementia and their families, even though support from donors has now ended.

Sources: Information provided by Amity.

See http://amity-yu.org/index.php?option=com_content&view=frontpage&Itemid=62 and http://amity-yu.org/images/pdf/zivot_bez_secanja_istrzivanja.pdf (in Serbian).

¹³ For more information see <http://alzheimer-europe.org/Policy-in-Practice2/Glasgow-Declaration-2014>

Investment in dementia care and research as a measure to combat discrimination

Allocating resources to dementia care should be seen as an investment that can generate employment, know-how and better quality of life for the whole of society. Private investments may be encouraged via tax deductions and bonuses or through the facilitation of public-private partnerships. The use of innovative financial instruments and mechanisms, such as Social Impact Benefit Bonds in the United Kingdom,¹⁴ should be explored in order to mobilize private and non-profit funding to finance dementia care and research. New financial mechanisms could be used in conjunction with advanced and ‘smart’ delivery of services, which, by combining local authority actions and innovative technologies can alleviate the high costs associated with avoidable institutionalization, support people with dementia and their caregivers in remaining independent and active in their communities, and reduce the overall costs of care services.

B. The role of communities and environments

Media and public perceptions of dementia: combating stigma

There is still a low level of general public knowledge about what dementia is, what its implications are for society, families and individuals, and what the protective and risk factors are – especially as compared to other high-impact diseases, such as cancer. Initiatives for awareness-raising and knowledge creation are therefore important. In this respect, NGOs and other civil society institutions can make a significant contribution to raising the awareness of the media about the topic, and can influence the way in which it is represented to the general public. As suggested by the UNECE policy brief No.12, ‘Images of older persons’,¹⁵ opportunities could be provided for people affected by dementia wishing to portray themselves in the media. In this respect, governments may also have an active role to play. The media often appear to be inclined to report on cases in which the dignity of people with dementia is violated (e.g. abuse episodes in nursing homes or home care), rather than illustrating a more positive and realistic image of persons living with this health condition. While raising the alarm about negative events is clearly an important role of the media, going beyond the existing negative stereotypes to show what persons with dementia can still do is an equally important role. In so doing, the media could increase public understanding of dementia and move society from awareness to acceptance, as stated by the World Health Organization.¹⁶

Productivity and participation in the labour market

Dignity can be protected through the maintenance of an active and meaningful role for people with dementia in the community and in the labour market. Remaining active at work can be particularly valuable, especially for younger people with dementia, who are more likely to face certain challenges in this regard than older persons, such as still having dependent children and/or ageing parents who need care, or financial commitments such as mortgages.¹⁷ There is a tendency (both among those diagnosed and among those around them) to treat a dementia diagnosis as a signal for the end of productive life, the retreat from the labour market and the beginning of a life of illness - but the reality is filled with examples of people who have continued to be active and fully engaged in society despite having dementia. These examples should be used to fight the negative impact of labelling people with dementia as ‘dementia patients’. A positive example is that of the writer Terry Pratchett who, after being diagnosed with Alzheimer’s disease in 2007, kept working on his novels and started an intense fundraising campaign for dementia research. Pratchett also worked with UK broadcaster the BBC on a successful two-part documentary about his illness, ‘Terry Pratchett: Living with Alzheimer’s’.¹⁸

¹⁴ Social Benefit Bonds, also known as Social Impact Bonds, are a form of social finance contracts usually involving public sector commissioners, social investors, service providers, and often an intermediary. In a typical contract, public sector commissioners partner with private for-profit or Third Sector social investors to fund interventions that seek to tackle complex social problems. Charities and/or private investors cover the upfront costs necessary to set up the interventions implemented by service providers, while the commissioner commits to pay rewards if pre-defined desired outcomes are later reached. For more details see:

<http://www.piru.ac.uk/assets/files/Trailblazer%20SIBs%20interim%20report%20March%202015,%20for%20publication%20on%20PIRU%20site%20amendedpdf11may.pdf>

¹⁵ UNECE, (2012).

¹⁶ WHO, (2012).

¹⁷ France has focused efforts on ensuring the rights of younger people with dementia. A centre for young people with dementia specializes in issues such as the right to be told one’s diagnosis, social protection of pension plans and paid medical care for this sub-population. For more details see <http://www.centre-alzheimer-jeunes.fr/>

¹⁸ For more information on the documentaries see <http://www.bbc.co.uk/programmes/boohrt1x/episodes/guide>

Social participation of people with dementia

The participation of people affected by dementia in social activities can be promoted by identifying and combatting the causes of their exclusion. NGOs often focus on the provision of adequate community support at home, but there is an additional need for a focus on getting people out of the home, since social interaction is of particular value. This can be achieved, for example, by offering a wider range of community activities (not only befriending and one-to-one support, but also opportunities for people with dementia to be active as volunteers). Associations can organize activities, events and meetings for persons with dementia and their caregivers, including using innovative formats such as ‘Alzheimer Cafés’¹⁹ which have received very positive feedback by users. Such activities should also take the opportunity to promote healthy lifestyles, such as healthy diets and physical activity, since these represent one of the most effective measures to slow down the progression of the disease. Likewise, self-help groups and group-based psychosocial interventions may also be considered in such informal contexts. In this respect, collaboration with professionals working in public care services might prove fruitful, as they can share their knowledge in the community and reach a wider audience.²⁰

Driving cessation and public transport needs

Even when opportunities for social engagement are available, accessible public transport is often an important prerequisite for participation. Much research and many initiatives have been undertaken so far to promote the mobility of older people with functional or cognitive impairments. The way public transport services are designed can influence the mobility patterns of a person with dementia and his or her ability to participate in social life. This is true especially when these persons have to stop driving. For many, driving cessation represents a difficult transition point, since giving up the driving licence can be distressing both for the persons with dementia and for their families. Many people become socially isolated and depressed, with an exacerbation of the symptoms of the disease.

Available information suggests that ‘intermediate’ transport solutions, lying somewhere between standard public transport services and the so-called ‘special needs services’ (which are highly individualized, expensive, and potentially somewhat stigmatizing mobility services for eligible persons with disabilities), can provide a satisfactory middle ground for people with dementia following their cessation of driving. Such intermediate services, sometimes referred to as ‘Demand Responsive Transport’,²¹ are designed for people with functional limitations and can increase the ability of beneficiaries to travel. However, the benefits of such systems (e.g. a possible reduction in home care and medical care requirements) need to be more widely recognized if they are to attract further investment.

Even when transport services are available, people affected by dementia might require extra attention. Promising initiatives such as ‘travel training’ and ‘travel buddies’,²² implemented for instance in Australia, can be informative examples for policymakers whose aim is to increase the social participation of this population through an increased use of transport services.

Dementia-friendly environment and housing policies

Discrimination and loss of dignity can be a consequence of inadequately-designed physical environments. As the disease progresses, affected persons develop their own special needs in relation to safety and privacy. Accessible and safer environments (e.g. clutter-free environments, where knives and scissors are absent, the use of colours or images to facilitate orientation, etc.) take on particular importance. The concept of ‘dementia-friendly environments’²³ has been developed to indicate a physical environment which works well for people living with dementia, whether in a person’s own home, outside or in a care home.

¹⁹ For more information see <http://www.alzheimerscafe.com/public.html.alzheimersatoz.com/Welcome.html>

²⁰ Several good examples of initiatives promoting the integration and support of people with dementia and their carers in the local community are those collected and awarded by the Living Well with Dementia in the Community Award of the European Foundations’ Initiative on Dementia (EFID). -EFID is an initiative involving the Atlantic Philanthropies (Ireland), the Fondation M d ric Alzheimer (France), the King Baudouin Foundation (Belgium), the Robert Bosch Stiftung (Germany) and lately, the Joseph Rowntree Foundation (United Kingdom).

For more information see: <http://www.nef-europe.org/efid/>

²¹ Brake, Mulley and Nelson, (2006).

²² See <https://nsw.fightdementia.org.au/sites/default/files/NSW/documents/Meeting-the-Transport-Needs-of-People-with-Dementia-Summary-Report.pdf>

²³ Stewart and Page, (1999).

An example of a policy contributing to the creation of dementia-friendly environments is the housing adaptations policy in Sweden. Housing adaptations are defined by the Swedish legislation as alterations of the permanent physical features in the home and the immediate outdoor surroundings that aim to enhance the independent living of individuals with functional limitation. In Sweden, citizens are entitled to receive grants from the municipalities, covering part or full costs of the adaptation, irrespective of the applicant's financial situation and whether the home is rented or owned. Approximately 73,000 housing adaptation requests are granted each year for a total cost of over 100 million euros.²⁴ Another informative example is that of 'preventative home visits' undertaken in Denmark by occupational therapists or other professionals, which includes home interventions aimed at increasing the ergonomics and safety of home environments, assessing quality of life and identifying and preventing loneliness.²⁵

With respect to external environments, the specific needs of people with dementia should be considered during the design phase. Fixed standards and legal requirements to ensure accessibility for people with physical disabilities in new buildings are common today in many UNECE countries. However, such standards do not ensure the suitability of buildings for people with dementia. In this respect, closer collaboration between professionals with clinical expertise and those in the architecture field could be beneficial. In case of old urban spaces, refurbishments can be expensive and difficult to afford for municipalities. But governments nevertheless have an important role in updating existing building standards, promoting innovative financial instruments, and providing ad hoc funds or tax benefits to finance part of the refurbishment costs.

Ireland — Living Well with Dementia in Stillorgan-Blackrock, County Dublin

The Living Well with Dementia project is a clear example of a comprehensive and multi-actor initiative to actively engage people with dementia and their families in the community. The project brings together people with dementia, family members, healthcare professionals, voluntary, social and sports organizations of the Stillorgan-Blackrock area in a consortium which works together in supporting people with dementia in their community. With the person with dementia at the centre, and their voice heard through focus groups and one-to-one meetings, every component of the project stems from their expressed need and requirement of the families who care for them.

Several supports, services and initiatives have been implemented in a coherent and integrated manner:

1. Information for people with dementia and family members: a regular space for family members to meet health care professionals, get information and build a vital network of peer support.
2. Direct supports and respite for people with dementia: the project provides end-of-life care to people wishing to die at home with dignity, a befriending programme which offers weekly respite to over 30 persons and, where appropriate, also assistive technology.
3. Activities for people with dementia in the community: the project offers people with dementia the opportunity to participate in community-based social activities including exercise groups and bridge clubs. Two 'Musical Memories' choirs, creative writing groups and one-to-one home-based music therapy have been piloted within this initiative. All of these groups are supported by a trained team of intergenerational volunteers.
4. Awareness-raising and mobilising support among the community.
5. Joint initiatives with local businesses and groups to make Stillorgan-Blackrock a dementia-friendly environment: an ongoing community awareness programme has garnered the support of retail, schools, sports groups, active retirement movements, libraries, police, residents and local citizens.

Sources: Information provided by Dun Laoghaire Local Health Office, Irish Health Service Executive, and retrieved from <http://livingwellwith-dementia.ie>

²⁴ Annual Report from Boverket, the Swedish authority on urban planning, urban development, construction and housing (in Swedish): <http://www.boverket.se/globalassets/publikationer/dokument/2014/bostadsanpassningsbidragen-2013.pdf>

²⁵ For a review of the different typologies of preventative home visits carried out in Denmark see Fagerström, Wikblad and Nilsson, (2009).

Persons with dementia as consumers

The special needs, interests and preferences of people with dementia should be taken into account by producers and service providers addressing this growing segment of the market. The UNECE Policy Brief No.3 on ‘Older people as consumers’²⁶ stressed the importance of a “design for all ages” approach to all areas of life (e.g. public transport, urban development, housing, information, and communication technology, etc.). Likewise, it is highly relevant for the dignity and non-discrimination of people with dementia that they should be able to find in the market those goods and services that really meet their preferences and needs, for instance in terms of usability, acceptability and safety.

Policymakers are responsible for implementing technical standards and rules, but also for ensuring that the products and services are accessible for people at risk of discrimination, such as those living in remote rural areas or poor urban neighbourhoods. In addition, policymakers should ensure adequate protection of people with dementia on the market: simple contracts and advertisements, being given adequate time to consider and reconsider contractual undertakings, sales techniques and warranties that minimize the potential to confuse, frighten or mislead the person with dementia.

Civil society organizations are well placed to promote the concept of dementia-friendly products and services. NGOs, together with research centres and universities, can promote communication between private companies and older consumers, including persons with dementia, ensuring that their needs and preferences are comprehensively considered. Likewise, they could take the lead in reporting to private and public producers and service providers when people with dementia are discriminated against on the market and their dignity is violated.

New technologies and dignity

New Information and Communication Technologies (ICTs) and the new Ambient Assisted Living Technologies represent both an opportunity and a risk for the dignity of persons with dementia. On the one hand, these innovations can support independent living of persons with dementia and compensate for certain lost or diminished functionalities. On the other hand, the issue of data protection and privacy needs to be addressed in a more systematic way than has been done until now. A well-known example is that of the use of technologies collecting data from multiple sensors for monitoring the safety of the person at home or in institutions. In many cases, informed consent for the use of such instruments is not requested from the person him or herself but from family members and professional caregivers, resulting in a clear violation of privacy, one of the main components of dignity.

In addition, new technologies open up opportunities for new uses of existing data, e.g. possibilities for ‘big data’ analysis and genetic data use, but most people (not only those with dementia) lack adequate knowledge and competence to make an informed decision and express their choices. Clearer rules and ethical codes are required in this context, both at legislative and organizational levels.

C. Non-discrimination and dignity in dementia care*The opportunities and risks of care services*

As the severity of dementia advances, the affected person requires increasing support from the social and health care systems. On the one hand, receiving appropriate care services is a means to ensure non-discrimination and dignity of people with dementia. On the other hand, care systems themselves can be the contexts where discrimination takes place and dignity is violated. This occurs especially when services are not adequately funded and service availability is low, staff are poorly trained and the voice of people with dementia is not considered. It has been demonstrated that inadequate and/or low quality care might even lead to an inappropriate use of health care resources (e.g. antipsychotics) and malpractices (e.g. use of physical constraints).²⁷

It is crucial to seek insights on what quality of care actually means for an individual person with dementia, and how this concept varies from person to person. Once these important aspects are understood, external monitoring or the assessment of quality of care based on objective indicators will still be required (e.g. with support of caregivers and NGOs) since people with dementia, as consequence of the very nature of the disease in its later stages, may be not be in a condition to report on their perceived quality of care.

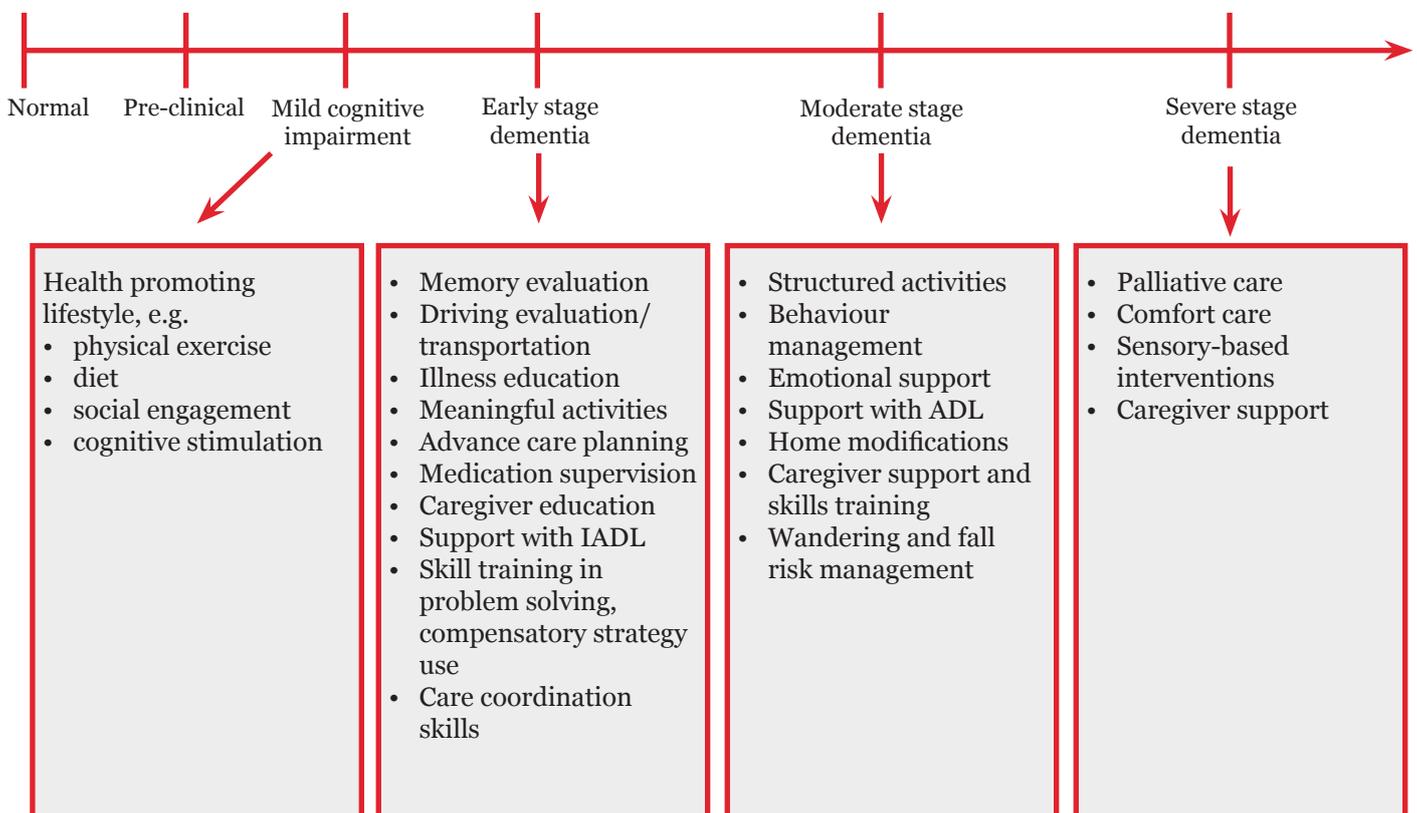
²⁶ UNECE, (2009).

²⁷ France and the UK have worked extensively to reduce the use of antipsychotics and demonstrated the link between a high quality of care and the decreased need for antipsychotic (neuroleptic) treatment. The awareness of such a link should inform strategies to optimize care interventions for people with dementia.

Personalized and person-centred care as a prerequisite for dignity

Figure 3 illustrates the challenge of responding effectively to the needs of persons with dementia. Generally speaking, the intensity of the support required increases with the progression of the disease. While initially, the focus should be on light care interventions, such as those in the area of health promotion, at a later stage people with dementia require more intensive care and even palliative interventions. The pharmaceutical approach should be constantly monitored and periodically reviewed by medical doctors (either general practitioners or specialists depending on a country's health care organization). Developing guidelines and standards of practice for dementia care is indeed of central relevance, but it has to be considered carefully that each person with dementia has his or her unique personal socioeconomic, cultural and health profile. This means that "each person's journey is different".²⁸ Consequently, a key success factor for care interventions to support people with dementia is that they should be personalized based on person-specific needs. 'Excess of care' can paradoxically have the same negative impact as a low availability of care, since in some situations a person would be better supported by not being 'wrapped up in cotton wool' but by being given only the level of support that is required and actively wanted.

Figure 3
Support for people with dementia as the disease progresses²⁹



Ensuring personalization of care is the aim of the 'This is me' tool,³⁰ developed by the Northumberland Acute Care and Dementia Group (United Kingdom), for people with dementia who are receiving professional care in any setting: at home, in hospital, in respite care or in a care home. The tool enables people to communicate to staff their needs, preferences, and interests. It enables care professionals to deliver person-centred care, preventing problems with communication, or serious conditions such as malnutrition and dehydration.

²⁸ <http://www.healthline.com/health/alzheimers-disease/life-expectancy#Age6>

²⁹ As in the case of figure 1, this figure is derived and adapted from the work of Laura Gitlin and Nancy Hodgson, as illustrated in the course 'Living with Dementia: Impact on Individuals, Caregivers, Communities and Societies' (see footnote 2).

³⁰ For more information see: <http://www.alzheimers.org.uk/thisisme>

United States of America — University of California, Los Angeles (UCLA) Alzheimer's and dementia care programme

Putting the person with dementia right at the centre is a key success factor for care interventions involving multiple care providers. This is clearly reflected by the UCLA Alzheimer's and dementia care programme, which aims to maintain the independence of persons with dementia to the highest degree possible, through a personalized and tailored care plan. It is designed to help the person and his or her family with the complex medical, behavioural and social needs of dementia. A 'dementia care manager' is at the heart of the programme and works with primary care doctors to develop and implement the personalized care plan.

The programme is based on five main components: 1) recruitment into the programme; 2) structured needs assessment of participants with dementia and their caregivers; 3) creation and implementation of individualized dementia care plans based on the needs assessment and input from the participant's primary care physician; 4) monitoring and revision of care plans as needed; and 5) access to assistance and advice at any time from the dementia care manager or a UCLA geriatrician.

One of the most interesting aspects of the programme is the regular follow-up telephone calls or in-person visits to ensure the plan is implemented or modified as needed, and the 24/7, 365 day-a-year access for caregivers who need assistance and advice in order to avoid Emergency Department visits and hospitalizations.

In-person visits are covered by Medicare (the United States' national social insurance programme for older people). Telephone calls and many other services such as, support groups, educational programmes, and referrals to community-based organizations are delivered at no cost for caregivers.

Sources: Information provided by UCLA and the Administration for Community Living, United States Department for Health and Human Services, and retrieved from <http://dementia.uclahealth.org>

Timely and accurate diagnosis

Access to a timely and correct diagnosis is extremely pertinent, both for ensuring that dignity is not affronted at the moment of diagnosis, and to protect dignity as the care process unfolds following diagnosis. Dementia can go undiagnosed for several years. On average it takes 2.8 years after the first appearance of symptoms for a diagnosis of Alzheimer's disease to be given.³¹

The importance of how the diagnosis is communicated to the person and his or her family must also be considered. This is a sensitive step, often overlooked, and an important moment for people's dignity. According to the available evidence, most persons with dementia want to be told their diagnosis in a clear, straightforward way.³² However, many professionals tend to be reluctant to directly disclose the diagnosis, fearing that this may cause excessive psychological harm to the person. The personal opinions and attitudes of the person being diagnosed should be central to decisions about delivering the diagnosis. In many countries, people are routinely asked about the desire to know their diagnosis, and this information can be of great importance for the medical doctors who eventually have to make the decision.

Medical diagnosis should lead to the provision of a number of services at home and in institutional care settings, such as early case-management and integrated health and social services. If not, the potential of early diagnosis is wasted. Last but not least, establishing dementia registries or electronic health records is an important strategy to ensure that diagnoses are always shared between professionals and that relevant information is available even where confusion and memory loss might limit the communication between the doctors and the persons with dementia. In general, better recording and 'safe' sharing of patient data is essential for the provision of personalized care and improvement of care coordination.

Dignity and non-discrimination in home care

Care in the community for people with dementia should be more proactive. The establishment of multidisciplinary and coordinated services should be encouraged for better management of comorbidities. The role of general practitioners in this context is central; it is therefore recommended to increase their availability on-site or on call and their integration with the network of specialists in such fields as geriatrics and neurology. Such availability has been proved to be crucial to reduce avoidable use of emergency departments, hospital care and inappropriate medications.

³¹ Brookmeyer and others, (2002).

³² Robinson and others, (2011).

Slovakia — MEMORY Centre, Bratislava

Integrated responses should be made available promptly for persons diagnosed with dementia, in order to permit them to profit from the potential of an early diagnosis. Providing such rapid responses is the mission of the MEMORY Centre, a non profit organization which aims at providing the best possible treatment and care for people with dementia and their families through an integrated programme of diagnostic and therapeutic services, research, education and daily care.

The main activities provided by the centre include: diagnostics and pharmacotherapy; daily care; non-pharmacological interventions; memory training for older people without memory impairment; cognitive training for people with early and intermediate memory complaints; advice and counselling, workshops for caregivers and relatives, for professionals and employees in residential care.

Interventions provided by the Centre include: motor exercises, occupational therapy, art therapy, dance and music therapy, training for self-care activities, and cognitive rehabilitation. The therapeutic work is performed in groups or individually, according to the type of activity, goals, or cognitive ability of participants. The staff also train the family of the person with dementia on how to support him or her more effectively. The MEMORY Centre team members provide training to the staff of other social and medical institutions through the organization of courses. An international scientific conference on 'Activation of seniors and non-pharmacological approaches in treatment Alzheimer's Disease' is organized every year. The MEMORY Centre cooperates very closely with the Institute of Neuroimmunology of the Slovak Academy of Sciences and with the Slovak Alzheimer Association, which promotes support groups for family members and caregivers in Slovakia.

Sources: Information provided by the MEMORY Centre, Bratislava, Slovak Republic, <http://www.alzheimer.sk/centrum-memory.aspx>

It is self-evident that delivery of high-intensity home services can be costly, since such services are typically labour-intensive and often the travel time of care staff represents a significant cost driver. However, effective strategies to reform the traditional organization of services in a cost-effective manner have been already suggested by the scientific literature. These strategies might include the use of new technologies, the involvement of informal caregivers and volunteers, and the provision of alternative forms of respite care, such as Alzheimer Cafés or Day Care Centres.

Dignity and non-discrimination in institutional care

As mentioned, support interventions can be delivered either in a community or institutional care setting. Although a majority of people in European countries say that they have no intention of moving from their home environment even if or when their physical or mental health conditions start to become a major impediment to everyday life,³³ in some specific cases institutional care is nevertheless the best available solution both for a person with dementia and their caregivers. This happens when the home is not adequate to ensure dignified care and/or the caregivers are themselves at substantial risk of adverse outcomes. Therefore, it must be borne in mind that an excessive focus on community care to the exclusion of institutional care may be detrimental for the dignity of those persons who cannot be provided with adequate assistance in their homes. In such situations, the availability of institutional care options is important to ensure dignity of the person with dementia. Innovative forms of institutional care may represent an opportunity to improve the quality of life and reduce the risks of discrimination of people with dementia. However, it is essential that the care provided within these institutions is tailored around the needs of the person. For example, following routines in daily activities such as those surrounding meal times, or making meal times more sociable, involving families and volunteers in social activities, are effective strategies to improve quality of care and reduce the use of antipsychotics. The literature provides several ideas on how to improve the outcomes for care home residents. However, the deployment on a larger scale of innovative experience is hindered by financial constraints, lack of know-how among staff and low political visibility of the issue of quality of institutional care.

³³ European Commission, (2007).

Dignity and non-discrimination in hospital care

While the use of hospital care is sometimes absolutely necessary in order to treat acute health problems, entry into hospital can be a critical transition event for people with dementia. Many frail older patients have to struggle with the side effects of hospital stays such as increased disability, hospital infections, use of antipsychotic medications and adverse outcomes of changes in their drug therapy. People with reduced cognitive abilities may encounter particular difficulties in coping with the unknown hospital environment. Removed from their familiar setting, the hospital can make them feel lost, vulnerable and exposed and can trigger intense anxiety. It is not uncommon for people with dementia to become confused and experience a steep progression in the disease severity following a move to a hospital setting. In such conditions, the risk of dignity violations is raised: depersonalization, lack of privacy, passive acceptance of the predefined routines, under- and over- treatment and prescription, and non-access to usual religious and other meaningful rituals, foods and activities.

Making the hospital environment more suitable to the needs of people with dementia is a challenge, but several good practices are available from UNECE countries. These can entail multi-component interventions such as: use of dementia case-managers; providing advice and training to caregivers; personalized drug treatment; physiotherapy and occupational therapy; speech therapy; listening to patients' and caregivers' concerns; help with use of appliances, equipment, and daily living aids; modifications of the hospital environment to promote mobility and cognitive integrity (e.g. use of clocks, removal of potential barriers and other risk factors). The 'Butterfly Scheme' used in the UK is an illuminating example.³⁴ Eligible patients with cognitive problems, assisted by their carer, can choose to use a butterfly symbol to request the scheme's care response from the staff, who are trained to offer them a specific targeted response. Family and other caregivers are also invited to fill in a form, offering hints and tips which will make life easier for the patient and for the staff. The scheme has been adopted by over a hundred hospitals across the UK and its advantages are evident. Persons with dementia can receive more personalized and appropriate care, reducing their stress levels and increasing their safety and well-being in the hospital.

Germany — Wolgast district dementia-friendly hospital

An informative policy intervention aimed at reducing the negative impact of hospitalization among people with dementia can be found in Western Pomerania, Germany. Here an integrated centre for geriatric medicine will be developed using a network/hub organizational model, and a number of integrated interventions are currently being set up as part of the Wolgast district dementia-friendly hospital initiative.

A 'dementia navigator' has been appointed in the local hospital. This professional will act as a case-manager for persons with dementia and their relatives, and will become a reference point for the staff of the hospital. The dementia navigator will be responsible for liaising with community care services, mainly those in the geriatric network of Western Pomerania ('GeriNet Vorpommern'): family doctors, long-term care facilities, home care teams, physical and occupational therapy practices, and for getting in contact with existing self-help groups (such as those organized by Alzheimer's Associations).

New professional competences in dementia care are being disseminated among all hospital staff, not just those working in geriatric departments. This will be done thanks to training courses and also via public events in the hospital to inform people about the role of the dementia navigator.

Information and training opportunities will be provided to relatives of people with dementia admitted to hospital care, in order to grant them the opportunity to learn new skills to better cope with their relatives' dementia after discharge. These events will mainly be organized by the dementia navigator and they will involve the full range of hospital professionals.

Last but not least, individual post-discharge care plans will be tailored to each person with dementia. The plans will be implemented and monitored using a new communication system between the hospital and the community care services.

Sources: Information provided by Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, Germany (dorika.seib@bmfsfj.bund.de) and retrieved from <http://www.kreiskrankenhaus-wolgast.de/index.php?id=15> (in German)

³⁴ See <http://butterflyscheme.org.uk/>

Dignity in advanced dementia and palliative care

Even in the most advanced stages of the disease, when cognitive functions and communication are at their most limited (see figure 1), it is still possible to take action to ensure that dignity is not violated. A major issue relevant for dignity is that of recognizing and tackling pain. Detection of pain among people with severe dementia is sometime challenging for professionals and caregivers due to the existing communication problems and other dementia-related symptoms. This leads in many cases to under-treatment of pain among this group. Training of staff and caregivers is therefore necessary to tackle this, to reduce avoidable pain and improve the quality of end-of-life care.

Furthermore, the topic of ‘dying with dignity’ is important for those in the most advanced stages of the disease, as well as for their families and for health professionals. Research has demonstrated the importance of developing closer links between palliative care teams and specialists, both in hospitals and at the community level. People with dementia should have the possibility to choose the place where they wish to die. Access to palliative care outside a hospital environment, however, needs to be improved in most UNECE countries and, in addition, the specific needs of people with dementia, as compared with those without cognitive impairment, must be better recognized and catered for in the provision of such care.

The importance of training and capacity-building

Many care staff are inadequately prepared to tackle the challenges entailed in managing the complex needs of people affected by dementia. One important skill to be developed among care staff is the ability to establish a positive relationship with a person with dementia and his or her caregivers. Being able to understand the needs and interpret the specific feelings of each case has been shown to improve overall health outcomes.³⁵ Positive results have been achieved in this regard by including methodologies from the psychosocial field in educational curricula.

The ability of care staff to work in multidisciplinary teams is also an important asset in dementia care, as professionals should be able to recognize the role of, and if necessary refer the person to, specialists in various disciplines. This is of special relevance if case management skills are to be further strengthened. Filling these knowledge gaps is a shared responsibility of care managers, policymakers and, ultimately, care staff themselves. In this respect, curricula, teaching methods and training models should be revised to meet the challenges of developing high-quality dementia care.

Malta — Training programme on ‘ensuring quality of care for people with dementia’

Persons with dementia are often stereotyped as passive and dependent individuals, and such stereotypes among nurses are likely to affect their attitude during care. Proper education and training of nurses who work with persons with dementia is important to ensure dignity during their care and, consequently better quality of life for persons with dementia.

The University of Malta has partnered with the Parliamentary Secretariat for the Rights of Persons with Disability and Active Ageing to carry out a training programme on ensuring quality of care for people with dementia. This training programme, funded by the European Social Fund, is targeted at all nurses and health care support staff working in residential or nursing homes for older people and for nurses working in the community. The programme covers a range of topics including: introduction to dementia care; communication with people with dementia; access to services; activities for older people with dementia; behavioural issues in dementia care; dementia-friendly design and assistive technologies; policy development in dementia management and care.

Sources: Information provided by the Ministry of Health, Elderly and Community Care, Malta.

³⁵ Alfonso, Krishnamoorthy and Gomez, (2010).

D. Family and everyday relations

The role of persons with dementia in the family

Dementia has been described as a ‘family disease’, because the relatives of the people with dementia are often themselves affected by high levels of stress and anxiety. Providing care to a person with severe dementia can represent a serious burden for many relatives, who, according to available evidence, are exposed to an excess mortality risk compared with the caregivers of older people with conditions other than dementia. Thus, although the family and other informal networks represent an important asset for people with dementia, often being their primary source of care, the challenge of ensuring the dignity and non-discrimination of people with dementia is at the same time heightened by this reality.

Protecting choices

The dignity of persons with dementia must be preserved in their relations with other family members, not only direct caregivers. As the disease progresses, family members are often called upon to act as substitutes for a person’s decisions, many times in situations lacking a clear normative definition (see paragraph Legal protection of people with reduced capacity). In order to protect the choices of persons with dementia it is important that all potential issues, such as those related to the management of financial assets or those relating to anticipated care needs, should be dealt with in advance by the person with dementia when cognitive abilities are still intact, with the involvement and understanding of family members.

Spain — Empowerment workshops for relatives of people with dementia: ‘Care while you live or live while you care’

The role of informal caregivers is invaluable, both for persons with dementia themselves but also for the public services, which are relieved from some of their care responsibilities. Implementing support initiatives for these caregivers in the most effective manner is therefore imperative. A valuable model for support is that provided by the empowerment workshops ‘Care while you live or live while you care’, a group-based therapy programme for relatives of people with dementia provided by an ‘Alzheimer Flagship Centre’ in Salamanca. The sessions are held weekly over an eight-week period. The main aim of the workshop is to strengthen participants’ resources and skills in dealing with the negative consequences of caregiving, through the development of new coping strategies, increasing self-esteem, self-awareness and resilience, and fostering a greater understanding of the carer role. Following a self-help group format, the workshops do not focus on care, but on the empowerment of caregivers in all their personal dimensions.

The idea underlying this programme is that group-based psychotherapy is an effective intervention to reduce psychopathological side effects of caregiving (depression, anxiety, stress and blame), while increasing positive ones (resilience, self-esteem, etc.). Through this programme, a higher level of personal well-being is achieved, this leading to more successful management of daily caregiving activities.

The empowerment programme has been running since 2012 (there have been five iterations of the programme so far). Following the positive results obtained in previous rounds, the organizers are currently setting up an evaluation process to investigate the relative effectiveness of the empowerment group intervention approach versus more traditional self-help groups.

Sources: Information provided by the Spanish Institute for Older Persons and Social Services (IMSERSO) and the Salamanca State Reference Centre, <http://www.crealzheimer.es/>

Supporting informal carers

As mentioned, informal caregivers of people with dementia are exposed to an increased risk of morbidity and mortality as a consequence of their stress and burden. Evidence suggests that, if the negative feelings associated with care responsibilities overwhelm the positive ones, the dignity of the people with dementia can be violated as a consequence. Support interventions, such as the provision of respite care, self-help groups, counselling and training activities and case management, in combination with the use of new technologies, can improve caregivers’ condition with positive outcomes both for their own quality of life and for that of the people with dementia for whom they provide care. However, the availability of such support is often limited, for several reasons. Care systems are still dominated by an excessive focus on hospital care, and this limits the availability of other community/primary care services which have a clear prevention potential. In other cases, even when services are available, factors such as the lack of information or the complexity of procedures can prevent caregivers from accessing supportive care.

Increasing the availability of services can thus be an important measure to improve caregivers' situation; such actions should also be accompanied by interventions aimed at recognizing their important role in society and informing them about the existing support options.

The role of research

Dementia research: an underfunded area

Progress in the field of research into dementia prevention and cure is slow, as a consequence of the biological and clinical complexity of the disease, but also as result of the relatively small investments in the field which are only a fraction of what today is spent on research into other diseases such as cancer.³⁶ There is a substantial lack of data, qualitative and longitudinal studies on shared challenges and needs of older people living with dementia. The specific needs of their sub-groups e.g. older migrants, indigenous people,³⁷ persons with multiple conditions in addition to dementia, and their caregivers are also under-researched. Establishing and maintaining dementia research centres could be one means of spreading know-how in the care services and in society as a whole. In addition, it is clear that the topic of dignity in the field of dementia care is under-investigated. The development of dignity-oriented interventions and care is low on research and practice agendas.

Canada — The Murray Alzheimer Research and Education Programme (MAREP)

The Murray Alzheimer Research and Education Program is an innovative programme that adopts a partnership approach and integrates research and educational activities in an effort to improve dementia care practices in Canada and around the world. Although MAREP's research projects are funded by research grants, all of its knowledge translation activities are funded through donations and charitable gifts from individuals and groups. MAREP is involved in a number of on-going and new initiatives that have made significant advances in translating research into practical tools to ensure research gets to those who can use it the most. These initiatives consist of workshops and training (in-person and online) designed for staff working in residential care environments such as long-term care homes, and train the trainer programs for educators. MAREP has also developed a significant number of products and resources for a wide variety of audiences, such as persons living with dementia, family care partners, and professionals working in the dementia field.

The By Us For Us© Guides (BUFU guides) developed by MAREP are a series of guides created by a group of talented and passionate persons with dementia and/or partners in care. The guides are designed to equip persons with dementia with the necessary tools to enhance their well-being and manage daily challenges. What makes these guides particularly useful is that they are created by persons with dementia and/or partners in care, for persons with dementia and/or partners in care.

Sources: Information provided by the University of Waterloo, <https://uwaterloo.ca/murray-alzheimer-research-and-education-program/>

Listening to the voice of people with dementia

In research, the voice of persons with dementia has long been neglected. People with dementia have tended to be considered as passive 'subjects' of research and interventions, while more attention has been given to their formal and informal caregivers. Only recently has there been an increased awareness of the need to engage this group as active participants in research by taking into account their views and opinions.³⁸

³⁶ See http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=429

³⁷ For example, the First Nations and Inuit Home and Community Care Program 2014-2017 in Canada is aimed at training that focuses on health promotion through raising awareness of brain health, prevention interventions taking into consideration the First Nations cultural understandings of "What is dementia?" and "Early warning signs and symptoms of dementia" and finally, creating an environment where family/friends and health care providers feel supported to better care for clients living with dementia.

³⁸ In a recent guidance note about patient and public involvement in research (JPND, 2015), the focus group method is suggested as an effective means of involving people with cognitive impairments. The U.S. Department of Health and Human Services Food and Drug Administration (FDA, 2009) discourages using proxy reported outcome measures in persons with cognitive impairment, and notes that the length of study interviews is an important consideration. A too lengthy interview will contribute to respondent burden, but a too short interview will not allow for discussions.

Informed consent and ethical clearance

Informed consent and ethical clearance should to the fullest extent possible be collected from the person with dementia him or herself before undertaking any research. In this regard, the importance of effective communication of research rationale and objectives must be stressed. Given that more effective collection and use of data can contribute to advances in knowledge regarding dementia and its cure, it is of key importance that privacy rights are not neglected.

Strengthening collaboration among scientific disciplines, especially experts from law, can be an effective measure to improve the ways in which people with dementia are engaged in research activities.

Conclusions and recommendations

Ensuring the dignity and non-discrimination of people with dementia must be a comprehensive endeavour employing a multilevel strategy to coordinate the efforts of all stakeholders. The importance of such a strategy is clear given that dementia affects not only the increasing population of people living with dementia, but also family caregivers, professionals in many public sectors, public and private producers and service providers and society as a whole.

Several examples of multilevel strategies already in place can be found looking at the Dementia-Friendly Communities (DFC) programme, first launched in 2012 by the UK Alzheimer Society. The programme focuses on improving inclusion and quality of life for people with dementia through the creation of dementia-friendly communities, where they are empowered to feel confident, knowing they can contribute and participate in activities that are meaningful to them. The DFC programme gives public recognition and support to communities which are taking steps towards being more inclusive of people with dementia in the UK, and following the success of this initiative, Alzheimer's Disease International recently released a document that illustrates the progress of DFC projects across the world.³⁹

UNECE member States vary widely in many aspects, e.g. in terms of national income, the organization of their welfare systems, and indeed in the broad characteristics of family structures. However, the socioecological model adopted by this policy brief highlights the fact that there are common areas for potential intervention with the aim of ensuring the dignity and non-discrimination of persons with dementia. It is important to note that, although cost can be an issue for some particular measures, the overarching goal of ensuring dignity of the persons with dementia can also be pursued via non-expensive or low-cost measures targeting, for instance, the cultural and social dimensions of the phenomenon.

By providing a systematic framework of possible intervention strategies, this policy brief offers a reference for policymakers aiming to address this issue in the UNECE region and beyond.

³⁹ DFC projects are grouped into six key areas of community planning: a) public awareness and information access; b) planning processes; c) the physical environment; d) access and consideration for dementia among local businesses and public services; e) community-based innovation services through local action; f) access to transportation. The report is available at <http://www.alz.co.uk/adi/pdf/dementia-friendly-communities.pdf>

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Checklist: Dignity and non-discrimination for persons with dementia

Main areas	Areas of implementation	Key elements
Macro/Policy level	Policymaking at the macro level	<ul style="list-style-type: none"> • Comprehensive strategy • Intersectoral cooperation • Multilevel approach (central & local)
	Legal protection of persons with dementia	<ul style="list-style-type: none"> • Legal capacity • Proxy decision-making
	Justice system	<ul style="list-style-type: none"> • Prevention of abuse • Collaboration with other sectors
	NGOs and civil society	<ul style="list-style-type: none"> • Advocacy and promotion of rights
	Investments in research and care	<ul style="list-style-type: none"> • Innovative financial instruments • Funding for research as investment
Communities and Environments	Media and public perception	<ul style="list-style-type: none"> • Combating stereotypes • From awareness to acceptance
	Participation in the labour market	<ul style="list-style-type: none"> • Remaining active • Creating opportunities
	Social participation	<ul style="list-style-type: none"> • Maintaining and promoting engagement
	Driving and transport	<ul style="list-style-type: none"> • Accessible transport options • Support in driving cessation
	Environment and housing	<ul style="list-style-type: none"> • Dementia-friendly environments
	Products and services	<ul style="list-style-type: none"> • Protection of consumers • Dementia-friendly products
	New technology	<ul style="list-style-type: none"> • ICT support • Safeguarding privacy
Care systems	Structure of the care system	<ul style="list-style-type: none"> • Quality of care
	Personalized care	<ul style="list-style-type: none"> • Progressive response • Low availability vs. excess of care
	Timely diagnosis	<ul style="list-style-type: none"> • Effective communication • Diagnosis followed by care services
	Home care	<ul style="list-style-type: none"> • Preventative and proactive models • ICT-enriched care
	Institutional care	<ul style="list-style-type: none"> • Innovative solutions • Involvement of volunteers
	Hospital care	<ul style="list-style-type: none"> • Reduction of hospital use • Dementia-friendly practices
	Advanced care	<ul style="list-style-type: none"> • Personalization and choice • Appropriate treatment of pain
	Training and capacity-building of carers	<ul style="list-style-type: none"> • Continuous training • Multidisciplinarity
Family and significant others	The family context	<ul style="list-style-type: none"> • Family as an asset
	Protecting choices	<ul style="list-style-type: none"> • Respect for the person's decisions • Early planning of care
	Support for informal carers	<ul style="list-style-type: none"> • Care for carers • Information, training and support
Research	Financing	<ul style="list-style-type: none"> • Pooling of funding for research
	Engagement of users in research	<ul style="list-style-type: none"> • Listening to the person's voice
	Informed consent and ethics	<ul style="list-style-type: none"> • Communication of research aims • Collaboration with law experts