

Community care for people with dementia: A handbook for policymakers



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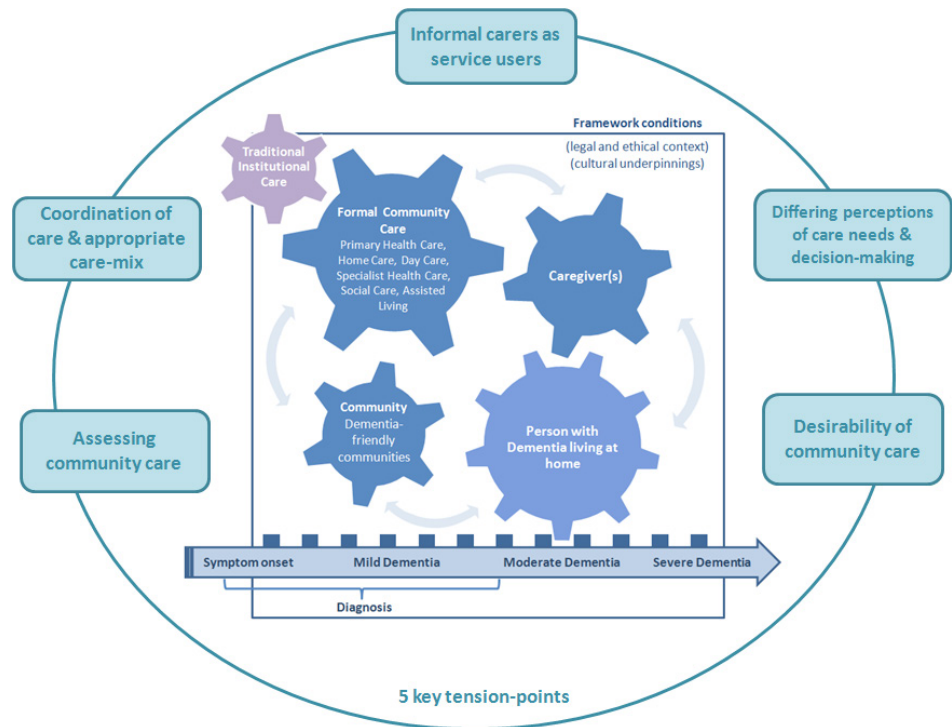
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Executive Summary

Our handbook sets out to explore what constitutes good community care for people with dementia and to develop a concise overview of the knowledge-base that should ground future development and reorganization of community-based care arrangements for people with dementia.

We draw on a scoping review of the academic and grey literature published between 2008 and 2016, on two expert workshops, and on a series of expert interviews in four European countries to propose a conceptual framework for community care for dementia. Our framework attempts to capture the complexities and interdependencies inherent to the organization of community-based dementia care along the disease trajectory, recognizing the roles played by the various actors involved. Furthermore, we include the socio-cultural, economic, and legal and governance context of community care for people with dementia in our framework. While we do not develop each of these dimensions in depth, we emphasize instead how each interacts with and affects the organization and quality of community-based care by linking them with 5 core tensions, or ‘Tension Points’ within the system.

Conceptual framework and five tension points in dementia community care



We call these dimensions ‘Tension Points’ because each points to a challenge or a series of challenges that can arise when different actors, interests and external factors intersect, and which in turn can directly or indirectly affect the quality of care.

The desirability of community care focuses on the delicate balance between cost-efficiency and user preferences, as well as safety and independence. The preferences of older people with dementia to receive care in their homes should be at the center of care planning and reflected in all care policies. Also important are the preferences of informal carers, most often women - their support needs and their wellbeing factor heavily in the indirect costs of community care. In fact, caring for people with early to moderate dementia at home has lower costs than institutional care, but as the disease progresses, the reverse may become true. At a certain point over the course of the disease trajectory, care at home becomes unsustainable because of the intensity of care needs. Appropriate and adequate community care can, however, go a long way to delaying that eventuality for as long as possible.

Differing perceptions of care needs and decision-making along the trajectory of the disease captures the conflicts arising from the different perceptions of the actors involved in the care process. Given the cognitive impairment associated with the disease, people with dementia suffer impairments to their decision-making capacity. This places a heavy burden on family members who often have to step in, and can have very practical implications in terms of matching care services to care needs. While persons with dementia are generally more concerned with being socially isolated and with the consequences of losing their memory, family carers identify practical support with daily activities as main care needs, and care professionals tend to emphasize more clinical, medical needs. It is not surprising then that care services are often evaluated as being ill-suited to user needs.

This latter point makes the case for support services for family carers and the third tension point: **informal caregivers as service users**. Family carers have been referred to as the ‘invisible second patient’ because their own needs are often overlooked. A large body of research has shown that caring for someone with dementia can have detrimental effects on carers’ health and wellbeing, employment, and financial standing; with important differences for women and men across each of these dimensions. Although the needs of informal family carers are increasingly being recognized, formal services that are

tailored to their needs are still lacking in many countries. Peer-to-peer support groups and services providing support with daily care and activities have been found to be most helpful, together with access to professional counseling and advice services.

The **care coordination and appropriate care mix** tension point highlights the challenges people with dementia and their families face when navigating the range of fragmented and mismatched community-based services. Case management can be a beneficial tool in achieving coordinated care services; not just for its capacity to inform and guide families and organize care services, but also for the role played by case managers in mediating conflicts within families, and between families and care providers. In general, most countries have a long way to go before services at the local level are fully integrated and coordinated. Major obstacles are the divide between acute care settings and outpatient and home-based care as well as underdeveloped training systems for care professionals.

Finally, tensions arise from difficulties in **assessing community care** for people with dementia. To achieve valuable and effective benchmarking of community care for people with dementia, a conceptual shift needs to take place in terms of what dimensions and measures of care and support are deemed most important. This includes the development of more accurate measures of quality of life and wellbeing of people with dementia and their caregivers, as well as developing measures that reflect the importance of other community actors in supporting people with dementia and their families. Equally important is the need to build the data collection infrastructure around dementia care and support so that monitoring becomes feasible.

Ethical and legal issues in community care for dementia

Among the numerous ethical issues that arise in dementia care, our handbook highlights four that emerged as particularly salient and amenable to change through coordinated policy action.

Safety vs. autonomy

In the case of dementia, maintaining autonomy is often at odds with the goal of reducing exposure to harm. An over-emphasis on safety can come at the cost of individual freedoms and disregards the right of people with dementia to choose to take risks in order to participate in society and in life more fully. This raises key issues for policymaking considering that the stringency of legal provisions can, in effect, mandate the primacy of safety concerns over autonomy, or vice versa. English law, in which a more paternalistic approach prevails, and Scottish law, which in contrast emphasizes autonomy, provide interesting case studies of this point. While in practice the assessment of risk remains subjective to individual circumstances, through progressive legislation Scotland has successfully promoted a culture of autonomy and joint decision-making.

Capacity and care decision-making

In the case of dementia, maintaining autonomy in decision-making is legally contingent on the person with dementia's ability to rationally comprehend and weigh the consequences of his/her choices. If a person lacks mental competence, a substitute decision-maker is empowered to make decision on his/her behalf. In order to preserve the autonomy of people with dementia while at the same time safeguarding them from potentially impaired decision-making, a series of legal provisions can be instituted: advanced directives and care planning, enduring power of attorney, task specific capacity assessments, etc. France provides an interesting case in that its three-tiered system of guardianship allows for the flexibility to adjust to the representation needs of the person.

Right and access to support

The dominant medicalized approach to dementia tends to overemphasize treatment and medical approaches to care. This can result in a lack of recognition that other forms of support are still necessary in order to manage the symptoms and ensure a high quality of life. The emerging rights-based approach to dementia care builds on the understanding that human rights are universal and should not be overlooked for any group of people. It endows individuals with a right to action and to claim their rights if they are not being met—via legislation, procedures and mechanisms that enshrine these rights. A landmark application of the rights-based approach to dementia care is the Scottish Post-diagnosis Support Guarantee ensuring that every person who receives a dementia diag-

nosis and their families receive support in planning for future care and decision-making, understanding the disease and managing symptoms and building peer support networks.

Dignity and end of life care

Advanced dementia is a terminal illness and people with dementia as well as their carers should have access to appropriate palliative care and support. It is important to emphasize that palliative care is not only necessary when end of life is imminent, but rather can be appropriate for up to several years prior. Unfortunately, access to palliative care services for people with dementia is limited, in hospitals, in the home and in dedicated institutions, e.g. hospices. In the Netherlands, palliative care is increasingly being used by people with dementia and is becoming more appreciated by care professionals. The Netherlands has one of the most permissive legal frameworks for end-of-life decision-making. In 2016, it legalized the use of advanced written requests for physician-assisted suicide for people with dementia, a controversial issue that has been at the center of ongoing debate.

Select recommendations for action ...

At the individual level

- Get informed about available diagnostic, care and support services and programs through a variety of media and familiarize yourself vis-à-vis your rights (e.g. advanced care directives, assigning of legal guardianship, consent or non-consent to medical procedures, etc.);
- Discuss concerns about your own or a family member's cognitive function with a physician;
- Have frank and open conversations with family members and friends about aging, about the risks of dementia, and about preferred care arrangements in case of diagnosis;
- Seek out and ask for practical and psychological support (from care services, family and friends) when the burden of caring for a person with dementia becomes too large to bear alone;

- Be sensitive and supportive of people with dementia in daily life, while at the grocery store, waiting in line at the bank, at public events, on the street, etc.

At the community and organizational level

- Establish a public forum to discuss the topic of dementia and related issues;
- Fight the stigma associated with dementia by providing platforms for people with dementia to interact with their local community and tell their story;
- Provide support for informal, family carers, i.e. day care programs, respite care, counseling and peer-to-peer support for informal, family carers is available, accessible, and is tailored to meet individual and gender-specific needs and schedules;
- As formal care providers, take a holistic, person-centered approach to care in which the person with dementia's life wishes and preferences guide care planning;
- As formal care providers, aim to relieve family members of the most physically intensive caring tasks and to increase the 'quality time' between people with dementia and their loved ones;
- All care decision-making should be participatory and care professionals should actively seek to involve the persons with dementia and their family carers in all care decision-making.

At the state level

- Develop legislation and procedures that allow people with dementia to be involved in all decision-making related to their care and to keep control over their lives for as long as possible;
- Invest in rigorous research and pilot interventions that include people with dementia as participants and co-designers;
- Invest in rigorous qualitative research to define quality of life and wellbeing from the perspective of people with dementia;
- Create space for diverse stakeholders to participate in and contribute to drafting legislation, including patient advocacy groups and experts from different professional groups, including ethicists;

- Draft and implement agreements in collaboration with other countries on standardized benchmarking guidelines to make international comparability possible for researchers and policymakers;
- Strengthen health information sharing infrastructure to enable the sharing of health data across institutions.

Chapter 1.

Introduction

Awareness of dementia-associated challenges is growing among European policymakers

In 2001, France became the first European country to launch a national dementia strategy, with the overarching objectives of promoting early diagnosis and improving care for people with dementia (PwD)¹. Eleven other European countries have since launched national plans or strategies for dementia and virtually all European countries have introduced policies aimed at supporting and improving care for PwD. In 2009, the European Parliament voted to adopt a European Action plan on dementia, firmly cementing dementia in the European policy agenda. While these steps testify to an increased awareness of the scale in and impact of dementia on European countries and to the political will to address it, many of the same issues remain at the forefront of research and policymaking. This is evidenced by the fact that France's newly launched national dementia strategy from 2014 (The neurodegenerative diseases plan for 2014-2019²) included markedly similar objectives as had been set more than a decade earlier.

Today, 10.5 million Europeans are living with dementia and an estimated 2.5 million new cases arise each year (Prince et al., 2015). As the incidence of dementia has grown rapidly and the number of people with the condition is expected to almost double every 20 years, experts are calling for a renewed and concerted effort to address the “*dementia epidemic*”. Almost two decades since dementia first gained widespread recognition as a key public health challenge and with no medical cure on the horizon, there is increased urgency to step up efforts to manage, and ultimately to prevent and effectively treat the disease³. In this context, we believe it is timely to take stock of the knowledge and experiences that researchers and practitioners have accumulated with regard to improving dementia care. Such insights can serve to inform efforts to make dementia a health policy priority both at the national and international level and can contribute to the evidence base for more effective and better targeted policies and strategies for dementia.

The shift of dementia care towards community settings has been slow and problematic

Among the approaches with the most diffuse support is the relocation of the bulk of care away from residential institutions and towards the community (Moise et al., 2004). Two core arguments underpin this shift: the prioritization of user preferences and quality of life by allowing PwD to remain at home for as long as possible; and the pursuit of cost efficiency in light of increased pressure on public budgets to maintain fiscal sustainability (Ilinca et al., 2015). But while many countries have long pursued the development of community-based services with the intention and in the hope that it will gradually reduce the need for

institutional care, progress has been slow and halting. In fact, experts estimate that anywhere between 20 and 50 percent of people with Alzheimer's disease in Europe are cared for in institutions (Alzheimer Europe, 2006) and that the majority of older residents in long-term care institutions have some form of dementia (Matthews & Denning, 2002) – with more recent estimates placing the figure above 80 percent (Quince, 2013).

Against this backdrop, we set out to explore what constitutes good community care for PwD, and to develop a handbook for policy decision-making that can serve as a basis for future assessment of community-based care arrangements for PwD.

We discuss an analytical framework and 5 tension-points in dementia community care

We draw on a scoping review of the academic and grey literature published between 2008 and 2016 to propose a conceptual framework for community care for dementia (for a detailed description of the review parameters please refer to the Methodological Annex). The framework forms the basis of our analysis in subsequent chapters of the handbook and attempts to capture the complexities and interdependencies inherent to the organization of community-based dementia care along the disease trajectory, recognizing the roles played by the various actors involved. Furthermore, we include socio-cultural, economic, and legal and governance elements of community care for PwD in our framework. While we do not develop each of these dimensions in depth, we emphasize instead how each interacts with and affects the organization and quality of community-based care by linking them with 5 core tensions, or 'Tension Points' within the system. The framework was refined and validated in the course of an expert focus group convened for that express purpose. The focus group included representatives of 5 European countries and consisted of a mix of academics, practitioners and representatives of patient groups (for more details, please refer to the Methodological Annex). From the reflections of our expert participants, we distilled a series of critiques and recommendations, some addressing well-documented gaps and challenges in the provision of community care for dementia, others describing more broadly the consensus of the group on trends in the field and desirable policy developments. The discussion of the ethical and legal dimensions of community care for PwD (Chapter 8) was informed by the initial literature review, additional desk research, and by 5 interviews with experts from France, the Netherlands, and the UK (Scotland and England).

The handbook is structured as follows: Chapter 2 introduces our conceptual framework for dementia community care and the 5 Tension Points. In subsequent chapters each of these dimensions is addressed in turn, focusing on how each issue is framed in the specialized literature and on the potential solutions

and opportunities for improvement in practice. Chapter 3 addresses questions related to the *desirability of community-based care*, from costs and safety to user preferences and care quality. Chapter 4 shifts the focus to potential conflicts arising from the *different perceptions of care needs* arising in community care for PwD and how these are reflected in decision-making processes. *Recognition of the needs and experiences of informal caregivers* is the theme of Chapter 5, in which the complexities of organizing effective formal support services for family caregivers are discussed. Chapter 6 delves into the challenges related to *care coordination and what constitutes an appropriate mix of formal care* for persons with dementia living in the community, taking into consideration the roles that different groups of care professionals play. Chapter 7 focuses on issues related to *assessing community care for PwD*. In Chapter 8, the most prominent *ethical and legal issues in dementia care* are described and further explored through the presentation of 3 country case studies. Finally, in Chapter 9 we synthesize the main findings and insights from each of the chapters in order to propose a series of *recommendations to guide policymaking related to community care for PwD*. Throughout the subsequent chapters, we include ‘*In the Spotlight*’ text boxes detailing internationally occurring initiatives related to community care for PwD. It should be noted that not all of these initiatives have been rigorously evaluated and thus should not be considered ‘good practice’, but rather interesting praxis examples for further consideration.

Notes

- 1 Alzheimer Europe: <http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Strategies>
- 2 Ministère de l'Éducation nationale, de l'Enseignement supérieur et de la Recherche & Ministère des Affaires sociales et de la Santé (2014) - Plan maladies Neuro-dégénératives 2014-2019, Stratégie Nationale de Santé
- 3 Dementia is not a specific disease. The term is used in a general sense to describe a wide range of conditions associated with decline in cognitive skills. The most common types of dementia are Alzheimer's disease (60-80% of all cases), vascular dementia, dementia with Lewy bodies, mixed dementia and Parkinson's disease.

Chapter 2.

Theoretical framework & The 5 ‘Tension Points’

Framework recognizing the complexity of dementia care over the life course

Our analysis builds on a conceptual framework (see Figure 1), which attempts to capture the way in which community care for people with dementia (DCC) is arranged in practice. Fundamental to this conceptualization is the recognition of the different, albeit interdependent, roles played by different actors/stakeholders. The interaction between different actors is the determining characteristic of our framework for DCC, and for this reason we choose a set of interlocking cogwheels to represent the dynamic relationship between the system’s core components. The arrows placed within the diagram are intended to suggest not directionality but rather reciprocal action: just as the movement of one cogwheel has consequences for the workings of the larger machine, so too the activation and involvement of each individual actor at different points in the trajectory of the disease has an impact on the overall system of care.

People with dementia co-participate in the care process

At the center of the care process and represented by the deep blue cogwheel in our diagram, is positioned the *person with dementia*. Within this framework, the person with dementia is considered not only a patient or an ‘end-user’, but also an individual with a life story that precedes the symptoms and diagnosis of dementia; an individual with needs that extend beyond the scope of nursing care, and with express wishes and desires about how he/she wants to live their life. In addition, the framework considers self-management of dementia – despite receiving relatively little attention in the literature (Quinn et al., 2015) – a key part of the care process as individuals with dementia learn how to deal with symptoms, compensate for accumulating cognitive deficits, manage day-to-day tasks and address the progressive functional decline. Equally important, PwD cope with the psychological consequences of diagnosis and living with dementia, adjusting their lifestyles accordingly.

Informal caregivers are both providers and users of care

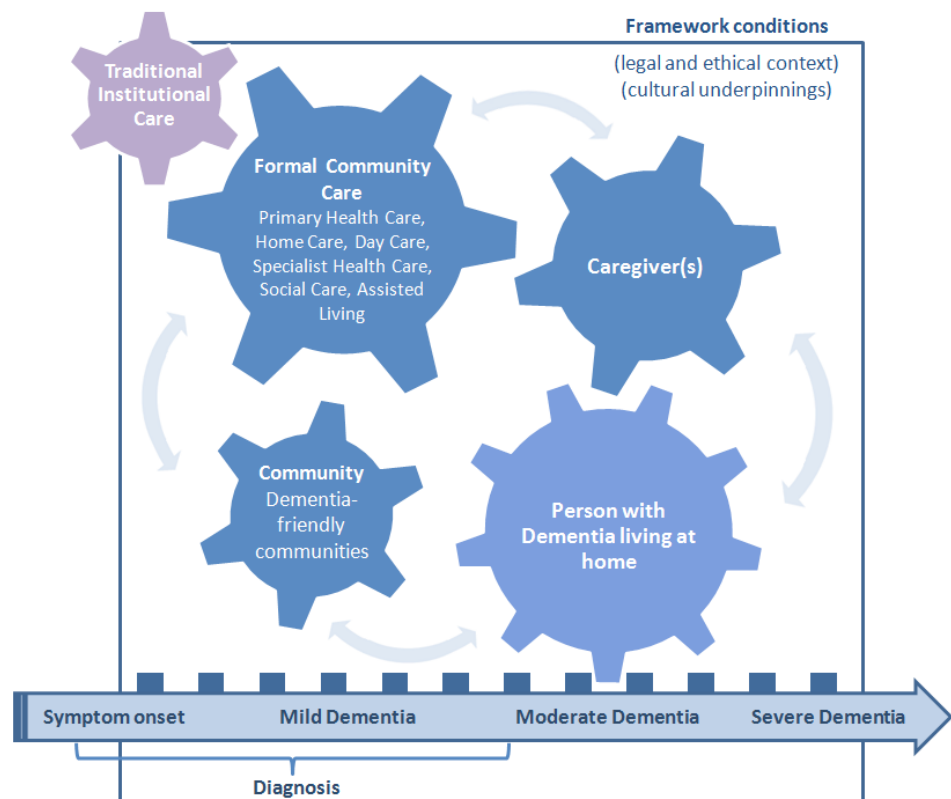
Three light blue cogwheels surround and interface directly with the ‘person with dementia’ cogwheel. They depict the actors that interact directly with the person with dementia in the process of community care. On the right-hand side, the *informal caregiver(s)* provides companionship and support to the majority of individuals living with dementia in Europe. In fact, as is the case with care for older people more generally, most dementia care is provided at home by family members (often spouses or adult children), the large majority of it by women (Erol et al., 2015). Caring for someone with dementia can be emotionally and physically challenging, so the framework considers family caregivers as both

providers of care as well as a group in need of a range of formal and informal support.

**Dementia
community care relies
on accepting and
supporting local
communities**

Crucially, in our concept of community care, PwD and their family carers should be able to rely on members of the wider community not only for support in the day-to-day management of the disease, but also for the assurance that neither they nor their loved one with dementia will be stigmatized or discriminated against because of their condition. A comparatively large body of research on enabling dementia-friendly communities has demonstrated that in **communities** where awareness of the disease is widespread, attitudes towards people with the disease are positive, and persons with dementia and their caregivers face fewer barriers in accessing key services, feeling empowered and remaining engaged in community life is made possible (Alzheimer Europe, 2015; Green & Lakey, 2013; Innovations in Dementia, 2011). Simple housing, transportation and navigation solutions can help PwD remain in their home environments longer and can help avoid social isolation and its detrimental health effects.

Figure 1. A conceptual framework for community-based dementia care



The third blue cogwheel represents formal care providers that contribute to caring for and supporting persons with dementia living in their home environment. Under the label **formal community care**, we group together primary health care (e.g. diagnosis, pharmacological treatment, referral, monitoring), specialist and in-patient health care (e.g. diagnosis, treatment of co-morbidities, management of behavioral symptoms), home care (e.g. personal care, skilled nursing care, household maintenance, companionship), day care and respite care programs, and other health and social care services (e.g. mental health counseling, rehabilitation and occupational therapy) provided in the individual's home or in an assisted living environment.

Institutional care services also play a role in community-based care

In the upper-left corner of our diagram, a violet-colored cogwheel represents **institutional care services**. This category of services is peripheral to community care, and is most often an alternative rather than a component of community-based services. To be clear, we define institutional care as long-term nursing care provided in dedicated residential facilities, e.g. nursing homes. This is distinct from assisted living facilities, alternative group housing and the like, which can be considered part of community care. Nonetheless, while we place long-term institutional care on the edge of our framework, we do not exclude it entirely as many nursing homes in Europe also provide services for PwD living at home (e.g. by operating dedicated day centers for PwD and offering temporary respite for family caregivers). As the different coloring suggests, we consider institutional care services in our framework and in our analysis only in as much as they act as episodic contributors to community-based care.

The dark blue rectangle surrounding the network of actors represents the **framework conditions**, or the legislative and socio-cultural context within which DCC operates. The legal and cultural context in which a national long-term care system is embedded defines the scope and the boundaries of community-based care services and can act both as facilitator and barrier to service development and operationalization. For example, legislation governing entitlement to and eligibility for care and support services will determine to a large extent the services that are available and accessible to older PwD. Conversely, prevailing cultural attitudes and values can, in practice, undermine or render less relevant legal provisions. A good example of this is the stigma associated with dementia in many countries.

Care needs change along the disease trajectory

Finally, the dark blue arrow located in the lower part of the diagram and pointing left to right marks the **disease trajectory**, or the main milestones in the progression of dementia as experienced by the person with the disease. Individuals with dementia have to cope with the onset of symptoms, followed by progressive cognitive decline (from mild to moderate and finally severe or advanced

cognitive impairment) with a diagnosis generally being made as mild or moderate symptoms manifest themselves. An important caveat here is that under-diagnosis remains a crucial challenge in improving access to and quality of dementia care services. Approximately half of those experiencing symptoms of dementia never receive an official medical diagnosis (Prince et al., 2015). For this reason, we do not consider diagnosis to be one of the phases of the disease trajectory in our framework, but include it rather as an independent element. The disease trajectory arrow adds a dynamic dimension to the framework. Dementia is an evolving, degenerative condition and as cognitive functioning declines, the care and support needs of persons with dementia change and often intensify. While many PwD self-manage with little support during the early stages of the condition, as they progress through moderate and severe cognitive impairment, often linked to ADL dependency, they become increasingly reliant on family and formal caregivers. In other words, as we move along the disease trajectory, the roles of the different actors and the balance of care among them shifts in order to respond to the changing needs.

As the foundation for our conceptual framework, we propose the following definition for dementia community care:

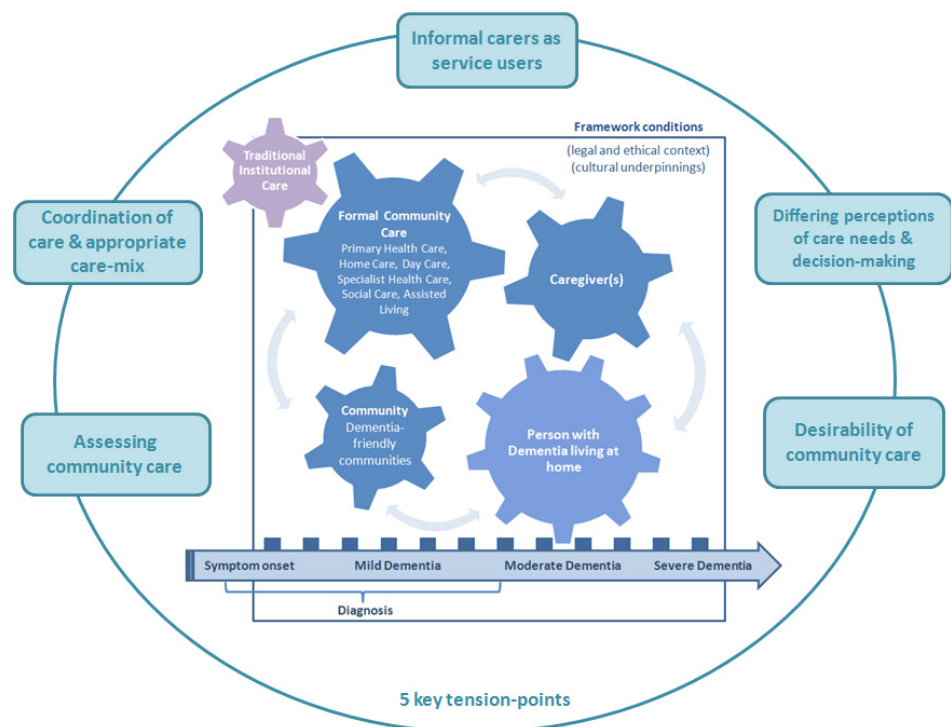
Care for PwD living in the community is generally understood to include all forms of assistance for the person with the disease as well as support for their informal caregivers (Low et al., 2013; Jansen et al., 2009). This encompasses a range of services provided in the home (e.g. personal care, nursing care), in the community (e.g. health care, day care programs, transportation and meal delivery services) and in dedicated facilities (e.g. rehabilitation, respite care) by care professionals, families, volunteers and wider social networks.

Community care extends beyond the services provided in the formal sector

The definition we propose emphasizes that community-care services are not directed exclusively at PwD but also at informal caregivers. Caregivers are increasingly recognized as key service users by researchers, practitioners and policymakers alike. Furthermore, our framework underscores that community care in its fullest sense extends beyond care provided by care professionals and the formal sector. It is the care provided by families, friends and local communities that accounts for the vast majority of support provided to persons with dementia living in their homes. It is therefore vital to the efficient functioning of community care that the resources of the wider community are successfully mobilized and that families are supported in their efforts to provide care. Finally, our definition reflects an integrated approach to care, whereby a multitude of care professionals across the health and social care settings and across institutional boundaries coordinate their efforts in order to provide seamless access to comprehensive services for persons with dementia living at home.

To summarize, the definition and the conceptual framework we propose seeks to capture the complex nature of community-based dementia care. Specifically, by recognizing that care for PwD is co-produced by a variety of actors and that it is a dynamic process that is constantly evolving in order to adapt to users' changing needs. Building on this schema, we formulate five key dimensions involved in community care as they emerge from a review of the literature and from consultation with experts in the field (Figure 2).

Figure 2. Five “tension-points” in dementia community care



5 Tension points arise from the interaction of actors and different needs and perspectives

We call these dimensions ‘Tension Points’ because each pinpoints a challenge or a series of challenges that can arise when different actors, interests and external factors intersect and which directly or indirectly affect the quality of care. They are:

- **Desirability of community care** – focusing on the delicate balance between cost-efficiency and user preferences, as well as safety and independence of the person with dementia;
- **Differing perceptions of care needs & decision-making** – focusing on the conflicts arising from the different perceptions of diverse actors involved in the care process;
- **Informal carers as service users** – focusing on the often overlooked role of family carers and the need to develop better support services that are tailored to their needs;

- **Coordination of care and appropriate care mix** – focusing on the challenges involved in defining an optimal care mix and ensuring that care delivery is integrated;
- **Assessing community care** – focusing on the challenges involved in the measurement of outcomes, processes and structures in dementia community care.

While we have attempted to be as comprehensive as possible and cover the most important dimensions of care for PwD in our analysis and framework, we recognize certain limitations of the present study. Topics that we were unable to address in detail due to the restricted scope of our research include: the use of pharmaceuticals in dementia care; the role of ICT-based solutions, e.g. smart homes; early-onset dementia; the realities of dementia care in urban versus rural environments; elder abuse; PwD with migrant backgrounds and migrants as carers; and persons with dementia as informal carers themselves. These are areas of significant importance meriting further research and investigation.

Chapter 3.

Desirability of community care

In a concerted move away from traditional institutional care, providing community-based care services for older people living at home is increasingly the preferred policy in many European countries (Mansell et al., 2007; Lipszyc et al., 2012; Verbeek et al., 2012). As with general LTC services, community-based care for PwD is considered preferable from a user (societal) perspective (López et al., 2012; von Kutzleben et al., 2012; Singh et al., 2014; Nikmat et al., 2015). Yet citing widespread user preference for community-based home care neglects consideration of the additional demand that caring for someone with dementia requires of family members and other informal caregivers (Bleijlevens et al., 2015).

User preference for community care

The importance of remaining in one's home environment has become a prominent theme in aging discourse in recent years, underlined by the 'aging in place' movement and increasing support at the EU and national levels for policies that support 'independent living' and 'active aging' (Walker, 2008; WHO, 2002; von Kutzleben et al., 2012). Considerable research demonstrating people's preference for living at home as they age has been carried out (Iwarsson et al., 2007; Nikmat et al., 2015). For PwD, the preference for living at home and utilizing community care services is perhaps even more poignant as a number of international studies have shown that environmental factors, specifically being in a familiar environment, can mitigate the psychological distress and behavioral symptoms that commonly accompany the disease (Gabriel et al., 2015).

People with dementia express a strong preference for care in their homes...

In terms of the impact of care in different settings on the wellbeing of PwD, the evidence base is less well developed and less straightforward in its message. One of the few studies to compare quality of life (QoL) of people with (mild) dementia living at home versus in institutional care finds that PwD receiving home care self-report higher QoL on all measured scales, as well as higher levels of social connectedness (Nikmat et al., 2015). Beerens and colleagues (2014), however, comparing QoL and quality of care (QoC) of persons with dementia in institutional long-term care and formal home care in 8 European countries, do not find significant differences in self-reported QoL across care settings within the different countries. The study measures QoL using the Quality of Life-Alzheimer's Disease Scale (QoL-AD), collecting self-reported data from the PwD (unless cognitive function, as measured by the standardized Mini Mental State Ex-

... But it is not clear that QoL is higher for those receiving community care

amination instrument-MMSE is below a certain threshold) and from proxy reporting by a family caregiver (Beerens et al., 2014). While significant differences in self-reported QoL are not identified overall, QoL measured by proxy reporting in England, Germany, the Netherlands, and Sweden was rated *higher* in institutional long-term care settings than in home care. In Spain, by contrast, QoL measured by proxy reporting for PwD receiving care at home was rated higher (Beerens et al., 2014).

The preferences of PwD should be weighed against those of their caregivers

Assessing QoL of PwD continues to be a challenge for researchers given the reliance of many measures on proxy reporting and the lack of congruence between reporting by the person with dementia and formal and informal carers (see Chapter 7). Designing a more accurate measure of QoL is one of the points highlighted by the expert focus group as a priority requiring further investigation as well. The general preference for aging in place must be considered jointly with the preferences and wellbeing of family caregivers in light of the significant role informal carers play when someone with dementia is being cared for at home (Gustavsson et al., 2010). Caring for someone with dementia can be both physically and psychologically taxing (Alzheimer's Research UK, 2015; Bunn et al., 2015; Alvira et al., 2015), with evidence suggesting that in many families, there comes a point at which family caregivers consider home care no longer to be tenable due to the burden of informal care, concerns about the safety of the person with dementia, and often the presence of co-morbidities (Bleijlevens et al., 2015; Borsje et al., 2015, 2016).

Safety versus autonomy

Can carers recognize a right to risk for people with dementia?

The safety of the person with dementia is another important consideration to be weighed when making decisions about care. Being cared for in the community exposes an individual with dementia to risks and may expose others as well. However, the literature suggests that care professionals and family caregivers tend to overestimate the need for supervision (Alzheimer Europe, 2014). A review by Bunn and colleagues (2015) demonstrates that one of the primary conflicts between family carers and PwD revolves around questions of safety versus user choice and autonomy. While PwD often associate formal care with loss of independence and are reluctant to sacrifice their autonomy, caregivers are much more likely to give primacy to safety concerns (Bunn et al., 2012; von Kutzleben et al., 2012; Alzheimer Europe, 2014). In Chapter 8, the ethics of the autonomy versus safety debate and the legal provisions applied in different country contexts are described in greater detail.

A mixed picture in terms of costs of community versus institutional care

The picture afforded by national and international studies carried out to date concerning the cost of community-based versus institutional care is mixed (Wimo et al., 1997; Gustavsson et al., 2010; Quentin et al., 2010). From a public sector costs (economic) viewpoint, the cost of caring for someone with dementia in a traditional institutional setting, i.e. a nursing home, is more expensive for public budgets due to accommodation costs and the high unit costs and intensity associated with nursing care (Sköldunger et al., 2012; Wübker et al., 2014). Yet once disease severity, the societal costs of community care (e.g. cost of informal care), and the specificities of different countries' LTC systems are taken into account, the picture becomes decidedly more complex.

The importance of including informal care in cost estimates

A study using data from the German Study on Ageing, Cognition and Dementia in Primary Care Patients (AgeCoDe) finds that the societal costs of caring for PwD in the community can be considerably higher than nursing home costs (Leicht et al., 2013). Likewise, in a study from Taiwan, Kuo and colleagues (2010) conclude that while the direct and total costs of institutional care are significantly higher than home care, the indirect or societal cost (defined here as unpaid care cost provided by informal carers) of home care is, not surprisingly, significantly higher in home care than institutional care. The authors also find that while direct costs were significantly influenced by both the type of care (home versus institutional care) and level of physical dependence of the person with dementia (measured using the Barthel's Index of ADL), indirect costs are affected only by the type of care (Kuo et al., 2010).

Costs to informal carers account for 30 to 60 percent of community care costs

Focusing on data from Spain within the framework of the RightTimePlace-Care study (Farré et al., 2016), the authors find that informal care for PwD (defined as assistance with ADL and IADL) accounts for 75 percent of all care provided and generates the majority of costs (€1,956/month, or €23,120/year). Community care, defined by the authors as care provided by a district nurse, home help, day care and transportation assistance, comes second in terms of costliness (Farré et al., 2016). This pattern is supported by findings from another multi-national study comparing Spain, Sweden, the UK and the US and which looks at 3 different measures of dementia disease severity (cognitive function, ADL ability, behavioral symptoms) as predictors of the costs of care for PwD living in the community (Gustavsson et al., 2011). The authors of the study

demonstrate that the primary resource component utilized is informal care costs, ranging between 30 and 60 percent across the countries included in the study, followed by community care costs, ranging between 10 and 40 percent (Gustavsson et al., 2011).

In terms of general cost patterns across countries, the ICTUS study (Gustavsson et al., 2010), a research endeavor comparing resource use and costs across 12 European countries, finds that whereas community care and medical care costs are highest in Western Europe and lowest in Southern Europe, the cost of informal care is highest in Southern Europe and lowest in Northern Europe. It is evident from this and other comparative studies (Dodel et al., 2015; Tucker et al., 2015; Farré et al., 2016) that country variation in costs across different care settings is closely linked to differences in respective countries' long-term care systems and the availability, accessibility, and quality of formal care services. In Northern European countries, where formal care services are generous relative to, for example, the family-based care tradition that prevails in Southern European countries, and where various forms of residential care are more prevalent than in other care regimes, the costs of informal care and overall societal costs are lower.

In the Spotlight

In the Spotlight: MODEM Dementia Evidence Toolkit (UK)

Recently developed by a multi-disciplinary team of researchers across the UK, the MODEM Toolkit relies on a comprehensive set of quantitative methods in order to model the outcomes and cost-impact of interventions for patients with dementia and their caregivers up to 2040. In 2016, the publicly available web tool was launched which gives policymakers, care providers, interest groups, persons with dementia and their families access to a searchable database of international research, to summaries of the evidence on specific interventions; and to the web tool, which allows visitors to the site to make their own projections of expected care needs, the outcomes and costs.

More information at: <http://toolkit.modem-dementia.org.uk>

Functional ability as most important measure of disease severity in cost of illness studies

Different costs become more relevant at different stages of the disease

The different conditions grouped under the umbrella of dementia are all characterized by their degenerative quality, though the progression and the nature of the different disease stages can vary considerably from one type of dementia to another and indeed from one individual to another (Wimo & Prince, 2010). With few exceptions, as the dementia becomes more advanced, people with the condition tend to require more care and the associated costs increase (Leicht et al., 2013; Gustavsson et al., 2011; Quentin et al., 2010), particularly

when general frailty and multi-morbidity associated with advancing age are also considered (Bunn et al., 2015). In their systematic review of dementia cost of illness studies, Quentin and co-authors (2010) establish that across studies, the overall costs of dementia double from the mild to the severe stages. One study by Schwarzkopf and colleagues (2011), however, finds that the early stage of the disease can also incur high costs. The costs of medical care in particular, driven by diagnostics and initial treatment, are proportionally higher in the early stages of cognitive impairment than at later stages. By contrast, costs associated with informal and long-term care become more prominent in the moderate stage of the disease. Disease severity is thus a crucial predictor of costs of care.

Decline in cognitive functioning may not be the best measure for disease severity

While earlier research focused on cognitive function as the most accurate measure of disease severity, recent studies argue strongly for using measures of functional dependence, primarily assistance with activities of daily living (ADLs) but also instrumental activities of daily living (IADLs), as functional dependence has been shown to be a stronger predictor of and more easily translatable to a PwD's care needs (Farré et al., 2016; Gustavsson et al., 2010; Gustavsson et al., 2011; Dodel et al., 2015; Leicht et al., 2013; Wübker et al., 2014). ADL has been found to be a strong determinant of both formal and informal care costs, with IADL ability mainly anticipating informal care costs (Gustavsson et al., 2010). Gustavsson and colleagues (2011) look at three measures of disease severity – cognitive function, ADL ability and behavioral symptoms – and the relationship each has with the cost of care. They discover that while the different measures are correlated, for PwD living and receiving care in the community, stratifying by ADL ability reveals starker differences in costs as the disease progresses than cognitive function or behavioral symptoms. This finding holds true in all countries included in the study (ES, SE, UK, US) but is especially pronounced in Sweden, where the authors point to a 194 percent increase in the costs of care from high to low ADL function, compared to a 68 percent increase from mild to severe dementia, as measured by evaluation of cognitive function (Gustavsson et al., 2011).

A recently published study by Åkerborg and co-authors (2016) analyzes disease severity and healthcare resource utilization data from the Swedish National Study on Aging and Care (SNAC) to argue that dependence, as measured by the Dependence Scale (see Stern et al., 1994), should be considered an important measure of disease severity and progression in cost modeling on the grounds that it accounts for cognitive function, ADL ability and behavioral symptoms in a composite measure. The study reveals significant differences in cost from the first disease severity quartile to the fourth: total annual cost for a PwD increased from €9,140 in the first quartile, to €16,979 in the second, €33,671 in the third, and €72,571 in the fourth (Åkerborg et al., 2016).

Challenges in generalizing cost patterns

Despite some general commonalities in terms of the patterns of cost of care for PwD cited above, recent studies taking a comparative approach make it clear that it is difficult to make definitive generalizations about how much care actually costs in different care settings and at different points in the disease trajectory. This is due to real differences in terms of service availability and care mix across and between countries, and just as importantly, to the different methodological approaches applied in respective studies. As addressed earlier in this section, the primary measure of disease severity (e.g. cognitive function, behavioral symptoms, or functional ability) employed and the instruments used to assess it are far from uniform. A review of cost of illness studies reporting costs by disease stage (Quentin et al., 2010) maintains that a study's choice of objectives (determination of total costs vs. net costs), user sample (community-dwelling, institutionalized, or both), and cost categories (crucially, inclusion of informal care) largely explain variations in the pattern and size of calculated costs.

The Takeaway

If asked, most people will say they want to grow old in the comfort of their own homes, and PwD are no different. The preferences of older PwD concerning their care and end-of-life arrangements should be at the center of individual care planning and should be reflected in policies and provisions governing care at the national and regional levels. However, from a policymaking point of view, there are a number of other considerations that should also be taken into account. Foremost among these is the preference of informal, family carers. The care provided by family members, their support needs and the potential effects on their wellbeing factor heavily in the indirect costs of community care. Costing exercises that do not take a societal perspective, i.e. that do not consider indirect costs, do not provide an accurate picture of the real benefits and drawbacks of community-based care versus institutional care. While research tells us that caring for people with early to moderate dementia at home has lower direct costs than institutional care, as the disease worsens and particularly as functional dependence increases, the direct costs of care in the community increases substantially as well. Also important to consider is balancing concerns of safety and security of the person with dementia and of the community at large against limitations on his/her personal liberties. Most experts agree that at a certain point over the course of the disease trajectory, care at home for PwD becomes undesirable and unsustainable because of the intensity of care needs. Appropriate and adequate community care can, however, go a long way to delaying that eventuality for as long as possible.

Chapter 4.

Differing perceptions of care needs and decision-making over the disease trajectory

As depicted in the conceptual framework presented in Chapter 2, the four primary actors involved in community care for PwD are: the PwD him-/herself, the family caregiver(s), the formal care provider(s), and other stakeholders from the wider community. It is reasonable to expect that each group has different perceptions and experiences of the progression of the disease, and of the care needs of the person with dementia. Tensions can arise between the viewpoints, particularly between that of the person with dementia, and that of the formal and informal caregivers. While such tensions often arise in the case of other health conditions as well, dementia is distinguished from other age-associated diseases by its degenerative quality and by its effect on cognitive function, notably memory and verbal communication.

Stigma and fear still hamper open dialogue and support

The attitudes and reactions of members of society with respect to PwD and to a dementia diagnosis are likewise important to consider in the context of community care. Having dementia or having a family member with dementia can be stigmatizing, especially in countries where services are less well developed and public awareness of the disease is low. People with limited knowledge of the condition may assume that from the time someone is diagnosed with dementia, his/her mental capacity and decision-making capacity should be disregarded. This perception can have deleterious consequences for a person with dementia's employment status, and on everyday interactions within the community, e.g. in stores, in banks, etc. Indeed, studies have shown that one of the foremost barriers to early diagnosis is stigma, and the accompanying fear of being treated differently because of how members of the community perceive one's abilities and needs (Bunn et al., 2012; Maki & Yamaguchi, 2014).

The voice of PwD can be crowded out by those of their formal and informal caregivers

As different stakeholders interact during care processes and the relative negotiating power of each shifts as the disease progresses and needs and circumstances change, the question becomes: whose voice and interests are at the center of decision-making? From an ethical standpoint the interests of the person with dementia should always be at the core of the care process (Alzheimer Europe, 2014). Yet practical considerations often take precedence, and the wishes of the person with dementia can become subsumed by those of the family caregivers and professional carers.

Perceptions of care needs

People with dementia report fewer and different care needs than their caregivers

Care needs here refer to the physical, social, and psychological needs of the PwD, as well as the family caregiver (see Chapter 5). Differences in subjective and objective care needs of PwD are common and can be stark (Low et al., 2013; von Kutzleben et al., 2012; Miranda-Castillo et al., 2013). Family members sometimes underestimate the cognitive capacity of the PwD. In a systematic review of studies focusing only on the expressed needs of PwD, von Kutzleben and colleagues (2012) indicate that the majority of needs voiced by PwD are related to social inclusion and maintaining a positive sense of self and overall well-being (von Kutzleben et al., 2012). In general, PwD report fewer unmet care needs than their formal or informal caregivers, and emphasize different kinds of needs.

A study from the Netherlands (van der Roest et al., 2009) in which dyads of PwD and their family caregivers are interviewed to elicit perceived care needs of the person with dementia from both perspectives, finds that frequently reported unmet needs by the person with dementia include memory, information, and psychological distress, while caregivers most commonly cite memory, daytime activities, and company (van der Roest et al., 2009). Miranda-Castillo and colleagues (2013), interviewing PwD, their informal caregivers and formal care professionals in the UK, determine that PwD report fewer unmet needs than either informal or formal carers. Formal care professionals, representing a sorely under-researched perspective, were also found to report significantly more unmet needs than either PwD or informal caregivers (Miranda-Castillo et al., 2013). The authors also find that while all three groups most commonly report daytime activities (e.g. social, stimulation or leisure activities), company, and psychological distress as the foremost unmet needs, the latter is most frequently reported by PwD (Miranda-Castillo et al., 2013). These findings underline the point that wellbeing, particularly its social and psychological components, is the most important consideration for PwD, while caregivers tend to concentrate on needs associated with practical, day-to-day concerns.

More services to combat psychological distress and social isolation are needed

Nonetheless, there does seem to be consensus across the three groups that psychological distress, social isolation, availability of information, and daytime activities are the main areas that should be targeted by services for PwD. In an Australian study of community-dwelling PwD and their informal caregivers, Harrison and co-authors (2014) find that the joint expectations of persons with dementia and their informal caregivers – tasks around the home, personal care and transport – do not correspond to assessed unmet needs, which include social and leisure activities, needs for physical activity, socializing, and eating and dietary requirements. The misalignment in the number and type of unmet care

needs recorded in the literature and reported by the different stakeholders emphasizes the importance of capturing the perspective of the person with dementia and including them in decision-making about their care, in the design of services, and in future research on the subject.

The geographical coverage of community care services should be improved

One study from Canada (Jansen et al., 2009) provides insight into formal home and community care professionals' views about the needs of PwD and their family carers, and the extent to which existing services are succeeding in meeting those needs. Care professionals included in the study perceived the need for comprehensive personal care for the person with dementia, together with the application of specialized knowledge about dementia (Jansen et al., 2009). In addition, care professionals cited a lack of community-based dementia care infrastructure, particularly in the rural areas, which manifested itself in the mismatch between the needs of persons with dementia and their family caregivers, and in the ill-suited design of existing palliative and respite care services (Jansen et al., 2009).

In the Spotlight

In the Spotlight: Into D'mentia (NL)

The Into D'mentia project aims to help care professionals and informal carers better understand the experience of living with dementia by providing trainings using virtual reality simulation that can take a carer "into the world" of a PwD. The project has been inspired by the belief that a lack of understanding about what care recipients are experiencing often leads to carers becoming overstressed and hampers their efforts to provide effective support.

The training program was developed by a consortium of universities, health institutions and companies, and consists of a one-hour virtual reality simulation of how a PwD experiences the world and tackles daily tasks. The training program was introduced into the Dutch LTC system in 2013 and has received positive reviews from users.

More information at: [http:// www.intodmentia.com](http://www.intodmentia.com)

Each viewpoint – that of the person with dementia, of family members and other informal caregivers, and that of care professionals – offers important insights about the needs and preferences of the person with dementia and the family caregiver(s) over the disease trajectory, and each should be taken into consideration in the design of services and in the development of individual care plans, with an emphasis on placing the voice of the person with dementia at the center of care planning.

Objectives and design of care services vis-à-vis care needs

The disconnect between what people expect care services to provide and what they actually deliver, and the presence of unmet needs suggests that the design of existing community-based services is in some cases inappropriate. In certain country contexts, this is due to the fact that long-term care is not designed to be person-centered, nor is it tailored to the specific needs associated with dementia. Take-up of community-based care and support services for PwD and their informal caregivers are commonly under-utilized in many countries (Ploeg et al., 2009; Gabriel et al., 2015; Weber et al., 2011), both because of a lack of awareness and information about the services available, and because some services are not considered useful or helpful by target groups. Respite care for family caregivers is an apt example. Despite knowledge of the negative impact that sleep disturbances on the part of PwD can have on the health and well-being of caregivers (Borsje et al., 2015; Alzheimer's Research UK, 2015), overnight respite care is seldom available.

Inappropriate design and lack of development for some support services

Between research and practice there exists an interesting paradox in that a significant number of studies have investigated the effectiveness of interventions targeting family caregivers, and many scholars have urged policymakers internationally to invest in services for informal carers, yet actual implementation of such services is lagging (see Chapter 5). On the other hand, methodologically rigorous studies assessing interventions for PwD are scarce because of the difficulties researchers face in involving PwD in clinical trials, and because of the unsatisfactory quality of outcome measures that have been developed to date (Zabalegui et al., 2014). Specifically, research shows that commonly identified issues associated with the design of services for PwD and family caregivers include: the emphasis of care professionals on addressing acute, emergency situations rather than on providing continuous support that addresses the full range of users' needs, importantly psycho-social support (Carpentier et al., 2008; Bunn et al., 2012); the lack of understanding on the part of care professionals of family caregivers' needs, together with the general lack of low-threshold (i.e. easy to access) formal services aimed at supporting family caregivers (Singh et al., 2014); and lastly, the scarcity of palliative and end-of-life care for PwD (Rosenwax et al., 2015; Goodman et al., 2010).

Palliative care services for community-dwelling PwD are both much needed and under-developed (Goodman et al., 2010; Rosenwax et al., 2015). Specifically end-of life care is in most contexts insufficiently tailored to the needs of users with dementia in the way it is structured, in its approach to care provision, and

with respect to the availability of specialist support and level of staff training. A review of end-of-life care by Goodman and colleagues (2010) finds that of the limited research available evaluating palliative care services for PwD, a majority demonstrate that utilization of palliative care by people living in the community is low, and services have not been shown to significantly improve the well-being of either the person with dementia or the family caregiver. A retrospective study of hospital use in the last year of life among recently deceased persons with and without dementia from Australia (Rosenwax et al., 2015) reveals that more than 70 percent of both the dementia and non-dementia cohorts in the study attended hospital emergency departments in the last year of life. Only six percent of the dementia cohort used community-based palliative care compared to 26 percent of patients in the non-dementia cohort, indicating that community-based palliative care does not appropriately target the needs of PwD. The study also reveals that those PwD who did not use community palliative care were hospitalized significantly more often than those who did (Rosenwax et al., 2015). This constitutes a missed opportunity in terms of improving the end-of-life experiences of people with the disease, which could be addressed by improving the design and communication of services.

Decision-making over the disease trajectory

Due to the nature of dementia, family members occupy a central position in care decision-making, even more so than in the case of other age-related chronic conditions. Family caregivers are often characterized as ‘access to care agents’ or as the initial ‘gatekeepers’ to care services for PwD because of the key role they play during the initial diagnosis stage and in coordinating care later on (Thorpe et al., 2009). Family caregivers are also often the only stakeholders with oversight of their loved one’s condition. They are relied on by the person with dementia to make care-related choices on their behalf, and are likewise relied on by professional carers to provide the narrative of the person’s experiences with the disease when he or she is no longer able to do so (Bunn et al., 2013; Thorpe et al., 2009).

Family carers are *de facto* gatekeepers to care for PwD

Reliance on family caregivers to serve as gatekeepers to care for PwD raises a number of ethical and practical issues. First and foremost, even in the best cases, it raises concerns about whose interests are actually being represented in decisions about care. As discussed earlier, even with the best intentions, a family member will have a different perception of the needs and preferences of the person with dementia than the person with dementia him-/herself; not to mention families where the person with dementia does not have relatives who have his/her best interests at heart, or where family members live far away

and are unable to provide more than perfunctory support and counsel. Lastly, it underlines the importance of providing family carers with adequate support services. A US study (Thorpe et al., 2009) on the barriers to take-up of community-based outpatient services for PwD reveals that the assessed life satisfaction of family caregivers affects whether or not PwD access certain services. People with dementia whose caregivers reported low life satisfaction or inadequate levels of external support were significantly less likely to access both primary care and specialist mental health care (Thorpe et al., 2009).

In the Spotlight

In the Spotlight: The Freiburg Model: shared responsibility for care through expansion of the welfare mix (DE)

The Freiburg Network of Residential Group Homes for People with Dementia (*Netzwerk Wohngruppen für Menschen mit Demenz*) is a network of group homes for people living with dementia in and around the German city of Freiburg. The Network's members share a common philosophy and approach to care for PwD, one which emphasizes the concept of shared responsibility for and co-production of care by different stakeholders including the person with dementia, family members, care professionals, and civic actors at the regional and local level. Importantly, this cooperative approach is embedded also in the governance and financing structures of the Model, whereby family members actively participate in the management of the group homes alongside professionals, and costs are co-financed through the private contributions of residents, government funds and fund-raising.

Established in 2004 following its conceptual development and piloting by the Department for Aging and Care at the Protestant University for Applied Sciences in Freiburg, the Freiburg Model is an innovative type of care arrangement for PwD in Germany, located in the grey area between home care and institutional care. The Model is thus heavily influenced by efforts in Germany and elsewhere to expand the welfare mix, to deinstitutionalize, and to return to a community-based, local ownership and production of care. The Freiburg Model places the person with dementia's quality of life at the center of its approach to care. The daily routines of residents are structured around familiar domestic activities and tasks rather than on care as an end in and of itself. Each group home draws residents from the local community in an effort to promote residents' existing social networks and to encourage family members, friends and neighbors to participate in the daily lives of the person with dementia.

Since its inception, the Freiburg Model has paved the way for similar care arrangements by working with national, regional and local stakeholders to carve out space for its innovative approach within Germany's complex regulatory system.

Source:

Klie & Schuhmacher, 2007; <http://www.freiburger-modell.de/index.php>

Advanced care planning can help ensure the voice of the PwD is heard over the course of the disease

A continuing challenge in dementia care planning is how to ensure that PwD do not lose their voice and continue to take part in decision-making, even as the disease progresses. As described above in the section on different perceptions in care needs, the discrepancies in reported unmet care needs by the different stakeholders confirm the importance of including PwD in decisions related to their care. Higher correlation between family caregivers and care professionals than between PwD and their family caregivers indicates strongly that the wishes of PwD are not being fully represented (Miranda-Castillo et al., 2013). Encouraging PwD and their families to take part in advanced care planning (ACP) and advanced directives dictating care at or near the end-of-life, is one way to ensure that the person with dementia's preferences are heard. Unfortunately, relatively few people make such care plans, and decisions about end-of-life care are made too late, when the decision-making burden by necessity falls on family members (Van der Steen et al., 2016).

Most European countries have legal provisions in place making advanced care planning possible, usually through advanced care directives and/or the assigning of legal guardianship to a designated family member. The specifics of such provisions vary, however, from country to country, as does their actualization in practice. In France, for example, while multiple legal provisions are in place to accommodate the changing needs of individuals with dementia and other incapacitating diseases, the stigma that continues to be attached to dementia has meant that in practice, advanced care planning between care professionals and families has not been promoted to the fullest extent. In the case of the Netherlands, a technical aspect of the law governing advanced care directives has met with criticism for its ambiguity. The law states that a healthcare provider can deviate from a patient's written directive if "...he considers that there are well-founded reasons for doing so" (Dutch Civil Code, Article 450§3; cited in Nys and Raeymaekers, 2013), without specifying what such reasons might be. In Chapter 8, the ethical and legal dimensions of advance care planning are described in further detail.

There seems to be some progress in terms of research to develop innovative ways of involving PwD in decision-making as long as possible. An Australian study (Conway & Chenery, 2016) evaluates a multimedia tool designed to facilitate communication between PwD and formal home care professionals, and finds that the tool, specifically designed to overcome barriers to communication resulting from cognitive-linguistic impairments associated with dementia, brought about significant improvements in care professionals' self-reported awareness of their clients' needs, and in their skills in providing care to meet those needs (Conway & Chenery, 2016).

In the Spotlight**In the Spotlight: EmMa (DE)**

Led by a multidisciplinary research group at the Goethe University in Germany, the EmMa project aims to develop 'enhanced consent procedures' for PwD in order to improve their ability to participate in medical decisions and consent to treatment.

The researchers are utilizing new communication processes and methods in an attempt to compensate for the difficulties with verbal communication that PwD experience. To date, the team has developed an algorithm for the application of enhanced consent procedures in such a way as to take account of the individuality of PwD, and is currently running the evaluation phase at three test sites across Germany (Frankfurt, Heidelberg, Schlüchtern).

More information at: www.uni-frankfurt.de/53964717/EmMa

The Takeaway

Though each has its particularities and manifests differently and at different rates for each person, the diseases that fall under the umbrella of dementia distinguish themselves by eroding cognitive function over time. As a result, the decision-making capacity of PwD becomes impaired, making the act of decision-making about care and about other facets of life a major challenge for PwD and their families. The evidence suggests that not only does this place a heavy burden on family members who often have to step in, but that it can have very practical implications in terms of matching the care provided to perceived care needs. Studies investigating perceptions of care needs by the three main stakeholders involved – the person with dementia, the family carer and the care professions – have found that each group tends to emphasize different aspects of care and support. Persons with dementia are generally more concerned with being socially isolated and with losing their memory, while family carers point to support with daily activities as the most pressing need. Care professionals (a mixed group in itself), while they may have a better overview of the different kinds of care needs, tend to emphasize more clinical, medical needs. It is perhaps not surprising then, that recent research has pointed to a number of ways in which existing services are ill-suited to meet disparate needs, most notably in the cases of support services for family carers (e.g. respite care) and palliative and end-of-life care for PwD. While the tide is turning in some countries, the stigma associated with dementia remains one of the key barriers to open discussion about care needs (i.e. advanced care planning), both within families and in the public discourse.

Chapter 5.

Carers as service users

Family caregivers are “the invisible second patient”

Persons with dementia living at home are usually accompanied and supported over the course of the disease by family members and other informal caregivers. In this way, caregivers share in the burden of care, often with negative consequences for their wellbeing. By taking on various, and in some cases intensive, care tasks for which they are seldom remunerated, they shift a considerable part of the societal economic costs of dementia (as discussed in Chapter 2) to personal costs. It has been shown that informal caregiving can have negative effects on financial standing, earnings potential and the ability to remain in the workforce (Brodaty & Donkin, 2009). Furthermore, family caregivers of PwD are vulnerable to a host of adverse health and social outcomes, including but not limited to psychosocial and physical morbidity, social isolation and reduced quality of life (Schulz et al., 2006; Torti et al., 2004; Eters et al., 2008). As PwD become increasingly more dependent, so too do the burden of care borne by family caregivers and the risks to which caregivers are exposed. As caregiving intensifies, family caregivers’ needs in terms of support increase, so much so that some authors describe this group as *the invisible second patient* (Brodaty & Donkin, 2009).

Caregiver burden and distress

Informal caregivers are at risk of psychological and physical morbidity

Caregiver burden or strain can be defined as the subjective and multidimensional response to stress and negative appraisal resulting from the process of caring for a dependent individual (Eters et al., 2008; Brodaty & Donkin, 2009). Systematic reviews of the literature reveal that most caregivers of PwD struggle with psychological symptoms: estimates of depression rates among caregivers vary widely across countries, anywhere between 23 and 85 percent (Brodaty & Donkin, 2009), while anxiety is estimated to affect up to a quarter of informal caregivers (Cooper et al., 2007). Poor mental health is often paired with physical health problems. Caregivers are more likely to report worse general health and a greater number of symptoms than non-caregivers (Schulz et al., 1990) and have been shown to be at increased risk for chronic conditions, cardiovascular diseases and risky health behaviors (Brodaty & Donkin, 2009). However, while all caregivers are exposed to the risk of being over-burdened by their care responsibilities, not all display equal vulnerability to stressors. The literature emphasizes as important determinants and moderators of family caregiver burden: behavioral symptoms of the person with dementia (e.g. agitation, aggression);

IADL dependency; intensity of informal care (i.e. time spent on care tasks); the nature of the relationship between the person with dementia and the family caregiver; lack of support from other family members; level of informal caregiver self-esteem; and schedule disruptions (Park et al., 2015; Alvira et al., 2015; Eters et al., 2008). In addition, as stressed by participants in the expert focus group, caregiving is not necessarily perceived as a burden by the carers themselves, with many finding joy in caring for their loved ones. As is well established in the literature on family care, there is a strong gender dimension to caregiving, with men and women reporting differences in how they experience and cope with caregiver burden. The culturally informed expectation that women take on family care tasks when they arise because they are 'natural' caregivers can lead to feelings of guilt and anxiety (Lavarone et al., 2014). Female carers tend to report higher rates of caregiver burden and are more likely to report negatively on the stress of providing care to a family member with dementia (Erol et al., 2015; Lavarone et al., 2014; Papastavrou et al., 2007). In terms of coping strategies, evidence suggests that while men tend to focus on problem solving and taking care of practical tasks, women adopt coping strategies that are more emotion-focused (Eters et al., 2008; Lavarone et al., 2014). It is thus important to keep the gendered experience of caring in mind when developing support services for informal carers.

Caregiver strain and QoL improve after institutionalization...

The negative health effects of intense caregiving can be ameliorated as care obligations are reduced or cease altogether. One research group within the international comparative RightTimePlaceCare study⁴, a project looking at best practices in the transition from formal home care services for PwD to institutional care, investigates the health-related QoL (HRQoL) of informal caregivers of PwD, drawing comparisons across the 8 study countries (Bleijlevens et al., 2015). They find that informal caregiver burden decreases and psychological wellbeing increases following admission of the family member with dementia to institutional care, albeit with significant differences across countries in terms of self-reported caregiver burden and HRQoL. Family caregivers in Southern and Eastern European countries reported higher care burden and lower HRQoL than their counterparts in other countries, a finding likely due to differences in availability and utilization of formal home care, as well as cultural factors. Similarly, Borsje and colleagues (2015) in their systematic review of the progression and course of neuropsychiatric symptoms in PwD living at home, note that psychological distress of informal caregivers improves after the person with dementia transitions from home to institutional care. Because of the strain this group of symptoms places on the relationship between the person with dementia and his/her family caregiver(s), neuropsychiatric symptoms are considered a strong predictor of institutionalization (Borsje et al., 2015; 2016).

... But institutionalization can also trigger anxiety, anger and guilt for informal caregivers

While a growing body of research supports the finding that institutionalization relieves caregivers of persons with dementia of strain and distress, guilt, anger and anxiety have also been documented responses among caregivers once the PwD transitions into residential care (Tornatore & Grant, 2002). Such reports highlight the need for support services for informal caregivers as they transition from their role as primary caregiver to being the relative of an institutionalized person with dementia. The overarching message is clear and well-supported by research: although caring for a loved one with dementia at home may be a matter of course for many families, without adequate support, the decision to do so can result in a heavy burden on the primary caregiver.

Need for support among informal caregivers

Services supporting family caregivers need to be further developed

Due to the proximity of the family caregiver to the person with dementia and their integral role in maintaining a high quality of life of those requiring care, it is often neither possible nor desirable to relieve family members of their caring responsibilities by shifting them fully onto formal service providers. Instead, caregivers should receive the support they need in order to alleviate the perceived strain and ensure that their wellbeing and health are safeguarded. Focus group experts stressed that formal care services should aim to relieve family carers of the 'heavy-lifting' or physically taxing tasks, thereby enabling them to focus on lighter tasks and tasks that are essential for maintaining their relationship with the person with dementia. The literature documents a host of interventions that have proven effective in reducing caregiver burden and improving carers' health outcomes, but it falls short of definitively establishing which specific services are most successful and which care professionals are best positioned to offer them.

Initiatives that are multi-dimensional and include both the PwD and the caregiver are most effective

In a meta-analysis of the literature, Brodaty and colleagues (2003) found that psychosocial interventions can help reduce psychological problems among caregivers and allow the person with dementia to be cared for at home longer. Such interventions are aimed directly at the caregiver and seek to provide the necessary tools and skills for coping with the burden of care (e.g. educational programs on dementia, therapeutic skill training, trainings to improve symptom management and problem solving skills) as well as psychological and emotional support (e.g. personalized or support group counseling). Because psychosocial interventions are well suited to respond to the need of advice and access to information that caregivers most often cite (Zwaanswijk et al., 2013) they have received much attention among researchers. Unfortunately, effects from such initiatives are mixed and often only temporary, but there is consensus in the literature that programs that are multi-dimensional, individualized and tailored to the specific needs of each caregiver, that actively involve both the caregiver

and the person with dementia in the intervention, and that are provided on a stable and continued basis are more likely to show positive, long-term effects (Zabelegui et al., 2014; Pinquart & Sorensen, 2006; Brodaty & Donkin, 2009). For example, as part of a comprehensive review of interventions for PwD living at home, Zabelegui and colleagues (2014) document the effectiveness of multi-component interventions that included case management, respite care and special physician training in reducing institutionalization and the use of other community services. It is noteworthy that the initiatives involved both PwD and their informal caregivers.

In the Spotlight

In the Spotlight: REACH II (USA)

The Resources for Enhancing Alzheimer Caregiver Health (REACH) program offers a service mix specifically designed to address the most commonly identified support needs of caregivers of PwD. This multi-site, multi-component program offers training (including information provision, role-playing, problem-solving, skills training, stress management techniques), counseling, telephone support and a peer support component. Interventions are tailored to individual needs evaluated through a caregiver assessment of depression, burden, self-care and healthy behaviors, social support, and problem behaviors.

Caregivers using REACH reported better quality of life, lower depression and care burden and higher self-care and social support. REACH II has been successfully adapted to use in the community.

More information at: <http://www.apa.org>

Nurses can play a key role in providing psychosocial interventions for caregivers

While generally described as formal care services, it is important to note that not all psychosocial interventions require the direct provision of formal care by professionals. As an example, peer-support groups have proven helpful to caregivers and can be organized and managed with limited professional involvement (Bunn et al., 2015). This raises a question about the extent to which care professionals are suited to provide caregiver support services, and which professional groups should do so. Because they are often the formal care providers with most direct contact with family caregivers and PwD, nurses are, in theory, well positioned to play a central role in managing family support, especially during the early disease stages (Alvira et al., 2015). Given their proximity to families, nursing professionals could help informal caregivers avoid negative health outcomes, provide individualized information, identify areas of need and direct caregivers towards the most appropriate support services. A UK-based review on the effectiveness of interventions provided by specialist mental health nurses (known as admiral nurses) to family caregivers of PwD, finds evidence, albeit weak, of positive results (Bunn et al., 2016). While caregivers value the support they receive, it is still unclear at what point in the disease trajectory there is

most scope for such interventions or whether they are comparatively more effective than other types of psychosocial support. Nonetheless, the existing body of evidence points to the necessity of ensuring that care professionals in all settings are better informed with respect to available services and care pathways and more able communicators; a situation most likely to be achieved within the context of case management (see Chapter 6 for further details). Information that is provided face-to-face and that addresses their personal and specific concerns is appreciated by caregivers much more than content provided online or in printed informational material (Gabriel et al., 2015).

In addition to informational and emotional support, caregivers of PwD living at home often express a strong need for practical support (Zwaanswijk et al., 2013). Such tasks as preparation of meals, podiatry services and management of medication can become burdensome for caregivers who welcome advice and support from care professionals (Gabriel et al., 2015). Similarly, access to transportation services and assistance in making home modifications which allow PwD to navigate their home and immediate surroundings with a greater degree of independence can considerably reduce the pressure on caregivers to monitor the whereabouts of the person with dementia and prevent their own social isolation (Gabriel et al., 2015).

Availability and flexibility of respite care arrangements need to improve

Another type of caregiver support that has been advocated for as instrumental in reducing caregiver strain is respite care. It encompasses a wide range of services provided either in the home or in institutional facilities (e.g. day care center, residential care facility) by care professionals or even by volunteers for a length of time that can vary between a few hours and weeks at a time (Maayan et al., 2014). What all these services have in common is the goal of providing temporary care to a person with dementia so as to temporarily free the primary caregiver of his/her care tasks for a determined period of time or in an emergency situation (emergency respite can be extremely useful to manage periods of ill health for the caregiver).

Caregivers value the time for themselves and the temporary break from their caring responsibilities (Low et al., 2013), and report feeling invigorated even after short respite periods (Salin et al., 2009). In fact, carers commonly express a need for greater availability and flexibility of respite services (Low et al., 2013; Maayan et al., 2014; Gabriel et al., 2015). To date, however, the evidence on the effectiveness and cost-effectiveness of respite care is inconclusive, with no significant effect being found on either reducing institutionalization rates for PwD being cared for at home or reducing caregivers' burden (Maayan et al., 2014). Wider availability, better targeting and more methodologically sound evaluations of respite care services in the future could help establish effectiveness.

In the Spotlight**In the Spotlight: Sonnweid Centre (CH)**

The Sonnweid Center applies to all its services a philosophy of inclusion of family caregivers in the design of care. The Centre personnel always hold interviews with the family members of the person with dementia who has passed away or left the institution (1 month later and then again 6 months later). Families are asked what kind of support was insufficient or lacking and how, in retrospect, the situation could have been improved and the information is fed back into the design and organization of care. Interestingly, the vast majority of caregivers report they regret not having used the available support earlier.

More information at: <http://www.sonnweid.ch>

Availability and take-up of carer support services

While the literature increasingly recognizes the salience and utility of a range of support services for caregivers, in practice, the provision of services lags behind. Caregivers often complain about gaps in service provision, about difficulties in accessing information and about the appropriateness and quality of services (Raivio et al., 2011). It is therefore not surprising that take-up of support services among caregivers of PwD living at home remains low, due mainly to limited awareness and a lack of effective referral by care professionals (Brodaty et al., 2005; Ploeg et al., 2009; Weber et al., 2011). Interestingly, female carers are less likely than men to accept and take-up external support (Erol et al., 2015). The stigma associated with dementia and the shame reported by many family carers of having a family member with the condition is also a demonstrated barrier to seeking both informal and formal support (Werner et al., 2012; Werner & Heinik, 2008). More effort should go into ensuring that present and potential future caregivers have enough information about service availability, how to navigate the system, and whom they can turn to for assistance. Importantly, support services geared towards family carers should also include counseling services that seek to reduce the stigma and feelings of shame experienced by family carers.

Good communication between formal and informal carers is essential

Gaps in information availability are partially explained by the tendency among care providers, in their discourse and in their assessments, to focus on the needs of the person with dementia, neglecting the support needs of family caregivers. Reviewing the literature on interfaces between formal and informal care for dementia, Carpentier and colleagues (2008) describe a lack of understanding between caregivers and care professionals that might explain the mis-

match between caregivers' needs and provision of services. On the one hand, practitioners seem to possess insufficient time and knowledge to orient caregivers towards the required services through the most effective care pathways. On the other hand, the reactions of caregivers themselves, whether driven by denial, stigmatization or other emotional responses, can be difficult to manage and render communication with care professionals difficult. Collaboration and effective communication between family caregivers and care professionals is crucial to the quality of dementia care provided in the home and to the experience of caring from the perspectives of both the informal caregiver and the care professional. Singh and colleagues (2014) point to three crucial stages along the disease trajectory when effective communication and good collaboration between formal and informal carers is most important: i) when early symptoms appear; ii) when significant changes in care needs are evident; and iii) when the burden of care surpasses the ability of the caregiver to provide support. At these key turning points informal caregivers are most in need of being supported and steered through the care process and care professionals are called upon to provide the necessary information and guidance. Unfortunately, if communication between formal and informal providers is deficient, trust between them as well as the successful transfer of information in both directions will be significantly reduced.

The Takeaway

Family carers have been referred to as the 'invisible second patient' because of the central role they play in providing home-based care for loved ones with dementia and because their own needs are often overlooked. People take on caring roles out of a mix of love, a sense of duty or obligation, and because alternative care arrangements are either unavailable or undesirable. A large body of research has shown that caring for someone with dementia can have a wide range of consequences for informal carers, including detrimental effects on their health and wellbeing, employment, and financial standing. Although the needs of informal family carers are increasingly being recognized, formal services that are tailored to their needs are still lacking in many countries. Peer-to-peer support groups and services providing support with daily care and activities have been found to be most helpful, together with access to professional counseling and advice services. Importantly, research indicates that formal support services should aim to alleviate the physically taxing aspects of care and the overall intensity of care, enabling family members to focus on spending quality time with the person with dementia.

Note

- 4 Countries included in the RightTimePlaceCare study are: Estonia, England, Sweden, Finland, Spain, France, Germany and the Netherlands (<http://rtpc.progressima.eu/index.php?id=14213>).

Chapter 6.

Care coordination and appropriate care mix

The need for multi-disciplinary services and care professionals

**Dementia
community care is a
multi-actor and
multi-disciplinary effort**

Formal care services should reflect the needs of both the person with dementia and the informal caregiver, both in terms of the kinds of services available as well as in the professional profile and skill level of care professionals. Community-based care encompasses a wide range of care providers and services across the health and social care sectors, from primary care to home nursing care, and day care programs to occupational therapy, mental health counseling, as well as programs offered outside the formal care sector by community non-profit organizations, charities, etc. It is by definition multi-disciplinary. Heterogeneous groups of care professionals, i.e. consisting of people with different professional backgrounds and qualifications and different professional experiences, are better positioned to respond to the diversity of needs of PwD and their family carers (Carpentier et al., 2008).

One of the key challenges for community-dwelling PwD and their families is effectively navigating the different service offerings. This is a well-documented challenge for users of LTC generally speaking, but persons with dementia have complex and evolving needs, as do their family caregivers, and as a result care can become particularly difficult to manage. A study by Ploeg and colleagues from Canada (2009) reports that family caregivers find that access to community care services can be a challenge because of the variety of small agencies providing services, the lack of a central access point, and a lack of easily accessible information concerning the availability of such services. Similarly, while acknowledging that multi-disciplinarity of community care services is desirable and indeed necessary to comprehensively meet the needs of PwD and their families, UK-based scholars (Sutcliffe et al., 2014) determine that currently, while the UK system promotes diversity in services available and the working together of multiple professional groups, the actual integration of these services and professional groups has yet to be achieved. The authors call for improved communication pathways between the different formal care professionals in order to be able to effectively develop personalized care plans jointly (Sutcliffe et al., 2014). Another study (Robinson et al., 2009) reinforces these findings, pointing to the need for better communication and information exchange between formal carers, specifically better accessibility and transferability of (trustworthy) informa-

Coordination and communication between different providers is essential

tion concerning patients with dementia. The same study also reveals that while the different provider groups expressed similar concerns regarding access and trustworthiness of information, each group was largely unaware of the overlaps in their concerns, a further indication of the low level of exchange taking place across professional groups (Robinson et al., 2009).

Complex care management: The role of case managers

Case management improves coordination

Case management has been widely applied as a tool for achieving care coordination in long-term care and is considered good practice in the context of care for PwD also. It is defined as, “collaborative activities that assess, plan, implement, coordinate, monitor, and evaluate options and services to meet an individual’s health needs through communication and available resources” (Gletler & Leen, 1996; cited in Zabelegui et al., 2014: 181). While integration and coordination of care – across the health and social care divide as well as the informal and formal care divide – are recognized challenges for long-term care services generally (Allen et al., 2013; Ferrer, 2015), the importance of the case management function is heightened in care for PwD. Case managers can mediate diverging viewpoints within families concerning care needs, and crucially provide continuous support as needs change over the trajectory of the disease. They ensure that family caregivers receive the support they need, not least by sharing the burden of care coordination and serving as a source of counsel and advice. That said, the focus group experts stressed that case managers should be introduced only once managing care becomes a hardship for the family caregiver and the person with dementia; doing so beforehand can be construed as interference in the private lives of families.

Evidence on the effectiveness of case management in care for PwD is generally positive in terms of its impact on the use of community care services and on delaying institutionalization (Low & Fletcher, 2015; Zabelegui et al., 2014). Two studies looking specifically at the effectiveness of interventions for PwD that incorporate a case manager position show that case management may increase utilization of community care services and delay admission to long-term institutional care (Low & Fletcher, 2015; Tam-Tham et al., 2013). In their systematic review of dementia case management interventions and their effects on institutionalization, however, Tam-Tham and colleagues (2013) caution that most studies conducted to date carry out participant follow-ups at most after 18 months, making it difficult to assess long-term impact. Interestingly, multi-component interventions that target both the person with dementia and the

family caregiver and that include case managers as their core function have been found to be more effective in reducing institutionalization when compared to single component interventions (e.g. interventions consisting of either psycho-educational or supportive components only) (Zabelegui et al., 2014).

Competence and coordination among formal care professionals

Primary care professionals (PCPs) are key actors in community care for PwD. They may conduct diagnoses, often refer patients to specialists and psychosocial support services, and ideally, follow-up to monitor their patients' conditions (Iliffe et al., 2009). Although diagnostic procedures vary from country to country, primary care professionals are in most settings the first formal care providers that people visit with concerns about changes in cognitive function and other symptoms of early stage dementia. Early diagnosis for dementia, in which people with mild symptoms of cognitive impairment undergo diagnostic testing, can be conducted at primary care clinics (Maki & Yamaguchi, 2014). Early diagnosis can enable people to engage in advanced care planning and embark on a pharmaceutical treatment plan early on in the course of the disease. On the other hand, it requires considerable sensitivity and knowledge on the part of health care providers involved (Maki & Yamaguchi, 2014).

Need for better dementia competencies and knowledge in primary care

Once a diagnosis is made, there is evidence to suggest that within health care services, PCPs receive more visits from PwD than do specialist providers, and that overall, PwD make use of health care services much more frequently than they do of community-based care, in large part due to a lack of awareness of available community-based services (Ploeg et al., 2009; Weber et al., 2011). Yet the literature shows that the level of competence and preparedness of PCPs is in some instances a barrier to quality care (Robinson et al., 2010; Raivio et al., 2011; Bunn et al., 2012; Lathren et al., 2013), as is the lack of awareness on the part of some PCPs of the non-medical care services available in their communities (Weber et al., 2011; Raivio et al., 2011; Singh et al., 2014). In a review by Bunn and colleagues (2012) of the factors that shape patient and family caregiver experiences with diagnosis and treatment, the authors find that one of the main barriers to timely diagnosis is that PCPs are slow to recognize symptoms of cognitive impairment and are in some cases reluctant to make a diagnosis. Certain studies also reveal inconsistencies between diagnostic outcomes made by PCPs and by specialists (Parmar et al., 2014). Scholars agree on the need to better integrate diagnostic and management processes across the different levels of care, and on the need to shore up PCPs dementia-related knowledge and

diagnostic competence (Parmar et al., 2014; Lee et al., 2010). It is important to note, however, that not everything can be attributed to PCPs lack of sufficient training. Based on their narrative review of the role of PCPs in caring for community-dwelling persons with dementia, Iliffe and co-authors (2009) argue that under-diagnosis of dementia is not necessarily just a function of a lack of diagnostic skills, but rather a combination of case complexity and structural challenges that include time pressure and the disincentives resulting from different countries' reimbursement systems.

Beyond diagnosis, there is consensus that the integration of systematic follow-up for patients with dementia and their family caregivers into primary care should be standard practice to ensure that patients and their carers receive coordinated and person-centered care (Robinson et al., 2010), though further research to evaluate such interventions is needed. Likewise, research into palliative, end-of-life care for PwD reveals that PCPs together with other formal care providers (e.g. nurses, home care professionals, etc.) often do not possess the skills to discern when someone with dementia is nearing the end of life (Goodman et al., 2010). Part of this challenge derives from unsatisfactory prognostic indicators of end-of-life for PwD (Goodman et al., 2010), with some authors arguing that dementia-specific indicators are actually less accurate in predicting end-of-life than measures of advanced age, anorexia, and functional ability (Schonwetter et al., 2003).

Many community care services are provided by low-skilled professionals

The training and qualification of formal care providers more generally also merits attention. It is well established that in most countries, low-skilled professionals carry out the majority of formal care for community-dwelling PwD (i.e. auxiliary nurses, assistant nurses and staff with no formal training) (Hallberg et al., 2014). Two exceptions, cited in findings from the RightTimePlaceCare study are Finland and Sweden, where home care professionals undergo more extensive training (Hallberg et al., 2014). In a UK study on palliative, end-of-life care for PwD living in the community, a lack of professional knowledge and expertise in dementia care was manifest in failures to attend to personal care and hygiene, and in the lack of confidence reported by care professionals in addressing palliative care needs such as pain and discomfort (Lawrence et al., 2011). It is clear that improving the skill mix of PCPs and other professionals working within primary care is necessary to promote high quality care for PwD and their family caregivers (Robinson et al., 2010).

Exchange of information between the different groups of formal care professionals is another important area for improvement to enable person-centered, integrated care, both in terms of the source of information, as well as the kind of patient information that is captured and shared among different care providers. A study investigating the information needs of diverse professional groups

working with PwD (PCPs, community health nurses, home carers, residential aged care facility staff, and aged care assessment team members) demonstrates that across groups, providers share similar information needs surrounding diagnosis, patient behavior, and services (Robinson et al., 2009). Providers also share similar concerns about the exchange of information, notably untrustworthy information and poor information transfer, all of which results in service fragmentation (Robinson et al., 2009). All care provider groups involved in the study cited a single entry point to access patient information, e.g. by way of an electronic database, as a highly desirable tool for reducing fragmentation of and unnecessary overlaps in care provision. Notably, of all the professional groups involved, PCPs reported significantly fewer information needs than others. This finding highlights the potential challenges of care coordination given that other professional groups in the study reported the lack of information forthcoming from PCPs (particularly concerning dementia diagnosis) as contributing to their difficulties in providing care to clients with dementia (Robinson et al., 2009).

Acute care for people with dementia

Discharge procedures can help integrate hospital and community care

Hospitalization of PwD – whether for reasons directly related or unrelated to their dementia – brings with it considerable challenges both during the period of hospitalization and after discharge. Hospital visits are unpleasant for anyone, but they can be especially so for PwD for whom being in an unfamiliar environment, surrounded by strangers, can lead to disorientation and agitation, and in some cases, aggressive behavior. In-patient facilities and staff are often ill-prepared to cope with the special needs of PwD. As a result, PwD often leave hospitals cured of their acute complaint but in a worse psychological and cognitive state. A study on care service utilization from the US indicates that older PwD are hospitalized more frequently than older people who do not have the disease (Weber et al., 2011), an indication of the complexity and difficulty of providing acute care for someone with dementia, as well as of the difficulties facing family caregivers in overseeing the transition from hospital to home. The challenges of transitioning home after a hospital stay can lead to re-hospitalization, and ultimately, to placement in institutional care (Weber et al., 2011). Appropriately managing this transition is thus crucial to ensuring that the wellbeing of PwD is maintained during hospitalization and that they are able to return to and remain living at home.

More awareness of dementia is needed in hospital settings

Providing awareness and competencies training to hospital staff, not just to care professionals, e.g. doctors, nurses and nursing aides, but also to administrative and custodial staff, is fundamental to creating hospital environments that are ‘dementia-friendly’ (Galvin, 2010). A review of the literature on hospital discharge procedures for PwD finds low-quality discharge and transitional

care arrangements to be prevalent following hospital admission, and calls for improved coordination and communication between those physicians working in hospitals and PCPs (Chenoweth et al., 2015). The findings from two studies lead to the same conclusion that the lack of awareness among hospital staff, poor communication between professional groups, and poor coordination across care settings is highly detrimental to the quality of care (Bunn et al., 2015; Sutcliffe et al., 2014).

Different models and approaches to community care for people with dementia

Limited evidence on how different models of dementia care compare

To our knowledge, Low and Fletcher (2015) have conducted the only international direct comparison of different home care models for PwD. In their review, they identify four main types of care models: 1) case management, 2) integrated care, 3) consumer-directed care, and 4) restorative care. Case management is characterized by the presence of a case manager (or case management team) who assesses the needs of the person with dementia and of family members, provides counsel on available services, creates and implements a care plan and continuously coordinates care. Adapting the WHO's definition, Low and Fletcher define integrated care as the consistent management and delivery of care services across the different levels and settings of the health and social care sectors (WHO 2008; WHO, 2015a; Low & Fletcher, 2015).

A consumer-directed care model operates on the conviction that PwD and their families should have more choice in the services they use than is traditionally offered, through the implementation, for example, of cash benefits or personal budgets for care. Likewise, according to this model, PwD and their family should be able to actively participate in defining their own needs and subsequently, in planning and coordinating their care. Lastly, restorative care, less well-recognized and less widespread than perhaps the other models, is characterized by its focus on preserving, and to the extent possible, improving the functional ability, independence, and HrQoL of PwD (Low & Fletcher, 2015). Although these are conceptualized as distinct models, the authors acknowledge that in reality, they are not mutually exclusive and components from each often overlap. Analysis of the evidence on the implementation and impact of the different care models respectively reveals benefits to each.

Case management & consumer-directed models show positive results, but no evidence of impact on outcomes

Case management is shown in some cases to increase the use of community care services and to postpone institutionalization, while integrated care is correlated with higher reported rates of user satisfaction, an increase also in the take-up of community care services, and decreases in the duration of hospitalizations, yet little is known about its effects on clinical outcomes (Low & Fletcher,

2015). It emerges that consumer-directed care can lead to greater user satisfaction and utilization of community care services, but has minimal impact on clinical outcomes. The study also shows that though restorative care has been demonstrated to lead to better functional ability and increases in QoL, none of the care models evaluated included PwD in the analysis, rendering the findings speculative for our purposes (Low & Fletcher, 2015).

In the Spotlight

In the Spotlight: Geriant (NL)

Geriant, an independent dementia organization providing community-based services, was among the first in the Netherlands to provide case management for dementia. The Geriant model – with clinical case management embedded in multidisciplinary dementia care teams at its core – has been since replicated in other Dutch regions. It relies on high integration of services and care coordination, in order to ensure care can be provided in the home of the person with dementia from the appearance of first symptoms up until severe impairment.

The Geriant model showcases that, as the complexity of the care needs of PwD increases, the integration of services across a network of different providers ensures the needed flexibility to provide personalized, successful care.

More information at: <https://www.geriant.nl> (only in Dutch)

Evidence of the effectiveness of many community care services is still scarce

As was touched on previously in Chapter 4, evidence about the effectiveness of specific interventions for PwD living in the community is scarce, making it difficult to draw generalizations about the best approach to care for this group. Nonetheless, certain types of interventions have demonstrated benefits. Specifically, there is evidence that cognitive rehabilitation and environmental interventions improve the functional capacity and wellbeing of PwD, respectively, though the benefits over the long term are not known in either case (Zabelegui et al., 2014; van Vracem et al. 2015). Environmental interventions (i.e. interventions that address the impact of light, smell, noise, temperature, nature, color and spatial configuration on the wellbeing of someone with dementia) have been shown to be a viable alternative to medication in cases of agitation and aggression, and to relieve the burden on family caregivers, though the evidence to date is also limited (van Vracem et al., 2015). An important consideration with this latter group of interventions is the consultation and cooperation with family members, as re-arranging and adapting living spaces is commonly required.

In the Netherlands, implementing dyadic (i.e. targeting both the person with dementia and the family caregiver) community-based day care centers, known locally as Meeting Centres Support Programme (MCSP), has been shown to be more effective than day care programs offered in nursing homes that only ad-

dress the needs of the person with dementia (van Haeften et al., 2015; Van't Leven et al., 2013). The MCSP day care centers incorporate several activities for PwD, including purely recreational activities as well as therapeutic ones (e.g. cognitive stimulation and psycho-motor therapy). For family caregivers, the program provides educational workshops and a regular forum for group discussion and peer support (van Haeften et al., 2015). It also offers a weekly consultation hour to both PwD and carers, and holds regular meetings with users of the service to collect feedback. Crucially, MSCPs are easy to access and are usually located in community centers, promoting integration within the wider community.

**Dementia
community care should
be person-centered,
responsive to changing
needs and coordinated**

There is consensus in the literature and among the experts assembled for the focus group on a number of points related to ensuring good community-based care for PwD. First and foremost, that care should be person-centered and take into consideration the physical, psychological and social needs of PwD and their family caregivers (Bunn et al., 2012). Secondly, timely diagnosis, follow-up and monitoring at regular intervals, and end-of-life/palliative care that is tailored to the specific needs of PwD must be emphasized. Thirdly, different care providers and services operating across the health and social care sectors should be coordinated, with the majority of evidence available on the subject pointing to the benefit of having a dedicated case manager. Proper coordination of care also means striking a balance between provision of a range of different services and interference in personal family matters. Lastly, a community care model needs to incorporate the potential contributions of stakeholders from the wider community to support and integrate PwD and their families. The details of how these various elements should be integrated and implemented are to a large extent context-specific and must be examined case by case.

Experts participating in the focus group underscored an extension of the last point. Several participants argued that it is essential to find ways to engender greater solidarity among members of the community and to promote a model of care that sees neighbors helping neighbors and encourages volunteerism. In this way, rather than necessarily through expanding formal service options – which many thought a pipe dream in the current financial climate – will PwD and their families be adequately supported. Another important question when considering the appropriate care mix is whether or not there should be specialized formal care services for PwD in the first place, a query with strong implications for social inclusion. In other words, is it preferable to elevate all existing long-term care services and the competencies of all professionals to be able to cope with the demands of caring for someone with dementia alongside other service users, or should services that cater exclusively to PwD and specialized qualifications for professionals be implemented? It is a question without a definitive answer in the literature published to date, but one that calls urgently for further deliberation and examination.

In the Spotlight**In the Spotlight: Aktion Demenz (DE)**

Aktion Demenz is carrying out a pilot project in collaboration with Diakonie Gießen and the local government of Gießen called “Demenz – Entlassung in die Lücke” (Dementia – Discharged into the gap) to investigate how best to ensure that PwD receive the care they need after being discharged from hospital. With the involvement of both care professionals and civil society actors, the project aims to develop the necessary support structures for PwD, so that they can be cared for in their homes. Another key objective of this project is to raise awareness of dementia in the wider community and to instill a culture of helping and supporting PwD in the community.

More information at: <http://www.diakonie-giessen.de>

The Takeaway

Navigating the range of community-based services can be daunting for PwD and their families, making some form of care coordination essential. Case management has been shown to be a beneficial tool in achieving coordinated care services; not just for its capacity to inform and guide families and organize care services, but also for the role played by case managers in resolving conflicts that arise within families, and between families and care providers. In general, most countries have a long way to go before services at the local level are fully integrated and coordinated. A major obstacle is the divide between acute care settings and outpatient and home-based care. Many in the medical profession, particularly physicians and nurses who do not deal with dementia in their day-to-day practice are not well versed in the nuanced symptoms and manifestations of the disease, nor in the ways to cope with these symptoms in a sensitive and appropriate manner. This can prove particularly problematic in acute healthcare settings, e.g. hospitals, where a lack of knowledge about the specific needs of older patients with dementia can be highly detrimental. This recalls a general challenge confronting LTC systems to integrate services and coordinate care professionals’ skills and qualifications jointly with health and social care sectors. The literature pinpoints training for care professionals as a highly under-developed and important area to address if services are to be improved. The literature also tells us that in terms of appropriate care mix for community-dwelling PwD, the evidence base is small. Certain psychosocial and environmental interventions have shown promise in improving the wellbeing of PwD and their family carers, but much of the evidence is derived from small-scale pilot programs.

Chapter 7.

Assessing community care for people with dementia

Previous chapters have identified a number of key areas that policymakers should prioritize in order to ensure that services appropriately and adequately meet care needs. As we have documented in several places, however, it is difficult to make generalizations about which specific interventions work and which do not because the evidence base for this target group and this care setting is underdeveloped.

Evidence is scarce due to conceptual, methodological and political challenges

The reasons for the lack of evidence on what constitutes good community care for PwD are partly conceptual, partly methodological and partly policy-driven. Conceptual in the sense that multiple definitions of community care have been circulated, and given the complexity and scope of community care broadly defined, research has tended to focus on interventions addressing single components therein (e.g. home care, day care, respite care). In addition, very little of the available literature has focused on developing sets of measures to assess care provided to PwD living at home, with most research investigating outcomes in institutional care settings.

Methodological challenges also hinder the evidence base in the sense that researchers are applying a range of outcome measures and instruments – in various combinations – in their evaluations. This is most apparent in the costing literature, where a range of instruments are used to assess different outcomes measures, including cognitive function, functional ability, behavioral and psychological symptoms, clinical health status, and wellbeing and QoL among others, resulting in a lack of comparability across contexts (Farré et al., 2016; Quentin et al., 2010; Gustavsson et al., 2011). Dissatisfaction with existing measures of QoL is emphasized in the literature as well as by the focus group experts. Two of the more commonly used instruments measuring QoL of PwD, the EQ-5D and QoL-AD, have both been criticized for failing to incorporate the social components of a person's QoL (Kuo et al., 2010; Hounsome et al., 2011). Also, as a number of studies have uncovered discrepancies between QoL as reported by the person with dementia and by family caregivers and care professionals, the validity of using proxy measures in this area has come under intense scrutiny (Kuo et al., 2010).

Lastly, part of the explanation for the lack of evidence emerging from the literature may also be the lack of clear, prioritized objectives set forth by EU-

and certain national-level policymakers. While the majority of European countries have some kind of dementia strategy in place, these can be rather abstract in their goal-setting and prescriptions for research and practice with regard to which perspectives to emphasize and which kinds of interventions to focus on (Alzheimer Europe). Data availability, another major methodological challenge, is directly related to insufficient investment in data infrastructures, e.g. national registries collecting dementia-specific information, and in many countries, non-existent or ineffective legislation governing data sharing practices across institutions (OECD, 2015; Prince, 2015). Some progress has been made in recent years, however, in prioritizing the goal of measuring and monitoring dementia care, and in increasing the international comparability of individual countries' experiences. This is in large part due to a number of specific initiatives at the international level, starting with the G8 Summit on Dementia in 2013, which declared dementia a policy priority; and the establishment of the World Dementia Council the following year which has worked since its inception to identify and develop innovative treatments and care interventions for PwD.

Data collection for benchmarking purposes is still not feasible in many settings

In terms of benchmarking performance and progress in care for PwD at the system level, Alzheimer Europe, the OECD, the UK-based National Institute for Health and Care Excellence (NICE), the American Medical Association (AMA), and the INTERDEM Network (Early detection and timely INTERvention in Dementia) have developed sets of measures and indicators to mark progress in dementia care and support, each with its own particular focus (Alzheimer Europe, 2009; Anderson & Oderkirk, 2015; NICE, 2013; AMA 2014; INTERDEM). While the OECD guidelines take a system performance approach, the Alzheimer Europe and the INTERDEM guidelines focus on measuring quality of psychosocial interventions, and the AMA set of guidelines emphasizes the more clinical aspects of dementia care. The NICE pathway for dementia care incorporates both measures of health and social care services, as well as more holistic measures of independence and wellbeing of the person with dementia.

A second OECD publication, also published in 2015 called "Addressing Dementia – the OECD Response" formulates a series of policy objectives and suggests corresponding measures and indicators (OECD, 2015). The 10 policy objectives proposed in this report address a range of issues from prevention and minimizing risk of dementia, to dignity and dying at home, and realizing the potential of technology to support dementia care (OECD, 2015) (see Table 1). While a comprehensive set of objectives is proposed, the authors of the report explicitly state that many of the proposed measures and indicators suggested to monitor progress in these areas are not yet feasible due to a number of constraints, most notably the lack of available data. Similarly, the UK-based National Institute for Health and Care Excellence's (NICE) 'Pathway on Dementia' identifies 13 areas or dimensions of care and support for PwD (see Table 1). Each

of these 13 areas are further developed with suggestions for outcome measures and data sources in the quality standard “Dementia: support in health and social care” (NICE, 2010), and in its follow-up, the “Dementia: independence and wellbeing” quality standard (NICE, 2013). When taken together, the NICE quality standards are quite comprehensive in the dimensions they propose for measuring quality of care. The latter in particular emphasizes aspects related to social inclusion of PwD in the wider community (NICE, 2013). As with the OECD guidelines, the measures proposed in the NICE quality standards are largely aspirational given the availability of data in most countries.

Table 1. Comparison of OECD and NICE Benchmarking domains for Dementia Care

OECD Policy objectives	NICE Pathway on Dementia
Risk of developing dementia is minimized	
Dementia is diagnosed quickly	↔ Investigation of suspected dementia
PwD have access to safe and high quality LTC services	<ul style="list-style-type: none"> Staff training Promoting choice Interventions for non-cognitive symptoms and challenging behaviour
Health services recognize and effectively manage PwD	<ul style="list-style-type: none"> Providing support Needs arising from diagnosis Specialist assessment services Inpatient care and care in an acute hospital
Care is coordinated, pro-active and delivered closer to home	↔ Integrated and coordinated care and service provision
PwD live in safe and appropriate environments	↔ Living arrangements and care home placements
Those who care for PwD are supported	↔ Support for carers
PwD die with dignity in the place of their choosing	↔ Palliative care and end-of-life care
Communities are safer for and more accepting of PwD	↔ Promoting independence and maintaining function
Potential of ICT to support dementia care is realized	

Source: adapted from OECD, 2015 and NICE 2010, 2013

While the two sets of guidelines are formulated differently – the OECD as objectives with a clear focus on policymaking, and the NICE guidelines rather on specific services – it is evident when comparing the two that there is con-

siderable overlap in the areas indicated by both for monitoring (See Table 1). The 2013 NICE quality standard “Dementia: independence and wellbeing” is most in line with a community-based approach to caring for PwD, identifying ‘Involvement and contribution to the community’ and ‘Maintaining and developing relationships’ as sub-dimensions of the ‘Promoting independence and maintaining function’ area of the pathway. The OECD guidelines also have as one of its dimensions ‘Communities are safer for and more accepting of PwD’. Taking a community care based approach, however, would require that communities are incentivized to take a more prominent role than simply being made aware of the needs of its residents with dementia. It would require that specific stakeholders from within the community are encouraged to actively participate in providing support, and benchmarking guidelines should reflect this.

Need to further develop measures of service organization and structure, as well as outcomes and QoL

Participants in our expert focus group emphasized the need to develop more accurate and dementia-specific instruments with which to measure QoL, as well as the need for including measures related to access to care services. They proposed a number of policy objectives to assess progress in dementia community care that address outcomes for PwD and their family caregivers, as well as process- and structure-related dimensions of care quality (Donabedian, 1988). In some cases, the experts also included tentative suggestions for measures to use to monitor the proposed objectives, indicated here in parentheses. In terms of structure, they identified: affordability; flexibility of services; and ease of access to services. Related to care processes, they proposed: timely diagnosis (measured by global deterioration scale); services are culturally/gender/age sensitive; services are non-stigmatizing and inclusive; and continuity and competence of formal carers. Lastly, in terms of outcomes, the following measures were proposed: prevention of premature institutionalization where desirable (before onset of severe dementia); reduction in caregiver burden (baseline, follow-up once a year); prevention of avoidable hospitalization; support for informal caregivers (time for reflection with professional counselor/support group).

The Takeaway

To achieve valuable and effective benchmarking of community care for PwD, a conceptual shift needs to take place in terms of what dimensions and measures of care and support are deemed most important. This includes the development of more accurate measures of QoL and wellbeing of PwD and their caregivers, as well as developing measures that reflect the importance of other community actors in supporting PwD and their families. It has also been widely suggested that benchmarking of community care should encompass not only outcome measures, but structural and process-based measures as well. Equally important is the need to build the data collection infrastructure around dementia care and support so that monitoring is made possible.

Chapter 8.

Ethical and legal issues in dementia care

Within our analytical framework, we acknowledge the key role that framework conditions play in shaping and constraining the space in which different actors interact and operate (graphically represented by the dark blue rectangle surrounding the network of actors; see Figure 1). In the broadest sense, framework conditions refer to legal and ethical frameworks as well as the socio-cultural context, i.e. collective attitudes and values surrounding dementia and care for PwD. While we acknowledge the importance of all framework conditions, our focus here is on the ethical and corresponding legal issues associated with dementia care in the community, as these are more tangible and more readily comparable across countries than socio-cultural aspects. Ethical and legal aspects also feature more prominently in policy debates and are more amenable to change through coordinated policy action.

The four bioethical principles ...

Ethical discussions related to dementia care are grounded in the field of bioethics and revolve for the most part around four core bioethical principles: 1) *respect for autonomy*: the person with dementia has the right to make decisions about his/her own care; 2) *beneficence*: the benefits of treatment must be balanced against the risks and costs involved; 3) *non-maleficence*: the causation of harm must be avoided; and 4) *(distributive) justice*: the ideals of fairness, entitlement and equality must be applied (National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1978; Beauchamp and Childress, 1983). To these four one could add numerous other principles arising from the study of medical ethics, social ethics or research ethics⁵. In the following sections, we limit ourselves to providing an overview only of those particularly salient to dementia care. First, the right to and protection of *dignity*, enshrined by numerous conventions and charters, is a cornerstone of human rights and medical ethics approaches despite the difficulty in providing a standard and comprehensive definition. The principle of dignity encompasses the complementary principles of *human dignity*, referring to the inherent value belonging to every human being, and *social dignity*, referring to qualities of worth and respect and how they are conveyed through individual and group behavior (Jacobson, 2007). Closely related and equally difficult to define is the principle of *personhood*, referring to how we define what it means to be a person and how we determine the boundaries of this state of being (Baldwin and Capstick, 2007). For ethicists, personhood is often equated in practice with the possession of certain intellectual capacities, with obvious implications for the case of persons

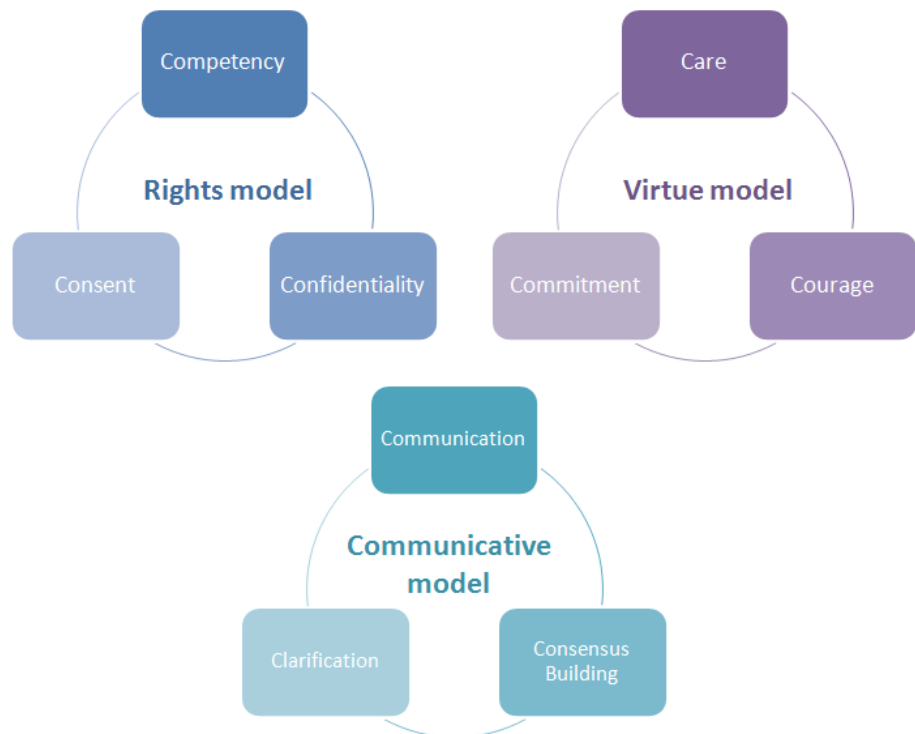
... As well as dignity, personhood and solidarity ground the ethical discussion of dementia care

with dementia. Second, the principles of *solidarity* and *interdependence* refer to mutual interests and the sharing of common principles that tie groups and communities together, and which engender a sense of shared responsibility for other members of the group (Nuffield Council on Bioethics, 2009). In practice, these principles are most clearly reflected in the perceived obligations to one's family and community.

Ethical approaches should consider and build on the relationships between PwD and carers

Carrying forward the principles of solidarity and interdependence, some scholars have argued that the social relationships that underpin care for PwD, and the lived experiences of PwD and of their carers, should form the foundation for any ethical approach to dementia. This is in contrast to both the rights-based and virtue-based models (see Figure 3), which focus on the rights of individuals with dementia and on the virtues carers should bring to their care work, respectively ('virtues' include patience, compassion and prudence, as identified by Christine K. Cassel). In developing his communicative model of ethics Moody argues that, "what is called for is not an ethics of individual decisions whether patients' rights or professional virtues, but a genuinely social ethics, a communicative ethics based on free discourse leading to deliberation and negotiation" (Moody, 1993: 37).

Figure 3. The three C's in the Rights, Virtue and Communicative models in ethics



The remainder of this chapter addresses four key ethical issues relevant to dementia care in the community and the main legal provisions associated with each. This discussion is grounded in the ethical principles outlined above, though the focus is on identifying policy approaches for addressing ethical issues in praxis, rather than on describing different theoretical approaches to dementia care in detail. Specifically, the following points are addressed in turn: i) the complexities involved in balancing safety of the PwD with the principle of autonomy; ii) issues arising from the loss of intellectual capacity of the PwD and the need for decision-making about care; iii) the right and access to care and support for PwD and for family carers; and iv) maintaining dignity at the end of life. After introducing each issue, we present three country case studies (UK, NL, FR) with the purpose of comparing ethical and legal approaches in different European countries, and identifying good practices and innovative approaches in policy-making and regulation. The concluding section weighs the role of legislative versus ‘soft’ interventions in the context of caring for PwD in the community.

Safety versus Autonomy

The right to autonomy and control over one’s life is not just desirable in and of itself but can also contribute significantly to increasing wellbeing and life satisfaction for people with care needs (Bjørkløf et al., 2013). In the case of dementia, even more than other diseases, the goal of maintaining autonomy is often at odds with the goal of maintaining safety and reducing exposure to harm. As cognitive function declines along the trajectory of the disease, carers often feel an increased urgency and necessity to safeguard PwD from risky activities, e.g. leaving the house alone, driving, etc. In fact, carers will often justify placing increasing restrictions on, and generally exerting greater control over the activities of PwD with the claim, “it’s for their own safety”. While understandable, this reaction can result in the person with dementia essentially being ‘locked in’ in their own homes, an outcome that runs counter to the goal of community-based care of enabling independent living and preventing social isolation.

PwD should be afforded the same right to risk that all individuals enjoy

While reducing risk and ensuring safe environments for people in need of support is a crucial component of care, an over-emphasis on safety can come at the cost of individual freedoms and autonomy. PwD should be afforded the right to choose to take risks in order to remain engaged and participate in life experiences more fully – a concept described as dignity of risk (Nay, 2002). Ideally, throughout the care process, the desire to safeguard the autonomy of the PwD would be balanced against ensuring their safety and the safety of the community (Nuffield Trust-UK Dementia strategy). To this end, it is important that carers factor the ubiquitous nature of risk in day-to-day life into their risk assessments – i.e. recognize that most individuals engage in activities that carry calcu-

lable risks on a regular basis (biking, playing sports, carrying heavy loads, etc.), risks that are rarely acknowledged while the person is in good health and still independent.

The autonomy versus safety dilemma raises a number of practical issues for policy-making when one considers that the stringency of legal provisions can, in effect, mandate the primacy of safety concerns over autonomy, or vice versa. Often discussed within this context is the use of monitoring and surveillance devices to aid in the care of PwD. While the use of such devices has increased in Europe in recent years, debates revolving around intrusiveness, privacy and consent are still common in policy and research discourse. Another important issue emerging from this debate is the rescinding of certain privileges with advancing cognitive decline, e.g. suspension of driving license. Also highly contested are the use of restraints, understood here as any action that limits the freedom of movement of PwD broadly speaking, and the use of non-therapeutic drugs. Although these are more commonly associated with care in institutional settings, they nonetheless constitute potential ethical challenges in community care as well.

Capacity and Care Decision-Making

The principle of autonomy, as described above and as codified in the legal systems of all European countries, ensures that individuals have the right to make choices regarding their own care. Of particular importance in the case of dementia, however, is the fact that maintaining autonomy in decision-making is legally contingent on the person with dementia's ability to rationally comprehend and weigh the consequences of his or her choices (Nuffield Council on Bioethics, 2009). Under current legal frameworks in most European countries, as the mental capacity of a person with dementia becomes increasingly limited, family members or care professionals can instigate a legal assessment process in which his or her competence is evaluated. If a person is declared *non compos mentis*, or lacking mental competence, a substitute decision-maker, usually a family member, is empowered to make decisions on their behalf.

Pwd should remain at the centre of decision-making even when their cognitive skills decline

It is a common misconception that once a person experiences cognitive decline associated with dementia, his or her autonomy is eroded and decision-making capacity is immediately in doubt. In fact, while the person with dementia may depend increasingly on both physical and decision-making support from others, he or she should remain involved, and indeed at the center of decisions about his or her own care to the extent possible. In order to preserve the autonomy of PwD while at the same time safeguarding them from potentially impaired decision-making, a series of legal provisions can be instituted. Most wide-

ly applied across (Western) Europe is the legally stipulated right of PwD to make legally binding decisions concerning their future care as long as they retain the capacity to do so (Alzheimer Europe, 2005). Such legal provisions are known by a variety of names, including advanced directives, advanced decisions, advanced care planning, etc. While advanced directives are potent legal instruments, they work best in complementarity with systems of substitute (e.g. guardianship, health proxy) and increasingly, supported decision-making, with the latter placing greater emphasis on guided decision-making in which the person with dementia still takes a central rather than a secondary role (Alzheimer Europe, 2016). Some countries have introduced considerable flexibility for PwD in nominating a person they trust as their future proxy decision-maker (e.g. enduring power of attorney), but many maintain fairly rigid systems of court-appointed guardians.

Loss of capacity is not all-or-nothing, but rather task-specific

It is also important to note that while few question the ethical argument for implementing decision-making safeguards for people with moderate and severe cognitive impairment, existing assessment procedures and the practical application of relevant legal provisions have come under increased criticism. One common objection refers to the “all-or-nothing” nature of legal capacity, which fails to recognize that the capacity to make decisions is task-specific (Alzheimer Europe, 2008; Mitty, 2012). A person with dementia may find it difficult to comprehend and decide on complex medical treatment, while remaining fully capable of making decisions and expressing preferences related to their daily personal care. Additionally, some have argued that the capacity to think rationally and analytically should not be the sole basis for maintaining autonomy in care decision-making. Even once cognitive abilities are impaired, PwD should be encouraged to express their values and preferences (Nuffield Council on Bioethics, 2009) as emotional capacity can remain intact past the threshold of severe cognitive impairment (McCarthy et al., 2016).

Right and access to support

Despite increased recognition of the needs and circumstances of people living with dementia, a medicalized approach dominates professional and public discourse. Dementia tends to be construed as a degenerative disease for which no cure exists, placing overemphasis on treatment and medical approaches to care. This can result in a lack of recognition that other forms of support (other than medical treatment) are still necessary in order to manage the symptoms and ensure a high quality of life. Through the efforts of national dementia associations, a different approach – generally described as a rights-based approach – has entered the debate in recent years. It builds on the understanding that human rights are universal and should not be overlooked or trampled for any

group of people, as it sometimes happens with PwD (WHO, 2015b). Rights-based approaches endow individuals with a right to action and to claim their rights if they are not being met via legislation, procedures and mechanisms that enshrine these rights. It is however common to associate rights-based approaches with entitlement to public services – e.g. in Europe, the right to health care is reflected in universal access to health care at the point of need, a situation not paralleled in access to social care services (Mental Health Foundation, 2015).

In the wake of the disability rights movement, a number of international and national conventions and laws recognize and protect the rights of persons with disabilities. While the concept of disability is not attached to specific conditions, it encompasses all “those who have long-term physical, mental, intellectual or sensory impairments in interaction with various barriers [that] may hinder their full and effective participation in society on an equal basis with others” (UN General Assembly, 2006) and therefore can be understood to apply to people affected by dementia as well.

Rights-based approaches to dementia care empower individuals to remain in control of their lives

A rights-based approach to dementia can empower affected individuals to remain in control of their lives and their care, and to remain engaged and active in their communities. A rights-based framework can also have practical implications for entitlement and eligibility to services and support (Mental Health Foundation, 2015), and provide patient advocacy groups with the foundation on which to challenge under-investment in services that enable PwD to continue leading active lives (e.g. assistive technologies, dementia-friendly communities, house modifications), as is their right. Finally, a rights-based model would help disconnect access to support services from old age, and could promote wider recognition of younger onset dementia (Mental Health Foundation, 2015).

In the Spotlight

International instruments and processes relevant for the protection of rights of people with dementia

The UN framework

- The Madrid International Action Plan on Ageing (MIPAA)
- The UN Convention on the rights of persons with disabilities (UN CRPD)
- The Independent Expert on the enjoyment of all human rights by older persons

The Council of Europe framework

- The European Convention on Human Rights (ECHR)
- Recommendation on the rights of older persons

The European Charter of the rights and responsibilities of older people in need of long-term care and assistance

Dignity and end of life care

Palliative care, defined by the WHO as “an approach that improves the QoL of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering [...]”⁶ has become an increasingly prominent issue in dementia care. While not uniformly recognized as such, advanced dementia is a terminal illness and PwD as well as their carers should have access to adequate palliative care and support. It is important to emphasize that palliative care is not only necessary when end of life is imminent, especially as in the case of dementia it can be difficult to estimate, but rather can be appropriate for up to several years prior to end of life (Alzheimer Europe, 2008). Palliative care does not aim to prolong life, but rather to improve the quality of remaining life and to ensure a comfortable and pain-free death for PwD, as well as support for carers and families. While recognizing the right to choice of each individual person with dementia, Alzheimer Europe and numerous other stakeholders have affirmed their belief that a palliative care model should be adopted for advanced dementia as attempts to cure and prolong life are futile and inappropriate (Alzheimer Europe, 2008; NICE, 2006; van der Steen et al., 2014; Harris, 2007).

Limited access to palliative care for people with dementia

Unlike palliative care for people with terminal cancer, for example, the paucity of evidence on how to define and how to organize good palliative care for PwD is only now being gradually addressed in research and policy (Harris, 2007; Sampson, 2010). As discussed in Chapter 4 (p. 22) of this report, while evidence on the subject is generally scarce, it is well established that access to palliative care services for PwD is limited, in hospitals (Morrison & Siu, 2000), in the home (Rosenwax et al., 2015) and in dedicated institutions such as hospices (McCarthy & Volicer, 2009).

In the following sections, we build on these ethical and legal issues by describing the experiences of three countries: the United Kingdom, the Netherlands and France. The case studies draw on reviews of the specialized literature and on expert interviews, and have been selected in order to maximize the variability of approaches to dementia-related ethical frameworks and legislation, while at the same time tracing innovative approaches and practice with respect to community-based dementia care. In each case we focus on *what is different* and attempt to analyze these differences in a comparative European context.

Case study 1: The United Kingdom

Profound differences in service organization and legislation between countries in the UK

The United Kingdom is an interesting case to study as it cannot be treated as one single case, but rather as four, each focusing on one of the constituent nations: England, Wales, Scotland and Northern Ireland. Of course, in many other countries one can also point to regional and local variability in the organization and management of community-based services, yet the UK stands apart due to the profound nature of the differences, a true natural laboratory for social experiment (Andrews, 2014). We focus here on the comparison between England and Scotland, the two most populous regions. Each jurisdiction organizes social care (generally through local authorities) and medical care independently (NHS England and NHS Scotland are independent organizations), pursues progress in dementia care differently (they have separate national dementia plans), recognizes different entitlements to support services and is guided by different legal underpinning (Alzheimer's Disease International, 2012; Bell & Bowes, 2006).

Cases in point are the different legal frameworks for assessing capacity and protecting the rights of individuals who lack capacity to make decisions related to their care. In England and Wales, the relevant laws are the Mental Health Act (1983) and the Mental Capacity Act (2005). The latter – very wide in scope – covers decision-making in every aspect of life for people with diminished capacity, as well as how capacity should be defined and assessed. The Act enshrines the protection of autonomy for incapacitated individuals as the first of its statutory principles, by establishing the presumption of capacity unless it is determined otherwise (Brindle & Branton, 2010). Furthermore, under English legislation, tests of capacity are decision-specific and all possible steps in support of the individual's independent decision-making must be exhausted before the lack of capacity is established. In practice, however, one notices a tendency of the courts to make global assessments on lack of capacity too readily at times, according to expert opinion.

Scottish mental health legislation emphasizes individual rights and autonomy

In Scotland, the legal framework for the protection of rights of individuals lacking capacity due to mental illness builds mainly on the Adults with Incapacity (Scotland) Act (2000) and the Mental Health (Care and Treatment) Act (2003). All decisions on the welfare of an individual with diminished capacity must follow the least restrictive option, always pursue the benefit of the person, take account of her wishes and feelings and they must be inclusive (i.e. carers, relatives, attorneys and guardians must be consulted whenever relevant). The person with impaired capacity must be involved in the decision-making to the widest extent possible and he/she must be encouraged to use existing skills and be supported to develop new skills that can aid in decision-making. The legislation has been hailed as ethically sound, with a strong emphasis on autonomy rather

than paternalism, on individual rights and capacity (Darjee & Crichton, 2004). The Adult Support and Protection (Scotland) Act (2007) and the Mental Health (Scotland) Act (2015) have continued in the tradition of strengthening and safeguarding individual rights, leading to the creation of one of the most progressive approaches to human rights within a mental health framework in the world.

We wish to emphasize here a key difference in the approach to the autonomy versus risk dilemma, as it reflects in the relevant legislation and practice in England and Scotland. While in England a more paternalistic approach prevails and risk aversion has dominated interpretation and practice, the Scottish legislation does not emphasize dangerousness and risk avoidance, while autonomy features prominently. Of course the assessment of risk in practice remains subjective to individual circumstances and differences in legislative frameworks can sometimes overstate the differences as experienced in practice by service users. Nonetheless, Scotland has successfully promoted a culture of joint decision-making between the person concerned, his/her family and carers and the relevant care professionals (expert opinion).

In England a key debate on deprivation of liberty has received considerable attention leading to the Supreme Court judgment of 19 March 2014 in the case of *Cheshire West*, and prompted the introduction of amendments to the Mental Health Act in 2007 to increase safeguards, protect the best interest of the person with diminished capacity and signal an increased concern for promoting autonomy rather than risk avoidance.

In the Spotlight

In the Spotlight: Risk Enablement Guidelines (England)

In 2010, England's Department of Health published a guiding document on best practice in assessing, managing and enabling risk for PwD. It promotes a person-centered approach in risk assessment and the concept of risk enablement, or positive risk management, which highlights the negative effects of avoiding risk altogether.

The guidelines recommend that practitioners avoid imposing their own values on PwD but rather approach them in an open and direct conversation, ideally leading to the creation of a risk enablement plan as part of an individual care or support plan. Furthermore, family carers must be involved in all phases of risk assessment and planning and be provided with information and support.

Risk enablement plans must always account for variability in degrees of risk over time and from one person to another.

More information at: <https://www.gov.uk>

Scotland applies a rights-based approach in its dementia strategy and care

A further important difference, already hinted at in the above, lies in the rights-based approach that Scotland is promoting in dementia care. Dementia is recognized in Scotland as a disability and extant legislation (most noteworthy the Mental Health [Care and Treatment] Act 2003 and the Adult Support and Protection Act 2007) closely reflects the principles of the UN Convention on the Rights of Persons with Disabilities (UN CRPD). In a recent publication, the Mental Welfare Commission for Scotland reporting on progress towards meeting the commitment of the 2012-2015 Mental Health Strategy recommends explicitly building future strategies around a rights-based approach and consolidating training initiatives around the UN CRPD framework (Scottish Human Rights Commission & MWF Scotland, 2015). This approach is defined as “a way of **empowering** people to know and claim their rights; and increasing the **ability** and **accountability** of individuals, organizations and professionals responsible for respecting, protecting and fulfilling rights” (SHRC & MWF, 2015: 5) (emphasis in the original). It emphasizes that the wishes and preferences of people in need of support should be respected and protected, and underlines the legal duty of those delivering support to fulfill human rights⁷. In so doing, it addresses the risk of marginalization, isolation, abuse and institutionalization that PwD (especially in advanced stages of the disease) face. Despite the scarcity of evidence, it has been proposed that a human rights based approach to mental health (and dementia care as a sub-case) should be promoted not only on moral grounds but also on the grounds that such an approach can contribute to positive therapeutic outcomes and to potentially reducing the costs of care (Mann et al., 2016). While no parallel development is apparent in England, PwD in need of support are entitled to services subject to a functional needs assessment and many stakeholders have shown increased interest in promoting rights-based approaches to dementia care (Mental Health Foundation, 2015).

Advanced decision-making and care planning is supported by UK legislation and encouraged in practice

Emphasizing human rights in dementia care brings into focus one of the key ethical issues discussed above: decision-making along the trajectory of the disease. According to this approach, the person with dementia should be at the center of all decision-making processes and all precautions should be taken to ensure that his/her engagement is facilitated (e.g. use of accessible language and dementia-friendly communication methods, provision of necessary information). A key tool in this regard is advanced care planning, which enables PwD to express their wishes for their care while they retain the ability and capacity to make decisions about their future. Both in England and in Scotland, current legislation allows for the formalization of one’s wishes with respect to their care and medical treatment (all types of treatment including life-sustaining treatment, e.g. resuscitation) to be applied if and when the situation arises. Furthermore, in both countries the use of such tools is encouraged and promoted. The NICE guidelines on dementia care (2006) make a specific recommendation to health and care professionals to discuss the use of advanced expression of wish-

es while the PwD retains capacity. Similarly, in Scotland, support by a trained professional to plan for future decision-making for PwD and their families is one of the five pillars on which the post-diagnostic support guarantee has been built (Alzheimer Scotland, 2011).

In the Spotlight

In the Spotlight: The Post-diagnosis Support Guarantee (Scotland)

The Post-diagnosis Support Guarantee is intended to ensure that every person receiving a diagnosis of dementia in Scotland is entitled to and receives access to support from a trained professional. The Guarantee covers a minimum of 1-year of support and is based on the Alzheimer Scotland Five-Pillar model: 1) Supporting community connections, 2) Peer support, 3) Planning for future care, 4) Understanding the disease and managing symptoms, and 5) Planning for future decision-making.

The main goal of the policy is to “give people time and space to access services and receive high quality support in a way that meets their individual needs”. It encourages them to think early on about care and support options along the trajectory of the disease and emphasizes participatory decision-making together with family and informal carers. The Post-diagnosis Support Guarantee is a powerful recognition of the right to care and support services of all PwD irrespective of age, gender and residence.

Implementation of the Guarantee has fallen short of expected targets, however, with recent figures presented during parliamentary proceedings indicating that only 2 out of every 5 people diagnosed with dementia are receiving the post-diagnosis support promised as part of the service (<http://www.parliament.scot/msps/currentmsps/donald-cameron-msp.aspx>).

More information at: http://www.alzscot.org/campaigning/five_pillars

UK legislation discourages care professionals from disregarding advanced care directives

While terminologies differ, there are many parallels between the relevant Scottish and English legislation with respect to advanced decision-making for people with limited capacity⁸. Advanced decisions to refuse treatment (formal documents signed by the interested person and a witness) are legally binding in England and Wales and must be followed by care professionals, as long as they comply with the Mental Capacity Act. Advanced statements of will and preferences are less formal and can be more general in scope, but they are not legally binding for care professionals, although they should always be taken into account in all decision-making related to the care of the person in question (expert communication). In Scotland, advanced directives allow for the refusal of future medical treatment under specific circumstances but their role is advisory, not compulsory. Medical professionals can, in principle, disregard the advance directive. If the medical decision were to be challenged in court, however, a ruling in favor of following a valid and applicable advanced directive would be the most likely outcome (expert communication).

Given that it seems impossible to foresee and plan all situations that might arise in the process of care, PwD are also advised to consider nominating a proxy decision-maker – i.e. a person who is familiar with their wishes and preferences and who can represent the interests of the person with dementia once she is unable to do so herself. Proxy decision-making rights for close relatives are not recognized in England or in Scotland, therefore the PwD is generally advised to register a Lasting Power of Attorney for health and welfare (England) or a Continuing and Welfare Power of Attorney (Scotland). These are written documents that must be signed and registered with competent authorities and that come into force only once the person concerned has been assessed as lacking capacity for decision-making⁹.

It is unfortunate that, despite efforts to raise awareness and train care professionals to promote its use, advanced care planning is not commonplace in dementia care either in Scotland or in England. In fact, PwD are generally less likely to plan future care than people with other terminal diseases, most notably cancer patients (Harris, 2007). The lack of effective advanced care planning is likely to contribute, in no small part, to the type of care PwD receive towards the end of their lives and the underutilization of palliative care approaches in their care (Marie Curie Cancer Care, 2015). Both in England and Scotland, the need to increase palliative care access has been recognized and addressed in various care guidelines (see 2006 NICE dementia guidelines; Scottish Government's Standards of Care for Dementia in Scotland, 2011) and by advocacy groups. Still, palliative care approaches remain the exception rather than the norm. Among the causes is the failure to acknowledge dementia as a terminal illness by the person with dementia, their family carers and often their care professionals (expert communication). This is well reflected in the underreporting of dementia as a cause of death: between 2001 and 2010 the number of cases where a mention of dementia was recorded in death certificates doubled both in England and in Scotland, but considering the prevalence of the disease, progress is overshadowed by the scale of the problem (Marie Curie Cancer Care, 2015). Steps towards addressing the issue have already been taken. The Scottish Parliament passed in 2011 the Certification of Death (Scotland) Act, with the goal of improving accuracy in death certification, introducing a national review system and guidance and support to doctors who certify cause of death.

Palliative care for dementia is underdeveloped and underused in the UK

Training programs for care professionals who interact with PwD and their family carers are needed in order to improve their knowledge and skills with respect to palliative care approaches (expert communication). Furthermore, palliative care services should be further integrated with community-based care for PwD in order to ensure access is facilitated. Finally, PwD should be informed about the benefits and values promoted by palliative care approaches and should be encouraged to think of and express their wishes with respect to end of life care (expert communication).

Case study 2: The Netherlands

The Netherlands is recognized for progressive, autonomy-promoting legislation for dementia care

The case of the Netherlands is particularly interesting to study as a beacon of progressive legislation and a generator of and frontrunner in innovation. While the Netherlands currently spends an estimated 5 percent of its healthcare budget on providing care for PwD (Netherlands Organisation for Health Research and Development, 2013) and approximately one third of individuals diagnosed with dementia live in residential facilities, policy and practice is strongly geared towards the promotion of autonomy and community-based care. Currently, the Netherlands is implementing its third and most ambitious National Dementia Strategy. The Deltaplan Dementia started in 2013 (for a duration of 8 years) with the ambitious, albeit criticized as vague, goals to: fund research into the prevention and cure of dementia, improve the quality of care for PwD and create a dementia-friendly society (Netherlands Organisation for Health Research and Development, 2013).

Use of assistive devices and intensive formal care support are key tools in avoiding institutionalization

It is important to emphasize that expected improvements in care quality are defined with respect to the wishes and desires of PwD and their ability to support individuals with dementia to live at home and to provide the necessary support for families and informal carers. The philosophy of maintaining QoL and promoting autonomy and dignity by allowing individuals dependent on support to continue living in the community is deeply embedded in the Dutch long-term care system and is reflected strongly in dementia care. The Special Admission to Psychiatric Hospitals Act (BOPZ) passed in 1994 governs the conditions for involuntary institutionalization for people with mental conditions, but has been criticized for failing to address many of the moral issues related to the care of PwD in residential care facilities (Hertogh & Eefsting, 2004). Subsequent legislation, the Act on the agreement of medical treatment (WGBO, 1995); the Act for patients' complaints (1995); and the Act on the quality of care in health care institutions (1996) have helped reinforce patient rights and autonomy in decision-making, leading to a situation where, in current practice medical or psychiatric treatment can only begin after the person concerned or a legal representative has consented to treatment (Schene & Faber, 2001). In dementia care the emphasis falls on promoting autonomy and the wishes of the person with dementia weigh heavily in decision-making relative to their care. When risks increase, care professionals will generally consider the use of assistive technologies and intensifying support to informal carers in order to better manage safety concerns, before recommending institutionalization (expert communication). In fact, the use of assistive devices is increasingly more accepted and prevalent in the Netherlands, both in residential and home care settings.

The focus on the maintenance of autonomy and dignity is also apparent in the strong emphasis on community support and avoidance of isolation. In fact, the Netherlands is one of the European countries that constantly pilots and implements innovative care solutions in order to improve the quality of life of PwD and support them to remain involved in their communities (the Deltaplan's third strategic goal). Noteworthy are initiatives like the Dementia Village¹⁰, Dementia-friendly Together¹¹, Alzheimer Cafes, and Geriant¹², which emphasize both the need to mobilize community to play a larger role in dementia care and the need to coordinate resources across care settings and between different care professionals in order to enable community-based care approaches.

The extensive case management programs in the Netherlands are reaching an increased number of PwD

Dementia is not specifically recognized as a disability in the Netherlands. It is most often described as a degenerative neurological disease and discussed from a medical perspective. Nonetheless, formal support is available for all PwD from diagnosis to end-of-life care. During the early phases of dementia most of the support is provided by primary care practitioners and relatives, with increasingly prominent roles for other health and home care professionals as the disease progresses, and finally residential and palliative care. Extensive case management programs for PwD in the Netherlands are becoming accessible to increasing numbers of users, although regional differences in availability persist. Such initiatives have proved successful in increasing continuity (bridging and organizing the work of multiple care professionals at different disease stages) and quality of care for dementia and have led to increased caregiver and patient satisfaction levels (Minkman et al., 2009). However, availability of community-based dementia services in the Netherlands can vary considerably between large urban areas and more remote or rural localities.

Advanced care planning is used with increased frequency in the Netherlands

The emphasis on autonomy for PwD in the Netherlands is also reflected in the approach to care decision-making along the trajectory of the disease. Likely due to appreciation of its importance and subsequent information efforts by care professionals and patient associations, advanced care planning is being used with increased frequency. Most PwD are informed about care planning decisions that they will face soon after diagnosis by their GPs (expert communication). It is of the utmost importance that advance care planning is not forced on the person with dementia and that they receive the necessary support and are afforded time before they address future care decisions. As GPs are often the first point of contact and information for PwD, increases in training on how to handle discussions on end-of-life care would be welcomed in the Netherlands (expert communication).

The current legal framework allows for representation by close relatives – i.e. the partner, parents, children and siblings of a person with dementia hold health proxy rights and must be consulted by care professionals on the care

and treatment of a person lacking capacity (Nys & Raeymaekers, 2013). Family members, however, lose the status of proxy decision-makers when the person with dementia has appointed an attorney, in accordance with article 465 §3 of the Dutch Civil Code. The durable power of attorney must be made in writing by the person with dementia herself before the loss of decision-making capacity. An attorney can make decisions related to the care and treatment of the person concerned, but such decisions are binding to care professionals only if the behavior of the attorney is 'not compatible with the level of care expected from a conscientious provider' (Moratti & Vezzoni, 2011). Such vague statements of invalidating conditions raise concerns with respect to the possibility that care professionals could too easily disregard the expressed decision of a health attorney.

Vague legislation on conditions for care professionals to disregard advanced directives

Similar concerns have been raised with respect to invalidating conditions for written advanced directives by the person with dementia. Following article 450 §3 of the Dutch Civil Code (amended by the Law on Medical Treatment Contracts 1995) a person with dementia can register, in writing, his/her wishes with respect to care and which treatments he/she chooses to forgo (refusal of consent), including life-saving interventions. The advanced directive must be made while the person retains full capacity and can be retracted at any later time while capacity is still retained (Moratti & Vezzoni, 2011). Care providers are bound by the law to follow the express wishes of the person with dementia unless they 'consider that there are well-founded reasons for not doing so'. While it is generally understood that the personal views and beliefs of care professionals, medical professional standards or the life-threatening effect of foregoing treatment are not to be considered 'well-founded reasons', the vagueness of the legal text has led to some criticism (Nys & Raeymaekers, 2013).

Finally, because no national registry of advanced directives exists, the issue of doctors not being informed of their existence in emergency situations unless relatives or health attorneys bring them to the attention of health professionals has arisen. According to a fact sheet from the Ministry of Health, Welfare and Sport released in 1995, medical professionals are under no obligation to identify whether an advanced care directive exists in emergency situations (Nys & Raeymaekers, 2013). This leads to concerns that, despite a legal framework that authorizes advanced decision-making on the part of the person with dementia, in practice, these might be all too easily overridden.

Assisted suicide and euthanasia are legal in the Netherlands for people with dementia or impaired cognitive skills

A feature of the Dutch legal framework with deep ethical implications surrounds end-of-life care and the right to choose to end one's own life via physician-assisted suicide or euthanasia (administering of lethal drugs at the request of the patient). In Europe, only three countries currently have legislation allowing medical professionals (under strict conditions – i.e. due care criteria¹³) to assist patients in ending their lives: the Netherlands, Belgium, and Luxem-

bourg¹⁴. The ethical underpinnings of allowing individuals to choose death over an incurable and debilitating illness rest in the beliefs that human dignity should always be protected and that the individual holds the ultimate right to choose how his/her dignity is best safeguarded. This view remains morally controversial and critics have likened the practice to murdering older citizens, especially those with cognitive impairments who cannot readily consent to the procedure as it is being carried out (Beaufort & Vathorst, 2016).

In the Spotlight

In the Spotlight: (Advance) Written Request for Euthanasia for PwD (the Netherlands)

Assisted suicide has been legal in the Netherlands since April 1, 2002 with amendments stipulating possible extensions to the applicability of the legislation to specific patient groups in 2004, 2013 and 2015. The strict requirements of the law surrounding voluntary expression of will while fully able to consent has, in practice, limited PwD from making advanced end-of-life decisions (although euthanasia statistics show 81 out of over 5000 cases of euthanasia in 2014 were carried out on persons with advanced dementia). In December 2015, the Ministry of Health published an updated guide on the application of the law that explicitly expanded the use of legal euthanasia to persons with dementia, conditional on an advanced written request.

More information at:

<https://www.rijksoverheid.nl/documenten/brochures/2015/12/17/handreiking-schriftelijk-euthanasieverzoek-publieksversie>

PwD can express end-of-life wishes in advanced directives, to be carried out at later disease stages

Myriad ethical issues can and have been raised and debated within the context of voluntarily ending one's life, and to what extent medical professionals should be involved in the process. Central to the debate surrounding specifically physician-assisted suicide and euthanasia for PwD are the issues of voluntariness/decision-making capacity and suffering (Beaufort & Vathorst, 2016). The former stems from the need to make the decision at a time when the person with dementia still has full mental competence. By necessity, this is possible during the early stages of the disease, which for most PwD is earlier than they would prefer to end their lives. Alternatively, under Dutch Law, a person with dementia can express his/her end-of-life decision in an advanced directive, made while the person retains full capacity, but that is to be enforced once the person with dementia has reached a stage of the disease (previously described in detail) that he/she considers unbearable (see text box above). In this situation, unlike in more common forms of advanced directive documents, one would have to describe as precisely as possible the situations in which and the conditions under which the wishes apply. While the possibility of advanced written request for euthanasia offers a potential solution to the inability to con-

sent due to loss of capacity for PwD, it is not without its drawbacks. The person making the decision early in the disease trajectory might not be, in a philosophical sense, the ‘same person’ as in the later stage of the disease. A very practical critique is that medical professionals might refrain from participating in euthanizing people with impaired capacity to consent. Many doctors find it psychologically difficult and morally unacceptable to perform euthanasia on a person who cannot clearly express her will at the moment of the procedure and who is doubtful to fully comprehend its consequences (Kouwenhoven et al., 2015).

The second central ethical issue that one must confront in the case of assisted suicide decisions for PwD is the possibility of establishing whether the distress and suffering caused by the disease is indeed unbearable (as per the due-care criteria) (Beaufort & Vathorst, 2016). In fact, at the time at which a decision for assisted suicide is made one can reasonably argue that the person with dementia is in no or little physical pain as a result of the disease. The pain is most likely to be psychological and rooted in the idea of an unbearable loss of dignity and of one’s self as the disease inevitably progresses to advanced stages (Beaufort & Vathorst, 2016). The anticipation and fear of unbearable future pain, critics have pointed out, is not the equivalent of experiencing that pain and in no way guarantees that the actual experience will reflect the expectation of the person with dementia. These and many other ethical issues surrounding end-of-life decisions for PwD merit further attention and debate and are likely to receive it in years to come in the Netherlands and elsewhere. However, the ethical debate on the potential and limitations of anticipatory decision-making for end-of-life care in dementia must be paralleled by a deeper understanding of how PwD themselves perceive and face the choices available to them and what are the care and treatment they desire (Hertogh et al., 2007). As research and public interest have lagged in this area, we strongly encourage the development of an open dialogue and more structured research into this field.

Case study 3: France

The 4th French National Plan takes an integrated approach by including all neurodegenerative diseases in its scope

In 2001, France became the first country to implement a national dementia strategy. While the first three iterations of the national strategy focused on Alzheimer’s disease and related conditions, the 4th and latest incarnation takes an innovative, more inclusive approach in that it focuses on all neurodegenerative diseases, including Parkinson’s disease and multiple sclerosis. It is thus appropriately called, “The Neurodegenerative Diseases Plan, 2014-2019” (*Le plan maladies neuro-dégénératives 2014-2019*).

As a result of strong and successful advocacy on the part of specific stakeholders in France over the past few decades – most prominently the French Alzheimer’s disease association (*France Alzheimer & Maladies Apparentées*) – dementia, and specifically Alzheimer’s disease, has benefitted from consistent policy attention and funding, to the detriment of other chronic conditions affecting older people. An evaluation of the third national dementia strategy (2008-2012) identified the need to move away from the silo approach to tackling Alzheimer’s disease that has dominated in France, towards a more integrated approach not only in the coordination and delivery of services, but also in terms of funding research into different aspects of this cluster of neurodegenerative diseases in order to make the most of available resources (Ankri & van Broeckhoven, 2013).

Reflecting on ethical issues in care and support for PwD is prioritized in the 4th National Plan

The 4th plan has 3 overarching priorities: 1) Improving the diagnosis and management of patients; 2) Ensuring the quality of life of patients and their caregivers; and 3) Developing and coordinating research (Ministry of Education & Research and Ministry of Social Affairs & Health, 2014). One of the specific issues that is raised within the framework of these broad priorities is making human rights and ethical reflection levers for improving how society – individuals and institutions collectively – think about and cope with people with neurodegenerative diseases in an inclusive way. Specifically, the plan highlights the need to improve professional practices and attitudes to allow people with neurodegenerative diseases to participate in decision-making and management concerning their care and their lives. The plan points to important work that has already been carried out in this field by the National Committee for Welfare and Rights (CNBD), by the National agency for the evaluation and the quality of establishments and social and medico-social services (ANESM), and by the National space for ethical reflection on Alzheimer’s Disease (EREMA) initiative, developed and initiated within the framework of the 3rd national Alzheimer Plan (2008-2012).

Moving forward, the 4th plan underscores the challenges that health and social care professionals face on a daily basis in ensuring that the care and support they provide is ethically sound, particularly with respect to the challenge of reconciling different perspectives and views in making decisions concerning the care of PwD and other neurodegenerative diseases, however small or minor those decisions might be. The plan calls for further action to support professionals in their work: “formalizing a collective space of ethical questioning responds to a need to re-establish or consolidate this questioning on a daily basis, since the actors realize that ethical reflection is weakened or endangered, for example by an excessive technicization of practice” (Ministry of Education & Research and Ministry of Social Affairs & Health, 2014: 78).

**Newly passed
legislation reforms
end-of-life and
palliative care to avoid
suffering and to make
PwD's wishes the focus**

This emphasis on ethical reflection and on bringing about changes in how society relates to and interacts with people with neurodegenerative diseases overlaps with recent legislation enacted in France, specifically about decision-making and end-of-life care for vulnerable adults. In the following paragraphs, we will address these two issues, as well as discuss legislation relevant for the issues of safety versus autonomy, and right and access to care and support.

In the Spotlight

In the Spotlight: ISATIS Association – Ethical Reflection Committee (France)

Isatis is a French non-profit care provider, offering both residential care as well as home care and day care centers for older people, including PwD. In 2014, following two years of regular meetings by a working group made up of care managers on the topic of challenging ethical issues in daily practice, it was decided that a more formal body was needed to address these challenges in a systematic and collegial manner. Thus, the Ethical Reflection Committee was born. The main questions the committee seeks to address are: 1) How to raise staff's awareness on ethical issues in day-to-day care? and 2) How to move towards better involvement of care professionals in considering ethical issues arising from practice?

Members of the committee consist of volunteers from each professional group employed by Isatis (auxiliary nurse, nurse, home help, physician, team manager, psychologist, administrative staff, social worker, occupational therapist, home care manager), as well as of family representatives, board members of Isatis, and external experts specialized in gerontology as well as ethics of care. Isatis staff are encouraged to bring cases to the committee, where these cases are then discussed and possible ways forward are identified that are in keeping with ethical values. Crucially, the committee is not a decision-making body; rather it is a forum in which care professionals can openly share the ethical dilemmas they are confronted with, and in which they can exchange and receive advice from their peers and from experts. The risks associated with the freedom to come and go, the refusal of care, the limits of care, and the end of life, are just a few of the issues that have been addressed within the framework of the ethical reflections committee.

More information at: <https://www.isatis.asso.fr/association>

Euthanasia remains criminalized in France, and until the passage of a new law in February 2016¹⁵, which has created new rights for end-of-life care for people in ill health, an article of the Public Health Code stipulated that if a patient expresses the will to forgo or stop life-saving treatment, and this wish puts the patient's life in danger, the doctor must do everything in his/her power to convince the patient to accept treatment. This stipulation was in direct conflict with the code of medical ethics which stated that physicians should refrain from 'unreasonable obstinacy', i.e. pursuing treatment that is futile.

The new 2016 law both creates new rights for PwD at the end of life and amends certain legal provisions of the Public Health Code. Specifically, it clarifies prior confusion around the concept of ‘unreasonable obstinacy’, explicitly rejecting it once and for all. Within the framework of the new 2016 law, the physician is required only to inform the patient of the consequences of his/her decision to forgo or stop treatment. Additionally, the law places the will of the patient at the center of end-of-life care decision-making, requiring that the attending physician take the patient’s will into consideration. Importantly, the new law also requires that, in the case of people who are unconscious or unable to express their will, physicians engage other members of the healthcare team in joint decision-making. There is some scepticism, however, about how this joint decision-making will work in practice, as the law does not specify any conditions for its application.

In addition to concretizing the rights of patients to refuse medical interventions at the end-of-life, the same 2016 law also enshrines the right of the patient to receive palliative end-of-life care in any care setting, including in one’s own home. Specifically, the law states that patients at the end of life have the right to be placed under continuous and deep sedation until death, with the objective of avoiding suffering. Crucially, this kind of sedation can only be instigated at the request of the patient him-/herself. If the patient is unable to express his/her will, the same law authorizes physicians to initiate a terminal sedation, again after engaging in a joint decision-making process with other members of the healthcare team.

Same legislation also makes advanced directives binding in effort to prioritize the PwD’s expressed wishes over medical staff

Closely linked to the aforementioned issue of end-of-life care is the matter of advanced directives. The same 2016 law makes a number of changes to the previously existing legal framework in an effort to ensure that people’s expressed preferences are respected over the course of the disease, and ultimately, at the end of their lives. Where previously the law granted only the right of refusal of medical intervention to the patient, it now endows people with the ability to state their preference with regard to pursuing, limiting, and refusing medical treatment or intervention. Also, where previously advance directives had to be renewed every 3 years, under the new law they have no expiration and are considered valid indefinitely; they can be revised when and if the person sees fit.

Perhaps even more significant is the fact that the new law makes advance directives binding. Under the previous law, it was already stated that anyone could draw up an advanced directive, however, the enforcement of these directives was quite loose, with physicians only required to consult the directive, not to act on it. Under the 2016 law, doctors are required to consult and carefully

In practice, stigma of dementia remains a barrier to ACP as evidenced by relatively low utilization of advanced directives

consider an advance directive before undertaking any investigation, intervention or treatment. Two exceptions to this regulation are included in the law in order to avoid undue burden on the physician. The first applies in cases of medical emergency in order to grant the physician time to ascertain the contents of the patient's directive, and the second in cases where the directive is entirely inappropriate or out of line with the person's medical condition. This new legal provision has the potential to fundamentally shift the balance of decision-making power between the patient and the physician, and succeeds – at least theoretically – in placing the wishes of the patient at the center of end-of-life decision-making for PwD. The practical challenge here involves promoting the take-up or use of advanced directives. According to the experts interviewed, viewing advanced care planning (ACP) as a process to be undertaken diligently and openly is not part of the French mindset. This is closely tied to the reality that the stigma associated with dementia remains strong in France, a fact that discourages individuals and families from discussing such matters and planning ahead.

In 2007, the French government passed a new law on the protection of vulnerable adults, which came into effect in 2009 and which served to update outdated legislation from the 1960s and 70s¹⁶. The 2007 law lays out the framework for guardianship and proxy decision-making for PwD, reinforcing and at the same time harmonizing the pre-existing, three-tiered system of guardianship, with the aim of safeguarding people's wellbeing (Alzheimer Europe, 2010). The three levels of guardianship are intended to be flexible in the sense that the type of guardianship can change according to the needs of the person requiring protection. The three levels are as follows:

- Judicial protection (*sauvegarde de justice*): applies to a person who needs temporary protection, or who is in need of representation through a specific process or with a specific task;
- Curatorship (*curatelle*): applies to a person who is not able to handle his/her affairs independently, but who is also not fully incapacitated, and who needs assistance and support in carrying out civic responsibilities;
- Tutorship (*tutelle*): applies to a person who is almost or fully incapacitated and who thus needs continuous representation in carrying out civic responsibilities.

Three-tiered system of guardianship allows for flexibility according to the PwD's representation needs

Under the updated 2007 law, any person who is not already under the tutorship level of guardianship can appoint – without legal proceedings – one or more individuals to represent them in case they are no longer able to conduct their own affairs. In the context of PwD, this provision, known as the mandate for legal protection (*mandat de protection future*) ensures that people can pre-

pare for and exert control over future decision-making by choosing the person(s) who will represent them. At each level of legal guardianship, anyone who has been appointed in advance by the individual in need of representation can fill the guardianship role. This can be a family member, a friend, or for example a lawyer or a notary. Medical professionals or medical assistants, or members of the pharmaceutical profession, as well as beneficiaries of any trust set up by the person under guardianship, cannot be appointed. If no person has been appointed in advance, preference is given to family members, in first order spouses or partners. If there is no family member who can be considered, the court appoints a legal trustee. Legal trustees are registered with the courts and are chosen from a list maintained by the respective local authority.

In terms of the right to care and support, a law passed in 2002 aimed to make more explicit the rights of users to access health and social care services, and to reform the approach to these services to make them more person-centered and tailored to individual needs¹⁷. In particular, the 2002 law diversified the types of services and the care settings available to beneficiaries, including community resource centers and mobile teams for adults with disabilities as institutional categories, and home help services under new types of services. These reforms have important implications for the rights of PwD to access services in the community.

One area where the law seems to contradict itself with important implications for practice is in the matter of guaranteeing persons the right to freedom of movement and to autonomy. The French constitution protects the rights of people to freedom of movement, but as safety and security are regulated by the 2002 law on the rights of people to health and social care, the right to autonomy is sometimes challenged in institutional contexts through the use of closed units, magnetic bracelets for tracking movement, and restraint belts for psychiatric patients and PwD (Alzheimer Europe, 2010). A new law passed in 2011 on the rights of people with mental health disorders¹⁸ reinforces the ethical argument that mental health disorders do not justify restricting an individual's freedom, and that measures to ensure their security must be commensurate with the individual's mental state. Importantly, the law also requires that the person must be informed continuously of his/her rights and of any measures or interventions being taken. The challenge here is that this law is designed mainly with psychiatric patients in mind and does not necessarily apply to the situation of PwD. The experts interviewed maintained that while professionals have long considered the use of closed units and restraints to be poor practice, these two security measures in particular are still commonly employed across the country.

Patient advocacy groups and family carer groups need to be more involved in ethical and legal debates and discourse

While the legal framework in France is relatively comprehensive in addressing the rights and needs of PwD, the experts we interviewed concluded that, in practice, there is still considerable progress to be made in enforcement of these rights, as well as in relaying and making sure that people are aware of their rights. The experts also underlined that the medical profession has a strong lobby and is a powerful stakeholder in the development of legislation related to the rights of patients, including those with dementia. Patient advocacy groups and family carer advocacy groups are not nearly as well represented, an under-representation that has significant consequences for the direction that legislation takes, and for its translation into practice.

The Takeaway

In addition to the organizational, financial and professional challenges underlined in previous chapters, community-based dementia care must contend with and satisfactorily address formidable ethical and legal challenges. Societies throughout Europe must recognize and safeguard the right to autonomy and dignity of PwD and afford them a measure of control over their lives and care. By the very nature of the disease affecting them, PwD will find their decision-making ability eroded. It is therefore crucial that every effort is made by formal and informal carers alike to adhere to a communicative model of ethics (Moody, 1993) whereby PwD are supported in developing and maintaining the necessary skills to participate actively in all decisions that concern them through open dialogue and communication. At the same time, a paradigm shift is required in how care professionals, families and communities perceive dementia: not an incurable disease beyond the ability of medical science to address but an impairment that can be compensated for with adequate support; not a loss of self and purpose but a change in needs and abilities.

If wider communities can expand their support and participation in dementia care we can expect a significant reduction in the burden of care on families and primary caregivers and increased opportunities for PwD to remain actively involved and feel empowered as part of their local communities. The experts we interviewed agreed that a key role in increasing community support for dementia care is to be played by informational and educational approaches to reducing stigma and supporting families and communities to better understand the needs of PwD, be they medical, physical, psychological or emotional.

While we have tried to emphasize throughout this chapter the importance of legislation and regulation on shaping community-based dementia care, it must be clearly stated that prescriptive and regulatory approaches are severely limited in the context of community care with respect to, for example, residen-

tial care settings. In other words, while one can in principle hope to define, monitor and enforce standards of care and care practices and procedures in formal care settings, policymakers are all but powerless to shape inner-family dynamics and care provision with the same tools. It is also in this sense that investment in information and educational programs must become a keystone of strategies for developing community-based dementia care.

Notes

- 5 For a comprehensive overview, the reader is encouraged to refer to the various reports on ethics in dementia care published by Alzheimer Europe. Available at: <http://www.alzheimer-europe.org/Publications/Alzheimer-Europe-Reports>
- 6 The complete definition is available at: <http://www.who.int/cancer/palliative/definition/en/>
- 7 Please refer to the Charter of Right for People with Dementia and their Carers in Scotland (2009) for an overview of the principles that base a human rights approach to dementia care. Available at: <http://www.dementiarights.org/charter-of-rights/>
- 8 Detailed information on legislation and procedures is available at: <http://www.alzscot.org> and <https://www.alzheimers.org.uk>
- 9 Further details can be found at: <http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/2010-Legal-capacity-and-proxy-decision-making>
- 10 More details available at: <http://www.dementiavillage.com/>
- 11 More details available at: <https://samendementievriendelijk.nl/>
- 12 More details available at: <https://www.geriant.nl>
- 13 The due-criteria in the Netherlands are: 1) the request is voluntarily made; 2) the request expresses an enduring wish; 3) the suffering is unbearable and without prospect of hope and relief; 4) no reasonable alternative means exists to make life bearable; 5) the individual who expresses this wish is considered to have decision-making capacity/has competence (Berghmans, 2010)
- 14 In Switzerland the practice of physician and non-physician assisted suicide is tolerated and not prosecuted (Guillod & Schmidt, 2005)
- 15 French National Law No. 2016-87 of 2 February, 2016. Available online: <https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000031970253&categorieLien=id>
- 16 French National Law No. 2007-308 of 5 March, 2007. Available online: <https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000000430707&categorieLien=id>
- 17 French National Law No. 2002-2 of 2 January, 2002. Available online: <https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000000215460&categorieLien=id>
- 18 French National Law No. 2011-803 of 5 July, 2011. Available online: <https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000024312722&categorieLien=id>

Chapter 9.

Concluding remarks and recommendations for policy and research

A framework to support evidence-based policy-making in dementia care...

As its title suggests, the aim of this handbook has been to arm (primarily) policymakers with a framework to aid evidence-based decisions concerning care for PwD and their families, with a special focus on care delivered in the community to PwD living at home. The impetus for developing such a framework is the increasing emphasis in advocacy, research and policy circles on providing care and support to PwD closer to home. The underlying reason for this heightened emphasis on home and community care is the mounting evidence emerging in recent years of both user preferences for home-based care and support as well as cost savings from the point of view of public sector health and social care systems.

... That gives families and local communities a prominent role

To this end, based on a review of the literature and input from experts gathered over the course of a focus group, we developed a conceptualization of community care for PwD in Chapter 2 (see Figure 1), which places the person with dementia at the center of the model, yet which recognizes the key role played by other actors including first and foremost informal carers (family carers), by health and social care services, and by the community itself. The distinguishing feature of our model – borrowing heavily from the international Age Friendly Cities and Dementia Friendly Communities initiatives established in the past few years – is the prominence granted to the community as an important player in the lives of PwD and their family members. Importantly, within our framework, community care transcends traditional understandings and applications of what care for PwD should consist of. Although we go into considerable detail to describe optimal interventions and care arrangements in the context of formal health and social care services, we underscore the need to strengthen the links between formal care services and the resources and capacity of community stakeholders in providing both practical and emotional support. Community stakeholders include civil society organizations with dementia-specific programs, local businesses, community centers and neighborhood associations, transportation authorities, schools and training centers, sports facilities, as well as individuals and informal groups of community residents. We recognize that a potential danger of promoting a greater role for the community as such is that this will be understood as shifting the perceived responsibility for care onto the shoul-

ders of private and non-governmental actors. This is decidedly not what is intended, and formal care services lie at the core of our model. Rather, what we try to suggest is that formal care services, working in conjunction with existing, informal structures of support, can improve the care provided to PwD and promote overall wellbeing.

... With a dynamic conceptualization of need progression along the disease trajectory

The other notable feature of our model is its handling of the progression of the disease itself and of the associated care and support needs of persons with dementia and family members. Many frameworks that we encountered in our research divided the trajectory of the disease into distinct phases, assigning specific interventions and services to each phase or stage. While there are certain services that are more appropriate at certain stages than others, evidence strongly suggests that dementia manifests itself differently for each individual. Add to this that ‘dementia’ is an umbrella term for a group of diseases, each with its own distinguishing characteristics, and it becomes clear that a more fluid, dynamic conceptualization of needs and appropriate services is needed. In our framework, while we recognize a generic progression from early to advanced dementia, we emphasize that this is rarely a static trajectory, and people’s needs and the relative importance of different support and care services are constantly shifting.

In addition to the construction of the conceptual framework, the literature review and expert focus group led to the identification of 5 ‘Tension Points’, or points of potential friction, which present themselves over the course of caring for PwD and which are important to consider in the development of care and support models for PwD. These are:

1. Desirability of community care (Ch. 3)
2. Differing perceptions of care needs and decision-making over the trajectory of the disease (Ch. 4)
3. Carers as service users (Ch. 5)
4. Care coordination and appropriate care mix (Ch. 6)
5. Assessing community care for PwD (Ch. 7)

In the respective chapters of this handbook, each Tension Point has been presented in depth, highlighting the main issues at stake, the key stakeholders involved, and possible solutions to overcome the potential challenges and pitfalls of designing and implementing care and support services in this area. In the following sections, we propose a series of policy-oriented recommendations targeting the individual, organizational/ community, and state levels.

The recommendations build on our findings in each of the five ‘Tension Point’ dimensions (Ch. 3-7), as well as in the legal and ethical dimension, which is identified in the conceptual framework as an important contextual aspect of caring for PwD (Ch. 8).

Recommendations for action at the individual level

Individuals, whether the person with dementia himself or herself, family members, or friends, form the core of care and support networks for PwD. There is a great deal that individuals can do to steer their own care and/or contribute to good care and support for their family members, friends and other members of the community:

- Increase awareness about the risk factors and symptoms of different diseases that fall under the umbrella of dementia, and about what it means to live with dementia;
- Get informed about available diagnostic and care and support services and programs through a variety of media (online information platforms, web-based applications, television and print media, etc.);
- Discuss concerns about one’s own or a family member’s cognitive function with a physician;
- Have frank and open conversations with family members and friends about aging generally, about the risks of dementia, and about preferred care arrangements in case of diagnosis;
- Familiarize oneself vis-à-vis one’s rights – as a person with dementia, as a family member of someone with dementia, or as a member of an informed public – with regard to advanced care directives, assigning of legal guardianship, consent or non-consent to medical procedures, monitoring devices and restrictions on movement and driving, end-of-life, etc.;
- Look for and ask for practical and psychological support (from care services, family and friends) when the burden of caring for a person with dementia becomes too large to bear alone;
- As carers, actively encourage the participation of PwD in all decisions related to their life and care;
- Volunteer with organizations providing support to PwD and their families;

- Be sensitive and supportive of PwD in daily life, while at the grocery store, waiting in line at the bank, at public events, at the hairdresser's, on the street, etc.

Recommendations for action at the community and organizational level

Community stakeholders from both the public and private sector are fundamental to the provision of effective care and support to PwD and their families. We divide our recommendations here between the community (local advocacy associations and community centers, local businesses, transportation authorities, schools) and formal care providers.

The community

- Organize community events in such a way as to be inclusive of PwD and their family members, to be partly accomplished by familiarizing, training, and organizing staff in the special needs of PwD;
- Establish a public forum to discuss the topic of dementia and related issues, e.g. how it affects individual residents and the wider community, how communities can come together to support families in coping with the disease; such a forum could take the form of a seminar series with invited speakers, or a monthly gathering at a coffee shop, etc.;
- Establish and make community facilities available for social clubs and informal meet-up groups where PwD and their family members can engage with each other and with other members of the community;
- Fight the stigma associated with dementia by providing platforms for PwD to interact with their local community and tell their story (e.g. local social and political events, information events in schools);
- Provide a range of opportunities for volunteering in the area of support for PwD and their families by creating networks with different community groups;
- Initiate neighborhood events where neighbors can get to know one another;
- Train local businesses' staff in how to show sensitivity towards PwD and how to act if a client with dementia is in need of assistance;

- As part of other ‘active aging in the workplace’ and ‘health in the workplace’ initiatives, local employers should raise awareness among employees of symptoms of dementia, and human resource departments should implement dementia-friendly policies to support employees diagnosed with dementia.

Formal care providers

- Primary care physicians make it a priority to discuss the risk factors for and symptoms of dementia with their patients, from middle-age onwards;
- The different medical professionals engaged in diagnosis and follow-up care share patient information with one another; information sharing is especially critical between primary care physicians and specialists, and between medical and social care professionals;
- Care providers take a holistic, person-centered approach to care in which the person with dementia’s life wishes and preferences guide care planning, and in which the person with dementia is encouraged to take an active part in planning their own care;
- Care and support is provided by multi-disciplinary teams of professionals, and services range from clinical nursing care to psychosocial interventions, and palliative and end-of-life care;
- Care and support provided by professional carers aim to relieve family members of the most physically intensive caring tasks and to increase the quality time between PwD and their loved ones;
- Support for informal, family carers, i.e. day care programs, respite care, counseling and peer-to-peer support for informal, family carers is available, accessible, and is tailored to meet individual needs and schedules;
- Available services are affordable and accessible for all who need them, with a particular emphasis on PwD living in rural regions;
- Provision of care and support is coordinated by a case manager who regularly consults with the person with dementia and with family members, and who is trained to consider the needs and perspectives of both parties and to resolve conflicts that may arise;
- Medical professionals – notably physicians, nurses and other staff working in acute care settings – receive training on how to recognize when someone has dementia, how to appropriately treat someone with dementia, and which services they should be referred to if necessary;

- Medical and care professionals are sensitive to the psychological burden that a dementia diagnosis places on the person him-/herself and on the family and understand that a person with dementia will need time and space to come to terms with the diagnosis and plan future care;
- All care decision-making should be participatory and care professionals should actively seek to involve the persons with dementia and their family carers in all care decision-making;
- When care at home is no longer possible or desirable based on consultation with the person with dementia and his/her family, transition to community-based residential care is made available.

Recommendations for action at the state level

Policymaking at the state or national level is fundamental to creating the necessary structural conditions for good community care for PwD to flourish. Our recommendations for these stakeholders include:

- Implementing legislation addressing the legal rights of PwD that carefully considers underlying ethical issues; including maintaining the autonomy of the person with dementia while still safeguarding their safety and the safety of others, establishing guardianship laws that are transparent and flexible, etc.;
- Developing legislation and procedures that allow PwD to be involved in all decision-making related to their care and to keep control over their lives for as long as possible;
- Creating space for diverse stakeholders to participate in and contribute to drafting legislation, including patient advocacy groups and informal carer advocacy groups, and experts from different professional groups;
- Though not specific to care for PwD, integrating the financing and governance of health and social care authorities in order to enable proper coordination and delivery of care;
- Investing in rigorous research and pilot interventions that include PwD as participants and co-designers;
- Investing in rigorous qualitative research to define quality of life (QoL) and wellbeing from the perspective of PwD, and that works towards development of an appropriate measure of QoL;

- Developing and implementing benchmarking guidelines that include measures of structural, procedural, and outcome quality (importantly, QoL) of community care for PwD; with the aim of monitoring progress over time;
- Drafting and implementing agreements in collaboration with other countries on standardized benchmarking guidelines to make international comparability possible for researchers and policymakers;
- Strengthening health information sharing infrastructure to enable the sharing of health data across institutions;
- Recognizing the importance of taking a societal perspective when examining the costs of community care and in planning care services for PwD;
- Promoting the implementation of ‘dementia-friendly communities’ initiatives.

To conclude, one of the most important insights we gained over the course of this study is the recognition that increasing formal care offerings alone is not the complete answer when it comes to enabling good community care for PwD. Instead, while it is essential that high quality care services (medical and social care) that are tailored to the needs of PwD are available to all who need it, the guiding aim of community care should be to support families to care for their loved ones at home as long as possible in a way that utilizes the resources and capacity of the community to the greatest extent possible. The need to find ways to engender solidarity within communities came up frequently in our research, particularly in our exchanges with experts. A community care model should also have as a main objective reducing the stigma of dementia, by raising awareness at the individual and community levels about the support needs of PwD and their families. Lastly, in adherence with a communicative model of ethics, it should work to enable the continued participation of PwD in decision-making, and inclusion in society of both PwD and the family members who care for them.

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