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# Integrated Care for Frail Older People Suffering from Dementia and Multimorbidity

# 22

Henk Nies, Mirella Minkman, and Corine van Maar

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## 22.1 The Challenge

Due to improved living conditions and better health care, life expectancy is expanding very rapidly in many countries (Colombo et al. 2011). Overall, we consider this as a blessing. But this blessing is to some extent ambiguous. Many people also extend their life with years in which they suffer from multiple chronic diseases, disabilities or frailty. One could wonder, whether quality of care has improved quality of life and whether the solution—better treatment and decreased

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mortality—has become a problem. It is a challenge to add life to years, instead of adding years to life.

This requires reconsideration of what we see as ‘good health’. The concept of health as defined by the World Health Organisation dating from 1948 -a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’—appears to be outdated (WHO, 2006). According to this conceptualization, everyone who is not completely successful in life, could be seen as unhealthy (Nordenfelt 2009). Also, the WHO definition is a rather static conceptualisation of health, recognising that being healthy is ambiguous and a dynamic process.

It can be argued that this conceptualization of health contributes to an over-medicalization of society. Machteld Huber and colleagues (2011, 2016) recently proposed a new concept of health: the “ability to adapt and self-manage in the face of social, physical, and emotional challenges” (Huber et al. 2011: 235). Resilience and self-management are key to achieving as good as possible quality of life and wellbeing. The challenge for care professionals, organizations and to society is to support older people in living a meaningful life in dignity, in spite of the ‘social, physical, and emotional challenges’ they are faced with.

In this chapter we will explore avenues to meeting the multiple health challenges for frail older people, in particular people suffering from dementia and multi-morbidity. We will take their needs as the point of departure for our analysis. Secondly, we will address how integrated care for these people can be organized. We will use the Dutch so called Care Standard Dementia as an example of a framework for service integration at regional level. Thirdly, we will discuss how the implementation can be monitored in regional networks on dementia care by using indicators of integration. Then, we will address our view on future developments in integrated care by applying principles of person centred care and personalized care. Generic standards need to be translated to individuals, as frail older people require tailored care and support. Finally, we will discuss how the organisation of integrated care for frail older people suffering from dementia and/or multiple problems may be built up of similar elements. Adequate diagnostics and multiple interventions by care professionals and organizations will not suffice. A community approach combined with a holistic point of view is also required to improve healthy life styles, as well as adapting the environment.

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## 22.2 Service Users’ Needs for Integrating Services

Before thinking about (multiple ways towards) solutions, the needs of the service users are to be explored. Frailty, dementia and multi-morbidity are frequent among the older population.

*Frailty* is often used to describe the high vulnerability of older people. It manifests itself in adverse health outcomes such as falls leading to immobility, disability and dependency, and other negative health outcomes, which may on their turn lead to increased institutionalization and mortality. Frailty represents an imbalance of the person’s homeostatic reserve, with a weakened resistance to harmful agents (Fried et al. 2004; Puts et al. 2005; Gobbens et al. 2011; Castell

et al. 2013). The phenotype has been reported to include sarcopenia, loss of endurance, decreased balance and mobility, slowed performance, inactivity, and often decreased cognitive function (Fried et al. 2004; Wick 2011). It is a condition of increased risk caused by functional decline and manifested by three or more core “frailty” elements like weakness, poor endurance, weight loss, low physical activity, and slow gait speed (Fried et al. 2004). In other words, frailty is a multi-dimensional condition. It is estimated that a large proportion of the older population are frail, ranging from around 5% among people aged 65–70, to more than 15% in persons aged 80 and over, with significant differences among various subpopulations (Fried et al. 2004; Castell et al. 2013).

*Dementia* occurs relatively often in old age. The term ‘dementia’ refers to a syndrome and **describes a wide range of symptoms** associated with a decline in memory. According to the World Health Organisation (2015) ‘It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.’ Alzheimer’s disease is the most prevalent and best known form of dementia. It accounts for 60–70% of all cases of people with dementia (WHO 2015). The second most common type of dementia is vascular dementia, accounting for about 10%. Other types are Dementia with Lewy Bodies, mixed dementias, dementia as a manifestation of Parkinson’s disease, Frontotemporal Dementia and Creutzfeldt-Jacob Disease. There are also reversible conditions that can cause symptoms of dementia, such as thyroid problems, and vitamin deficiencies (Alzheimer’s Association 2015).

Dementia primarily occurs in the ‘oldest old’. After the age of 80 the prevalence increases rapidly from around 15% in the age group 80–84 to almost 50% among the 95+ population (OECD 2015). It is expected that worldwide the number of people suffering from dementia will rise from 47.5 million at present to 75.6 million in 2030 and 135.5 million in 2050 (WHO 2015). In the Netherlands dementia is in the top 5 of diseases with the highest mortality among women, it accounts for 5.3% of total health spending in the Netherlands, being the second most expensive disease (Nationaal Kompas Volksgezondheid 2014).

*Comorbidity* can be conceived as the presence of additional diseases in relation to an index disease in one individual, when the nature of conditions, the time span and sequence of conditions are considered (Valderas et al. 2009). This assumes one disease taking a central place (for instance Alzheimer’s disease), in terms of being dominant in terms of the care and well-being of the individual. *Multimorbidity* is defined as the ‘co-existence of two or more chronic conditions, where one is not necessarily more central than the others’ (Boyd and Fortin 2010: 453). This implies that differentiating the nature of conditions is critical to the conceptualization of comorbidity (Valderas et al. 2009).

Data on incidence and prevalence of multimorbidity are complex to aggregate. Studies vary in the populations being studied, sources of data, data collection methods, age groups and diagnoses that are included (Boyd and Fortin 2010). Data from The Netherlands suggest that around two thirds of the Dutch seniors (65+) have more than one chronic condition. In the 85+ population this is around

85% (Van Oostrom et al. 2011). However, multimorbidity is not only a phenomenon in the older population. An Australian cohort study found more than 40% of the people with multimorbidity are younger than 60 years of age (Boyd and Fortin 2010). The bad news is that prevalence of multimorbidity is rapidly increasing; the good news is that most older people with multimorbidity remain independent and self-supporting, and most people don't feel limited in daily functioning. However, this is different in the oldest age group. Of the Dutch 85+ population, 28% of the men and 46% of the women did envisage serious impairments (Deeg 2012).

Studies into the comorbidities of dementia are scarce. From the few studies that exist, it is known that people with dementia have on average two to eight additional chronic diseases or comorbidities. One of the larger studies among nearly 73,000 people aged 65 and over in Spanish primary care centres, showed that 12% of the people suffering from dementia had dementia as the only diagnosis, almost 70% had at least two comorbidities, nearly 50% had three or more. These figures are around 50% higher than in the total older population. Like in the general population, hypertension and diabetes were most often observed among people with dementia. However, the conditions that were most strongly associated with dementia are Parkinson's disease, congestive heart failure, cerebrovascular disease, anaemia, cardiac arrhythmia, chronic skin ulcers, osteoporosis, thyroid disease, retinal disorders, prostatic hypertrophy, insomnia and anxiety and neurosis. Some of these can be considered as risk factors, others as complications and others just as comorbidities (Poblador-Plou et al. 2014). What these studies show, is that dementia often doesn't come 'alone' and that, also related to ageing, more health challenges have to be faced.

Frailty, dementia, co- and multimorbidity are multi-faceted conditions, which require multi-faceted interventions. These multiple, mental and physical problems are often associated with (psycho-) social problems, such as limited participation in society, loneliness or weak social relations, restricted mobility, feelings of meaninglessness or uselessness, anxiety, depression and loss of dignity. From a traditional point of view of health care—being compartmentalised and organized according to medical, paramedical, psychosocial and social disciplines and organizational entities—these needs cannot be met by simply adding up single interventions. On the contrary, coherent multiple interventions are required from professionals, but also from non-professional carers, such as next of kin and neighbours, as well as by the community at large (Nies 2014). In our view, the perspective should be oriented to the new—above depicted—concept of health, in strengthening self-management and resilience. Thus, an integrated approach for these groups of people is needed which goes beyond connecting medical and social care. The new paradigm of health needs focuses on domains such as bodily functions, mental functions, perception, spiritual/existential issues, quality of life, social and societal participation and daily functioning (Huber et al. 2016). To put it in simple wordings: it is about 'living your day-to-day life in a satisfactory way'.

In practice of care delivery this means that while drafting an individual care/support plan with a person suffering from dementia, one needs first to discuss what matters for this person. Before thinking in solutions for care and support, a deeper insight in to what is important for a satisfactory, meaningful way of living is

necessary to guide interventions that do not only address the physical and mental condition. It is about how the household can be run, how social contacts can be maintained, what the person can do or mean for his or her relatives, what role intimacy and sexuality plays, whether membership of activities such as a choir or a lunch club, whether spiritual needs are being met and so on. It requires professionals to have attention beyond traditional professional domains. It requires care providing organisations to operate in collaboration in networks of relevant professional and non-professional organisations (volunteers, citizens' initiatives). It requires dementia friendly communities, in which public (police, clubs, public transport etc.) and private services (shops, restaurants, museums etc.) and infrastructure (signage, ramps, housing etc.) are attuned to people with dementia (Davis et al., 2009).

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### 22.3 Inter-organisational Collaboration by Care Standards

In order to organise care and support for older people with complex needs, new coherent inter-professional and inter-organizational arrangements are required. As in many countries, in the Netherlands care and support for people with dementia could and can be improved. Although GP services, diagnostic clinics and home care are available for all persons in the Netherlands, the quality of dementia care is subject to multiple shortcomings and inter-regional differences. Areas for improvement include early detection of the disease, support after medical diagnosis, and under-diagnosis of patient and caregiver depression. Lack of care coordination, timely referrals and information flows between health professionals and informal carers are other improvement areas (Minkman et al. 2009).

To improve dementia care, a number of incentives were initiated in the last decade. In 2008 the National Dementia Program was launched sponsored by the Ministry of Health, Welfare and Sports. This four-year program was coordinated by the knowledge centres Vilans and CBO and the patients' federation Alzheimer Nederland. The latter ensured the users' perspective. Besides implementing improvements in the care delivery process for persons with dementia, a result was also the forming of regional networks of regional care providers. Encouraged and facilitated by the National Program these networks were initiated and further developed by the local care and welfare providers, often in close collaboration with the local users' organisations. At this moment there are about 85 dementia care networks in the Netherlands. In these networks professionals and managers of different organisations (e.g. mental health care, home care, long term care, municipalities) and local Alzheimer users' organisations work together for more coherent dementia care. The needs as defined by users and their informal carers, formulated in their language, were taken as the point of departure for the regional plans (Nies et al. 2009; Minkman et al. 2009).

To prevent that every region had to figure out their own way of setting up inter-organizational arrangements, for this purpose a so-called Care Standard can be helpful. A Care Standard is a document developed multidisciplinary, which describes what the important ingredients are for dementia care and support, based

on the most state-of-the-art (evidence based) knowledge and guidelines. Based on this national standard, solutions can be contextualised to adapt to the specific needs of the local communities.

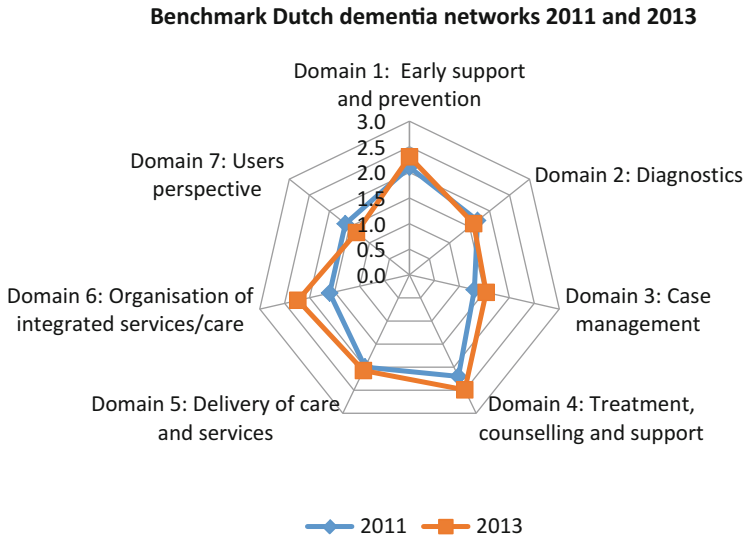
The emergence of the dementia care networks and the needed collaboration between a wide range of professionals showed that for providing the best care and support guidelines from one perspective or profession were not sufficient. Therefore, a national Care Standard for dementia was developed, led by Alzheimer Nederland, supported by Vilans, and launched in 2013 (Alzheimer Nederland, Vilans 2013). The instrument resembles to a certain extent the NICE guideline on *Dementia, disability and frailty in old age* (NICE 2015), but is more specific in term of what in these services should be organised. The process of developing this standard was time consuming, as all relevant professionals and stakeholders were involved. In the end, the care standard was authorised by all these parties, a current requirement for being acknowledged by the National Quality Institute. In this authorization process different points of view between professional groups became apparent. However, eventually the care standard was established.

The standard focusses on six domains:

1. Early recognition and prevention
2. Diagnostics
3. Case management
4. Treatment, counselling and support
5. Delivery of care and services
6. Organisation of integrated services/care

These domains describe what ‘good’ care should be, based on—for as far as possible—established guidelines and consensus, and how it should be organised. The sixth domain is of a different order, in the sense that it describes how the interconnections of the services along the process should be structured and managed; it is about the integration of service delivery. The standard does not define *which* professional (group) is eligible for providing care, this is held to the professional organisations and the local context.

Since 2013 a large number of dementia networks started to implement the care standard. However, there is a gap between the (total) standard and the actual delivery of individual person centred dementia care. To bridge this gap a number of networks started to describe a regional or local standard or pathway, which translated the ‘national standard’ into a regional version. This is a necessary step, because the standard gives a functional description of what should be considered or arranged, not whose task this is or how it looks like in practice. Translating the national standard into a regional version, facilitates implementation and guides steps that can be taken.



**Fig. 22.1** Progress of implementation of dementia care networks in the Netherlands 2011–2013

## 22.4 Implementation

In order to monitor progress of regional dementia care networks and the implementation of the care standard, the quality of regional collaboration is measured bi-annually by a set of indicators based on the care standard. The above-mentioned domains are measured by a number of operationalised indicators, which are solicited from each dementia network through a digital questionnaire. The user perspective is added as the seventh domain. Figure 22.1 gives an overview of the average scores per domain of the care standard for the years 2011 and 2013. During these years respectively 55 (2011) and 65 (2013) integrated dementia networks participated in the benchmark study (Van Maar et al. 2014).

These results highlight a number of areas for improvement:

1. There are significant differences between regional networks, also with respect to the collaboration with municipalities (which have a role in social support and prevention);
2. Commitments on diagnostics and follow up activities exist, but are not always followed in day-to-day practice;
3. Often, there is no structural funding for case management;
4. Inter-organizational collaboration is not fully implemented;
5. Network partners can further develop what the network has to offer;
6. Structural funding of the networks is still a challenge;



7. Commitments regarding quality of life of people with dementia and their informal cares can be improved.
8. Progress was monitored on the majority of domains, however attention for the client perspective was lagging behind.

In spite of these critical remarks, the networks are realising also progress. They report to work more according to the principles of the Care Standard. Moreover, the coordinators are more connected to other networks in the region, in particular generic networks for care for older people and networks for palliative care. Some of the networks are focusing on one of the domains of dementia care, such as case management, others are focusing on the full range of services.

The Care Standard provides an external framework for inter-organisational collaboration. It is also used as a basis for commissioning services by health care insurers, although not very strictly. Health care insurers are working on process and outcome indicators to make quality and progress visible. The aforementioned network indicators will be used to monitor progress, next to indicators that measure quality of life of service users. Experiences are now being collected, to combine both process and outcome measures on network and client level. Outcome indicators are for instance quality of life of the person with dementia as rated by the principle professional caregiver. Also quality of life of the informal carer is rated, as well as the time he or she thinks he can endure further care tasks.

The example demonstrates that a care standard provides a national framework based on (inter)nationally agreed evidence and consensus which is to be translated at regional level as a basis for—in the terminology of Valentijn et al. (2013)—normative and functional integration of services. It needs regional or local contextualisation to make collaboration work.

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## 22.5 Personalization

The term ‘Care Standard’ suggests that care is standardized and that personalized care is not feasible. However, the instrument of a Care Standard does recognize individual needs and requires tailoring services to needs. There are two ways of tailoring service provision to needs: one is to apply methodical principles of person centred care in interacting with the service user and his or her informal carers and that are applicable across various groups of service users. The other is to develop more evidence on which interventions work for particular groups of users and—more specifically—for which persons and under which conditions.

For person-centred care a number of main ingredients can be defined. *The key is putting the person and the family at the heart of every decision and empowering them to be genuine partners in their care.* The focus shifts to new models of care that change the conversation from “What’s the matter?” to “What matters to you?” Initiatives that focus on person-centred care are trying to demonstrate that engagement, co-design and co-production with individuals and families improves health, quality and value. A starting point of person-centred care is that people’s care

preferences are understood and honored, including at the end of life. In providing care, collaborating with partners on programs designed to improve engagement, shared decision-making and compassionate, empathic care is important (Barry and Edgman-Levitan 2012). In this scope it is not only about care, but a much broader perspective on daily living is captured, in line with the aforementioned new paradigm of health (Huber et al. 2011; Huber et al., 2016). Working with partners to ensure that communities are supported to stay healthy and to provide care for their loved ones closer to home is the leading societal perspective.

On a more detailed level personalized care requires evidence on ‘what works for whom?’ Most studies on interventions in frail older people and people with dementia are generic. They do not make distinctions between the characteristics of the subgroups, the circumstances in which they are effective and the specific outcomes. However, effects of interventions, also in multi-problem target groups can be enhanced by tailoring services to the idiosyncrasies of the person and his or her social network. A review by van Mierlo et al. (2010) analysed the effectiveness for people with Alzheimer’s disease and non-specified types of dementia. Furthermore, a distinction was made in people living in an institutionalized setting, or living in the community. Within these categories distinctions were made such as severity of dementia (mild, moderate, severe), behavioural problems (general, agitation, aggression, disruptive wandering behaviour, repetitive disruptive vocalisations), mental health problems (withdrawn behaviour, depression, bipolar disorders, sleep disorders, irregular sleep-wake rhythm), ADL dependency, living circumstances, gender, and the intervention taking place in a small group or a large group. The outcomes were categorized in factors such as quality of life, behavioural functioning, cognitive functioning, mental health and physical health. Interventions such as reminiscence therapy, behavioural therapy, progressive muscle relaxation, cognitive stimulation, meeting centres support, dementia special care units, were assessed according to these categories. The wide array of interventions demonstrates differentiated effects for different types of dementia for people in different circumstances. The study provided first evidence for referrals and interventions that are more tailored to subgroups of people suffering from dementia. It yielded information which can be implemented and translated by professionals (with a particular specialisation).

A similar review was carried out on the effectiveness of support to informal carers of people with dementia (Van Mierlo et al. 2012). The key message of these studies is that we need to tailor interventions to specific characteristics of frail older people and that a ‘one size fits all’ policy is not the most effective in dementia care. This personalized knowledge can underpin care standards and the included professional and non-professional interventions, even—or maybe just—in integrated settings. Reality is, that we have a long time to go before there is a sound body of knowledge on personalized interventions.

## 22.6 Future Perspectives

The current state of play is that dementia is a syndrome that with some exceptions cannot be cured, is multifaceted and asks for person-centred integrated care. The same holds for frailty and to a large extent for the accompanying complex multimorbidities. The symptoms can be alleviated and people can be supported in their self-management and resilience. At macro-level the best strategy is prevention of diseases and disability. Recent research shows that the prevalence of dementia is substantially decreasing in some countries if corrected for age, sex, area and deprivation status. Although there are various factors that could have increased dementia prevalence at specific ages, associated with diabetes, survival after stroke, and vascular incidents, it appears that other factors such as improved prevention of vascular disease and higher levels of education appear to have a greater effect (Matthews et al. 2013; Larson et al. 2013). This implies that preventive measures, improvements in treatment and care, and disease modifying interventions combined will be the most effective strategy for the future (Prince et al. 2013).

In a recent report, the OECD (2015) describes the key elements of such a strategy. Generic lifestyles recommendations such as non-smoking, physical activity, healthy diets, cognitive training and formal education are linked to reduced risk of dementia. Treatment of medical conditions such as brain injury, diabetes, mid-life obesity, mid-life hypertension and depression are a second line of reducing the risk of dementia. What at present cannot be influenced are hereditary factors and age.

Following this analysis of risk factors, the OECD defines ten elements of dementia policy:

1. Risk reduction by healthy ageing strategies targeting generic risk factors;
2. Selective early diagnostics (standardized needs assessment) for people who are concerned about symptoms and post-diagnostic support to people;
3. Safer communities for and more acceptance of people with dementia by awareness raising, dementia education at schools, training of people who get in contact with people with dementia in the community;
4. Support of relatives and friends who care for people with dementia respite services, peer to peer support networks, training to informal carers etc.;
5. Safe and appropriate environments including alternatives to institutional care for living with dementia in dignity, making houses suitable for living with dementia and communities safer and more accessible for people with dementia (dementia friendly communities);
6. Access to safe and high quality long-term care services by recruiting and training a dementia care workforce, systematic attention to behavioural symptoms, including the use of antipsychotics and physical restraints, and promoting independence and self-determination through user-directed support;
7. Health services recognizing and dealing with people with dementia effectively, supported by registries or electronic health records, trained, dedicated and specialized staff in hospitals;

8. Increasing opportunities for dying in dignity in the place of people's choosing, trained home care staff in palliative care;
9. Coordinated, proactive and closer to home delivered primary care, multidisciplinary management of comorbidities;
10. Applying the potential of technology to support dementia care.

The OECD translates user-directed support also in financial terms for users and informal carers. It signals that financial systems should support independence and give control to service users and their families. This can be strengthened by appropriate benefits in the form of cash benefits, vouchers or personal care budgets, instead of services in kind. This allows people with dementia to choose the type of services they prefer, which may go well beyond traditional care and across financial, legislative and professional barriers.

Changes in funding and legislation, in roles between stakeholders and in collaboration also have consequences for governance. Governance of (traditional) organisations need reframing, because inter-organisational collaboration becomes more important and asks for new dynamics and governance which is linked to the community (Nies and Minkman 2015).

Lastly, it can be argued that most of the above mentioned elements for dementia policy are also relevant for frail older people and people with multi-morbidities. Hence, one of the key elements is safe and supportive living at home, be it in the community or in a care facility supported by—when useful—technology and by informal caregivers and people in the community. These elements relate to the earlier described new concept of health of Huber (Huber et al. 2016) in which 'whole person thinking' is key.

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## 22.7 Conclusions

The challenges of care for frail older people with dementia and multi-morbidity are increasing, partly due to our improved health care services and increased life expectancy. This challenge is not an easy one. It requires innovative approaches in order to face these challenges and to reduce current and future burden of service users, their families and society. It is a challenge that requires new care paradigms and new organizational paradigms. Working towards the principles of a new concept of health, working towards personalized and person-centred care in networks, based on shared normative and functional frameworks needs full attention of policy makers and care providing organisations. But the challenge of an ageing population is not merely a professional task in the field of health, long-term and social care. The solution also lies in the community. It has to get tuned to a changing demography, supporting people with limited functioning and supporting healthy behaviour at all ages. Communities need to get acquainted with a changing population, where people sometimes behave 'differently'. Therefore, health and long-term care professionals and services should not limit their focus of integrated

care to their peers or care partners; it is a challenge to society and to local communities.

New questions need to be addressed such as how to create adoptive and resilient communities and organisations? What are effective approaches and which preconditions are necessary? How do we improve collaboration between the public sector in a broad sense such as schools, clubs, welfare services, public transport, police on the one hand, and the private sector and private life of citizens, such as housing, shops, banks, neighbours' support, volunteers and the dementia care sector? Examples such as Dementia Friends (see: <https://www.dementiafriends.org.uk/>) and dementia Friendly Communities (see: <http://www.alzheimers.net/2013-12-12/building-dementia-friendly-communities/>) (Scharlach and Lehning 2013) are promising, but ambitious. Turning population ageing into a blessing requires high ambition on a wide variety of societal actors, integrating their strengths to meet the challenging social and individual needs of frail older people suffering from dementia and accompanying problems.

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