

Housing and care for older adults with dementia: a European perspective

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Abstract The ageing of society goes together with an increasing number of older adults with dementia. This group has specific housing and care needs reflecting their physical and mental health status, which has implications for the housing market, the public housing task, and the related provision of care. Within the European Union, there are various care and welfare regimes that constitute an underlying cause of the broad range of solutions chosen to organise care and housing of older adults with dementia. These regimes also account for the large differences that exist in the current housing situation of older adults with dementia in relation to the level of care they receive and the involvement of relatives. The paper zooms in on the situation in the Netherlands, where national policies focus on (1) ageing-in-place, (2) the separation of residence and care, and (3) substitution of institutional by non-institutional types of living. Within institutional settings, a transition is made towards small-scale group accommodation (SSGA) for older adults with dementia. Solutions within the domain of care consist of facilitating family carers, whereas housing solutions are directed to SSGA and use of technology and implementation of modifications to the living environment.

Keywords Dementia · Housing · Care · European Union · The Netherlands · Policy

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1 Introduction

The population of Europe is ageing rapidly. Older adults do not comprise a homogeneous population, particularly in terms of health and lifestyle. About 24.3 million people worldwide cope with dementia. This number will treble by the year 2040 (Ferri et al. 2005). On the level of the individual occupant, age-related health problems can be the basis for home modifications and retrofitting, moving, or simply living under less favourable conditions (van Vliet 2004). Older adults with dementia (OAWD) have specific housing and care needs, given their physical and cognitive status (van Hoof and Kort 2009), which in turn have consequences for the housing market, the public housing task, and the provision of care. National and local governments are in a process of transforming the sectors of housing and care in order to accommodate the growing population of OAWD and to provide them with the type and right amount of care they need. Unfortunately, the figures and policies regarding housing and care for OAWD in Europe are not centrally documented. O’Malley and Croucher (2005) state that “throughout the policy literature there is little to guide practitioners, service planners or relatives in housing-related choices or issues for older people with dementia. As the incidence of dementia rises against an apparent policy vacuum, it is timely and relevant to examine the research evidence that exists with regard to housing for this relatively neglected minority of older people”. This paper provides some information relevant to these professionals and may contribute to solving the aforementioned issues for OAWD.

This paper explores and summarises (1) the demographics of dementia in Europe, (2) the framework in which the care and welfare regimes of EU member states are organised, and (3) the solutions that EU member states choose for care and housing of OAWD. The paper zooms in on the situation in The Netherlands, a country that is actively transforming its policies and practice in relation to dementia.

2 Demographics in the EU

Within Europe, there are large differences in the total number of people with dementia per country (Table 1), as well as in prevalence rates (Wimo et al. 2007). According to Alzheimer Europe (AE 2006a), there were about 5.4 million people with dementia in the EU-25 in 2005. Numbers are predicted to double for Western Europe and to treble for Eastern Europe by 2040. According to Brookmeyer et al. (2007), there were about 7.21 million people with dementia in Europe in 2006. This number is estimated to be 16.51 million for the year 2050. The highest number of people with dementia is given by Wimo et al. (2007), who estimate the number to be 8.07 million.

3 Care and welfare regimes in the EU: financing

The way care and health services are provided depends partly on a country’s care and welfare regime. According to Nies and Berman (2004), four main types of regimes can be distinguished in the EU, primarily based on the perspective of financing of care.

1. The ‘Beveridge’ or Anglo-Saxon system: public provision and ‘single payer’ financing from taxes, in which the paying authority is responsible for managing the services provided.

Table 1 Dementia in the EU in 2005

Country ^a	Number of people with dementia (×1,000) ^b	Number of people with dementia (per 1,000 inhabitants)	Direct costs (×10 ⁶ €) ^c	Scenario 1: 1.6 h of informal care/day			Scenario 2: 3.7 h of informal care/day			Scenario 3: 7.4 h of informal care/day					
				Costs for informal care (×10 ⁶ €) ^c	Per person price level (%) ^d	Relative price level (%) ^e	Costs for informal care (×10 ⁶ €) ^c	Per person price level (%) ^d	Relative price level (%) ^e	Costs for informal care (×10 ⁶ €) ^c	Per person price level (%) ^d	Relative price level (%) ^e			
Estonia	12.1	9.0	68	34	103	8,500	62	80	148	12,200	60	160	228	18,800	58
Slovenia	18.9	7.8	141	90	232	12,300	72	209	350	18,500	78	417	559	29,600	83
Latvia	21.7	9.4	94	39	133	6,100	-13	89	184	8,500	-18	178	273	12,600	-21
Ireland	33.7	8.2	469	167	637	19,000	50	387	856	25,400	-3.3	773	1,242	36,900	-9.7
Lithuania	34.1	10.0	166	70	236	6,900	41	162	328	9,600	34	324	490	14,300	29
Slovakia	42.1	7.8	232	105	337	8,000	35	243	475	11,300	30	487	719	17,100	26
Finland	63.5	12.1	680	184	864	13,600	-8.0	425	1,106	17,400	-19	850	1,531	24,100	-28
Denmark	68.5	12.7	817	645	1,462	21,300	26	1,491	2,308	33,700	37	2,983	3,800	55,500	45
Bulgaria	79.8	10.3	253	110	363	4,600	20	255	508	6,400	15	511	763	9,600	11
Austria	95.1	11.6	1,092	545	1,637	17,200	24	1,261	2,353	24,700	22	2,523	3,614	38,000	21
Czechia	97.2	9.5	612	282	893	9,200	30	651	1,263	13,000	26	1,302	1,914	19,700	23
Hungary	100.3	9.9	579	314	893	8,900	40	725	1,304	13,000	40	1,450	2,030	20,200	40
Portugal	113.0	10.7	750	206	957	8,500	-0.5	477	1,227	10,900	-13	954	1,704	15,100	-22
Belgium	132.9	12.7	1,425	759	2,184	16,400	41	1,754	3,179	23,900	38	3,598	4,933	37,100	36
Sweden	141.2	15.7	1,451	581	2,032	14,400	30	1,345	2,796	19,800	-2.9	2,689	4,140	29,300	-7.5
Greece	142.9	12.8	1,099	556	1,655	11,600	0.8	1,286	2,385	16,700	-0.5	2,572	3,670	25,700	-1.5
Romania	180.5	8.3	544	281	826	4,600	-8.4	651	1,195	6,600	-9.2	1,301	1,846	10,200	-9.8
The Netherlands	181.3	11.1	1,921	1,035	2,956	16,300	2,393	4,314	23,800	4,787	6,707	37,000			
Poland	313.6	8.2	1,399	961	2,360	7,500	44	2,222	3,621	11,500	51	4,443	5,842	18,600	57
Spain	541.9	12.6	4,897	2,552	7,448	13,700	-0.4	5,901	10,798	19,900	-1.1	11,803	16,699	30,800	-1.6
France	796.2	12.7	7,978	2,774	10,752	13,500	3.6	6,414	14,393	18,100	-5.0	12,828	20,807	26,100	-12

Table 1 continued

Country ^a	Number of people with dementia (per 1,000 inhabitants (>1,000) ^b)	Number of people with dementia (per 1,000 inhabitants)	Direct costs (€) ^c	Scenario 1: 1.6 h of informal care/day			Scenario 2: 3.7 h of informal care/day			Scenario 3: 7.4 h of informal care/day					
				Costs for informal care (×10 ⁶ €) ^c	Total costs (×10 ⁶ €) ^c	Per person price level (%) ^d	Costs for informal care (×10 ⁶ €) ^c	Total costs (×10 ⁶ €) ^c	Per person price level (%) ^d	Costs for informal care (×10 ⁶ €) ^c	Total costs (×10 ⁶ €) ^c	Per person price level (%) ^d			
UK	811.7	13.5	8,481	4,353	12,834	15,800	7.0	10,065	18,546	22,900	6.0	20,131	28,612	35,300	5.2
Italy	850.0	14.5	8,326	4,199	12,525	14,700	46	9,710	18,036	21,200	44	19,420	27,746	32,600	42
Germany	1,086.8	13.2	11,409	6,249	17,658	16,200	-1.4	14,451	25,860	23,800	-1.1	28,902	40,311	37,100	-0.8

Direct costs of care are shown together with costs for informal (ADL) care for three scenarios [taken and adapted from Wimo et al. (2007)]. Price levels are compared to those in the Netherlands, based on net domestic purchasing power

^a Only countries with over 10,000 people with dementia are shown

^b The number of people with dementia may differ from other studies or national institutions

^c All cost figures are derived from US\$ figures at a rate of 1:1.27 (mean exchange rate 2005)

^d The comparison to price levels in The Netherlands is based on net domestic purchasing power by UBS (2005) of the capital cities (Germany: average of Berlin and Frankfurt; Spain: average of Madrid and Barcelona)

2. The ‘Bismarck’ or Central European system: a variety of ‘quasi-public’ payers and corporatist arrangements with the state, social insurance-funded and controlled by legal private organisations.
3. ‘Mediterranean’ or Southern European systems: mixed systems with elements of national health insurances and others from social insurance models. Strong element of family responsibility and a less-developed public long-term care sector.
4. ‘Eastern European’ or developing former socialist systems: strong tradition (and expectation) of state provision. Resources are scarce and the role of the state has changed.

According to Pommer et al. (2007), there are roughly three ways in which health care regimes are organised in Western Europe. In short, the Scandinavian model is based on the individual autonomy of citizens; it puts primary responsibility for the own care provision on individuals. Governments step in when individuals experience health problems. The Continental model, which is based on the autonomy of the nuclear family, puts responsibility primarily on direct family members in case of health problems. In the Mediterranean model, this responsibility is placed on the extended family (Pommer et al. 2007), although its role is changing due to demographics and economic processes (AE 2006a). These models are based on the perspective of responsibility for providing care. Based on the perspective of the provision of care, Pommer et al. (2007) distinguish four regimes, ordered from the perspective of formal or informal carers:

1. Families have a legal obligation to provide care. The state takes over this responsibility in exceptional cases (Greece).
2. Family responsibility exacted by the state. The state is responsible when families are unable to fulfil responsibility for caregiving (Italy, Spain).
3. There is collective responsibility for people that require intensive forms of care. This responsibility is ratified by law. Informal networks are responsible for people with a minor demand for care (Germany, Austria, France).
4. There is collective responsibility for people that require intensive forms of care. This responsibility is ratified by law. Informal care is stimulated but cannot be exacted by the state (Sweden, Denmark, The Netherlands).

The various care regimes directly determine the type and quality of services such as housing and home care. There are great differences in terms of state responsibility, funding, the role of families, and the actual availability of home care services, between and within EU member states (AE 2006a).

3.1 Costs of care

The financial and societal costs of care for people with dementia are rather significant. According to Wimo et al. (2007), the costs of informal care in 2005 were an estimated € 26.8 billion for the EU, or about € 4,700 per person with dementia (Table 1). The direct costs of dementia care are an estimated € 54.3 billion, or € 14,200 per person with dementia (Table 1). Informal care constitutes a major cost component, in particular in economically less developed regions (Wimo et al. 2007). The costs per person can vary considerably, even within the more developed countries and when considering the net domestic purchasing power (Table 1). In countries where relatives are responsible for providing care, dementia care can take about 10–25% of a family’s average net annual income (AE 2006b), including telephone costs and expenses for travelling and

transportation. The ratio of time spent on care for (instrumental) activities of daily living (IADL/ADL) at home by informal carers versus formal carers in Sweden is roughly 4:1. This ratio is likely to be higher in Mediterranean countries (Moise et al. 2004). Many informal carers are older adults themselves, and health problems may arise from the stresses of caring for a loved one (Tjadens and Duijnsteet 1999). In order to alleviate the burden of care, respite care is available in many countries to OAWD living at home or even in residential institutions (Moise et al. 2004). Similar to programmes for informal carers, most countries do not provide dementia-specific home help services, as do Germany, Sweden and the United Kingdom (Moise et al. 2004). Alzheimer Europe (AE 2006b) explored the impact of dementia on informal carers and found that for the majority of carers important services such as home support, day care, and residential or nursing home care were not available. About two-thirds paid themselves for home care, over half for day care, and almost 90% for residential or nursing home care (AE 2006b).

4 Care and housing solutions for dementia

The types of housing and care services and dementia care policies in various EU member states are summarised in Table 2. Some services are provided all over Europe, including assistance with small household repairs. Day care centres are available all over Europe, except for Spain and Romania. Provisions for night-time care are offered mainly in the 'North Sea countries' (AE 2006a).

4.1 Southern Europe

The organisation and provision of home care services (domestic and personal care) cannot be considered in isolation from family carers, particularly in Southern Europe (AE 2006a), where there is a cultural tradition as well as a legal obligation to care for dependent relatives. The provision of home care services by the state is considered as optional, and the availability of appropriate services tends to be unevenly distributed or simply lacking (AE 2006a). In Italy and Spain, institutional settings are limited to those people who have no access to adequate informal care and with insufficient financial resources (Pommer et al. 2007). Greece hardly offers public institutional care, meaning that people have to turn to regular medical care or private institutions. There are a limited number of institutional state facilities for those with few financial resources. People with financial means can turn to private care. There are no home care services in two-thirds of Greek municipalities (Pommer et al. 2007). In Portugal, family accommodation or boarding out (housing dependent people within families) is a form of care given to those without relatives or financial means (AE 2006a).

4.2 Central Europe

In German-speaking countries and in France, the family forms the primary mode of care. Collectively organised systems can provide formal care in situations requiring prolonged and regular care. Austria had a low use of institutional settings. In France, these settings have a poor reputation (Pommer et al. 2007). Diagnosis of Alzheimer's disease is a factor for a non-specialised institution to refuse admission, even though France has less than ten specialised psychogeriatric institutions (Moise et al. 2004). In Germany, institutional settings play an important role (Pommer et al. 2007), including dementia-specific

Table 2 Available support systems, types of housing, and health care policies for dementia in a selection of nine EU member states

	The Netherlands	UK	Italy	Spain	France	Poland	Greece	Germany	Sweden
<i>People with dementia living at home and presence of family carers</i>									
People at home	65%	About 63.5% of people with late onset dementia live in private households				63%	97%		
<i>Family carer/ spouse present</i>									
(Martin et al. 2007)	Informal carers spend 78% of time on care	80% of people with dementia in Italy live at home, assisted by relative (Valla and Harrington 1998)		45%, as a percentage of co-residents spouse-carers	18% spouses, 53% adults children (45.5 h/week)	28% spouses, 22% adult children (45.5 h/week)		Spouses present in 91% of males, 72% of females. 80% of time spent on (I)ADL by informal carer	
<i>Available support systems</i>									
Home support, reported	Home care is open to everyone who needs this service. Most clients are older adults. Over 600,000 people receive home care annually. This number increases due to ageing-in-place and early discharge from hospitals	Dementia-specific ADL help and nursing help available nationwide. Care from a registered nurse is always provided free by the NHS, regardless of setting.	Home support is received by 1% of all people aged 65 and over	Available for 44% of people. Systematic ADL and nursing help services are being developed. There are ~175,000 places available in assisted living facilities	Available for 37% of people. Home nursing care services exist to prevent, postpone or shorten stays in hospital or residential care institutions	Available for 54% of people	Available for 34% of people, based on the Long-term Care Supplementary Act. Home support is received by 6.5% of all people aged 65 and over	Dementia-specific help with ADL available. Eligibility varies among municipalities. Home support is received by 10% of all people aged 65 and over	

Table 2 continued

	The Netherlands	UK	Italy	Spain	France	Poland	Greece	Germany	Sweden
Type of home care services provided by housewives	Home nursing, personal care, domestic care, day care, respite care, night care and assistive devices. A special service called 'alpha care' consists of home care that is provided by housewives	Personal care, domestic care, shopping, short breaks/ respite care, home adaptations, meals, information about local services, day care & transportation, advocacy services, befriending services, provision of equipment to help with daily tasks and alarm systems, provision of disability aids and equipment, assistance with adaptations to the home	Home help, meals, personal care, nursing, rehabilitation, and prosthesis supply, meals-on-wheels, tele-alarm services, In practice, home care services are more or less limited to household tasks, since personal care is considered a task of the family	Depending on availability per community: social work, domestic care, meals-on-wheels, tele-alarm services, In practice, home care services are more or less limited to household tasks, since personal care is considered a task of the family	Accompanying the person, home modifications, administrative help, day or night care at home, delivery of medication (emphasis on rural areas), meal assistance, granny sitting, hospitalisation at home, home services, domestic help, keeping the person company, meals-on-wheels (not very popular), mobile library, paramedical service, repair service for small repairs, respite care, social nocturnal emergency services.	Managing the household, preventing social exclusion/ promotion of social integration, doing small repairs, laundry, transport, day care centres	KAPI centres offer: preventive medical services, physiotherapy and occupational therapy programmes, health education, and recreational activities. Many KAPI centres collaborate with the Help at Home project, which offers a range of social and health care services, as well as family assistance. In the two largest cities, there is a 24-h tele-alarm system linked to family, neighbours, the police or the ambulance service	Home care services covered by the LTCI: personal hygiene, nutrition: assistance with eating, mobility, domestic care, organised care, respite care, day care and night care, and nursing/ technical aids	Help with care means personal help with tasks needed in order to satisfy the person's physical, mental and social needs; help with I(C)DL, activities to break isolation, home cleaning and laundry, measures for safety and security at home, or a safety-alarm (for people with mild dementia). In addition to home help, other municipal services for the aged include transportation services, foot care, meals on wheels, security alarms, housing adaptations and disability support

Table 2 continued

	The Netherlands	UK	Italy	Spain	France	Poland	Greece	Germany	Sweden
Day care	Service offered by care and nursing homes. Over 20,000 people made use of day care in 2001	Semi-residential structure, within the district. Opened during weekdays, 7 h a day, for the provision of health/social care services	By 2007, 13,000 extra places in therapeutic day care centres and respite centres, which represents a fourfold increase in available places.	Day care centres offer 4–8 h of care per day.	A number of day care centres have been set up since the introduction of the National Social Care System in 1998. These are closely linked to KAPIs	Day care centres offer 4–8 h of care per day.	A number of day care centres have been set up since the introduction of the National Social Care System in 1998. These are closely linked to KAPIs	Day care for people with dementia available since the early 1990s. Services for dementia vary by region	Day care for people with dementia available since the early 1990s. Services for dementia vary by region

(Kallen et al.
(2006)

Table 2 continued

	The Netherlands	UK	Italy	Spain	France	Poland	Greece	Germany	Sweden
Long-term care facilities	17% of people with dementia live in a care home, and 18% in a nursing home	Since 2000, free nursing care under the National Health	Residential structure organised into small groups. Provision of health care, social care, and functional rehabilitation. Patient care can be extensive or intensive. Includes temporary accommodation for long-term care and rehabilitation, intensive rehabilitation with high medical importance, and palliative care	There are 3,328 homes (amount of places for dementia unknown), of which 43.93% are privately owned, and 22.86% are publicly-owned. Varying levels of medical care are provided. Admission is based on presence of a family carer. There is also a residential type network	In 2000, there were 247,000 places in long-term care centres (amount of places for dementia unknown), of which 45.93% are privately owned, and 22.86% are publicly-owned. Short-term, part-time (day or night), or full-time institutional care is available. Small-scale group-living; over 1,000 places.	In 2000, there were approximately 8,900 nursing homes (about 621,000 places). About 60% of residents have dementia. In some municipalities, special dementia care units are integrated within nursing home facilities. Increase of small home-like units with all the medical and technical resources of a nursing home. Although there are no dementia-specific group-living facilities, 15,000 of the 17,000 available beds are occupied by dementia patients	In 2000, there were 23,000 with dementia. In some municipalities, special dementia care units are integrated within nursing home facilities. Increase of small home-like units with all the medical and technical resources of a nursing home. Germany knows a system of group-living, up to 15 persons (for instance, Detibarn-Reggentin 2003)	In 2000, there were 29,000 beds, of which 23,000 with dementia. In some municipalities, special dementia care units are integrated within nursing home facilities. Increase of small home-like units with all the medical and technical resources of a nursing home. Germany knows a system of group-living, up to 15 persons (for instance, Detibarn-Reggentin 2003)	

Table 2 continued

The Netherlands	UK	Italy	Spain	France	Poland	Greece	Germany	Sweden
Respite care	Available throughout the country	Available for 51% of people with dementia in Scotland. Services available throughout the country, including day care respite, carer respite, sitter services, and respite admissions to hospitals and nursing homes. Day care respite is restricted to people living at home	Available for 3% of people with dementia. Hybrid respite programs (expert centres) available for people with dementia and their carers more flexibility in the care setting, be it at home or in an institution	Available for 10% of people with dementia (see day care), although there is also a respite hospitalisation programme.	41% of people with dementia	The main source of respite care is through acute admissions to hospitals	Available for 48% of people with dementia, for instance, in day centres.	Short-term (1–2 weeks): provides break for personal and medical reasons. Respite care at home is available in 87% of municipalities. Extended over the last few years. Regular shift model: 2 weeks at home and 3 weeks at care centre or vice versa. Group-living: small group home for 6–8 people. Residents have their own room, but share communal areas and have access to service and care provided by resident staff around the clock
<i>Health care policy</i>								
Care regime	Scandinavian	Beveridge/Anglo-Saxon system	Mediterranean/Southern European system	Mediterranean/Southern European system	Continental/Bismarck/Central European system	Eastern European system	Mediterranean/Southern European system	Continental/Bismarck/Central European system

Table 2 continued

	The Netherlands	UK	Italy	Spain	France	Poland	Greece	Germany	Sweden
Directed by the state	Exceptional Medical Expenses Act (AWBZ) costs for care of long-term chronic illness, including residential/nursing care. Scope of AWBZ	Large differences within the UK. National Service Framework for Older People (2001) sets national standards for the care of older people (at home or in institutions) in England. Scotland aims to provide support and services for people who live at home or in a care home system (The Community Care and Health (Scotland) Act, 2002)	National Health System (1978). In 2000 a legal framework and financial basis for a national development of social services. The objective of the National Plan for Elderly People was to better coordinate medical and social services so as to ensure their integration within the home care services system	All citizens are entitled to "health protection". Access to health services is a citizen's right. Citizens do not have a legally established right to social services. The need is also recognised to help subjects with few resources	The Elderly Dependency Act (2001): individual attendance allowance (APA) to cover the costs of human and technical assistance, not the provision of care which would be covered by health insurances. The APA can take the form of services or cash and is paid irrespective of living situation. Any person over 65 without sufficient resources may benefit from home help or a place in a private home or establishment	The Health Insurance Act (1999): obligatory health insurance system. People living alone, who require the help of others and do not receive it have the right to help in the form of care services. People aged 75 and over have the automatic right to a nursing benefit regardless of their state of health. People over 75 living in institutions are not entitled to this benefit. State policy concerning assistance	There is no long-term care insurance. Home help services developed by voluntary associations and organised agencies (private sector). They are not supervised by the State. The State has taken measures to increase community care services, including the creation of open care community centres for older people (KAPIs) and the help at home programme	Long-term care insurance (1994), oriented towards basic ADLs; neglects aspects of care important for dementia (general supervision and attention, social and emotional support).	Welfare is divided between 3 levels of government: (1) at national level: the government (responsible for establishing policy aims and directives by means of legislation and economic steering measures), (2) at regional level: the county councils (responsible for the provision of medical and health care), and (3) at local level: the municipalities (responsible for meeting the social services and housing needs)

Table 2 continued

The Netherlands	UK	Italy	Spain	France	Poland	Greece	Germany	Sweden
Directed on a local level. Most social care is provided by local authorities (LAs), which concentrate their efforts on community needs rather than on medicalised homes. The kind of services and the way these are delivered vary per LA. LAs are not legally obliged to provide community care for individuals if this would cost more than moving them to a residential or nursing home, although they sometimes will. LAs should make arrangements for the provision of certain services in their area, although services can be provided by a variety of organisations	Local Health Authorities (USL) (1978) are controlled by the municipalities. The provision of home care services is in the stage of development with about 20% of communes offering such services. Home care services are free for people who are on the minimum pension. Home social services are financed jointly by the Ministry of Social Affairs, the regional ministries of Social Welfare and the municipalities. In addition to government-provided services, voluntary associations and not-for profit and public expenditure on health services is fairly low	Health care services are organised by the autonomous communities. The house alarm systems are often financed by regional governments. There is a growing number of freelance nurses. Home care services are free for people who are on the minimum pension. Home social services are provided by volunteers and are therefore cost free	Certain services, such as meals-on-wheels and house alarm systems are often provided by home health assistants and housekeepers who provide assistance with household chores.	The local authorities are responsible for organising social assistance. They do this through Social Care Centres. A variety of services are provided by different organisations, such as washing, bathing and personal hygiene, are performed by health care workers (e.g. community care nurses). Meals are distributed thanks to the Polish Red Cross, the Polish Committee on Social Welfare and NGOs. Some of the meals come from canteens in care homes and schools	Some local authorities provide home help services and grants to dependent, mainly poor and isolated, seniors. Open care centres for old people were set up by voluntary organisations funded by the State. Some local authorities provide home care services but such services are not provided uniformly throughout the country. In some areas, local authorities and many parishes provide free meals at home to people in need	Non-medical home care services are often provided by home health assistants and housekeepers who provide assistance with shopping and simple household help may also be provided by young men who decide to do community service instead of military service.	A total of 144 out of 290 municipalities have responsibility for daily care. In the others, county councils are responsible. Municipalities can provide services (voluntary day care, relief/support for relatives, assistive devices) themselves or by private providers. Support for community-dwelling people with dementia varies per community: 9% of the communities (2002) had specially arranged home care for dementia. Only young people (<65) with dementia have a right to receive help from a personal assistant instead of home care. Support from voluntary organisations is limited	

Table 2 continued

	The Netherlands	UK	Italy	Spain	France	Poland	Greece	Germany	Sweden
Role of the family	To be considered eligible for care, assessments take place by the CIZ, organisation that determines how much and what kind of care a person is entitled to receive. Family plays a role in these assessments	Assessments should account for the wishes of the individual and his or her carer, and of the carer's ability to continue to provide care. Scotland: People over 65 years of age were granted free personal as well as nursing care. This is not dependent on financial status, capital assets, marital status or the amount of care provided by an unpaid carer	Strong emphasis on support from the family, particularly women: children and to a lesser extent siblings) are accepted as normal and legitimate that covers the community and institutions should become involved only after the family resources—	Providing informal care is seen as a family obligation. The spouse and their parents and other ascendants if in need. This obligation extends to daughters-in-law and sons-in-law	Adult children have a legal obligation to provide maintenance to their parents and other ascendants if in need. This obligation extends to daughters-in-law and sons-in-law in certain circumstances with regard to their parents-in-law	Children are legally obliged to provide for their elderly or disabled parents and this can be enforced in court if necessary. A person can make an agreement with someone to exchange the ownership of property for help and nursing in case of sickness	The majority of older people continue to live at home, with or without relatives. Family is responsible for the care of dependent relatives of all ages, without direct support from the State. If a family is unable to care, the dependent person is taken care of by the Social Security system. In many areas, neighbours, friends and volunteers offer sitting services	Due to the character of the LTCI, it has also been argued that family support or a stable social network is presupposed, which in turn hinders the development of more comprehensive, complex care arrangements for people with dementia.	Health service authorities are obliged to provide home care services if the needs cannot be met in any other way. Much of the care is carried out by families. There is no statutory obligation for children to care for or financially support their parents

Data are derived from AE (2006a), AE (2006b), and Moise et al. (2004), although many data are unknown or poorly described in international literature

long-term care institutions and special care units (SCUs) called ‘Demenzstationen’ (Moise et al. 2004). Novel strategies of dementia care are supported at the national level, including group care, memory clinics, day centres, trained home visiting helpers, alternative living arrangements, group living, and music therapy (Singelenberg 2002; Diehl et al. 2003; Moise et al. 2004; Klie et al. 2005). Small-scale group accommodation (SSGA) is found both in France (*cantou*) and Germany (*Wohngruppen*) (Klie and Schmidt 2002; Klie et al. 2005). Luxembourg, Germany, Austria, and Flanders/Brussels have long-term care insurances that cover home care based on assessed needs (AE 2006a). Policies are aimed at helping people to maintain their independence and age-in-place.

4.3 Scandinavia

In Scandinavia, the governments and local authorities also take responsibility for providing care to older adults with a limited demand for care (domestic care), either directly or by granting allowances that people can use to purchase services. Partners bear primary responsibility to care for a spouse. Services are mainly funded through general taxation. There is a wide system of institutional facilities, but ageing-in-place is stimulated. Ageing-in-place has led to deinstitutionalisation movements, limiting the capacity of institutional settings to the benefits of semi-residential facilities and home care (in modified dwellings) (AE 2006a; Pommer et al. 2007). In Sweden and Denmark, SSGA was introduced as a substitute for nursing home capacity. Particularly Sweden has embraced SSGA as a successful housing arrangement (Moise et al. 2004; Klie et al. 2005). Although there are no dementia-specific group-living facilities, about 90% of available beds are occupied by OAWD. In fact, SSGA is so successful that facilities are now being integrated into other assisted-living facilities (Moise et al. 2004). Throughout Scandinavia, some nursing home capacity is used for short-term care (Moise et al. 2004).

4.4 The British Isles

In the British Isles, there are differences within the separate countries. According to O’Malley and Croucher (2005), the UK policies regarding the development of extra-care housing neglect the long-term future of OAWD and the progressive nature of dementia (Fig. 1). Moreover, policy tends to treat housing separately from care, and even more so from dementia, while an integral approach is needed. Generally, people are encouraged to age-in-place, and the UK government is promoting the construction of lifetime homes (DCLG 2008). Group-living is also common on the British Isles. Communities and Local Government plays a role in ensuring that housing support teams work to enhance joint health and social care mental health teams in the community so OAWD and (in)formal carers receive support in a range of housing settings (DCLG 2008). Access to community care services in the Republic of Ireland varies from one region to the next and has been limited. In England and Wales, the state is obliged to provide an assessment of care needs but is not actually obliged to provide the services. There is a general commitment on the part of the state to provide services to enable independence within the own home environment (AE 2006a). In Scotland, people aged 65 and over are entitled to free nursing, free personal care, and increased access to direct payments for home care services (AE 2006a). In the UK, OAWD are often referred to memory clinics when available, but are more likely to be referred to a specialist for treatment (Moise et al. 2004).

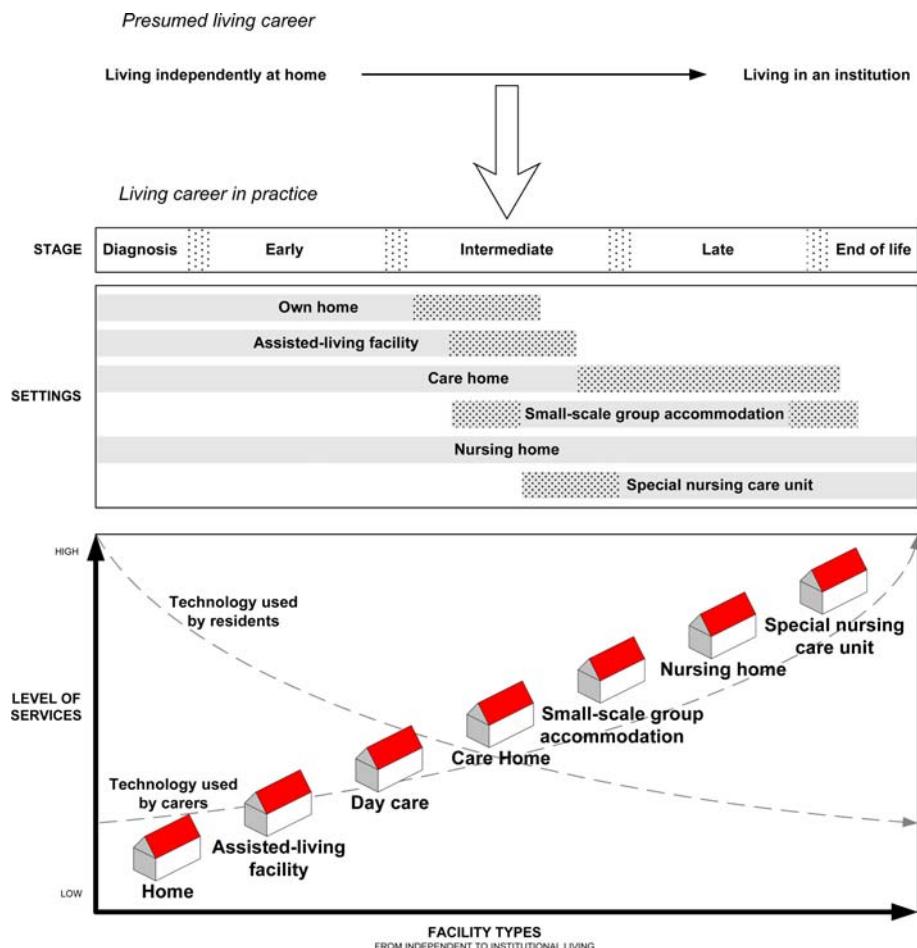


Fig. 1 The housing continuum for persons with dementia. The presumed succession of living situations starts from living independently at home, which can be followed by living institutionally if health declines and people survive. Although this housing sequence is seen in the majority of persons with dementia, some develop dementia when residing in care and nursing homes for somatic reasons, while others pass away while living at home. The transfer from one home to the other depends on the state of the home or facility, care regime and policies, and the presence of family care. The lower diagram, partly based on Cohen and Weisman (1991), illustrates the relationship between level of services and environmental options matching the types of housing

4.5 Eastern Europe

In Bulgaria and Poland, some home care services are provided by the state. Priority is given to older adults who lack financial means and live alone (AE 2006a). In Bulgaria, Hungary, and Poland, one can draw up a contract with third parties, which includes ceding property in exchange for care and/or maintenance (AE 2006a). In the Czech Republic, assistance with everyday tasks is not routinely provided. However, there is a commitment on the part of the state to facilitate independent living. Also in Hungary and Estonia, there is no legal obligation to provide home care services, although there is a commitment on the

part of the state to provide support for the aged. In Romania, home care services only cover nursing care, which is limited to a certain number of days per year (AE 2006a).

5 Policies on housing and care for dementia in the Netherlands

According to the Dutch Alzheimer Society, there were approximately 270,000 people with dementia in 2008 (of which 10,000 are younger than 65), out of a total population of 16.4 million inhabitants. This number will rise to over 400,000 by the year 2050 (HCN 2002; VWS 2004). Nationally, dementia ranks number 10 among the most disabling health problems (VWS 2004). About half of the care dependence of older adults is allocated to dementia (HCN 2002), because intensive care is needed.

The housing trend for all older adults in The Netherlands is a succession of living situations that match the level of care needed or the amount of service desired (Fig. 1). This range generally runs from independent living in the own home with optional home care, to assisted-living facilities, residential homes for the aged or care homes, and nursing homes (van Vliet 2004). The number of older adults receiving professional care in relation to housing on a daily basis is not very large. Only 15% receive home care, 5% live in a care home, and about 2.5% reside in a nursing home (Schuurmans and Duijnste 2003). The Netherlands Ministry of Health, Welfare and Sport works together with the Ministry of Housing, Spatial Planning and the Environment in the field of housing, care, and welfare. In order to support OAWD, the Dutch government has three main focal points in their policies, which impact the way OAWD are housed and cared for:

1. Ageing-in-place in the own dwelling or assisted-living facilities,
2. The separation of financing of residence and care, and
3. Substitution of institutional by non-institutional living.

5.1 Current living situation

The housing situation of the current generation of OAWD in relation to the care they receive is very diverse. The housing types mentioned in this study include the own home, care homes, nursing homes, and SSGA. The places where people with dementia live depend on the stage of dementia (Table 3; Fig. 1) and cognitive status, but also on the availability of informal carers and their ability to cope with the stresses of caring for a loved one.

5.1.1 Ageing-in-place

An estimated 166,000 people with dementia live at home (65% of all OAWD) (HCN 2002). About 87% receive informal care only; the other 13% receive professional care at home. Professional home care and day treatment to supplement informal care are only available for a limited number of hours per week (HCN 2002). Temporary housing, so-called 'short-stay accommodation', is offered as respite care. In these facilities, OAWD are housed in a home-like atmosphere. There they receive care by professionals for a period of time ranging from half a day to several weeks in order to provide a break for carers (Tjadens and Duijnste 1999; Moise et al. 2004).

When dementia progresses, OAWD become more dependent on others and eventually need 24-h monitoring or company (HCN 2002). This need cannot be fulfilled by regular professional home care. The availability, coherence, and continuity of formal care

Table 3 Overview of stages of dementia in relation to housing conditions and care support

de Graaff and Hupkens (1985)		Reisberg (1986)	
Dementia stages	Housing conditions and support	FAST stage	Housing conditions and support
1. Premanifest	Own home	1	Own home
2. Early dementia	If person with dementia lives alone, the person is still able to live independently as long as (s)he does not move to another dwelling	2	Own home
3. Moderate dementia	The person can maintain living at home with the help of formal care (GP, home care, occasional day care) and family care	3	Own home. People can still perform all basic ADLs satisfactorily
4. Severe dementia	Older person can maintain living at home with help in case behavioural problems have (no longer) come into prominence, or have been adequately countered by medication. Many will move to a nursing home	4	Own home. People can still function independently in the community, although functioning is compromised. Some persons get institutionalised, although a smaller percentage stays to reside in the community for 3–4 more years
5. End-stage dementia	Institutional housing and care	5	People can no longer function independently in a community setting. Caregiver assistance required. Day care programmes may be useful for the person with dementia, as well as continuous support groups for the carer
		6	Full-time home health care assistance is frequently useful at this stage. In certain cases, institutionalisation should be discussed with the family. Most people in this stage are institutionalised
		7	People live institutionally, requiring complete care at all times. Full-time assistance in a community or institutional setting is a necessity at this stage

provisions determine whether informal carers can keep on giving support. Very old seniors with dementia are more likely to live alone or with a partner in need of help him/herself who cannot deal with the physical strain of caring (HCN 2002). Even though ageing-in-place is generally propagated and stimulated, the often emotional admission to a nursing home is sometimes the best and most sensible solution for all parties involved.

5.1.2 Care homes and nursing homes

In the Netherlands, about a third of all people with dementia are institutionalised (Table 2). People may develop dementia while residing in an institution for somatic reasons, or they may be institutionalised after having lived in the community (Fig. 1).

Care homes primarily provide care for older adults who are no longer capable of living entirely independently (VWS 2004) and offer single patient rooms (sometimes double patient rooms) or apartments. Provision of care forms an integral part of residence in such facilities (VWS 2004).

Nursing homes are institutions for people requiring permanent supervision, care, nursing, or convalescence that they cannot receive (to a sufficient degree) at home or in a care home. The criteria for admission to nursing homes are explicit, and a differentiation is made during assessments between the need for psychogeriatric and somatic care. Admission may be temporary or permanent. Most newly-built nursing homes consist of single patient rooms. Both care homes and nursing homes are undergoing an intensive transition process towards less general capacity and another system of financing. This includes the separation of residence and care in an effort to separate the costs for care and rent, or residence, in institutional settings. Currently, residence and care are integral parts of the services provided. Providing residence will no longer be part of public care but become part of the public housing task.

A special feature in institutional settings is the dementia special care unit, a dedicated nursing unit that provides enhanced care and a specialised programme of activities for people with dementia.

5.1.3 Small-scale group accommodation

In the light of deinstitutionalisation, an increasing capacity of SSGA has been created in the direct vicinity of, or at some distance from, large-scale institutions. In 2005, there were over 4,400 places available in these SSGAs in 349 locations. SSGA capacity is expected to rise from 4,442 in 2005 to 6,392 places in 2010 (van Waarde and Wijntjes 2006), although the demand is even larger. SSGA is characterised by a surveyable size (6–8 people) and integration of a ‘normal’ householding as part of the 24-h care and surveillance offered by one or two staff members (VWS 2004; Wijntjes and Paquay 2004). There is room for one’s own furniture and goods in a private living/bedroom. The kitchen unit, living room, and in most cases the sanitary units are shared. There are four types of SSGA: (1) stand-alone group accommodation in a neighbourhood, (2) group accommodation near or within a care home (or assisted-living facility), (3) group accommodation near or within a nursing home, and (4) group accommodation as part of the provision of care for the neighbourhood as a whole (lifetime neighbourhoods) (Wijntjes and Paquay 2004). In the Netherlands, the basic concept of SSGA originates from care for people with a mental or physical handicap. The most important motive for creating SSGA is a combination of the increased quality of care and housing for clients in small-scale settings and the presence of large-scale availability and efficiency of the care organisation.

6 Discussion

The range of health care services and types of housing is unique per country and, contrary to popular belief, can differ a lot from the national situation even compared to neighbouring countries. Apart from the national choices in terms of financing, national values seem important too.

6.1 Care solutions

Moise et al. (2004) explicitly mention that dementia is a relatively new area of policy focus, and not all developed nations have specific policies for the condition. Housing is mentioned as one of the services for the provision of care. The policy focus has shifted to favour care of people with long-term needs within the community rather than in institutions. Responsibility for dementia is often given to one particular government ministry, although housing is of importance to several areas of government.

For the EU, there are great disparities in the provision of home care services and the need for greater support for carers, including respite care, technological solutions (AE 2006b), and appropriate housing. Even though current provisions reflect the historical, economic, political, cultural, and religious developments of each member state, governments should recognise and respect the right of people to appropriate and affordable home care services. On a macro-economic level, the provision of informal ADL care is cheaper than formal care. However, it is questionable if relatives are able to cope with the emotional burden, apart from the financial consequences. Another process in health care is task redistribution, for instance in SSGA. There, skilled nurses are replaced with people trained on a lower level in surveillance while more effort is expected from informal carers. Also, more input in terms of assistance is requested from relatives of people in SSGA compared to those in care and nursing homes.

All countries with high levels of services witness the same political processes of stimulation of ageing-in-place and deinstitutionalisation. In Europe, the chance of receiving formal care is the largest in The Netherlands and about equal in France and Denmark. Formal care is hardly an option in Greece, though in countries like Germany and Italy informal care is dominant as well (Pommer et al. 2007). These figures are likely to also apply to care for OAWD. The Netherlands has traditionally been a country with a large institutional sector. A mere two-thirds of all Dutch OAWD live at home, compared to an assumed 73% in all developed countries together (Wimo et al. 2007).

6.2 Housing solutions

The current housing stock in the EU is not able to cope with the rise in the number of people with dementia, neither quantitatively nor qualitatively, and new development is needed. A request for assistance is thought to be interpreted as an inability to continue independent living, so many older people ask for less help than necessary (Kort and Bakker 2004). Assistance, however, can also be given in the form of architectural modifications and technological solutions. These solutions may even alleviate or substitute care given by informal and professional carers. Adaptations in the level of technology in and around the dwelling take place over time due to technological progress and diminishing abilities to work with technology (Fig. 1). The use of technologies in the dwelling for daily support shifts from the resident to the (in)formal carer. People with dementia pose special restrictions on the kind of home or technology that is suitable due to a decline in cognitive function, an altered sensitivity to environmental stimuli, and frequent falling (van Hoof and Kort 2009). The slow realisation of new supportive housing projects, the methods of financing home modifications and services, and the familiarity of OAWD, their relatives, and even state services with the possibilities for specific home modifications form risk factors to ageing-in-place from a housing perspective. Even though deinstitutionalisation of the health care sector is progressing, it is unlikely that all living arrangements for people with dementia will one day be non-institutional. A scenario of all people with dementia

being cared for with the help of informal and formal care in homes that have undergone modifications is not realistic. There will always be a group of OAWD that, due to health status, family situation, or financial limitations, needs institutional care and residence. However, a new gap lies around the corner; the health care sector is increasingly facing a shortage of schooled personnel, while relatives have jobs that do not allow them to care for a loved one.

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