

Journey of Caring: an analysis of long-term care for Dementia.

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Alzheimer's Disease International

Bupa

World Alzheimer Report 2013

Journey of Caring

AN ANALYSIS OF LONG-TERM CARE FOR DEMENTIA



World Alzheimer Report 2013
Journey of Caring
An analysis of long-term care for dementia

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Foreword

Dementia, including Alzheimer's disease, is one of the biggest global public health challenges facing our generation. Today, over 35 million people worldwide currently live with the condition and this number is expected to double by 2030 and more than triple by 2050 to 115 million.

We believe that Alzheimer's disease and other forms of dementia must become a national and international public health priority so that countries can develop adequate long-term care systems to look after people living with the condition now, and in the future.

Dementia is a degenerative condition with no known cure. Symptoms, such as memory loss, cognitive impairment, difficulty communicating and changes in mood get worse over time. These experiences are distressing for the individual and upsetting for their loved ones. However, people living with dementia can still have a good quality of life throughout the dementia journey, provided the right long-term care plan is in place and being delivered.

The two organisations we lead are together the only international federation of Alzheimer associations and global voice on dementia, and the largest international provider of specialist dementia care. Individually, and in partnership, we intend to revolutionise care for people living with dementia and to campaign to ensure these people live well, and that their family and friends are properly supported.

Our World Alzheimer Report examines the latest global and regional trends of older people needing dementia care, and provides an analysis of long-term care systems around the world. We believe this is an invaluable resource and source of inspiration for anybody developing dementia policy and delivering dementia care around the world.

We believe that everyone, everywhere, can and must do their bit to help people with dementia live well throughout the dementia journey. There is enormous power and possibility in families, friends, carers, healthcare professionals, commissioners or purchasers of care, providers, society and governments working together to improve long-term care in their country.

We're committed to shaping global dementia care and having people living with dementia lead happier, more fulfilled lives, for as long as they can. That is our vision and intent.





Marc Wortmann

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World Alzheimer Report 2013
Journey of Caring

AN ANALYSIS OF LONG-TERM CARE FOR DEMENTIA

Introduction

The Global Observatory for Ageing and Dementia Care, hosted at the Health Service and Population Research Department, King's College London, was founded in 2013. Supported by Alzheimer's Disease International, and King's College London, the Observatory has a tripartite mission:

1 To build upon ADI's 10/66 Dementia Research Group program of population-based and intervention research in low and middle income countries, maximising the impact that research findings from our data can have upon policy and practice.

2 To developing, evaluate, and promote primary care and community interventions for people with dementia.

3 To synthesise global evidence for policymakers and public, in particular, continuing and developing our role in the preparation of high impact evidence-based reports for Alzheimer's Disease International (World Alzheimer Reports 2009, 2010 and 2011), the World Health Organization (Dementia: a public health priority, 2012) and other relevant intergovernmental organisations.

The World Alzheimer Report 2013 was independently researched and authored by Prof Martin Prince, Dr Matthew Prina and Dr Maëlenn Guerchet on behalf of the Global Observatory for Ageing and Dementia Care. The evidence reported in Chapters 1-6, and the inferences drawn, are the responsibility of the authors alone. The key messages and recommendations were developed jointly by the Global Observatory and Alzheimer's Disease International.

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Key messages

Background

- Dependence (sometimes referred to as needs for care) is defined as 'the need for frequent human help or care beyond that habitually required by a healthy adult'. The nature of the help or care has been further defined as 'beyond what would be expected by virtue of family or social ties'. According to this definition around 5% (one in 20) of the world's population is dependent rising from 1% among children aged 0-14 years, to 5% among adults aged 15-44 years, to 7% among those aged 45-59 years, and 13% among those aged 60 years and over.
- The global profile of dependence is changing, mainly because of population ageing. Between 2010 and 2050, the total number of dependent people worldwide will nearly double from 349 million to 613 million, but the numbers of older people with needs for care will nearly treble from 101 to 277 million. Increases in numbers of dependent older people will be particularly dramatic in low and middle income countries.
- Long-term care for older people is, mainly, about care for people with dementia. Dementia and cognitive impairment are by far the most important contributors, among chronic diseases, to disability, dependence, and, in high income countries, transition into residential and nursing home care.
- Around half of all people with dementia need personal care (and the others will develop such needs over time). Around half of all older people who need personal care have dementia, while four-fifths of older people in nursing homes are people with dementia.
- Policymakers need to pay much more attention to the importance of dementia as the most common underlying condition, and, very often, the root cause of older people's needs for care.
  - The current and future costs of long-term care will be driven to a large extent by the course of the global dementia epidemic. Our success in designing and implementing effective strategies for the prevention of dementia, and in identifying treatments that can alter the course of the disease will be important determinants of future health and social care costs.
  - People with dementia have special needs for care. Compared with other long-term care users they need more personal care, more hours of care, and more supervision, all of which is associated with greater caregiver strain, and higher costs of care.
  - Their needs for care start early in the disease course, and evolve constantly over time, requiring advanced planning, monitoring, and coordination. People with dementia merit special consideration in designing packages of care and support that meet their, and their caregivers needs. The challenge is to support 'living well with dementia' across the journey of care.
- It is inevitable that numbers of dependent older people will increase markedly in the coming decades particularly in middle income countries. It is therefore imperative that governments worldwide make policies and plans for the future provision and financing of long-term care.

The architecture of the dementia long-term care system

- Long-term care is a complex system with broad boundaries. Many different tasks and functions may need to be performed, and the needs of each individual and family are specific.
- Different agencies may be involved in providing, supporting, organising and financing care. The family will always have a central role, supported to a greater or lesser extent by formal professional or paraprofessional care services. Care can be provided at home, in the community, or to a resident of a care home.
- A comprehensive system of long-term care for people with dementia comprises both health and social care services - diagnostic and medical continuing care services; informal family care (the cornerstone), supported and supplemented as necessary by paid home caregivers; respite opportunities, high quality care homes; and palliative end-of-life care.
- Reducing transitions into care homes is an important part of high income country governments' cost-containment strategies. It is often claimed that people with dementia would prefer to live at home for as long as possible cared for by their family, that this option is associated with better quality of life, and that care at home is cheaper than care in a care home.
- None of these rationales is fully supported by evidence. Care in care homes is a preferred option for a significant minority of older people, particularly when presented with a scenario of dementia with complex intensive needs for care. Currently available evidence suggests that subjective quality of life is similar for those with dementia cared for in care homes and those cared for at home, and may even be better in care homes for those in the advanced stages of dementia. Societal costs of care in care homes and care at home are similar, when an appropriate cost/ value is attached to the unpaid inputs of family carers.
- Care in care homes is, and will remain, an important component of the long-term care system for people with dementia. Currently around one-third to one-half of people with dementia in high income countries, and around 6% of those in low and middle income countries are cared for in care homes. Demographic, social and economic trends are likely to increase demand for high quality formal care services (paid care at home, or in a care home), particularly in low and middle income countries where they are very rudimentary.
- Caregiver multicomponent interventions (comprising education, training, support and respite) maintain caregiver mood and morale, and reduce caregiver strain. This is also the only intervention that has been proven to reduce or delay transition from home into a care home. Such interventions seem to be particularly effective when applied early in the journey of care. Nevertheless, we are aware of no governments that have invested in this intervention to scale-up provision throughout the dementia care system, and hence coverage is minimal.

Improving the quality of care

- Evidence reviewed in this report indicates that there are concrete actions that can be taken to build quality into the process of care and support for people with dementia and their caregivers across the journey of care. The key guiding principles are that 'living well with dementia' is an attainable goal, and that maintaining or enhancing quality of life is the ultimate objective. Action is required to:
  1 Measure and monitor the quality of care
  2 Promote autonomy and choice
  3 Coordinate and integrate care for people with dementia
  4 Value and develop the dementia care workforce
- Quality of care can be measured through structures (available resources), process (the care that is delivered), and outcomes. Regulators have tended to focus upon structures and process, the aim being to identify deficiencies rather than excellence in care. This may miss the essence of care quality, namely the maintenance of personhood and wellbeing through a conducive physical and social care environment.
- Quality of life, and satisfaction with services are person-centred holistic outcome indicators that summarise the impact of all relevant structure and care process issues. It is feasible to obtain this information directly from those with mild to moderate dementia, and from family and professional caregivers. A recent survey of care home residents in the UK indicates a generally high quality of life and satisfaction with services, but considerable variation among care homes.
- Accessible information regarding the quality of care provided by services, assessed using person-centred outcomes as well as inspection data, should inform choice and encourage competition based upon driving up standards. This may be more effective than compliance regulation alone.
- No two families are alike in their needs for care and support, and we need to find ways to make care more person-centred, and care packages more flexible and individualised. Earlier diagnosis enables the person with dementia to make decisions about the care that they will receive, through advanced care directives, which are still underutilised. Personalised care budgets put people with dementia and their caregivers in control of their packages of care, and empower them to ensure that their preferences are respected, and their needs met.
- While good quality dementia care can be both complex and resource intensive, the systems and services must be made as simple, seamless, transparent and accessible as possible. Families need to be guided and supported in accessing information and exercising choice, with case managers playing an important role. Case managers can provide continuity across the journey of care, and advocacy, not least through the relationships of trust that they can develop with those whom they support.
- Case management should also facilitate coordination of care, helping clients to use services more efficiently. However, evidence suggests that to be effective and efficient the long-term social and health care systems that the case manager coordinates need themselves to be better integrated and subject to a unitary process of planning, commissioning and governance and delivery of care.

- Family carers and paid caregivers share much in common. They all carry out difficult, demanding and socially useful roles, with minimal training and preparation. Informal carers are paid nothing, are less likely to have paid jobs and they and their families often experience high out-of-pocket costs. Paid carers are paid around the minimum wage, experience low job satisfaction, and there is a high turnover and high job vacancy rate. Undervaluing of caregivers impacts negatively on the quality of care.
- All caregivers, paid or unpaid, should be valued and recognised by society for the essential, difficult and demanding work that they carry out, and recompensed appropriately. Incentives need to be built into the system to encourage family caregivers to continue to provide quality care at home, and to promote retention, skills development and career progression among paid care workers. Investment in these areas may well be cost effective both in reducing downstream costs including transition into care homes, and in improving outcomes for people with dementia and their caregivers. As recently recommended in an OECD report, this is a 'win, win, win' strategy.
- To effect these changes, we must make dementia a priority. Only carefully thought through national dementia strategies and plans, with input and support from all relevant stakeholders, and accompanied by sustained political will and new funding, have the necessary authority and resource to reengineer long-term care systems to suit the needs of people with dementia, who are the majority, and most cost-intensive older clients of these services.

Affording good quality dementia care

- In the 2010 World Alzheimer Report, Alzheimer's Disease International (ADI) estimated that the annual societal costs of dementia worldwide were US$604 billion, or 1% of the aggregated worldwide Gross Domestic Product (GDP). If dementia care were a country, it would rank between Turkey and Indonesia and be the world's 18th largest economy.
- In all world regions the direct cost of medical care is modest, reflecting limited help-seeking, delayed diagnosis, and the paucity of effective interventions to change the disease course. In high income countries, the direct costs of social care (paid home care, and care in care homes), and the indirect costs of informal care provided by unpaid family caregivers contribute similar proportions to total costs, while in low and middle income countries, the cost of informal care predominates given the lack of structured formal care sector services.
- 80% of total worldwide costs are incurred in high income countries, reflecting the dominance of informal care in less developed countries, and their much lower average wages (used to estimate informal care costs).
- Costs will increase at least in line with increases in numbers of people with dementia, assuming that the age-specific prevalence of dementia, patterns of service use, and unit costs of care remain the same. On this basis, ADI in its 2010 World Alzheimer Report predicted a near doubling in worldwide societal costs from US$604 billion in 2010 to US$1,117 billion by 2030.

- Age-specific prevalence of dementia may be sensitive to improvements of decrements in population health, with reports of recent declines in prevalence in Europe, and increases in China. It is likely that there will be a considerable shift from informal (family) care to formal (paid) care services, particularly in low and middle income countries. This will have a fiscal impact, but little influence on the overall cost to society. Demand for better quality, more comprehensive long-term care services may drive-up unit costs. However, modelling exercises conducted for a recent European Union Report on Ageing suggest that even under quite extreme assumptions, these factors are likely to have little impact on the projected increases in the costs of long-term care, which are driven to a very large extent by population ageing.
- Since those who will be old in 2060 are already born, the impact of population ageing on future long-term care needs and costs is both predictable and inevitable. Governments and the societies that they represent have no excuse if they find themselves inadequately prepared.
- The financial sustainability of the long-term care system in high income countries has been called into question, with the costs of long-term care set to double over the next 50 years as a proportion of GDP (from 1.2% to 2.5% in the 27 countries of the European Union). Cost increases for some countries with more generous provision are even more striking 3.4 to 8.5% in the Netherlands, and from 2.2 to 5.1% in Norway. Standard and Poor's have advised sweeping changes to age-related public spending on health and social care, and consider that, despite the cushion of economic growth, the need to tackle demographically-driven budgetary challenges is hardly less pressing in rapidly developing countries such as India and China.
- Population ageing should be a cause for celebration, and confers many benefits on society. The future cost of long-term care will be affordable, but only if governments act now to implement required policies and reforms. We have advised seven key strategies;
  - bolstering social protection for all older people in low and middle income countries
  - generating a 'second demographic dividend'
  - pooling risk
  - ensuring that long-term care schemes are 'fully-funded'
  - rationing (targeting) of public spending on care
  - supporting and incentivising informal care by family carers
  - having a national discussion.
- Universal social pensions provide security in old age, and insurance against uncertainties (how long you live, and in what state of health, and whether care and support is available when you need it). They bolster traditions of intergenerational reciprocity, including incentivising family provision of long-term care should it be needed.
- The first demographic dividend (enhanced economic growth generated by the large working age population born before fertility begins to decline), should be invested wisely. Priorities should be: investment to boost workforce participation and productivity in the next generation (e.g. health and education); savings to provide for the future long-term care needs of the 'baby-boomer' generation.

- Equity of access to long-term care is best assured through risk pooling, whether this be through general taxation, public insurance, mandated private insurance or a combination of these approaches. Most OECD countries already use this approach, but this is a particularly important reform for low and middle income countries to consider. Means testing is problematic in the context of dementia care, often leading to enormous out of pocket payments (spending down assets) before eligibility for benefits cuts in.
- 'Pay as you go' (PAYGO) financing is inherently fiscally unsustainable, since, with demographic ageing, future generations of working age adults will struggle to produce enough to pay for the long-term care needs of their parents' generation. The transition to 'fully-funded' programs, in which each generation of working-age adults collectively accumulates the resources necessary to fund their own expectation of needs for care, may be painful, but is absolutely necessary.
- Cost containment is necessary, but policies need to be planned and implemented cautiously to avoid or mitigate adverse effects on coverage, and access to good quality care. For people with dementia and their caregivers access to support and case management from early in the disease course, and throughout the journey of care is likely to be cost saving.
- Direct payments (cash transfers) to caregivers, or care recipients allow their contribution to be recognised by society. Funding can be used, flexibly, to substitute or complement family care, or to compensate for lost earnings. Increased formal support for caregivers may reduce strain, improve mental health, and facilitate retention or resumption of paid employment outside of the home. Increased support for family caregivers may enable them to continue in their valuable role for longer, hence reducing the cost to public funds.
- The changes outlined above need to be considered as part of a wide-ranging and ongoing national discussion on current and future long-term care, led by government, and involving all stakeholders, most particularly an informed general public. Each country will have its own culturally determined set of values and preferences, but the key questions are universal and timeless. Who needs care? Whose needs should be prioritised? How should care be delivered, and by whom? What cost would be reasonable and affordable? How should this be financed?

Recommendations

In this report, we have identified four domains within which specific actions could lead to improvements in the quality of care for people with dementia, and seven key strategies for making long-term care more affordable. Since people with dementia have special needs, some recommendations are specific to this sub-group of users of long-term care. However, they constitute the majority of older users of long-term care, and some recommendations, particularly those relating to the financing of long-term apply to long-term care in general.

Overarching recommendation

- All governments should make dementia a priority. This should be signified by developing National Dementia Plans to ensure that health and social care systems are adequately structured and funded to provide high-quality care and support to people throughout the dementia journey.
- All governments should initiate national debates regarding the future of long-term care, with all stakeholders and an informed public. For future generations of older people, the numbers of older people requiring long-term care, and their profile of needs is already predictable within narrow limits of uncertainty. Debate may focus upon:
  - The balance of roles and responsibilities of the state, private companies, the third sector, and the families in providing care.
  - The structure of the long-term care system, the services that should be prioritised, and who should be eligible to receive them.
  - The financing of long-term care (with a focus upon the need to shift from 'pay as you go' to 'fully-financed' systems in which each generation of working adults pays, collectively, for their own future needs for care).

Supporting recommendations

- Governments should ensure there are systems in place to measure and monitor the quality of dementia care and support in all settings.
- Governments and other stakeholders should ensure that autonomy and choice is promoted at all stages of the dementia journey. For example, information should be available to people, their family and friends on the condition as well as the range of treatment, care and support options available to them. The voices of people with dementia and their caregivers should be heard, and prioritised.
- Health and social care systems should be better integrated so that there are co-ordinated care pathways that meet people's needs. Case managers (one for up to every 60 people with dementia) are likely to add value when working from the community, across the journey of care, as part of a fully integrated long-term care system for older people.
- Governments and providers of care should ensure that healthcare professionals and the dementia care workforce are adequately trained to provide person-centred care.
- We need to value those that provide frontline care for people with dementia. This includes paid, as well as unpaid family caregivers, who share much in common. Governments need to acknowledge the role of caregivers and ensure that there are policies in place to support them.
  - Additional investment, through direct payments for family caregivers and improved pay and conditions for paid carers is likely to repay dividends – greater stability of the paid caregiver workforce, reduced caregiver strain, and better quality care.
  - Increasing the coverage of caregiver multicomponent interventions (support, education and training), early in the course of the illness. There is a strong evidence-

base that such interventions are highly effective in reducing caregiver strain, and delay and reduce rates of transition into care homes.

- Care in care homes is, and will remain, an important component of the long-term care sector, and should be valued as such. More attention needs to be given to assuring the quality of care in these settings, which is best judged through the quality of life of residents. Monitoring should capture this core care quality outcome indicator in addition to resource and process indicators that have focussed on compliance with minimum standards.

Recommendations for research

As highlighted in this report, investment in research and development into dementia; prevention, treatment, cure and care; is currently an order of magnitude lower than would be indicated given the burden and cost of the disorder. We call upon governments and research funders worldwide to transform their system of priorities, ensuring at least a tenfold increase in current levels of investment to bring research funding in line with other conditions, such as cancer. With respect to long-term care for people with dementia, more research is required into:

- The possibility that primary prevention may reduce future age-specific prevalence and incidence of the disorder.
- The development and trialling of treatments that might reduce the incidence of dementia among those with mild cognitive impairment, and/ or limit the progression of the disorder among those that develop dementia.
- The values and preferences of people with dementia and their caregivers. These are likely to vary between countries, cultures and generations. Improved understanding could inform evidence-driven policymaking and commissioning of services that were more likely to meet the range of needs that will be present in any population.
- The impact of different approaches to the delivery of long-term care on client quality of life and service satisfaction. Such research would need to be stratified on stage of dementia, and the availability of informal care.
- Exploration of approaches to implement and scale up person-centred care across community care and care home settings, addressing the gap between efficacy (when implemented in tightly controlled research studies) and effectiveness (when implemented in ‘real world’ circumstances). Such research could inform training programs for basic curricula and continuing professional development. Outcomes should be broadened to include the quality of life and satisfaction of people with dementia and caregivers, and possible benefits for professional care workers (mood, burn out and retention).
- Implementation research into approaches for scaling up coverage of caregiver multi-component interventions, and the cost-effectiveness of national programs.
- Research into the cost-effectiveness of introducing case management into more fully integrated long-term care systems.

CHAPTER 1

Background and context



Introduction

Over the next 40 years, numbers of dependent older people will increase nearly threefold from 101 million in 2010 to 277 million in 2050. Nearly half of those older people with needs for care are likely to be living with and experiencing the effects of dementia.* Dementia and cognitive impairment, along with other conditions of the mind and brain, are by far and away the leading chronic disease contributors to dependence, and, in high income countries, to transitions from independent or supported living in the community, into care homes.

In this report, we consider the extent of the increase in numbers of older people needing care, the regional distribution of the problem, and the reasons for this, including the contribution of the global epidemic of dementia to these trends. We will map out the key components of a comprehensive system of continuing care and support for people with dementia, addressing some of the challenges in optimising quality of care, and the quality of life of those most affected.

It is essential first to understand the context in which these changes are taking place, including ageing populations (the demographic transition), shifts in the burden of disease (the epidemiologic transition) and profound social and economic change (linked to economic development and globalisation).

A world in transition

Over the last century the world's more developed countries have been undergoing profound shifts in their population age structure (the demographic transition) and in the profile of health conditions that are responsible for most of the disease burden (the epidemiologic transition) – see Box 1.1 for details. The net results have been

1 A tailing off of population growth, with total population size becoming stable or even beginning to decline

2 Ageing of the population, with increases in life expectancy, increases in the absolute numbers of older people, and in the size of the older population relative to that of children (aged 0-14) and working age (aged 15-59) populations

3 Reductions in the incidence of infectious (communicable) diseases, reproductive and nutritional health problems that impact mainly on children and mothers

4 An increase in the frequency of chronic (non-communicable) diseases such as ischaemic heart disease, cancer, stroke, arthritis, chronic obstructive pulmonary disease, dementia, depression and other mental disorders.

* This is an estimate and does not indicate that the number of people with dementia has increased from the 2009 World Alzheimer's Report figures. The most accurate number remains that 36 million people worlwide live with Alzheimer's disease or other dementias.

Box 1.1

A world in transition

The demographic transition

The demographic transition describes a shift from high fertility, high mortality states to low fertility, low mortality states. Economic and social development, and improvements in public health lead to falling child mortality. For a period, the population grows rapidly, but then fertility rates also begin to fall (people have fewer children) until it reaches replacement rates (two births per woman), so population growth slows and stops. In many countries fertility has fallen well below replacement rates (1.39 in Japan, 1.41 in Italy, and 1.20 in Singapore), and without immigration, the population size will fall considerably. Improvements in adult health occur alongside improvements in child health, and mortality rates fall in older adults, further increasing life expectancy. In Japan, total life expectancy is now 86 years at birth for women and 79 years for men [3]. Those reaching the age of 60 can expect to live a further 28.1 years, and those reaching the age of 80, a further 11.3 years. The demographic transition is occurring much faster in some rapidly developing middle income countries than was the case in the 'old world'. Thus, the transition from 7% of the total population aged 65 years and over, to 14% took 115 years in France (1865-1980), 69 years in the USA (1944-2013), and 45 years in the United Kingdom (1930-1975). The same transition will be accomplished in just 21 years in Brazil (2011-2032), 23 years in Sri Lanka (2004-2027) and 26 years in China (2000-2026). It is important to recognise that while the demographic transition is proceeding particularly rapidly in low and middle income countries, population ageing is continuing in the world's more developed regions. Thus, the proportion of those aged 80 years and over in OECD countries will increase from 4% of the total population in 2010, to 10% in 2050.

The epidemiologic transition

Changes in the profile and patterning of disease happen in part because of the demographic transition, and population ageing. Chronic diseases tend to be strongly age-associated. The prevalence and incidence of dementia, for example, doubles with every five year increase in age. Hence as populations age, and there are more older people, then so chronic diseases become more common, and have a bigger impact.

The epidemiologic transition refers to a process in which:

1 With economic and social development, and improvements in the health sector, infectious diseases are brought under control, and childhood and maternal health improves. These infectious, infant and maternal diseases account for mortality at young ages, but also (for example HIV/AIDS, tuberculosis, malaria, polio, cerebral palsy) result in much childhood/ lifelong disability, most of it preventable.

2 At the same time changes in behaviour and lifestyles; towards a 'western' pattern of a sedentary lifestyle, high dietary consumption of salt, fat and sugars, smoking and alcohol use; drives an increase in the incidence of certain chronic diseases including particularly cardiovascular diseases, cancers, diabetes and obesity. Since the same set of risk factors also seems to increase risk for dementia [4], then there are likely also be adverse effects on brain ageing within populations undergoing this transition. The behavioural and lifestyle changes are driven by many factors including globalisation, industrialisation and urbanisation. Chronic diseases have now taken over as the leading cause of death in every world region.

These transitions are already well under way in middle income countries, and are gathering pace in many low income countries, including some of the poorest regions in sub Saharan Africa and Asia. The consequences are profound for every level and sector of society. The reduction in child mortality will translate over one generation to an increase in the size of the working age population, transiently increasing productivity and economic growth ('the demographic dividend'). However, as fertility declines, but the chances of surviving into old age increase there are fewer working age adults to provide economic and practical support for a growing number of older people, among whom there is a particularly high prevalence of chronic diseases, disability and dependence. In developing countries, health systems that have been orientated to the acute treatment of infectious diseases in otherwise fit and well children and young adults, are not well suited (organised, trained and funded) for the assessment and continuing treatment and care of chronic diseases (for example hypertension, diabetes, dementia) in an increasingly frail older population.

Social and economic trends linked to development are also an important part of the wider context, and constitute a third transition occurring alongside demographic and epidemiologic change. Social protection, particularly for older people, is not yet well established in most low and many middle income countries. Pension coverage is low, leading to poverty, and/ or a reliance on children or charity for income support. This, together with low coverage of health insurance limits affordable access to healthcare, in the context of increasing needs and demands.

The traditional system of unpaid 'informal care' by family, friends and community is increasingly coming under threat because of

1 Declining fertility – smaller families, and fewer younger people to care for the older generation
2 Changing attitudes and expectations among the younger generation
3 Urbanisation and increased workforce mobility – structured jobs afford fewer opportunities to make flexible arrangements to balance work and care; children migrate away from their parents to work in cities and abroad
4 Better education of women (who constitute the large majority of informal carers). More education leads to more workforce participation, and less availability for informal care.

Box 1.2

The development of the british social welfare state

- **The Old-Age Pensions Act 1908 (non-contributory pensions for those over 70 years)**
- **National Insurance Act 1911 (sick leave pay, free treatment for tuberculosis, time limited unemployment benefit)**
- **Beveridge Report 1942 (adequate income, health care, education, housing and employment for all, assured by government)**
- **National Insurance Act 1948 (comprehensive universal benefits – Death Grants, Unemployment Benefit, Widow's Benefits, Sickness Benefit, and Retirement Pension)**
- **National Assistance Act 1948 (a social safety net for those that did not pay National Insurance contributions)**
- **National Health Service Act 1948 (universal access to health care, free at the point of delivery)**

Future challenges

In High Income Countries, governments are struggling to find ways to sustain the high levels of social protection that are the cornerstone of their welfare states (entitlement to pensions, benefits, and comprehensive health and social care) in the context of stagnant economic growth, ageing populations, and rapidly increasing demand for cost-intensive services. The OECD predicts that spending on long-term care will double or even triple between now and 2050, with rising prices given demand for better quality and more responsive, patient-oriented social-care systems [1]. The credit rating agency Standard and Poor's now considers global ageing to be a significant threat to economic stability, since without changes to age-related public spending, sovereign debt could become unsustainable [2].

It took the United Kingdom nearly forty years incrementally to put into place the policies and legislation that founded the modern welfare state (Box 1.2). In Low and Middle Income Countries (LMIC), given the pace of the demographic transition (Box 1.1) governments have much less time to respond. Rapid economic growth in these emerging economies provides some fiscal 'breathing space', but also increases demand for social protection. The formal care system (including homecare, and care homes) is very little developed, with much greater reliance on the informal, unpaid support of family and community. While governments have in the past resisted development of the formal care sector, as a matter of policy, its growth, led by demand seems both necessary and inevitable. In developing long-term care (LTC) policies and systems LMIC governments and other stakeholders will want to learn from the

experiences of the past. As was pointed out in a recent OECD report: [1]

> **'In many countries, LTC policies (are) being developed in a piecemeal manner, responding to immediate political or financial problems, rather than being constructed in a sustainable, transparent manner.'**

What is required instead is a comprehensive and sustainable plan, that blurs the distinction between formal and family care arrangements, considering both elements, and, in particular their integration. Sustainability depends particularly on the financing of long-term care, which is a particularly vexed issue, considered in detail in Chapter 6.

Conceptual issues

What do we mean by dependence (needs for care)?

Dependence (sometimes referred to as needs for care) is defined as 'the need for frequent human help or care beyond that habitually required by a healthy adult' [5]. The nature of the help or care has been further defined as 'beyond what would be expected by virtue of family or social ties' [6]. Independence is the converse of dependence, describing a person who is self-reliant in all important respects. There is naturally a close relationship between dependence (needing help and care) and caregiving (the provision of that help and care). Caregiving has been defined by Schulz [7] as

> **'…the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting.'**

What is the relationship between disability and dependence?

Dependence arises from disability, but disability represents only a limitation in the performance of activities of daily living (for example cooking, shopping, laundry, household finances, washing, dressing, toileting, and eating) [8]. The limitation may mean that the person may take longer to do the task, or has to do it in a different way, or experiences pain or discomfort – this does not necessarily mean that they need or want help to perform the task. Thus disability may be experienced without dependence, but dependence always implies some degree of disability, usually of a more advanced and severe form. Since disability arises from a health condition, then dependence also requires the presence of one or more health conditions to account for the underlying disability. A rich person may be 'dependent' upon their chauffeur to drive them to work, but this is not the issue that we are addressing in this report.

Disability is commonly assessed in terms of the number of domains in which activity is limited and the severity of that limitation. For the World Health Organization's Disability Assessment Scale (WHODAS

Box 1.3

Assessing disability

The WHO Disability Assessment Scale (WHODAS 2.0) [9,11] (WHO)

This questionnaire asks about difficulties due to health conditions

Health conditions include disease or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Think about the last 30 days and answer these questions thinking about how much difficulty you had doing the following activities.

1 **How much difficulty did you have in standing for long periods such as 30 minutes?**
2 **How much difficulty did you have in taking care of your household responsibilities?**
3 **How much difficulty did you have in learning a new task, for example, learning how to get to a new place?**
4 **How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?**
5 **How much have you been emotionally affected by your health problems?**
6 **How much difficulty did you have in concentrating on doing something for ten minutes?**
7 **How much difficulty did you have in walking a long distance, such as a kilometer [or equivalent]?**
8 **How much difficulty did you have in washing your whole body?**
9 **How much difficulty did you have in getting dressed?**
10 **How much difficulty did you have in dealing with people you do not know?**
11 **How much difficulty did you have in maintaining a friendship?**
12 **How much difficulty did you have in carrying out your day to day work and usual activities?**

2.0),[9] each of 12 activities (see Box 1.3) is coded from no difficulty through to extreme difficulty / cannot do. Note that the 'activities' include indicators of social and community participation as well as self-care, and that these are assessed at the level of the person, rather than organ or body part – function in most of these domains could be affected by depression, cognitive impairment, or visual impairment. The WHODAS is also consistent with the WHO International Classification of Functioning, Disability and Health [8] in that the assumption is that disability arises through an interaction between impairments in the person's body function, and an environment that is imperfectly adapted to that person's needs – a person with limited mobility because of hip arthritis could get around much better with a mobility scooter. Dependence is sometimes inferred from the presence of severe disability, that is that someone with extreme difficulty or incapacity to perform a task is presumed as needing help or care. This is a reasonable approach, since studies have shown high levels of agreement between severe disability and dependence. In the 10/66 Dementia Research group surveys, dependence is assessed directly by interviewing a family member or other key informant, who should be the main caregiver if care is provided (see Box 1.4). A series of open ended questions are used to assess provision of assistance and care, given difficulties in using a single structured approach across different countries and cultures (see next section). The coding of the level of dependence is based upon the length of time during which the person could manage without human assistance – sometimes referred to as the 'interval of need' [10]. The 10/66 Dementia Research Group defined those needing care much of the time (at least daily) or occasionally (less often than that), or not at all (fully independent). Within a broader classification of interval of need 'long interval' needs are those which must be provided less often than once a day (for example getting food provisions, or helping with household budgets). 'Short interval' needs are those required at least daily (for example preparing meals, washing and bathing). 'Critical interval' needs are those required unpredictably throughout the day (such as assisting someone to use the toilet). People who need more or less continuous help and supervision (for example someone with advanced dementia, disturbed behaviour, and wandering with risk for falls) are sometimes included in an additional category of 'intensive care needs'.

Box 1.4

Assessing dependence

10/66 DRG survey [12,13]

Who shares the home with your xxxx?

What kind of help does your xxxx need
– inside of the home?
– outside of the home?

Who, in the family, is available to care for your xxxx?

What help do you provide?

Do you help to organise care and support for your xxxx?

Is there anyone else in the family who is more involved in helping than you?

What about friends and neighbours?

CODING MADE BY INTERVIEWER

The older person:

1 **needs care much of the time**
2 **needs care occasionally**
3 **does not need care; they are able to do everything for themselves**

Influence of culture and other factors

What people can do, or in fact habitually do is modified by cultural expectations, and gender, and changes with age [14]. This can complicate the definition and assessment of dependence, and its comparison across countries and cultures. In traditional, less developed and rural settings, many older people live in large, extended households, often spanning three generations including one or more children under the age of 16 [15]. Help is often provided to all older people in both core and instrumental activities of daily living, regardless of whether the older person would be capable of performing the task independently if they had to. There is often no expectation that older people should be involved in complex instrumental activities of daily living, for example budgeting, shopping and cooking. This can make the identification of needs for care 'beyond what would be expected by virtue of family or social ties' more difficult than in more developed settings [13,16]. It probably also reflects relatively robust family and community systems of informal support and care for older people. However, the health infrastructure is poorly resourced and the primary focus of governments and health providers is communicable diseases. Care homes for older people are rare in Africa, Asia and Latin America, and formal homecare or care home sectors are less developed than in high income countries. Most families cannot access financial benefits, disability or retirement pensions and have to pay out-of-pocket for health care and services [4,17,18]. The lack of adequate health or social system in most of those countries adds to the burden of care among the families [19].

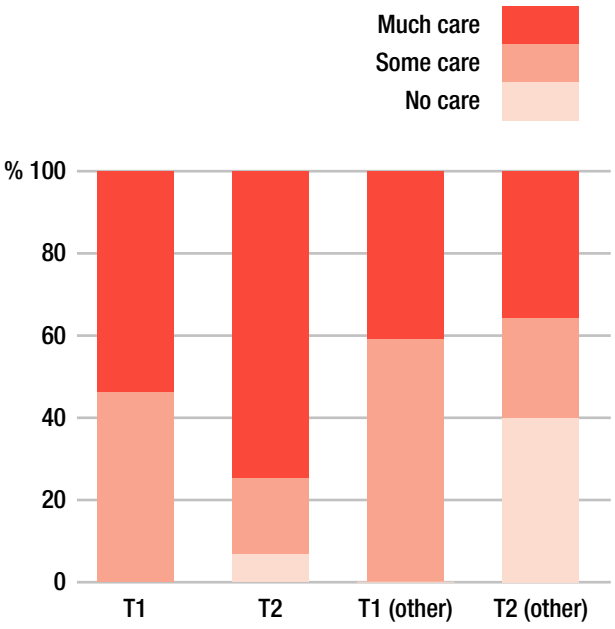
The course of dependence

Dependence may get worse, remain stable, or get better over time. The outcome depends to a large extent on the nature of the health condition or conditions that

are contributing to the underlying disability, and their prognosis. Dependence tends to be quite stable in younger people affected by birth injuries or illnesses, and after life changing accidents or illnesses. In older people, the accumulation of chronic diseases affecting different organ systems, and a tendency for progression of the severity of those conditions over time means that dependence once established, tends to be chronic (long-term) and progressive. For people with dementia, the onset of needs for care and caring is hard to define; it emerges naturally from support customarily given and received before the onset of dementia, and may precede or post-date a formal diagnosis [20]. Needs for care typically escalate over time, from support for instrumental activities of daily living (IADL – household, financial and social activities), to personal care (core ADL – bathing, dressing, toileting, feeding), to what may be almost constant supervision and surveillance [7].

The natural course of needs for care for people in the 10/66 Dementia Research Group surveys is illustrated in Figure 1.1, the analysis restricted to those who had needs for care at the baseline of the survey and who survived to be reinterviewed at follow-up three to five years later. Outcomes are compared for those a) with dementia and b) with other conditions accounting for their needs for care, but no dementia. These data indicate a clear and marked progression over time of needs for care among those with dementia, but no overall progression, and indeed considerable evidence for recovery of independence among those with other health conditions.

Figure 1.1
The course of needs for care



The course of needs for care between baseline (T1) and follow-up assessments (T2), conducted 3-5 years later, among those with dementia (n=254) and other health conditions (n=188). 10/66 Dementia Research Group population based baseline and follow-up surveys

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CHAPTER 2

Prevalence of dependence



The global prevalence of dependence in the general population

Disability has been widely studied, especially through the Global of Burden Disease (GBD) Report, but studies focusing upon dependence are less common.

In 2004, the prevalence of dependence was estimated for several country groups using data from the GBD Study [1] and United Nations population projections [2] to make predictions of trends in numbers of persons affected by dependence up to 2050 [3,4]. Prevalence and numbers were estimated for eight country groups, defined by the World Bank as being economically and demographically similar. These were: Established Market Economies, the former Socialist economies of Europe, sub-Saharan Africa, Latin America and the Caribbean, the Middle-Eastern crescent, China, India, and 'other Asia and Islands'. Both disability levels and dependence were ultimately inferred from diagnoses. Assuming a close relationship between dependence and disability, needs for care (daily, weekly or less than weekly) for 22 disabling health conditions were estimated by an international group of health professionals. People considered to require at least daily care were those with any of the most disabling conditions (active psychosis, dementia, quadri- or paraplegia, severe continuous migraine, blindness or severe depression), or a combination of two or three conditions considered less severe (for example Down syndrome, mild mental retardation, recto-vaginal fistula) [4].

In 2010, the whole population prevalence of dependence varied narrowly among regions, from 4.7% in Established Market Economies, Latin America and Caribbean, and Middle-East Crescent to 5.6% in China [3,4] (Table 2.1). This represents 349 million people worldwide with needs for care, of whom 18 million (5% of the total) will be children aged under 15, and 101 million (29% of the total) older adults aged 60 years and over. The prevalence of dependence increases markedly with age, from 1% among children aged 0-14 years, to 4.8% among adults aged 15-44 years, to 6.9% among those aged 45-59 years, and 13.2% among those aged 60 years and over.

Trends in the global prevalence of dependence

The projected increase in whole population prevalence through to 2050 is modest – prevalences in 2050 range from 5.3% in the Established Market Economies to 7.6% in China [3,4]. However, this conceals seismic shifts in the total numbers of people with needs for care, and their age distribution within the population. By 2050 it is predicted that there will be 613 million dependent

Table 2.1
Prevalence of dependence, and dependency ratio, by the country groups and year, based on the Global Burden of Disease Study disability categories [3,4]

Region	Year	Total population (millions)	Number of dependent people (millions)	Prevalence of dependence (%)	Increase in numbers (compared to numbers in 2000, %)	Dependency ratio* (%)
Established Market Economies	2010	885	42	4.7	10	7.8
	2030	925	48	5.2	28	9.7
	2050	928	49	5.3	31	10.4
Former Socialist Economies of Europe	2010	322	17	5.3	0	7.9
	2030	290	17	5.8	-1	9.7
	2050	252	16	6.2	-8	12.5
India	2010	1164	64	5.5	23	8.8
	2030	1409	90	6.4	74	10.0
	2050	1572	113	7.2	119	12.1
China	2010	1366	76	5.6	18	8.3
	2030	1485	102	6.9	57	11.6
	2050	1462	111	7.6	70	14.0
Middle-East Crescent	2010	755	35	4.7	29	7.8
	2030	1044	55	5.2	100	8.5
	2050	1283	77	6.0	180	9.8
Other Asia and Islands	2010	918	46	5.0	24	7.9
	2030	1131	66	5.8	78	9.3
	2050	1274	84	6.6	126	11.1
Latin America and Caribbean	2010	594	28	4.7	23	7.5
	2030	723	40	5.5	73	8.9
	2050	806	49	6.1	115	10.6
Sub-Saharan Africa	2010	829	42	5.0	29	9.6
	2030	1279	70	5.5	118	9.6
	2050	1760	115	6.5	257	10.5
Worldwide	**2010**	**6833**	**350**	**5.1**	**20**	
	2030	**8286**	**488**	**5.9**	**68**	
	2050	**9337**	**614**	**6.6**	**110**	

* The dependency ratio is the number of dependent people divided by the working age population

people worldwide of whom 277 million (45% of the total) would be aged 60 and over.

The changes in global geographic distribution of dependence are summarised in Table 2.1 and Figures 2.1 and 2.2. The numbers of dependent people in the former socialist economies of Europe will actually decline, because of low fertility and relatively poor survival into old age; by 25% in Ukraine, 32% in Bulgaria and 36% in Estonia. Numbers of dependent people will increase by 31% in the Established Market Economies; increases will be smaller in Europe and Japan (0-20%) and larger in North America and Australasia (60%). Numbers in China will increase by 70%. India, Latin America and Caribbean, Middle-East crescent and other Asia and Islands will undergo an increase of over 100%. The highest increase in numbers (257%) is projected for sub-Saharan Africa with 115 million dependent people in 2050 out of a total population of 1.76 billion. A five-fold increase (over 400%) will occur in Burkina Faso, Congo, Liberia, Niger, Somalia, Palestine and Uganda. The net result is an overall shift in the burden towards low and middle income countries. In 2010, 65% of dependent people were to be found living in the least developed regions. In 2050, the proportion living in those regions is projected to have increased to 69%.

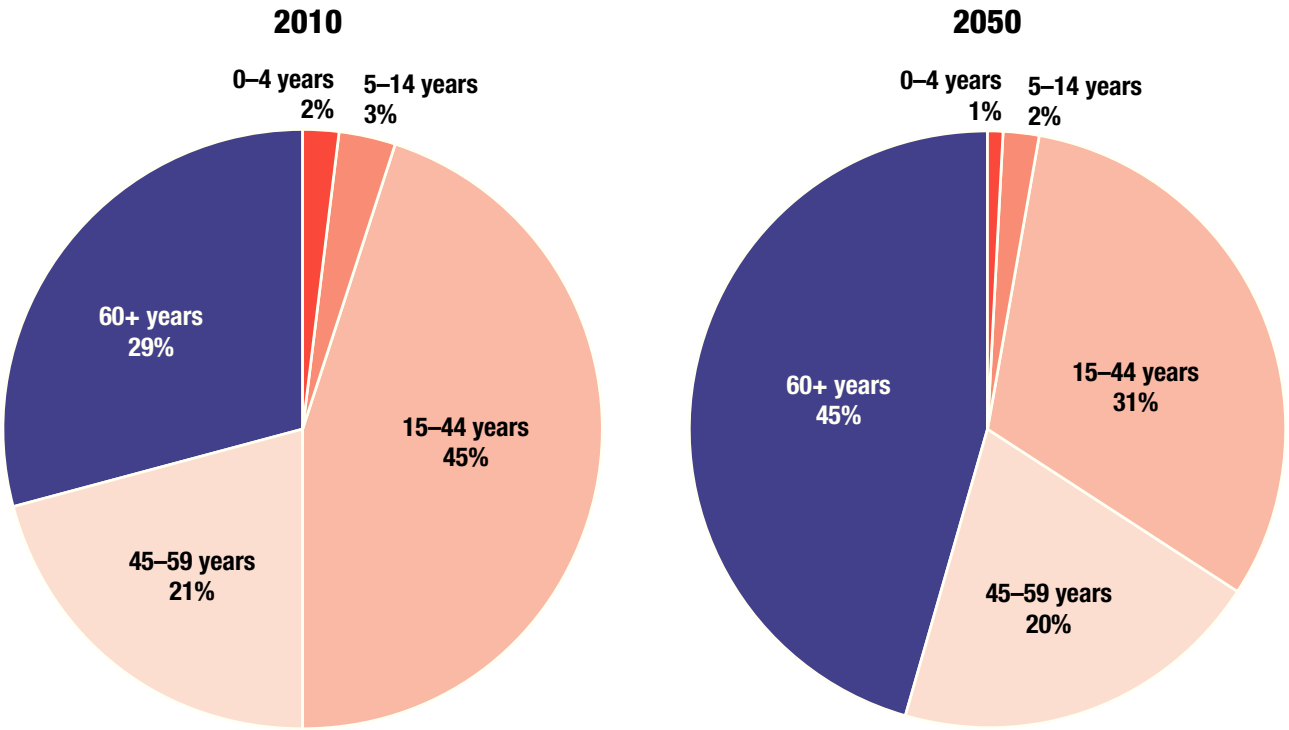
These increases are partly driven by population growth, but more particularly by population ageing. In low and middle income countries, there will be unprecedentedly rapid increases in the numbers of older people, and

the prevalence of chronic diseases amongst them. Dependence, a consequence of chronic disease disability, will increasingly come to dominate the health and social care agendas in these countries. The proportions of dependent persons who are aged 60 and over will increase between 2000 and 2050 from 29% to 45% overall; from 21% to 30% in sub-Saharan Africa, from 23% to 44% in India, from 23% to 47% in Latin America, and from 30% to 60% in China, compared with from 45% to 61% in high income countries [3]. Over this period the numbers of dependent older people are forecast to quadruple in most low and middle income countries, while numbers of dependent younger people in those regions remain relatively stable.

Therefore dependence is increasingly concentrated in low and middle income countries, while in all world regions it is rapidly becoming a problem predominately associated with older people and ageing processes, particularly chronic disease morbidity.

While the predicted increases in the number of people who need daily care seem to be enormous for some countries, this needs to be understood in the context of the size of the working-age population (i.e. the total population aged 15-59 years). The 'dependency ratio' has been defined in different ways, but here we have reported the number of dependent people (needing care because of a health problem) divided by the working age population, expressed as a percentage. The dependency ratio is controversial since many carers are themselves over the age of 60, or children, hence those that need care are not always dependent upon working age adults. Also, while the dependency ratio is intended to be an index of the impact of dependence upon the productive economy, many dependent people continue to work or make other valuable contributions to their families and society. Nevertheless, this is generally considered to be a useful indicator of the fiscal impact of population ageing and the health transition upon economies worldwide. The dependency ratio will increase slowly in the Established Market Economies, from 7% to 10% by 2050, reaching 13% in Japan (mainly because of a decreased in the size of the working age population due to low fertility). Greater decreases in the size of working-age population than of the number of dependent persons will also lead to an increase in the dependency ratio in former Socialist economies, from 8% to over 12%. A similar pattern is expected in some western European countries, such as Italy and Spain, affected by a very low fertility rate and high life expectancy. With large increases in the numbers of dependent people, the dependency ratio will increase from 8% to 14% in China (to 16% in Hong Kong) and from 9% to over 12% in India. Other regions with large increases in the numbers of dependent people (e.g. Latin America and the Caribbean, Middle East crescent, sub-Saharan Africa and Other Asia and Islands) will experience only slight increases in dependency ratios as the whole population, including the working-age population, will increase simultaneously. However, in some parts of southern Africa high mortality at young ages from HIV/ AIDS will also drive an increase in the dependency ratio.

Figure 2.1
Projected changes in the global age distribution of dependence [3,4]



The prevalence of dependence among older people

As has been noted, the prevalence of dependence increases markedly with age. Population based studies of dependence (defined according to various criteria) among older adults in high income countries provide fairly consistent estimates of between 12 and 17% needing regular care:

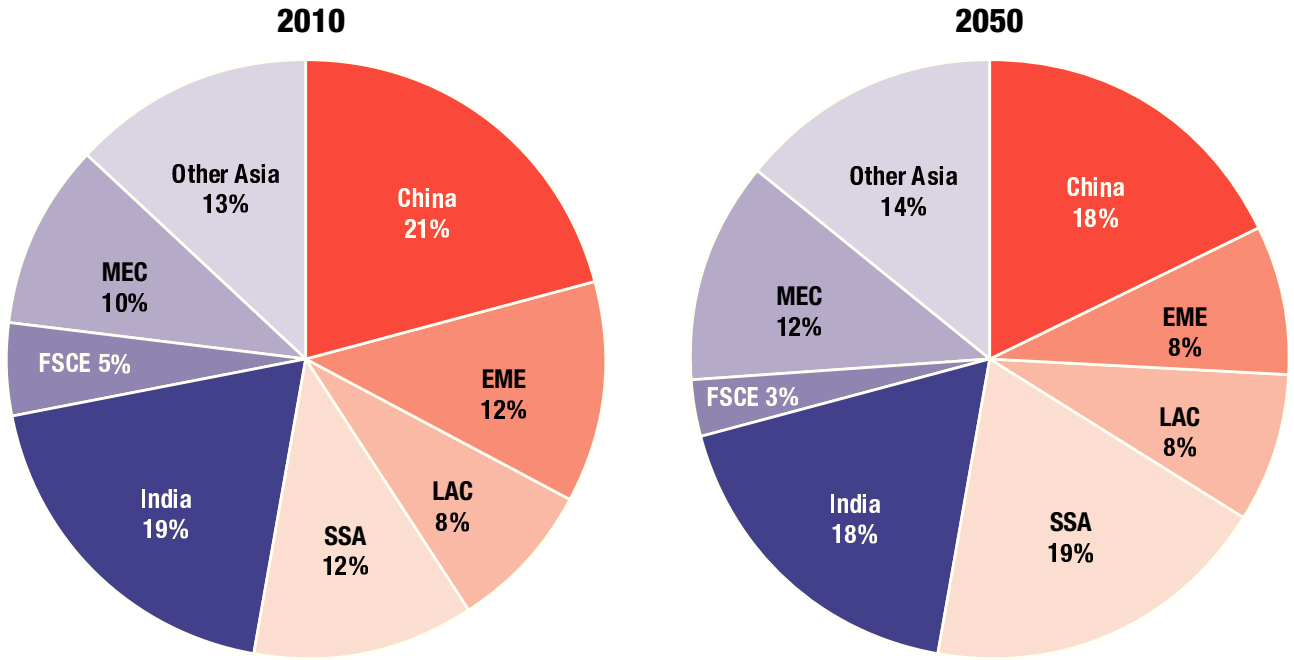
- 15.7% (11% of men and 19% of women) with disability in England and Wales, among whom 86% needed help on a daily basis [5],
- 15% with short interval dependence in Scotland [6],
- 15.5% with dependence in one or more of seven ADLs in Spain [7]
- 12.4% confined to home or bed in France [8]
- 17.1% disabled in one or more activities in Daily Living or living in care home in the USA National Long Term Care Survey [9].

The 10/66 Dementia Research Group population-based survey provided estimates of the prevalence of dependence among older people aged 65 years and over living in low and middle income countries (LMIC) [10,11]. A strength of this study was that dependence was ascertained directly using open-ended questions during the interview of a key informant (co-residents and family members were prioritised, unless others knew the old person best, and could give the clearest and most detailed account of current circumstances) – see Box 1.4. Needs for care were described as: no care required, care needed occasionally ('some care'), or care needed much of the time (at least daily – 'much care').

In catchment areas in eight Middle Income Countries (Cuba, Dominican Republic, Puerto Rico, Venezuela, Peru, Mexico, China and India), the crude prevalence of dependence varied from 2.9% in urban India to 15.7% in urban China [11] (Figure 2.3). Generally the prevalence of dependence was lower in the less developed countries. However, prevalence was particularly high in rural Nigeria, where 24.3% needed care, including 7.8% who needed much care [10]. In all countries, except India, prevalence was lower in rural than in urban catchment areas. The prevalence of dependence nearly doubled with every five year increase in age, and was generally lower in men than in women, particularly in the older age groups (meta-analysed Prevalence Ratio per 5 year age band 0.83, 95% CI 0.75-0.95). Older people with better education tended to have a lower prevalence of dependence (Prevalence Ratio per level of education 0.89, 95% CI 0.84-0.94). Differences in the prevalences of the main chronic diseases (rather than compositional differences in age, gender and education) seemed to explain much of the observed

Figure 2.2
Projected changes in the global geographic distribution of dependence [3,4]

EME= Established Market Economies
LAC = Latin America and the Caribbean
SSA = Sub-Saharan Africa
FSCE = Former Soviet Countries in Europe
MEC = Middle Eastern Crescent



variation in the prevalence of dependence between sites [11].

Comparison of prevalence of dependence among older people between high income and lower income countries

The crude estimates of the prevalence of dependence among those aged 65 years and over in the 10/66 surveys tended to be somewhat lower than previous estimates (12-17%) for surveys conducted in high income countries [5-9]. Age-standardized morbidity ratios (SMR) for dependence showed that the prevalence of dependence in the 10/66 middle income country sites was generally between one half to three-quarters of that in the USA (SMRs of 50 to 75). The SMRs for urban India (22), rural Peru (28) and rural China (38) were strikingly low, while that for urban China (98) indicated a similar prevalence to the USA reference population. The lower than expected prevalence among older people in less developed, and, especially, rural settings might be explained by:

1 an underascertainment of dependence among older people living with their families who routinely provide high levels of care and support

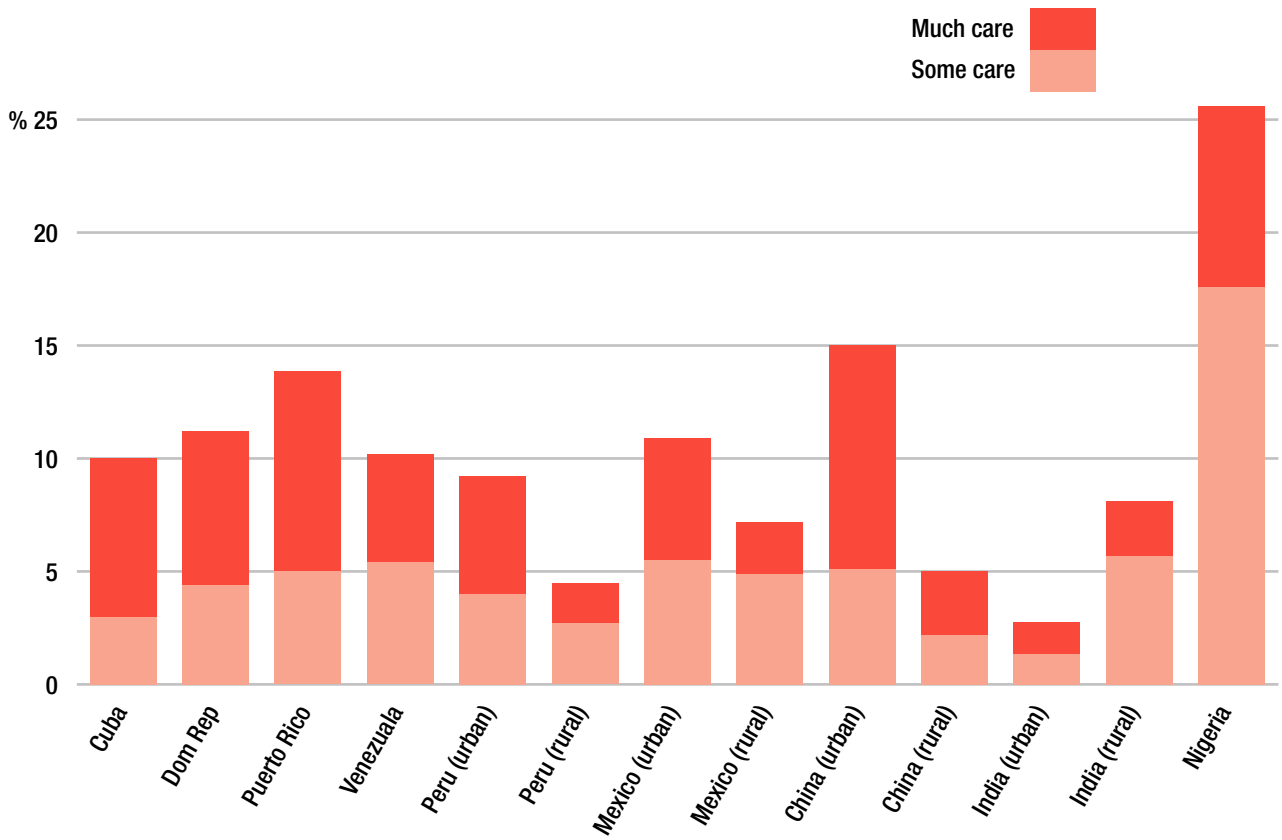
2 a high mortality rate, and hence a shorter survival of those who develop needs for care. Prevalence is a product of incidence and duration. Hence the incidence of dependence may be as high as in high income countries, but prevalence is lower because those affected survive for shorter periods without access to good quality medical and social care.

3 a lower prevalence of chronic diseases that contribute to disability and dependence. The age-adjusted prevalence of dementia is generally similar to that seen in HIC, although slightly lower in some rural and less developed 10/66 DRG survey sites [12]. A similar pattern of findings is seen for hypertension [13] and stroke [14]. Health circumstances of older people could be better in some less developed settings both because they represent a 'survival elite' given the high child and younger adult mortality in their pre-1940s birth cohorts, and because they may have had relatively low levels of exposure to cardiovascular risk factors pre-epidemiologic transition (see Chapter 1).

Future trends in the prevalence of dependence among older people

An optimistic future scenario is that future generations of older people will enter old age in a better state of health, and that there will be 'compression of morbidity' [15], signifying that increases in life expectancy would comprise additional years of healthy life, and not life lived in a state of disability and dependence. An alternative and more pessimistic

Figure 2.3
The prevalence of dependence in 10/66 Dementia Research Group population survey catchment sites



scenario is one in which declines in mortality in old age may be due to the reduced fatality of disabling chronic diseases rather than a reduction in their incidence [16], hence older people might live longer in a state of ill health, and we might instead experience an 'expansion of morbidity'.

The evidence on compression versus expansion of morbidity is very mixed. In the USA, compression of morbidity was observed to have occurred in successive cohorts enrolled into the American's Changing Lives study [17]. Thus, at least for those with higher levels of education, increases in life expectancy tended to comprise additional years of healthy life, rather than years lived with disability. For the least educated the pattern of a linear decline in health and functional status persisted in successive cohorts. However, a review conducted of survey data from 12 OECD countries [18] found evidence of a secular decline in disability among older people in only five countries (Denmark, Finland, Italy, the Netherlands and the United States). In three countries (Belgium, Japan and Sweden) the age-specific prevalence of severe disability among people aged 65 seemed to have increased in the previous decade, and in two countries (Australia, Canada) the prevalence seemed to be stable over time. In France and the United Kingdom, data from different surveys showed differing trends. The current consensus for future projections is that the age-specific prevalence of disability and dependence is likely to remain stable for the foreseeable future, as neatly expressed in the conclusion of the authors of the OECD report on disability trends: [18]

> **'One of the main policy implications that can be drawn from the findings of this study is that it would not be prudent for policymakers to count on future reductions in the prevalence of severe disability among elderly people to offset completely the rising demand for long-term care that will result from population ageing.'**

Summary and conclusion

The gradient in the prevalence of dependence among older people, between higher and lower income countries, and between urban and rural and least and more developed sites in the 10/66 Dementia Research Group surveys suggests the potential for a substantial shift in the global profile of dependence, occurring mainly in low and middle income countries, and linked both to rapid demographic ageing and the epidemiologic transition. As these transitions impact on low and middle income countries, the extent to which the chronic disease epidemics are prevented and controlled, and the extent to which improvements in public health and clinical care are equitably distributed are likely to have an important impact on future long-term care requirements, and the attendant societal costs. There is an urgent need for these trends to be monitored in low and middle income countries, using similar methodologies to the surveys conducted in high income countries.

Preventive interventions targeting older dependent people, and those at risk of dependence should be prioritised, mindful that according to the compression of morbidity hypothesis, healthy ageing, and healthy lifestyles may postpone the onset of chronic ill health and disability in the final years of life [19]. Regardless of the success of such initiatives, numbers of dependent older people will increase markedly in the coming decades particularly in middle income countries, and the dependency ratio (the ratio of the dependent population to the 'working-age' population) is also set to increase from 8% to 14% in China and from 9% to 12% in India, compared with from 7% to 10% in developed countries. Under the most pessimistic scenario, by 2050 the dependency ratio will have reached 20% in China. It is therefore imperative that governments worldwide make policies and plans for the future provision and financing of long-term care [20].

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CHAPTER 3

The contribution of dementia to dependence



The impact of dementia across the course of the illness

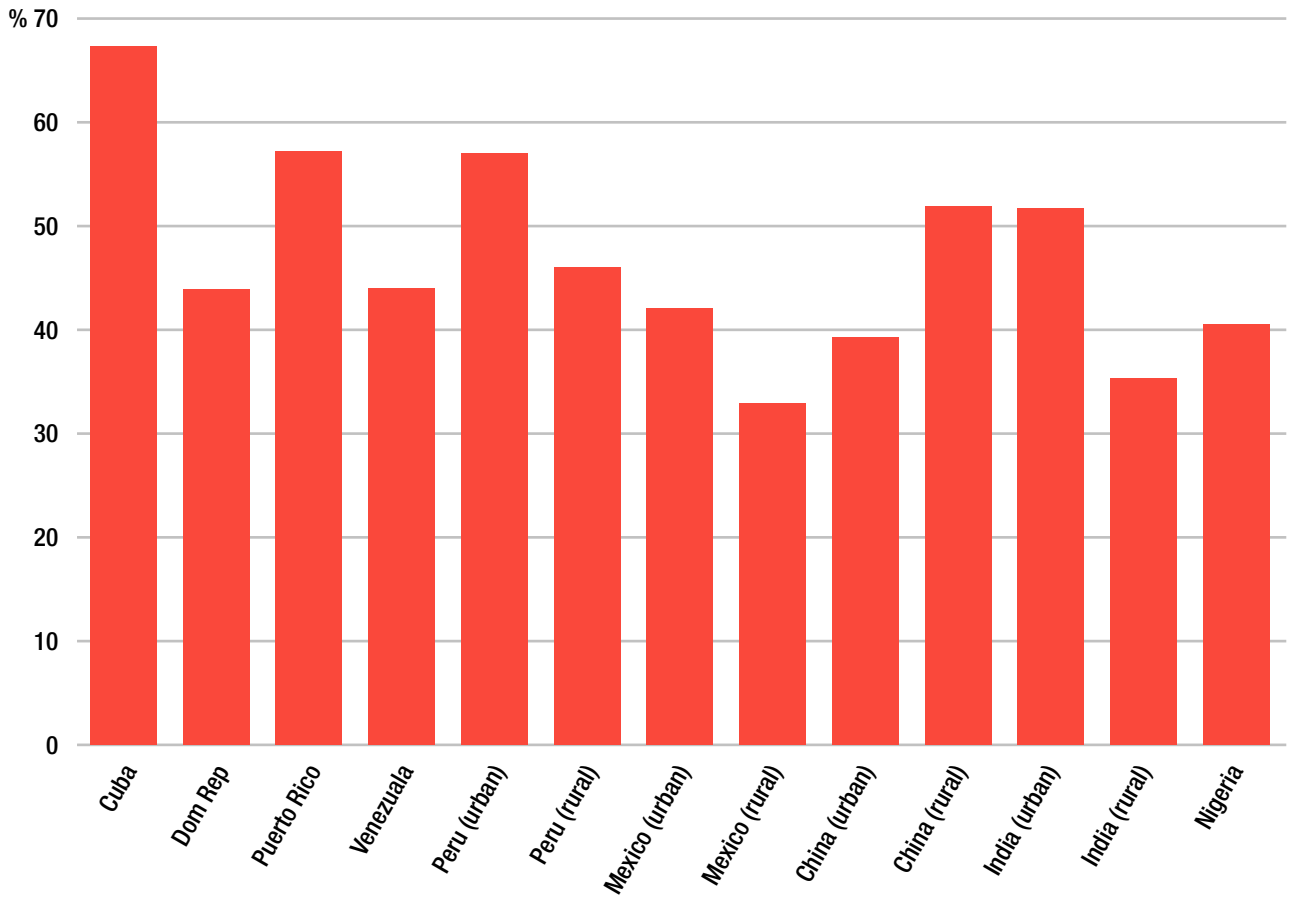
Unlike most other chronic conditions, people with dementia can develop needs for care in the early stages of the disease, and become increasingly reliant on caregivers throughout the course of the disease (see also Figure 1.1). Progression in needs for care over time is linked to deterioration in cognition, function and behaviour [1]. While presenting symptoms are different for different subtypes of dementia (e.g. Alzheimer's disease, vascular dementia, frontotemporal dementia and Dementia with Lewy Bodies), as the condition progresses, which it tends to do inexorably, all brain regions, and hence all brain functions come to be globally affected. The course of dementia varies considerably among individuals, but there are characteristic features at different stages.

In the early stages, those affected become forgetful, show orientation difficulties (confusion about time, place and people), and have difficulties in making decisions (including managing personal finances) and in carrying out household tasks. Furthermore, mood and behaviour can be affected, with a loss of motivation and interest, symptoms of depression, or uncharacteristically angry reactions. Caregivers have then to provide emotional support, to remind the person about events and tasks and to provide assistance with instrumental activities (for example managing finances and shopping).

In the middle stage, all of these symptoms become worse. Difficulties in communication increase, and need for help with personal care often extends to personal hygiene. Older people with dementia are no longer able successfully to prepare food, cook, clean or shop – hence living alone can be challenging even with support from family or paid caregivers. Behaviour changes (including wandering, repeated questioning, and calling out, clinging, agitation and aggression) can occur, sometimes driven by psychological and organic features (delusions, hallucinations, disturbed sleep pattern). Such behaviour can be challenging and/ or unsafe at home or in the community, meaning that the person with dementia must be more or less constantly supervised. Communication strategies to aid understanding are necessary. Help with carrying out personal care and with other activities of daily living is increased (food preparation, appropriate dressing, bathing, toileting).

In the final stages of the illness people with dementia can be unaware of time and place, unable to recognize relatives, friends, or familiar objects, unable to eat without help, severely restricted in their mobility, and sometimes bed-bound. Care, support and supervision needs are more or less constant. Full physical care has to be provided, while caregivers may still have to deal with behavioural problems (WHO 2012).

Figure 3.1
Proportion of those needing care that have dementia, by country
Data from the 10/66 Dementia Research Group baseline population surveys (people aged 65 years and over)

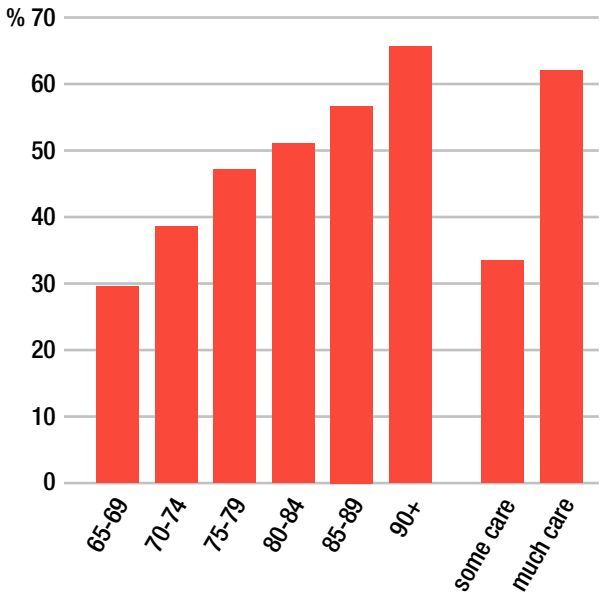


The prevalence of dementia, among older people who need care

A simple way of looking at the contribution of dementia to needs for care in the older population is to assess the proportion of dependent older people that have dementia. Data from the 10/66 Dementia Research Group baseline surveys in Latin America, China, India and Nigeria is displayed in Figure 3.1. Overall, across all countries combined, nearly half older people who needed care (937 out of the 1931, or 49%) were living with dementia. This proportion varied from 39% in urban China to 67% in Cuba, but was just over or just under half in most sites.

The proportion of those needing care that have dementia also increases with age (from 30% of those aged 65-69 to 66% of those aged 90 and over), and is nearly twice as high among those needing much care (62%) compared with those needing some care (34%) (Figure 3.2)

Figure 3.2
Variation in the proportions of those needing care that have dementia, by age and level of care
10/66 Dementia Research Group baseline surveys



The contribution of dementia to dependence, taking into account the effect of other common chronic diseases

The fact that older people who need care commonly have dementia does not necessarily imply that it is dementia, or dementia alone, that is giving rise to dependence. Older people frequently have multiple health conditions, chronic physical diseases coexisting with mental or cognitive disorders, the effects of which may combine together in complex ways leading to disability and needs for care. One approach for disentangling the independent contribution of different, often comorbid chronic diseases is to use multivariable statistical models to identify the independent contribution of each condition, controlling for the effects of others. This approach has been used in several studies in both high income and low and middle income countries, generating both relative risks (how many times more likely people with dementia or other conditions are to experience needs for care) and population attributable fractions (the proportion of needs for care in the population that are attributable to dementia as opposed to other causes, and hence how much needs for care could notionally be avoided if dementia could be completely prevented or cured). Such studies concur that, among older people, cognitive impairment and dementia make the largest contribution to needs for care, much more so than other types of impairment and other chronic diseases.

In a cohort study of Medicare recipients in the USA the onset of dementia at 12 months was strongly associated with the onset of dependence by 36 months (adjusted odds ratio [OR] 7.5), with low body mass index (OR 6.1), psychiatric disorder (OR 4.5), stroke (OR 2.5) and obesity (OR 2.1) also being independently associated. The onset of coronary heart disease, cancer, hypertension, lung disease, diabetes and hip fracture did not predict dependence [2]. Similar findings were reported from a three year follow-up of a population-based cohort study in Sweden, with dementia identified as the main risk factor for the onset of functional dependence [3].

Using data from the 10/66 Dementia Research Group baseline prevalence surveys (in urban sites in Cuba, Dominican Republic and Venezuela, and both rural and urban sites in Peru, Mexico, China and India), analyses were conducted to better understand the independent contribution of dementia, other chronic diseases and impairments to both disability [4] and dependence [5] (see Table 3.1 for results). Dementia, depression, stroke, ischemic heart disease, hypertension, and Chronic Obstructive Pulmonary Disease (COPD) were the six main diagnoses considered, together with a list of 12 common self-reported physical impairments (paralysis, weakness or loss of a limb; eyesight problems; hearing difficulties or deafness; stomach or intestine problems; arthritis or rheumatism; heart problems; breathlessness, difficulty breathing or asthma; persistent cough; faint or blackouts; and skin disorders such as pressure sores, leg ulcers or severe burns). Each 10/66 research site contributed representative samples of 1,000 to 3,000 people aged 65 years and over, with over 15,000 participants in total. Poisson regression working models were used to estimate the independent associations (prevalence ratios) of each health condition with dependence, controlling for age, gender, marital status, education and all other health conditions. Models were run for each site, and the results combined meta-analytically. Dementia, limb paralysis or weakness, stroke, depression, eyesight problems and arthritis were each independently associated with dependence, but the association with dementia was much the strongest, those with dementia being four and a half times more likely than others to have needs for care [5]. Also, according to the population-attributable prevalence fraction (PAPF) dementia made by far and away the largest independent contribution to dependence, with a median PAPF across sites of 34%, ranging from 23% in rural Mexico to 59% in Cuba. Other important contributors were limb impairment (median PAF 9%, range 1%-46%), stroke (8%, 2%-17%), depression (8%, 1%-27%), eyesight problems (6%, 0%-16%) and arthritis (4%, 0%-6%); hearing difficulties, self-reported heart problems, ischaemic heart disease, hypertension, COPD, difficulties breathing, persistent cough, intestinal problems, faints or blackouts, and skin disorders were not significantly associated with dependence [5]. For the analyses assessing the independent contributors to disability, the results were very similar, with the same five leading contributors, in more or less the same order of importance, and the same dominant contribution of dementia [4]. However, the outstanding unique impact of dementia, both in terms of relative risk and population attributable fraction, was much more evident for the outcome of dependence than for disability.

Another proxy indicator of the relevance of dementia to dependence is the extent to which older people with dementia use different types of care services that reflect increasing levels of needs for care, and the extent to which they are over-represented among older users of those services. In the USA, it has been estimated that people with dementia account for 37% of older people who use non-medical home care services, at least half of attendees at adult day centres, 42% of residents in assisted living and residential care facilities, and 64% of Medicare beneficiaries living in a nursing home [6]. In a US study of older people who needed help with personal care or instrumental activities of daily living, those with cognitive impairment were more than twice as likely as others to receive paid home care, and used the services twice as intensively as did cognitively normal users of paid home care [7]. Approximately 30-40% of older Americans with

dementia live in a care home, compared with just 2% of older adults without dementia [6,8]. Moving into a care home (sometimes unfortunately referred to as 'institutionalization') is generally a marker of particularly high needs for care, although other factors can be involved (see 'Home care, or care in a care home?' on page 33). Predictors of transition into a care home in the USA have been studied in a review including 77 reports across 12 data sources that used longitudinal designs and community-based samples [9]. Cognitive impairment was the health condition that most strongly predicted transition, with a 2.5 fold increased risk (RR 2.54, 95%CI 1.43-4.51). Other major chronic conditions also conferred a significantly increased risk: RR 1.04 for hypertension, 1.15 for cancer and 2.35 for diabetes, but these were modest compared to the risk associated with cognitive impairment. Other chronic conditions including arthritis, lung disease or cardiovascular disease did not show any significant association. In a study conducted in Sweden, dementia was the main predictor of transition into a care home, with a population attributable fraction of 61% [10].

Summary and conclusion

Dementia and cognitive impairment are the leading chronic disease contributors to disability, and, particularly, dependence among older people worldwide. While older people can often cope well and remain reasonably independent even with marked physical disability, the onset of cognitive impairment quickly compromises their ability to carry out complex but essential tasks and then even to meet their basic personal care needs. The need for support from a caregiver often starts early in the dementia journey, intensifies as the illness progresses over time, and continues until death. As such, when policymakers consider the important topic of 'long-term care' among older people (see Chapter 4) they need to pay much more attention to the importance of dementia as the most common underlying condition (affecting around one half of all care dependent older people) and, very often, the root cause of their needs for care. As we shall see, given the character of the illness, people with dementia deserve and need special consideration in designing packages of care and support that meet their and their caregivers' needs (Chapters 4 and 5).

Table 3.1
Prevalence ratios¶ for the independent associations between health conditions (impairments and diagnoses) and a) disability [4] and b) dependence [5]

	a) Associations with disability		b) Associations with dependence	
Health conditions, ranked in order of contribution to dependence	Meta–analysed PR (95% CI)	Median PAPF (range by site)	Meta–analysed PR (95% CI)	Median PAPF (range by site)
Dementia	1.9 (1.8–2.0)	25% (19–44%)	4.5 (4.0–5.1)	34% (23–59%)
Limb paralysis or weakness	1.8 (1.7–1.9)	11% (6–34%)	2.8 (2.4–3.2)	9% (1–46%)
Stroke	1.4 (1.3–1.5)	11% (2–21%)	1.8 (1.6–2.1)	8% (2–17%)
Depression	1.4 (1.3–1.5)	8% (1–23%)	1.7 (1.5–2.0)	8% (0–27%)
Eyesight problems	1.1 (1.1–1.1)	7% (2–18%)	1.2 (1.1–1.3)	6% (0–16%)
Arthritis or rheumatism	1.3 (1.3–1.4)	10% (3–35%)	1.1 (1.0–1.3)	4% (0–6%)
Stomach or intestine problems	1.1 (1.1–1.2)	7% (0–23%)	*1.1 (1.0–1.3)*	*2% (0–16%)*
Hearing difficulty	1.1 (1.1–1.2)	2% (1–9%)	*1.1 (0.9–1.2)*	*1% (0–5%)*
Difficulty breathing	1.2 (1.1–1.3)	4% (2–9%)	*1.2 (1.0–1.4)*	*1% (0–6%)*

¶Adjusted for age, sex, education, marital status and other health conditions

Figures in *italics* indicate conditions not statistically associated with dependence that have positive PAPF values

The current and future costs of long-term care will be driven to a very large extent by the coming epidemic of dementia (Chapter 6). Our success in designing and implementing successful strategies for the prevention of dementia [11], and in identifying treatments that can alter the course of the disease will be important determinants of future health and social care costs, currently rising inexorably in the context of population ageing.

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CHAPTER 4

Long-term care services and the journey of care for people with dementia



What is 'long-term care'

Long-term care has been defined by the World Health Organization [1] as:

> **'The system of activities undertaken by informal caregivers (family, friends, and/or neighbours) and/or professionals (health, social, and others) to ensure that a person who is not fully capable of self-care can maintain the highest possible quality of life, according to his or her individual preferences, with the greatest possible degree of independence, autonomy, participation, personal fulfilment, and human dignity.'**

The important elements of long-term care can be described both in terms of the apparatus of the care system, and its functions [1].

The apparatus of long-term care:

- assessment and evaluation of social and health care status, resulting in explicit care plans and follow-up by appropriate professionals and paraprofessionals;
- supportive services and care provided by culturally sensitive professionals and paraprofessionals.
- care in an institutional or residential setting when necessary;
- palliative care and bereavement support as necessary and appropriate;

The functions of long-term care:

- maintenance of involvement in community, social, and family life;
- environmental adaptations in housing and assistive devices to compensate for diminished function;
- programmes to reduce disability or prevent further deterioration through risk-reduction measures and quality assurance;
- provision for recognizing and meeting spiritual, emotional, and psychological needs;
- support for family, friends, and other informal caregivers;

Within the concept of long-term care, it is implicit that the physical, mental or cognitive problems of the person that lead to loss of independence are such that the care is likely to be required for an extended period of time, although what exactly constitutes 'long-term' is generally not explicitly defined. With many chronic health conditions, particularly in older people and particularly with dementia, loss of capacity is progressive leading to steadily increasing needs for care. However, not all losses of capacity are irreversible; for example a person may recover a lot

of function after a stroke. Therefore the types, levels, and duration of support required may be difficult to predict, and will need to be reassessed regularly. A key priority is to provide a seamless continuum of care, as needs evolve and change across the course of the health condition or conditions that have led to the person losing independence. This is particularly true for dementia.

Long-term care is a complex system with broad boundaries. Many different tasks and functions need to be performed, and the needs of each individual and family are specific. There is no unitary long-term care system; different agencies will be involved in providing, supporting, organising and financing care. The family will always have a central role, supported to a greater or lesser extent by formal professional or paraprofessional care services. Care can be provided at home, in the community, or to a resident of a care home. Some of these complexities are considered in the following sections, specifically the complementary role of health and social care agencies; formal and informal care; and home care versus care in a care home.

Options for long-term care provided for people with dementia

Is long-term care health or social care?

Long-term care requires both health and social care services. The classification of which components or activities are considered to constitute 'health' and which 'social' care varies from country to country, making it difficult to compare the type and extent of services provided, and the overall investment that countries make in long-term care. The boundaries between health and social care inputs for older people requiring long-term care are not distinct. Total long-term care spending is calculated as the sum of healthcare and social services of long-term care. In many countries, and according to current international definitions health care services include; long-term nursing care; health services in support of family care; and personal care services (supporting core activities of daily living); and palliative care. Relevant social services include; home help (for example, domestic services); care provided in residential care or assisted living facilities; care assistance (supporting instrumental activities of daily living); and other social services. Evidently these distinctions are to some extent artificial and arbitrary. Furthermore, the integration of health and social care components into a single structure for the purposes of funding and delivery of services is a current policy priority for many OECD countries [2] (see Table 4.2).

Informal (family) or formal (paid) care

It is common to distinguish between care provided unpaid by family, friends and community, and care provided by paid care workers. Unpaid care provided by family is generally referred to as 'informal' care and paid care as 'formal' care.

Different terminology is used in different countries to describe paid care workers. In the USA they are referred to as direct-care workers, and comprise nurse aides, home health aides and personal- and home-care aides providing care at home, while in nursing homes, nursing assistants make up the majority of staff who work with cognitively impaired residents [3]. Paid care workers can be employed by the government, private (for-profit or not-for-profit) nursing homes or community social care agencies, or directly by families. They face a difficult and demanding job role, often with relatively little training, and with very modest remuneration (see 'Valuing dementia care workers' on page 62). This leads to problems of retention, and a high turnover of staff, to the detriment of care.

Family caregivers can, and commonly do provide all of the regular 'hands-on' care provided by paid care workers, but they also have an important role in advocating for the person with dementia, and organizing their care, sometimes from a distance [3]. Data from similar surveys of those aged 50 years and over in a range of OECD countries (in Europe) suggest that between 8% and 16% of those aged 50 and over are informal caregivers providing support for core activities of daily living (not specifically for a person with dementia) [2]. If the definition of caregiving is broadened to include support for instrumental activities of daily living then that proportion increases to between 18% and 44% [2]. The majority of the caregivers are women. Most provide relatively low intensity care, with slightly more than half reporting an average of 0-9 hours of direct care input per week. The Alzheimer's Association estimates that there are 15.4 million Americans aged 18 years and over who provide unpaid care for a person with dementia, contributing an average of 21.9 hours of care per caregiver per week, or 17.5 billion hours of unpaid care annually [3]. In contrast to the picture emerging from the OECD analysis of caregiving in general, the Alzheimer's Association highlights the typically high intensity of caring for a person with dementia, and the increased requirement for assistance with personal care. Caregivers of people with dementia were more likely than caregivers of people with other conditions to be required to provide help with getting in and out of bed (54% vs. 42%), dressing (40% vs. 31%), toileting (32% vs 26%), bathing (31% vs. 23%) managing incontinence (31% vs. 16%) and feeding (31% vs. 14%) [3]. These findings were confirmed in reports from the 10/66 Dementia Research Group; in the Dominican Republic and in China among those needing care, those with dementia stood out as being more disabled, as needing more

Box 4.1

The impact of caregiving in dementia

Practical impact

For the World Alzheimer Report 2010 [6], a systematic review of the world literature on the demands of care giving was carried out; 10 studies where time spent assisting with basic ADLs was quantified, covering 25 countries; 42 studies of time spent assisting with basic ADLs and IADLs combined covering 30 countries; and 13 studies of time spent in generally supervising the person with dementia covering 25 countries. This suggested that caregivers spend an average of 2.0 hours daily assisting with basic ADLs, 3.6 hours with basic ADLs and IADLs combined, and a further 2.6 hours spent generally supervising the person with dementia. This amounts to an average weekly total of between 14 hours (ADL alone) and 43 hours (ADL, IADL and supervision). There was no obvious or consistent pattern of variation across world regions.

Psychological impact

There are adverse effects on caregivers' physical health [7,8], but the effect on psychological well-being is most frequently studied [9]. Ninety-three studies comparing depression symptoms between caregivers and non-caregivers have been meta-analysed, and show significantly higher symptom levels among caregivers, the difference being larger for studies that focus on exclusively on dementia caregivers [9]. A systematic review of 10 studies assessing major depressive disorder among caregivers of people with dementia using structured clinical interviews, reported a prevalence of between 15% and 32%, three to 39 times higher than in controls [10]. In the 10/66 Dementia Research Group studies in Latin America, India and China, living with an older person with dementia was associated with a two-fold increased risk of psychological morbidity in co-residents [11]. Living with older people with physical conditions and depression was also strongly independently associated with co-resident psychological morbidity, and the effects were only partly mediated (explained) by the demands of caring. Other mechanisms must also be involved, including perhaps the costs of purchasing healthcare and the worries of living with an older person in declining health.

Economic impact

In an analysis of European and North American survey data conducted by the OECD of caregivers of older people (not dementia caregivers specifically) a one percent increase in hours of care was associated with a reduction in the employment rate of caregivers by around 10% [2]. In a survey of American caregivers conducted by the Alzheimer's Association (US), 13% had to go from working full- to part-time, 11% had to take a less demanding job, and 11% had to give up work entirely [3]. In the 10/66 Dementia Research Group studies in Latin America, India and China, the median proportion of caregivers who had given up or cut back on work to care across 11 sites was 33.3% (interquartile range 22.9-37.0%) [12]. Cutting back or giving up on work to care was associated with higher caregiver strain, while strain was reduced by hiring a paid caregiver, or having additional informal support [12].

care (particularly support with core activities of daily living), and as being more likely to have paid caregivers – dementia caregivers also experienced more strain than caregivers of those with other health conditions [4,5].

There is a large literature attesting to the extent of the strain that caregivers experience, which is practical (hours spent caregiving detracting from other activities, particularly leisure and socializing), psychological (emotional strain, leading to a high prevalence of anxiety and depression), and economic (increased costs, coupled with giving up or cutting back on work to care). See Box 4.1 for further details.

The distinction between formal and informal care is one that matters as far as governments are concerned in that richer countries are heavily involved in financing long-term care through public expenditure. While formal care at home or in care homes accounts for an average of 1.5% of GDP (range 0.1-3.6%) in OECD countries [2], informal care is often considered not to have any fiscal impact. This, of course depends upon the value attached to informal care. If the family caregiver was not contributing, then their efforts might need to be substituted by a paid caregiver, with costs to the family and/ or the state. In the USA, the Alzheimer's Association has costed the 17.5 billion hours of unpaid care by family caregivers, on this basis, at US$216 billion per year [3]. There is also the substantial evidence of opportunity cost, with the family caregiver often cutting back on or giving up paid work to care (see Box 4.1), with a cost to family

finances and a negative impact on national economic productivity and government taxes.

In many other ways the distinction is unfortunate. There are many dependent older people who receive care exclusively from family or other informal caregivers. However, it is rare for long-term care to be provided exclusively by paid caregivers, even for care home residents. Paid caregiving may either substitute some of the functions previously performed by family caregivers, or supplement what they have been able to do. Paid caregivers can help to alleviate the strain experienced by family caregivers particularly that arising from the most common sources of strain – the practical demands of caring; coping with behavioural problems; and social restrictions on the caregiver leaving the home, socializing or going to work [13]. Usually the formal and informal family care providers are working side-by-side with an important interface between the two systems requiring sensitivity, collaboration, discussion and planning. Paid caregivers value the time that they have to develop their relationship with the care recipient and their family [14]. In many ways, paid and unpaid family caregivers have a lot in common, most particularly their shared responsibility for providing the best possible quality care to the person living with dementia.

Nonetheless, as pointed out by Dorie Seavey in a thoughtful policy brief [15]

> **'in the worlds of advocacy and policy making these caregiving systems are almost never considered as two parts of a complex whole. Each has its own lobbyists and allies, and each is addressed as if it functioned independently of the other. Recognition that, while there are differences in culture, roles and training, family and paid caregivers share a common reality – society's undervaluing of caregiving labor, stemming in large part from caregiving's long history as a female-dominated sphere. For paid workers, this results in low pay, poor working conditions and lack of respect. For family members, the view that this work is unexceptional yet obligatory 'domestic labor,' has resulted in a dearth of public policies designed to help families balance caregiving and workplace responsibilities and has left caregivers isolated in their private, domestic worlds.'**

Home care, or care in a care home?

Care homes for people with dementia typically comprise:

- residential care or assisted living facilities, staffed by care assistants, which provide assistance with activities of daily living, and supervision, but no onsite specialist medical or nursing care
- nursing homes, staffed by registered nurses as well as nursing and care assistants, and able to attend to medical and nursing care needs, as well as high levels of personal care
- dementia special care units, staffed by specialist dementia nurses, and attended by multidisciplinary care teams, capable of providing specialist care for those with advanced dementia, behavioural problems and psychological symptoms, and complex medical comorbidities.

These are often referred to in the literature as 'institutional care' but we prefer the collective term 'care homes', since institutional care does not reflect what the majority of the providers in this sector aspire to offer, or do offer their clients. Likewise we refer to 'transition into a care home' rather than 'institutionalization'.

In high income OECD countries, more than half of all care recipients aged 80 years or over receive care at home in most countries, and only a third of all long-term care users receive care in care homes [2]. Nevertheless, 62% of total direct costs of long-term care are incurred in care homes, reflecting the intensity and high cost of care in those settings [2]. There is evidence to suggest that, among users of long-term care, people with dementia are over-represented among care home residents. A study in the USA suggests that up to three quarters of people with dementia may move into care homes at some stage in their illness [16]. Estimates of the proportion of all people with dementia living in care homes in high income countries vary from 30-40% in the USA [3,17], 35-50% in the UK [18,19], and 50% in Canada [20]. The worldwide questionnaire survey conducted by ADI for its 2010 World Alzheimer Report was much less robust in its methodology, using expert opinion, but covered 48 countries from all world regions [6]. The mean proportion estimated to live in care homes was 34% (95% confidence interval 32-36%) in high income countries, but only 6% (95% confidence interval 4%-6%) in low and middle income countries.

Reasons for moving into a care home

Several empirical studies have been conducted to identify factors that predict transition into a care home. Table 4.1 summarises the evidence from two systematic reviews [21,22], including some studies not limited to people with dementia. Other than the obvious, that transition into a care home is associated with cognitive impairment and functional incapacity, the noteworthy findings are that transition is more likely to occur; when the care recipient and caregiver are older; when the caregiver experiences psychological distress or strain, and has expressed a wish for the care recipient to move into a care home. Previous nursing home admissions are also associated with the transition into a care home. Since, in high income countries such as the UK [18], the largest future increases in numbers of people with dementia will occur in the oldest age groups, who are more likely to have complex comorbidities and older

Table 4.1
Summary of findings from two systematic reviews on factors associated with transition into care home [21,22]

Predictors	Strong evidence	Moderate evidence	Weak evidence	Inconclusive evidence
Age	●			
Housing, not own house	●			
Ethnicity, white American	●			
Self-rated health status, low	●			
Functional impairment	●			
Cognitive impairment	●			
Prior nursing home placement	●			
Number of prescriptions	●			
Caregiver age	●			
Caregiver stress	●			
Caregiver desire to institutionalise	●			
Caregiver psychological distress	●			
Employment status, employed		●		
Social network, low contacts		●		
Activity level, low		●		
Diabetes		●		
Caregiver's social support		●		
Duration of dementia		●		
Caregiving hours			●	
Marital status, married			●	
Gender, male				●
Living situation, living alone				●
Education, low				●
Income				●
Stroke				●
Hypertension				●
Arthritis				●
Respiratory diseases				●
Incontinence				●
Depression				●
Prior hospital use				●

Levels of evidence:

Strong	consistent findings in at least 75% of studies in at least three high quality studies
Moderate	consistent findings in at least 75% of studies in at least two high quality studies
Weak	findings of one high quality study and of at least two moderate to low quality study or consistent findings (≥75%) in at least four or more moderate to low quality studies
Inconclusive	inconsistent findings

caregivers, this suggests potential for increases in the proportion of people with dementia cared for in care homes. Conversely, consistent with the finding that caregiver strain is a driver for transition into care homes, interventions that provide support, education and training for caregivers have considerable potential to reduce or delay transition into a care home, as demonstrated in several randomized controlled trials [23]. In the USA one such intervention maintained over a longer period was associated with a 28% reduction in the rate of transition into a care home, and care home admission was delayed by a median of 559 days [24].

Empirical data of this kind does not give a full sense of the complex and difficult decision-making regarding the transition from care at home into care in a care home. Moreover, in countries where care homes are prevalent, transition from home into a care home setting often represents a 'forced choice', associated with escalation of needs for care beyond what family and community care services can manage. All too often, the transition occurs at a time of crisis, or following admission into acute hospital care [25].

The Alzheimer's Society conducted a survey of 1,139 caregivers who had recently completed this transition asking them to nominate the main reasons (see Box 4.2) [25].

Box 4.2

Most common reasons nominated by UK caregivers for admission

More than one option could be coded hence these do not sum to 100%. Alzheimer's Society DEMFAM survey [25]

33%	**unable to cope with increasing care demand**
26%	**could no longer live independently/ needed 24 hr care**
23%	**safety issues**
16%	**advised by health or social care services**
14%	**challenging behaviour (abusive, aggressive etc.)**
14%	**caregiver had issues of their own (e.g. failing health)**
11%	**personal care or hygiene issues (e.g. incontinence)**

What are the potential risks and benefits of moving into a care home?

The transition into a care home can be traumatic for a person with dementia. Health and psychological status can deteriorate significantly after admission, with a high mortality risk, significantly higher than for those admitted without dementia [26,27]. However, much of this may be explained by selection effects given the indications for admission with dementia, and the fact that this often occurs at times of crisis.

The important question of whether, over the longer term, the quality of life (QoL) of people with dementia is better preserved by remaining at home, or moving into a care home, is difficult to resolve. The theoretical benefits of transition into a care home have been nicely described: [28]

> **'Nursing home care enhances delivery of kin care; provides security for care recipient and peace of mind for caregiver; re-establishes elder's sense of competence and well-being; provides refuge from inadequate or unsatisfactory kin care. Families who provided care before formal services were used continue to do so in a more focused and efficient manner.'**

The question would be best tested through a randomised controlled trial but this is neither practical nor, probably, ethical. Cross-sectional comparison of the two groups is bedevilled by confounding since the reasons for transfer to a care home may well influence QoL. Missotten and colleagues, in their cross-sectional study of people with dementia, found that QoL was no better for those living at home, compared with those living in care homes [51]. For two other studies in which crude analysis suggests better QoL among those who continue to live in their own homes, these differences are explained by the greater dementia severity and needs for care of those living in care homes [29,30]. In one of these studies, QoL was actually higher for care homes residents compared to those living in their own homes among those with a high degree of care dependence, suggesting that the effect of care setting on QoL may vary with the stage of dementia [29]. In the other study, once dementia severity, neuropsychiatric symptoms, depression and functional dependence were controlled for, QoL was better in those living in care homes [30]. Studies that have used a longitudinal approach are too small in size to permit any clear conclusions regarding impact of place of residence upon QoL in dementia [31,32]. Remarkably little research seems to have been conducted into changes in QoL after moving into a care home, but in one such example, QoL of Japanese people with dementia (n=25) improved over the three months after moving into a group home, with the acquisition of roles within the group home possibly influencing the increase in QoL [33]. The tendency, noted in a large US study of QoL in nursing home residents, for QoL to be strongly positively associated with length of stay, is also

reassuring [34]. This suggests, at least that deterioration in QoL over time is unlikely, and that accommodation to changed circumstances, and settling into a new way of life could even be associated with subjective QoL improvement. We are not aware of any studies that have specifically assessed caregiver's QoL post-transition, although place of residence is likely to have an important impact on this outcome.

The place of care homes in the long-term care system

Care homes have an important part to play in the long-term care system, and should not necessarily be seen as an option of last resort, to be avoided wherever possible. There is a clear danger that the cost containment policy agenda in high income countries, asserting the universal preference for care at home, and the better quality of life and care in the home setting may unfairly stigmatize users and providers of care home services. More information on preferences is provided in 'Incorporate service users values and preferences into care' on page 54 and on the relative costs of home care and care in care homes in 'Systematic review of the literature on the contribution of residence in a care home to the costs of dementia' on page 74. Certainly, much can and still needs to be done to improve the quality of care and quality of life for people with dementia living in care homes. This issue is considered in detail in Chapter 5, page 42.

The relevance of care homes is not limited to high income countries. As we have seen, provision and use in low and middle income countries is currently very limited, but growing, particularly in urban settings in middle income countries. However, in many parts of the world, the alternatives to family care (if this is not available) are charitable or state provided homes for the indigent where care is highly institutionalised. In a study in Goa, India, a residential care home run by a religious order was found specifically to exclude people with dementia from admission, although several residents had developed dementia and continued to be cared for until the end of their lives [35]. In a survey of large public hostels in Rio de Janeiro older people were over-represented (14% of all residents), and most had become homeless for the first time late in their lives [36]. Disability was an important route into homelessness and these older people were much more likely to have been referred to the hostel directly from hospital. The high prevalence of cognitive impairment in this group suggested that incipient dementia in those lacking family support may have been a contributory factor for this subgroup of older people. In China long-term care needs for older people are mainly met by families, according to traditional values of filial piety and the PRC Elderly Rights and Protection Law of 1996. However, care homes, previously reserved for the 'three nos' (no children, no income, no relatives) are now less stigmatised, open to all, and proliferating rapidly in cities, particularly in the private sector [37].

Other important long-term care services in the continuum of dementia care

Respite care

Respite care is the temporary provision of care for a person with dementia at home or in a care home by people other than the primary informal caregiver. The rationale is to give the primary caregiver a break from their caregiving responsibilities (to rest, see friends and family, take holidays, catch up on other tasks),

Box 4.3

Palliative care

According to the WHO [48], palliative care:

- **provides relief from pain and other distressing symptoms;**
- **affirms life and regards dying as a normal process;**
- **intends to neither hasten nor postpone death;**
- **integrates the psychological and spiritual aspects of patient care;**
- **offers a support system to help patients live as actively as possible until death;**
- **offers a support system to help the family cope during the patient's illness and in their own bereavement;**
- **uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;**
- **will enhance quality of life, and may also positively influence the course of illness;**
- **is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes investigations needed to better understand and manage distressing clinical complications.**

and thereby reduce strain. Reduction in strain and 'recharging the batteries' may improve or preserve the relationship between the caregiver and the person with dementia, and could, in theory, allow the caregiver to continue to care for them at home for longer. Respite can also be used to re-evaluate the needs of a person with dementia, and provide rehabilitation.

Respite care can take place in the home of the person with dementia, a day care centre or a residential setting. It can be provided by trained or untrained staff or volunteers. Respite may last for anything from a few hours to weeks. Respite care may also be planned, or unplanned for example in response to a crisis in the home care arrangements.

The availability of accessible and flexible respite care is a common request from caregivers, suggesting that value is attached to these services. Nevertheless, uptake is not always that high among those offered the service [38]. It may be that caregivers are coping well, or that they make private arrangements with friends and family. When caregivers use respite services it tends to be in the advanced stages of the disease [39]. Reluctance may arise from a conflict between caregivers' desire for respite and the feeling that they would be neglecting or abandoning the person with dementia. Potential barriers include; worries about the impact of residence in a care home on the person with dementia [40]; the potential for disruption in routines of care and daily life [41]; and the negative emotions experienced by some caregivers when a respite care period ends [42].

The evidence base for the effectiveness of respite care is not particularly strong. A Cochrane review (initially published in 2004 and updated to 2009) found only three randomized controlled trials and these were either small and/or of poor methodological quality [43]. The largest of the three trials was also the most flawed [38]; it suggested a small delay in transition into care homes associated with receipt of respite, but this, in the opinion of the Cochrane reviewers was an unsafe conclusion. Other than this no benefits of respite were identified for caregiver strain, or other outcomes for the caregiver or the person with dementia. A subsequent larger systematic review of respite care for frail dependent older people (including trials involving people with dementia) also found no clear evidence of benefits for caregivers, and no evidence of delayed transition into care homes [44]. A review of mainly non-randomised controlled studies suggests possible small benefits in reducing symptoms of depression and strain among dementia caregivers, but again no effect on transition into care (RR 0.76, 95% CI 0.44 to 1.32) [45].

The main justification for including respite services as part of a comprehensive package of long-term care services is the uniformly high levels of caregiver satisfaction associated with their use, reported from many studies [44]. They may not suit all families, but may be very helpful for some.

End-of-life care

Dementia is an incurable and life-limiting illness, and death with dementia is increasingly common. The World Health Organization stated that 'every person with a progressive illness has a right to palliative care' [46] (Box 4.3). Palliative care (referred to as 'hospice care' in the USA) can be provided at home, in a care home setting, in hospital or in a specialist hospice unit. Historically, palliative care has been closely linked to cancer care rather than long-term care for people with dementia; most beds in European palliative care centres are taken by oncology patients. Only 9% of people with dementia at the end of life on acute medical wards were referred to palliative care specialists, compared to 25% of people without cognitive problems [47]. Dementia is not often thought of as a terminal illness that requires specialist care. The lack of specific dementia training for staff working in end-of-life facilities could play a role in this.

Providing good quality end-of-life care for people with dementia

A working group was set up in 2007 by Alzheimer Europe to better understand good practice, which resulted in a set of recommendations, focusing on people with dementia, caregivers, healthcare professionals, and policy makers. The full set of recommendations can be accessed at www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/End-of-Life-care-for-people-with-dementia

a) Attention to symptom burden

Symptom burden for people with dementia is a common problem towards end of life. The most experienced symptoms are pain, pressure sores, shortness of breath, eating and swallowing problems, infections, agitation and other psychological symptoms (Box 4.4). Some of the symptoms, in particular pain, are often under-detected in dementia patients [49]. This is likely to be the result of increasingly prevalent communication difficulties in advanced dementia, combined with lack of good assessment skills by some health professionals [49]. Under-detection can lead to under treatment of symptoms, and this has been reported as a concern in some studies [50]. On the other hand, over-treatment with burdensome interventions, such as tube-feeding and antibiotics, in the period leading to end of life is also to be avoided [50].

b) Legal considerations

People with dementia and their caregivers have the opportunity to create advance care plans for their wishes. Advance care plans are covered in more details in 'Promote autonomy and choice' on page 49 of this report.

c) Supporting caregivers and families

Families and caregivers should be given clear information about the illness course trajectories, about potential complications of dementia and what to expect from the latter stages of the illness. Support for

Box 4.4

Symptom burden at the end of life

Pain Depending on the setting, the stage of dementia, and the method of ascertainment, between 20% and 50% of people with dementia report some form on pain in the course of their illness progression [55], with higher proportions affected towards the end of life [50,56]. People with dementia are more likely to experience pain in the last 6 months of life, compared to cancer patients (75% vs 60%) [57].

Pressure sores several studies have recorded the prevalence of pressure ulcers towards the end of life, varying from 17% in a study of terminal dementia [58] to 47% in a study of older adults with advanced dementia living in seven Italian long-term institutions [59]. This is a key indicator of quality of care.

Shortness of breath a recent review of the literature identified that shortness of breath is a common symptom in about half to three-quarters of people with dementia [50], and increases closer to death [56].

Eating and swallowing problems Problems with swallowing are common in advanced dementia. However, the use of feeding tubes, while widespread, is controversial, and needs to be evaluated carefully with respect to patient and caregiver preferences, and the balance of risks and benefits for individual patients. A Cochrane systematic review suggests that tube feeding in dementia patients does not confer any benefit regarding nutritional status, reduction of pressure sores, mortality risk or survival time [60].

Infections Pneumonia and other infections are often the direct cause of death for people with dementia. Up to 71% of dementia deaths are directly linked to pneumonia [61], a condition which can cause much discomfort, but which can be alleviated through effective palliative care.

Agitation and other psychological symptoms It has been estimated that 90% of people with dementia will develop some form of behavioural and psychological symptoms of dementia (depression, anxiety, hallucinations, delusions, wandering, agitation, aggression), and that over half of people with dementia remain agitated, and distressed towards the end of life [49].

caregivers needs to be culturally sensitive and take into account ethnic differences in caregiving experiences, attitudes to end-of life-care and bereavement reactions [51]. It has been reported from the USA that while end-of-life care for patients with dementia was extremely demanding of family caregivers, they often showed considerable resilience in the face of bereavement; intervention and support services were needed most before the patient's death [52].

d) Professional staff training and development
Communication and shared decision-making are key factors in end of life care. Having trust in doctors and surrounding staff is an essential factor for patients and caregivers during palliative care [53]. However, many nurses and care home staff do not feel well prepared to deal with issues related to end-of-life and dying with dementia, and there is a need to improve training for nursing home and specialist palliative care staff to deal with advanced dementia, and to achieve best practice for people with dementia at the end of life [54]. Symptom management, focusing on pain and behavioural and psychological symptoms, and also ways of approaching and dealing with patients and their families, are two areas that have been highlighted as requiring improvement.

Summary and conclusion – future directions in long-term care

All of the various components of the long-term care system for people with dementia; informal family caregivers, formal home care, respite care, residential care, nursing home care, dementia specialist care units, and end-of-life care could and should form part of a seamless continuum of provision across the course of the illness, from the time of first help-seeking and diagnosis, to the death of the person with dementia, and beyond. However, there are many barriers to achieving this objective including:

1 The late stage at which a diagnosis of dementia is made, with consequent missed opportunities for effective intervention in the early stages of the illness, and advanced care planning [62]

2 The lack of continuity of care post-diagnosis, meaning that many families have to struggle to re-establish contact with services when problems begin to arise [63]

3 The lack of coordination and integration of services, particularly between health and social care providers, and the often bewildering range of agencies with whom people with dementia and caregivers must interact

4 The limited opportunities for people with dementia to express their preferences for how they would like to be supported and cared for

Table 4.2
Long-term care policy priorities among OECD governments

Rank	Priority	Proportion (%) of countries reporting this among the top five priorities
1	Ensuring fiscal and financial sustainability	85%
2	Encouraging home care arrangements	67%
3	Enhancing standards of quality of long-term care services	67%
4	Care coordination between health and long-term care	52%
5	Providing universal coverage against long-term care costs	31%
6	Encouraging informal care	28%
7	Providing coverage to people in need only	22%
8	Sharing financing burden across society (including older people)	21%
9	Individual responsibility for financing long-term care	21%
10	Encouraging formal care capacity and training	19%
11	Immigration for legal foreign born caregivers	6%

5 Insufficiently person-centred packages of care, meeting the individual and particular needs of people with dementia and their caregivers.

There are some signs that policymakers are mindful of these challenges, and responding in radical and innovative ways. For example the UK government's White Paper on long-term care 'Caring for our future: reforming care and support' [64] includes as key priorities, the needs to:

- focus on people's wellbeing and support them to stay independent for as long as possible
- introduce greater national consistency in access to care and support
- provide better information to help people make choices about their care
- give people more control over their care
- improve support for carers
- improve the quality of care and support
- improve integration of different services

The perception of European government policy developments over the last decade is that these have involved 'progressive shifts (i) away from institutionalized care and towards home care; (ii) away from public provisions and towards private or mixed services backed up by cash transfers; (iii) in favour of services that complement rather than replace informal care' [65]. The shift towards cash transfers (direct payments – see also 'Person-centred care in the community' on page 56) could provide greater diversity of choice, and place more control in the hands of people with dementia and their families in designing individual packages of care and support. For example, in the UK the Localism Act (2011) envisages a move from larger social care employers to smaller bespoke organizations, with the creation of a more flexible workforce, and the encouragement of local voluntary and community groups to take on provider roles. There would also be more potential for joint working between public, third and private sectors. The increased use of cash transfers – putting money directly in the hands of families to use to purchase care – has been described as the most promising innovation in terms of improving service integration, and breaking down the budgetary 'silo mentality' that limits flexibility and choice [66].

However, cost-containment is likely to be a fundamental driver of long-term care policy at least in high income countries. A survey of relevant ministries in 28 OECD countries identified 11 commonly reported national priorities for long-term care policy (see Table 4.2) [2]. Cost-containment was explicit in the top priority (ensuring fiscal and financial sustainability), and implicit in six others (encouraging home care arrangements; encouraging informal care; providing coverage to people in need only; individual responsibility for financing long-term care; and immigration of legal foreign-born caregivers). Delivering improvements in the quality, comprehensiveness and coverage of long-term care services in this context will be a significant challenge, to be considered in more detail in the following two chapters of this report.

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CHAPTER 5

Quality of care and how it can be improved



In 2009, the Department of Health in England enunciated a bold vision for the future of care services for people with dementia, in its National Dementia Strategy 'Living well with dementia' [1].

> **'Our vision is for the positive transformation of dementia services. It would be a system where all people with dementia have access to the care and support they need. It would be a system where the public and professionals alike are well informed; where the fear and stigma associated with dementia have been allayed; and where the false beliefs that dementia is a normal part of ageing and nothing can be done have been corrected. It would be a system where families affected by dementia know where to go for help, what services to expect, and where the quality of care is high and equal wherever they might live … The Department's goal is for people with dementia and their family carers to be helped to live well with dementia, no matter what the stage of their illness or where they are in the health and social care system … by the provision of good-quality care for all with dementia from diagnosis to the end of life, in the community, in hospitals and in care homes'.**

This agenda was subsequently formalised by the National Institute for Health and Care Excellence into a series of ten key quality standards for supporting people to live well with dementia) [2] (see Box 5.1).

Many, mainly high income countries are beginning to make significant progress towards the realisation of these goals. In other settings, awareness is much lower, and dementia is yet to be recognised as a leading priority for health and social care; available resources are few, and service development is in its infancy. In this section of the World Alzheimer Report, we consider the underlying principles and practical actions that may need to be considered by all nations as they seek to develop a comprehensive and high quality system of care and support. As with previous reports, we have focused on the evidence-base that exists to support specific interventions and practices. We have chosen to highlight four priority areas for action that the evidence suggests are of fundamental importance

1 Measure and monitor the quality of care

2 Promote autonomy and choice, with four sub-sections:
   a Plan ahead (advance care planning)
   b Make information available to consumers (knowledge is power)
   c Incorporate service users' values and preferences into care
   d Make care person-centred

Box 5.1

National Institute for Health and Care Excellence quality standard

Ten quality statements for supporting people to live well with dementia (QS 30)[2]

1 **Discussing concerns about possible dementia**
People worried about possible dementia in themselves or someone they know can discuss their concerns, and the options of seeking a diagnosis, with someone with knowledge and expertise.

2 **Choice and control in decisions**
People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.

3 **Reviewing needs and preferences**
People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change.

4 **Leisure activities of interest and choice**
People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.

5 **Maintaining and developing relationships**
People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.

6 **Physical and mental health and wellbeing**
People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

7 **Design and adaptation of housing**
People with dementia live in housing that meets their specific needs.

8 **Planning and evaluating services**
People with dementia have the opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.

9 **Independent advocacy**
People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.

10 **Involvement and contribution to the community**
People with dementia are enabled, with the involvement of their carers, to maintain and develop their involvement in and contribution to the community.

3 Coordinate and integrate care for people with dementia

4 Value and develop the dementia care workforce

The evidence presented in this section comes mainly from services already in place in high income countries. For those mainly low and middle income countries that, as yet, have very limited formal care sectors, models of service development need not replicate those used in the past. However, we should learn from the experiences of those countries in the vanguard of the global epidemic dementia.

Measure and monitor the quality of care

Care quality is an elusive concept, and difficult to measure both directly and comprehensively. Methodologies originate from health service and system research[3]. The first issue to note is that the context, perspective or purpose for which care quality is being measured is a crucial determinant of the measurement strategy. The commonest rationales for attempting to measure quality of care are to:

1 Inform policy making or strategy at a regional or national level

2 Improve the quality of care within a system or at a facility

3 Monitor the performance of a service funder or provider

4 Identify poor performers to protect public safety

5 Provide consumer information to facilitate choice

Each of these is potentially relevant to the assessment of dementia care quality.

The structures/processes/outcomes framework has been influential in health services evaluation [3]. **Structures** refer to the resources available for delivering a service, and also to how these are deployed and managed. **Processes** refer to the delivery of care. **Outcomes** are the results, positive or negative of the care process. In essence:

Structure + Process = Outcome

Structures, processes and outcomes can all be used as indicators of care quality. The main advantage of outcome-based measures is that they tend to be intrinsically important. Improved quality of life, and client or caregiver satisfaction with services are desirable in their own right, regardless of how they may have come about. Outcome indicators also capture the impact of all of the care processes, including those that are difficult to measure (for example, is the care 'person-centred'?), or those that were not measured since their impact was not anticipated. However, results of outcome evaluations can be difficult to interpret, since aside from the quality of care, outcomes may be affected by differences in the type of client (the case mix), differences in measurement approach, or chance. Hence an outcome indicator such as functional status, or agitated behaviour may be much worse in specialist dementia care units than in other nursing homes, simply because such facilities typically care for clients with more advanced dementia. The main advantage of process indicators is that they are a more direct indicator of care quality, and are often quite easily ascertained, sometimes through routinely collected data. However, a process indicator, for example care workers spending more time engaging in structured activities with residents, is

Table 5.1
Care quality indicators
Summarised from the Care Quality Commission National Minimum Standards applying to Care Homes in England

Structure indicators	Process indicators
Staff training	Safe dispensing of medication
Adequate staffing levels	Adequate diet
Staff development activities	Informed consent sought for investigation and procedures
Management	Personal needs assessment carried out
Safety of equipment	Opportunities afforded to live as independently as possible
Cleanliness and hygiene in the home	Accurate personal and medical records, kept safely and confidentially
	Complaints dealt with appropriately

Table 5.2
Care quality indicators for the Centres for Medicare and Medicaid Services minimum data set
Nursing Home Quality Initiative

Process indicators (%)	Outcome indicators (%)
Residents assessed and appropriately given the seasonal influenza vaccine	Residents experiencing one or more falls with major injury
Residents assessed and appropriately given the pneumococcal vaccine	Residents who self-report moderate to severe pain
Residents who have/had a catheter inserted and left in their bladder	High-risk residents with pressure ulcers
Residents who were physically restrained	Residents with a urinary tract infection
Residents who received an antipsychotic medication	Low-risk residents who lose control of their bowels or bladder
	Residents whose need for help with activities of daily living has increased
	Residents who have depressive symptoms
	Residents who lose too much weight

only relevant to the extent to which it leads to desired outcomes. Process indicators should therefore be selected carefully to represent evidence-based care interventions or approaches, previously shown to confer policy-relevant and cost-effective client benefit. Then the main issue of concern would be the coverage and uptake of the care process, since the outcome, if implemented, could be taken as read.

Care quality assessments in practice

For the evaluation of the quality of care services for people with dementia, the focus has been mainly upon the structures and processes of care. This is particularly the case for regulators, one of whose main functions is to ensure safety and prevent harm and abuse, by enforcing compliance with standards. The indicators employed by the Care Quality Commission in England to assess the quality of care in care homes are a good example of this approach (Table 5.1) [4]. These reflect minimum standards, and in terms of quality, detect deficiencies, but not excellence.

In the USA, the Centres for Medicare and Medicaid Services (cms.gov) have developed a minimum data set of indicators of quality of care for residents of care homes [5]. This is part of a wider Nursing Home Quality Initiative, addressed mainly at the needs of consumers; facilitating choice of a nursing home (see 'Make information available to consumers (knowledge is power)' on page 52 for more details); providing information about the care at a nursing home where people already live and receive care; and facilitating discussions with staff regarding the quality of care. An additional aim is to 'give data to the nursing home to help them in their quality improvement efforts'. The quality indicators supplement information collected during regulatory inspections, which are more similar to the CQC approach. The CMS care quality indicators comprise a mix of five process and eight outcome indicators. When contrasted with the Care Quality Commission national standards for England, these are more outcome orientated, and much better operationalised, and hence more likely to be measurable in a valid and reliable way, facilitating comparisons between facilities. They are, however, focused upon biomedical care processes, and measure outcomes mainly at the level of impairments affecting particular body parts or systems rather than the whole person in a more holistic way. Taken together, it would be reasonable to suppose that they would be fairly effective in distinguishing between good and bad care, since the outcomes probably reflect systemic strengths and weaknesses in the care system.

Limitations of current approaches

There is a clear danger, particularly for care for people with dementia, that commonly used process and outcome indicators may fail to capture the very essence of good quality care. The Alzheimer's Society in the UK, for example, considers that there are three areas intimately connected with quality of life in care; environment, activities and relationships [6], and refers to the English Community Care Association's Dementia Pledge (www.dementiapledge.co.uk) to provide care according to four abiding principles

1 Know the person who is living with dementia

2 Quality of life, not quality of care

3 Everybody has a leadership role

4 Value focused care.

The translation of such aspirations into measurable indicators is a challenge. However, it is clear that there is:

a) a move away from indicators of structure and process, and towards simple, valid and informative outcome measures

b) a desire for a focus upon more global, holistic outcomes

c) a growing interest in service satisfaction measures, and in the assessment of quality of life as an overarching indicator and 'final common pathway' for quality of care.

Future directions

Some progress is being made towards the systematic assessment of satisfaction with services. For example, in the UK, the Alzheimer's Society recently conducted a pioneering survey of family members of people with dementia receiving care in care homes (DEMFAM), care home workers (DEMSTAF) and people with dementia [6]. Family members were contacted through the society's magazine, and online with 1,139 respondents. Care home staff were contacted through direct mailing to 300 care homes as well as targeted approaches, with 647 responses. Only 34 responses were obtained from people with dementia living in care homes. Satisfaction ratings were generally high among family members; 74% of DEMFAM participants said they would recommend the care home to others, and 68% said that they thought that the quality of care was good. However, only 41% thought that the quality of life of the person with dementia was good, and 28% said it was poor. Only 44% of family respondents felt that opportunities for activities in care homes were good. Staff views were similarly negative, with only 26% holding the view that people with dementia experienced a good quality of life (however, 61% said 'yes, to some extent'). People with dementia were much more positive; 25 of the 34 were happy and six happy sometimes. Only two said they were not happy. Thirty (88%) said they could 'be themselves' in the home. However, wider public opinion, assessed in a YouGov opinion poll commissioned by the Alzheimer's Society was much more negative; only 30% of respondents thought that people with dementia in care homes were generally treated well, and 64% expressed concerns that not enough was done to prevent abuse.

The main limitations of the Alzheimer's Society surveys were the non-representativeness of the family and staff samples, and the very limited information from care home residents.

In an initiative driven by the UK care home sector, Ipsos MORI were commissioned in 2012 by 'Your Care Rating' (an independent not for profit organisation established for the purpose) to design and conduct an independent, confidential and standardised annual survey of residents living in UK care homes to give them the opportunity to provide their views and feedback regarding the care they received [7]. The funding for the survey is provided by the care providers, 13 of whom joined the scheme in the first year, entering all of their care homes into the survey – covering more than 45,000 residents in over 850 homes. There were nearly 14,000 responses.

The questionnaire contains three key sections; Living here (which asks about aspects of life and services in the care home); Staff (focusing on care and support in the care home); and Overall views (asking residents to rate their care home at an overall level). Responses were grouped into four underlying themes:

1 Staff and Care (e.g. 'Staff understand me as an individual', 'I am happy with the care and support I receive') – accounting for 17% of the variance in overall satisfaction

2 Facilities and Home (e.g. 'The food served at mealtimes is of good quality', 'The home is clean and tidy') – accounting for 9% of the variance in overall satisfaction

3 Choice and Control (e.g. 'I have a real say in how staff provide care and support me', 'I can choose what time I get up and go to bed') – accounting for 8% of the variance in overall satisfaction

4 Security and Procedures (e.g. 'This home is a safe and secure place to live', 'I can take part in activities/ hobbies if I want to') – accounting for 7% of the variance in overall satisfaction

These are being used to develop an Overall Performance Rating for each care home, with four sub-ratings for these key themes, which have been identified as driving overall resident satisfaction.

The Overall Performance Rating (OPR) score varies between 0 (worst possible) and 100 (best possible). The average OPR across all respondents was 87.5, the lowest scoring care provider scoring an average of 82.5 and the highest 91.3. However, for individual care homes the variation in OPRs was much greater, from a low of 54.2 to a high of 100. Supporting the high OPR scores, the responses to the single question regarding overall satisfaction with the care received indicated that 62% were 'very satisfied', and 96% were satisfied or very satisfied, with only 2% expressing dissatisfaction. The questionnaire also used the 'Friends and Family' test, which has now been rolled out across the British National Health Service as a key indicator of care quality. For the care home survey the question was 'If somebody you knew needed similar care to you, how likely would you be to recommend this care home?'. Responses were rated from 0 'not at all likely' to 10 'extremely likely'. Those rating 9 or 10 were considered 'promoters' (59% of respondents), those scoring 7 or 8 'passives' (45%) and those scoring 0 to 6 'detractors' (14%). The 'Net Promoter Score' (NPS) is derived by subtracting the % of detractors from the % of promoters, giving in this case an NPS score of +45. NPS scores varied widely by provider from +67 to +28. Likelihood of recommending the home to others was most strongly associated with residents' perceptions that they had a real say in how staff provide care and support, and that staff had time to talk to them. The work carried out by Ipsos MORI across a range of other sectors and service indicates that an NPS score of +45 or greater is positive. Scores for Local Authorities (-56), Fire Services (+14) and Police (-21) show the care home ratings in a generally favourable light. Residents were also asked if they agreed or disagreed that, overall, they are happy living in their care home. 92% agreed that this was the case, with 55% agreeing strongly. The highest average % by provider was 95%, and the lowest 88%.

The main strengths of the Your Care Rating exercise are that the opinion of residents has been sought directly, using a robustly developed and validated psychometric assessment tool. This includes satisfaction ratings, and happiness (an aspect of quality of life – see next section). While ratings generally were very positive, there was some variation between providers, and much variation between individual care homes, suggesting that this information could be valuable to consumers in selecting the best homes, and to providers in identifying problems and driving up standards. The weaknesses in the approach were the relatively low response rate, and the lack of knowledge (given that questionnaires were mailed directly to residents) as to whether the questionnaires were independently self-completed, or with assistance from staff or family. The likely high prevalence of dementia and cognitive impairment among residents will have been a complicating factor, and those with more advanced dementia will have been over-represented among non-responders.

Taken together, these two surveys do provide some reassurance regarding the quality of care in the UK residential and nursing home sectors, where 80% or more of residents have dementia or significant cognitive difficulties. However, the Alzheimer's Society highlights a problem of low expectations among family members and staff, who are perhaps too ready to to be satisfied with quality of care, when not enough is being done to maintain quality of life [6]. There also seems to be a disjunct between public opinion, that dreads ever having to live in a care home, and considers quality of care to be poor, and the much more positive reality revealed by the Alzheimer's Society and Your

Care Rating surveys. The surveys indicate that it is feasible to obtain standardised information regarding satisfaction with care quality, and the measurement approach of the Your Care Rating survey is particularly attractive. However, a significant challenge will be rolling surveys out to cover the whole care home sector. Providers participating in the Your Care Rating survey were self-selected, and therefore the findings cannot be taken as representative of the UK care home sector in its entirety. Care quality standards may have been much worse among non-participating providers. In the UK, while the ten largest providers operate a quarter of care home beds, two-fifths are controlled by small providers with one or two homes only. Only a uniform national system would serve the twin purposes of ensuring consumer protection and informed choice ('Controversies regarding the relative costs and benefits of ratings' on page 52).

Box 5.2

The DEMQOL quality of life scale

(Version 4)

First I'm going to ask about your feelings. In the last week, have you felt …

1. Cheerful?	2. Worried or anxious?	3. That you are enjoying life?
4. Frustrated?	5. Confident?	6. Full of energy?
7. Sad?	8. Lonely?	9. Distressed?
10. Lively?	11. Irritable?	12. Fed-up?

13. That there are things that you wanted to do but couldn't?

Next, I'm going to ask you about your memory. In the last week, how worried have you been about …

14. Forgetting things that happened recently?
15. Forgetting who people are?
16. Forgetting what day it is?
17. Your thoughts being muddled?
18. Difficulty making decisions?
19. Poor concentration?

Now, I'm going to ask you about your everyday life. In the last week, how worried have you been about …

20. Not having enough company?
21. How you get on with people close to you?
22. Getting the affection that you want?
23. People not listening to you?
24. Making yourself understood?
25. Getting help when you need it?
26. Getting to the toilet in time?
27. How you feel in yourself?
28. Your health overall?

We've already talked about lots of things: your feelings, memory and everyday life.
Thinking about all of these things in the last week, how would you rate …

29. Your quality of life overall? very good / good / fair / poor

www.bsms.ac.uk/research/our-researchers/sube-banerjee/demqol/

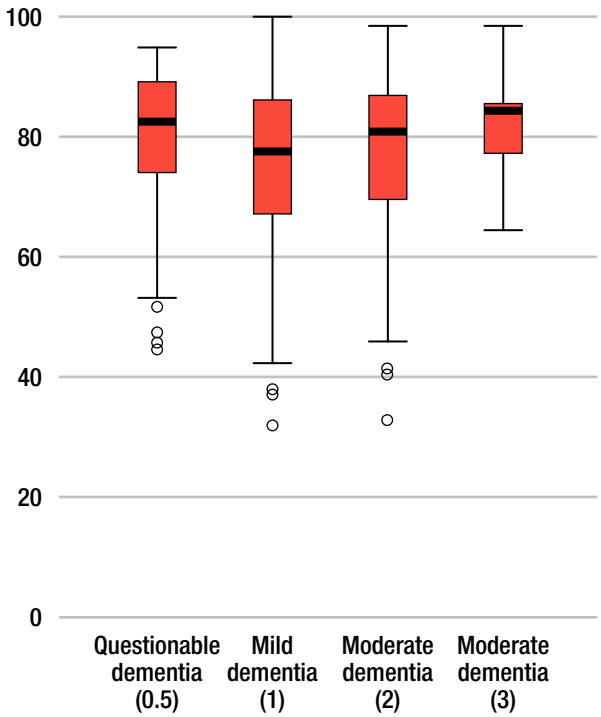
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Quality of life as a potential indicator of quality of care

Quality of life (encompassing different domains; emotional; physical; social and environmental; of a person's wellbeing) is considered nowadays to be a crucial outcome measure for health service research. This reflects concerns that clinically orientated assessments are insufficiently patient-centred and holistic, and hence fail to capture all of the important ways in which health conditions impact on the person, and by which different approaches to treatment and care can bring about meaningful change. For dementia, measures of overall clinical severity, cognition, functional ability and disturbed behaviour have traditionally been used to monitor the disease course and to evaluate the effectiveness of interventions. The limitations of this approach have been recognised for some time [8]. Arguably, the maintenance and promotion of quality of life should be the primary and overarching objective in providing care for people with dementia.

Much theoretical and formative research has been conducted to better understand how people with dementia perceive their quality of life, the important domains of life quality, and the factors that influence it. Tom Kitwood's early work on the concepts of personhood and wellbeing has been very influential [9]. Kitwood proposed four global states of wellbeing relevant to the quality of life of humankind: personal worth, agency, social confidence and hope; which were particularly apt to be compromised through the adverse physical and social environment experienced by people living with dementia. He subsequently proposed Person-Centred Care as an approach to restructure the delivery of care holistically around the individuality of the person with dementia, rather than the impairments that afflict them. This is guided by Dementia Care Mapping, an observational assessment tool to advance and evaluate the implementation of person-centred care in care settings (see ''Dementia care mapping' on page 57). Parse [10] described four dimensions of quality of life based on a series of detailed interviews with people with dementia: calm vs. turbulence; freedom vs. restriction; certainty vs. uncertainty; togetherness vs. aloneness. Brod and colleagues [11] conducted focus groups with people in the early stages of dementia, co-resident caregivers of people with dementia, and service providers. Their conceptual framework included aesthetics (enjoying beauty, nature and surroundings); positive affect (humour, feeling happy, content and hopeful); absence of negative affect (worry, frustration, depression, anxiety, sadness, loneliness, fear, irritability, embarrassment and anger); self-esteem (feeling accomplished, confident, able to make decisions); and feelings of belonging (feeling loveable, liked and useful).

Figure 5.1
Clinical dementia rating score
Self-reported quality of life in dementia according to disease stage. 10/66 DRG follow-up survey in Latin America, China and India. DEMQOL assessments from 450 people living with dementia.



Note: The box plots represent the median score (black line), the 25th and 75th centile scores (margins of the red boxes) and extreme outliers (the circles beyond the whiskers)

Several scales have been developed to assess quality of life (QoL) in dementia [12]. Research suggests that the subjective perceptions and experiences of those with mild to moderate dementia can be assessed, validly and reliably, by asking a person with dementia directly. The DEMQOL is one example of such a scale (see Box 5.2), its items reflecting those areas that British people with dementia considered important to their QoL. For those with more advanced dementia, there are also proxy scales for the assessment of QoL in dementia, whereby a family or professional caregiver who knows the person with dementia well, gives their impression of the cared for person's QoL [13].

The self-reported QoL of people with dementia does not seem to change with the passage of time, or clinical progression of dementia [14]. This is, in many ways, a remarkable finding, since clinical outcomes (cognition, functional ability and neuropsychiatric symptoms) tend to show progressive deterioration. Interestingly, caregiver assessments of the quality of life of the person with dementia do seem to show progressive deterioration, associated with cognitive and functional decline, suggesting that their ratings may be more influenced by perceptions of clinical decline [14]. Maintenance of self-reported QoL is an encouraging sign that it is perfectly possible to 'live well with dementia'. In the follow-up phase of the 10/66

DRG survey in sites in Latin America, China and India, 450 people with dementia successfully completed the DEMQOL questionnaire. There was no relationship between dementia stage (Clinical Dementia Severity Rating – CDR) and QoL (Figure 5.1). However, there was considerable variation in QoL at each stage of dementia severity. The challenge then, in supporting 'living well with dementia' is to drive up QoL for all those with the condition, to the best that can be achieved.

Determinants of quality of life in dementia

Currently, very little is understood about the factors that influence self-reported QoL in dementia. It is not associated with sociodemographic or clinical factors [15]. The only reliable association from studies conducted in the community [14] and in care homes [16] is for an effect of mood; more depression symptoms are linked to a lower QoL. In residential care there is some evidence that pain, falls, and the use of physical restraints may be associated with worse QoL [17].

Quality of life as an outcome assessment in care homes

More attention has been given recently to the understanding of how the characteristics of care homes may influence the QoL of individual residents. Pioneering work from a survey of 2,000 residents of 40 nursing homes in five states in the USA demonstrated that a significant component of the variance in resident QoL was between facilities rather than among residents within facilities, suggesting an important impact of the care environment or culture at facility level [18]. QoL was assessed according to resident's sense of comfort, autonomy, privacy, dignity, meaningful activity, relationships, food enjoyment, security, functional competence, and spiritual well-being. Drilling down, it seemed that homes with more private rooms had better average scores on the comfort and privacy QoL domains, while private nonprofit homes had better dignity, security, and spiritual well-being scores than private for profit or public homes. For residents with cognitive impairment, homes could mostly be distinguished in terms of their residents' perceptions of QoL relating to functional competence, dignity, meaningful activity, and security. The impact of individual and care facility characteristics on resident QoL was also studied in the 2007 Minnesota Nursing Home Resident Quality of Life and Consumer Satisfaction Survey, with 13,983 residents interviewed in 390 Medicaid certificated nursing homes [19]. The average number of hours of Certified Nursing Assistant and activity personnel staff time per resident per day had a strong positive relationship with resident QoL. This is consistent with evidence from another study that social engagement at the individual resident level and the ratio of activity staff to resident at the facility level are positively associated with resident QoL [20]. The authors pointed out that Nursing Assistants provide the majority of hands-on resident care in nursing homes, including tasks that are deeply personal and strongly connected to individual dignity such as bathing, toileting, dressing, and feeding. They concluded that the significant association between nursing assistant staffing levels and QoL suggests that greater availability of these staff for needs ranging from personal care to conversation also increases residents' feelings of well-being. Having controlled for cognitive impairment, residents of dementia specialist care units also had enhanced QoL. Such units address individualized resident needs, specifically residents with cognitive or behavioural difficulties. Features that might increase resident QoL include specialized staff training, reduction in environmental stressors, frequent use of private rooms, smaller unit sizes, the increased availability of natural light, and flexible resident routines [21]. Residence in such units had previously been shown to be associated with a reduced use of tube feeding, a reduction or abolition of the use of restraints, and lower rates of hospitalization [21-23].

Promote autonomy and choice

It is widely accepted that people with dementia and their caregivers should have more choice and control over decisions regarding the care and support that they receive throughout the course of their illness, including care arrangements, place of residence, and what happens at the end of their lives. The National Institute for Health and Clinical Excellence has highlighted this issue in its recently released report on quality standards to support people to live well with dementia (see Box 5.1).

The application of this broad principle has important implications:

1 The ability (capacity) of the person with dementia to participate actively in important decisions tends to deteriorate as the condition advances, because of worsening cognitive impairment affecting their ability to understand and retain information, reason and make judgments, and communicate decisions clearly. Therefore it may be important for them to consider possible future scenarios, and record their wishes and preferences at an early stage in the dementia process, while they still retain 'decision-making capacity'. They may also wish to appoint a proxy to make decisions for them when capacity is lost. These issues are considered under the heading of 'Advance Care Planning'.

2 The effective exercise of consumer choice depends upon ready access to information about the availability of services, their particular characteristics, and their quality

3 People differ in their values and preferences, and this in turn influences choices made regarding how care is to be planned and delivered. Better understanding of the distribution of these preferences at service or system level could inform

planning and allocation of services that is more responsive to needs. People with dementia and their caregivers should also be actively consulted and involved in the planning, development and evaluation of services.

4 Values and preferences can be used to construct more person-centred packages of care and support, tailored to meet personal circumstances.

Plan ahead (advance care planning)

Advance care planning (ACP) features in end-of-life care policies of many countries and it is a key feature of guidelines produced by UK bodies such as NICE (National Institute for Clinical Excellence) [2], SCIE (Social Care Institute for Excellence) [24], the Royal College of Physicians [25] and the NHS National End of Life Care Programme [26]. The key features of ACP are presented in Box 5.3.

Advance care planning – more than just end-of-life care

ACP has its origins in decision-making for end-of-life care ('End-of-life care' on page 37). In that context studies have suggested that those dying with advanced dementia are less likely to be seen as having a terminal condition, and much less likely to be managed palliatively; thus US nursing home residents with dementia were eight times less likely than those with cancer to have do-not-resuscitate orders and three times less likely to have do-not-hospitalize orders, and were much more likely to experience burdensome interventions such as tube feeding, laboratory tests and restraints [29]. Older people have expressed understandable concerns about the link between ACP and end-of-life care; worries and difficulties related to thinking about and discussing death and dying; the perceived link between advance care statements and euthanasia, and the possibility that anticipated preferences might not reflect a readiness to 'disengage' from their lives when the time came [30]. However, ACP has a much

Box 5.3

What is Advance Care Planning (ACP)?

Advanced care planning is 'a process to make clear a person's wishes and that will usually take place in anticipation of future deterioration of an individual's condition, with loss of capacity, to make decisions and/or ability to communicate wishes to others' [26].

When was it first introduced?

Forms of ACP first appeared in the 1960s in the United States, but it was not until the 1990 that they became more widespread, after the introduction of the Patient Self Determination Act, stipulating that patients should be told by Medicaid and Medicare providers that they have the right to make an advance directive at time of admission [27].

What form does it take?

ACP can take different forms and lead to different outcomes, and there is often no formal way of recording advance care plans. Discussions can result in a statement of preferences or wishes, the appointment of a Lasting Power of Attorney (LPA), or an Advance Decision to Refuse Treatment (ADRT) in specific future circumstances [25].

What is a statement of preferences or wishes?

An oral or written statement to communicate to others preferences or wishes related to future care or personal preferences (e.g. preferred place of residence, type of care). Preferences cannot be made for acts such as assisted suicide that may be illegal.

What is a Lasting Power of Attorney?

The nomination in a prescribed form of a person responsible for taking decisions on the behalf of a individual with dementia on economic, health or personal matters, in case of loss of capacity. The definition and procedures for assessment of loss of capacity vary between countries. Any decisions taken by the appointed person have to be made in the patient's best interests [26].

What is an Advance Decision to Refuse Treatment?

The decision to refuse treatment should loss of capacity ensue. This decision should be made under the supervision of someone who understand the intricacies of the process, and by someone who has mental capacity at the time of the decision [28].

broader application for people with dementia for whom many important decisions may need to be made after decision-making capacity has been lost, but some time before death. The problem here may be that frail dependent older people may be reluctant to engage with what they see as hypothetical questions regarding possible scenarios arising in the context of chronic disease care many of which are depressing to contemplate [31]. They are, somewhat paradoxically, more willing to confront the more concrete realities of treatment decisions in end-of-life care and dispositions to be made after death.

How widespread is advanced care planning?

A population survey from Ireland suggests that conversations with family members regarding long-term care preferences were, in general, unlikely to have occurred (only 24% of all those aged 65 and over), although this was more likely for better educated respondents, those who were older, and those who already had moderate to severe difficulties with functional independence [32].

However, the use of ACP among people with dementia is on the increase in many countries. In a recent study of just over 1000 people with dementia in Belgium, 52% had made some form of advance care planning (just 6% initiated by the individual concerned, most having been prompted by a clinician, and only 9% had a legal representative) [33]. In a survey conducted in 2005 in the USA, 65% of older people attending a memory service with cognitive impairment or dementia had a durable power of attorney and 56% a living will [34]. These proportions represent a sizeable increase from a US study of nursing home residents in 1996, in which it was reported that only 21% had a living will, 40% a 'do-not resuscitate order' and only 6% a treatment restriction relating to medication, feeding or other interventions [12]. These surveys were conducted in countries that have policies in place to encourage ACP, underpinned by legislation. Internationally, there is little available evidence on its use, but this is likely to be highly variable, and much lower in those countries where awareness of dementia is limited, where ACP is not discussed, and where advanced directives may not carry legal force. For example, in a recent study conducted in Spain among people with dementia and other chronic conditions that impact on life expectancy (e.g. Parkinson's disease, heart failure, cancer) only 16% of participants had made some advance care planning [35]. In dementia care as for other clinical contexts, the use of ACP is much more common among those with better education, and in the USA among white compared with black Americans [34]. A letter on the topic from Taiwan has highlighted that the acceptability of ACP to the individual making the ACP and their families may be culturally variable [36].

How effective is advance care planning?

The effectiveness of advance care planning for people with dementia living in nursing homes has been recently summarised in a systematic review [37]. In two studies, use of ACP was associated with a reduction of unnecessary hospital admissions [38,39], and in one study there was a significant increase in hospice use in the group with ACP in place [40]. A recent study showed that advance care planning resulted in having end-of-life wishes more likely to be followed, and in particular that ACP was associated with an improvement in caregivers' stress, anxiety and depression [41]. A small qualitative study also suggested that making ACP was associated with a decline in worry about the future for people with early dementia and their caregivers [42]. Studies assessing how ACP can improve outcomes in people with dementia are still few, compared to other clinical populations with life-limiting conditions where the effectiveness of these directives has been studied in more detail [43-45]. For example, Silveira and colleagues identified that having an ACP in place resulted in receiving care that was associated with the stated preference, and with a reduction of deaths in hospital [43]. In a study of advanced cancer patients, ACP was associated with receiving less aggressive health care and also with improved quality of life towards end of life [45], which also translated into a reduction of medical costs in the last week of life [44]. More studies are currently being carried out, designed specifically to explore the potential impact of ACP among people with dementia, including randomised controlled trials [46].

Issues in implementing advance care planning

People with dementia, and their caregivers may have different views regarding who should be making decisions about care, as one study identified [47]. Those with mild cognitive impairment (MCI) or mild dementia were asked to rank who should have the greatest say in medical and social care decisions, including stopping driving and relocation to a care home. For medical care decisions, patients wished to be guided by their physicians. For social care decisions they wanted physicians to have very little influence. For decisions in general they wished their relatives and caregivers to have little influence, compared to their own wish to participate in the process. The converse was true for relatives. Objective tests of decision making capacity revealed significant problems even among these patients with MCI and mild dementia, but those with more impaired decision-making capacity generally had a less pronounced desire to participate in decision-making. Although very little research of this kind has been conducted, the findings of this small study support the use of advanced care planning in early dementia to promote patient autonomy. There is also reassurance with respect to proxy decision making in end-of-life care, from another study of people with MCI and mild dementia, in which spouse preferences

for the patient correlated moderately well with patient preferences [48]; the finding from previous research in other contexts that proxies tend to be guided by what they would have wanted for themselves rather than acting in the patients best interests, was not confirmed.

Practical issues related to Advance Care Planning were raised in a qualitative study conducted in the UK, using focus groups and individual interviews with professional staff that had contact with clients living with dementia, and their families [49]. These are summarised in Box 5.4. Better standardisation for ACP may be needed if guidelines on this subject are to be implemented.

Box 5.4

Some issues in implementing advance care planning in dementia

- **When should ACP be discussed with clients with mild cognitive impairment (MCI) or dementia? Timing is extremely important as there is a point when cognition drastically decreases and advance care plans can no longer be made [50].**
- **Which professionals should start conversations about ACP?**
- **What happens when preferences change through the course of illness, and which professionals should review these?**
- **What happens when wishes and preferences differ between people with dementia and their caregivers?**
- **ACP may offer 'false promises', as it is not always possible to follow someone's advance wishes [49].**
- **Legal frameworks for ACP vary across different countries, and some staff may be afraid to follow ACP [49].**
- **There is not a single professional group that consider capacity assessment as their responsibility [49].**

Make information available to consumers (knowledge is power)

The US experience

In 2001, Robert and Rosalie Kane [51] noting that the US government spent $242 million annually on regulating (surveying and certificating) care homes argued that

> **'The resources devoted to regulation could instead be allocated to a more market-based approach that emphasizes information. Such an approach would require collecting enough standardized data to provide consumers with better information on which to base better-informed LTC decisions. Data on various types of care could be arrayed to show measures of quality (of care and of life), the nature of the services provided, staffing stability, and consumer satisfaction. The information could be disseminated through Web sites, but it could also be packaged to make it readily accessible to case managers.'**

The goal that they aspired to has been more or less achieved. Nursing Home Compare (www.medicare.gov/nursinghomecompare/search.html), run by the US government regulating authority, provides detailed information on every Medicare and Medicaid certified nursing home in the country. Descriptions and ratings can be found by searching for particular nursing homes, and all nursing homes in and around a particular location can be identified and compared. The site uses the information generated from certification inspections, and the minimum data set of outcome indicators (see Table 5.2). The performance of the nursing home can be compared against norms for the state and the US nationally, and each home is given an overall quality rating from one to five stars. The site includes a helpful guide to choosing a nursing home, and a checklist of desirable characteristics. This tool (also available as a smartphone app) undoubtedly acts as a powerful tool for informed consumer choice. However, the money spent on regulation has not been re-directed into providing light touch outcome indicators as the Kanes had envisaged. Rather regulation persists, or has even been intensified, and the data generated from this process has been made available to the public. The costs of regulation in the US system have been recently estimated at 1.5% of total nursing home care costs [52]. In most jurisdictions, these costs are passed on to the providers, and ultimately to the purchasers, whether this be individual consumers, or the state in subsidized systems.

Controversies regarding the relative costs and benefits of ratings

Regulation, or rather the extent of regulation is controversial, with some care sector providers arguing that it is excessive, and its benefits not fully demonstrated. Arguably in a perfectly performing free market, regulation would not be necessary.

However, choice, even when information is freely available, is restricted. Placement in a nursing home too often occurs in the context of a crisis, and high bed occupancy rates mean that choice may be limited. Choice is also constrained by finding a match for the individual's needs for care, and within a certain budget determined by personal finances plus or minus any government subsidy. As such, regulation to maintain minimum standards remains necessary, and the question rather is the cost-effectiveness of the regulation and mandated data collection procedures. This requires an understanding of the benefits as well as the costs of regulation and ratings, and this research remains to be conducted [52]. While there is some evidence that the introduction of Nursing Home Compare ratings has led to critical improvements in sub-standard providers, there was also evidence of distortion with providers tending to 'play the system' by focusing on improving the limited set of clinical care indicators, with little attention to overall care quality and quality of life [52].

In England, the Nuffield Trust was recently commissioned by the Secretary of State for Health to explore the potential for a national care quality ratings system [53]. Their recommendation is that any new system would need to be:

- Simple, for ease of communication, but capable of assessing complexity
- Based on assessment of safety, effectiveness, and user experience
- Linked to effective surveillance to pick up problems quickly and provide public assurance
- Updated regularly, with data made available to the public in a timely way
- Supplementing information from inspections with routine process and outcome data indicating quality of care
- Transparent with respect to the selection of care quality indicators, and their assessment; involving all relevant stakeholders, and service users in their development
- Minimal with respect to the additional burden imposed, which would need to be clearly quantified, and cost-benefit analyses instituted from the outset
- Adequately resourced with respect to the organisation (probably the care Quality Commission) that would be responsible for overseeing it.

As such, some important lessons would seem to have been learnt from the North American experience, but it remains to be seen whether the report recommendations are accepted and fully implemented.

How do families seek and use information to choose services?

Helpful research conducted by the Alzheimer's Society in the UK has cast some light on family caregivers' use of information in locating a suitable care home for a relative with dementia [6]. One quarter of the caregivers interviewed reported that they had found it difficult to find a suitable home. Most caregivers (45%) stressed the importance of a visit to the home and meeting with and talking to staff, and the care home providers were the leading source of information influencing choice of home (for 59% of caregivers). Social worker case managers were also an important source of information (40%). Regulators (23%) and the Alzheimer's Society (21%) were less frequently consulted, although the Alzheimer's Society has published a guide 'your handy guide to selecting a care home', and the Social Care Institute for Excellence (SCIE) has a website 'Find me good care' www.findmegoodcare.co.uk which includes provider information and results of the most recent regulator (Care Quality Commission Inspection). The survey also asked what three factors were most important to caregivers in choosing a care home (see Box 5.5). These were similar to the set of priorities identified when the same questions were asked in a survey of the general public but asking the hypothetical question, 'if you were looking for a care home for a relative…?'. The Alzheimer's Society noted that several factors that might have an important impact on quality of life in care homes (for example, design, access to open space, activities) tended not to be prioritised either by family caregivers or the general population.

Box 5.5

Choosing a care home

Options selected by caregivers as most important in choosing a care home for a person with dementia

Alzheimer's Society DEMFAM survey [6]

87%	staff understanding of dementia
51%	friendliness of staff
44%	cleanliness of the home
42%	proximity to the family of the person with dementia
32%	activities residents were offered
25%	quality of food in the home
19%	costs of care
15%	design
12%	proximity to the home of the person with dementia
11%	access to outdoor space

Incorporate service users values and preferences into care

What are values and preferences?

Values are broad beliefs about aspects of life to which people attach importance, while preferences are more specific choices that flow from the values that people hold [54]. Both values and preferences are influenced by underlying enduring traits of personality and by attitudes. Moulded by our life histories and experiences, values and preferences define who we are, and distinguish us from others. It would seem self-evident therefore that providers who were interested in quality of care would give due regard to values and preferences when tailoring packages of care to suit individual needs.

How can values and preferences be used in dementia care?

Pioneering work by Kane and Degenholtz in the 1990s [55] identified a series of values and preferences that seemed to be relatively important to older people who were consumers of community and home-based long-term care in Minnesota, USA. These included such issues as; the involvement of family in their care (to be involved or not involved); daily routines (flexible or structured); privacy (a complex construct comprising a general need for privacy, and specific needs for privacy with respect to their body, their financial transactions, and their social interactions); a trade-off between safety and freedom (to come and go as they please, or to accept restrictions to optimise safety); participation in activities; and having goals or projects (some or none). They then developed an assessment tool for use by case managers, which assessed the importance to the service user as well as the content of the preference [55]. Older clients of home care services were enthusiastic participants in this process making considered judgments, and carefully calibrating the relative priority of these domains. In general, values and preferences relating to freedom/ safety and family involvement were most likely to be considered important, and the nature of routines least likely. Questions regarding 'If somebody not related to you was helping with your care … what kind of a person or personality would you be hoping for?' and 'What, if anything, do you prefer in a home or place where you live? What makes it a home for you?', which were only asked of a subset of participants, were also rated as highly salient. While all of the issues were generally rated as important, the older people expressed quite diverse preferences. While some of these were associated with the perception of the importance of the domain (those who were relaxed about routines did not consider this to be important, while those wanting structure did), others were not (those who wanted safety, freedom, or were ambivalent all considered this to be an important issue). The implications seemed clear – the values assessment could help case managers become aware of their clients as individuals 'with their own perspectives on quality of life and with idiosyncratic reactions to and opinions about their care' [55]. The explicit twofold aim of the approach was to raise expectations among users of the service based upon discussion of their preferences, and to increase the attentiveness and responsiveness of providers to expressed needs.

Barriers to using values and preferences to design person-centred care

In the Minnesota study described above, there were problems with implementation since case managers (characterised as 'pragmatic, practical and problem orientated') found it difficult to explore clients' values and preferences, with some resistance encountered to devoting the necessary time, attention and interest to the assessment. Concerns were expressed that eliciting preferences might raise unrealistic expectations that could not be met in a subsidised public service with budgetary constraints. The status quo was a 'cookie-cutter' approach to allocating packages of care, with one or other of a limited choice of care plans applied to almost all clients regardless of individual characteristics, needs or preferences. The authors concluded, sensibly, that 'any case management program wishing to incorporate a values assessment protocol needs to build in a long time line for training as well as policies and procedures for using the information' [55].

What are older people's preferred long-term care arrangements?

It is commonly stated that older people in general, and people with dementia in particular would prefer to be supported to remain in their own homes, for as long as possible, and this aspiration is enshrined in policies and plans relating to dementia care in many countries. Living at home is conflated with the concept of independence, and is assumed to be associated with better QoL. Actually, very few studies have examined these questions in a rigorous manner, but such evidence as there is calls into question the universal validity of these assumptions.

Several general population surveys have been conducted to assess preferences for care arrangements in the event that a respondent (generally middle to younger older aged, and community-dwelling) should develop long-term needs for care. There are evidently limitations with this approach. The question is hypothetical, and the respondent may find it difficult to imagine themselves into this situation. Their knowledge and experience of the care settings that they are being asked to choose between may be limited. Their preferences might well depend upon the nature of the condition or conditions underlying the needs for care, the level of care required, and the likely course and prognosis, but this is generally not specified or varied experimentally in the scenarios provided.

Unsurprisingly such surveys generally indicate a strong preference for care being provided in one's own home, by family and friends. For example, in a survey of those aged 40-70 in Maryland, USA [56] in terms of the proportion rating a care arrangement as 'very agreeable', the preferred option was to be cared for by family in their own home (64%), followed by care by paid caregivers in their own home (47%), care by family in the family member's home (33%), as a resident of an assisted living facility (30%) and as a resident of a nursing home (10% – 50% finding this option 'very disagreeable'). However, when preferences for community versus care home setting, and kin versus non-kin care were collated and dichotomised, while 52% would prefer to be cared for by family at home or in the community, a substantial minority (31%) expressed a preference to be cared for by non-kin in a care home setting [56]. Similar findings were reported from the 2007 Alabama Long Term Care preferences survey; two-thirds of Alabama residents age 35 and over indicated a preference for long-term care services provided with help from family, friends, and home care professionals in their home, but 16% preferred to receive such care in a care home [57]. In this survey an overwhelming majority (98%) considered it important to have home and community-based care services that would allow them to remain in their own home as long as possible; financial considerations may have been to the fore, since 59% of respondents reported they were not confident they could afford the cost of nursing home care for one year. In a representative survey of 562 people aged 65 and over living in Northern Taiwan, respondents were asked to choose between institutional care, home care or community care options 'if you needed long-term care services' [58]. Overwhelmingly the preference was for home care (74%) over care in care homes (17%) and community day care (10%). In another Taiwanese survey, of caregivers of people with dementia, 35% of the people with dementia were reported to have discussed their views regarding care arrangements at the end of life, and among those a quarter had favoured nursing home care [59].

A different approach was taken by investigators in the Baltimore Women's Health and Aging Study; the focus in this study was upon older women who were already receiving assistance in IADL or ADL from a family member [60]. They were presented with three scenarios depicting different levels of physical and cognitive care needs; the first referred to needs for IADL support, the second to ADL support, and the third to care for a person with dementia (If a person has Alzheimer's disease or dementia which will get worse as time goes by, is that person better off…?) The five care arrangements to be ranked in order of preference were; in their own home with help from family; in their own home with help from someone paid to come in; living with an adult child; in an assisted living facility or a continuing care residence; or in a nursing home. Care preferences were strongly influenced by the scenario presented; for a person requiring support with IADL unpaid help from family and friends in one's own home was preferred by 66% of respondents, followed by 23%, who preferred help in one's own home from a paid caregiver. For those requiring support with ADL informal care was preferred by 48% and paid care in one's own home by 28%. However, when presented with the a scenario of dementia, nursing home care was considered optimal by 50% of respondents, with a markedly lower proportion of women indicating a preference for informal (20%) or paid (15%) help at home.

While the costs of continuing care services are well understood, their benefits in terms of the well-being that can accrue to service recipients have not been assessed in a rigorous way. A better understanding of the values attached by different individuals to particular service configurations could inform more efficient resource allocation. With this goal in mind, an internet survey was conducted in the Netherlands among a general population sample of 1082 persons aged 50–65 years, using a discrete choice experiment to elicit preferences for long-term care [61]. Respondents were presented four separate scenarios; a physically frail older person, or a person with dementia, in each case either living alone, or with a partner. Preferences for different aspects of a package of care were assessed in terms of 'willingness to pay'. Care at home was clearly preferred over sheltered homes or nursing home settings, for all scenarios other than people with dementia living without a partner. For people with dementia, relatively greater value was attached to having a single care provider, coordinated care services and more participation in organized social activities. In general, a higher value was attached to care that had the potential to enrich the social environment of the individual, for example transportation and organised social activities, compared with for example additional hours of personal care. Interestingly personalised care was accorded a relatively low value, other than among higher socioeconomic status respondents.

The limited research into determinants of long-term care preferences suggests that these may well be gendered, with women being notably more likely than men to express a preference for home-based care [56,58]. It may also be that care in care homes is deemed more acceptable by those for whom this is a more distant prospect; those with worse health, chronic conditions and requiring home visits for medical care were more likely to prioritise home care [56,58]. Cultural (or at least ethnic sub-group) influences on long-term care preferences were apparent in several of these studies. In US studies, Black Americans are more likely to opt for care provided by family and friends than for paid home care, and in the context of dementia, more likely to opt for paid home care than care in care homes [60,62]. In Taiwan, care in care homes was more acceptable for

mainlanders than indigenous Taiwanese (Hakka and Holo), among who the traditional value of filial piety is more culturally entrenched [58].

Make care person-centred

What is person-centred care?

Person-centred care can be linked to three attributes of good quality care, that is: the involvement of the service user; taking into account users' individual needs, and their views as to how those should be met; and the provision of flexible and responsive services.

Person-centred care is now advocated in good practice guidelines for dementia care [63,64], particularly in care home settings where it can be learned through education and staff support, and where it has been widely applied. However, the approach is applicable and relevant throughout the journey of care.

Person-centred care in the community

In the UK, nearly ten years on from some of the formative work in the USA on values and preferences, the Joseph Rowntree Foundation commissioned a study into the state of person-centred care at the frontline of the delivery of social care in the community [65]. The backdrop to this report was that through a series of policy pronouncements and enabling legislation, person-centred care had become the touchstone for the delivery of community care in the UK [66], and was now effectively considered synonymous with good quality care. The main finding of the report was that practice lagged well behind policy rhetoric and ideology. Service users were generally not familiar with the term person-centred care, but when it was described to them, they were clear that this was not what they were receiving. Frontline care workers were more knowledgeable, and some attempted to apply what they had been trained to do. However, they felt constrained by top-down management practices that overlooked or undervalued the importance of the relationship between client, family caregivers and care worker, and by budget-led approaches to delivering care that limited the time spent with clients, and the flexibility with which care could be provided. There were very limited opportunities for people with dementia and their caregivers to become involved in the planning or governance of care services. As pointed out in the National Dementia Strategy for England, while continuity, flexibility and reliability of services were valued, 'current practices of specifying tasks rather than outcomes, not having the time or consistency of worker to develop the relationship between the individual and the care worker, and care workers being rushed and visiting for short (e.g. 15-minute) periods are particularly problematic for people with dementia' [1].

More recent advances in person-centred care, with respect to care in the community, have mainly come about through work on care coordination and case management (see 'Coordinate and integrate care for people with dementia' on page 58). In countries where the state has historically been the dominant provider of care services, the introduction of personal care budgets (or direct payments) has enabled the care recipient to have more control over the structure and organisation of care, by contracting directly with community service providers, and even employing care assistants directly. At their simplest level, personal budgets involve a discussion with the clients of the service about the money allocated to meet their care needs, their preferences as to how this should be spent, and recording these views in an agreed care plan. However, in the United Kingdom, a recent Alzheimer's Society report indicated that there had in practice been little take up of this option, which had been available for adults with social care needs since 1996 [67]. Just 23% of 878 respondents (people with dementia and/ or their caregivers who had been assessed and were receiving social services support) were using a personal budget or direct payment arrangement. A further 15% said they had been offered a direct payment or personal budget but had declined. People who lived alone, and older people with dementia appeared to be less likely to be offered, or use, direct payments or personal budgets. Direct payments were used particularly for personal care in the home, and respite services, but they were also used to purchase other services that would not form part of a conventional care package, for example support with gardening, or additional support to go on a holiday. There was some evidence that survey respondents using direct payments were more satisfied with particular aspects of their care and services than those not using direct payments, for example provision of information, and comprehensiveness of the support received. However, they did not in general feel that services were any more flexible. Those who had refused the direct payment option did so mainly because they were satisfied with current arrangements, and/ or perceived management of direct payments as complicated, difficult or stressful.

The Alzheimer's Society found the current arrangements to be insufficiently adapted to the specific needs of people with dementia and their caregivers, who needed more support to participate in the direct payment system. This included provision of more information, and specific support and advice when the person with dementia lacked decision making capacity. An additional problem was that the local market in community care services was often insufficiently developed to provide the diversity of options that would allow personal care budgets to be used to their maximum potential.

Person-centred care in care homes

The 'traditional' approach to care in care homes has been characterised as originating from biomedical models, applied on a 'one size fits all' basis, and task-

centred around physical nursing care and support with activities of daily living. Neglect of the physical and social environment in which the person receives care, and their unique psychosocial needs means that many people with dementia are left isolated, understimulated, frustrated and emotionally distressed. Person-centred care has been proposed as a more holistic alternative that can help to maintain personhood in the face of cognitive impairment and dementia. Brooker [68] has described the four essential elements of person-centred care in the 'VIPS' model:

V a Value base that asserts the absolute value of all human lives regardless of age or cognitive ability

I an Individualised approach, recognising uniqueness

P understanding the world from the Perspective of the service user

S providing a Social environment that supports psychological needs.

Personhood is then either enhanced or diminished, depending on whether the person is being valued or depersonalised in care. Implementation of person-centred care is always based upon a careful review of residents' life histories. A rich physical environment should promote orientation, and provide outdoor space, different activity areas, and enough space to walk around. Relevant social environment factors include the continuity and presence of staff, the use of respectful forms of communication, and verbal and nonverbal techniques to improve meaningful interaction with clients and engage them in activities. Evidence from the Alzheimer's Society 'Home from Home' report suggests that the availability of activities and opportunities for occupation is a major determinant of quality of life, also affecting mortality, depression, physical function and behavioural symptoms [69]. However, these activities were seldom available – 54% of caregivers reported that their relative did not have enough to do in a care home, and observational studies suggested that the typical person in a care home spent just two minutes interacting with staff or other residents over a six-hour period of observation (excluding time spent on care tasks) [69].

Training for person-centred care

Initial training in person-centred care requires up two days. The purpose of the training is to help staff to:

- reinterpret behaviour (including 'challenging behaviour') as a form of communication
- recognise that feelings persist despite cognitive impairment,
- be aware of, and acknowledge feelings during social interactions,
- focus on the unique way that each resident expresses their feelings and needs, with the aim of changing 'usual' care to 'individual' care.

Trainers work with staff to:

- explore how staff actions contribute to resident's behaviours in the context of dementia
- emphasise that social interactions, especially engaging residents on an affective level, help to preserve personhood and build meaningful relationships

Dementia care mapping

Dementia Care Mapping (DCM) is a structured method of implementing person-centred care in institutional and day care settings. The DCM tool [70] includes an observational assessment instrument that can be used both to aid implementation of PCC and evaluate its outcomes. Factors influencing behaviour are identified, and observations are used to create create individual person-centred care plans. A key component of DCM is the engagement of care staff to take an active and accountable role in the process of change, thinking about the degree to which the care they provide is person-centred. Implementation of DCM comprises a cycle of:

1 briefing and preparation of care staff and leadership
2 DCM observation
3 DCM data analysis and report-writing
4 feedback of results to care staff and leadership
5 action-planning by care staff based on the DCM results
6 realization of the action plan.

This process is relatively time and cost intensive given the need for staff training, observation and data collection, and external consultants [ref.]

The effectiveness of person-centred dementia care

The effectiveness of person-centred care approaches has been studied mainly with respect to their impact on disturbed behaviour, particularly agitation and aggression. In a cluster randomised controlled trial in London care homes randomisation to a person-centred care training intervention was associated with a 19% reduction in the use of neuroleptic medication, although there was no difference between the intervention and control nursing homes in the levels of agitated or disrupted behaviour [71]. Cohen-Mansfield did, however, demonstrate a reduction in agitation in an individual randomised controlled trial of assessment and non-pharmacological management of advanced dementia in nursing homes, based upon personalised approaches [72]. In a small trial of a bathing practices intervention, randomisation to a person-centred approach to showering or towel bathing was associated with a marked and statistically significant reduction in agitation, discomfort and aggressive incidents in nursing home residents with dementia [73].

There have been just two large scale definitive cluster-randomised controlled trials of person-centred care (PCC) and DCM in care home settings, one conducted in Sydney, Australia [74], and the other in the Netherlands [75].

In the Australian trial, 15 residential care sites in Sydney were selected because they had a task-focused rather than person-centred care systems. A subset of 324 residents were considered eligible in that persistent need-driven behaviours made it difficult for staff to provide them with quality care. Sites were randomised to person-centred care, dementia care mapping or usual care. DCM and PCC interventions were administered by the researcher teams, in an intensive and strictly controlled fashion. Agitation scores among residents were much lower in both the DCM (p=0.04) and PCC homes (p=0.01) compared with the units randomised to usual care. However, there was no statistically significant difference between the three arms of the trial in overall neuropsychiatric symptoms, or observer ratings of the quality of life of residents, all of whom had advanced dementia. Use of neuroleptic medication was higher in the PCC arm than in the DCM intervention or usual care arms.

The Dutch trial had a more pragmatic design, in that 34 dementia special care units from 11 care homes, including 434 residents and 382 nursing staff members, were randomly assigned to receive DCM training (two four-month cycles), or to continue with usual care. The homes were not specially selected, and the DCM intervention was led by staff from the care homes who had received training and certification in the technique. In this trial, intention-to-treat analysis showed no statistically significant effect on agitation, but more neuropsychiatric symptoms overall were noted in the intervention group compared with usual care (p = 0.02).

Results of these trials suggest that while there can be clinical benefits of DCM this is most likely to be evident in homes that have not adopted person-centred care cultures, and when the implementation is conducted in a careful and controlled way. Effects on quality of life in those with less advanced dementia, and on satisfaction with care among residents and caregivers have yet to be tested. In both trials, there appeared to be some beneficial effects on care home staff. In the Australian trial, staff in the units randomised to DCM reported lower levels of burnout [76], while in the Dutch trial intervention staff reported fewer negative and more positive emotional reactions during work.

Coordinate and integrate care for people with dementia

The need for coordination and integration of care

Imagine a scenario of a 67 year old man with recently diagnosed mixed Alzheimer's disease / vascular dementia, who also has long-standing diabetes with visual impairment, and has recently been depressed. He lives with his younger wife, who still works, and two school age children. Aside from the neurologist who is managing his dementia, he will need regular assessment in a diabetes clinic, treatment from an ophthalmologist for his diabetic retinopathy, and he has been referred to a psychologist. His wife and children need to be informed about his condition, and supported. Home care needs to be organised, and attendance at a local day centre considered. This may be the time for advance care planning, and his capacity to make relevant advance decisions needs to be assessed, and this discussed with him and his family. His condition will evolve over time, as will his needs for care and support, and the demands that this places on his family. Other health problems may intervene. There is a clear risk that the various health and social care professionals and agencies involved in his care will not communicate directly, will not be aware of all of the issues involved in his care, and will fail to assess, treat and support him and his family in a holistic manner. Fragmentation of dementia care increases the burden to caregivers, adversely affects people with dementia, and is also likely to increase costs [77,78].

What is case management?

Coordination through case management is a potential alternative to improve care and to reduce costs. The Case Management Society of America (CMSA) describes case management as 'a collaborative process of assessment, planning, facilitation and advocacy for options to meet an individual's health need through communication and available resources to promote quality cost-effective outcomes [79].

In a recent systematic review of the effectiveness of case management on health care costs and resource utilization [80], case management interventions were operationalised as

> **'any intervention involving interaction between a case manager and patient-caregiving dyads and providing continuity and advocacy over time, support, information about community services, care and disease evolution, financial and legal advice. The case manager could also reduce fragmentation among services, monitor medication to avoid adverse reaction and give advice on behavioural management strategies tailored to the needs of patients and families'**

The potential roles of case management are more clearly described according to 18 characteristics proposed by Pacula in 1995 as a measure of the intensity of case management [81] (see Box 5.6)

Is case management effective?

In the 2011 World Alzheimer Report we looked at the evidence base for case management focusing particularly on the effects in early stage dementia. We identified a systematic review of 12 randomised controlled trials (RCT), all conducted in high income countries, eight in the US [80]. A subsequent small RCT from the Netherlands focused on effects of

case management in early stage dementia, with no benefits identified [82]. Of the six trials in the review rated as 'good quality', four reported a positive impact on institutionalization delay. Three RCTs included economic evaluations with none identifying a net cost-benefit of the intervention. Four RCTs included an evaluation of the effect of case management upon hospitalization rates or emergency visits, with no evidence of positive impact favouring the case management group. The conclusion was that there was some evidence to suggest that case management may be efficacious in delaying institutionalization in people with more advanced dementia. There was no evidence that case management in dementia increased the efficiency with which health services are used (reducing hospitalizations or emergency care), and, at best, the economic impact on health care costs seems to be cost-neutral.

A more recent overlapping review of case management in dementia [83] included just six randomised controlled trials, probably because stricter inclusion criteria were applied in judging what constituted case management. A broader range of outcomes was studied, with moderate evidence for a beneficial effect on quality of care, quality of life, and satisfaction with services. Evidence regarding impact on resource utilization and costs was again inconclusive. However, statistically significant benefits with larger effect sizes tended to be seen in trials in which a) case management was delivered with greater intensity, b) case management was targeted on those with particularly complex health and social care needs, and c) case management was delivered in the context of a high degree of functional integration between agencies, particularly health and social care.

Box 5.6

Intensity of case management

A measure of the intensity of case management, defining the various roles of a case manager [81]

1 Works with fewer than 60 clients (caseload)
2 Spends at least 50% of his/her time face-to-face with clients
3 Does the initial eligibility assessment him/herself
4 Personally communicates with primary care physician (and his/her team)
5 Organizes multidisciplinary team meetings
6 Puts in place the services provided by the organization that employs him/her
7 Puts in place the services that the client pays for directly
8 Puts in place the services that an organization other than the one that employs him/her pays for
9 Helps the client make decisions regarding care
10 Helps the client express decisions
11 Participates in educating clients about health problems
12 Provides advice to individuals (social work)
13 Provides advice to families (social work)
14 Meets with the client regularly
15 Monitors the client's situation via home visits
16 Monitors the client's situation by having him/her come in for a consultation
17 Works with clients being institutionalized
18 Works with clients during hospitalization

Intensity score = Number of criteria (/18)

The importance of integrated approaches to care

A compelling example of successful integration is the PRISMA model in Quebec, Canada, which targets frail dependent older people in general rather than those with dementia specifically. In a quasi-experimental trial this 'coordination-type integrated service delivery system' was associated with reduction in functional decline, unmet needs, visits to emergency rooms and hospitalizations, and with an increase in service satisfaction and empowerment [84]. In the districts where PRISMA was introduced, a Joint Governing Board was established of all health care and social services and organizations from the public, private, and voluntary sectors. The Joint Governing Board is responsible for the governance, management and delivery of all services. There is a single entry point for all PRISMA services via telephone contact or written referral. A case manager is responsible for conducting a needs assessment, planning the required services, arranging access to the services, organizing and coordinating support, directing the multidisciplinary team of practitioners involved in the case, and advocating, monitoring, and reassessing the patient as frequently as necessary according to the needs. Crucially, the case manager works for the local Joint Governing Board and is accredited to work in all institutions and services in the area.

The PRISMA model has some similarities to the innovative MAIA system (Maisons pour l'autonomie et l'intégration des malades d'Alzheimer), which is a central feature of the Plan Alzheimer in France. This will give every patient access to a local 'one stop shop', the

MAIA, where a specifically dedicated case-manager will design an integrated plan of health and social care suitable for the patient. The plan will increase the quality and integration of health and social care, with a focus on improved home-based support, new respite structures and adaptation of housing to cognitive handicaps. Each case manager will have a caseload of no more than 40 clients. The system is in the process of being rolled out nationally, with 148 MAIAs established, and 400 to come by 2014.

Co-ordinated care across the disease course – planning the move to a care home

It is estimated that between 75% and 90% of people with dementia living in high income countries move into care homes at some stage of their illness [85,86]. Transition to a care home is often inevitable due to a lack of co-resident caregivers, or the demands of round-the-clock care exceeding the capacity of co-resident caregivers even with support from community

Table 5.3a
Factors potentially influencing resident adjustment to moving to a nursing home
Adapted from [95]

Positive factors	Negative factors
Resident input into the decision to move to a nursing home [96,97]	Resident perceived lack of control over decision to move to a nursing home [94,102,103]
Orientation of residents and their families to the facility prior to the move [98]	Unable to visit the nursing home prior to admission [104]
Home-like environment, including small unit size, increased lighting, appropriate outdoor areas, and easy access to toilets [88,89,91,92,99]	Loss of familiar surroundings, people, and lifestyle [101]
Introduction procedures such as a buddy system on arrival [98]	Unmet care needs such as lack of stimulation, company, and help with vision and hearing problems [105,106]
Collaboration with families into the care planning process [93,98]	Cultural dissonance in the form of language and/or cultural issues [98,107-109]
Telephone calls to update families on residents' adjustment to the facility [98]	Feeling abandoned by family [110]
Devising 'This is Your Life' books [100] to assist staff in understanding and supporting new residents	
Sensitive person-centred care [94]	
Activities appropriate to the individual, e.g. music therapy [101]	

Table 5.3b
Factors potentially influencing family adjustment to the person entering a nursing home

Positive factors	Negative factors
Adequate information and advice with regard to quality care, financial implications, care options, and complexities of 'the system' [104,111]	Lack of information and assistance completing the necessary paperwork [93,121]
Fewer physical demands on caregiver to provide care [112]	Difficulty locating a nursing home which is geographically accessible and appropriate to the individual's care needs [93,111]
Support for caregiver from family, friends, nursing home staff, and healthcare workers [93,98,113-115]	Dissatisfaction with quality of resident care [122,123]
Greater involvement of caregiver in supporting the resident's well-being [107,115-117]	Feeling a loss of control [104,118] and that the decision is 'out of their hands' [112]
Staff greeting family members, showing them to their relatives, and introducing them to other residents [118]	Lack of effective communication with staff [118,124]
Keeping the family informed [117,118]	Feelings of guilt, failure, and/or betrayal [112,114,115,118,121,125]
Experienced 'lay experts' to mentor the family throughout the placement process [119,120]	Difficulty letting nursing home staff take over primary care [120,126]
A sense of relief that the person with dementia was receiving better care than could be provided at home [115]	Family conflict [115]
Personal 'word of mouth' recommendation for the nursing home [111,119]	Caregiver questioning their decision to admit their relative to a nursing home [111]

care services and other formal caregivers. However, the transition into residential care can have important health and psychological consequences for the person with dementia [87-89], and their caregivers and family. A qualitative study with caregivers that was conducted in Canada [90] reported that'

> **'the transition from being the primary caregiver with total responsibility for looking after their family member to now watching strangers do those same activities they had done so frequently before placement was challenging for them. After placement, the caregivers were left to sort out the change that had just occurred. In this 'sorting out' process, the caregivers identified feelings of ambivalence and articulated strategies they used to deal with the change and with the institutional system. This ambivalence on the part of the caregivers resulted in feelings of guilt as well. Of particular concern was the lack of communication between caregivers and the staff at the long-term care facility.'** [90]

Guilt, sadness and emotional distress in caregivers are recurring themes highlighted in several studies [91-94]. There are ways to improve the transition to nursing home, as summarised a recent evidence-based review [95]. A summary of synthesised evidence into positive and negative factors influencing adjustment to the transition for both people with dementia and their families is presented in tables 5.3a and 5.3b respectively.

More experimental research is needed to understand best practice strategies enabling people with dementia to live at home as long as possible and also identifying the right time and best approach for managing transfer to a care home. There is clearly an important role for trusted case managers to discuss and plan the transition with the person with dementia and their family, and to provide stability and continuity of care across the transition. New epidemiological and intervention studies, such as the RightTimePlaceCare study in eight European countries [127], will add evidence and help to develop evidence-based guidelines to support best practice in the transition to residential care.

Value and develop the dementia care workforce

What is the dementia care workforce?

If people with dementia are to be enabled to live as full a life as possible, participating actively in their local community, dementia is, or should be, everybody's business. Awareness, sensitivity and skills are needed in all sections of the workforce and wider society.

People with dementia certainly need informed understanding and support from all the health, welfare and social care agencies that they come into contact with, not only from specialist dementia services. This would include, for example, ambulance services, primary care receptionists, physiotherapists and opticians. Therefore basic curricula for undergraduate professional qualifications, and continuing professional development for doctors, nurses, therapists, other relevant health service staff and social care staff should all contain modules on dementia care.

In a 'dementia friendly' community, shops and businesses, housing services, police, utility companies, banks and lawyers would all have a part to play. Perhaps the most visible and hopeful sign of progress in this regard are the national 'Dementia Friends' programs rolled out in Japan (four million friends recruited and trained in the past eight years), and more recently in the United Kingdom where free coaching is being provided to one million people

> **'to spot the signs of dementia and provide support to people with the condition, whether that is a friend, family member or someone you meet through your job' (www.dementiafriends.org.uk)**

In high income countries, family caregivers are supported and complemented by a large and growing cadre of paid care workers (nurse aides, home health aides and personal- and home-care aides) operating in the home care and care home sectors, and responsible for delivering much of the difficult, demanding and sensitive 'hands on' personal care to people with dementia. It is difficult to estimate their numbers, but in the United Kingdom it is estimated that there are currently 1.6 million people employed in the frontline social care sector, with this number set to double in the next twenty years [128]. In the USA it is estimated that an additional 3.5 million formal health care providers – a 35% increase from current levels – will be required by 2030, with the Bureau of Labor Statistics predicting that personal- and home-care aides and home health aides will represent the second- and third-fastest growing occupations between 2006 and 2016 [129]. It is increasingly recognised that these workers are generally poorly paid, lack clear professional structures, are too often not well trained or prepared for the demanding work in hand, and have limited opportunities for career development. It is upon these 'frontline' or 'direct-care' workers that we focus in the following sections of the report – specifically their needs for training and development, and the necessity to ensure that their essential work is properly valued and remunerated.

Training and workforce development

A lack of knowledge and skills in the direct care workforce can lead to harmful, neglectful or abusive care practices that add to rather than alleviate the problems experienced by the person with dementia and their family caregivers. Providing adequate training and support is likely to have wider benefits beyond improvements in the quality of care delivered; staff

morale should be improved, and recruitment and retention problems eased. Developing a stable team of staff, with the right attributes and skills, and keeping them motivated should be core objectives for the managers of care services.

However, reports from both sides of the Atlantic underline the parlous state of training and preparation for direct care workers. In the USA, the Institute of Medicine's Committee on the Future Health Care Workforce for Older Americans noted in 2008 that while patient care had become much more complex, the federal minimum of 75 hours of training for nurse aides had not changed since it was mandated in 1987 (although many states had higher numbers of required hours) [129]. Home health aides had similarly low requirements, and very little was done to ensure the competence of personal-care aides. A review published in 2000 reported that the minimum training provided to direct-care workers had very little focus on issues specific to dementia care [130]. Direct-care workers in nursing homes were unlikely to receive adequate dementia training due to insufficient administrative support; however, evidence suggests that staff training programs to improve the quality of dementia care in nursing homes are effective [131]. Similarly, while 73% of social workers had clients age 55 and older and around 8% of social workers were directly employed in long-term care settings, only 4% percent had formal certification in geriatric social work [129]. In the UK, the Care Quality Commission notes persisting concerns regarding the quality and coverage of training among frontline care home staff. One quarter (24%) of registered nursing homes and 16% of residential care homes failed to meet minimum standards for training and supervision. According to most of the staff who took part in the Alzheimer's Society's DEMSTAF survey, most training was conducted 'in house', arranged or delivered by the care home management [6]. Just over three-quarters of care workers (77%) had received training with regular refreshers, and 38% had a National Vocational Qualification in dementia care. However, there was a widely felt and expressed need for more training (more than a fifth of respondents said that they needed a lot more training and nearly two-thirds at least some more training). The five areas that were most commonly mentioned as deficiencies were; responding to challenging behaviours; use of antipsychotics, and alternatives; recognising pain in people with dementia; suspected abuse of people with dementia; and emergency first aid.

The solutions to the deficiencies are relatively clear cut

1 The minimum mandated requirements for training for direct care workers need to be increased. The Institute of Medicine's Committee on the Future Health Care Workforce for Older Americans recommended that Federal requirements for the minimum training of certified nursing assistants and home health aides should be raised to at least 120 hours and that this should include demonstration of competence in the care of older adults as a criterion for certification.

2 Core and more advanced competencies should be identified for direct care staff who are not otherwise professionally qualified or registered. This would help care providers identify learning and development needs, focus the attention of training organisations on producing courses that meet the needs of the sector, and assist regulators in identifying quality in dementia care.

3 The responsibilities for ensuring that the social care workforce has adequate knowledge and skills need to be clarified. Care provider organisations, regulators and local and national government all have a part to play. This will include enforcement of minimum standards, and ensuring the availability and funding for good quality, locally accessible training opportunities.

4 Implicitly, as part of this process, to begin to professionalise these occupations. As The Institute of Medicine's Committee on the Future Health Care Workforce for Older Americans recommended

'To help improve the quality of these jobs, more needs to be done to improve job desirability, including improved supervisory relationships and greater opportunities for career growth.'

Professionalisation will come about, in part when training and acquisition of skills is seen as a continuing process of career development, and a striving for excellence rather than merely a question of meeting minimum regulatory standards. It should be noted that concerns have been expressed that by 'professionalising' a still relatively easy to enter sector, rigidity may be introduced into jobs that are currently attractive because of their flexibility, hence harming recruitment [132]. However, there is evidence that attaching importance to direct care jobs as a 'profession' does bring benefits; the Netherlands and Japan, which have both put emphasis on professionalising the sector, have been successful at creating a large workforce [132]. Public awareness initiatives to improve the public image of this work might also improve the status of the workforce, and, ultimately, improve retention.

Valuing dementia care workers

The low status of direct care workers

In an effort to drive up care quality, expectations placed upon direct care workers are rising, including that they should be trained and qualified to a higher level. Despite this, these have always been low wage jobs. With remuneration close to minimum legal wage levels, pay is often not sufficient to support an adequate standard of living (a living wage). If the employee is the only household breadwinner this

necessitates taking on another job, or living in poverty and/or on social assistance. Union representation tends to be low. Also, partly because of the low wages offered, these sectors recruit selectively from marginalised population sub-groups with a lot of non-work social, psychological and economic stresses in their lives, including those who are unmarried or divorced, single parents, and those from minority groups who may have recently migrated. There is now ample evidence that the chronic undervaluation of social care has important adverse consequences for those working in the sector, service providers, and their clients.

In the USA, analysis of the US Census Bureau's 2006 Annual Social and Economic Survey of the Current Population Survey (CPS) permitted a comparison of the characteristics of direct care workers (based upon occupation and industry variables for the longest job held in the previous year) and other women in the US workforce [133]. The sample comprised 2673 direct care workers of whom 2389 (89%) were female. Half of the female direct care workers were from black and other minority ethnic groups. Median hourly wages were $11.06 for hospital aides, $9.13 for nursing home aides and $8.50 for home health aides. 22% of direct care workers relied on public health insurance, lacking private sector or employer insurance. Compared with all female workers (see Table 5.4), direct care workers were less likely to be married, more likely to be separated and to be a single mother. They were more likely to be from the minority black population, had much lower levels of education, and were more than twice as likely to be living in poverty [133]. In the United Kingdom the social care workforce has a very similar profile [128]. A third of adult social care jobs are in residential care, almost half were in domiciliary care, five per cent of jobs were in day care services and 14% were community based. Four-fifths (82%) of UK social care workers are female, with an average age of 43 years. Social care workers have an average of seven days sickness absence per year, compared with a UK average of 5.5 days. Pay ranges from £6.09 ($9.44) to £12.03 ($18.65) per hour, with a median of £7.93 ($12.29). Most workers therefore receive pay close to the national minimum wage of £6.08 ($9.42). Despite half of the workforce being qualified to at least National Vocational Qualification level 2, their pay profile is only slightly better than that of retail cashiers and check out operators.

Table 5.4
Demographic Characteristics of US Female Direct Care and Child Care Workforce, 2005
Data from the US Census Bureau's 2006 Annual Social and Economic Survey of the Current Population as reported in Carsey Institute Policy brief [133]

	Direct care workers	All female workers
Characteristics		
Mean Age	41 years	42 years
Married	38%	54%
Divorced or separated	31%	21%
Single mother	24%	14%
Race and ethnicity		
White, non-Hispanic	51%	70%
Black, non-Hispanic	30%	13%
Education		
High school or less	62%	37%
Economic status		
Average hours work per week	37	37
Average annual earnings	US$17,228	US$30,441
Percent living in poverty	19%	8%
Percent living in low-income family	49%	22%

Across Europe, evidence gathered for a report on long-term care provision [134] included analysis of standardized national full-time monthly wages for care professionals (as a ratio of the OECD average wage level for that country). For the 17 European countries for which comparable data on pay and conditions were available, in only two (Denmark and Iceland) did workers in residential care with basic skills earn at least as much as the average worker. For almost half of the countries studied, wages were two-thirds or less than the average. Professionals (social workers and nurses) did better than their less qualified colleagues, but not as well as their level of education and skill would warrant. While data for the private, irregular sector were limited, evidence indicated that earnings for home care workers and professionals hired informally on the grey market are available at a considerable 'discount'.

The problem of unregulated 'informal' paid care workers

In low and middle income countries information on the paid workforce for long-term care is for the most part lacking. In the 10/66 Dementia Research Group studies in Latin America, China, India and Nigeria, paid caregivers for people with dementia were common only in two urban catchment area sites, Beijing (China) and Lima (Peru), where around a half and a quarter of people with dementia respectively were cared for predominately by paid live-in caregivers. In those sites, giving up work to care was relatively uncommon, suggesting that this practice had arisen mainly for economic reasons. The potential loss of earnings for city-dwelling family members exceeded the cost of recruiting a woman from the country as a live-in caregiver. For the paid caregiver, the modest salary combined with board and lodging enabled them, usefully, to remit unspent salary to their families. Anecdotal information suggests potential pitfalls,

including lack of experience or training to cope with the complex demands of dementia care, lack of regulation, and potential for work-related, economic and sexual exploitation.

These problems are not limited to internal migration within rapidly developing and urbanising middle income countries. The International Labour Organisation (ILO) estimates around 90 million migrant workers around the world (of whom around 15% are estimated to have an irregular status). They contribute to the economies of their host countries, and the remittances they send home help to boost the economies of their countries of origin. Yet at the same time migrant workers often enjoy little social protection and are vulnerable to exploitation and human trafficking. A recent report from a UK migrant worker NGO Kalyaan [135], identified a growing 'grey market' for low cost private home-based migrant care workers in the UK, subject to no regulation, and with considerable evidence for potential and actual abuse. Such workers were specifically excluded, according to their 'migrant domestic worker' visa regulations, from National Vocational Qualification training in care of older people. Only 30 percent of respondents had participated in some form of eldercare training. They were generally required to fulfil domestic worker roles (cooking, cleaning, shopping) in addition to intensive personal care tasks, leading to excessively long working hours with little possibility of personal recreation. A more striking example of the same phenomenon comes from Italy where according to a 2013 seminar conducted by e Forum Internazionale ed Europeo di Ricerche sull'Immigrazione (FIERI) under the auspices of the ILO [136], the employment of domestic workers has boomed in recent years, especially in the field of home care for older people, as a result of severe budgetary constraints to the welfare sector; advanced population ageing; a substantial growth of female employment; and Italian immigration policies that have made domestic care one of the main portals into the national labour market. More than 80% of domestic workers in Italy are migrant women, mostly from Eastern Europe, Latin America or Philippines, often employed as live-in workers in the older adult care sector. Public authorities were said to have ceded responsibility for provision of care services to the market and third sector organizations, and the need to increase the involvement of the State in the organization, coordination and management of the care sector was, apparently, one of the key issues that emerged during the debate.

Reports from two culturally contrasted developed countries in other regions where, anecdotally, migrant labour accounts for a considerable proportion of the home care sector for older people, highlight the vulnerability of these workers. 10/66 Dementia Research Group studies are currently underway in both Singapore and the Lebanon, with the potential to cast some light on an oft discussed but thinly evidenced arrangement for the care of frail older adults, including those with dementia.

A recent report from **Singapore** [137] notes that

> **'middle- and upper-income families in the more developed economies of East Asia have turned to low-cost live-in foreign domestic workers for their eldercare needs, for such workers are available around the clock and are able to cover other household duties. Furthermore, having domestic workers at home instead of sending the elderly to care institutions helps sustain the deep-rooted Asian ideologies of filial piety and familialism, at least on the surface. This in turn reduces the pressure on the government to provide quality public care for the elderly. As such, domestic workers provide a solution that is financially affordable, practically convenient, ideologically desirable and politically expedient'.**

In Singapore, the process is incentivised by the employer levy on domestic workers being reduced in the event that they are also providing care for a person aged 65 years or over. However, in contrast to the formal healthcare sector, there is no further reduction in the employer levy if the worker acquires relevant qualifications. The average monthly salary for a qualified nurse home caregiver is Sing$600 (US$477), around 50% higher than that for an unqualified domestic worker. Remarkably, according to surveys conducted by the authors, 80-90% of long-term care home staff are also foreign healthcare workers, as compared to just 20% of hospital staff.

In the **Lebanon**, a report in the Daily Star (June 18, 2013) [138] referred to a request from migrant domestic workers for their rights enshrined in the ILO Domestic Workers Convention to be assured. Workers requested better preparatory training from their own countries, and basic instruction in Lebanese Arabic, in addition to information about working conditions in the Lebanon. They also asked for more 'humane treatment' from the Lebanese state in the event of imprisonment or deportation, and for someone to follow up on the conditions of sick and injured workers receiving hospital treatment, and that efforts to prosecute those who subject them to harsh working conditions be followed through. Migrant workers, the Daily Star noted 'have no defined legal protection, leaving many vulnerable to exploitation'.

The problem of high turnover of direct care workers

The most direct consequence of the low profile, status and valuation of direct care work is a high turnover of staff. In England, where national monitoring systems are in place, annual staff turnover for the sector is currently 19%, with a 3% vacancy rate – higher than all other industrial, commercial and public sector employment fields [139]. The reports of the Care Quality Commission in England indicate ongoing concerns

with staffing levels with only 77% of nursing homes and 84% of residential homes meeting minimum standards for staff numbers [140]. In the USA, in a 2002 national survey 37 of 43 states reported serious shortages of direct care workers [141], and studies of turnover report annual rates ranging from 25% to well over 100% [142]. A high turnover of staff is causally linked to low staffing levels (due to unfilled vacancies) and extensive use of temporary agency staff. This in turn increases work stress for those that remain, and impacts on quality of care. In the USA, where pay and conditions vary somewhat across the sector, the relationship between low pay and retention has been demonstrated through analysis of an individually matched data file from the US CPS 2005–2006, comparing characteristics of direct care workers who were retained in the same position, versus those that changed occupations; retention in the direct care workforce was higher for those with higher incomes, older care workers, and hospital or nursing home aides versus home health aides [133].

There is now clear evidence from the USA that lower staffing levels, a high turnover of direct care staff, and high levels of use of agency staff are each independently associated with adverse resident outcomes in nursing homes. A systematic review of 87 studies (1975–2003) indicated a significant relationship between high staff turnover and, among residents, a lower functional ability, a higher incidence of pressure ulcers, and greater weight loss [143]. In a more persuasive analysis of longitudinal data, those homes with improving staffing levels, declining staff turnover rates and reduced use of agency staff tended to show greater improvements in the percent of residents experiencing indicators of adverse quality of care; subject to physical restraint, with indwelling urinary catheters; with moderate to severe pain; and with pressure sores [144]. The data used came from a survey of nursing home administrators (Nursing Home Compare), the Online Survey Certification and Reporting (OSCAR) data, and the Area Resource File. The staffing variables of Registered Nurses, Licensed Practical Nurses, and Nurse Aides were measured quarterly from 2003 through 2007, from 2839 care home facilities. The costs of turnover are considerable, and often underestimated by providers [145]. The direct costs (arising from separation payments, and the costs of recruiting and training a replacement) have been estimated from a meta-analysis of US studies to be in the region of US$1000 – $6000 per direct care worker. However, the indirect costs of lost productivity, reduced quality of care, deterioration in organisational culture and employee morale, and lost client revenue are difficult to calculate and may amount to much more than this. For 2004, Seavey [145] estimated national sector-wide costs for the USA of $4.1 billion annually (assuming, conservatively, a direct care workforce of roughly 2.6 million, an average annual staff turnover rate of 45%, and an average turnover cost of $3,500 per employee). Sixty-one percent of this cost is met by the taxpayer through Medicare and Medicaid payments.

Stabilising the direct care workforce

Increased wages, improved benefits and working conditions for paid caregivers seem key to boosting retention [146]. However, increased awareness of the problem and its consequences has not translated into concrete changes in policy or practice with potential to effect meaningful change. Introduction of national or state level minimum wages benefits care workers, since they are a substantial part of the low wage sector. However, these policies address absolute but not relative poverty, do not guarantee a living wage, and make the jobs no more appealing for as long as they are among the least well paid in society. In the USA, States can set minimum wages for specific occupations through legislation. It is also possible to raise reimbursement levels through Medicaid, linked to improved wages for direct care workers ('wage pass through' provisions). These targeted initiatives are not always effective due to lax monitoring to ensure that these are passed on as increased wages, and since they are restricted to the nursing home sector. Other programs include 'living wage' campaigns and provisions, health insurance initiatives, and promoting collective bargaining for care workers. Arguably, the introduction of more free market principles into the mixed economy that prevails in the long-term care sector might help to establish pay levels that more accurately reflect the intrinsic value of the labour provided. Governments' wishes to control costs that they subsidise or reimburse are an important factor in determining levels of pay. On the other hand, even within the fiscal constraints imposed by government, non-governmental providers (for profit and not for profit) might find it in their interests to improve pay and conditions, through 'investing to save'. It has been argued [145] that providers need to

a) **Calculate staff turnover rates carefully**
   Accurate computations of staff turnover rates as well as per-worker turnover costs are essential for making informed decisions. Ideally these need to be assessed and tracked uniformly across the sector, and over time.

b) **Know the true costs of staff turnover**
   These are substantial, and often underestimated, due to failure to account for indirect costs to the business. High turnover reduces profit, and drains provider finances that might otherwise go into service development and improvement.

c) **Reduce turnover costs by investing in effective retention strategies**
   Once turnover is estimated accurately, and its economic impact properly understood, providers can make informed decisions regarding how much they can afford to invest in retaining employees, and assess whether or not such investments are

improving their bottom line. Put simply, the financial drain created by turnover can be diverted into programs and policies that encourage retention; paying more in salaries and benefits may save costs overall, as well as increasing productivity.

At the level of policy research and practice, it is currently unclear, in any mature health and social care system, which public policies are likely to be most effective in promoting retention and career development in the direct-care workforce. In particular there is no clear understanding of the relative merits of improved compensation versus other strategies for improving the quality and professional status of the jobs. More work is needed into the relationship between turnover and care quality, both to determine if there are benchmark critical turnover rates beyond which care quality is inevitably and seriously compromised, and to establish the relative importance of absolute staffing levels and turnover on care quality.

In the United Kingdom, workforce simulation models by Skills for Care [128] suggest that the number of paid adult care social care jobs needs to increase by 24-82% between 2010 and 2025, increasing from 1.6 million currently to 2.1 million to 3.1 million depending upon the scenarios considered. This is certainly a challenge, but may represent more of an opportunity than a threat. Imbalances occur when there is a discrepancy between the quantity (or quality) of the available workforce and the quantity (or quality) required by employers. Such imbalances are inevitable, but risks only occur in the context of rapid fluctuations in supply or demand, where planning and foresight is insufficient to allow adjustments to be made quickly enough. The Centre for Workforce Intelligence, noting the relatively high proportion of older workers in the workforce recommends that younger people should be attracted into social care professions. The European Union notes in a recent report, that

> **'In practically no country have concrete efforts to encourage more men to enter this sector made it on to the policy agenda.'**

They further note that there could be a lost opportunity

> **'…for the economy, and not only for gender equality, if the prevalent response to the financial crisis were confined to rationalizing provisions and putting pressure on the family to insource rather than outsource care. Rather, the challenge lies in reversing this perspective and turning a rapidly expanding sector like long-term care into an employment growth engine. At the same time, employment expansion could also be used to turn this employment segment into a port of entry for men into the larger care sector.'**

Summary and conclusions

The evidence review in this chapter indicates that there are concrete actions that can be taken to build quality into the process of care and support for people with dementia and their caregivers across the journey of care, from the time of diagnosis to the death of the person with dementia, and beyond. The key guiding principles are that 'living well with dementia' is an attainable goal, and that maintaining or enhancing quality of life is the ultimate objective.

No two people with dementia, and no two families, are alike in their needs for care and support, and we need to find ways to make care more person-centred, and care packages more flexible and individualised. Earlier diagnosis enables the person with dementia to make decisions about the care that they will receive, through advanced care directives, which are still underutilised. Personalised care budgets put people with dementia and their caregivers in control of their packages of care, and empower them to ensure that their preferences are respected, and their needs met.

While good quality dementia care can be both complex and resource intensive, the systems and services must be made as simple, seamless, transparent and accessible as possible. Families may need to be guided and supported in accessing information and exercising choice, with case managers playing an important role. Case managers can provide continuity across the journey of care, not least through the relationships of trust that they can develop with those whom they support. Case management should also assist in the coordination and integration of care, but evidence suggests that to be effective and efficient the long-term social and health care systems that the case manager coordinates need themselves to be better integrated and subject to a unitary process of planning, commissioning and governance.

It is often said that family caregivers are the cornerstone of the long-term care system for people with dementia. This is undeniable. However, their efforts are complemented, particularly in high income countries, by a growing cadre of paid direct care workers, without whom home care would often be unsustainable, and upon whom we rely to deliver quality care in care home settings. All caregivers, paid or unpaid should be valued and recognised by society for the essential, difficult and demanding work that they carry out, and recompensed appropriately. Incentives need to be built into the system to encourage family caregivers to continue to provide quality care at home, and to promote retention, skills development and career progression among paid care workers. Investment in these areas may well be cost effective both in reducing downstream costs including transition into care homes, and in improving outcomes for people with dementia and their caregivers. As recently recommended in an OECD report, this is a 'win, win, win' strategy.

To effect these changes, we must make dementia a priority. Only carefully thought through national dementia strategies and plans, with input and support from all relevant stakeholders, and accompanied by sustained political will and new funding, have the necessary authority and resource to reengineer long-term care systems to suit the needs of people with dementia, who constitute the majority and most costly sector of older clients of these services.

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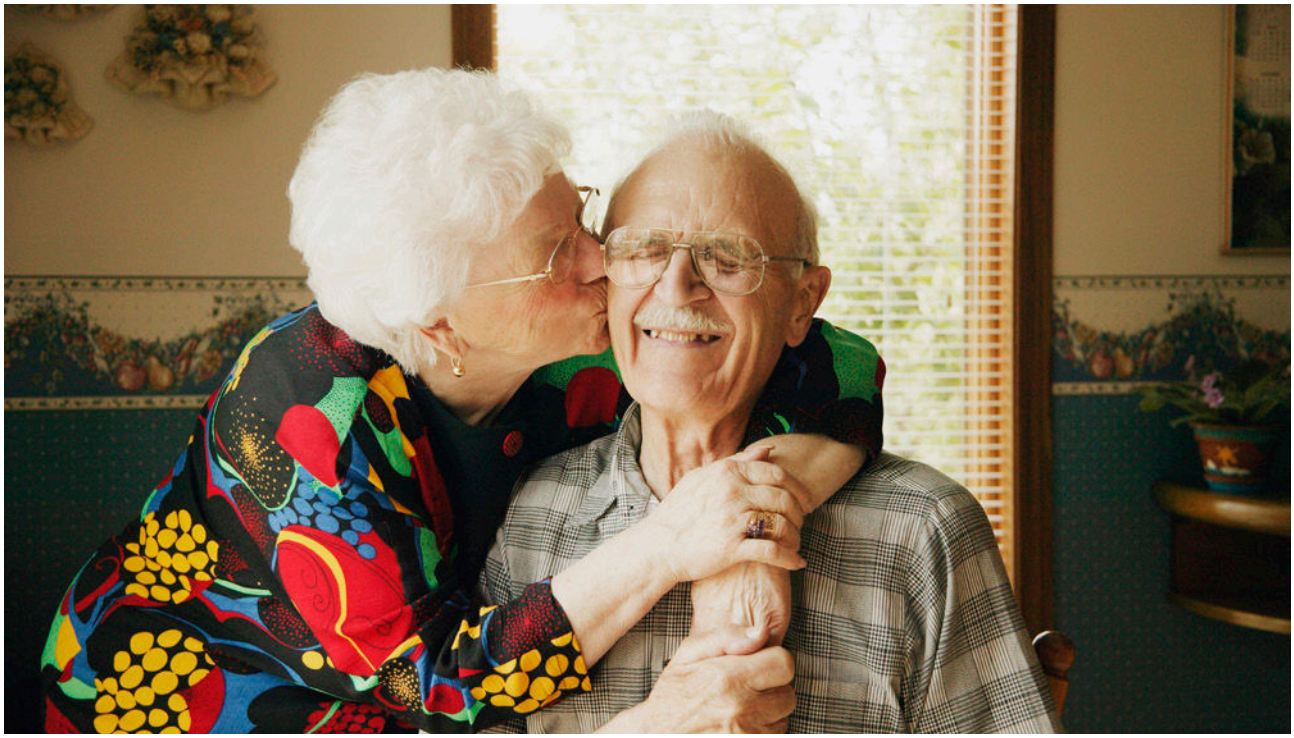
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CHAPTER 6

Financing long-term care for dementia



The global costs of dementia

In the 2010 World Alzheimer Report, Alzheimer's Disease International (ADI) estimated that the annual societal costs of dementia worldwide were US$604 billion [1,2]. 'Societal costs' refers to a comprehensive method of estimating the total costs of a health condition to society, which takes no account of how those costs are met (i.e. who is paying), and includes indirect costs (resources foregone as a result of a health condition) as well as direct costs (the costs of purchasing a service). The costs of dementia included (and were sub-divided into) three components: the direct costs of medical care, the direct costs of social care (paid home care, and care in care homes), and the indirect costs of informal care provided by unpaid family caregivers.

Clearly, dementia has an enormous impact on socio-economic conditions worldwide. It is difficult to envisage so large a sum. US$604 billion corresponds to 1.0% of the aggregated worldwide Gross Domestic Product (GDP), or 0.6% if only direct costs were considered. If dementia care were a country, it would be the world's 18th largest economy, ranking between Turkey and Indonesia. If it was a company, it would be the world's largest by annual revenue exceeding Wal-Mart (US$414 billion) and Exxon Mobil (US$311 billion). The scale of these costs is understandable given that:

- the 35.6 million people worldwide in 2010 comprise 0.5% of the world's total population [3]
- a high proportion of people with dementia need some care, ranging from support with instrumental activities of daily living, to full personal care and round the clock supervision
- in some high income countries, one-third to one half of people with dementia live in resource- and cost-intensive residential or nursing homes [4,5].

The distribution of total cost by country income status

The average costs per person with dementia varied considerably by World Bank income classification, from US$868 in low income countries, to US$3,109 in lower middle income countries, to US$6,827 in upper middle income countries, to US$32,865 in high income countries (Table 6.1). When multiplied by the estimated numbers of people with dementia this generated total costs of US$4.4 billion in low income countries, US$29.2 billion in lower middle income countries, US$32.4 billion in upper middle income countries, and US$537.9 billion in high income countries. The total cost, as a proportion of GDP varied from around 0.2% in low income countries to 1.2% in high income countries, with the highest proportions (1.3%) in the North America and Western Europe regions. Therefore, the costs of dementia are very unevenly distributed.

Table 6.1
The global societal cost of dementia, by country income status [1]

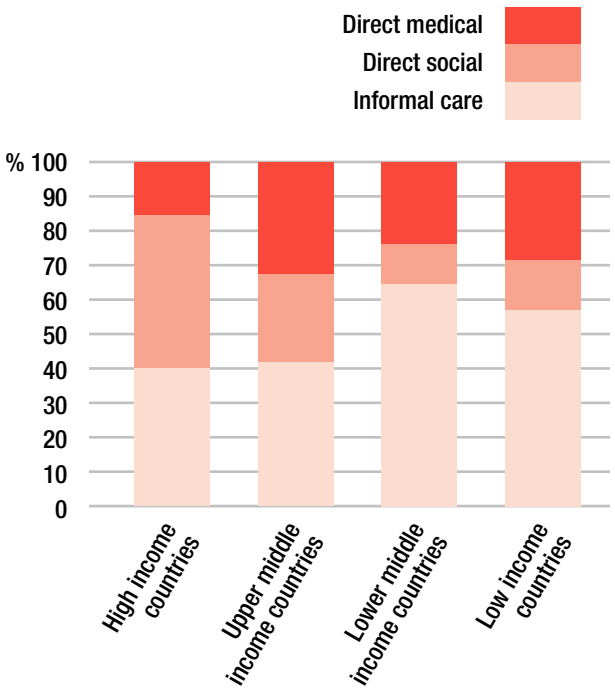
	Per capita cost	Aggregated cost (billions)	Cost of dementia, as % of GDP	% of global prevalence	% of global costs
High Income Countries	US$32,865	US$537.9	1.24%	46.0%	89.1%
Upper Middle Income Countries	US$6,827	US$32.4	0.50%	13.4%	5.4%
Lower Middle Income Countries	US$3,109	US$29.2	0.35%	26.4%	4.8%
Low Income Countries	US$868	US$4.4	0.24%	14.2%	0.7%

About 70% of the global societal costs of dementia are incurred in just two world regions; Western Europe and North America, and 89% of the total costs are incurred in high income countries. However, the minority (46%) of people with dementia live in high income countries, 39% of people with dementia live in middle income countries (where 10% of costs are incurred) and 14% in low income countries (accounting for less than 1% of the total costs).

The distribution of total cost by category

The distribution of total costs between sectors was also very different in countries with different income levels. In high income countries, the costs of informal care (accounting for 45% of the total) and the direct costs of social care (40%) contribute similar proportions to total costs, while the contribution of direct medical costs (15%) is much lower (Figure 6.1).

Figure 6.1
The breakdown of dementia costs by cost category, by country income status



However, in low and lower middle income countries direct social care costs are small and informal care costs predominate. Thus, while the total cost per person with dementia is 38 times higher in high income countries than in low income countries, the direct costs of social care are 120 times higher. In the ADI worldwide survey of care home utilization conducted for the 2010 World Alzheimer report, the proportion of people with dementia living in care homes was significantly higher in high income countries (30%, 95% CI 23-37%) than in low and middle income countries (11%, 95% CI 5-17%).

The marked imbalance in the global distribution of prevalence and costs arises, in part, because of the imbalance of costs between sectors. In low income countries, the formal social care sector (accounting for the direct costs of care in the community by paid social care professionals, and from costly care provided in care homes) is practically non-existent. Therefore, responsibility falls largely on unpaid informal carers, and informal care costs predominate. Since average wages (used to estimate informal care costs) are much lower in less economically developed countries, this has an important impact on comparative total costs. In high income countries the direct costs of social care account for nearly half of all costs. This is not, however, uniform across all high income countries. In the European Eurocode study of dementia costs, for example, informal care costs accounted for 56% of total costs [6]. However, this proportion was much higher in southern European countries (80%), and lower in western (48%) and northern European countries (32%). In Europe the reasons for these discrepancies will be complex, relating partly to the availability of formal care services, but also to the financing of long-term care, to eligibility rules, and to differences in demography, household living circumstances, and cultural attitudes towards formal versus family care. The onus on families to provide informal care remains strong in southern Europe, and has been enshrined in law in some countries [6,7].

The attributable cost of dementia, and comparisons with costs of other major chronic diseases

Since the 2010 World Alzheimer Report, further cost of illness studies have been released from high income countries, notably from the USA using data from the Health and Retirement Study and its dementia sub-study (Aging, Demographics and Memory Study – ADAMS) [8]. This furnished estimates of US costs from a nationally representative sample of people aged over 70 years, with linkage to comprehensive service utilization and cost data. Another strength of this study is that the investigators looked at the costs attributable to dementia as well as the total costs associated with dementia. Not all of the associated costs (costs incurred by people living with dementia) are necessarily attributable to the condition, since they may also arise from other comorbid health problems. The attributable costs were taken from multivariable models adjusting for the effects of other common chronic conditions on cost. Two methods were used to value informal care; the cost of foregone wages (similar to the approach used in the ADI report) and the costs of hiring a replacement carer. Using foregone wages for informal care costs, the total annual associated cost of dementia per person was US$47,920. The cost attributable to dementia was only a little lower; US$41,689 per person. Using the attributable costs, and foregone wages models, 68% of total costs arose from the direct costs of health and social care, and 32% from the costs of informal care. If the costs of hiring a replacement carer were used instead, then the contribution of informal care rose to 49% of total costs. Aggregated up to national level, the total attributable cost of dementia, using foregone wages to value informal care, was US$159 billion, of which US$109 billion arose from the direct costs of health and social care. These direct costs of care could be compared with US costs for other chronic health conditions calculated in a similar ways; the US$109 billion for dementia was similar to the US$102 billion for heart disease, and significantly higher than the US$77 billion for cancer [9].

Estimates of the comparative cost of dementia in the USA are broadly consistent with those recently derived from analyses of data from the UK and Sweden. In the UK, a report commissioned by the Alzheimer's Research Trust sought to compare like-for-like chronic disease costs with national expenditure on research [10]. The societal costs of dementia (£23 billion) almost matched those of cancer (£12 billion), heart disease (£8 billion) and stroke (£5 billion) combined. However, for every £1 million in costs arising from the disease, £129,269 was spent on cancer research, £73,153 on heart disease research and £4,882 on dementia research. In Sweden, the costs of dementia were compared with estimates for other chronic disorders [11]. The annual costs of dementia (50 billion SEK) was higher than for depression (32.5 billion SEK), stroke (12.5 billion SEK), alcohol abuse (21-30 billion SEK) and osteoporosis (4.6 billion SEK). In two other cost of illness studies, one taking a UK perspective, and the other a European perspective, the total societal costs of leading brain disorders were computed and compared, for people of all ages [12,13]. In the UK, while the most prevalent brain disorders were headache, anxiety disorders, sleep disorders, mood disorders and somatoform disorders, the five most costly disorders (€ billion) were: dementia: €22.2; mood disorders: €19.2; psychotic disorders: €16.7; addiction: €11.7; and anxiety disorders: €11.7 [12]. In Europe the six leading contributors were (€ billion) mood disorders: €113.4; dementia: €105.2; psychotic disorders: €93.9; anxiety disorders: €74.4; addiction: €65.7; and stroke: €64.1 [13]. The authors of the UK report highlighted that, with the exception of psychosis, the five leading disorders ranked amongst those with the lowest direct medical expenditure per person (<€3,000), arguing that while translational neurosciences research had the potential to develop more effective treatments, this was currently relatively underfunded [12].

What drives the cost of dementia?

Individual correlates of the cost of dementia

For people with dementia, total costs of illness are positively associated with the degree of cognitive impairment [14], behavioural and psychological (non-cognitive) symptoms of dementia [14-16], and with overall disease severity (Clinical Dementia Rating) [17,18]. However, ultimately, these effects are mainly mediated through disability in instrumental and core activities of daily living [19-21], and hence through needs for care. This may seem self-evident, but it is not always the case with other disorders, such as cancer and heart disease for which the costs of medical interventions predominate over social care costs. It should be emphasised again that for dementia this is mainly a function of the relative lack, but also the underprovision and underutilisation, of effective healthcare interventions, particularly in the early stages of the disease [22]. Low levels of help-seeking, and the fact that an estimated 28 million of the 36 million people with dementia in 2010 had yet to receive a diagnosis will have contributed to the very modest health care costs in all world regions [1,22].

The contribution of residence in a care home to the cost of dementia

At the aggregate level, it is often stated that the main cost-driver in high income countries is the cost of residence in care homes. This is true in part, but

Table 6.2
The relative average costs of high intensity home care, and care in a care home in the USA [23]

Service	Daily cost	Annual cost
Home care (paid health aide)	**$21 per hour or $168 for an 8 hour day**	**$61,320**
Adult day centre	**$70**	**n/a**
Assisted living facility	**$117**	**$42,600**
Assisted living facility providing special services for people with dementia	**$158**	**$57,684**
Nursing home (private room)	**$248**	**$90,520**

requires some qualification. The average cost of care services in the USA [23] is summarised in Table 6.2.

It can be seen that the cost of residence and care in care homes is high, and escalates with the level of care required, from general assisted living facilities, to those providing specialist dementia care, to nursing home care. However, admission to these facilities would generally be restricted to people with dementia with complex and advanced needs for care. The overall costs are comparable to those of employing a home care assistant for eight hours per day, or for an unpaid carer to provide an equivalent input of time, if using a replacement cost basis for valuing their care inputs. In making this cost comparison, it is important to bear in mind that the care home costs include 'board and lodging' costs (room rent, food, electricity etc) in addition to the specific costs of personal, nursing and medical care, which have not been included in the costs of high intensity home care.

Systematic review of the literature on the contribution of residence in a care home to the costs of dementia

In an attempt to clarify this issue, we carried out a fully systematic review for this year's World Alzheimer Report, identifying and summarising the existing world literature on the relative costs of dementia care at home versus in care homes.

Methods

A literature search to explore how dementia care costs vary according to community versus residential care was conducted in April 2013 on Pubmed/Medline and on the NHS Economic Evaluation Database. The following search terms were used on Medline ('alzheimer disease'[MeSH Terms] OR 'alzheimer'[All Fields] AND 'disease'[All Fields]) OR ('alzheimer disease'[All Fields] OR 'alzheimer'[All Fields]) OR ('dementia'[MeSH Terms] OR 'dementia'[All Fields] OR 'alzheimer disease'[MeSH Terms]) AND (('Costs and Cost Analysis'[Mesh]) OR ('cost'[All Fields] OR 'costs'[All Fields]) OR ('Economics' [MeSH Terms])).

Studies were included that reported or estimated costs (indirect or direct, or both) associated with dementia for people living in the community or in a care home. Studies were excluded if they only reported residential or nursing home costs alone, without comparison. Studies were also excluded if they did not provide a currency and a year for the cost estimation. Titles and abstracts of all of publications identified during the literature search were screened by Matthew Prina and Theodore Cosco, and excluded if they were clearly not relevant. Full text was obtained for the remaining publications, which were read by the same researchers, who then decided whether the publication fulfilled inclusion and exclusion criteria. Reconciliation and discussion was carried out at the end of this stage. The reference lists for the papers were also scanned to identify other studies.

A standardised data extraction form was used to collate relevant information from each selected paper, including information on country, year of publication, and year of the cost assessment, currency, sample size, type of costs included, and separate estimates for direct and indirect costs. All the costs were presented per person per annum, and were converted utilising GDP deflator index values and Purchasing Power Parities conversion rates produced by the International Monetary Fund and the Organisation for Economic Co-operation and Development. The common metric that was used for this report was American Dollars, using the 2010 price year.

Results

3965 abstracts were identified by the first search on PubMed and 124 on the NHS Economic Evaluation Database. 20 studies fulfilled the inclusion and exclusion criteria and were selected for this report. Three papers that were not published in English (from Germany, the Netherlands and Taiwan) were not read due to the time frame of this report, but will be included in a full review at a later stage. The characteristics of the 17 included studies are summarised in table 6.3. Most studies were carried out in Europe, Australasia and North America, and one study was carried out in Latin America (Argentina). All of the studies included the costs of informal caregiving for community resident people with dementia, but the comprehensiveness of the estimation, and the assumptions used to value informal caregiving varied between studies.

In all of the studies, with the exception of one study conducted in Taiwan [24], and one in Hungary [25], residential care was more expensive than community care (Table 6.4). However, in four studies [25-28] the differences in costs were not statistically significant. The excess annual cost of care in care homes ranged from minus US$16,284 [24] to plus US$31,571 [29], with a median difference of plus US$8,288.

Table 6.3
Characteristics of studies comparing the costs of care for dementia at home and in care homes

Authors	Year of publication	Country	Currency	Sample Size			Included costs	
				Community	Institution	Total	Direct	Indirect
Schwarzkopf [32]	2013	Germany	Euros	5,484	2,934	8,418	medical costs, medication, medical aids, rehabilitation, home health care, informal care (measure by long-term care insurance)	n/a
Vickland [30]	2011	Australia	Australian Dollars	139,200	92,800	232,000	formal care	informal care
Reese [19]	2011	Germany	Euros	272	123	395	medical costs, nursing care, and medication directly attributable to dementia	productivity losses for caregivers and people with dementia who would cut back on or gave up work
Kuo [26]	2010	Taiwan	New Taiwan Dollar	89	51	140	medication, care, transportation, food and equipment	informal care, travelling costs
Kraft [33]	2010	Switzerland	Swiss Franc	59,485	43,075	102,560	medical, care, medication	informal care
Ersek [25]	2010	Hungary	Euros	125,659	6,519	132,178	medical, care, diagnostic, transportation, social services	informal care
Allegri [34]	2007	Argentina	US Dollars	80	20	100	medical, medications, care, other services	informal care
Suh [35]	2006	Korea	US Dollars	85,822	10,178	96,071	medical, care, meals, social care, out of pocket purchases	informal care
Scuvee-Moreau [29]	2002	Belgium	Euros	218	168	386	medical, medications, care, visits, equipment	informal care, travelling costs
Beeri [27]	2002	Israel	US Dollars	71	50	122	medical, care, medication, paid help	informal care, housekeeper, handyman, book-keeper, nurse's aide
Chiu [24]	2001	Taiwan	New Taiwan Dollar			32,393	nursing care, medication	informal care, travelling costs
Fox [36]	2001	USA	US Dollars	93	94	187	formal care	informal care
O'Shea [31]	2000	Ireland	Irish Pounds	22,761	5,031	30,023	medical, formal care	Informal care
Leon [17]	1998	USA	US Dollars	354	325	679	medical, medications, care	informal care
Ostbye [37]	1994	Canada	Canadian Dollars	9,008	1,255	10623	medical, counselling, support group, physio, occupational, care	informal care
Rice [28]	1993	USA	US Dollars	93	94	187	medical, care, medications, social	informal care
Hu [38]	1986	USA	US Dollars	25	19	44	formal care, social	informal care

Table 6.4
Summary of comparisons of costs of care for those care for at home, and in care homes

Authors	Year of comparison	Currency	Reported results						Converted results (USPPP$2010)						Difference: care home vs community	Higher costs
			Community			Care home			Community			Care home				
			Direct	Indirect	Total	Direct	Indirect	Total	Direct	Indirect	Total	Direct	Indirect	Total		
Schwarzkopf	2006	Euros	9,765	n/a	**9,765**	1,388	n/a	**21,388**	12,128	n/a	**12,128**	26,564	n/a	**26,564**	+14,436	Institution
Vickland	2010	Australian Dollars	2,073	20,257	**22,330**	48,980	4,286	**53,267**	1,343	13,128	**14,472**	31,743	2,778	**34,521**	+20,049	Institution
Reese	2009	Euros	1,137	727	**1,864**	6,122	267	**6,389**	1,361	870	**2,232**	7,650	320	**7,970**	+5,738	Institution
Kuo	2008	New Taiwan Dollar	n/a	287,904	**431,951**	464,193	35,665	**499,858**	8,656	17,300	**25,956**	27,893	2,143	**30,036**	+4,080	No SD
Kraft	2007	Swiss Franc	8,720	46,581	**55,301**	66,891	n/a	**68,891**	5,305	28,340	**33,645**	41,913	n/a	**41,913**	+8,268	Institution
Ersek	2007	Euros	n/a	n/a	**6,432**	n/a	n/a	**6,086**			**7,870**			**7,446**	-423	No SD
Allegri	2001	US Dollars	3,189	4,941	**8,130**	14,448	416	**14,837**	3,902	6,044	**9,946**	17,675	509	**18,184**	+8,238	Institution
Suh	2002	US Dollars	3,617	4,916	**8,536**	n/a	n/a	**11,593**	4,354	5,918	**10,272**	n/a	n/a	**13,957**	+3,684	Institution
Scuvee-Moreau	1996?	Euros	4,326	1,021	**5,347**	25,526	1,734	**27,261**	6,232	1,470	**7,703**	36,775	2,498	**39,273**	+31,571	Institution
Beeri	1999	US Dollars	7,030	10,700	**17,730**	14,510	2,485	**16,995**	8,985	13,676	**22,661**	18,545	3,176	**21,721**	+939	No SD
Chiu	1998	New Taiwan Dollar			**999,708**			**597,396**			**40,512**			**24,228**	-16,284	Community
Fox	1998	US Dollars	19,070	45,870	**64,940**	63,7 84	7,365	**71,149**	24,732	59,489	**84,221**	82,722	9,540	**92,262**	+8,041	Institution
O'Shea	1996 1998	Irish Pounds	1,054	5,404	**6,458**	16,299	n/a	**16,299**	2,288	11,731	**14,019**	27,870	n/a	**27,870**	+13,851	Institution
Leon	1996	US Dollars	8,196	13,440	**18,588**	36,864	684	**37,548**	10,901	17,875	**28,776**	49,029	910	**49,939**	+12,391	Institution
Ostbye	1992	Canadian Dollars			**16,000**			**19,100**			**18,743**			**22,374**	+3,631	Institution
Rice	1990	US Dollars	12,572	34,517	**47,083**	42,049	5,542	**47,591**	19,310	53,017	**72,328**	64,586	8,512	**73,099**	+771	No SD
Hu	1983	US Dollars			**11,735**			**22,458**			**22,593**			**43,237**	+20,644	Institution

There are probably three main factors that account for the variation among studies in the relative costs of care at home and care in a care home; 1) approaches used to ascertain and value informal care; 2) the extent of control for the different levels of dementia severity (and hence needs for care) among those cared for at home and in a care home; and 3) whether or not 'board and lodging' costs were included in the costs of care in a care home.

1 The indirect cost of informal care was an important component, and indeed usually the dominant component of the cost of illness among people with dementia living in the community. However, the proportion of total costs for people with dementia living at home, attributed to informal care, varied between 19% [29] and 91% [30] by study. This reflected, largely, the methods used to assess informal care, and the assumptions made regarding the values to be attached to informal unpaid caregiving. Thus, in the Belgian study in which informal care costs made the lowest proportional contribution to the costs of dementia in the community, and in which the costs of care in care homes exceeded that of care at home by the largest margin, the important contribution of spouse caregivers was ignored in the estimation of costs [29]. In the modelling exercise conducted to estimate national costs for Ireland [31], it was pointed out that if replacement costs (£3 per hr for a home help) had been used instead of opportunity costs* (£1.35 per hr), then costs of informal care would have more than doubled; if the national average industrial wage (£6 hr) had been used the costs would have quadrupled. Under either of those scenarios the cost of care at home would have exceeded the cost of care in care homes. In the one (Taiwanese) study to show a clear excess of costs at home over costs of care in a care home [24], an exceptional effort was made to ascertain all of the costs of care, prospectively over a one month period. These included as 'non-medical costs' the extra expenses for food, clothing, transport, equipment and other miscellaneous items related to caring for the person with dementia. Caregivers diarised all of their care inputs over a one month period, prompted by telephone calls to do so. The hours of informal care inputs were valued at the market cost of a replacement professional caregiver.

2 The four studies in which 'like for like' comparisons of the cost of care among those with severe dementia were carried out, all indicated that for this group the costs of care at home either exceeded those of the cost of care in a care home [24,26,28], or that the cost differential was diminished with respect to that seen for mild or moderate dementia [17].

3 The Taiwanese study that indicated a higher cost of home care specifically excluded the costs of 'board and lodging' from estimation of care home costs [24]. Care home costs included only the costs of care, comprising; nursing care (25%), rehabilitation (20%), dietary services and nutritional counselling (24%), administration, maintenance and security (13%), medical care (18%) and dental care (9%).

Perhaps one of the best designed and most informative studies of the relative costs of care at home and care in a care home cannot be included in this meta-analysis since it was a longitudinal study of costs incurred over an 18 month period, and since costs were estimated from a multivariate bootstrapped model in which the effect of nursing home versus community residence at baseline was controlled for age, gender, comorbidity, ADL and IADL disability and depression [21]. The predicted total costs of nursing home residence were €9,108 less per year than the costs of living at home ($p<0.01$). This was accounted for by the reduced cost of informal care in care homes (€18,484 lower, $p<0.001$) exceeding the increased costs of formal care in those settings (€12,938 higher, $p<0.001$).

The conclusion from these studies is that

1 The difference in the costs of dementia, from a societal perspective, between those with dementia cared for at home and those cared for in a care home are negligible when the costs of unpaid informal care are properly ascertained, accounted for, and valued.

2 The main effect of moving into a care home is to shift the cost contribution from an indirect cost (income foregone by a family caregiver), into a direct cost of care provided by a care home worker.

3 The cost of care in care homes relative to care at home is inflated by the inclusion of 'board and lodging' costs in the former, but not the latter set of cost estimates.

4 It is important to control for dementia severity in comparing the costs of care at home with care in a care home. Having done so, the cost differences are diminished or no longer apparent. Societal costs of care for those with more advanced dementia are probably lower in care homes than in the community.

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* Assuming that if the caregiver was not providing care, 24% would go to paid work; 37% to unpaid work in the home; 7% to voluntary work; and 32% to leisure activities.

Future trends in the cost of dementia

Future trends in the cost of dementia are notoriously difficult to predict, and largely speculative [1]. Most studies that have attempted this have simply factored in projected increases in the numbers of people with dementia, assuming that age-specific prevalence, patterns of service utilization, and unit costs (at baseline prices) remain constant. Thus, ADI in its 2010 World Alzheimer Report predicted an 85% increase in worldwide societal costs from US$604 billion in 2010 to US$1,117 billion by 2030 [1]. In the USA ADAMS study estimates, the societal burden of dementia was projected to increase by 79% from 2010-2040, when expressed as an average per capita cost for every adult aged 18 years and over [8].

Assumptions regarding constant prevalence of dementia

These estimates will be pessimistic if improvements in population health mean that brain ageing is less pronounced in future cohorts of older people; it is estimated that realistic reductions (10-25%) in levels of exposure to cardiovascular and other risk factors for dementia could lead to a 3-9% reduction in the annual incidence of the disease [39,40]. Recent European population-based studies have reported reductions in the last 20 years in the prevalence (UK) [41], or incidence (Rotterdam) [42] of dementia, although this secular trend was not confirmed for Goteborg [43]. Conversely, there is evidence from China that the age-specific prevalence of dementia may have increased over the last 20 years [44]. This would be consistent with a recent modelling exercise [45], focusing on recent increases in obesity among middle-aged Chinese, and assuming that the observed association between mid-life obesity and dementia in high income country long-term cohort studies is causal; under these assumptions the model suggested that future dementia prevalence in China may have been underestimated by up to 19% given the additional impact of epidemiologic transition [45].

Assumptions regarding patterns of service utilization

The composition of the population with dementia will change over time in high income countries; due to demographic ageing there will be a much larger relative increase in the numbers of 'oldest old' with dementia [4]. This trend would be accentuated by any tendency towards longer survival with dementia. The oldest old with dementia are much more likely to require care in a care home [4], since they will be frailer with more physical comorbidity, and will be less likely to have a living spouse, or at least a spouse or child fit and well enough to provide care at home. As previously outlined (see 'A world in transition' on page 13), other global social and economic trends, including declining fertility, increased female labour force participation, increased workforce mobility, and a change in intergenerational attitudes towards and expectations of informal care are very likely to have an important impact on patterns of care. The main effect will be a shift from informal care, provided unpaid by families, towards formal care by professional caregivers at home, or in a care home. The shift from indirect to direct costs will have a fiscal impact, although the overall effect on costs from a societal perspective may be more neutral. The largest changes in this respect would seem likely to occur in the most rapidly developing middle income countries (China, India, Latin America), where demographic ageing is proceeding very rapidly, where social and economic change are likely to give rise to a demand for formal care services, and where such services are currently very underdeveloped.

Assumptions regarding unit costs for long-term care

Consumers of long-term care, including people with dementia and their caregivers, are, rightly, becoming increasingly vocal in demanding more comprehensive, more affordable and better quality care. This is particularly the case in high income countries where awareness is high and growing, and where consumer advocacy groups are well organised stakeholders in the national conversation regarding long term needs and how they should be met. Government policymakers and ministers would naturally always seek to drive up quality while reducing costs (in particular public costs). However, it is uncertain how feasible this will be in the medium to long-term. For example, of the core recommendations in our report for improving the quality of care for people with dementia (Chapter 5, page 42), most of these; e.g. measure and monitor the quality of care; incorporate service users' values and preferences into care; make care person-centred; improve training, increase professionalization and increase pay for care workers; seem very likely to increase unit costs of care. There is some evidence that advance care planning can reduce unnecessary and unhelpful service utilisation ('How effective is advance care planning?' on page 51), and a theoretical basis at least for hoping that making information available to consumers may drive costs down through the more efficient operation of a free market ('Make information available to consumers (knowledge is power)' on page 52). Coordination and integration of care is also meant to increase efficiency and reduce costs, but with little hard evidence to support this as yet ('Is case management effective?' on page 58).

Modelling the effect of demographic and epidemiological change, social trends, and policy change on projections for future costs of long-term care

The European Commission in its 2009 Ageing Report [46] applied a complex model designed to assess the impact of variables that affect long-term care expenditure on the proportion of national gross domestic product (GDP) that is allocated as public funding for long-term care. Specifically, the model analysed the impact of changes in assumptions made about:

- future numbers of older people, through changes in the population projections used;
- future numbers of dependent older people, by making changes to the prevalence rates of dependence;
- the balance between formal and informal care provision;
- the balance between home care and care in care homes (referred to as 'institutional care' in the EU report) within the formal care system;
- the unit costs of care.

The results of the analysis are broken down into:

a) the EU 15 countries; that is the original 15 countries in the European Union (Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, Netherlands, Portugal, Spain, Sweden, United Kingdom) prior to the accession of ten further countries in May 2004

b) the EU 12 countries; that is those mainly eastern European countries joining the EU after May 2004 (Bulgaria, Cyprus, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Romania, Slovakia, Slovenia).

At baseline in 2007, the proportion of dependent older people who relied on informal care only (or no care) was 52% in the original EU 15 countries, but 81% in the EU 12 accession countries. Even among the EU 15 there was considerable variation – around 70-80% for Portugal, Italy and Spain, around 50% in the UK, Germany and Belgium, around 30% in France, Austria, Ireland and Greece, while in Denmark, Netherlands and Sweden (in which countries current long-term care expenditure is among the highest in the EU), numbers of formal care recipients actually exceed the predicted number of dependent older people. For the EU 12 accession countries, the proportion of dependent older people relying on informal care only ranged from 52% (Czech Republic) to 92% (Cyprus). In 2007, the % of GDP spent by governments on long-term care was 1.2% for the original EU 15 countries, and just 0.3% for the EU 12 accession countries (Table 6.5). Again there was considerable variation among countries within these blocks; from 0.1% (Portugal) to 3.5% (Sweden) in the EU 15, and from 0.0% (Cyprus) to 0.4% (Poland) within the EU 12.

The base scenario for the future cost projections was the 'pure demographic' scenario, with no changes in age-specific prevalence of disability or dependence, the only driver of future trends being demographic ageing (the increases in the number of older people). GDP% increases from 2007-2060 were forecast to be 0.5% for EU 12 countries (hence increasing to 0.8% of GDP by 2060) and 1.3% for EU 15 (hence increasing to 2.5% of GDP by 2060) (Table 6.5). Particularly

Table 6.5
Publicly funded costs of long-term care in European Union Member State blocs, expressed as a percentage of GDP in 2007, and (projected) for 2060, under a range of different assumptions [46]

	EU 15[a]	EU 12[b]	EU 27[c]
2007	1.3%	0.3%	1.2%
2060	2.6%	0.8%	2.5%
Change 2007-2060 (pure demographic scenario[d])	+1.3%	+0.5%	+1.3%
Change 2007-2060 (constant disability scenario[e])	+1.1%	+0.4%	+1.0%
Change 2007-2060 (shift to home care[f])	+1.5%	+0.6%	+1.4%
Change 2007-2060 (shift to care homes[g])	+1.9%	+0.6%	+1.9%
Change 2007-2060 (shift to home care and care homes[h])	+1.7%	+0.6%	+1.6%
Change 2007-2060 (faster growth in unit costs[i])	+1.6%	+0.6%	+1.5%

a Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, Netherlands, Portugal, Spain, Sweden, United Kingdom
b Bulgaria, Cyprus, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Romania, Slovakia, Slovenia
c All 27 EU countries
d Assuming only increases in numbers of older people resulting from demographic trends
e Assuming, also, improvements in the health of successive cohorts of older people, and reduction in age-specific prevalence of disability and dependence
f Assuming, also, 1% per annum shift from informal care to home care
g Assuming, also, 1% per annum shift from informal care to care in care homes
h Assuming, also, 1% per annum shift from informal care, split evenly between home care and care in care homes
i Assuming, also, more rapid growth in LTC unit costs (1% above baseline projections)

large increases are forecast for some of the more generous current providers (from 3.4% to 8.5% for the Netherlands, from 3.5% to 6.0% for Sweden, and from 2.2% to 5.1% of GDP for Norway, as well as for some countries with more modest provision (e.g. from 1.4% to 3.8% for Greece). The UK, which is unusual among European countries in providing a means tested safety net rather than a comprehensive state insurance for long-term care, will increase public spending on long-term care from just 0.8% of GDP in 2007 to 1.4% by 2060.

Applying a fairly extreme and implausibly optimistic 'constant disability' scenario, in which all additional years of life expectancy are healthy active years rather than years spent in a state of dependence has a surprisingly small effect on projected increases in long-term care expenditure, which are attenuated by just 0.1-0.2% compared with the baseline 'pure demographic' scenario. Likewise, a gradual (1% per annum) shift from informal care to formal (paid) home only increases % of GDP spent on long-term care by a similarly small margin. It is only when the shift is from informal care towards care in care homes that there is a more sizeable 0.6% increment in % GDP allocated to long-term care, but limited to the EU 15 countries. Assuming a more rapid than expected increase in unit costs for long-term care (1% above annual increases in GDP per worker) again has only modest impacts on future cost projections, restricted to the original EU 15 countries.

The conclusions from these modelling exercises are that:

1 Some Member States (particularly the EU 12) rely heavily on the informal provision of long-term care by unpaid family caregivers and their expenditure on formal care is accordingly small, while others provide extensive public services for older people, and devote a significant share of GDP to fund their policies.

2 The major driver for future increases in long-term care spending in Europe is demographic ageing. Since those people who will be old in 2060 are already born, this is both nearly completely predictable, and inevitable.

3 Improvements in the health of future cohorts of older people, promoting informal care, restricting access to formal care, and limiting rises in unit costs would all tend to reduce projected cost increases, particularly for the wealthier EU 15 countries with their better established long-term care systems. However, the effects would be marginal with respect to the sizeable budget increases anticipated as a result of demographic ageing

4 The EU 12 countries will experience particularly large increases in the numbers of dependent older people. This will, as in rapidly developing middle income countries, increase demand for subsidised provision of formal care in care homes and in the community, along the lines of that which is provided by most of the EU 15 countries.

Figure 6.2
Typical income and consumption (per capita) across the economic lifecycle (0-90 years) [52]



The looming 'crisis' in long-term care funding

In most low and middle income countries, long-term care policy is premised on the questionable assumption that informal provision will suffice [47,48]. Standard & Poor's now considers global aging to be the dominant threat to global economic stability, predicting that without sweeping changes to age-related public spending on health and social care, sovereign debt in developed economies will soon become unsustainable [49]. For emerging economies, strong economic growth may give governments more time to consider policy options. However, with increasing demand for more effective social protection, Standard and Poor's considers that the need to tackle demographically-driven budgetary challenges is hardly less pressing than that now faced by advanced economies.

There are other more positive narratives that reflect upon the extraordinary human development and public health success that population ageing represents, and also acknowledge the contribution that older people make through wisdom imparted, care provided, and capital transferred to younger generations.

> **'Ageing is a development issue. Healthy older persons are a resource for their families, their communities and the economy. Their usually unpaid and unsung contributions are indispensable for development.' (WHO Brasilia Declaration on Ageing, 1996)** [50]

> **'We celebrate rising life expectancy as one of humanity's major achievements … this**

Figure 6.3
Typical income and consumption (aggregated across the whole population) across the economic lifecycle (0-90 years) for a low income country in the early stages of demographic transition [52]

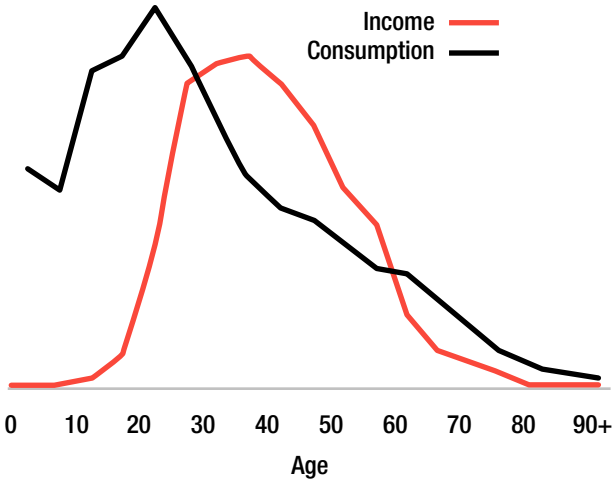
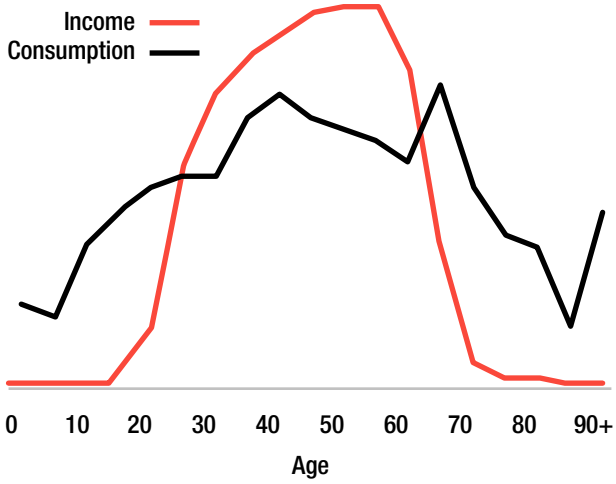


Figure 6.4
Typical income and consumption (aggregated across the whole population) across the economic lifecycle (0-90 years) for a high income country in the advanced stages of demographic transition [52]



> **demographic transformation challenges all our societies to promote increased opportunities for older persons to realize their potential to participate fully in all aspects of life.' (Madrid International Plan of Action on Ageing, 2002)** [51]

Nevertheless, Standard and Poor's clearly have a point. How affordable and sustainable are the current levels of provision for long-term care given the large projected increases in the numbers of older people with needs for care, coupled with a decrease in the size of the working age population? Standard and Poor's concern, expressed even before the eurozone crisis, was that Germany, the UK, the USA and other previously robust economies, quite apart from Spain, Italy, Greece and Portugal, would risk being downgraded to junk bond status unless immediate action was taken either to mitigate the future costs of long-term care for their ageing populations, or to find more sustainable ways of financing them. The crisis in middle income countries such as India and China would only be 20 to 30 years delayed.

The crisis explained

In all societies, throughout history, children and older people consume (in goods and services) more than they produce, while the working age population produces more than it consumes. This can be represented in an 'economic life cycle' function which, per capita looks rather similar in all world regions, regardless of their stage of economic development or demographic transition (see Figure 6.2).

These lifecycle deficits and surpluses are sustainable because of the complex systems that have arisen informally or been implemented by governments to enable flows of economic resources from surplus to deficit ages. In traditional societies the arrangements are entirely informal but enshrined in cultural, philosophic and religious principles that value the nurturing of children by their parents, and the care and support of older parents by their children. The extended family, and the wider community provided a safety net. In what are now considered high income countries, the state began to take on an important role, supplementing that of parents, children, families and charity, initially to provide a safety net of last resort, and later to promote equity; universal access to education and health care; protection against unemployment and other economic shocks; and income security and social protection for older people through contributory and social pensions. In this way, the public sector reallocates resources through social mandates embodied in laws and regulations. Education, public pensions and health care programmes are important examples of public reallocation programmes, but all aspects of public spending involve age reallocations to the extent that taxes are disproportionately born by some age groups while benefits accrue to all. Private-sector (informal) reallocations persist in all societies (for example private savings, remittances, gifts and charitable contributions), and these are governed by voluntary contracts, social conventions, and deeply ingrained and culturally sanctioned attitudes and behaviours that are mediated by markets, households, families, charitable organizations and other private institutions.

These intergenerational transfers rely upon:

a) a broad societal consensus for intergenerational reciprocity; that this is the right way in which society should be ordered, and

b) feasibility and sustainability; that is that there are adequate resources generated to be transferred to those that are less economically productive and

need support or care, and that everything is in balance.

Each of these pillars of the traditional system of intergenerational reciprocity is threatened by rapid demographic ageing, in ways that become apparent when production and consumption are aggregated across all individuals in the population, and the resulting economic life cycles compared for low income and high income countries at different stages in the process of demographic transition. In low income countries, pre-demographic transition, children predominate (Figure 6.3), while in mature post-demographic transition high income countries, the high consumption of the much greater relative number of older people predominates (Figure 6.4). These two fairly typical examples are modelled on the Philippines and Germany in 2003 [52]. In the Philippines the child deficit is almost 15 times larger than the old-age deficit, while in Germany the old-age deficit is 50 per cent larger than the child deficit. When the area under the income (production) curve exceeds the area under the consumption curve, a nation is in sound economic health. When the reverse is true, which is generally the case when the old-age deficit predominates, then a crisis of the kind alerted to by Standard and Poor's [49] is in the offing.

In the course of transition, developing countries enter into a period in which, as a result of declining child mortality, but persistently high fertility, the productive population is growing at a faster rate than the total population, per capita incomes increase, and economic growth is assured. This is often referred to as the 'demographic dividend' and accounts for up to 15% of the stratospheric economic growth currently seen in rapidly developing and industrialising countries such as China and India. However, as the demographic transition continues, fertility declines, choking off the growth of the working age population, while passage of the large pre-transition birth cohorts into old age, with increased survival and life expectancy, means that growth in the working-age population will be slow relative to that of the older retired population. All things being equal, the effect will be to depress growth, because the number of older consumers is growing more quickly than the number of workers.

The United Nations * has accurately described the challenge that population ageing poses for societies and governments worldwide:

> **'to ensure that people everywhere can grow old with security and dignity and that they can continue to participate in social life as citizens with full rights'.**

While at the same time respecting the principle that:

> **'the rights of old people should not be incompatible with those of other groups, and reciprocal intergenerational relations should be encouraged.'**

How can this challenge be met?

By bolstering social protection for all older people in low and middle income countries

Some governments have sought to encourage or coerce families to shoulder their responsibility for the financial support and care for older parents [53]. For example, the Indian parliament passed a law in 2007 requiring children to support their parents. The legislation states 'old age has become a major social challenge and there is need to give more attention to care and protection of older persons. Many older persons... are now forced to spend their twilight years all alone and are exposed to emotional neglect and lack of physical and financial support'. The Social Justice Minister, Meira Kumar said 'This bill is in response to the concerns expressed by many members over the fate of the elderly. With the joint family system withering away, the elderly are being abandoned. This has been done deliberately as they (the children) have a lot of resources which the old people do not have.' The legislation also provides for the state to set up old age homes that the minister said should be the 'last resort for the poor and the childless.' While such policies are understandable in the context of the very real social problem identified by Indian lawmakers, they seem destined to fail in the longer-term due to the reduced availability and willingness of children (principally daughters and daughters-in-law) to care [53].

More sustainable poverty reduction strategies include universal non-contributory social pensions (the focus of a campaign run by HelpAge International †), targeted disability pensions and caregiver benefits (see also 'By supporting and incentivising informal care by family carers' on page 85). For older people in developing countries 'dependency anxiety' [54-56] – not wanting to be a burden on relatives, fearing inadequate support, and therefore wishing to maintain independence from the family – is a key motivating principle. Social pensions address these concerns directly, providing insurance against the risks that older people face, including uncertainty over how long they will live, how long they will remain healthy, whether they can count upon the support of others if they need it, and how long they can earn an income. Social pensions play a significant role in alleviating chronic poverty in that that they can support whole families [57,58]. Older people consistently invest the money they have in income-generating activities and the health and education of dependants [59]. Most importantly they serve to reinforce reciprocal family ties, changing the perspective from

* United Nations, World Population Ageing 1950-2050, Population Division

† www.helpage.org/Researchandpolicy/Socialprotection

one in which older people are seen as a dependent drain upon household resources to one in which they can be properly valued for their non-economic as well as their economic contributions. Dependent older people would be particularly likely to benefit – informal care would be bolstered and formal/paid care would be more affordable.

By generating a 'second demographic dividend'

Mason and Kinugasa have argued that a 'second demographic dividend' can still be generated even in the context of global population ageing: [60]

a) if resources generated by the first demographic dividend are wisely invested in physical capital, and in children's health and education, hence increasing productivity of the next generation; and if,

b) policies and programs are implemented that improve labour participation rates and labour income, particularly for young workers who comprise large segments of these populations; and if,

c) workers are incentivised to save and invest to provide for their own retirement costs rather than drawing on the resources of younger generations

Increased incentives for saving and investment (including investment in their children's education) would be expected to come about when people perceive that it is more likely than not that they will survive into old age. However, problems arise with incentives and feasibility when the risks are not pooled, and when existing social welfare schemes are not fully funded.

By pooling risk

In countries with very limited social and income protection for older people the risks of protracted and costly dependence in late life are still relatively modest, and it is unlikely that all individuals, particularly the poorest in society will be able to make adequate provision. Equity, as well as motivation to save, is best promoted by some form of risk pooling, most commonly through a state organised or mandated insurance scheme [61]. This provides a degree of social security, independent of ability to pay, and freedom from worries about the risk of becoming dependent. Most OECD (high income country) governments have established collectively-financed schemes to support long term personal and nursing care costs [61]. One third of OECD countries have universal coverage either as part of a tax-funded social-care system (the Scandinavian model), or through dedicated social insurance schemes (e.g. Germany, Japan, Korea, Netherlands and Luxembourg). Several countries have a universal system of personal-care cash benefits (e.g. Austria, France and Italy), which can then be used to purchase care. Just two countries, the UK and the USA have 'safety-net' or means-tested schemes for long-term care costs. Private long-term care insurance has yet to find a foothold in the financing systems of most OECD countries.

By ensuring that long-term care schemes are 'fully-funded'

The second scenario is that arising in many high income countries, when the established social security system is financed through 'pay as you go' (PAYGO) rather than 'fully funded' principles. A fully-funded scheme is one in which each generation collectively makes provision for their own future needs for pensions, healthcare and long-term care. A PAYGO system is one in which the current working age population makes provision for the needs of the previous generation that is currently aged, usually through general taxation. PAYGO systems operate best when the relative number of contributors and beneficiaries under the system are fairly stable. This is clearly not the case in countries in which demographic ageing is advancing rapidly. Then, the growing numbers of people reaching retirement age are supported by shrinking numbers of active workers. PAYGO effectively removes the incentive for appropriate levels of saving and investment, at the same time fostering a misplaced sense of entitlement for benefits that have not been fully paid for, the bill for which will be passed on to the next generation.

PAYGO systems are widely recognised to be fiscally unsustainable, and pose a threat to intergenerational reciprocity. However, shifting from a PAYGO system to a fully-funded system is difficult, since the current generation of workers will be required to make increased contributions often for lesser benefits than are being enjoyed by their parents' generation, and there may also have to be restrictions in the benefits available to the current older generation. Such radical transformations to the social welfare system also threaten the consensus that exists for intergenerational reciprocity, and are politically unappealing, particularly in democracies where the older population constitutes a sizeable proportion of the electorate. As such, cross party consensus, and courageous political leadership of an open and honest national debate is needed for definitive action to be taken.

By rationing (targeting) of public spending on care

In nearly all OECD countries that have well-developed government funded social care systems, eligibility for home care services and admission to a care home has been tightened, with the effect that only those with much more advanced needs for care are eligible for receipt of subsidised services. Demand for long-term care services, and their cost to the public purse, can also be controlled through requiring copayment for some or all services. The extent and effect of this rationing varies across the best provisioned northern European countries, such that, for example, only 5-15% of those with only occasional needs for care

in most countries receive formal home care services, but the proportion is as high as 33% in Belgium and 58% in France [62]. International variation in the coverage of formal home care services is much less for those requiring more intensive daily care, with 45% or more receiving formal home care services in all the northern European countries, other than Germany.

Rationing could be perceived more positively as appropriate and efficient targeting of scarce public resources on those with the greatest need, and the greatest potential to benefit. However, there are some legitimate concerns regarding how this plays out for people with dementia. For example, the UK and the USA are two of the very few OECD countries where access to subsidised social care is means tested, with the state providing, in effect, only a safety net for those without the means to pay, or who have exhausted most of their assets in doing so (see Box 6.1).

According to the Alzheimer's Society, in the UK, increasing the eligibility thresholds for accessing support for people with dementia in the community has had a knock-on effect leading to earlier, crisis-driven and avoidable admissions to care homes owing to lack of community support [63,64]. Much UK spending on the support of people with dementia is late in the condition [65]. However, earlier diagnosis and timely intervention with support, education and training for caregivers can substantially reduce the risk of future transition to care home [22]. People with dementia require continuity of care and support from the time of diagnosis to death. While their needs evolve over time, with increased needs for personal care in the later stages, there is a clear risk that rationing of care may lead to a gap in services in the crucial early years when investment in advanced care planning (see 'Plan ahead (advance care planning)' on page 50), case management (see 'Coordinate and integrate care for people with dementia' on page 58), caregiver education and support, and peer support may all

Box 6.1

Rationing of publicly funded long-term care in the UK and USA

In the UK, while health care is free at the point of delivery, social care is means tested, other than small numbers of tightly controlled NHS continuing care places for people with advanced dementia and complex needs for care. Government contributions are capped (shortly to be increased to £75,000 pa [US$117,420]) – and those that wish to pay for places that cost more can top-up from family assets. Only those with assets of less than £23,250 (US$36,400) qualify for subsidised care, although this will increase to £123,250 (US$192,960) in 2017. Currently it is estimated that of those receiving care in care homes, 43% are self-funders, 43% are fully funded by the government, and 14% are funded by the government up to the cap, with the family providing a top-up. Alzheimer's Society surveys [67] indicate that those who self fund come from all sectors of society not only the most affluent.

In the USA, in response to the continued growth in the number of long-term care facilities and beds, a moratorium was introduced restricting the increase in supply of nursing home and long-term hospital care services to allow Medicare time to develop criteria for admission. By the expiry of the moratorium in December, 2012, programs to regulate nursing home beds were in place in 37 states, including in several states a restriction on the supply of beds and/or facilities. Rationing is also applied through strict means testing. The onus is upon Americans to spend down their income or assets on the costs of long-term care before accessing benefits. Only around 7 million Americans had long-term care insurance in 2010 [68], and that has shrunk substantially since then due to providers exiting the market, and premiums increasing beyond affordability. Therefore, few Americans with dementia have sufficient long-term care insurance or can afford to pay out-of-pocket for long-term care services for as long as the services are needed. Medicaid covers nursing home care and long-term care services in the community for those who meet strict requirements for level of care, income and assets. Medicaid beneficiaries must have low incomes, and spend all of their income, except for a very small personal needs allowance, to pay for nursing home care before Medicaid then makes up the difference. The Alzheimer's Association (US) has estimated that the aggregated costs for long term health and social care for people with dementia aged 65 and over (US Medicare Beneficiaries Survey) amount to US$203 billion [69]. Of this, 53% is covered by Medicare, 17% by Medicaid, 13% by other sources including long-term care insurance, leaving 17% or US$34 billion covered by out-of-pocket expenses [69]. In the US nationally representative ADAMS study, after controlling for demographics and comorbidities, those with dementia had more than three times the annual out-of-pocket expenditure of those who were cognitively normal (US$8216 per annum for those with dementia compared with $2570 for those with normal cognition), and the higher out-of-pocket spending was almost entirely accounted for by their much greater expenditures on nursing home care [66].

reduce the risk of unwanted interventions, transition to a care home, and attendant costs.

In both the USA and the UK, private individuals make a substantial and direct contribution to the costs of long-term care through out-of-pocket payments. The means testing is intended to ensure that only those who can afford to do so are required to make these payments. However, the low level of the threshold of income and residual assets at which the benefits cut in, and the high level of the cap on out-of-pocket payments means both that enormous expenditure can be incurred while assets are being spent down, and that this financial burden can affect almost all sectors of society, not only the richest. Evidently this can lead to financial worries, reductions in discretionary spending, and even in spending on essential items, and a greatly reduced quality of life [66]. It is for these reasons that means testing thresholds are soon to be relaxed in the UK (see Box 6.1). This is welcome, but increases the pressure on the public purse, and does not have any net effect on funds available for long-term care.

The OECD has recommended that governments explore the use of innovative financial instruments to alleviate the pressure of out-of-pocket payments, while still generating copayments by mobilising cash from equity, for example reverse mortgages on property, or combined life and long-term care insurance policies [61]. The board and lodging component of nursing home fees is substantial, but, ordinarily, the resident only frees up cash to contribute to this if they were living alone prior to moving into the care home. Home owners who cannot sell their homes can still do this through such equity release schemes.

By supporting and incentivising informal care by family carers

The OECD in its recent report 'Help Wanted? Providing and Paying for Long-Term Care' came out very strongly in favour of increased investment in this area, calling it a 'win-win-win' situation [61]. The three wins arise from

1 Benefits to carers who, without support, are at increased risk of giving up or cutting back on paid work, living in poverty, and have a 20% higher prevalence of mental health problems [61].
2 Benefits to care recipients, who generally prefer to be looked after by family and friends
3 Benefits to public finances, because it involves less public expenditure for a given amount of care than if this was provided in the public sector.

These findings are also amply demonstrated for the care of people with dementia; indeed the intensity of the care, and its negative impacts on caregiver economic productivity, mood and physical health are all significantly greater than for those receiving long-term care who do not have dementia (see Chapter 4).

These problems can be mitigated: by introducing cash benefits; by making working arrangements more flexible; and by offering support, education and training to careviers.

a) Introducing cash benefits

As we have seen, from a societal perspective, the cost of homecare is similar to that of care in a care home, when the inputs of informal carers are valued at the same level of a professional paid carer ('Systematic review of the literature on the contribution of residence in a care home to the costs of dementia' on page 74). In terms of the actual direct cost to the public purse, home care is much cheaper, because the informal carer is, generally, not being paid. OECD argues that they should be, not perhaps directly, but through the medium of cash benefits, which may not be as generous as a proper wage, but nevertheless provides some measure of compensation and concrete societal recognition of the contribution that they are making [61]. Cash benefits may take the form of direct payments to the caregiver (a caregiver's allowance) or to the care recipient (which could be used to purchase respite or substitute home care, or to compensate the household income for the loss of the caregiver's paid employment). Direct cash payments have been an important part of the state response to long-term care in France (Chèque emploi services universel), Italy, United Kingdom and Netherlands. In the Netherlands, where the cash benefit equals on average EUR 14,500 annually, and the restrictions on its use are minimal, evaluations have indicated a high allocative efficiency with low administrative costs, and a high satisfaction among beneficiaries. In Italy, there seems to have been widespread use of the cash benefits to hire migrants as live in substitute caregivers. Benefits to caregiver quality of life have not yet been clearly demonstrated [61]. The potential danger of cash benefits is that they may lock family caregivers into a role that is still poorly remunerated, and provides few opportunities for participation in the paid labour force.

b) Making working arrangements more flexible

OECD has demonstrated that that chances of an informal caregiver having paid work outside of the home declines by 10% with every 1% increment in hours of personal care provided [61]. This impact can be mitigated by flexible working schemes, which can include paid carer leave, flexible working hours, or working from home. Such schemes have been introduced with some measure of success in the UK, USA and Australia. In the UK, employers are required by law to consider requests from carers for flexible working arrangements, which should not, unreasonably, be refused.

c) Offering support, training and education to caregivers

There is ample evidence that caregiver psychosocial interventions, particularly those that include multiple interactive components, can be beneficial in improving caregiver mood and quality of life, and in delaying transition into a care home [70]. Caregiver multicomponent interventions (including elements

of training, support, enhanced coping and respite) have typically targeted caregivers who are already actively engaged in substantial practical caregiving tasks, and who may be experiencing psychological strain as a result. However, there is evidence that such interventions may be especially effective in delaying transition into a care home when started relatively early in the disease course [71]. In the US, family members of those with early stage dementia did identify needs for education, advice and support. These included educational information on the disease, and on research and clinical trials, emotional support (including peer-to-peer programs), and practical advice on employment, disability benefits, financial and legal issues. There is therefore a very strong argument for making psychoeducation and support available to all caregivers from the time of diagnosis, and then providing more focused multicomponent support as the condition progresses [22]. This is a cheap and cost-effective intervention with an almost universal indication, but which is yet seriously underutilised. The coverage of this intervention within the health and social care systems for dementia should be monitored closely, with policies implemented to increase coverage rates up to target levels.

By having a national discussion

The WHO policy document 'Towards an International Consensus on Policy for Long-Term Care of the Ageing' [72] describes principles to inform policies for sustainable programs in long-term care that are consistent with the priorities of countries at different levels of development, as a first step towards devising an international consensus.

Having noted the huge variation in the nature and extent of resources available for long-term care, the cultural differences in the understanding and expression of chronic disease and disability, and hence the differing notions of 'dependence' and 'needs for care', the report's authors stated as their first guiding principle

> **'With due attention to the appropriate balance of private and public responsibilities, each community should be able to determine objectively the level and kind of assistance required by an older person in need of care or by family members providing this care. The subsequent eligibility and payment for this assistance must also be addressed.'**

And as four essential points, stemming from this principle:

- recognition of fundamental basic standards
- assurance that care is of a high quality
- clarification of the values and aspirations, roles, and responsibilities of individuals and families as defined by their particular social context, within the larger society, and in relation to their own government
- reconciliation of the differences between these groups, and in the process, stressing the focus on the individual and the family.

The World Health Organization was calling, in effect, for detailed, comprehensive and ongoing national dialogues involving government, policymakers, key stakeholders, and an informed public. The agenda is still highly relevant, since most countries have yet to reach a settled, sustainable and comfortable consensus on who needs care; whose needs should be prioritised; how should that care be delivered, and by whom; what cost would be reasonable and supportable; and (perhaps most important of all) how should this be financed.

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Alzheimer's Disease International

About ADI

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Each of our 79 members is a non-profit Alzheimer association supporting people with dementia and their families.

ADI's vision is an improved quality of life for people with dementia and their families throughout the world. ADI aims to make dementia a global health priority, to build and strengthen Alzheimer associations, and to raise awareness about dementia worldwide. Stronger Alzheimer associations are better able to meet the needs of people with dementia and their carers.

What we do

- Support the development and activities of our member associations around the world.
- Encourage the creation of new Alzheimer associations in countries where there is no organization.
- Bring Alzheimer organizations together to share and learn from each other.
- Raise public and political awareness of dementia.
- Stimulate research into the prevalence and impact of Alzheimer's disease and dementia around the world.
- Represent people with dementia and families in international platforms at the UN and WHO

Key activities

- Raising global awareness through World Alzheimer's Month™ (September every year).
- Providing Alzheimer associations with training in running a non-profit organization through our Alzheimer University programme.
- Hosting an international conference where staff and volunteers from Alzheimer associations meet each other as well as medical and care professionals, researchers, people with dementia and their carers.
- Disseminating reliable and accurate information through our website and publications.
- Supporting the 10/66 Dementia Research Group's work on the prevalence and impact of dementia in developing countries.
- Supporting global advocacy by providing facts and figures about dementia and monitoring as well as influencing dementia policies.

ADI is based in London and is registered as a non-profit organization in the USA. ADI was founded in 1984 and has been in official relations with the World Health Organization since 1996. You can find out more about ADI at www.alz.co.uk.

Bupa

About Bupa

Bupa's purpose is longer, healthier, happier lives.

A leading international healthcare group, we serve over 14 million customers in more than 190 countries.

We offer personal and company-financed health insurance and medical subscription products, run hospitals, provide workplace health services, home healthcare, health assessments and chronic disease management services. We are also a major international provider of nursing and residential care for elderly people.

With no shareholders, we invest our profits to provide more and better healthcare and fulfil our purpose.

Bupa employs more than 62,000 people, principally in the UK, Australia, Spain, Poland, New Zealand and the USA, as well as Saudi Arabia, Hong Kong, India, Thailand, China and across Latin America.

For more information, visit bupa.com.

About Bupa's social care services around the world

Bupa cares for more than 30,000 people in more than 460 care homes and retirement villages in the UK, Spain, Australia, New Zealand and Poland.

Bupa is the largest international provider of specialist dementia care, caring for more than 19,000 residents with dementia.

In the UK, Bupa Care Services looks after more than 17,900 residents in almost 300 care homes.

In Australia, Bupa Care Services Australia currently operates 60 care homes caring for 5,300 residents.

In New Zealand, Bupa Care Services New Zealand cares for more than 4,600 people in 48 homes, 21 care villages and seven rehabilitation sites and also provides telecare services via a personal alarm network.

In Spain, Bupa (Sanitas Residencial) cares for around 4,400 residents in 40 care homes.

In Poland, Bupa (LUXMED) has a large care home in Warsaw.

For more information, visit bupa.com/dementia.

Alzheimer's Disease International: The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc. is incorporated in Illinois, USA, and is a 501(c)(3) not-for-profit organization

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