



**Alzheimer's Disease
International**

The global voice on dementia

World Alzheimer Report 2013 Journey of Caring

AN ANALYSIS OF LONG-TERM CARE FOR DEMENTIA

SUMMARY SHEET

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 13% of the world's population aged 60 years and over are dependent.

The global profile of dependence is changing, mainly because of population ageing. The numbers of older people with needs for care will nearly treble from 101 to 277 million. These increases will be particularly dramatic in low and middle income countries.

Long-term care for older people is, mainly, about care for people with dementia. Around half of all people with dementia need personal care (and the others will develop such needs over time).

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. People with dementia have special needs for care, starting early in the disease course, and evolving constantly over time, requiring advanced planning, monitoring, and coordination.

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. 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.

A comprehensive system of long-term care for people with dementia comprises both health and social care services.

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.

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.

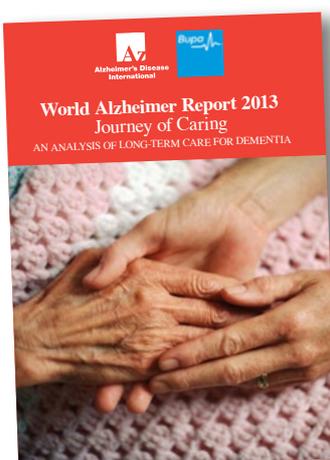
Care in care homes is, and will remain, an important component of the long-term care system for people with dementia. Currently around one-third to one-half of people with dementia in high income countries, and around 6% of those in low and middle income countries are cared for in care homes.

Caregiver multicomponent interventions (comprising education, training, support and respite) maintain caregiver mood and morale, and reduce caregiver strain.

Improving the quality 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



The full report can be downloaded from the ADI website www.alz.co.uk

Quality of care can be measured through structures (available resources), process (the care that is delivered), and outcomes.

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.

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.

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.

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.

Case management should also facilitate coordination of care, helping clients to use services more efficiently.

Family carers and paid caregivers share much in common. They all carry out difficult, demanding and socially useful roles, with minimal training and preparation.

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.

Affording good quality dementia care

Costs will increase at least in line with increases in numbers of people with dementia. 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. 89% of total worldwide costs of dementia care are incurred in high income countries.

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.

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.

The future cost of long-term care will be affordable, but only if governments act now to implement required

policies and reforms. Universal social pensions can provide security in old age.

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.

'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.

Direct payments (cash transfers) to caregivers, or care recipients allow their contribution to be recognised by society. Increased support for family caregivers may enable them to continue in their valuable role for longer, hence reducing the cost to public funds.

Recommendations

- 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.
- Governments should ensure there are systems in place to measure and monitor the quality of dementia care and support in all settings.
- Health and social care systems should be better integrated so that there are co-ordinated care pathways that meet people's needs.
- Governments and providers of care should ensure that healthcare professionals and the dementia care workforce are adequately trained to provide person-centred care.
- Governments and other stakeholders should ensure that autonomy and choice is promoted at all stages of the dementia journey.
- Care in care homes is, and will remain, an important component of the long-term care sector, and should be valued as such.

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Our vision is an improved quality of life for people with dementia and their families.

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The World Alzheimer Report 2013 was independently researched and authored by Prof Martin Prince, Dr Matthew Prina and Dr Maëlynn Guerchet on behalf of the Global Observatory for Ageing and Dementia Care. The key messages and recommendations were developed jointly by the Global Observatory and Alzheimer's Disease International.