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 longterm 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.

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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.

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• 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.
- 89% 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 & Poor's have advised sweeping changes to agerelated 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.

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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.

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- '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 workingage 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?