Non-Communicable Diseases in an Ageing World

A report from the International Longevity Centre UK, HelpAge International and Alzheimer's Disease International lunch debate

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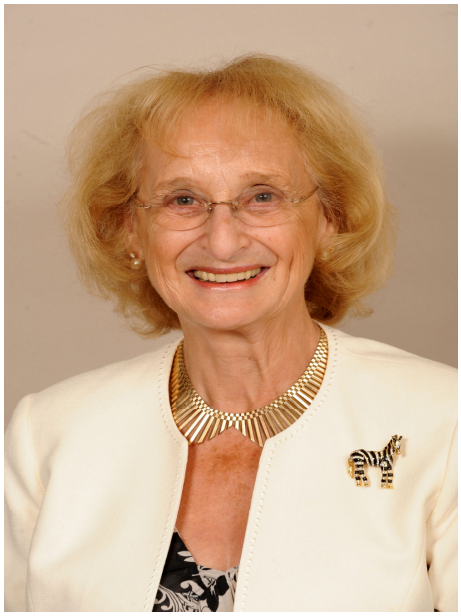

On the 19th and 20th September 2011 the first UN High-Level Meeting on Non-Communicable Diseases (NCDs) will be held in New York. However despite the prescient need to discuss NCDs across the life course at the international level, the focus on 'preventable death' below the age of 60 with cardiovascular diseases, cancers, chronic respiratory diseases and diabetes, and the omission of dementia is indicative of the low priority ageing and age related NCDs are afforded in the wider NCD debate.

Ageing has been recognised as the first of four key drivers of NCDs in developing countries and figures from the World Health Organisation show that deaths of over-60s caused by NCDs in the developing world are over twice the number of those below 60. Moreover, the impact of dementia on the ageing population is set to grow exponentially in the next decades. According to Alzheimer's Disease International, currently there is an estimated 35.6 million people with dementia globally, two-thirds of whom live in low and middle income countries. This figure is set to increase to 115.4 in 2050 and will especially affect developing countries.

Against this backdrop, Alzheimer's Disease International, HelpAge International and the International Longevity Centre - UK came together to consider how best to ensure the UN High-Level meeting adopts a genuine life-course approach to NCDs and recognises the importance of dementia. To this end I hosted an expert stakeholder lunch meeting in the House of Lords on 4th May 2011 to discuss this critical agenda and bring together many of our civil partners who expressed concerned that older people and dementia were conspicuously absent from the agenda.

This report, which is based on the discussion and recommendations from the expert meeting, will hopefully deliver a clear message about the need for a life-course focus on prevention, treatment, management and related care issues on NCDs and for dementia to be addressed as a global priority for action.

I would also like to take this opportunity to thank all the participants for their insightful contributions to the debate and I do hope we can continue, together, to push this agenda forward.

Baroness Sally Greengross

Chief Executive of ILC-UK

Introduction

This report is informed by a recent expert stakeholder lunch held in the House of Lords on the 4th May 2011 organised by Alzheimer's Disease International, HelpAge International and the International Longevity Centre - UK. The intention of the meeting was to galvanise support and bring together key experts to discuss the glaring omission of ageing and of Alzheimer's disease and related dementias from the current focus of the UN High-Level Meeting on Non-Communicable Diseases, taking place on 19th and 20th September 2011. Over 20 experts attended drawn from the academic, political, public and voluntary sector to discuss this agenda and agree a possible roadmap for future action.

The first part of the report highlights salient policy and political issues on the NCD question and summarises some of the key international developments in this regard. The latter section of the report provides a summary of the presentation by Professor Martin Prince, and identifies some of the key themes which emerged from the meeting.

Attendees were asked to consider a number of questions during the lunch, these included:

1. How do we achieve recognition of the central importance of the global ageing transition and older people in the NCD epidemic?
2. Is a 'whole life course' approach, inclusive of all ages, convincing as a key element of strategies for prevention, and innovations for treatment and cure, relating to NCDs?
3. How can we achieve recognition of Alzheimer's disease and other dementias as NCD priorities?
4. How can we work towards High-Level Meeting outcomes that ensure cost effective interventions and increasing access of older people and those with Alzheimer's disease and other dementias to health and social services?
5. There is currently very little research money for dementia and other chronic disease areas that are not seen as life threatening diseases. Do we need a Global Fund against Alzheimer's disease and other dementias to try to include this in the existing Global Fund?
6. How can we work beyond the High-Level Meeting to highlight the economic burden of care giving and the impact particularly on family caregivers and recognise that combating these burdens is an essential pathway for the achievement of the Millennium Development Goals?
7. How can the High-Level Meeting and its outcomes advance the right to health of older persons, in the light of the following statement "Health is a fundamental human right, indispensable for the exercise of many other rights, and necessary for living a life in dignity. Nevertheless, for millions of people around the world, the full enjoyment of the right to health remains an elusive goal. This is especially true for older persons, who are particularly vulnerable to infringements of their right to health".

The final part of the meeting was dedicated to formulating conclusions and priorities for future action. From these discussions Alzheimer's Disease International, HelpAge International and the International Longevity Centre - UK have developed specific recommendations which we hope many of the stakeholders involved will be able to take forward.

The political and policy context of the debate

The challenge of demographic change

Demographic transition and medical and technological advances have heralded a new dawn in the population landscape, with a wave of population ageing across the developed and developing world. While the world's older population has been steadily growing over time, it is the accelerated pace of ageing which distinguishes this development as a distinctly modern phenomenon. The rate of growth is rapid with both overall numbers and proportions of older people compared to younger people rising rapidly. The number of older people worldwide is expected to exceed the number of children by the year 2045. In 2009, there were more than 700 million older people and this number will increase to 2 billion by 2050, with the most rapid increases expected in developing countries.[1] Indeed it is a common misunderstanding to assume ageing is a concern only in countries with low birth rates, high incomes and effective geriatric health care. In 2008 more than 80% of the increase in older people in the year up to July 2008 was seen in developing countries and by 2040, the developing world is projected to witness more than 1 billion people aged 65 and over - accounting for 76% of the world total.[2] Though it should be noted the current level and pace of population ageing varies widely both within and by geographic regions.[3]

The "epidemiological transition"

While we may be living longer, the effects of increased unsupported longevity are a major concern and pose distinct health challenges. National morbidity profiles are now demonstrating a greater incidence of chronic and degenerative diseases[4] which represent the major cause of mortality and morbidity among older people in both the developed and developing world. This is the phenomenon of the "epidemiological transition," a phrase coined to describe the long-term change in leading causes of death, from infectious and acute to chronic and degenerative conditions. Developing countries are currently in various stages of the transition.[5] This was recognised by the UN Secretary-General's note of September 2010 transmitting the World Health Organization's global status report on NCDs, which refers to ageing as the first of four drivers of NCD predominance in developing countries. The figures of the World Health Organization show that deaths of over-60s from NCDs in the developing world are over

[1] UN General Assembly sixty-fifth session (13th September 2010), Note by the Secretary General transmitting the report of the Director General of the WHO on the global status of NCDs.
[2] Pilkington, E. (2009) The Guardian, http://www.guardian.co.uk/world/2009/jul/20/census-population-ageing-global.
[3] Alzheimer's Disease International, World Alzheimer Report 2009, http://www.alz.co.uk/research/world-report.
[4] Alder, J., Mayhew, L., Moody, S., Morris, R., Shah, R.(2005) The chronic disease burden - An analysis of health risks and health care usage, Cass Business School London, Special Report, www.nkm.org.uk/flyers/SpecialReports/CDB_Oct05.pdf.
[5] US Census Bureau Report (2009), An Ageing World: 2008, http://www.census.gov/prod/2009pubs/p95-09-1.pdf.

twice the number of those below 60.

Large numbers of older people are suffering from cardio-vascular disease, stroke and diabetes in developing countries. With regard to diabetes, for instance, 118 million of the 177 million people with type-2 diabetes are estimated to live in the developing world and the greatest increase in prevalence of type-2 diabetes in older people is expected to occur in Asia and Africa, with a peak of patients predicted by 2030. The increase in the incidence of diabetes in developing countries is thought to be following trends such as urbanization and lifestyle changes particularly "Western-style" dietary patterns high in fat, meat and sugar which are not just confined to more affluent groups, affecting populations in developing countries as a whole.

Double jeopardy – dementia

While NCDs are recognised as a pressing global health challenge, dementia has been relatively under-prioritised in international agreements, plans and policy guidelines. Despite the predicted growth in Alzheimer's disease and other forms of dementia, dementia is linked more to disability than to mortality and therefore has been historically overlooked as a policy priority.

The World Alzheimer Report 2009 produced by Alzheimer's Disease International reports that there are currently 35.6 million people with dementia, with the numbers set to double every 20 years to 65.7 million in 2030 and 115.4 million in 2050.[6] Proportionate increases over the next twenty years will occur in low and middle income countries, compared with high income countries. 58% of all people with dementia at the moment live in low and middle income countries with this set to rise to 71% by 2050.[7]

Many studies show the overall prevalence for males and females doubles for every five year increase in age after the age of 65. However this association with age has been the subject of some recent discussion, with the suggestion that the relationship between age and dementia is not age dependent but age related.

Dementia is considered to be among the most disabling of all chronic diseases. The middle to late stages of the disease in particular, signal a loss of autonomy, physical and cognitive function and independence for most individuals affected. In order to quantify disease burden in 1990 the World Health Organization introduced a new metric – the Disability-Adjusted Life Year (DALY). DALYs for a disease or health condition are calculated by the sum of the Years of Life Lost (YLL) due to premature mortality in the population and the Years Lost due to Disability (YLD) for incident cases of the health condition.[8] According to the most recent Global Burden of Disease report, as cited in the World Alzheimer Report dementia contributes to 0.8% of all DALYs worldwide. 1.6% of Years Lived with Disability and just 0.2% of Years of Life Lost. As dementia is a disease

[6] Alzheimer's Disease International, World Alzheimer Report 2009, http://www.alz.co.uk/research/world-report.
[7] Ibidem.
[8] World Health Organization (2009) Global Health Risks, http://www.who.int/healthinfo/global_burden_disease/GlobalHealthRisks_report_full.pdf.

which primarily affects the older population, the proportionate contribution is considerably higher among those aged 60 and over, accounting for 4.1% of DALYs, 11.3% of Years Lived with Disability and 0.9% of Years of Life Lost.[9]

While dementia is more commonly associated with disability and cognitive impairment, dementia is slowly being recognised as an underlying cause of death.[10] The dementia specific mortality rate was found to be twice the rate of people without dementia, controlling for co-morbidities and socio-demographic factors. Analysis from the Global Burden of Disease Report 2004[11] showed a similar picture in many world regions, but the male and female mortality rates were in no way uniform.

Dementia is thus not only exacting a heavy cost on individuals and families, but the current and future economic development of all countries. Indeed the global prevalence of dementia is far greater than initially assumed, which drives the costs to 1% of global GDP or $604 billion.[12] The true cost of caring for those affected is felt by families that as yet do not have secure resources to call on, especially in the developing world. In the developed world, the model of care for individuals in the moderate to severe stages of dementia is often based on long-term care in institutions. Though it should be noted, given the high disability burden of dementia, a significant proportion of care particularly in the early to middle stages of the disease is provided by unpaid carers. In developing countries, formal care provision for dementia is virtually non-existent and even if it were available, it would be beyond the financial grasp of most families. The public health sector is primarily focused on curative and preventative health care, private health services are few and far between and do not meet the costs of continuing care. Thus the model of care is based on informal care provided by the family or the close community or in some cases non-governmental organisations.

It should also be noted that as dementia is a relatively new phenomenon for the developing world, the care for people with dementia has received little attention. Historically it has been an uncommon condition with few people surviving into the age

[9] Alzheimer's Disease International, World Alzheimer Report 2009, http://www.alz.co.uk/research/world-report.

[10] Aguero-Torres, H., L. Fratiglioni, et al. (1998) Dementia is the major cause of functional dependence in the elderly: 3-year follow-up data from a population-based study, Am J Public Health 88(10):1452-6.
Baldereschi M, Di Carlo A, et al. (1999) Dementia is a major predictor of death among the Italian elderly, ILSA Working Group, Italian Longitudinal Study on Aging, Neurology 52(4):709-13.
Dodge, H. H., C. Shen, et al. (2003) "Functional transitions and active life expectancy associated with Alzheimer disease." Arch Neurol 60(2): 253-9.
Helmer, C., P. Joly, et al. (2001) Mortality with dementia: results from a French prospective community-based cohort, Am J Epidemiol 154(7):642-8.
Jagger, C., K. Andersen, et al. (2000) Prognosis with dementia in Europe: A collaborative study of population- based cohorts. Neurologic Diseases in the Elderly Research Group, Neurology 54(11): S16-20.
Witthaus, E., A. Ott, et al. (1999) Burden of mortality and morbidity from dementia, Alzheimer Dis Assoc Disord 13(3):176-81.
Wolfson, C., D. B. Wolfson, et al. (2001) A reevaluation of the duration of survival after the onset of dementia, N Engl J Med 344(15):1111-6.

[11] Mathers C., M. Leonardi, WHO Global burden of dementia in the year 2000: summary of methods and data sources, www.who.int/healthinfo/statistics/bod_dementia.pdf.

[12] Alzheimer's Disease International, World Alzheimer Report 2010, http://www.alz.co.uk/research/files/WorldAlzheimerReport2010.pdf.

group most at risk.[13] Hence developing countries have not developed the capacity or health or social care infrastructure to respond to what is now a looming threat for their populations. Furthermore there remains widespread misunderstanding of Alzheimer's disease and other forms of dementia across many communities; dementia may be considered to be simply an extension of the ageing process or even worse, in some instances, the individual with dementia is considered to be simply 'mad'. Without this basic awareness and knowledge of dementia at the population level, many old people not only suffer discrimination and prejudice as a result of their advancing age, but also face the double jeopardy of the stigma often associated with dementia as well.

Conceptual reductionism – do we need to redefine old age and ageing?

In many respects population ageing and in most countries an increase in life expectancy is a testament to our development and success as a global society. Such changes pose not only the widely attested questions of how, for example, our economic, health and social care systems should respond, but also less tangible concerns of the potential of human lifespan and how we may need to redefine entrenched concepts of old age in light of this. The ageing of the population represents a distinct and immediate challenge to policy-makers, especially given the mainstream discourse framed generally in relation to cost and consumption. The current policy focus is in danger of overlooking the current and potential contribution of older people to their families, communities and wider civil society.

Indeed the widespread negative discourse on the growth of the ageing population more generally encapsulated in pejorative terms such as 'burden', 'problem', and 'dependency' has invariably encouraged reactive policy-making at the expense of a more planned and preventative approach. Policy interventions in health and social security regarding older people generally are not widely represented as an 'investment' in the future and yet it has been demonstrated that low-cost prevention interventions will reduce the need for further help and enable people to continue contributing to society.[14] In low and middle-income countries such as, Costa Rica and Sri Lanka, effective public health provision which is inclusive of older people have enabled these countries to achieve life expectancies at aged 60 of 20 years or more.[15]

The rapid pace of our ageing populations and increased life expectancy also arguably challenges our traditional definitions of old age and what it means to be old. At what age do you start being old? When society deems you to be old through statutory retirement age for example, when younger generations perceive you to be old or when you feel old? It is not uncommon to meet a very active person in their 80s, or on the contrary,

[13] Prince, M (1997) The need for research on dementia in developing countries, Tropical Medicine and International Health 2(10): 993-1000.
[14] Raine, R. et al (2009) Sociodemographic variations in the contribution of secondary drug prevention to stroke survival at middle and older ages: cohort stud, BMJ 338:b1279
[15] Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat (2009). World Population Prospects. The 2008 Revision. Highlights. http://www.un.org/esa/population/publications/wpp2008/wpp2008_highlights.pdf.

somebody with high support needs aged 65 or younger. A study for Help the Aged on the 'voice' of older people by the ILC- UK supports this view. The report suggests there is little evidence that the widespread perception of the older population as an entity is shared by older people themselves. Such an essentialist view of older people may provide external simplicity to the understanding of identity, but critically the individuals concerned invariably fail to recognise the prescribed characterisation. Thus at present there is an apparent disconnect between public and policy discourse on older people's identity and how older people view themselves. Being old has become an all-purpose explanation eschewing the complex realities of an individual's myriad attachments and affiliations by the simplifying process of stereotyping. This in turn has serious consequences for how we treat older people, in terms of age discrimination, in health and social care, equal and fair access to goods, facilities, services and treatment in employment.

Equity and accessibility in health care in old age

Thus a one size fits all policy approach seems somewhat outdated given the diversity and heterogeneity of the ageing population and yet healthcare provision based on arbitrary age limits remains the default model in many countries. For example preparations and suggested indicators for the upcoming UN High-Level Meeting on NCDs make reference to specific ages for calculating 'premature death', setting a measurement range of 30 – 70 years. However selecting an arbitrary cut-off point for 'premature death' discriminates against older people by rationing health provision on the basis of age and can be interpreted as a denial of the right to health. Moreover it is impossible to set a global age limit across very diverse demographic, health, economic and social realities. Any attempt at creating a single global cut-off age of 'premature death' for NCDs could inadvertently encourage governments to withhold much needed diagnosis, prevention, treatment and care without reference to the actual needs of its older population.

The International arena

While the international arena is slowly waking up to the challenges demographic change may pose, in terms of the health and development agenda, there is a very clear focus on communicable diseases, primarily health care for children and mothers and those in reproductive years, which reflect the priorities of the Millennium Development Goals. While it is important to focus on these issues, addressing older people's health needs has historically received low (or no) priority in health policies and programme financing. This is despite the fact that both the demographic and epidemiological transition is increasingly placing the greatest burden of disease on non-communicable conditions more associated with older age. Arguably addressing ageing is essential to achieving the Millennium Development Goals (MDGs) as well as responding the NCD burden, which is itself is a major contributor to poverty in old age. In fact action on ageing and poverty is explicitly called for in the 2002 Madrid International Plan of Action on Ageing, and 'Advancing health and wellbeing in old age' is the second "priority direction" of the 2002

Madrid International Plan of Action on Ageing 5 which is due for its ten year review and appraisal in 2012.

It is therefore not acceptable that to date preparations and preparatory documents for the High-Level Meeting so far omit references to NCD prevalence in older age. While strengthening the link of NCDs to the development agenda is vital, the challenge of NCDs for older people in the developing world cannot be overlooked. The invisibility of older people in the NCD debate is an example how ageing populations continue to have a peripheral place in development.

Conversely a focus on a whole life course approach to NCDs which is inclusive of older people presents opportunities for innovative solutions which both keep people healthy and active longer, and have beneficial social and economic impacts.

Expert Stakeholder Lunch on the UN High-Level Meeting on Non-Communicable Diseases

Summary of the debate

Baroness Sally Greengross – International Longevity Centre - UK

Baroness Greengross, in her position as chair, welcomed the attendees and thanked Alzheimer's Disease International and HelpAge International for joining forces with the International Longevity Centre - UK to organise the expert stakeholder meeting. Baroness Greengross stated that the aim of the meeting was to highlight the need for ageing and, in particular, Alzheimer's disease to be included in the UN High-Level Meeting on Non-Communicable Diseases (NCDs) which will take place 19-20 September 2011 in New York. Baroness Greengross expressed concerns regarding the fact that the agenda for the High-Level Meeting currently focuses on younger age groups at the expense of older people and underlined the need to work out how to push for a more inclusive meeting which assumes a life course approach. She then invited the speaker, Professor Martin Prince, to open the debate.

Professor Martin Prince

Professor Prince opened his presentation by stating that dementia is and should be classified as a NCD and be accorded the same public health status as other chronic diseases such as diabetes or cardiovascular disease. Dementia currently presents a significant public heath challenge to all countries and as yet, regardless of the levels of informal or formal care provision, decent quality care for individuals with dementia remains elusive for almost all global citizens. The lack of new treatments which could either delay the onset of dementia or prevent dementia, also arguably hampers rates of diagnosis. If people thought new treatments were available they would arguably be more likely to come forward and present their symptoms to GPs or health professionals.

He commented that Baroness Greengross was right to highlight the startling statistics on dementia. In the World Alzheimer Report 2009, Alzheimer's Disease International estimated that there are 35.6 million people living with dementia worldwide in 2010, increasing to 65.7 million by 2030 and 115.4 million by 2050. Nearly two-thirds live in low and middle income countries, where the sharpest increase is likely to occur. The World Alzheimer Report 2010 explored the global economic impact of dementia, highlighting the total estimated worldwide costs of dementia are US$604 billion in 2010. These costs account for around 1% of the world's gross domestic product. He explained that if dementia care were a country, it would be the world's 18th largest economy and if it were a company, it would be the world's largest by annual revenue exceeding Wal-Mart (US$414 billion) and Exxon Mobil (US$311 billion). With regard to the distribution of total costs worldwide, direct medical care costs are only 16%, with the rest of the costs distributed in similar proportions on informal care and the direct costs of social care. He

posited that there could be a number of reasons to explain why health care costs are small in comparison, including: low levels of awareness, thereby influencing diagnosis rates, stigma, lack of available treatments and traditional misconceptions that dementia is just part of the ageing process and not a medical condition that necessitates medical interventions.

The high levels of informal care costs and social care costs can to a large extent be explained by the high disability burden associated with dementia. Dementia is considered to be among the most disabling of all chronic diseases and is the number one contributor to years lived with disability. In developing countries, formal care provision for dementia is virtually non-existent and even if it were available, it would be beyond the financial grasp of most families. The public health sector is primarily focused on curative and preventative health care with private health services few and far between. Thus the model of care is based on informal care provided by the family or the close community or in some cases non-governmental organisations. In low and middle income countries 80% of the care for individuals with dementia is provided by unpaid carers. In the developed world, the model of care for individuals in the moderate to severe stages of dementia is often based on long-term care in institutions. However it should be noted, given the high disability burden of dementia a significant proportion of care particularly in the early to middle stages of the disease is provided by unpaid carers.

Professor Prince, however, said it should not be assumed this model of informal care will continue, since several demographic and societal threats particularly in developing countries imply a dramatic shortfall in informal care provision. The World Alzheimer's Report identifies four trends which could have dramatic consequences: the education of women and their increasing participation in the workforce, migration, which leads to increasingly mobile populations and a breakdown of traditional family and kinship structures, declining fertility rates in the final state of the demographic transition and in Sub-Saharan Africa, and the HIV/Aids epidemic which has led to 'orphaned' parents as well as children.

With regard to the forthcoming high level meeting on NCD's, the focus is mainly on cardiovascular diseases, cancers, chronic respiratory diseases and diabetes is predicated on preventing mortality and common risk factors. While he stressed this was indeed important, it is also critical to protect against disability. Similarly other mental conditions such as depression are also conspicuously absent from the agenda. He said this misplaced focus eclipses the cost of long term care, one of the pressing threats to particularly middle and high income economies. According to a recent report by Standards and Poors, developed countries have between four to six years to address the issues of long term care and dementia care, before economies crumble under the strain. He stressed that given the rapid increase in prevalence in developed and particularly developing countries; all communities will feel the strain and impact of dementia.

Summary of key themes

Prevention agenda for dementia

Several attendees observed that the dementia agenda is often overlooked when policies for prevention and treatment of NCDs are proposed. The key preventative factors for developing dementia include a healthy diet, promoting physical and cognitive activity and controlling cardiovascular risk factors such as diabetes, high cholesterol and hypertension. There is the potential for synergy with wider prevention and public health messages for NCDs. One attendee highlighted that there needs to be more and greater exploitation of longitudinal population studies to further understanding of the ageing process, and to identify the risk and protective factors relating to dementia. In line with the findings of the Ministerial Advisory Group on Dementia Research, it was also suggested the analysis of combined epidemiological datasets should be promoted to help tease out the effects of comorbidities and the relationships between environmental and genetic factors.

An inclusive lifecourse approach

While the primary focus of the meeting was to debate the omission of older people and more generally ageing in the preparatory documents for the UN High-Level Meeting on NCD's, one attendee noted that several organisations promoting the rights of children in health had voiced their concerns that the younger generation were also overlooked. Many attendees felt there was a need for a more inclusive agenda which covers the entire age spectrum. For this reason a whole life course approach, inclusive of all ages, was desirable.

Holistic care framework

With regards to care, many attendees also agreed that as a society both at the national and international level there is a need to manage care more holistically, bringing a greater level of interaction between formal and informal health and social care provision. Basic primary health care interventions, an improvement with regard to workforce development and training and more targeted geriatric health care, are all factors which are perceived to improve health outcomes.

Given the various stages of transition of developing countries, it was felt by some attendees to be somewhat unrealistic to discuss universal models of general health care for older people or for people with dementia. It was suggested by one attendee that in light of the vast differences between health and social care systems, typologies of health care models should be developed.

Managing the demand for care

In light of the growing care burden of dementia across the developing and developed world, the need for governments to introduce non-health related policy reforms to alleviate care and mitigate against a possible carer shortfall was also raised. The need for flexible working for carers was highlighted as a policy priority by one attendee. For

example, the Work and Families Act 2006 extended the right to flexible working for carers in England, Scotland and Wales.

One delegate suggested that while the growing burden of care is slowly being recognised as a policy challenge, many people do not feel we have, as yet, reached a tipping point and this may be why there is not such a strong drive for policy reform in this area. However a recent report by Standard and Poors argued that the cost of long-term care constitutes the biggest threat to the future sustainability of developed economies.

Ageing, development and rights

The debate on dementia encompasses the wider debate of how as a society we view old age and older people and the arbitrary classifications of ageing which currently exist. Traditional conceptions of paternalism and the increasing public and policy rhetoric of the ageing population being described in terms of 'burden' and 'dependency' do not help promote the rights of older people. Indeed the rights of older people to equal access to health care and treatment in particular were raised as important issues. For example while gender equality is mainstreamed across almost all international health initiatives, the right of older people to the highest attainable standard of health remain conspicuously absent.

This latter point was also highlighted with regard to the development agenda. It was argued that there remains a very clear focus on communicable diseases, primarily health care for children and mothers and those of reproductive age, which reflect the priorities of the Millennium Development Goals. While this is unquestionably important, it was suggested that a more inclusive life course approach is essential, particularly with regard to the prevention of NCDs in later life, which also impoverish families across generations. Increasingly in low income countries older people are primary carers of children as well as being heads of households that are affected by HIV and AIDS, conflict and migration. The outcome of the Summit must be relevant to them and supportive of their needs.

Research

There was discussion on the need to develop the research base on ageing, NCDs and dementia. Investment in dementia research has been historically overlooked compared to cancer and heart disease, and yet the cost of dementia to society is greater. The need to improve levels of understanding and support for dementia research was considered to be vital, as there remains no cure. Greater investment in pharmacological and non-pharmacological research was also considered necessary to help alleviate future care levels and improve quality of life for the individuals affected.

The need to understand how communities and families are responding at the ground level to ageing was also raised as an area for future research, for example how many older people have caring responsibilities, how do they still contribute to their families and societies and how are they cared for with the onset of dementia. This was considered to be particularly pertinent for low and middle income countries where awareness of dementia is low and there is a paucity of research on age and dementia management.

Many countries have insufficient monitoring and recording systems of births and deaths, for example, which makes it problematic to understand NCD prevalence in these countries.

Action and ideas for the High-Level Meeting

Several attendees felt there was a need for dementia organisations to be part of the NCD Alliance. Discussions are already underway with Alzheimer's Disease International in this regard. However while this was considered a positive development, one attendee suggested caution should be observed that dementia is not subsumed in policy priorities by other diseases which sometimes have a higher profile - for example heart disease - which could be a danger when engaging with umbrella organisations of this nature.

One attendee also voiced concern that while dementia should be included alongside the other major NCDs by the UN, it should also be afforded a distinct priority, given the critical role that social and cultural norms play with regard to diagnosis, treatment and care. The problem is not only one of awareness, but discrimination, prejudice and stigma. Dementia in some countries is seen as an inexorable part of the ageing process or even worse as a sign of madness in a few communities; hence the need to challenge these norms is also essential in order to improve health outcomes.

With regard to the potential for influencing the UN High-Level Meeting on NCDs, some attendees queried whether it could be too late, as the agenda and preparatory documents have already been drafted. However several attendees suggested there are still influencing opportunities in terms of outputs, and it represented a chance to highlight the omission of ageing and dementia, even if this serves as a stepping stone for future engagement. Simply the inclusion of dementia as a NCD and/or ensuring the language and tone of the written outputs are inclusive of older people would still be beneficial, particularly for example the language on premature death. There was also the suggestion that the UK delegation could assist in the organisation of a fringe event to help raise the profile of dementia and ageing, bringing the issues of ageing and mental health to the forefront in its own preparations for the meeting.

The wider question of the need to raise the profile more generally of NCDs was also highlighted; at the national level, public and media attention on NCDs is extremely low. Perhaps trying to link the rise of NCDs with demographic change, which has recently garnered increasing media interest could be one mechanism employed to improve this situation. Focusing on the challenges of an ageing population would also help to embed dementia as a NCD in policy, practice and research.

Alzheimer's Disease International, HelpAge International and International Longevity Centre - UK Recommendations

The High-Level Meeting outcome should deliver commitments to:

1. Ensure access for people throughout the life cycle to the highest possible standards of health through age-friendly health care systems.

2. Implement costed programmes that deliver detection and diagnosis, prevention, management, treatment and care throughout the life cycle.

3. Promote integrated health care design and management, ensuring affordable and equitable access of people at all stages of life to the health and social services they need due to suffering from one or more NCDs including Alzheimer's disease and other dementias.

4. Support risk reduction measures such as exercise and healthy diets which may delay the onset of Alzheimer's disease and other dementias, saving future health care costs.

5. Support caregivers who provide the overall majority of care for people with Alzheimer's disease and other dementias and need to be supported better in order to continue caring and prevent them from developing other chronic diseases.

6. Ensure comprehensive care and support in national health and disease-specific plans to encompass physical, psychosocial, socio-economic, legal, nutritional and palliative care services, including pain relief.

7. Endorse the importance of costed social protection programmes to alleviate the financial burden of NCD costs and of caring, linking NCD outcomes to the achievement of the Millennium Development Goals.

Attendees

Surname	First Name	Job Title	Organisation
Bamford	Sally-Marie	Senior Researcher	International Longevity Centre - UK
Barker	Baroness Elizabeth		House of Lords
Baugh	Vanessa	Adviser in the Health Section	Commonwealth Secretariat
Beales	Sylvia	Head of Strategic Alliances	HelpAge International
Beattie	Allison	Health Services Team Leader	Department for International Development
Chidgey	Andrew	Head of Policy and Campaigns	Alzheimer's Society
Foulkes	Lord George	House of Lords	House of Lords
Gorman	Mark	Director of Strategic Development	HelpAge International
Graham	Nori	Emeritus Consultant in the Psychiatry of Old Age	Royal Free Hospital
Greengross	Baroness Sally	Chief Executive	International Longevity Centre - UK
Hopkins	Kelvin	MP	House of Commons
Hughes	Jeremy	Chief Executive	Alzheimer's Society
Jay	Baroness Margaret		House of Lords
Lloyd-Sherlock	Professor Peter	Professor of Social Policy and International Development	University of East Anglia
Lodge	Mark	Director of Programme Development	International Network for Cancer Treatment and Research UK
Mitchell	Michelle	Charity Director	Age UK
Prince	Professor Martin	King's College London	Professor of Epidemiological Psychiatry
Ridley	Simon	Head of Research	Alzheimer's Research Trust
Scobie	Jane	Director of Advocacy and Communication	HelpAge International
Serra	Valentina	Research Assistant	International Longevity Centre - UK
Siba	Noreen	Managing Director	International Longevity Centre - UK
Tyson	Kathryn	Director of International Affairs	Department of Health
Watt	Nicola	Global Health Team Leader	Department of Health
Wicks	Malcolm	MP	House of Commons
Wortmann	Marc	Executive Director	Alzheimer's Disease International

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