

All-Party Parliamentary Group on Dementia inquiry into dementia and co-morbidities - call for evidence

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The All-Party Parliamentary Group (APPG) on Dementia is seeking responses to a call for evidence for their 2015 inquiry into dementia and co-morbidities.

Introduction

In 2014, around 850,000 people in the UK were estimated to have dementia (both diagnosed and undiagnosed), and some 670,000 people acted as primary carers for people with dementiaⁱ. These figures are likely to increase significantly as the UK's population ages, with the total number of people with dementia predicted to exceed 1 million by 2021ⁱⁱ. Alzheimer's disease and other forms of dementia were the third leading cause of death in the UK in 2013ⁱⁱⁱ.

Dementia mainly affects older people – around 95% of people with dementia in the UK are 65+. By that age, many people will already have other conditions.

Someone who develops dementia is already likely to be coping with one or more long term conditions. From experience on the ground the interplay between dementia and other long term conditions appears to be a significant area of concern for people with dementia but in which there has been comparatively little research or understanding and, to date, little attention.

1. What are the common problems faced by people living with dementia and more than one other health condition? What is your organisation doing to help people overcome these problems?

The Alzheimer's Society reports that seven out of ten people with the condition have another long term condition as well. It's worth noting that various studies have widely different numbers of comorbidities.

Dementia leads to severe functional deterioration. It is highly likely that having dementia – a condition with doctors already find difficult to manage and diagnose- will interfere with other conditions that the person with dementia has to cope with and will complicate care planning. An understanding of the interplay with other conditions is therefore crucial to treatment and to our understanding of care for people with dementia. How we deal with people with multiple morbidities is part of the current overall global challenge of healthcare, especially in the environment of a rapidly ageing population

A very recent literature review examined the extent, range and nature of research activity around dementia and comorbidity. Evidence suggests that people with dementia do not have the same access to treatment and monitoring for conditions such as visual impairment and diabetes as those with similar comorbidities but without dementia^{iv}. The high rate of comorbidity – with the average of 3-4 comorbidities accompanying dementia^v - also emphasises the need to provide person-centred, integrated care services which are suited to catering for a wide range of individual needs within a local population.

Malnutrition is an issue which can go unrecognised. There are over a million older people living in our community who are malnourished or at real risk of becoming so. Around a third of older people are already at risk of malnutrition by the time they reach a hospital or care home.

People with dementia can often experience problems relating to eating and drinking including poor appetite; communication problems; difficulties coordinating their movements to enable them to eat independently and even the ability to see foods on their plate. These problems can have a compounding effect on person's health and on some of the symptoms of their dementia, which can result in weight loss and worsen confusion.

The Malnutrition Taskforce is a partnership of an independent group of experts across health, social care and local government, including Age UK. The Taskforce is raising awareness of malnutrition through the Malnutrition Prevention Programme.

Age UK's Integrated Care Programme operates across England. Some of the learning from the programme is relevant to the types of service models that could be developed for people living with dementia and long-term conditions. Our Integrated Care pathway brings together voluntary, health and care organisations in local areas to help older people who are living with long-term conditions and are at risk of recurring hospital admissions.

We work with the organisations to co-design and co-produce an innovative combination of medical and non-medical support that draws out the goals the older person identifies as most important to them.

Age UK is running further integrated care pilots across the country, with a greater focus on how to support people living with dementia and their carers.

Age UK supports people with dementia through the provision of specialised services and via mainstream, community-based services. This has involved, in some local areas, joint working with the Alzheimer's Society and/or the Dementia Action Alliance, notably through the dementia advisers' programme.

While we cannot alone solve all the challenges facing people with dementia and their carers, it is undeniable that through mainstream services, Age UK and our network of partners have a huge role to play in providing the kind of support that people with dementia say they need to live well.

Since 2012, Age UK has worked with 61 local Age UKs to help them to make their mainstream services more dementia-friendly. We started working with 15 local Age UKs in 2012 (funded by Department of Health Strategic Partnership) and another 15 joined the Dementia Friendly programme in Autumn 2013 followed by another 31 in Summer 2014, through funding provided by Big Lottery Fund. Since 2013, participating local Age UKs have also received an additional element of support around the development of wellbeing services, in part building on the success of the "Fit as a Fiddle" programme. An experienced consultant, Innovations in Dementia, led the project offering tailored advice around increasing the accessibility of mainstream services. Another leader in the field, Dementia Adventure, joined us in 2013 to focus on physical activity and wellbeing for people living with dementia.

Age UK is also in the early stages of implementing a new pilot programme among five local Age UKs to support people with cognitive decline, dementia and their carers, and post diagnosis. Our aim is to support local partners to test out new ways of working that will evidence good practice and provide opportunities for shared learning. Age UK is working with partners for a year to develop service models, expand services where there is demand and evaluate the success of services in meeting the required outcomes.

At the national level, Age UK has also taken steps to become dementia-friendly, including through the training of staff as Dementia Friends and Dementia Champions. More than 30 Dementia Friends sessions have been organised in the past few months and over 350 members of staff have become Dementia Friends.

Age UK's Information and Advice team has developed a number of guides relating to dementia, including *Living with early stage dementia* and *Caring for someone with dementia*. They are also in the process of developing a guide about adapting home environments for people with dementia.

We have also been at the forefront of research on cognitive health through the Disconnected Mind project – a multi-disciplinary research project led by Professor Ian Deary at the University of Edinburgh which focuses on how our thinking skills change with age, and what we can do to protect our cognitive health in later life.

2. Regarding the management of dementia and co-morbidities, what currently are the chief barriers to improving:

- a) Information provision
 - b) Self-management
 - c) Support
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Comprehensive support after diagnosis is important in order to equip individuals and their carers and families with the tools, connections, information and plans they need to live with dementia as well as possible, and prepare for the future, when they are ready to do so. This should include ensuring that the wishes of people living with dementia are upheld, should they not be able to make or express decisions for themselves. However, while there are pockets of good practice, too many people are not receiving the emotional, practical and information support they need after diagnosis^{vi}. A recent survey showed that 89 per cent of people with dementia feel they do not have enough information to get what they need^{vii}. There are also concerns that diagnosis is delivered bluntly, with limited support or information^{viii}, or little attention towards the person's other healthcare needs and comorbidities (e.g. mental or physical health issues, etc.).

3. Regarding dementia and co-morbidities what can the statutory sector (NHS, Local authorities, regulators) do to promote and deliver:

- a) Information provision
 - b) Self-management
 - c) Support
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Information provision

Many existing authoritative reports and guides on dementia barely mention comorbidities. The 392 page NICE/SCIE guide to dementia only makes two single sentence references which say the same thing: “At the time of diagnosis of dementia, and at regular intervals subsequently, assessment should be made for medical comorbidities”. For an authoritative guide to dementia, it is essential that this issue is addressed, and information provision for professionals, people living with dementia and their carers, is comprehensive. As previously mentioned a recent survey showed that 89 per cent of people with dementia feel they do not have enough information to get what they need^x.

Self-Management/support

We know that any people with dementia also have other serious medical conditions. Coexisting health conditions affect when and how people with dementia enter and use health and social care services. Unfortunately, they say that less is known about service organisation and delivery or the views and experiences of people with dementia and their family carers.

Unlike Scotland, there are still no minimum requirements of post-diagnosis support in England – although we understand that NHS England is currently looking at this issue (NHS England, *Business Plan 2015/16*, 2015) – and it is unclear whether responsibility for support should sit with the NHS or social care, or both. We also know that a number of GPs still do not diagnose dementia in people because they feel that ‘nothing can be done to support them’^x. Tackling inadequate provision of post-diagnosis support as well as raising awareness among GPs of what services are available locally therefore seems essential to encouraging timely diagnosis and support for people with dementia.

4. Could you outline any areas of best practice in the management of co-morbidities?

It is important that care is centred around the person. Personalised, integrated care and support is now recognised widely as the key to improving patient outcomes and patient experience. The Age UK Integrated Care Programme is aimed at those with complex and long-term health problems. At the heart of the programme is a pathway that brings together local voluntary and health and care organisations to help put the older person in control of their health and enable them to regain their independence and quality of life.

An example of good dementia care in England is the PETALS system provided by Somerset Care, which is an independent, not-for-profit provider, which can be used in the home or in a care home. The service focuses on six key features:

- Person-centered
- Empowerment
- Trust
- Activities
- Life History and
- Stimulation

The service places the individual and their family at the centre of the support package.

5. What are the implications for the training and development of the health and care workforce?

It is clear that training and development for health and care staff is essential in order for them to feel confident in managing and supporting the care of those living with dementia and comorbidities. This is a complex picture, as it includes the diagnosis of dementia itself.

As touched on previously, GPs themselves have expressed concerns around their ability to diagnose dementia accurately and questioned the purpose of diagnosis. A GP survey by the National Audit Office in 2010 found that a third of respondents were not confident in diagnosing dementia and fewer than half felt they had received sufficient basic and post-qualifying training to understand and support those who live with dementia

Pre-registration training and revalidation of all health and social care professionals should include sufficient time devoted to dementia care and the needs of people living with frailty and multiple long-term conditions. Levels of training should be regularly monitored, including through Care Quality Commission's inspections.

Examples of commitments as part of the Prime Ministers Challenge on Dementia, are that by 2020 all NHS staff will have received training on dementia; all hospitals and care homes as well as all government department and public sector organisations have become dementia-friendly. The Alzheimer's Society has delivered an extra 3 million Dementia Friends in England.

Age UK Training, a national training provider, has developed a person-centred training programme, 'Remember Me', which is designed for health and social care professionals, as well as people working in businesses, who come into contact with people with dementia and cognitive decline.

ⁱ Deloitte UK Centre for Health Solutions and Alzheimer's Society, *Dementia today and tomorrow - A new deal for people with dementia and their carers*, February 2015

ⁱⁱ All-Party Parliamentary Group on Dementia, *The £20 billion question*, July 2011

ⁱⁱⁱ GBD 2013 Mortality and Causes of Death Collaborators, Global, regional, and national age–sex specific all-cause and cause-specific mortality for 240 causes of death, 1990–2013: a systematic analysis for the Global Burden of Disease Study 2013, *The Lancet*, 2015; 385: 117–71

^{iv} Bunn F et al, *BMC Medicine*, 2014

^v Poblador-Plou B et al, *BMC Psychiatry*, 2014

^{vi} All-Party Parliamentary Group on Dementia, *Building on the National Dementia Strategy: Change, progress and priorities*, 2014

^{vii} Dementia Action Alliance, *An assessment to progress, a commitment to change – Dementia Action Alliance annual report 2014/2015*, 2014

^{viii} Deloitte UK Centre for Health Solutions and Alzheimer's Society, *Dementia today and tomorrow - A new deal for people with dementia and their carers*, February 2015

^{ix} Dementia Action Alliance, *An assessment to progress, a commitment to change – Dementia Action Alliance annual report 2014/2015*, 2014

^x Department of Health, *Dementia – A state of the nation report on dementia care and support in England*, 2013