Homecare and Dementia

Helping people stay at home

A digest of Dementia and Homecare: Driving Quality and Innovation, produced as part of the Prime Minister’s Challenge on Dementia
Some quick facts on dementia

850,000 people in the UK currently live with dementia

1 million people in the UK will live with dementia by 2021

Two thirds of people with dementia live at home

Only 1 in 3 with dementia receive homecare

Around 1 in 3 people with dementia do not have a formal diagnosis or contact with specialist services

85% of people would want to stay at home for as long as possible if diagnosed with dementia, rather than go into a care or nursing home

A person with dementia usually has at least four long-term health conditions

For source references please see page 13
Foreword

It is a well-established fact that most people living with dementia would choose to remain at home, in familiar surroundings and with the people they love and communities and friends they know.

Sadly, at present, people who have dementia face a number of barriers to receiving the care and support they need to be able to live at home in an environment which could significantly maintain or improve their quality of life. Many face ignorance, embarrassment and prejudice.

All of this is unnecessary. Skilled homecare has a crucial part to play in enabling people to remain living as full lives as possible in their homes; supporting family carers and allowing them to remain economically active as well as easing stress; identifying changes in condition and behaviour and signposting to other sources of support in the community.

Homecare workers should be skilled in supporting people with all forms of dementia. Their pivotal role should be recognised and valued. The commissioning of homecare services by the state (still over 70% of homecare in the U.K.) should facilitate and support a good relationship between the individual and worker and care to be given in a way which protects and promotes the person’s dignity and independence. Homecare workers should be properly supported, trained, respected and remunerated for their contribution.

I hope you will read this digest and the full report, with the intention of playing your part in improving the lot of people living with dementia in England today.

Bridget Warr
Chief Executive, United Kingdom Homecare Association (UKHCA)
Chair of the Dementia Health and Care Champion Subgroup on Homecare – part of the Prime Minister’s Challenge on Dementia
The challenge for people living with dementia in your constituency

How confident are you that people living with dementia in your area receive care and support in the environment of their choice?

What support structures are in place in your local area to make sure people living with dementia can live at home for as long as possible?

How many people living with dementia in a residential or nursing care home in your local area would prefer to be at home?

How many family carers have had to leave work in your local area to support someone living with dementia?

How many people in your local area living with dementia were delayed from returning home from hospital? How many could have avoided admission with the correct support in the first place?

We need you to raise these issues in your constituencies to help us campaign for people who live with dementia to have choice and control over their care.
We ask that you as a Parliamentarian...

- Call a meeting with local councillors and senior council officers to ask the questions on the facing page.
- Involve Clinical Commissioning Groups and heads of local NHS Trusts
- Champion homecare as a key facilitator of dementia care and information
- Communicate through social media, and other channels, your support for homecare services as a key element in providing choice & control for people living with dementia in the environment of their choice
- Put forward a parliamentary question – for example: “What percentage of people living with dementia were discharged into a nursing or care home from hospital, compared to people living without the condition?”
- Engage with local Alzheimer’s Society groups and Dementia Friends on the questions posed on the previous page.
- Familiarise yourself fully with the issues and opportunities touched on in this digest by reading the full report on Dementia and Homecare: Driving Quality and Innovation. (Available to download at: www.ukhca.co.uk/downloads.aspx?ID=488).

You can find details for homecare agencies in your constituency through the UKHCA “Finding care” page at: www.ukhca.co.uk/findcare/
Homecare’s role...

Skilled professional homecare has a vital role to play throughout the journey of dementia for both the individual and their family, in combatting the condition and living as full a life as possible.
For people living with dementia homecare can...

- Alert health professionals to changes in a person’s condition through regular contact
- Assist in making homes dementia friendly
- Support people to remain at home for as long as possible
- Enable people living with dementia to go out and remain connected with their community
- Help with appropriate nutrition to maintain health
- Avoid changes of environment, which can be particularly unsettling for people living with dementia
- Support with safe medication management and administration.

For families supporting someone with dementia homecare can...

- Offer ongoing support through live-in care or care by the hour
- Reduce pressure on family carers and friends by providing respite care
- Enable family carers to remain in work
- Offer family training and signpost to emotional support.

For the wider health system and economy homecare can...

- Help to discharge people who are ready to return home from hospital
- Provide support and signpost to services that can reduce admissions to hospital
- Reduce the number of people leaving work to care for a loved one.
Homecare’s role in... Risk reduction

Risk reduction and the opportunity to delay or perhaps even prevent the onset of dementia, is a growing focus for researchers and policy makers. Issues around physical and mental health and psychosocial wellbeing are increasingly linked to prevalence of dementia.

Professional, skilled homecare can...

• Help people to understand the possibilities around risk reduction
• Deliver information on diet; exercise; brain and heart health
• Provide and facilitate mental and social stimulation
• Advise on whom to inform (or make a referral) if there are signs of self-neglect or poor health
• Promote healthy, active lifestyles
• Signpost individuals and families to local support networks.

What can you do?

Encourage constituents to plan for their old age.

Call on councils to introduce care and support to people early enough to make a difference, not delay until there is already critical need.

Investigate whether local authorities are meeting their statutory duties under the Care Act to supply information for people with dementia, including to people who will be funding their own care.
Homecare’s role in... Improving diagnosis

Homecare workers can be instrumental in achieving a timely diagnosis. Often they will spend more time with an individual than any health professional, and are well placed to notice a change in condition or behaviour. Gaining a timely diagnosis is vital to establishing appropriate lines of support.

Professional, skilled homecare can...

- Help to breakdown the stigma related to dementia
- Reassure individuals and their families about the process of diagnosis
- Recognise and record possible signs of dementia
- Know how and when to report concerns in a sensitive way, leading to an initial assessment
- Signpost individuals and their family to local support
- Explain why achieving a timely diagnosis is important.

What can you do?

Promote training developed by UKHCA and Alzheimer’s Society.

Work with local health trusts to push local diagnosis rates to 75%.

Make yourself aware of the range of medical and social services in your constituency to help people with dementia.
Homecare’s role in... Supporting people to live well

We must recognise that people can continue to live well with dementia. Homecare is ideally placed to help this happen, offering services that preserve daily living and preferred activities. Quality care will recognise the needs, aspirations and wishes of the person, not just see the condition.

Professional, skilled homecare can...

- Understand the individual nature of dementia
- Support independence for the individual
- Preserve connections with the community
- Link into the emotional needs of the individual and their family
- Involve the family in the support package
- Promote positive risk taking
- Suggest and implement useful technologies
- Maintain records that can be shared with other professionals
- Alert, recommend or change issues relating to the home environment, such as lighting or flooring.

What can you do?

Encourage joint commissioning locally, promoting wellbeing and maintaining a quality of life that leads to fewer acute admissions.

Champion homecare as a way to help people remain at home in familiar surroundings and in the community.
Homecare’s role in... a good death

More than 70% of people want to die at home, yet this is the experience for only 6% of people living with dementia. This is unacceptable and underlines the inequalities to choice and control faced for people with the condition and their families.

Professional, skilled homecare can...

• Promote personal choice
• Enable the individual to stay at home until they die
• Help individuals and their family make timely decisions about end of life care
• Provide specialist communication and care during latter stages of the condition
• Signpost to emotional or legal support
• Sensitively inform individuals and their family about options around end of life.

What can you do?

Search for and promote local efforts that help people to die at home if they wish.

Call for up to date figures around location of death for people with dementia through a Parliamentary Question.
In order for people living with dementia to receive the support they need, in the environment they want it, we now need to work together to call on all parties involved to:

1. Champion homecare as the key facilitator of dementia care and information throughout the person’s life with the disease.

2. Give greater flexibility for homecare providers to innovate and shape care with and for the individual.

3. Recognise and realise the value of homecare to reduce risk.

4. Prioritise homecare as a cost effective form of intervention.

5. Commission sufficient time to deliver the care people with dementia need, in the way they want.

6. Ensure that social care, health and other services are commissioned around the needs of the individual.

7. Call for research on care, as well as cure.
Further information/sources


Further information/sources continued

DEPARTMENT OF HEALTH (2016)
*Prime Minister’s Challenge on Dementia 2020 – Implementation Plan*

*Adapting clinical guidelines to take account of multimorbidity.*

HEALTH AND SOCIAL CARE INFORMATION CENTRE (for Department of Health)
*Patients in England with a Record of Dementia Diagnosis on their Clinical Record (Oct 2015)*

NATIONAL INSTITUTE FOR CLINICAL EXCELLENCE (NICE)
*Homecare: delivering personal care*
NICE: www.nice.org.uk/guidance/ng21

UNITED KINGDOM HOMECARE ASSOCIATION (2015).
*Market Stability Survey.*
www.ukhca.co.uk/pdfs UKHCAMarketStabilitySurveyAnalysisVersion11201509.pdf
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<thead>
<tr>
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<td>This is a digest of the UKHCA report “Dementia and Homecare: Driving Quality and Innovation”, which formed part of the Prime Minister’s Challenge on Dementia 2012. This digest provides a summary of why staying at home is so important to people living with dementia and how professional, skilled homecare can enable this to happen. A full copy of the document can be found at: <a href="http://www.ukhca.co.uk/downloads.aspx?ID=488">www.ukhca.co.uk/downloads.aspx?ID=488</a>.</td>
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About UKHCA

United Kingdom Homecare Association (UKHCA) is the national professional and representative association for organisations providing care to people in their own homes.

Our mission is to promote high quality, sustainable care services so that people can continue to live at home and in their local community.