



UKHCA Dementia Strategy and Plan

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Prepared for UKHCA member organisations by:

Jennifer Roberts, UKHCA Dementia Lead

United Kingdom Homecare Association Ltd
Sutton Business Centre
Restmor Way
Wallington
SM6 7AH

Telephone: 020 8661 8188
E-mail: policy@ukhca.co.uk
Website: www.ukhca.co.uk

Company Registration Number 3083104
Registered in England

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Disclaimer

Whilst every effort has been made to ensure the accuracy of this strategy and plan, it is a summary, rather than a definitive statement of the law; advice should be taken before action is implemented or refrained from in specific cases. No responsibility can be accepted for action taken or refrained from solely by reference to the contents of this strategy and plan.

UKHCA Dementia Strategy and Plan

Foreword

Supporting those with dementia is one of the greatest challenges facing society today.

With over 400, 000 people in the UK living with dementia but not yet diagnosed, and over 60% of people receiving homecare with some form of dementia, the scale of the challenge is clear.

At the forefront of caring for those with dementia in their own homes are homecare organisations and their care workers. They provide vital care for people every day and sometimes overnight too, and offer valuable respite to carers and families. If the homecare sector is to have the capacity to meet the challenge of greater numbers of people with dementia in future, it needs to plan now and that means thinking strategically.

UKHCA, as the professional association which represents homecare providers, has already shown its commitment to supporting the sector by signing up to the Dementia Care and Support Compact, in response to the Prime Minister's Challenge on Dementia, and the Dementia Action Alliance (DAA).

In our new UKHCA Dementia Strategy and Plan we go further. We set out the detail of how we propose to represent and support homecare providers to meet the challenges and opportunities of developing personalised dementia services.

Produced with funding from Skills for Care, but designed to support providers across the UK, I am delighted that our new Strategy and Plan will provide the blueprint for our work helping homecare organisations develop their dementia services regionally and nationally.

This is an exciting initiative for UKHCA, and I look forward to inviting our members and other homecare providers to get involved, as we implement our Plan in the coming months.

Bridget Warr
UKHCA Chief Executive

February 2013

UKHCA Dementia Strategy and Plan

Introduction

While diagnosis and post-diagnostic support for people with dementia remains patchy across the UK, new initiatives are being designed to meet the challenges ahead. There are variations in approaches being adopted; the key drivers/policies can be identified as:

- A general move towards maintaining people in their own homes for longer, avoiding inappropriate or early admissions into hospitals and care homes;
- Increasing and improving earlier diagnosis of dementia;
- Developing early interventions and post-diagnostic support services to ensure people can live comfortably with their dementia for longer;
- Increasing and improving information and awareness about dementia;
- Creating dementia-friendly communities and societies;
- Investing in dementia research;
- Improving standards of dementia care and services in hospitals, care homes and homecare;
- Improving services and support for family carers (right to assessments and their financial, respite and other needs being met).

Dementia Care and Support Compact

In England, as part of meeting the Prime Minister's Challenge, UKHCA is signed up and committed to the Dementia Care and Support Compact and sits on the National Dementia Strategy Workforce Advisory Group. As part of the Care and Support Compact, signatories have agreed to provide the right care, in the right place, at the right time. People with dementia using services will be able to say:

- I am respected as an individual;
- I get the care and support which enables me to live well with my dementia;
- Those around me and looking after me are well supported and understand how to maximise my independence;

- I am treated with dignity and respect;
- I know what I can do to help myself and who else can help me;
- I can enjoy life;
- I feel part of a community and I am inspired to participate in community life;
- I am confident that my end-of-life wishes will be respected. I can expect a good death.

As part of the homecare commitment, providers will:

- Focus on quality of life for people with dementia, as well as quality of care. By knowing the person, their life history and their personal culture, care staff will deliver a personalised package of care and support;
- Set a benchmark for high-quality relationship-based care and support for people with dementia. UKHCA will inspire and encourage the sector to take responsibility for delivering this, building on existing good practice;
- Engage and involve the wider community to improve their support for people with dementia, including GPs and healthcare professionals;
- Support the wider community, sharing the knowledge and skills of care staff, and inviting people into care settings;
- Work with commissioners of care for people with dementia to ensure they commission quality care services appropriately; *and*
- Clearly set out how delivery of the Compact makes a difference for people with dementia, their carers and families. This will link into the work on quality and transparency being taken forward as part of the Care and Support White Paper.

Whilst this Compact applies to England, the principles can be easily applied to the other devolved administrations.

The homecare sector is often the first to provide a service for people who are showing signs of cognitive impairment, many of whom have not had a diagnosis of dementia. The sector has a vital role to play in meeting the needs of people with dementia and their family carers and developing a range of innovative approaches and solutions to deliver quality dementia services from early diagnosis through to end of life care.

UKHCA has made a clear commitment to inspire and encourage high quality support for people with dementia and their carers, working with the wider communities, developing partnerships and raising awareness about the homecare sector and what it can provide.

The next step is to have a strategy and project plan to illustrate how UKHCA will meet these commitments as an association and to providers of care. This has led to the launch of the UKHCA Dementia Strategy and Plan, which has already received funding from Skills for Care for development in England. UKHCA will seek to develop similar partnerships with leading organisations in the devolved administrations.

While the strategy will be clearly focused on dementia, there will be opportunities for UKHCA to sustain the programme through:

- Developing partnerships with like-minded organisations and the business sector;
- Attracting new members to the Association and maintaining existing members by raising the profile of the homecare sector and what it can provide in the field of dementia;
- Providing a range of resources designed to support providers in their development of quality based dementia services.

Strategy

The strategy will be focused on the following four key work streams:

1. Dementia awareness, education, information and resources;
2. Developing dementia-friendly communities;
3. Development and delivery of quality homecare services;
4. Raising the profile and role of homecare providers in dementia.

This will form the framework for the way ahead, taking into account and reflecting the differences between the devolved administrations.

Management and delivery of the plan

The success of the dementia strategy and developing and delivering a dementia plan will be down to increasing awareness of the sector's commitment to dementia, marketing what is being done and promoting the work that has already been achieved (i.e. supporting the PM's Challenge).

UKHCA Dementia Lead's principal role and responsibilities

Dementia will be the main focus and the responsibility will be to:

- Meet the objectives of the project plan;
- Undertake all the ground work;

Key work streams will often cross boundaries (i.e. dementia awareness, education and resources may well cross with work coming from developing dementia-friendly communities).

When developing the plan each development will be considered on its merit and how it contributes to meeting the aims and objectives of the sector. UKHCA will prioritise developments and ensure they are the most cost-effective way of delivering the strategy.

For example, with training:

- Researching, developing, writing and delivering a range of dementia training courses/products internally;
- Working in partnership with another organisation to develop and produce a training course with joint recognition that is domiciliary care focused.

It is very important that, the sector is kept informed of how much work is being done to represent the sector's interest in the field of dementia and the level of support available. UKHCA will ensure that information is cascaded down and mechanisms are in place to enable the sector to engage, allowing for the collection of models of good practice and development whilst listening to the challenges they are experiencing. This will help to identify and decide what support is needed and how it can be provided.

UKHCA will develop a free flowing communication channel to the provider and from the care worker level back up to UKHCA. This will improve the sector's ability to represent interests, raise awareness of the sector's challenges, innovative approaches and the range of services that can be provided.

Proposed development of dementia website

As part of the dementia strategy, a website will be developed to allow people to be directed quickly to the services that can be provided and access the information they require.

When the website is updated, the following layout could be adopted to follow the strategy:

Dementia

- General information
- Care and Support Compact
- The National Dementia Strategy Workforce Advisory Group
- Specific dementia strategy plans and relevant links
- Dementia helpline
- Dementia email
- UKHCA lead contact details
- Focus groups: contact details
- Dementia ambassadors
- Other relevant material

Dementia awareness training and resources

- Copies of dementia *Homecarer* articles
- Dementia training pack
- Dementia training courses (UKHCA or links to others)

- Relevant publications (i.e. Skills for Care Newsletter, Alzheimer and UKHCA handbook)

Dementia-friendly communities

- Link to DAA site, encourage to join
- Guidance on completing action plans for homecare providers
- List of dementia homecare ambassadors and groups
- Links to other organisations and partnerships

Development and delivery of quality dementia care services

- Role of homecare providers in early diagnosis
- Role of homecare providers in post-diagnostic support
- Homecare providers supporting carers
- Good practice template
- Good practice models of development

Dementia Plan

The following tables illustrate how the Dementia Plan will be rolled out in phases 1 to 3 in order of priority:

UKHCA overview

| Aim | Achieved by: | Development phase | Notes |
|--|---|-------------------|--|
| To raise awareness, campaign and represent the home care sector's interest in dementia. | Part of the Care and Support Compact. | Already in place | |
| | Representation on the National Dementia Strategy Workforce Advisory Group. | Already in place | |
| | | | |
| | Monitor any relevant dementia campaigns, consultations. Disseminate information. | Phase 1 | Important to identify how to support any campaigning, any resources required and the lead in the overseeing, liaison role and ongoing development (i.e. attending meetings, commenting on reports/consultations etc). |
| | Identify and attend conferences, workshops, events, exhibitions etc as a delegate or contributor. Provide feedback to inform appropriate follow-up and development opportunities. | On-going | |
| To strengthen our position through developing links, partnerships and alliances with like-minded organisations. | Identify key organisations (i.e. SCIE, Alzheimer's Society, Alzheimer Scotland, Life Story Network, Lewy Bodies Association). | Phase 1 | Important to clearly identify: 1. How a provider would fit in to the overall approach; |
| | Review the benefits of linking up with the organisations. Identify areas where there is common ground that may benefit both all organisations. Network and develop links, utilising social media where appropriate. | On-going | 2. To share information among directors and relevant staff members to decide the best way to proceed. Options could be: <i>To encourage them to join UKHCA as a commercial member;</i> <i>To support a piece of work to be delivered;</i> <i>To create links for providers to benefit from their expertise.</i> |

UKHCA/SfC (England only) supporting providers

| Aim | Achieved by: | Development phase | Notes |
|--|--|-------------------|--|
| To ensure members are supported to maintain their knowledge about dementia. | Maintain regular dementia focused articles in the <i>Homecarer</i> and SfC newsletters | On-going | These initiatives will contribute to maintaining and provider quality standards. |
| | Cascade relevant information via policy alerts. Inform of relevant links to organisations that can help (i.e. Alzheimer's society, SCIE). | On-going | Potential to attract new members for UKHCA, particularly if UKHCA is seen as the leading organisation in dementia developments in homecare and is sponsored by Skills for Care in England. |
| To provide resources to help workforce development. | Promote the UKHCA dementia helpline and email. Review current dementia training pack resources and workshop approach. Explore opportunities to develop these resources (i.e. webinars, e-learning modules, as outlined above). | On-going | |
| To develop dementia focus groups. | Look to develop virtual groups rather than structured face to face meetings (these may come in time). Communication will be by email, social networking and telephone. In due course identify a leader/facilitator of the group and make them a UKHCA/SfC dementia ambassador. | Phase 1 | This network crosses over with the work in developing dementia-friendly communities. |

Develop dementia-friendly communities

This is one of the main areas of focus in the Prime Minister’s Challenge. In essence, it is designed to build up local community networks and partnerships to support people with dementia and their carers who live within their community. The Dementia Action Alliance is an organisation set up to help organisations and communities to meet this challenge.

UKHCA overview

| Aim | Achieved by: | Development phase | Notes |
|---|---|-------------------|---|
| To deliver on the commitments made in the Care and Support Compact. | Sign up to the Dementia Action Alliance. | Completed | The action project plan will underpin commitment to facilitating and developing partnerships between homecare and local community businesses. |
| | DAA creates an opportunity to link up with other organisations signed up to the alliance. Encourage providers to sign up to the DAA. | Ongoing | |
| To break down barriers between home care providers and other local businesses. | Look for opportunities to facilitate and develop relationships that help different businesses and sectors to engage with homecare. | Phase 2-3 | Assistive technology providers want to engage with the social care sector, suggesting a good practice event, enabling homecare providers to explore the technology, and see how it might work for their business without any hard sale. This makes use of knowledge and expertise from supporting this kind of development with local authorities. |
| | UKHCA will support, help and enable homecare providers to create and develop links and partnerships (i.e. with GPs, Primary Care etc). By maximising on existing publications and resources (i.e. choosing care and personalisation toolkit, SfC publications and developing resources as required). | Phase 2-3 | |
| Potential income generation. | Dementia awareness training. Concept outlined in the notes could be developed for others (i.e. solicitors, optometrists, dentists). | Phase 2-3 | Links to providing dementia training to other organisations. This could generate further partnership working. |

UKHCA/Skills for care (England only) supporting providers

| Aim | Achieved by: | Development phase | Notes |
|--|---|-------------------|---|
| To support the development of dementia-friendly communities. | Encourage providers to sign up to the DAA via policy alerts, piece in the <i>Homecarer</i> , SfC newsletters | Phase 1 | The action project plan will underpin commitment to facilitating and developing partnerships between homecare and local community businesses. |
| Develop a network of homecare dementia focus groups, to support community developments. | <p>Look to develop virtual groups rather than structured face to face meetings (these may come in time).</p> <p>Communication will be by email, social networking and by telephone.</p> <p>In due course identify a leader/facilitator of the group and make them a UKHCA dementia ambassador</p> | Phase 1 | This network crosses over with the work in dementia awareness education and training. |

Development and delivery of quality homecare dementia services

Looking at the role UKHCA/Skills for Care (England only) play in raising awareness about the opportunities and challenges in developing and delivering quality dementia care services in a homecare setting.

UKHCA Overview

| Aim | Achieved by: | Development phase | Notes |
|---|---|-------------------------------|---|
| <p>Supporting PM's challenge</p> <p>1.</p> <p>To support an increase and improvement in earlier diagnosis of dementia.</p> | <p>Encourage and support homecare providers as a sector that is ideally placed to make referrals to a GP or memory clinic for a dementia diagnosis.</p> <p>Represent and raise awareness about home care providers' role in contributing accurate information to enable early diagnosis, underpinned by their ongoing relationship and the amount of time they spend with a client.</p> | <p>Phase 3</p> <p>Phase 3</p> | <p>Dementia can be difficult to accurately diagnose and often a diagnosis is reached via a series of tests that eliminate other possible causes. Homecare providers are often the first to come into contact with and spend most time with people with dementia and their carers. They can play a key role in identifying signs of dementia, sharing information about a person's cognitive abilities observed over a period of time rather than from a snapshot in a given moment of time.</p> |
| <p>2.</p> <p>Develop early interventions and post-diagnostic support services to ensure people can live well with their dementia for longer.</p> | <p>Raise awareness and profile of the homecare sector and the part it can play in developing and delivering post-diagnostic support via local authorities, primary care and health (i.e. through consultations, attending meetings, networking, links and publishing articles etc).</p> <p>Collect and disseminate information about good practice and models of care that identify and promote examples of post-diagnostic support provided by homecare.</p> | <p>Phase 3</p> | <p>Identifying existing post-diagnostic support services and putting forward recommendations on how homecare services can be improved</p> <p>This will highlight some valuable universal key messages that UKHCA can learn from and develop. Carers right to assessments.</p> <p>Be aware of & make referrals to appropriate parties (i.e. social services for financial benefits, maximising income, power of attorney etc).</p> |

UKHCA/Skills for care (England only) supporting providers

| Aim | Achieved by:- | Development Phase | Notes |
|---|--|-------------------|--|
| Supporting homecare providers to design, develop and deliver quality dementia care services. | Use the dementia focus groups as a mechanism for members to identify and discuss the challenges that developing and delivering a quality dementia service presents. Opportunity to collect info about good practice and models that work. | Phase 2 | Opportunity to show the benefits UKHCA can offer across the UK. With the focus on dementia, providers can learn/share the good and bad points from development and incorporate them into their own practice. |
| | Create a good practice template for providers to complete and list them on UKHCA good practice database or link up with an existing one (i.e. Skills for Care in England). | Phase 3 | |
| | <p>Monitor and disseminate developing models, innovative approaches and good practice frameworks that will help or can be adapted for the homecare sector (i.e. Alzheimer Scotland five pillar model of post-diagnostic support, dementia mapping).</p> <p>Take the models of good practice, key challenges and opportunities already identified, as a foundation to build upon and share these with providers as examples of development models</p> | Phase 3 | Scotland is leading the way with the five-pillar model of post-diagnostic support *. Some of the concepts in this model may well inspire and motivate providers to develop these ideas in England, Northern Ireland and Wales. |
| Improve services and support for family carers. | <p>Produce information in the form of guidance sheets, articles in <i>Homecarer</i> (that address how important it is to support the carer, family and friends).</p> <p>Guidance on building a relationship with family and friends.</p> <p>Information on the importance of undertaking carer assessments and building on an individual's circle of support.</p> <p>Provide links to other like-minded organisations that could help.</p> <p>Share models of good practice & examples of partnership working between other practitioners and family carers.</p> | Phase 3 | Disseminate info via dementia groups. |

Training

This project will generate substantial interest for providers to become acutely aware of the need for training and would provide an ideal platform in England (through Skills for Care) to promote not only the Workforce Development Fund but also the significance of the Workforce Development Dementia Fund.

Raising the profile and roles of homecare providers in dementia

By completing this project, the profile of homecare providers and the role they can play in supporting people with dementia will be raised in many ways.

There is a general move towards maintaining people in their own homes for longer, avoiding inappropriate or early admissions into hospitals and care homes. As GPs and other practitioners start to meet the target of increasing the rate of early diagnosis, so the homecare sector will play a major part in caring for people with dementia and their families in partnership with health and social care. This will involve homecare organisations being in a position to provide a wide range of initially low level of support and personal care which can be increased as an individual's dementia journey progresses.

UKHCA believes many of the homecare sector providers are well placed to meet these needs. They have invested in training and developing their workforce and are experienced in providing care in a variety of home settings and working with family and friends.

UKHCA, supported by funding for Skills for Care in England, can play a vital part in raising awareness about the sector's ability to meet this challenge, continue the campaign for a fair price for this type of care service and highlight the benefits of enabling a person to remain in their own homes for longer – and the considerable financial saving that can be made in avoiding inappropriate admission to hospitals and care homes.

Look at the following link for details on Scotland's five-pillar model for post-diagnostic support:

*<http://dementiascotland.org/dementia-strategy/2012/getting-post-diagnostic-support-right-for-people-with-dementia-the-five-pillars-model/>

Author

Jennifer Roberts, UKHCA Dementia Lead
dementia@ukhca.co.uk

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Prime Minister's Dementia Challenge <http://dementiachallenge.dh.gov.uk/about-the-challenge/>

National Dementia Vision for Wales

<http://wales.gov.uk/docs/dhss/publications/110302dementiaen.pdf>

Scotland's National Dementia Strategy

<http://www.scotland.gov.uk/Resource/Doc/324377/0104420.pdf> and:

<http://www.scotland.gov.uk/Topics/Health/Services/Mental-Health/Dementia>

Northern Ireland Assembly Regional Strategy for Improving Dementia Services

<http://www.dhsspsni.gov.uk/improving-dementia-services-in-northern-ireland-consultation-may-2010.pdf>

Dementia Action Alliance <http://www.dementiaaction.org.uk/>

Alzheimer Society <http://www.alzheimers.org.uk/>

Alzheimer Scotland <http://www.alzscot.org/>

The UKHCA Dementia Strategy and Plan is available as a pdf document from:
www.ukhca.co.uk/downloads.aspx?ID=377

If you have particular needs which make it difficult for you to read this document, please contact 020 8661 8188 or accessibility@ukhca.co.uk and we will try to find a more suitable format for you.

✉ UKHCA, Sutton Business Centre, Restmor Way, Wallington, SM6 7AH
☎ 020 8661 8188 | 📧 enquiries@ukhca.co.uk | 🌐 www.ukhca.co.uk

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