

Dementia & Homecare: Driving Quality & Innovation



**The Health and Care Champion
Subgroup on Homecare, part of the
Prime Minister's Challenge on
Dementia (October 2015)**

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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 environment which could significantly maintain or even improve their quality of life. A huge number of people do not have their condition properly diagnosed in a timely way. Many face ignorance, embarrassment and prejudice. If they are admitted to hospital, they frequently experience inappropriate care which does not take their condition into account and they tend to remain in hospital longer than others.

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.

People have a right to accurate and timely diagnosis when they have dementia and the diagnosis should trigger a flow of relevant information and support – both for themselves and for family carers. A range of local support functions should be co-ordinated around the individual and (where possible) under his or her direction.

Homecare workers should be skilled in supporting - and providing services for – 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 and remunerated for their contribution.

This report outlines what is needed to ensure that people living with dementia can live safely at home and maximise their independence. It identifies a number of practical steps required to achieve this and indicates what is needed of whom to move forward, in addition to sharing a significant amount of excellent practice that highlights what can be done. It is intended, as part of the continuing Prime Minister's Challenge on Dementia, as a call to action for a range of people and organisations.

I am delighted and honoured to have led the hard-working, knowledgeable and committed working group (see 'Acknowledgements' for the full list) who made this possible.

My gratitude to them all; particular thanks, too, to UKHCA's Dominic Carter who has willingly taken on the mammoth task of collecting masses of information and forming it in to a single report.

At the front of the report is an aspirational description of how we think a person's experience of living with dementia might be, if all the changes we are recommending are implemented.

I hope you will read it with the intention of playing your part in improving the lot of people living with dementia in England today.

A handwritten signature in black ink that reads "Bridget Warr". The script is cursive and fluid, with the first letter of each word being capitalized and larger than the others.

Bridget Warr

Chief Executive, United Kingdom Homecare Association (UKHCA)
Chair of the Dementia Health and Care Champion Subgroup on Homecare
October 2015

2020: A vision for the future of dementia care at home

My name is Anne and in 2015, nearly five years ago, I was diagnosed with dementia. I would like to tell you of the journey my family and I have been on since then.

Before my diagnosis, I lived at home alone, managing various long term conditions with the help of my son and a small team of professional homecare workers from a local regulated agency. I was renowned in my community for being well organised and able to convey my views in a clear, concise manner, but I had not been feeling myself for some months and it had started to affect my daily life. My ability to focus on what I was doing had deteriorated and I wasn't always sure where I had left things.

My homecare workers, all of whom had received a wide range of specialist training, including dementia care, suggested whilst in conversation with me and my son that I visit my GP. The homecare agency had invested time in building a profile about me so that any carer who came to visit was sensitive to who I was and what I liked, but there was one who knew me best, and she came with me to my GP appointment at my request. Between us we were able to explain the changes I had been feeling and showing, which helped the GP achieve a more thorough assessment. A series of tests ensued and the GP recommended I see a specialist consultant, one based in my community, along with a counsellor who was able to allay my fears over a potential diagnosis. To my relief the GP and the homecare agency agreed to arrange the appointment and told the consultant about me, and within a week I was visited by a consultant who was already up to speed with my personal history and details on how I had been feeling. This time both my son and the homecare worker were present.

At a second appointment the consultant confirmed the thoughts of the GP, and I was diagnosed with Alzheimer's, the most common condition of many that make up the umbrella term of dementia. I had read a lot of upsetting news about dementia, but the consultant and my homecare worker reassured me that they knew of a number of avenues of support existed that would help me to live well.

Following the diagnosis, there was a great deal of activity and a huge amount of information to take in. My son, the homecare team and Dementia Support Worker were instrumental in making sure I wasn't overwhelmed by detail on support groups, assessments, new care plans and medication courses. They documented this information, and signposted me to what I needed, when I needed it. That my care workers were able to identify certain symptoms to allow for a timely diagnosis and knew where to locate relevant information for support was invaluable. It allowed me to arrange for the people around me

to help in the best way and to feel a little more that I was in control of the condition and the support I wanted, not the other way around.

Navigators from primary care services and members of my local authority social services ensured both I and those caring for me knew where to find further support. It felt like the local offer in my community, services either run by volunteers or by professional workers, were well connected and worked smoothly together. I could share my fears and learning from people who had been around dementia for many years helped me to come to terms with the diagnosis and how to move forwards.

Regular communication between my homecare agency and my local authority social worker meant I was quickly reassessed to see how social services could continue to help me achieve what I wanted to do on a daily basis, and whether I could access financial support for those services.

Being out and about and interacting with my neighbours and local businesses was what I wanted to do, and between them the commissioning team and my homecare agency created a package that would enable that to happen. Although this would mostly involve a package of care at home, it also involved local voluntary organisations. I was given the option of a direct payment, and decided that for time being, as I didn't want to handle the money myself, a supported arrangement called an Individual Service Fund would be ideal. Through the ISF, my homecare agency manages the money for the service I want, be it through them or additional services elsewhere.

The ISF meant I had a good measure of control to work with the homecare agency and wider partners in the voluntary sector to create my care plan. I could use the funds allocated to me through my council assessment to tailor the plan to reflect what I wanted, when I wanted it. Three days a week my son stayed with me, so I didn't want any other assistance then, but I did want extra on the other days. The ISF allowed me to do this and it meant my son didn't have to give up work to care for me full time.

Just as important as help with washing and dressing was the ability to have trips out, either to the shops or to singing or art classes held by one of the local charities. I like it because I can interact with other people, but my doctor tells me it is especially helpful to stimulate my mind and keep me physically active as it may help to maintain skills and independence. It also means I see at least one friendly face every day.

I knew that caring for many hours a week took a great deal out of my son, but my care package meant that on occasion I could spread my hours of homecare across the week, and the homecare provider knew of local voluntary services that could provide additional support. This allowed my son time to take holidays with his friends and to recharge his batteries, which was essential as his help as part of my wider package of care meant I was

able to stay where I wanted to be, home. He recently had a carer's assessment with social services, which will help to ensure his needs can be met too.

Living with dementia has been an extraordinary challenge, and increasingly I find everyday activities, such as how to put on the kettle, a frustrating activity that I cannot quite negotiate. To help me to continue doing what I want to do, my needs and care plan are under regular, rolling review, with input from the homecare workers, GP and community nurse as well as my son and myself. Together we check to see how my supporting services and the funding behind it may need to change to help me live well and do what I want to do, as well as putting plans in place for the future regarding Lasting Power of Attorney.

On one occasion my care package was even reduced slightly as I had been doing well. On the other hand I had a bad chest infection last winter. The doctor spoke to social services and through the ISF they increased the support I could use, to ensure I was staying warm, eating properly and taking my medication. The increase had the desired effect and my health improved - a great result not least as it had prevented me from going into hospital over the Christmas period (who knows how long I could have been in there!)

A team of people from various services worked together to suggest adaptations to my flat that would allow me to do more at home and make me more comfortable. Some, like signs and pictures on cupboard doors were simple but useful, plain carpets helped me to feel less anxious, whilst assistive technologies like the telecommunication system installed in the hall and the device that moves my bed up and down to help me get out has given me greater independence and has afforded my homecarers more time to spend with me.

The homecare manager has often asked me and my son about their service, and is always keen to adapt how they work to meet my needs. The care workers frequently tell me of what they have learnt in their most recent training course, everything they do now has a focus on dementia including learning around nutrition and many of them have an advanced qualification in dementia care, although they often say it's me that teaches them the most.

The support I receive from the homecare workers, community services and my son have allowed me to remain in the home environment in which I feel most comfortable – without them it wouldn't be possible. I am confident that as my care needs increase, those involved in the service I receive are communicating to ensure my needs and aspirations are continuing to be met, and this gives me peace of mind.

Moving forwards, there is the option of live-in care workers, who would be able to help around the clock, which is something I think I will look into further. I have lived in this flat for fifty years, and I plan to be here for many more.

Introduction

There are around 850,000 people in the UK living with dementia (Alzheimer's Society, 2014), with over 42,000 developing the condition before they reached 65. By 2021, reliable estimates suggest the 850,000 may have increased to over a million, presenting one of the biggest challenges to health and social care in the 21st century.

It is believed that more than a third of people living with dementia receive personal care from homecare workers, which would equate to about 280,000 people (Alzheimer's Society, 2011). Homecare providers estimate that some 60% of people using their service have some form of dementia (UKHCA, 2013), many of whom do not have a formal diagnosis.

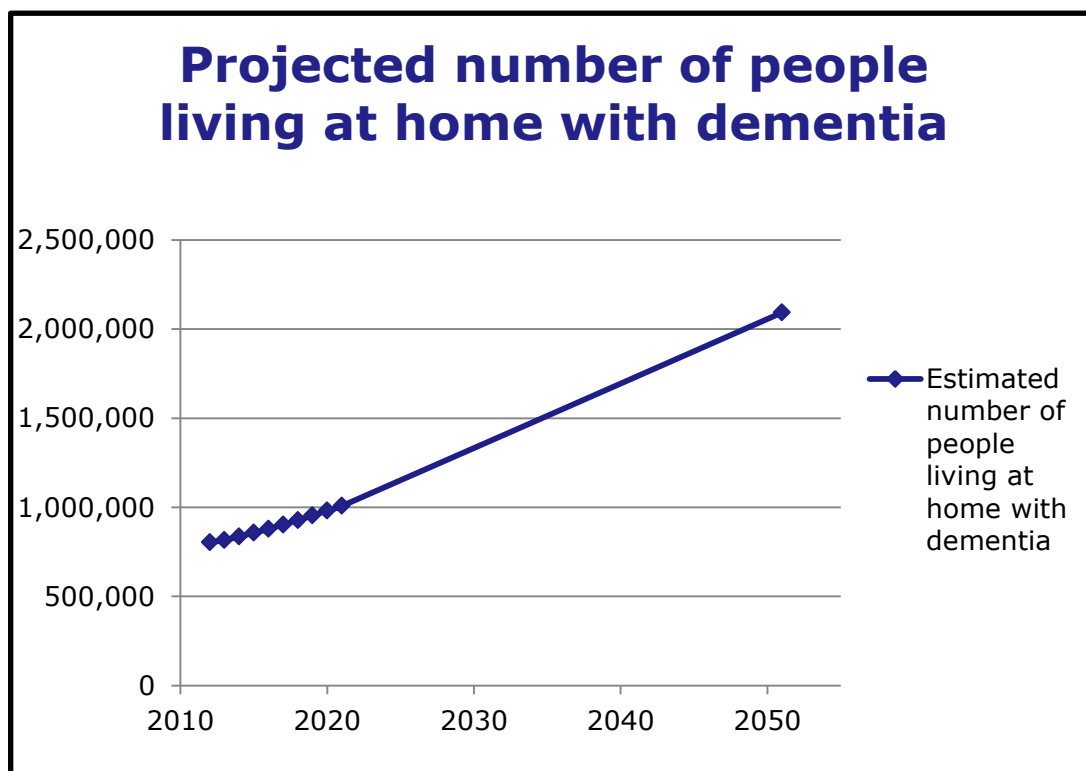
Homecare workers in the U.K provide a growing range of vital care and support services to enable people to live well with dementia in their own homes, including personal care, administration of medication and more general support. In a relatively short period of time, dementia care in the home has progressed significantly, and continues to evolve as a result of improved training methods, new technology and a wider understanding of what the condition entails. But there is a way to go.

Dementia is now a public and political priority, with the Prime Minister's Challenge on Dementia 2020 (February 2015) building on the initial Challenge (March 2012) and the 2009 National Dementia Strategy to drive improvements in health and social care and research, in addition to creating 85 (as of January 2015) communities working towards being dementia friendly.

A recent YouGov poll for the Alzheimer's Society (2014) found 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, and it is recognised that changes of environment can be particularly unsettling for people living with dementia.

The Department of Health's 'State of the Nation Report on Dementia Care and Support in England (2013)' states 'an estimated one third of people

with dementia live in residential care with two thirds living at home'. If correct, it would imply around 570,000 people live at home with dementia, supported by family, informal carers and regulated homecare services. There does, however, appear to be a lack of absolutely reliable statistics in this area and we call for greater research.



Projected numbers based on Alzheimer's Society (2014) total figures and estimate that 2/3 of people with dementia live at home

To accentuate the absence of reliable figures, an estimated 40% of people with dementia do not have a formal diagnosis or contact with specialist services (diagnosis rates vary across the country) (Health and Social Care Information Centre, 2015). Diagnosis rates appear to be particularly poor for people of Black, Asian and other Minority Ethnic origin, partially due to low levels of awareness of dementia and a lack of access to culturally sensitive or accessible services. This is particularly problematic given prevalence of dementia within BAME communities is expected to double in the next ten years alone. (APPG on Dementia, 2013)

Despite some inconsistencies and gaps in numbers it is evident that a very large number of people in England are living at home with dementia. It is vital that for their own wellbeing and that of those closest to them that a range of high quality, sensitive and appropriate services should be available to them to support them in remaining independent.

Skilled, regulated homecare will play a pivotal role in this support, both in terms of caring and in providing essential advice and information, and this report identifies features of such good homecare and what needs to change to ensure that this is readily available to everyone who needs it.

Remaining safely and confidently in the community also requires a number of other features. The understanding and 'dementia friendliness' of others in the community is currently being addressed by The Dementia Friendly Communities programme, to ensure that those people who remain in their own homes do not become isolated, anxious or too fearful to go out and do the things they want to in their own community.

Interest in enabling people to live well in the community for longer is also growing among the financial, business and retail sectors, the role of civil society and the voluntary sector, and in how assistive technology can contribute.

It is clear that in order properly to address the growing needs of society in relation to dementia, a wide range of people and disciplines need to pull together to ensure that a comprehensive 'package' of social and medical support, together with a welcoming environment can be available for each individual and their family.

Disclaimer

Whilst every effort has been made to ensure the accuracy of this document, 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 document.

Purpose

This report considers key aspects of a 'package' of care and support for each person living with dementia at home, how it could be developed across the country and how it can be maintained as needs increase.

Much of the content in this report has been developed through discussions at the Dementia Health and Care Champion Subgroup on Homecare. The Subgroup consisted of policy makers, carers, homecare providers and dementia specialists, and was set up with the focus of driving improvements in care for people living with dementia in their own homes. Part of this remit was to highlight both innovative practice and some of the challenges to spreading more widely this practice, in addition to possible ways forward.

The report aimed initially to provide key information related to dementia and homecare to the main Health and Care Dementia Champion Group, responding to the Prime Minister's Challenge on Dementia, combined with a longer term ambition to support and inspire commissioners and homecare providers and others at a local level to improve outcomes for people with dementia and their carers.

There were two other parallel Health and Care Dementia Champion sub-groups - one group sought to support Social Care providers and commissioners improve their care of people with dementia in care homes and the other aimed to improve end of life care for people with dementia and their carers.

Alongside the Health and Care Champion Groups there were also Dementia Champion sub-groups on Research and Dementia Friendly communities.

Actions for change

The Dementia Health and Care Champion Subgroup on Homecare makes the following recommendations, based on the findings of this report, to help the sector turn identified instances of good practice into normal practice used throughout the country.

1. Champion homecare as the key facilitator of dementia care and information

Perhaps the greatest need for people living with dementia is access to appropriate support and care at home. 85% of people want to remain in their own home, yet it is believed that only two thirds of people with dementia do so. For many people, facilitating their wish to stay at home will require skilled and co-ordinated support, delivered through a package of care at home. For many people homecare services are the most regular contact they have, and homecare providers can offer a vital role in the signposting and navigation of local information which can assist the individual and their family in making informed, personalised choices.

How can we make this happen?

- *Access to sustainable, quality homecare for everyone who needs it as a priority for commissioners.*
- *Funding of homecare to deliver a high quality service as the key enabler to living well at home.*
- *Recognised training established for care workers and managers around provision and signposting of information.*
- *A multi-disciplinary approach across the health, social care and voluntary sectors focused on providing care in the community.*
- *Local Authorities to commission external, independent information and advice on the local homecare offer, regardless of how that care is funded, to fulfil Care Act requirements on information.*

2. Deliver a personalised approach focused on outcomes for the individual & their family

Innovative dementia care practice in homecare would blossom if the wider social care and health system, from assessment and diagnosis to end of life care; from planning, commissioning and procurement of services to the delivery of front line care was co-ordinated and collaborative. Care should be focused on the needs and choices of the individual and their family and on enabling people with dementia to achieve the outcomes they wish. Rather than seeing the person as the condition, they should be based on seeing the person as an individual, living with the condition.

How can we make this happen?

- *The principles enshrined in the Care Act 2014 to be delivered, such as the right to a personal budget, emphasis on maintaining well-being, signposting to vital information and a focus on prevention must be delivered for a personalised approach to flourish.*
- *A holistic assessment should be developed and delivered, covering a 360 degree view of needs regardless of the source of funding or care, using information and language which can be used and understood across the system.*
- *People with dementia should be offered personal budgets, Direct Payments and Individual Service Funds in the same way as everyone else.*
- *Carer's assessments under the Care Act must recognise and address the emotional and physical pressures on those caring for people with dementia.*

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

Innovative dementia care at home that responds to people's changing needs requires a degree of freedom and flexibility, to allow providers to implement and mould new ideas into everyday practice and to provide care in the way best suited to the individual. The Subgroup on Homecare considers greater autonomy for providers to work with the individual and their family to shape how and when care is delivered to be of high importance. Greater freedom and support for homecare providers to implement and experiment with technology solutions alongside personal contact, becoming a modern sector that utilises the equipment and applications that are more readily available is needed.

How can we make this happen?

- *Health and Wellbeing Boards, and/or CCGs should commission something similar to dementia care user reviews for care providers and dementia care peer reviews across local authorities' commissioning teams.*
- *The consumer led reviews could, for instance, in part be facilitated through guidance and support from the Alzheimer's Society and UKHCA, with Dementia Friends Champions potentially playing a key role in conducting surveys.*
- *The Care Quality Commission should take a lead in encouraging providers and commissioners to provide quality dementia care – include dementia specific questions during inspection and an increased focus on recognising innovative dementia care.*
- *The establishment of a 'Dementia Star' (working title) to recognise and celebrate excellence and innovation. The criteria could be based on a combination of positive User Reviews and specific evidence from 'Good'/'Outstanding' CQC reports. UKHCA and Alzheimer's Society could publish examples of best practice.*
- *Improved transparency and communication between commissioners and providers when negotiating care at home packages, and from regulatory inspectors and council monitoring teams to facilitate and drive good practice.*

4. Recognise and realise the value of homecare to reduce risk & lessen the negative impact of dementia progression

The value of homecare in reducing the risk of developing or delaying the progression of dementia, with increasingly sophisticated approaches designed to improve health and wellbeing and cognitive stimulation, must be recognised. It can make a significant difference in reducing the impact on the individual and their family, in addition to helping them live well at home for longer.

Commissioners across health and care services should recognise the value of homecare as a key option in preventative care and in maintaining wellbeing. Additionally there should be a greater role for homecare workers (who are able to build a close understanding of the individual they work with and identify any changes in their condition), to be involved in the referral, assessment and diagnosis process, as well as to flag when more or less care is required.

How can we make this happen?

- *Homecare workers to be recognised as an integral part of reviews of care needs, informing a wider picture the individual, rather than through just spot checks with the GP.*
- *End the 'islands of information' held about an individual across the health and social care sectors. The flow of information between GP and those carrying out care is essential – an agreement for shared responsibility and commitment for carer workers to produce information on the progression of the individual receiving care, on the provider to ensure that information is produced and recorded and on the GP to use and act upon the information they receive should be created.*
- *Homecare professionals should play a key role in a multi-disciplinary approach to dementia care, including involvement in case conferences.*

5. Prioritise homecare as a cost effective form of intervention

As a society we need to explore new approaches that will support progressively increasing demand for homecare and other care services. There is an excellent opportunity to create a system wide, whole person approach to funding dementia care that looks at meeting the needs of the individual regardless of the care setting in which those needs are met.

Any system-wide approach should recognise the contribution homecare can make to savings in the NHS, by moving more care into the community, keeping people at home for longer, helping them return home from hospital sooner, supporting family carers to keep going or remain in work and promoting the prevention agenda set out in the Care Act.

How can we make this happen?

- *Health and Wellbeing Boards are well placed to recognise where money is best spent on intervention and prevention should be empowered to have a greater say in how care is approached and funded.*
- *Health sector and ADASS should work closely with local homecare providers to recognise additional capacity for people with dementia to be discharged from hospital earlier.*
- *Health and Wellbeing Boards and Better Care Fund money could be used to collect tangible data on the value of homecare as a preventative measure.*
- *Schemes that some areas are putting into place as a result of the Better Care Fund, that focus on providing care and preventative support in the community, should be monitored and promoted.*

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

A vast amount of the good practice identified in this document starts with similar basic principles. These focus around the individual, and often require an in depth understanding of what the individual and their family wishes to achieve and how they would like to go about their ambition. For this to be seen as a feasible outcome, it is essential that care workers are given the time to develop this understanding and to shape how the service is delivered through the wishes of the individual. On that basis it is vital that we rethink how services are commissioned. A UKHCA commissioning survey in 2012 found that 73% of homecare visits in England were for 30 minutes or less and there is evidence that commissioned visits have become even shorter. This is clearly completely inappropriate for providing good care to someone who might be confused or anxious.

We are pleased that, in response to the Care Act consultation, the Department of Health has clarified that 'very short home care visits are not normally appropriate'. However, we believe that this must go further if more people are to receive the kind of quality service identified in this report.

How can we make this happen?

- *Review how services are commissioned, moving away from commissioning 'time and task' based services, towards a holistic, more flexible outcome-focused package of care at home that links seamlessly to other services.*
- *New commissioning models that take the above approach should be signposted and promoted with both commissioners and providers trained.*
- *Accessibility, support and information relating to Direct Payments and Individual Service Funds/integrated personal budgets for people living with dementia should be improved.*

7. Develop consistent and reliable homecare services and training

Dementia care requires an important array of skills and knowledge, delivered by a workforce which is sufficient in size and quality. Greater effort is needed to enshrine a focus on dementia in all aspects of training.

In addition, the Subgroup on Homecare would like to see an advanced training qualification that is accredited, made widely available to homecare providers across the country at a reasonable cost (or publicly funded) for care workers who wish to specialise. In addition to raising the quality of care and support,

this could help to highlight the value of the work that is carried out, in addition to helping establish a clearer career path for homecare workers as professional experts.

How can we make this happen?

- *An accredited, advanced dementia training qualification should be established.*
- *Directors of Adult Social Services should acknowledge and honour their responsibility for the training of staff in providers as well as their own direct workforce.*
- *The public image of the sector should be improved through wider coverage and recognition of good care and commissioning.*
- *Training of the workforce should be publicly funded and supported against clear standards to help retention of staff and consistency of care.*

8. Help providers to implement & experiment with technology

The Dementia Friendly Technology Charter explores how technology can assist people living with dementia and their carers. Whilst not a solution for everyone, technology can be used in a variety of ways, from enabling people to live as full a life as possible without putting themselves or others at risk to enhancing quality of life through reminiscence and telecommunications, and supporting people to manage and assess health outcomes.

The Subgroup on Homecare supports the ambitions of the Charter, which includes sign up from all clinical commissioning groups, local authorities and service/technology providers. This should lead to greater freedoms and support for homecare providers to implement and experiment with technology solutions, working towards a modern sector that utilises the equipment and applications that are increasingly readily available alongside personal care.

How can we make this happen?

- *Pursue the ambitions of the Dementia Friendly Technology Charter (see 'Further Resources' section), which explores how technology can assist people living with dementia and their carers are supported.*
- *Designers of assistive technology should collect and make use of data and information from homecare providers and people using services as part of their research and development into new products.*

- *Commissioners and providers should work together to implement technology that supplements, not replaces, personal contact.*

9. Develop research on care, as well as cure

It is encouraging to see significant increases in investment in dementia research in recent years, and it is essential that this continues. The Subgroup on Homecare proposes more focused research into what constitutes the best care at home. Currently there is a dearth of research and reliable data surrounding the opportunities for preventative measures and risk management in the home to achieve improved wellbeing and savings for the NHS. Currently only 10% of funding for research allocated to the four leading causes of death is allocated to dementia. Wider research into care, as well as cure will also help people to continue talking openly about dementia, improve the quality of care and fuel greater understanding and reduce associated stigma.

How can we make this happen?

- *Wider research on what works well in homecare, including the potential benefits of using technology to support care at home.*
- *Collection and analysis of information and data surrounding preventative measures in the home to create longer term savings for the NHS.*
- *A ring fenced budget should be created for homecare research around cost effectiveness and positive impact on wider health.*
- *Research into the root causes behind more people entering residential and nursing home care settings than have expressed a wish to.*

The person, the individual

An important starting point for any homecare provider or commissioner, and therefore any related report, is the need to recognise and value the individuality of the person living with dementia that they are caring for, rather than just the condition.

An umbrella term, 'dementia' describes the symptoms that occur when the brain is affected by certain diseases or conditions, with Alzheimer's disease the most common cause of dementia. Each person with dementia, and their families, will experience the condition differently, and it is essential that the health and care system is able to reflect and respect that. Individual preferred outcomes, choices and ambitions must be recognised when shaping services. Furthermore the subject of homecare for someone who has dementia is extremely broad, as it encompasses not only changes throughout the lifetime of the dementia, but also the situation of family, cultural requirements and preferences, access to appropriate help, and as importantly, to the type of dementia concerned.

The Subgroup on Dementia and Homecare has approached this project with a commitment to promote an approach to care that sees the whole person, and not just the condition. As reflected in our recommended actions, a care and health system that better recognises no two people with dementia are alike will be better placed to deliver the desired outcomes of the people it is designed to support.

In order to find and develop innovative practice in homecare when working with dementia, it is vital that our analysis is founded on what people with dementia have identified as being important to them. Through the National Dementia Declaration (2010), people living with dementia and family carers identified seven key outcomes. The first six outcomes in particular are highly relevant to helping people live in their own homes.

- 1.I have personal choice and control or influence over decisions about me.**
- 2.I know that services are designed around me and my needs.**
- 3.I have support that helps me live my life.**
- 4.I have the knowledge and know-how to get what I need.**
- 5.I live in an enabling and supportive environment where I feel valued and understood.**
- 6.I have a sense of belonging and of being a valued part of family, community and civic life.**
- 7.I know there is research going on which delivers a better life for me now and hope for the future.**

This report will use these key outcome/'I statements' at the heart of what is considered and recommended. To ensure that the Dementia Champion Subgroup on Homecare pursued these objectives, the subgroup consulted with a focus group of people living with dementia, their carers and professional care workers.

Family carers often provide the bulk of care to people living with dementia. This can be both demanding and challenging and these carers' needs must also be met if the individual is to remain safely at home.

The following details some of the experiences of a family and their friend who have been living with the effects of dementia. These experiences serve to remind us of the need for good quality homecare and the challenges faced by those living with and around the condition.

I am Eileen, I am 92 years old and I am living with dementia.

I still clean the flat and cook for my husband, wash and dress myself, but my husband and daughter tell me I do none of these.

I have difficulty walking these days and so I sit most of the day in my chair.

Sometimes the man in my flat is not my husband, although he says he is. When I tell him to leave, he won't, and when I tell him to call my daughter and she comes over, she tells me he is my husband and that I have been married to him for 45 years.

Sometimes we sit down to eat but I tell the man I can't begin until my husband comes home, so in the end I don't have the food. Sometimes I'm sure the flat is not my home and I want to go back to my mother, or my brothers – but my husband and daughter tell me they are all long gone.

I still have a job, but I am told I retired 40 years ago.

I'm scared.

(Eileen lives with mixed dementia. She relies on support from her family and a homecare package to allow her to remain at home)

I am John, Eileen's Husband

I am John, I'm 84 and I live with my wife Eileen.

In the past Eileen did everything in the house, but these days she can't do much more than sit in her chair, so I have to do it all for us. I am with my wife all the time, except when I can go out and buy some food.

Recently, taking Eileen out at all has been getting very difficult, even if I say we are going to her daughter's, as she has become very nervous of leaving home and suddenly says she is "very ill".

I have to make sure Eileen takes all her medications, though that can be difficult at times. She may spit them out, or hide them. She will take medication from the carer who comes in.

Though I cook meals for her, she often won't eat as she wants to wait for her first husband, her brother, or her mother, all of whom died years ago. While she can still go to the toilet on her own, she can't manage washing herself.

In the daytime, she needs help as she can be really fragile on her feet, but at night, she wanders around without help. I still have to stay awake to make sure she is safe, so I am very tired. In a similar way, when she is with me, she is very muddled, but can appear much more normal when she sees her consultant, or even other family members. It is frustrating.

Life is not good as Eileen won't watch television as she can't follow programmes and she can no longer read anything because she can't follow a storyline in print. So she wants to talk to me all the time.

We have two daily visits from carers who help her wash, dress and take her medications, though she often resists them.

I am Nina, Eileen's daughter

I am Nina, I am 70 and I live a few minutes away from my mother and step-father John.

For the past several years I have visited or seen my mother on most days, enabling my step-father to have a few hours to himself and to go shopping.

When she was first diagnosed, Mum was often very agitated and I would be called in to try to defuse things. She would become physically aggressive and, when she was last really bad, she spent some months in hospital for assessment. We finally brought her home after we had asked the consultant to try an anti-psychotic medication, and this was what finally enabled her to go home. The hospital had previously expected her to go straight to a nursing home.

Between us, we give my mother constant attention, but this is at a cost to my step-father and I who are both getting on in years, and find it physically and mentally very draining. With my mother's deterioration, it is taking so much out of me that I am unable to give the rest of my family the attention they need.

I am worried because if either John or I are unable to continue our caring role, or if the daily care worker visits are stopped or reduced, my mother would most certainly be moved into permanent care. It is constantly on my mind and I am never at rest.

I am Bruce, a family friend

I am Bruce, I'm 67 and I help Nina and John care for Eileen. I have been a family friend for 50 years.

My late wife had the same mixed dementia and I am using my experience of many years caring for her to help Nina, John and of course Eileen, and to help share the load.

While personal care of someone who has dementia can be a problem, dealing with the behavioural and other presentation issues of the condition is also a major thing.

I learned to enter the world of my wife and not to expect her ever to be able to enter mine, or to be able to learn new things, and also learned strategies for dealing with repeated conversations, fears, and seeing behind seemingly strange situations. I'm passing this knowledge on.

Without prior knowledge of these things, coping at home would be a very different matter. That is not to say it makes it easy.

We have realised that our experience is often as appropriate as the professional care team's, and we have successfully managed Eileen's care with them in active partnership.

Together we are a team that has very effectively given Eileen over 12 months of extra time in her own home, so far.



Building a case for homecare

Timely Intervention & Support

According to mortality statistics from the Office of National Statistics (2014), dementia is the leading cause of death in women and the third leading cause among men. In the absence of a known cure, risk reduction is vital in reducing the numbers of people developing dementia, postponing the onset and mitigating the impact. All too frequently society appears to prefer crisis management rather than proactive, early support. However worldwide, risk reduction and prevention is increasingly becoming a key focus of those involved in dementia care, as demonstrated through inclusion in the World Dementia Council statement of purpose. In section 2 of The Care Act 2014, a duty is placed on local authorities to provide or arrange services that reduce the need for support among people and their carers, and contribute towards preventing or delaying the development of such needs.

Evidence suggests that effective public health policies to tackle the major chronic disease risk factors of smoking, physical inactivity, alcohol and poor diet across the population will help reduce the risk of dementia in later life. Public Health England and the UK Health Forum published the



Alzheimer's Society (2014)

Blackfriars Consensus Statement (2014), signed by 60 leading figures and organisations from across the dementia and public health community, as well as all UK health ministers. It states that 'the scientific evidence is sufficient to justify action on dementia prevention and risk reduction.'

The Consensus (2014, p. 3) also highlights that...

'As with so many other diseases, the impact that dementia has on people's function and their lives, depends on their overall state of health and the balance between protective and risk factors across the life course. There are a number of unique risk and protective factors for dementia which are amenable to change such as social isolation; cognitive reserve; cognitive stimulation; prompt treatment of infection, and depression. Both policy and research agendas should maintain a focus on these as well as on factors shared with non-communicable diseases.'

The Consensus is an important step in evolving the way in which society considers dementia, and underlines the need to emphasise the value of wider wellbeing, prevention and early support in delaying or slowing the condition. With dementia estimated to cost the U.K. economy over £26billion a year (Alzheimer's Society, 2014), a figure higher than for cancer or heart disease, it is increasingly clear that there is a need to re-evaluate how resources are being spent, when they are spent and how they might be used more effectively. Encouragingly, the debate and action surrounding integration between social care and health implies a desire to focus a shift in budgets and attitudes towards early support within the community.

It is here, in delivering timely care, wellbeing and improved health, that homecare can offer such important, and currently undervalued, support.

Timely assessment and diagnosis

The first Prime Minister's Challenge on Dementia set a national ambition that two-thirds of the estimated number of people with dementia should receive a diagnosis and appropriate post-diagnosis support by March 2015. It is believed that dementia diagnosis rates in England are around 59% (Department of Health, 2015). Despite that figure representing a 28% increase since 2012, there remain a significant number of people living with dementia without a diagnosis.

Without diagnosis they are often unable to access appropriate formal and informal support and care services, and this frequently leads to unplanned costly admissions into long-term and acute care settings. Homecare workers who know the person well are often in an ideal position to spot early signs of dementia, as trained professionals offering support with other conditions they are well placed to identify symptoms and can act as important links to community health services for diagnosis. More than seven in ten people with dementia have another chronic condition, which may mean they already require some degree of homecare (Alzheimer's Society, 2014). The average number of long-term health conditions for a person with dementia is a little over four (Guthrie, Payne et al, 2012).

To help increase diagnosis rates, it is important a joined up, holistic assessment of need is carried out, which includes the input and knowledge of homecare workers, in addition to the individual and their family. Often homecare workers are ideally placed to report on a longer and more reliable timeframe of contact time than in the short period taken into consideration in an assessment.

What are some of the challenges?

- Homecare providers/carer workers often excluded from the assessment stage.
- Communication and IT systems between different services are inadequate.
- High percentage of 15/30 minute visits commissioned (73% 30mins or fewer found by UKHCA in 2012), means that this opportunity can often be missed.
- Skills for Care 'NMDS' (2014) tables suggest turnover rate of frontline homecare workers in England is 31.7%. Some organisations struggle to provide the same carer for each visit and it can be difficult for a new care worker to pick up on signs of dementia.

Value of timely support

A report published by the International Longevity Centre (2014) presents data showing that people over the age of 55 fear developing dementia more than any other condition. This is partly due to stigma that remains around dementia, in addition to concerns over the lack of a known cure. For this reason in some cases GPs are reluctant to make a diagnosis.

Yet diagnosis and establishing support structures at a timely stage can be vital to the continuing wellbeing of someone living with dementia. It can provide more time for both the individual and their family to learn about and come to terms with the condition, in addition to a greater chance to access appropriate health care and to build early links with community support networks. It can also allow the individual to take charge of their own health and to make changes that may delay the progression of the condition at an early stage. Timely support is essential in allowing people to feel they are in control of their dementia, and not the other way around. For this to occur, the social care system needs to ensure that advice, information and support networks are readily and visibly available.

Many homecare providers offer a flexible range of services that aim to provide that early support. Initially, they are ideally placed within the community to offer targeted information and advice that can help the individual and their family better understand the condition and to access further local support services.

In developing a relationship with the individual and their family through timely access to homecare, the provider and care workers are able to form a deeper understanding of the wishes and the history of the individual, something which can positively enhance the quality of care when those care needs increase. It also provides the individual and their family the opportunity to shape how care is to be delivered throughout their journey with dementia.

Additionally, by offering timely support, there is increased opportunity to make a meaningful impact on the overall long-term health and wellbeing of the individual. Homecare at a timely stage can assist with medication, nutrition and personal care to support the person living with dementia to delay the progression of symptoms.

This can help someone with dementia continue their preferred daily activities, reassure them that support is available, reduce anxiety and stress by helping them to remain in familiar surroundings, and lower the need for unplanned, and expensive, admissions into hospital as well as supporting family carers.

Timely intervention, example of innovation - Right at Home Guildford & Farnham and Right at Home Sutton & Epsom

Alastair Shanks, Managing Director at Right at Home Guildford & Farnham, is a Dementia Friends Champion and holds a keen interest in dementia research developments. As a result he is aware of the growing consensus surrounding the importance of wider health considerations such as diet, exercise, social activity and stress avoidance in delaying the progression of dementia.

To reflect this research, and coupled with the experience and expertise of their CareGivers, Right at Home Guildford & Farnham and Tim Haigh, Right at Home Sutton & Epsom have developed the DELAY programme. This is based on 'Diet, Engaging with others, Learning and mental stimulation, Avoiding stress and Your body and exercise'. Targeted support surrounding these five key areas is provided as soon as possible following a diagnosis of dementia, in addition to being encouraged amongst all people receiving services from the provider. A lead, named CareGiver, trained to deliver the programme, will work with the person living with dementia and their family to develop a personalised lifebook and care plan, with the latter focusing on the five pillars of the DELAY programme aimed at slowing the progression of the condition. This care plan will then be adjusted as necessary as the condition develops.

DELAY is ideally delivered through longer sessions of homecare than are typically currently commissioned by local authorities, up to around four hours, but can be highly effective with only one or two sessions per week. A key element of the DELAY programme is to help people living with dementia to maintain vital connections with the community, engaging with local people and taking part in group events, many of which are organised by Right at Home themselves.

Timely support and intervention, example of innovation – The Good Care Group

The Good Care Group, a provider of live in care services to people in their own homes, through effective incident management tracking and risk management practice, have proven that solid intention and risk management methods makes a difference. In 2013, 90% of their clients living with chronic, progressive conditions (75% dementia) showed improvement in health outcomes;

Only 45% of clients experienced behavioural challenges compared to over 90% of the general population (ref: Alzheimer's Society).

9% of clients are prescribed anti-psychotic medication vs. 20% of care home residents (ref: Aldred 2007)

Only 45% of clients experienced behavioural challenges compared to over 90% of the general population (ref: Alzheimer's Society).

Only 35% of clients have experienced a UTI – only 10% have experienced recurrent UTI's. 50% of care home residents experience UTI's

Only 11% of clients receiving skilled homecare experienced a fall. Between 50-75% of care home residents fall in any one year, vs. 25-37% of older people in the community

Re-admission rates for hospital stays are less than 5% of those who are admitted once

Timely support, example of innovation - Partnership with Primary Care services and General Practitioners

The National Association of Primary Care (NAPC) and Health Education England (HEE) have joined forces to create and deliver a new training programme for GP practices and community pharmacy 'Primary Care Navigators for Dementia' to signpost people with dementia and their carers to the full range of support they need for all aspects of life and wellbeing post-diagnosis. The Navigator role is simple yet effective. This work forms part of the growing consensus that getting a timely diagnosis of dementia can save people from enormous unnecessary suffering and provide much greater wellbeing – IF they have easy access to further support. Many of these sources of help and support will be from local initiatives within the community, such as homecare providers. The project initially included 20 GP practices and 20 community pharmacies, with plans to expand following an evaluation of initial results published by Deloitte in 2015.

Combatting loneliness & boosting health

The Blackfriars Consensus, an agreement made in 2014 by fifty nine organisations and dementia experts with a focus on dementia risk reduction, champions the need to focus on an individual's overall state of health. Homecare providers have the scope to play a key role in maintaining or boosting the wider wellbeing of the person who is using their service. In the Alzheimer's Society report, 'The hidden voice of loneliness' (2013), more than a third (39%) of people with dementia who responded to a survey said they felt lonely. This figure grew to nearly two-thirds for those people living alone with dementia. A third of people living at home with dementia do so alone.

In the same report, it was found that more than two-thirds of people who responded had stopped doing things they used to due to a lack of confidence. In turn this is likely to lead to a loss of independence and potentially a greater sense of social isolation. Some felt that as they lived alone, there was no one around to encourage them to be active or carry on regular activities.

Loneliness has been shown to link very closely with incidents of poor health, depression, reduced mobility and increased cognitive impairment, all of which present an increased risk of requiring hospital treatment.

Homecare services offer an avenue of support which can help alleviate social isolation and loneliness, and to live a fuller, more enjoyable life. This may be as simple as through regular interaction between the homecare worker and the person using the service. Here, continuity of care is vital, and can allow the individual and the care worker to develop a trusting bond.

Providers are increasingly using life stories to help stimulate interesting conversation and develop understanding. Many homecare providers encourage their workers to become Dementia Friends, an initiative through the Alzheimer's Society to which more than a million people have signed up so far.

Homecare services can also encourage people with dementia and their carers to remain socially active, maintaining stronger ties with the local community and other support services through trips out and signposting to information and events. Knowledge of group activities in their area and services offered by the voluntary sector are particularly helpful. Direct Payments and Individual Service Funds in particular are giving people with dementia who are at risk of social isolation the flexibility to design care services with social interaction as the central focus.

Importantly this may also help alleviate some of the isolation felt by family carers, offering vital support and respite and enhancing enjoyment in life.

Advances in technology are also proving to be extremely useful in helping isolated people remain connected, both with the help of homecare services and independently of them. Mobile communications hardware and software such as mobile phones, tablets and laptops are an increasingly accessible and affordable option. Telecare services are helping homecare providers build close, but unobtrusive ties with the people to whom they deliver services.

Combatting loneliness, example of innovation – Trinity Homecare

Looking at all the photos in Betty's home, it's obvious she's been a much loved wife, mother and grandmother. But Betty's story became one of isolation and sadness after her husband died; she lost her daughter to cancer and her only grandson was killed in a car crash.

At 84, Betty is physically very fit, but her dementia has made her vulnerable. When Betty wandered out alone at night earlier this year, was rescued by a stranger, taken to A&E, and finally taken home by the police, completely bewildered, a review of her needs agreed that it was the right time for Betty to progress with Trinity Homecare to full-time, live-in care. This is a 24hr form of constant, considered, one-on-one care shaped to individual requests.

Betty has lost the ability to communicate her most basic needs; she can't say when she's cold and doesn't know when to go to bed or what might be harmful.

Judith, a qualified nurse trained in dementia care and Betty's carer, is a sensitive person and the relationship that has developed between them has been crucial in reducing Betty's sense of isolation. Judith is able to read non-verbal cues about what Betty might need or what the problem might be. When Betty puts on her coat, intending to go to the shops for food, Judith knows she's hungry. Betty kept removing her polo neck jumper repeatedly on one occasion despite the cold and Judith recognised that Betty had a sore throat. Mutual trust and understanding has helped Betty return to a more normal and healthy routine, including regular day centre trips and dancing, leaving her feeling happier and less lonely.

Reducing isolation, example of innovation – Home Instead Chesterfield

This office has a client who was once the life and soul of parties and enjoyed regular lunches out and trips to the theatre with her wide circle of friends.

Since being diagnosed with dementia she had become withdrawn and had stopped going out.

Home Instead was keen to see if they could re-invigorate the lady when they started caring for her a year ago. They were willing to move away from the usual care model to do so, and one of the first activities they involved her in were regular trips to a jazz club which she thoroughly enjoyed - something which kept her and her caregiver out until past midnight on numerous occasions. In turn these visits opened up a former circle of friends that the client had lost touch with and they were all able to enjoy the music together once again.

'Side by side' befriending, example of innovation – Alzheimer's Society

Mr P was originally referred to Alzheimer's Society's Side by Side Befriending in October 2011 by the Manager of the day centre he attends. Mr P was diagnosed with Alzheimer's disease in 2008. Since his return home Mr P had become more confused and Mrs P was finding it more difficult to manage due to her own health needs. Mr P receives calls from carers twice daily to attend to his personal care needs but the couple spend the rest of the day alone together as their family live away and are unable to visit regularly.

Since January 2012 Mr P has had a regular befriender who has spent time with him at home each week discussing his life in the RAF and reminiscing over his

memoirs. The volunteer has also taken him out for a walk when his mobility has allowed and played dominoes, chess and scrabble when the weather was bad.

Mr P really benefits from the social interaction of the visits and enjoys talking about his life and family. The physical activity of the walks helps with his mobility and general sense of wellbeing at being outdoors lifts his mood. Also the mental stimulation of the activities helps him to maintain skills and his sense of purpose.

Mrs P benefits greatly from the time she has to herself while the befriender spends time with Mr P. She has time to catch up on paperwork and chores or to just have a rest if she wants to. It has also helped link Mr and Mrs P to other services run by Alzheimer's Society.

Support and respite for family carers

Caring for someone with dementia can be mentally and physically demanding, and requires a great deal of selflessness. For many family carers, their dedication can result in there being a detrimental effect on their own health. The support of a homecare service can offer an opportunity for family or friends with caring responsibilities to take a rest, prevent burnout and reduce the risk of feeling overwhelmed or developing health issues that require medical assistance such as depression. The Alzheimer's Society's 'Dementia UK: Second Edition' (2014) highlights that 1.34 billion hours of unpaid care are provided to people with dementia in the UK, to the estimated value of £11.6 billion to society. The importance of supporting and maintaining this essential source of care is paramount.

Recent research led by Gill Livingston at University College London (2014) found that dementia carers who were given emotional support and strategies on how to cope through a 'Strategies for Relatives' (START) trial were seven times less likely to develop clinically significant depression.

Respite care can be provided for a few hours, days or even several weeks to allow the family carer to recharge their batteries, and can be part of a regular arrangement or organised with immediate effect.

Good homecare providers work effectively alongside family carers. In addition to relieving some of the pressures, it can improve the quality of care by using the experience and knowledge of the family carer with the individual, as well as upskilling and training the family member in areas of care with which they feel less familiar.

Support for families, example of innovation – Helping Hands Home Care

Helping Hands, a live-in homecare specialist, formally launched their own Dementia Family Days in 2014. As an organisation that invests a great deal in training their care teams, it made sense to share it with families too.

The Dementia Family Days are held across the country and aim to give practical advice and tips to families, and to make them aware of the different care services available to them and their loved ones. In addition to sharing knowledge on different types of dementia, communication, different stages of the condition and responding to challenging behaviours, the Family Days give those in attendance the power to connect with each other and develop their own personal support networks too.

Support for families, example of innovation – Home Instead Senior Care

Since 2013, Home Instead has been offering Alzheimer's Family Workshops, free of charge, in local communities. The workshops were designed to go beyond the "awareness" level offered by many dementia information programmes, bringing a practical element to dementia support that can be implemented immediately. The Family Workshop starts by explaining what dementia is, how it is diagnosed and various classifications and symptoms.

Practical illustration, such as passing round two bags of rice which reflect the relative weights of a human brain and that of a brain affected by dementia, help to cement an understanding of the effects of the disease. The final section discusses how to manage these behaviours. Bringing the personal information of a 'Life Journal' and tactics such as diversion, accepting blame, appropriate communication and a host of other practical tools, introduces ideas that can be practised immediately. The practical outcome of the workshops is that family carers leave better informed, with new contacts for support and a range of practical ideas to refine and develop in their daily support of a loved one.

Potential benefit to the economy

A Centre for Economics and Business Research report for Public Health England and the Alzheimer's Society (2014) highlighted that dementia caring obligations cost English businesses £1.6 billion a year. The report also states that in 2014, 50,000 carers will have quit their jobs due to caring responsibilities, with a further 66,000 having to make adjustments to their working routine. By 2030 this figure is expected to rise to over 83,000.

Homecare can offer an ideal option for people who are juggling work and care commitments. Support through a homecare package can allow family carers to remain in the workplace. In addition to increasing productivity by maintaining their employment status and economic activity, it can also avoid greater expenditure on benefits and reduce employer costs on recruitment. A considered, personalised approach to homecare can give family carers the peace of mind and confidence to continue in the workplace. This can be especially effective if employers are willing to accommodate some flexibility to assist employees with caring responsibilities.

With current government policy dedicated to reducing the nation's economic deficit, efficiency savings are being sought in many sectors, and social care is no different. Homecare services provide an ideal opportunity to provide quality care, whilst offering an option that can offer significant overall economic advantages.

This report has already explored some of the potential health benefits in early support for people with dementia, and these same benefits could help to reduce expenditure within the National Health Service. By receiving care, helping reduce isolation and maintaining an individual's health and well-being, that person may be less likely to fall into a condition where long term institutional or acute hospital care is required. The cost of staying in a hospital setting is estimated to be at least £300 a day, considerably more than homecare services, even when a homecare worker is living in the home. Analysis by Deloitte (2013) found that funding £1.2 billion on lowering eligibility thresholds for state funded social care to 'moderate' for disabled adults could lead to net savings of £355 million. Changing the threshold and introducing

homecare earlier would also reflect the preventative agenda set out in the Care Act 2014, and could help delay the need for acute care.

Furthermore a vibrant local homecare market helps to ensure money is not unnecessarily wasted on keeping people with dementia in hospital who are ready to be discharged. 'Delayed-discharge' is now a common term in hospitals across the country, a situation which arises when there are inadequate social care arrangements in place to help the patient safely return home. It is an issue which has been escalated in recent years, and NHS indicators showed 1.6million 'delayed days', when a patient is ready to depart from the current care setting but is still occupying a bed, were lost due to delayed discharges in the twelve months to May 2015, a 15% increase from the previous twelve months. Winter pressures in late 2014/early 2015 led to significant issues in A&E departments across the country.

An estimated 25% of hospital beds are occupied by someone with dementia (Alzheimer's Society, 2009). We also know that admissions to hospital can cause deterioration of health and distress for people with dementia, whilst studies suggest that people with dementia currently stay in hospital for longer than others and are more likely to die there.

Local Authorities, Hospital Trusts and CCGs must work to understand the potential homecare capacity in their locality, and focus on increasing and making best use of that capacity to help people recover quicker and alleviate pressure on the NHS. Close working between Social Care and Health and recognising the vital role care in the community can play should be of paramount importance, both for the wellbeing of the individual and the associated cost of delaying their transfer of care back into the community.



Developing a homecare workforce for the future

Knowledge and Skills for Dementia Care

In order to improve both health and social care outcomes for people living with dementia, their families, friends and representatives, homecare organisations and their staff need to be equipped with the knowledge and skills to enable a deep understanding of the condition affecting them.

The aim should be to promote wellbeing and positive outcomes for people with dementia including enabling them to stay in their own homes for as long as they want, promoting stimulation and interaction with others, a sense of overall wellbeing whilst ensuring timely medication reviews, encouraging social activity, challenging and reducing antipsychotic usage, and reducing incidences of behaviour that challenges, preventing falls, urinary tract infections and hospital admissions.

An innovative training strategy for homecare providers will aspire to achieve;

- A fully accredited **qualification recognised across social care and health** specific to dementia care.
- The delivery of a training programme which not only meets but **exceeds regulatory requirements** at all levels, with dementia specific awareness training as part of the induction for all employees an absolute minimum (as included in the Care Certificate).
- A focus on the **interface between care workers and family carers**.
- Training which enables specialist dementia care, with potential for homecare workers to become **dementia specialists within the organisation**, advising and signposting colleagues as well as delivering excellent care and developing a dementia friendly culture throughout the organisation.

- Opportunities and encouragement for workers from every level of the organisation to take part in training and to develop a **dementia friendly culture** throughout the company.
- **Partnering with external experts**/charities to raise awareness and share best practice, in addition to CCGs and GPs.
- A learning pathway enabling **continuous professional development** utilising a phased and varied approach to learning that recognises the different learning needs of different workers.
- A **variety of training techniques** including classroom, remote, e-learning, interactive, practical, on site coaching, reflective practice and assessment based to ensure all learning styles are accounted for.
- Encouragement and support (including access to initiatives like the Workforce Development Fund) to take Qualification and Credit Framework (QCF) **accreditation** modules specific to dementia.
- A programme underpinned by **strong leadership development** in the issues that face people living with dementia
- Recognition, as highlighted in the Blackfriars Consensus (2014), that **dementia prevention and risk reduction** should be incorporated into training for workforces across health and social care.

All of the above should aim to achieve improved health and social care outcomes, preventing unnecessary pressure on the system from both a volume and financial perspective.

Training, example of innovation - Home Instead Senior Care

Home Instead has developed a unique City & Guilds accredited dementia training programme for its caregivers.

The programme teaches innovative techniques for supporting people with dementia. Rather than focus on the symptoms and treatments of the disease, caregivers are trained in effective techniques for managing the many different and sometimes challenging behaviours associated with dementia including refusal, delusions, aggression, false accusations, wandering, and agitation. A

key outcome is that caregivers learn to respect the person with dementia as an individual and observe, honour and support their lives.

Rather than trying to force those living with Alzheimer's or another dementia to live in our world in the here and now, the training suggests caregivers meet them in the past and the programme helps caregivers to achieve this.

Dementia care often focuses on keeping the person with dementia from doing unwanted behaviours, thereby creating a behavioural void. The new programme looks to teach caregivers to focus on supporting wanted behaviours.

Staff Development, example of innovation - Mid Yorkshire Care Ltd

Mid Yorkshire Care feel strongly about establishing career pathways for members of staff, drawing on their particular strengths. They are committed to supporting care workers develop in areas that are of interest to them. One care worker wanted to progress her career by moving from working in the field to working in the office and was given the opportunity to try different office based roles, such as care coordinator. However, she showed particular aptitude for interacting with people, so Mid Yorkshire Care developed her into an assessor/reviewer role, but also identified her deep interest in all matters relating to dementia care. Mid Yorkshire Care arranged and funded a variety of dementia related training courses and supported her commitment to be a Dementia Friend and Purple Angel, leading to the member of staff being appointed a 'dementia specialist' within the organisation.

As a dementia specialist, she is responsible for assessing and drawing up person centred care plans for service users with dementia which she then discusses with the allocated members of staff prior to starting the service and she is there to help them with any problems they encounter. Just as importantly, she is there for the service users and their family members to offer support and information about other things that could help such as equipment, day/respite care and individually tailored solutions to specific behavioural issues. The process has not only helped

to upskill the member of staff and provide a clearer long-term career path, but has also created a key role in helping Mid Yorkshire Care to provide a specialist service for people in the area living with dementia.

Recruitment

The recruitment and retention of good homecare staff is a constant challenge for many care providers while pay remains low, and yet is fundamental to the delivery of high quality, sustainable homecare.

Many providers are responding to recruitment challenges by targeting specific demographics, working closely with government initiatives, acting quickly when candidates contact them, making use of referrals and frequently changing job adverts. This can help to optimise the number of candidates applying.

It is now recognised that a person's character, attitude and values are more reliable indicators of the likely quality of the worker than simply qualifications or prior experience. Enlightened providers are using more sophisticated recruitment techniques beyond the standard interview to effectively screen candidates. For example a number of providers now use online personality and attitude assessments to identify the qualities of a good care worker and dementia workers (for more see <http://www.skillsforcare.org.uk/Finding-and-keeping-workers/Value-based-recruitment/Value-based-recruitment-tool.aspx>). Unfortunately none of these responses alone addresses the greater structural challenges in the market.

One solution is to make homecare an attractive career. One way to achieve this might be for homecare providers to create career pathways with specialist lanes. Accessing funding currently allocated to either the health sector or through the Departments of Work and Pensions and Health would allow providers to invest in training and enable staff to develop their skills and competencies which should be mapped to a career pathway and related pay.

Another route some providers are pursuing involves the development of a specialist dementia team. Highly skilled and regarded by colleagues and people using services, this pathway offers opportunities for further training, skill development and a competitive working environment, valuable in attracting new recruits.

Homecare providers are also finding that developing a strong and unique image based on core values is helping them to appeal to potential jobseekers, who are keen to be associated with an organisation dedicated to improving the circumstances of the people they support. There are many groups who feel working in care is right for them over other options, including people who are currently or have recently cared for someone close to them and people over the age of 55 who either looking for a

What are some of the challenges?

- Low pay sector, largely driven by local authority commissioning and low rates.
- As the economy and job market picks up, potential pool of applicants reduces, particularly in rural areas.
- Poor media representation of the sector, with good news stories rarely covered.
- Homecare work can be challenging physically, mentally and emotionally.
- Many view the sector as a transitional role rather than seeing a career pathway.
- Lone working can leave care workers feeling isolated and distanced from their organisation. Communication technology, supervisions and support is important.
- Temptation (given shortage of applicants) to appoint staff without the appropriate values and attitudes).
- Specialist care, skills and training must be reflected in commissioned rates paid to providers.

change of role or to remain economically active. For many, the flexible nature of homecare is appealing, as it is possible to juggle personal responsibilities with work.

Developing a quality, sustainable local care workforce, example of innovation – Hertfordshire Care Providers Association

The Hertfordshire Care Providers Association has established the following agreement: 'We 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, our staff will deliver support to care providers to deliver a personalised

package of care and support'. This agreement is brought to life through a number of initiatives, which include:

Provided fully funded training in becoming a Dignity Champion (funded via Local Authority)

Designed an 'Advanced Dementia Champion Pathway'

Shared best practice through networking events held quarterly.

Run NHS/Care sharing groups to discuss joint working.

Through the local Forum of Fractures, Falls and Fragility (FoFFF) worked alongside public health to deliver training in falls prevention for managers, a falls study day and piloted an exercise programme for people living with dementia to provide them with confidence, muscle strength, bone density and circulatory health.

Created a Personal Assistant Quality Assurance (PA QA) scheme which enables homecare providers to access specific personalisation training and through quality assurance, kite mark the domiciliary care organisation to work with Direct Payment Budget holders. This scheme was endorsed by the Local Authority Commissioners.

Offer mentoring to those care workers who specialise in engagement activities for those with dementia in the community.

Continue to offer Tailored Leadership Training, through the HCPA leadership suite, to ensure Care Providers offer excellent care leadership in dementia settings.

Recruitment, example of innovation – The Good Care Group

In 2012 The Good Care Group recognised that they needed to respond to higher than expected staff turnover levels. The project they embarked on led to a 30% reduction in carer turnover in 2013 and they continue to see a further decline thereafter. Using psychometric profiling, TGCG reviewed the characteristics of their high performing team members, managers and senior managers. They conducted in depth face to face interviews with each individual and used this information to recreate their competency framework and restate the organisation's mission and values. This combined with a full review of their

interview process (which also considers skills, qualifications and experience) has not only led to decreased turnover but has positively impacted on both carer and client engagement.

93% of clients at TGCG said they trusted their carer, 88% said they had the confidence that their carer understood their medical needs and 82% said their carer was skilled and confident in their delivery of care. Furthermore 82% of clients said their carer had real knowledge and expertise.

A by-product of the profiling tool is the improved quality of carer profiling which has been used to further refine the carer and client matching process with over 80% of carers identified being deemed the appropriate match not only of a skills level but in terms of interests and personality traits.

Values based recruitment, example of innovation – Jewish Care

At Jewish Care we are proactive about our recruitment strategy and have found that it is imperative that we recruit in a values oriented way. We have a strong values culture which supports a personalised approach to care, demonstrated by our recent Investors In People Gold accreditation and service user feedback. It is therefore important to us that applicants live our values of excellence, enabling, creativeness, inclusiveness and integrity, and in turn we reflect these values in the process.

Throughout our recruitment process, we treat all prospective employees with respect and ensure that they have a fair and insightful recruitment journey. We put the candidate at the heart of everything we do in the recruitment process. We are looking for applicants who will fit in with our Jewish Care values and ethics. To do this we have started to use personality assessments, assessments for safeguarding and we ask explicit questions about values during the interview process, going well beyond standard checks such as DBS. This approach will be adopted across the whole organisation over the next 6 months.

Once applicants are successful they are invited to an induction programme which helps them assimilate into the organisation and learn how we live and lead by our values.

A personalised approach

The best of current homecare ensures that the correct best practice aims of the service are specific, personalised and achievable. These aims must be defined by the person and family carers as appropriate and have the full involvement of all relevant social and health care teams, the individual or his/her representatives and all other appropriate stakeholders. Each part of the service must be provided at the most appropriate stage of the individual's journey, delivered in their chosen environment by the most suitably qualified/experienced member of a multi-disciplinary team, and communication between all involved is vital.

The personalisation agenda has been leading some of the positive recent changes in social care. It aims to give people who use social care services more choice and control over the care and support they receive. While personalisation is often associated with new payment methodologies such as Direct Payments, Individual Service Funds and personal budgets, it also requires that services are tailored to the needs and desired outcomes of the individual, rather than being approached in a 'one size fits all' manner.

Although dementia is often still seen by society as a homogeneous condition, it is important to recognise that dementia is in fact an umbrella term for as many as fifty different types of disease. Additionally each person with dementia will live with the condition in a different way.

The Care Act 2014 placed personalisation on a statutory footing for the first time in England, guaranteeing anyone eligible for state funded care and support the right to an individual budget from their local authority.

Homecare providers are increasingly seeking to reduce their dependency on local authority managed contracts (UKHCA, 2015), because the constraint on contracts due to restricted budgets and the constant

downward pressure on fees progressively make the delivery of high quality, responsive homecare very difficult to deliver. Instead many are focusing on working with self-funding clients or those on Direct Payments or Individual Service Funds. This is an option which can afford them greater flexibility to manage and change care plans based upon the clients' preferences, aspirations and needs through daily interaction, rather than one established from an occasional assessment. Many are finding this can lead to a more responsive and appropriate service, particularly for people with fluctuating needs. It can also help a provider to deliver care in more suitable time slots than 15 or 30 minutes.

Individual Service Funds in particular offer a flexible option for individuals, their family and homecare services to share the requirements and responsibilities of arranging and managing a personal budget. This can help professional care services to work with and around the needs of family carers, allowing the individual to stay at home for longer.

Homecare providers often engage with people paying for care from their own funds at a very early (or pre-diagnosis) stage. The earlier providers can start to build a relationship with a person with dementia and their family the more likely they are to be able to provide the best service to that individual, establish a rapport and learn about their life history and what is important to them. The care worker has time to adapt and change the service delivered along with the person with dementia, to meet their changing and complex needs and preferences.

Commissioners and providers are increasingly seeking to design support services that are 'outcomes based'. This approach is important to the personalisation agenda, as it relies on a customised way of delivering services to each person to reach goals that have been shaped by the individual to maximise their potential to live as fully and independently as possible. Positively, an outcome based approach relies on all parties involved to be fully engaged in reaching chosen objectives, helping the whole system to work collaboratively around the person, and involves a significant step away from time and task based models of care and support.

What are some of the challenges?

- Services commissioned by local authorities too often remain time and task based and are inadequately funded.
- Rigid support plans prevent services from responding to what the individual wants.
- Providers are either unable or unwilling to try and pursue innovative practice if they feel they will be penalised for not following prescriptive support plans.
- Access to personal budgets for people living with dementia remains limited, and is rarely promoted as a viable, long term option by local authorities.
- Limited public awareness over the range of homecare options available, including live-in care.
- Personal budgets often take too long to set up, a particular issue given that care needs for people living with dementia may change/increase quite quickly.
- Outcomes based approach requires a longer term view than is currently operated.

Person centred care, example of innovation – Somerset Care, PETALS service

Homecare provider Somerset Care have spent a number of years developing an innovative and award winning service, known as PETALS. This service focuses on six key features: Person-centred, Empowerment, Trust, Activities, Life History and Stimulation.

The service places the individual and their family at the centre of the support package. Focus is placed on creating individual life stories, working with families to produce a memory box, maintaining daily living skills, regular leisure opportunities, inclusive mealtimes and creative use of activities to stimulate and motivate the person with dementia when they are on their own. As a result the service can help to ensure people using the PETALS service feel involved in their care, remain independent and active at home, are left with meaningful tasks once

staff leave, and are supported by a small dedicated team who are flexible to their individual needs.

Personalisation, example of innovation – The Good Care Group, mapping 'trigger points'

The Good Care Group, a live-in care provider, appreciates that each individual living with dementia will experience the condition differently. To help reduce anxiety and distress, they have implemented an approach to logging and mapping incidents and behavioural 'episodes'. By recording what had occurred in the build up to any incident, the highlight and lowlight of any incident, and the number of times over a period the individual had become agitated, the provider has been able to build a clearer picture of trigger points that have led to difficulties for each person with dementia they provide care for.

The recorded data can be used to identify themes in an individual's behaviour, and informs different approaches to see what works best for that person to avoid future incidents. Different strategies are tracked and developed with the help of family carers to create a care plan and approach that creates the least anxiety for the individual. This in turn can also help the carer to build a trusting and co-operative relationship with the person they are caring for.

A small cohort of clients who were experiencing very high levels of distress, which translated into behaviour that challenges, who were identified for the intervention. Within 10 months of the initial intervention all behaviour that challenges had been eliminated and levels of wellbeing restored.

Personalisation, example of innovation – DoCare 'I am' booklets

Central to the support DoCare delivers is a commitment to treating each person as an individual, adopting a person-centred focus, and finding out particular areas of interest, so activity-based methods are bespoke to that individual.

In the first instance, for all people, whether or not they have dementia, an 'I Am' booklet of preferences is completed, which details as much information about the individual as possible including likes and dislikes, hobbies and interests. Building on this, support workers are expected to be very observant, noticing the small things about the individual or about their environment.

Using all this information, activities can then be devised, some of which will be ad hoc and others more prescribed. These activities are designed to stimulate people with dementia, and which add value to visits by making them much more than functional and practical.

Continuity of care and matching of care workers as well as sharing of information is key to providing a quality service. The benefits of this strategy are to be found in the consistency of contact between the care worker and service user, which is particularly important where the person's memory is impaired. This will ensure that the individual's specific preferences and needs are clearly understood and met over the duration of their care package.

Continuity in care, example of innovation – Trinity Homecare

Trinity Homecare, a live-in care provider, believes care continuity is a key aspect of creating a person-centred approach to dementia care. The primary focus when creating rotas is to ensure the same carer(s) remain with the same person they are caring for over an extended period of time. This allows the carer and the person using the service to develop a close bond and trust. This also helps the carer to build a connection to the likes, dislikes, history and feelings of the person they are sharing a home with. This can be a significant advantage in developing a care package which is focused upon each individual and creates an environment for the person living with dementia that they are most familiar and comfortable with.

Supporting culturally sensitive services

While the incidence of dementia appears to be higher in Black and Asian Minority Ethnic (BAME) communities in Britain, they are underrepresented in terms of receiving dementia services, and specialist services based on understanding of particular cultures are not widespread.

A report published by the Race Equality Foundation and Age UK (2013) identified that in contrast to the relative inconspicuousness of BAME communities to homecare services, African-Caribbean and South Asian UK communities are at greater risk of developing dementia than the indigenous white population. This is partially due to individuals being more prone to risk factors such as cardiovascular disease, diabetes and hypertension. Estimates suggest there are almost 25,000 people with dementia from such communities in England and Wales, a figure predicted to grow to 50,000 by 2026 and 172,000 by 2051.

There are a number of reasons why people from BAME communities living with dementia are not always connected to the care services they need. In part it is down to services being culturally insensitive to their needs, poor outreach that fails to address unfamiliarity with UK care systems and inadequate sources of information when English is not a first language. Additionally, for some families in BAME communities there is a limited understanding of the condition and significant stigma remains, both of which can deter individuals from seeking wider support.

Although a long way from attaining the required understanding and range of services necessary to provide BAME communities with the information and support they need, the homecare sector is making an effort to redress the imbalance.

There are a range of activities that could help with this, from recruiting members of staff from a particular cultural background to match individuals using services, to training care workers to understand that dementia might enhance cultural traits, such as a tendency to revert to the person's first language, and accommodate and support those traits rather than to suppress them. A key element of providing sensitive dementia care surrounds the need for a homecare provider and care workers to see each client as an individual with a history before the onset of dementia and individual preferences and cultural requirements, and to appreciate that association with a specific community does not necessarily mean the individual will automatically have particular preferences.

Developing culturally sensitive services, example of innovation- Sevacare and Association for Dementia Studies, University of Worcester

Sevacare is a mainstream homecare provider who also offers specialist services to BAME communities. As part of their work to specifically meet the needs of these communities, Sevacare have commissioned the Association of Dementia Studies (ADS), University of Worcester, to deliver a bespoke leadership dementia education programme. The programme aims to support Sevacare to be confident that their service is of the highest quality, person centred and culturally competent for people living with dementia.

Through its research, education programmes and knowledge transfer activities, ADS are committed to supporting home care providers to help people with dementia to live well. To support other home care providers to similarly provide person-centred, culturally competent dementia care, ADS have secured funding from the Working Advisory Group to develop a Training Manual based on this education programme for use with other domiciliary care companies. Sevacare are leading by example by recognising the need for home care providers to invest in this model of education and training to ensure that people with dementia and their family members receive high quality care at home that takes into consideration people's life histories, cultural norms and values.

Integration and working in partnership

The integration agenda (social care, health, housing and other relevant services working together to meet the holistic needs of the individual) also offers opportunities to innovate in relation to dementia care at home. Co-ordination of care for people with dementia can be poor; however there is great scope for improvement that maximises continuity of care and a better care experience. Government driven initiatives such as the Better Care Fund and Care Act 2014 underline wider ambitions on integration to facilitate a broader view of what people need and therefore what should be strategically commissioned and how individuals can be enabled to access the support they want and need.

Through the requirements of the Care Act, local authorities, Clinical Commissioning Groups and Health & Wellbeing Boards across England will need to commission more care at an early point of need, within the community. As long ago as 2008 The Department of Health report, 'Commissioning domiciliary care for people with dementia and their carers' (2008, p.19) encouraged commissioners to look to 'outcomes technology', something that suggests 'authorities should see themselves as investors, rather than as funders or purchasers, and that this denotes a very different kind of relationship – much more one of equality and partnership – with providers'.

Integration provides an excellent opportunity to make best use of homecare services, many of which already take an active part in areas previously considered to be the domain of the National Health Service. Homecare providers and workers are ideally placed to lead co-ordinate a multi-disciplinary approach and to provide a smooth transition between health and social care services in a range of settings, reducing associated anxiety, stress and potentially cost for the person with dementia. It is most important that a person living with dementia receives 'joined-up' services from social care and health without having to manage multiple arrangements.

Stakeholders have a variety of roles to develop partnership working:

- **Local authorities** – Social services teams working alongside local providers in the service planning and development stages.
- **Hospitals** – Homecare providers supplying useful information about a person with dementia that can help hospital staff. Hospitals should have wider discourse with providers in build up to discharge. NHS Continuing Healthcare commissioners increasingly look to homecare providers to deliver services.
- **Housing/accommodation** – Close links between housing providers and homecare providers, to help people with dementia receive the services and home adaptations they need, helping to avoid unnecessary trips to hospital or residential care, including accessing the Department of Health's Care and Support Specialised Housing Fund to develop dementia-friendly accommodation.
- **GP and Primary Care Services** - Relationships between homecare and the primary care sector are still largely based on an individual relationship/partnership rather than a whole system approach. Telehealth and telecare advances means homecare services are able to play a leading role in monitoring conditions within the home.
- **Third Sector** – The third sector has an important role in contributing to social care delivery in England. Ties between the third sector and homecare providers need to be close to create co-ordinated care across the services someone with dementia might receive.
- **Further education, sports and leisure** providers to ensure that people can access welcoming, 'dementia-friendly' support to keep active in brain and body.

Homecare providers are increasingly expanding the services they offer by working with a variety of external agencies. Stronger relationships between homecare providers and other organisations can help to create smoother transitions between services and more joined-up, co-ordinated person-centred care.

One person should be identified as having a co-ordinating role between the number of different agencies providing care and support. This could be any relevant worker/professional, the person themselves or a family carer.

What are some of the challenges?

- The division of budgets. Whereas for the treatment of many conditions, such as cancer, costs of treatment are largely covered under the National Health Service, support for dementia still falls largely under the remit of social care services, much of which is paid for by the individual.
- Restricted social care eligibility criteria mean there is a wider gap than ever before between access to NHS and social care services.
- Joined up care is a significant challenge, particularly if homecare workers are not included or welcomed into a multi-disciplinary approach.
- Integrated care will require new, co-ordinated systems of commissioning and sharing of information across health and social care.
- Providers of sport, leisure and further education services often overlook the particular needs of people with dementia.

Partnership with the health sector, example of innovation - Derbyshire County Council

Derbyshire County Council has created a specialist homecare service in Chesterfield. The service provides short-term, intensive support to people with dementia and their carers. Crucially, it is a multi-disciplinary service provided jointly by Derbyshire County Council's Adult Care department and the Chesterfield Community Mental Health Team.

It aims to support people in a time of crisis and to assist in stabilising their situation through intensive support for 6-8 weeks. It is available to people living in the community who are of any age and have dementia or are presenting with symptoms of dementia or are caring for someone with dementia. The service prevents avoidable and inappropriate admissions to hospital or long-term care, equips family carers with skills and support to help them manage, promote independence and utilise other preventative services.

Once the situation has been reviewed and considered stable, the specialist service will work with the chosen mainstream/alternative provider to ensure a smooth and successful handover of care and support.

Co-ordination with other services, example of innovation - Jean Allen Care Services Ltd (Home Instead Senior Care)

As a domiciliary care provider, we - Home Instead Senior Care - wanted to work with Mrs K to help her live as independently and happily as possible towards the end of her life. This required a great deal of patience, flexibility and coordination of services across health and social care. Key to our care workers' approach was the continued consideration of what gave the client most pleasure, ensuring that quality of life was a central focus of care delivery.

Our Care Manager gathered information from Mrs K, her neighbour and the social worker. Involving Mrs K in decisions about her care was an essential step in the care planning process.

Before care workers started caring for Mrs K, they were given a detailed briefing on her background and care needs. This included what to do if Mrs K refused entry to them or evicted them from her house whilst delivering care.

The Home Instead team kept in close contact with both the social worker and district nurse team and over time took over full responsibility for the running of the house. Any visits by a health professional or someone such as the hairdresser were timed for when a care worker was present, otherwise they may well have been sent away or unwittingly exacerbated Mrs K's confusion.

As a result of the cooperation between domiciliary care, social services and the NHS Mrs K was able to remain in her home till the last month of her life, despite her dementia.

Partnership with the wider community, example of innovation - Supportive Communities Programme, Jewish Care

The Supportive Communities Programme, supported by the Department of Health, has been a great success with relatively small costs and is now, going forward, to be embedded as outreach through community centres. Jewish Care identifies people who live near to each other and who are lonely or have very few social contacts. Members are invited to monthly tea parties, hosted by a volunteer and supported by drivers. The tea party acts as a catalyst for creating mutual support, activity and lasting friendship. Alleviating loneliness has been proved to have significant health benefits, and the activities help to stimulate the mind. The events also provide an opportunity to signpost visitors to further services in the community.

Integrated information offer, example of innovation - the NHS and councils in Hertfordshire and Gloucestershire

Local authorities and NHS partners in Hertfordshire and Gloucestershire have designed a universal 'Handbook' to support a person with dementia live well and take an active role in planning the care that meets their individual needs. The Living Well with Dementia Handbook is held by the person with dementia and their carers. It provides essential information following diagnosis, with additional information being added in a timely manner. The handbook will contain a person centred care plan designed by the homecare provider, a distress/pain assessment tool, Alzheimer's Society's 'This is Me' leaflet for hospital admissions, and information on further community based support services.

The Handbooks detail information about that person and their support needs, that helps new homecare workers quickly connect with that individual, as well as helping homecare and acute care services to co-ordinate in a smooth fashion.

Technology & Adaptations

Advances in technology offer huge potential benefits for people with dementia and their carers. From personal telecommunication devices to additions to the home to assist mobility, technology can enable people with dementia to live independently for longer, as well as providing greater choices about their care.

In June 2014 a task and finish group on dementia-friendly technology, set up by the Alzheimer's Society, released a 'Dementia-friendly technology charter' (see 'Further reading'). The charter is designed to help every person with dementia benefit from technology that meets their needs. It considers potential technological opportunities for each stage of the dementia journey, from pre-diagnosis to help with complex multiple needs and crisis care.

Adaptations to the home can be both simple and cost effective, and can help someone living with dementia to remain in an environment where familiarity and habits of a lifetime are engrained. They can also help to reduce admissions to hospital, which is particularly important since people living with dementia, when admitted to hospital, are more likely

to stay there longer, to be readmitted, and to die there than similar people without the condition (Care Quality Commission, 2014).

Examples of such technology and adaptations include:

- Information Technology solutions that enables a person and their family/GP/homecare provider to stay in touch (such as Skype and tablet computers)
- Sensors and alarms to alert family or professionals for when a person wanders out of the house or shows unusual patterns of movement.
- Practical support e.g. talking microwaves/toilets that can wash and dry.
- Simple changes such as contrasting colour around doorways and plain carpet to minimise confusion and anxiety.

What are some of the challenges?

- The price of the latest technology can be prohibitive to widespread use.
- Many larger technology companies have not yet tapped into the potential market of social care users and workers, especially outside care homes.
- Learning to use new devices/technology can be daunting or may require training. It should not be seen as an option for everyone.
- Technology must be seen as a way to facilitate quality care and more face to face time, not as a replacement for care or interaction.
- The design of some homes may be incompatible with some adaptations.
- It is difficult to identify all that is available and relevant.

The King's Fund and Alzheimer's Society (2015) have released a useful guidance document, 'Making your home dementia friendly'. The guidance focuses on small, effective changes to the home in the form of a design checklist.

Advances in technology are also proving to be an essential branch of support for lone workers, as is often the case in homecare. Increasingly providers are turning to telecommunications to develop links between the office and staff out in the field, helping to maintain a strong and supportive bond between the two.

Innovative commissioning of homecare by local authorities & CCGs

Key to good services is joint health and social care commissioning, focusing on all the requirements of the individual and the outcomes they would like to achieve in order to live well with dementia. This might include:

- A multi-disciplinary assessment and diagnosis service that takes and uses information from a variety of health, care and family sources. A holistic assessment that considers what will help that person live and enjoy their life is needed, not just help with activities of daily living or treatment for dementia. This will require understanding of wider health and care needs, both physical and mental, and interests and background of the individual. Requirements related to assessments have been enshrined in law through the Care Act 2014 (sections 9 to 12), which includes a requirement for local authorities to consider the outcomes the adult wishes to achieve in day-to-day life.
- Creating support packages which delivers seamless and effective provision of care around the individual, incorporating both health and social care.
- Information and advice – leaflets, websites, helplines, face to face assistance – pointing the individual with dementia and those close them in the direction of useful services and support. This should also enable access to more preventative/social support, such as reminiscence, music, art, therapies, physical activity etc., in addition to homecare services and other specialist services within the community.
- Creating effective links between voluntary and third sector services and homecare providers so that the individual can receive wider support.

- Effective use of integrated funds (such as the Better Care Fund) – recognising and realising the potential of community based services such as homecare to provide early support and reduce pressure and costs on the NHS in the long term, working with homecare providers as partners.
- Efforts to help people living with dementia manage and use personal budgets, with the necessary accessible information and support to help make this a viable choice for more people.
- Use of Individual Service Funds where the person may not wish to handle the money themselves but want closer day to day involvement with the shape and nature of support.
- Co-ordinated commissioning that allows homecare workers adequate time to care and support in the context of dementia. Equally important is to commission services which allow for flexibility of homecare provision, to react to the changing needs of that individual at any given time to work towards desired outcomes.
- Commission services that encourage and make provision for dementia training throughout the system, including in acute care and primary care and ranging from homecare workers to nurses, from pharmacists and therapists to GPs.
- Commissioners are ideally placed to proactively design innovative services in partnership with providers and individuals or their families, which are supported by the latest equipment and technology.
- Commissioners should also be encouraged to take accredited dementia training, to help foster a dementia friendly and familiar culture throughout the care system.
- Market Position Statements (or their equivalent) should make clear the types of local support that are likely to soon be sought (&fully funded) so that providers can be innovative in designing services that will meet need.

What are some of the challenges?

- Significant challenge in training commissioning for outcomes. 'A Route Map' for commissioning for outcomes is now available (see 'further resources' section)
- Providing choice and flexibility of service requires the system to have spare capacity, which creates costs current budgets cannot handle.
- 'Specialist' care to deliver outcomes may cost extra: Staff with greater experience and higher wage demands, additional back-staffing support and communications technology etc.
- Challenges associated with 'market shaping'
- Difficulties related to collaborating with other sectors and budgets, such as housing or NHS partners

There is a need to think differently about how strategically to commission support for people with dementia in their own homes. This is about how to ensure the kinds of services people need and want are there and about redesigning these services to better provide the holistic support that people need.

Local authorities are the major commissioners of homecare services (at more than 70% across the UK) – usually through block, spot or cost and volume contracts. If people need additional support, such as day services, social contact, transport, mental stimulation, equipment or telecare these are all sourced separately – sometimes from council in house services sometimes through contracts or through the voluntary sector.

To enable more people with dementia to be able to stay at home for longer there must be consideration for the full package of support required, resulting in the commissioning of a 'care at home' service, rather than a homecare service. This may sound expensive but if seen as an alternative to earlier admission to residential or nursing care (where the full range of needs is covered as part of the service) and if designed to include voluntary and community sector input this kind of support package could be cost effective as well as better meeting the aspirations set out in the National Dementia Declaration.

Vitality, there needs to be a degree of acceptance and management of some level of positive risk in helping people to live well with dementia.

Coordinated commissioning is particularly important when the person is living with dementia. Not all care and support can be delivered by the same individual and specialist staff are trained and recruited for a reason.

There must be a clear understanding over who does what. Further support from specialists like occupational therapists or dieticians should be coordinated and built into a sensible and manageable support plan, which is co-ordinated by an identified individual.

There is also a need to ensure capacity to offer specialist intermediate care, reablement, rehabilitation, step up and step down services or beds to people with dementia. People with dementia can recover from physical illnesses like other people yet too often are considered unsuitable for rehabilitation or reablement, with some reablement schemes still refusing to accept referrals for people living with dementia. Successful outcomes from such services will require staff that can offer the physical rehabilitation or enablement support but who can do this in the context of a person's dementia.

People with dementia should be able to access specialist enablement and intermediate care services. Short term services might prevent admission to hospital or enable a timely discharge home. This is particularly important given the disorientation involved in a hospital stay which can look like permanent deterioration when it is actually temporary whilst being physically unwell.

Step-up, step-down service, example of innovation - Stockport NHS

Intermediate Care

Intermediate Care in Stockport is delivered in partnership between primary and secondary health care and local authority services. It is designed to reduce hospital admissions and to ensure the step-up/step-down transition between the home and hospital is as smooth as possible.

In 2014 Intermediate Care provided the following services: -

A rapid response service in people's own homes to prevent avoidable hospital admissions.

A step-up home based service – a multi-disciplinary team that includes homecare workers and members of the intermediate care team providing short-term rehabilitation.

Step-down home based service – supported discharge to a service user's own home, with multi-disciplinary therapy, nursing and homecare support to allow rehabilitation and recovery at home.

Step-up and step-down residential bed based service – residential rehabilitation for service users who do not need 24hr consultant led medical

care, ranging from one to six weeks. Multi-disciplinary team work to ensure people are ready and able to return home, with designated beds for patients with dementia.

Co-ordinated commissioning, example of innovation – Hertfordshire County Council and NHS Hertfordshire Valleys CCG

West Hertfordshire has developed a Delirium Recovery Programme (see 'sources', often for patients with an underlying dementia which is clouded by the delirium episode. The aim is to discharge people home from hospital that have potentially reversible components of confusion as soon as possible in order that they can be cared for in a familiar environment which reduces delirium. The busy and noisy environment of a hospital with unfamiliar faces and disruptive routines hinders the potential recovery process and can increase the length of hospital stay significantly.

Remaining in hospital for longer risks further 'hospital acquired morbidity', including functional decline, falls and infection.

For the Pathway to work, it is important for the patient, family, hospital, council social services team, GP and care provider to work together to establish an agreed care plan and next steps to be actioned.

So far there has been great success in keeping people on the Programme at home, with an initially intensive live-in homecare package in place to provide necessary care and support. Carers involved in the work receive training from the Multi-Disciplinary team (consisting of a Consultant Geriatrician, Consultant Psychiatrist and an Occupational Therapist). The intention is for self-care and independence to be promoted, resulting in a reduction of the level of input from the carers over a three or four week period, taken on a case-by-case basis. Regular integrated health and social care assessments in the community take place to decide what actions are required next.

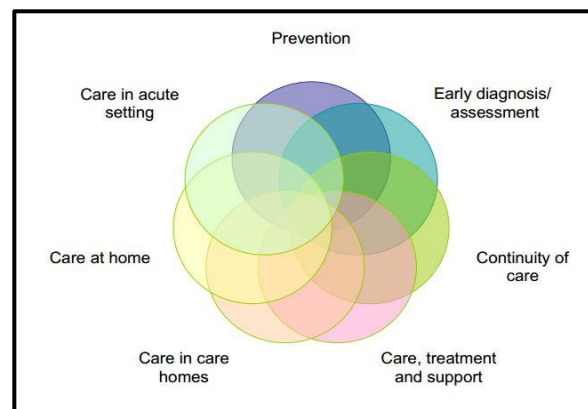
In addition to health and wellbeing benefits to the patient and their family, feedback from staff suggested significant satisfaction in helping people to settle and thrive back at home.

Analysis has also found financial benefits for Hertfordshire County Council as the Programme reduces the need for long term acute, residential or nursing placements. The full year net cost benefit for the Programme, with only 20 patients, is estimated at £225,648.

Co-ordinated commissioning, example of innovation – The Derbyshire Dementia Strategy

-Derbyshire County Council and NHS Derbyshire have joined together to develop a strategy which sets out plans for improving services for people with dementia including:

- Good quality early diagnosis and intervention for all
- Easy access to care, support and advice following diagnosis
- An informed and effective workforce across all services
- Good quality care in hospital
- Community personal support services.
- A telephone brokerage service that links people to homecare services in their local area.
- As shown in the diagram below, the Strategy aims to connect all commissioned dementia services.



The Derbyshire Dementia Strategy

Commissioning relationship based care – The Raglan Project, example of innovation – Monmouthshire County Council

The Raglan Project is an award winning pilot project looking at how to deliver a high standard of relationship-based home care to people with dementia. It is replacing task-based care with flexible care that is focused on outcomes and the social and emotional needs as well as the physical needs of the person being supported.

Five full-time salaried staff work on a fixed rota with 12 to 15 people living at home with dementia. Before the care begins, staff members establish a relationship with the person receiving care. Staff are then given the freedom to decide for themselves how the relationship and care should be managed – and their decisions are supported rather than controlled by management.

Feedback from interviews, care management reviews and the journals that each staff member completes provides evidence that the project is consistently successful.

It has been possible for people with complex care needs to stay at home rather than moving to permanent residential care or hospital. People who had disengaged from their local community and were neglecting themselves have been supported back to independence and re-engagement with their local community. Community-based social events that were established for all sections of the community are now independent and self-sustaining.

There is also clear evidence that staff have better morale, health, wellbeing and job satisfaction. Sickness has remained at 0 per cent for 18 months.

Moving forwards and spreading innovation

What next?

This report has highlighted many of the ways in which homecare services can help provide a better quality of life for someone living with dementia, and some of the examples of innovative practice that help to deliver that.

Realistically however, if as a society we fail to address some of the issues also identified in this report, for many individuals and their families care and support services will too often be able to do little more than crisis management.

In the early pages of this report the Subgroup on Dementia and Homecare outlined actions that we believe should be a key focus for policy makers, providers, commissioners, regulators and health partners. We believe delivering these actions would have led to significant, lasting change for people living with dementia in the UK.

- 1. Champion homecare as the key facilitator of dementia care and information**
 - 2. Deliver a personalised approach focused on outcomes for the individual & their family**
 - 3. Give greater flexibility for homecare providers to innovate and shape care with and for the individual**
 - 4. Recognise and realise the value of homecare to reduce risk & lessen the negative impact of dementia progression**
 - 5. Prioritise homecare as a cost effective form of intervention**
 - 6. Ensure sufficient time to deliver the care people with dementia need, in the way they want**
 - 7. Develop consistent and reliable homecare services**
 - 8. Help providers to implement & experiment with technology**
 - 9. Develop research on care, as well as cure**
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Somerset Care

DoCare

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County Council/Monmouthshire County Council

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Appendix II - Sources and further reading

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