

Promising approaches

to living well with dementia



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Foreword



I am pleased to welcome this new guide from Age UK, which contributes to the growing debate about what it means to live well with dementia.

By starting from the perspectives of people with dementia, this guide adds to the ever growing knowledge base of what 'living well' really means. And, further, it offers thoughts on how this can be achieved particularly through support and engagement in meaningful activities.

This report is full of examples of interesting approaches which are already in place in some parts of this country, but as it makes clear the next step will be to open dialogues with local authorities up and down the country to reduce the current postcode lottery.

The framework the guide offers for supporting people will hopefully prove useful to those seeking to improve things, and there is comprehensive sign-posting to effective interventions for those seeking inspiration.

To place great emphasis on the rights of people affected by dementia is central to this work and is consistent with my own work with the Dementia Engagement & Empowerment Project (DEEP) Think Tank.

Rights-based approaches will be vital in taking forward our discussions with providers in the community. The new *Dementia Statements* set out a clear set of expectations and reminding people of these can help to ensure that people with dementia are not disregarded or overlooked. I have a copy of the new statements framed and mounted for easy reference on my office wall. Maybe all interested parties should copy this example or carry them in their diary for inspiration!

No matter who you are there is certainly something in this report for everyone touched by dementia, be they a person with a diagnosis, someone living with a person who has dementia or a professional seeking to better understand and care for those of us who seek to live as well as possible for as long as possible.

Keith Oliver

Alzheimer's Society Ambassador

Kent and Medway NHS Dementia Service User Envoy

Executive summary

This report is intended as a practical resource for individuals and organisations working in communities to support people living with dementia, and their carers. Its focus is on what works in supporting people with dementia to live well – looking at services and supports beyond the traditional domains of health and care services.

It was developed through a programme of work rooted in a rights-based approach to dementia, and in the social model of disability. The programme placed people with dementia at the centre, and focused on what people told us ‘living well’ meant to them. The key factors identified could be broadly grouped under the following headings:

- personal wellbeing
- positive relationships
- active daily lives.

The report showcases **approaches** which relate to these domains of quality of life, and which show *promise* in positively impacting upon quality of life outcomes – either directly, or by improving key aspects of life which people with dementia said were related to their quality of life (such as social connection, sense of self-worth, getting on with day-to-day activities). It also proposes a **new framework** for understanding these approaches, to help to make sense of the way in which these approaches could be brought together in communities.

The lived experience of people with dementia pulses through this framework, with the three key contributors to living well – personal wellbeing; positive relationships and active daily lives – at its heart. Linked to these, we have identified a range of **direct interventions** which are focused on one or more of those three key contributors, which aim to enable people with dementia to realise their aspirations in these areas.

Around these sit the **foundation services** which support people with dementia to access and navigate the direct interventions in a timely fashion.

Also vital are the **enabling services**, including transport, technology, housing and care. These services, while sometimes presented as interventions in themselves, are understood here as enabling people with dementia to access and enjoy the things they most value. These services are most often noted in their absence or when their delivery is disabling, but when harnessed effectively, they have the potential to facilitate more cost-effective and timely direct interventions.

The final category in our framework is **structural factors**. These are the approaches in policy and practice which support and enable the more effective development of appropriate services and systems in communities. They include rights-based approaches, and the Dementia Friendly Communities programme.

The report offers a range of **case studies** from a wide range of organisations, programmes and services which demonstrates these approaches in practice, and from which others can learn.



While we highlight the evidence we have found to demonstrate that these approaches work, we also argue that there is still **too little evidence** about the impact of interventions on people's wellbeing and quality of life. There are also too many initiatives which are **confined to pockets of the country** and so not widely available to people with dementia. There is, in effect, a **postcode lottery** of support for living well.

As we move forward, it is vital that a **more strategic approach** is taken to ensuring that communities can put in place the systems, structures and supports people need to live well with dementia. It is also important that action is taken to broaden and deepen the evidence base on what works in supporting people with dementia to live well.

We make the following recommendations:

People with dementia and their carers could:

- Consider using this report to think about what 'living well' means to you – could any of the approaches featured here help you to **carry on doing the things you enjoy** most?
- This report is full of examples of interesting approaches which are already in place in some parts of this country. Could this report be helpful in **starting a conversation** with your local authority about what more is needed in your community to help you to live well?
- Consider taking a **rights-based approach** to your discussions with providers in your community. The new *Dementia Statements* set out a clear set of expectations – reminding people of these can help to ensure you are not disregarded or overlooked.

Service providers should:

- **Build on the insights** in this report to start a discussion with the people with dementia they serve, about the key areas of life that matter most to people, and to consider how they can help people to live well.
- Play their part in **building the evidence** around what works in promoting quality of life among people with dementia by collecting robust data on the impact of their services.



Those involved with planning community responses to dementia, in both **local authorities and local health bodies**, should:

- Adopt **structural approaches** which promote living well with dementia: taking a rights-based approach to ensure that action taken recognises the equal citizenship of people with dementia; considering working towards becoming a dementia-friendly community, as a means of drawing in a wider range of partners to the work to support people living with dementia in the community.
- Develop **foundation services** offering people with dementia and their carers timely, accessible and person-centred support, through which people can recognise and maximise their own strengths and capabilities, and draw upon those of the wider community.
- Focus on ensuring **enabling services** such as appropriate housing and care, transport and technology, are available in the community, through which people can more easily access the things that they value and which support their quality of life, and without which their ability to live well will be severely impaired.

All partners involved in supporting people with dementia to live well need to commit to **building the evidence** for the impact of their work, by measuring impact on **quality of life**.

Introduction

Introduction

Dementia in the UK

The term 'dementia' describes a set of symptoms which often include memory loss and difficulties with thinking, problem-solving or language, as well as changes in mood or behaviour. Dementia is caused when the brain is damaged by diseases such as Alzheimer's disease, or a series of strokes. Alzheimer's disease is the most common cause of dementia, but not the only one. The specific symptoms that people with dementia experience depend on which parts of the brain are damaged and the disease that is causing the dementia.

Around 850,000 people were thought to have dementia in the UK in 2015. Numbers of people with dementia in the UK are forecast to reach over 1 million by 2025 and over 2 million by 2051, primarily as a result of the UK's ageing population profile. Around one in every 79 members of the entire UK population, and one in every 14 of the population aged 65 years and over, has dementia.¹

Growing prevalence has brought new focus to tackling dementia – both through renewed attempts to find a cure, and efforts to improve diagnosis rates and care for people with dementia. In 2009 England's first national strategy for dementia was published² and this was followed up with a 'Prime Minister's Challenge' on dementia in 2012.³

Two key initiatives designed to promote dementia awareness, breakdown the stigma of dementia and the barriers to accessing goods and services faced by many people with dementia, were also launched in 2012. The Dementia Friends⁴ and the Dementia Friendly Communities⁵ programmes have now been widely taken up with some 2 million people now signed up as Dementia Friends.

In 2015, a further Prime Minister's challenge was launched.⁶ The Prime Minister's Challenge on dementia 2020 set out more than 50 specific commitments, which together were intended to make England the world-leader in dementia care, research and awareness by 2020. The challenge set out priority actions, across four key themes:

- risk reduction
- health and care
- awareness and social action
- research.

These efforts are slowly starting to reap rewards – with some improvements in rates of diagnosis. This is largely on the back of the inclusion of incentive payments for dementia diagnosis in the Quality Outcomes Framework for GPs,⁷ and new funds being developed to research the condition.⁸ However, arguably less progress has been made in improving the care and support offered to those who find themselves with a diagnosis of dementia.⁹

About this report

This report is intended as a practical resource for individuals and organisations working in communities to support the development of effective networks of support and intervention for people living with dementia and their carers.

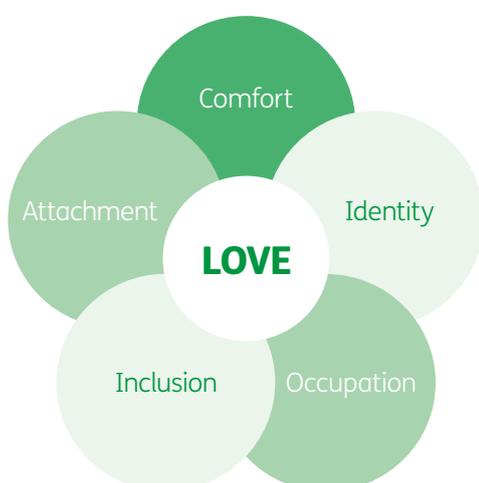
It is based on a programme of work taken forward by Age UK and Innovations in Dementia, with strategic support from the Mental Health Foundation. This work identifies what helps people live well with dementia, and what can be done, in practice, to support people to live well with dementia. The aim was to develop a solution-focused resource around ‘living well with dementia’, showcasing a range of evidence-based ‘promising’ approaches to inspire future policy and practice; and offering a framework for developing structures of support for people living with dementia and their carers, built upon the views of people with relevant lived-experience. You can find more detail about how this project was developed in Appendix 1.

Dementia rights and the social model of disability

The approach taken to this project was premised on Age UK’s overall vision for living well in later life, and on our belief that dementia is only one part of the lives of those who have a diagnosis, and of those who support them. It is rooted in a rights-based approach to dementia¹⁰ and on the social model* of disability.¹¹

Older people with dementia were at the heart of our approach to this programme, and in our discussions with them, it became clear that while external factors – including environmental design etc – are significant to people’s experience of living well, there are also significant inter- and intra-personal obstacles, which also affect their wellbeing. Their comments reflected the insights expressed in the ‘Kitwood flower’ (see below), highlighting the wide range of factors which impact our personhood and, in turn, our wellbeing. Tom Kitwood pioneered the concept of person-centred care for people with dementia and recognised and rejected the ‘malignant social psychology’ through which the personhood of people with dementia is eroded.¹²

Psychological needs¹³

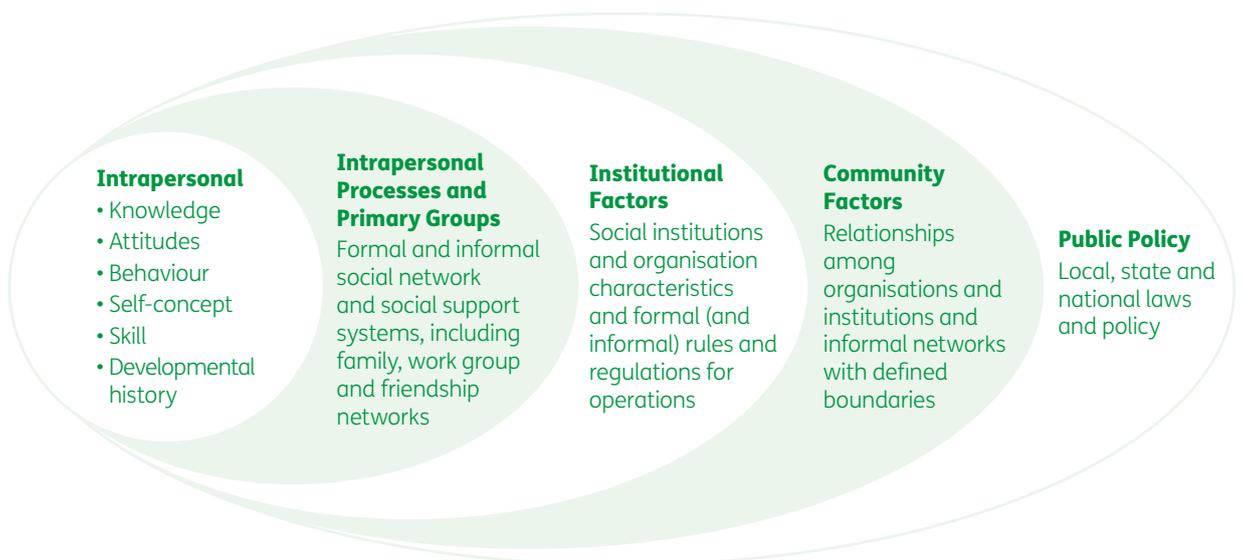


* The social model argues that, rather than seeing disability as a condition of the individual, we need to recognise that it is the features of the communities within which people with disabilities live (the built environment, product design, modes of provision, but also norms and attitudes etc.) that are disabling. In the social model, people with disabilities are at centre stage and are recognised as equal citizens with rights.

In recognition of the steer people with dementia gave us, we have adopted an extended social model of disability for this project, which involves:

- a focus on abilities instead of losses;
- a recognition of the way in which people with dementia are discriminated against and marginalised;
- the importance of listening to personal experience of dementia;
- the importance of the social and built environment in enabling or disabling people with dementia;
- finally, a recognition that the human rights of people living with dementia should be respected, and that failing to make services inclusive of people with dementia may well be unlawful under the Equality Act 2010.¹⁴

The diagram below¹⁵ illustrates the breadth of factors which we considered in this programme.



Why focus on ‘living well’ with dementia?

Despite a growing focus on improving dementia care and support, there are still major challenges facing people living with the condition and their carers.

This is often compounded by a lack of understanding of what matters most to people’s quality of life, and a lack of evidence around what works best in supporting people to live well. Recent qualitative research with people working in the dementia field found that: ‘The difficulty of deciding what to measure and evaluate in the context of public service provision highlights the importance of a clear definition of living well with dementia, as the basis for designing and evaluating effective and ethical care policy and practice that keeps the dignity of the person at the centre of both ends and means.’¹⁶

In developing this report, we wanted to focus on the areas which lie beyond the immediate priorities of the health and care system, and which require a wider community response. Significant emphasis has been placed on the importance of caring for people with dementia, and increasingly on the need to accelerate efforts to identify new drug treatments either to prevent, manage or cure dementia. However, little focus has been given to how to support individuals who have dementia to live well.

Our starting point in this work was the perspective of people with dementia. We wanted to explore both their understanding and definition of what made life good for them, and their sense of what might support them in achieving their goals.

Our programme started with a phase of engagement activities, with consultancy support from Innovations in Dementia, including:

- Five group discussions with people with dementia who belong to groups within the DEEP (Dementia Engagement and Empowerment Project) network.
- One-to-one (or small group) conversations in day centres with ten people with more advanced dementia, a group whose voices often go unheard.
- Two separate day-long focus groups organised with two local Age UKs, Age UK Herne Bay and Age UK South Staffordshire. The discussions involved both people living with dementia, and their carers. Discussions with carers were sometimes held in parallel with those with people with dementia, through a volunteer-supported ‘buddying up’ approach.

These discussions enabled us to define the domains of living well. We then discussed the findings from our engagement activities with a wider group of experts. The group helped us to draw up a list of potential approaches which supported people living with dementia and their carers in these aspects of life. We then sought to assess the evidence that supports these interventions, and to find examples of these approaches in practice. For more information on how we developed this report see Appendix 1.

What does it mean to live well with dementia?

In our discussions with older people living with dementia and their carers, we wanted to find out:

- What does a ‘good life’ mean?
- What are the qualities of a ‘good life’?
- What are the building blocks that make a ‘good life’?
- What promotes, or is a barrier, to a ‘good life’?
- What services, support or amenities need to be in place to enable people to live a ‘good life’?

Throughout our discussions with people with dementia, and their carers, a wide range of factors were mentioned as contributing to a good life. These could be broadly grouped under the following headings:

- personal wellbeing
- positive relationships
- active daily lives.

Our findings chimed with the wider literature on the subject of living well with dementia¹⁷ and reflected some of the key rights identified in the recently refreshed *Dementia Statements* developed by the Dementia Action Alliance which state:

- We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.
- We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.
- We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.
- We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.
- We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.¹⁸

Below we explore in more detail what the people we met told us about these domains of living well.

Personal wellbeing

In our discussions with people with dementia, and their carers, about what ‘living well’ meant to them, it was striking that many of the things people described as important were deeply personal and individual, relating only to the individual and their feelings about themselves (i.e. ‘intrapersonal’ features). These included things like having a good sense of oneself, being able to cope as an individual, and having a sense of acceptance and understanding of one’s condition.

People with dementia recognised a range of tactics and characteristics that were potentially supportive of this personal wellbeing, including positive thinking and maintaining a sense of humour. There was also recognition of some things which could damage personal wellbeing, including loss of confidence, feeling a burden or of lower worth, or having other health conditions or disability, including, in particular, hearing loss.

Carers also noted the importance of ‘intrapersonal’ factors to them living well, but in general, they reported much lower levels of satisfaction with life. Some reported feeling overwhelmed

and/or depressed, while others reported feeling high levels of stress due to their caring roles, feeling trapped, and feelings of guilt.

Positive relationships

Another crucial aspect of living well was maintaining positive relationships.

Relationships between people with dementia and their primary carers – usually a spouse, or son/daughter – were most often described as important. Overall, carers were much less positive about the state of their relationships than were people with dementia. Identified challenges to these relationships presented by dementia, included:

- Difficulties with communication.
- A sense of guilt about the perceived burden on the carer.
- Changing roles – e.g. wives or husbands taking on tasks that the other person used to do, or child/parent role reversal.
- A need for time away from the other person, and a sense that this was now more difficult (this was expressed by people with dementia, and (more frequently) their carers).
- Carers missing activities they used to be able to do with the person with dementia.
- A sense, among carers, that they often bore the brunt of the frustrations of the person for whom they cared.

In terms of other relationships, friends, and especially peer groups, were seen as important, for both people with dementia and carers. Family members were also recognised as a potential source of support in living well. However, some people had experienced challenges with their wider circle of family and friends providing immediate support following diagnosis or crisis, but then drifting away over time. Difficulty with hearing was also mentioned by people with dementia/their carers as a practical challenge to both social lives and wider interpersonal communication.

Active daily lives

People with dementia told us that a key factor in living well was having the ability to carry on with ‘day-to-day’ activities. In fact for many of the people with dementia we spoke to, this was a higher priority than ‘functional’ capacity, such as memory or other cognitive function.

For carers, the ability to share activities with the person with dementia they cared for was seen as particularly important, especially among those caring for a partner. Travel, holidays and day trips were often cited as key examples of such activities, but also important were more everyday activities such as gardening, dealing with finances, home renovations. For many people with dementia the ability to drive, or the loss of it, was felt to have a significant impact on quality of life.

In discussing the everyday activities that added value to their lives, people with dementia highlighted a wide range of activities, including outdoor pursuits such as walking and gardening; physical activities such as keep fit or dancing; learning new skills; participatory activities such singing as part of a choir, or being involved in activism; and a wide range of activities in the home including reading, watching television, and maintaining and decorating the home.

What works in supporting living well?

In discussing how they accessed services to support them to live well, most people with dementia and their carers cited the GP as their main point of contact. Many also talked about support they had received from voluntary sector organisations. However, several had experienced support from health and care services ‘tailing off’ following diagnosis.

Public transport and, in particular, bus services, were often mentioned as being inadequate to meet people’s needs, which in turn exacerbated issues associated with giving up driving.

Thinking about the kind of support services people wanted to access in the community, some people with dementia and their carers had a clear preference for specialist services and dementia-specific provision. In some cases, this was because people with dementia and their carers had faced difficulties with general providers lacking the understanding of dementia needed to support them to feel at ease and confident enough to participate. In others, they had encountered other service users or members of the public whose response to people with dementia – either through lack of understanding or prejudice – was off-putting.

The evidence on dementia interventions

In this report, we have, with support from our panel of experts, sought to identify approaches which show promise in supporting and enabling people with dementia and their carers to live well, in the three key areas we identified as being most pertinent to what people with dementia and their carers described as ‘living well’, i.e.:

- personal wellbeing
- positive relationships
- active daily lives.

As well as seeking to identify approaches that support the aspects of life that people with dementia said that they valued, we also looked for approaches that improved people’s quality of life and wellbeing as assessed by objective measures, and which were supported by robust evidence of their efficacy.

However, through the course of this programme, it has become clear that the evidence base in this area is still in need of development. While individual initiatives have been evaluated and show real promise, the evidence is not yet strong enough to allow objective assessment of the relative effectiveness of interventions. Nor has there been significant work to draw out the key characteristics of effective approaches to supporting quality of life.

This document therefore showcases approaches which demonstrably relate to the domains of quality of life which people with dementia told us were most important to them, and which show promise in the outcomes they are able to impact, be that measures of quality of life, or other improvements in key aspects of life which people with dementia said relate to their quality of life.

Chapter 1:

A new framework
for supporting
people to live well
with dementia

Chapter 1: A new framework for supporting people to live well with dementia

In examining the things that people with dementia, carers and our wider panel identified as critical to supporting people to live well, we identified an enormous diversity of approaches. In this section we offer a new framework for understanding these approaches, which seeks to make sense of the way in which they could be brought together in our communities to ensure people living with dementia can live well.

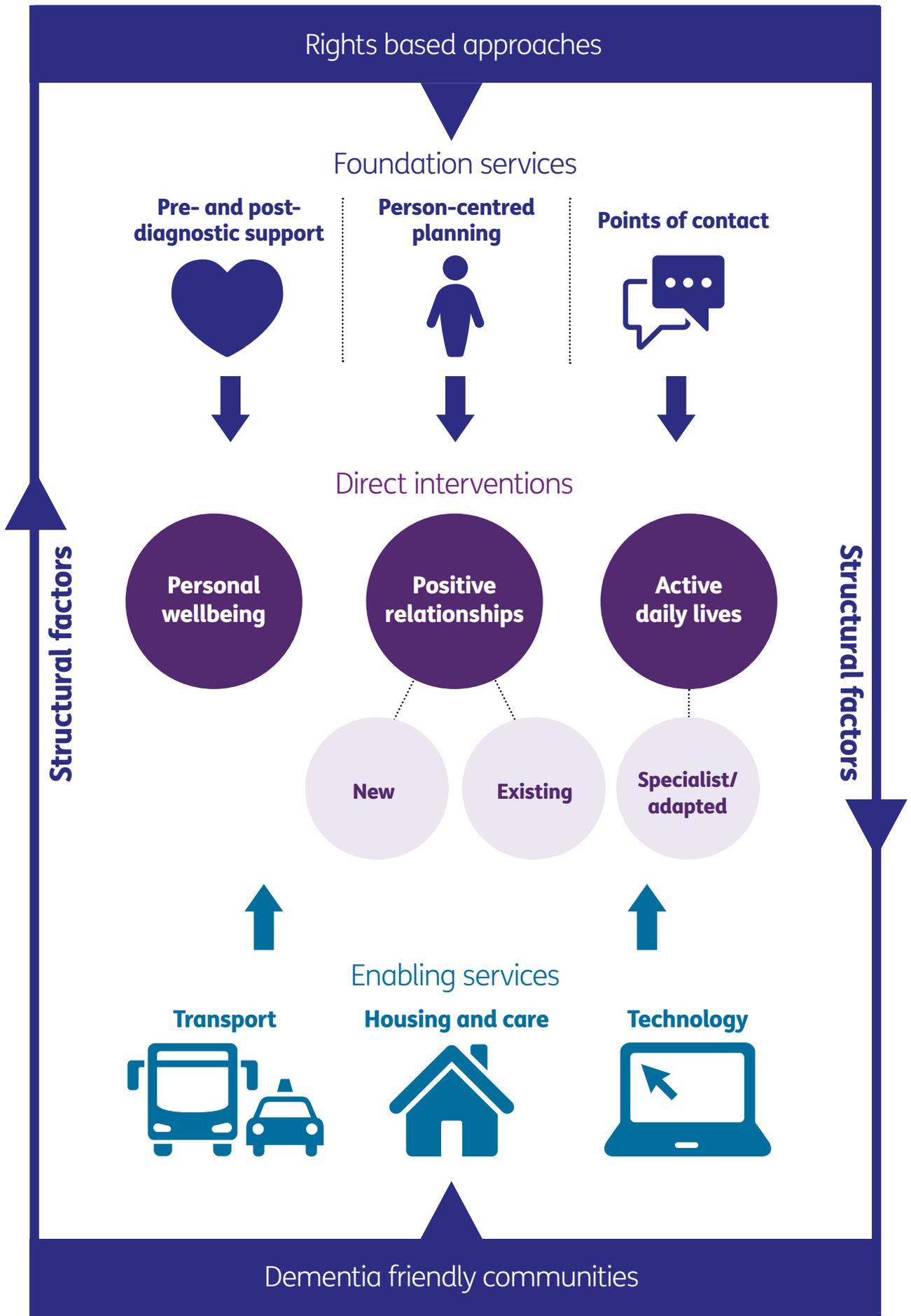
In creating this framework, we have unashamedly drawn on the framework set out in our previous publication, with the Campaign to End Loneliness, *Promising Approaches to reducing loneliness and isolation in later life*.¹⁹ Central to that framework was an understanding of the nature of the experience of loneliness. In the same way, the lived experience of people with dementia is the central plank of this framework.

Therefore, the three key contributors to living well, which were identified by people with dementia – personal wellbeing; positive relationships and active daily lives – are at the heart of the framework. Linked to these we have identified a range of **direct interventions** which are focused on one or more of those three key contributors to living well, and which aim to enable people with dementia to realise their aspirations in these three key areas. Around these sit the **foundation services** which support people with dementia to access and navigate the direct interventions in a timely fashion.

Also vital are the **enabling services** which, while sometimes offered as interventions in themselves, are better understood as enabling people with dementia to access and enjoy the things they most value. These services are the lynchpins of living well with dementia. In discussion with people with dementia, they were more often noted in their absence or when their delivery was disabling, than when they were working effectively. Nevertheless they have the potential to facilitate more cost-effective and timely direct interventions when harnessed effectively.

The final category in our framework is **structural factors** – the approaches in policy and practice through or against which the most resonant support is developed. These are not interventions in themselves, but rather approaches which support and enable the more effective development of helpful interventions in the community.

‘The three key contributors to living well, which were identified by people with dementia – **personal wellbeing, positive relationships and active daily lives** – are at the heart of the framework.’





Chapter 2: Foundation services



Chapter 2: Foundation services

Foundation services are those which enable people living with dementia to identify and articulate the things that are most important for their continued quality of life, and access services and supports through which they can achieve their aspirations in these areas.

A wide range of approaches – such as providing service directories and advice websites – have been taken to help people with dementia to access timely support in pursuing their aspirations. However, the approaches highlighted here were identified as being most likely to ensure that people were able to access services which would not just enable them to continue to function, but also to thrive in later life.

An important feature of these services was that they recognised the assets and capabilities of people with dementia and created space and time to enable people to identify their priorities in three key domains of living well – personal wellbeing, positive relationships, and active daily lives. They also offered access to a wide range of support in these areas, offering support far beyond traditional health and care services.

2.1. Pre- and post-diagnostic support

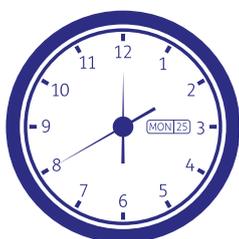
It is clear that the point of dementia diagnosis is vitally important in the lives of many people living with dementia. Improving rates of dementia diagnosis is, rightly, an important focus of government policy. There is good evidence that timely diagnosis helps to reduce anxiety and improve empowerment, and to ensure appropriate and timely access to treatment and support.²⁰ However, it is equally clear that not everyone's experience of the process of being diagnosed with dementia is positive and that often this opportunity for guiding people towards effective support for living well is not capitalised upon.²¹

In our discussions with experts, it was clear that effective support pre-diagnosis was perceived to be important to people's personal wellbeing, and to the wellbeing of carers. Experts argued that the period before diagnosis offered an opportunity to help people consider and manage the potential impact of a diagnosis on their sense of self. However, we were not able to identify specific evidence of the impact of pre-diagnosis support services.

Also important was the follow up given to people post-diagnosis. It was widely recognised that there was often a significant period between receiving a dementia diagnosis and becoming eligible for/needing formal health and social care services, and that often people were offered little support in this period. Some of the people with dementia to whom we spoke, described being offered a large amount of information at the point of diagnosis, but then feeling 'cut off' afterwards.

Effective post-diagnostic support (PDS) can help people to better manage their condition for longer, improve quality of life, and support people to remain independent for longer. In Scotland, the Health Improvement, Efficiency, Access and Treatment (HEAT) Standard of April 2013 includes a commitment to a minimum of one year of PDS. In England, the Prime Minister's Dementia Challenge 2020 made a commitment to effective PDS and in Wales, plans for a Dementia Strategy are underway. However, access to PDS remains patchy.

Scotland's PDS offer is based on the 'Five Pillars' model, developed by Alzheimer Scotland.²² This model sets out five key elements which are essential to supporting a person after their diagnosis.



‘There is good evidence that **timely diagnosis helps to reduce anxiety and improve empowerment**, and to ensure appropriate and timely access to treatment and support.’

The Five Pillars of Post Diagnostic Support



In the Five Pillars model, over a period of a year, the person with dementia, along with their partner and family, work with a designated worker who offers help and support to work through the Five Pillars. The aim is that, by the end of a year of support, the individual (working with their family, where appropriate), will have developed a robust personal plan that makes use of all of their own natural supports, and gives them access to peer support and support in the community, so that they can live well and independently with dementia for as long as possible.

Case study 1: Post-Diagnosis Support in Glasgow – Alzheimer Scotland

People with a dementia diagnosis in Glasgow can access a year of support from a Post Diagnosis Link Worker using the Five Pillars model of PDS.

The Five Pillars model was initially piloted in the Glasgow South area as a partnership between the NHS and Alzheimer Scotland and has now been extended city-wide, with seven Link Workers with a case load of around 50 individuals each.

Referral for PDS is automatic. Once patients receive a diagnosis, their details are added to the NHS EMIS database and, if appropriate, passed on to the Alzheimer Scotland Post Diagnostic Link Worker team. At present, some localities have a small waiting list for the service. In the interim patients are sent a pack of information and advice about dementia, and on where to find local support, including through local Dementia Resource Centres.

Once service starts, Link Workers make contact with the person diagnosed with dementia to explain PDS and to arrange a first meeting, which usually takes place at the diagnosed person's home or another local facility of the individual's choice. People who initially refuse a first meeting are reminded, after around six months, of their right to support, should they wish to take up the offer at a later date.

Through a series of meetings, Link Workers work through the Five Pillars with the person with dementia and their carers – the first meeting is normally the longest and lasts around two hours. This is an opportunity to talk through the individual's needs, circumstances and aspirations. A number of follow up meetings are then arranged to work through the various themes set out in the Five Pillars model. Most individuals need around eight further meetings, but this is flexible and telephone support is often needed. At the end of the 12 months of support the aim is to have a Personal Plan and for the individual to be in a position to self-manage their condition for longer.

Glasgow's Link Workers are employed by Alzheimer Scotland, but are given an honorary contract with the NHS GGC Health & Social Care Partnership. This allows workers to fully integrate with the wider Community Older People's Mental Health team supporting people with dementia, their carers and their families. This contract also enables Link Workers to access the NHS EMIS database and so to update the patients' records directly and to make Personal Plans available to other NHS staff, where appropriate. Link Workers are highly trained and qualified up to the enhanced level of Scotland's Promoting Excellence framework. They work closely with other health professionals across the Community Older People's Mental Health teams in the city, and also bring the knowledge, experience and resources of Alzheimer Scotland, enabling access to a wide range of community activities.

Positive results from the partnership working led to the recommissioning of Alzheimer Scotland's service across the city, and a commitment from NHS Greater Glasgow and Clyde Health and Social Care Partnership to fund the service for four years.

'You have no idea how much of a difference it has made. Before I felt very alone in my situation with no one to talk to about things.'

'I like the way you operate. It's good to have someone different coming in. Good to be listened to by someone who knows your situation.' Person with Dementia

'I get in such a muddle sometimes, it's good to have someone explain why.'

Person with Dementia

2.2. Person-centred planning

In our conversations with people with dementia and our wider panel of experts, it was clear that genuinely person-centred care planning could offer an effective route to support with living well. While the Five Pillars model is an example of such an approach, the principles of person-centred care planning have wider application throughout the dementia journey and can be supportive of living well at any stage. Person-centred approaches are those which offer people the individual time and space to consider their needs and aspirations and to assess where they might be able to meet these by drawing on their pre-existing strengths and assets and where additional support is needed. These approaches are therefore significant not only in helping people to identify services which would meet their priorities, but also in enabling people to identify what is most important to them.

Person-centred care has been recognised as best practice by NICE,²³ among others, and there is good evidence of its positive impact. In one study, taking a person-centred approach to care was shown to reduce anxiety and aggression among people with dementia and reduce the need for medication.²⁴ Such approaches are also supportive of carers' wellbeing, as best practice in person-centred care planning suggests that carers should be involved in planning discussions and their strengths, wishes and aspirations also taken into account.

Since 2015/16, the development and review of care plans for people with dementia has been supported through incentive payments under the Quality and Outcomes Framework (QOF) for GPs,²⁵ However while guidance states that care planning should be person-centred,²⁶ it is not clear to what extent this is being realised.

2.3. Points of contact

Also critical to ensuring that people with dementia can have timely and appropriate access to support, is ensuring that people know of, and have ready access to, points of contact within the system of support in a community.

As our discussions with experts demonstrated, support is provided by a wide range of organisations and actors across the public, private and voluntary sector. However, what is clear is that people need to be confident that, when a need arises, they can readily find a way into this complex web without having to make multiple approaches.

In discussions, people with dementia and their carers were most likely to identify the GP as their main point of contact with the wider network of services and support in their communities. There is therefore a strong case for ensuring that primary care teams are equipped to act as a link between people with dementia and the wider network of support in their community.



Case study 2: Dementia Wellbeing Coordination – Age UK Norfolk

Age UK Norfolk's Dementia Wellbeing Coordination service, working in close coordination with a local Admiral Nurse Service, offered person-centred support to people with dementia who had high-level needs. The scheme followed on from a two year pilot and ran from April 2015 to March 2016.

The coordinator role was created as a result of the initial pilot and was designed to be a cost effective model which allowed Admiral Nurses to focus on delivering specialist interventions while coordinators provided emotional and practical support.

Coordinators worked closely with people with dementia and their carers to deal with a range of practical, social care and advice issues which might otherwise have led to a referral back to the Admiral Nurses, or which may not have been dealt with at all. The pilot made referrals out across a wide range of services and support, including a small number of other Age UK services. The service worked between four clusters of GP practices each with a linked Admiral Nurse, and provided social support, practical help, advice and information, using a standardised plan produced by the Admiral Nurse. All referrals were received from the Admiral Nurses. The team generally met service users face to face to build trust and understanding. The approach was person-centred and focussed on building resilience. Initial interventions were relatively short, but people were given a number to call if they needed further support.

Coordinators were often called upon to provide practical support, for example with power of attorney forms and benefits claims, as well as working with extended family and providing intensive support in times of emergency.

Evaluation found service users' wellbeing (measured on the WEMWBS) improved significantly following intervention, that the service was highly valued by carers, and helped to reduce burdens on the Admiral Nurse service. In some cases the team's involvement enabled statutory mental health services to reduce or end their involvement with people.



'I would give them ten out of ten. It is nice to know that I can get in touch with someone. They are nice people. I feel like I am battling and taking each day as it comes. I will get in touch with them when I need to. They weren't directive at all and just made suggestions. They told me about things that were available and provided a lot of information. **It is very good. I did not know it existed and I am very grateful.** They have been very helpful and very sympathetic.'

Carer

Case study 3: Primary Care Navigators

The Primary Care Navigator (PCN) is a new role in general practice developed to find and support patients with dementia, and their families and carers to access the health and social care system, through better navigation, and social rather than clinical prescribing.

The scheme enables specific targeting and fast tracking of people with dementia, their families and carers to health and wellbeing support. The role of the PCN is to:

- Communicate with patients and carers, asking open questions and actively listening;
- guide people to all-sector sources of help and support, from the most local to national, and;
- support case finding through referrals from clinicians and opportunistic screening in clinics.

The PCN role was developed by Oxford Terrace and Rawling Road Medical Group (OTMG-RR) – a GP practice, situated in Central Gateshead – in partnership with the National Association of Primary Care (NAPC). This was in response to the growing numbers of patients who were receiving a dementia diagnosis, and the increasing challenges encountered in trying to meet their needs through ten minute GP appointments. Practice staff recognised that many of their dementia patients' most pressing needs were related to social care and wellbeing rather than acute clinical need. In addition, many carers were not being identified and were therefore not receiving the support they needed. As a result the on-call doctor was overwhelmed, patients and carers frustrated, staff were struggling and the quality of care in danger of being compromised. There was also a high level of unplanned hospital admissions among people with dementia.

The new role was introduced without additional funding, as existing health care assistant and receptionist roles were redesigned to incorporate the PCN role. The new role has now been extended to support all social prescribing for people with complex care needs in the practice, and will be the foundation of implementing the 'House of Care' approach to the management of long-term conditions in the practice.

The introduction of the PCN role was found to support increased assessments for dementia, and increased carer registration. It also helped to ensure that more people with dementia had a care plan, and reduced pressures on GPs. There was also some evidence that the introduction of PCNs led to reduced hospital admissions for people with dementia.

NAPC have successfully trained 190 PCNs across multiple sites, moving from a focus on dementia and diabetes to people with long-term conditions, and frailty, and older people. Since Oxford Terrace received NAPC's PCN training, they have continued to inspire others within the programme and encourage others to join and share the continuous learning.

Chapter 3: Direct interventions



Chapter 3: Direct interventions

Direct interventions are those which directly address one of the three key areas of living well highlighted by people with dementia and their carers – i.e. personal wellbeing; positive relationships; active daily lives.

3.1. Personal wellbeing

Dementia has a profound impact on the individuals it affects, so it is unsurprising that the people living with the condition to whom we spoke emphasised the importance of a range of personal factors in living a good life, including:

- keeping a sense of who you are
- maintaining a sense of humour
- feeling a sense of dignity
- feeling valued.

While carrying on with day-to-day life was valued more highly than cognitive function per se, maintaining certain aspects of cognitive function – such as continuing to know close family members – was seen as important to continued quality of life.

In this section we highlight a range of interventions which are designed to support people with dementia to develop or maintain personal traits and capacities that could help them to cope with their condition, and which can contribute to maintaining cognitive function. These interventions have the potential to help individuals to maintain their personal wellbeing and sense of self while living with dementia.

Psychological support

These interventions offer tailored programmes of psychological support, drawing on established models of psychological intervention such as Cognitive Behavioural Therapy (CBT) to offer people with dementia support in dealing with some of the impacts of the disease and in preparing for the future. A number of these kinds of programmes have been robustly evaluated and have been shown to have positive impacts both on people with dementia and their carers.²⁷

Case study 4: Age UK Camden – Counselling for People with Dementia

Age UK Camden offers a counselling service for people aged 55 and over who are registered with a GP in the London Borough of Camden, which is available to people in the early stages of dementia. Home visits are available for housebound people.

The service offers support both to people who are experiencing memory issues and may be feeling anxious about seeking a diagnosis, and those who have been diagnosed with dementia, irrespective of ethnic and religious background or sexuality. The scheme is offered as part of the local Improving Access to Psychological Therapies (IAPT) scheme, and funded by the local NHS. Individuals can be referred to the scheme via their GP or memory clinic, or can self-refer. Following an initial assessment, individuals are offered a course of between six and 20 weekly, 50-minute counselling sessions. Support is offered with whatever issues the individual wishes to discuss, but common issues faced in the counselling room include anxiety about the diagnosis and about the future, and issues in relationships.

The impact and effectiveness of the counselling service is regularly measured against recognised scales, and individual feedback is sought at the end of each course of counselling.

‘I feel lighter at the end of my sessions.’

Person with dementia



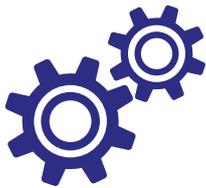
‘Support is offered with whatever issues the individual wishes to discuss, but common issues faced in the counselling room include anxiety about the diagnosis and about the future, and issues in relationships.’

Cognitive Stimulation Therapy

Cognitive Stimulation Therapies are designed to support people with dementia to maintain their cognitive function. Given the clear links between quality of life and cognitive function, and the value placed by people with dementia on maintaining cognitive function,²⁸ there is good reason to believe that cognitive stimulation therapies have an important role to play in a package of support aimed at promoting quality of life.

There are two main forms of Cognitive Stimulation Therapies currently being practiced:

- Cognitive Stimulation Therapy (CST) itself is a brief treatment for people with mild to moderate dementia. CST was designed following extensive evaluation of research evidence²⁹ and is recommended by NICE.³⁰ Importantly, CST has been shown to improve both cognitive function and quality of life.³¹
- Maintenance Cognitive Stimulation Therapy (M-CST) is designed to follow on from CST, with the aim of maintaining the benefits of CST over the longer term. M-CST has been evaluated in randomised control trials and has also been found to be effective at maintaining cognitive function, though with less convincing results in maintaining quality of life benefits.³²



‘There is good reason to believe that **cognitive stimulation therapies have an important role to play** in a package of support aimed at promoting quality of life.’

Case study 5: Cogs Clubs

Cogs Clubs offer people with mild to moderate dementia a five-hour weekly session of fun and stimulation – to ‘oil the cogs’ of their brain and body. The programme is based on the robustly-evaluated CST programme, but instead of offering a time-limited intervention, Cogs Clubs offer a full-day programme and are available for as long as members are able to benefit.

Most Cogs Clubs are run by local Age UKs, but there are also groups provided by churches, Crossroads Care, and in a residential home. There are 35 Cogs Clubs currently operating across the UK.

Sessions are open to people with mild to moderate cognitive impairment, who are able to communicate, and manage their own toileting and medication. People with very impaired hearing and/or sight may not be able to participate, as sessions are quite interactive.

Referrals to Cogs Clubs come from a wide range of sources including memory clinics, CST groups that are ending, social services, and other health and care professionals. Most groups also accept self-referrals and referrals from families and friends.

Members pay a weekly subscription, with costs set with a view to ensuring the sustainability of the clubs. Staff costs vary from one organisation to the next, depending on whether sessions are run by volunteers or by volunteers in combination with staff. Costs to members are lower than day care costs, so that members are able to meet costs out of their Attendance Allowance. The current range of costs is from £8–£22 per day.

Cogs Club will provide guidance and advice to any organisation that wishes to set up a club, providing training for staff as well as advice and guidance on issues such as venues and advertising. Support is offered free of charge, and all clubs are provided with the Cogs Manual, a CST Manual and support to the facilitators on their opening day and subsequent weeks as needed.

An evaluation of Cogs Clubs in 2013 found that members felt the clubs helped them to stay well mentally and physically and that carers drew benefit from the opportunity to have a break knowing their loved-one was well cared for, and from meeting other carers in a similar position to them.

‘Members felt the clubs helped them to **stay well mentally and physically** and that carers drew benefit from the opportunity to have a break knowing their loved-one was well cared for.’



3.2 Positive relationships: existing

Our research with people with dementia demonstrated the central importance of positive relationships to living well. It was clear that people valued both the maintenance of their existing relationships and the opportunity to develop new relationships.

For many of the people we spoke to, the most important relationship was that between the person with dementia and their primary carer, who was often a spouse or son or daughter. However, both people with dementia and their carers acknowledged that living with dementia created direct and immediate pressures on these relationships. Support that enables continued positive relationships is therefore likely to be important.

In this section we examine approaches being taken to support people living with dementia to maintain and manage their existing relationships.

Support for couple relationships

There is significant evidence that dementia places a strain on couple relationships, particular where one partner is acting as primary carer for the other.³³ However, these relationships are also vital to the wellbeing of both people with dementia and their carers. Supporting the relationships of people with dementia would therefore seem to be an essential focus for intervention.

Tavistock Relationships have recently piloted couples therapy for people living with dementia and their partners, and the evaluation shows some promising results, particularly among those in the early stages of dementia.³⁴ However, at present this intervention is only available in very few locations. Given the significance of relationships to people's wellbeing, it will clearly be important to stimulate further development of such schemes.

Supporting carers

Providing support to carers can also play a vital role in supporting continued positive relationships, by helping to alleviate pressure on carers and equipping them to cope with their roles. This support can take a range of forms, from formal training to enable carers to develop a better understanding of dementia, its impacts and how best to manage the condition; to more informal peer support mechanisms; to more structured approaches such as Circles of Support which seek to enable people with dementia and their carers to come together with a wide range of other formal and informal sources of support to help to understand each other's roles, needs and capabilities to arrange workable care.

Case study 6: Living Together with Dementia

The Living Together with Dementia (LTwD) programme aims to improve the quality of life and mental health of couples living with dementia through couple-focused psychosocial interventions. The programme involves couples meeting on a regular basis with a member of the LTwD team, who visits them at home, where they discuss their experiences and feelings and carry out everyday activities together, with a focus on increasing emotional involvement and understanding between the partners and finding new strategies for enhancing this.

LTwD is a person-centred intervention, working with the uniqueness of each couple's life experiences and tailored to their strengths and needs. It utilises the resilience of the couple's relationship and the capacity for the relationship to survive and act as a protective resource; and supports couples to adjust to dementia, helping to contain care needs.

The LTwD programme was developed by Tavistock Relationships, based on pilot work with couples. This revealed a need for support at the point of dementia diagnosis. Small scale schemes have run in Camden, and City and Hackney in London since 2013, funded through innovation grants. At the moment, Tavistock Relationships offers training in this couple-focused intervention programme for people working in dementia care. In each training course, staff from Tavistock Relationships train health and social care professionals to work with couples following a dementia diagnosis, delivering the LTwD interventions through home sessions with the couple.

Initial results have shown that the intervention supports the stability of the couple relationship with positive trends towards a reduction in perceived burden in the carer role.



‘When I brought him tea in bed the other day, he was chatting away, pointing out things about someone who was walking past the window. **It’s like having the old Stan back, like he is still there after all.**’

Participant

‘The other day my husband came into the kitchen and asked if he could help me when I was making dinner. He hasn’t done that for years... I thought **he was making a connection with the work we have been doing with you** – and I thought, ‘thank you.’’

Participant

Case study 7: Carer Information and Support Programme (CrISP) – Alzheimer’s Society

CrISP aims to provide information and support for carers of people living with dementia in a closed workshop setting. It aims to connect, inform and empower carers, and to provide an understanding and supportive space where carers can share experiences, discuss challenges and find practical solutions together. The sessions are led by a trained Alzheimer’s Society facilitator and supported by volunteers.

In the London Borough of Havering, CrISP was most recently commissioned to run across consecutive Thursday afternoons in March 2017. Sessions were run in a local community centre with an activity for cared-for individuals running alongside.

The service was promoted through the local Alzheimer’s Society and newsletter, and received referrals from the local Admiral Nurse, Memory Clinic and Community Mental Health Team. Workshops were limited to 12 participants and facilitators chatted to those applying to attend to understand whether the service was suitable and to help them tailor sessions.

CrISP groups are often full to capacity, with a wide mix of participants. In the most recent sessions, ages ranged from 50–80 and yet everyone connected though being ‘in the same boat’, and valued knowing they were not alone. One group of women who met at the sessions now have a regular ‘ladies lunch club’ for informal peer support.

After each session, factsheets and further reading is provided as well as referrals or information about other services in the borough or nationally. When CrISP finishes, attendees are referred to further support and invited to other Alzheimer’s Society services in the borough.

Independent evaluation of CrISP by the University of Brighton found that information provided on the courses supported caring practices and carers’ needs, improved their understanding of dementia and its progression, and helped them access practical suggestions for support of people with dementia. Participants found that they maintained relationships with other carers that they met on the course for peer support.

CrISP is offered by Alzheimer’s Society across England, Wales and Northern Ireland and courses are run regularly.

‘The CrISP Workshops which I attended were excellent. As a participant/carer, I found that group facilitation and learning was very appropriate and helpful. **A small group meant that we were able to develop a sense of security and confidence in sharing our experiences without being judged.** Our sharing meant we acquired new information on different types of dementia, further understanding and knowledge of the unique nature of others’ caring and needs, and how to access help and support and share new techniques of how to manage and cope better with the challenges we face. It’s never too much. All with a good measure of fun and laughter between us.’

Marie, participant

Case study 8: Circles of Support

Circles of Support help people to come together around an individual with support needs, to plan with them how best to ensure they can achieve the life they want. Circles of Support were trialled between 2011 and 2014 with people with dementia in a pilot led by NDTI (The National Development Team for Inclusion) and Innovations in Dementia. The project operated in four areas across the south of England and aimed to learn how Circles could work best for people with dementia.

Circles of Support aim to help the person with dementia to think through how they want their life to be, and to plan for life now and in the future using person-centred approaches. This involves finding out what the person would like to change in their life, what is important to them, what aspirations they may have and how they can best be supported to achieve them.

Circles of Support are ideally made up of family, friends and professionals who are in the life of the individual being supported. They work best when there is someone to facilitate or coordinate the group, including in meetings through which the group comes together to consider how a person with dementia can be supported to maintain their connections and to continue doing what matters most to them. Facilitators can be professionals who are involved with the person such as memory advisors, or support workers, volunteers or family members.

With the person at the centre of conversations, people in the group plan how they can support the person to achieve their wishes. Planning takes into account the person's health and social care support needs, and works out how a range of natural support (e.g. families and friends), as well as professional support (e.g. home care), can help the person live the life they want. The person may also have a written care and support plan which builds on the planning with the individual and their circle, or is developed as part of a Circles of Support discussion.

The pilots found that one of the key benefits of having a Circle of Support who really understood what matters to the person, was that the person and their carer did not feel alone when help was needed, and crises were often avoided.

However, the project also found that some people's natural networks of support had shrunk following a diagnosis of dementia and they needed support to rebuild their circle. In some cases this led to groups forming to focus on shared activities such as a walking group and a London outings group.



'I feel completely supported, days, hours. Having people I know and trust.'

Participant quoted in evaluation



3.3 Positive relationships: new

In our conversations with people with dementia, it became clear that, as well as maintaining existing relationships, building new relationships following diagnosis, particularly with other people with dementia, was also an important aspect of living well. For carers, developing networks among other carers was also considered important to living well.

Peer support

Peer support is a common and growing part of the offer made available to people with dementia and their carers. The relatively low cost of this approach is a major part of its attraction, however there is also good evidence for its effectiveness in enabling people with dementia and their carers to live well.³⁵

Befriending

Befriending services are also likely to be an important part of the patchwork of support in communities for people with dementia. While the evidence around the impact of befriending is generally mixed – and this is equally true for befriending among people with dementia – it is also the case that befriending services tend to be highly valued by those who access them.³⁶

Furthermore, befriending is often the only viable service intervention for socially isolated people with dementia who have significant personal care needs, as many group-based services are not able to meet the needs of these individuals, and social care packages are rarely sufficient to support people in accessing services outside the home.

Case study 9: Standing Together

The Standing Together Project is a three-year project running between 2015 and 2018, which facilitates peer support groups in extra care and retirement schemes, including, but not exclusive to, tenants with dementia.

The groups meet for 90 minutes a week for up to six months, and are facilitated by an experienced Mental Health Foundation (MHF) staff member. The groups are structured with a warm-up and main activity and include tea and cake. Beginning with building relationships between participants, sessions are facilitated using a range of asset-based themes which enable conversations about emotional well-being in later life.

The programme was developed on the back of the Dementia Self-Help Project which ran from 2011 to 2013, supported by MHF and Housing & Care 21, which facilitated and evaluated three self-help groups for people with early stage dementia who were living in extra care housing schemes in London. Groups ran for six months and 50 tenants participated, with evaluation finding that groups had a positive impact on participants' wellbeing, social support and practical coping strategies. Of particular note in the evaluation was the fact that other tenants without dementia wanted the opportunity to attend groups too. As a result the new, more inclusive, programme was established.

Standing Together groups are open to anyone living in a scheme run by one of the project partners (currently either Housing & Care 21 or Notting Hill Housing Trust), in the London area, where the pilot is being facilitated. The groups are for people in later life who experience mental health problems, memory loss, learning difficulties and those who are significantly isolated. The Big Lottery Fund is funding the pilot phase, and MHF hopes to minimise future costs by training volunteers and existing staff members as facilitators.

The project has shown encouraging improvements as it is being evaluated against a range of outcomes including reducing feelings of loneliness and social isolation; improving emotional wellbeing; and increasing levels of meaningful activity, sense of purpose and community engagement. Results will be made available.



‘When I came here last week, I thought, this is it! This is great because I managed to get to talk to people. I didn’t know anybody; you get in the lift, ‘Good morning’ or ‘Good night’, nothing else, nobody talks to you. Most people here say they didn’t know their next-door neighbour, it shouldn’t be like that.’

Participant

Case study 10: BUDS Befriending Service

The BUDS (Better Understanding for Dementia in Sandwell) befriending service offers people with dementia living in the Sandwell area the opportunity to receive a weekly visit from a volunteer for a couple of hours.

BUDS aim to visit at a time to suit the person, either on a day when they may not receive other visitors or to fit in around family carers' needs. All BUDS volunteers receive training and supervision and are referenced and DBS checked.

BUDS volunteers flex activities around the interests of the person, and include having a chat, talking over concerns, reminiscing, engaging in hobbies, watching TV or reading a book.

The service is open to anyone living in the Sandwell area who has a dementia diagnosis, and is provided free of charge. Referrals are received from a wide range of services, and self-referrals are also taken. Once referred, a visit is arranged to the person with dementia and their family to talk about their needs and to match them with a suitable volunteer.



'The befriender was a wonderful person and although we had never met before, I was able to go out knowing my husband was in capable, efficient and kindly hands and, **most importantly, he was happy.**'

Carer



'BUDS volunteers **flex activities around the interests of the person**, and include having a chat, talking over concerns, reminiscing, engaging in hobbies, watching TV or reading a book.'

3.4 Active daily lives

Beyond the personal and interpersonal aspects of living well that people with dementia identified, there were a whole raft of other aspects of living well which related to people's daily lives in the wider world. These were the activities of life which brought meaning, colour and interest into people's days and created a 'life worth living'. They range from leisure and learning activities to day-to-day community interaction. In our discussions with people with dementia, it was clear that 'normal life' activities – i.e. being able to go to the shops or take a walk – were just as significant as more formal activities in terms of their impact on wellbeing. In this section we examine the approaches which are being taken to ensure that people with dementia continue to have access to a 'life' beyond an 'existence'.

There are two broad forms that this provision takes – specialist provision – i.e. provision designed especially for use by people with dementia – and adapted provision – i.e. adaptations to mainstream provision designed to ensure people with dementia are equally able to access services.

Accessibility and adaptation

There are a wide range of approaches being taken to ensure that people with dementia and their carers are able to access activities and services which are meaningful to their lives. One such approach is to adapt mainstream services to enable people with dementia and their families to more easily participate. As was clear from our discussions with people with dementia and their carers, access to specialist services and contact with others in similar circumstances was valuable – but people also wanted to be able to access mainstream provision including leisure services and holidays and to be able to access basic public services.

As awareness of dementia, and its prevalence, increases, more and more services and industries are waking up to the need to adapt their offer to meet the needs of people with cognitive disabilities. For example, Age UK recently published guidance on 'age-friendly banking' in partnership with the US-based older people's organisation AARP, showcasing best practice from the financial services sector including in meeting the needs of customers with dementia.³⁷

In this section we explore how mainstream provision is being adapted to ensure that people with dementia are able to access and enjoy these services. Much of the work to adapt services and to support the participation of people with dementia is taking place in the context of broader community programmes such as Dementia Friendly Communities. These are discussed in more detail in chapter 5.



Case study 11: Dementia Friendly Heathrow

Heathrow Airport joined the Dementia Friendly Business pilot scheme in 2015 as part of its commitment to inclusion and access and has been working since then with the Alzheimer's Society and the Dementia Friends programme to develop their plans for Dementia Friendly Heathrow.

Heathrow Airport was keen to think about changes that could be made to improve the experience of passengers with dementia and their carers at the airport, recognising the constraints that exist around the built environment and 'fixed' characteristics of the airport experience – such as the inevitable hustle and bustle and noise.

Around 1.4 per cent of the passengers that pass through Heathrow Airport each year – or around 1.2 million people - need special assistance during their journey. It is estimated 1-2 per cent of these have 'hidden' disabilities, including autism and dementia. Heathrow has been considering how to improve the experience of these passengers, learning from best practice around the world.

Staff training has been recognised as a core priority for creating a dementia-friendly Heathrow and the airport has pledged to roll out training to all frontline staff. Staff prioritised for training include those providing special assistance to passengers, ambassadors and hosts within the various areas of the airport, and security and immigration staff. Immigration and security are areas of the airport experience which have been identified as the most stressful for passengers with hidden disabilities such as autism and dementia.

As well as supporting people with dementia and their carers through staff training, Heathrow has produced an assistance guide which gives people information about what to expect when they come to the airport and offers tips on, for example, where to find quieter environments. The guide also explains where to find help around the airport – flagging key symbols which identify where people can access assistance, including the 'helping hands' logo and the 'dementia-friendly' flower.

Airport staff are working with researchers from the University of Plymouth to consider how to standardise the signage and access processes across airports, so that passengers do not have to encounter different systems each time they travel. The team are also working with designers who are looking at future airport expansion plans to ensure that insights around how to design age and dementia friendly environments are built in from the outset.

As this scheme is new, it has not yet been subject to evaluation. However, the airport's disability consultative committee is actively involved in designing ways of effectively measuring the impact of these accessibility programmes.

Case study 12: iSPACE – Dementia Friendly GP Surgeries

iSPACE is a quality improvement and innovation programme, which aims to better manage the pathway of patients with dementia and their carers through primary care. The iSPACE model was developed from a hospital-based model and planned and piloted in the Oakley and Overton Partnership practice in North Hampshire with funding from the Wessex Academic Health Science Network (WAHSN).

The programme involves surgeries going through six key steps:

- I** – Identify a dementia champion
- S** – Staff training
- P** – Partnership working with patients, carers, and the voluntary sector
- A** – Assessment and oversight of use of anti-psychotics
- C** – Care planning and use of tools such as ‘This is Me’
- E** – Ensure the environment supports people with dementia and other disabilities

Evaluation of the pilot demonstrated a number of benefits for staff, patients and carers, including a 15.9 per cent increase in dementia diagnosis rates for people aged over 65; a 26 per cent increase in the number of patients with dementia with a care plan review; and a 16 per cent reduction in clinical consultations by people living with dementia.

On the back of positive evaluation, the programme is now being spread across Wessex – with 150 surgeries having completed the steps set out in the programme. The programme has been mainstreamed to all CCGs in Wessex.

The key to the spread of iSPACE is the engagement of staff teams and a recognition that people with dementia need a more personalised care plan and access to resources to help them and their carers better manage the pathway.

‘Evaluation of the pilot demonstrated a number of benefits for staff, patients and carers, **including a 15.9 per cent increase in dementia diagnosis rates for people aged over 65.**’

Case study 13: Dementia Adventure

Dementia Adventure is an award-winning charity which aims to help people live well with dementia, have contact and connection with nature, and retain a sense of adventure in their lives.

Dementia Adventure works across the UK and internationally, providing a range of services all with nature in mind. Their emphasis is on what people can do and not what they can't. They offer:

- Dementia supported holidays – small-group short breaks such as sailing, canal boat and walking holidays and other small bespoke group holidays as an alternative to traditional respite.
- Training and consultancy – for carers, conservation charities, care homes, health and social care services, and local authorities – with the aim of developing understanding, increasing outdoor activity, and encouraging positive risk taking.
- Research – into the benefits of outdoor activity for people with dementia.

Dementia Adventure's services are diverse and range from park walks to holidays in locations such as Cornwall, Essex, the Isle of Man and Turkey. Each couple joining a Dementia Adventure holiday is supported by a trained team member. The Dementia Adventure Trust underwrites the costs of holidays and breaks to make them as affordable as possible. The Trust is supported by a range of funders including the People's Postcode Lottery.

James, whose Dementia Adventure involved getting back behind the wheel of a car at a disused airfield, said:



'There are too many people (whoever they are) stopping you from enjoying your hobbies even with a trained supporter. **Naturally there are some things which are just not possible**, but always consider alternatives.'

'Were there side effects from my exhilarating experience? Yes there were; good ones. When I got home, I found I could walk faster, as for some time I had been walking slowly, head bent. I found that I was able to recall facts from 50 years ago, things I had completely forgotten about. I was able to help more about the house, taking a little of the burden off my wife. I was able to write this article by myself. My short term memory, notoriously bad, improved slightly. **My sense of wellbeing was high. It will be interesting to see how long this feeling of euphoria lasts.**'

Case study 14: The Butterfly Scheme

The Butterfly Scheme provides a system of hospital care for people living with dementia or who simply find that their memory isn't as reliable as it used to be. The Butterfly Scheme has now been adopted by over 150 hospitals across the length and breadth of the UK and Ireland.

The scheme supports hospitals to make adaptations to improve the way that people with dementia and their carers are treated during their time in hospital. The most obvious of these is the use of a simple butterfly logo which can be placed on the bed of a person with dementia to allow the easy and non-stigmatising identification of people who might be in need of additional support.

Calderdale and Huddersfield NHS Foundation Trust was an early adopter of the Butterfly Scheme, having started using it in 2011. The scheme was introduced under the initiative of the Trust's nurse consultant for older people who was looking for a programme which would support improved care for people with dementia.

The Trust was attracted to the scheme because it combined a number of core elements alongside the simple Butterfly symbol. These included the scheme's approach to ensuring that people with dementia and their carers are fully identified and understood through the completion of what is known as a 'See Who I Am' form in the Calderdale and Huddersfield Trust and the REACH principles for improved care.

REACH is an easy-to-understand shorthand for the five taught key skill areas offering effective support for people with dementia. All staff across both the Huddersfield Royal Infirmary and Calderdale Royal Hospital are trained to think through the REACH principles when dealing with people with cognitive impairment, as part of their wider training in this area.

A simple example of the way this has changed practice is that now, when a person who has been identified as having cognitive impairment with the butterfly symbol uses the call bell, instead of simply asking what the patient wants, staff are able to recognise that the individual may have forgotten why they called and will act as 'detectives' to work out what might have been the reason for the call looking for verbal and nonverbal signs and using the information on the 'See Who I am' form to inform their investigations.

The cost of the scheme to the hospital is very low 'around £200 per year' and for this the Trust is involved in networking and has access to support as well as to a range of updates and tools, including for evaluation. Over the years the Butterfly Scheme's way of working has become part of the culture, and staff and carers are keen to ensure patients are registered with the scheme when they come to the hospital.

Huddersfield and Calderdale are planning to start using the scheme's specially developed evaluation tools over the next few months, which will provide valuable data on the impact of the scheme.

Specialist provision

Another key approach being taken to ensure people living with dementia are able to maintain active daily lives is to develop specialist services which have been designed explicitly to meet the needs of people with dementia. While some of these are generic – such as day centres, cafes and support groups – others offer more specialist activities, and are often rooted in theory around the additional value of engaging in particular kinds of activity for people with dementia.

Physical activity-based provision, for example, has been demonstrated to have positive impacts on wellbeing, not only because it creates opportunities for social interaction and meaningful engagement, but also because of the direct health and wellbeing benefits of the activity, which the evidence suggests can include slowing the progress of dementia itself.³⁸

Outdoor activity is another area of specialist provision, where, again, emphasis is placed in the literature on the potential additional therapeutic benefits offered by being outdoors, going beyond the benefits linked to social interaction and meaningful activity.³⁹

Reminiscence-based activity is a long-established form of provision for people with dementia. In reminiscence-based groups, people are encouraged to explore their memories around particular issues, periods or subjects that may have been of significance to them prior to their diagnosis. Several individual reminiscence activities have demonstrated positive results through evaluation, but there is still more to do to develop the evidence base in this area.⁴⁰

There has also been significant interest in the potential of arts-based activities to support wellbeing. Arts-based programmes have gathered some evidence to demonstrate their potential for positively impacting quality of life, however there are still gaps in the evidence.⁴¹ However, one area in which there is particular current interest, and developing evidence, is that of music-based activities and particularly choirs, given their potential to offer both social, emotional and (to some degree) physical activity, through the collective act of singing. A large number of choirs for people with dementia have been established over recent years, many under the auspices of the Alzheimer's Society 'Singing for the Brain' programme. A recent systematic review for the What Works Centre for Wellbeing concluded that there was evidence of wellbeing benefits of singing among people with dementia.⁴²

While there is a wide diversity of provision, what unites these programmes is that they offer people with dementia the opportunity to engage in activity with their peers, creating opportunities for enjoyment and social interaction. And the evidence seems to support the view that specialist provision of activities such as those profiled below can support the wellbeing of both people with dementia and their carers.⁴³

While providers working in particular areas of provision are often keen to assert the particular benefits of their form of provision, the evidence base is not yet sufficiently well-developed to make an overarching judgement. However, what seemed most important to the people with dementia and their carers to whom we spoke, was that the activities aligned with their sense of themselves and their own interests and aspirations.



Case study 15: Roller Mill – Day Opportunities from Age UK South Staffordshire

Age UK South Staffordshire offer a range of day services to older people living with dementia and other long term conditions in Southern Staffordshire, including a popular day service at the Roller Mill centre.

Day Opportunities are delivered by a highly trained specialist team who work to make their centres feel like a home away from home. The environment is designed to create a sense of belonging, with service users encouraged to bring in personal possessions. The aim is to offer a welcoming, relaxed and friendly environment with activities which help to stimulate cognitive, physical, recreational, and social skills. Door-to-door transport is provided, and both drivers and passenger escorts recognise their role in providing continuity of care. Meals which reflect users' cultural and dietary requirements are provided.

Referrals are made through social care and health teams, GPs, Community Mental Health Teams, and occupational therapists. Self-referrals are also accepted. Team leads and service managers make contact with those referred and their carers or family members, to arrange visits to complete a comprehensive, outcomes-based assessment of need. A person-centred tailored support and action plan is created for each individual to identify opportunities to build on strengths and abilities to find ways to compensate for losses brought about by dementia. Carers of people attending the centre are supported with meetings and telephone contact. Monthly carers' groups are also facilitated, further supporting carers in the care giving role.

The service is partly funded by social care and health through a block booked contract, and partly self-funded via a direct payment/personal budget or independently.

Day Opportunity intervention has proven to be a significant support enabling main carers to continue in the care giving role while supporting people living with dementia to continue living in their chosen environment for as long as possible.



‘What a difference coming to the Roller Mill has made to mum. On days she is with you she gets up much quicker, eager to go. She is much more interested in the world around her and is chatty and sings a lot more than ever she used to. Mum will chat on her return home about what she has done through the day. On occasions when she can't remember, the diary you have put in place helps me prompt her to remember what she has done. **I can't thank you enough, you are all stars. Bless you all and carry on the good work.**

Carer

Case study 16: Sporting Memories

Sporting Memories groups work with older people experiencing dementia, depression and loneliness, to engage in reminiscence and other activities centred around sports, as a means of reducing isolation and improving wellbeing.

Sporting Memories groups are volunteer-led and community based. There is no fee to attend and they are open to any sports fan over the age of 50. Group activities include reminiscing about sport, but also playing sport and taking part in physical activity. Groups take place at football, cricket, rugby and all sorts of sports stadia, libraries, museums, housing associations and even pubs. Many of the groups are supported and promoted by professional sports clubs.

Referrals to groups are often made by GPs, memory services and social services. Word of mouth and recommendations from group members to friends are also significant routes of entry for participants.

The Sporting Memories Network CIC has received funding from a wide range of funders including the Life Changes Trust, Big Lottery Fund, Comic Relief, the Premier League Charitable Trust, the PFA, Spirit of 2012 and many councils or CCGs.

The groups have been evaluated by a number of funders and researchers and have been shown to improve wellbeing and engagement by providing peer support, carer support, facilitating new friendships, and getting people active and mentally stimulated. Work is currently underway to assess the social return on investment of Sporting Memories groups.

Over 100 groups are currently being supported and sustained throughout the UK, and funding has been secured for a further 50 new groups in 2017. Plans for a national project across Wales has the support of over 75 organisations including all professional sports clubs and the First Minister of Wales.



‘The Sporting Memories group is tailor made for me and has been great, because it’s discussing and talking about a subject that I’ve been involved in and have memories of in the past, it has given me an automatic air of confidence.’

Participant

Case study 17: Dance Well

The Dance Well project provides dance and movement workshops for people living with dementia and their carers, led by a professional South Asian dance artist.

The workshops are suitable for all abilities, seated or standing, and often carried out in a circle to ensure inclusion. Participants practice different techniques depending on the artist available – styles include Kathak, Bollywood, Bharatanatyam and Odissi. While the emphasis is not on technique, artists encourage participants to learn new movements such as mudras (hand gestures) for storytelling, new rhythms using hands, feet, sticks or bells, and explore their own creativity. Props are often used, such as silk scarves, giant scrunchies and a South Asian fabric parachute. Props help to connect members of the group across the circle, particularly those who might be unsure about joining in.

The workshops are part of a three-year community participation project run by South Asian dance charity Akademi, operating mainly in the London Borough of Camden in community centres, care homes, hospitals, and day centres. The project has been funded by the Big Lottery Fund. Akademi bring two decades of experience in working in community settings using South Asian dance as a medium.

Workshops are led by a member of Akademi staff along with the dance artist, and staff and carers are encouraged to participate in the workshop as well. Participants are provided with a Dance Well diary to record their own reflections on each class, and have exercises/creative tasks to carry on with at home. A key aspect of the work is social engagement, so participants are encouraged and supported to develop their confidence and to interact with other members of the group, slowly building a strong rapport during the series of workshops. This often includes a short time for tea and biscuits after the workshop, providing time to develop friendships.

Participants are recruited through partner organisations including Arts4dementia, carers' groups and day centres. There has been increasing interest from local community centres which are seeing an increase in the number of members living with dementia and are looking for activities to refer them to.

The current cost of setting up and running an eight-week course of workshops is approximately £20–£25 per person.

Collection of data for evaluation has proved a challenge, but Akademi have started using the arts observation scale to garner information on participants' experiences. Qualitative evaluation suggests participants find the activities stimulating, and value the social interaction and sense of community.



'I feel awake. I like that it was stimulating, coordinating hands and body movements.'

Participant

Case study 18: Thrive

Thrive is the leading charity in the UK using gardening to change the lives of disabled people. The charity provides specially tailored, structured horticultural therapy programmes for people with dementia at centres in Reading, London and Birmingham.

The Dementia Project at Thrive Trunkwell Gardens, Beech Hill, Reading, Berkshire, runs on a Tuesday afternoon from 2.00–3.30pm. It operates in the ‘Secret Garden’, which has been specially designed for people with dementia, incorporating circular paths, open views and raised beds, and follows a programme specially designed for people with dementia.

Clients generally pay to attend schemes – though some schemes are subsidised through grant funding.

Evaluation of a pilot scheme run for people with Young Onset Dementia (YOD) found that structured gardening may have a positive impact on the wellbeing, cognition and mood of people with YOD. Of particular interest was the observed relationship between the wellbeing of participants and their cognition, as results from this study suggest that wellbeing can be maintained despite the presence of a cognitive deterioration.

Testimonials from service users and their carers attest to the benefits for individual and carer wellbeing.



Dad had a fantastic visit with you all today. **It is impossible to say how much it meant to him.** The first little task Vicky gave him was perfect as he has always kept runner beans. So he felt he had been valued and entrusted. He was chatting away to the girls Vicky and Wynne (therapist and volunteers) and so relaxed.’

‘The ‘Secret Garden’, has been specially designed for people with dementia, incorporating circular paths, open views and raised beds.’

Case study 19: Shake Your Tail Feather

Shake Your Tail Feather is a touring event for care homes across the UK created by JABADAO.

Shake Your Tail Feather events involve a team of five specialist dancers and acrobats going into care homes and supporting an entirely person-led event using very little language, and with a rich musical score. The aim of the programme is to nurture non-verbal expression, especially for people with later stage dementia, for whom words are often tricky.

The JABADAO team includes dancers, acrobats and non-verbal communication specialists who also use the event as training, modelling person-centred physical activity in realistic everyday settings.

Each tour is supported through specific fundraising, sometimes through care home providers. The Arts Council England has provided support to the last two tours, along with Sanctuary Housing and Suffolk County Council.

The project is relatively expensive, as this highly professional team tours nationally. Care homes are asked to make a realistic contribution and JABADAO raises the remainder.

An internal evaluation of the tour in Suffolk found that the events were highly valued by participants, care home staff and family members of residents. Participants and care home staff were keen to have the events repeated.



‘Imagine what the morning would have been like without you.’

Participant

‘The aim of the programme is to **nurture non-verbal expression, especially for people with later stage dementia**, for whom words are often tricky.’

Chapter 4:

Enabling services

Chapter 4: Enabling services

4.1. Technology

It is interesting to note that, in the literature around approaches to promoting wellbeing among people with dementia, there is significant interest in the potential of technological interventions. However, in conversation with people with dementia, few highlighted technology as being supportive of their wellbeing, suggesting a mismatch between the interests of people with dementia and their carers, and the current focus of research.

Over recent years, a wide range of assistive technologies has been developed with a view to supporting people with dementia – from the simplest – including clocks which display phases of day and night to support those struggling with their sense of time – to the most complex – including sophisticated wearable technology to enable remote monitoring of vulnerable adults. However, the evidence of the effectiveness of these technologies is very mixed, and interestingly several studies found a mismatch between the expectations and experiences of carers, and those of people with dementia.⁴⁴

Overall, it seems there may be a role for technology – in the broadest sense – in enabling people with dementia to live well. One potential role for technology may be in enabling older people to access wider support in their community – such as in the example below – or in streamlining the delivery of provision.

‘One potential role for technology may be in **enabling older people to access wider support** in their community.’



Case study 20: The Salford Way

The Salford Way dementia app has been designed by Salford CVS to provide a guide to shops, services and businesses in the city that are dementia-friendly. The app was further improved in partnership with Salford Dementia Action Alliance and the Dementia Champions group and funded by Salford CCG Integrated Commissioning Board Innovation fund.

The Salford Way app was first developed as a means of supporting people with early onset dementia to remain independent, and to engage more businesses in the work of the city's Dementia Action Alliance. The purpose of the app is to enable businesses to signal their commitment to supporting people with dementia to feel more confident in accessing local services.

The app was developed by a Salford-based technology company called Eagle Eye Solutions, and is accessible on IOS (Apple) and android platforms. It can be downloaded free of charge and helps people to know which organisations within Salford welcome people with dementia.

Businesses and organisations wishing to be featured within the Salford Way app apply via Salford Community and Voluntary Services. Organisations must sign up to the aims and objectives of the Dementia Action Alliance, and agree to some members of staff undertaking a Dementia Friends session. The app now includes a wide range of services and organisations, from shops and cafes, to bars, restaurants, leisure facilities, garages, pharmacists, and health services etc.

The app went live in September 2016 following a development period of around eight months. Over 230 people have now downloaded the app, which is regularly promoted to people with dementia and their carers through various forums and groups around the city as well as online and through local newsletters.

The app is also used to communicate relevant population health messages, such as flu vaccination reminders and there are plans to develop this feature further. The app allows users to leave feedback on their experience of services, helping to generate more information on what users can expect and creating an incentive for businesses and services to provide a good quality service.

While the app has yet to be formally evaluated, informal feedback suggests that people with dementia find it very helpful. Knowing that they will find people who have an understanding of dementia, and are committed to providing a good service, helps people feel more confident in getting out and about and accessing services. While initially it was expected that the app would mainly be used by people with young onset dementia, there are signs that the app is also proving helpful to older adults with dementia and people with mild cognitive impairment.

Plans are now being laid for a new stage of development, in collaboration with Salford University, who hope to use the app to provide insight into the movements and behaviour of people with dementia, and thereby to contribute to wider research into dementia. One option is to use beacon technology, which (where users have given prior permission) would flag up when an app user entered the premises of an organisation registered with the scheme allowing users to receive information about special offers, promotions and so on. This would also allow researchers to track how people with dementia use services within the local community, and enable service providers to be more proactive in supporting people with dementia who access their services.



4.2. Transport

Another key enabler for living well with dementia is appropriate and accessible transport.

It was clear from our conversations with people with dementia and their carers that the loss of ability to drive had a big impact on people's quality of life. Effective alternative transport is self-evidently vital to ensure people can continue to access the things which support their quality of life.

However, few specific initiatives were identified as part of this work, and no specific evaluation of transport schemes on the quality of life of people with dementia were found.

'It was clear from our conversations with people with dementia and their carers that **the loss of ability to drive had a big impact on** people's quality of life.'

Case study 21: Blackburn with Darwen Connect

Blackburn with Darwen Connect is a community-wide scheme which aims to support active travel across the Borough of Blackburn with Darwen in East Lancashire – including for people with dementia.

The scheme includes a range of elements including group based healthy walking and cycling activities specially tailored to the needs of people with disabilities, like people with dementia.

There is also support available to people with dementia in using the bus network: The Connect programme offers an ‘Introduction to Bus Travel’ session, during which people with dementia and other needs are taken on a guided day out by bus. Participants are given a specially simplified schedule for the day and arrange to meet at the main bus station. They are given a tour of the station, and supported to identify where to look for information on departures etc. They take a bus trip out, with trips scheduled to include an interchange to promote familiarity with changing buses, spend a day out and then return by bus. Participants report increased confidence in their ability to use buses.

Another innovation has been the Vulnerable Adult Card which is made available to anyone who feels they need extra support in using public transport including buses, trains and taxis. It acts as a simple way of communicating to the operator that the person carrying the card may need extra assistance for example in identifying their stop, making payments, getting to their seat.

The cards were produced following consultation with the borough’s learning disability partnership board, but have proved popular with people with dementia also. The scheme is promoted through providers and is part of the training package for staff of public transport operators.

Cards are available to anyone who fills in a simple application, with application forms distributed through various local forums and support groups, and available on the borough website. The cards have been professionally produced with a quality design to reduce the stigma of carrying them.



‘The **Vulnerable Adult Card** is made available to anyone who feels they need extra support in using public transport including buses, trains and taxis.’

4.3. Housing and care

Another fundamental pillar of living well is access to appropriate housing and care.

Appropriate housing and high quality and accessible care can enable people with dementia and their carers to remain independent and to continue to enjoy high quality of life for longer, but the absence of these can blight people's lives. Unfortunately, too many people with dementia lack access to appropriate advice and support around their housing needs, and in many localities housing, health and care services are not coordinated with each other.⁴⁵

It is not the focus of this report to assess in detail the relative merits of the wide range of provision available for people with dementia and their families and carers. However (as noted in the section on person-centred care), flexibility, dignity and responsiveness are all key features of high quality support.

Appropriate housing can enable older people with dementia and their carers to continue to live well together and, conversely, poor quality or inaccessible housing can act as a barrier. Models of housing with care – such as extra care housing – are an important part of the landscape of options which will be needed to enable people with dementia to live well.

Access to flexible and supportive respite care is another critical area of need for people who are supported by family or friends, as adequate respite is vital to maintaining carer wellbeing and preventing carer breakdown. Respite models such as Shared Lives can form one part of the landscape of care for people with dementia, in offering people an opportunity for residential respite in a homely environment.



‘Unfortunately, too many people with dementia **lack access to appropriate advice and support** around their housing needs.’





Case study 22: Shared Lives for Dementia

Shared Lives schemes match an adult who has care needs with an approved Shared Lives carer. These carers share their family and community life, and give care and support to the adult with care needs. Shared Lives schemes can be used as an alternative to residential care or for the provision of short-break or day respite services.

Between 2010 and 2013, Innovations in Dementia and Shared Lives South West undertook a three year programme to assess how Shared Lives schemes could support people with dementia and their families. The project was funded by the Esmee Fairbairn Foundation.

During the programme, most of the people with dementia who used Shared Lives did so for short-break support, including overnight stays, weekend breaks and occasionally longer stays. Some attended for a day on a regular basis.

The evaluation found that people with dementia who used the Shared Lives schemes felt it was very personal, reliable and that the person with dementia had had a great time. However, it was recognised that Shared Lives schemes needed to be 'tweaked' and staff needed special training to ensure services were most effective.

While the evaluation found that Shared Lives schemes were not necessarily cheaper than residential care, there was some initial evidence that they could deliver better outcomes for people with dementia and their carers and could be preferable for some service users.

'During the programme, most of the people with dementia who used Shared Lives did so for short-break support, including overnight stays, weekend breaks and occasionally longer stays. Some attended for a day on a regular basis.'

Chapter 5:

Structural factors



Chapter 5: Structural factors

In this chapter we discuss the broader approaches, which can be adopted as a matter of policy at a systemic or community level, to embed a different approach to dementia within a particular locality or organisation. Where these structural factors form part of the approach to dementia, we are more likely to see services, systems and approaches being developed that will be supportive of people living well with dementia, and less likely to see an approach which emphasises deficit and dependency.

5.1. Rights-based approaches

As noted in our introduction, people with dementia are increasingly making the case for the condition to be understood as a disability and for a rights-based approach to dementia. For example, the Dementia Policy Think Tank – a member of the Dementia Engagement & Empowerment Project (DEEP) network – recently produced a guide entitled *Our Dementia, Our Rights*, designed to support people with dementia to understand and access their rights and entitlements, and to promote cultural change.⁴⁶

Rights-based approaches can be effective in supporting the development of services that enable people to live well. They do this by helping to shift emphasis away from ‘managing’ people with dementia towards enabling them to live the lives they choose, and away from the ‘deficits’ associated with the disease of dementia, towards breaking down the barriers experienced by people living with the condition. Understanding dementia through the frame of the disability rights agenda helps to widen the scope of services and systems that need to be part of a community’s response to dementia, as demonstrated in the examples below, and create an impetus for action through the implementation of actionable legal rights to equal treatment afforded under the Equality Act 2010.

Case study 23: The Liverpool Service User Reference Forum – SURF

The Liverpool Service User Reference Forum (SURF) is a group of people who represent the views of people living with dementia, their carers and families across the city of Liverpool.

SURF is part of the DEEP network which brings together groups of people with dementia from across the UK, to support them in making change.

SURF's vision is to improve the quality of life for people living with dementia, their carers and families and also to make Liverpool a dementia-friendly city. It brings together people with dementia and carers, alongside a range of commissioners, dementia leads, and members of the Liverpool Dementia Action Alliance. The group is co-chaired by two people with experience of living with dementia. Everyone has the chance to put forward new issues they would like to address, and these are voted on to establish the priorities for future work.

SURF Liverpool was formed in 2014 out of Mersey Care NHS Foundation Trust's post diagnostic support courses and memory group, at the end of a year of dementia action in Liverpool. From the start, it had the strong support of the Mossley Hill Hospital and the Clinical Commissioning Group (CCG), which initially provided some funding for rooms and catering. SURF invites people from relevant organisations to the meetings, including Mersey Care NHS Foundation Trust, Alzheimer's Society, community organisations, theatres, and Liverpool City Council. SURF also found the support of the former Lord Mayor particularly helpful. After about a year the group decided to become an unincorporated society with its own constitution and bank account, which has given them more freedom as they are no longer bound by so many rules and regulations.

SURF members have been involved in a wide range of projects in the local community, including co-creating new services and information for people with dementia. Projects range from working with transport companies to improve services for people with dementia to collaborating in a photography exhibition at the Tate Liverpool. SURF members are currently taking part in the steering committee of a research project which is testing out a human rights based approach in care homes and hospitals. The project is running public engagement events to help people with dementia and families recognise that they have rights, and creating a resource to heighten awareness.

While the group has a significant programme of work, and are in much demand for their input, they also insist that being part of the group should be fun – and this is written into their constitution.

'The amount of experience that is within the group really gives us the right to be called experts by experience, and it's this experience that will help the service providers and the general public with the understanding to be able to ensure that my peers and carers still feel part of society. **SURF is a family united by dementia, a family that wants to share with others ways of improving the lives of our peers and their families**, we understand that no one can get through dementia alone.'

Tommy Dunne BEM – Service User

'SURF has allowed me to recognise that **I'm not alone and need not be alone into the future with the disease**. I am grateful through building up friendships with many other service users and their carers that we can help each other in overcoming obstacles that present themselves along the way in living happy and fulfilling lives.'

Roy Foden – SURF Chair

Case study 24: Tesco Dementia Friendly Checkout

The UK's first Dementia-friendly checkout till was opened at the Chester branch of Tesco following an initiative by local Dementia Nurse Specialist, Andy Tysoe.

The initiative came out of discussions with Tesco staff after they attended Andy's '#DementiaDO... the Basics,' NHS mandated dementia education sessions opened up to all, not just NHS staff.

A key aim of the training is to raise the profile of dementia as a cognitive disability and to encourage participants to recognise the duty to make reasonable adjustments to support the inclusion of people with dementia under the Equality Act 2010, just as they would for people with physical disabilities.

Andy reminds the businesses with which he works, of how support for people with physical disabilities has changed over time. At first supermarkets developed special 'wheelchair friendly' aisles where adjustments were made to one aisle, but now all checkouts are made so that people using wheelchairs can use them. He argues that we need to go on the same journey from being 'friendly' to full inclusion for people with cognitive disabilities.

In response to Andy's challenge, staff from the local Tesco branch agreed to make adaptations to the checkout process for people with dementia, by providing a special aisle where people could be offered additional support.

Following consultation with people with dementia, it was agreed that this should be called a Dementia Friendly Checkout and would include adaptations such as a large size reminder display of coins, a de-cluttered checkout environment, including leaflets about dementia and the support available, and special training for checkout operators, so that they can give more time to people with dementia, but more importantly, have an understanding of why additional support is needed.



'Staff from the local Tesco branch agreed to make adaptations to the checkout process for people with dementia, by **providing a special aisle where people could be offered additional support.**'

5.2. Dementia-friendly communities

The Dementia Friendly Communities programme was developed by the Alzheimer's Society in partnership with the Dementia Action Alliance to create a framework through which dementia-friendly communities could be developed across the UK.

A dementia-friendly community can be described as: 'A city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia-friendly community, people will be aware of and understand dementia, and people with dementia will feel included and involved and have choice and control over their day-to-day lives.'⁴⁷

The aim is to involve organisations and individuals across the community – from government and health boards, to the local corner shop and hairdresser – in sharing a responsibility for ensuring that people with dementia feel understood, valued and able to contribute to their community.

The guidance for dementia-friendly communities recognises a wide range of actions necessary for a community to become dementia-friendly.

A dementia-friendly community can be described as: 'A city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life.'



Dementia-friendly communities⁴⁸

Empowering people with dementia to have high aspirations, confidence and know they can contribute.



Shaping communities around the views of people with dementia and their carers.



Ensuring early diagnosis, personalised and integrated care is the norm.



Maintaining independence by delivering community-based solutions.



Appropriate transport.



Challenging stigma and building awareness.



Empowering people with dementia and recognising their contribution.



Businesses and services that respond to customers with dementia.



Ensuring that activities include people with dementia.



Easy to navigate physical environments.



Befrienders helping people with dementia engage in community life.

Evaluation of dementia-friendly programmes has shown that the process is helpful in broadening the range of organisations responding to the needs of people with dementia in a community.⁴⁹ Experience from the programme in York, for example, demonstrated that by bringing together private sector organisations with public sector bodies, there was potential for each to act as a catalyst to the others' activities.⁵⁰

Communities that meet seven basic foundation criteria can be formally registered as working towards dementia-friendly status. The criteria are:

- Ensuring the right local structure is in place to maintain a sustainable dementia-friendly community.
- Identifying a person or people to take responsibility for driving forward the work to support the community to become dementia-friendly and ensure that individuals, organisations and businesses are meeting their stated commitments.
- Having a plan to raise awareness about dementia in key organisations and businesses within the community that support people with dementia.
- Developing a strong voice for people with dementia living in the community, to give plans credibility and to ensure they focus on areas people with dementia feel are most important.
- Raising the profile of the work to increase reach and awareness to different groups in the community.
- Focusing plans on a number of key areas that have been identified locally.
- Having a plan or system to update the progress of the community after six months and one year.



Case study 25: Dementia Friendly York

York Dementia Action was established in 2013 as an alliance of local organisations which are together driving a vision for the City of York to become a dementia-friendly city, enabling people to live well within their communities. It brings together a range of organisations committed to becoming more dementia-friendly in their everyday service areas, and working together to raise awareness, involve people with dementia, share information and improve service quality.

The Alliance was developed out of a Joseph Rowntree Foundation action research project called 'Dementia Without Walls', which worked with people with dementia to understand what factors could help York become a dementia-friendly city and to work out how to overcome barriers to achieving this.

The starting point of the project was to make contact with existing forums, key individuals and organisations in the city that could put them in touch with people with dementia and their carers. Early discussions uncovered a need for a wide range of partners to be involved, including services across the public, statutory and commercial sectors. It was clear that it was not just health and social care services which were of significance to people with dementia, but rather people were concerned with being able to go about their everyday lives. Fortunately, the project uncovered examples of innovative ways of working with clients or customers who may have dementia, across a wide range of organisations. These included the British Transport Police who worked to support colleagues to become dementia champions, the City of York Council's Leisure Services, as well as local organisations, such as the Aroma cafe in Haxby and local taxi firm Fleetways which gave dementia awareness training to their drivers. Partners agreed that the Dementia-Friendly Communities agenda helped to give this activity a push.

Dementia Friendly York was evaluated over a ten-month period from February 2014. It was found that the approach taken of allowing 'many flowers to bloom' had encouraged a wide range of organisations to take steps to improve their work with people with dementia, but that there was a need for this to be developed into a more strategic approach and given support not just at leadership level, but at all levels throughout the city. York Dementia Action provides this ongoing strategic approach, enabling partners in all sectors to focus on the changes they need to make together to ensure that people with dementia are fully included in everyday life in York.

Conclusions and recommendations

As is clear from the case studies included in this report, there is already a significant amount of activity going on in communities around the UK which is supportive of the aspirations people with dementia told us they had for their later lives.

However, it is also clear that there is still too little evidence about the impact of interventions designed to support people with dementia on their wider wellbeing and quality of life. There are also too many initiatives which are confined to pockets of the country and which are therefore not widely available to people with dementia. As a result, people with dementia face a postcode lottery for support with living well.

As we move forward, it is vital that a more strategic approach is taken to ensuring that communities can put in place the systems, structures and supports people need to live well with dementia. It is also important that action is taken to broaden and deepen the evidence base around what works in supporting people with dementia to live well.

We make the following recommendations:

Recommendations for **people with dementia and their carers**

- Consider using this report to think about what ‘living well’ means to you – could any of the approaches featured here help you to **carry on doing the things you enjoy** most?
- This report is full of examples of interesting approaches which are already in place in some parts of this country. Could this report be helpful in **starting a conversation** with your local authority about what more is needed in your community to help you to live well?
- Consider taking a **rights-based approach** to your discussions with providers in your community. The new *Dementia Statements* set out a clear set of expectations – reminding people of these can help to ensure you are not disregarded or overlooked.

Recommendations for **service providers**

People involved in designing and delivering services should:

- **Build on the insights** in this report to start a discussion with the people with dementia you serve about the key areas of life that matter most to people, and to consider how they can help people to live well.
- Play your part in **building the evidence** around what works in promoting quality of life among people with dementia by collecting robust data on the impact of their services.

Recommendations for **local authorities**

Those involved with planning community responses to dementia, in both **local authorities and local health bodies**, should:

- Adopt **structural approaches** which promote living well with dementia, taking a rights-based approach to dementia to ensure that action taken recognises the equal citizenship of people with dementia, and consider working towards becoming a dementia-friendly community, as a means of drawing in wider partners to the work to support people living with dementia in the community.
- Develop **foundation services** offering people with dementia and their carers timely, accessible and person-centred support through which people can recognise and maximise their own strengths and capabilities, and can draw upon those of the wider community.
- Focus on ensuring **enabling services**, such as appropriate housing and care, transport and technology, are available in the community, through which people can more easily access the things that they value and which support their quality of life, and without which their ability to live well will be severely impaired.

Recommendations for **those involved in research**

All partners involved in supporting people with dementia to live well need to commit to **building the evidence** for the impact of their work, by measuring impact on **quality of life**.

Appendix 1: How this report was developed

This report was developed on the back of a project initiated by Age UK and developed in partnership with Innovations in Dementia, and the Mental Health Foundation. The aim was to identify what helps people live well with dementia, and what could be done in practice to support people to live well with dementia.

The project started with a thorough phase of engagement activities, led by Innovations in Dementia, and involving 54 people living with dementia and 12 carers. Our engagement activities included:

- Five group discussions with people with dementia who belong to groups that are part of the DEEP (Dementia Engagement and Empowerment Project) network.*
- One-to-one conversations (or conversations in very small groups) in day centres with ten people with more advanced dementia, a group whose voices often go unheard.
- Discussions at two separate day-long focus groups organised with two local Age UKs, involving both people living with dementia and their carers. Discussions with carers were sometimes held in parallel with those with dementia through a ‘buddying up’ approach with the help of volunteers.

We then moved on to discussing the findings from our engagement activities with experts and put together a list of potential approaches and solutions addressing the issues raised by people living with dementia and their carers when it comes to living well with dementia.

We then undertook a review of research and practice, through which we sought to test and refine our list of potential ‘promising approaches’ against academic and practical evidence (literature and case studies), to group these approaches and to build a framework of promising approaches.

Demographic breakdown of research participants

People with dementia (n54)		People with dementia (n54)	
Men	60 per cent	‘White British’	86 per cent
Women	40 per cent	‘White other’	10 per cent
50–59	4 per cent	‘Indian’	5 per cent
60–69	16 per cent	Carers (n12)	
70–79	64 per cent	Men	17 per cent
80	17 per cent	Women	83 per cent

* DEEP - The UK Network of Dementia Voices - groups that are members of the DEEP network are independent groups of people with dementia that come together to have a say locally and nationally in decisions that affect their lives. www.dementiavoices.org.uk

Appendix 2: Contact information for case studies

- 1 Post Diagnosis Support in Glasgow – Alzheimer Scotland**
Email: glasgowservices@alzscot.org
Website: www.alzscot.org
- 2 Dementia Wellbeing Coordination – Age UK Norfolk**
Email: information@ageuknorfolk.org.uk
- 3 Community Wellbeing Practices – Halton**
Tel: **020 7636 7228**
Email: sheinaz.stansfield1@nhs.net or katherine.andrews@napc.co.uk
Website: www.napc.co.uk
- 4 Age UK Camden – Counselling for People with Dementia**
Website: www.ageuk.org.uk/camden/services/counselling-service/
- 5 Cogs Clubs**
Email: jackie.tuppen@hotmail.co.uk
Website: www.cogsclub.org.uk
- 6 Living Together with Dementia**
Website: www.tavistockrelationships.org
- 7 Carer Information and Support Programme (CrISP) – Alzheimer’s Society**
Cathy Baldwin
Email: cbaldwin@alzheimers.org.uk
- 8 Circles of Support**
Email: madeline.cooper-ueki@ndti.org.uk
- 9 Standing Together**
Jolie Goodman
Email: jgoodman@mentalhealth.org.uk
- 10 BUDS Befriending Service**
Tel: **0121 565 3721**
Email: info@buds.co.uk
Website: www.buds.co.uk
- 11 Dementia Friendly Heathrow**
Email: special_assistance@heathrow.com
- 12 iSPACE – dementia friendly GP surgeries**
Email: katherine.barbour@wessexahsn.net
Website: www.wessexahsn.org.uk/ispace
- 13 Dementia Adventure**
Website: www.dementiaadventure.co.uk
- 14 The Butterfly Scheme**
Email: barbara@butterflyscheme.org.uk
Website: www.butterflyscheme.org.uk
- 15 Roller Mill – Day Opportunities from Age UK South Staffordshire**
Email: slyvia.dunn@ageuksouthstaffs.org.uk
Website: www.ageuk.org.uk/southstaffs
- 16 Sporting Memories**
Website: www.sportingmemoriesnetwork.com
- 17 Dance Well**
Email: claire@akademi.co.uk or info@akademi.co.uk
Website: www.akademi.co.uk/dance-well/
- 18 Thrive**
Tel: **0118 988 5688**
Email: info@thrive.org.uk
Website: www.thrive.org.uk
- 19 Shake Your Tail Feather**
Email: penny@jabadao.org
Website: www.jabadao.org
- 20 The Salford Way**
Tel: **0161 787 7795**
Email: lesmond.taylor@salfordcvs.org or admin@salfordcvs.co.uk
Website: www.salfordcvs.co.uk/salford-way-dementia-app-0
- 21 Blackburn with Darwen Connect**
Email: cheryl.sandford@blackburn.gov.uk
Website: www.bwdconnect.org.uk
- 22 Shared Lives for Dementia**
Tel: **01626 360170**
Email: enquiries@sharedlivessw.org.uk
Website: www.sharedlivessw.org.uk
- 23 SURF Liverpool**
Website: www.surfdementia.org
- 24 Tesco Dementia Friendly Checkout**
Website: www.dementiado.org
- 25 Dementia Friendly York**
Website: www.yorkcvs.org.uk/yorkdaa/

Appendix 3: Experts involved in consultations

Colin Angel

United Kingdom Homecare Association (UKHCA)

Hazel Boyd

Designability/Bath Institute of Medical Engineering

Sue Cliffe

Age UK Herne Bay

Clare Devine

Design Council

Nigel Franklin

Arts4Dementia

Iris Kapelouzou

UK Finance

Rebecca Langford

Money Advice Service

Louise Marks

Carers Trust

George McNamara

Alzheimer's Society

Steve Milton

Innovations in Dementia

Dr Jill Rasmussen

Royal College of General Practitioners (RCGP)

Audra Streeting

Age UK Herne Bay

Jane Vass

Age UK (Co-chair)

Annemarie Leach

Age UK (Co-Chair)

Su Ray

Age UK

Lea Renoux

Age UK

Vikram Saklani

Age UK

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