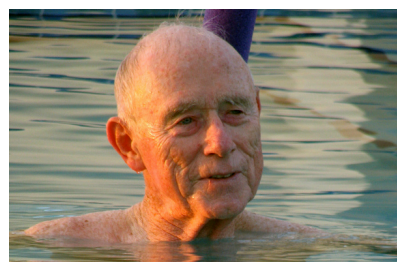
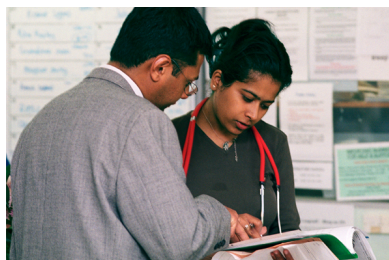




Transforming models of care for people living with dementia

Improving experiences and outcomes for people with dementia and their carers and families



Full report

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Foreword

Since the National Dementia Strategy for England was published in 2009, there has been a great deal of guidance on how to improve outcomes for people with dementia. It was pointed out by the National Audit Office that one of the risks in implementing the Strategy was that there was inadequate evidence for improved service design. This report 'Developing a new model of care for dementia' can help commissioners and providers transform services whilst recognising some of the challenges.

People affected by dementia were consulted widely in the making of this report. Here are some comments we recorded from a variety of stakeholders including people with dementia, which highlight and support the report's findings:

People want support to maintain their independence not necessarily services. They want to keep active and stay connected.

- Two people described themselves as keen golfers and gardeners. They now need a buddy to help them continue but cannot find one.
- People want to keep their identity; they want to maintain a role in their community.
- Services are currently developed around services not the person.
- The role of the carer, family and friends is very important as they often have the knowledge and expertise about the person's likes and dislikes. This often gets dismissed through consultation and assessment.
- How the diagnosis is given has a significant bearing on how people live their future lives.
- Although professionals don't like to talk about stages - people like to as it helps them conceptualise, appreciate and recognise the changing faces of dementia. It also helps people plan for the future!

The report has as its starting point what people with dementia need and want and this theme continues throughout looking at how services should be delivered using a positive, asset-based approach with the person at the centre. It outlines some current and past practice of an over-

medicalised deficit-based system which does/did not deliver the outcomes that people would want, and sets out five new ways to rethink models of care. The report also covers the key elements of the pathway to diagnosis, stigma, education and training through the eyes of people living with dementia, reflecting the huge amount of input from people living with dementia who want to contribute and have a voice about how they want to live.

'Models of Care' challenges services' and commissioners' assumptions about people's needs, and asks the question: Are we actively listening to the person and their families?

Through our stakeholder engagement, people have come up with some quick wins for organisations to tailor services - and the good news is that there are many which will not cost a lot of money. There is an important role for the voluntary sector in primary care and in memory services, signposting people to groups, organisations, information and support. We need to be better connected and work in partnership more to enable services to be delivered in the community, led by primary care. We do hope that the principles contained within this report are adopted.

Anne Rollings

Debbie Donnison

Alzheimer's Society

March 2012



Chapter 1: Introduction

Background

Dementia

Dementia is a term used to describe a range of neurological conditions that affect memory, cognitive and other functions. The most common of the dementias is Alzheimer's Disease (AD) which accounts for more than 62% of dementia in England.¹

Vascular dementia – caused by problems with the supply of oxygen to the brain following a stroke, for example - is the next most common form of dementia, followed by dementia with Lewy Bodies, which shares symptoms with Parkinson's Disease (Parkinson's Dementia may be a separate condition). Fronto-temporal dementia affects 2% of people with dementia in England and often affects those under 65.

The Alzheimer's Society stressed the importance of differentiating between the dementias because their presentation can be quite different and people's needs can differ significantly². They note, for instance, that people suffering from vascular dementia may not initially show memory problems, whilst those with fronto-temporal dementia might more obviously show aggressive behaviour. Thus there will be differences in where people show up in the care pathway and what is needed at each point.

There are increasing numbers of people with dementia in the UK. The National Audit Office (NAO) estimated that there are currently 560,000 people with dementia living in England, at a cost to the NHS and social care of £3.3bn a year.³ Two thirds of those people live at home, and around

¹ National Audit Office (2007) *Improving services and support for people with dementia*. London, National Audit Office.

² National Institute for Health and Clinical Excellence (2006) *Dementia Consultation Table May-July 2006*. London, NICE.

³ Ibid 1.

476,000 people act as unpaid carers to people with dementia. A report for the Alzheimer's Society recently suggested that by 2020 there will be 750,000 people with dementia living in England.⁴

Risk increases with age, but there is a significant group of people with dementia under the age of 65. The NAO reported around 12,000 people in this group in England, although they point out that people under 65 are even more likely to be under-diagnosed than people over 65.

National policy developments

A number of key policy initiatives are currently in place around dementia. Living Well with Dementia: A National Dementia Strategy was published in 2008 (Department of Health), outlining the agenda for change. The strategy covers all aspects of care from a good quality early diagnosis through to living well with dementia and end of life care. With 17 key objectives, it demands a transformation in service provision for people with dementia. Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy (Department of Health, 2010) presents the Department of Health's revised, outcomes focused implementation plan for the national Strategy. In 2011 (Department of Health), the NHS Outcomes Framework reflects the needs of people with long term conditions, and sets the intention to develop an indicator on enhancing the quality of life for people living with dementia.⁵

Other important policy developments, going as far back as 2001, although not specifically about dementia, are also relevant. For example:

- End of Life Care Strategy: promoting high quality care for all adults at the end of life (Department of Health, 2008).
- Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own (Department of Health, 2008).
- Putting People First: A shared vision and commitment to the transformation of adult social care (Government Concordat, 2007).

⁴ Kings College London and London School of Economics (2007) [Dementia UK. A report to the Alzheimer's society on the prevalence and economic costs of dementia in the UK](#). London, Alzheimer's Society.

⁵ Department of Health (2011). *NHS Outcomes Framework 2012-2013*. Department of Health, London.

- Supporting People with Long Term Conditions: An NHS and social care model to support local innovation and integration (Department of Health, 2005).
- The National Service Framework for Older People (Department of Health, 2001).

The National Institute for Health and Clinical Excellence, and the Social Care Institute for Excellence have also published several useful pieces of relevant guidance including best practice in dementia, guidance on memory assessment services and, most recently, a set of quality standards⁶.

This report

Despite the plethora of policy and guidance, the National Audit Office recently outlined a number of risks in the development of improved quality outcomes for people with dementia⁷. One set of key risks focused on inadequate evidence for improved service design. Even with examples of positive practice, local commissioners and providers need more guidance to develop best services and translate into everyday practice the much needed transformation demanded by the national strategy. In July 2011, the Department of Health published a Dementia Commissioning Pack which providing a range of guidance and tools for commissioners.⁸

This document reports on a project commissioned by the South West Dementia Partnership. The aim of the project has been to support improvements in the experience of, and outcomes for people living with dementia, including carers and families, through the development of a model of care that can help commissioners and providers redesign and transform services.

⁶ For example, see National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) (2006) *Clinical guideline 42 'Dementia: Supporting people with dementia and their carers in health and social care'*. London, NICE / SCIE. NICE (2010) *Dementia Quality Standard*. London, NICE.

⁷ National Audit Office (2010) *Improving Dementia Services in England – an Interim Report*. London, National Audit Office.

⁸ Department of Health (2011) *Dementia Commissioning Pack*. Department of Health, London. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_127381.

This report offers a new model of care for dementia, updating existing models and approaches. It is based on:

- talking to commissioners, providers, staff and other experts in the South West of England
- listening to local people with dementia, and their carers/families;
- visiting local services
- non-participant observation/shadowing practitioners
- taking into account evidence of good practice, policy and relevant literature.

Please note: the findings from this project have informed the recent Department of Health Dementia Commissioning Pack and constitute the basis for the Pack's Commissioning Framework.⁹



⁹ Ibid 8.

Models of care

What is a model of care?

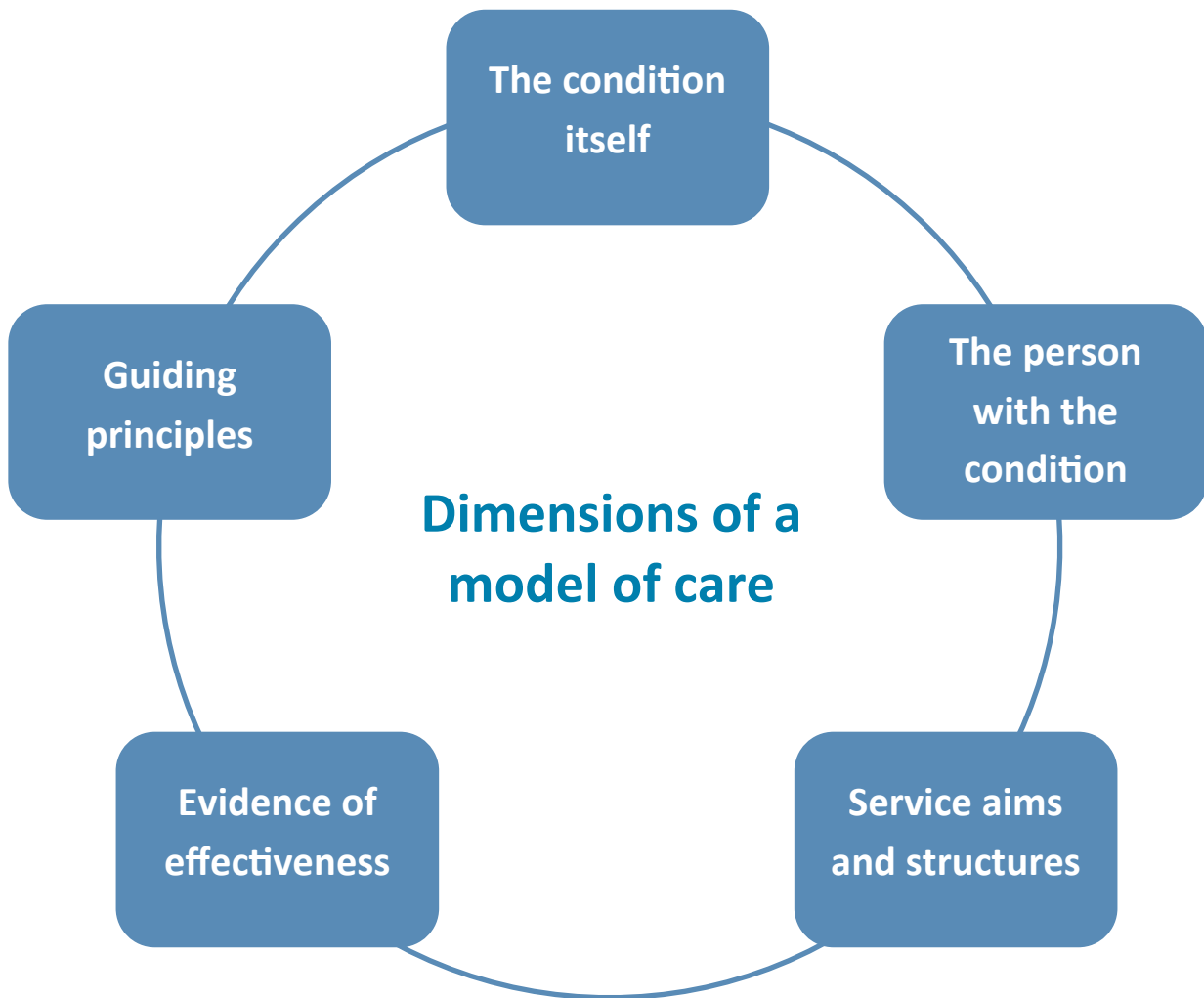
The term 'model of care' is used in a number of ways, often without definition or explanation.

Here the term 'model of care' is being used to describe an overarching design for the provision of a service, based on a number of dimensions as shown in Figure 1 on page 12 ¹⁰:

- theoretical concepts about the condition or disorder and the person living with it
 - the nature of a condition or disorder – for example, what is its course, what effects does it have, is it debilitating, does it affect mind and/or body?
 - the person living with that disorder (in this case, dementia) – for example, are they fundamentally changed by the disorder, do we conceptualise them as individuals or part of a system, do they have capacity to make decisions?
- service aims and type of provision – for example should it provide treatment, advice, hospital or home-based care?
- evidence or consensus around the effectiveness of treatment and interventions – for example what helps to prevent and manage problematic behaviours?
- guiding principles and ethical considerations that underpin the model.

¹⁰ After Davidson, P. et al (2006) Beyond the rhetoric: What do we mean by a model of care? *Australian Journal of Advanced Nursing*, 23, 3, 47-55

Figure 2: Dimensions of a model of care



These dimensions are explored in relation to dementia throughout this paper.

Why develop a new model of care for dementia?

Policy changes

The National Dementia Strategy, *Living Well with Dementia* (Department of Health, 2009)¹¹, heralded a set of national policy initiatives focusing on dementia. For the first time, policy makers described outcomes and services that people with dementia and their carers should be able to access to improve their experiences. But all the recent dementia policy initiatives have together highlighted some common themes for improvement:

- better access to services
- services to include health, social care and other services such as telecare and housing
- dementia services should not be based on age
- service integration
- early diagnosis and treatment
- help and support for carers/families
- support independent living
- a whole systems, or 'joined up' approach to commissioning

Two years after the publication of the National Dementia Strategy, improvements have been implemented – notably in the provision of early diagnosis and (medical) treatment through the commissioning and development of memory services across the country. However, reports continue to indicate that many of the other themes – including integrated services, a whole systems approach to commissioning, and support for independent living – have yet to be addressed.

Improve clarity of purpose

In practice, models of care are not implemented in a 'pure' way but are likely to incorporate elements of a mixture of models; furthermore, the model might be implicit rather than explicit.

The problem with not being explicit about a model, or a variety of models, is that it can lead to a lack of clarity about the purpose, aims and necessary features of a service. Commissioners might

¹¹ Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. London, Department of Health.

hear conflicting advice about how to specify the service, for example, and practitioners might be unsure about their roles. Furthermore there is evidence to suggest that practitioners, commissioners and other stakeholders frequently use a values-based model in their language but in practice there is much ambiguity about what this means and how it is translated into practice.¹²

Instead, it has been argued that having a clearly defined and articulated model of care can help ensure that:

- all those involved have the same understanding of what they are trying to achieve
- all are working towards a common set of goals,
- outcomes and performance can more easily be measured ¹³.

Case study: Lack of clarity as a barrier to implementation of person-centred care into ¹⁴

In a wide-ranging comprehensive study, researchers looked at the application of models of care for dementia, with particular emphasis on respite and person-centred care. They found that the term person-centred care was unfamiliar to people with dementia and carers, and was not clearly understood by frontline staff. Staff knew of the term and felt an imperative to deliver person-centred care, but many staff did not know what it entailed in practice. Some staff thought that anything provided on a one-to-one basis or in a small group constituted person-centred care. This lack of clarity resulted in a barrier to implementation of person-centred care and what the researchers described as unacceptable variation in quality (Bamford et al, 2009).

¹² See for example, Waine, B. et al (2005) *Developing social care values and principles*. SCIE: London

¹³ Ibid 12.

¹⁴ Bamford, C. et al (2009) *Person- and carer-centred respite care for people with dementia: developing methods for evaluating the effectiveness of different models. Report for the National Institute for Health Research Service Delivery & Organisation*. London, HMSO.

Improved quality of care and outcomes

Despite improvements in recent years, quality and outcomes are still falling behind increasingly high expectations of the public and people living with dementia. Evidence suggests that applying a systematic approach to service models and delivery might contribute to better outcomes.

Case study: randomised control trial of a model-based approach vs standard care¹⁵

A trial compared 'usual care' with the application of a systematic guideline-based, comprehensive dementia care management intervention, based on a long-term ("chronic") care model. The care management staff had clear assessment and planning protocols and intervention tools, and engaged with carers as well as multi-agency colleagues. At follow-up, there was significantly better adherence to dementia guidelines for the people in the care management group and their quality of life was significantly better. Improvements were noted in all the domains measured, including safety. Large process improvements – such as higher carer contact with community agencies and greater social support – were also found (Vickrey et al, 2006).

Better use of resources through integrated care, reduced inpatient stays and preventative approaches

At a time when resources for health and social care are reducing, and in the face of increasing demand, diligent use of resources is more necessary than ever. The National Audit Office identified the lack of joined-up health and social care planning and delivery as a barrier to improvements in dementia, whilst noting the increasing costs due to increasing numbers of people with dementia in the population¹⁶.

Costs are mostly attributed to residential costs, most of which are funded through health and social care funding. If a model of care is developed that is preventative, joined up and can help

¹⁵ Vickrey, B. G. et al (2006) The effect of a disease management intervention on quality and outcomes in dementia care: a randomised controlled trial. *Annals of Internal Medicine*. 145,713-726.

¹⁶ Ibid 1.

keep people at home as long as possible, not only is this generally preferred (as long as real support is in place) but it is likely to reduce the cost of care through reduced use of care homes and inpatient services and reducing the number of unplanned admissions.¹⁷

It is widely accepted that preventative, joined-up approaches to health and social care should help improve efficiency, which in turn will achieve cost savings. Given the high costs associated with caring for patients in care home settings, investing in services that allow people to remain in the community could yield significant 'downstream' savings. Commissioning Support for London (CSL) argues that: 'on a purely financial basis and just concentrating on the NHS component, the investment boils down to: investing "upstream" to yield savings "downstream" in two key areas: reduced use of care homes and a reduction in overall healthcare costs by for example reducing the number of emergency admissions to acute hospitals' ¹⁸.

Implications for a refreshed model of care for dementia

Taken together it could be argued that these issues require a complete rethink around commissioning and providing services for people living with dementia. Indeed, one of the findings of this project is that simply inserting new service elements in line with policy does not automatically lead to the hoped-for improvements. For example, memory services are now in place in most, if not all, communities. They appear to be leading to increased rates of diagnosis and prescription of anti-dementia medication. However, they are not always joined up with other services and some people living with dementia report feeling abandoned with the diagnosis without any help until the condition becomes much worse.

This experience was recently reinforced by Clare Gerada, Chair of the Royal College of GPs, who responded positively to the Department of Health's national awareness campaign, but also warned:

¹⁷ Healthcare for London (2009) *Dementia Services Guide: Appendix 6*, p7. London, NHS London.

¹⁸ Ibid 17.

“We have to make sure we're not simply extending the time someone lives with a dementia diagnosis, without giving them the support they need.”¹⁹

Dr Gerada went on to advocate a range of services available to primary care to support people living with dementia to lead healthy, independent and productive lives for as long as possible.

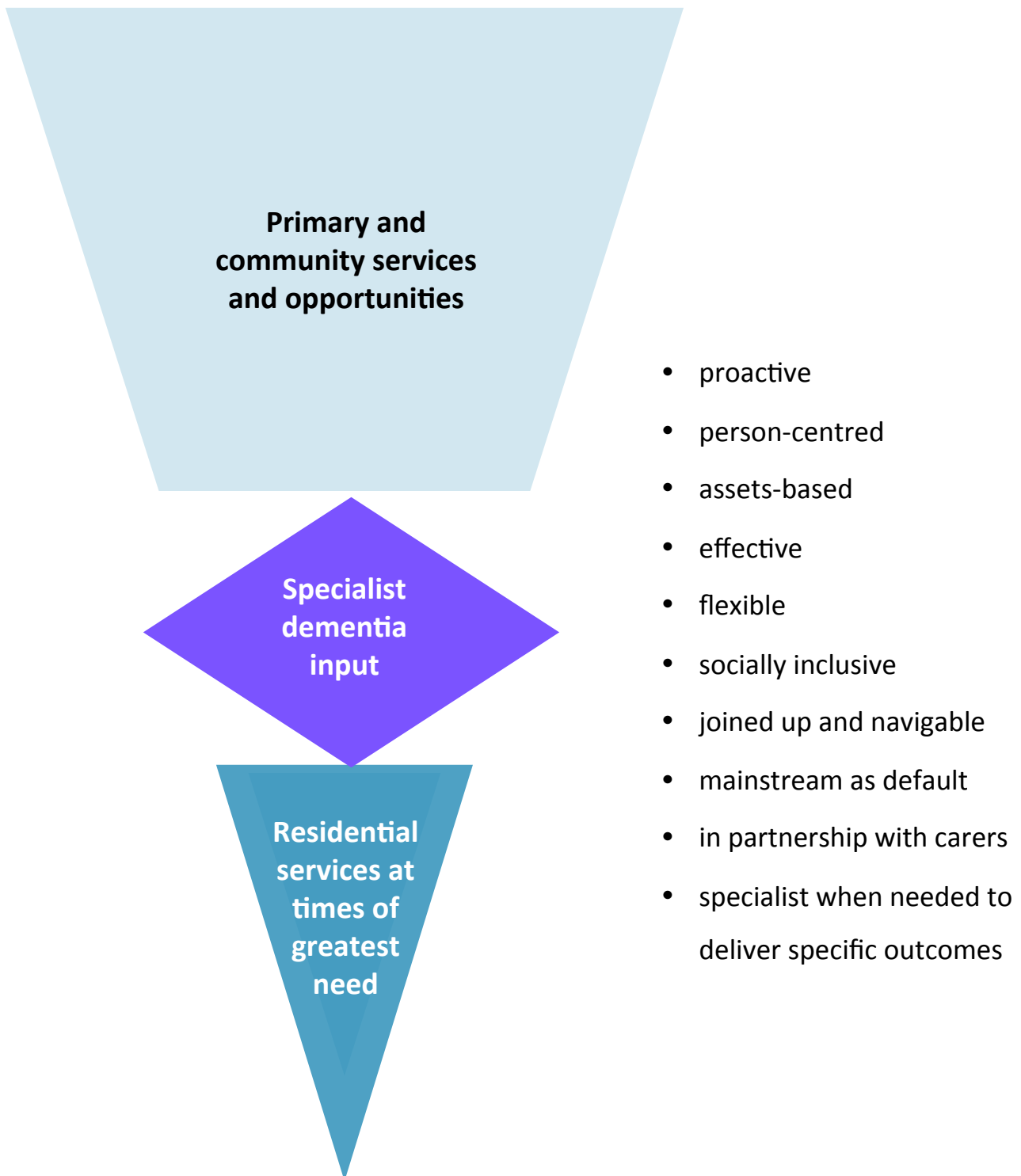
Implications for a refreshed model of care for dementia, then, include:

- the whole model needs to be rethought – not just one or two elements
- a range of community- based, mainstream services, that are easily navigable by those who need them, should be the default
- interventions and support need to be early, proactive and effective
- services need to be person-centred
- specialist services, including inpatient care, need to be limited to times of greatest need and have a clear focus and remit
- carers are essential partners in delivering services, and need and have a right to support.

Figure 2 on page 18 shows an initial service framework for a revised model, based on these implications. It reflects the need for mainstream services, primarily based in community settings, with specialist input where necessary.

¹⁹ Hughes, J. (07 November 11) Look out for dementia warning signs, families urged. *BBC News*. <http://www.bbc.co.uk/news/mobile/health-15581986>

Figure 2: An initial service framework for a revised model of dementia care



Chapter 2: The experiences and views of people living with dementia in the South West ²⁰

In this report, the phrase ‘people living with dementia’ refers to people who have a dementia and their families, friends and/or carers. A number of clear themes surfaced from listening to people living with dementia in the South West of England, and were used to inform the emerging model of care. These themes can be split into three areas, as shown in Figure 3:

- essentials for people with dementia and their families/carers
- what services are needed
- how services should work.

These themes constitute some of the fundamental building blocks for the model that follows.

Figure 3: Consistent themes from people living with dementia

Essentials for people living with dementia	Services people say they need	How services should work
<ul style="list-style-type: none"> • Recognition of the person • Inclusion - social, age, minority groups • Managing stigma • Normalising • Family involvement • Early diagnosis with sensitivity • Dignity and respect 	<ul style="list-style-type: none"> • A range of services aimed at keeping people at home • Working with early diagnosis and help early on • Information • Out of hours support • Education and training • Crisis prevention and resolution • Voluntary sector 	<ul style="list-style-type: none"> • Knowledgeable • Proactively anticipating needs and concerns, thinking ahead • Flexibly and informally • Locally • With compassion, humanity and hope • Through building relationships • Valuing contribution of person with dementia and their carers / families

²⁰ When quoting the experiences and voices of people with dementia, names and some details have been changed to ensure anonymity

Essentials for people living with dementia

Recognition of the person and preserving identity

People living with dementia were overwhelmingly keen to stress that their value as people – their personhood – should be recognised and respected. People wanted to talk about their lives, jobs and positions in society, relationships and so on. The flipside of this sentiment is a constant fear that the dementia label could dominate everything in people’s dealings with community, organisations and services. As a recent literature review, tellingly entitled ‘My Name is Not Dementia’, has pointed out, some of this fear could be described as self-stigma²¹. The authors noted that in one study, participants associated a diagnosis of Alzheimer’s Disease with devaluation, mistreatment, social exclusion and loss of friends.

A number of approaches have been developed in the South West to help to address this fear. These included an information pack about the person with dementia, being designed by a carers’ group and aimed at supporting personhood in general hospital. Another was the ‘This is Me’ personal information leaflet²².

‘This is Me’ – a brief profile of a person with dementia to enhance experience in hospital

‘This is me’ describes a short personal profile, aimed at enabling hospital staff to understand better the needs of a person with dementia by seeing him or her as an individual. It gives a snapshot of the person with dementia in the form of a brief leaflet with sections to be completed by the person or their carer with help from the person with dementia. It also includes space for needs, preferences, likes and dislikes, habits and interests.

‘This is me’ was created by the Alzheimer’s Society, supported by the Royal College of Nursing (see www.alzheimers.org.uk).

²¹ Alzheimer’s Society (2010) *My name is not dementia*. London, Alzheimer’s Society. http://alzheimers.org.uk/site/scripts/document_pdf.php?documentID=1339

²² Alzheimer’s Society (2010) *This is me*. London, Alzheimer’s Society. http://alzheimers.org.uk/site/scripts/download_info.php?fileID=849

Social inclusion, managing stigma and normalising

Closely linked to recognition as a person, were the notions of social inclusion and dealing with stigma – both extremely important to people who contributed to this report. People with dementia, and carers, wanted very much to continue to be part of, and to contribute to, their social networks and communities, but feared being excluded from them and feared the stigma attached to dementia.

Fighting to contribute to her neighbourhood: one woman's example

Anna is in her 60s. She was diagnosed with dementia 18 months before we met. Anna is a member of the committee of her local community cinema project. She proposed visiting local schools to find out what films young people wanted to see and how much they would pay to see them. But the committee did not accept her idea, and she felt she could be easily dismissed because of her condition. She feels she is tolerated on the committee, rather than seen as a valuable member with worthwhile ideas.

One important social issue that arose for people with dementia was the question of driving licences – a particular concern for those living in rural or semi-rural areas in the South West. Losing a driving licence felt like losing an aspect of personal identity, independence, social identity and status. Losing a licence felt, in itself, stigmatising. On a very practical level, it severely compromised people's social inclusion by affecting their ability to engage with others, participate in community and social life, attend services, go shopping, and many other activities. Several people reported that they had been given erroneous information about having to give up their driving licence automatically following a diagnosis of dementia. However, the DVLA rules are that they must be notified of the diagnosis. A decision regarding fitness to drive will usually be based on medical reports. In early dementia, a driving licence may be issued subject to annual review; a formal driving assessment may be necessary.²³

²³ Subject to change. Rules at the time of writing based on DVLA (2011) *For Medical Practitioners: At a Glance Guide to the current medical standards of fitness to drive*. Swansea, DVLA.

The problem of communities' lack of awareness of dementia was frequently raised; it was recognised, too, that doctors, nurses, pharmacists, social workers and others working in public services were also members of communities, and might similarly lack awareness and knowledge of dementia. GPs were frequently mentioned in this regard, with many stories of GPs dismissing signs and symptoms of dementia as 'old age'. People with dementia themselves also might know little about the condition; this could prevent them from accessing early support.

Many people living with dementia preferred others not to know about their condition because of their fear of stigma. However, a few people with early dementia said that they had found it helpful to disclose their condition, for example in shops or on buses. This could help them, for example, to undertake transactions effectively or get home safely. They felt it might also help with raising awareness generally and that it was important to show that even with dementia, people could go about their business, enjoy life and do ordinary things.

Taken together, these themes of personhood and social inclusion underpin the very important notion of identity – personal, psychological and social identity. Actual or feared sense of loss of identity is therefore of critical importance to understanding the position of people living with dementia.

Family involvement

Some families were concerned that family members were either uninformed about dementia or unprepared to believe that their relative had the condition.

“My sister-in-law rings up and says, how’s Andrew? I think, how do you think he is? He’s not going to get better. But she’s in denial. I just find it insulting.”

Rita, whose husband has dementia

Because of this, some people found it hard to get the practical and emotional support and involvement they needed from family members, especially from siblings and their own children.

This in turn led to increased feelings of isolation. Families received little help with this problem from services, with no examples found of routine wider family involvement in care planning, interventions, or, for example, family information, advice and support as part of carers' courses. Yet, there is scope here for services to co-work with families to, for example, promote the social inclusion of people living with dementia, help with practical support and provide respite for primary carers. All of this might improve quality of life and help prevent breakdown in community living for the person with dementia and the carer, with its commensurate high emotional and financial costs.

Getting a diagnosis

The issue of getting a diagnosis of dementia has been raised repeatedly in commentaries and policy documents, yet it continues to be a major concern for people living with dementia. Policy tends to focus on diagnosis rates. However, whilst achieving a clear diagnosis is a critical issue for people living with dementia as it represents a 'ticket' into potentially receiving treatment and services, more complex issues about getting a diagnosis were raised by people during this project:

GP response

"The first stumbling block was the GP. I think he was just relaxing into retirement."

Anita, whose husband has early-onset Alzheimer's

Some people had helpful responses from GPs when they first voiced their concerns about memory problems, but many still had to deal with a lack of understanding or a failure to be taken seriously. Responses such as "It's just old age" were commonly reported. One person described a two-year set of encounters with the GP at the end of which they were told that all avenues were exhausted. It was only after seeing a second, and then a third GP, that they were offered a referral for a scan and the diagnosis was made.

When GPs knew patients well, it was sometimes more difficult because there was a risk that the GP would not refer a person to a memory service out of a misguided concern that the diagnosis of dementia would be too difficult to handle.

Receiving the diagnosis

When receiving a diagnosis, either from the GP or from a memory clinic, some people experienced apparently unnecessary hurdles, a lack of sensitivity and an absence of hope in the delivery of the news. One person said the psychiatrist could not look at her when he gave her the diagnosis. Another described it as like being given a death sentence. Yet another felt dismissed, and was told he would have to hand in his driving licence. Many people spoke of large batteries of tests that they experienced as stressful, humiliating and sometimes superfluous, especially in situations where the person's dementia was fairly obvious. The process was described by one person as unnecessarily "complex and opaque".

On the other hand some people had experienced a positive approach from their doctor, where they were asked in advance whether they would like to know their diagnosis.

"He asked me if I wanted to know. I said, hit me with it."

Lionel, who has Alzheimer's

After the diagnosis

As the National Dementia Strategy has started to have an impact, many people are being referred to memory services and getting a diagnosis, almost certainly earlier than in the past. Most, if not all, those who contributed to this project had been prescribed anti-dementia medication early on, which they and their families found very helpful. As a result of diagnosis coming earlier, and possibly of medication, many people's cognitive processes continued to be relatively intact and they were able fully to understand the diagnosis and its implications. One man had been diagnosed more than two years before contributing to the project, for example, and was happy to speak in public about his condition.

But the problem for many was that there appeared to be very little help with managing the diagnosis, clarity about next steps, or knowledge about future support available for this group of people. One person described early diagnosis as leaving her husband "*standing on the edge of a precipice.*"

Another said:

“We were given the diagnosis and that was it. After that no-one did anything. The GP didn’t even refer to it again.”

Jack, husband of a person with dementia.

Planning for the future

Once diagnosed, or even before, people living with dementia felt that they really needed help, information and support to plan for the future. Some of their biggest and most persistent worries related to not knowing what would happen next, what to hope for from services, how they might cope with the condition as it progressed, and so on. They might indeed have received information in the form of leaflets or (in a few areas) a directory of services and these were warmly welcomed. But they often had questions that felt very personal to them and were not routinely addressed, especially in written literature.

Questions and worries about the future included:

- a petite woman was worried that she would not be able physically to manage helping her tall, well-built husband if he became incontinent or unable to wash himself
- another woman was worried about sex with her husband as his condition progressed (“No-one talks about it”)
- what would happen if the family needed help out of hours
- what would happen if the main carer became ill or needed an operation (including hospitalisation and after discharge)
- how to cope with changing finances
- sleep management
- what to do if a partner became aggressive
- several people were worried about how to find out about the quality of local residential care options. Some had been given lists of local care homes but had no idea how to differentiate between them, could not visit them all, and were given no help to make decisions.

Importantly, as well as improving life with dementia and ameliorating anxieties, it is clear that addressing many of the questions raised could help prevent crises and costly admission to hospital or residential homes. For example, many concerns were about coping at home with challenging situations and behaviour, which if left to escalate, could lead to failure to continue to manage at home. Yet few people found themselves able to access this kind of ‘thinking ahead’ on the part of services. Where they did, they found it inestimably helpful:

“If I’m worried, I just ring [name of CMHT team leader] and she’ll give me advice. When she’s talking to you, you feel you’re special.”

Renee, married to a person with dementia.

Dignity and respect

A great concern for all was the issue of being treated with dignity and respect at all stages of the dementia journey, especially as the condition progressed and at later stages. ‘Dignity and respect’ is such a well-rehearsed phrase that it has almost become a cliché. However it remains of vital importance to people living with dementia and there is a consistent fear that dignity and respect will not be upheld, partly fuelled by some poor experiences. These included behaviours on the part of services that demonstrated lack of respect, such as not turning up when expected (even when a carer had made a specific journey to, say, a parent’s home for the scheduled visit), failing to follow up on requests for support, lack of courtesy and not providing basic information.

Jim, who has dementia, was admitted to general hospital. When Angela, his wife, went to visit him, he had been moved to another ward but nobody had told her. It led to Jim becoming very disoriented and upset. Angela also became distressed because she did not know what had happened to Jim. Angela felt strongly that she and Jim had been treated with a lack of respect.

Alisha received a letter from her GP practice, informing her that, as a carer, she was entitled to a flu jab and she should make an appointment. She duly attended the appointment. The practice nurse challenged Alisha about why she was there, because she was under 65 and did not have an eligible physical condition. Alisha explained about the letter but the practice nurse did not appear to believe her. The nurse left Alisha waiting while she checked. Alisha felt as though she were being accused of asking for something she was not entitled to.

People living with dementia were very worried about dignity and respect in care homes, hospital and other residential settings, when the dementia might be well advanced. The author witnessed some examples of lack of dignity in residential settings, such as 'day rooms' where people in later stages of dementia were seated around the edge of the room without the possibility of proper social interaction and staff talking to each other over a person with dementia. It should be noted that these incidents contrasted sharply with the vast majority of the author's encounters in residential and inpatient settings; however, that does not detract from the real fear and anxiety about this issue for people living with dementia.



Services people say they need

A range of services aimed at keeping people at home

What people say they want from services is rarely medical or psychiatric but practical help, emotional support, help to stay linked in to their community and information. People wanted help early on, at the beginning of the dementia journey, to prepare them to manage and live well with dementia.

However, people living with dementia found that the early help offered by services (usually memory services) tended to focus on the following main elements:

- achieving a diagnosis
- provision and monitoring of anti-dementia medication
- a short education group for carers
- more or less detailed information about dementia, and sometimes about services.

There were mixed feelings about these aspects of the service among the people who contributed to this project. They frequently recognised the value of the diagnosis and of anti-dementia medication, and a few had positive experiences of training for carers – particularly valuing opportunities to meet other carers and to hear information about dementia. But some found the courses patronising, irrelevant and not tailored to their needs and experience. More importantly, many people felt the lack of any ongoing practical help once the carers' group ended, experiencing only very infrequent medication monitoring. This could carry on for months or years before people's needs became severe enough for a more intensive service, or there was a crisis, precipitating more interventions. Practitioners themselves also recognised this gap and sometimes felt frustrated by it.

“What happens early on? We’re exploring it. If someone’s not ‘bad enough’ for our service, it’s usually just information. Informally, some of us put a date in the diary to check up on people.”

Community Mental Health Team practitioner

Practical help, respite and support out of hours.

Practical support was considered to be an essential element in helping people to keep as well and safe as possible at home. However, people who contributed to this project had little experience - or even knew about - practical support, such as home care, home-sitting, or assistive technology. Shopping, housework, physical care needs, short periods of time out, help with managing at night, getting to appointments, opportunities to meet and socialise with others, were all areas that carers needed support with, either now or lined up for the future as and when needs might arise. Many carers would have very much welcomed short spells of respite provided through practical support services, but felt that the only respite they received was through attending local non-statutory groups (see below). This was not the case in all parts of the South West; for example, in some areas there were day facilities offering opportunities for people with dementia to attend one or more days a week, and this was experienced as helpful respite for some although not without concerns about how their loved one felt about the day facility.

Several key issues arose within this category.

Firstly, several carers said they had not received any input at all from social care. When asked about a carer's assessment, few remembered receiving one or thought they were entitled to anything. This experience was validated by some practitioners, who had a view that local people were often "too affluent" to be able to benefit from a carer's assessment so there was no point in carrying one out.

Secondly, there appeared to be confusion among statutory services and families alike about entitlements. Few people had used direct payments, and some people found that they were turned down for Attendance Allowance because, they were led to understand, dementia was not an eligible condition (as it "is not a physical illness"). Some people had experienced a specialist team (finance and benefits team) whose role was to help people claim benefits they were entitled to, helping with completion of forms and enquiries but this service had apparently been discontinued.

Further, there was a noticeable theme among women married to people with dementia, that their husbands with dementia would not "let them out of their sight" or would "not accept anyone else in the house". This meant that they felt they could not seek practical help and/or could not leave

their husbands in the care of anyone else for even short spells of respite. Beliefs like this were strongly held and these wives felt under intense pressure. Yet talking about this to skilled practitioners, it was clear that such beliefs might be open to gentle, careful challenge to the benefit of both partners; this could be achieved in the context of practitioners building relationships with people living with dementia at an early stage. Where practitioners and people living with dementia did have such relationships, carers were able to accept interventions, and consequently were able to get some practical help.

Finally, people felt there was a distinct lack of respite facilities in some (though not all) parts of the South West. When people did get respite, this was usually at a point where they had become exhausted (they were often reluctant to ask for help at all); therefore, respite signalled a stepping stone towards the person with dementia leaving the family home and moving into residential settings. Thus 'respite' was no longer 'respite' but signified the end of the person's time at the family home.

Information, education and training

"We desperately need information."

Carer representative

The need for information, education and training were frequently mentioned as important by people living with dementia. They wanted information about the condition, services they were entitled to, local and national resources. They wanted to know, too, that this information could be made available to people in the community, including professionals, to help manage stigma.

"I want someone in every Tesco's, wearing a badge that says, 'Dementia? I can help you'."

Maria, whose husband Arnie, has dementia.

Moreover, people were clear that they wanted information in a variety of formats: leaflets, from peers through talking, from GPs, websites, and on video or television. They also wanted recognition of the need to be able to access information at their own pace.

The corollary of all this was that many people felt ignorant about dementia, and especially about possible services and opportunities available to help carers and people with dementia. They often did not know where to turn for advice or came upon it by accident. Where information was made available by local specialist services or groups – such as the comprehensive service directories provided in some parts of the South West or Carers' Days – this was highly valued.

"I don't know what's possible, so I don't know what questions to ask."

Carer of a person with dementia

Many carers, and some people with dementia, had experienced short 'courses' following a diagnosis of dementia or memory problems, usually run through the local memory service. These were usually well received though some people did find some aspects of the courses patronising (for example, about nutrition). By contrast, information about dementia, service availability and help with communication were all areas that they welcomed. They particularly liked meeting other people going through similar experiences and learning and getting support from each other. There was a question about how many men participated in these courses, and whether they were able to access support in the same way as the women. There was also awareness among providers that people from minority groups, including Black and minority ethnic communities and lesbian and gay communities, might not be accessing courses:

"I suppose it might be difficult. I ask [carers] to say who they are and who they are supporting. I suppose, yes, it might be difficult to say 'I'm supporting my partner' if you're gay."

Carers' support worker

None of the carers contributing to this project had specific experience of sustained training, to enable them to think differently about dementia, anticipate, cope with, intervene and handle difficult behaviour, or to support others to understand dementia better. A few carers were interested in undertaking something like this, at a more advanced level than some of the memory service courses that were on offer.

Informal social and support groups

People living with dementia accessed a variety of support and social groups that they valued enormously. These groups were set up, facilitated and managed by non-statutory sector organisations (or sometimes, by individuals), notably the Alzheimer's Society. Dementia or Memory Cafes and Singing for the Brain sessions were generally well-attended and clearly enjoyed by people living with dementia at various earlier stages of the dementia journey. Tips, information and ideas are exchanged as well as valuable social contact. People would often travel distances to attend, in testament to the value placed on these groups. It was possible to see the benefits physically and emotionally as people's facial expressions changed and they became more animated during the course of the sessions. A noticeable dimension of these groups, however, was their social uniformity: no people from minority ethnic groups were present at any of the meetings attended by the author, all the refreshments were traditionally English, and the settings were conventional. There were also no participants younger than around 70 years old. A separate support group for younger people living with dementia was passionately supported, although there was a risk to the funding of this group.



Health and social care staff did not appear regularly to attend many of these informal gatherings. Where they did, it was useful for people living with dementia because they could access services easily and informally, and keep contact going, and also useful for practitioners who were able to monitor the health and wellbeing of people in the early stages of dementia.

There appeared to be fewer opportunities like this available to people at later stages of dementia, although where there was social support on offer (for example, a voluntary sector organisation offering social events to people living in care homes), this was very popular.

How services should be delivered

“We are blessed with our mental health team. Kind, thoughtful, helpful. They make us smile. They approach things with a bit of fun.”

Edward, husband of Alice who has dementia

“[Name] is an angel. We call her our Guardian Angel. [Name] and her team are our salvation.”

Margaret, wife of George who has dementia.

People living with dementia were as interested in how services were delivered, as much as what was delivered. Attitudes and values were really important to them. They wanted practitioners who work with compassion, humanity and could offer hope. These are practitioners who see the importance of the relationship with clients, who value it, and see it as an important tool in the effective management of dementia. When people with dementia came across practitioners like this, they immediately recognised something different and valuable. There were a number of practitioners like this – in the statutory and non-statutory sectors – in the South West.

Most people did not question that specialist practitioners had knowledge and skills. However, there was some doubt about memory services, with one carer being told by a memory service nurse that she had been moved into the job when the memory service was set up, but had not received further training and did not feel she had the skills required. Further, doubts were expressed about some of the knowledge and skills of professionals who were not dementia specialists but who nonetheless had ongoing contact with people living with dementia, such as cancer nurses, podiatrists, and doctors.



Chapter 3: A new model of care for dementia

As a result of this project, a new model of care for dementia is proposed. It comprises

- a description of the dementia journey from the perspective of people living with dementia
- a set of person-centred outcomes linked to the phases of the journey
- a refreshed, more contemporary approach to the various elements of existing models, with a summary of key implications for commissioning and service development.

The ‘dementia journey’

The work carried out for this project has resulted in the elaboration of a dementia journey from the point of view of people living with dementia. By understanding the journey, services can be designed around the perspective of those who need them. Other commentators have suggested similar approaches (most notably, the Windows of Opportunity approach)²⁴.

Table 1: the dementia journey

Phase 1	When memory problems have prompted me, and/or my carer/family to seek help.
Phase 2	Learning that the condition is dementia.
Phase 3	Learning more about the disease, how to manage, options for treatment and care, and support for me and my carers/families.
Phase 4	Getting the right help at the right time to live well with dementia, prevent crises, and manage together.
Phase 5	Managing at more difficult times (including if it is not possible to manage at home).
Phase 6	Receiving care, compassion and support at the end of life.

²⁴ Social Care Institute for Excellence (SCIE) (2011) *Windows of Opportunity: prevention and early intervention in dementia*. London, SCIE.

The critical premise of a journey – albeit one that can take different turns and is not always linear – is that there are some common predictable elements (or phases), which enables planning and prevention for the people living with dementia and those providing services. There are needs and issues to be addressed at each phase and proactive actions can be identified early on to prevent problems in later phases. Furthermore, outcomes can be identified, linked to each of these phases or - more usually - that cut across the phases of the journey.

Person-centred outcomes

The following outcomes associated with each phase of the dementia journey directly reflect the issues raised by people living with dementia who contributed to this report. They also derive from available literature, linking with the NICE Quality Standards for Dementia ²⁵, and the Quality outcomes for people with dementia: building on the work of the National Dementia Strategy (Department of Health, 2010).

Person –centred outcomes at Phase 1: When memory problems have prompted me, and/or my family to seek help

- I am confident that my primary health care worker/GP has taken my concerns seriously. S/he understands the nature and cause of memory problems, and will refer me quickly for an appropriate assessment if needed.
- I can access a range of information and guidance in the community about memory problems, and resources to support me and my family.
- My GP/primary health care worker work with me to help me to stay well and live well. I don't have to wait long for an assessment, and I have the option of having the assessment at home.

Person –centred outcomes at Phase 2: Learning that the condition is dementia

- I am confident that any tests that I have are necessary.
- I have a choice about whether I receive a formal diagnosis.
- If I am given a diagnosis, it is delivered with sensitivity.

²⁵ National Institute for Health and Clinical Excellence (2010) *Dementia Quality Standard*. London, NICE. <http://www.nice.org.uk/aboutnice/qualitystandards/dementia/>

- I am able to discuss the condition (and possible diagnosis) with a health professional; my questions and concerns are addressed; and I receive relevant information at the right time for me, and in the right way for me.
- My carer's/family's needs and concerns are considered and advice, support and help are available to them.

Person –centred outcomes at Phase 3: Learning more about the disease, self-management, options for treatment and care, and support for me and my carers/families

- As a carer/family member, my contribution and experience inform the assessment, and next steps. My own information and support needs are considered and addressed.
- My personal circumstances, and my needs, preferences, strengths and assets are acknowledged and understood.
- I am helped to understand what I need to know, and want to know about the disease, treatment options, and support available to me and my carer/family.
- Together we can think ahead to plan for the future.

Person –centred outcomes at Phase 4: Getting the right help at the right time to live well with dementia, prevent crises, and manage together.

- I can access a range of services to enable me to remain at home as long as possible.
- As a carer, I can access support, including training, to help cope with the ongoing role of caring for a person with dementia.
- As a carer, I have early and flexible access to different types of respite. The respite options suit me and the person I am caring for. They enable me to live well, to continue to provide care, and for the person I care for to continue to live at home.
- People who support me at home understand my condition, and know how to help prevent, modify or make adjustments to manage any behaviours that challenge.
- People who support me help me to live as independently and actively as possible.
- My choices and preferences for living my life are respected and I am involved in decisions about my life.
- I can access a range of information and guidance in the community about memory problems, and resources to support me and my family.

- I can remain involved with friends and my community. I enjoy life.
- My GP/primary health care worker will work with me to help me to stay well and live well.
- As a carer, I know who to contact in an emergency.
- I know who to contact for more information, guidance and support as my needs change.
- I feel confident that effective help and support is available to me, now and as my condition develops, to help me live life as fully as possible.
- I know what the next steps are; and I have a care plan that reflects my strengths, wishes, preferences and lifestyle, as well as my needs.
- I understand the range of issues I need to think about and plan for, and what to do to ensure that my wishes for future care options are respected
- My GP is informed about my condition, s/he contributes to my care plan, and we review my needs regularly to help me to stay well and live well.

Person –centred outcomes at Phase 5: Managing at more difficult times (including when it is not possible to manage at home)

- I know what my options are, and I have had an opportunity to discuss these with someone who can advise me.
- I know that I will be respected as a person, and that I will receive good quality care.
- My rights, preferences, interests and culture will be respected.
- People supporting me will have the knowledge, skills and attitudes to understand my condition, and care for me with compassion. I feel safe.
- I feel understood by the people who are looking after me.
- My physical and mental health needs are met; I am not taking any unnecessary medication.
- I am able to return home if and when possible, as soon as it is possible.
- Residential care home and ward staff have the knowledge, skills and values to work with people with dementia. They understand dementia; what can help alleviate distress; how to manage different behaviours and prevent crisis. They are supported to work in this way.
- I know that residential care home and ward staff know how to get expert advice, and are able to access help and advice when they need it.

Person –centred outcomes at Phase 6: Receiving care, compassion and support at the end of life

- I am confident that everything will be done to ensure that I die where I want to, well supported, and that my cultural needs and expectations will be respected.
- My carer's/family's needs are respected and supported.

A refreshed model of care for dementia

Earlier in this paper, a framework for understanding models of care was described. The elements of a model were presented as follows:

- guiding principles
- the condition itself
- the person with the condition
- service aims and structures
- effectiveness.

These elements in respect of the revised model of care for dementia are shown in Figure 4 on page 40, starting with the guiding principles. Each of these elements are then discussed more fully below in each section.

Note that statements about existing approaches are necessarily simplified. Of course, not all services or communities are currently working according to existing approaches or within any one model. Indeed there are many positive practice examples from existing services. The emphasis is on where we can move to, rather than on where we are moving from.

Figure 4: Elements of the revised model of care: a summary

<p>Principles</p>	<ul style="list-style-type: none"> • From disease centred principles, focussing on managing an individual’s problems, risks and deficits • To person centred principles, focussing on and respecting the unique person and understanding their perspective and that of their carers / families
<p>Dementia</p>	<ul style="list-style-type: none"> • From a debilitating untreatable terminal illness of old age • To a long term condition affecting memory, cognitions, health and behaviour, experienced by a person and their family
<p>Person with dementia</p>	<ul style="list-style-type: none"> • From a frail old person without mental capacity • To a person with a life story, family, community and social network, who will need help and increasing levels of support as the condition progresses
<p>Services</p>	<ul style="list-style-type: none"> • From reactive secondary care services that seek to contain and control risk, with voluntary sector add-ons commissioned and provided separately • To proactive community and primary care services, anticipating and responding to the person’s journey through dementia, commissioned and provided collaboratively
<p>Effectiveness</p>	<ul style="list-style-type: none"> • From a sense that very little helps, with reliance on medication and institution-based treatment • To a consensus that positive outcomes such as living well with dementia, prevention of crises and a good death can be achieved

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Rethinking the model 1: Guiding principles for a revised model of dementia

From: A set of principles that underpin the service model, that are disease-centred, and focused on needs, problems, risks and deficits

To: A set of principles that are:

- **person-centred**
 - valuing and protecting rights
 - recognising and respecting the unique person
 - understanding the perspective of the person with dementia and their family/carers
 - using the person's journey as a basis for commissioning and planning
 - providing support to enable the person to remain in relationships
- **assets-based**
 - using, and drawing on a person's assets and strengths, and those of their families, friends and community
 - seeing the person as a citizen, a part of a wider community and network
 - promoting equality and diversity
- **proactive**
 - understanding current needs,
 - thinking ahead and anticipating change, and planning for the future
- **effective**
 - ensuring safe and effective services and support are in place.

Building on similar person-centred principles is the VIPS model²⁶, which can be summarised as

- V** A value base that asserts the absolute value of all human lives.
- I** An individualised approach, recognising uniqueness.
- P** Understanding the world from the perspective of the service user.
- S** Promotion of a positive social psychology in which the person living with dementia can experience relative well being.

These guiding principles are inherent in the approach to the dementia journey, and underpin the service model proposed below.



²⁶ Brooker, D. (2007) *Person Centred Dementia Care: Making services better*. London, Jessica Kingsley Publications.

Rethinking the model 2: Understanding of dementia

From: A debilitating, untreatable terminal illness of old age

To: A long term condition affecting memory, physical & mental health and behaviour, experienced by the person with dementia and their family/friends. It can be treated in its early stages and there will be a series of relatively predictable needs and phases (a journey) that can be understood, sometimes prevented, planned for and alleviated.

Some implications for services

Three key service implications

- 1 Work sensitively with early concerns
- 2 Manage the range of issues associated with dementia
- 3 Promote social engagement and inclusion

1. Working sensitively with early concerns

- The assessment and diagnosis of dementia should be carried out with sensitivity. Loss and fear of loss of identity and capacity need to be acknowledged but there is also a place for hope and a sense of the future. A House of Commons Select Committee (2008) stated that the moment of diagnosis can and should be used to give information and instill hope for the life that people with dementia have afterwards.²⁷
- A diagnosis of dementia has a significant impact. An assessment and diagnosis service needs to take into account that the earlier the diagnosis, the more risk of suicidal behaviour in those who receive it, as people's cognitive functioning and ability to plan

²⁷ House of Commons Committee of Public Accounts (2008) *Improving services and support for people with dementia*. London, HMSO.

remain intact²⁸. A range of socially inclusive services and opportunities, ongoing support, psychological therapies, information and training are all likely to help manage suicide risk.

“We have a growing number of young people with dementia, some as young as 40. What services have we got to offer them?”

Practitioner

- Mild cognitive impairment (MCI) might be an early sign of dementia. When people present to their GP with MCI, this needs to be taken seriously with a period of “watchful waiting”, rather than being disregarded as simply an inevitable part of aging.

2. Recognising and managing the range of issues associated with dementia

- Mental health and life-limiting factors are only part of the picture of needs and issues. Rather, a range of physical, mental health, behavioural and social needs requires a range of services working together. The authors of a paper describing a positively-evaluated primary-care based memory service in Canada attributed part of the service’s success to its use of an interdisciplinary model that regarded dementia as a multi-faceted, long-term condition which would require planning, community support and management.²⁹
- This range of services needs to be easily accessible and navigable. People are likely to need support with understanding the services on offer, knowing when and how to access them, and navigating their way through them.

3. Promoting inclusion and social engagement

- Studies have indicated that a rich social life and engagement with the social world may help prevent or delay dementia, and may also be likely to help delay symptoms worsening. For example, a recent study found that social activity and social support were associated with better cognitive function.³⁰

²⁸ Draper, B. et al (2010) Early dementia diagnosis and the risk of suicide and euthanasia. *Alzheimer's & Dementia* 6 75-82. New South Wales, Australia.

²⁹ Lee, L. et al (2010) Enhancing dementia care: A primary-care based memory clinic. *Journal of the American Geriatric Society*, 58:2197–2204.

³⁰ Krueger, K. et al (2009) Social Engagement and Cognitive Function in Old Age. *Experimental Aging Research* 35 (1), 45-60.

- Services need actively to promote inclusion of people living with dementia , regardless of age, as currently dementia's association with old age can mean that younger people experiencing memory problems are not able to access help.

Good practice example: a supportive assessment

We do a full memory assessment at home. We ask the person if they would like a diagnosis. We also ask what else they would like. Once we are able to make the diagnosis, if the person has said they want to know, we offer an appointment at home or at the clinic with a nurse and the doctor. Then the nurse follows up at home and we go over everything again. People don't always remember what they've been told; they are in a state of shock. We put them in touch with local groups if that's what they want. We have a folder of all the local groups, not just for dementia but, for example, adult-education courses, and we can access the Community Resource Team. We can also offer real hands-on work if people would like that [through a partnership with a work-based organisation].

Older people's mental health team, South West

Rethinking the model 3: Understanding of the person with dementia

From: A frail old person without mental capacity

To: A person with a personal and social identity, a life story, a family, a community and social network, who also has a long term condition affecting their memory and functioning. The person can continue to enjoy a good quality of life, make decisions and contribute to society. He or she will need help at times and who will need increasing levels of support as the condition progresses.

Some implications for services

Four key service implications

- 1 Focus on the unique person
- 2 Involve people living with dementia
- 3 Work proactively and preventatively
- 4 Recognise the needs & assets of carers

1. Focus on the person

- Services need to offer individualised, person-centred care that recognises and promotes the value of the unique person and his or her identity. This includes maximising opportunities for social and community involvement in line with the person's preferences and interests.
- Evidence suggests that it is critical to pay attention to essential human worth, the person's retained capacity for relationships, pleasure, communication. Rather than focus on the negative when making a needs assessment, providing information on the range of psychosocial supports and services available may help to counteract a sense of futility.³¹

2. Involvement of people with dementia

³¹ Bowns and Bowers (2008) Caring for people with dementia. *British Medical Journal*, 336;225-226.

- People living with dementia should be able to expect to be involved in the assessment process, decisions about care and treatment and forward planning. The NICE/SCIE guidelines stipulate a range of requirements for assessment and care planning, that include involving and getting the endorsement of the service user and carer, taking into account individual needs arising from diversity (from example age, ethnicity, gender, sexual orientation, religion), and ensuring review times are in place and agreed with the service user and carer.³²
- People with dementia can also act as peer supporters. A number of schemes are in place internationally.

3. Working proactively

- Notwithstanding that individuals will have individual experiences of dementia, there is a relatively common dementia ‘journey’ that many people can recognise, with some predictability within it. Commissioning and designing services in relation to this journey can help with prevention and planning. Recognition of this journey allows services to identify opportunities to work proactively with people living with dementia and to know what, how and when to offer help that will enable people to live well with dementia, improve their quality of life and prevent crises.
- Commissioning services to work proactively and preventatively is likely to mean better use of resources as well as improved quality. Unnecessary hospitalisation and other high cost services could be avoided or deferred, in line with quality, innovation, prevention and productivity principles.

“When we work earlier on with people, we definitely prevent crises later on. The thing is the relationship.”

Team leader

4. Recognising the needs and assets of carers

- Dementia affects not only the person with the diagnosis but also their carers and family, and there is a responsibility to support their health and wellbeing as well. Services need to

³² National Institute for Health and Clinical Excellence and Social Care Institute for Excellence. (2006) *Dementia: Supporting People with dementia and their carers in health and social care. NICE Clinical Guideline 42*. London, NICE / SCIE.

be in place to ensure carers are fully supported, practically, emotionally, with their physical health and wellbeing and with the ability to take part in social and community life. The notion of the 'dementia journey' can also be deployed here: carers' needs will change as the condition develops.

- As before, providing support proactively will probably help prevent crises – both for the person with dementia and the carer. It has been found that reducing carer stress helps to prevent unplanned (and costly) entry into care homes.³³

“We do carers’ assessments ourselves [within the CMHT]. We think working with the carer is the most important way to support very many people.”

Team leader

Good practice example: Carer support in an integrated team with strong partnership with local carers’ group

In Torbay, carer support is an integral part of the joint health and social care team working with people with dementia. There is a strong local carers’ group with a clear say on how services work. Carers are always offered an assessment, a short education package and an open-ended carers’ support group. They are also offered counselling vouchers that they can use, if they wish, to access 10 free individual counselling sessions. People might not access this immediately but they can do so later, as they experience different responses to the diagnosis. The carer support practitioner holds a caseload, and provides emotional support as well as help with accessing social care packages and other sources of support. Carers may register on the local carers’ register which links them in with the local carers’ group, and they can have an emergency card.

³³ Schneider, J., Murray, J., Banerjee, S., et al (1999) EURO CARE: a cross-national study of co-resident spouse carers for people with Alzheimer’s disease: I – factors associated with carer burden. *International Journal of Geriatric Psychiatry*, 14, 651–661.

Rethinking the model 4: Service aims and structures

From: services that seek to contain & to control risk and are often:

- based on problems and age
- based in secondary psychiatric care
- based on strict eligibility criteria for social care
- reactive
- unclear about purpose
- dependent on individual good practice
- commissioned separately and provided separately

To: services and opportunities that are:

- based on needs and assets
- based in primary care and the wider community
- personalised and flexible
- clear about proactive and preventative aims
- clear about roles & expectations of practitioners
- commissioned and provided in an integrated way

Some implications for services

Four key service implications

- 1 Work in partnership with people living with dementia
- 2 Provide services predominantly in the community
- 3 Clarify role of specialist services
- 4 Deliver personalised, co-ordinated care

1. Working in partnership with people living with dementia to address range of needs and assets

- Assessment and interventions should be carried out flexibly, and based on physical, mental health, social and psychological needs, assets, preferences and context.

Good practice: working flexibly and managing risk in context

Lilian always lived with her brother, and they shared a life that was considered to be eccentric and unusual, for example, sleeping outside. Her brother died, and Lilian was left alone for the first time in her life, in her eighties. She does not like services and will not see a GP or other doctor. The team was called because Lilian had set herself on fire accidentally – she had tried cooking on the floor because she did not trust the gas. She was not physically harmed but there was a question of whether she could stay in the flat. The team responded by visiting her and offering support but recognised that Lilian’s cultural context and personal preferences meant she was unlikely to accept it. They managed risk by offering Lilian open access to the team, ensuring she was able to access food and adequate nutrition (through for example food that did not need cooking) and arranging for a fire officer to visit her flat to maximise fire safety. They offered her ongoing support and adopted an open-door policy so that if, in the future, she felt she needed them she could drop in at any time.

- People with dementia, family and carers have expertise as well as needs and their involvement could enrich and enhance service provision. Services should embrace the opportunity to work with them collaboratively as partners in care informally or formally. For example, carers ‘graduating’ from carers’ courses could co-run future courses with practitioners. People with an early diagnosis could opt to talk about their experiences in presentations within training programmes for primary care teams (or other non-specialist teams).

Good practice example: Involving people living with dementia in raising awareness and developing services.

In Stoke on Trent two linked initiatives involve people living with dementia to improve local community awareness and to improve services.

NHS Stoke on Trent's website contains the testimony of Maurice, a person who has dementia, as well as the testimonies of two carers. The testimonies, part of the section on Dementia Awareness, are frank and open and show people living with dementia in a positive light.

Secondly, Maurice and his wife were asked to join an NHS-led group to tackle inequalities in dementia services locally:

"We jumped at the chance as we saw the opportunity to discuss our own experiences in the hope that it would help to reshape services locally. Putting our own perspective on things may well help others in similar situations. We are now core members of this group and feel our experiences are valued and used to help in the remodeling of dementia services."

See http://www.stoke.nhs.uk/health/maurices_story

2. Delivering care primarily in, and with, the community as the default

- Most services could be delivered in the community through, and led by, primary care, with joint working with mental health or dementia specialists as needed. For example, memory services should routinely offer home assessment³⁴.

³⁴ Audit Commission (2000) *Forget me Not*. Audit Commission, London.

- GPs could act as case managers in a role similar to that used with the long term conditions model. Case management has been shown to reduce hospital admissions for people with dementia.³⁵ Most people with dementia would be provided with supported self-care, a small proportion of those at higher risk have specialist support, and those with highly complex needs have their care ‘actively managed’. Active case management includes personalised care, integrated service provision and working collaboratively – all key features of the model proposed here. GPs already act as Responsible Medical Officers for care homes, so the case manager role could complement this. Community matrons and other members of the primary health care team may also provide an active case management role.
- The notion of ‘risk’ is often invoked as a rationale for admitting people with dementia to hospital or residential settings, but it is often unclear what the ‘risk’ is and how hospital treatment, for example, might reduce it and help manage it in the future. In a revised model of care, ‘risk’ needs to be thought about in a different way, as something to be understood, prepared for and managed rather than completely avoided.

“There’s the issue of risk avoidance versus being brave. But how to get the organization behind you?”

Practitioner

- Support, education and training in primary care based services is needed to ensure staff feel confident, knowledgeable and skilled to work effectively with people living with dementia.
- Involving the local community in the co-production of services, and of developing opportunities for people living with dementia, should be considered by commissioners and providers.
- There needs to be plurality of provision, including a sustainable, fully commissioned voluntary sector especially for services and opportunities in the early phases of the dementia journey.

³⁵ Ibid 1.

3. Clarify the role of specialist dementia services and practitioners to include specifying outcomes to be achieved and sharing knowledge and skills

- The role of specialist services needs to be clarified, and to a certain extent, challenged. What is it that people living with dementia need from specialist care that cannot and should not be provided within (normalising) mainstream services? This issue is addressed further in the next section.
- Services with specialist knowledge in dementia (whether or not this is in the mental health field) should be required to share their knowledge and skills. A key role would be to train and support community, acute hospital, and residential care-based colleagues to work preventively, anticipate needs and enable access to more specialist help when needed.

Good practice: Sharing specialist knowledge through a Dementia Link worker scheme

The Dementia Link Worker scheme in Gloucestershire is an approach to improving care in care homes by asking homes to identify staff members who can develop expertise in dementia. These are the Dementia Link Workers, who undergo training and receive support and supervision from the local NHS Foundation Trust (where there are dedicated staff to run the project).

The focus of the training is on firstly developing an informed workforce in residential care, and then on an effective workforce. People with dementia are involved in the training package. There is also an emphasis on supporting Link Workers to take back and operationalise their learning in the care home.

There is no financial gain in doing the course, and care homes have to release staff to undertake the role, but it has had impressive take up. Since the scheme has been in place there has been a marked decrease in referrals from care homes into secondary care.

See <http://www.gloucestershire.gov.uk/index.cfm?articleid=22616>

4. Co-ordinated and personalised care

- Services need to be personalised for both the person living with dementia and their carers and families. This means moving away from a standard response to a tailored response based on the person, their families and their circumstances, at all stages of the dementia journey. For example, it has been suggested that carers fall into two groups as far as information needs are concerned: those who want everything ‘up front’, and those who want information incrementally. Practitioners should ask carers how much information they want, and when.³⁶

Good practice example: Personalised care in a residential care home

Gordon was a new resident at a small private care home that prides itself on a personalized approach and considers itself as real home-from-home for people with severe dementia. Where possible, pets are accepted, residents help with cooking wholesome and well-thought-out meals, and there is an atmosphere of warmth and involvement. Initially some of Gordon’s behaviour was unusual, he seemed agitated, and other residents found him disruptive. He would come into a room and start to take objects, such as lamps, apart. The owner of the care home talked to Gordon’s family and it emerged that one of Gordon’s favourite pastimes had been to potter in his shed, taking apart and mending broken objects. The care home owner arranged with the family to relocate Gordon’s shed into the care home’s large garden for Gordon to potter in as before. He has now settled in happily.

³⁶ Keady, J. (1994) Younger onset dementia: developing a longitudinal model as the basis for a research agenda and as a guide to interventions with sufferers and carers. *Journal of Advanced Nursing* 19 (4) , 659–669.

- With a range of services to address different needs, care needs to be co-ordinated. A dementia care navigator role could use a system of case management similar to those used in other long term conditions, making use of multidisciplinary skills³⁷. A navigator role, similar to cancer care navigators, could be considered. In cancer care, especially in the USA, the patient navigation role has three key elements:
 - individualized assistance offered to patients, families, and carers
 - help to overcome barriers within the service ‘system’
 - and facilitating timely access to quality care.

The Dementia Adviser role, which could have a similar function, is currently being piloted nationally; the role is being implemented differently in different locations so results may be difficult to translate. An evaluation of this role, and related roles has been published by the South West Development Centre; this indicates that there are clear benefits to the implementation of this role in primary and community services.³⁸



³⁷ Challis, D. et al (2002) Care management, dementia care and specialist mental health services: an evaluation. *International Journal of Geriatric Psychiatry* Apr;17(4):315-25.

³⁸ Cartmell, N. and Bardsley, D. (2011). *An evaluation of dementia support worker roles*. Bridgwater, South West Dementia Partnership. www.southwestdementiapartnership.org.uk/dementia-support-workers/

Rethinking the model 5: Understanding of effectiveness

From: a sense that very little helps, with reliance on

- medication
- institution-based treatment
- stand-alone services.

To: a consensus that outcomes such as living well with dementia, improved quality of life, prevention of crises, and a good death can be achieved through a variety of opportunities, therapies and approaches.

Some implications for services

Seven key service implications

- 1 Design services around person-centred outcomes
- 2 Rethink inpatient psychiatric admission
- 3 Rethink acute inpatient care
- 4 Specify the role of specialist services and treatment
- 5 Reduce reliance on medication
- 6 Use more technology
- 7 Join up services and opportunities

1. Designing services around person-centred outcomes

- The most important implications lie in identifying person-centred outcomes that could be achieved for people living with dementia and the design and implementation of services aimed at achieving those outcomes.
- Suggested person-centred outcomes were presented earlier in this paper.
- While there is no 'cure' for dementia, the outcomes that are important to people living with dementia relate to prevention, social inclusion, involvement, practical support, and thinking and planning ahead together.
- The achievement of these sorts of outcomes needs to set the tone for service commissioning, design, and delivery. This presents a considerable challenge for most commissioners and planners, as current service configurations tend to rely heavily on a medical model of care based in secondary mental health services for people with the most complex presentations. Desired outcomes, if expressed at all, tend to be based on containment and management of risk.

2. Rethinking the need for inpatient psychiatric care

- Institution based treatment – particularly psychiatric inpatient care – appears to have a limited role and to lack a clear, commonly agreed purpose which makes it difficult to assess any kind of effectiveness. Although the Royal College of Psychiatrists advocates inpatient care for older people for “specialist expertise, with intensive levels of assessment, monitoring and treatment that are not possible in other settings”³⁹, evidence about effectiveness or outcomes regarding inpatient psychiatric care for people with dementia is not readily available.
- The psychiatric inpatient environments visited for this study were of good or excellent quality with, for example, models of excellence using Dementia Care Mapping, and informally shared care between a medical and mental health ward in a small community hospital. However, generally speaking, the experience of inpatient care for people living with dementia is rarely positive. Indeed, it is often distressing for someone to be admitted to a new and bewildering environment, it can be distressing for the family, and there are risks associated with admission, such as hospital-acquired infection and falls.

³⁹ Royal College of Psychiatrists (2011) *Inpatient care for older people within mental health services. Faculty Report FA/OA/1 p,7*. London, Royal College of Psychiatrists.

- There were some unsettling incidents observed, such as a person with dementia repeatedly trying to leave the ward through a fire exit. This person was encouraged to move away from the door by a staff member but there appeared to be no effort to engage with him to discuss why he wanted to leave or other causes of his agitation.
- In addition to these ethical concerns, costs of inpatient care are high at around £300 per bed day⁴⁰. This compares with a high cost health & social care package of £626, that is less than £100 a day. Given these ethical and resource implications, there is a serious question about the continued use of inpatient psychiatric beds for people with dementia.
- Many services are reducing their reliance on psychiatric inpatient care but they nonetheless continue to be a high cost resource in many areas. Where this is still a key element of the service model, questions need to be asked about the purpose and function of psychiatric inpatient care for people with dementia, what preventive approaches are being used, what alternatives are in place, and how to facilitate early, planned discharge. Local audits tracing a person's journey in to and out of inpatient care might help identify flash points where preventative measures could be used effectively to prevent admission or reduce length of stay.
- The role of the local Crisis Resolution and Home Treatment (CRHT) team in preventing admission for people with dementia should also be explored. These teams appeared to vary widely in the region, in terms of whether or not they were willing and able to work with people with dementia. But the CRHT model – in which, where possible, people at risk of admission are provided with intensive home support for a limited period in order to avoid or defer admission and to facilitate early discharge – could be well used in dementia care. The available evidence does suggest that, with skilled teams in the community, such as outreach services, and crisis resolution and home treatment teams, less than 1% of people with dementia should require treatment in an inpatient unit.⁴¹
- Services should be available to respond out-of-hours to social needs and emergencies, as well as health needs.⁴²

⁴⁰ Curtis, L. (2011) *Unit Costs of Health & Social Care 2010*. Manchester, Personal Social Services Research Unit, University of Manchester. <http://www.pssru.ac.uk/pdf/uc/uc2011/uc2011.pdf>

⁴¹ Brodaty, H., Draper, B.M. & Low, L.F. (2003) Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery. *Medical Journal of Australia*, 178, 231–234.

⁴² Ibid 32.

3. Rethinking general and community hospital care

- If a person with dementia is physically ill, admission to general hospital results in worse outcomes, compared with someone who does not have dementia. For example, a person with dementia who suffers a fractured neck of femur is more than 2.5 times more likely to die in the six months following admission, will have a longer length of stay, and is almost 18 times more likely to be admitted to a care home following discharge than a person who does not have dementia.⁴³
- Admission and readmission to acute (general) hospital care can be avoided and lengths of stay reduced by finding alternative non-acute care settings, which are both preferred by people living with dementia, less likely to result in complications, and are less costly.⁴⁴
- Standards of care in general hospitals need to be appropriate for the needs of people with dementia, and staff looking after patients with dementia must be competent to assess their needs and provide proper person-centred care.⁴⁵
- Again, the issue is not just about avoiding admission but also facilitating earlier, and successful, sustainable, discharge. This means thinking about the whole system of care, of which the inpatient component is a part. Such whole system approaches for managing delayed discharge have been widely promoted.⁴⁶

4. Specialist dementia care and treatment

- As discussed in the previous section, the revised model proposed here emphasizes the provision of a range of services and opportunities that are 'dementia-friendly'. These services and opportunities are rarely specialist, but are informed, knowledgeable and skilled, and aimed at continued social inclusion and citizenship. The model implies that mainstream everyday services, especially in primary care, should be the main port of call for people living with dementia.

⁴³ Ibid 27.

⁴⁴ Ibid 1.

⁴⁵ Royal College of Psychiatrists (2005) *Forgetful but not forgotten: assessment and aspects of treatment of people with dementia by a specialist old age psychiatry service*. London, Royal College of Psychiatrists.

⁴⁶ NHS Institute for Innovation and Improvement (NHS III) (2008) *Health Management Briefing: Delayed transfer of care*. London, NHS III.

- However, there is a need for more specialist dementia care at certain points of the dementia journey. Specialist services could include:
 - specialist information about dementia and services that are likely to be of need to people living with dementia, early on
 - specialist assessment, early on
 - managing memory better, early on
 - guidance and forward planning, early on
 - consultation and advice on living well with dementia, throughout
 - advice on medication and prescribing, throughout
 - help with identifying, preventing and managing behaviours that can be a problem, such as wandering and aggression – throughout, but particularly as the condition progresses
 - direct therapeutic interventions for people with dementia and for carers
 - training supervision and support for carers, residential care staff and others working with people with dementia.
 - care co-ordination and a single port of call for people living with dementia.
- Psychological and talking therapies are an important form of specialist intervention that can be effective. Well known approaches, such as reminiscence therapy are well established. But recently studies have found that other psychological therapies such as cognitive stimulation therapy can be effective in the treatment of dementia⁴⁷. Talking therapies/Improving Access to Psychological Therapies services could be more proactive in working with people with dementia; many services still do not offer equitable access to treatment for older people.
- Taking a more imaginative approach to providing interventions has also been shown to help. For example, one study found that exercise training, combined with teaching carers behavioural management techniques, may improve physical health and depression in people with Alzheimer’s Disease⁴⁸. Looking at sensory-based

⁴⁷ Knapp, M. et al (2006) Cognitive stimulation therapy for people with dementia: cost-effectiveness analysis. *British Journal of Psychiatry*. Jun;188:574-80.

⁴⁸ Terri, L., Logston, R. G. and Peskind, E., et al (2000) Treatment of agitation in AD: a randomized, placebo controlled clinical trial. *Neurology*, 55, 1271–1278.

approaches, another study found that lemon balm applied topically to the face and arms of people with dementia reduced agitated behaviours.⁴⁹

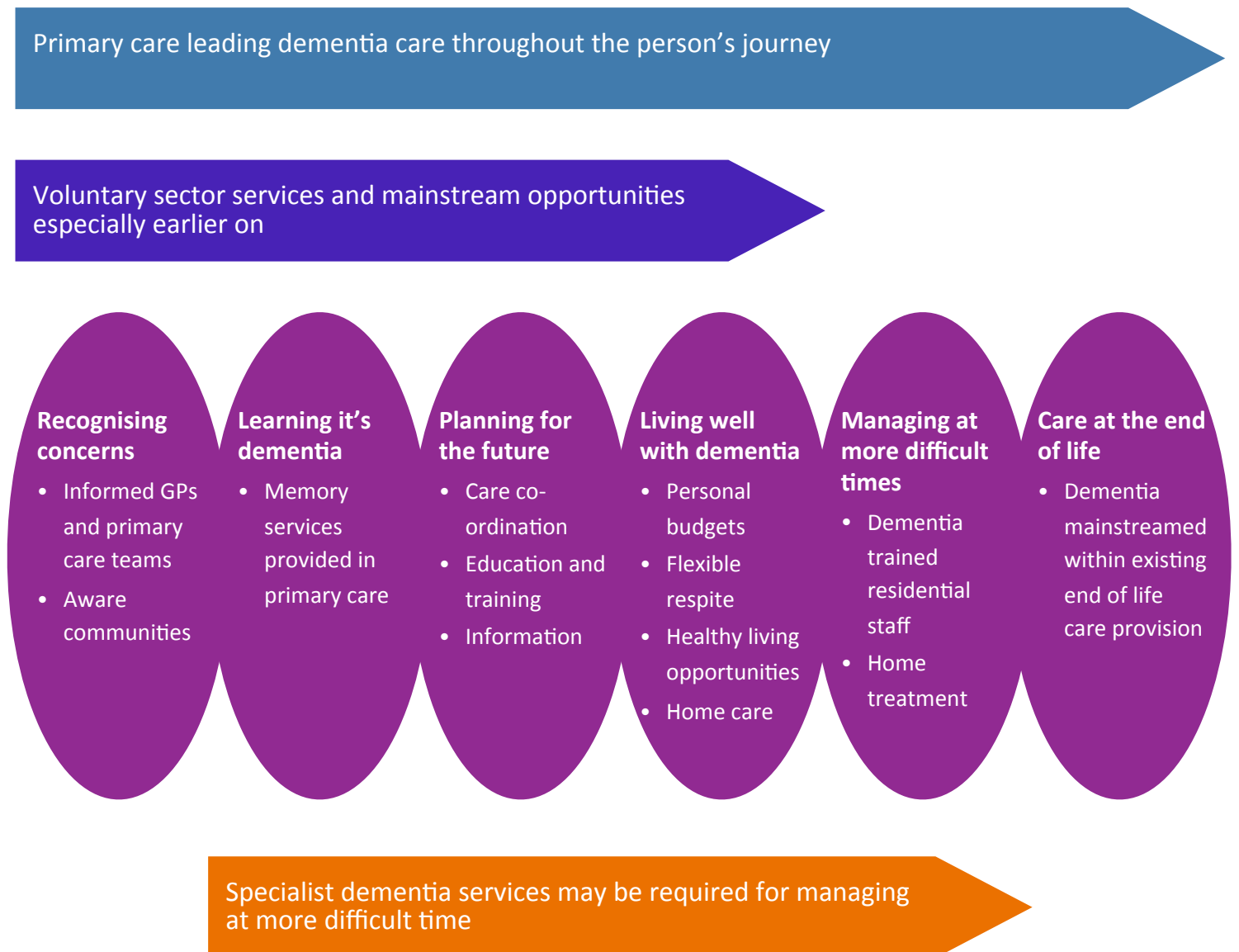
- The critical factors here are that the specialist provider(s) are clear about their role and the outcomes they seek to achieve, that they work collaboratively with mainstream services in the statutory, non-statutory and non-service sectors, and that they involve people living with dementia in the design and delivery of their services. Historically secondary mental health services may have provided some of these specialist functions. However, this model does not presuppose that specialist dementia care must necessarily be provided by secondary mental health services. Indeed, it could be argued that there is a question as to whether the 'mental health' function is required at all in most circumstances, except where there are co-existing psychiatric disorders.

Figure 5 on page 62 shows how a revised model might look in terms of who provides services across the dementia journey. The model is led by primary care (in blue), with community services and opportunities (in orange) integral to earlier phases of the journey, and specialist input (in purple) at times of greater need. More detail of which services might be provided at each point in the journey can be found in the Appendix.



⁴⁹ Ballard, C., O'Brien, J., and Reichelt, K., et al. (2002). Aromatherapy as a safe and effective treatment for the management of agitation in severe dementia: The results of a double blind, placebo-controlled trial with Melissa. *Journal of Clinical Psychiatry*, 63, 553-558.

Figure 5: Service providers along the dementia journey



5. Reduce reliance on medication

- Acetylcholinesterase inhibitors have been shown to help delay the course of some dementias and were well received by people living with dementia who participated in this project. However, the UK is in the bottom third of European countries when it comes to prescribing rates.⁵⁰
- Where people are receiving medication for dementia, it is important that monitoring of medication does not take place independently from other parts of the service but is integral to the package of care. Otherwise, medication monitoring is at risk of becoming a paper exercise. Indeed, it was observed during this project that some people appeared to continue to be in receipt of medication well into the later stages of dementia with perhaps little benefit. Information about other aspects of their care and experience was not regarded as part of the medication monitoring role.
- The use of antipsychotic medication in dementia has been widely criticized, despite an estimated 20% of people with dementia receiving antipsychotics. A leading report for the Department of Health highlighted how inappropriate prescribing of antipsychotic medication can have significant and dangerous consequences including increased risks of falls and injuries and even exacerbating dementia symptoms⁵¹. The consequences include 1800 additional strokes and 1600 additional deaths annually among people with dementia in the UK. The same report recommended partly replacing the need for medication through preventative interventions, including improving primary care skills and training at home and in residential settings, to help manage behavioural and psychological aspects of dementia.
- Dementia Action Alliance, in collaboration with the NHS Institute for Innovation and Improvement, has launched a '@Call 2 Action' on the use of antipsychotic drugs for dementia. The aim is for all people with dementia who are currently receiving antipsychotic medication to receive a clinical review to ensure that their care is compliant with current best practice and guidelines, and that alternatives to medication have been considered.⁵²

⁵⁰ Ibid 1.

⁵¹ Bannerjee S (2009) The use of antipsychotic medication for people with dementia: Time for action. London, Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_108303

⁵² Dementia Action Alliance and the NHS Institute for Innovation and Improvement (NHS III) (2011) *The Right Prescription: A Call to Action on the use of antipsychotic drugs for people with dementia*. London, NHS III.

6. Technology

- The service model needs to include imaginative use of technology, existing resources and resource streams for example assistive technology, personal budgets, community development funds to provide a range of supports for people living with dementia enabling people to live at home and stay part of their communities for as long as possible.

7. Joined up community based services and opportunities

- Based on the findings of a variety of studies and in talking to people living with dementia, it would appear that a range of joined up local, community-based services and options to enable people living with dementia to stay at home as long as possible, in the care of primary care, are likely to be effective in improving quality of life. Integration, plurality and collaboration within a whole system seem to be important. When services work collaboratively, quality of care improves and behavioural and psychological symptoms decrease for both service users and carer, and can be cost effective (for example, by avoiding an increase in medication such as hypnotics) ⁵³. In one controlled trial, people cared for in a co-ordinated system, which included a clear set of guidelines for management, received more, higher quality health and social care than those in the usual system of care. Quality of life and social support were also better in the co-ordinated group. ⁵⁴ Many practitioners in the South West were clear about the importance of integrated care:

“[Lack of integration with social care] is a huge gap. We have to send a referral to an access team in [another town]. They process it and it goes to another team who deal with it.”

“Co-location is so much better. Informal everyday practice can be discussed and shared.”

⁵³ Callahan, C. et al (2006) Collaborative care for older people with Alzheimer’s Disease in primary care: A randomized controlled trial. *JAMA* 2006;295(18):2148-2157

⁵⁴ Vickrey, B., Mittman, B., Connor, K. et al (2006) The Effect of a Disease Management Intervention on Quality and Outcomes of Dementia Care: A Randomized, Controlled Trial. *Annals of Internal Medicine* 145, 10, 713-126

Good practice example: Collaborative working in Somerset to improve care in residential settings

The Specialist Care Development Nurse (SCDN) scheme in Somerset involves a collaboration between the Primary Care Trust Cluster, Adult Social Services, Somerset Partnership NHS Foundation Trust and local independent sector providers of residential care homes.

Contracts were worked up by all the partners involved in the collaboration. Residential care homes taking part in the scheme have all their beds block-booked so that there is no problem related to funding. Ten local homes are accredited within the scheme.

The SCDN works both with care homes as a lead in liaison, and with people with dementia who will be resident. The SCDN visits each home frequently and regularly; the approach is to support the home, build a relationship, give advice (including on environmental issues) and be a regular ongoing presence. They work with individuals with dementia to assess whether the home is right for them and help arrange the transition into residential care. An evaluation has shown that there is improved quality of life and a reduction in behaviours that challenge.

- An integrated approach between palliative and primary care may lead to improved experiences. For example, the PEACE Programme⁵⁵ attempted to integrate palliative care into primary care from the time of the diagnosis until death. Using clinical nurse specialists, the focus was on advance care planning, symptom management, education, carer support, optimal use of community resources and improved coordination of care. Early results suggested high satisfaction rates, better pain control, and people approaching end of life in their place of preference.

⁵⁵ Shega, J.W., Levin, A., Hougham, G.W., et al. (2003) Palliative Excellence in Alzheimer Care Efforts (PEACE): a program description. *Journal of Palliative Medicine*. 2003;6:315–20.

Chapter 4: Conclusions: From a new model of care to a dementia service for a community

Listening to people living with dementia

People living with dementia are clear about the experiences and outcomes that will improve their quality of life, maintain their lives as part of their communities, and help them plan for their futures.

There are many examples of positive practice where services are achieving better outcomes. The best of these show:

- collaboration and partnership (for example, between commissioners, health & social care providers and non-statutory sector)
- practitioners who demonstrate not only knowledge and skills, but also empathy, flexibility and compassion and carry those values into their everyday work
- clarity of roles
- involvement of people living with dementia
- foresight and an emphasis on planning and early intervention in order to manage the person's journey proactively.

However, in many instances people living with dementia find themselves frustrated at the lack of forethought, information, knowledge, skills and person-centred values that they encounter in their local services.

Six key messages

The model throws up a number of overlapping issues; however, key messages for future service design and delivery have emerged. These messages have at their heart the values outlined at the start of the description of the service model.

They can be summarised as:

1

Recognise the dementia journey, and work sensitively, proactively and preventatively to help pre-empt and manage crises.

2

Deliver personalised, co-ordinated care that focuses on the unique person, and design services around person-centred outcomes.

3

Work together with people living with dementia, including carers, recognising their needs and assets.

4

Manage the range of issues associated with dementia – not just ‘mental health’; social engagement is critical. Make sure services and opportunities are joined up.

5

Provide services predominantly in the community, led by primary care.

6

Specify the role of specialist services and treatment, promoting therapies, rethinking the role of inpatient care and reducing reliance on medication.

Designing services focused on outcomes

This paper proposes a model that focuses on improving experiences and designing services that aim to achieve person-centred outcomes related to the dementia journey. If commissioners and service developers adopted this model, they could consider a range of services with a clear remit where people living with dementia and practitioners and providers alike know what to expect, what can be achieved and how, and where their relative contributions are valued.

Applying this kind of revised model of care for dementia will differ in each health and social care community. Nevertheless, there are some good indications of which services might be needed to deliver the suggested outcomes. Appendix 1 proposes services at each phase of the dementia journey, with the suggestion that most services in blue indicating primary care, mainstream or community based services and opportunities. Purple is used to indicate services that might be best delivered through specialist providers.

Facing the challenge of a new model

Establishing a new model of care is likely to be felt as a challenge and requires a cultural and even a language shift. Thinking about people living with dementia as having assets as well as problems, as being able to contribute to services, as needing not so much an increase in services as more access to opportunities, and undergoing a journey that is relatively predictable and can be managed proactively -all of this constitutes a step-change for the health and social care community. A key concept here is the notion of co-production. Co-production has been defined as a “potentially transformative way of thinking about power, resources, partnerships, risks and outcomes. The transformative level of co-production requires a relocation of power and control, through the development of new user-led mechanisms of planning, delivery, management and governance”.⁵⁶ Co-production principles apply not only at the macro-level of service design but also at the micro-level of the relationship between the service user and the practitioner. This means a new way of working for everyone.

Furthermore, there are implications for workforce and resources, potentially requiring:

- new roles
- new skills
- rethinking of resources.

The South West Dementia Partnership has published a series of resources that will help address many of these issues, alongside a leadership programme to support the management of change. It is an ambitious programme, but one that the increasing numbers of people living with dementia need and deserve. www.southwestdementiapartnership.org.uk.

⁵⁶ SCIE (2009) *Co-production: an emerging evidence base for adult social care transformation*. London, SCIE.

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- ³ Ibid 1.
- ⁴ Kings College London and London School of Economics (2007) *Dementia UK. A report to the Alzheimer's society on the prevalence and economic costs of dementia in the UK*. London, Alzheimer's Society. <http://www.lse.ac.uk/collections/pressAndInformationOffice/newsAndEvents/archives/2007/AlzheimersReport.htm>
- ⁵ Department of Health (2011). *NHS Outcomes Framework 2012-2013*. Department of Health, London. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_131700
- ⁶ For example, see National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) (2006) *Clinical guideline 42 'Dementia: Supporting people with dementia and their carers in health and social care'*. London, NICE / SCIE. NICE (2010) *Dementia Quality Standard*. London, NICE.
- ⁷ National Audit Office (2010) *Improving Dementia Services in England – an Interim Report*. London, National Audit Office.
- ⁸ Department of Health (2011) *Dementia Commissioning Pack*. Department of Health, London. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_127381.
- ⁹ Ibid 8.
- ¹⁰ After Davidson, P. et al (2006) Beyond the rhetoric: What do we mean by a model of care? *Australian Journal of Advanced Nursing*, 23, 3, 47-55
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- ¹² See for example, Waine, B. et al (2005) *Developing social care values and principles*. SCIE: London

¹³ Ibid 12.

¹⁴ Bamford, C. et al (2009) *Person- and carer-centred respite care for people with dementia: developing methods for evaluating the effectiveness of different models. Report for the National Institute for Health Research Service Delivery & Organisation*. London, HMSO.

¹⁵ Vickrey, B. G. et al (2006) The effect of a disease management intervention on quality and outcomes in dementia care: a randomised controlled trial. *Annals of Internal Medicine*. 145,713-726.

¹⁶ Ibid 1.

¹⁷ Healthcare for London (2009) *Dementia Services Guide: Appendix 6, p7*. London, NHS London. http://www.london.nhs.uk/webfiles/Dementia/20110412_London%20Dementia%20Needs%20Assessment%20Revised%20FINAL.pdf

¹⁸ Ibid 17.

¹⁹ Hughes, J. (07 November 11) *Look out for dementia warning signs, families urged*. BBC News. <http://www.bbc.co.uk/news/mobile/health-15581986>

²⁰ When quoting the experiences and voices of people with dementia, names and some details have been changed to ensure anonymity

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Appendix 1: Proposed services at each phase of the dementia journey

