Supporting People to Live Well: Dementia, Carers and Falls Prevention

Older people are an important and growing population in South Gloucestershire. We celebrate the fact that we are living longer. To maintain good health and to stay well we need to work together as a community to provide care and support both when people are well and when their health is not so good.

In South Gloucestershire we want to make real change for older people and over the coming months we are consulting on three issues that significantly impact on older people’s wellbeing: dementia services, falls prevention and support for carers. Many carers care for older people, and many are older people themselves.

We recognise that becoming a carer can happen at any age. We are also asking adult carers under the age of 50, and young carers, under the age of 18, what they think our priorities should be.

These matters do not affect anyone in isolation. All three can be part of an individual’s daily life and it makes sense to seek people’s views on them at the same time. We would like to encourage you to take the time to let us have your comments and feedback on any one or all of these matters.
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Welcome


In South Gloucestershire there are approximately 3,300 people with dementia and this is set to increase to 5,200 by 2025. We know that as well as changing the life of the person with dementia, dementia has a significant impact on the lives of relatives, friends and neighbours who often take on caring roles.

We want people with dementia and their carers to live well and be supported to do so throughout the progression of the disease. They will know about and be able to access the right support and services at the right time. We want dementia to become everyone’s business. That means that we need to ensure everyone knows about dementia and that people can live well with dementia in South Gloucestershire.

This strategy sets out how South Gloucestershire Council and South Gloucestershire Clinical Commissioning Group will work together to improve the lives of people with dementia and their carers and we hope that you will support and join us in this challenge.

Peter Bagshaw, Peter Murphy, Heather Goddard,
Introduction

Improving care and support for people with dementia is a priority for South Gloucestershire Council and South Gloucestershire Clinical Commissioning Group.

Dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. It is caused when the brain is damaged by diseases such as Alzheimer's disease or a series of strokes. Dementia is progressive, which means the symptoms will gradually get worse. Dementia is rare at ages less than 65 years but becomes progressively more common as people age.

There are high human and economic costs associated with dementia. These costs include impact on the health and wellbeing of the person with dementia and people close to them, as well as the cost to society of their services and support.

In recent years there has been an increased focus on dementia both nationally and locally because the population is ageing, and this has led to increasing numbers of people with dementia.

This strategy has been developed by South Gloucestershire Council and South Gloucestershire Clinical Commissioning Group in conjunction with local partners from the statutory and voluntary sector, as well as through talking to people with dementia and their carers about their experiences in South Gloucestershire.

This document is a consultation draft of the final Strategy. It has been developed to seek your comments and suggestions, between April and June 2016, which will form the basis of the action plan for 2016/17 to 2018/19.

The main purpose of the strategy is to provide a framework for commissioning and service delivery which ensures that people in South Gloucestershire with dementia and their carers are able to live well and are supported to do so throughout the progression of the disease. This will be achieved by enabling access to the right support and services at the right time, whether that be from their local community or health and care services.

We recognise that minimising people’s risk of developing dementia is also important for the population as a whole and the strategy also describes ways in which we will
raise awareness of the healthy lifestyle choices people can make to reduce their risk of dementia, and stay fit, well and independent as they get older.

Dementia is everybody’s business: looking after our personal health and to support people with dementia and their carers in South Gloucestershire is not just the reserve of specialist care services.

The South Gloucestershire Dementia strategy will:

- Set out the vision for what we want to achieve
- Help co-ordinate the excellent work that is already on-going
- Identify key priorities for what needs to improve
- Maximise opportunities for identifying synergy and potential for cross-agency working
- Engage local people in discussion on what works best for them
- Ensure that we keep people living with dementia central to everything we do.
1. Why we need Better Care

People tell us that the local health and care system doesn’t always work well for them. It can be complicated and difficult for people to move from one service to the next. Health and care professionals often work independently of each other, rather than together, when looking after people. We also know that some services which are currently delivered in hospitals would be better delivered in the community, close to people’s homes.

At the same time, we know that demand for health and care services is rising. We have an ageing population and a growing number of elderly people needing more intensive care and support. Without a significant increase in resources to meet these challenges it is clear that we need to work differently to deliver the care that we will need, now and in the future.

2. Our Aim

That people in South Gloucestershire with dementia and their carers are able to live well and are supported to do so throughout the progression of the disease.

What we want to achieve

Our vision is for joined-up health and care service and support that has the individual at the centre and empowers them to remain independent and well for as long as possible.

We know that better coordinated support, that focuses on a person’s well-being as well as their health and care needs, can reduce their dependency on services in the long run and reduce or prevent hospital admissions. Better Care is our way of putting this approach into action. We want to provide more care in the community so that people can be supported to live safely and independently at home for as long as they wish. We also want to make sure that services work together more effectively to support people and their families, while helping people to access the voluntary social networks that are available in their communities.
Our Priorities for Action

1. Increase awareness and understanding of dementia amongst professionals and the public.
2. Improve diagnosis rates and ensure a timely diagnosis for those with dementia.
3. Ensure high quality information about dementia, local services and support is available to all those with a dementia diagnosis and their carers.
4. Develop care and support to meet the needs of individuals with dementia and their families and other carers, to maintain independence and avoid crisis.
5. Recognise the contribution of carers, and encourage and enable them to look after their own health and wellbeing as well as those they care for.
6. Improve provision for people who can no longer live at home, supporting care homes to meet the needs of people with dementia and developing alternatives.
7. High quality hospital care for people with dementia, including pathways to ensure appropriate and timely discharge.
8. High quality end of life care

Common themes across these work streams

- Safeguarding is everybody’s business.
- Planning and service provision based on evidence and intelligence about local need.
- The benefits of a healthy lifestyle in reducing the risk of dementia and slowing its progression.
- Services and support are available near to people’s homes and in community settings.
- The Five Year Forward View for Mental Health NHS Plan and complementary initiatives in social care, housing and the wider voluntary sector.
- Working with people with dementia, their families, other carers and providers of mainstream and specialist dementia services and support to meet their need.
- Strategic partnerships with colleagues in Bristol and the local Universities through the Dementia Health Integration Team (HIT) of Bristol Health
3. About dementia

What is dementia?

Dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. Dementia is rare at ages less than 65 years but becomes progressively more common as people age. Dementia is caused when the brain is damaged by an illness, such as Alzheimer's disease or a series of strokes. This damage may have been developing for many years by the time that the person has symptoms.

Dementia is progressive, which means the symptoms will gradually get worse. As dementia progresses it leads to loss of intellectual function and severe decline in ability to care for oneself which will have a major impact on individuals and their families and can place great strain on carers.

In terms of severity dementia is generally categorised as:

- **Mild** – impairment of attention and memory, forgetting recent information, occasional confusion, able to cope with daily routine and personal care, but needing help with changes to routine.

- **Moderate** – amnesia for recent events, disoriented about time and place, very poor reasoning and understanding of events, becoming dependent on others for help with personal care and daily routine.

- **Severe** – speech impaired, often unable to recognise close relatives, decline in mobility and continence, completely dependent on others for daily routines and personal care.

There is also a lesser stage of cognitive decline which is not dementia but recognises that the person is not normal but not yet at the stage when a dementia diagnosis can be given. It is called mild cognitive impairment (MCI). People diagnosed with MCI may progress to dementia but some will continue to have MCI.
and not progress. At the current time it is difficult to predict whether progression to dementia will occur.

In terms of day to day living with dementia:

- People with mild dementia live independently and can have active, fulfilled lives.
- All dementia is progressive and in later stages dementia can be associated with complex needs and, high levels of dependency and morbidity.
- The life expectancy of a person with dementia is unpredictable. Time from diagnosis to death can be as short as a few months to up to 20 years although most people will progress more rapidly than this.
- There is no common journey for people with dementia – it affects everyone differently.

Currently there is no cure for dementia. Some medical treatments are available that can help to alleviate symptoms or to slow the progression of the dementia for many people. Support is also available to help someone to live well with dementia.

**People at risk of developing dementia**

Age is considered the highest risk factor for dementia, and the percentage and numbers of older people in the population is increasing. There is evidence for mid-life healthy lifestyle approaches to delay or prevent onset of dementia; the potential impact on future prevalence and service demand is not yet fully understood.

**National Institute for Care and Health Excellence (NICE 2015) recommends:**

- Encouraging healthy behaviours
- Integrating dementia risk reduction prevention policies
- Raising awareness of risk of dementia, disability and frailty
- Producing information on reducing the risks of dementia, disability and frailty
- Preventing tobacco use
- Improving the environment to promote physical activity
- Reducing alcohol-related risk
• Supporting people to eat healthily

It has also been found that keeping one’s mind active and being socially active can also help reduce the risk of dementia. There is concern that due to the large areas of rural geography in South Gloucestershire, people may become socially isolated.

Dementia with Learning Difficulties

People with learning difficulties, particularly those with Down’s syndrome, are at increased risk of developing dementia. About 1 in 5 people with a learning disability who are over the age of 65 will develop dementia. People with learning disabilities who develop dementia generally do so at a younger age. Studies have estimated that 1 in 50 people with Down’s syndrome develop dementia in their 30s, rising sharply to more than half of those who live to 60 or over. If a person with a learning disability develops dementia, they will face different and additional challenges to people who do not have a learning disability (Alzheimer’s Society Factsheet).

Dementia generally affects people with learning disabilities in similar ways to people without learning disabilities. However, there are some important differences. People with a learning disability:

• often show different symptoms in the early stages of dementia
• are more likely to have other physical health conditions which are not always well managed
• are less likely to receive a correct or early diagnosis of dementia and may not be able to understand the diagnosis
• may experience a more rapid progression of dementia, although this can be complicated by difficulty or delay in diagnosis
• may have already learned different ways to communicate (e.g. more non-verbal communication if their disability affects speech)
• will need specific support to understand the changes they are experiencing, and to access appropriate services after diagnosis and as dementia progresses. These may be specialist services for those with a learning disability or general services for older people.
**People with dementia and their carers and families in South Gloucestershire**

According to the Dementia UK 2014 report (Alzheimer's Society, 2014), the total age standardised prevalence of dementia amongst those aged 65+ in the UK is 7.1%, equal to 1 in 14 of those aged 65 and over. If this proportion is applied to the South Gloucestershire population this equates to nearly 3,300 people aged 65 or over that are estimated to have some degree of dementia.

Although dementia predominately affects older adults, it can affect younger adults. It is estimated that 4.1% of men with dementia and 1.6% of women with dementia in South Gloucestershire are under the age of 65.

There are currently approximately 1,900 people on the dementia register in South Gloucestershire, this represents a diagnosis rate of approximately 60% of the 3,300 South Gloucestershire GP registered patients estimated to have dementia.

The number of people with dementia in South Gloucestershire is predicted to increase to 5,200 by 2025 and 7,000 by 2035 – almost doubling current numbers (POPPI, 2015) if age-specific prevalence remains stable, and increases are only driven by demographic ageing.

As the population ages and life expectancy increases, the age group that is predicted to see the largest increase in the prevalence of dementia is those aged 90 or over – an age group most likely to require residential care and / or have additional health care needs, co-morbidities or mobility issues. Estimates suggest a near threefold increase in persons aged 90+ with dementia from 700 in 2012 to 2,700 by 2037 (POPPI, 2015).

An estimated 12.5% of people with dementia have it in the most severe form and will therefore be most likely to be in receipt or in need of care and nursing (Alzheimer's Society, 2014), this equates to approximately 412 in 2013, rising to 925 by 2037 in South Gloucestershire.
People with dementia are substantial users of hospital care. A quarter of all hospital beds and up to 70% of places in care homes are occupied by people with dementia (Alzheimer’s Society, 2009) and over 60% of people receiving homecare services have dementia (Alzheimer's Society, 2014).

There are high economic costs associated with dementia care. These arise from: services and support provided by health and social care, as well as the cost of unpaid care which accounts for 44% of the total cost of dementia. The overall economic impact of dementia in the UK has been estimated as £26.3 billion, working out at an average annual cost of £32,250 per person. This is predicted to rise as the number of older people in the population increases (Alzheimer's Society, 2015).

4. Where are we now?

National and local policy, legislation and guidance

In recent years there has been an increased focus on dementia nationally because the population is ageing and this has led to increasing numbers of people with dementia. According to the National Dementia Declaration (Dementia Action), public awareness of dementia is high but understanding is poor and a stigma around dementia remains as a significant barrier to people seeking help.
There are a number of national strategic drivers that have helped to shape the strategy. These include: **The National Dementia Strategy, ‘Living Well with Dementia’ 2009** (Department of Health, 2009) which sets out a vision that services and society should transform their approach and attitudes to enable people with dementia and their carers to live well with dementia, no matter what the stage of their condition or where they are in the health and social care system. This approach includes of all types of dementia, in all groups affected, including people under the age of 65.

These key themes were carried through into ‘**Quality Outcomes for People with Dementia: Building on the Work of the National Dementia Strategy 2011**’ (Department of Health 2010), the updated implementation strategy for the 2009 strategy, and **The Prime Minister’s Challenge on Dementia 2020 – Delivering Major Improvements in Dementia Care and Research by 2015** (Department of Health, 2012), which explicitly describes the imperative for the Coalition Government in terms of dementia.

More operationally, the 2016/17 NHS planning guidance expects services to achieve measurable improvement in all areas of the Prime Minister’s challenge on dementia 2020, including:

- Achieve and maintain a diagnosis rate of at least two thirds (67%);
- Increase the numbers of people receiving a dementia diagnosis within six weeks of a GP referral; and
- Improve quality of post-diagnosis treatment and support for people with dementia and their carers.

**Safeguarding is Everyone’s Business**

It is important to recognise that people with dementia and their careRs may be vulnerable and at risk of abuse and neglect. The largest proportion of abuse happens in people’s homes, but can happen wherever they live. Unintentional abuse can occur at any time.

Abuse and neglect can take many different forms including physical, medical or emotional neglect, physical or psychological abuse, financial or sexual abuse. There is evidence to show that abuse is higher than average among people with dementia
and that people with dementia can be particularly vulnerable to abuse. Dementia can make it harder to detect when abuse is taking place:

- People may find it difficult to talk about their experience of abuse.
- They may worry that they will not be believed if they speak out about abuse
- They may appear to be an ‘easy target’ for abuse because they do not have the capacity to understand what they are being told to do or the cognitive ability to remember what has happened to them.
- Many common behavioural reactions to abuse, such as withdrawal from communication or wanting other people present all the time, can also be symptoms of dementia.
- Additionally there are particular issues around mental capacity for people with dementia (ref. www.alzheimers.org.uk)

Our objective continues to be to prevent and reduce the risk of significant harm to adults from abuse or other types of exploitation, whilst supporting individuals in maintaining control over their lives and in making informed choices without coercion. Safeguarding is everybody’s business, with communities playing a part in preventing, identifying and reporting neglect and abuse and having measures in place locally to protect those least able to protect themselves. Accountability and transparency are required by all partners in delivering safeguarding.

**Technology**

Technology can be used to support people with dementia in many different ways. People with dementia and their carers already use various types of telecare to help them complete daily tasks and live safely. We are working with various partners to develop and pilot innovative ways to support people with dementia.

**Current service provision in South Gloucestershire**

Improving care and support for people with dementia is a priority for South Gloucestershire Council and South Gloucestershire Clinical Commissioning Group. Dementia features in a number of work streams including the Better Care Fund programme and Urgent Care and includes:

- Dementia Action Alliance and Dementia Friendly initiatives
- Improving diagnostic pathways
• Preventing unplanned hospital admissions
• Improving hospital care
• Reducing delayed transfers of care
• Support for care homes and end of life care planning.

More strategically the Dementia Health Improvement Team (HIT) work together and have developed action plans for five work streams:

• Transforming Care
• Dementia friendly
• Patient and Public Involvement
• Workforce
• Research

A key theme of all this work is a change in focus on toward risk reduction, early intervention and community based support, thereby delaying the point where a person’s care needs become more serious. Since 2015 South Gloucestershire Council, South Gloucestershire Clinical Commissioning Group, Avon and Wiltshire Partnership and other partners have been increasingly working together in clusters of GP practices through their multi-disciplinary team meetings.

The largest asset in dementia care is unpaid carers, families, friends and informal community support mechanisms around the person with dementia. We need to continue to raise awareness about dementia across our communities enabling carers and communities to support individuals as the disease progresses.

Implementation of recommendations and actions from the National Dementia Strategy 2009 and Prime Minister’s Dementia Challenge 2012 has brought about some significant changes however there are still gaps in services and opportunities for improvement both nationally and locally.

There are a range of services and sources of support available to people with dementia and their carers in South Gloucestershire. The diagram on the next page describes the assets and services available. It illustrates the potential ‘circle of support’ around people with dementia and their families and other carers in South Gloucestershire. This model is currently being tested with stakeholders.
GPs in South Gloucestershire have been instrumental in raising the proportion of people with dementia who have a diagnosis. Since 2012 the proportion of people estimated to have a confirmed diagnosis has increased from 37% to 60%. Our challenge now is to achieve the 67% national aspiration. It is estimated that over 40% of all medical admissions, aged 70 years or over, have dementia but only half have a confirmed diagnosis (NICE, 2006).

South Gloucestershire Clinical Commissioning Group commissioned a dementia services review (Expanding Options for people living with dementia, by Trevor Eardley of Organi Consulting, 2015) which found that service users and their carers feel that there is a lack of coordination of support across agencies. This is a particular problem for those with complex needs. Another problem identified is that the majority of support is only accessible between normal office hours and the availability of emergency respite is limited and difficult to access.

We also acknowledge that a number of organisations bring a significant income into South Gloucestershire through fundraising activities.

We have also commissioned various pieces of research in recent years. We have brought this research together to understand what it tells us in the Dementia Joint Strategic Needs Assessment (JSNA). We now need to listen to what people with dementia, their carers, staff and partners say to understand local gaps in communities, support and services. This is the purpose of the consultation which will inform the final version of this strategy and our action plan.
5. Where we want to be

By delivering the priorities and actions set-out in this strategy we aim to ensure that people with dementia and their carers are treated as individuals and are able to access the right support and care, at the right time so that they can continue to live well with dementia within supportive and understanding communities.

This means that truly delivering our vision for South Gloucestershire involves every member of the community. We will work with local communities to support, understand and include people with dementia so that they can live well as active and valued members of our society. This will be achieved by continuing to deliver dementia friendly communities across South Gloucestershire.

For those living with dementia we will ensure that services are joined up so that it is easy for people to access the support and care and that they need, to avoid crisis, without falling in to gaps between services.

We will develop a diagnosis pathway to help younger people with memory concerns and develop support tailored to younger people living well with a dementia diagnosis.

We will take a proactive approach to supporting people to stay within their home and community wherever possible through the provision of care and support so that they can live well on a daily basis. At difficult times, such as crisis or illness, if people do need to travel to health or care services that cannot be delivered within their community, e.g. acute hospitals and/or specialist inpatient hospitals, this will be for as short a time as possible, with the aim to get the person back to their home as soon as possible.

We would like to review the ways in which we offer hospital care for people with dementia. We will investigate and develop a range of options and community facilities to offer range of care and support to meet the various and sometimes complex and challenging behaviours of people with dementia. This will prevent and reduce hospital admission and therefore reducing acute care costs.

Wherever possible, South Gloucestershire Council and South Gloucestershire Clinical Commissioning Group will work with these organisations to co-produce new service developments to complement existing service provision and strategic approaches.

Most of the recommendations in the ‘Expanding Options for People Living with Dementia’ report relate directly to services, but the three below are about how we plan these services and support:
• The dementia strategy should be fully costed and be underpinned by a detailed implementation plan, the delivery of which should be regularly monitored and reported on (recommendation no 1).

• There is a detailed mapping exercise which plots high levels of dementia in the population, ward by ward, against the location of current services (recommendation no 2).

• A project management discipline should be adopted for the delivery of projects and initiatives within an overall programme dictated by the dementia strategy (recommendation no 3).

We will endeavour to adhere to these principles in the delivery of this strategy.

6. Key Influences

Care Act, 2014

The Act has most relevance for people with dementia and their carers in these areas:

• General responsibilities of local authorities
• Determining who is entitled to care and support
• Charging for care and financial assessment – personal budgets
• Integration and partnership working between health, social care and housing
• Information Advice and Advocacy
• Adult safeguarding

Five Year Forward View, 2015

This plan for the NHS is far ranging and gives priority to:

• Helping people to lead healthier lives;
• Giving people more control of their own care;
• More integrated treatment and care, across health and social care, primary and secondary care and physical and mental health (‘Parity of Esteem’);
• Care provided in a un-institutional setting as possible;
• Stronger partnership between NHS, Councils and local communities

Asset Based Community Development (ABCD)

Building on existing resources, recognising the unique contribution of:

• People with dementia themselves and their potential to live well;
• Families and friends capacity to support them to live well;
• Neighbours and local communities welcoming people living with dementia;
• Voluntary sector capacity building, community development and advocacy;
• Public sector funding person centred services, infrastructure and support;
• Private sector welcoming people living with dementia as customers;
• Partnerships to combine above strengths to help people with dementia live well.

Models of Care
There are different models of care for people with dementia displaying distressed including Contented Care and The Newcastle Model.

The Newcastle Model
A biopsychosocial approach to improve the care and support of people with dementia whom care providers understandably find challenging.

Someone who cannot communicate very effectively through speech will often express their unmet needs through their behaviour. A person centred approach based on this understanding is likely to be much more successful than one that sees behaviour as a symptom of dementia that needs to be treated or removed.

The Newcastle model is one such approach, it is a structured way of working with care staff to get them to generate ideas and then test these out systematically. The Care Home Liaison Team at Avon and Wiltshire Partnership has been trained in this approach and use it in their support for local care homes.

7. Our Priorities
Increase awareness and understanding of dementia amongst professionals and the public.

Context
Increasing awareness of and understanding of dementia is important for a number of reasons: to enable people to take steps to reduce their risk of dementia, to encourage people with symptoms to access support, to enable communities to support people with dementia and recognise symptoms in friends and family, and to promote professional understanding.

There is growing evidence indicating that certain medical conditions - such as high blood pressure, diabetes and obesity - may increase the risk of dementia, whereas a healthy lifestyle may reduce the risk. We recognise that minimising people’s risk of developing
dementia is also important for the population as a whole. We will raise awareness of the healthy lifestyle choices people can make to reduce their risk of dementia, and stay fit, well and independent as they get older.

**Ongoing Work**

South Gloucestershire Dementia Action Alliance will continue to work with Dementia Friends and other partners to increase understanding of dementia and build community support for people with dementia.

South Gloucestershire Council has a range of initiatives to encourage older people to have active and healthy lifestyles.

Promote the local 'Living Well with Dementia' Roadshows and new Dementia Guide to Services which includes healthy living messages.

**Could Do**

Continue focus on raising awareness of dementia amongst minority communities.

Use national public health initiatives promoting healthy lifestyles amongst people over 50 years of age.

Develop mix of Roadshows, delivering them in GP surgeries as well as in large community facilities.

Ensure that health and care staff are aware of and promotes the importance of healthy lifestyles.

Through the Dementia HIT link up health, social care and hospitals to create generic dementia training. Enabling the workforce to move between sectors without needing to take additional training.

Improve diagnosis rates and ensure a timely diagnosis for those with dementia.

**Context**

For people with dementia, their carers and families timely diagnosis will promote choice, allow them to plan for the life changes they will experience, and access support needed to maintain independence.

GP education and awareness raising has been a key focus in South Gloucestershire over recent years and diagnosis rates have increased. However more needs to be done to
make people aware of the signs and symptoms of dementia and the help available, to encourage them to seek help and get access to timely treatment and support.

**Ongoing Work**

Supporting GP practices to ensure that all people with memory concerns have a timely assessment, and diagnosis if appropriate.

Working with Avon and Wiltshire Partnership and other partners in the Strategic Clinical Network’s Dementia Improvement Group to enable us to demonstrate that people referred to the Memory Service for assessment receive their diagnosis within 6 weeks.

The Care Home Liaison service is developing its offer to care homes, a combination of support with the management of individual residents and training tailored to the needs of their staff.

We use a specific dementia screening tool for people with Downs Syndrome called the DLD. We try to establish a baseline assessment as early as possible and we closely monitor people for potential changes. For other learning difficulties we use the same assessment, but gain a baseline when changes are already indicated. We maintain a local data base to ensure that repeat DLDs are completed in a timely way and all changes are recorded to ensure people are supported through the Dementia pathway.

**Future Plans**

Build on the current GP knowledge base to improve the recognition of cognitive decline and normal changes with age.

Consider a self-referral clinic for people worried about their cognition.

Improve diagnosis pathway for younger people with dementia to ensure a timely diagnosis.

Investigate the feasibility of ongoing monitoring of people that have had a diagnosis of mild cognitive impairment for potential progression to a dementia diagnosis.

Ensure collaboration between different services so that they can all be aware that someone may have a diagnosis of dementia (because the person with dementia may not remember this) and that undiagnosed cognitive impairment is reported back to the GP to investigate from secondary care services or social care.
Continue to develop the message to the public that there are positive aspects to having a diagnosis including remaining ‘in charge’ of decisions by making and appointing a Lasting Power Of Attorney.

South Gloucestershire Clinical Commissioning Group will support GP practices to be recognised as ‘Dementia Friendly Surgeries’.

Sirona and other providers of community health and voluntary sector services will ensure that people with cognition concerns are offered screening tests and referral to their GP where appropriate.

Ensure high quality information about dementia, local services and support is available to all those with a dementia diagnosis and their carers

**Context**

Everyone needs good quality information to enable them to make the right choices to plan their future, make the best decisions possible in relation to their care and support needs and to make decisions for a time in the future when they may not be able to make those decisions themselves. This is particularly important the people with dementia and their carers.

We originally used Dementia Challenge funding to improve and increase the information available to people with dementia and their carers including: the development of the ‘Living Well with Dementia’ Roadshows and a Dementia Information Prescription.

**Ongoing Work**

The ‘Living Well with Dementia’ Roadshows will continue in 2016/17, these will be less frequently and complemented by the piloting of ‘mini Roadshows’ in GP Practices.

The Avon and Wiltshire Partnership Memory Service offers post-diagnostic support to all people with dementia diagnosis and their carers.

Over recent years we have improved and continue to improve services and support for people living with dementia are available on the Well Aware website and telephone help line.

A new, more accessible ‘Dementia Guide to Services’ has been developed and is available to replace the Information Prescription.
The Alzheimer’s Society offer a local and national information and advice helpline, a range of factsheets, carers groups and social activities to support people with dementia and their carers.

The Community Learning Difficulties Team has a range of accessible information about having a learning difficulty and dementia which includes: where you can get support and who might give you that support, information for people who may be more likely to get dementia and the various tests and treatments you might expect if you are being investigated or treated for dementia and have a learning difficulty.

**Future Plans**

New Dementia Advisors will be the main contact to enable people with dementia and their carers to access information and services to meet the needs of the person with dementia generally and when in crisis. Ensuring that they can access the right support and services at the right time.

Ensure support and services are available for younger people with a diagnosis of dementia.

New Community Connectors will support individuals: to access a range of information and activities, to develop skills and develop strong local support networks. The aim is to improve individual wellbeing and self-care using social prescribing techniques. The Community Connectors project is a community led by volunteers who will be supported by paid staff, in 6 neighbourhoods.

We are working with various partners to develop and pilot innovative ways to support people with dementia and are hoping to recruit people to support this initiative.

**Develop care and support to meet the needs of individuals with dementia, their families and other carers, to maintain independence and avoid crisis**

**Context**

Once someone has received a diagnosis of dementia there will be a range of different types of support they and their families will need. If the condition is already advanced, some will be in need of health and care support straight away, while others may not have reached that point yet. However, everyone will need support, advice and help to understand what it means to have dementia, what they can do to live as well as possible with the condition and to enable them to plan for the future.
**Ongoing Work**

South Gloucestershire Council, South Gloucestershire Clinical Commissioning Group, Sirona and the Alzheimer’s Society are collaborating to offer support specifically for people living with dementia in each cluster of GP practices. This service will start in 2016/17 and will be provided by a Mental Health nurse in Cluster 5 and Dementia Advisor or the Alzheimer’s Society in each of the other five clusters. The Alzheimer’s Society will continue to work across South Gloucestershire. The Dementia Advisor posts are funded for a year, by the South Gloucestershire Clinical Commissioning Group. This collaboration means that people with dementia and their carers will have a named contact that they will be able to liaise with they need support in crisis.

**Future Plans**

Collaboration between Dementia Advisors, Community Connectors, Integrated Care Practitioners, Frailty Service and Health Champions to develop community resources in each cluster and enable individuals to access them and thereby reduce isolation.

Early experience of the Dementia Advisors can help shape future provision of support for people with dementia and carers with particular regard to:

- The scale of support people require, and the model.
- How to meet the needs of different people e.g. younger people with dementia, people from black and other minority communities and those diagnosed with mild cognitive impairments.
- The level of demand and potential benefit from non-pharmaceutical therapies including Cognitive Behavioural Therapy, mindfulness and meaningful activities specifically for people with dementia.

We have developed a day of specialist training for care home staff to support people with a learning difficulty and a dementia diagnosis. We are hoping to adapt this training and to roll it out to supported living providers and family carers.

Commissioning arrangements for individuals living in the community should be reviewed. This should give providers discretion to deploy additional staff on a temporary basis to better manage crises, due either to changes in behaviour, or because of physical illness, thereby avoiding unnecessary hospital admissions. Any flexibility should be time limited, monitored closely and contribute towards the CCG’s personalised care target (Expanding Options report recommendation no 4).
A dementia ‘Hub’ should be developed which may include at its core extra care housing and/ or nursing care, day services and emergency respite. This new facility could provide a base for out of hours/ crisis response teams (Expanding Options report, recommendation no 13).

Commissioners should keep under review the need for a crisis response team specifically for people living with dementia which also operates out of normal working hours (Expanding Options report, recommendation no 19).

Recognise the contribution of carers, and encourage and enable them to look after their own health and wellbeing as well as those they care for.

Context
Supporting carers should be an integral part of the care and support package for people with dementia. When carers are well supported, they can provide better care for the person with dementia, leading to better outcomes for all.

Ongoing Work
A new ‘Understanding and Supporting the Needs of Carers’ strategy is out to consultation at the same time as this Dementia Strategy. It focuses on improving support for all carers including those caring for a family member or a friend with dementia.

The Alzheimer’s Society and Carers Support Centre deliver training for carers, some specifically for carers of people with dementia, but their capacity to do so is limited.

The Alzheimer’s Society offer a local and national information and advice helpline and a range of factsheets to support people with dementia and their carers.

Both local acute trusts (North Bristol Trust and University Hospitals Bristol) have carers strategies and carers support workers to support people in hospital including people with dementia and their carers.

Future Plans
Commissioners should support carers organisations to develop strategies to increase the number of training sessions in relation to carers supporting people with dementia.

Training should be based on real life experience Avon and Wiltshire Mental Health Partnership, South Gloucestershire Council, Sirona and other partners are piloting ‘Hints
and Tips for Real Life with Dementia’ training for carers of people with dementia in early 2016/17.

Investigate support for people who do not wish or are unable to attend groups.

**Improve provision for people who can no longer live at home, supporting care homes to meet the needs of people with dementia and developing alternatives**

**Context**

By encouraging people to live well with dementia it is hoped to reduce the number of people who will need care homes services, but knowing there is good, affordable care available to people with dementia can reduce anxiety for both carers and the person with dementia. In South Gloucestershire there is a shortage of nursing home places for people with dementia, and little or no alternative provision. On occasion this results in people being placed away from their communities; a lack of availability for respite beds and people whose dementia was causing them to exhibit, behaviours that challenge means that they often spent longer than necessary in hospital where they might need the support of a single worker 24 hours a day.

**Ongoing Work**

There is no nationally recognised training for care and support workers, providers often purchase training by a variety of providers. South Gloucestershire Council has worked with Skills for Care to develop work in this area as well as providing training for people working with people with dementia for home care, care home and other health and social care staff.

During 2016 we plan to introduce a new outcome based person centred care home contract and specification. During consultations with care home providers we heard that on occasion there was a reluctance to accept new placements into their home for people with behaviours that challenge. This was because of concerns about the safety of other residents, their staff lacked confidence in dealing with anti-social behaviours and they felt community support services did not support them if they experienced difficulties. We also heard from the care home providers that often when someone exhibited anti-social behaviours, the only alternative open to them was to arrange admission into a hospital setting.
Care Home Liaison at Avon and Wiltshire Partnership support care homes to manage the residents they find most challenging, most of whom have dementia. In 2015/16 the South Gloucestershire Clinical Commissioning Group made an additional investment to enable them to work with all 40 care homes. A further three year’s funding has recently been agreed to enable them to continue to do so, and to develop and deliver training programmes in the care homes. We anticipate through their intervention the lives of people with dementia and living in care homes will be enriched and stable, creating a greater confidence that people with dementia can live well in care homes and reduce the fears and anxiety of people diagnosed with dementia. From a safeguarding perspective it is hoped that improved staff knowledge about meeting the individual needs of people with dementia will reduce the number of incidents between residents.

It has been calculated that one new care home with nursing that provides services for people with dementia needs to open in South Gloucestershire annually. We know about 3 new care homes with nursing which will provide services for people with dementia being built in the area, we will work to encourage further private investment to build care homes to provide choice for people considering living in a care home.

We have developed a day of specialist training for care home staff to support people with a learning difficulty and a dementia diagnosis.

**Future Plans**

Investigate respite support for carers of people living with dementia to make it more creative, flexible, and accessible. This should include investigating the development of “pop in”, overnight care, or evening sitting service rather than the service user being placed in a specialist respite accommodation for a number of weeks throughout the year (Expanding Options report recommendation no 6). Potentially redistributing funding from acute hospitals into community provision.

Map information to give precise details of the number, location and additional capacity needed to address the shortfall in specialist care home provision. (Expanding Options report recommendation no 7).

Investigate the development of specialist extra-care housing for people with dementia (Expanding Options report recommendation no 8).
Explore whether specialist Shared Lives placements could be an alternative to care home placements and/or emergency respite (Expanding Options report recommendation no 9).

Investigate requiring specialist care homes to become accredited to the Dementia Quality Mark for Care Homes, or similar quality mark (Expanding Options report, recommendation no 10).

High quality hospital care and alternatives to hospital care for people with dementia, including pathways to ensure appropriate and timely and discharge

Context

The length of stay of for people in North Bristol Trust has reduce in the past two years but the length of stay for people with dementia is twice that of people of the same age who do not have dementia.

Most people admitted to the South Gloucestershire Clinical Commissioning Group’s beds in Laurel Ward, Callington Road Hospital stay for months not days. Their health often deteriorates before they can be discharged, and other people are denied access to assessment.

Ongoing Work

North Bristol Trust has a dementia team of: clinical lead, dementia matron and a dementia trainer. The Trust is working towards improving the admission for people with dementia, by providing meaningful activity programmes and a better environment, developing the care pathway for people with cognitive impairment or dementia.

Hospital is not the right place to make a diagnosis of dementia so GPs are informed when the inpatient team thinks there may be a problem with cognition. All members of staff (clinical and nonclinical) receive training in dementia. There is a cognitive care bundle which should allow personal care plans to be in place for each person.

North Bristol Trust and the Alzheimer’s Society have established a Memory Café at Southmead Hospital that has been of great support to people living with dementia and carers.

We have specialist Learning Difficulties Hospital Liaison Nurses at Southmead Hospital to support people with learning difficulties and dementia.
Work has started to define operational standards consistent with the Choice Directive for Laurel Ward at Callington Road Hospital. A priority for 2016.

Avon and Wiltshire Partnership improved the physical environment on Laurel Ward and Callington Road in 2015.

**Future Plans**

Laurel Ward at Callington Road Hospital should be supported to undertake a further streamlining of existing processes in order to reduce delays and minimise risks associated with protracted lengths of stay (Expanding Options report recommendation no 14).

Consider any potential value in co-locating adult social work practitioners within inpatient units (Expanding Options report recommendation no 15).

Share the learning from initiatives in the acute sector and Avon and Wiltshire Partnership, where appropriate, and apply to relevant parts of each organisation (Expanding Options report, recommendation no 16).

Laurel Ward at Callington Road Hospital should clarify and widely publicise its admission criteria and explore how its staff team can be creatively deployed to support safer discharge (Expanding Options report, recommendation no 17).

Commissioners should explore the feasibility of a ‘Discharge to Assess’ model and possible associated step down facility for people with dementia (Expanding Options report recommendation no 18).

Commissioners should develop, with partner agencies, appropriate guidance for the implementation of the Choice Directive (Expanding Options report, recommendation no 20).

We are investigating the Discharge to Assess process to ensure that people with learning difficulties have the same access to this service. Considering whether there is a need to commission specialist beds in the future.
High quality end of life care

**Context**

Dementia is a progressive condition for which there is currently no cure. All people who develop dementia will have dementia at the end of their lives, either as the condition they die from or as a factor which may complicate the care of a different condition.

Diminishing capacity means that it is important for the person with dementia to plan for the end of their life at an early stage. Problems with capacity and communication can also contribute to undignified treatment and the under treatment of pain in people with dementia at the end of their lives.

The Department of Health (2008) suggests that, for many, a good death would involve being treated as an individual, with dignity and respect, without pain and other symptoms, in familiar surroundings and in the company of close family and friends. However people with dementia may not be referred for specialist end of life care or receive inappropriate treatment.

People with dementia have the same right to a good death as people with other health conditions.

**Ongoing Work**

We offer courses for managers and practitioners who work with people with dementia to consider approaches and practices that work well when connecting with people who live with dementia as the disease progresses.

The End of Life Co-ordination Centre operates seven days per week and coordinates referrals for end of life care in the last few months of an individual’s life to enable people to choose where they want to be cared for. We know that most people want to die at home instead of in hospital but it doesn’t always happen. We want to make sure individuals and their carers feel supported and confident to cope at home at end of life where this is a person’s preference and that the right care is provided at the right time by the right services and staff.

Our practice ensures that there is a specific focus on good end of life care and planning for people with learning difficulties and dementia.
**Future Plans**

Dementia Advisors should encourage all people with dementia to record their wishes for person with dementia to plan for the end of their life at an early stage.

We should always focus on quality of life, rather than length of life, in the final stages of dementia. Withholding or withdrawing treatment is especially ethically complex and emotionally challenging for a person with dementia as they may lack the ability to communicate, the capacity to make decisions and may not have prepared instructions about their wishes. There should always be an honest and open discussion between medical professionals and family, friends and carers about any decisions to withhold or withdraw treatment.

The quality of life and comfort of the person with dementia is paramount. Palliative and comfort care should be available to the person at all times and appropriate emotional support should be available for families.

Declining ability to communicate characterises the later stages of dementia. All health and social care professionals should be trained to provide high-quality, person-centred care to improve dignity and quality of life even when communication has diminished. We need to ensure that people working with someone at the end of their life are able to communicate honestly and sensitively, both to the person with dementia and their families.

8. Measuring success, action plan and governance

Outcomes

The Department of Health (Quality Outcomes for People with Dementia: building on the work of the National Dementia Strategy, September 2010) developed the outcomes below for use by local areas to ensure that they are working to the standards in the National Dementia Strategy. We will know that we have succeeded when individuals, both those with dementia, their carers and people generally say:

- I am encouraged and given the opportunity to have a healthy, active lifestyle.
- I was diagnosed early and with the correct medication and treatment package.
- I understand the implications of my diagnosis in order for me to make good decisions and provide for future decision making.
- I get the treatment and support which are best for my dementia and my life.
• I am treated with dignity and respect.
• I know what I can do to help myself and who else can help me, especially in times of crisis.
• Those around me and looking after me are well supported.
• I can enjoy life.
• I feel part of a community and I’m inspired to give something back.
• I am confident my end of life wishes will be respected. I can expect a good death.

Action Plan

The detailed commitments that will help us achieve this strategy will be developed after the consultation and will be included in our action plan. The action plan will also addresses the priorities, improvements and gaps identified in the Dementia JSNA.

The action plan will be led by South Gloucestershire Council and South Gloucestershire Clinical Commissioning Group and will be delivered in partnership with the local organisations from whom we commission services.

Governance

The action plan will be overseen by the South Gloucestershire Dementia Planning Group. This group is a multiagency group that is jointly chaired by South Gloucestershire Clinical Commissioning Group and South Gloucestershire Council and consists of representatives from health and social care organisations and the voluntary sector. It meets bi-monthly and is accountable to the Better Care Fund Delivery Group and the Health and Wellbeing Board via the Older People’s Planning Group.

9. Bibliography

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