

A toolkit for developing a local Health and Social Care Dementia Strategy

1. Introduction

This toolkit follows on from the 2010 – 2015 Dementia and Older People's Mental Health Strategy. It is designed to aid the development of local action plans and approaches to diagnosing and supporting people with dementia and their carers. It is not designed as an exhaustive resource, rather a tool to signpost commissioners, service developers, and providers towards information about what might need to be considered to deliver good dementia services for a local area. It may also be helpful for people living with dementia and their families to find out more.

The previous strategy was based on five tiers:

- Health promotion
- Primary and Community Care
- Intermediate Care
- Hospital inpatient care
- Long term care
- Carers

Over the past five years there has been significant progress in the development of local action plans and partnership working to improve access to services in health settings and in the community. However with the changing landscape of health and social care local Clinical Commissioning Group areas will have responsibility for driving forward local action. It will be imperative that these focus not only on improving clinical diagnosis rates but also on support to people with dementia and their carers in the community after a diagnosis.

2. Key achievements of the 2010-2015 strategy

- Countywide public awareness campaign for Dementia Friendly Surrey
- Improved access to information and advice within the community and health settings through information boards, website reviews and developing local directory of services
- Established Dementia Local Implementation Groups responsible for developing local area responses to the Surrey strategy and developed a local pathway for each area.
- Worked in partnership with borough and district councils to increase community based support for people with dementia
- Increased access to dementia training for the community and health and social care workforce and established a dementia training consortium.
- Increased diagnosis rates across the county through local pilot schemes
- Supported partnership working with care homes with area care home forums
- Supported the increase of telecare for people with dementia by accessing demonstration sites in each of the live Wellbeing Centres
- Worked with acute trusts to establish clinical leads at all acute hospitals in Surrey
- Established the butterfly scheme
- Improved information and services for end of life care with end of life care planning document
- Established a pool of dementia navigators across the county responsible for providing 1:1 support for people living with dementia and their families
- In process of improving day care options for people with dementia to offer a more flexible service for people with dementia and their carers.

3. Gaps identified and work still to do

- Young Onset
- Access to specialist dementia training in care homes
- Parity for learning disabilities
- Sustainability of dementia local implementation groups and ensuring a continued local forum
- Clinical gaps

4. What should a local strategy / action plan include?

When developing a local strategy or action plan, the following areas should be considered. Included in here are guidelines on how to commission dementia services as well as identifying the local need of the population, and where to access information and advice specific to your local area.

➤ **What is good practice?**

- In 2013, Visits were carried out to a sample of Clinical Commissioning Groups which highlighted the tremendous work being undertaken to improve the timeliness of diagnosis and post-diagnostic support. Several CCGs reported having effective multi-agency groups, with good patient and carer representation to coordinate and drive forward local improvement initiatives. Involvement of the voluntary sector was seen as clearly making a huge difference in many areas. During the visits a number of challenges were identified, including issues around the role of GPs in diagnosis and follow up, cultural issues, waiting times for assessment and diagnosis, support available to people with early onset dementia and workforce training. The visits provided an opportunity to listen and learn, and highlight actions that need to be carried out to help and support organisations to fulfil the national ambition by 2015. It is hoped this report is informative and promotes discussion. Further feedback or observations are both welcomed and encouraged. Read the report here <http://www.england.nhs.uk/wp-content/uploads/2014/04/learn-ccgs-rep.pdf>
- DemTalk is the online toolkit for effective communication with and for people living with dementia. It offers free advice and shares ideas about how everyone can make communication easier and better. Read more here <http://www.demtalk.org.uk>
- This guide includes the mapped areas of care for the NICE quality standard for end of life care for adults and covers settings in which care is provided by health and social care staff to adults (aged 18 years and over) approaching the end of life, and adults who die suddenly or after a very brief illness. It also includes support for families and carers of people in these groups. Read more here: <https://www.nice.org.uk/guidance/cg42>
- This 'Support for commissioning' summarises the key commissioning issues and the resource impact that will arise from implementing the recommendations in NICE guidance and other NICE accredited guidance, to support the improvements in the quality of care for older people with dementia, in line with the statements and measures that comprise the NICE quality standards for dementia. Read more here: <https://www.nice.org.uk/guidance/cm948>
- Commissioning tool <https://www.nice.org.uk/guidance/cg42/resources/cm948-nice-support-for-commissioners-of-dementia-care2>

➤ **Local good practice examples**

- NW Surrey Crisis response
- Care Home Forums
- GP nurse, admiral nurse, Link worker etc

➤ Understanding the local population

Dementia Prevalence calculator

The Dementia Prevalence Calculator (The calculator) has been revised and updated for 2014-15. The calculator presents an opportunity for all health communities to gain a better understanding of their local estimated prevalence of dementia in the community, and among people living in local care homes. The tool enables General Practices and commissioners to establish a baseline by which to set and work toward local quantified ambitions for improvement in diagnosis rates, as set out in NHS Mandate, and inform local joint strategic planning, commissioning, and service redesign and improvement.

In particular, the calculator should be used in conjunction with the following NICE resources:

- [NICE cost impact and commissioning assessment quality standard for dementia](#)
- [CMG48 NICE support for commissioners of dementia care](#)
- [QS1 Quality Standard for dementia](#)
- [QS30 Quality standard for supporting people to live well with dementia](#)
- [CG42 Dementia: Supporting people with dementia and their carers in health and social care](#)

Other resources

- This NICE quality standard defines a high standard of care with specific, concise quality statements, measures and audience descriptors to provide patients and the public, health and social care professionals, commissioners and service providers with definitions of high-quality care. This covers direct contact with people with dementia in hospital, community, home-based, group care, residential or specialist care settings. It should be considered in conjunction with [NICE Quality Standard 30 on supporting people to live well with dementia](#) (QS30).

Surreyi

- [Surreyi](#) has a wealth of information available on population statistics and commissioning needs for local areas including access to the Joint Strategic Needs Assessment which has a specific chapter on dementia, locality commissioning profiles, and health and wellbeing information.

➤ Prevention

- As the exact cause of dementia is still unknown, there is no way to prevent the condition. However, there are some steps you can take that may help to delay the onset of dementia. To read more click here: <http://www.nhs.uk/Conditions/Alzheimers-disease/Pages/Prevention.aspx>
- This [Myths and facts about dementia](#) leaflet highlight some of the common misconceptions about dementia and how it can develop and be prevented.

➤ Improving diagnosis rates

- Generally, we all forget things but if it starts to be a problem and interfere with the ability to do every day activities, it should not be ignored. Forgetting important dates or events, or asking for the same information over and over again are signs to look out for and speak to the GP about. The GP can offer information and advice about a range of support options available and help people continue to lead a full and active life. The dementia friendly surrey programme lead a county wide public awareness

campaign in September 2013, September 214 and January 2015. To access the materials, please visit www.dementiafriendlysurrey.org.uk

- [Dementia Diagnosis & Care in England: learning from clinical commissioning groups reports the findings from visits to several CCGs to look at the work being done around timely diagnosis and support.](#) The visits provided an opportunity to listen and learn, and highlight actions that need to be carried out to help and support organisations to fulfil the national ambition by 2015. It is hoped this report is informative and promotes discussion. Further feedback or observations are both welcomed and encouraged.
- An objective of the National Dementia Strategy is to increase the number of people receiving a good quality early diagnosis of dementia which allows for planning and receiving treatment and care earlier. This is a link to a NICE guidance on improving early identification, assessment and diagnosis. <https://www.nice.org.uk/guidance/cm948/chapter/51-improving-early-identification-assessment-and-diagnosis>
- The Primary Care Toolkit is a guide developed in partnership by NHS England aimed at GPs and practice nurses around diagnosis and treatment of dementia., <http://www.england.nhs.uk/wp-content/uploads/2014/09/dementia-revealed-toolkit.pdf>

➤ **People with learning disabilities**

- People with Down's syndrome are at a particular risk of developing the disease. According to the Down's Syndrome Association, as many as one in three people with the condition develop dementia in their lifetime, usually as a result of Alzheimer's disease.
- Symptoms of dementia in people with Down's syndrome are generally similar to those in the general population, although there are a few differences. For example, people with Down's syndrome are more prone to epilepsy, to a younger onset of the disease and to faster progression.
- **The Down's Syndrome Association** provide a publication entitled '[Down's Syndrome and Alzheimer's Disease: A Guide for Parents and Carers](#)' (PDF).
- **The foundation for people with learning disabilities** has a wealth of information <http://www.learningdisabilities.org.uk/help-information/learning-disability-a-z/d/dementia/>
- **British Institute for Learning Disabilities (BILD)** has produced several publications on learning disabilities and dementia including 'Down's syndrome and dementia' (for professionals), 'About dementia' (for people with learning disabilities) and 'About my friend' (for friends of people with Down's syndrome and dementia).
- **The Royal College of Psychiatrists** has provided [guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia.](#)
- **Joseph Rowntree Foundation (2010)** [Supporting Derek - a new resource for staff working with people who have a learning difficulty and dementia](#)

➤ **Support following a diagnosis**

Clinical support - **Dementia Partnership Board to input**

- NICE guidance for clinicians/ health commissioners to refer to for information on medication, treatment and management <https://www.nice.org.uk/guidance/conditions-and-diseases/mental-health-and-behavioural-conditions/dementia>

Community based support

- Increased investment in the identification of people with dementia means that greater numbers of people are being diagnosed with dementia, often at an early stage. This creates greater demand for services that support people with dementia to live well and independently for as long as possible. However, there is evidence that this care can help prevent crises, avoid unnecessary hospital admissions, reduce the avoidable use of residential care and improve quality of life. Support in the community can range from information and advice about the illness, and helping people to cope with a diagnosis. It can also refer people to support services such as day care or community opportunities, This support should be able to service anyone diagnosed with dementia irrespective of age. Services for young onset dementia are historically rare in the UK and commissioners should look to identify where there are gaps in specific provision or assess how people may be supported with within existing services. <https://www.nice.org.uk/guidance/cm948/chapter/52-living-well-with-dementia>
- The NICE Quality Standard for supporting people to live well with dementia should be read alongside NICE Dementia quality standard (QS1). It is aimed at care providers and carers with resources and practical tools <https://www.nice.org.uk/guidance/qs30>

Dementia Roadmap.

- The tool aims to assist busy primary care professionals in Surrey to provide effective support to people with dementia and their families. For more information click [here](#).

How to develop Dementia Friendly Communities

- People with dementia and their carers have told Dementia Friendly Surrey what would make their community better. Lots of ideas have been generated and feedback highlights that it is often the simple things that can make the biggest difference. A summary of what people told us and the steps being taken as a result has been is available to download [here](#)
- A national report has also captured the experiences of people with dementia and carers and offers ten areas of focus for communities working to become dementia friendly. Download the report [here](#).
- For more information see Dementia Friendly Surrey web pages http://www.surreyinformationpoint.org.uk/kb5/surrey/sip/guided_knowledge.page?outcome=h26 or Alzheimer's Society website <http://www.alzheimers.org.uk/site/scripts/downloads.php?categoryID=200436>

Dementia Champions.

Dementia Friendly Champions were set up as part of the Dementia Friendly Surrey Project in 2013. Champions are volunteers in the local community and could be interested individuals or representatives from an organisation. They are not expected to commit a fixed amount of time to dementia friendly activity. Some examples of how Dementia Champions might be able to benefit their local community are:

- ✓ share your experience of dementia with other people to help them understand what it is like to live with dementia or care for someone who has dementia
- ✓ raise awareness of dementia in your workplace, school or groups you belong to
- ✓ help to promote Dementia Friendly Surrey and encourage others to become Dementia Friendly Surrey Champions
- ✓ encourage your employer to consider signing up as a Dementia Friendly Surrey Champion organisation
- ✓ attend training to learn more about what it is like to live with dementia and how you can support people with dementia in your community
- ✓ volunteer with an organisation that supports people with dementia

Wellbeing Centres

- Wellbeing Centres are local hubs of information and support for people worried about their memory or have a diagnosis of dementia. There are currently nine open in Surrey with plans for a further two to develop over the next 12 months. They are open to anyone, whatever their situation and whether they are concerned about themselves or others. Services and support vary at each centre so please refer to your local Wellbeing Centre for information about what is going on in your area.
- Carers, in particular, may find the Wellbeing Centre support and services very helpful in their caring role. At your local Wellbeing Centre, specialist support workers called dementia navigators can assist you to navigate through the maze of services and get the help and support you need when dealing with memory loss and changing behaviours.

http://www.surreyinformationpoint.org.uk/kb5/surrey/sip/site.page?id=S1jUru_aU5Q

Dementia Navigators

- The Dementia Navigators are a service provided by The Alzheimer's Society in Surrey, commissioned jointly by health and social care and are available in each borough and district. They provide vital assistance to people following a diagnosis of dementia by helping them to navigate the maze of services and support available in Surrey. They help support people to access benefits they may be entitled to, provide information about the illness and the dementia journey as well as help them access peer support groups or local activities to support individuals with dementia and their carers.

Information and advice

- The Alzheimer's Society website has a range of useful forums and information and advice <http://www.alzheimers.org.uk/>
- Surrey Information Point is a website detailing support for people looking for information about local care and support services in their local area. http://www.surreyinformationpoint.org.uk/kb5/surrey/sip/guided_knowledge.page?outcome=h2

➤ **Support for carers.**

- In England, the Care Act now requires local authorities to assess carers' support needs and, if they are eligible, provide support.
- Research evidence shows that there is a lack of information at all stages of the caring journey (Carers' Trust 2013). Carers must be provided with timely information, advice and guidance to help them make effective decisions about care and support and develop effective caring strategies. This should include access to training programmes, such as the Society's Carer Information and Support Programme, to allow carers provide more effective care as dementia progresses. The Care Act now requires local authorities to provide information, advice and guidance to carers.
- Many carers would be unable to continue caring without respite care. However, one-third of carers of people with dementia had no access to respite and one-fifth found that respite was not dementia friendly (Carers' Trust, 2013). Short, regular, planned respite care provided in a person with dementia's own home is low cost and avoids undue stress.
- Research evidence shows that peer support groups for carers of people with dementia improve mental wellbeing
- For more information, please go to [Surrey Information Point Step by Step guide Looking After someone](http://www.surreyinformationpoint.org.uk/kb5/surrey/sip/guided_knowledge.page)

- Improving support for carers is a key component of the [Prime Minister's challenge on dementia](#). There are around 670,000 people in the UK acting as primary carers for people with dementia^[25]. Carers can experience high levels of anxiety, depression and stress yet their needs often go unrecognised. They save the economy millions each year. However, they need greater emotional, psychological and social support to prevent increasing admissions to residential care homes and hospital settings.
- The [NICE quality standard for dementia](#) states:
 - ✓ Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs. ([Quality statement 6](#))
 - ✓ Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia. ([Quality statement 10](#))
- Commissioners will need to:
 - ✓ Ensure they commission carers assessments that are routinely offered at the time of diagnosis to all carers (see [section 5.2.1.1](#)).
 - ✓ Identify local peer-support groups for carers that can be tailored to the needs of carers of people with dementia.
 - ✓ Ensure there is adequate capacity in services that can provide emotional, psychological and social support to carers and family members of people with dementia.
- For more information, please click on the following link <https://www.nice.org.uk/guidance/cm48/chapter/53-supporting-carers-of-people-with-dementia>
- The Carers Care Pathway is a way of helping to ensure carers receive the type of support outlined above. Depending on their role, health professionals may come into contact with carers face to face, or be involved in planning services for them or the people they look after. The Carers Care Pathway detailed below serves two purposes: to provide generic pathway for incorporation into all patient care pathways and hospital discharge procedures; and to help health staff in identifying, recognising and supporting carers. Also included is a checklist for practitioners to help ensure each stage is considered, together with links to relevant supporting information. <http://www.carerspathway.org.uk/>
- Our Plan offers helpful information for family and carers of people with dementia. It provides six steps to guide you through the dementia journey. It also provides forms to record how a person with dementia wishes to be cared for in the future. <http://www.surreyinformationpoint.org.uk/kb5/surrey/sip/site.page?id=hmLh2cpriOc>

➤ **Young Onset Dementia**

- The needs of younger people with dementia differ. This is because their lifestyle and circumstance means that they may still have a job, dependent children, mortgages and other responsibilities less likely in someone older. Support for people with Young Onset Dementia is vital to help prevent deterioration and to help people live as independently as possible for as long as possible.
- People diagnosed with young onset dementia may have support from a young carer, or their carer may have additional responsibilities' such as looking after children or being in employment. It is vital that we support carers of people with young onset dementia in the best way possible. For more information please to the following link: <http://www.surrey-youngcarers.org.uk/about-syc/>

➤ **Supporting the BME community**

There are some difficulties and barriers faced by BME carers of people with dementia, consider the following;

- Family and community expectations, stigma towards dementia sometimes regarded as a mental condition means that carers feel they do not want to bring shame onto the family by admitting someone in the family is suffering from a mental condition.
- Religious expectations of duty to care, carers feel that their faith places responsibility to care for the person with dementia. Even when carers recognise that services exist to support them there may be outside pressures from the community which means they do not access the support as doing would mean they were struggling to carry out their duty and obligation to look after the elderly.
- BME carers of people with dementia may feel that there is little or no cultural understanding or competency by practitioners to offer the most appropriate care and a 'one size fits all' approach is used.
- In order to effectively support the BME community to access dementia services it is important for practitioners and assessors to know more about the family and the role of the different genders within a household.
Dementia services need to promote what they offer and give information to support BME carers and communities rather than waiting to be contacted by potential service users.
- Above all dementia service providers need to give BME carers an opportunity to express their fears and concerns. Help and support for family and carers should meet their needs and not what the service providers think they need.
- The following Health Services Journal highlights the challenges of the growing number of older people from BME communities living with dementia and highlights that services need to be developed to support them. The article suggests navigators and befriending is a useful approach.
<http://www.hsj.co.uk/home/commissioning/dementia-the-untold-story-of-our-bme-population/5067082.article#>
- Friends with Dementia is a free-of-charge, information and support service for black and ethnic minorities in Woking, West Elmbridge and Spelthorne in Surrey. For more information visit www.fote.org.uk

➤ **Technology**

- Technology offers huge potential benefits for people with dementia, whether it's a familiar gadget such as a mobile phone and TV or a specific piece of technology to remind someone to take medication. It can enable people to live independently for longer, reducing stress on people affected by dementia. It can also potentially enhance the quality of life for both people with dementia and carers, and give them greater choices about their care.
- Dementia Friendly Technology Charter is a charter to outline available technology and how it could support people with dementia and their carers. The aim is to encourage best practice for organisations which support people with dementia. It is useful for commissioners, people with dementia, providers of technology and housing, as well as health, housing and social care professionals
http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2256
- The Wellbeing Centres also include a telecare demonstration suite, where anyone can try out the telecare equipment and understand more about how it can support people to live independently. More information on telecare can be found at:www.surreytelecare.com.

➤ **Housing and support**

- Specialist housing provides an alternative to more institutionalised forms of accommodation, such as residential or nursing. With the increasing prevalence of dementia, commissioners need to plan to meet growing demand for services, including appropriate specialist housing options. Dementia-specialist Housing as a term includes retirement accommodation, Extra Care housing and Residential / Nursing accommodation. A number of new developments now combine a range of services on one site, some or all with a dementia focus
- Within Extra Care settings in Surrey, there are many examples of individuals with dementia successfully remaining independent with care and support available to them in their homes and specialist housing can allow couples or those with caring responsibilities to remain together.

Design and environment

- Design and environment within buildings is so important for people with dementia. It can aid orientation, access and make people feel more comfortable. The following documents provide more information about what makes a dementia friendly environment and should be considered by commissioners and providers of residential and nursing care for people with dementia:
 - A guide to creating a more [dementia-friendly environment](#)
 - A guide to becoming a [dementia-friendly business](#)
 - <https://www.gov.uk/government/publications/dementia-friendly-health-and-social-care-environments-hbn-08-02>
- Services and support for people with dementia should not be commissioned in isolation. In addition to health and social care stakeholders, it is helpful to work with planning and commercial property companies: Commissioners are encouraged to engage with local planning departments to facilitate good design principles in housing for older people incorporating the dementia design principles

Support to live at home

- The NICE commissioning guide to living well with dementia includes a specific section on living at home, and links to extra care and dementia commissioning checklist <https://www.nice.org.uk/guidance/cmg48/chapter/52-living-well-with-dementia>
- Surrey County Council has information on extra care in Surrey <http://new.surreycc.gov.uk/social-care-and-health/care-and-support-for-adults/accommodation-and-housing/extra-care-housing>
- The following website gives a useful case study on how extra care schemes can support a couple affected by dementia to remain living at home together http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1101&pageNumber=3
- An extra Care Housing and Dementia Commissioning checklist is designed to help stakeholders commission extra care schemes to support people with dementia and their families. It is divided into topics which are important to consider in developing a scheme for people with dementia. <http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Commissioning/?parent=5048&child=7950>

Shared lives

- Shared Lives helps people to find a supportive homes environment where you can live as part of a family. This might be for the long term, on a short term basis or for some respite care so that your full time carers can have a break. Shared Lives is a national scheme and in Surrey it is operated by Surrey Choices. For more information please click [here](#)

Residential care and support options

- In many cases, as dementia deteriorates, a care home may become the best setting in which to care for the person with dementia. Discharge from hospital may be directly into a care home if the person is unable to manage at home. Many care homes offer the specialist care which is suited to the particular needs and requirements of the person with the condition. For information as to what a good residential care home can offer, please refer to the guides in the design and environment section above. Care homes must be registered and inspected by the Care Quality Commission (CQC). Each care home receives a star rating, making it possible to compare homes. Reports on individual care homes can be found on the CQC website. <http://www.cqc.org.uk/>

➤ **Acute care – does this form part of clinical section above? Discuss at DPB who can input**

- Hospital discharge
- Admissions avoidance
- Specialist liaison? <https://www.nice.org.uk/guidance/cmg48/chapter/52-living-well-with-dementia>

➤ **Training**

Surrey Skills Academy

- Surrey Skills Academy is a 'single point of information' for people to access a wide range of training and learning opportunities including courses, information, and signposting to partner organisations. <http://surreyskillsacademy.learningpool.com/>

Dementia Friendly Surrey Self Study Pack

- The self-study pack is available for anyone who wants to increase their awareness of the experience of dementia. This will help you to know how to support 'customers' with dementia in your workplace. By completing this self-study pack you will be participating in part of the action being taken to work towards a more Dementia Friendly Surrey. This self-study pack provides you with up to date information about dementia to read, questions to answer and case studies to complete. Download the [Self-study Pack](#).
- Skills for Care has developed a number of dementia resources and qualifications to support those who care for people with dementia, to provide good quality of life at every stage in their condition, allowing them remain active and engaged for as long as possible. <http://www.skillsforcare.org.uk/Skills/Dementia/Dementia.aspx>
- The Gold Standards Framework End of Life Care for People with Dementia Distance Learning Programme was introduced as pilot programme to identify the level of need for bespoke Dementia Care for people nearing the end of their lives. The Programme was developed in conjunction with Staffordshire University. <http://www.goldstandardsframework.org.uk/dementia-care-training-programme>