

The Sussex Integrated Dementia and End of Life Care Guidance July 2013

Sussex has the highest prevalence of dementia in the country, with more than 26,500 people living with dementia.

Access to the right information, advice and support at the right time are crucial for people living with dementia, their relatives, carers and friends to be able to manage their condition.

The Sussex Integrated Dementia and End of Life Care Guidance has been designed to help you understand what support to expect, what is possible and what support to ask for at each phase.

We hope people living with dementia, their relatives, carers and friends will use this guidance to get the help they need, when they need it and by doing so are enabled to live, and to die, well.

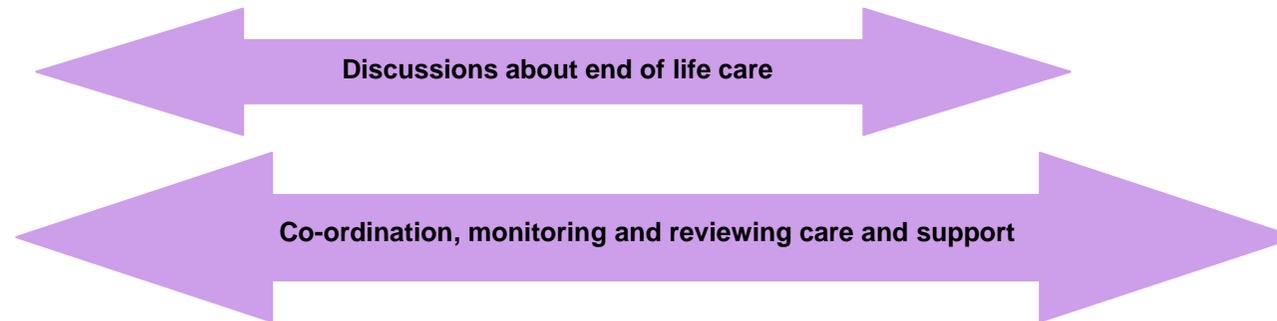
The guidance has resulted from a consultation with more than 1,800 people across Sussex. This includes people whose lives are directly affected by dementia as well as health and social care practitioners.

There are six phases of the condition:

1. Recognising there is a problem (awareness)
2. Discovering that the condition is dementia (assessment, diagnosis and involving the person with dementia in planning for their future care where appropriate)
3. Living well with dementia (maximising function and capacity to enhance wellbeing and planning for future care including end of life)
4. Getting the right help at the right time (accessing appropriate and timely support. Reviewing advance care plans)
5. Nearing the end of life, including the last days of life (palliative care and ensuring advance care plans are reviewed and respected)
6. Care after death for relatives, carers and significant others (supporting to maintain their wellbeing)

The Sussex Integrated End of Life and Dementia Care Guidance

Phase 1	Phase 2	Phase 3	Phase 4	Phase 5	Phase 6
Recognising there is a problem	Discovering that the condition is Dementia	Living Well with Dementia	Getting the right help at the right time	Nearing the end of life including care in the last days of life	Care after death for relatives, carers and significant others



It is important to remember that people with dementia can move back and forth through phases three and four and the timescale will vary according to individual circumstances and the type of dementia.

At each phase of the condition you will find internet links to sources of information, advice and local and national support. We hope this will help you to learn more about the condition, what to expect and practical ideas for managing situations that may arise. The links to local services are there to enable you to access to more direct face-to-face support.

You will also find some useful documents that will help you to plan for the future. Just click on the document icon (symbol) to download and either save to your computer to complete or print and complete.

Click on the highlighted and underlined links to access each resource.

Phases		The person with dementia, their relatives, carers and significant others are
1	Recognising there is a problem	<p>Able to easily access information about dementia to enable you to recognise early signs and how to access diagnosis, exclude other causes of changes, access appropriate support as well as understand the condition and how to positively manage its impact on daily life</p> <hr/> <p>Resources to support general understanding of dementia</p> <p>Department of Health (2011). Worried someone close to you is losing their memory?</p> <p>NHS Choices. Benefits of early diagnosis.</p> <p>NHS Choices. Symptoms of dementia See also other articles under Symptoms and diagnosis tab.</p> <p>Alzheimer’s Society. Worried about your memory?</p> <p>Age UK. Recognising symptoms of dementia</p>

2	Discovering that the condition is Dementia	<p>Offered a referral to Memory Assessment Services for diagnosis, support and Carer's Assessment if appropriate</p> <p>Given relevant information advice and support when you need it. For example, information to help you better understand dementia and its impact on daily living, financial planning, Wills, Lasting Powers of Attorney (LPA), how to live well and maintain independence, driving, future care considerations and how others can support the person's spiritual and cultural needs</p> <hr/> <p>Gov.uk (2013). Dementia and driving</p> <p>NHS Choices. Living well with dementia See also other articles in Living with dementia and Care and support tabs.</p> <p>Alzheimer's Society. Living with dementia</p> <p>Information for families, carers and significant others</p> <p>NHS Choices. Carer's Assessments</p> <p>Alzheimer's Society. Caring for a person with dementia.</p> <p>Information on legal and financial aspects of caring</p> <p>Gov.uk (2013). Financial help if you're disabled</p> <p>Gov.uk (2013). What to do if you become disabled</p> <p>Gov.uk (2013). When a mental health condition becomes a disability</p> <p>Alzheimer's Society (2012). Financial and legal affairs</p> <p>Alzheimer's Society (2012). Mental Capacity Act 2005</p> <p>NHS Choices (2012). Managing someone's legal affairs</p>
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<p>3</p>	<p>Living Well with Dementia</p>	<p>Supported to work together with professionals to maintain wellbeing, an active life, inclusion in the local community and usual everyday activities</p> <p>Given regular health and wellbeing checks by GP and care team</p> <p>Given the opportunity to discuss future care plans with relatives, carers, significant others and professionals who support you.</p> <p>Given the opportunity to record your life story which will help you and others in the future to better care for you and meet your individual needs</p> <p>Given relevant information advice and support when you need it. e.g. benefits, activities, care, respite support, Lasting Powers of Attorney (LPA)</p>
	<p>Caroline Walker Trust (2011). Eating well for older people and older people with dementia: Practical Guide</p> <p>NHS Choices. Care and support: your essential guide to social care</p> <p>NHS Choices. Living Well with Dementia - Includes external links to websites with advice and information</p> <p>Alzheimer’s Society. Eating</p> <p>Alzheimer’s Society. Exercise and physical activity for people with dementia</p> <p>National Council for Palliative Care (2012) How would I know? What would I do? How to help someone with dementia who is in pain or distress</p> <p>Department of Health (2012). Personal health budgets easy read leaflet</p> <p>NHS England. About personal health budgets</p> <p>Dementia Web information, advice and a 24 hour helpline</p>	

3	General Information	<p><u>Dementia Services Development Centre University of Stirling</u> An online interactive tool that illustrates good practice in design for people with dementia</p> <p><u>Caring Memories</u> An online tool to help you make a personalised album of memories</p> <p><u>Life Story Network</u> They aim to educate, empower and enable in order to encourage and embrace relationships built on empathy.</p> <p><u>Visit Woods</u> – information, advice and ideas about accessing and enjoying woodland</p> <p><u>Dementia Adventure</u> – A social enterprise company that provide training, research and consultancy services all with nature in mind and enabling people with dementia to take an active part in outdoor activities</p> <p><u>Active Minds</u> – activity resources for people with dementia</p>
	Local Documents	<p>Documents to support person centred care / personalisation (for person with dementia, relatives, carers (family or paid) to complete)</p> <p>This is Me Document (used in East Sussex, Brighton & Hove)</p> <div style="text-align: center;">  <p>This Is Me booklet.pdf</p> </div>

3	Local Support Services	<p>East Sussex County Council – Dementia Hub web pages with a range of information, advice, resources, support and contacts for people with dementia, their relatives and carers and professionals living and working in East Sussex</p> <p>Our Health South East - information about dementia scroll down to the ‘Support for families and carers’ tab to find out about services in Brighton & Hove, East and West Sussex</p> <p>East Sussex 1space - resource for finding help, advice and services in East Sussex to enable people to live independently, safely and in good health.</p> <p>Sussex Partnership NHS Foundation Trust - ROCK – Recovery Orientated Community Kit – information about local community resources to support mental wellbeing. Also dementia services</p>
4	Getting the Right Help at the Right Time	<p>Offered the opportunity to regularly review and record, with their GP and/or other health professionals, future care plans, their Advance Care Plan (ACP) and/or discuss Advance Decisions to Refuse Treatment. This may be annually, when there are any changes in general health and wellbeing, prior to any treatment or care when requested</p> <p>Given timely access to information and advice about common changes; how to maintain independence for as long as possible; what to do to avoid crisis; who to contact; care and support options available</p> <p>Given the opportunity to discuss and put in place contingency plans in place to manage unexpected changes and/or deterioration in wellbeing</p> <p>Offered timely and appropriate referral to specialists as need arises</p> <p>Provided with prompt access to appropriate crisis support</p> <hr/> <p>Alzheimer’s Society (2011). Assistive technology: devices to help with everyday living</p> <p>AT Dementia Website initially funded by Department of Health to raise the profile of assistive technology and provide information.</p> <p>National End of Life Care Programme 2009 Advance decisions to Refuse Treatment – A Guide</p> <p>Independent Mental Capacity Advocates – their role in supporting decision making</p> <div style="text-align: right;">  ADRT A Guide May 2009.pdf </div>

4	Local Support Services	<p>East Sussex County Council – Care for people who are dying – information, advice, documents e.g. Preferred Priorities for Care and links to all hospices in East Sussex and Brighton and Hove and other services</p>
5	Nearing the end of life including care in the last days of life	<p>Supported to access sufficient support and funding to enable the person to be cared for, as far as possible, according to their expressed wishes as recorded in the future care plan or Advance Care Plan</p> <p>Supported in ways to encourage understanding and peaceful acceptance</p> <p>Referred to and supported by services</p>
		<p>NHS Choices. End of Life Issues</p> <p>NHS Choices Accessing palliative care</p>
	Local Support Services	<p>East Sussex County Council – Care for people who are dying – information, advice, documents e.g. Preferred Priorities for Care and links to all hospices in East Sussex and other services</p>

6	<p>Care after death for relatives, carers and significant others</p>	<p>Supported sensitively and compassionately</p> <p>Provided with appropriate advice and support to meet spiritual and cultural needs</p> <p>Directed to appropriate practical and bereavement support</p> <hr/> <p>Gov.uk (2013). What to do after someone dies This page includes financial information.</p> <p>Dying Matters (2010).Leaflet 3: I could do with a chat: how to help someone close to you who has been bereaved and Leaflet 4: Someone you know is bereaved: What to do if someone you know has been bereaved</p> <p>NHS Choices. Bereavement</p> <p>NHS Choices. End of Life Issues This article for carers includes information on legal and financial issues around the death of the person they have been caring for.</p> <p>Royal College of Psychiatrists (2011). Bereavement</p> <p>Alzheimer’s Society factsheet Grief and bereavement (2010)</p> <p>Support groups</p> <p>Cruse Bereavement Care</p>
6	<p>Local Support Services</p>	<p>East Sussex Care for Carers – former carers support groups</p> <p>East Sussex County Council – Coping with bereavement</p>

	Resources Relevant to the Whole Pathway
Organisations and support groups	<p><u>Alzheimer’s Disease International</u></p> <p><u>Alzheimer’s Society</u> The website has information on all aspects of the condition. The organisation has a helpline and an online forum to discuss dementia. They also offer <u>tailored support for LGBT people with dementia and their carers</u>,</p> <p><u>Carers Trust</u> - Advice, information and network of local support groups for carers</p> <p><u>Culture Dementia UK</u> Support group for black / Afro-Caribbean people with dementia and their carers</p> <p><u>Dementia UK</u> The website has information on all aspects of the condition. The organisation provides the Admiral Nurses phone line</p> <p><u>Fronto-temporal dementia support group</u> This website provides information and has an online forum.</p> <p>Patient information leaflets</p> <p>NHS Choices (2013). <u>Dementia guide</u> An exhaustive leaflet with information on all aspects of the condition. See the Care and support tab for information about finances, legal affairs, etc.</p> <p>Patient.co.uk (2012). <u>Memory loss and dementia</u></p> <p>Alzheimer’s Research UK. <u>Dementia information</u> The charity works in research and policy only, but their website includes patient information on all clinical aspects of the disease, and a list of support groups.</p> <p>Age UK. <u>Dementia</u></p> <p><u>Lewy Body Society</u> This organisation’s primary aim is to fund research, but there is some patient information on their website.</p> <p><u>Know Dementia</u> – Sussex based charity run by family carers whose aim is to provide education, advice and information</p> <p><u>The Silver Line</u> - A free confidential helpline providing information, friendship and advice to older people open 24 hours a day seven days a week Telephone 0800 4 70 80 90</p>