

Sussex has 26,500 people living with dementia making it the county with the highest number of people living with dementia in England.

Access to the right information, advice and support at the right time is 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 stage of your care.

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 which will help them to manage their condition and live well.

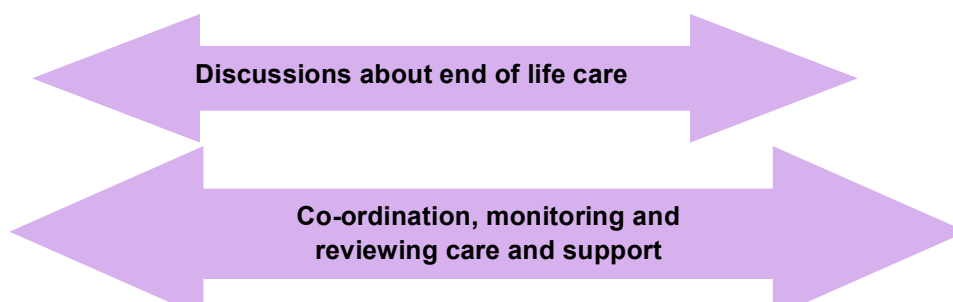
The guidance has resulted from a consultation with more than 1,800 people across Sussex. This includes people whose lives are directly affected by dementia as well as health and social care practitioners.

There are six stage of your care are:

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**

Stage 1	Stage 2	Stage 3	Stage 4	Stage 5	Stage 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 stages three and four and the timescale will vary according to individual circumstances and the type of dementia.

At each stage of your care 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.


Stage of your care	What to expect from your care
<b>Stage 1</b> <b>Recognising there is a problem</b>	<p>At this stage you should be able to easily access information about dementia to help you, or your carers, recognise early signs.</p> <p>You should be able to get help in receiving a diagnosis, explore any other causes for changes in your health and access the right support for you. In this stage you should start to understand your condition and how to manage how it affects your daily life.</p>
<b>General Information</b>	<p><b>Sussex Integrated Dementia and End of Life Care Guidance Leaflet</b>                       Dementia leaflet                      Final 25.02.14.pdf</p> <p><b>Resources to support general understanding of dementia</b></p> <p>Department of Health (2011). <a href="#">Worried someone close to you is losing their memory?</a></p> <p>NHS Choices. <a href="#">Benefits of early diagnosis.</a></p> <p>NHS Choices. <a href="#">Symptoms of dementia</a> See also other articles under <b>Symptoms and diagnosis</b> tab.</p> <p>Alzheimer’s Society. <a href="#">Worried about your memory?</a></p> <p>Age UK. <a href="#">Recognising symptoms of dementia</a></p>

<p><b>Stage 2</b></p> <p><b>Discovering that the condition is Dementia</b></p>	<p>Here you will be offered a referral to a Memory Assessment Service for your diagnosis, support and carer's assessment, if that's what you need.</p> <p>You will be given relevant information, advice and support when you need it. For example, information to help you understand your dementia and its impact on your life, financial planning, including Wills and Lasting Powers of Attorney.</p> <p>You will also get help with how to live well and maintain independence, driving, future care considerations and how others can support your spiritual and cultural needs</p>
<p><b>General Information</b></p>	<p>Gov.uk (2013). <a href="#">Dementia and driving</a></p> <p>NHS Choices. <a href="#">Living well with dementia</a> See also other articles in <b>Living with dementia</b> and <b>Care and support</b> tabs.</p> <p>Alzheimer's Society. <a href="#">Living with dementia</a></p> <p><b>Information for families, carers and significant others</b></p> <p>NHS Choices. <a href="#">Carer's Assessments</a></p> <p>Alzheimer's Society. <a href="#">Caring for a person with dementia.</a></p> <p><b>Information on legal and financial aspects of caring</b></p> <p>Gov.uk (2013). <a href="#">Financial help if you're disabled</a></p> <p>Gov.uk (2013). <a href="#">What to do if you become disabled</a></p> <p>Gov.uk (2013). <a href="#">When a mental health condition becomes a disability</a></p> <p>Alzheimer's Society (2012). <a href="#">Financial and legal affairs</a></p> <p>Alzheimer's Society (2012). <a href="#">Mental Capacity Act 2005</a></p> <p>NHS Choices (2012). <a href="#">Managing someone's legal affairs</a></p>

<p><b>Useful Documents</b></p>	<p><b>Patient information on Advance care planning</b></p> <p>National End of Life Care Programme (2012)</p> <p><a href="#">Planning for your future care: A guide</a></p>  <p>Planning for your future care 010212.p</p> <p><b>Advance Care Planning Documents</b></p> <p>National End of Life Care Programme (2011).</p> <p><a href="#">Preferred Priorities for Care</a> (document can be downloaded from here)</p> <p>This tool is designed to help patients think about their preferred priorities for care at the end of life. It is used in Brighton and Hove and East Sussex.</p> <p>Usual Version  PPC v22 rev 20111.pdf</p> <p>Easy Read version  PPC v4 Easy Read Version.pdf</p> <p><b>West Sussex Advance Care Plan – Planning Future Care</b></p>  <p>Planning Future Care - Ver 2013 .pdf</p>
	<p><b>Local Support Services</b></p>


<p><b>Stage 3 Living Well with Dementia</b></p>	<p>This stage is about supporting you as you live with dementia. You, your family, and the professionals looking after you will work together to help you look after your wellbeing, live an active life, be included in the local community and take part in everyday activities.</p> <p>You will receive regular health and wellbeing checks by your GP and care team and be given the opportunity to discuss future care plans with relatives, carers, friends and professionals who support you.</p> <p>You will be given the opportunity to record your life story which will help you, and others in the future, to care for you and meet your needs. You will also be given relevant information advice and support when you need it, for example about benefits, activities, care, respite support and Lasting Powers of Attorney (LPA)</p>
<p><b>General Information</b></p>	<p>Caroline Walker Trust (2011). <a href="#">Eating well for older people and older people with dementia: Practical Guide</a></p> <p>NHS Choices. <a href="#">Care and support: your essential guide to social care</a></p> <p>NHS Choices. <a href="#">Living Well with Dementia</a> - Includes external links to websites with advice and information</p> <p>Alzheimer’s Society. <a href="#">Eating</a></p> <p>Alzheimer’s Society. <a href="#">Exercise and physical activity for people with dementia</a></p> <p>National Council for Palliative Care (2012) <a href="#">How would I know? What would I do? How to help someone with dementia who is in pain or distress</a></p> <p>Department of Health (2012). <a href="#">Personal health budgets easy read leaflet</a></p> <p>NHS England. <a href="#">About personal health budgets</a></p> <p><a href="#">Dementia Web</a> information, advice and a 24 hour helpline</p> <p><a href="#">Talking Photo Album</a> - A creative way to share information or for enjoyable trips down memory lane!</p>
<p><b>General Information</b></p>	<p><a href="#">Dementia Services Development Centre University of Stirling</a> An online interactive tool that illustrates good practice in design for people with dementia</p> <p><a href="#">Caring Memories</a> An online tool to help you make a personalised album of memories</p> <p><a href="#">Life Story Network</a> They aim to educate, empower and enable in order to encourage and embrace relationships built on empathy.</p> <p><a href="#">Visit Woods</a> – information, advice and ideas about accessing and enjoying woodland</p> <p><a href="#">Dementia Adventure</a> – 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><a href="#">Active Minds</a> – activity resources for people with dementia</p>

<p><b>Local Documents</b></p>	<p><b>Documents to support person centred care / personalisation</b> (for person with dementia, relatives, carers (family or paid) to complete)</p>
	<p><b>This is Me Document (used in East Sussex, Brighton &amp; Hove)</b></p> <div style="text-align: right;">                   This Is Me booklet.pdf             </div>
	<p><b>Knowing Me (used in Coastal West Sussex)</b></p> <div style="text-align: right;">                   2013 07 03 Knowing Me.doc             </div>
<p><b>Local Support Services</b></p>	<div style="display: flex; justify-content: space-between;"> <div style="width: 30%;"> <p><b>This is About Me – Crawley Me – Mid Sussex</b></p> <div style="text-align: right;">                   This is About Me Crawley - 02.13.pdf             </div> </div> <div style="width: 30%;"> <p><b>This is About Me – Horsham</b></p> <div style="text-align: right;">                   This is About Me Horsham final.pdf             </div> </div> <div style="width: 30%;"> <p><b>This is About Me – Mid Sussex</b></p> <div style="text-align: right;">                   This is About Me Mid Sussex final .pdf             </div> </div> </div>
	<p><b><a href="#">East Sussex County Council</a></b> – 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><b><a href="#">West Sussex County Council</a></b> - web pages with a range of video clips with personal stories, information, advice, resources, support and contacts for people with dementia, their relatives and carers and professionals living and working in West Sussex</p>
	<p><b><a href="#">Our Health South East</a></b> - information about dementia scroll down to the ‘Support for families and carers’ tab to find out about services in Brighton &amp; Hove, East and West Sussex</p>
	<p><b><a href="#">West Sussex Wellbeing Hubs</a></b> – information source for local activities and support groups in West Sussex aimed at maintaining wellbeing</p>
	<p><b><a href="#">East Sussex 1space</a></b> - 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 - <b><a href="#">ROCK – Recovery Orientated Community Kit</a></b> – information about local community resources to support mental wellbeing. Also <b><a href="#">dementia services</a></b></p> <p><b><a href="#">Singing for the Brain – in Brighton</a></b></p>

<p><b>Stage 4</b></p> <p><b>Getting the Right Help at the Right Time</b></p>	<p>At this stage you and your carers will be offered the opportunity to regularly review and record, with your GP and other health professionals, future care plans, your Advance Care Plan (ACP) and/or discuss Advance Decisions to Refuse Treatment. This may be every year, when there are any changes in your general health and wellbeing, or before any treatment or care.</p> <p>You will be 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 and what care and support options are available</p> <p>You, and your carers, will be given the opportunity to discuss and put in place plans to manage unexpected changes in your wellbeing or if you become more unwell.</p> <p>You will be offered timely and appropriate referral to specialists as need arises and provided with prompt access to the right support for you if you are in crisis</p>
<p><b>General Information</b></p>	<p>Alzheimer’s Society (2011). <a href="#">Assistive technology: devices to help with everyday living</a></p> <p><a href="#">AT Dementia</a> 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 <b>Advance decisions to Refuse Treatment – A Guide</b></p>  <p>ADRT A Guide May 2009.pdf</p> <p><a href="#">Independent Mental Capacity Advocates</a> – their role in supporting decision making</p>
<p><b>Local Support Services</b></p>	<p><a href="#">East Sussex County Council</a> – 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> <p><b>Hospices in West Sussex</b></p> <p><a href="#">St Barnabas House Worthing</a>      <a href="#">St Catherine’s Hospice Crawley</a></p> <p><a href="#">St Wilfrid’s Hospice Chichester</a></p> <p><b>Hospices in Brighton &amp; Hove and East Sussex</b></p> <p><a href="#">The Martlets Hove</a>      <a href="#">St Peter &amp; St James Hospice Lewes</a></p> <p><a href="#">St Michael’s Hospice Hastings</a>      <a href="#">St Wilfrid’s Hospice Eastbourne</a></p> <p><b>Mind in Brighton &amp; Hove</b> – <a href="#">Advocacy Service for Older People</a> – free advocacy services for people in Brighton, Hove and West Sussex</p> <p><a href="#">Brighton &amp; Hove Mediation Service</a>- useful to resolve disputes that may arise in relation to future care decisions</p>

<p><b>Stage 5</b></p> <p><b>Nearing the end of life including care in the last days of life</b></p>	<p>Your carers will be supported in getting the right help, advice and funding to help care for you, as far as possible, according to your wishes that you have recorded earlier on in your treatment.</p> <p>Your carers will be supported in understanding and accepting this stage of your illness and will be referred to and supported by the right services for them.</p>
<p><b>General Information</b></p>	<p>NHS Choices. <a href="#">End of Life Issues</a></p> <p>NHS Choices <a href="#">Accessing palliative care</a></p>
<p><b>Local Support Services</b></p>	<p><a href="#">East Sussex County Council</a> – 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> <p><b>Hospices in West Sussex</b></p> <p><a href="#">St Barnabas House Worthing</a></p> <p><a href="#">St Catherine’s Hospice Crawley</a></p> <p><a href="#">St Wilfrid’s Hospice Chichester</a></p> <p><b>Hospices in Brighton &amp; Hove and East Sussex</b></p> <p><a href="#">The Martlets Hove</a></p> <p><a href="#">St Peter &amp; St James Hospice Lewes</a></p> <p><a href="#">St Michael’s Hospice Hastings</a></p> <p><a href="#">St Wilfrid’s Hospice Eastbourne</a></p>



<p><b>Stage 6</b></p> <p><b>Care after death for relatives, carers and significant others</b></p>	<p>Your relatives and carers will be supported sensitively and compassionately and provided with the right advice and support to meet yours and their spiritual and cultural needs.</p> <p>They will also be directed to appropriate practical and bereavement support.</p>
<p><b>General Information</b></p>	<p>Gov.uk (2013). <a href="#">What to do after someone dies</a> This page includes financial information.</p> <p>Dying Matters (2010). Leaflet 3: <a href="#">I could do with a chat: how to help someone close to you who has been bereaved</a> and Leaflet 4: <a href="#">Someone you know is bereaved: What to do if someone you know has been bereaved</a></p> <p>NHS Choices. <a href="#">Bereavement</a></p> <p>NHS Choices. <a href="#">End of Life Issues</a> 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). <a href="#">Bereavement</a></p> <p>Alzheimer’s Society factsheet <a href="#">Grief and bereavement</a> (2010)</p> <p><b>Support groups</b></p> <p><a href="#">Cruse Bereavement Care</a></p>
<p><b>Local Support Services</b></p>	<p>East Sussex Care for Carers – <a href="#">former carers support groups</a></p> <p>Brighton and Hove Carers Centre - <a href="#">Bereaved carers support</a> - Information on how to access this service</p> <div data-bbox="1236 1288 1492 1400">  <p>BereavedCarersFlow chart [Compatibility M]</p> </div> <p>West Sussex Carers Support – <a href="#">Carers groups</a></p> <p>Brighton and Hove City Council – <a href="#">Organisations that help the bereaved</a></p> <p>East Sussex County Council – <a href="#">Coping with bereavement</a></p> <p>West Sussex County Council – <a href="#">Bereavement Guide</a></p>

## Resources Relevant to the Whole Pathway

### Organisations and support groups

#### [Alzheimer's Disease International](#)

[Alzheimer's Society](#) 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 [tailored support for LGBT people with dementia and their carers](#),

[Carers Trust](#) - Advice, information and network of local support groups for carers

[Culture Dementia UK](#) Support group for black / Afro-Caribbean people with dementia and their carers

[Dementia UK](#) The website has information on all aspects of the condition. The organisation provides the Admiral Nurses phone line

[Fronto-temporal dementia support group](#) This website provides information and has an online forum.

### Patient information leaflets

NHS Choices (2013). [Dementia guide](#) An exhaustive leaflet with information on all aspects of the condition. See the Care and support tab for information about finances, legal affairs, etc.

Patient.co.uk (2012). [Memory loss and dementia](#)

Alzheimer's Research UK. [Dementia information](#) 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.

Age UK. [Dementia](#)

[Lewy Body Society](#) This organisation's primary aim is to fund research, but there is some patient information on their website.

### Information, advice and support

[Know Dementia](#) – Sussex based charity run by family carers whose aim is to provide education, advice and information

[The Silver Line](#) - 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