

# Your Care in Sussex: Dementia and End of Life Care Guidance

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

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 and live well.



# THE SUSSEX INTEGRATED DEMENTIA AND END OF LIFE CARE GUIDANCE

The different stages of your care	What you should expect from your care
<b>1</b> Recognising there is a problem	<p>At this stage you should be able to easily access information about dementia to help you, or your carers, recognise early signs. 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>2</b> Discovering that the condition is Dementia	<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. 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>
<b>3</b> Living Well with Dementia	<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>

## The different stages of your care

## What you should expect from your care

4	Getting the Right Help at the Right Time	<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>
5	Nearing the end of life including care in the last days of life	<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. 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>
6	Care after death for relatives, carers and friends	<p>Your carers will be supported sensitively and compassionately and provided with the right advice and support to meet yours and their spiritual and cultural needs. They will also be directed to appropriate practical and bereavement support.</p>

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 information, advice and support they need to help them to 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.

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 friends

**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.**

**You will find information about dementia in your local GP surgery as well as libraries and in many community facilities. The following are sources of information**

**Sussex Alzheimer's Society helpline:** Telephone 0140 3213017

Website [sussex.helpline@alzheimers.org.uk](mailto:sussex.helpline@alzheimers.org.uk) Open - Mondays to Fridays - 9am to 1pm

**National Alzheimer's Society helpline:** Telephone 0300 222 11 22

Website [helpline@alzheimers.org.uk](mailto:helpline@alzheimers.org.uk) Open - Monday to Friday 9am-5pm, Saturday and Sunday 10am-4pm

**Talking point** (24 hour online forum for carers and people with a dementia):  
[forum.alzheimers.org.uk/index.php](http://forum.alzheimers.org.uk/index.php)

**Know Dementia** – A Sussex based charity run by family carers offering education, advice and support to anyone affected by dementia

Telephone 01273 494300 Website [www.knowdementia.co.uk](http://www.knowdementia.co.uk)

**The Silver Line Telephone** 0800 4 70 80 90 [www.thesilverline.org.uk/](http://www.thesilverline.org.uk/) A free confidential helpline providing information, friendship and advice to older people open 24 hours a day seven days a week.

**You will find more information about dementia and available support by visiting either your local Clinical Commissioning Group (CCG) or Local Authority website as indicated below:**

**NHS Brighton and Hove CCG**  
[www.brightonandhoveccg.nhs.uk](http://www.brightonandhoveccg.nhs.uk)

**NHS Coastal West Sussex CCG**  
[www.coastalwestsussexccg.nhs.uk](http://www.coastalwestsussexccg.nhs.uk)

**NHS Crawley CCG**  
[www.crawleyccg.nhs.uk](http://www.crawleyccg.nhs.uk)

**NHS Horsham and Mid Sussex CCG**  
[www.horshamandmidsussexccg.nhs.uk](http://www.horshamandmidsussexccg.nhs.uk)

**East Sussex County Council**  
[www.eastsussex.gov.uk/socialcare/healthadvice/mentalhealth/dementia/default.htm](http://www.eastsussex.gov.uk/socialcare/healthadvice/mentalhealth/dementia/default.htm)