

The ROYAL MARSDEN

NHS Foundation Trust

Dementia and memory loss

A guide for patients and carers



NHS

What is dementia?

The word dementia describes a set of symptoms that may include:

- Memory loss
- Difficulties with thinking
- Difficulties with problem-solving or language.

Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes.

Each person is unique and will experience dementia in their own way. The different types of dementia tend to affect people differently, especially in the early stages. How others respond to the person, and how supportive the person's surroundings are, can also affect how well someone can live with dementia (Alzheimer's Society 2015).

Dementia is caused by damage to brain cells and is a progressive illness, meaning it will gradually get worse. The rate of progression will differ with each individual.

There are many different types of dementia. The most common is Alzheimer's disease. There is also vascular dementia, dementia with lewy bodies, and many more.

How will I know if I have dementia?

You are unique and will experience dementia in your own way. It may be that your family and friends are more concerned about your symptoms than you are yourself.

You, or your loved ones may notice:

- Loss of memory: It is usually your short-term memory that is affected. For example, you may forget what happened earlier in the day, or you may not be able to recall what you have been talking about. You may repeat things or forget the way home from the shops. Your long-term memory usually remains intact.

- **Mood changes:** You may feel withdrawn, sad, frightened, or angry about what is happening to you.
- **Communication problems:** It may be hard to find the right words for things, and you may find yourself having to describe what an item does instead of being able to name it.
- **Daily living skills:** People living with dementia sometimes find it difficult to maintain their daily routine and activities independently. Patience, prompting and support can encourage independence and can have a big impact on how capable and confident a person living with dementia feels.

How is dementia diagnosed?

It is vital that you receive a proper diagnosis. This means that all other conditions that cause symptoms of dementia such as delirium and depression, have been ruled out.

Dementia can be diagnosed by your GP or a specialist doctor. Your GP or a Dementia Specialist Nurse will carry out some tests to check your memory, thinking and ability to carry out daily tasks. They may also book some further tests for you including blood tests and a brain scan.

A diagnosis allows you, your family and your carer to plan for the future. Depending on the type of dementia you are diagnosed with, there may be medications which can be prescribed to help manage the symptoms.

What we will do at The Royal Marsden

Within 24 hours of your admission or at pre assessment, we ask the question:

Has the patient become more forgetful in the last 12 months to the extent that it has significantly affected their daily life?

If you indicate yes, we will carry out further screening to see if there could be a cognitive impairment (an indicator that further assessment is required for a formal diagnosis). If it is established that you may have dementia, we will discuss this

with you and your family or carers and your clinical team and make sure you have a care pathway suitable to your needs.

Once you are discharged, we will send our findings to your GP who can refer you for further assessment and give you information about services available to you at home.

What is mild cognitive impairment?

You may be having problems with your memory, but your doctor may not think the symptoms are severe enough to diagnose you with a type of dementia, particularly if you are still managing well. Some doctors call this condition 'mild cognitive impairment' (MCI).

Recent research has shown that people with MCI are more likely to develop dementia but having MCI does not always mean that you will go on to develop dementia.

I have dementia, how will I be cared for at The Royal Marsden?

It is important that we understand your needs and will ask you or your family to complete a 'This is me' hospital passport. This is a very important document and will tell us about you and how to best care for you.

Where possible, you will be admitted to one of our dementia friendly wards which has access to a day room with day activities, good orientation and staff who are knowledgeable of this condition.

We will offer flexible visiting to your family.

Our friendly catering staff will ensure your preferences for meals, snacks and drinks are taken into account and will offer something suitable for your needs.

During your time at The Royal Marsden, we want you to remain as comfortable as possible. We encourage you to bring in clothes and small belongings that are familiar and comforting to you.

We also welcome you to bring in activities that are meaningful to you such as books, music or activities that you would enjoy doing at home.

We also have Dementia Champions on wards who can provide additional advice and support.

Carers; looking after yourself

When you are caring for someone with dementia, it can be easy to ignore your own needs and forget that you matter too.

If you are caring for someone with dementia, be prepared for the fact that you will need support at some point. You will probably need a lot of different types of help and support, ranging from practical care to give you time off from being a carer, to having someone to talk to about your feelings and concerns. Think about what help you might need, that way, when the time comes, you will know where to turn.

Be clear about what support you need, especially when you ask for help in the form of services. It is important to receive the support that **you** need for yourself in order to continue with your caring role.

Carer Centres provide a range of services to family members who informally care for another family member or friend.

Further information and support

- **The Royal Marsden Help Centre**

This offers support to all patients, their families and friends. Confidential chat, support and signposting is available at the Help Centres in both Sutton and Chelsea.

0800 783 7176 (Freephone)

- **Welfare Rights Service**

If you are experiencing financial, employment or welfare rights issues, you can arrange to see a welfare rights advisor.

They can complete a welfare benefit check to ensure that you and your family are in receipt of all benefits which you are entitled to.

020 8661 3386 (Sutton)

020 7808 2484 (Chelsea)

- **National Dementia Helpline:** 0300 222 11 22

- **Carers UK Advice line:** 0808 808 7777
(Mondays and Tuesdays, 10am – 4pm)

- **Admiral Nurse Dementia Hotline**

A national helpline and email service, provided by experienced Admiral Nurses which is for family and professional carers, people with dementia and those worried about their memory. It gives practical advice and emotional support to anyone affected by dementia.

0800 888 6678

Email: helpline@dementiauk.org

If you would like to discuss any of the topics outlined in this leaflet, or if you need more support, please speak to your Clinical Nurse Specialist, key worker or clinical team.

References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre
Freephone: 0800 783 7176
Email: patientcentre@rmh.nhs.uk

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.



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