



Mersey Care
NHS Foundation Trust

Living well with Dementia



I have received a diagnosis of dementia...



What do I do now?

Many people find it hard receiving a diagnosis of dementia and living with it can be challenging. Services are designed to provide support throughout this experience and enable you to live well with dementia.

This leaflet will provide you with basic information about the different types of dementia and the immediate support you will be offered. You will be provided with more information in the form of an information pack when a member of your care team contacts you.



What is dementia?

An introduction

Dementia is the name given to a group of conditions which affect the way a person thinks, understands and remembers information. This can cause difficulties in communicating with others, remembering information, times and dates and carrying out activities that have previously been

easy. It can also affect the way a person moves, judges distances, and recognises people and places. This can lead to the person feeling frightened and upset, and it can cause the same feelings in others if they don't understand what is happening.

Accessing services

Accessing mental health services can be daunting; we understand that you need it to be as simple as possible so you can get help and support when you need it. The service you are in will make contact and will let you know who your point of contact will be should you need support.

Your care teams will be able to signpost you and your carers to the different services available and will provide information and advice about dementia on an ongoing basis on topics such as:

- What to do if you are worried
- Adaptations around the home to make life easier
- How to access support groups and social events
- How to ensure you are receiving the right benefits
- How to access social services
- Practical issues such as driving
- Keeping yourself well.

Everyone who receives a diagnosis of dementia will be supported by a named person who will provide information about the services available. If however you would like to contact them before this you can ring them on the number below:

Your care team may contact you periodically to check how you are doing but you can contact them any time you want whether it is to ask a question, find out about services or just to get some support. An interpreter can be provided if needed.

Whatever the question may be, your care team will be there to help.

What to do now?

Regardless of which type of dementia you have been diagnosed with services are set up to enable you to live as well as possible with dementia. Although it is a progressive condition (changes over time) the care team will endeavour to provide psychological and practical support, training, and information for you and your family throughout the experience of dementia. It is important to keep in touch with us and get the help and support you require.

You will be offered various types of post diagnostic support. Many people find it helpful to attend a post diagnostic support group where you can learn more about dementia, how to manage the difficulties that might arise and meet people in a similar situation to yourself. You will be given a separate leaflet about this group.



Alzheimer's Disease

This is the most common type of dementia. A build up of protein in the brain and a reduction in certain brain chemicals causes problems with nervous impulses (similar to electrical charges) passing from one nerve cell to another. This means messages do not get passed across the brain as they used to and, as a result, some brain cells die.

Common symptoms people may notice first are problems with short term memory, forgetting the time and date (disorientation to time), and forgetting appointments etc. As the condition progresses people can experience other problems that can affect their abilities to carry out daily tasks.

Vascular Dementia

The brain has an extensive supply of blood vessels which transfer the blood throughout the brain. The blood carries oxygen that the brain cells need to work properly. Sometimes the blood supply can be stopped temporarily or cut off from an area. This causes the cells in that particular part of the brain to be starved of oxygen and they can die.

This can be due to fat building up in the blood vessels (embolus), a small clot (thrombus) building up or a blood vessel bursting (aneurysm). This is called a stroke.

There are different severities of stroke. Some may be referred to as a major stroke whilst some may be termed a transient ischemic attack (TIA) or a 'mini stroke'. A series of mini strokes can lead to vascular dementia as can one major stroke. Sometimes the rest of the blood vessels can compensate for this by re-routing the blood flow after the initial problem has settled down.

Common symptoms may be fluctuating or changing levels of confusion, well preserved insight and or changing moods.

It may be that there is an evident physical change depending on which part of the brain has been affected (for example: weakness in a limb, facial weakness and a speech problem). These vary from person to person and may be temporary.

Dementia with Lewy Bodies

This is a particular type of dementia which affects an area in the brain called the basal ganglia. A type of protein builds up in the nerve cells and changes their structure, this affects the way that they work.

Common symptoms experienced are problems with movements, which are similar to those seen in Parkinson's Disease. These may include rigid arms and legs, changes in walking patterns and frequent falls. Alongside this, people may experience hallucinations which can be very frightening. Being confused and having problems with planning and working things out (reasoning) is common, however, memory may not be severely affected.

People may do things which are impulsive or out of character. They may seem unaware of the effect on other people that their actions are having.

Mixed Dementia

Sometimes there is evidence of two or more types of dementia, for example, Alzheimer's disease and Vascular dementia occurring at the same time. This is called a mixed dementia.

Other dementias

There are many other types of dementia, including dementia associated with neurological (involving the nervous system) conditions like Multiple Sclerosis, Progressive Supra-Nuclear Palsy, Motor Neurone Disease and Parkinson's Disease. Other health problems can also cause dementia.

Fronto-temporal Dementia

This is a type of dementia that affects the front part of the brain (the frontal and temporal lobes). This area is very important in helping us to plan, reason, speak and modify our own behaviour.

Common features of this condition are sometimes described as a change in personality.

Mild Cognitive Impairment

Some people are told they have a Mild Cognitive Impairment (MCI). This means that they may have some difficulties similar to those seen in dementia such as memory loss but they are not impacting significantly on functioning. A proportion of people with MCI will go on to develop dementia, but others won't so it is important to continue with your life as normal. More information on MCI may be obtained from your GP.

You can record the details of your care team here



Where can I get more information?

You will be given an information pack that will provide you with extra information on dementia and available services. In the meantime you may find the following websites and numbers useful:

- Mersey Care: www.mersecare.nhs.uk
- Directory of Services: www.livewellliverpool.info
- Dementia UK: **0800 888 6678** or www.dementiauk.org
- NHS England: <https://www.nhs.uk/conditions/dementia/care-and-support/help-and-support/>
- Alzheimer's Society National Helpline: **0300 222 1122**



Our patients matter

Mersey Care NHS Foundation Trust listens and responds to patients and their carers to help improve the services we deliver. If you have any comments, compliments or concerns you can speak with a member of staff or contact our Patient Advice and Liaison Service (PALS) and Complaints Team.

Phone: **0151 471 2377**

Freephone: **0800 328 2941**

Email: **palsandcomplaints@merseycare.nhs.uk**

To request this leaflet in an alternative format or language, please speak to a member of staff.

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