Living Well with Dementia

Dementia is an umbrella term for a group of brain disorders which progressively affect the ability to live life independently.

There are many types of dementia but Alzheimer’s Disease is the most common.

Dementia can occur as a result of an organic disease process, or may follow a stroke or heart attack, or be the result of other diseases affecting the brain. It is a term used to describe many different brain problems that have in common loss of brain function, which is progressive and will eventually be severe. A person diagnosed with dementia will find it progressively harder to remember, understand, communicate, problem solve and reason, and therefore independence will be increasingly compromised.

The progression of dementia varies and each person’s experience will be unique to them taking into account their individual health needs, values and attitudes and personality traits. It also makes a difference how much support and information people receive to enable them and their family to live positively with dementia as their needs change.

Dementia can affect anyone, and is not linked with intelligence, social class, gender, ethnic group or geographical location. Dementia is more common among older people, but younger people are also affected, although this is less common.

What causes dementia?

We do not know exactly what causes dementia, although some lifestyle factors such as smoking and obesity are being linked to an increased risk of developing dementia. Dementia may be a part of other health problems, such as stroke or TIA’s, or may stand alone. Changes in the structure of the brain result in the loss of nerve cells or neurons, which makes our ability to function in daily life increasingly difficult. Below is a brief overview of some of the more common types of dementia.

What will I see happen to someone with dementia?

Memory:

Usually, there will be difficulties recalling new day-to-day information such as what was in the newspaper, what they had for breakfast, or new names and phone numbers. Longer term memories will usually be preserved for much longer.

Language:

Word finding difficulties are common, as are changes in spelling or reading abilities, and difficulty in expressing or understanding what has been said.
Visuo-spatial skills:  
This means difficulties with practical skills such as drawing simple pictures (e.g., a clock face) or becoming lost in familiar surroundings and recognising familiar landmarks. This may happen at home or outside.

Thinking and problem solving abilities:  
This affects organising day to day activities such as planning and cooking a meal, or working out the sequence of events needed to pay a bill, or being able to think abstractly and anticipate the results of actions. Planning into the future is progressively difficult.

Number and calculation skills:  
You may observe the person having difficulty in managing money when shopping, banking or dealing with household accounts.

Visual perception:  
Progressive difficulty in recognising and identifying familiar faces or surroundings is common.

Changes in personality:  
A person with dementia may become more emotional or more volatile, or behave in ways which are unlike their usual self. This is often caused by the dementia, but can also, especially in the earlier stages be the person way of expressing their frustrations and fears about what is happening to them.

STEP 1: Talk to family and friends about your observations, concerns and worries. Remember that there may be other explanations for the difficulties, such as stress or depression, or physical illness. If these have been ruled out and there are still concerns make your GP aware and request an appointment. If the person you care for does not want to go, try to persuade them but don’t push too hard. Ask the GP for advice on how best to approach getting them to surgery, or consider a home appointment.

STEP 2. Be clear and list what you have observed and are concerned about, and over what period of time. Ask the GP to investigate and see if other reasons for the problems are found. Request a referral to the memory clinic for further investigation, and do not be afraid to request a second opinion. If the cause remains unclear, either memory clinic, neurology, or psychology may all be involved in further investigations. If the reasons for this are not made clear, please ask.
STEP 3. At the Memory Assessment Service. More detailed memory assessments will take place, if the person gives their consent. You will both be introduced to a specialist dementia nurse who should explain the rationale behind tests and investigations, the diagnosis, offer support and advice with regard to the future, as well as signpost you to other services which you may find useful, either now or in the future.

What happens at the Memory Assessment service?

The initial appointment is an information gathering interview and will involve the person referred, you, a specialist doctor and a nurse. This appointment is an opportunity to discuss concerns and takes approximately one hour. Ideally the person should be accompanied by someone who knows them well and who can also give information about them and their life. Normally this will be a spouse, family member or close friend.

Following the initial appointment is an assessment period, which may include several appointments over a period of weeks, with other members of the specialist team.

The assessment is unique to the person and will address specific concerns and needs. This will include:

A memory assessment – a specific questionnaire designed to test memory and other aspects of intellectual function. This assessment can take place either in the clinic or in your own home, wherever is most comfortable for the person being assessed. In most cases it will be performed by the specialist nurse already known to you.

Physical investigations may also be requested as a part of making a diagnosis. This may include a brain scan or CT (Computerised Tomography) which is a deep X-Ray of the brain and an ECG (Electrocardiogram) which is a reading of heart activity.

Appointments for these will take place at the General Hospital. If not already done by the GP, the specialist doctor will also want a blood sample.

On completion of assessments – the person will be asked to return for an appointment where the Doctor will discuss the results of the tests and a diagnosis given, where appropriate.

Treatment – options will be discussed once a diagnosis has been made.
Are there drug treatments for dementia?

There are some drugs available for some people with dementia. These drugs are not a cure but may temporarily slow down the progression of symptoms, however they are not suitable for everybody, and your specialist doctor should discuss these with both the person diagnosed, and with you, once a diagnosis is made. If they are not appropriate for the person you care for this should be explained.

There is a great deal that can be done to support people with dementia as well as ways to support you, the carer through all stages of the condition. It is important to learn about this complex condition, and develop ways of living positively rather than focus too much on what has been lost. Both their needs and yours will be different over time, so good relationships with services that can offer different types of support as things change are a vital part of living well, for everyone affected by dementia. Please ask any of the health care professionals for more information when you have questions or concerns, and they will either help you address them or redirect you to other services that can help.