Carers Choices
peace of mind

The White House
Kiln Road, Benfleet
Essex SS7 1BU
01268 881130
www.carerschoices.org

Silver Birch Centre
by Carers Choices

After a diagnosis

Receiving a diagnosis of dementia can be a difficult and emotional time. The diagnosis may come as a shock or it might provide answers to the problems you, or someone close to you, have been having. It can be hard to come to terms with it and know what to do next. Some people might even feel a sense of relief from knowing what is wrong and what steps to take. This factsheet looks at things to consider after a diagnosis of dementia, including possible treatments, planning for the future, sources of support, and how to live well with the condition.

Support after a diagnosis is very important. The person with the diagnosis and their close family should be able to talk things over with a range of professionals. They might want to ask questions about the diagnosis and what it means for them. They should take some time to think about and discuss the future. Information on the help and support available, and on how to stay physically and mentally well, can also help.

A diagnosis of dementia shouldn’t stop people being in control of their lives or doing many of the things they enjoy. They should be supported to remain independent, active and engaged, and fully involved in making decisions and choices for themselves, for as long as they can.

What is dementia?

The word dementia describes a set of symptoms that may include memory loss and problems with thinking, problem-solving or language. Everyone experiences dementia differently. Different types of dementia, for example Alzheimer’s disease or vascular dementia, affect people differently, especially in the early stages. For someone who has been diagnosed, knowing the type of dementia they have can help them to understand some of the difficulties they may face, and ways to manage them.

Coming to terms with a diagnosis

Coming to terms with a diagnosis may take a long time. The person might experience a range of emotions, including shock, anger, fear, or even relief at having their symptoms explained. This is normal, and feelings may change from one day to the next. The person's friends and family are also likely to experience a range of emotions and their own difficulties coming to terms with what is happening.

It can help people to talk about their diagnosis, and how they feel about it, with family and friends. Talking about things openly and honestly can help them to think about how they can support each other, and look at ways for the person to carry on living an independent and active life. Talking can also help the person think about the future.

The person may want to talk about their diagnosis with others as well. This could be a counsellor, a health or social care professional, or other people with dementia. In some areas there will be post-diagnosis support groups. This will help the person, and those close to them, come to terms with the diagnosis and look at ways to live well with dementia. Someone might also be offered counselling, giving them an opportunity to talk through their diagnosis and their needs. The local memory service or GP can give more information about post-diagnosis support groups and counselling.

Who to tell about a diagnosis, and how much to say and when, are all up to the individual. They may be worried about how others might react. Some people only tell their close family; others tell friends as well. Some people tell neighbours or members of their community. Whatever the person decides to do, it should be what they feel is right for them.

Treatments

Although there is no cure for dementia, drug treatments may help to alleviate some of the symptoms. Non-drug treatments can also help someone to manage their condition, and support them to live well after a diagnosis.

Drug treatments

Someone with mild to moderate Alzheimer's disease may be prescribed donepezil (eg Aricept), rivastigmine (eg Exelon) or galantamine (eg Reminyl). These are called acetylcholinesterase inhibitors. They do not cure Alzheimer's, but may relieve memory problems and improve alertness for a while. Someone with moderate Alzheimer's disease who can't take an acetylcholinesterase inhibitor may be offered memantine (eg Ebixa). Memantine is also given for severe dementia. For more information speak to your GP.

For someone with vascular dementia, the doctor should offer drugs that treat the underlying conditions (eg high blood pressure). These may help to slow the progression of dementia. If someone has dementia with Lewy bodies, the doctor may offer one of the acetylcholinesterase inhibitors to help alleviate distressing symptoms such as hallucinations or delusions. Someone with the behavioural variant of frontotemporal dementia may be prescribed an antidepressant.

Non-drug treatments

There are a range of non-drug approaches that can help people with any type of dementia to live well. These include talking therapies, such as counselling, which help someone address and come to terms with their diagnosis. Cognitive behavioural therapy, which helps people to change how they think (‘cognition’) and what they do (‘behaviour’) may be offered for depression. A person with dementia may also benefit from cognitive rehabilitation (which aims to reduce the impact of poor memory on a person’s quality of life) and cognitive stimulation (involving activities and exercises designed to improve memory and communication skills). Other popular activities include life story work, creative activities (eg art), music-based activities or aromatherapy. The GP, memory service or local Alzheimer’s Society can tell people what is available in the local area and what might work for them.

Living well / Staying healthy

Having dementia shouldn’t make someone feel ill or unwell. Any physical illness can make a difference to a person’s ability to cope. It may also make them more confused or forgetful. If the person with dementia does feel ill or unwell, they should speak to their GP. Having regular check-ups with the GP is important. People with other long-term health conditions (eg diabetes) also need to ensure these are managed well.

Having dementia puts someone at increased risk of developing depression. If they regularly feel low, anxious or irritable, they should speak to their GP; treatments for depression are available.

Anyone with a diagnosis who is taking more than four medicines should ask their GP for a medication review. Medication can cause side effects that can affect wellbeing, such as dizziness or increased confusion.

A person with dementia should have regular dental check-ups to help maintain good oral health. They should also have regular sight and hearing check-ups, as problems with these can affect how well they manage their dementia.

Eating a balanced diet and drinking plenty of fluids are important for maintaining physical and mental wellbeing. A person with dementia should eat a variety of foods; a dietitian can provide advice on eating and drinking. The person’s GP can make a referral.

Exercise can have a significant impact on wellbeing. It is good for both physical and mental health. Exercise could include walking, chair exercises, gardening or tai chi, and can be adapted to meet a person's needs. The most effective exercises are ones that the person enjoys and that they can incorporate into their everyday routine. For more information see factsheet 529, Exercise and physical activity for people with dementia. Staying socially involved and physically and mentally active is important. Remaining involved and active can help a person with dementia to maintain their skills and independence, and reduce loneliness. It may also help to improve sleep patterns and potentially prevent depression. Activities can be anything that the person finds enjoyable and wants to do. They should be incorporated into their everyday routine. It may help to adapt an activity to make it easier, or to try new activities that may be more enjoyable. It is important that the person and those around them don't worry too much about the 'result' of the activity, but instead focus on the process and the enjoyment the person gets from it. Staying involved and active.

Maintaining independence

Having dementia makes everyday life more difficult, and a person with the condition may need to change how they do things. There are a variety of assistive technologies and gadgets that can help, which a person with a diagnosis may want to consider using. These could include memory aids (eg clocks, calendars and medication prompts) and telecare (eg falls sensors). It is important that the person is shown how to use these aids properly, so they can get the best out of them. The person's local disabled living centre or Alzheimer's Society office can provide more information about this. Assistive technology can also help people remain safer in their homes. It can help to think about changes that can be made in the home environment to enhance independence and safety. For example, it can be helpful to increase light levels and remove trip hazards such as loose rugs. The local fire service can offer a free home safety visit. An occupational therapist (OT) can provide more information on staying independent and safe at home. The GP or social services can arrange a referral to an occupational therapist.

Planning ahead

Someone who has received a diagnosis of dementia may want to spend some time thinking about the future and their wishes. As the condition progresses, it will become more difficult for them to make decisions about their health, care (including end-of-life care) and finances. Mental capacity is the ability to make decisions for yourself. People who cannot do this are said to 'lack capacity'. Planning ahead allows the person with dementia to make choices and decisions in advance about their future care, in case there is a time when they cannot make these decisions for themselves. A person with dementia should discuss their wishes with family and other people close to them.

Wills

A will allows someone to choose who inherits their money and possessions when they die. It is still possible to make or change a will after a diagnosis of dementia, as long as the person can show that they understand the decision they are making, and the implications that any changes will have. A solicitor can help with making or updating a will. For more information see factsheet 467, Financial and legal affairs.

Lasting Power of Attorney

Making a Lasting Power of Attorney (LPA) allows a person with dementia to give someone they trust (the attorney) authority to make certain decisions on their behalf. This is often a family member or close friend. All decisions made by the attorney must be in the person's best interests. There are two different types of LPA:

Health and welfare LPA –The attorney can make decisions about the person's healthcare (eg medical treatment) and welfare (eg where they live). These powers can only be used if the person can no longer make these decisions for themselves

Property and affairs LPA – The attorney has the power to manage the person's money, property and affairs on their behalf. This could include paying bills, collecting income and benefits, accessing bank accounts and even selling a house.

The attorney will not immediately get to take control when the LPA is made. In order for the LPA to be used, it first needs to be registered with the Office of the Public Guardian. The attorney can only make decisions on the person's behalf once the LPA has been registered, and when they can act may depend on how the LPA has been set up. Anyone wanting to set up an LPA will need to have the mental capacity to do so. A solicitor can be paid to help with setting it up, but this isn't compulsory.

Advance statements

An advance statement is a record of a person's preferences and priorities for the future. It could cover where they wish to live or how they like to do day-to-day things (eg preferring a bath over a shower). It will be used if someone becomes unable to make decisions for themselves. An advance statement isn't legally binding, but it should be taken into account when deciding what is in the person's best interests. If the person does set up an advance statement, they should tell people about it and keep it somewhere safe.

Advance decisions

An advance decision ensures that a person has a say in their future medical care, by enabling them to refuse – in advance – specific medical treatments or procedures. This is in case the person becomes unable to make these decisions for themselves. Decisions might include whether the person would be resuscitated if their heart stopped. An advance decision is legally binding. Anyone who would like to set one up should speak to their GP. It is important to review an advance decision regularly, and revise it as necessary, so that it continues to reflect the person's views. For more information see factsheet 463, Advance decisions and advance statements. In Northern Ireland advance decisions are known as advance directives. For more information on advance directives see factsheet NI467, Financial and legal tips.

Financial matters

Someone who has just received a diagnosis of dementia may want to check that their financial affairs are in order. It is important that all their essential details can be easily found. These could include details of bank accounts, tax, benefits, pension, mortgage or rent documents, insurance policies and their will.

Putting things in order as early as possible can help the person to feel prepared for the future. It will also mean that when things become more difficult to manage, they know that everything is arranged as they want it. For more information see factsheet 467, Financial and legal affairs.

Benefits

A person with a diagnosis of dementia may be eligible for a range of benefits. The local benefits agency, Citizens Advice Bureau or Age UK can carry out a benefits check to see what they may be entitled to. The main benefits that may be relevant are Attendance allowance (AA) for people 65 and over, or Personal independence payment (PIP) for those under 65. PIP replaced Disability living allowance (DLA) from June 2013. These benefits aren't based on a person's financial situation or national insurance contributions. They are also tax-free.

Driving

A diagnosis of dementia doesn't automatically mean that someone needs to stop driving immediately. However, they must tell the Driving and Vehicle Licensing Agency (DVLA) in Great Britain or the Driving and Vehicle Licensing Northern Ireland (DVLNI) about the diagnosis. They must also let their car insurance company know. The DVLA or DVLNI will request a report from the person's doctor and may also ask the person to take a driving assessment. These will be used by the DVLA or DVLNI to decide whether the person can continue to drive.

As dementia progresses, there will be a time when the person will need to stop driving. Having to stop driving can be very difficult, and can take a lot of adjustment. For more information see factsheet 439, Driving and dementia.

Working

Someone may receive a diagnosis of dementia while they are still working. This doesn't necessarily mean that they will need to give up work straight away, but there are some things they may want to think about.

Talking to the employer – It may help for the person to talk to their employer about the diagnosis. In some jobs, there may be a legal obligation to tell the employer: this will be in the person's contract. Once this conversation has taken place, the employer is obliged to make 'reasonable adjustments' to support the person to keep working if they want to.

Thinking about the future – The person may want to take some time to consider the future, and to seek advice on their rights, pension and work-related benefits entitlements.

Leaving work – The person may decide to retire early or stop working. If they do, they should seek advice about their pension.

Benefits – Someone of working age may be eligible for a range of benefits. This will depend on their individual circumstances. A full benefits check will help the person find out what they are entitled to.

It's important that a person with a diagnosis seeks advice about working and dementia. They can speak to their human resources department, trade union (if they have one), the Advisory, Conciliation and Arbitration Service (ACAS), the local Citizens Advice Bureau or the disability employment adviser at Jobcentre Plus.

Support and services

After a diagnosis of dementia, someone may be unsure what to do next or where to go for help. Asking for support can be difficult, and the person may feel they don't need it. However, it can help for them to look into what's available in their area, should they need support now or in the future. Information, advice and support are available from a range of places.

The NHS provides services such as the local GP or memory service. There are a range of other NHS professionals who may be able to help, including occupational therapists and counsellors.

Charities and not-for-profit organisations such as CARERS CHOICES can provide support, advice and information for people with dementia and their carers. These can be national or local. They may run a range of local services including dementia adviser or dementia support worker services, support groups, activity groups and telephone helplines.

Social services and social care can help work out the care and support needs of a person with dementia and their carer. They can also arrange for care and support to be provided. For more information about this, the person or their carer can contact their local social services department. Anyone wishing to have their needs assessed should ask about a community care assessment. Carers can have their needs assessed too: they need to ask for a carer's assessment. Information and advice from social services are free.

The memory clinic, social services, local Alzheimer's Society office or other local voluntary organisations can provide information on what is available in the person's local area. Some services may be available for free, but others may have a cost.

Services for younger people with dementia
Someone under 65 who has been diagnosed with dementia may want services that are specifically designed for younger people with dementia. These may include specialist support groups, advocacy, counselling and day centres. The person's family may also benefit from specialist support. The provision of specialist services for younger people with dementia is patchy, but the number of services is rising. The memory clinic, GP or Alzheimer's Society office can provide information on what services and support are available locally.

Citizens Advice Bureau: To find details of your nearest Citizens Advice Bureau (CAB), look in the phone book, ask at your local library or consult the CAB website at www.citizensadvice.org.uk
Your local CAB is often the best starting point for financial and legal advice, such as help with benefits or finding legal support. The service is free, confidential and independent. Most CABs have a solicitor and some have an accountant available at certain times to give free initial advice.

Drivers Medical Group
Driver and Vehicle Licensing Agency (DVLA)
Swansea SA99 1TU
T 0300 790 6806 (Monday to Friday 8am–5.30pm, Saturday 8am–1pm)
W www.gov.uk/dvla-medical-enquiries
The section of the DVLA concerned with drivers with a medical condition that may affect their fitness to drive.

Office of the Public Guardian (OPG)
PO Box 16185
Birmingham B2 2WH
T 0300 456 0300 (9am–5pm Monday–Friday)
E customerservices@publicguardian.gsi.gov.uk
www.justice.gov.uk/about/opg

Customer services provide free booklets on Lasting Power of Attorney and Deputyship.

Solicitors for the Elderly
Solicitors for the Elderly Ltd
Room 17, Conbar House
Mead Lane
Hertford SG13 7AP
T 0844 567 6173
E admin@solicitorsfortheelderly.com

Solicitors for the Elderly is an independent, national organisation of lawyers, such as solicitors, barristers, and legal executives who provide specialist legal advice for older and vulnerable people, their families and carers.

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