



RARE DEMENTIA SUPPORT

ESSENTIAL INFORMATION BOOKLET



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INTRODUCTION

We know that receiving a diagnosis of a rare dementia can be incredibly daunting. It can be completely overwhelming even to start contemplating what the future might hold and what first steps you should think about taking.

Here, we have tried to pull together information about some of the most important benefits and services that may be available to you. This is, deliberately, a succinct summary, and for more detailed information we would encourage you to look at the web pages maintained by the [Alzheimer's Society](#): these are comprehensive and an extremely valuable resource.

This booklet was originally written by the Cognitive Disorders Service at the National Hospital for Neurology and Neurosurgery (NHNN).

We have now adapted it for Rare Dementia Support members and hope that you will find it helpful.

If you have any questions please do not hesitate to contact us – a member of the team will be happy to try to answer them for you.

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Please note that you assume full responsibility and risk in the use of information contained on our website, in our newsletters, at support group meetings and in subsequent correspondence. Our support group based correspondence is generic in nature and we are limited in our ability to offer specific advice via this means. We aim to ensure that all information is as accurate as possible but we accept no responsibility for any errors, omissions or inaccuracies, or for any adverse consequences of any kind arising from the use of support group based content. Our regional group facilitators are volunteers. They may refer to regional facilitator guidelines from RDS but are not governed by RDS. They operate independently and with best intention and you assume full responsibility for your contact and engagement with them and in the regional groups they facilitate. Please see the clinician responsible for your care, a social services representative, or your GP if you have specific needs which require attention. Any medical decisions should be taken in discussion with an appropriate health care professional.

INFORMATION ABOUT BENEFITS AND SUPPORT

People with a rare dementia diagnosis and their carers may be entitled to the following benefits:

Personal Independence Payments (PIP)

For people between 16-64 years old. The Personal Independence Payment is a non-means tested benefit paid to people who need help either with personal care, mobility or both. You could receive between £22.65 and £145.35 a week.

Details can be found on the [Government web pages](#) and advice on how to fill out the forms is available from the [Citizens Advice Bureau](#).

You can also [apply for exemption from paying vehicle tax](#) if you get the enhanced rate mobility component of Personal Independence Payment.

Attendance Allowance

For people 65 years and over. A non means-tested benefit paid to people who need help with personal care. You could receive either £57.30 or £85.60 a week.

Details can be found on the [Government web pages](#) and information on how to fill out the forms is available from the [Citizens Advice Bureau](#).

Carers' Allowance

This is available to carers who spend at least 35 hours a week looking after someone receiving either Attendance Allowance or Personal Independence Payments (although there are specific eligibility criteria here – please see the links below for more information).

Carers are not eligible for Carer's allowance if they earn more than a certain amount each a week after the deduction of allowable expenses, if they are in full-time education, or if they are receiving more than a specified amount from certain other pensions or benefits.

Details can be found on the Government web pages [here](#) and Citizens Advice Bureau pages [here](#).

Statutory sick pay

For those below retirement age who are in employment. You could receive £92.05 per week if you are too ill to work. This benefit is paid by employers to employees for up to 28 weeks in any one period of sickness. To qualify, a person must earn a certain amount or more each week before tax and be unable to work because of an illness or disability.

Details can be found [here](#).

Employment and Support Allowance (ESA)

This benefit may be paid once statutory sick pay has ended, or if the person is not entitled to statutory sick pay. To qualify individuals must have paid sufficient national insurance contributions. If the person is entitled to the highest rate of the care component of the Personal Independence Payments, they can receive long term incapacity benefit after 28 weeks.

Details can be found [here](#).

Council Tax Discounts

For households where someone is receiving Attendance Allowance or middle rate Personal Independence Payment.

If in a two person household one person is receiving disability benefits they may be eligible for council tax reduction. Someone living on their own and receiving appropriate benefits may be exempt from paying any council tax. Those on low income may also qualify for reduction of council tax.

Details can be found [here](#).

People receiving Income Support, income-based Jobseeker's Allowance, Pension Credit, Working Tax Credit or income-related ESA may be eligible for free prescriptions and support:

Free prescriptions

1. Free dental treatment from NHS dentists
2. Free sight tests and vouchers towards the cost of glasses – sight tests are also free for anyone aged 60 and over
3. Help with hospital travel costs for NHS treatment and free appliances for outpatients or day patients.

Details can be found [here](#).

If you are uncertain whether you may be eligible for certain benefits or need help filling in the application form,

If you are uncertain whether you may be eligible for certain benefits go to www.gov.uk for more information about each benefit. If you need help filling in the application, Citizens Advice or Age UK can help.

Support

There are a variety of services available for people with dementia and their families to support them in independent living. Most of these are organised by the NHS, Social Services and by charities such as the Alzheimer's Society, which helps people with all different kinds of dementia – not just Alzheimer's disease.

There are variations in the types of services offered in different parts of the UK. To find out what is available for you contact your local Social Services department or your GP.

COMMUNITY CARE ASSESSMENT

You can contact social services directly or you can ask your GP or other health care professional to make a referral for an assessment of need. More details can be found [here](#).

The social services department of the local council may carry out a social care assessment. Each local authority has its own criteria for eligibility for the assessment and provision of services based on the person's level of risk for safety and independence. It is essential that adequate information about the person's circumstances and medical condition is provided.

The assessment of needs usually takes place in the person's home and it is advisable for the family members or friends closely involved to be present.

The process involves assessment of the person's needs and circumstances, their personal finances and which of the needs identified can be met through the services available. It is important to prepare for this assessment, and more advice about that preparation is available from [Age UK](#) and the [Alzheimer's Society](#).

After the assessment has been completed, a care plan is written to describe what services will be provided, when and by whom. An assessment of the person's finances will determine how much they will need to pay towards the services, if anything.

The social services work closely with other services, such as health services and voluntary organisations to provide services to meet each individual's needs. Examples of services that may be available include:

Improvements or adaptations in your home

An occupational therapist may assess if any safety adaptations are needed at home. For example they can arrange equipment such as a bath seat or hand rails.

Meals at home services

If you have difficulty cooking meals for yourself, your council may deliver ready-made meals to your home. This service is sometimes known as 'meals on wheels'.

Home Care

Carers can visit you at home to help with personal care.

Day Centres

Can offer organised and meaningful activity in a safe environment from once to several times a week.

Care homes (residential and nursing)

These can offer respite, short or long term care. Social services have lists of Care Quality Commission monitored homes.

Direct payments

If the person has been assessed as needing help from social services, they can opt to receive direct payments to choose and buy the services they need for example help with cleaning, shopping and gardening.

NHS – Community Mental health Teams (CMHT)

Community Mental Health Teams include Psychiatrists, Community Psychiatric Nurses (CPN), Support Workers and occasionally Social Workers. CMHTs are experienced in providing help and support for people with complex needs. They provide assessment, treatment and sometimes support for people with mental health problems and dementia.

To access the services provided by the local CMHT you need to be referred by your GP.

Other

Examples of other professionals that may be able to help with specific difficulties or problems:

- Admiral Nurses
- District nurses and community nurses
- Health visitors
- Practice nurses
- Physiotherapists
- Chiropodists
- Speech and language therapists
- Continence advisers

- Dietitians
- Audiologists
- Optometrists

The voluntary services available vary from area to area. Contact your local social services department, Citizens Advice Bureau, Council for Voluntary Service or library for information about what services and groups are available in your local area. The Alzheimer's Society and Age UK may also be able to provide information about services available locally.

Carers' Assessment

Carers are also entitled to a Carer's Assessment which is a separate assessment focussing on of the needs of the carer, although you can often ask for this assessment to be made at the same time as a care needs assessment for the person with dementia.

More details can be found on the [NHS](#) and [Alzheimer's Society web pages](#).

PLANNING FOR THE FUTURE

You may wish to think about issues and situations that may change due to your diagnosis. Future planning allows you to have time to consider what is important for you, how you would like situations to be managed and who you would like to speak for you in case you will not be able to do so yourself.

Everyone's circumstances will be different but most people will benefit from considering the issues listed below.

You may choose to take action on some but not on others, and perhaps revisit them later on. It is good to involve those close to you in discussions about the future.

Daily activities

Thinking about what is important to you in your everyday life may help you to prioritise your activities. You may need to modify your activities according to your abilities and it is useful to maintain routine as far as possible.

Concentrate on your strengths, and aim to continue with activities that you are able to do and give you pleasure. Consider letting others help where necessary.

Living arrangements

As time goes on you may need more help from other people to support your independence. It is important to think about safety at home and any adaptations or changes that may need to take place. You may wish to discuss different options such as home care and care homes with those close to you in advance of these being required.

Financial and legal matters

Organising your financial and legal affairs will allow you to have peace of mind that all issues can be dealt with in the way you have chosen. Please consider the following issues:

- Make sure you are receiving all benefits you are entitled to (please see the benefits section)
- Make a will
- Arrange bills to be paid by direct debit and benefits to be paid directly into the bank account
- Consider having joint accounts with your spouse or partner
- Seek advice from solicitor or financial adviser if needed (especially with complicated matters such as setting up a trust)

Lasting Power of Attorney (LPA)

Lasting Power of Attorney (LPA) is a legal document which gives the person (or persons) you have chosen the right to make decisions on either financial or health care matters or both in case you lose capacity to make decisions yourself.

The LPA gives the person a choice of conferring broad or limited powers to make decisions on their behalf, and a choice of who to appoint. For example, it is possible to appoint relatives to make welfare decisions, but a professional adviser for decisions relating to their property and affairs.

A property and affairs LPA gives the attorney(s) the power to make decisions about financial and property matters, such as selling a house or managing a bank account.

A personal welfare LPA gives the attorney(s) the power to make decisions about health and personal welfare, such as day-to-day care, medical treatment, or where the person should live. A personal welfare LPA only ever takes effect when a person lacks capacity to make decisions. A property and affairs LPA can take effect as soon as it is registered, even while the person in question still has capacity, unless they specify otherwise. The person can, of course, specify that the attorney may only start managing their financial affairs after they lose capacity, at some point in the future.

More details can be found [here](#).

Advance Care Planning

Many people with dementia are concerned about how decisions about their medical treatment would be made if they lost the ability to decide for themselves. Some people wish to think about future health care options in advance, whilst others do not. Advance care planning is a dynamic process involving discussion between you, those close to you and professionals providing care for you. During these discussions you may wish to express your views, preferences and wishes about your future care.

Advance care planning may take place at any time you feel is right for you. The process is entirely voluntary. The aim is to identify your wishes and preferences and ensure that people are aware of them.

Some of the issues that are included in the advance care planning discussions include:

Identifying wishes and preferences

You may have strong views about specific treatments or types of care you may be offered now or in the future. Where you would be cared for might be important for you. For example you may wish to stay at home and receive all care there even if you become very unwell.

You may have spiritual or religious beliefs that you wish to be taken into account in your care. There may be practical things that are very important for you for example whether you prefer to shower or have a bath. Or you may have concerns such as who would take care of your pets if you become unable to do so yourself.

You might wish to identify someone close to you to represent your views. This is different from Lasting Power of Attorney as it is not a legally binding document but Health and Social care professionals are expected to take your views or those of your representative into account when planning for care. Sometimes it may not be realistic or practicable to follow your wishes.

It is not necessary to have your wishes and preferences written down, but it is often useful for those involved in your care if your views are in writing.

Refusing specific treatment

An advance decision to refuse treatment (previously known as a living will or advance directive) is a decision you can make to refuse a specific type of treatment at some point in the future. You may wish to refuse a treatment in some specific situations but not in others. It is important to specify the details of the circumstances.

There are specific rules if you wish to refuse a life sustaining treatment, such as ventilation. A decision to refuse treatment must be put in writing, signed and witnessed. If you wish to refuse a treatment you are advised to discuss this with an experienced care professional who knows your medical history well.

Driving

Having a diagnosis of dementia does not necessarily mean a person cannot drive. However those with a diagnosis of dementia have a legal responsibility to inform the Driver and Vehicle Licensing Agency (DVLA) of their diagnosis.

The driving insurance company should also be informed. If you are not able to drive there are other ways of getting around. Many people have found practical solutions such as allowing family and friends to help or arranging an account with a local taxi company.

The Medical Advisory Branch of the DVLA decides using the information provided by you, your GP or hospital consultant whether you can continue to

drive. It may be necessary to take a driving test conducted by the Driving Standards Agency. It may be possible to issue yearly licences, renewed in consultation with the medical practitioner.

More details can be found [here](#).

CONTACT DETAILS OF ORGANISATIONS PROVIDING CARE AND SUPPORT

Below we have listed some organisations that may be helpful. This list is by no means exhaustive and we cannot accept responsibility for information by other organisations.

Age UK

A charity providing services for older people in the UK. Local activities vary from providing advice and information to running day centres, over-60s clubs, transport schemes and home-sitting services.

Website: <http://www.ageuk.org.uk/>

Admiral Nurses

Some areas have Admiral Nurses who offer care and support to carers of people with dementia.

They also offer a telephone information and support line for family carers, people with dementia and professionals.

Website: www.dementiauk.org.uk

Alzheimer's Society

Provides support through a network of branches, support groups and contacts. A wide range of services are available, ranging from day centres and sitting services to information and advice. Fact sheets about various aspects of dementia are available on their website.

Website: www.alzheimers.org.uk

They also have extensive information on benefits and dementia [here](#).

At Dementia

This website brings together information about assistive technology that has the potential to support the independence and leisure opportunities of people with dementia. Website: www.atdementia.org.uk

Carers' Trust

Crossroads and the Princess Royal Trust for Carers merged to form the Carers Trust. A network of Carers' Centres and a Care Attendance scheme is available.

Website: <http://www.carers.org/>

Carers UK

Aims to encourage carers to recognise their own needs, to provide information and advice, to campaign for carers and to develop appropriate support for carers. They have a range of useful publications, including an information pack for Young Carers.

Website: www.carersuk.org

Citizens Advice Bureau

The service has welfare rights workers who offer advice on benefits and enduring power of attorney. They may also have information on grants available for adaptations that you may need in your house.

Website: www.citizensadvice.org.uk

Dementia Carers Count

This is a new initiative from the Royal Surgical Aid Society that aims to provide support to partners, friends, and families responsible for someone with a diagnosis of dementia.

Website: <https://dementiacarers.org.uk/>

Department for Work and Pensions

The government department responsible for employment and social security. Its website gives details of the various benefits and how to claim them, and has claim forms available to download.

Website: www.dwp.gov.uk/

Department of Health

The government department responsible for health, social care, and the National Health Service (NHS). Provides a range of information and literature, including on help with NHS costs.

Website: www.directgov.co.uk

Drivers Medical Group (DVLA)

The section of the DVLA concerned with drivers with a medical condition that may affect their fitness to drive.

Website: <https://www.gov.uk/driving-medical-conditions>

Medic Alert

A non-profit making, registered charity providing identification bracelets or necklets for individuals with hidden medical conditions and allergies. In an emergency, vital information is available on the back of the MedicAlert® Emblem. Medical and emergency personnel can then telephone the given number and by quoting the ID number and after clearing security checks, they can receive further important details where appropriate. For example name and address, doctor's details, current drug therapy or next of kin.

Website: www.medicalert.org.uk

Office of Public Guardian (OPG)

The OPG supports and promotes decision making for those who lack capacity or would like to plan for their future, within the framework of the Mental Capacity Act 2005. It provides information on Lasting Power of Attorney and receivership. The Court of Protection is at the same address.

Website: <https://www.gov.uk/government/organisations/office-of-the-public-guardian>

RADAR Key

A RADAR key gives access to 9,000 locked toilets around the UK. Toilets fitted with National Key Scheme locks can now be found in shopping centres, pubs, cafe, department stores, bus and train stations and many other locations in most parts of the country.

Website: <https://www.disabilityrightsuk.org/shop/official-and-only-genuine-radar-key>