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1. Introduction

About this pack

This guide was developed with the help of carers, and with carers in mind.

A special thank you to the Carers Project Group who kindly offered their time, information and caring experience, which enabled us to develop this guide.

Thank you to the health service who also helped make this guide possible by sharing information and advice on dementia and caring.

This guide is for adult carers living in Newcastle or caring for someone living in Newcastle. We hope the information will help you in your caring role, whether you are caring for someone with dementia or with mild cognitive impairment.

About carers

Carers are unpaid and provide support to friends, family or neighbours who could not manage without their help and support. The level of caring can vary and every carer’s situation is completely different. Carers can benefit from specialised services to help them cope in their caring role and find their way around health and social care services.

Newcastle Carers provides dedicated support for carers aged 18 and over who live in Newcastle or care for someone who lives in Newcastle. Support is based on
the person’s individual needs and ranges from 1-1 carer support, emotional support, advocacy & mediation, information, training, groups, activities & events, and opportunities to have a say on issues that affect carers. You can contact Newcastle Carers about individual and group support available, or can ask to be put on the mailing list to receive their newsletters. (See contact details in the directory on page 36)

The Alzheimer’s Society provides information, advice and support services to people with dementia, their carers and families. Services in Newcastle include a Dementia Support Service that offers 1-1 support, as well as support through a monthly carers’ group and Dementia Café. They also offer an activity-based day centre for people with a diagnosis of dementia. The day centre specialises in providing support and stimulation, and enables clients to maintain social interaction through activities in a safe and secure environment. (See contact details in the directory on page 32)

Dementia Care is a Newcastle-based charity that provides specialist care, support and advice to people with dementia and other neurological disorders such as acquired brain injury, stroke, multiple sclerosis and Parkinson’s disease. Dementia Care helps carers and family members by sharing knowledge through offering training and advice on practical care support and when needed, specialised respite care. Their services include: support in people’s homes which can range from 30-minute calls to 24-hour care, take-out and sitting service, residential respite care, a dementia-designed specialist day service at Brunswick Village and a unique supported-living housing scheme. All staff are trained in best practice in dementia care. (See contact details in the directory on page 34)

Carers’ top tips:

- Talk to someone - you will need to. Don’t wait until crisis point; get in touch with an organisation, such as those mentioned, as soon as possible. They can help you be more prepared and to manage your caring role and give you information any time you need it.
- Meeting other people in the same position as you can be very useful and reassuring.
- Gather as much knowledge and information as early on as possible.

Memory loss and dementia

Memory loss does not always mean someone has dementia. A GP can do a number of tests, including a memory test, to decide if a referral to a specialised memory service is needed to investigate memory loss further. There could be a number of other causes for memory loss such as stress, depression and side effects from medication.

Dementia happens when the brain is affected by a disease. It affects the brain’s ability to function. Symptoms vary from person to person and can include: memory loss; changes in thinking speed; mental agility; language; understanding; and judgement. In order for dementia to be diagnosed, the loss of skills must be significant enough for the person to start needing help with everyday activities. The problem also needs to be getting worse over time. If the problems are only
mild, or they do not seem to be getting worse, it is possible that the person may be diagnosed with mild cognitive impairment rather than dementia (see page 7). Although people diagnosed with dementia may live fulfilling lives for years, they may gradually begin to behave in ways that can be frustrating and challenging for carers.

Dementia is the umbrella term for various conditions. The most common are Alzheimer’s disease, vascular dementia and dementia with Lewy Bodies. Please see the glossary on page 43 for a definition of these terms.

Dementia with Lewy bodies

Dementia with Lewy Bodies (often shortened to DLB) is less common than Alzheimer’s disease but affects up to 100,000 people in the UK. People with this type of dementia have memory difficulties and confusion but also have some of the movement and balance problems associated with Parkinson’s disease.

There is a specialist clinic in Newcastle for diagnosing and treating people who may have DLB. This is based at the Memory Assessment and Management Service which is within the Centre for the Health of the Elderly on Westgate Road (formally Newcastle General Hospital). People can be referred to this service either by their GP or by a consultant who they may already be seeing for a memory or movement problem.

A DLB support and information group is also run at this venue. This provides three daytime sessions which carers and patients can attend together. The groups are small and there is a friendly atmosphere. Attending helps people to understand and cope with some of the particular challenges of DLB. Within the group people can meet others in a similar situation and find ways to stay positive. People can refer themselves to this group or they can ask a relative or health professional to do so. (See contact details in the directory on page 35)

Mild Cognitive Impairment (MCI)

This is a medical term used to describe problems with memory and brain function which are milder than those found in dementia. The symptoms can still be very frustrating and you can still ask Newcastle Carers for help. People with MCI are more likely to get dementia in the future. However, it is important to realise that many people with MCI don’t get dementia and many will actually improve.

Younger people and dementia

People with dementia who are under the age of 65 years are often referred to as ‘younger people with dementia’. There are over 17,000 younger people in the UK with dementia. Younger people with dementia may have very different support needs compared to people over the age of 65. For example, many younger people with dementia may be employed and have a young family.

In Newcastle, there is a dedicated community-based service working with people under 65 with a diagnosis of dementia. This service is based at the Centre for the Health of the Elderly, Campus for Ageing and Vitality
(formally Newcastle General). The Team has a Consultant Psychiatrist, Community Psychiatric Nurse, Occupational Therapist and there is access to a Clinical Psychologist.

The team offers a specialist service providing appropriate support, education and treatment for younger people with dementia, and their families and carers.

They also run a number of patient and carer groups to provide advice and information in dealing with memory problems (See contact details in the directory on page 35).

**Carers’ top tips:**

- If you have any concerns about the health of the person you care for it is best to check with a GP as soon as possible.
- As soon as you start to see signs of memory loss, start keeping a list of changes and behaviours you see in the person you care for, then give that list to the GP to help with diagnosis.
- Always try to be present at the appointments with the person you care for. This helps you to understand the process and the illness better and you might also need to provide information about the person that they can’t give themselves.
- Make sure you get information on the type of dementia the person has - it will also help to pass this on to anyone else who might help to look after them.

**Memory Assessment and Management Service**

A GP or other hospital specialist can refer someone of any age to this service due to concerns about their memory. Many people experience problems with declining memory. The effects will vary from person to person and may occur for different reasons. Carers can attend appointments at the Memory Assessment and Management Service with the person they care for.

The service has a team of specially trained Health Professionals including Doctors, Nurses, Clinical Psychologists and Occupational Therapists who all have different roles and expertise. Most people are seen in clinic by the professional best able to assist them which may be one or all members of the team.

The service provides:

- Comprehensive assessment and diagnosis of memory disorders.
- Access to treatments and other therapies or interventions.
- Support and advice to patients and their families.
- Collaborative working with other appropriate services.
- Initial treatment follow-up and short-term monitoring.

The service is based at the Centre for the Health of the Elderly. (See contact details in the directory on page 35)
Belsay and Melville Units

The Belsay and Melville Units are 2 units in Newcastle upon Tyne run by Geriatricians, together with a team of Nurses, Physiotherapists, Occupational Therapists with access to Speech and Language Therapists, Podiatrists and Dieticians. The Belsay Unit is situated at the Campus for Ageing and Vitality (previously The General Hospital) and the Melville Unit at the Freeman Hospital.

Geriatricians have particular expertise in looking after complex physical health problems, specialising in the management of falls, stroke and Parkinson’s disease; two of the geriatricians also have a specialist interest in dementia. A GP may refer a person to them if they have both mental and physical health problems, which will mean that they can have both things assessed in one place. This is particularly useful for people with stroke-related problems and also those with dementia with Lewy bodies, who may need medication for problems with movement.

Carers are welcome to attend visits with the person they care for. This means that valuable information can be passed on. Staff at the Belsay and Melville Units also welcome the opportunity to get to know carers and families, as well as the person with dementia.

2. What you need to know as a carer

Caring for yourself

It is important to make sure you are not neglecting your own health when you are caring for someone else, and that you are still able to do some of the things in life that are important to you. Caring for yourself can mean different things to different people - it might be keeping in touch with a good friend, going to the GP for regular check-ups, doing some exercise, or getting a takeaway, but it also means taking a break from caring. There are a number of ways to take a break. For example, doing a hobby or class, day trips, coffee with a friend, or weekend trips. There are grants available to help you pay for a break. Remember that you are just as important as the person you care for, and many carers say that taking a break is essential to allow them to keep going.

Carers’ top tips:

- Make sure to take some time out each week to do something just for you.
- Try to book a break every now and then to take some time away to relax and recharge.
- Newcastle Carers administers the Carers Opportunities Fund - funding support to get a break, household goods to give some relief (for example a washing machine), courses or driving lessons. Contact Newcastle Carers for more information.
- Complementary therapy such as an aromatherapy massage can be a really good way to relax.
- Remember to drink plenty of water and eat well - plenty of fruit and veg!
- It helps to learn to cook if you think you may have to take over in the kitchen. Taking some cooking classes can teach you to make simple and healthy meals on a budget.
Tell your GP you are a carer - they will be more helpful with arranging appointments. You may be able to get a free flu jab and you should also ask for a regular health check.

Caring for the other person

In the early days, changes in the person you look after may be small and you may not feel your role is really one of a carer. For each person things are different, and timescales vary. Gradually things may change, and although many carers say caring can be rewarding, you may find that living with someone with dementia can be very difficult to cope with at times.

There are good days and some not so good days. There can be unexpected changes which might cause you to become stressed and frustrated. The person may be able to do something one minute and then not the next. They might have difficulty communicating clearly and understanding things. They also may be restless or ask the same questions repeatedly, and these changes in behaviour can be confusing and irritating.

Remember not to feel guilty when you feel frustrated; these are normal feelings and reactions, and there are ways to get help. Talk to a professional about how you are feeling, they will be able to help you through your frustration and could help find a solution.

The Alzheimer’s Society factsheet “Communicating” gives tips and advice on ways to communicate with someone with dementia.

Respite services

A short break away from your caring role can allow you to recharge your batteries and have time to yourself. Short-break services are often known as ‘respite’ care. When considering having a break from your caring role, this may bring up feelings of worry or guilt. As a carer it is important to remember that you need to get regular breaks to ensure you are looking after your own well-being and health to enable you to continue to care.

There are various types of respite care, including:

- **Care at home** - arranging for someone to come into the home of a person with dementia to care for the person for a certain period of time.
- **Day care** - a purpose-built day facility for people with dementia. At day care there will often be activities, music, relaxation and opportunities to socialise.
- **Short breaks away** - arranging for a person with dementia to be cared for away from their home, including a short stay in a care home.

Adult Social Care can help you to arrange respite care. A Social Worker can assess your needs and see what support may be available to help you in your caring role. This is further explained on page 29.

Carers’ top tips:

- If you’re feeling stressed and find some behaviours difficult to deal with on your own then talk to someone: a friend, family member, GP or Carer Support Worker, to make sure you are getting the support you need.
Sometimes a change of scenery can stop repetitive questions. Talking to the person in a calm voice may help with repetitive actions.

- Repetition, sleeplessness, and boredom can sometimes be solved through physical activity. Going on a walk with the person can help, as can social activities with other people.
- A reassuring touch may help when a person with dementia is feeling frightened, agitated, or scared.
- Taking a break away together can help both of you – think of things you have enjoyed doing together and take the time away when you can.
- It could become difficult for the person you care for to understand the concept of time. Keeping a daily timetable visible can be helpful so that they know what they are doing each day. Some carers find using a whiteboard on the wall works, writing on what’s happening that day such as appointments, lunchtime, shopping, or any visitors coming.
- Newcastle Libraries have reminiscence books that you can borrow to go through and discuss with the person you care for. (See contact details in the directory on page 37)

Behaviours that challenge

As the disease progresses, some people with dementia can develop behaviours that we can find challenging. This behaviour particularly may be very difficult and frustrating to cope with. Listed below are a number of examples of behaviour changes that you might see in the person you care for, but please remember that everyone is different and so these may or may not happen:

- **Repetition** - repeating questions or actions - this may be because the person does not remember they have said or done something. They may be bored or they may be uncomfortable.
- **Getting very agitated** - this could be for a number of reasons: boredom; hunger; constipation; lack of exercise - to name a few examples.
- **Lack of inhibition** - the person you care for may do things in public that you find are inappropriate and embarrassing, for example, shouting or screaming. For some people with dementia, this may be because of their dementia affecting certain parts of the brain.
- **Aggression** - there could be a number of reasons for this. For example, they might be confused, anxious, scared, angry or frustrated, or having a hallucination.
- **Night-time waking** - some people with dementia can become confused about time. They can find it difficult to have regular sleeping patterns, for example waking up in the middle of the night. Carers may find themselves not able to sleep because the person they care for keeps waking up. This can be exhausting for carers.

Remember the person with dementia is not being deliberately difficult, and you should try not to take the behaviour personally. This can be very difficult to do. It may help to remember people with dementia are trying to communicate something and it can help to take time to try to work out what it is. There is always
a reason behind behaviours and if you can try to work out what is causing it, it may then be possible to avoid it happening in the future. Try to communicate clearly and listen to what they are trying to say. Also try to avoid loud background noise such as a television or radio. Always give time for the person you care for to answer a question. One possible reason for certain behaviours is the person is in pain, so it is worth going to their GP with them so this can be checked out.

You are dealing with a very stressful situation so it’s important not to feel guilty for being frustrated. If the behaviour becomes really difficult to cope with or aggressive, then seek advice and support from your GP or another professional.

The Alzheimer’s Society factsheets “Unusual behaviour” and “Dementia and aggressive behaviour” have more detailed information on the causes of those behaviours and give techniques on how you may want to deal with them.

**Delirium**

One reason for challenging behaviour is delirium. Delirium is a condition where someone becomes more confused for an underlying medical reason. It can happen at home or when the person is in hospital. People with dementia are especially at risk of developing a delirium. Medical problems, surgery and medications can all cause delirium. It often starts suddenly and improves when the underlying cause gets better. It can be quite frightening for everyone involved.

When someone becomes suddenly more confused (agitated, aggressive, hallucinating or a combination) or less active (quiet, withdrawn, slow or sleepy) they may have a delirium. When someone suddenly becomes more confused they need to see a doctor urgently and it is important that someone who knows them well is with them to describe what has happened. If the person becomes more confused in hospital it is important to let the care staff know about it.

There are a number of causes of delirium including infection, medications such as pain killers, dehydration, surgery, constipation, or even being in a new place that is not home. Treatment involves careful medical assessment and looking for and treating the underlying cause. Sedative medication should be avoided as it can cause the person to become more confused or unwell, but sometimes when the person is very distressed or putting people at risk a small dose is necessary. Recovery can be quick but it can also take several days or weeks.

When someone you know is delirious, there are some things that you can do to help. These include:

- Staying calm
- Talking slowly and clearly, making sure the person understands what is being said
- Reminding the person of where they are and what time of day it is
- Listening to them and reassuring them that they will be okay
- Making sure they wear their glasses and if they use a hearing aid making sure it is in working order
- Helping them to eat or drink
• Spending time with them where possible
• If in hospital, bringing in familiar items such as photographs from home
• Having a light on at night so they can see where they are when they wake up

Delirium can be quite a frightening experience for the person with dementia and those around them. But there are things that you can do. For further information there is a helpful leaflet on delirium published by the Royal College of Psychiatrists. (See contact details in the directory on page 40)

Carers’ top tips:

• Try not to take any of these actions personally, they are effects of the dementia and the person does not mean you any harm.
• It is sometimes possible to distract someone - play their favourite music, sing a song, do a household activity, reminisce, for example look at old photographs.
• Some actions may be very persistent and you may not find solutions right away. It could help to talk to a professional who could have a useful suggestion.
• Make sure you take a break.

Safety at home

The person you care for may feel they need to walk about, and potentially out of the house. For people with dementia, walking can help stop boredom and can also help the person to exercise. For carers, walking can be worrying. It is important for people with dementia to stay as independent as possible. However, some carers may feel concerned for the safety of the person they care for. There are steps that you can take to help to reduce the risk of something happening:

Community Care Alarm Service

This service is provided by Your Homes Newcastle. It can help with providing safety to the person you care for and give you reassurance when you are not there or when you are asleep. Services they can provide include a special alarm unit that is linked to a 24-hour response centre when you press the unit’s alarm button. A personal pendant can also be provided, which can be worn around the neck or wrist, and acts as a portable alarm button.

In addition to an alarm unit and personal pendant, Telecare can also be provided. Telecare is a system of electronic sensors that work with an alarm unit to dial the response centre for help automatically, when a safety risk has occurred, such as a fall. Examples of Telecare equipment include: fall detectors, flood detectors, pill dispensers, bed occupancy sensor and door exit sensor.

There is usually a charge for these services.

Carers’ top tips:

• A Carer Support Worker from Newcastle Carers, a Social Worker from Adult Social Care or another professional can refer you to the Community Care Alarm Service.
Keep car keys out of sight; think about storing them in a drawer when you get home.

You can get the person you care for an identification bracelet, or put a card in their pocket or handbag which can help them be easily identified if they do wander off.

Reduce tripping hazards by keeping wires and cords tucked away and repair any damaged floors or carpets.

Keep cleaning products stored away in a cupboard.

Handrails and grab rails in the home, amongst other adaptations, might be a good idea - talk to a social worker about getting an assessment for your home.

Make sure there is even lighting throughout the home; it would also be a good idea to leave a hallway light on at night.

Have your smoke detectors and carbon monoxide detectors checked regularly by the Fire Brigade. They can also advise about a fire blanket or fire extinguisher for the kitchen.

What to do in a crisis

In an emergency, we all know to ring 999. However, what if you need some urgent support or information? If the concern is about the condition of the person you care for, you can:

- ring your GP; or
- ring the Memory Assessment and Management Service or the Melville Clinic if you have been given a number by them for this purpose.

If the crisis is due to a change in your circumstances or your ability to care for someone then you can ring Social Services:

- Monday - Friday, 8am - 6pm, Community Health and Social Care Direct - Telephone: 0191 278 8377; Textphone: 0191 278 7878.
- During the evening or on a weekend, telephone: 0191 232 8520 and ask for the Emergency Duty Team.

Carer’s Emergency Contact Scheme

A lot of carers worry about what would happen to the person they care for if something happens to them. Carers can be part of the Carer’s Emergency Contact Scheme. This means registering a plan with the British Red Cross about who they should contact in an emergency if you are unable to care. If they cannot contact anyone, they will ensure that support is put in place. You carry a card with you at all times and The British Red Cross provides a free rapid response 24 hours a day, 7 days a week, including bank holidays. (See contact details in the directory on page 33)

Housing options

With the right support many people with dementia can stay at home for as long as possible. There is a range of services that can help with this such as: help within the home; Community Care Alarm service; Assistive Technology (see Glossary). As dementia progresses, for
some people staying at home can become more difficult. There are various housing options available:

- **Sheltered housing (often called retirement housing)** - people can stay independent with the reassurance of help when needed, for example, in an emergency. Sheltered housing often has communal facilities; a Warden to manage the sheltered housing; Community Care Alarm service; and social activities to take part in. Sheltered Housing does not give support and care, such as personal care. This would be arranged through Adult Social Care.

- **Extra care housing** - purpose-built apartments for people who need more care and support but want to remain independent. They often include: care staff 24 hours a day, apartment security system, specific areas for social activities, specially designed facilities to make independent living easier.

- **Care homes** - there are two types of care homes: residential care homes and care homes with nursing. Residential care homes can help with personal care such as washing and dressing. Care homes with nursing help with personal care but also have nurses available 24 hours a day. The type of care home a person with dementia needs depends on their care and support needs. A person with dementia may have another health condition, such as a stroke, and may therefore need nursing care.

- **Dementia Care Supported Living Houses** - this type of housing helps people to stay independent with the option of practical and emotional support during the day and night.

People with dementia have a room of their own and share a bathroom, kitchen, living space and garden. (See contact details in the directory on page 34)

If the time comes when you need to consider different housing options for the person you care for, a needs assessment will be carried out (usually by a Social Worker). This is to make sure the needs of the person you care for will be fully met.

**When the person you look after is in hospital (The Newcastle upon Tyne Hospitals NHS Foundation Trust)**

Being in hospital can be worrying for everyone but for people with dementia and their carers it can be a particularly stressful time. The hospitals in Newcastle provide a wide range of health care, investigations and treatment both on a planned and unplanned (emergency admissions) basis.

Whilst the person you care for is in hospital, staff should work with you to ensure that they get the best possible care. It is unlikely that your relative will be admitted as a direct result of their dementia. However, staff in all areas of the Trust now receive training in dementia awareness and have access to support and ongoing development via a Dementia Champions Network.

To ensure that the care provided is sensitive to the individual needs of patients with dementia, the Trust has introduced the ‘Forget me not’ scheme. This helps staff get to know the person you care for: their likes...
and dislikes, as well as their interests and how they like to spend their time. The more detail you can give the better – even things such as suggestions for topics of conversation are helpful. If the person you look after goes into hospital, please ask the nursing staff for a ‘Forget me not’ card to fill in, and for more information.

Some people with dementia may have completed the Alzheimer’s Society ‘This is me’ booklet. ‘This is me’ is a free booklet people with dementia can use to tell staff about their needs, interests and likes and dislikes. Staff find the information provided by ‘This is me’ extremely helpful and welcome the opportunity to look at the information provided.

Generally, visiting times are from 2pm-4pm or from 6pm-8pm. However, staff understand that people with dementia often need a more flexible approach. Please talk to the Sister or one of the registered nurses about visiting times and agree what is best for you and the person you care for. They also welcome carers and family members who wish to continue to provide care whilst their loved one is in hospital. An example of this might be providing assistance at meal times.

At some stage the person you care for may be seen by a member of the liaison psychiatry team. This will either be a consultant or a member of the nursing team. They provide specialist assessment and then give advice to the ward team. Please ask the ward doctor or nurse if you wish to speak to them.

The Trust have a patient information leaflet called ‘Being in Hospital’. This leaflet explains what to expect when someone is admitted to hospital. (See contact details in the directory on page 37)

Planning ahead

Mental Capacity

The Mental Capacity Act 2005 is a law that was put in place to protect people who are not able to make decisions for themselves for a number of reasons, for instance, if they have dementia. Someone might be considered to be unable to make a decision (this is called lack the capacity to make a decision) if they are: unable to understand and retain information given to them; unable to prove their full understanding of the options available; and unable to communicate their decisions or wishes.

Lasting Power of Attorney

‘Lasting Power of Attorney’ is when someone chooses who can legally make decisions on their behalf. This needs to be in place before someone is unable to make their own decisions. Once someone is no longer able to make decisions, it is very unlikely a Power of Attorney can be put in place because they will not be seen to have the Mental Capacity to make a decision about who to choose.

There are two types of Lasting Power of Attorney:

1. **Health and welfare** - Decisions can be made about daily routine, medical care, moving into a
care home and/or refusing life-sustaining treatment.

2. Property and financial affairs - Decisions can be made about money and property, such as bills, collecting benefits, managing or selling your home.

Carers' top tips:

- Don’t wait until it’s too late - put a Lasting Power of Attorney (information below) in place at the very start - this will make things much less complicated later on.
- If you are in doubt about someone’s ‘mental capacity’, speak to a GP
- A support worker or social worker can help direct you to a service that can provide advice on getting a Lasting Power of Attorney.
- It can be very reassuring to know that you or another trusted person can legally make decisions once the person with dementia is no longer able to.
- The process of setting up Lasting Powers of Attorney together means you know the person’s wishes, and that makes things easier later on.

Trusts

A Trust is a way to ensure assets, such as property or savings, are managed in a way that the person chooses. There are various ways a trust can be set up and it may be beneficial to seek help from a solicitor or financial adviser, as trusts can often be quite complex. It is important to set up a Trust before someone is starting to show signs of memory loss and especially before any signs that a person may need care in a care home.

Talking about what care might be needed in the future

It is useful to talk to the person you care for about what kind of care they may want in the future. Having these conversations early on after someone has been diagnosed with dementia can make it much easier for you to feel confident about decisions you may need to make later on their behalf.

A Memory box and/or a life story book

It might be useful to make a memory box with the person you care for. This can be a bag, a cardboard box, whatever they would like. Together you can put in things that are important to them - photos, a favourite ornament or tool, a favourite book or CD - whatever they like.

You can also make a life story book together, with photos of them, their family and favourite places, and with some writing about the person you care for and their life.

In the future, a memory box and/or book will help the person you care for and those around them remember the things important to them in their life.
Carers’ rights and entitlements

Carer’s Allowance

Benefits can have a significant impact on your quality of life and you could ask for a benefits check to see if you qualify. You may be eligible for Carer’s Allowance if you spend at least 35 hours per week looking after someone who receives the middle or highest rate of Disability Living Allowance (DLA), Personal Independence Payment (PIP) or Attendance Allowance. You are not eligible for Carer’s Allowance if you are receiving a pension, but you could be eligible for pension credit.

As a carer you might also be entitled to claim other benefits, such as Employment and Support Allowance, Jobseeker’s Allowance or Tax Credits.

Claiming some benefits can have an effect on other benefits that you are already receiving, for example if you are receiving Income Support - this is why it’s good to speak to someone and get some advice.

Carers’ top tips:

- You might be entitled to help with your rent or a discount on your Council Tax.
- If you’re having problems with your benefits contact Newcastle Welfare Rights Service. (See contact details in the Directory on page 38)
- The person you care for might be eligible for high rate DLA if they are up in the night time.
- Get support to manage money if you are finding it too stressful - remember that sometimes bills can come in a few weeks late e.g. respite care bills.

A Carer’s Assessment from Adult Social Care Direct Team

You can request a Carer’s Assessment from a social worker. At the assessment a social worker will look at your role as a carer and how being a carer affects you. They will look at how much caring you are doing, and talk to you about whether you have time to be involved in things other than caring. They will also assess what other support you might need and help you plan how to get it.

Adult Social Care - The Carer Support Allocation

If the council decide that the person you look after can get help from adult social care, they will complete something called a Support Needs Questionnaire (SNQ). This helps them to work out how much support the person can have.

At the same time, the SNQ works out an amount of money that they can give you to make things easier and to help you to carry on caring. This is called a Carer Support Allocation. They usually give a Carer Support Allocation as a Direct Payment - that means giving you the money to pay for the things that you and the social worker have agreed will help you as a carer.

Carers’ top tips:

- If you are given a Carer Support Allocation, a direct payment can be set up so that you can manage the money yourself. You will need to agree with Social Services what you will spend
the money on, and remember to keep proof of payments as they will need to see these.

Rights at work

If you are caring for a relative or for someone who lives at the same address as you, and you have worked for your employer for at least 26 weeks, then you have a right to request flexible working hours.

If they do not take up your request they have to give you a clear reason for not doing so. Flexible working could be in the form of flexible start and end times, compressed hours, job sharing or home/tele-working.

You also have the right to take a ‘reasonable’ amount of time off from work in order to deal with any emergencies regarding the person you care for. It is up to the employer as to whether or not this leave is paid or unpaid.

Carers’ top tips:

- It might help to tell your employer that you are a carer, they may be able to support you.
- If you are thinking of giving up work to care fulltime, the carers centre can advise you about this.
- If your caring responsibilities are affecting your employment, you can talk to Adult Social Care to see if they can provide some, or more care for the person you look after.

Giving feedback

As a carer, you may want to give feedback to services about the care they have provided or how you feel you have been treated. This may be negative or positive, but may improve things in the future for you and other carers. Often services are grateful for constructive feedback, but if you would like to do it anonymously you can contact:

- North of Tyne Patient Advice and Liaison Service (PALS) on telephone number: 0800 032 02 02; or email: northoftynepals@nhct.nhs.uk. PALS provide confidential support and information on health-related matters. North of Tyne PALS can also liaise on your behalf with services or give you information about what steps you can take yourself.
- For Newcastle City Council you can contact the Customer Relations Team, telephone number: 0191 211 4955; or email: adultservices.customer@newcastle.gov.uk. You can also visit their website: www.newcastle.gov.uk.
- For information about services, Healthwatch Newcastle offer a free helpline with confidential and independent information about health and social care services in Newcastle. Their helpline is available Monday to Friday, 9am to 5pm on telephone number: 0808 178 9282 (free from landlines) or text: 07551 052 751.
3. Directory of other useful organisations

Local Services

Advocacy Centre North

Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocacy Centre North provides a range of services for people in vulnerable circumstances, mainly to adults living in Newcastle.

Address: Advocacy Centre North, NCVS, Higham House, Higham Place, Newcastle upon Tyne, NE1 8AF
Telephone: 0191 235 7013
Email: advocacy@cvsnewcastle.org.uk
Website: www.cvsnewcastle.org.uk

Alzheimer’s Society

Alzheimer’s Society also offers in Newcastle a day-care service at their Connie Lewcock Day Centre. For more information about Connie Lewcock Day Centre, telephone 0191 267 0198; or email: newcastle@alzheimers.org.uk.

A free copy of ‘This is me’ booklet can be ordered by contacting Alzheimer’s Society Newcastle office on 0191 298 3989. A copy can also be downloaded for free online at: www.alzheimers.org.uk.

Newcastle office address: Room 1, Ground Floor, The Beacon, Westgate Road, Newcastle upon Tyne, NE4 9PQ

Email: newcastle@alzheimers.org.uk

Carer’s Emergency Contact Scheme - British Red Cross

The British Red Cross offers free emergency support to a person whose carer suddenly becomes unable to return and offer care in the usual way. They provide rapid response and are available 24 hours a day, 7 days a week, including bank holidays.

Address: British Red Cross, Croft House, Western Avenue, Newcastle upon Tyne, NE4 8SR
Telephone: 0191 273 7961

Community Health and Social Care Direct (Newcastle City Council)

Community Health and Social Care Direct provides advice, support and information to people living in Newcastle, and access to social workers for people who need care and carers, for example for a Carers Assessment. Services also include equipment and adaptations, home care, respite services and day care.

Monday to Friday 8.00am - 6.00pm
Telephone: 0191 278 8377
Textphone: 0191 278 8359

At any other time (emergencies and Bank Holidays) contact the Emergency Duty Team on 0191 278 7878.
The local authority also holds a list of local Kitemark-approved independent agencies that provide social care services which can be purchased using your personal budgets. The Kite Mark makes sure all services provided by organisations are doing so at a minimum level and providing a quality service.

**Dementia Care**

Dementia Care help carers and family members by sharing knowledge through offering training and advice on practical care support and when needed, specialised respite care. Dementia-friendly day club and respite are offered through the **The Bradbury Centre**, Darrell Street, Brunswick Village, NE13 7DS.

**Telephone:** 0191 217 1323

**Email:** info@dementiacare.org.uk

**Website:** www.dementiacare.org.uk

**Dementias and Neurodegeneration (DeNDRoN)**

Carers often report involvement in dementia research can offer hope and be rewarding. All research taking place in Newcastle is co-ordinated by The Dementias and Neurodegeneration research team (part of NHS Clinical Research Network for the North East and Cumbria).

**Address:** Dementias and Neurodegeneration (DeNDRoN), St Nicholas Hospital, Jubilee Road, Gosforth, Newcastle upon Tyne, NE3 3XT

**Telephone:** 0191 223 2740

**Email:** dendron@ntw.nhs.uk

**Disability North**

Disability North promotes inclusion, independence and choice for disabled people and provide information and advice on disability.

**Address:** The Dene Centre, Castle Farm Road, Newcastle upon Tyne, Tyne & Wear, NE3 1PH

**Telephone:** 0191 284 0480

**Email:** reception@disabilitynorth.org.uk

**Website:** www.disabilitynorth.org.uk

**Memory Assessment and Management Service**

This is a specialist service for comprehensive assessment and diagnosis of memory disorders.

**Address:** Campus for Ageing and Vitality (formerly Newcastle General Hospital), Westgate Road, Newcastle upon Tyne, NE4 6BE

**Telephone:** 0191 246 8753
Newcastle Carers

Newcastle Carers provides dedicated information and support to adult carers living in Newcastle or caring for someone living in Newcastle.

Address: 135-139 Shields Road, Byker, Newcastle upon Tyne, NE6 1DN
Monday to Friday 10.00am - 4.00pm
Telephone: 0191 275 5060
Fax: 0191 265 1191
Email: info@newcastlecarers.org.uk
Website: www.newcastlecarers.org.uk

Newcastle Citizens Advice Bureau (CAB)

Newcastle CAB offers free services providing general advice and information across a wide subject area. They can offer help with: debt, housing, benefit entitlements, consumer, and employment issues. They have drop-ins across the city; call the main telephone line to find the nearest one to you.

Main office address: St Cuthbert’s Chambers, 35 Nelson Street, Newcastle upon Tyne, NE1 5AN
Main Telephone: 0191 229 2750
Advice line: 0344 245 1288, Monday to Friday, 10am-4pm. Calls to this service cost the same as calling 01 and 02 numbers. Call from mobiles on 0300 330 0650 to avoid paying high mobile charges.

Debt Telephone Line: 0191 261 8522
Email: citycab@newcastlecab.org.uk

Newcastle Continence Service

Newcastle Primary Care Trust continence service can assess someone’s bladder and bowel needs. The GP or district nurse can refer the person into the service for an assessment.

Address: Walkergate Clinic, 45 Scrogg Road, Walker, Newcastle upon Tyne, NE6 4EY
Telephone: 0191 282 6308

Newcastle City Library

Newcastle Libraries provide books, information and free computer use at branches across the city. Contact details for the City Library are:

Telephone: 0191 277 4100
Email: information@newcastle.gov.uk
Address: City Library, Charles Avison Building, 33 New Bridge Street West, Newcastle upon Tyne, NE1 8AX

Newcastle Hospitals Switchboard: 0191 233 6161
Address: Royal Victory Hospital (RVI), Queen Victoria Road, Newcastle, NE1 4LP
Newcastle Welfare Rights Service
The service provides benefit information and advice.

**Telephone:** 0191 277 2627

*Monday – Friday, 9:30am – 12noon*

**Debt queries** - telephone: 0191 277 1050

*Monday, Tuesday, Thursday and Friday - 9.30am – 11.30am*

Your Homes Newcastle
Your Homes Newcastle provides a range of housing services, including the Community Care Alarm service.

**Head office address:** YHN House, Benton Park Road, Newcastle upon Tyne, NE7 7LX

**Telephone:** 0191 278 8600

**Email:** yhn@yhn.org.uk

**Website:** www.yhn.org.uk

National organisations

Care Quality Commission (CQC)
Independent regulator of health and social care services. They rate the services that are available and can provide information and reports on care services such as care homes.

**Telephone:** 03000 616161, Monday - Friday, 8.30am - 5.30pm

**Email:** enquiries@cqc.org.uk

**Website:** www.cqc.org.uk

Care Aware
Advice, information and advocacy about care homes, and funding for care.

**Telephone:** 0161 707 1107, Monday - Friday, 9am - 5pm

**Email:** enquiries@careaware.co.uk

**Website:** www.careaware.co.uk

First Stop
Independent and free information service provided by the national charity Elderly Accommodation Counsel (EAC) on housing options.

**Advice Line:** 0800 377 7070, Monday - Friday, 9am - 5pm
Email: info@firststopadvice.org.uk
Website: www.firststopcareadvice.org.uk

Royal College of Psychiatrists
Professional body responsible for education, training, setting and raising standards in psychiatry.
Telephone (switchboard): 020 7235 2351 or 020 7977 6655
Email: reception@rcpsych.ac.uk
Website: www.rcpsych.ac.uk

The Pensions Service
Information on State Pension eligibility, claims and payments.
Telephone: 0800 731 7898, Monday - Friday, 8am - 6pm

Useful websites

- Alzheimer’s Society - a range of factsheets and other publications available to download free of charge: www.alzheimers.org.uk
- AT Dementia - information on Assistive Technology to help people with dementia live more independently: www.atdementia.org.uk
- Carers Trust - a range of information for unpaid carers about caring and caring issues: www.carers.org
- Carers UK - expert help and support to unpaid carers: www.carersuk.org
- GOV.UK - information about government services and information, including benefits: www.gov.uk
- Information Now - information and advice website for people over 50 in Newcastle, their families and carers: www.informationnow.org.uk
- My Ageing Parent - information on things such as care options, funding and paying for care, activities, staying healthy, legal issues: www.myageingparent.com
- Newcastle Council - latest information about city-wide news, events and services. Also, information about health and social care, including adult social care: www.newcastle.gov.uk
- NHS Choices - official website for the NHS. Information including a ‘Dementia Information Service’, health A-Z, care and support, living well and health news: www.nhs.uk/Pages/HomePage.aspx
4. Recommended Reading
A small list of well-known books about dementia and caring.

- **Alzheimer’s and Other Dementias** by Alex Bailey (Class Publishing 2014).
  Information about the different types of dementia and advice about how to support someone living with dementia.

- **And Still the Music Plays: Stories of People with Dementia** by Graham Stokes (Hawker 2010).
  A practical book which examines unusual or unexplainable behaviour, and looks at ways to help with such behaviours.

- **Still Alice** by Lisa Genova (Simon and Schuster 2012).
  Fifty year old Alice, a university professor, wife and mother of three children, finds herself in the grips of Alzheimer’s disease. A story of how Alice lives through each day.

- **Telling Tales About Dementia: Experiences of Caring** by Editor Lucy Whitman (Jessica Kingsley 2009).
  Thirty carers from different background share their experiences of caring for someone with dementia.

- **Understanding Alzheimer’s disease and Other Dementias** by Nori Graham and James Warner (Family Doctor 2009).
  Information about dementia to help people better understand what causes the condition and how it is diagnosed and treated.

Alzheimer’s Society has produced a guide called ‘The Dementia Guide’. This is a useful information booklet for anyone who has recently been told they have dementia. The guide can also be used by carers, families or friends, as it includes information about dementia and caring. The guide is available to download on Alzheimer’s Society website: [www.alzheimers.org.uk](http://www.alzheimers.org.uk), or by telephoning 0300 303 5933, or emailing: orders@alzheimers.org.uk.
5. Glossary

Agnosia
A loss of the ability to recognise objects, faces, sounds, shapes or smells when the primary sensory organ still works and there is usually no significant memory loss.

Alzheimer’s disease
A progressive condition causing deterioration of the brain and leading to the loss of brain cells. Affects the short-term memory; causes problems with language and speech; and can lead to personality changes. It is the most common form of dementia.

Aphasia
A condition affecting the brain and leading to the loss of the ability to comprehend and communicate language.

Apraxia
The loss of the ability to coordinate and perform skilled movements or gestures (e.g. waving goodbye).

Assistive Technology
A term often used to describe when equipment and devices are put in place to help someone to live independently. For example, a medication device to help people with dementia to take their medication at the right time.

Care Plan
Everyone with a long-term condition can have a care plan if they want one. A care plan is an agreement between a patient and a health professional (and/or social services) to help you manage your health day-to-day. It can be a written document or something recorded in the patient notes. Everyone who has a long-term condition can take part in making their care plan. It helps to assess what care is needed and how it will be provided.

Central Nervous System
The brain and spinal cord make up the central nervous system. It helps all parts of the body to communicate with each other.

Dementia
An umbrella term used to describe the various types of dementia that affect the brain’s normal functioning. It can cause loss of short-term memory, communication difficulties and changes in mood.

Dementia with Lewy bodies
Lewy bodies are small clumps of abnormal proteins that form in the brain disrupting the brain’s normal ability to function. The proteins interfere with the signals between brain cells.

Encephalitis
Inflammation of the brain. The inflammation is usually caused either by an infection in the brain, or through the immune system attacking the brain in error.
Frontotemporal dementia

Frontotemporal dementia affects the frontal and temporal lobes of the brain. It is a less common form of dementia and a significant cause of dementia in younger people (under the age of 65). Symptoms usually include changes in personality and behaviour and can also include problems with speaking and language.

Korsakoff’s Syndrome

Brain disorder associated with large amounts of alcohol consumption over long periods of time. If people drink large amounts of alcohol over time they can become thiamine deficient (vitamin B1) which can affect the brain and nervous system. It causes loss of short-term memory.

Memory Box

A Memory Box contains photos and other items such as mementos from a person’s life. It is useful both to help the person remember and also as a way of letting others know about the person’s life.

Mild Cognitive Impairment

Mild Cognitive Impairment (MCI) is used to describe a condition involving problems with mental abilities such as thinking, knowing and remembering.

Parkinson’s Disease

Parkinson’s disease is a progressive condition where part of the brain becomes more damaged over many years. The main symptoms of Parkinson’s disease affect movement, including shaking, stiffness and slowness of movement.

Respite

Short-term care used as an alternative to the usual care arrangements in order to provide carers with a temporary relief in their caring role.

Sundowning

This is a term used to describe when people with dementia have periods of increased confusion in the evening. This confusion usually continues throughout the night.

Vascular dementia

A form of dementia caused when there are problems with the supply of blood to the brain. Symptoms can initially begin suddenly, for example, after a stroke. Symptoms can also remain steady for some time then suddenly deteriorate. Vascular dementia is the second most common form of dementia.
6. Notes Section

This section is for you to note any extra information. For example, personal contact numbers, important appointments or dates or if you have a specific question for the GP or care worker.
Getting to us

We are located half way along Shields Road in Byker.
135 - 139 Shields Road, Byker, Newcastle upon Tyne, NE6 1DN

Buses to/from Shields Road 1, 12, 15, 15a, 22, 39, 40, 62, 63
Buses to/from Heaton Road 16, 18, A3, 32a

Byker Metro within 100 meters

Sat Nav Address 137, NE6 1DN

Parking: there is 2 hour parking on minor roads at the back of the centre

t. 0191 275 5060  e. info@newcastlecarers.org.uk
Tweet: @NCLCarers  Facebook: /NewcastleCarers
www.newcastlecarers.org.uk

Important information about this guide

This booklet is for adult carers living in Newcastle or caring for someone living in Newcastle. This booklet is only a guide and does not cover individual circumstances. Every effort has been made to ensure that the information in this guide is correct as at January 2015. Newcastle Carers cannot accept liability for errors or omissions and are not responsible for the quality of services referred to in this guide.

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