



Carers' support information

This information (and our group) is based on the Wellness Recovery Action Plan (WRAP for short), which was developed to help you cope with life's challenges (see www.mentalhealthrecovery.com). It covers five concepts, which we will go through in the following.

This information covers five key concepts:

- Education
- Personal responsibility
- Self-advocacy
- Hope
- Supporters

This information aims to:

- Provide you with information about dementia
- Provide strategies to help you stay well, both mentally and physically
- Help you develop an action plan for different problematic situations

Education

What is Dementia?

Dementia is a common condition that affects approximately 800,000 people in the UK. "Dementia" is an umbrella term that describes a range of symptoms that are associated with an ongoing decline of the brain and its abilities. See below what areas are commonly affected:



Memory loss



Language



Thinking speed



Understanding and judgement

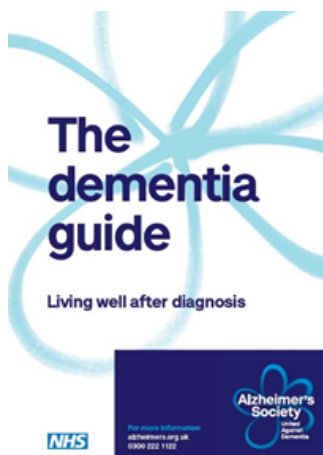


Mental agility

There are over a hundred different forms of dementia, the most common ones are: Alzheimer's Disease, Vascular Dementia, Lewy Body Dementia, Frontotemporal Dementia and mixed dementia (when the person has more than one type of dementia). Especially early on, the different dementias impact on abilities differently. Memory problems might not be the first thing that you notice, it could be for example problems with word finding or problem solving.

Often the person's family and friends will notice the symptoms before the person themselves. Dementia is progressive, which means the symptoms will gradually get worse. How quickly dementia progresses depends on the individual person and also on the type of dementia they have. Each person is unique and will experience dementia in their own way.

A lot of research is going on to help people with dementia. As yet we have not found a cure. For some types of dementia, for example Alzheimer's Disease, there is medication that can slow progression down. If we cannot prescribe medication that does not mean that there is nothing that will help.



Healthy living and remaining active is important for everyone. It can help to live independently for longer and also help slow down the dementia progressing. You can find out more information about the different forms of dementia, treatments, support etc. in the Dementia Guide from the Alzheimer's Society (you were given a copy at the diagnostic appointment).

You can also download it from the Alzheimer's Society website or order a paper copy by ringing the Dementia Support Line: 0333 150 3456. The Alzheimer's Society also produce a wide range of publications and factsheets designed to support and inform anyone affected by dementia (see www.alzheimers.org.uk).



A brilliant way to link up with others and learn more about dementia is an offer by the Alzheimer's Society called Dementia Friends. Dementia Friends is a social action movement that aims to increase understanding

of dementia and inspire people to take action to support people affected by dementia in their community. If you are interest in attending a dementia friend's session please contact dementiafriendsweb@alzheimers.org.uk for further information. Further information can be found at www.dementiafriends.org.uk/



There are other organisations who provide help, such as DementiaUK. They have a helpline for carers Tel: 0800 8886 678, as well as useful resources and videos at www.dementiauk.org/

Personal responsibility

Looking after and supporting someone can be stressful. It is easier to support someone when we link with other people and groups. We usually advise to contact services in your local area, such as community groups, or offerings from day centres, luncheon clubs or other organisations.

There are organisations you can ring for support, such as:

Newcastle Carers

Mon to Fri, 9am – 5pm
on 0191 275 5060

Alzheimer's Society

Mon to Fri, 9am – 5pm
on 0191 298 3989

Dementia Matters

Mon to Thurs 9am – 5pm
Fri 9am to 4.30 pm
on 0191 217 1323

Silverline Memories

Mon to Fri, 9am – 5pm
on 0191 603 0095

Memory Assessment and Management Service (MAMS)

Mon to Fri, 9am – 5pm
on 0191 246 8753



Another helpful organisation is Carer UK. Their telephone Helpline is available on 0808 808 7777 from Monday to Friday, 9am – 6pm or you can contact them by email (advice@carersuk.org) They also have a really good website with plenty of information: www.carersuk.org/



It might also be helpful to request a **Carers Assessment** through social services. Any carer over 18 years old who is looking after another adult over 18 years old who is disabled, ill or elderly can ask for an assessment. The assessment will look at for example, physical, mental and emotional needs, and whether you are able or willing to carry on caring.

You do not need to live with the person you support. If you are sharing caring responsibilities with another person, or more than one person, you can each have an assessment.

Your assessment should cover:

- your caring role and how it affects your life and wellbeing
- your health – physical, mental and emotional issues
- your feelings and choices about caring
- work, study, training, leisure
- relationships, social activities and your goals
- housing
- planning for emergencies (such as a Carer Emergency Scheme).

The local council should be able to tell you more about what they can do to help you plan for an emergency. You can request a carer's assessment here:

Newcastle

Newcastle City Council - Social Care Direct Tel: 0191 278 8377
Newcastle Carers Tel: 0191 275 5060

North Tyneside

North Tyneside Council - Care and Connect Tel: 0191 643 7474
North Tyneside Carers Centre Tel: 0191 249 6480

Self Advocacy

We can only really care for someone when we are also looking after ourselves. It is up to you to do things that support your well-being. Take a moment and think of your own needs. Think of things that keep you well. Make a note of this:

Looking after yourself includes looking after your physical and emotional needs and staying connected with others for social support. Some people like to be active, others like to have a rest or be sociable.



Friends



Relaxing



Love and
belonging



Exercise



Fun

Making sure that you keep yourself well and have your own needs met is really hard at the moment. We are all staying in and might not get the support we normally get. Please make sure you take care of your basic needs: have enough rest, make sure you eat well and drink enough fluids. Have regular breaks during the day and also make space for some fun!

There might also be things that make you feel less well. Have a think, what puts you in a bad mood or gets you stressed? Make a note of this:

If possible, try and avoid the things that you know will upset you. Or you might find a way to stop things from getting worse.



Plan ahead



Ring a friend



Get some fresh air



Distract yourself



Take a step back

So, by looking after your own well-being, planning ahead what to do in difficult situations and avoiding what might upset you, you are likely to manage a lot better!

Here are some ideas of what you can do:

Make sure you **stay in touch** with friends and family. Schedule regular phonecalls to catch up, or arrange to meet at a safe distance. You can also set up video-calls if you have a mobile phone or computer, and use applications such as Zoom, Skype, WhatsApp or FaceTime.

If you enjoy **exercise** and have internet access, there are websites such as www.royalvoluntaryservice.org.uk - search for 'exercises' for ideas of physical activities that you can do at home.

Allow for some **fun** in your day. There might be a television or radio programme that makes you laugh, or some games you can play.

If you are getting **stressed**, talk to someone and ask for help. It might be helpful to write down what upsets you. What's important is keeping yourself and your loved one safe, both physically and emotionally. If you are noticing that this is becoming harder to do, use the helplines and support services at the end of this information to reach out or support, before reaching a crisis point.



Hope

A diagnosis of dementia can be difficult. This is where hope comes in. **Hope** is a positive feeling. It involves expectation and desire for a (good) thing to happen. **Hope** is a feeling of trust.

We often find patients and their families being able to find support as well as new sources of meaning and even joy. People are able to notice the little things, such as sharing a memory or appreciating music.

What does **hope** mean to you? Have a go and write down a few words or thoughts:

We encourage carers to look out for and appreciate the good times they share with the person they care for. Here is what other carers have told us about hope:





Take a moment and think about the following, and write your answers in the box:

What are your sources of strength and hope?

Who do you turn to when you need help? In what ways do they help?

What inner resources do you draw upon?

Where do you go for comfort and support?

Who or what do you depend on when things go wrong?

The answers you put down may help you to stay hopeful. It can be helpful to carry a card with you in your wallet or purse that reminds you to stay hopeful. We have included a couple of **'hope-cards'** for you to have if you wish to keep.

Relaxation



When you are on the go all the time, you may get headaches, have trouble sleeping and overall not feel so well. Relaxation techniques are a great way to help: they can help you cope with everyday stress and with stress related to various health problems, such as heart disease and pain.

You can find a lot of good videos on the internet on YouTube which show you how to do this. Search for “Guided meditation”.

We have included instructions from Laura Mitchell’s (1990) book ‘Simple relaxation: physiological methods for easing tension’.

Make sure you are comfortable. You can sit in a comfy chair or lie down.

Be aware of your body resting and being supported, be aware of your breathing with your abdomen rising and falling as you breathe.

1. Your **shoulders** – pull your shoulders down and count slowly to 4. Stop and let go – notice how your shoulders feel.
2. Your **elbows** – move your elbows a little away from your body, count 1, 2, 3, 4. Stop and let go – notice how your arms feel.
3. Your **hands** – spread your fingers wide and stretch your hand open ... count 1, 2, 3, 4. Stop and let go – notice how your hands and fingers feel loose.
4. Your **hips** – roll your hips so your knee caps turn out, count 1, 2, 3, 4. Stop and let go – notice how your hips feel loose.
5. Your **knees** – move your knees so they feel comfortable, count 1, 2, 3, 4. Stop and let go. Notice how your knees feel loose, and your legs feel comfortable.
6. Your **feet/ankles** – push your feet away from your hips and count 1, 2, 3, 4. Stop pushing and let go. Notice how your feet feel loose.
7. Your **body** – push your body into the support (e.g. your chair, or floor) and count 1, 2, 3, 4. Stop pushing and let go. Notice your body feeling supported.

8. Your head – push your head down into the floor or against the head rest, pulling in your chin, count 1, 2, 3, 4. Stop pushing and let go. Notice how your head feels supported and your neck is loose.
9. Your face – With your lips gently touching, pull your jaw down so your teeth part count 1, 2, 3, 4. Stop and let go. Notice how your jaw feels loose.
10. Your forehead – lift your eyebrows upward 1, 2, 3, 4. Stop and let go. Notice how your forehead feels loose.
11. Your **eyes** – if your eyes are open, allow them to close gently.
12. Now think about each part of your **body**. Notice your breathing – how slow and gentle it is. You should not fall asleep, but be aware of your body.
13. Now slowly become aware of your surroundings again. Open your eyes slowly, stretch your arms and legs, and when you are ready, get up.



Free resources from Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

Relaxation techniques - available in a male or female voice
www.cntw.nhs.uk/relaxation

Mental health self help guides - 23 guides which cover topics such as anxiety, stress, depression and low mood, sleeping problems
www.cntw.nhs.uk/selfhelp

Carer resources - a range of useful information for carers, including the carer promise and carer card
www.cntw.nhs.uk/carers

Useful contacts

Newcastle Carers

Dedicated Carer Information and Advice Worker supporting people caring for someone with dementia. Practical tips on caring for someone as looking after yourself.

Tel: 0191 275 5060

Website: www.newcastlecarers.org.uk

Email: info@newcastlecarers.org.uk

Dementia Matters

Provides specialist care, support and advice for people with dementia and their carers. We also help carers and family members by sharing our knowledge through offering training and advice on practical care support and when needed, specialised respite care.

Tel: 0191 217 1323

Website: www.dementiamatters.net

Newcastle City Council

Ring Social Care Direct

Tel: 0191 278 8377

Alzheimer's Society

Alzheimer's Society's dementia advisers can support you directly by phone or face to face, as well as connect you to a range of local services.

Tel: 0333 150 3456

Mon-Wed 9am – 8pm, Thurs-Fri 9am – 5pm, Sat-Sun 10am - 4pm

North Tyneside Carers Centre

Our Adult Carers Support service can help adult carers minimise the impact of caring on their lives by providing individually tailored advice, information, support and groups.

Tel: 0191 249 6480

Website: www.northtynesidecarers.org.uk/

Email: enquiries@ntcarers.co.uk

North Tyneside Age UK

If you look after a partner, relative or friend who is disabled or ill due to physical or mental health, you are a carer, even if you don't think of yourself as one. Find out about the emotional, practical and financial support available to you.

Tel: 0191 280 8484

Website: www.ageuk.org.uk

National Tel: 0800 678 1602 – available daily 8am - 7pm

North Tyneside Council

Ring Care and Connect

Tel: 0191 643 7474



Further information about the content, reference sources or production of this leaflet can be obtained from the Patient Information Centre. If you would like to tell us what you think about this leaflet please get in touch.

This information can be made available in a range of formats on request (eg Braille, audio, larger print, easy read, BSL or other languages). Please contact the Patient Information Centre Tel: 0191 246 7288

Published by the Patient Information Centre

2024 Copyright, Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

Ref, PIC/840/0124 January 2024 V2

www.cntw.nhs.uk Tel: 0191 246 7288

Review date 2027

Follow us on social media, search for CNTW