Things to think about after a diagnosis of dementia



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What is Dementia?

Dementia describes a group of symptoms that include problems with memory, thinking or language, and changes in mood, emotions, perception, and behaviour.

Dementia is a progressive disease, which means symptoms may be relatively mild at first, but they get worse over time. There are many types of dementia, but Alzheimer's disease is the most common. (Definition taken from "What is Dementia?" by the Alzheimer's Society)

Dementia can affect a person at any age but it's more common in people over the age of 65.

Getting a diagnosis of dementia helps to determine the care plan that will be put in place to support you and your carer.

You will be supported by several Health, Social Care and Voluntary agencies who will contribute to your care plan, which is tailored to your needs.

Your care plan should be overseen by a named professional worker and will be monitored and changed when needed.

This booklet contains advice and information about local organisations and services that can help you.

This leaflet is split into two sections. Section 1 provides information for people who have a diagnosis of dementia. Section 2 provides information for carers.

This information has been put together by the Cheshire East Dementia Steering Group.

Section 1: Your diagnosis

Once you receive a formal diagnosis, you will be referred to the Dementia Reablement team (or you can self refer as long as you have had a diagnosis of dementia)

Dementia Reablement Service: This service provides support for you and your family help you live as independently as possible.

The Dementia Reablement Service works in partnership with other dementia support services like Alzheimer's Society and Age UK Cheshire and Age UK Cheshire East

Call the South Team (based in Crewe) on 01270 371 273.

Areas covered:

- Audlem
- Crewe
- Nantwich and Rural
- Sandbach, Middlewich, Alsager, Scholar Green, Church Lawton, Haslington.
- Holmes Chapel

Call the North Team (based in Macclesfield) on 01625 378287.

Areas Covered:

- Alderley Edge
- Congleton
- Handforth
- Holmes Chapel
- Knutsford
- Macclesfield
- Poynton
- Wilmslow

Slowing Progression of Dementia

Did you know that healthy living is good for your physical and mental health?

Some of the causes of dementia cannot be prevented, such as age and genetics. However, some types of dementia can be affected by certain lifestyle factors, so to reduce our risk, or delay the onset of dementia we can:

- Take advantage of 'well-person health checks' at your GP surgery so your blood pressure, weight and cholesterol levels are monitored and well managed
- Maintain a healthy weight and eat healthy food
- Minimise alcohol intake
- Stop smoking

Exercise regularly

Dementia UK has further information on their website: https://www.dementiauk.org/about-dementia/dementia-information/prevention-and-risk-factors/

Dementia Research

If you sign up to Join Dementia Research, the information you provide is used to match you to studies you may be able to take part in, both online, nationally and in your local area. The service connects registered volunteers with dementia researchers across the UK who are looking for people to join their studies.

You can find them on the link below

<u>Join dementia research - register your interest in dementia research : Home (nihr.ac.uk)</u>

Diagnosing Well

Find out more about your diagnosis

The Dementia Guide: You can get The Dementia Guide from the Memory Clinic or Alzheimer's Society to help you understand more about the diagnosis.

The guide also talks about things to think about going forward, like living well, future care planning and different types of medication.

Access a Dementia Advisor or Dementia Support Worker:

Once you have been transferred from the Memory Clinic back to your GP you will be automatically referred to the local Dementia Support Worker service in your Care Community area, should you have one. There are currently, Dementia Support Workers in the following areas of Cheshire East:

Crewe
Nantwich and Rural
Sandbach, Middlewich, Alsager, Scholar Green and Haslington

There is a Dementia Advisor in the **Macclesfield** area.

Your Dementia Support Worker / Advisor will be able to talk to you over the telephone or meet you at your home or somewhere more convenient to answer your questions and let you know what help and support is available.

Alzheimer's Society Dementia Connect Telephone Hub: Dementia advisors are available on the phone to give people the support they need. You can arrange regular calls so they can keep in touch to find out how you are and offer support and advice when things change.

If you need more support, you can be referred onto one of our community Dementia Advisors who will support you face to face. Call **0333 150 3456** or Welsh Speaking: **03300 947 400**

Opening times:

 $\begin{array}{ll} \mbox{Monday} - \mbox{Wednesday} & 9:00 \mbox{ AM} - 8:00 \mbox{ PM} \\ \mbox{Thursday} - \mbox{Friday} & 9:00 \mbox{ AM} - 5:00 \mbox{ PM} \\ \mbox{Saturday} - \mbox{Sunday} & 10:00 \mbox{ AM} - 4:00 \mbox{ PM} \end{array}$

Alzheimer's Society factsheets and online community: You can download fact sheets from the Alzheimer's Society website at www.alzheimers.org.uk or request them from the Dementia Connect Telephone Hub.

You can sign up to Dementia Talking Point, which is the Alzheimer's Society's online community, where anyone affected directly by dementia can ask questions, share experiences, and receive support.

It is free and available 24 hours a day: https://alzheimers.org.uk/talkingpoint

Cheshire and Wirral Partnership NHS Foundation Trust
East & South Adult Community Learning Disability Team –
Specialised Memory Service for People with a Learning disability,
Downs Syndrome and/or Autism.

The Adult Learning Disability Team provides specialised memory assessments for people with a learning disability, downs syndrome and/or autism. These assessments are aimed at individuals who may struggle to access mainstream memory services due to their level of learning disability, or communication difficulties.

The Specialised Memory clinic offers people a holistic assessment of their needs with the aim to identify dementia at its earlier stages. People can self-refer if they have concerns about their memory. Your GP, family member, social worker or care team can refer into the team if you would like a memory screening.

Speak to a member of the team over the telephone:

Macclesfield Community Team on 01625 509013 Crewe Community Team on 01270 656335

Supporting Well

Benefits

You might be eligible for some benefits.

Get a benefit check: Get a benefit check to see if you are eligible for any benefits, including pension credit or housing benefit. If your carer is under state pension age, they might be able to claim Carers Allowance.

Attendance Allowance: Attendance allowance is a non means tested benefit for people who need help at home due to a long-term illness or disability. You must be over state pension age (If under state pension age you may apply for Personal Independent Payment).

There are two rates of Attendance Allowance: lower and higher. As of March 2022, the current rates as of are £60 (lower) and £89.60 (higher). If you need help completing the claim form, you can contact the Department of Work and Pensions, Cheshire Carers Hub, or Age UK Cheshire / Cheshire East.

To request a claim form or get help and information go to www.gov.uk to download a form or complete the interactive form online.

You can call the Attendance Allowance Helpline on 0800 731 0122.

Council Tax Discount: When you are getting Attendance Allowance you might be eligible for a reduction in your council tax. As long you are 65yrs + and of pensionable age you can still apply for the exemption from Council tax charges if you are not in receipt of

Attendance Allowance. If you are younger, then you will have to show evidence of benefit that you receive.

Contact Cheshire East Council for a claim form.
You can call Cheshire East Council Tax Information Line on **0300 123 5013**.

Apply for a Blue Badge: The Blue Badge Scheme is a national parking scheme for people with disabilities or health problems which mean they need to park closer to their destination.

To apply online or request an application form, go to: https://www.cheshireeast.gov.uk/benefits housing council tax/blue bad ge_scheme/apply-for-or-renew-a-blue-badge.aspx You can also contact Cheshire East Council to make an application.

Citizens Advice Bureau in Cheshire East provides free, independent, confidential, and impartial advice to everyone on their rights and responsibilities.

For information in all areas, call their advice line on **03444 111 444** or visit https://livewellservices.cheshireeast.gov.uk/Services/1293

Flexible Transport offers local community transport. If you cannot use public transport or live in a rural area, they provide such services as the Flexi Link bus service and shop mobility.

For information on all services, visit their website: https://www.cheshireeast.gov.uk/public transport/flexible transport services.aspx

You can call Flexi Link bus service on 0300 123 5110.

Snow Angels is a local social enterprise in Cheshire which supports older people to keep well and live independently. They offer support with various services, including such things as carrying out benefit checks and completing the Attendance Allowance forms for free. They will also assist in completing the Lasting Power of Attorney forms again for free.

Visit their website: http://www.snowangels.org.uk/ or call them on **0300 666 0002**.

Social Services and Adult Social Care provide assessments for the person with the diagnosis of dementia and their carer. They can help implement services if applicable. They can also be contacted out of hours in crisis situations.

Call Cheshire East Council Adult Social Care on **0300 123 5010** or out of hours on **0300 123 5022**.

Planning for accidents, illness, and emergencies

Carry a mobile phone in case you need to get hold of someone quickly.

Put your **contact details** in a pocket, bag, or wallet if you go out alone.

Keep essential telephone numbers by your telephone so they are easy to find.

Get a This is Me document from the Alzheimer's Society and fill it in. Take it to any care or hospital setting. It provides detailed information to help the people caring for you.

Find information on home fire safety and advice for carers on the Cheshire Fire and Rescue Service website at: https://www.cheshirefire.gov.uk/

Contact Number: 01606 868700

Install assistive technology to keep you safe at home, especially if you are at risk of falling. For more information visit: <u>www.cheshireeast.gov.uk/livewell/living-independently/equipment-for-independent-living/remote-support-to-keep-people-safe-telecare.aspx</u>.

The Council's Partner for Assistive Technology is Rosscare. You can call them to speak about accessing the service privately on **0800 130 0011 or** via www.mi-guardian.com.

You can also access the service via Cheshire East Council for a reduced charge if you are eligible for social care support and it is identified as something that would benefit you.

VAT relief for disabled people

If you're disabled or have a long-term illness, you will not be charged VAT on products designed or adapted for your own personal or domestic use.

For more information on if or how you may qualify, please check the link below:

<u>Financial help if you're disabled: VAT relief for disabled people -</u> GOV.UK (www.gov.uk)

Dementia and Driving

You must tell the Driver and Vehicle Licensing Agency (DVLA) that you have dementia. Write to The Driver Medical Group, DVLA, Swansea SA99 1TU. You can telephone on **0870 6000 301**.

Dementia and driving - GOV.UK (www.gov.uk)

Also tell your car insurers of your diagnosis – you may not have to stop driving immediately

Complete a 'Herbert Protocol' form with Cheshire Constabulary Vulnerable Adult Missing Persons Profile. This can be used to help the police trace someone if they go missing. Find out more information here:

https://www.cheshire.police.uk/SysSiteAssets/media/downloads/central/advice/herbert-protocol/herbert-protocol-form.pdf

If you need the Police, dial 999 and ask for the police if you are in danger and there is an immediate risk. Alternatively, you can contact the Police on 101 or online via the Cheshire Police website:

www.cheshire.police.uk

If you are Hearing Impaired, you can use **BSL 999** (link to website <u>999</u> <u>BSL</u>)

If you are hearing or speech impaired, you can also use **Text Relay** to contact the emergency services <u>Contact 999 using Relay UK - How to use Relay UK | Relay UK (bt.com)</u>

Living Well

Local support

Advanced Dementia Support Team: Admiral Nurses & Occupational Therapy providing specialist advice, guidance, and education.

This service works with professionals and informal carers to support the delivery of best practice for people with advanced dementia.

The person with dementia may live at home or in a care setting, and you need support for their health and wellbeing; management of symptoms, carer support to understand the advanced stage of dementia, support for advance care planning, education around dementia and the progression of disease.

To be eligible for this service the person living with dementia must already have a diagnosis and require 24/7 support.

Email: eolp.adst@nhs.net

Telephone: Referrals: 01270 904 490

Website page: https://eolp.co.uk/62-2/advanced-dementia-consultancy/

Age UK Cheshire offers a wide range of services and provide information and advice, advocacy, dementia support, day care, social activities and advice on money and benefit entitlement. They cover Crewe, Nantwich, and surrounding areas

Call Age UK Cheshire on **01606 881660** or visit their website https://www.ageuk.org.uk/cheshire/

Age UK Cheshire East offers a similar wide range of services for people living in the northern part of Cheshire East.

They provide information and advice, dementia support, day care, free counselling, scams awareness, prevention and aftercare and Help at Home.

Call Age UK Cheshire East on **01625 612958** or visit their website https://www.ageuk.org.uk/cheshireeast/

Local Area Co-ordinators (Cheshire East Council): This service coordinates information and offers advice and support to help you remain as independent as possible, giving you choice and control over the support you receive.

To access a Local Area Co-ordinator, you will need to contact the relevant Adult First Point of contact Team for your area, they will then screen your request and if a referral to the Local Area Coordinators is required, they will refer you on to them.

Please email:

adultcontactteamsouth@cheshireeast.gov.uk

AdultContactTeamEast@cheshireeast.gov.uk

Local activities: Local activities can be found on the Cheshire East website: https://www.cheshireeast.gov.uk/livewell/livewell.aspx. Enter dementia and your postcode in search boxes.

Companion Call Service - Alzheimer's Society Companion Call Service is a regular (ideally weekly) telephone call with a volunteer, designed to engage a person affected by dementia (person with dementia or a carer) in friendly conversation to reduce social isolation and feelings of loneliness. A companion call is not support and is deemed "light touch" it is time limited. A review will take place 5 months after the first call to assess if the service is still appropriate and still required. It can continue if these criteria are met. If not, the person can be referred on for more formal support.

Enquiries can be made through a Dementia Advisor or by emailing: CompanionCalls@alzheimers.org.uk

Singing for the Brain are held using Zoom on your computer, laptop, or tablet. To find out more call **0300 369 0570** or email cheshire@alzheimers.org.uk.

Singing for the Brain is based around the principles of music therapy and singing. The structured group sessions use music to encourage communication and participation and include opportunities to talk to other people. Each session includes a range of activities including vocal warm-up and singing a variety of familiar and new songs.

Living with Dementia Courses

The course is open to people living with dementia and the family members/loved ones that are open to Cheshire and Wirral Partnership services. At the moment they are only facilitating virtual workshops, so they are open Cheshire Wide. However, they are hoping to go back to face to face workshops in September.

For more information on their workshops or for any other query please call **01625 505647**

email: cwp.involve-and-recover@nhs.net or follow them on **Twitter** at **CWP IRWC**

Urgent Mental Health Support

If you have dementia and your mental state quickly worsens or deteriorates, you can seek support from the Mental Health crisis team. It is vital in this situation to get support quickly. If you feel you or someone you care for needs urgent mental health crisis support, call **0800 145 6485**. Open 24/7 to all ages for anyone known to the Cheshire and Wirral Partnership services, calls are free.

Shout 85258 is a free, confidential text support service for anyone who is feeling overwhelmed or struggling to cope. If you live in Cheshire East **text BLUE to 85258** for a conversation with a trained volunteer, at any time of the day or night.

Crisis Cafes - There are cafes, one in Crewe and one in Macclesfield.

- 'Crewcial' will be open will be open 1pm-10pm, seven days per week and people aged 18+ will be able to self-refer into the service by simply turning up on the day or by referral from a health or social care professional. The new café is located at 3 Partridge Close, Flat 2, Dunwoody Way, Crewe, CW1 3TQ.
- The Weston Hub is located at The Weston Centre, Earlsway, Macclesfield, Cheshire, SK11 8RL will be open from 10am to 10pm, seven days per week and can be accessed by referral from health and social care professionals, as well as through other voluntary organisations.

East Cheshire Hospice

East Cheshire Hospice currently provide 6 services for dementia support.

- Carers Wellbeing Programme is an 8-week structured programme open to carers of people experiencing dementia who have an East Cheshire GP.
- Community Dementia Companions Service is designed to match the person diagnosed with a companion volunteer to go out once a week for 2hrs so that their main carer who they live with can have a break.
- Singing Together is a monthly wellbeing group that uplifts and brings a sense of joy and improvement to wellbeing, for anyone who takes parts, not just the person living with dementia.
- Love to Move is like experiencing brain gymnastics, it works by carefully integrating the use of gymnastic foundation skills, cognitive stimulation therapy and social interaction activities.
- Admiral Nurse is a specialist dementia nurse who helps support family carers who are experiencing complex needs relating to the dementia support they provide – access is via internal referrals only
- Dementia Hospice Nurse can provide 1:1 support to enable a person experiencing dementia to live well with their dementia. This can include reviews, assessments and liaising with other professionals to resolve current issues – access is via internal referrals only

Full details about criteria and access to services can be found at https://www.eastcheshirehospice.org.uk/patients-families/sunflower-centre/dementia-support/

For general dementia enquires please call **01625 666990 (Mon-Fri 9-5)** To make a referral please post the form to the hospice or email the form to cmicb-cheshire.echospicedementia@nhs.net

Cheshire Fire and Rescue Service

Cheshire Fire and Rescue Service can offer free Safe and Well checks to a person living with dementia or a person caring for someone affected by dementia. Safe and Well visits are completed by trained Fire Service staff and offer advice, information, and intervention (where appropriate) in relation to improving home fire safety. This will include making sure

smoke alarms are working and/or installed in line with your needs. During a Safe and Well visit the fire service will tailor the information and advice to meet your needs, if you feel you or another person's needs change over time and a further visit might be required then please don't hesitate to get in touch.

The Fire Service also work with health and wellbeing partners to offer onward support and signposting where appropriate and with your agreement, they may discuss this with you during your Safe and Well visit.

You can make contact with the Fire Service on the number detailed on page 10, or you can find further information and advice via the following links:

https://www.cheshirefire.gov.uk/
Safe and well visits (cheshirefire.gov.uk)

Working

You may choose to carry on working after diagnosis – you may want to reduce hours and you may be able to claim benefits i.e., Employment Support Allowance or Universal Credit

Looking after your health

Healthy living is good for your mental and physical health. Exercise can help to slow the rate of decline in memory and thinking skills in older people.

Infections: You might still get ill in other ways, but your dementia might seem to be affected if you are unwell.

Infections can make people more confused so if you think you are unwell ask your GP to test a urine sample. If you need antibiotics, you should feel better very quickly.

Hospital Dementia Lead Nurse: The nurse may speak to you or your carers during your stay to help make your journey through hospital as comfortable and stress free as possible. We can also make sure any necessary support or referrals are in place for discharge. We will ask you or your carer to complete a "This is Me" document, which will help the ward staff to get to know you better, including your likes and dislikes.

The nurse is also able to support you through outpatient appointments, to help reduce any stress and make sure any necessary adjustments are made. The contact details for the dementia specialist nurse at Leighton can be found at www.mcht.nhs.uk/our-services/dementia

The Admiral Nurse (dementia specialist nurse) at Macclesfield can be contacted on 01625 661347 or ecn-tr.admiralnurse@nhs.net

Dying Well (Planning and Caring Well)

Looking after personal and financial matters

Paying bills: You might want to set up standing orders and direct debits to pay your bills. If you cannot use a cash machine or chip and pin you can order a chip and signature card from your bank.

Advance Care Planning

Make or update your will: If you do not have a will think about setting one up now. If you have not reviewed your will in a long time, think about reviewing it. This will make sure your wishes will be met in the future.

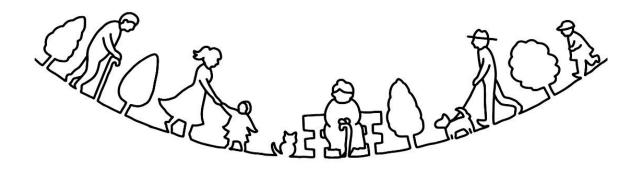
Lasting Power of Attorney: Lasting Power of Attorney gives someone you trust permission to help you make decisions or make decisions on your behalf. You might want to set this up now.

There are two types of Lasting Power of Attorney: Health and Welfare, and Property and Financial Affairs. You can set these up online or with a solicitor.

It is important to set up Lasting Power of Attorney while an individual has the mental capacity to do this. Visit the Government's website (https://www.gov.uk/power-of-attorney) to make an application or for more information.

Summary

There are lots of services and organisations (people) who will support you after your diagnosis. If you do not know who to speak to for advice or information, ask your local Dementia Reablement Team, Dementia Support Worker (if you have one) or your carer.



Section 2: Carers

Advice for carers

This leaflet includes information and advice about living with dementia in Cheshire, including resources and support. Please read both sections.

Carry a Carer Emergency Card: In the event of an accident or sudden illness this alerts others that you are a carer. This scheme is provided by Cheshire East Carers Hub who can arrange to send you a Carers Emergency card and peace of mind template

Call them on 0300 303 0208

Register as a Carer with your GP: If your GP is aware that you are a carer you may be able to access additional health checks or be eligible for a flu jab.

Some surgeries may also be able to take your caring responsibilities into account when issuing appointments.

Talk to friends and family about planning for emergencies and who can do what to help.

Ask for practical and emotional support from family, neighbours, and friends. Creating a network of support is very important.

Information for Carers

Cheshire East Carers Hub provides information, advice, and specialist support services to help adult and young carers continue in their caring role for as long as they choose and reduce the impact the caring role can have on their own health and wellbeing.

You can make direct contact into the service.

Fill in the online form and register here: www.cheshireeastcarershub.co.uk You can also email enquiries@cheshireeastcarershub.co.uk or call them on **0300 303 0208**

Dementia UK specialist Admiral Nurses

Admiral Nurses are specialist dementia nurses. They offer life-changing support with all aspects of dementia, including Alzheimer's disease.

Admiral Nurses help families manage complex needs, considering the person living with dementia and the people around them. They provide emotional support, tailored advice about symptoms and changes in behaviour, practical tips for caring, advice on finances and benefits, and support with arranging care. They also help families build links with other health and care professionals.

For advice and support from an Admiral Nurse, please call the free Dementia UK Helpline on **0800 888 6678 (Monday-Friday 9am-9pm,** Saturday and Sunday 9am-5pm) or email helpline@dementiauk.org

To book a telephone or Zoom appointment with an Admiral Nurse in Dementia UK's virtual clinics, please visit dementiauk.org/closer-to-home

For leaflets, videos, and other resources on dementia, from getting a diagnosis to advice for daily living, please visit dementiauk.org/get-support

St Luke's Cheshire Hospice

St Luke's Cheshire Hospice run a Dementia Carers' Workshop which is designed to help people who are supporting a person with dementia in their own home.

They offer an eight-week structured support programme for carers of people with dementia.

You are welcome to bring the person with dementia to the Hospice with you. While you attend the workshop, your loved one will be cared for and supported by our staff and volunteers in a nearby room within Day Hospice.

You can refer yourself or ask your GP, Macmillan Nurse, District Nurse, Social Worker, or other healthcare professional to refer you. For a friendly chat contact St Luke's directly on **01606 555681**

East Cheshire Hospice Carers Wellbeing Programme

The Carers Wellbeing Programme is an 8-week structured programme open to carers of people experiencing dementia who have an East Cheshire GP (please see detail on page 15)

Carer breaks

Carer breaks: Caring for someone can be a full-time job and all carers need a break every now and then. There are different types of breaks:

Cheshire East Carers Hub Carer Breaks: The Hub will be able to assist you in accessing a range of breaks and training workshops tailored to your needs. Call them for more information on **0300 303 0208**.

Respite breaks: Respite breaks enable you to take a planned break or holiday or provide help if you need respite care in an emergency.

A financial assessment will be undertaken to assess whether the person being cared for will need to contribute financially to the cost of this respite care.

If your assessment says you require carer respite and you can **book respite care.** If you are planning a short break, a night out or a holiday, it is easy to book a bed for the person being cared for. Call **01270 686428** or email <u>ce.contracts@cheshireeast.gov.uk.</u>

You can visit the website for details for each care home: https://www.cheshireeast.gov.uk/livewell/looking-after-someone/carers-of-adults/adult-and-carer-respite.aspx

Carers' Assessment

A Carer's Assessment from the Carers' Hub will determine whether a carer's needs mean that they require a break and might involve looking at extra support for the person who is being cared for so the carer can receive this break.

