Living well with Young Onset Dementia

Information about the support available for people of working age in the Central Lancashire area
About this leaflet

This leaflet was created by the Young Onset Dementia Action group. This group is made up of a number of organisations (listed on the back of this leaflet), young people with dementia and their carers.

If you are of working age and have been diagnosed with dementia, or are supporting someone with dementia you may need some specific information and advice. This leaflet can signpost you to the kind of support and services that are available nationally and in Central Lancashire.

You are not alone. In the UK there are estimated to be more than 40,000 people under 65 with dementia. In 2014 there were an estimated 825 people with young onset dementia in the Lancashire area.

You can use this space to write down the names and contact details for any people who are important in your care and support:

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Living Well With Dementia

You will have different interests and routines, depending on your physical needs and abilities, and it is important to continue with these to maintain your health and wellbeing.

Eating and drinking well is important as if you are not eating enough, you may be more tired and prone to infections. If you are not drinking enough fluids, this may lead to dehydration and confusion, which may have an impact on other symptoms.

Along with a good diet, exercise is a great way to maintain a healthy lifestyle and will enable you to maintain mobility, improve circulation, reduce stiffness and aid relaxation. Focus on doing the activities that you enjoy and are able to do. You may find that you will have to adapt the activity, depending on how you are feeling. Consider taking up different activities that will encourage taking part in social activities.

Socialising is another great way to maintain health and wellbeing. Keep in touch with family and friends, explain to them how you are feeling and how they can help you to maintain an independent lifestyle.

Alternative therapies

Alternative therapies are available to help you socialise, relax and to provide meaningful stimulation and self-esteem. Below are a range of therapies that may be of interest to you:

- Art therapy - provides an opportunity to express yourself in drawings or paintings
- Aromatherapy - provides a sensory and calming experience
- Complementary therapy - massage, reflexology, reiki
- Music Therapy - engagement in music, singing, listening & playing has been shown to improve wellbeing, social interaction and memory.
Some Local Activity Groups

There are a number of groups and activities happening locally that may be of interest to you. They may not specifically be for someone with a diagnosis of dementia but may be able to offer activities and support that can help. The details and times they meet can change so it is best to contact them directly for further information.

**Young Onset Dementia Social Group** is a monthly evening meeting and information hub at Charnley Fold in Bamber Bridge for people of working age with dementia and their carer. Contact Age Concern at Charnley Fold 01772 620876

**Sparks Café** is a sociable get together for people of working age with dementia or Parkinson's meets monthly in a café in Longridge. Contact Joanne or Pam on 07376034943 or email sparks.cafe.dp@gmail.com

**Chorley Sheds** is a community group for men and women within the local community who may be experiencing loneliness or lacking in confidence as a result of social isolation, for whatever reason. Email: chorleyshed@outlook.com Facebook: Chorley Shed Group Twitter: @ChorleyShed

**Sporting Memories** is an organisation that supports older people with dementia, depression and loneliness by engaging them in social activities and helping them to recall memories of watching or playing sport. You can find details of your local group at: www.sportingmemoriesnetwork.com

**Leyland Dementia Hub:** Advice, support, signposting, plus memories meeting Place. Contact Alison Hardman 01772 625327

**Information, advice and services** to help you live well with dementia or care for someone with dementia can also be found at: www.lancashire.gov.uk/health-and-social-care/your-health-and-wellbeing/staying-mentally-well/dementia/
Employment Matters

Dementia affects everyone differently, so a diagnosis does not mean you have to give up work. It may be better to carry on working for as long as you can, as this will help you both physically and emotionally.

Ensure you let your employer know, so that they can support you and ensure you are not disadvantaged. Your employer cannot dismiss you or force you to retire early because you have dementia, as the law states that your employer must make ‘reasonable adjustments’, including aids and extra equipment, flexible hours, part-time working, creating quiet spaces or putting up visual barriers to minimise distractions.

Statutory Sick Pay

Statutory Sick Pay is paid by your employer up to retirement age, for up to 28 weeks in any one period of sickness. To qualify, you must earn a set amount or more each week before tax and must be off work. If your SSP has ended, or you don’t qualify for SSP, you may be able to claim for Employment and Support Allowance. Contact Universal Credit on 0800 328 6544.

Leaving Work, Benefits & Disregards

If you are finding you are becoming less able to do your job, then you may decide to give up work. There are benefits available to support you if you are unable to work. If you have the option of taking early retirement, you should seek advice on your pension rights, from an Independent Financial Advisor.

You may be entitled to disability benefits such as Personal Independence Payment, Employment Support Allowance and support with your Council Tax. For more information you can contact Lancashire Welfare Rights on 0300 123 6739
Support for carers

If you care for someone who has memory concerns, you can ask for support from Lancashire Carers Service. You are entitled to have a carers assessment. The assessment will look at your caring role and the impact it is having on your wellbeing. Contact 0345 688 7113 for more information.

Help to pay your mortgage

You may be eligible for help towards paying the interest on your mortgage, if you are receiving certain benefits. This is called Support for Mortgage Interest normally paid direct to your lender. Contact your mortgage lender for more information.

Council Tax

You may be eligible for a reduction or exemption on your council tax bill. Contact your local council for more information.

Driving and Dementia

Your diagnosis does not necessarily mean you have to stop driving, but you must let the DVLA and your insurance company know immediately. You must give up your licence for all classes, if your doctor tells you to stop driving or you do not meet the required standards because of your condition. If you fail to tell the DVLA, you could be fined up to £1,000 and your insurance will be invalid.

You will need to fill in a CG1 form, available via www.gov.uk to tell the DVLA about your dementia. The information you give them is treated in confidence. Visit the www.gov.uk for more information or contact them on 0300 790 6806. They are open Monday to Friday 8am to 5.30pm and Saturday 8am to 1pm.
**Lasting Power of Attorney**

Many people with dementia will eventually reach a point where they are no longer able to make decisions for themselves and may need someone to make decisions on their behalf.

A lasting power of attorney is a legal document appointing one, or more, trusted people to make decisions relating to finances, health and welfare on your behalf. It is advisable to think how this can help you in the future and choose someone to make decisions for you should the time come. Contact the Dementia Helpline on 0300 222 1122 for more information.

**Advanced Decision**

An advance decision gives you the option to make a statement about your future wishes and care preferences. This can be done verbally or in writing, and ensures that future decisions are in line with your wishes.
Who’s who and how to contact them

Alzheimers Society Central Lancashire, Preston
Offer support and information. Open Monday to Friday 10am to 4pm
Contact : 01772 788700 | www.alzheimers.org.uk

Age Concern - Dementia Community Links, Preston & South Ribble
Free one to one support for those living with dementia and memory concerns
Contact : 01772 620876 | Open Monday to Friday 9am—5pm

Age UK operate a similar service in Chorley & West Lancs for further information please Tel 0300 303 1234

Patient Advice and Liaison Service (Preston, Chorley & South Ribble)
Dementia Fastrack - progress through your hospital appointment quicker. If you have an appointment at the hospital, phone them in advance for advice and support. Contact : 01772 522972

Lancashire Carers Service
Contact Lancashire Carers Service for a Carers Assessment, or speak to a Specialist Dementia Carers Support Worker. Contact: 03456887113 or visit www.ncompassnorthwest.co.uk

I-CANN Advocacy Support—24 hour answerphone service
Support for PIP and ESA assessments Contact: 01772 717461

Lancashire Welfare Rights
Free benefits advice and support—open Mon—Fri 8.30am to 5pm
Contact: 0300 123 6739 https://www.lancashire.gov.uk/benefits-and-grants/benefits-advice/

Disability Equality North West
Help with welfare rights, benefits, advice on form-filling, access to services and practical help. Open Monday to Friday 9am—5pm.
Contact: 01772 558863 | www.disability-equality.org.uk/
Enhanced Day Care Support, Charnley Fold, Bamber Bridge
Day services. Open Monday to Friday 9am—4pm.
Contact: 01772 645721

Adult Social Care
They can help to support you and provide access to social care services, respite and direct payments if eligible. Contact: 0300 123 6720

Dementia UK Helpline
One to one guidance, support and practical solutions
Contact: 0800 888 6678 | www.dementiauk.org

ACAS Employment Rights
Independent advice and guidance on employment concerns.
Contact: 0300 123 1100 | Open Monday to Friday 8am—6pm
www.acas.org.uk

Personal Independence Payment
Contact: 0800 917 2222 | www.gov.uk/pip
Memory Assessment Service
Contact: 01772 401621

DVLA medical queries
Contact: 03007906806 | www.gov.uk/dvla

Office of Public Guardian
Advice and support about making decisions, when lacking mental capacity
Contact: 0300 456 0300 | www.gov.uk
Other advice and support available

YoungDementia UK’s website shares information and personal stories covering all aspects of life with young onset dementia. The Find Support section includes a nationwide listing of young onset support groups and services. They also send out regular newsletters and are active on Twitter & Facebook. For more information go to www.youngdementiauk.org

The Young Dementia Network is a community of people living with young onset dementia, their family and friends, and professionals who work in dementia and social care. Free to join, it provides opportunities to connect with others and share experience and ideas via events and newsletters. For more information go to www.youngdementiauk.org

Provides specialist support to carers, people with dementia and professionals, through specialist dementia Admiral Nurses. The Admiral Nurse Dementia Helpline is open Monday-Friday 9am-9pm and weekends 9am-5pm. Call 0800 888 6678 or email helpline@dementiauk.org

Pathways Through Dementia provides free, accurate legal and financial information to support people living with dementia. Whether you’re a person diagnosed with dementia, a carer or family member, support is available to help you make the best decisions you can for yourself and/or the person you’re caring for. For more information go to www.pathwaysthroughdementia.org
This leaflet was created by the Young Onset Dementia Action group, made up of the following organisations, younger people with dementia and their carers.

Lancashire Care
NHS Foundation Trust

Alzheimer’s Society
United Against Dementia

Lancashire County Council

n|compass northwest
looking towards a brighter future

AGE CONCERN
Other sources of information:

The Wellbeing and Mental Health Helpline
This provides an information and listening service for people in Lancashire. It is available between 7:00pm and 11:00pm Mondays to Fridays and from 12:00 noon until 12:00 midnight on Saturdays and Sundays. **Freephone: 0800 915 4640.**

Hearing Feedback Team
If you would like to share feedback on your experiences with us, please contact the Hearing Feedback Team on: **01772 695315, freephone: 0808 144 1010** or email: hearing.feedback@lancashirecare.nhs.uk

Contacts and social media:
☎ 01772 695300 ☎ communications@lancashirecare.nhs.uk
듯  www.lancashirecare.nhs.uk  🌐 facebook.com/lancashirecare
🐦 @LancashireCare  📹 youtube.com/LancashireCare

If you have problems reading the print we can provide this leaflet in large print, audio book or Braille.

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Data Protection
Lancashire Care NHS Foundation Trust adheres to current data protection law. The Trust will endeavour to ensure that your information remains secure and confidential at all times. Our staff are committed to protecting personal data we collect, use and share. For further information regarding privacy and data protection, please visit the Trust website or ask a member of staff for a copy of our leaflet entitled “Protecting your Information.”

W przypadku jakichkolwiek problemów z odczytaniem tekstu z przyjaznością dostarczmy Państwu ulotkę z dużym drukiem, tasme do odluchu lub tekst w języku Braille.

本文件可以应要求，製作成中文（繁體字）版本。

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