

If you require translation services or a copy of this document in other languages, audio tape, Braille or larger print, please speak to a member of CWP staff, e-mail [info@cwps.nhs.uk](mailto:info@cwps.nhs.uk) or write to: Communications, Cheshire and Wirral Partnership NHS Foundation Trust, Upton Lea, Countess of Chester Health Park, Liverpool Road, Chester, CH2 1BQ.

যদি আপনার ট্রান্সলেশন সার্ভিসের বা এই দলিলের কপি অন্য ভাষায়, অডিও টেইপে, ব্রেইল বা বড় ছাপায় দরকার হয় তবে অনুগ্রহ করে সিউব্লিউপি এর স্টাফদের সাথে কথা বলুন, ইমেইল করার ঠিকানা [info@cwps.nhs.uk](mailto:info@cwps.nhs.uk) বা কমিউনিকেশন, চেশায়ার ও উইরাল পার্টনারশীপ এনএইচএস ফাউন্ডেশন ট্রাস্ট, আপটন লী, কাউন্টস অফ চেস্টার হেলথ পার্ক, লিভারপুল রোড, চেস্টার, সিএইচ২ ১ বিকিউ ঠিকানায় লিখুন।

如果您需要翻譯服務或想索取這份文件的其他語文、錄音帶、凸字或大字體版本，請向我們的職員查詢。您亦可以寄電郵至 [info@cwps.nhs.uk](mailto:info@cwps.nhs.uk) 或寄信到 Communication, Cheshire and Wirral Partnership NHS Foundation Trust, Upton Lea, Countess of Chester Health Park, Liverpool Road, Chester, CH2 1BQ.

જો તમારે ભાષાંતર સેવાઓ અથવા આ દસ્તાવેજની બીજી ભાષાઓમાં નકલ, ઓડિયો ટેપ, બ્રેઇલ અથવા વિશાળ ફંદની છપાઈની જરૂર હોય, તો કૃપા કરીને સીડબ્લ્યુપી (CWP) ના કર્મચારીઓ સાથે વાત કરો, ઈમેલ કરો: [info@cwps.nhs.uk](mailto:info@cwps.nhs.uk) અથવા આ સરનામે લખો: Communication, Cheshire and Wirral Partnership NHS Foundation Trust, Upton Lea, Countess of Chester Health Park, Liverpool Road, Chester, CH2 1BQ.

यदि आपको अनुवाद सेवाएं या इस दस्तावेज की अन्य भाषाओं में नकल, ऑडियो टेप, ब्रेइल लीपि या विशाल आकार में छपाई की आवश्यकता हो, तब कृपया सीडब्ल्यूपी (CWP) कर्मचारियों के साथ बात कीजिये, या ईमेल कीजिये: [info@cwps.nhs.uk](mailto:info@cwps.nhs.uk) या इस पते पर लिखिये: Communication, Cheshire and Wirral Partnership NHS Foundation Trust, Upton Lea, Countess of Chester Health Park, Liverpool Road, Chester, CH2 1BQ.

Jeśli wymagane jest tłumaczenie lub kopia niniejszego dokumentu w innych językach, na taśmie magnetofonowej, w języku Braille'a lub dużym drukiem, prosimy o skontaktowanie się z członkiem personelu CWP (Organizacja partnerska krajowego systemu zdrowia regionów Cheshire i Wirral) lub przez pocztę elektroniczną: [info@cwps.nhs.uk](mailto:info@cwps.nhs.uk) lub na adres: Communications, Cheshire and Wirral Partnership NHS Foundation Trust, Upton Lea, Countess of Chester Health Park, Liverpool Road, Chester, CH2 1BQ.

Os oes arnoch angen gwasanaeth cyfiethu neu gopi o'r ddogfen hon mewn ieithoedd eraill, tâp sain, Braille neu brint mawr, siaradwch ag aelod o staff CWP, e-bost [info@cwps.nhs.uk](mailto:info@cwps.nhs.uk) neu ysgrifennwch i: Communications, Cheshire and Wirral Partnership NHS Foundation Trust, Upton Lea, Countess of Chester Health Park, Liverpool Road, Chester, CH2 1BQ.

## Dementia and people with learning disabilities



For more information see [www.cwps.nhs.uk](http://www.cwps.nhs.uk).

© CWP NHS Foundation Trust

The information in this leaflet was valid at the date of production **April 2020** and is due for review in **April 2022**

Leaflet code: E-ECIL-07-132

An information leaflet for family, friends and carers

## Introduction

This leaflet has been written for carers and staff who are supporting an individual with a learning disability, and who may be or is experiencing dementia.

The leaflet provides information on:

- The definition of dementia—what the word dementia means.
- The common symptoms of dementia.
- The support available from the specialist learning disability community teams in Cheshire and Wirral.
- Some practical advice and ideas when supporting an individual who has dementia.
- Useful contact details of other support organisations.

*Sources of information; Dodd, Turk and Christmas (2002) Down's Syndrome and Dementia. Bild, Kerr and Wilkinson (2005) In the Know—Implementing Good Practice. Pavilion, Alzheimer's Society Information Sheet January 2000*

## What is dementia?

Along with the rest of the population people with learning disabilities are living longer. This increased life expectancy brings with it all the illnesses and conditions of older age. One condition which they may experience and indeed which people with Down's Syndrome are more likely to experience is dementia. People with learning disabilities are four times more likely to develop dementia than the general population.

The term 'dementia' is used to describe a collection of symptoms, including a decline in memory, reasoning and communication skills, and a gradual loss of the skills needed to carry out daily activities.

These symptoms are caused by structural and chemical changes in the brain as a result of physical diseases. The symptoms over time will get worse.

## Useful Organisations

### Alzheimers Society

Helpline: 0845 300 0336

Website: [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

### Downs Syndrome Association

Tel: 0845 230 0372

Website: [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

### The British Institute of Learning Disabilities

Tel: 01562 723 010

Website: [www.bild.org.uk](http://www.bild.org.uk)

### Patient Advice and Liaison Service (PALS)

(provides information and advice about health services and links to other organisations)

Tel: 0800 195 4462

### Advocacy Services

Advocacy is available to support people who have difficulty expressing their views or wishes effectively.

For information about advocacy services in your local area please contact either your local community team on page 6 or the Patient Advice and Liaison Service on 0800 195 4462

## Useful Information

The National Institute for Health and Clinical Excellence (NICE) have produced information for people with dementia and their carers to help understand the options that should be available to them in the NHS and social care.

The information can be obtained from the community teams on page 6 or direct from NICE.

### CG42 Dementia: Understanding NICE Guidance

Tel: 020 7067 5800

Website: [www.nice.org.uk](http://www.nice.org.uk)

## The community teams

The suggestions on page 5 are just some of the possible ways of helping an individual with dementia. The community team will be able to provide further, more individualised guidance and support.

The contact details for the community teams in Cheshire and Wirral are listed below:

### Wirral - The Millennium Centre

**Address:** Twickenham Drive, Leasowe, Wirral, CH46 1PQ  
**Tel: 0300 303 3157 Monday to Friday 8.30am -5pm**

### West Cheshire - Eastway

**Address:** Countess of Chester Health Park, Liverpool Road, Chester, CH2 1BQ  
**Tel: 01244 397 222**

### Central Cheshire (Vale Royal) - Wyvern House

**Address:** Wyvern House, The Drummer, Winsford, Cheshire CW7 1AH  
**Tel: 01606 275 690**

### Central Cheshire (South Cheshire) - Stalbridge Road

**Address:** 54 Stalbridge Road, Crewe, Cheshire CW2 7LP  
**Tel: 01270 656 335**

### East Cheshire - Rosemount

**Address:** Chester Road, Macclesfield, Cheshire, SK11 8QA  
**Tel: 01625 509 013**



There is also an information leaflet available which provides general information on the learning disability services within Cheshire and Wirral Partnership NHS Trust.

The leaflet is called 'An introduction to learning disability services' and is available by contacting the community teams on the above telephone numbers.

## Common symptoms to be aware of

There are many different types of dementia but most have similar symptoms and progress in a similar way.

It is important to remember that everyone who has dementia will also have their own individual symptoms.

The most common symptoms of dementia are:

- **Changes** in daily living skills e.g. dressing, eating and personal hygiene.
- Short term memory loss e.g. forgetting names, instructions, where things are.
- Increased tiredness, slowing down, general inactivity.
- Reduction of interest in usual activities e.g. hobbies and pastimes.
- **Changes** in social behaviour e.g. becoming withdrawn, stubborn, mood changes, more emotional.
- **Changes** in understanding and communicating e.g. difficulty finding words, repeating words, talking less
- Becoming disorientated and confused with time, places, people and objects e.g. wandering, getting up in the middle of the night.
- The onset of seizures (thought to occur 2-3 years after the onset of dementia).

## How can the community team help?

There are many conditions that can trigger behaviours and changes that are easily confused with dementia.

Some examples of these other conditions are thyroid problems, urinary tract infections, sensory loss (hearing and sight difficulties), depression and other mental health problems, effects of medication and changes in personal circumstances.

Many of the common symptoms of dementia described on page 3 may be present already **but** this does not mean that a person has dementia.

It is change and deterioration that indicate the possibility of dementia.

Carers are very important in helping to identify dementia by recognising deterioration and change.

If you have concerns that an individual you support may be showing symptoms the community team can help by:

- Assessing the individual for a diagnosis
- Suggesting medication when appropriate
- Supporting the individuals general health needs
- Providing advice on suitable environment and equipment
- Providing advice on structure and management of daily routines
- Supporting with communication, eating, drinking and/or swallowing difficulties
- Providing practical support in all aspects of mobility
- Assessing and managing changes in behaviour

Please contact the community team in your area if you have any concerns about the person you support.

The contact details for the learning disability community teams in Cheshire and Wirral are on page 6.

## Supporting people with dementia

It is important to remember that people who develop dementia are first and foremost people with individual personalities, life histories, likes and dislikes. This should always be considered when supporting people with dementia.

Listed below are some practical ideas to consider when supporting people with dementia:

- Structure the day so that activities happen in the same order.
- Outings should be to familiar places and with familiar people.
- Offer the person visual clues (pictures and objects) and planners to structure the day.
- Provide labels and other pictorial aids around the home.
- Encourage the person to do as much for themselves as possible. Use prompts and reassurance during tasks that they now find more difficult.
- Keep the environment calm with minimal disruption, maintain a familiar layout to help the person orientate.
- If speech is a problem:

Use good non verbal communication (gestures, body language). Simplify sentences and instructions (e.g. use shorter phrases). Listen carefully and give time for the person to respond. A life book with photos/mementos from the person's past may be a useful way to help the person interact and remember

- It is very important to review a person's general health regularly. Other conditions such as infections could make a person more confused.