



**MacIntyre**

Providing support...your way



**DementiaUK**

Helping families face dementia

## Learning disability and dementia



## Learning disability and dementia

A learning disability is a condition that affects the way a person learns new things, how they understand information and how they communicate. Learning disability can be caused by genetics, or by a physical change, such as an accident.

Caring for a family member who has a learning disability, or dementia, or both, can be physically and emotionally challenging.

Dementia UK supports families through our dementia specialist Admiral Nurses. MacIntyre provides learning, support and care for people with a learning disability or autism. Dementia UK and MacIntyre have jointly produced this leaflet to offer support to families caring for someone with a learning disability and a diagnosis of dementia.

As the learning disability population ages, more people are living with dementia, partly because they're more at risk of developing dementia – particularly people

living with Down's syndrome. Often individuals with a learning disability develop young-onset dementia, which is dementia in a person under 65-years-old. Dementia for these individuals can progress more rapidly, or at least appear to progress more rapidly if a timely diagnosis isn't made.

## Difficulties in getting a diagnosis

Getting an accurate diagnosis of dementia for a person with a learning disability can be difficult. Understanding amongst health and social care professionals about learning disabilities and dementia is still patchy, and as a result people with a learning disability often struggle to get a diagnosis, as many of their symptoms are often put down to 'behaviours'. Alongside delays in diagnosis, difficulties accessing appropriate treatment and support are common.

Sometimes people with a learning disability and their families find that learning disability professionals don't have expertise in dementia, and specialist dementia services – like

Memory Clinics – can lack in-depth understanding of learning disabilities or don't accept referrals for people with learning disabilities.

As a result, many people living with a learning disability and their family, can experience a lack of support, understanding and guidance. This lack of understanding and support places extra pressure on individuals

and families who may already be struggling due to changing care and support needs, additional health problems, health issues for family carers and caring for other family members.

The purpose of this leaflet is to try and provide some guidance and support to anyone experiencing the development of dementia alongside a learning disability.



*In this photo: Rachel*

### Facts and figures:

- Over the last 30 years, the lifespan of people living with a learning disability has increased markedly
- Studies have shown that one in ten people with a learning disability will develop young onset dementia
- The number of people with Down's syndrome who go on to develop dementia are even greater with:
  - one in 50 developing the condition aged 30-39
  - one in 10 aged 40-49 and
  - one in three people with Down's syndrome will have dementia in their 50s

### Recognising and diagnosing dementia in a person with a learning disability

Memory loss is usually one of the most recognisable signs that someone might be developing dementia, but this may not be the case for people with a learning disability.

Often, people with a learning disability might demonstrate other symptoms first, such as:

- changes in their personality or mood
- difficulty making decisions
- changes in the way they live their day to day life
- changes in the things they could normally independently manage

If you're noticing changes in the person you care for, it can be helpful to monitor these changes by keeping a record. Write down what you noticed, when it occurred, and whether these changes come and go, or whether they're permanent. Everyone can have a bad day, but several bad days in a row might be a sign of something more serious.

If the changes are more persistent, getting worse or are causing an impact on the person's activities or daily living, you should arrange for the person to see their GP, taking a record of these changes.

A number of other conditions and illnesses can cause these changes and it's important that these are



*In this photo: Arthur and Wendy*

ruled out by the GP as soon as possible. The GP should start by assessing whether the person has an underlying treatable condition, for example depression, vitamin B12 deficiency, or abnormal thyroid function. They should offer to take blood tests, a chest X-ray (if necessary), a scan and a urine sample to rule out any other physical health issues, if the person is able to participate in such tests.

They may also briefly test the person's cognitive abilities by asking the person to:

- state what day and date it is
- name some common items
- remember something to test concentration and short term memory

If similar tests were conducted prior to this assessment, the results of the two should then be compared to assess if the person's cognition has changed.

If all other physical or mental health conditions have been ruled out as possible causes of the changes in memory, behaviour and/

or personality/mood, the GP may then refer the person for further investigations. This could be at a memory clinic (a place for specialist assessment to diagnose, treat and support people with dementia), at a learning disability clinic or with a doctor who specialises in learning disability and/or dementia.

If a dementia diagnosis is the outcome of further investigations, the diagnosing clinician should be asked what type of dementia the person is believed to have. Certain symptoms are associated with different types of dementia, and knowing this information can help in the planning of care and support for the person.

### **Living with a learning disability and dementia**

Once a person has received a diagnosis of dementia, their care and support needs should be reassessed in light of this diagnosis.

As far as is possible, the person should remain in their usual routine, with adaptations and support if necessary, and reasonable adjustments put into place.

There are a number of practical steps that can be taken to support the person. These include:

- making the house dementia friendly (see Sources of support section at the end of this leaflet for Dementia UK's leaflet on Making the home dementia friendly and safe). This will help the person to maintain their independence, for example, by being able to navigate around their kitchen or find their way to the toilet
- finding support services such as Admiral Nurse services or MacIntyre Memory Cafes for people with learning disabilities and dementia, which might be available in your area. Speak to your local council or check their website to find out more about local services
- encouraging the person living with dementia to continue the things they still enjoy. At the same time, start making allowances for the things the person can no longer do
- thinking about how you communicate. Many people



*In this photo: Mark*

have difficulties communicating, understanding what's been said, or processing and remembering information. Think about the things that worked prior to the person developing dementia, as these methods might still work; however, you may have to change some methods of communication. It's generally good advice to keep explanations simple, sentences short and to ask less questions. (See Sources of support for Dementia UK's leaflet on Tips for communication)

- continuing to support choices but keep things as simple as possible. Don't seek to control the person: although their cognition may be impaired, every effort should be made to ensure that the person remains in control of their day to day life
- allowing more time. Feeling rushed can cause people with dementia to feel increased pressure and can in fact mean that tasks take longer, as the person gets more stressed and confused
- concentrating on feelings and emotions; look for opportunities to create laughter and joy. A person with dementia might not remember what you said, but they will remember how you made them feel
- ensuring physical health is looked after. Things like chest infections, urine infections, constipation, pain, hearing and sight loss can all make the person's dementia seem worse. Therefore, it's important you look out for these illnesses or conditions if the person with dementia seems to be struggling more, and make sure to visit your GP

- ensuring the person is eating and drinking well (never assume they are). Look for signs of hunger or thirst and be alert for weight loss, malnutrition and dehydration (See Sources of support for Dementia UK's and MacIntyre's resources on Eating and drinking)
- encouraging as much physical activity as the person can manage to help boost their wellbeing and help them to remain mobile
- supporting good sleep habits. Being sleep deprived can make a person's dementia symptoms more acute (See Sources of support for Dementia UK's leaflet on Good habits for bedtime)
- encouraging healthy lifestyle choices, like reducing or stopping alcohol intake and smoking
- engaging in 'life story' work (See Sources of support for Dementia UK's and MacIntyre's resources on Life story work)
- supporting the person's peers and friends to understand the changes that are happening to

the person's brain. Easy read documents are freely available (from MacIntyre's website) to support these interactions

If you're a family carer, please make sure you're receiving all of the support you need and are entitled to. This includes:

- a Carer's Assessment under the Care Act. This is an assessment from your local authority. This can determine what support and resources you need to care effectively, and whether you're eligible for funding (see Sources of support for Dementia UK's leaflet on the Carer's Assessment)
- registering your name on the GP surgery's carers register (check that you're on this so that you receive support such as carer health checks and flu-jab invitations)
- accessing some of the carer education programmes that are available from organisations like Dementia Carers Count [dementiacarers.org.uk](http://dementiacarers.org.uk) and TIDE [www.tide.uk.net](http://www.tide.uk.net)



*In this photo: Diane*

- Advanced Care Planning (See Sources of support for Dementia UK's and MacIntyre's resources on Advanced Care Planning)
- receiving help and support from Dementia UK's Admiral Nurse Dementia Helpline if you have any additional questions or concerns. The Helpline is open seven days a week on **0800 888 6678** or [helpline@dementiauk.org](mailto:helpline@dementiauk.org), Monday to Friday 9am-9pm and weekends 9am-5pm

The most important thing you should know is that a person with a learning disability and dementia is still first and foremost a person. With good care and support the person should be able to live as well as possible with both conditions, and all the advice that is generally available about supporting a person with dementia is applicable to a person living with a learning disability too.

## Sources of support

MacIntyre has produced an extensive range of resources that are aimed at people living with learning disability and dementia, their families and professionals.

[macintyrecharity.org/our-expertise/dementia/](http://macintyrecharity.org/our-expertise/dementia/)

## Other sources of information:

### **BILD**

[bild.org.uk/resources/ageingwell/dementia/](http://bild.org.uk/resources/ageingwell/dementia/)

### **Mental Health Foundation**

[mentalhealth.org.uk/learning-disabilities/publications/hidden-plain-sight-dementia-and-learning-disability](http://mentalhealth.org.uk/learning-disabilities/publications/hidden-plain-sight-dementia-and-learning-disability)

### **SCIE**

[scie.org.uk/dementia/living-with-dementia/learning-disabilities/](http://scie.org.uk/dementia/living-with-dementia/learning-disabilities/)

### **Learning Disability and Dementia:**

[learningdisabilityanddementia.org](http://learningdisabilityanddementia.org)

### **Dementia Carers Count**

[dementiacarers.org.uk](http://dementiacarers.org.uk)

### **Tide**

[tide.uk.net](http://tide.uk.net)

## Dementia UK leaflets and resources:

### **Making the home dementia friendly and safe**

[dementiauk.org/safe-comfortable-home](http://dementiauk.org/safe-comfortable-home)

### **The Carer's Assessment**

[dementiauk.org/the-carers-assessment](http://dementiauk.org/the-carers-assessment)

### **Advanced Care Planning**

[dementiauk.org/advance-care-planning](http://dementiauk.org/advance-care-planning)

### **Tips for communication**

[dementiauk.org/better-communication](http://dementiauk.org/better-communication)

**Good habits for bedtime**

[dementiauk.org/good-habits-for-bedtime](http://dementiauk.org/good-habits-for-bedtime)

**Life story work**

[dementiauk.org/life-story](http://dementiauk.org/life-story)

**Eating and drinking**

[dementiauk.org/eating-and-drinking](http://dementiauk.org/eating-and-drinking)

**MacIntyre leaflets and resources:**

**Dementia and learning disability**

[macintyrecharity.org/our-expertise/resources/dementia-and-learning-disability-wellbeing-for-life/](http://macintyrecharity.org/our-expertise/resources/dementia-and-learning-disability-wellbeing-for-life/)

**Signs and symptoms of dementia**

[macintyrecharity.org/our-expertise/resources/signs-and-symptoms-of-dementia-wellbeing-for-life/](http://macintyrecharity.org/our-expertise/resources/signs-and-symptoms-of-dementia-wellbeing-for-life/)

**Timely diagnosis**

[macintyrecharity.org/our-expertise/resources/getting-a-timely-diagnosis-of-dementia-wellbeing-for-life/](http://macintyrecharity.org/our-expertise/resources/getting-a-timely-diagnosis-of-dementia-wellbeing-for-life/)

**Eating and drinking**

[macintyrecharity.org/our-expertise/resources/eating-and-drinking-wellbeing-for-life/](http://macintyrecharity.org/our-expertise/resources/eating-and-drinking-wellbeing-for-life/)

**Dementia friendly environments**

[macintyrecharity.org/our-expertise/resources/dementia-friendly-environment-wellbeing-for-life/](http://macintyrecharity.org/our-expertise/resources/dementia-friendly-environment-wellbeing-for-life/)

**Changed behaviour**

[macintyrecharity.org/our-expertise/resources/changed-behaviour-wellbeing-for-life/](http://macintyrecharity.org/our-expertise/resources/changed-behaviour-wellbeing-for-life/)

**Life story**

[macintyrecharity.org/our-expertise/resources/life-story-wellbeing-for-life/](http://macintyrecharity.org/our-expertise/resources/life-story-wellbeing-for-life/)

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email [feedback@dementiauk.org](mailto:feedback@dementiauk.org)

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support Dementia UK, please visit [dementiauk.org/donate](https://dementiauk.org/donate) or call **0300 365 5500**.

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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Open Monday – Friday, 9am – 9pm  
Saturday and Sunday, 9am – 5pm



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