

# Learning disability and dementia

## A guide for carers





## Being Dementia Aware

The Age Scotland Early Stage Dementia Team would like to thank Dr Karen Watchman from the University of Stirling for her contribution in creating this guide.

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## Introduction

This guide is for family carers of people with a learning disability. It gives an explanation of learning disability and dementia, suggests some possible signs and symptoms of dementia in a person who has a learning disability and gives some practical information and advice on how both you and the person you care for can live well with dementia.

# ***What is a learning disability?***

A learning disability is a lifelong condition that impacts on a person's ability to communicate, understand information and to learn new skills. In 2017 there were 23,186 adults in Scotland known to have a learning disability.<sup>1</sup>

There are different types of learning disabilities with different causes. Most learning disabilities happen before birth, for example, Down's syndrome or Fragile X syndrome. Others develop during birth or in early childhood. These may be due to illness, injury, lack of oxygen at birth or premature birth. Sometimes there is no known cause for a learning disability.<sup>2</sup>

A person who has a learning disability may require additional support to look after themselves or live independently.

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<sup>1</sup> Scottish Commission for Learning Disability, 2017.

<sup>2</sup> Mental Health Foundation, 2017.

## **What is dementia?**

Dementia is an overarching term for a set of symptoms caused by damage to the brain from certain diseases or conditions. Dementia is usually progressive which means once a person has it, it will get worse over time. Currently, there is no cure for dementia and around 93,000 people in Scotland are living with the condition.<sup>3</sup>

People who have Down's syndrome are more likely to develop dementia in their early 50s and it may appear to progress more rapidly than someone with dementia who doesn't have a learning disability (although this can often be due to difficulty in getting a diagnosis). It is estimated that 1 in 3 people with Down's syndrome will develop dementia in their 50s which may rise to 2 in 3 of those who live in to their 60s. Approximately 1 in 10 people aged 50 to 65 with learning disabilities other than Down's syndrome are believed to have dementia. This rises to more than half of those aged 85 or over.

This suggests the risk for people with other learning disabilities is less than for people with Down's syndrome but may still be between two and three times greater than for the general population.<sup>4</sup>

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<sup>3</sup> Alzheimer Scotland, 2017.

<sup>4</sup> Alzheimer's Society 2015

There are over 100 conditions which cause dementia. Some types are more common than others;

- **Alzheimer's disease** is the most common form of dementia. It usually starts in the part of the brain vital for forming memories. It is also the most common cause of dementia in people who have learning disabilities, particularly for people with Down's syndrome.
- **Vascular dementia** is the second most common type of dementia. It is caused by a reduced blood supply to the brain due to conditions such as high blood pressure, stroke or irregular heart rhythms.
- **Dementia with Lewy Bodies** accounts for around 10 percent of cases. Lewy bodies are tiny deposits of protein that can build up in the cells of the brain and cause damage.
- **Frontotemporal dementia** is a less common type of dementia. It is caused by damage to the front areas of the brain.
- **Mixed dementia** is when someone has more than one type of dementia.

## Could it be dementia?

Dementia can affect people who have a learning disability in a similar way to the general population although there are also some differences. For many people, their friends, carers and family members will play an important role in helping to identify changes that could be caused by dementia.

Signs to look out for in a person with a learning disability are:

- A sudden change in daily routine or living skills,
- A sudden change in behaviour,
- A change in appetite,
- Change in sleep pattern,
- New difficulties with spatial awareness such as difficulty in crossing roads, or going up and down stairs.

Many of the early symptoms of dementia are also symptoms of other conditions. For example, stress, depression, anxiety, lack of sleep, infections, an underactive thyroid. Certain life events such as the loss of a parent or long-term carer, moving away from home or changes in routine and structure can also have an impact on how a person is feeling.

Current or previous physical, emotional or sexual abuse may also result in someone changing their usual pattern of behaviour or communication. If you are concerned that someone may be at risk of harm, you should report your concerns to the local council's social work department and/or the police.

## Getting a diagnosis

Tests that are typically taken to diagnose, or rule out, dementia are not suitable for most people with learning disabilities. There are some dementia screening tools that have been specifically developed for people who have Down's syndrome or other learning disabilities, one of which has been adapted for use in Scotland, The NTG.<sup>5</sup> The NTG – Early Detection Screen for Dementia is an administrative tool that can be used by staff and family carers to note functional decline and health problems and to record baseline information that can be useful for further assessment and review. People who have Down's syndrome should have a baseline assessment of their abilities by the time they are 30. This will help to identify any future changes.<sup>6</sup>

This baseline assessment can help to identify other treatable conditions that the person may be experiencing. Diagnosing dementia can take a long time – there is no one assessment or test that can be taken.

If someone does have dementia, a correct diagnosis as soon as possible is important for support and so that the diagnosis can be included in their future planning.

If you have concerns speak to the person's **Community Learning Disability Nurse** or the GP.

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<sup>5</sup> National Task Group, 2015.

<sup>6</sup> British Psychology Society, 2015.



## If dementia is diagnosed

Everyone who is diagnosed with dementia has the right to be told about their diagnosis. However, a person who has a learning disability may have difficulties in fully understanding their diagnosis and what it will mean for them. Not everyone will understand the word ‘dementia’.

**Jenny’s Diary**<sup>7</sup> is a free and useful resource to support conversations about dementia with people who have a learning disability. It includes a 4-step approach to helping someone understand their diagnosis including; understanding their current knowledge about their condition, how to simplify pieces of information to make it easier for them to understand, how to explain information bit by bit within their current knowledge and how to check and reassess they understand what is going on.

For more information and to download the *Jenny’s Diary* booklet and postcards visit **[www.learningdisabilityanddementia.org/jennys-diary](http://www.learningdisabilityanddementia.org/jennys-diary)**

You may find it useful to also look at the *Charter of Rights for People with Dementia and their Carers in Scotland*. The charter sets out the rights of people living with dementia at every stage of the condition, including those with a learning disability. These rights include being able to participate, to feel included and to be treated with dignity and respect. You can get a copy of the charter by contacting the **Health and Social Care Alliance Scotland** (also known as The Alliance) at **[www.alliance-scotland.org.uk](http://www.alliance-scotland.org.uk)**.

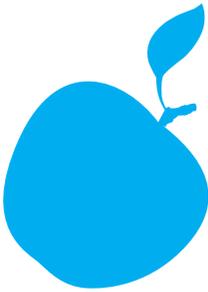
If the person you care for has been diagnosed with dementia, talk to their **Community Learning Disability Nurse** and GP about what support is available in your local council area.

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<sup>7</sup> Watchman, K. Tuffrey-Wijne, I. & Quinn, S, 2015.

## Living well with dementia

A dementia diagnosis does not mean that everything good in someone's life must end. It is possible to have a good quality of life with a learning disability and dementia by making changes to diet, staying active, maintaining enjoyable activities and more crucially continuing to be connected in their community.



### Diet

If someone with a learning disability lives on their own and cooks for themselves, additional support may be needed with menu planning and food preparation. Eating a varied, balanced diet is one of the best ways to contribute to good health. Having a healthy diet involved eating lots of fruits and vegetables, starchy foods such as bread and pasta and moderate amounts of meat and fish. Drinking plenty of fluids is also important. Some people living with dementia find not having enough to drink can make their symptoms worse. Water is a great choice, but fruit juice, diluted fruit juice, soup, smoothies and tea are all good too.

You may find that the person's likes and dislikes change, or that their appetite is smaller than before. Try exploring different types of food and find things that they may enjoy. If they do not have much of an appetite you may find that they may prefer smaller portions and regular snacks throughout the day or night.

See Age Scotland's **Eat Well** guide for more information.

## Staying Active

Regular physical activity is not only good for a person's health, but it can help to reduce stress and improve well-being. Being active can also make the person feel more positive, help them to concentrate on day to day activities and to sleep better.

**Paths For All** is a charity that promotes the benefits of being physically active through walking. It supports a network of community health walks throughout Scotland: free group walks which are led by trained volunteers and are accessible to everyone. Dementia friendly walking groups understand the needs of people living with dementia and what support might be needed.

**i** **Paths for All**  
Tel: **01259 218888**  
**www.pathsforall.org.uk**



## Community connecting

Taking part in community activities is a great way to get out and about, build social networks and to meet new people. Age Scotland's Community Development Officers support over 1000-member groups across Scotland which provide a range of services supporting older people, from Men's Sheds, to lunch clubs and befriending services.

**i** If you would like information on activities in your local area phone the **Age Scotland helpline** on **0800 12 44 222**.

## Smoking

It is common knowledge that smoking is bad for our health. If a person has a memory difficulty, it could also increase the risk of a fire. There is plenty of support available to help someone stop smoking. A good place to start is by speaking to a GP or talking to Smokeline.

**Smokeline** is Scotland's national stop smoking helpline. They can give information and advice about how to stop smoking and can work with you to come up with a plan that's right for you and considers the effects of living with learning disability and dementia.

● **Smokeline**  
**i** **0800 84 84 84** (open 7 days: 8am -10pm)  
**www.canstopsmoking.com**

## Alcohol

Many of us enjoy an alcoholic drink now and then, and alcohol can be an important part of socialising and celebrating. However, regularly drinking more than the recommended daily limits of alcohol can seriously harm your health. It increases the risk of developing conditions such as cancer, heart disease and stroke. Some people living with dementia also find drinking alcohol can make their symptoms worse.

For more information on cutting down on alcohol you can get in touch with Drink Wise, Age Well. They can help people make healthier choices about drinking as they age and can provide information on alcohol unit guidelines and tips on cutting down.

● **Drink Wise, Age Well**  
**i** **www.drinkwiseagewell.org.uk**  
Read our **Living well with dementia** guide for more information or call the **Age Scotland helpline** on **0800 12 44 222**.



## *Care for yourself*

Caring for someone close to you is an important and challenging role whether you are a parent, sister or brother. If you care for a family member with a learning disability who has had a diagnosis of dementia, you will not be new to caring – this diagnosis just adds a different dimension and you will require new and different information and support. It will be physically and emotionally challenging and it can be easy to overlook your own needs. Looking after yourself, seeking support and taking a break when you need it can help you cope with your role.

## Talk to others

You may find it useful to talk things through with your friends and family and explain how caring is affecting you. Even if you have managed well without support previously, a diagnosis of dementia can change your day to day lives and it is best to be as prepared as you can for changes that may lie ahead.

Carer's groups are a good way to meet with other carers. You can have a chat and share experiences with others. No matter what you are going through there is probably someone who has been through something similar and understands how you feel. Alzheimer Scotland runs groups across Scotland for people caring for someone with dementia.



### **Alzheimer Scotland**

Tel: **0808 808 3000** / [www.alzscot.org](http://www.alzscot.org)

### **Carer's UK**

You can also find out more information and your nearest local group through Carer's UK

Tel: **0808 808 7777** / [www.carersuk.org/scotland](http://www.carersuk.org/scotland)

## Support from health services

It is important to look after your physical and mental health. If you are finding things difficult or feeling stressed, tired or depressed, speak to your GP. Let them know you are a carer and tell them how you are feeling. Nobody can manage everything on their own so don't be afraid to ask for help. Your GP will take time to listen and discuss support options with you.

## Your rights

From 1st April 2018 carers in Scotland have new rights under the Carers (Scotland) Act 2016 and the Carers' Charter.

These give you the right to support from your local council in your caring role and to help you improve and maintain your own health and wellbeing.

Your council and health board must have a local carers strategy which looks at how the council will identify carers who need support and what support for carers is needed and available locally.

The council must make sure that an information and advice service is available for carers which can advise about rights such as the Carers' Charter, future social security benefits, advocacy services, health and wellbeing, bereavement support and emergency care planning.



To find more information on the Carers Act visit the Scottish Government's website **[www.gov.scot](http://www.gov.scot)** or to find your local carers centre contact **Care Information Scotland**

Tel: **0800 011 3200**

**[www.careinfoscotland.scot](http://www.careinfoscotland.scot)**

For more information and advice on looking after yourself in your caring role read our *Caring for someone with early stage dementia* guide and *Mental health: a guide for carers*.

## **Practical things to think about**

After a dementia diagnosis, it may be time to start discussing future plans if you haven't already done so. Below are some practical things to think about and discuss with the person you care for if this is possible. Engaging in life story work, an activity which involves writing down favourite memories, likes and dislikes, with people who have a learning disability and dementia can help to understand preferences and wishes as well as being an enjoyable activity for most families. Often conversations about end of life or funeral wishes are avoided, but this will not change the fact that dementia is a progressive condition for which there is no cure. The more we can understand about wishes and preferences the better.

### **Change of circumstances**

Many people who have learning disabilities will already have a level of care and support in place that is appropriate to their needs before being diagnosed with dementia. As their care needs and your support needs increase you may want to talk to a local Community Learning Disability Nurse or a Learning Disability Allied Health Professional about your change of circumstances and having your care needs reassessed.



For more information contact your local carers centre or call the **Age Scotland helpline** on **0800 12 44 222**.

## **Power of Attorney and Guardianship Orders**

If the person you care for has the mental capacity to do so they could appoint you as their Power of Attorney. This could give you the responsibility of helping them look after their finances, either straight away or if they lose the ability to do this themselves. It could also let you make decisions about their welfare if they lose the mental capacity to do this. For more information see Age Scotland's Guide to Power of Attorney in Scotland.

A Guardianship Order grants someone the legal authority to act on behalf of another person who has lost the capacity to make decisions for themselves. Granted by the Sheriff Court, the order can be in relation to someone's finances, personal welfare or both **[www.publicguardian-scotland.gov.uk/](http://www.publicguardian-scotland.gov.uk/)**

All Welfare Guardianship Orders and Financial Guardianships are administered by a Sheriff Court. Once the Order has been granted by a Sheriff, the Public Guardian will provide a registered copy of the powers they hold. For the Financial Guardianship you will normally have to show this to all banks and other institutions. The Guardian will also have to provide evidence of their own identity.

Under the Adults with Incapacity Act (Scotland) 2000, Guardians are strictly supervised. This can be carried out by the Office of the Public Guardian in Scotland in relations to financial powers or, by the local Social Work Department for welfare powers.

A Guardian's role and authority will end immediately when the person they represent dies, at which point when their Executor will become responsible for sorting out their estate.

The process involved in becoming a Guardian can be costly and may take some time.

**i** For more information on the application process and costs visit the **Office of the Public Guardian in Scotland** [www.publicguardian-scotland.gov.uk](http://www.publicguardian-scotland.gov.uk).

You can also find out more information through the **Age Scotland helpline** on **0800 12 44 222**.

## Will planning

If you haven't already, you may want to consider talking to a solicitor on having a will drawn up for yourself. This can include what happens to your money and other assets such as your home as well as setting out what you would like to happen for the person you care for.

It may be worth having a conversation with the person you care for to find out what they would like to happen in the event of your death. You should ask the solicitor how you can ensure that any money or property you leave to the person you care for would be looked after in their best interests after your death.

For more information read the Age Scotland **Making your will** guide.

## Change in accommodation

It is a good idea to plan when it comes to the future accommodation of the person you care for. Crisis or emergency moves (often to a care home for older people) can often cause distress and typically happen because something has gone wrong, such as a problem with your own health. A move in a crisis situation is best avoided where possible and planning can help this.

You should speak with the **Community Learning Disability Nurse** for information about suitable local care providers.

## Benefits

Most people with learning disabilities will already be receiving some form of financial support. This can come in the form of either **Disability Living Allowance (DLA)**, or **Personal Independence Payment (PIP)**. Someone living with a learning disability and dementia may also be entitled to means tested benefits such as **Employment and Support Allowance**, **Income Support** or **Universal Credit**. It is important that benefits are regularly reassessed to ensure they are receiving the proper support available to them.

Their entitlement may increase if dementia means that they need more care or supervision but get advice from a benefits adviser before asking for a claim to be reassessed.

As a carer, you may also be entitled to **Carer's Allowance** or means tested benefits.

 **Citizens Advice Bureau**  
Tel: **0808 800 9060**  
**[www.cas.org.uk/bureaux](http://www.cas.org.uk/bureaux)**



For more information on benefits see Age Scotland's publications *Benefits Maze* and *Benefits for people living with dementia*.



## ***Useful Contacts***

### ***Age Scotland***

Age Scotland is the largest charity in Scotland dedicated to enabling everyone to make the most of later life. We provide information for people through our publications and online. The Age Scotland helpline provides information, friendship and advice to older people, their relatives and carers.

Age Scotland helpline: **0800 12 44 222**

**[www.agescotland.org.uk](http://www.agescotland.org.uk)**

### ***Alzheimer Scotland***

Alzheimer Scotland is the leading dementia organisation in Scotland. It campaigns for the rights of people with dementia and their families and provide an extensive range of innovative and personalised support services.

Freephone 24 Hour Dementia Helpline: **0808 808 3000**

**[www.alzscot.org](http://www.alzscot.org)**

## ***Alzheimer's Society***

Alzheimer's Society provide a range of information and advice on living with dementia including for those with learning disabilities.

Tel: **0300 222 11 22**

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

## ***Carers Information Scotland***

Care Information Scotland (CIS) is a phone, webchat and website service providing information about care services for people living in Scotland.

Tel: **0800 011 3200**

**[www.careinfoscotland.scot](http://www.careinfoscotland.scot)**

## ***Carers Scotland***

Carers Scotland provide information and advice to carers on a range of issues including benefits, care and support services.

Tel: **0808 808 7777**

**[www.carersuk.org/scotland](http://www.carersuk.org/scotland)**

## ***Scottish Commission for Learning Disabilities***

The Scottish Commission for Learning Disabilities is an organisation committed to improving the quality of lives for those living with a learning disability. They offer information and advice on a range of issues.

Tel: **0141 248 3733**

**[www.sclld.org.uk](http://www.sclld.org.uk)**

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