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# Caring for people with epilepsy and learning difficulties



Hannah Hills 2007

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## A caring life



Marie and John McLeish have cared for their daughter Amanda her entire life. Since she had her first seizure at the age of just five months, Amanda has needed constant care. She is now 18 and her parents celebrate all the achievements she's made. This is despite Amanda having learning difficulties and a severe form of epilepsy known as Dravet syndrome.

They haven't always had access to information or top-level drugs. Like many carers, they often feel isolated. Marie, aged 43, says: "I didn't know anything about epilepsy. At the very beginning we were very frightened for Amanda. She stopped breathing and ended up in intensive care. There was no diagnosis at that time.

"We were told the prognosis was very, very poor. They didn't know the outcome. We didn't know if she would walk or talk or be able to do anything or have any independence. That was devastating. I think we went through a grieving process.

"We are delighted if she achieves a new skill and we are aware it will be at her pace. She can give you lots of love. Amanda is very innocent and there's a lovely part to that - she doesn't see anything as bad." Marie gave up her childcare job and John his hospital porter post to be full-time carers. Like many carers, they went from having salaries to living on benefits. They became unable to commit time to anything outside of constant attention for Amanda.

"The first years were very stressful and emotionally very demanding," she said. "We have had to fight for everything. We got to know the system and the right people. We have grown with Amanda's condition and we are still learning. The hardest thing is we can feel very isolated. You learn to cope with your stress as you go along, but our health has been affected by the demands of caring. John gets injections for his spine because of lifting her."

"I found it easy to ask for help, but didn't get the help I wanted. You learn a lot of new skills like patience, trying to stay positive on your approach, and being understanding. And you become aware of your own capacities and limitations and what you really need in life and what's really important. Your life is precious. I feel we have a more meaningful life now. We seem to get more rewards and we don't take anything for granted. Amanda's health is our wealth - she has taught us so much."

Marie says Amanda's transition into an adult world while having learning difficulties is challenging. Adult services don't really accommodate her condition.

"Amanda has been on life support seven times in her life," says her mum. "That lives with me every day. When she has a seizure, will she come out of it? If I take her out for the day, we take all this stuff with us - medical equipment, drugs. Despite this, we try to look like a normal family!"

"It sounds depressing but it's not. You take it in your stride and get on with it. Those positive moments are not something we would trade. We get so much from Amanda and she gives so much back. We appreciate her for what she is, not what she can't do."

The McLeish family do get support and took Amanda to Euro Disney for five days where she met other young people with Dravet syndrome. It was her first trip abroad.

## Are you an unpaid carer?

Most people who look after a son, daughter, partner, father, mother, brother, sister, or any loved one wouldn't class themselves as a carer. They're just doing what's needed.

You might help out with shopping or cooking. Or you might care for someone full time, attending to everything including the most basic needs. Thousands of Scots fulfil the roles of unpaid carers every day. They are of all ages and backgrounds.



Caring can be rewarding but it can also be very demanding. If you care for someone with epilepsy, you will learn a great deal about the condition. Each person is unique and the care you provide will be just as specific.

As a carer for someone with epilepsy you may need to:

- Support them during daily activities
- Help manage the person's seizures and medication
- Keep them safe during and after a seizure
- Provide support when they visit the doctor
- Help record the frequency and pattern of seizures
- Support the person to travel.

This leaflet will give you more information on being an unpaid carer. It will also tell you about caring for someone with epilepsy and learning difficulties. This will help you to ask the right questions and find the support you both may need.

## What is epilepsy?



Epilepsy means a person tends to have repeated seizures. More than 40,000 people in Scotland have epilepsy - that's one in 130 people. It is the most common serious brain (neurological) condition. Anyone can develop epilepsy at any age. However, it is more

common in childhood, teenage years and later life. For more detailed information about epilepsy please call our **Helpline on 0808 800 2200** or visit our website on **[www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)**.

## What are learning difficulties?

From birth we discover new skills and a better understanding of the world. But someone with learning difficulties usually finds this harder. This is because their brain development is affected. This can change how they communicate with others. It can be challenging and stressful to deal with for both.

Epilepsy is more common in people with learning difficulties. If you struggle with communication it can be difficult for you to say how you feel or how well the medication is working. Carers can find it particularly difficult to know if a person is having drug side effects if this cannot be expressed.

You can find out more about learning difficulties and behaviour from the **Ask Mencap** website on **[www.askmencap.info](http://www.askmencap.info)**. You can also contact **Enable Scotland** on **0141 226 4541** if you want to talk to someone in confidence about your child's learning difficulties, or visit their website **[www.enable.org.uk](http://www.enable.org.uk)**.

## Four ways to get support

Caring involves juggling many aspects of your life. This isn't always easy. Remember, you need support too.

### 1. GPs, nurses and occupational therapists

GPs, practice nurses and occupational therapists are there to help the person you're caring for and also you, the carer. You can, for example, ask your GP for a health check for yourself. **Carers Scotland** have a free carers health resource guide available on their website at **[www.carerscotland.org](http://www.carerscotland.org)**. GPs can also refer the person you care for to the learning disability team, neurologist or epilepsy specialist nurse.

You may want to ask your occupational therapist about changes around your home to make caring easier and safer for you. See our safety factsheet for some ideas. Your GP practice can also provide contact details for other organisations including carers groups.

Epilepsy specialist nurses are a useful source of information. They can answer your questions and discuss your concerns. You may find it helpful to write down any questions you have before a visit to your GP or epilepsy specialist nurse. It is also useful to keep a seizure diary for hospital appointments. This can help show the pattern and frequency of seizures. Some behaviours make it hard to tell whether they are caused by epilepsy or learning difficulties. Therefore, keeping track of changes and behaviours will help the experts help you.

As a carer, you may be concerned about possible side effects of medication. Someone with learning difficulties may find this hard to communicate. Medication can make the person slower or dull them down. Speak to your GP or epilepsy specialist nurse about any side effects of the medication. Epilepsy Scotland has a treatment factsheet that can help you understand more about epilepsy drugs.



Some people with epilepsy need emergency medication to stop seizures if they go on too long. People with epilepsy and learning difficulties are more likely to have these prolonged seizures. As a carer, you may need training to give this medication. Your GP will prepare a care plan with you detailing what is needed. Epilepsy Scotland provides training for giving emergency medication. Call us on **0141 427 4911** for course details.

## 2. Social work

This is an excellent source of help and advice. Social work staff can connect you with many services. They can help you with meals on wheels, respite care, aids and adaptations, allowances and benefits, home carers and day services. You can find your local social work department's contact details in your phone book.

Their staff can assess what support someone with epilepsy and learning difficulties might need. This is called a community care assessment. You may be able to access specialists to help the person you care for. These can be physiotherapists, occupational therapists and speech therapists.

Carers are also entitled to an assessment under the Community Care and Health (Scotland) Act 2002.

**Carers Scotland** have more information on such assessments. You can contact them by phoning **0141 221 9141** or visiting their website on **[www.carerscotland.org](http://www.carerscotland.org)**.

Social work staff need to find out and discuss where you are having challenges. They want to hear how you are managing, what you can and can't do, and what help you feel you need. They may need to ask other people or agencies who know you, to help them complete the assessment. And they will bring it back to you when it is finished to make sure all the information is correct.

If your circumstances change as a carer, it's important to know you can be reassessed for support. And if services from medical or social staff aren't right, you can complain. You can also contact our Helpline for more advice.

There may be a time when you will no longer be able to look after your loved one. This could be because of your own health. It could also be because the person you are looking after needs more support than you can provide. Equally, the person you are looking after may want to live more independently. In these situations, you can ask your local social work department for further help such as additional support at home or an assessment for supported independent accommodation.

## 3. Direct payments



Social work departments can make direct payments to anyone who is entitled to community care services. This allows you to buy your own care services rather than receiving them from social work. That way you have more control over when, how and where you get support services.

There are a number of rules related to direct payments and not everyone is eligible.

#### 4. Carers and other voluntary organisations

Most local areas have carers' centres. They work with the social work department and other groups to get support and information to those who need it. They can also offer a place to drop in. The staff there understand the demands of caring. You may also get some help or information on stress reduction, first aid training, safer lifting and other skills.

**The Princess Royal Trust for Carers** supports such centres and the thousands of carers across Scotland. You can contact them on **0141 221 5066** or visit their website on **www.carers.org**. Some carers' organisations have young carers' projects as many young people have carer roles.

##### A young carer



EVER since he was little, David Cherry has been doing two things - acting, and caring for his family. Both became second nature to David as he leads a normal life, going to Woodfarm

High School in East Renfrewshire and growing up like any teenager. But the 16-year-old has a dad with epilepsy and diabetes, a sister with epilepsy and severe learning difficulties and a brother with autism and learning difficulties. He shares caring responsibilities for them with his mum, Shona.

Sister Ruth, 15, can't feed herself and it's one of the main tasks David helps with, as well as lifting her and trying to communicate with her.

"Ruth can't speak at all," says David. "It's very hard for her and she can't use sign language. I've become reasonably good at gauging what she wants."

Care for any individual is as unique as the person themselves. David's dad, Iain, 44, rarely has seizures, but can't drive and isn't left alone with Ruth or Stuart in case a seizure leaves him disorientated and unable to look after them. Although Ruth has fewer seizures than she once did, her physical needs are largely met by her family. Caring for brother Stuart can be challenging. "With Stuart's learning difficulties, it's 24 hours a day," says David. "Epilepsy is just a worry at the back of your mind, but learning difficulties can be more tiring."

David says caring for his family has given him a unique and positive outlook on life. "If I was looking in at my life, I might see it as dumping a lot on me. But when it has come up, I have not known anything different. I'm used to it.

"The best thing is to look at the benefits of what you have got and what you're going to know before everyone else. It gives you a better insight than your peers. There's a lot worse off than me, and a lot younger carers who do more than me. In a way caring has given me a sense of maturity, though I hide it well!"

One of the best ways David has coped with his extra efforts has been Young Carers from the Princess Royal Trust. He says any young carer should seek out the local group in their area because it can give those breaks and time to relax with peers. Now David, who has been acting since he was three, aspires to study film, TV and theatre at Glasgow University and his family are right behind him - just like he has been for them.

It's important to remember you're not alone as a carer. There are many groups in your local area that help carers, both through listening and emotional support.



**The Carers and Information Support Line** have a confidential helpline service. You can phone them on **0141 353 6504** if you need help with any aspects of being a carer, or if you just need some emotional support.

Organisations such as **Crossroads** can provide respite care to give you a break. You can contact them on **0141 226 3793** or visit their website on **www.crossroads-scotland.co.uk**. For information and a chance to talk about epilepsy call our Helpline.

## Other sources of help

There are obviously many more ways to get support and help. Just because you are caring for a loved one doesn't mean you should neglect your own health and well-being. If you are not at your best, it may be harder to give others the care they need. Developing ways of managing stress can be important. Sometimes getting outside help so you can take a break can help.

## Holidays

A holiday is a great way to unwind and recharge the batteries, but it can be difficult for a carer to get those breaks. The person you are caring for will also benefit from the change of scene or seeing a new face.



Your local authority will take into consideration occasional holidays as part of their assessment. They may be able to help arrange respite care for the person you care for while you are away. However, you may want to travel with the person you care for. There are many organisations that can help with information and suggestions of places to stay, such as **Tourism For All** (**www.tourismforall.org.uk** or **0845 1249971**) or **Vitalise** (**www.vitalise.org.uk** or **0845 3451972**).

## Benefits

As a carer you may be entitled to benefits if the person you care for also receives certain benefits. This could be carers allowance or a carers premium for income support depending on your situation. Seek specialist help to find out more as the benefits system is complex. Your local **Citizens Advice Bureau** or **Welfare Rights Office** can help you with any benefits enquiries.

## Free bus travel/reduced fares on trains

The person you care for may also be entitled to free bus travel and reduced fares on trains. Some people get a companion card allowing free travel for their carer too.

If the person you care for has mobility problems they may qualify for the local authority blue badge scheme. This can be used by another person for parking as long as they are driving the disabled person somewhere.



## Transport to school



Education authorities can use their discretion to make arrangements they consider necessary to provide free transport to school for pupils living in their area.

If you are concerned about your child using public transport or a school bus, you can ask the education authority to consider arranging and paying for a taxi to take your child to and from school.

You need to get a letter of support from your GP and take this to your local education authority. You should ask to speak to a local authority education officer dealing with support for learning.

If you need any further advice and information on this, you can contact **Enquire** on their helpline on **0845 123 2303**. They also have information on any kind of additional support for learning on their website **[www.enquire.org.uk](http://www.enquire.org.uk)**.

## Flexible working laws

New laws also mean employers are required to consider flexible working hours to help carers juggle the different parts of their lives. **Carers Scotland (0141 221 9141 or [www.carerscotland.org](http://www.carerscotland.org))** have a leaflet called an Employees Guide to Work and Caring. This will tell you more about flexible working for carers.

## Further information

Epilepsy Scotland can give you further information on:

<b>Factsheets:</b>	<b>Guides:</b>
<ul style="list-style-type: none"><li>• Diagnosis</li><li>• Driving</li><li>• Employment</li><li>• First aid for seizures</li><li>• Leisure</li><li>• Memory</li><li>• Safety</li><li>• Seizures</li><li>• Treatment</li><li>• Triggers (including information on alcohol and photosensitive epilepsy)</li></ul>	<ul style="list-style-type: none"><li>• A guide to epilepsy - what you need to know</li><li>• Epilepsy and later life</li><li>• A parent's guide to epilepsy</li><li>• Men and epilepsy</li><li>• A woman's guide to epilepsy</li><li>• Guidelines for teachers</li><li>• An employer's guide to epilepsy</li></ul>

We also have information leaflets designed for people with learning difficulties. These include:

- All about epilepsy
- Safety and epilepsy
- Living with epilepsy



If you have questions after reading this leaflet, please contact our Helpline. Our trained staff are available during office hours and until 6pm on Thursdays.

If you would like this leaflet in a different format or language, please call 0808 800 2200.