

What to expect when...

You are new to caring

ATAXIA

brainstrust
the brain cancer people


Dochas Centre
Supporting Unpaid Carers


epilepsy scotland

neurological
alliance
of scotland


coalition
of carers in scotland
from recognition to rights

MND
Scotland
Supporting people affected by Motor Neurone Disease

scottish
huntington's
association



Being New to Caring

Across Scotland, there are over one million people like you, who provide unpaid care and support to a member of the family, a friend or a neighbour.

If your loved one has just been diagnosed with a neurological condition, or even if they haven't yet been diagnosed, you may not be aware of the help and support which is available to assist you in your new caring role. We know it can be bewildering or confusing at the beginning, but we hope to give you a quick guide and explanation to the help which is available to you from the NHS, Local Authority Social Care Services and other organizations such as charities.

Becoming a Carer

In some cases, making a diagnosis of a Neurological condition may take a long time. In others, the diagnosis is much shorter or immediate. Whichever applies to your situation, your caring role has actually begun. Many people don't recognise themselves as carers, thinking of themselves as partners, spouses or friends, but it's important that you recognise yourself as a carer so that you get the help and support you will need in your caring role.

The Carers (Scotland) Act 2016

Under the Carers (Scotland) Act, all people who provide unpaid care for another person now have the right to a personalised plan. For adult carers this is called an adult carer support plan. For young carers this is called a young carer statement.

The Carers (Scotland) Act includes:

- **A power to support carers and a duty to support carers who have needs that meet the local eligibility criteria**
- **A duty to provide an information and advice service to carers**
- **A duty to publish a Short Breaks Services Statement**

Local Health Boards have a duty to involve carers in discharge planning for the person they care for when they are admitted to hospital and a duty to prepare a local carer strategy with the relevant authority.

What to expect from Carers' Organisations

Many of the staff you'll meet in your local Carers Centre or organisation have themselves been carers. This means that they truly understand what you're going through.

You can drop in, and the staff will offer you a listening ear to hear your story and advise you on the Services they provide. They may offer Counselling, Advocacy and condition-specific Support Groups for carers. They will also talk you through services provided by other organisations such as the NHS, social work and other charities.

Money Matters

While many unpaid carers are retired, a huge number are juggling work or studying. It's important to let your boss, or school or college, know as soon as possible about your caring role, so that you can get time off in emergencies or if you need to take the person you care for to medical appointments.

If you need financial advice, your local Citizen's Advice Bureau or Carers Centre can put you in touch with someone who can check your situation. Some charities also have their own Welfare and Benefits officers who can assist you. You may be entitled to certain state benefits (such as Carers Allowance) or a reduction in your Council Tax.

In Conclusion

We know this is a difficult time and it can feel isolating, so please don't hesitate to ask for support if you need it and accept help if it is offered.

Caring for someone else can sometimes mean you forget to look after yourself. However, it's important to take some time for yourself. By looking after your own wellbeing, you will be better able to provide the care that your loved one needs.



Who might pay home visits

Health and Social Care professionals you may see:

- **Occupational Therapists** will check the home of the person you care for and suggest adaptations and equipment to help them maintain their independence for as long as possible.
- **Speech and Language Therapists** will monitor the speech and swallowing reflex of the patient.
- **Physiotherapists** can help with exercises to keep the body moving. This often gives the patient a psychological boost that they are doing something to help their body.
- **Dieticians** help ensure any prescribed diet is followed properly and the patient/carer are supported. They also measure any change in muscle size to see if there is a reduction.
- **Social workers** will be involved in creating a care plan for the person so that care is in place for them. If there are costs associated with the recommended care, they will explain the options on how to pay for them.

This is not an exhaustive list but each visiting professional should introduce themselves and explain their role clearly to help you understand who they are.