

What to expect..

When planning ahead

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



What is Anticipatory Care Planning

When you care for someone with a neurological condition, the thought of supporting them to plan ahead can feel daunting. It can involve some emotional but very important discussions that will help you truly understand the wishes and choices of your loved one.

There are two good reasons for having a conversation about creating an Anticipatory Care Plan (ACP). The time may come when the person you care for is less able to communicate their views relating to their care and treatment and they may have chosen you to advocate on their behalf. The time may also arise where the carer becomes sick and can no longer look after someone with a neurological condition. As difficult and emotional as these discussions can be, many have reflected on the sense of control they regained over their illness after discussing and documenting their feelings in advance.

Discussing an ACP with the person you care for also opens up the opportunity to make an Emergency Care Plan. This means that if an emergency happens, replacement care will be sorted out efficiently.

How to Have a Difficult Conversation

Many people are unsure how to talk to someone who might be distressed or in difficulty. Be assured that often thinking about the conversation is scarier than the conversation itself.

You may decide you or the other person are not ready to take on the conversation and choose to drop it. If you haven't come to terms yourself with what it is you need to talk about, then take some time to get it straight in your mind first.

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.

Supporting someone you care for to plan for the future may include:

- Talking openly and honestly about their views, feelings, wishes, and preferences
- Helping them complete an Anticipatory Care Plan
- Appointing a Power of Attorney
- Making a will, considering life assurances, and making funeral plans

If a will hasn't yet been prepared, or if it needs to be reviewed, some charities may help pay for the preparation of Wills and a Power of Attorney.

What is an Anticipatory Care Plan (ACP)?

This might also be known as an Advanced Care Plan. An ACP is a record of the wishes of the person you care for. It can contain as much or as little detail as wished. Planning ahead can help people feel more in control and able to manage any changes in their health and wellbeing. It allows other people to know what someone's wishes are whilst they still have the capacity to think about it.

What is a Power of Attorney?

A power of attorney (POA) is a written, legal document that gives someone else authority to act on a person's behalf. As long as the person is over 16 and has the cognitive capacity to do so, they can choose the person(s) they would like to take actions on their behalf and what powers they wish them to have.

The powers relate to welfare decisions and/or financial decisions. The document needs a signature from a practicing solicitor or licensed medical doctor whilst the person has capacity. The document is then registered with the Office of Public Guardian (Scotland) and will only be used in the future if the person becomes incapable of making their own decisions

Making a Will

When someone dies without having written a will this is called dying intestate and means money, property, or belongings are distributed by a rule called right of succession.

This, for many people, may not have been the way they intended things to be handled. By encouraging your loved one to have open and honest discussions about their views it will help them plan their will and this can reduce the worry, anxiety and fear of potentially distressing family disagreements.

You usually need to meet a solicitor in person to make or change a will.



Benefits of Anticipatory Care Planning:

- Allowing an individual to feel valued by listening to what matters to them in the context of their current and future health and care
- Delivering realistic healthcare with timely investigations and treatments and fewer interventions of low benefit, including unwarranted hospital admissions
- Effective care coordination to reduce repeated conversations with different professionals and teams
- Enabling more people to die in the right place for them.

Useful resources:

- <https://ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/>
- <https://ihub.scot/media/1982/my-acp.pdf>

Guardianship:

If someone loses mental capacity and does not have power of attorney, the court will appoint a guardian. Different principles apply to guardianship, it is a lengthy legal process and it can be more cumbersome for the carer to act as guardian.

<https://www.gov.uk/government/organisations/office-of-the-public-guardian>