Introduction

Once you have been given a diagnosis of Motor Neurone Disease (MND), it's important to consider planning ahead. By discussing your future with your family, friends and healthcare professionals, you can decide what things are important to you and let them know. Making plans when you're healthy means there is less to think and worry about should you become too unwell to discuss them.

Forward planning is the key to keeping ahead of MND. It is important to discuss any changes in your MND with your MND Clinical Specialist before they become an issue. The provision of equipment, coordinating care packages, and adaptations to your home all take time to organize.
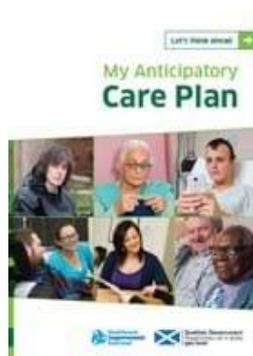
Anticipatory Care Planning

A document called an Anticipatory Care Plan (ACP) can be used to record your wishes, and your MND clinical specialist will help you to prepare one. Some people find talking about their wishes easy while others find it more difficult. You might find it less stressful to discuss your wishes in a series of short conversations rather than having a long, tiring conversation about sensitive or emotional issues.

Of course, you don't have to think about the future or prepare an ACP, but by doing so it lets others know what really matters to you. As well as discussing medical matters, you might want to record things like who will walk your dog, or do shopping for you should you become unable to do so. You can record your emergency contacts, medications you take as well as your spiritual and cultural beliefs.

The Scottish Government, in collaboration with Health Improvement Scotland, has created a tool-kit called 'My Anticipatory Care Plan' which discusses things to consider. You can find out more about it on their website https://ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/advice-for-individuals/

An ACP is not a legally binding document.

Have you prepared an Advance Directive?

An Advance Directive (AD) is a document which is used to record treatments that you don't want to be given in the future e.g. if your heart stops, you might wish to refuse CPR (Cardiopulmonary Resuscitation). While you cannot demand to be given any specific medical treatment, an AD lets you have a say in some of the decisions about your future care.

If you decide to prepare an AD, which is sometimes called a Living Will, it can be mentioned in your ACP, along with details of where it's stored.

Have you prepared a Power of Attorney?

A Power of Attorney (PoA) lets you nominate someone else to make decisions about your health or finances should you become incapable of making decisions about your own affairs. By preparing a PoA you will have peace of mind that your wishes are known about, recorded and respected. A PoA is a legally binding document.

You may also include a '**Letter of Wishes'** which would record things like the clothes you prefer to wear, or the television programs you enjoy. This can help people care for you should the time come when you need some help to look after yourself.

Find out more at the **MyPowerofAttorney** website https://mypowerofattorney.org.uk/

Have you prepared a Will?

It is important for you to make a will whether or not you think you have many possessions, property or much money.

If you die without making a will (this is known as **dying intestate**) there are certain rules which dictate how your money, property or possessions will be allocated. Without a will, your money or possessions may end up being distributed in a way that you would not have wished.

Useful resources

1. **My Anticipatory Care Plan -** Health Improvement Scotland and Scottish Government https://ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/

2. **Office of the Public Guardian** https://www.publicguardian-scotland.gov.uk/power-of-attorney

1. **Starting the Conversation** – **Planning ahead for your treatment and care**

   Compassion in Dying 2018   https://compassionindying.org.uk/library/starting-the-conversation/