Preparing for your death

a guide for people with learning disabilities and their carers
Introduction

It’s not a nice thing to think about, but everyone dies. It’s good to be open about death, to make things easier for ourselves and the people around us.

There are important things you need to think about if you haven’t got long to live, like making a will. A will is a document that tells people how you want things to be organised when you are gone. It makes things more difficult for the people you leave behind if you die without making a will.

If you care for someone, you’ll need to make sure they will be cared for after you’re gone.

You will also need help to deal with the sadness you will feel. It helps to talk about death with others and learn how to deal with your sadness.
What happens when you are going to die?

What is dying like?

Nobody knows what happens when you die. Some people believe that their minds or souls will go on living after they die. Other people believe that death is the end and their minds just stop.
Body changes

Some illnesses will make you feel very weak and tired as you get closer to death. You might lose weight no matter how much you eat. You might not want food any more. You might start to look older.

Doing everyday things might get harder as you get more ill. You might be too tired to get out of bed and get dressed.

Care and support

You will probably need more help to do things as you get weaker and more tired. You might want to lie still and sleep more. You might want to have someone sit with you.

Some people can keep talking right up until they die but most people will find it hard to talk when they are near to death. It is important to say the things you need to early on.
The last few days

You will probably be very weak and not able to get out of bed. You will spend a lot of time asleep. You might become very confused at times and not know who your family and friends are. You might see and hear things that are not there.

Your hands and feet might feel cold. It might hurt when people touch you. The people giving you care and support might have to be careful when moving or touching you. You might need medicines to take the pain away.
Planning Ahead

If you have found out that you don’t have long to live, there are some important things you need to think about. You will probably get weaker and more tired as time goes by so it is best to make plans as soon as you can.

How do you tell the people close to you?

You will have to tell the news to the people closest to you. If you have a job you should tell the people you work for. This will make you and them very sad so you have to think of the best way to do it.

If you need help with this, you can talk to your doctor or social worker.
Who else do you need to tell?

It’s best if you tell the authorities because you will probably have to fill in some forms about your benefits before you die. This will make things a lot easier for your family after you are gone.

You might want to discuss what forms you need to fill in with your doctor, social worker, or the local Citizen’s Advice Bureau.

Have you made a will?

It’s important to have a will so that your money and the things you own go to the right people after you’re gone. To find out more about making a will, contact your local Citizen’s Advice Bureau.
If you care for someone, who will look after them when you’re gone?

You will need to tell Social Work and your local Council and arrange with them to pick up the care of the person you care for. To find out more about this, call your local Social Work Department.

What kind of funeral do you want?

It is best if you tell your closest family or friends what kind of funeral you want. You can also discuss this with a funeral director or undertaker. An undertaker is a person whose job is to arrange funerals.
Do you want to donate your organs?

Parts of your body can be used to help other people after you are dead. This is called donating organs. Anyone over the age of 12 can choose to donate their organs in Scotland.

It is best if you have a think about this and make a decision before you die. Donating your organs could help to save someone else’s life.

To find out more about organ donation, contact your doctor (GP) or Organ Donation Scotland:

Website: www.organdonationscotland.org
Tel: 0300 123 2323
Useful contacts

Age Scotland
They work to improve the later lives of everyone on the ageing journey.
Tel: 0845 833 0200
Website: www.ageuk.org.uk/scotland/

Bereavement Register
Stops mail being sent to a deceased person.
Website: www.the-bereavement-register.org.uk

Carers UK
Help and advice for carers.
Tel: 0808 808 777
Email: info@carersuk.org

Citizen’s Advice Scotland
Can give advice on registering a death, arranging a funeral, wills etc.
Website: www.cas.org.uk
Citizens Advice Direct: 0808 800 9060

Cruse Bereavement Care Scotland
Help for people experiencing bereavement to understand their grief and cope with their loss.
Tel: 0845 600 2227
Website: www.crusescotland.org.uk
Email: helpline@cruse.org.uk
Good Life, Good Death, Good Grief
Useful resources and contacts about bereavement.
Website: www.goodlifedeathgrief.org.uk

Marie Curie
They provide care to terminally ill patients in their own homes or in hospices, and offer support to their families.
Website: www.mariecurie.org.uk

Samaritans
They give emotional support and help people get through tough times.
Tel: 08457 909090
Website: www.samaritans.org

Support Line
They offer confidential emotional support to children, young adults and adults by telephone, email and post.
Tel: 01708 765200
Email: info@supportline.org.uk