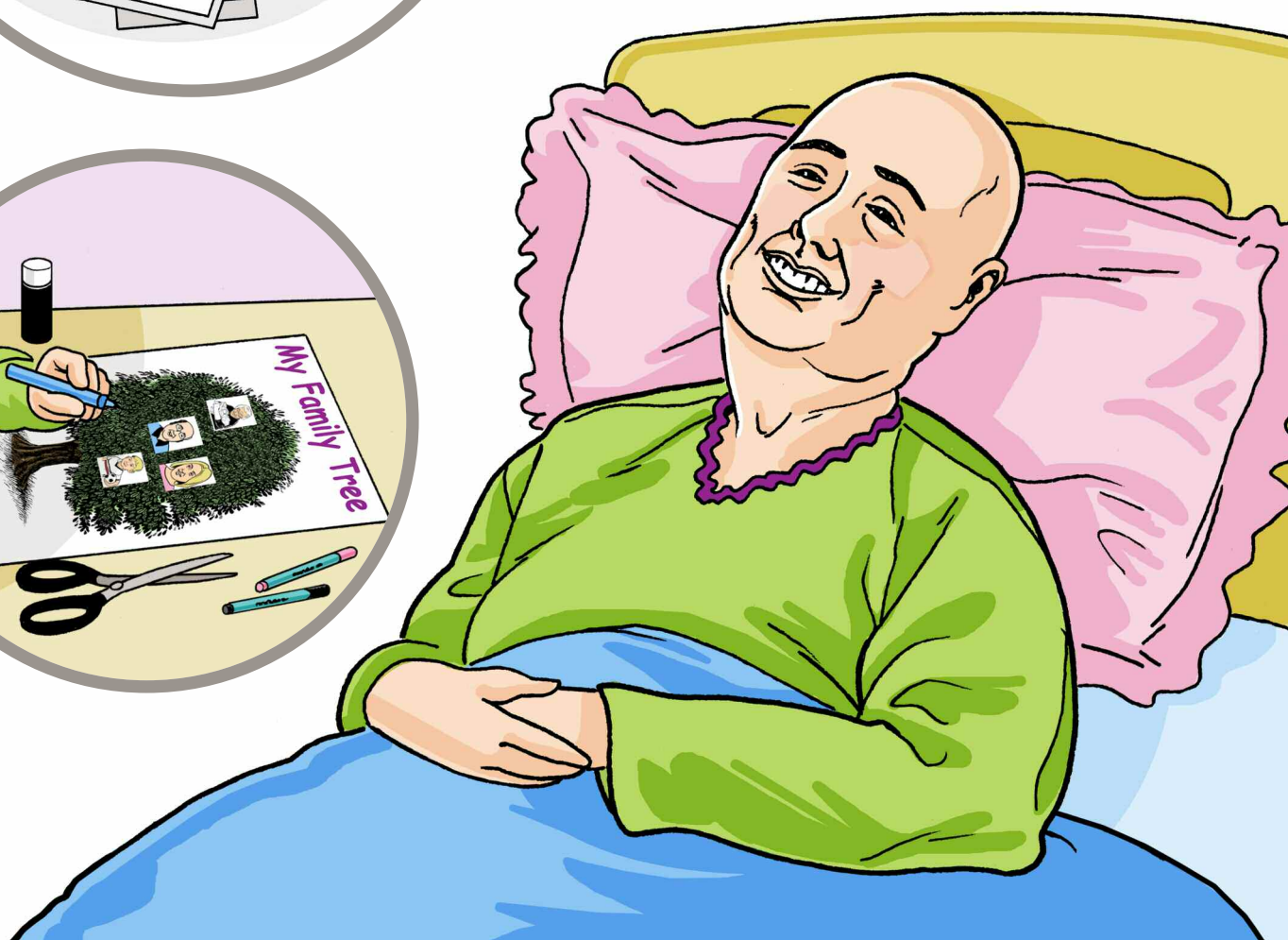


Getting ready to die

Palliative Care, End of Life Care and Bereavement



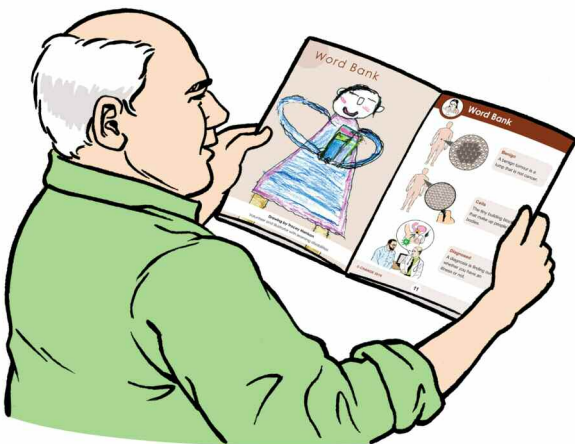
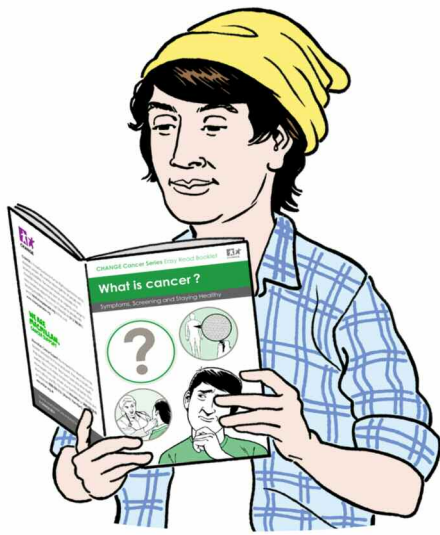
Introduction

This booklet uses easy words and pictures to help you get information about cancer.

You might want someone to help you look at the booklet so you can talk about it.

There is a Word Bank at the back of the booklet to help with hard words. Any words in **bold** you can find in the Word Bank.

This booklet can help you learn about cancer. But this is not the same as talking to your doctor. If you are worried about your health, you should talk to a doctor or nurse.





Getting ready to die



When people find out that they won't get better, they often want to plan how they will spend the time they have left.

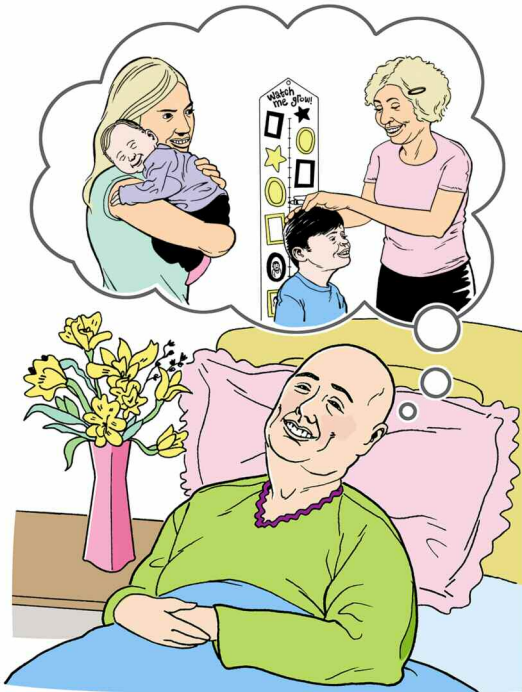


While you are still well enough to make decisions it can be a good idea to think about what you want at the end of your life.



Getting ready to die

Thinking about your life



It is important that the end of your life is also a time to celebrate and remember the good things about your life. It can be important to think about the people who will remember you.



A **Life Story Book** and a **Memory Box** are two things that you can make for others to remember you by.



A Life Story Book is a book where you can put photos of people who are important to you and pictures of things you have done in your life.



Getting ready to die



This can help you remember things that have happened. You can talk about your life as you make the book.



You can make a family tree with photos showing everyone in your family, and you.



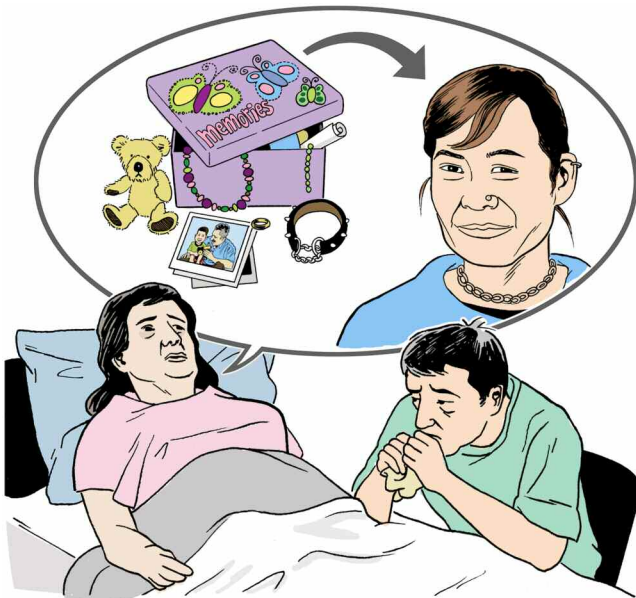
A Memory Box is a box where you can put things that are important to you. This might be things that remind you of a holiday or a special place, or photos.



Getting ready to die

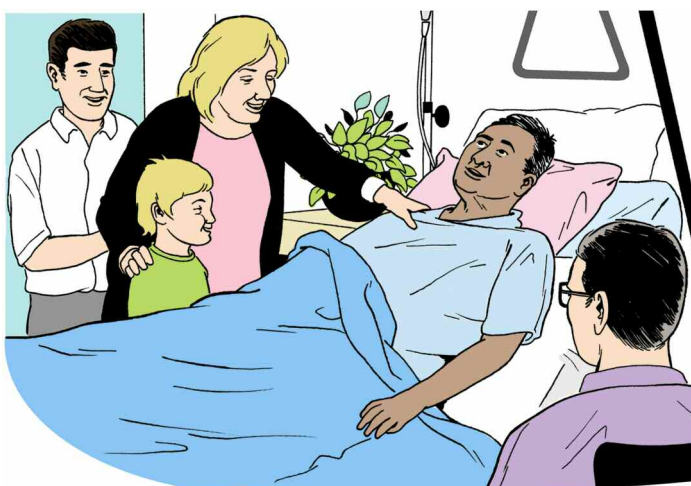


You can also put messages or letters to the people you love in the Memory Box.



You can say who you want to have the Life Story Book or Memory Box after you have died. Or you can give different things to different people.

Seeing people



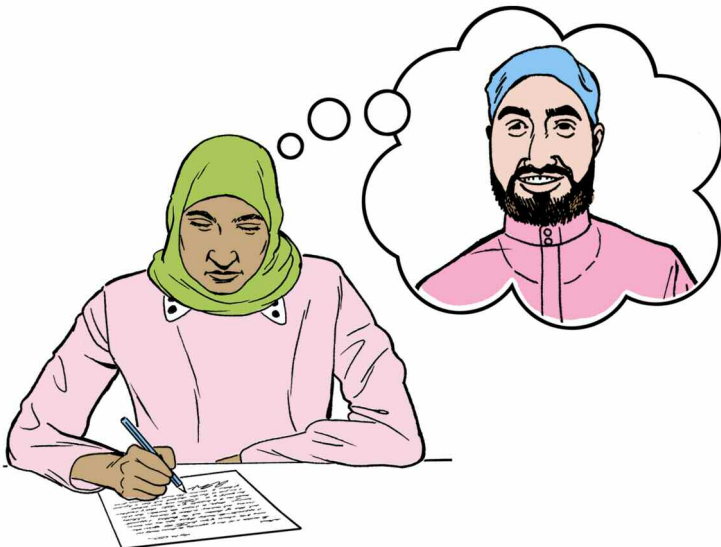
There may be family or friends who you want to talk to that you have not seen for a long time.



Getting ready to die

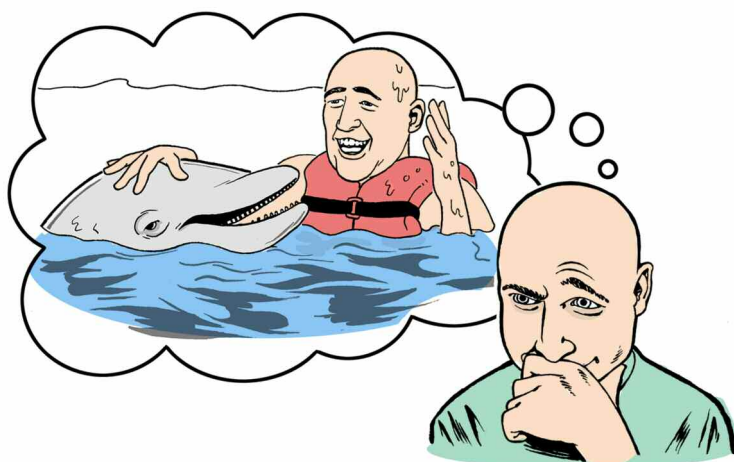


Get support if you need it to phone people and arrange to see them.



If there are people you will not be able to see then you could write letters to them. Ask for help with this if you need it.

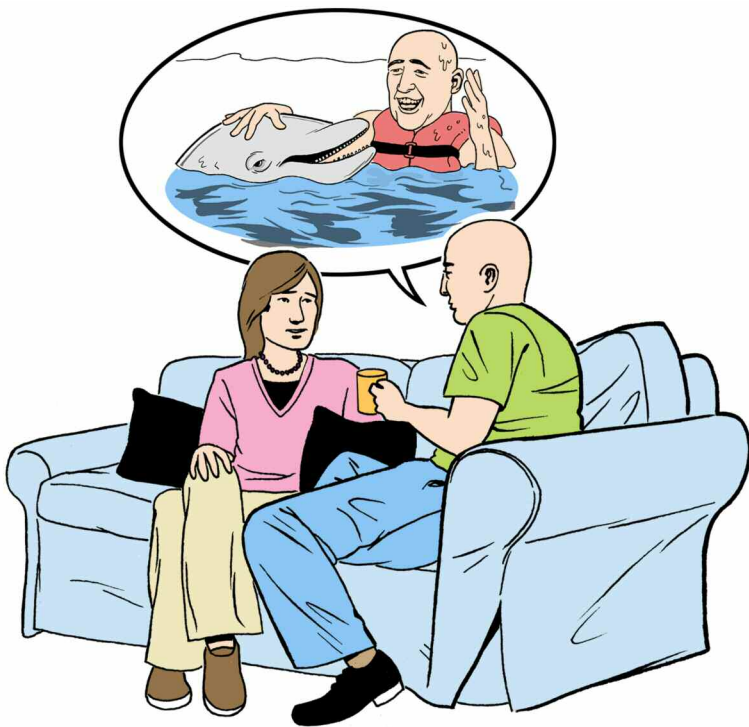
Support to do things



There might be things you want to do now that you might not be able to do in the future.



Getting ready to die



You can ask for support to help you do the things you want to do. It might not always be possible but you can ask!

Making a will



Making a **will** is writing down what you want to happen to your things after you die.



Getting ready to die



You can choose which of your things go to certain people so that they can remember you.



You may have money that you want to leave to people. You could also choose to leave money to a charity you like.

Word Bank

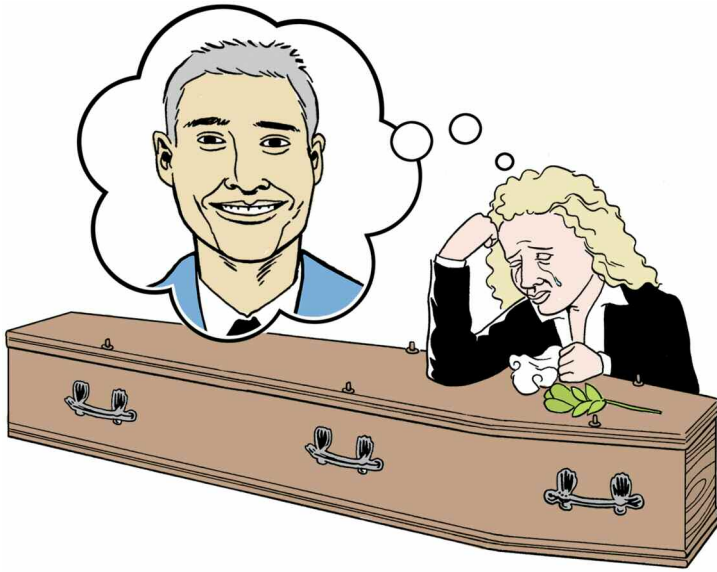


Drawing by Tracey Harrison

Volunteer and Illustrator with learning disabilities

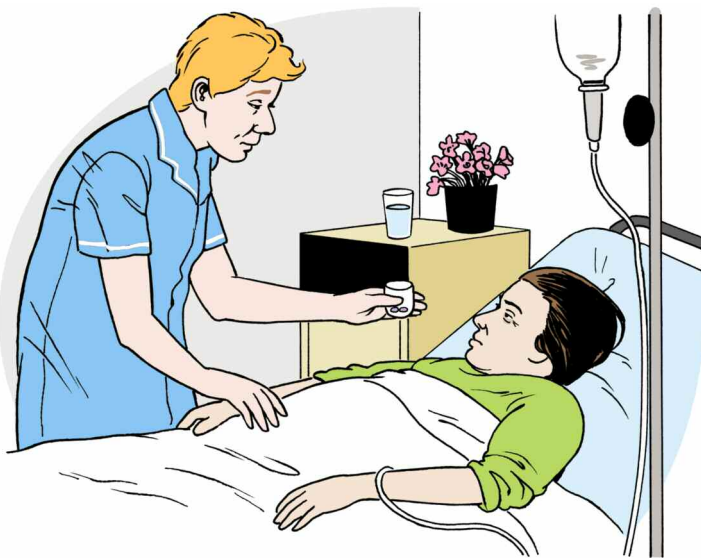


Word Bank



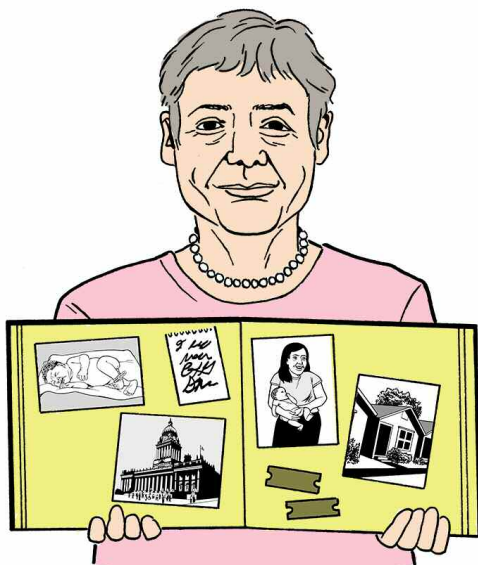
Bereavement

Bereavement is the feeling of loss and grief that someone may feel when someone they loved, or were close to, has died.



End of life care

This is care and support to help a person during the last weeks and days of their life until they die.

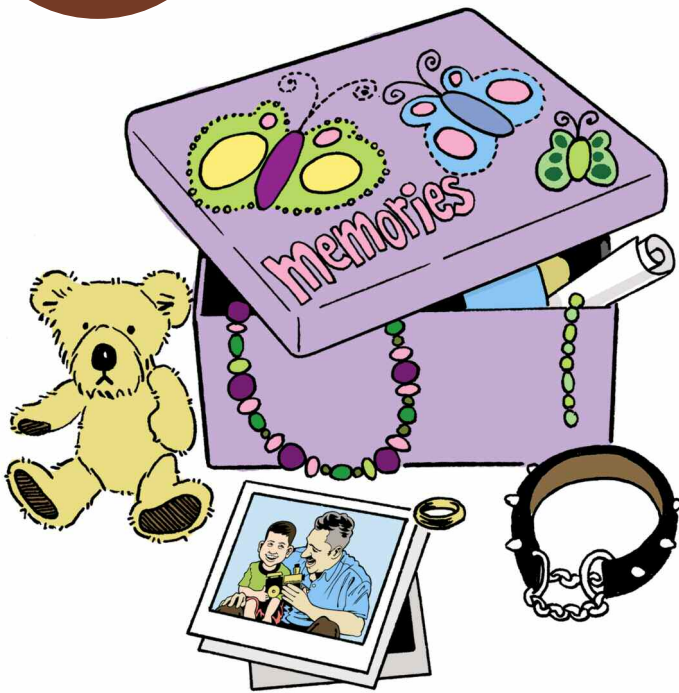


Life Story Book

A Life Story Book is a book where you can put photos of people who are important to you and pictures of things you have done in your life.

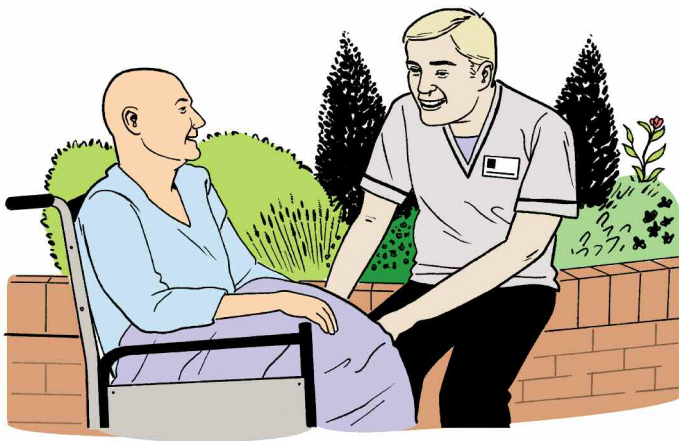


Word Bank



Memory box

This is a box where you can put things that are important to you. This might be things that remind you of a holiday or a special place, or photos. You can leave the box behind for others to remember you by.



Palliative care

This is the support and care people have when their illness can't be cured. It means making the person as comfortable as possible with medicines.



It also means helping them with their feelings and any spiritual needs.



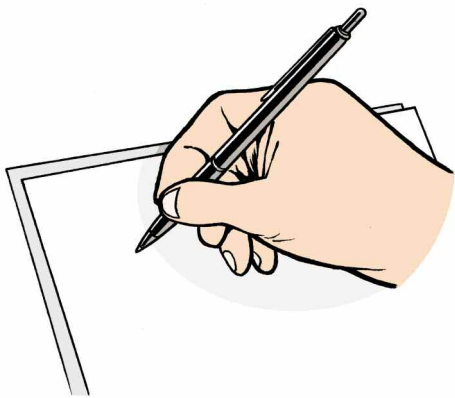
Word Bank



Will

A will is a legal document that a person makes before they die. It says what they want to happen to their things and their money after they die.

Notes...



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Useful contacts



Drawing by Tracey Harrison

Volunteer and Illustrator with learning disabilities



Useful contacts

Helpful organisations

Cancer Research UK

A charity that is researching treatments for cancer. Its website has lots of information about cancer.

Phone: 0808 800 4040

Web: www.cancerresearchuk.org

Hospice UK

Gives information about hospices in the UK.

Phone: 020 7520 8200

Web: www.hospiceuk.org



Macmillan Cancer Support

A charity that helps people who have cancer. They give practical, medical and financial support. They try to make cancer care in the UK better.

Phone: 0808 808 00 00

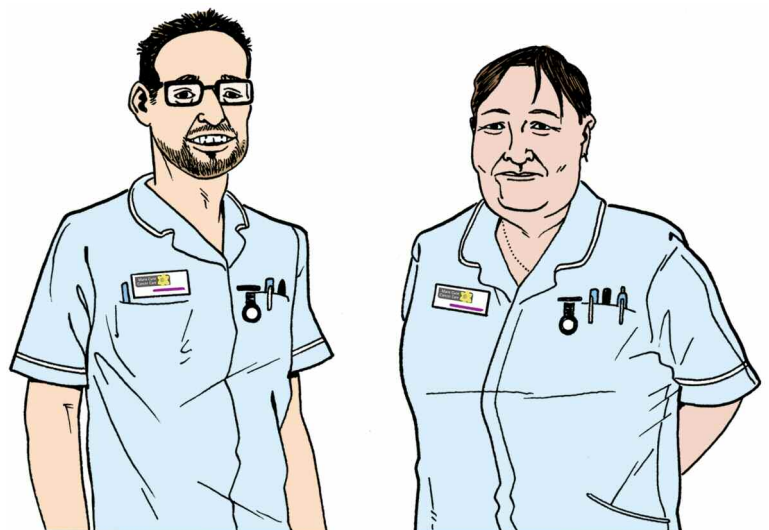
Web: www.macmillan.org.uk

Marie Curie

A charity that helps people who are dying.

Phone: 0800 090 2309

Web: www.mariecurie.org.uk





Useful contacts

NHS Contacts

These contacts give you information about your health and health services:

England and Scotland **Phone: 111**

Wales **Phone: 0845 46 47**

Northern Ireland **Web: www.hscni.net**



Palliative Care for People with Learning Disabilities Network (PCPLD Network)

A group of people sharing information to improve end of life care for people with learning disabilities.

Email: info@pcpld.org

Web: www.pcpld.org

Paul's Cancer Support Centre

Gives help, information and complementary therapies to people with cancer.

Phone: 0207 924 3924

Web: www.paulscancersupportcentre.org.uk

RESPOND

Gives therapy to people with learning disabilities after trauma or abuse. They also offer training and support to carers.

Phone: 0808 808 07 00

Web: www.respond.org.uk



Useful contacts

Samaritans

Helps anyone who is in distress or suicidal. They are open all the time - 24 hours a day.

Phone: 116 123

Web: www.samaritans.org.uk

Email: jo@samaritans.org



Written and audio material

Books Beyond Words

A series of picture books for people with learning disabilities. The books talk about cancer, health and bereavement.

Web: www.booksbeyondwords.co.uk

Phone: 020 8877 9799

Email: admin@booksbeyondwords.co.uk

FAIR Multimedia

Publishes a range of health leaflets, audio discs and CDs for people with learning disabilities. This includes a series on cancer.

Email: fair@fairadvice.org.uk

Phone: 0131 662 1962

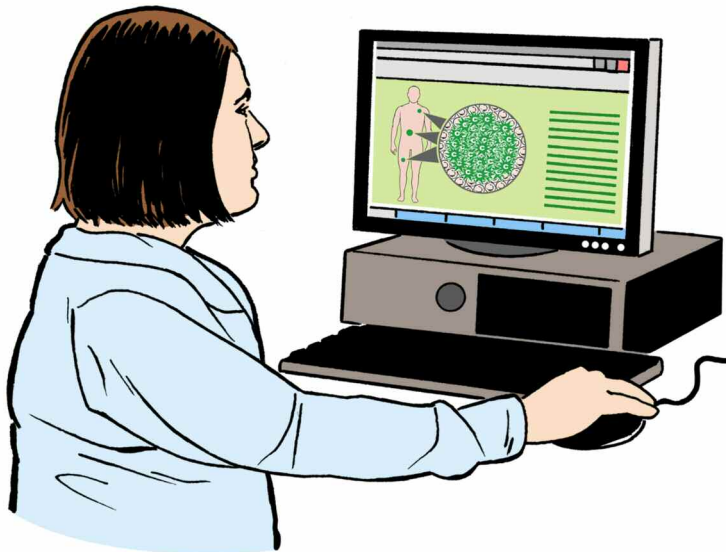
Web: www.fairadvice.org.uk/health-publications.php





Useful contacts

Online help



www.easyhealth.org.uk

Has lots of online health information that is easy to understand.

www.macmillan.org.uk

Has lots of information about cancer and where to get help. You can also talk to other people with cancer in the online community.

Videos and DVDs

Leeds Animation Workshop

Has animated films on social issues for people with learning disabilities. There is one called 'Getting Better' about going to the doctor and the health clinic.

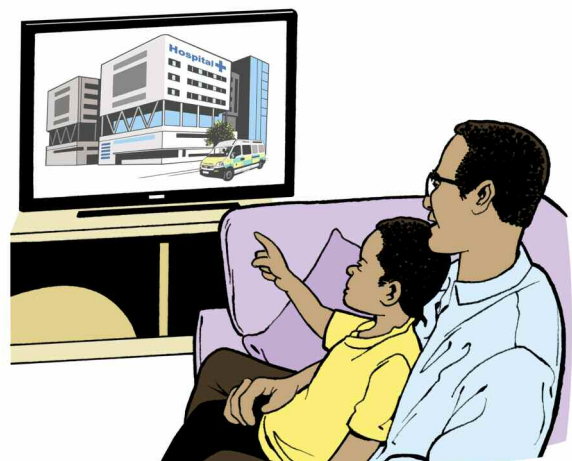
Phone: 0113 248 4997

Web: www.leedsanimation.org.uk/index.html

Speak Up Self Advocacy

Has DVDs and booklets for people with learning disabilities about health and illness.

Web: www.speakup.org.uk





CHANGE is a leading national Human Rights organisation led by disabled people. We work for equal rights for all people with learning disabilities. The cancer books and booklets that CHANGE have produced are part of an ongoing campaign to raise awareness about the issues of cancer for people with learning disabilities. You can call CHANGE on **0113 242 6619**, email **info@changepeople.org** or find us at **www.changepeople.org**

WE ARE MACMILLAN. CANCER SUPPORT

Macmillan Cancer Support has reviewed the information in this booklet and paid for it to be produced. They are a charity who help people with cancer. They have nurses and other health workers. They try to make cancer care in the UK better. They have experts who can answer your questions about cancer and how it affects your life. You can call **Macmillan** on **0808 808 00 00** or textphone **0808 808 0121 (Mon–Fri, 9am–8pm)**. Or go to **macmillan.org.uk**

This easy read booklet was produced by CHANGE

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