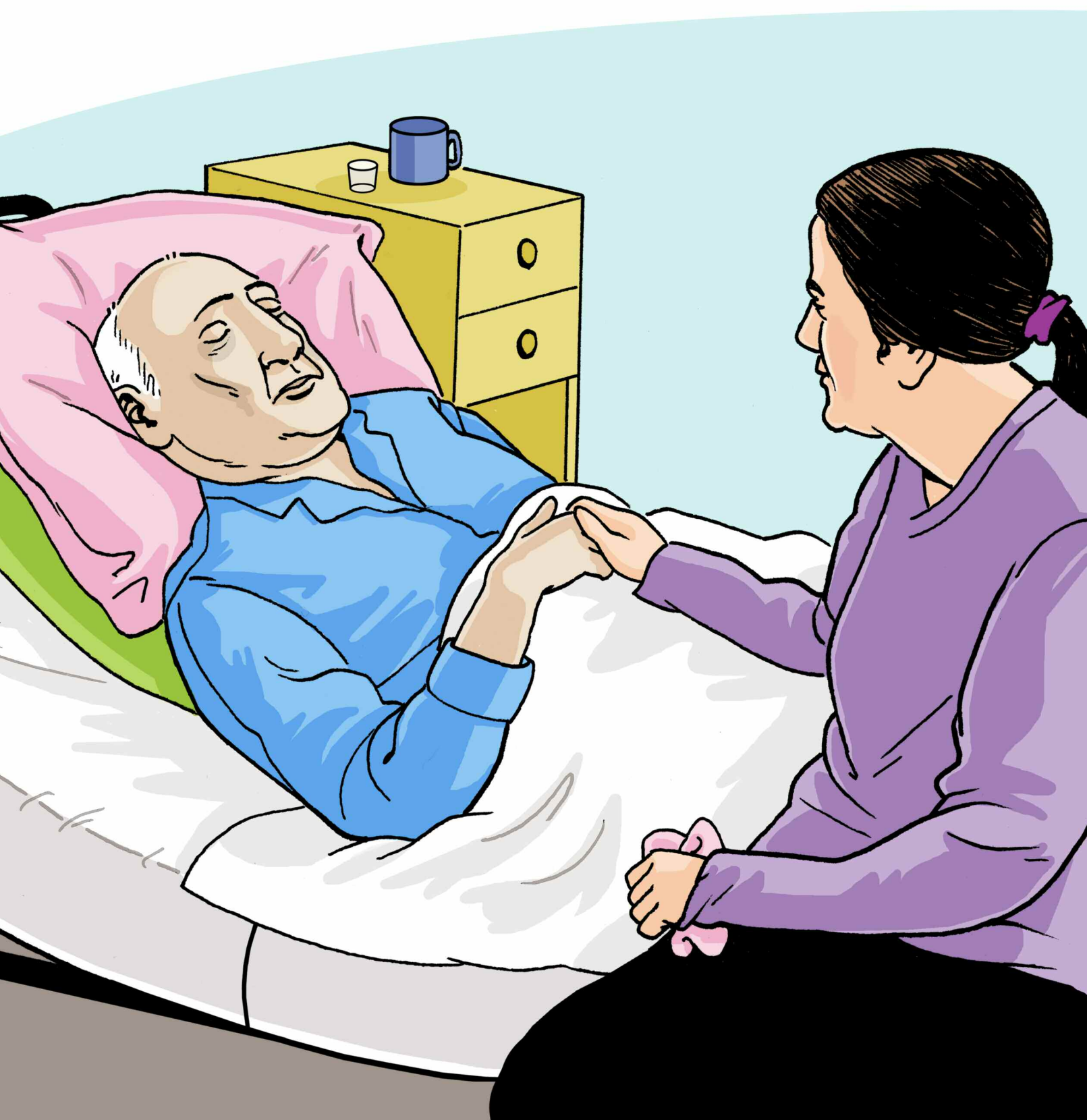


The end of life

Palliative Care, End of Life Care and Bereavement



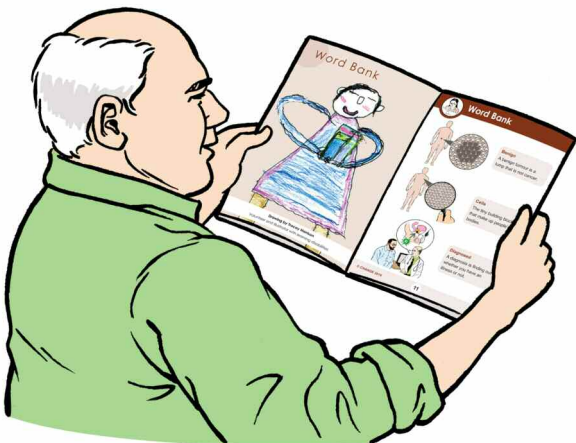
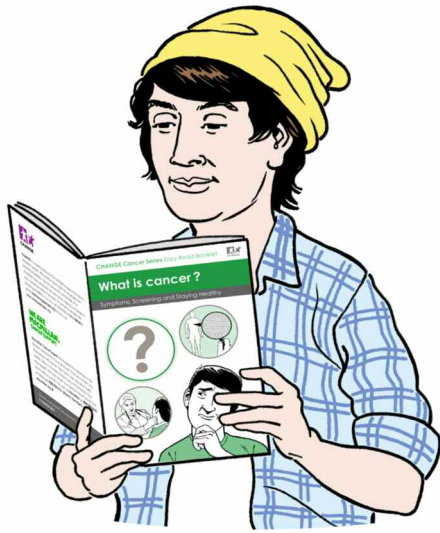
Introduction

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.

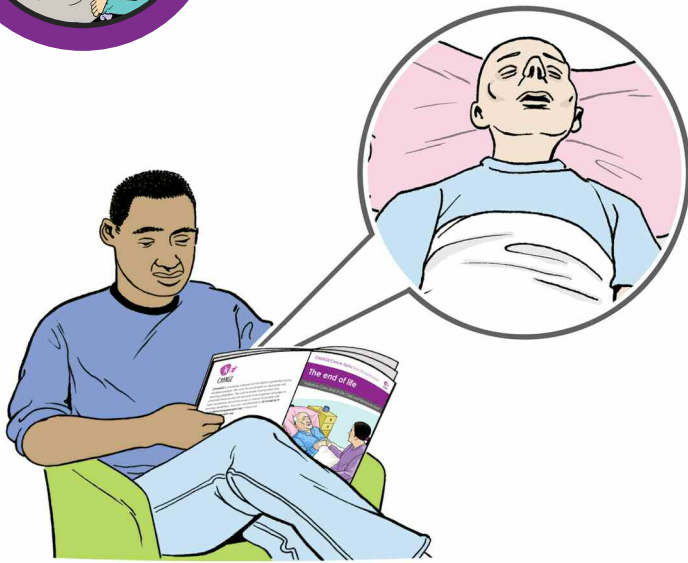
There is a Word Bank at the back of the booklet to help with hard words. Any words in **bold** you can find in the Word Bank.

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.





The end of life



You can read this booklet if you want to know what happens at the end of life.

The end of life - the last few days



When someone is dying, there are certain things that happen to them in the last few days of life.



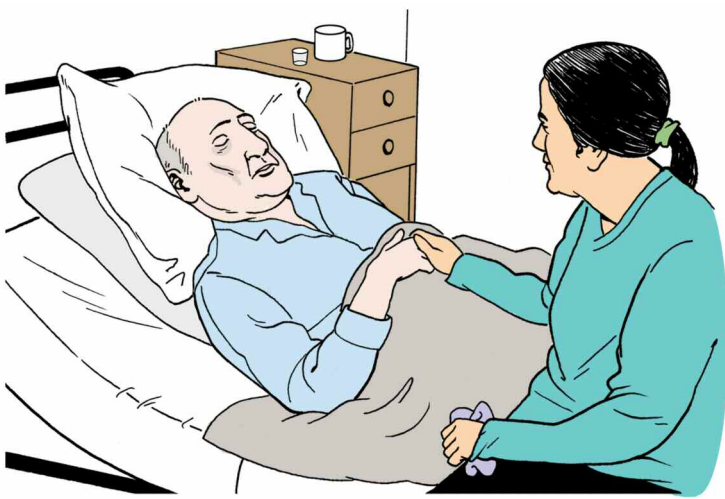
You may feel very tired and weak and want to sleep all the time. You will probably be in bed all the time and may not be able to move around much.



The end of life



Even if you just want to lie still or sleep, you can still ask for someone to stay with you.



You might want them to just be there to hold your hand or sit with you even if you do not want to talk.



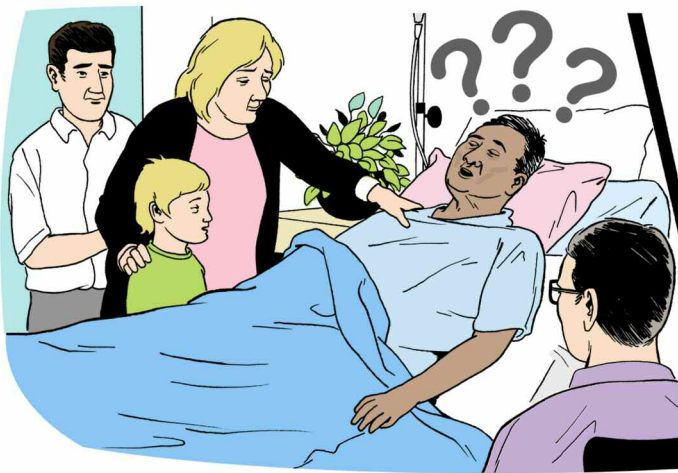
You might not want to eat or drink anything anymore.



The end of life



Your feet and hands may feel cold. Your skin may feel sensitive so people will have to be gentle when they are touching you.



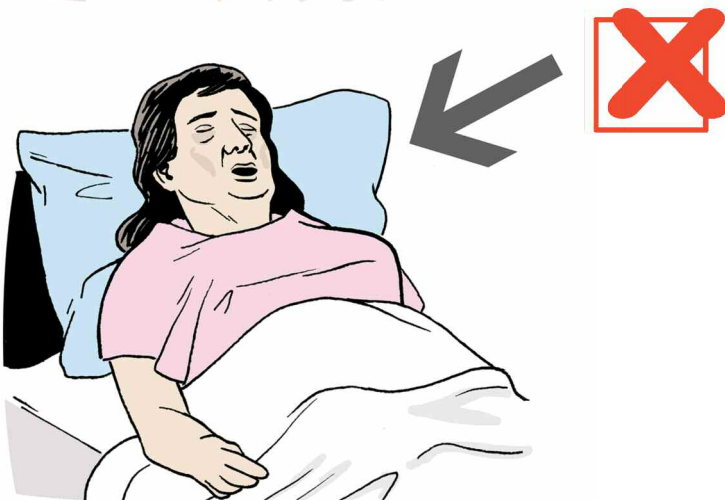
You might feel confused and not know who your family are or the people around you. You may feel like you are in a dream.



Slowly you may feel like you are in a deep sleep all the time. You can still hear people if they are talking to you. But you probably won't be able to talk to them.



The end of life



For most people their last moments of life are very peaceful. Their breathing gets slower and then stops.



After you have died your family and friends will be sad. But they will have different happy memories to remember you by.



The end of life



They will always remember you.

Word Bank

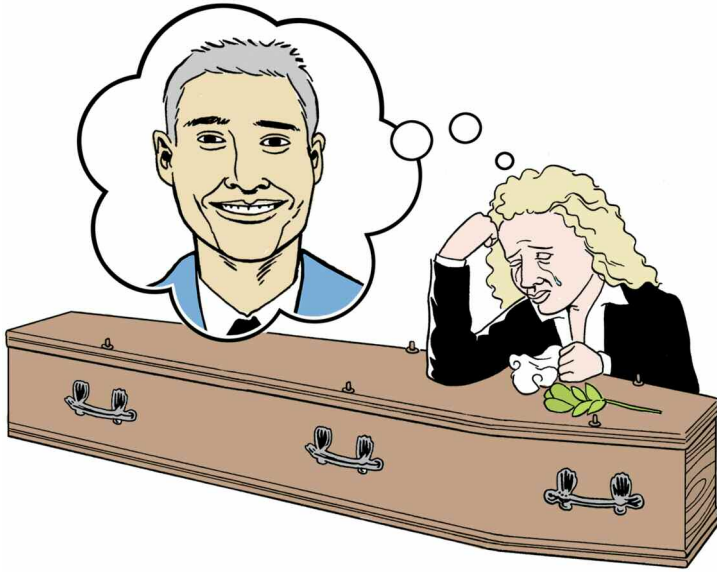


Drawing by Tracey Harrison

Volunteer and Illustrator with learning disabilities

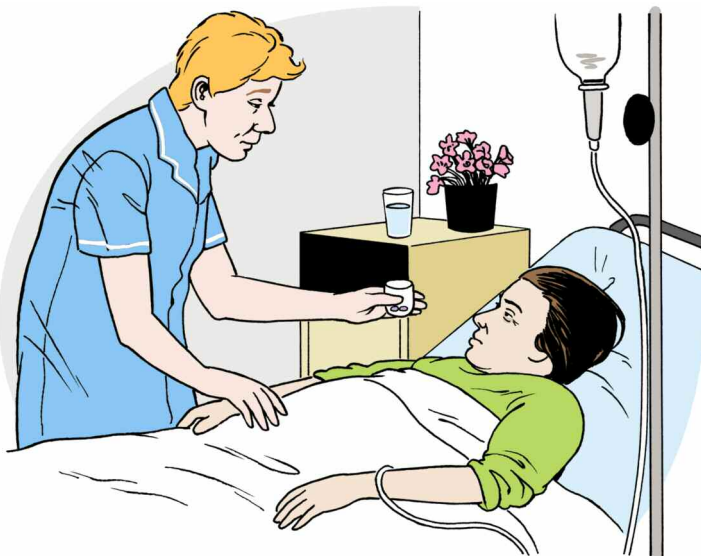


Word Bank



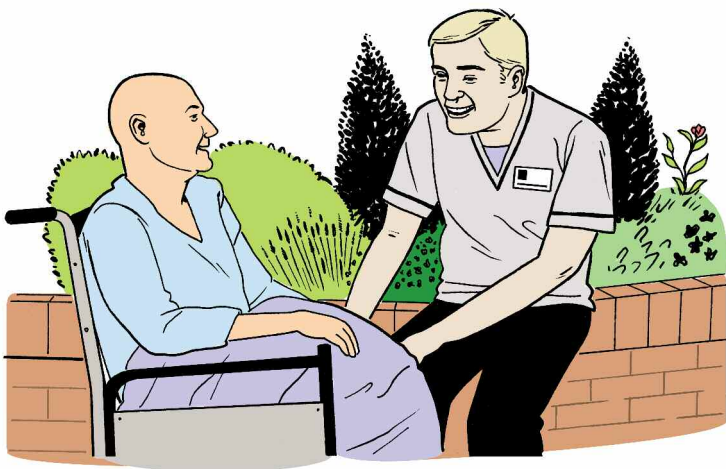
Bereavement

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.



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.

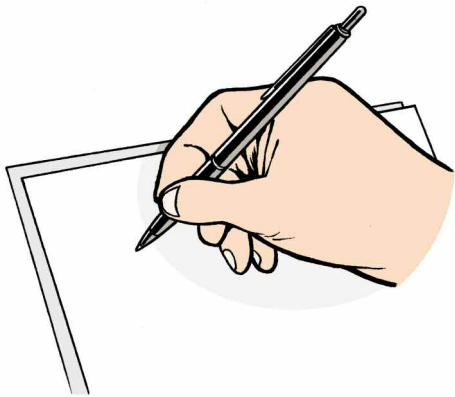


Word Bank



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

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

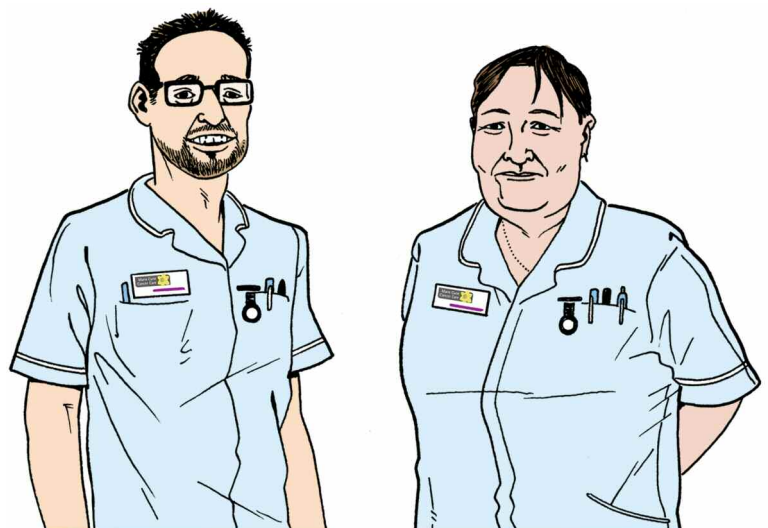
Web: www.macmillan.org.uk

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

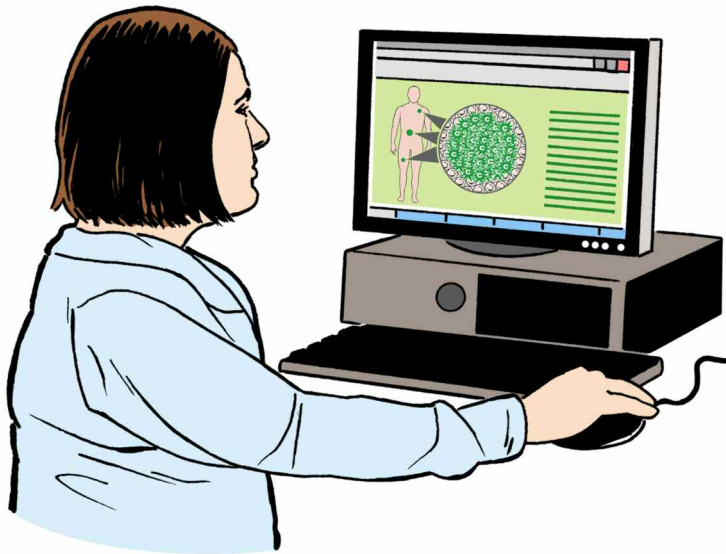
Web: www.fairadvice.org.uk/health-publications.php





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.

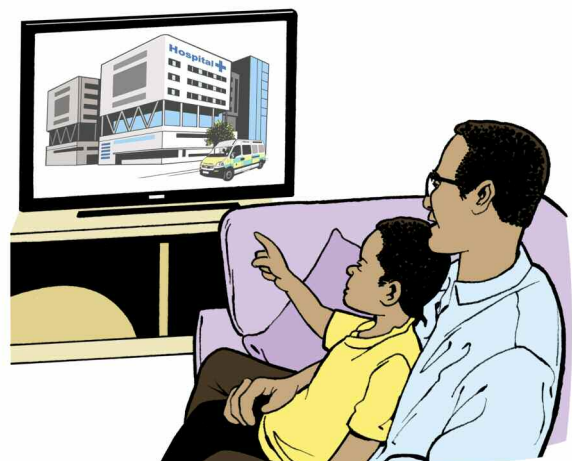
Phone: 0113 248 4997

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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