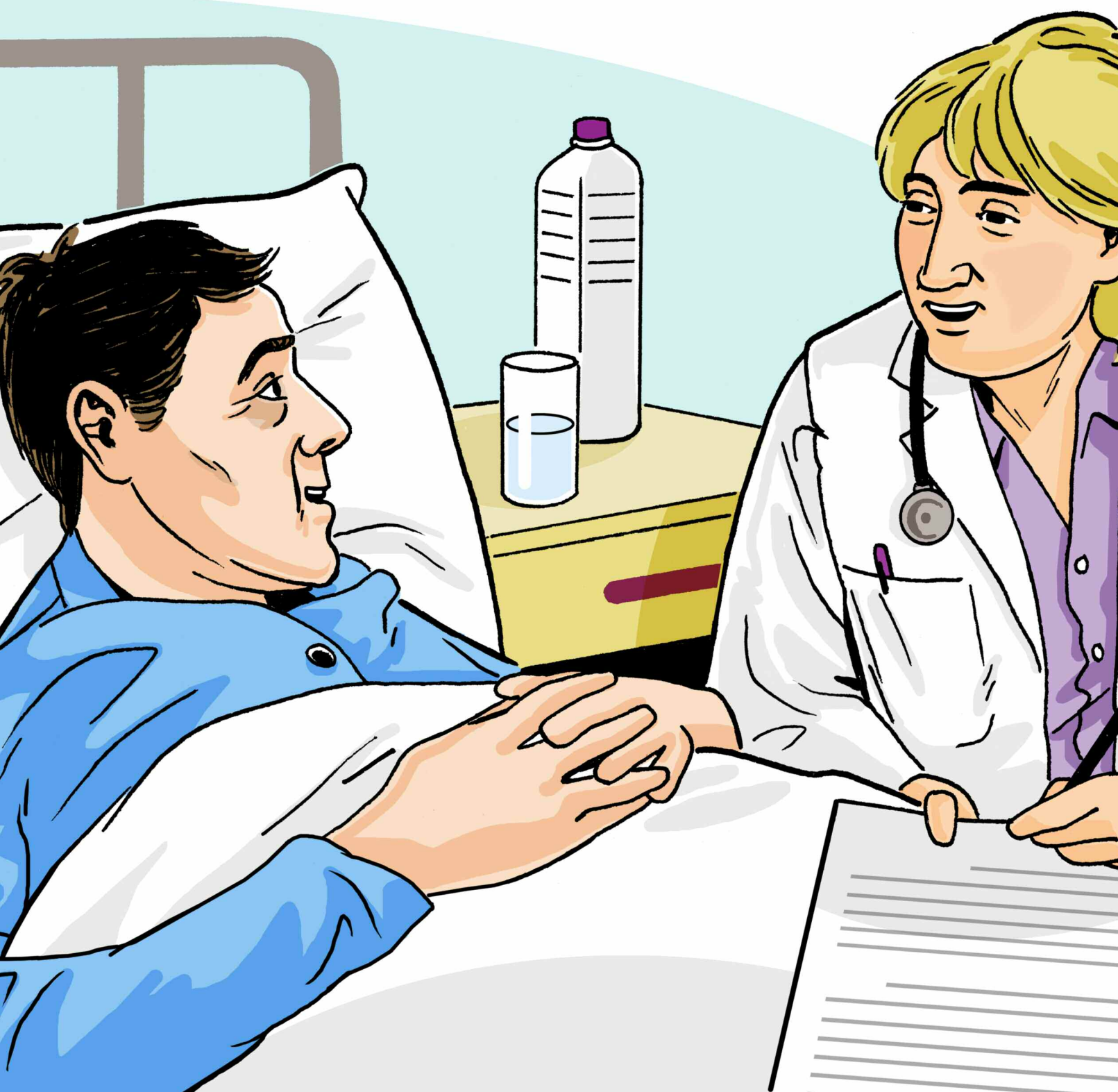


Making decisions about the future if you are dying

Palliative Care, End of Life Care and Bereavement



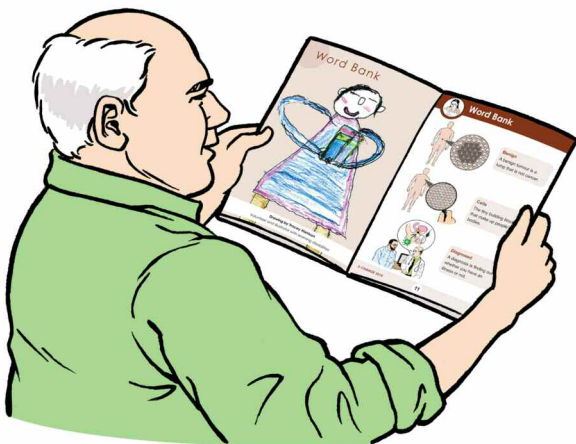
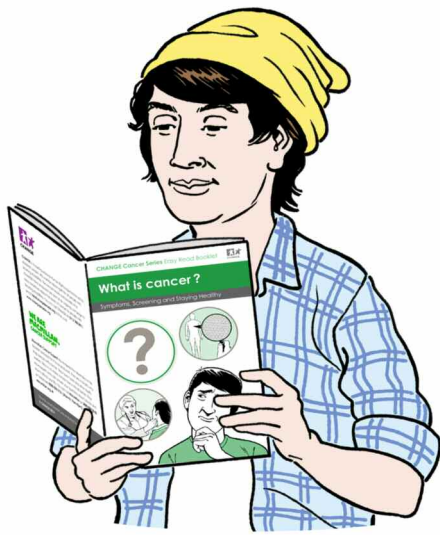
Introduction

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.

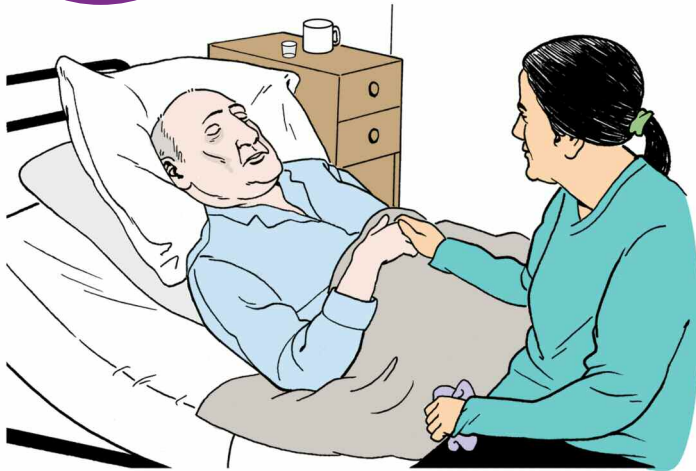
There is a Word Bank at the back of the booklet to help with hard words. Any words in **bold** you can find in the Word Bank.

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.





Making decisions about the future if you are dying



When people are dying they are sometimes too ill to make decisions anymore or let other people know what they want.



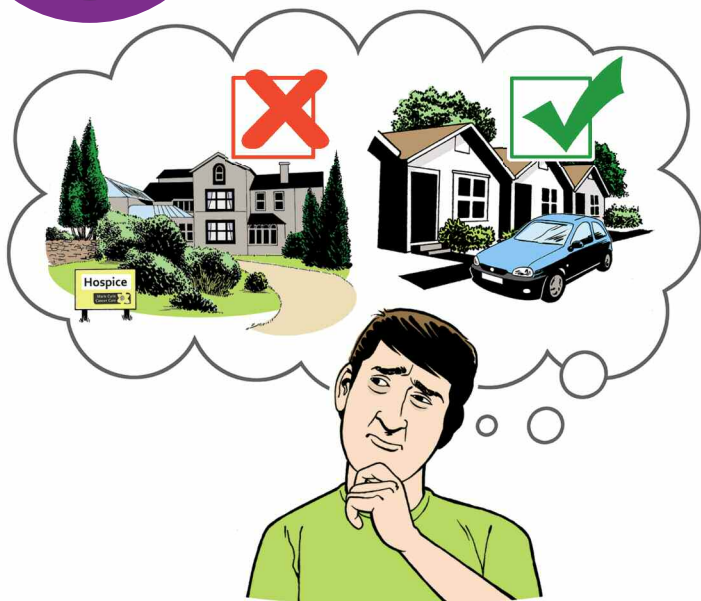
While you are still well enough, you can think about what you want for the future and make decisions now.



These can be written down so that other people know what you want. This is called an '**Advance Care Plan**'.



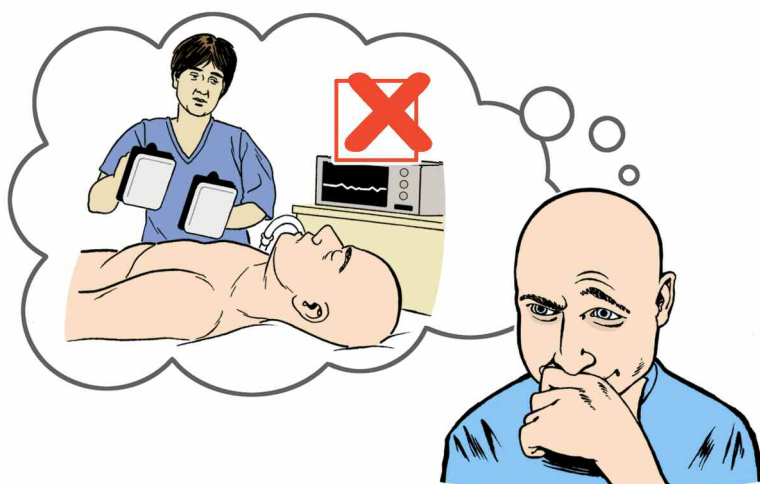
Making decisions about the future if you are dying



You can say what you want and do not want to happen. This might include things like:



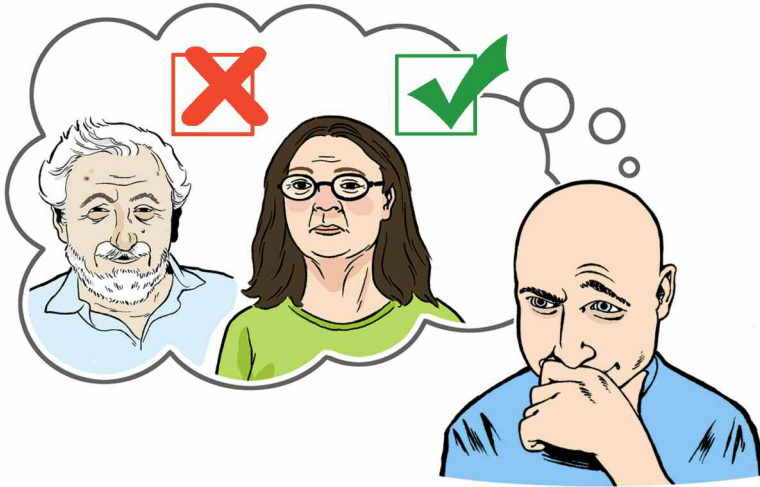
- You do not want to be taken into hospital in the last days or hours of your life.



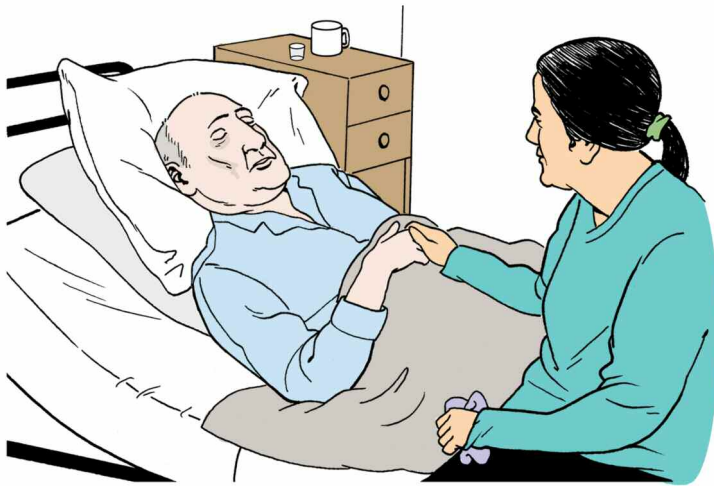
- You can decide now about your future treatment. For example, you may not want the doctor or nurse to give you treatment if you are very ill and your heart or breathing has stopped.



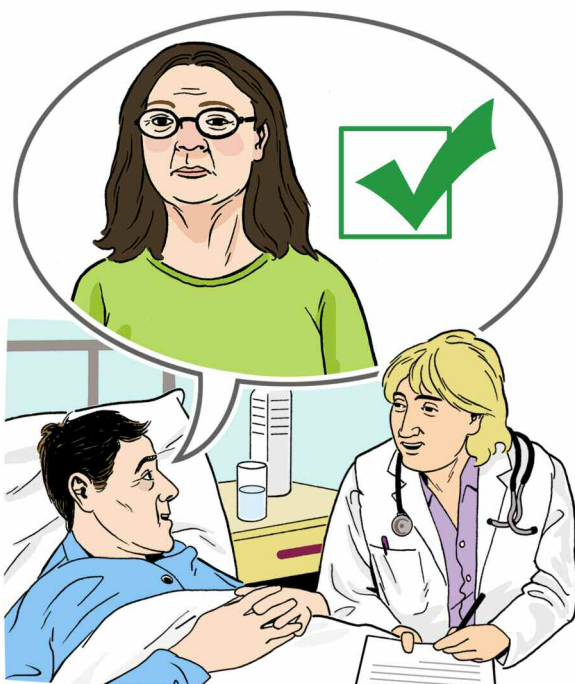
Making decisions about the future if you are dying



- You can decide who you want to be there with you when you are dying.



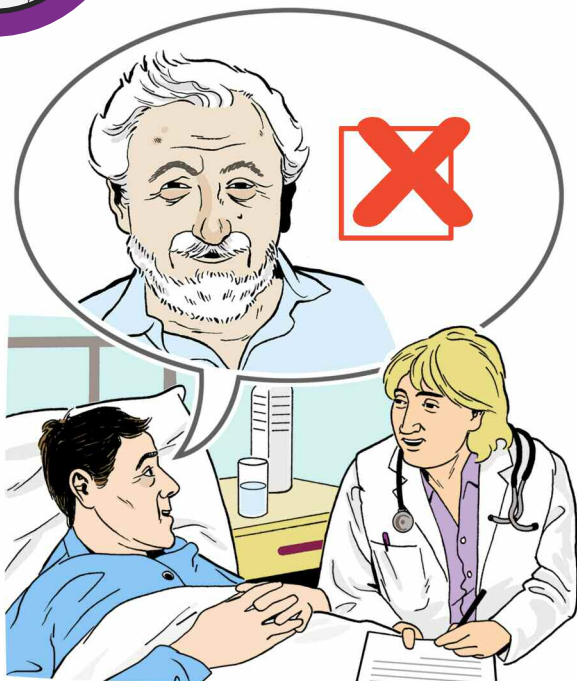
When people are dying they usually only want certain special people to be with them. This might be your partner, your family, your carer or a friend that you are close to.



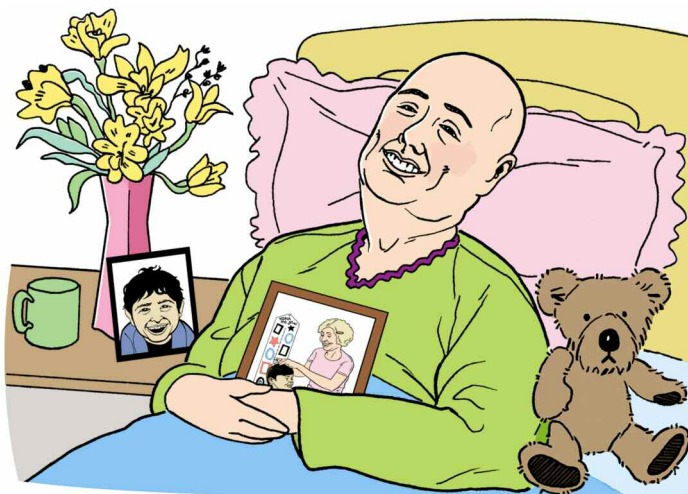
It is not always possible for all the people you want to be there, but if people know what you want then they will try to make that happen.



Making decisions about the future if you are dying



There may also be people that you do not want to be there. It is important to tell someone this.



You might want your favourite things to be near you.



You might like it if your pets come to see you.



Making decisions about the future if you are dying



- You might want people to help you look nice and dress you in clothes you like. You may not be able to do this for yourself.



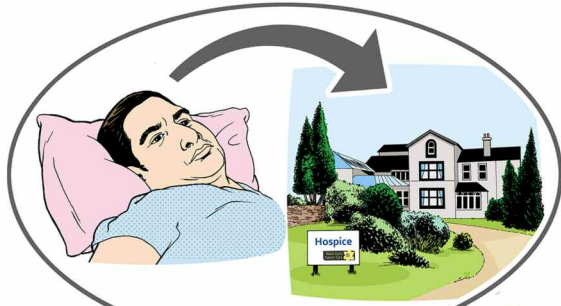
These are just examples of things you might want. Your own list of wishes may be different.



If you can't make decisions for yourself, then the people looking after you will decide about your care. Your doctor or nurse will meet with your family or a carer to make these decisions.



Making decisions about the future if you are dying



They will make decisions based on what they think is best for you.



Word Bank



Drawing by Tracey Harrison

Volunteer and Illustrator with learning disabilities

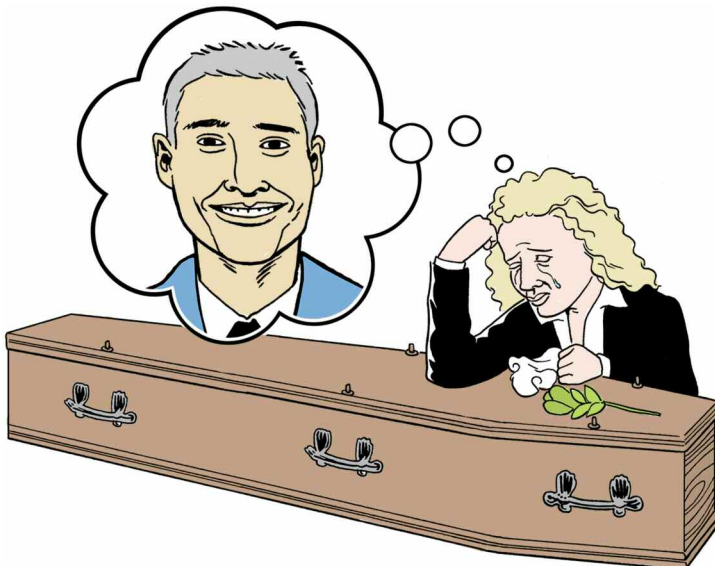


Word Bank



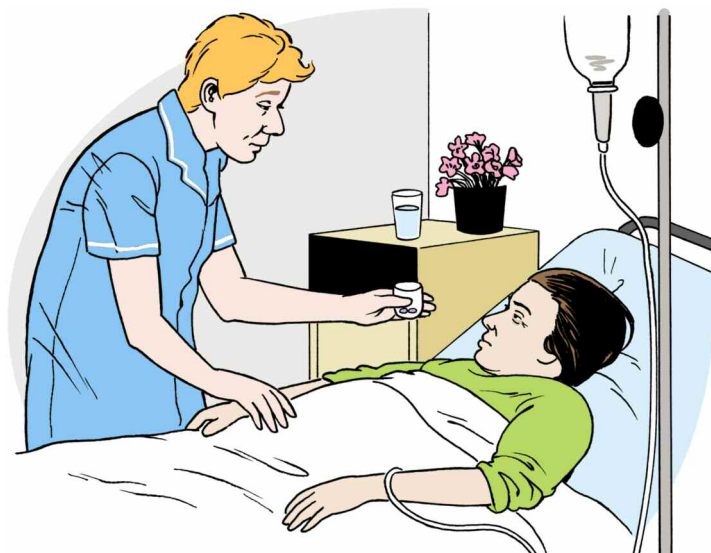
Advance Care Plan

A written plan of what you want and do not want to happen with your care. You can make this plan before you become too ill to make decisions.



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.



Word Bank

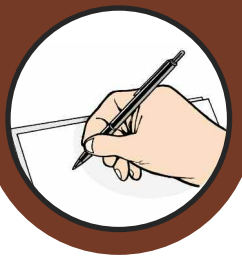


Palliative care

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.



Notes

A series of horizontal dotted lines for writing notes.

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

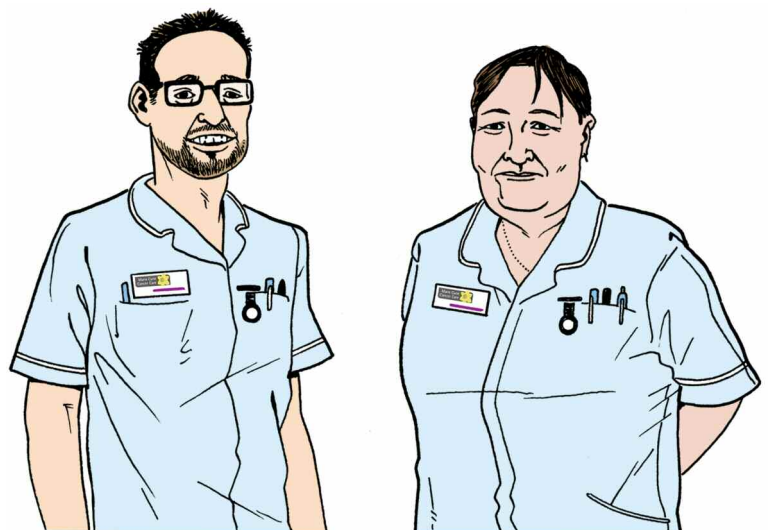
Web: www.macmillan.org.uk

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

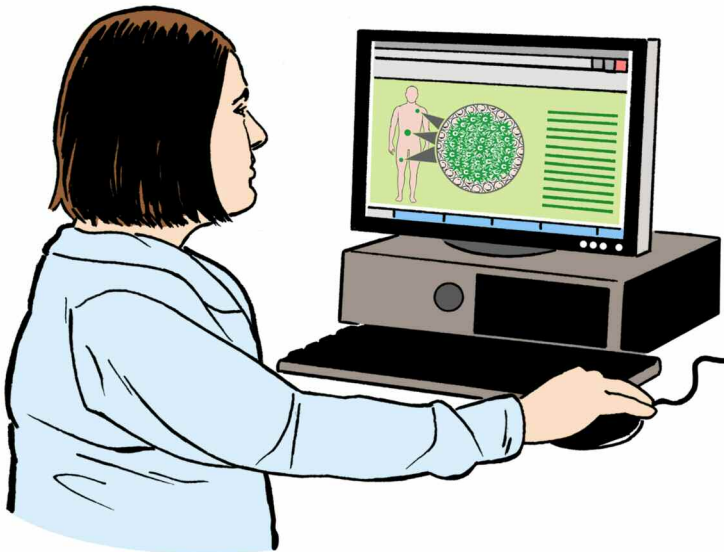
Web: www.fairadvice.org.uk/health-publications.php





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.

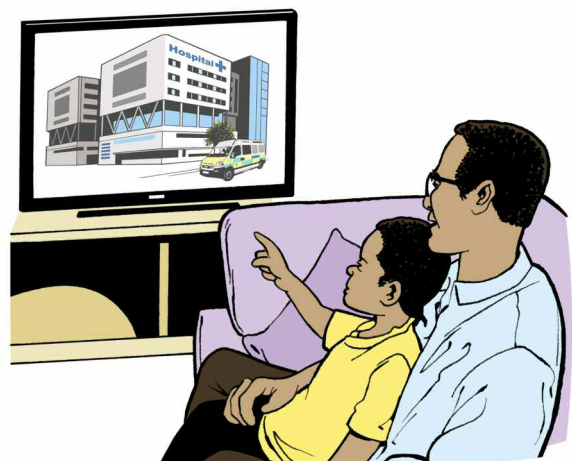
Phone: 0113 248 4997

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

© **CHANGE 2016**