

Choosing where to die

Palliative Care, End of Life Care and Bereavement



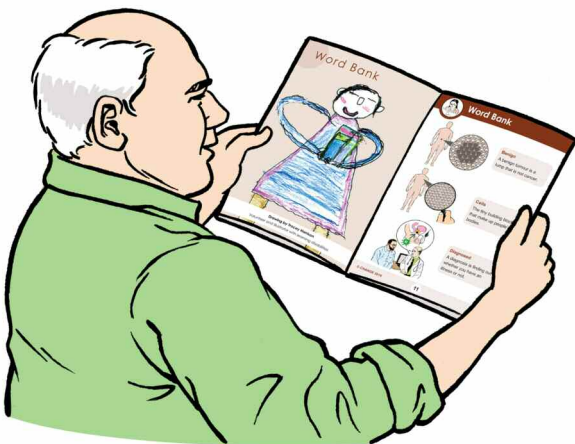
Introduction

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.

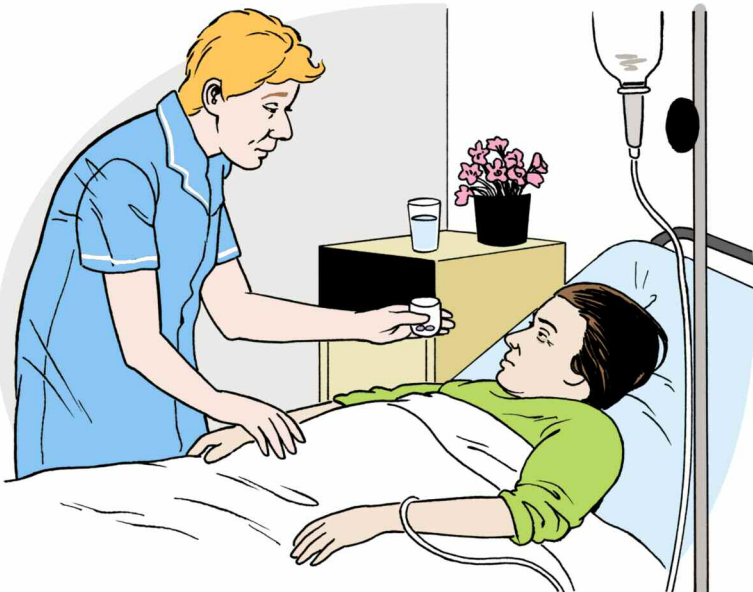
There is a Word Bank at the back of the booklet to help with hard words. Any words in **bold** you can find in the Word Bank.

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.





Choosing where to die



There are different places where people can get looked after in the last few months, weeks or days before they die. These could be:



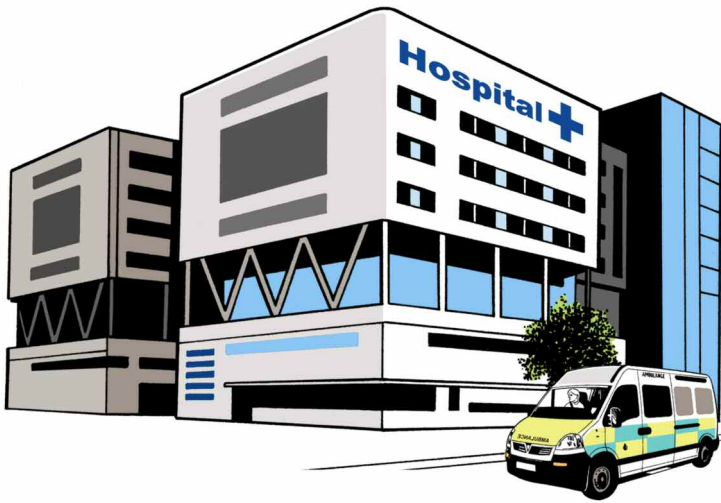
- At home



- In a hospice



Choosing where to die



- In a hospital



- In a care home

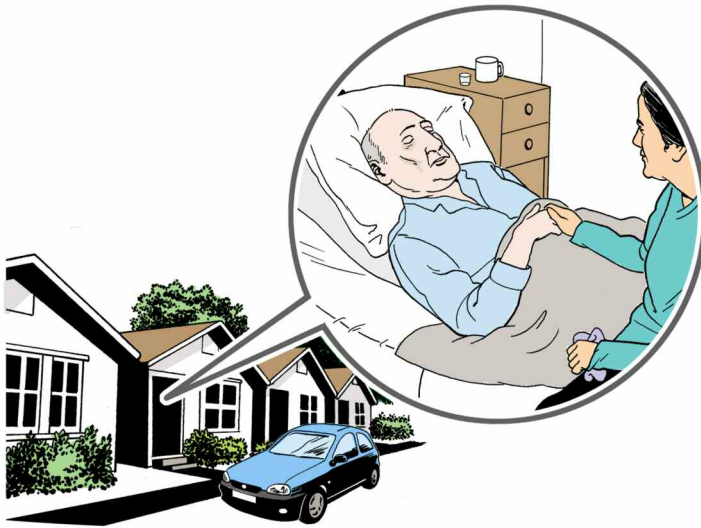


You can say where you want to die, but the place you choose might not always be possible because of the care you will need.

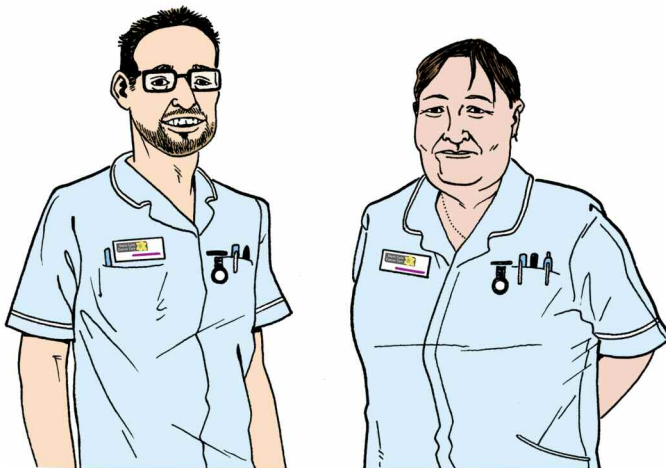


Choosing where to die

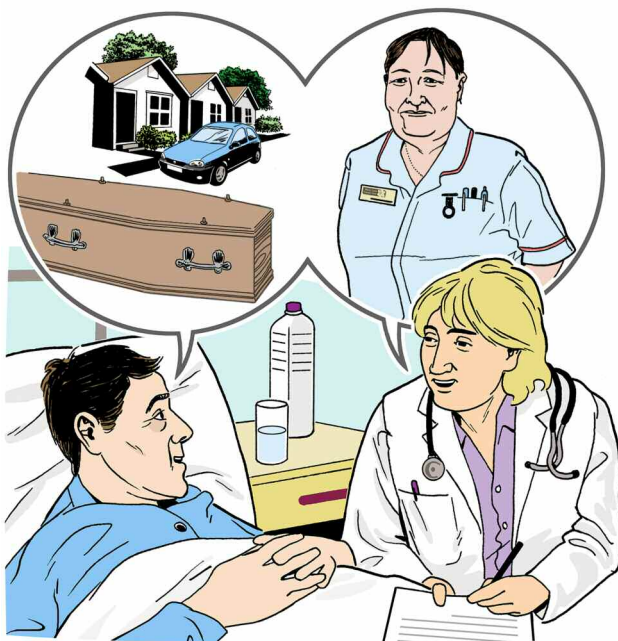
Staying at home



You should be able to die at home if you want to. There are people who can support you to do this.



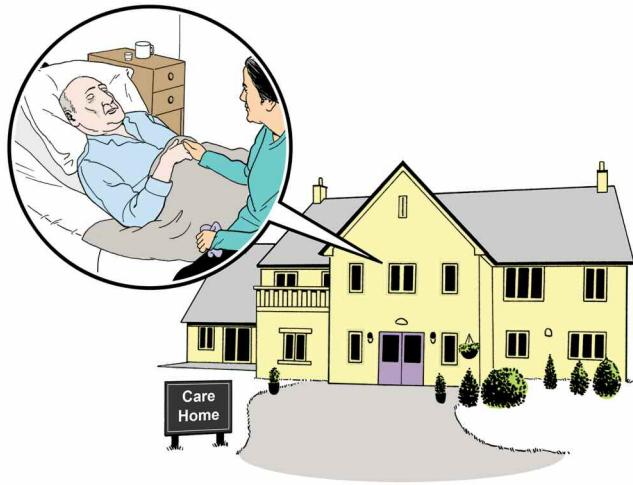
There are nurses who can help your family look after you at home.



If you live alone, it should still be possible for you to die at home if you want to. It will depend on what care you need.



Choosing where to die



Sometimes it may be easier for you to be looked after in a nursing home.



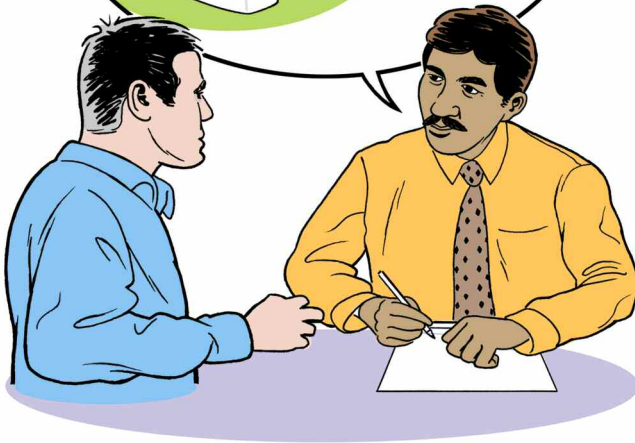
Your home can get very busy when you have lots of different people helping you every day.



Occupational therapists (OTs) can help you to live more easily in your own home.



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For example, they can arrange for you to have handrails in the bathroom so you can get in and out more easily.

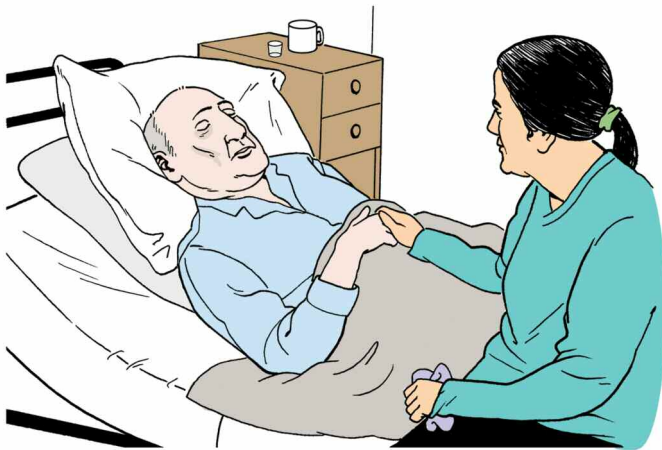
Living in a shared house



You may live in a shared home with other people with learning disabilities.



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This is your home, so you should be able to stay there to die if you want to.



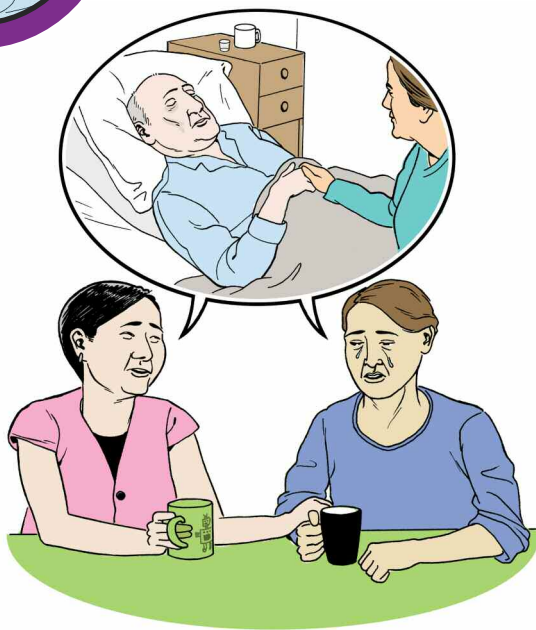
Your carers can get help from nurses to look after you.



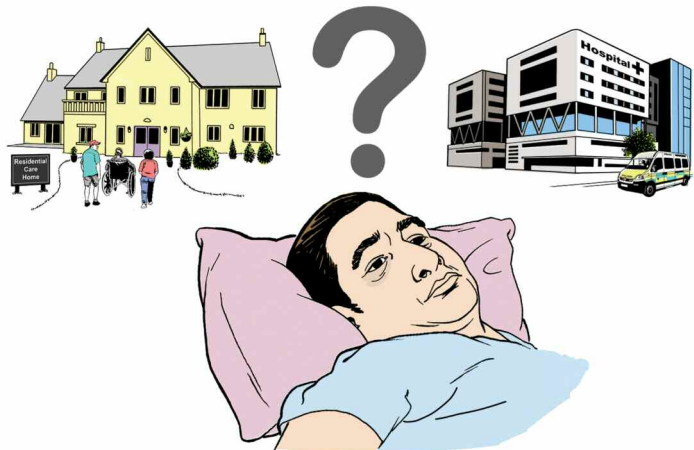
Your carers can get help so that they know the best way to look after someone who is dying.



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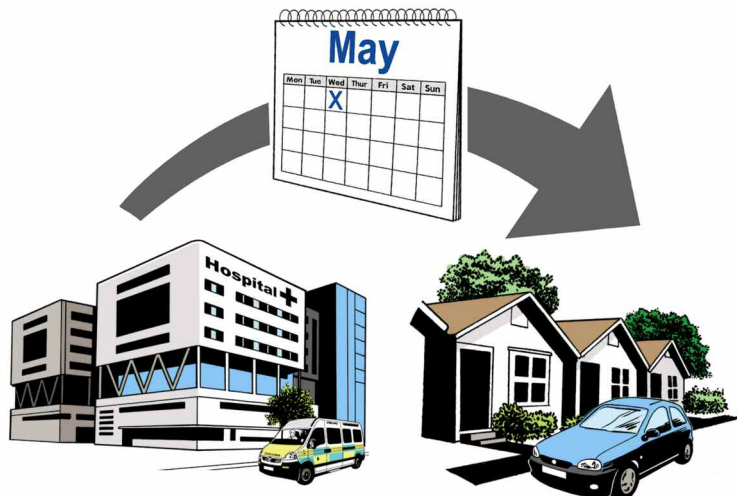


Your carers can support the other people who live with you as well.



Sometimes it won't be possible to look after you at home until you die. It depends on the kind of care you need.

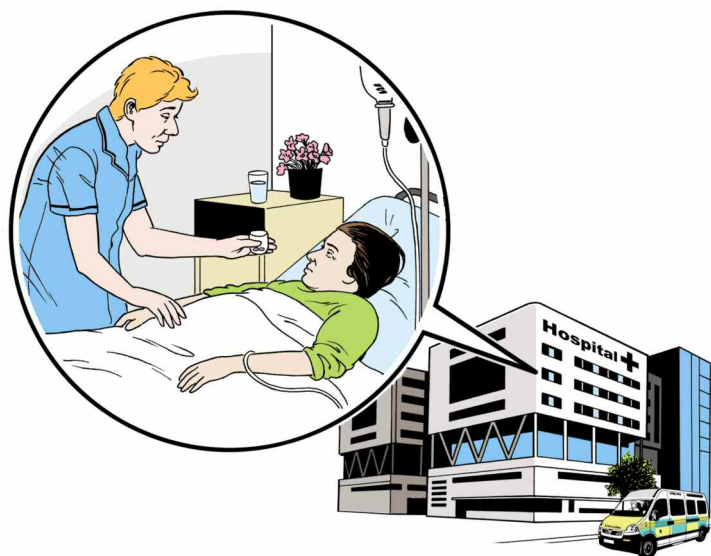
Hospitals



You may need to go to hospital if your illness causes problems. You might go in for a short time for some treatment and then come home again.



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Some hospitals have wards called **palliative care** units where the nurses are experts in looking after people who are dying.

Nursing and residential care homes



If someone needs nursing care day and night they might need to move to a nursing home to get the care they need.

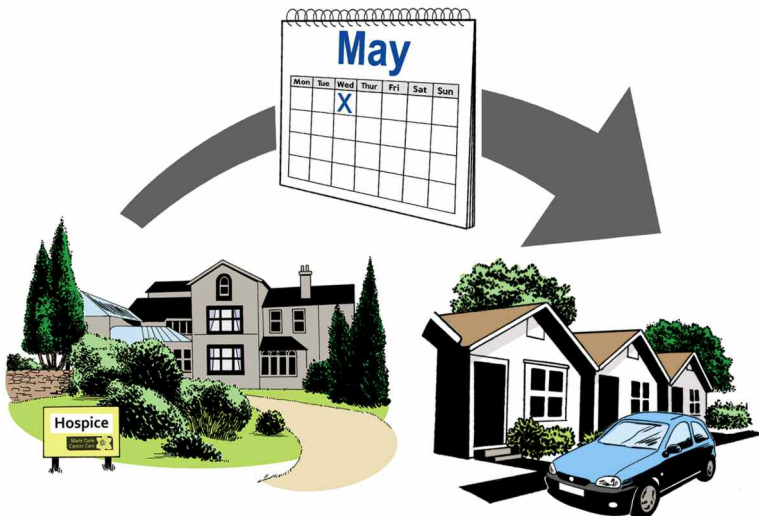


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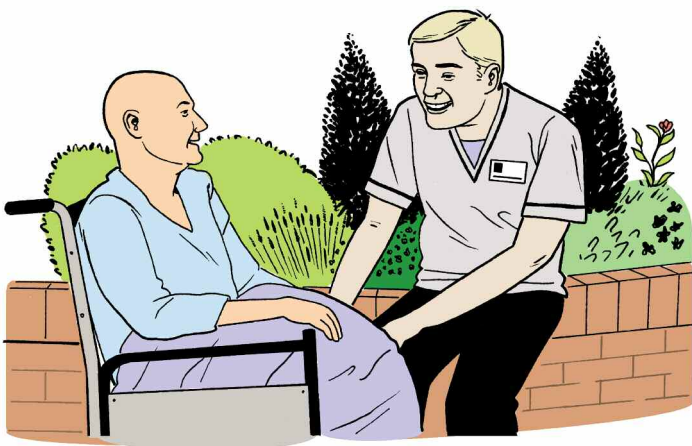
Hospices



Hospices are places that give help and care to people who have an illness or are dying. Hospices also help the person's family and carers.



Some people go to a hospice for a short time for treatment and then go home again.



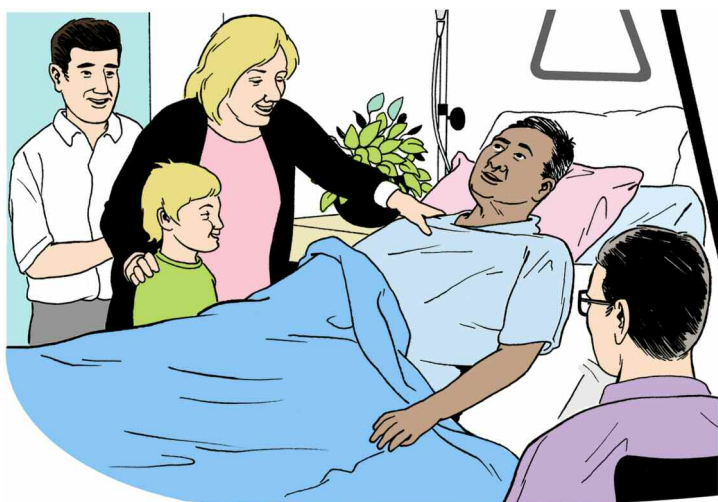
Hospices are smaller and quieter than hospitals. They are more friendly and more like a home.



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The hospice staff are experts at helping people stay as comfortable as possible while they are ill and dying.



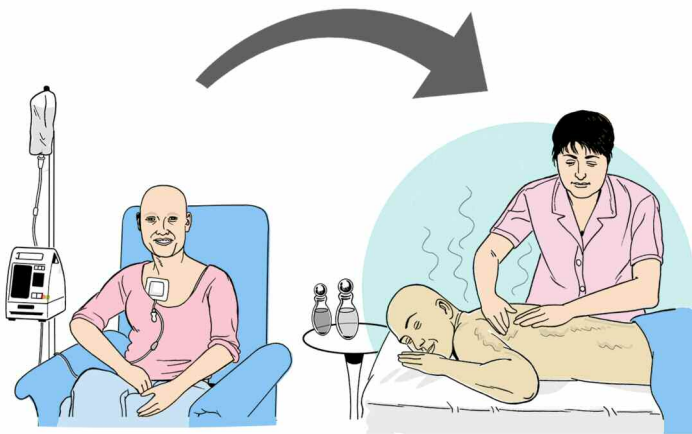
Your family and friends can still be around you as much as you need.



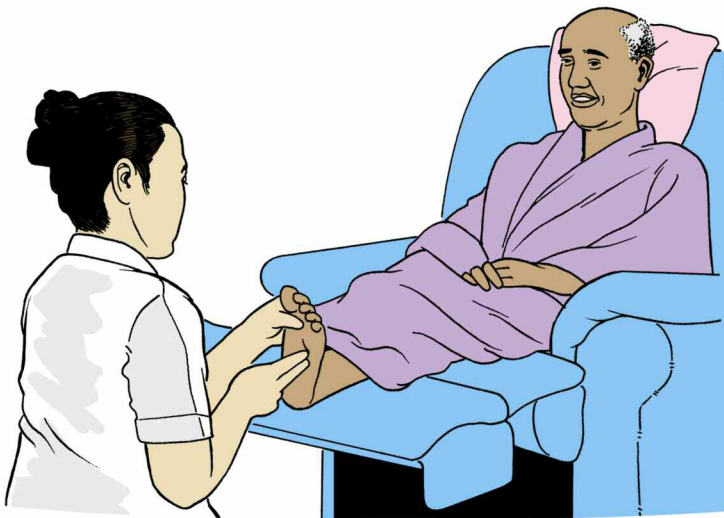
Hospices sometimes give other types of support like **complementary therapies**.



Choosing where to die



Complementary therapies are different types of treatments. They do not treat cancer but they can make you feel better.



Complementary therapies can help you to:

- Feel more relaxed and less **stressed**



- Feel less **depressed** or sad



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- Sleep better



- Reduce **symptoms**, like pain, feeling sick, or **constipation**



- Reduce some of the **side effects** of your cancer treatment

Word Bank

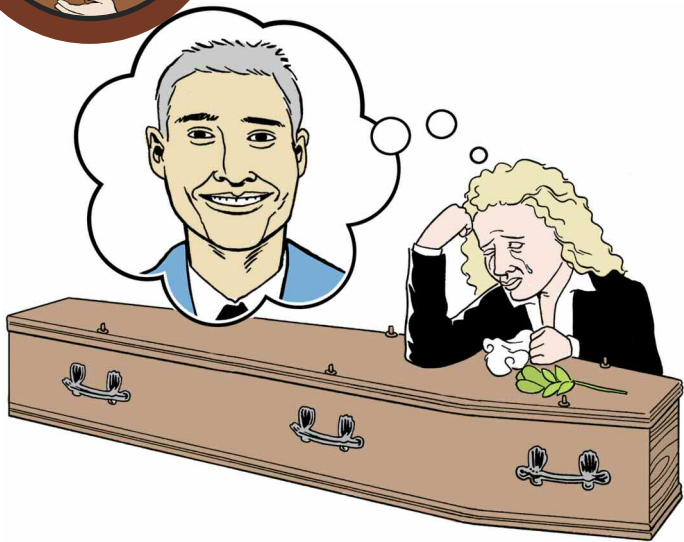


Drawing by Tracey Harrison

Volunteer and Illustrator with learning disabilities

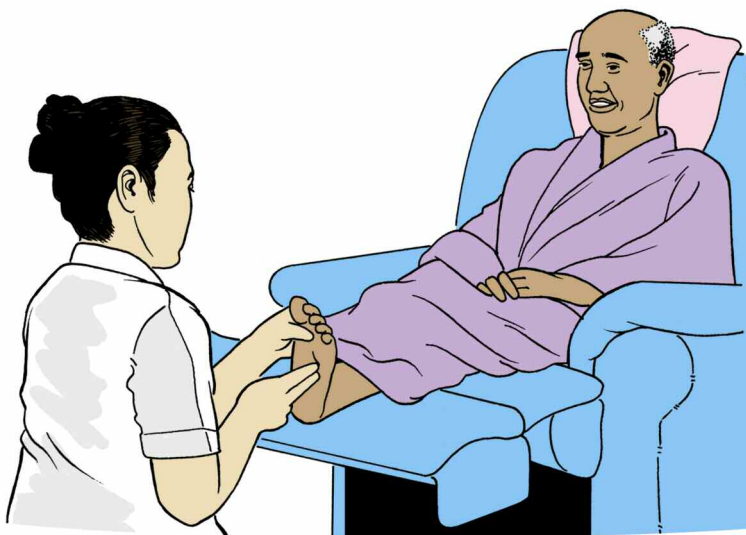


Word Bank



Bereavement

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



Complementary therapies

These are types of treatments such as massage, yoga, aromatherapy, reflexology and acupuncture. You may have them as well as your main cancer treatment.

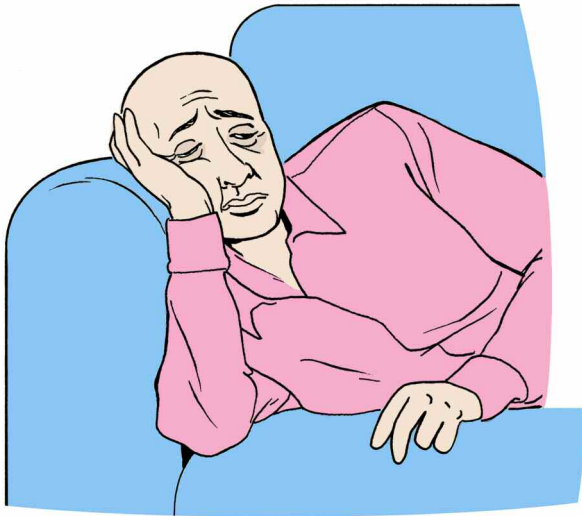


Constipation

Finding it hard to poo.

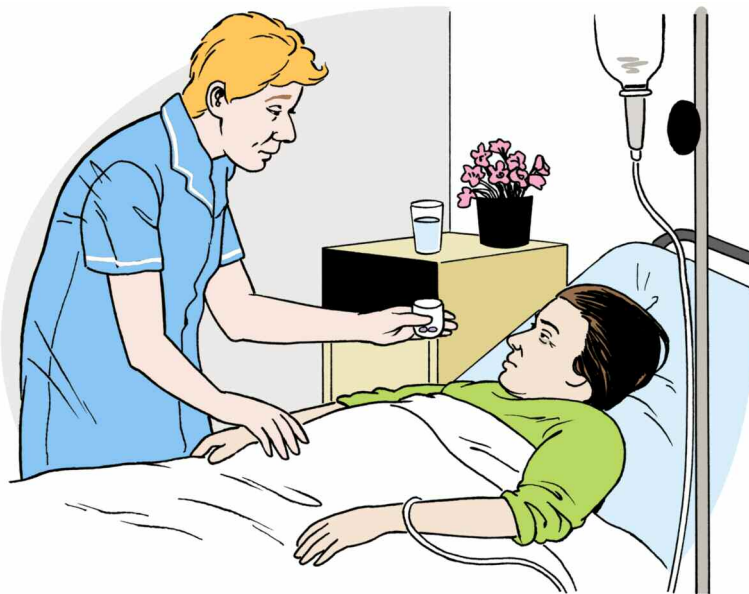


Word Bank



Depressed

When a person feels very sad and this sadness means day to day living is hard.



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.



Hospice

A home that gives care to people who are sick or very ill and expected to die.

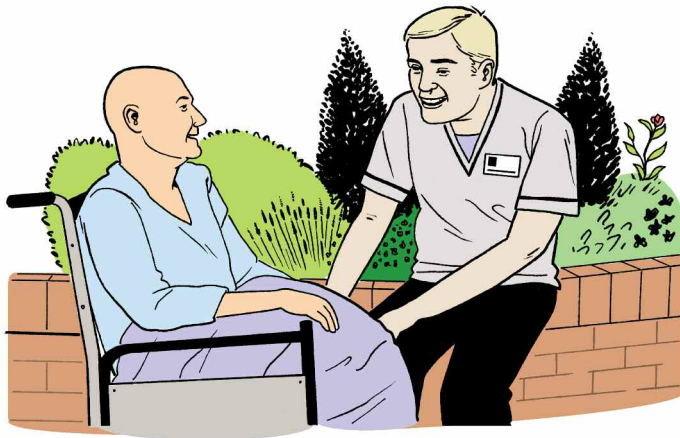


Word Bank



Occupational therapist

This is a professional who helps people who are too ill to do their usual daily activities.



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.

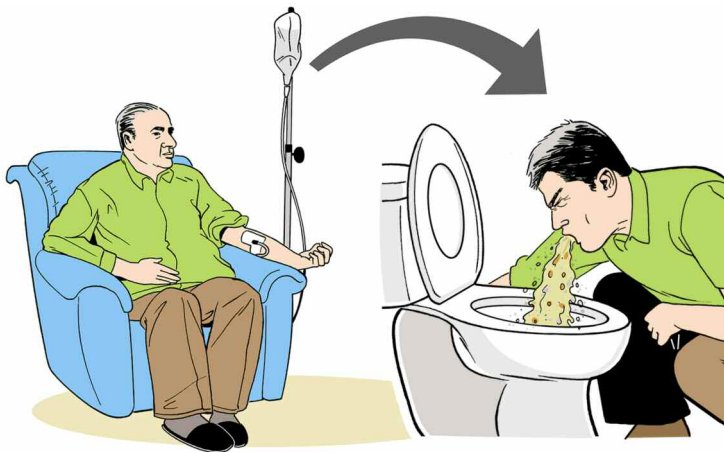


Word Bank



Residential care homes

A home where people live for a short or long time. They give people meals and personal care such as help with washing and eating.



Side effects

These are unwanted effects caused by having treatment, like feeling tired or sick.

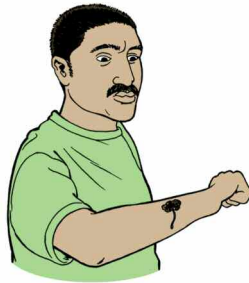


Stressed

When your mind and body feel bad due to worrying about something.



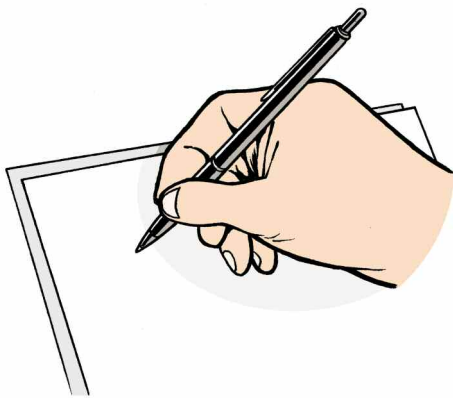
Word Bank



Symptoms

Symptoms are problems in your body caused by the illness.

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

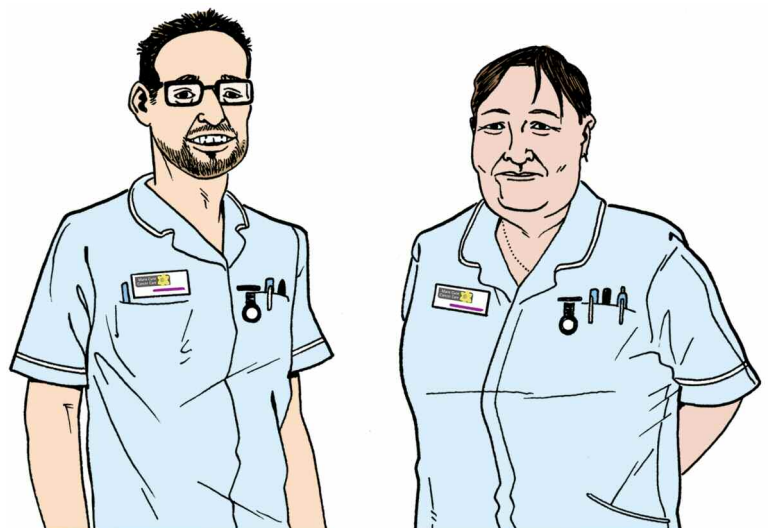
Web: www.macmillan.org.uk

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

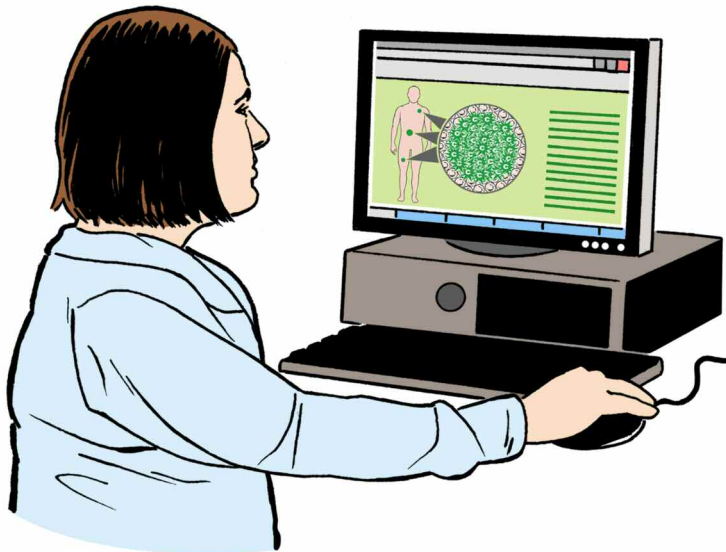
Web: www.fairadvice.org.uk/health-publications.php





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.

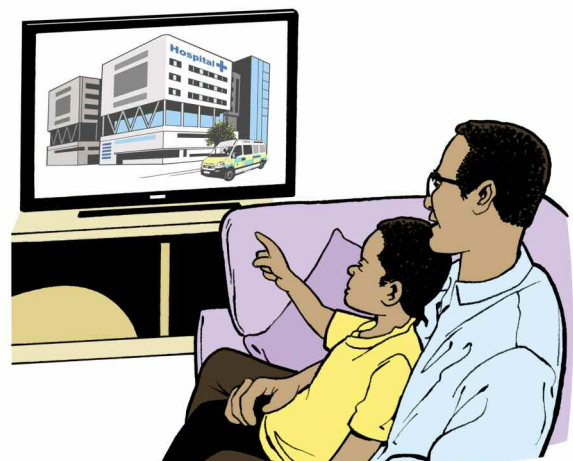
Phone: 0113 248 4997

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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