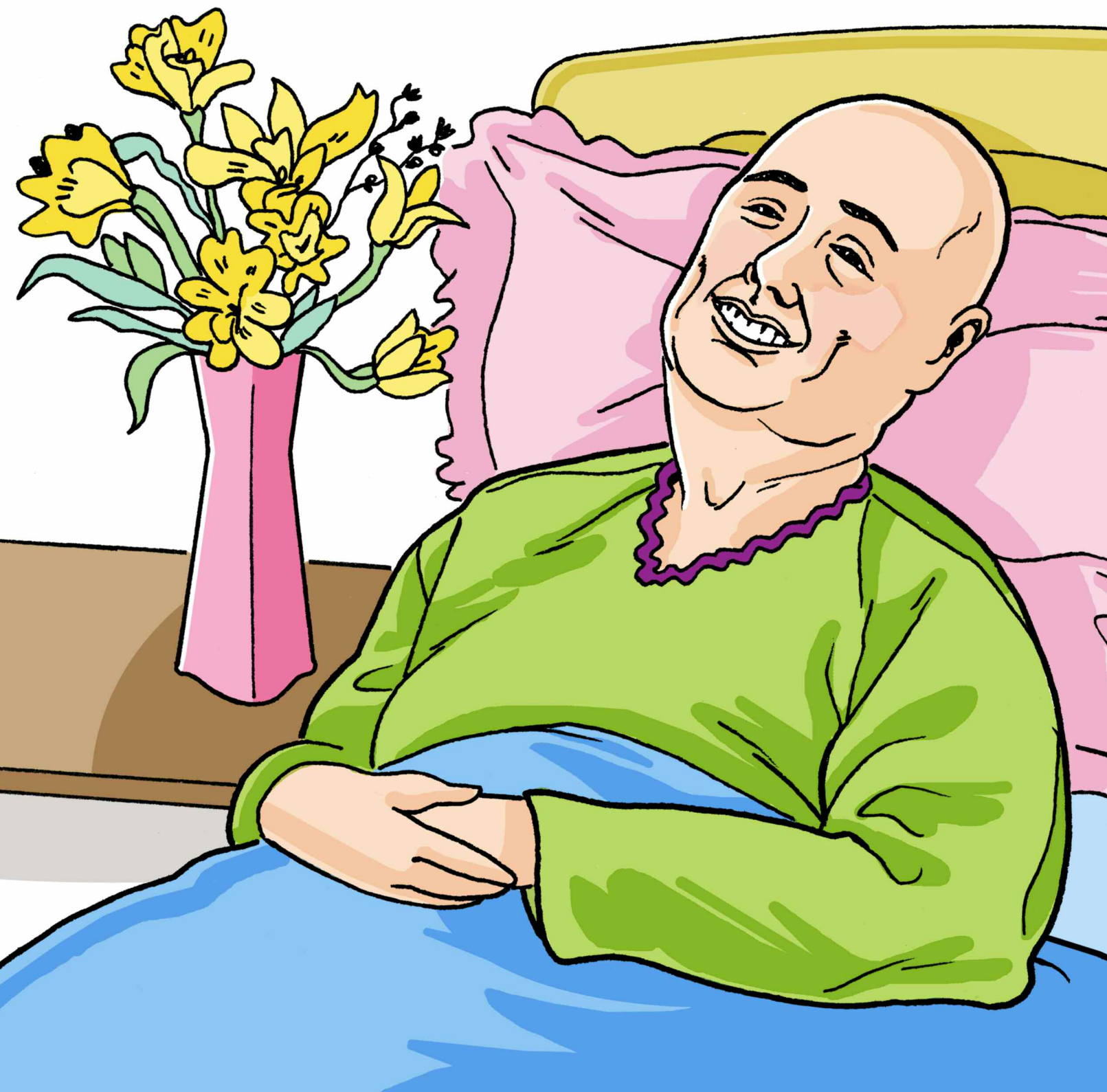


Changes that can happen at the end of life

Palliative Care, End of Life Care and Bereavement



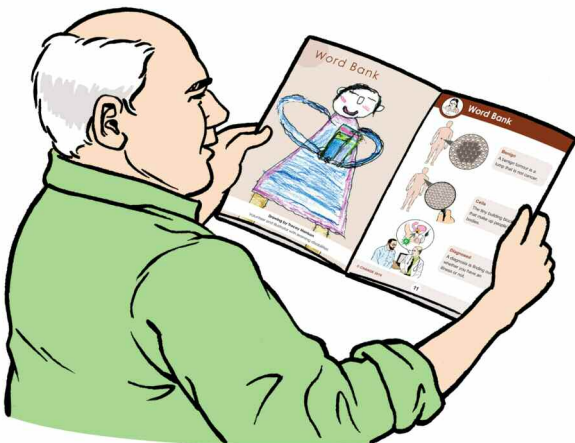
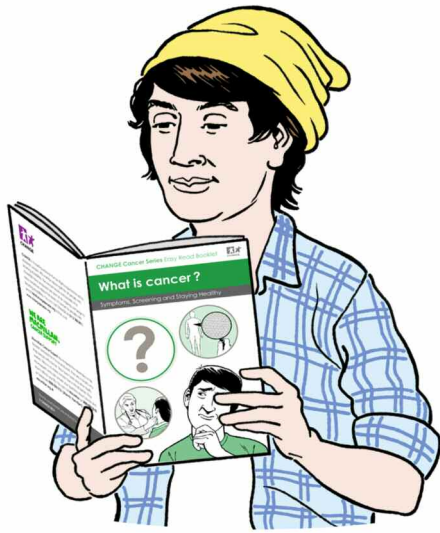
Introduction

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.

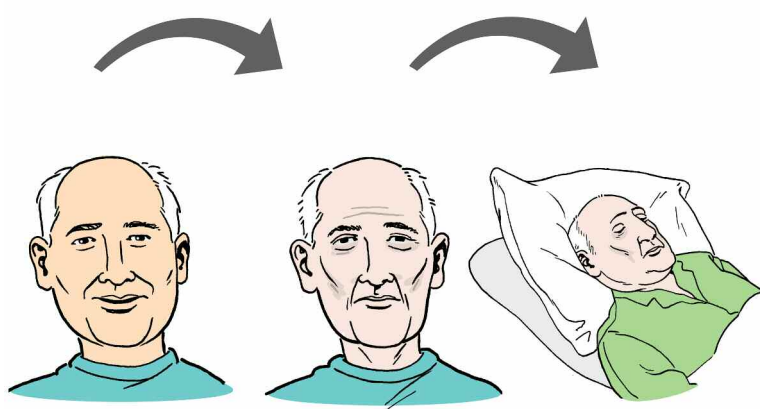
This booklet can help you learn about cancer. But this is not the same as talking to your doctor. If you are worried about your health, you should talk to a doctor or nurse.





Changes that can happen at the end of life

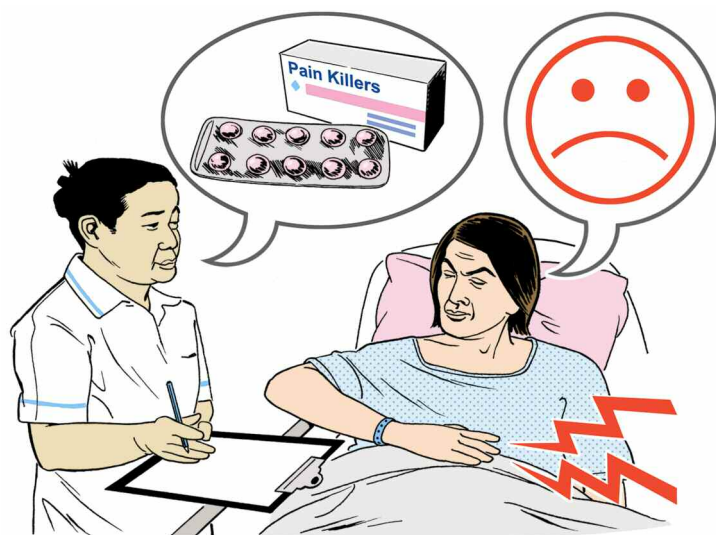
Changes that can happen as you become more ill



When someone has an illness that isn't going to get better, the illness becomes worse over time and causes changes in their body.



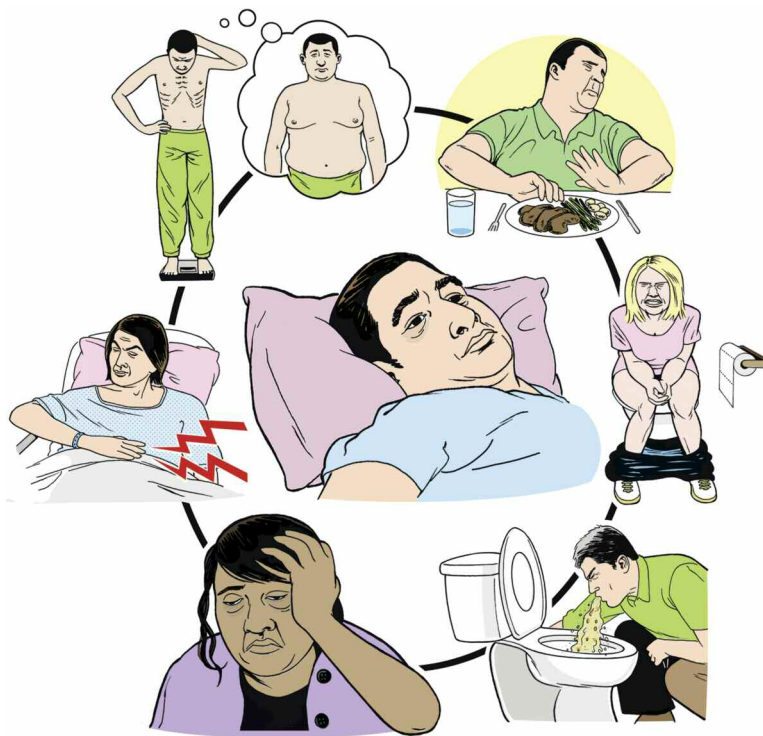
Doctors and nurses will try to make sure the person is as comfortable as possible during these changes. This is called **palliative care**.



They may give treatments or medicines that aren't going to cure the illness but will help with any problems caused by the illness.

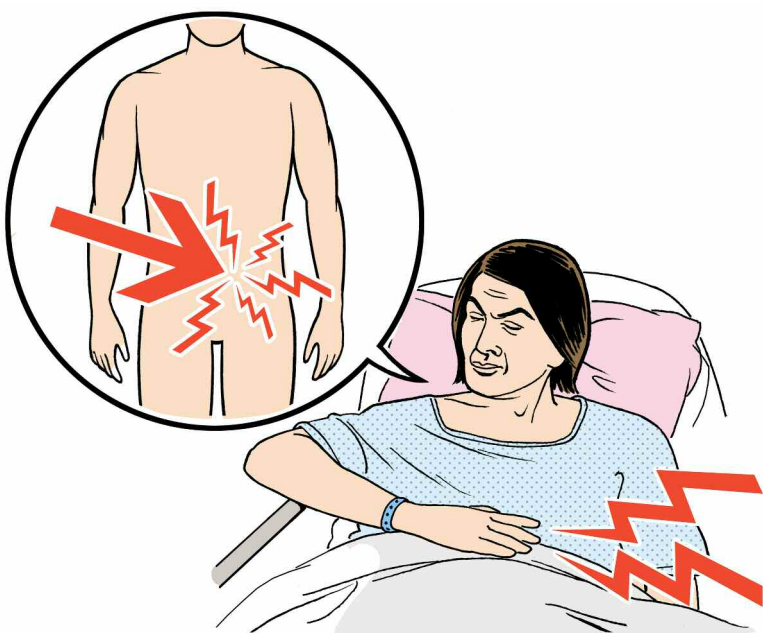


Changes that can happen at the end of life



Problems caused by the illness are called **symptoms**.

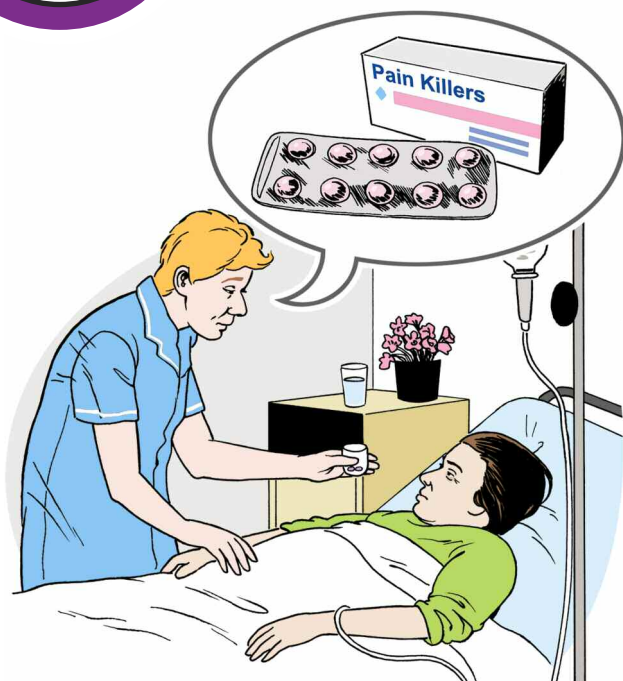
Symptoms that you may have



Pain

If you are in pain it is important to try to explain where the pain is and how bad it is.

Changes that can happen at the end of life

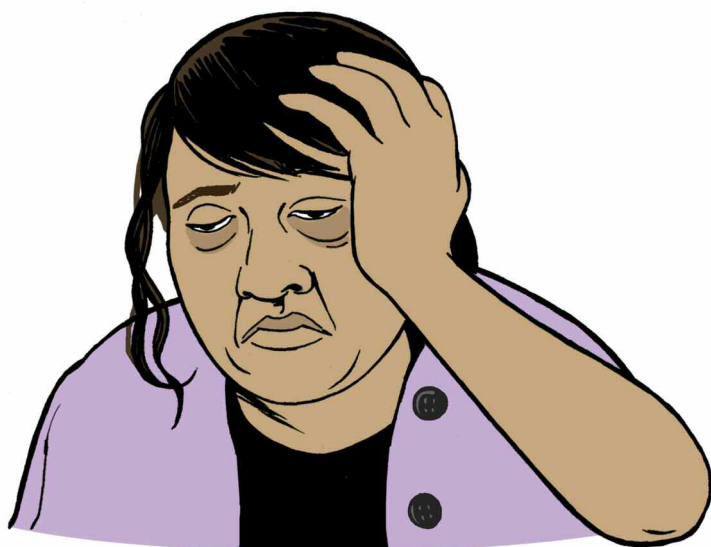


Then the nurse can give you the best medicine for your pain.



There may be some side effects from strong pain medicines.

Some of these can be:



- **Drowsiness**
Drowsiness is when you feel sleepy.



Changes that can happen at the end of life



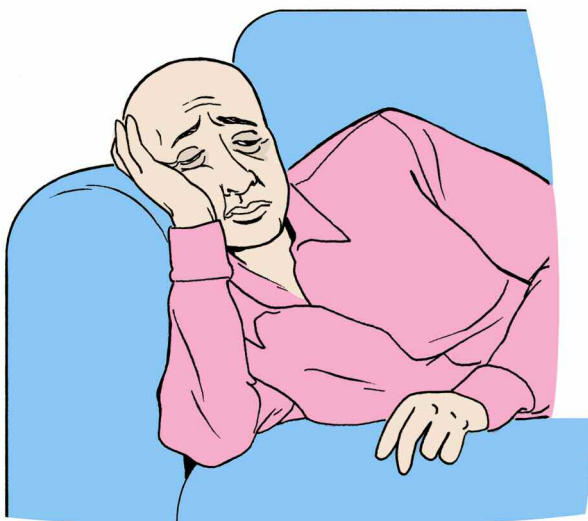
- **Sickness**

There are some medicines that can help stop this. Ask your doctor about this.



- **Constipation**

This means you find it hard to poo. Your nurse or doctor will give you medicine to help.



Tiredness

As people get more ill they lose energy and become tired and weak.

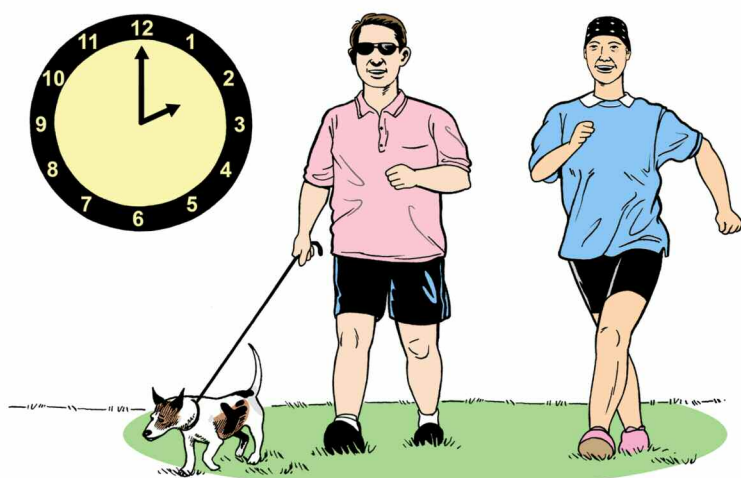
Changes that can happen at the end of life



If you are feeling very tired you might find it hard to do all the things you used to do. It is important you only do as much as you feel like doing.



Rest as much as you need to. You may feel like you want to sleep a lot even in the daytime.



You may find there are times of the day when you feel less tired. You might want to use these times to do some of your favourite things.

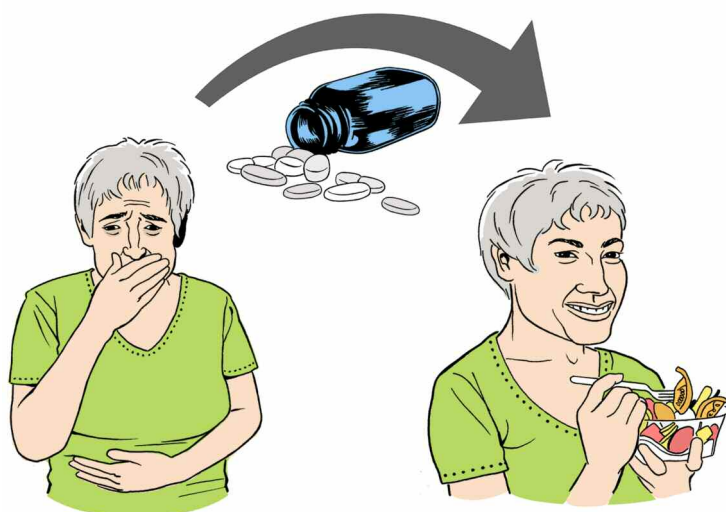


Changes that can happen at the end of life



Feeling sick

Your illness may be making you feel sick. Sometimes the medicines you are taking can make you feel sick.



If you are feeling sick or being sick, the doctor can give you some medicines to help.



Losing your appetite

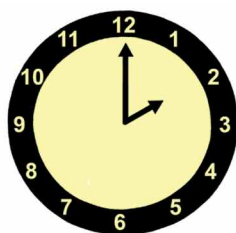
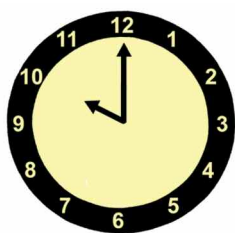
Losing your **appetite** means you do not feel like eating.



Changes that can happen at the end of life

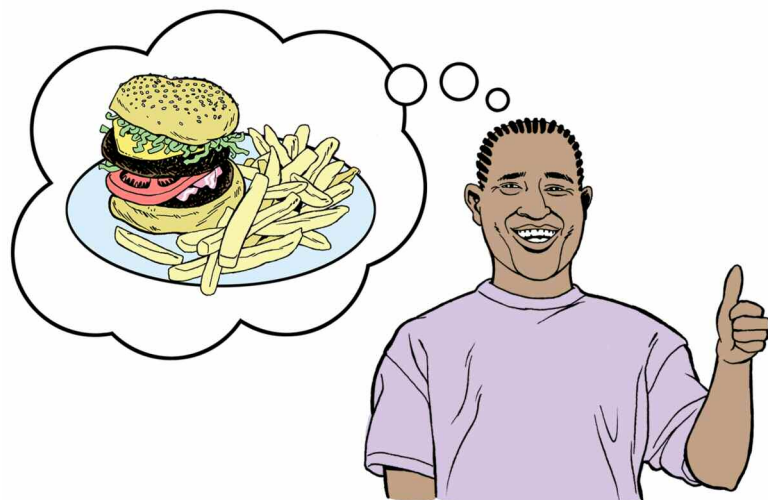


This might be because of your illness or because of the medicines you are taking.



It could be helpful to:

- Eat when you want to



- Only eat things you feel like eating



Changes that can happen at the end of life



- Eat small amounts or snacks

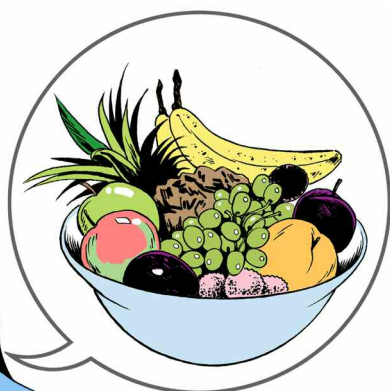


- Have **nourishing** drinks or liquid meals



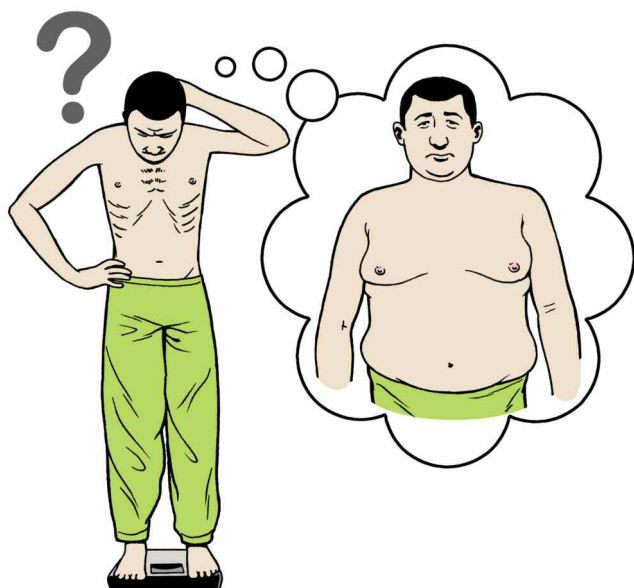
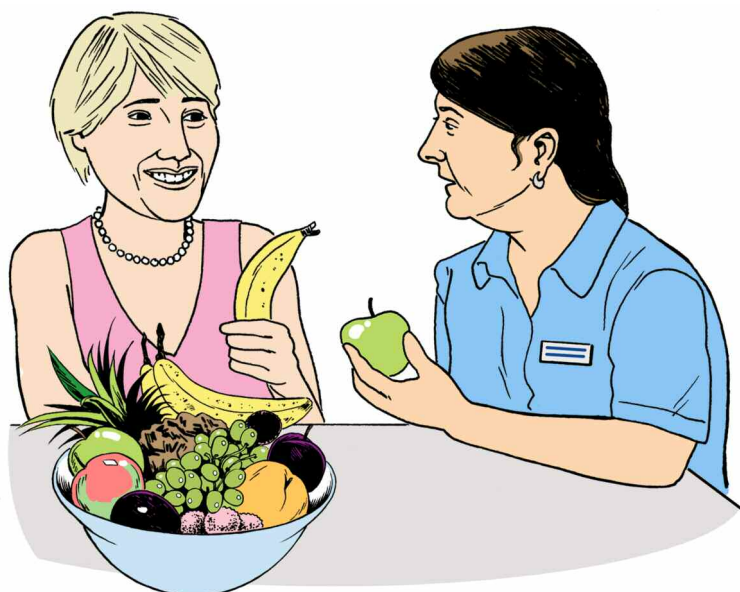
- If you have a dry mouth but do not feel like drinking then you can try sucking ice or ice lollies to keep your mouth wet. Pieces of fruit work too.

Changes that can happen at the end of life



A **dietitian** is a person who knows about food and eating. They will help you find the best foods to eat.

They will also help if you have problems with eating and drinking. Someone called a **speech and language therapist** can also help with this.



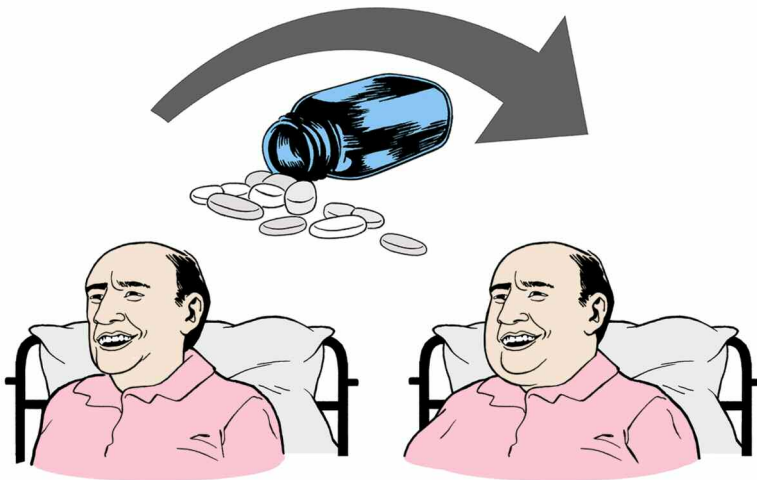
Changes in your weight

As you become more ill your body may lose weight and you can become thinner. This can be because of the cancer or because you are eating less.

Changes that can happen at the end of life



Sometimes people who are eating well can still lose weight. This is because of their illness.



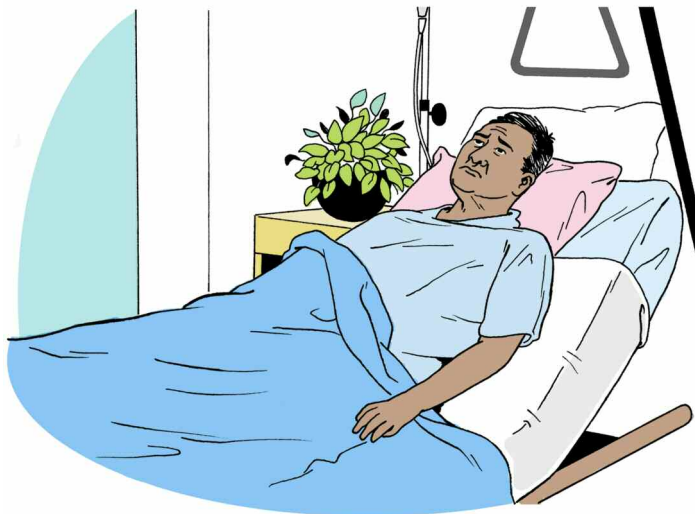
Some people put on weight because of their illness. Some medicines can also make you put on weight.



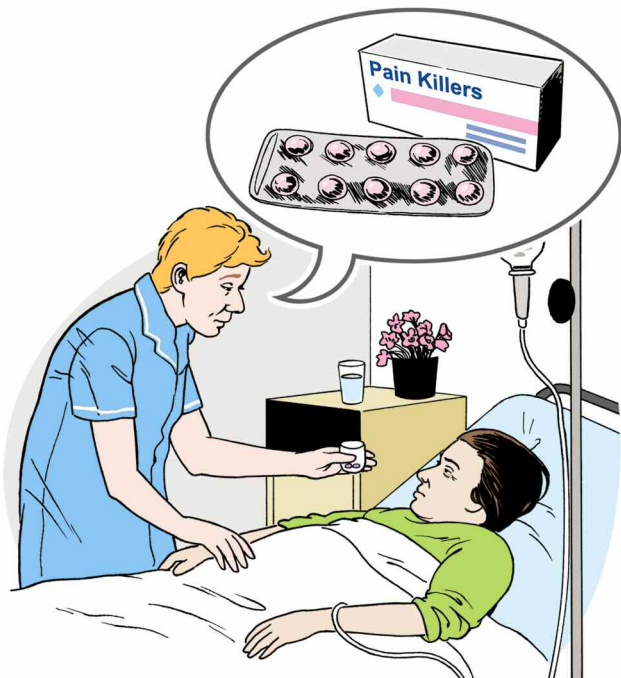
Constipation

Constipation means you may find it hard to poo.

Changes that can happen at the end of life



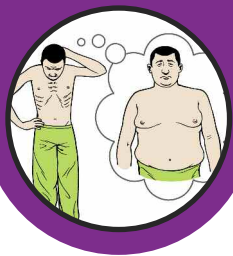
Constipation can become a problem as you become more ill. It can happen if you are not moving around as much anymore.



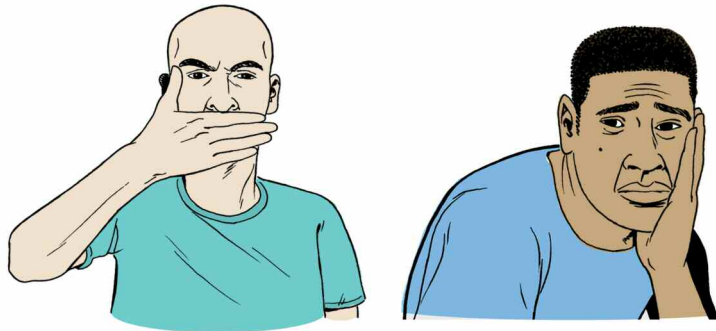
Or it can be caused by pain medicines.



You may also not be eating or drinking much. The doctor or nurse can give you medicines called **laxatives** to help you go to the toilet more easily.

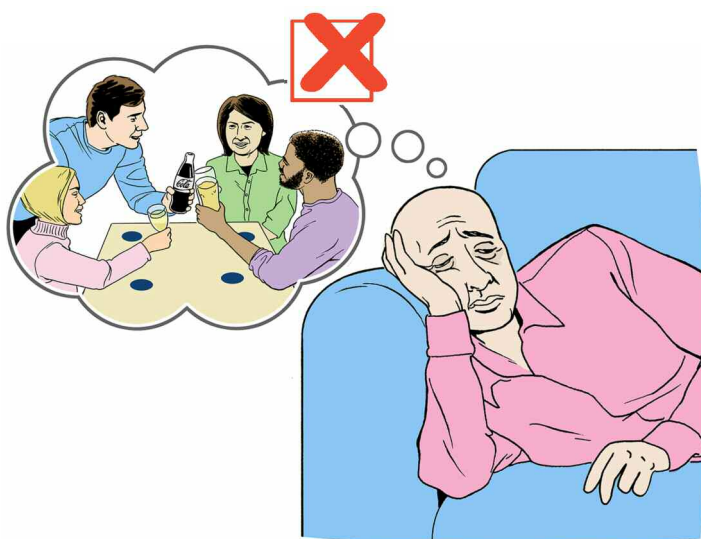


Changes that can happen at the end of life

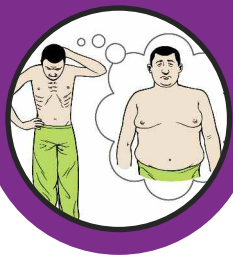


Changes in how you feel

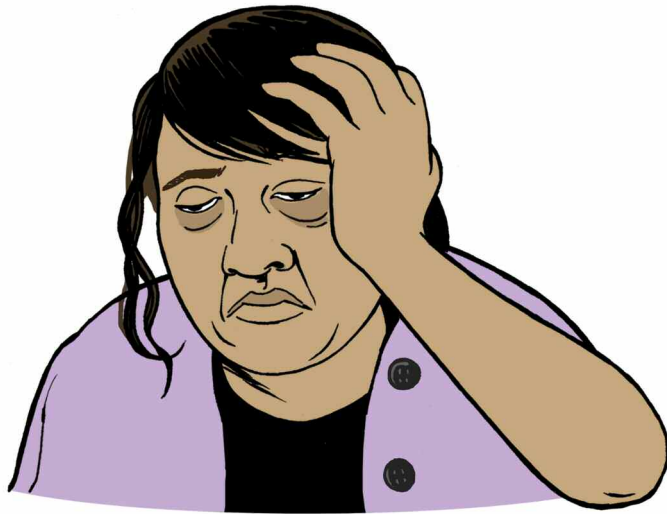
Becoming more ill can also affect how you feel.



You might feel that you are not interested in anything anymore, even things that used to be important to you.



Changes that can happen at the end of life



You may not want to do anything at all because you feel so tired. You may not even want to talk.



This is OK. But if you are feeling very sad, try talking to someone you trust. This can help.

Word Bank



Drawing by Tracey Harrison

Volunteer and Illustrator with learning disabilities

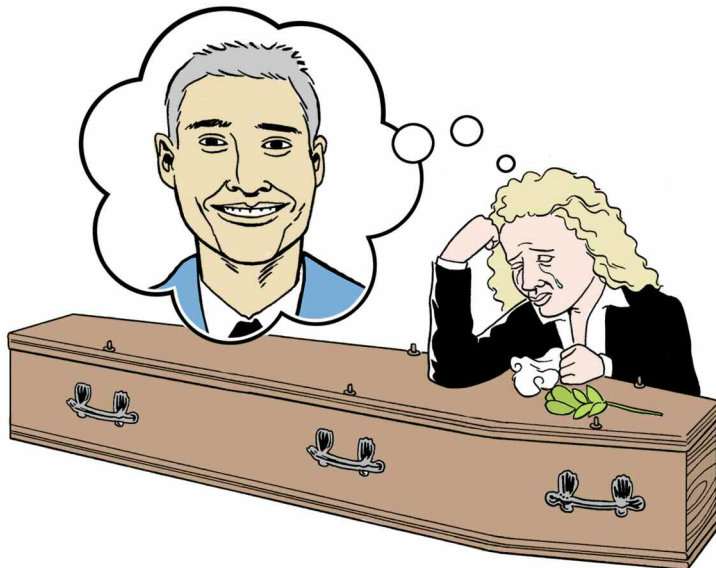


Word Bank



Appetite

Your appetite is how much you want food or drink.



Bereavement

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

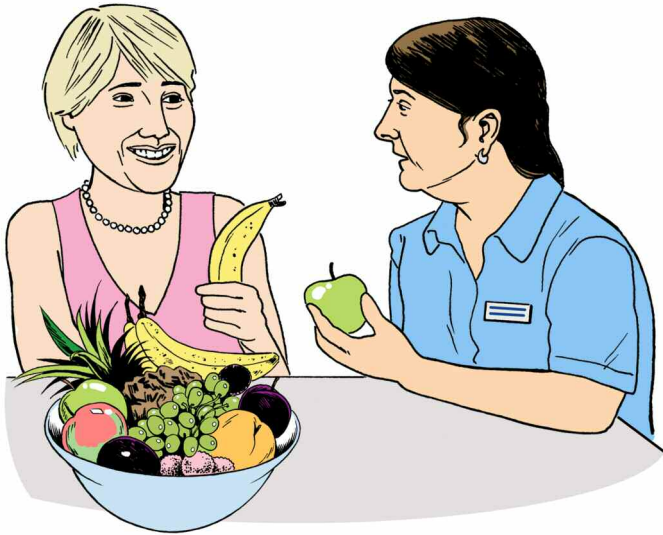


Constipation

Finding it hard to have a poo.

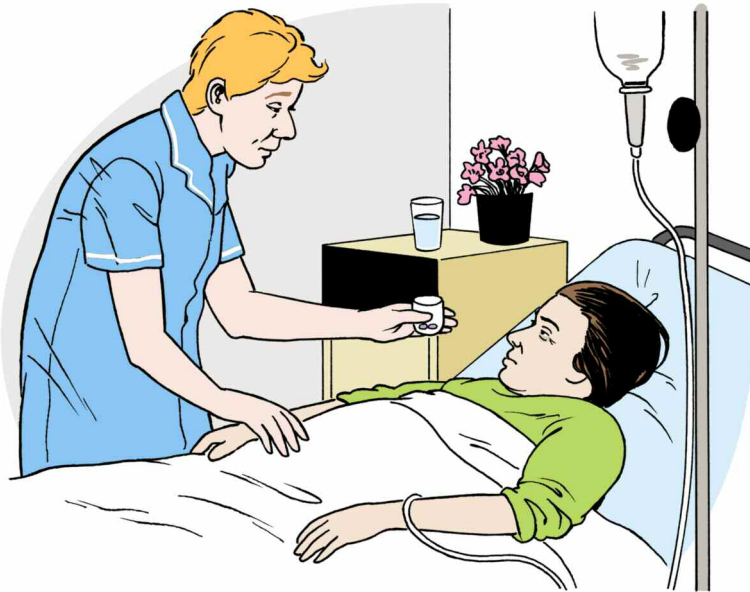


Word Bank



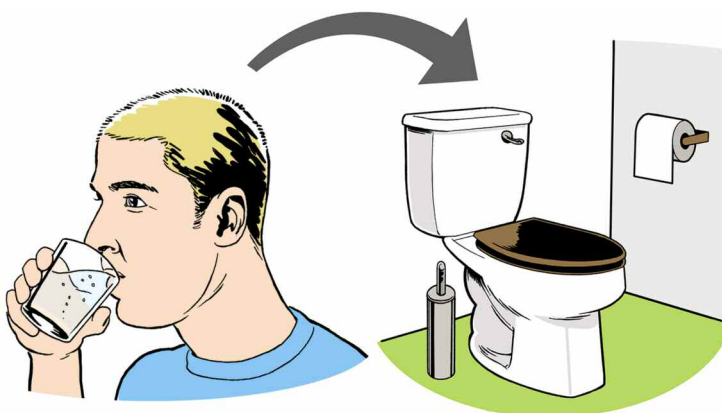
Dietitian

A dietitian is a professional who knows about food and diet. They can help with any problems with eating and food.



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.



Laxatives

Laxatives are medicines to help you poo if you have constipation.



Word Bank



Nourishing

Food or drink that will give you energy and help to keep you strong and healthy.



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



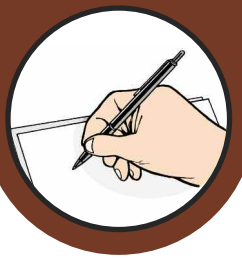
Speech and language therapist

This is a professional who can help with any speech and communication problems. They can also help if the person has any problems with chewing and swallowing.



Symptoms

Problems in the body caused by the cancer or the treatment, like pain or sickness.



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

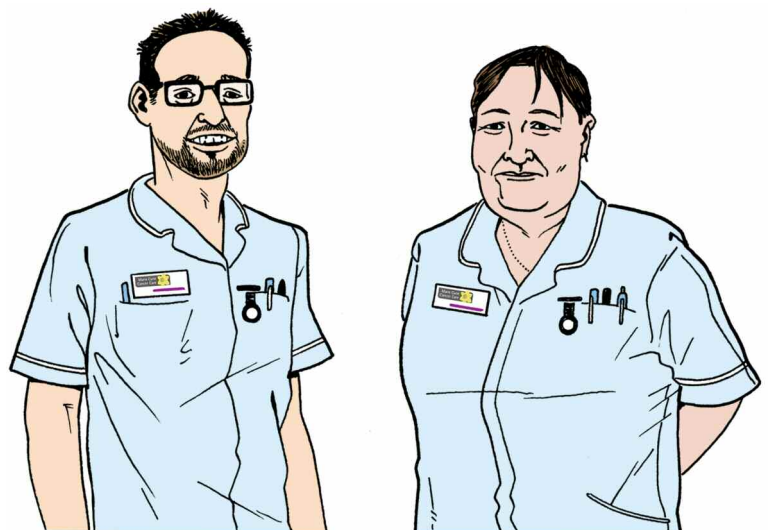
Web: www.macmillan.org.uk

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

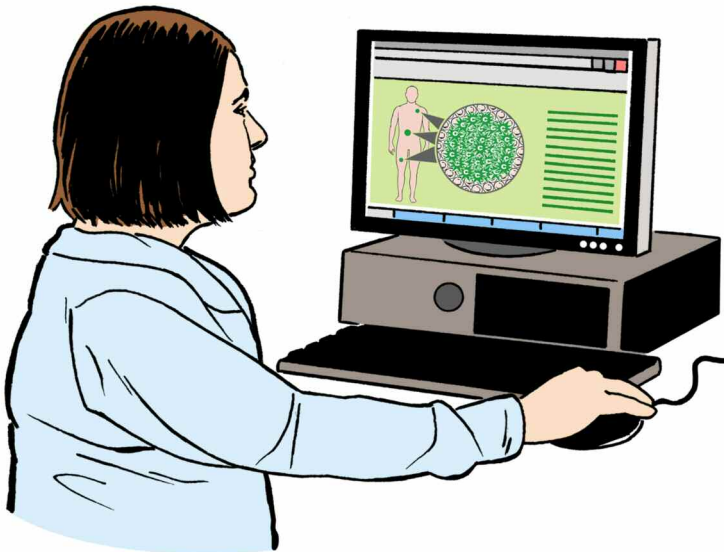
Web: www.fairadvice.org.uk/health-publications.php





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.

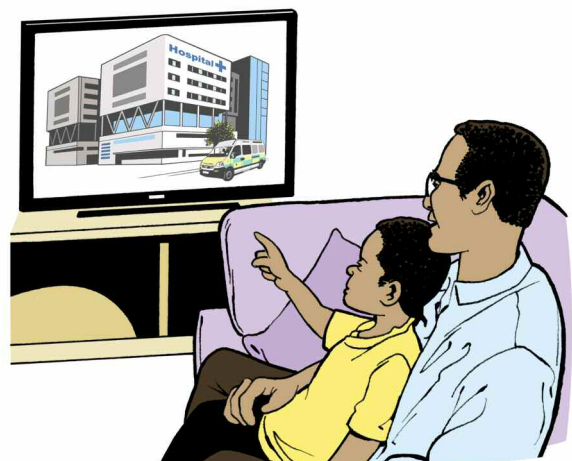
Phone: 0113 248 4997

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**