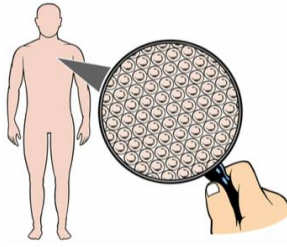
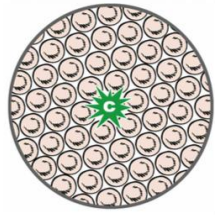



What is cancer?



Your body is made up of lots of tiny pieces called **cells**.




Sometimes these cells can go wrong.




One cell might go wrong which can make other cells go wrong and turn into a lump. This is called a **tumour**.

© CHANGE 2016 3

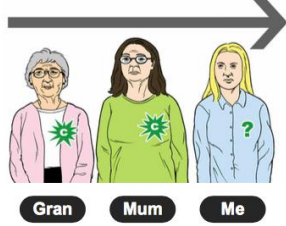
What is cancer?



More than 1 in 3 people are **diagnosed** with cancer in their lives.



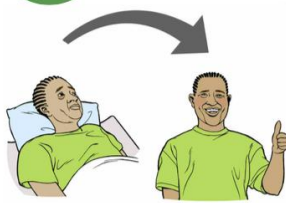
You can not get cancer from someone else. And you can not give it to anyone.




Some cancers are genetic. This means that you are more likely to get them if your parents or grandparents have had cancer.

© CHANGE 2016 5


What is cancer?



Cancer is a serious illness but lots of people get better.



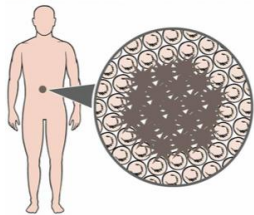
But, some people with cancer do die.



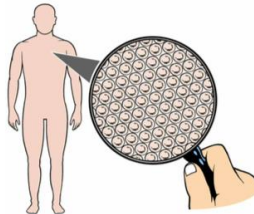
When a person has cancer they will need to go to a hospital for treatment.

© CHANGE 2016 8

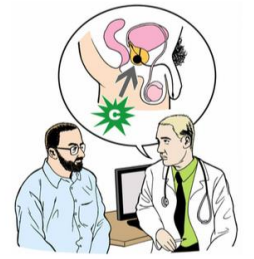
Word Bank



Benign
A benign tumour is a lump that is not cancer.



Cells
The tiny building blocks that make up people's bodies.



Diagnosed
Being diagnosed means finding out whether you have an illness or not.

© CHANGE 2016 11



Word Bank



Tumour

A lump in your body that should not be there. Not all tumours are cancer.

Notes...



.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....



Useful contacts

Helpful organisations

Breast Cancer Care

Gives information and support to women with breast cancer, and their family and friends.

Phone: 0808 800 6000

Web: www.breastcancercare.org.uk

Brook

Brook gives young people free, confidential information about health, sex and relationships. Find your local Brook centre on their website.

Web: www.brook.org.uk

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

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




Signs of cancer




Cancer can cause signs and **symptoms** in your body. You can look out for these.



Sometimes these signs and symptoms are caused by other illnesses. But it is important to have them checked.




If you have any of the following symptoms **see your doctor as quickly as possible**.




© CHANGE 2016 **3**


Signs of cancer




See your doctor:
If you start to feel tired all the time.



If you lose weight but do not know why.



If you have a nasty cough or sore throat that does not go away.



© CHANGE 2016 **4**

Signs of cancer



See your doctor:
If you find it hard to swallow food or drink.



If there is blood in your wee or poo.




If you find it hard to do a poo (**constipation**).




© CHANGE 2016 **6**


Signs of cancer



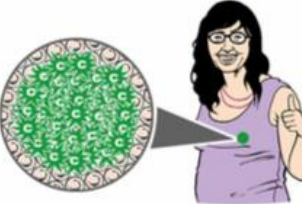
See your doctor:
If you have a headache all the time.



Some people who have cancer do not show any of these signs or symptoms.



Some cancers like **breast cancer** and **cervical cancer** may not cause any pain or symptoms.



© CHANGE 2016 **8**



Signs of cancer



Sometimes these cancers are found because the person goes to their doctor about something else.



It is very important to go for **screening**. Screening means having tests that can find cancer early.



Older people are more likely to get certain cancers.



Signs of cancer

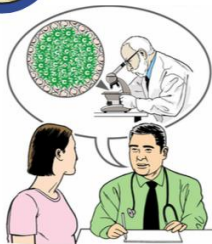


They will test for blood in your poo. This can sometimes be a sign of cancer.



If any blood is found in your poo, you will be asked to go for more tests.

Finding out you have cancer



If tests have found that you have cancer, the doctor will explain which type of cancer you have.

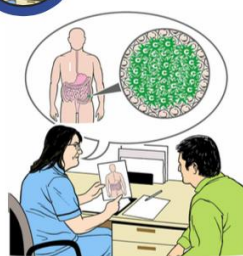


Cancer may also be called a **tumour** or a **malignant** lump. Malignant means it is harmful to the body.



The doctor will also explain about the different ways to treat cancer. It can be hard to understand all the things the doctor will tell you.

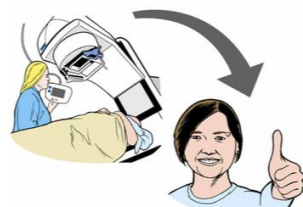
Finding out you have cancer



The doctor, nurses and your supporters can help you to understand what your **diagnosis** means and what will happen next.



It can be scary to find out you have cancer. You may be very worried about what will happen to you.

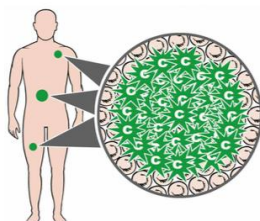


Even though cancer is a serious illness, many people get better after treatment.

Word Bank



Diagnosis
 A diagnosis is finding out whether you have an illness or not.



Malignant
 A malignant tumour is cancer. It will grow and can spread to different parts of the body.



Tumour
 A lump in your body that should not be there. Not all tumours are cancer.

Useful contacts

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


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

Having surgery


Having major surgery



Major surgery means having a bigger operation. Before major surgery, your doctor may arrange a few more tests. This is to make sure it is OK for you to have surgery.



These tests may include blood tests, scans, x-rays or other tests.




The doctor will also ask you about any medicines you are taking, for example for **asthma** or **diabetes**. The doctor will tell you if you need to change the way you take your medicines before surgery.

© CHANGE 2016 4


Having surgery



For major surgery you will have to stay in hospital for at least a few days. Sometimes it can be a week or two.




When you know how long you need to be in hospital you can pack a bag with anything you need. For example, your toothbrush, washing things, nightwear and some clothes.




When you come to the hospital you should wear loose comfy clothing.

© CHANGE 2016 6


Having surgery



Before the operation, you may need to take off your clothes and put on a hospital gown.



You will be given some medicine to help you relax.




The nurse will clean and possibly shave the part of your body that is going to be operated on.


© CHANGE 2016 8

Having surgery


Recovery after surgery



After surgery you will be taken to a recovery room. This is where you are looked after until you wake up.



If you have had a general anaesthetic you usually wake up within one to two hours.

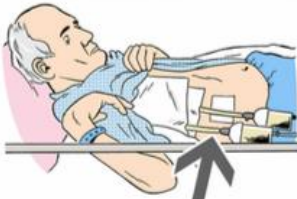


When you wake, you may still feel sleepy and dazed for some time.

© CHANGE 2016 10



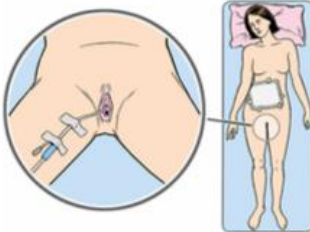
Having surgery



You might have some tubes coming out of your body where the operation was done.



These are called drains. They are used to collect any fluid that comes from your wound.



You might also have a tube coming out from where you wee. This is so you can wee without getting up to go to the toilet. This is called a catheter.



Having surgery



Side effects can be:

- **Pain:**
You will usually have some pain after an operation. It is very important to tell your nurse or doctor that you are in pain.



They can give you medicine to stop the pain.



- **Swelling, soreness and stiffness:**
It's normal for the area of the operation to be swollen, sore or stiff.



Having surgery



It is important that wounds are kept clean and the dressings are changed often. In hospital, a nurse will do this for you.



When you go home a nurse may come to your house to check and clean your wound.



If your wound becomes infected the doctor may give you some **antibiotics**. This is medicine to stop the infection.



Having surgery

Diet after surgery



After surgery you will need to eat healthy food. This helps your body to heal.




Some operations can make eating hard. For example, operations on your throat, stomach or bowel.




If your operation affects how you eat, you will see a **dietitian**.

Side effects from chemotherapy




Some people worry about having **chemotherapy** because it can cause side effects that make you feel ill.

Side effects are things that happen because of your treatment.



Your doctor or nurse can tell you about what will happen if you choose not to have chemotherapy.




You can then decide if you want to have the treatment or not


© CHANGE 2016 **3**

Side effects from chemotherapy


Side effect - Losing your hair



Some drugs don't change your hair very much.



Other drugs can damage your hair or make it all fall out. This can be very upsetting.



Sometimes these drugs can also make your body hair, like your armpit and **pubic hair**, fall out too.

© CHANGE 2016 **4**

Side effects from chemotherapy



If your hair falls out, this is usually after one or two treatments.



The good thing is that your hair will usually grow back after your treatment ends.


Losing your hair - what can help?




- Don't brush or comb your hair too roughly.

© CHANGE 2016 **5**


Side effects from chemotherapy



- There are special hats, scarves and turbans that you can wear.



- You could also wear a wig if you want to.



If your hair is going to fall out, ask the doctor or nurse about wigs before your treatment starts. They can get you a wig that is like your own hair colour.

© CHANGE 2016 **7**



Side effects from chemotherapy

Side effect - Feeling sick or being sick



Some chemotherapy drugs can make you feel sick (**nausea**).



And some can make you be sick (**vomit**). Sickness may start a few minutes into your treatment, or a few hours later. It may last a long or short time.



There are good treatments to help stop you feeling like this.



Side effects from chemotherapy



• Peppermints or peppermint tea can also help.



• Make sure you try to drink lots of liquids. Sip them slowly.

Side effect - Losing your appetite



Chemotherapy drugs can make you want to eat less.



Side effects from chemotherapy



• You can have special high energy drinks instead of some meals. Ask your **dietitian** about these.

Side effect - Problems going to the toilet



Some chemotherapy drugs can make your poo thin and watery (**diarrhoea**).



Some can make it hard to poo (**constipation**). Some anti-sickness drugs can do this too.



Side effects from chemotherapy



• Gentle exercise helps with constipation so try to have a walk every day.

Side effect - Your sense of taste



Chemotherapy can make your food and drink taste strange.



This will stop after your treatment ends.



Side effects from chemotherapy



When your treatment ends it may take a few months for you to feel less tired and get your normal energy back.

Side effect - Infection



When you are having chemotherapy you might get **infections** more easily, like a cold or flu.

Infection - What can help?



Here are some tips to help you avoid infections:

- Wash your hands often.



Side effects from chemotherapy



- Anaemia can also make your joints and muscles ache.



- Your doctor can treat you for anaemia.

Side effect - Bleeding and bruising



If you have nosebleeds or bleeding gums.



Side effects from chemotherapy



Your skin can become more sensitive to the sun.



Your nails may change colour and break more easily.

Changes to your skin and nails - What can help?



- Use moisturising cream on dry and flaky skin.



Word Bank



Fatigue

When you feel very tired and have no energy.



Infection

An infection is when your body is attacked by a bacteria or virus. Infections cause you harm and might make you feel unwell.



Mouth ulcers

These are painful round sores in your mouth, usually on the inside of your cheeks or lips.

Your feelings and cancer



As well as making changes to your body, cancer can also change the way you feel. It is normal to have lots of different feelings.



Some of the feelings you may have about having cancer are:

- Feeling sad or **depressed**



- Feeling worried or **anxious**

Your feelings and cancer



- Feeling alone or lonely, even if there are people around you



- Not wanting to be with other people

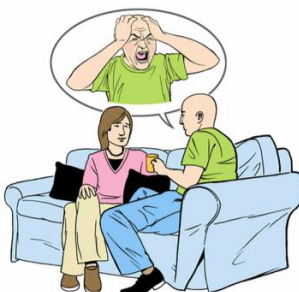


- Feeling bad about yourself

Your feelings and cancer



- Feeling angry



It is very important that you talk to someone about how you feel. They will be able to help you get the support you need.

Useful contacts



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

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

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.

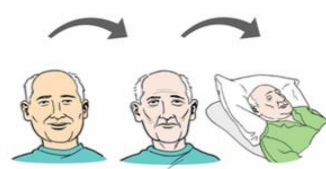


Losing your appetite
Losing your **appetite** means you do not feel like eating.

Changes that can happen at the end of life



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



- **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



- 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



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



Nourishing

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



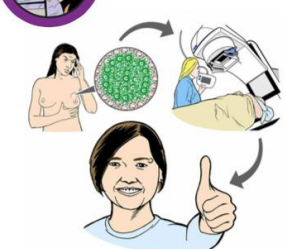
Palliative care

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.


If you are dying from cancer



Some people who have an illness get better again.



Other people who have an illness are not going to get better. They are going to die. This is because the doctor can't do any more to make the illness go away.



People with serious illnesses are sometimes ill for a long time.

© CHANGE 2016 **3**

If you are dying from cancer



Palliative care is the support and care people can have to help them live life as well as possible when they have an illness that they will die from.



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


Support and feelings




If you want to know more about your illness and talk about how you are feeling, there are people who can support you through this difficult time.

© CHANGE 2016 **4**


If you are dying from cancer



When this happens just hugging or holding hands can be enough. Sitting quietly together can also help.




If it is hard to talk to your family or the people you are close to, there are other people you can talk to like nurses and counsellors.




You can ask your doctor if you want to see a counsellor or a **psychologist**.

© CHANGE 2016 **9**


If you are dying from cancer



They are experts in helping people talk about their feelings.



They may be able to see you and your family member or friend at the same time, and help you listen to how each other is feeling.



Some people you know may find it difficult to talk about your illness or about dying. But they still care about you and want to help you in other ways.

© CHANGE 2016 **10**



If you are dying from cancer



Some people want to know how long they have to live. Other people don't want to know. You can ask the doctor or nurse about this if you want to.



You may feel upset and sad. It is OK to cry. You don't have to hide your feelings. Crying is normal for all of us.



You may feel angry. It is OK to feel this way.



If you are dying from cancer



You may feel that you want to be left alone. You may not feel like talking or being with other people.



This can be because you feel too ill and tired or it may be because you don't feel happy.



You might feel like you don't want to be alone. You may want to be with others all the time.

Making decisions about the future if you are dying (*Faire des choix pour l'avenir si vous allez mourir bientôt*) Livret 18 pages, 2016 (4 extraits)

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**'.




© CHANGE 2016 **3**

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.






© CHANGE 2016 **4**


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.



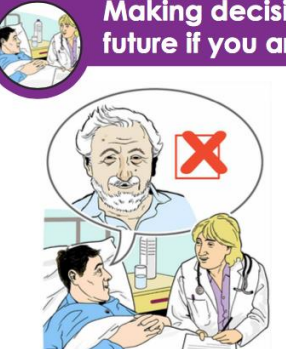
These are just examples of things you might want. Your own list of wishes may be different.




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.

© CHANGE 2016 **7**


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.

© CHANGE 2016 **6**

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



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.



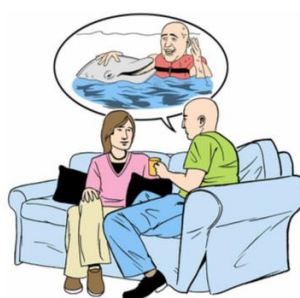
If there are people you will not be able to see then you could write letters to them. Ask for help with this if you need it.

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.

Spirituality and religion at the end of life



When people come to the end of their lives they sometimes think about what will happen after they die. No one really knows what happens after we die.

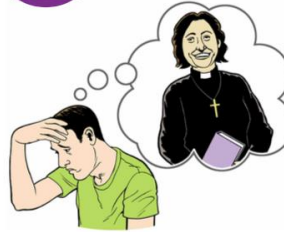


Religion and spirituality are beliefs and ideas that people have to help them understand life and death. Each person may have different ideas about spirituality or religion.



Different faiths and religions each have their own ideas of what happens when people die.

Spirituality and religion at the end of life



If you have a religion then you might find it helpful to talk to someone from your religion for support.



People like priests or spiritual advisors can support people at difficult times in their lives.



You may have your own spiritual ideas that give you personal comfort.

Spirituality and religion at the end of life



Some people find that doing things like walking in nature makes them feel more spiritual.



Some people find that listening to music makes them feel more spiritual.

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.



Religion and spirituality


Spirituality and religion are beliefs and ideas that people have to help them give meaning to life and understand death.

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




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

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.

© CHANGE 2016 **3**




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.

© CHANGE 2016 **4**


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.

© CHANGE 2016 **5**


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.



© CHANGE 2016 **6**