

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.





When someone dies, you may have lots of questions and feel confused about what is happening.

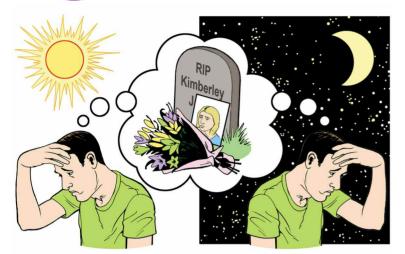


You may think that it is not true when someone dies. You may feel shocked and it can take time to accept what has happened.



You may find it hard to think about anything else except what has happened.





You may spend lots of time thinking about the person who died.



Thinking about the person who has died can make you feel very sad, but at the same time you may be remembering happy times you had with that person.



Quite often when someone has died you may imagine seeing them or talking with them. It is OK if this happens.

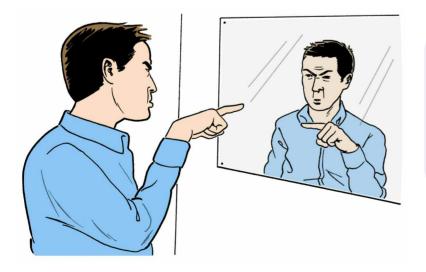




You might feel very upset. It is OK to cry if that is how you feel. But you should not feel guilty if you want to feel happy about other things.



You may feel angry with the person for dying and leaving you.



When someone dies you may blame yourself and feel like it's your fault they died.





You may feel afraid or worried about what will happen to you if the person looked after you.



When someone dies you may feel lonely.



You may find it hard to make decisions about things. This is OK. Get support if you need to make decisions, or wait until you feel you can.





The feelings you have after someone dies are called **grief**.



Grief can change what people feel like doing. You might not want to do the things you usually enjoy.



You might find it hard to be around other people and you might want to be left alone.





Or you might want people to be with you all the time.



Grief can also affect how people sleep. You might find it hard to sleep. Or you might want to sleep more.



Grief can affect your appetite. You may want to eat more or less than normal.



Grief can change how your body feels. You might not feel very well.



Sometimes people start drinking alcohol or taking drugs because of how they feel. Grief and loss can make people do things they would not usually do and take risks.



Sometimes people may feel so bad that they wish that their lives were over too.





Let other people know when you are feeling sad or upset. Talking to someone you trust can help.

Word Bank



Drawing by Tracey Harrison

Volunteer and Illustrator with learning disabilities

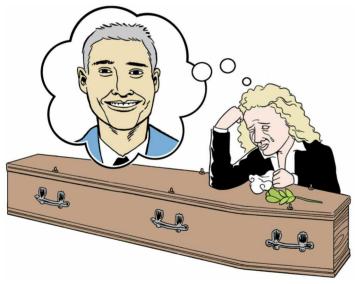


Word Bank



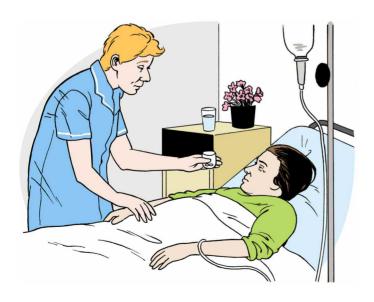
Appetite

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.



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



Grief

Grief is the feeling you have when someone has died. You may feel sad for a long time.



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.



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Volunteer and Illustrator with learning disabilities



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







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

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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

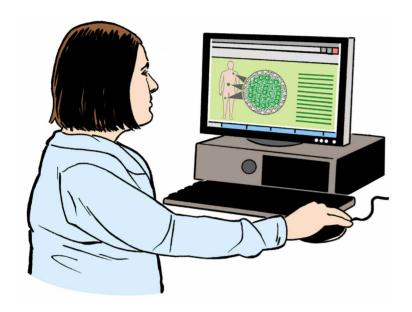
Web: www.fairadvice.org.uk/health-publications.php



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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.

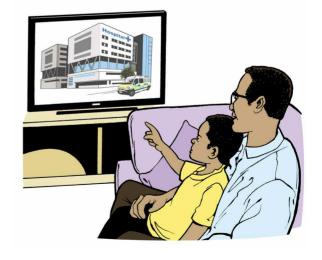
Phone: 0113 248 4997

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