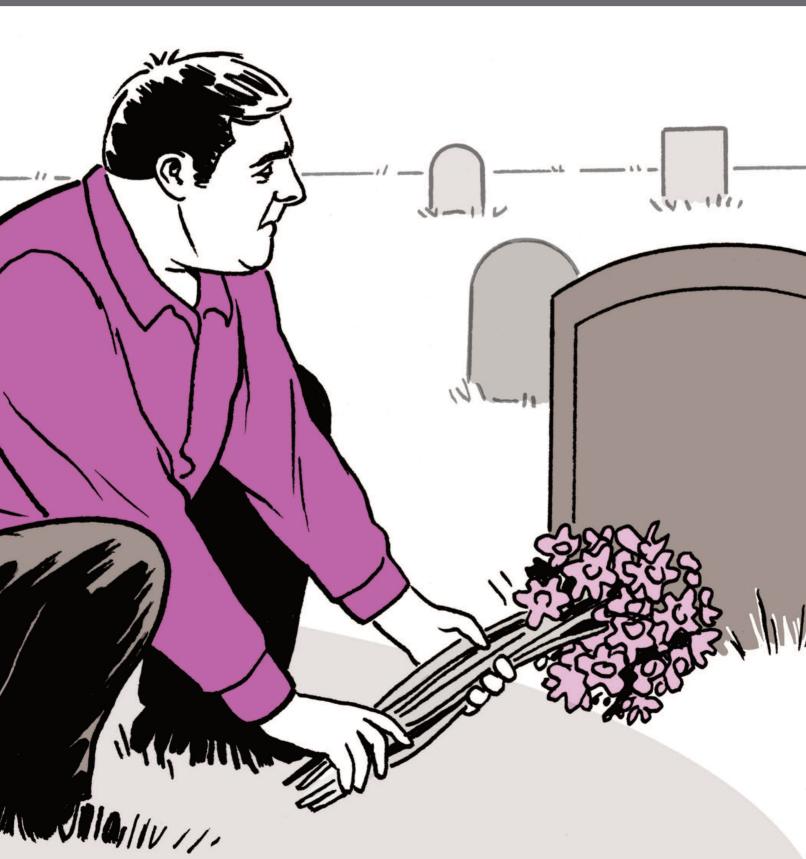


Palliative Care, End of Life Care and Bereavement



Introduction



This booklet uses easy words and pictures to help you get the information you need about cancer.



You might want someone to support you to look at the book so you can talk about it. There is a Word Bank at the back of the booklet to help you understand difficult words.



This booklet is written to help you understand more about cancer. It is not the same as getting advice from your doctor. If you are worried about your health, you should talk to a doctor or nurse.





This booklet is to help you if someone you loved or you were close to has died.



Dying is when someone's body stops working or can't keep working anymore. Their heart stops and their breathing stops.



When someone has died they won't move or talk or do anything anymore.





People die for different reasons: Sometimes people die because they had an illness that could not be made better.



Some people die because they have an accident.



Sometimes people die because they are old.











When someone dies it can be hard for the people who loved them. This is called grief and is also called experiencing loss.

Grief can make people feel lots of different feelings. It's ok to have lots of different feelings.



You may need support to help you with your feelings.





It is ok to talk about what you feel if that is what you want.

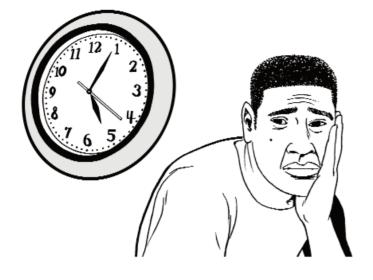


The person who is supporting you should be able to listen to you and be able to answer any questions, and help you with the different feelings you may have.



It is also ok if you do not want to talk about your feelings.





You may need some time to think about what has happened. You can ask at any time for support and someone to talk with when you feel ready to.

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.





Grief

Grief is upset and sadness which may go on for a long time. People may feel grief because of the loss of someone who has died.

Palliative care

This is the support and care people have when they have a life limiting illness. This means caring for the person's physical, emotional, social and spiritual needs.



Word Bank



Will

A will is a legal document that a person makes before they die, that says what they want to happen to their property and money after they die.



Notes...

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Helpful organisations



Help the Hospices

National charity that gives information about hospices and produces a directory of hospices in the UK.

Tel: 020 7520 8200 Web: www.helpthehospices.org.uk

Cancer Research UK

Cancer Research UK is the world's leading charity dedicated to beating cancer through research. Their website has a wealth of information about cancer.

Tel: 0808 800 4040 Web:

www.cancerresearchuk.org

Cancer Resource Centre (now called Paul's Cancer Support Centre)

Provides support, information and complementary therapies for people affected by cancer.

Tel: 0207 924 3924

Web: www.paulscancer supportcentre.org.uk

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Macmillan Cancer Support Macmillan Cancer Support improves the lives of people affected by cancer. They provide practical, medical and financial support and push for better cancer care. 89 Albert Embankment, London SE1 7UQ

Tel: 0808 808 00 00 Web: www.macmillan.org.uk

NHS Contacts

These contacts give you information about your health and health services: England and Scotland **Tel: 111** Wales **Tel: 0845 46 47** Northern Ireland **Web: www.hscni.net**

Marie Curie

Practical palliative nursing care. Tel: 0800 716 146 Web: www.mariecurie.org.uk



RESPOND

Offers a therapy service to people with learning disabilities in London and surrounding area. RESPOND also offers training and support to carers throughout the UK.

Tel: 020 7383 0700

Web: www.respond.org.uk

Telephone helpline service: 0808 808 0700



Samaritans

Provides confidential emotional support 24 hours a day to those experiencing despair, distress or suicidal feelings.

Tel: 0845 790 9090 Web: www.samaritans.org.uk

Palliative Care for People with Learning Disabilities Network PCPLDN

(formerly called the National Network for the Palliative Care of People with Learning Disabilities NNPCPLD) Emai: info@pcpld.org

Web: www.pcpld.org



Written and Audio material:

Books Beyond Words

A series of visual books for people with learning disabilities about different subjects including cancer, health and bereavement. **Web:**

www.booksbeyondwords.co.uk/books





FAIR Multimedia

FAIR Multimedia publishes a range of health leaflets, audio discs and CDs specifically designed for people with learning disabilities. They include a series on cancer. E-mail: multimedia@ fairadvice.org.uk Tel: 0131 662 1962 Web: www.fairadvice.org.uk/ health-publications.php

Online help



www.easyhealth.org.uk

An on-line library of health information that is easy to understand.

www.macmillan.org.uk

Here you will find a wealth of practical cancer information, as well as information on support groups, and on-line discussion forums.



Videos and DVDs

Leeds Animation Workshop

They have produced a number of animated films on social issues for people with learning disabilities, including 'Getting Better' a short film about going to the Doctor and the Health Clinic.

Phone: 0113 248 4997

Web: www.leedsanimation.org.uk/index.html

Speak Up Self Advocacy

They have produced a series of DVDs and booklets for people with learning disabilities on subjects around staying healthy, going in to hospital, and bereavement.

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 388 0011**, 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

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