

Living with Bone Cancer - A Quick Guide



Contents

This is a brief summary of the information on 'Living with bone cancer' from CancerHelp UK. You will find more detailed information on the website.

In this information there are sections on

- Coping with bone cancer
- Life after bone replacement surgery
- What to ask your doctor
- Bone cancer organisations

Coping with bone cancer

It can be very difficult coping with a diagnosis of cancer both practically and emotionally. You are likely to be feeling very upset and confused. The CancerHelp UK coping with cancer section contains lots of information you may find helpful.

There are sections on

- Your feelings
- Talking to people: who and what to tell
- How you can help yourself
- Who else can help you
- Financial support including Government benefits and charity grants

School and college

If you are at school or college, you may worry about telling everyone you've had cancer. Remember that who you tell is up to you. You may worry about missing coursework and exams. Colleges and exam boards are nearly always very helpful when students have health related problems. Talk to your favourite teacher or personal tutor as soon as you can.

Remember - schools, colleges and employers are not allowed to discriminate against anyone under the Disability Discrimination Act. This legislation includes people with cancer.

Life after bone replacement surgery

After bone or joint surgery, you will need lots of physiotherapy to get your limb moving again. Eventually you should be able to do almost everything you did before.

Your false bone or joint

False bones and joints very rarely break. But after several years there may be signs of wear and tear. They may need to be replaced. This is especially common with knee joints. Other possible complications are the prosthesis working loose, or a bone



infection developing. If you feel something is wrong with your false bone or joint, get in touch with your surgeon. If you have pain and fever, see your doctor. These could be signs of a bone infection.

If you are still growing when you get your false bone or joint you will have a growing prosthesis inserted. The growing prosthesis is lengthened regularly. Older types of growing prostheses required a minor operation to manually increase the length. Newer prostheses are lengthened using electromagnets. An internal device is turned on to start the lengthening process. This is a non invasive procedure so you will not need surgery, but means you will not be able to have MRI scans.

Changes in how you look

It can be very hard to accept changes in the way you look. Limb sparing surgery can leave you with a large scar. You may feel worried about how family and friends see you. You may feel that you are no longer as physically attractive, or feel less confident about sex. You may need more time to come to terms with all that has happened to you. It may help to talk things over with someone close to you.

The coping with cancer section of CancerHelp UK contains lots of information you may find helpful including information about who can help, counselling, changes in your sex life and more.

What to ask your doctor about coping with bone cancer

- How will my treatment affect me?
- Is there anything I shouldn't do after limb sparing surgery?

- What should I do if I am concerned about my arm / leg?
- When will I get a limb prosthesis?
- Who will help me get used to it?
- How often will I need a new prosthesis?
- What problems should I look out for with my prosthesis?
- Will I ever get back to normal, or will I have some long-term effects?
- Will I be able to go back to work / school / college?
- Where can I get help with claiming benefits and grants?
- What practical help is available?
- Can I have an occupational therapy assessment to see if I need any changes made at home?
- Why did this happen to me?
- Where can I get help dealing with my feelings?
- Can you refer me for counselling?
- Do I have to pay for counselling?
- Could you refer me to a Macmillan nurse?
- Can I see a social worker for help with claiming benefits and grants that may be due to me?

Bone cancer organisations

Cancer Research UK
 Main website: www.cancerresearchuk.org
 Patient information website:
<http://cancerhelp.cancerresearchuk.org>
 Cancer Information Nurses phone: 0808 800 4040

Limbless Association
 Website: www.limbless-association.org
 Helpline: 0845 230 0025



Bone Cancer Research Trust
 Tel: 0113 262 1852
 Email: info@bonecancerresearch.org.uk
 Website:
<http://www.bonecancerresearch.org.uk>

Sarcoma UK
 Email: info@sarcoma-uk.org
 Website: www.sarcoma-uk.org

Teenage Cancer Trust
 Website:
<https://www.teenagecancertrust.org/>
 Email: tct@teenagecancertrust.org
 Phone: 020 7612 0370

Notes

More information

For more information about bone cancer, visit our website
<http://cancerhelp.cancerresearchuk.org>

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for cancer trials in the UK. You can view or print the information in a larger size if you need to.

For answers to your questions about cancer call our Cancer Information Nurses on **0808 800 4040** 9am till 5pm Monday to Friday

Adapted from Cancer Research UK's Patient Information Website CancerHelp UK in November 2011. CancerHelp UK is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through CancerHelp UK and our nurse team is not a substitute for professional care and should not be used for diagnosing or treating a health problem or disease. If you have, or suspect you may have, a health problem you should consult your doctor. © Cancer Research UK 2011. Cancer Research UK is a registered charity in England and Wales (1089464) and in Scotland (SC041666).