

Living with Bone Cancer

A Quick Guide

Contents

This is a brief summary of 'Living with bone cancer' from our website. You will find more detailed information on there. In this information there are sections on

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

You can view this information in a larger print on our website.

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 coping with cancer section of our website contains lots of information you may find helpful. There are sections about

- 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 have cancer. Remember that who you tell is up to you. You may worry about missing coursework and exams. Colleges and exam boards are generally 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 the majority of things that you did before.

Your false bone or joint

False bones and joints (prosthesis) 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 or 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 our website 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 have some long-term effects?
- Will I ever get back to normal?
- 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?
- 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 specialist nurse?

Bone cancer organisations

Cancer Research UK

Website: www.cancerresearchuk.org/about-cancer
Cancer Information Nurses phone: 0808 800 4040

Sarcoma UK

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

Limbless Association

Website: www.limbless-association.org
Helpline: 0800 644 0185

Bone Cancer Research Trust

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

Teenage Cancer Trust

Website: <https://www.teenagecancertrust.org/>
Email: hello@teenagecancertrust.org
Phone: 020 7612 0370

For more information, visit our website <http://www.cruk.org/about-cancer>

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 trials in the UK. Our information is based on the best current scientific evidence and reviewed regularly by leading clinicians and experts in health and social care.

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 website in February 2015. Cancer Research UK's website is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through Cancer Research UK's website 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. Copyright Cancer Research UK 2015. Cancer Research UK is a registered charity in England and Wales (1089464), Scotland (SC041666) and in the Isle of Man (1103)