

## Will I need any further treatment ?

Your doctors may already have told you what they are recommending as follow-up (or adjuvant) treatment. If not they will do so once they have all the test results following your operation. Many patients will not need further treatment. Your case will be discussed by the sarcoma treatment team at the hospital. This team will include your surgeon and doctors who are experts in radiotherapy and chemotherapy. The pathologist who reviewed the tumour taken away during surgery, and the radiologist who has checked all the scans using CT, MRI, ultra-sound etc, will also be there.

Large and high grade tumours may well benefit from radiotherapy. The judgement will be made by an expert radiotherapy doctor (clinical oncologist). If there is a possible benefit from follow-up chemotherapy the medical oncologist will assess the situation and discuss it with you.

Every case is different so do not expect to have exactly the same treatment as someone else you met in hospital.

The hospital will have its own booklets explaining radiotherapy and chemotherapy. If such treatment is proposed you should be given a copy. If not, do ask.

## I need to claim benefits

If you are unable to work, or your treatment has left you disabled, you may be eligible for State Benefits. A benefits adviser may be attached to the hospital to help you through the claims process.

If you need to contact a benefits adviser in your local area Macmillan can help find one for you, call 0800 500800 (Freephone). Macmillan also has a benefits advice helpline on 0808 801 0304.

Sarcoma UK offers a series of short leaflets explaining the issues of living with sarcoma. These leaflets are available at the main treatment centres and at hospital information centres. We also publish a twice yearly newsletter which is available free to patients.

Sarcoma UK, PO Box 128, Ludlow,  
Shropshire, SY8 1YL  
Email: [info@sarcomauk.org](mailto:info@sarcomauk.org)

### Where to find more information

#### Freephone telephone help services

CancerBACUP 0808 800 1234  
Macmillan Cancer Relief 0808 808 2020

#### General information on sarcoma and its treatment.

[www.sarcomauk.org](http://www.sarcomauk.org)  
[www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)

#### Treatments

[www.cancerbacup.org.uk/Treatments/Chemotherapy](http://www.cancerbacup.org.uk/Treatments/Chemotherapy)  
[www.cancerbacup.org.uk/Treatments/Radiotherapy](http://www.cancerbacup.org.uk/Treatments/Radiotherapy)

#### Clinical trials

[www.cancerbacup.org.uk/Trials/Understandingtrials](http://www.cancerbacup.org.uk/Trials/Understandingtrials)  
[www.nelh.nhs.uk/clinicaltrials/](http://www.nelh.nhs.uk/clinicaltrials/)  
[www.cancerhelp.org.uk/trials/trials/default.asp](http://www.cancerhelp.org.uk/trials/trials/default.asp)

If you have had an amputation further information and advice is available from the Limbless Association on 0845 230 0025  
[www.limbless-association.org](http://www.limbless-association.org)

#### State Benefits

[www.macmillan.org.uk/abetterdeal/homepage.htm](http://www.macmillan.org.uk/abetterdeal/homepage.htm)  
Macmillan Benefits helpline 0808 801 0304

CancerBACUP information about treatments and trials are also available as booklets, free of charge from 020 7696 9003

# following surgery

some  
questions  
answered

Leaving hospital following surgery can feel quite strange. The life you led before the diagnosis and surgery may seem very distant, with all the stress and pressure of hospital visits, tests and then the operation itself to cope with. Adjusting to a new 'normality' may take some time.

It is during this time that a lot of new questions about your treatment can occur to you. Although your doctors are the best people to answer them this leaflet has been written to try and answer the most common questions and give you a general understanding of what sarcoma patients face.

## How will I be followed up?

There is no single standard for following up and monitoring sarcoma patients. Once you have recovered from surgery the doctors will suggest a routine of visits every few months, perhaps quarterly. The follow up will consist of some basic tests (eg blood test), a clinical examination, and possibly a chest x-ray or a scan (CT or MRI). It is quite usual to feel anxious as the time of a follow-up clinic draws near and the actual visit can also be stressful.

Prepare yourself for each follow-up visit. If you have any questions you want answered write them down beforehand. Wear clothing which is easy to remove so when the doctor wants to listen to you breathing, or inspect the site of the surgery, you don't have to be embarrassed by having awkward clothing to take off. When you are given the results of tests you may not understand what is said the first time. Ask the doctor to repeat what has been said and to explain any terms you don't understand. Ask to read the notes yourself, and do have a family member or friend with you who can make notes for you, or remind you of the questions you want answered.

Don't forget that the nurses in the clinic are also experts. There may also be a physiotherapist available to help with any difficulties you may be having in getting back to normal activity.

## What should I do if I find another lump?

Sarcomas can recur and one of the most common ways is for a lump to appear close to the site of the original tumour. If this happens it may not be another tumour – only the experts will be able to tell. So use the contact telephone number given to you by the hospital and talk to the nurse or another member of the sarcoma team. You will usually be given an appointment at the next available clinic.

If it is another tumour, and only expert examination and further tests will find that out, this is known as a local recurrence. The first treatment option which will be considered is further surgery. While it isn't a good sign that the cancer has recurred in this way the overall prospects for patients who have a local recurrence successfully removed are usually unchanged.

Local recurrence is often detected first by patients. Any new lump or pain at the site of the original tumour should be reported to your doctor immediately.

## Should I be on the look out for any other symptoms?

Sarcomas can also return in other parts of the body. It is important that you tell the doctors at the follow-up clinics any other symptoms you may be experiencing. Don't hide anything from them. A cough may be a sign that the sarcoma has spread (metastasised) to the lungs. Other aches or pains may be an indication that further investigation, and possibly treatment, may be necessary.

We all hope that will never happen but early diagnosis is best if more treatment is necessary.

The greatest risk of developing recurrent disease is in the first two years, which is why follow-up will be closest during this time. People with high-grade tumours are at the highest risk but this risk reduces with time and after five years is very low.

## Can I do anything to prevent a recurrence?

Very few sarcomas have a certain cause. The few that do are mostly rare inherited conditions and you would know if one of them was in your family. Recurrence is possible with most sarcomas but is more likely if the original tumour was high-grade, very deep, very large (over 5cm), or could not be completely removed. There is no specific medical way of reducing the risk of recurrence but your doctor will answer any questions you might have.

Some patients feel that they get benefit from complementary approaches, taking an antioxidant supplement, taking regular exercise, ensuring that their diet is well-balanced and includes plenty of fresh fruit and vegetables, or learning to relax and enjoy life. The important thing is to do what you are comfortable with, not what anyone else thinks you should be doing. If you are a smoker it also helps cut down risks if you can stop smoking.

It is important to ensure that any complementary treatments you take do not clash with medical treatments, so tell the doctors of anything you are taking, especially before chemotherapy.

## How long have I got?

Only your own consultant is in a position to give you an opinion on how you will fare in the future. Many sarcoma patients never have another problem and the worry which a cancer diagnosis brings with it fades after a time.

The factors your doctor will consider include the size of the tumour, the type of sarcoma, and the 'grade' of the tumour. This is an assessment of how aggressive the tumour was. The success of the surgery in removing all the visible cancer cells is also important. It is also necessary to know that the cancer has not spread (metastasised) to any other part of your body.

We strongly advise against trying to apply statistics which you might find on the Internet to your own situation. These statistics are based on large numbers of patients and cannot give an accurate picture for an individual patient because each person's case is different.

## I want to talk to someone about it all

Emotionally this can be a very difficult stage in your illness. Taking in and understanding all the information which your doctors need to give you is not easy. Sometimes it can be important to talk about your situation with someone, either in person or over the telephone.

Ask the nurse for information about support services at the hospital. There may also be a cancer support centre, or a self-support group, close to your home. Macmillan keeps a list of all support groups - call Macmillan CancerLine on 0808 8082020 (Freephone).

Metastatic disease is when the tumour spreads to another part of the body. Occasionally there may be more than one metastasis, and they may not all appear at the same time. The fewer the metastases and the greater the time interval from the original diagnosis the better the chances of a cure. Long experience has shown that chest x-rays are the most efficient way of detecting metastases, although CT scans may also be used.