

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. The doctors and nurses who treat you are the best people to answer them but this factsheet 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 this anxiety can continue during the actual visit.

There are some simple things you can do to prepare yourself for each follow-up visit. Here are some tips to help you:

- 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. The overall prospects for patients who have a local recurrence successfully removed are usually unchanged.

You are the most likely person to detect a recurrence of your sarcoma. If you experience a new lump or any pain at the site of the original tumour, see your doctor straightaway.

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

Sarcomas can sometimes return in other parts of the body. It is important that you tell the doctors at the follow-up clinics about any other symptoms you may be experiencing. Don't hide anything from them even if you think the symptoms are minor such as a cough or general aches and pains. The doctors will be able to carry out investigations and hopefully reassure you that all is well. If further treatment is necessary, the earlier any problems are picked up, the better.

The greatest risk of sarcoma recurring is in the first two years, which is why follow-up will be closest during this time. People with higher-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 which may improve general wellbeing. These may include 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 or supplements you take do not clash with medical treatments, so it is always best to check with your doctor, especially before chemotherapy treatment.

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, and ultra-sound 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.

The future

Many sarcoma patients never have another problem and the worry that a cancer diagnosis brings with it fades after a time.

Your regular check-ups will provide you with the opportunity to discuss any worries about the future with your doctor and to identify any further problems if they occur.

All sarcoma cases are very individual and this means that general statistics and information you may find on the internet may not be at all relevant to your own situation. Statistics are based on large numbers of patients and provide generalised conclusions that may be very different to your individual situation.

I want to talk to someone about it all

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 who understands.

Your hospital may have support available, either provided by the psychology team or at a cancer information centre.

There may be a sarcoma support group in your local area. Your nurse may know about it, or you can contact Sarcoma UK who can tell you where your nearest group is.

I need to claim benefits

If you need finance help or are unable to work as a result of your cancer or your treatment, you may be eligible for state benefits. A benefits adviser may be attached to the hospital or your GP's surgery to help you through the claims process. Macmillan Cancer Support also provides a local benefits advice service throughout the UK, often working with the local Citizen's Advice Bureau. Information is available on their website www.macmillan.org.uk or you can phone the Macmillan Support Line on 0808 808 0000 (Freephone).

Updated June 2012 Version 1.2

Sarcoma UK is the main charity in the UK dealing with all types of sarcomas. We provide information and support for anyone affected by sarcoma –patients, carers, relatives and friends.

How to contact us

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Registered charity: 1139869 (England and Wales) and in Scotland (SC044260)

A company limited by guarantee: 7487432