

## Some terms explained

**Metastasis** is the term used by doctors to describe cancer when it moves from the site where it was first found. Metastatic sarcoma is usually found in the lungs or the liver, but can occur in many places.

**Palliative** treatment is aimed at reducing and controlling the symptoms of an illness. With advanced sarcoma the responsibility for palliative care may be shared between hospital doctors, the patient's GP, and a nursing specialist.

**District Nurse.** The district nurse is the first line of community-based support and help with hospital prescribed treatments. They will call regularly, more than once a day if necessary.

**Macmillan Nurse.** Many of the specialist nurses funded by Macmillan Cancer Relief are experts in palliative care. They work with GPs and can also advise on other sources of help, including local hospices and, in some cases, financial support.

**Respite Care** may be available to help a patient and their carer when an illness becomes severe. It is usually arranged with a local hospice or community hospital by the GP. The patient will have a few days away from home receiving expert care and treatment, allowing members of the family a break from the caring role.

**Complementary Therapy** is treatment from alternative disciplines (such as spiritual healing, aromatherapy and acupuncture) delivered in association with more traditional medical treatment. Many patients with advanced cancer find it valuable.

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.

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This leaflet is dedicated to the memory of Simon Mellows

## 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.sarcoma-uk.org](http://www.sarcoma-uk.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 explained

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

### Information on Clinical Trials for sarcoma

[www.cancerhelp.org.uk/trials/trials/default.asp](http://www.cancerhelp.org.uk/trials/trials/default.asp)

### 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

# advanced sarcoma

You have been given this leaflet because your disease has advanced. The doctors may refer to the sarcoma 'metastasising', or to 'metastatic disease'. They may have told you that it has advanced so that they cannot now cure you.

It is important to understand that at this stage in the disease it can be treated.

This leaflet explains what treatments the doctors may be able to offer and the kinds of other support which you might find valuable.



Sarcoma UK is a company limited by guarantee with charitable objectives.

Registered in Cardiff 4896211

Printed by St Leonards Press, Ludlow. Tel: 01584 878283

You have been given this leaflet because your sarcoma has spread, also known as 'metastasis'. The doctors will continue to treat you and they will try to slow down the growth of the sarcoma or stabilise your condition.

This kind of treatment can give remission from the disease, sometimes for long periods of time. However, each individual responds to treatment in different ways.

The doctors will be especially concerned to ensure that you do not suffer any discomfort or pain and that any treatment you decide to accept will protect your quality of life.

### **What treatments are available ?**

The treatments which your doctors may offer could include surgery, radiotherapy or chemotherapy. Surgery may be used to remove or reduce the size of tumours. However it may not be an option because the tumours are in a difficult location, are growing too fast, or because of multiple tumours. Radiotherapy can be used to help control pain, or to reduce tumours, but it is not always appropriate because of where the tumour is in the body. Chemotherapy may be the only available treatment option.

Your doctor will explain the aims of the recommended treatment to you and if you agree to be treated you will be asked to sign a consent form saying that you give your permission for the hospital to treat you.

However it is important to discuss fully with your consultant and the nurse specialist exactly what this means for you and you can always ask for more time to decide if you feel that you can't make an immediate decision.

### **What does chemotherapy offer me?**

Everyone's response to treatment is different. Chemotherapy for advanced sarcoma can help control symptoms and can give extended remission to some patients.

Many people find the prospect of chemotherapy quite daunting. Treatment today is much better managed than in the past and some of the newer drugs have fewer side effects. Your hospital will be able to give you more detailed information about the proposed treatment, how it will be given, how side effects can be managed, and the support you will have during treatment. Chemotherapy may be given as an out-patient in a special chemotherapy unit or day ward, but some drugs have to be given as an in-patient. Some of the latest treatments are in tablet form and can be taken at home.

A course of chemotherapy is usually six cycles of treatment at 3-weekly intervals, but this may vary with some of the latest drugs. There will be a point during the treatment where progress will be assessed – probably using a CT scan.

### **Can I refuse chemotherapy ?**

The decision whether or not to receive chemotherapy is very personal and you are free to choose not to have the treatment. The doctors or nurses can explain what may happen if you do not accept it. You do not have to give a reason for not wanting to have treatment and your decision will be respected. No-one will argue against you. If in doubt, do not rush your decision. If you decide against having treatment, tell the doctor or nurse so that they know what you have decided.

### **What if chemotherapy fails?**

Your doctor can explain exactly what this would mean for you. It may mean the end of available treatments for the disease, leaving palliative care as the route forward.

### **How do I find out about new treatments?**

Research into new treatments takes place all the time. When a new treatment looks promising it will be tested to assess its safety and its effectiveness before doctors are allowed to offer it to their patients. This happens in clinical trials, during which small numbers of patients are treated.

### **Would a clinical trial help me ?**

Your doctors will know whether a clinical trial is available for your condition and whether you would be eligible. They can also refer you to another hospital if a trial is available somewhere else.

If you are interested in entering a trial you will be given full information about it and time to make up your mind. A nurse or doctor will be available to answer any questions you might have before you make your decision.

If you want to find out more about clinical trials, sources of further information are listed on the back page of this leaflet.

### **Does alternative medicine offer a viable treatment?**

Patients with advanced sarcoma can gain some benefit by using complementary treatments alongside their medical treatment. Relaxation, aromatherapy, acupuncture and healing have all

been used satisfactorily. Always tell your doctor about any dietary supplements you may be taking because some of them can clash with medical treatment. Using them as an alternative to medical care is not recommended.

### **How long will I live ?**

It is important not to pay too much attention to statistics about survival which may be found on the Internet. Even the best doctors can only suggest a probability of survival based on studies of large numbers of patients. The prognosis for an individual cannot be determined by studies of this kind. Every individual is different.

### **Who can I talk to ?**

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. You may want to bring a relative or friend with you when you visit hospital. It can be valuable to talk about your situation with someone independent from your family, 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 808 2020 (Freephone).

### **How can my GP help ?**

Your GP will be informed by the hospital of what they have told you and will help deliver any treatments suggested by the hospital consultants. The GP can arrange for visits from the district or Macmillan nurses, can organise support from social services and, if it would be helpful, from the local hospice who will also have access to appropriate complementary therapies.

### **Can I claim benefits ?**

If you are unable to work, or your treatment has left you disabled, you may be eligible for State Benefits. A benefits advisor 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.