

Patient information factsheet

Southampton sarcoma service

We have given you this factsheet because we would like to offer you a personalised care appointment as part of our Southampton sarcoma service. It explains what the Southampton sarcoma service is, what we offer and what to expect during a personalised care appointment. We hope it helps to answer some of the questions you may have. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

What is the Southampton sarcoma service?

The Southampton sarcoma service cares for and supports people in the Wessex region (including the Channel Islands and the Isle of Wight) who have been diagnosed with sarcoma (a rare type of cancer that can develop in the muscle, bone, nerves, cartilage, tendons, blood vessels and the fatty and fibrous tissues).

Our specialist team is made up of:

- three sarcoma cancer clinical nurse specialists (CNS) who have experience in caring for people with sarcoma
- two support workers who help with telephone enquiries and support people with sarcoma in various ways
- a sarcoma pathway care navigator who helps people diagnosed with a new sarcoma

The aim of the service is to transform care for people with sarcoma, giving them a voice and making sure their care is based on what matters most to them.

How can the Southampton sarcoma service support me?

Link with other healthcare professionals

As well as being responsible for coordinating your care, your sarcoma cancer CNS can also be a useful link between you and other healthcare professionals involved in your care, both here at the hospital and elsewhere, such as your GP surgery.

Someone to speak up for you (advocate)

Your sarcoma cancer CNS will also attend every sarcoma multidisciplinary team (MDT) meeting. The MDT is a team of specialist healthcare professionals who meet weekly to discuss the results of your investigations and decide on the best treatment to offer you.

Your sarcoma cancer CNS will express your views to the rest of the MDT on your behalf, ensuring your voice is heard when decisions regarding your care and treatment are made (this is known as 'shared decision-making').

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A personalised care appointment

Cancer affects people in different ways. During your diagnosis and treatment, you may experience a range of emotions. These emotions can be difficult to cope with and it's not unusual to have times when you feel low. It can sometimes help to talk things through, such as the different treatment options available to you, coming to terms with the news of your diagnosis or living with the impact that the diagnosis has had on you and your family.

We can help support you by offering you an opportunity to talk things through over the telephone with a sarcoma cancer CNS. This is known as a 'personalised care appointment'.

How should I prepare for my personalised care appointment?

Before your appointment, we recommend writing down any questions you may have or any topics you would like more information on. For example, you may like to know more about:

- your diagnosis
- your treatment options (chemotherapy, radiotherapy or surgery)
- managing side effects
- controlling symptoms
- medications
- financial or work-related concerns
- community help and support
- · coping with an altered physical appearance
- counselling services
- · physical, practical and psychological care

What will happen during my personalised care appointment?

During your telephone appointment, we will:

- answer any questions you may have.
- discuss any concerns you may have.
- complete a holistic needs assessment (a simple questionnaire that can help us identify
 and address your specific needs and concerns) to allow us to create a personalised care
 and support plan for you.

What will happen after my personalised care appointment?

After your personalised care appointment, we will provide you with a copy of your holistic needs assessment and personalised care and support plan. We will also share a copy of these with your general practitioner (GP).

Most people usually only have one personalised care appointment, but we may offer you another appointment in the future if we think this may benefit you.

Your feedback

We welcome your feedback about the Southampton sarcoma service. Please scan the QR code or click the following link to complete our feedback form after your appointment: https://gthr.uk/0421e



If you need any assistance with completing this form, please contact us.

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Contact us

If you have any questions or concerns, please contact us.

Sarcoma cancer clinical nurse specialist (CNS) team

Telephone: 023 8120 6752 or 07769 234598

(Monday to Friday, 8.30am to 4pm, excluding bank holidays)

If we're unable to answer your call, please leave a message with your name, hospital number or date of birth, contact number and a brief reason for your call, and we will aim to get back to you as soon as we can.

Useful links

www.sarcoma.org.uk

www.macmillan.org.uk

www.maggies.org/our-centres/maggies-southampton

www.macmillan.org.uk/healthcare-professionals/innovation-in-cancer-care/holistic-needs-assessment

www.nhs.uk/conditions/soft-tissue-sarcoma

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