



**University
Hospitals Sussex**
NHS Foundation Trust

The soft tissue and bony sarcoma clinical nurse specialist and support worker team

Patient information

Who are we?

The Clinical Nurse Specialist (CNS), is a registered nurse with specialist education and experience in cancer care.

The Cancer Support Worker, (CSW), is often the person who you will speak to on the phone or will answer your email. They may be able to answer any queries you have or redirect your inquiry to the most appropriate team member.

The team is based in Brighton and works closely with other members of the cancer care team both in the local area and at specialist centres.

What support and information will be offered?

You will normally have contact with the sarcoma CNS and Support Worker at the time of your diagnosis.

It is likely that the CNS will have arranged to see you in a face to face clinic, or organised a phone appointment, to explain your diagnosis to you and let you know what the next steps are.

The CNS will be able to offer advice on treatment options.

The team try to ensure you have the information and support you need throughout your cancer journey or signpost you to other professionals who may be able to help you.

They may also arrange for you to have an Holistic Assessment to identify any issues that may be concerning you.

Who will be involved in my care?

The Brighton CNS and CSW are available to support you at the time of diagnosis and if you have treatment or follow up at University Hospitals Sussex.

All soft tissue and bony sarcomas are referred to specialist centres for an opinion on management. This is a national requirement because sarcomas are very rare.

Many appointments and treatments will happen at the specialist centres. Sometimes it is possible to have investigations done locally.

For soft tissue sarcoma the specialist centre is usually The Royal Marsden Hospital in Chelsea, London.

For bony sarcomas the specialist centre is usually The Royal National Orthopaedic Hospital, (Stanmore), and University College London Hospital.

At Brighton there is a Consultant Oncologist who may arrange for you to have some of your treatment, like radiotherapy and chemotherapy, locally at University Hospitals Sussex.

Whilst you are under the care of the specialist centres the CNS teams based there will be your main point of contact.

The teams at the specialist centres and University Hospitals Sussex work together to try to ensure you are helped with any concerns or queries you may have.

What information and support will I get?

Being diagnosed with sarcoma can be a frightening and unsettling time.

The CNS and CSW are here to help you at this time.

They will talk to you alone, or with family or a friend, whichever you prefer. You can ask about your diagnosis and disease as well as your treatment plan and what it will involve. Sometimes they can arrange to see you in person either at Hove Polyclinic or at The Sussex Cancer Centre at The Royal Sussex County Hospital, Brighton.

They can explain the treatment options and signpost you to other professionals who may be best placed to help you further. People who you may be signposted or referred to include:

- Physiotherapists
- Nutritional advisors
- Activity and Exercise specialists
- Rehabilitation services
- Finance and Welfare services
- Cancer Information and Support Services

The CNS may also be able to help you with post treatment side effect and symptom advice.

Trials and Research

There are a few research studies which are looking into new and existing treatments for sarcoma.

If there is a trial that you may be eligible for it will be explained to you. These trials are conducted at the specialist centres. However, the local CNS will be happy to talk through trial information with you.

How to contact us

There is a dedicated email inbox and a phoneline which will go through to an answerphone:

Email: Uhsussex.sarcomacns@nhs.net

Phone: **01273 696955 Ext. 67420**

The inbox and answerphone is operational on weekdays between 08.30 and 16.00.

We aim to return calls and emails on the same working day, but it may take up to 48 hours to get back to you.

If you are having issues relating to treatment please use the contact numbers the treating team have given you for advice.

Please do not leave a message if you are feeling very unwell as we are unable to provide emergency / urgent care.

If you feel your symptoms need urgent attention we advise that you contact your GP surgery or call **111**.

If your symptoms are serious and you think you need immediate medical attention, then please call 999 or visit the accident and Emergency Department at your local hospital.

Where else can I get help or information?

National charities:

- **Sarcoma UK: The bone and soft tissue cancer charity**
 - **Phoneline:** [0808 801 0401](tel:08088010401)
 - **Email:** supportline@sarcoma.org.uk
 - **Website:** www.sarcoma.org.uk
- **Bone cancer Research Trust**
 - **Phoneline:** [0800 111 4855](tel:08001114855)
 - **Email:** support@bcrt.org.uk
 - **Website:** www.bcrt.org.uk
- **Macmillan Cancer Support**
 - **Phoneline:** [0808 808 00 00](tel:08088080000)
 - **Website:** www.macmillan.org.uk
- **Cancer Research UK**
 - **Website:** www.cancerresearchuk.org
- **NHS website**
 - **Website:** www.nhs.uk/conditions

Brighton Information and Support Centre:

Macmillan Horizon Centre

- **Address:** Bristol gate, Brighton, BN2 5BD
- **Phoneline:** [01273 468 770](tel:01273468770)
- **Email:** horizoncentre@macmillan.org.uk
- **Website:** www.macmillan.org.uk

Clinic Letters

The sarcoma team at University Hospitals Sussex have an opt out policy for clinic letters.

Patients are usually copied into letters to their GP and other healthcare professionals – please advise your consultant or CNS, whilst you are in the appointment, if you would prefer not to receive these letters.

Feedback

To help improve and develop services we are always happy to receive informal feedback either verbally or in writing.

You may be asked to give feedback in the form of an audit or survey – if you are not happy to be contacted about this please let us know.

If you would like to contact University Hospitals about the services we offer there are links for complaints and compliments on the website <https://www.bsuh.nhs.uk/your-visit/patient-feedback/>

To raise a concern or complaint you can:

Contact The Patient Advice and Liaison Service. PALS can provide information about our services and liaise with healthcare teams on your behalf:

- **Email:** uhsussex.pals@nhs.net
- **Phone:** [01273 664511](tel:01273664511)

Contact our patient experience team:

- **Email:** uhsussex.patient.experience@nhs.net
- **Phone:** [01273 664511](tel:01273664511)

**This leaflet is intended for patients receiving care
in Brighton & Hove or Haywards Heath**

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