

Accessing Support: Sarcoma

Sarcomas can bring about various emotional challenges and it is important to look after your mental health as you navigate life with your diagnosis. Below are some resources aimed at enhancing your understanding of sarcomas and how other patients have dealt with the associated practical and emotional challenges. You might quite understandably wish to receive some support at times. For some people family and friends can be supportive, but you might also wish to contact one of the many organisations/services that can provide information or support to those with sarcomas. It is important to recognise that life with a sarcoma diagnosis can be challenging at times, and to allow yourself to seek help if you feel you need it.



Below is a list of organisations who may be able to offer you some support, as well as some resources that you may find helpful to read/listen to. The range and quality of services/support available from such organisations may vary. This list has been gathered as signposting only, and The Royal Marsden cannot guarantee the accuracy of the information provided by an organisation listed or the quality of their services.

If you have any questions or would like further advice/guidance about where to seek specialist help in your local area, you can speak with a member of your Royal Marsden treatment team or the Adult Psychological Support Service.

Cancer Research UK – Sarcoma Resources and Support

A collection of organisations, support groups, books, videos and other resources to help you cope with a sarcoma diagnosis and treatment. This site also links to a service where you can ask nurses specific cancer-related questions.

Website link: <https://www.cancerresearchuk.org/about-cancer/soft-tissue-sarcoma/living-with/resources-books>

GIST Cancer UK

A charitable trust which supports people affected by gastrointestinal stromal tumours. They run a telephone helpline service for GIST patients and their carers and provide supportive and informational group meetings. The website tracks developments in the treatment of GIST, and there are various helpful publications in the information section of their site.

Website link: <https://www.gistcancer.org.uk/>

Support line: **0300 400 0000**



Macmillan – Soft tissue sarcomas forum

An online cancer support group for people with soft tissue sarcomas and their loved ones. The forum provides an opportunity to share experiences and support other people affected by sarcomas.

Website link: https://community.macmillan.org.uk/cancer_types/soft-tissue-sarcomas-forum

Sarcoma Insight Podcast

A podcast which aims to improve sarcoma education for patients, friends, families and trainees. The goal of the podcast is to shed light on the processes of diagnosis, treatment and follow-up for patients diagnosed with sarcoma or other tumours of bone and soft tissue.

Website link: <https://open.spotify.com/show/1SxDvvDROXRdKvRnMuxd4L>

Sarcoma South UK Support Group

This group is made up of a small number of sarcoma patients and carers who have got together to make friends and support each other. They meet online every couple of months: an exact schedule can be [accessed here](#). For more information, you can email at info@sarcoma-support-south.org.uk or telephone at: **020 7250 8271**.

Website link: <https://sarcoma-support-south.org.uk/>

Sarcoma UK

A charity offering information, help and support for people who have had a diagnosis of sarcoma. Sarcoma UK offers a free support line which can be reached via email or text if you would prefer not to speak over the telephone. The Sarcoma UK website also has useful information about sarcomas, and the diagnosis, treatment and information about what is available in your region.

Website link: <https://sarcoma.org.uk/>

Support line: Telephone: **0808 801 0401** (Mon-Fri 10am-3pm)

Email: supportline@sarcoma.org.uk

Text: **07860 058830**

London Sarcoma Support

A place for those affected by sarcoma to meet in a safe, friendly, and supportive environment.

Website link: <https://www.londonsarcomasupport.net/>

Or you email to enquire about attending a session: londonsarcoma@yahoo.co.uk



Look Good Feel Better

Aims to help boost the physical and emotional wellbeing of individuals living with cancer through free online workshops and video resources. The underlying principle of this organisation is that, through self-care and taking care of one's appearance, it is possible to improve your self-confidence following physical changes due to cancer. They have materials tailored to men, women and teenagers, and work to assist people of all skin colours, ages, and cancer variations. Workshops include skincare, nailcare, grooming, oral care, shaving, hair loss and wigs, make-up, and advice on nutrition and fitness. They work with people up to one year post active cancer treatment.

Website link: <https://lookgoodfeelbetter.co.uk/>

Other APSS Information and Resources

The Adult Psychological Support Service has a range of signposting information sheets on topics such as: coping at different stages of the cancer pathway, supporting your physical and emotional wellbeing, relationships, and information specific to certain types of cancer.

You can view the signposting information sheets on The Royal Marsden's [Patient Information Library](#) and the [Adult Psychological Support Service Website](#) (under 'Further information and resources'). You can also request a copy of these by emailing Psychological.SupportAdmin@rmh.nhs.uk or telephoning **020 7808 2777** (Chelsea) / **020 8661 3006** (Sutton).

Additional support services

Cancer Care Map

An online database of cancer support services. You can search by postcode or by particular themes e.g. cancer type.

Website link: <https://www.cancercaremap.org/>

Maggie's Cancer Centres

Cancer care centres with multiple locations, including The Royal Marsden Hospital, Sutton and Charing Cross Hospital, West London. Workshops, groups, information and one-to-one counselling available.

Website link: <https://www.maggies.org/>

Phone number: **0300 123 1801**

NHS Talking Therapies

NHS website to help you find your local psychological talking therapies service based on your GP address. Your local NHS talking therapies service can be helpful if you would like psychological support for cancer when you are no longer regularly coming in for appointments at The Royal Marsden, as well as for concerns unrelated to cancer or that predated your cancer and have become worse due to it.

Website link: <https://www.nhs.uk/service-search/mental-health/find-an-nhs-talking-therapies-service/find-your-gp>



If you need any specialist and personalised advice about your cancer treatment, symptoms or side effects, please contact The Royal Marsden Macmillan Hotline. This hotline is available 24 hours a day, seven days a week on **020 8915 6899**.

The Royal Marsden's Adult Psychological Support Service offers short-term, cancer-specific psychological and psychiatric support. You can either self-refer or ask somebody in your Royal Marsden healthcare team to refer you. For more information, visit [Adult Psychological Support Service | The Royal Marsden](#). Alternatively, contact us directly on **020 7808 2777** (Chelsea), **020 8661 3006** (Sutton), or email Psychological.SupportAdmin@rmh.nhs.uk.



If you have ideas for other signposting or information sheets, or if you would like to be involved in working with APSS to improve the service we offer, please scan the QR code to see more about our patient and public involvement, or email Psychological.SupportAdmin@rmh.nhs.uk or telephone **020 7808 2777** (Chelsea) / **020 8661 3006** (Sutton) with your ideas.

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