

## Accessing Support: Unexpected Stoma Surgery

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Undergoing a stoma surgery is a significant life change for any person. An unexpected stoma surgery can be especially challenging, as you may not have been educated and emotionally prepared for a stoma to the same extent as people who undergo planned operations. Given that your stoma was unexpected, it is natural to feel a range of emotions following your surgery. It is important to be patient with yourself, and to remember that in time you can adapt to life with a stoma and lead an active and fulfilling life.



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.

### A Bigger Life – Emotions Following Stoma Surgery

A website containing a short video and some ideas around dealing with emotions that arise as a result of your surgery.

Website link: <https://abiggerlife.com/new-way-forward/emotions-following-stoma-surgery/>

### Bladder & Bowel Community – Stoma Skincare

This website outlines good practice in preventing and treating sore skin around your stoma.

Website link: <https://www.bladderandbowel.org/bowel/stoma/stoma-skincare/>

### CliniMed – Glossary of Useful Stoma Terms

Advice around stomas can contain a lot of specific terminology. This website is a glossary to help you get acquainted with some of the key terms relating to stomas.

Website link: <https://www.clinimed.co.uk/stoma-care/support-services/glossary>



## Colostomy UK – A-Z List of our Factsheets and Information Booklets

This website has downloadable information mostly covering practical concerns around living with a stoma such as information on types of bag, travel advice, a sleep guide, and guidance on stoma-related pain and discomfort.

Website link: <https://www.colostomyuk.org/information/a-z-list/>

## Colostomy UK - Support

Shows when and where regional support groups are taking place, and includes contact information for individuals who run the groups.

Website link: <https://www.colostomyuk.org/support-groups/>

Colostomy UK also run a free helpline which can be accessed for practical or emotional support with your stoma.

Access at: **0800 328 4257**, or alternatively you can email using: [info@colostomyuk.org](mailto:info@colostomyuk.org)

The website linked below takes you to Colostomy UK's telephone befriending service. This service is run by staff at Colostomy UK, or volunteers who are living with a stoma, and supports individuals with a stoma through feelings of loneliness or isolation. The helpline can also support you in accessing the telephone befriending service.

Website link: <https://www.colostomyuk.org/support/telephone-befriending-service/>

## Dansac UK: Your sexual self after stoma surgery

A comprehensive booklet on sexuality, using some of the common themes that patients and stoma care nurses have highlighted. The booklet offers suggestions to those feeling a little lost, worried or curious with regard to your sexual recovery following stoma formation.

Website link: [l0d0177-your-sexual-self-booklet-uk-2024.ashx](https://l0d0177-your-sexual-self-booklet-uk-2024.ashx)

## Fittleworth - Recovering from emergency stoma surgery

This is a link to a blog post outlining a patient's experience following an emergency stoma surgery. The author includes some support resources that she found helpful when recovering from her surgery.

Website link: <https://www.fittleworth.com/recovering-from-emergency-stoma-surgery/>

## Hollister – One-to-one Counselling

Hollister is a company that manufactures ostomy care products. They offer stoma patients specialist one-to-one counselling. If this is something you would be interested in let your RMH stoma nurse know and they can refer you to Hollister's services.

Website link: <https://www.securestart.co.uk/>



## NHS: Living with Colostomy

A brief guide from the NHS outlining areas important when trying to adjust to life with a colostomy.

Website link: <https://www.nhs.uk/conditions/colostomy/living-with/>

## NHS - Stoma Support Services Finder

Enter a location in the search box to be shown nearby stoma support services and their contact details.

Website link: <https://www.nhs.uk/Service-Search/other-services/Stoma%20support/LocationSearch/388>

## SecuriCare – Stoma Care Advice and Support

The box on the left-hand side of this website provides advice on a range of stoma related topics, including common stoma problems, engaging in physical activity, and what to expect in the first few weeks after an emergency stoma operation.

Website link: <https://www.securicaremedical.co.uk/advice-and-support/stoma-care>

There is also a blog post outlining one patient's experience of waking up to an emergency ileostomy. She describes her emotions upon waking and how her feelings towards her stoma changed over time.

Website link: <https://www.securicaremedical.co.uk/blog/waking-up-to-an-emergency-ileostomy>

## 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](mailto: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>

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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](mailto: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](mailto:Psychological.SupportAdmin@rmh.nhs.uk) or telephone **020 7808 2777** (Chelsea) / **020 8661 3006** (Sutton) with your ideas.

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