

Supported self-management after cancer treatment

Conquest Hospital, The Ridge, St. Leonard's On Sea, East Sussex, TN37 7RD

Eastbourne District General Hospital, Kings Drive, Eastbourne, East Sussex, BN21 2UD

Introduction

You have now completed your cancer treatment and have agreed to supported self-management (also called Patient Initiated follow up) at a post treatment appointment with your Consultant. Along with this leaflet, you will also be provided a Macmillan booklet, 'Life after cancer treatment' to help you deal with some of the questions and feelings you may have. Please ask your Key Worker or specialist nurse if you have not received one.

How does self-management work?

Supported self-management means not having any pre-arranged or scheduled hospital appointments with your cancer team and taking an active role in your own health. To achieve this, you will be given an end of treatment summary including information about the type, stage and grade of your cancer, treatment you have had, the possible side effects of treatment as well as signs and symptoms of a recurrence to watch out for. This means making contact with your Key Worker/Clinical Nurse Specialist by telephone if you notice any changes in your health that you are concerned about or a sign or symptom, we have asked you to report to us, at any time, whether it be early on after your treatment or many months later.

How long after my diagnosis can I contact my specialist nurse?

Your recovery is a gradual process. Two years after completing treatment, the risk of a cancer recurrence is generally low, even more so after five years (you may see this written as a five year survival in cancer information leaflets) and is an important milestone. This means many women can be cautiously optimistic that the cancer is unlikely to cause a problem in the future. With this in mind, your Key Worker/Clinical Nurse Specialist will be able to offer advice up to five years after your cancer was diagnosed.

How to contact my specialist nurse

At diagnosis, you will have been given a Macmillan information and support pack containing a business card of your Key Worker. Currently there are two Clinical Nurse Specialists, one based on each hospital site. Generally speaking, Sarah Quinnell provides guidance to women living around the Hastings, Rye, Battle area and Emma Mathurine provides guidance to women around the Eastbourne, Seaford, Lewes area.

If you have a concern, please contact your specialist nurse. It is important to leave your full name and contact number to enable a return call within twenty-four hours or next working day.

Sarah Quinnell Work Mobile: 07970 595985
Macmillan Clinical Nurse Specialist Gynae-oncology (based at the Conquest)

Emma Mathurine Work Mobile: 07812 461564
Macmillan Clinical Nurse Specialist Gynae-oncology (based at Eastbourne DGH)

What signs and symptoms do I need to report?

You will still develop illnesses related to viruses such as coughs and colds, or stomach upsets and potentially other health conditions that are not related to your cancer or treatment. You may also be more aware of general aches and pains and become worried the cancer has come back. This is quite normal and we understand it can take time to feel confident and secure in resuming a 'normal' way of life and/or adapting to the physical and emotional challenges you have experienced.

The list below is a general guide for signs and symptoms to watch out for and make contact with your specialist nurse who will decide whether you need to attend for a face to face hospital appointment with your cancer team or if a scan or blood test needs arranging first. If the symptom you are experiencing is less likely to be related to a gynaecological problem, we will ask you to make an appointment with your GP. We also recommend you refer to the end of treatment summary provided specifically for you. Please report:

- Any vaginal bleeding, even if it is only once
- Any vaginal bleeding after penetrative sex
- New vaginal discharge that does not settle over a period of a few weeks
- Change in bowel habit that does not settle over a period of two to four weeks e.g. diarrhoea or constipation
- New pain or lump in your abdomen/pelvis
- Unintentional weight loss (without dieting or exercise)
- Feeling full easily and/or loss of appetite which does not improve over a two to four week period
- New leg swelling which could be lymphoedema or a deep vein thrombosis (otherwise known as DVT - this needs urgent medical attention and should be reported to your GP on the day)
- For women who have had a vulval cancer: vulval soreness, new lump in the vulval or groin area, persistent vulval itching or discomfort, difficulty passing urine and any of the above symptoms listed

Recovering from cancer

Hopefully you will not experience any further problems from your cancer but we understand emotional recovery after treatment can take longer than the physical impact. It is normal to have 'up' and 'down' days for a while afterwards and common feelings may include anxiety, feeling low and you may find it hard to believe you have had a cancer. It is important to know your feelings will usually get easier with time. We encourage you to talk to friends and family as

most people find this helps them cope and feel less alone. If however your feelings become worse and you are struggling emotionally, please do contact your specialist nurse as there is support available, such as talking to a Macmillan counsellor or accessing local support groups. You may also find the Macmillan booklet 'How are you feeling? The emotional effects of cancer' booklet helpful, which your specialist nurse can post to you.

Sources of information

Clinical Nurse Specialist Gynaecological cancer, Macmillan.

Important information

This patient information is for guidance purposes only and is not provided to replace professional clinical advice from a qualified practitioner.

Your comments

We are always interested to hear your views about our leaflets. If you have any comments, please contact the Patient Experience Team – Tel: 0300 131 4731 (direct dial) or by email at: esh-tr.patientexperience@nhs.net

Hand hygiene

The trust is committed to maintaining a clean, safe environment. Hand hygiene is very important in controlling infection. Alcohol gel is widely available at the patient bedside for staff use and at the entrance of each clinical area for visitors to clean their hands before and after entering.

Other formats

If you require any of the Trust leaflets in alternative formats, such as large print or alternative languages, please contact the Equality and Human Rights Department.

Tel: 0300 131 4434 Email: esh-tr.AccessibleInformation@nhs.net

After reading this information are there any questions you would like to ask? Please list below and ask your nurse or doctor.

Reference

The following clinicians have been consulted and agreed this patient information:

Mr Elhami Ebeid Consultant Gynaecologist and Gynae-oncology lead

Miss Kerry Sargant Consultant Gynaecologist with interest in gynaecological cancer

Miss Sarah Quinnell, Macmillan Clinical Nurse Specialist Gynaecological cancer

The Clinical Specialty/Unit that have agreed this patient information leaflet:

Obstetrics and Gynaecology

Next review date: February 2025

Responsible clinician/author: (Emma Mathurine, Macmillan Clinical Nurse Specialist Gynaecological cancer)

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