Information Leaflet

NHS
Liverpool Women's
NHS Foundation Trust

Care after Cancer of the Womb

Introduction

You have now completed treatment for cancer of the womb and this leaflet has been written to support you moving forward; with guidance on recovery, getting back to "normal", your follow up and to help you decide if, or when, you should contact your Gynaecology Oncology Clinical Nurse Specialist (CNS). Your CNS and cancer support worker will be happy to provide further information & advice on all of the aspects mentioned in this leaflet.

Recovering from Cancer Treatment

Recovering from surgery

There is very good evidence that encouraging patients to return to normal as quickly as possible reduces problems and complications. This is called enhanced recovery and you will have received information about this during your hospital admission.
Your recovery will depend on many things which makes it difficult to give an exact timeline. You should try to do a little more each day and use common sense to determine what is right for you. If you had keyhole (laparoscopic) surgery your recovery should be rapid and the majority of ladies are able to do most things after a few weeks. If you had a traditional, larger incision (laparotomy) recovery can be a little longer. It is usual for it to take several months for you to feel fully recovered.

Recovering from radiotherapy

Not all women have radiotherapy for their womb cancer; this section applies to those who have had this treatment. Additional information and advice will be provided by your CNS team.

The majority of side effects appear within the first or second year after treatment, but can start up to five years later. Treatment can cause the vagina to narrow and shorten, and become less elastic. This can cause discomfort or pain during intercourse or an internal examination. The regular use of vaginal dilators will help prevent vaginal narrowing and their use is recommended even if you are not sexually active. It is not unusual for women to experience a change in their emotions and feelings associated with sex. Most women will have some changes in the way their bladder or bowel works.

The impact of these side effects varies from person to person. For some women the effects may be minor and will not affect their daily life, some women may need to make changes to their lifestyle to be manage these effects. For a small number of the women the changes may be difficult to cope with. Much can be done to help if this happens; speak to your consultant about this - they can also refer you to a doctor who has a special interest in treating long-term side effects of radiotherapy.

Managing menopausal symptoms

Most women who experience womb cancer will have already gone through the menopause. Surgery for womb cancer can include removing the ovaries, which would then cause pre-menopausal women to go through the menopause.

Hot flushes and night sweats are the most common menopausal symptoms, but many women also notice weight changes, sleep disturbances, vaginal dryness and changes in libido. If you are suffering from vaginal dryness, vaginal lubricants and moisturisers can be prescribed.

Hormone Replacement Therapy (HRT) is generally not routinely recommended for women who have been treated for womb cancer. However, if the symptoms are affecting quality of life, the risks and health benefits of starting HRT can be discussed with your consultant. Alternatively some women find herbal remedies and complimentary therapies such as acupuncture, hypnotherapy, massage or aromatherapy helpful for their symptoms.

Do tell your CNS or GP if menopausal symptoms are troubling you.

Getting back to “normal”

Reaching the end of treatment can be a difficult time whilst for others it is a sign that things can start to get back to normal. Many women are able to return to normal, or find and be comfortable with a new normal, but for others this may be more difficult. There is no right or wrong way to feel. Your CNS will be happy to provide more information on all the areas mentioned below.

Support: Some people prefer not to talk things through, while others get support from speaking about their experience. Details of support groups can be provided by your CNS.

Work: You can return to work whenever you feel ready to do so. All jobs are different so it’s hard to be specific. Whenever you return, remember it may be a shock to the system to begin with and it can be very useful to return in a phased manner, increasing your work hours over a few weeks.

Financial concern: You will be eligible for free prescription, if you are not in receipt of this please speak to your CNS. You may also be entitled to certain grants and benefits, this can be individually assessed or you can call the Macmillan helpline on 0808 808 00 00. If any other financial issues are causing you worry, speak to your CNS who can advise who can help.

Resuming sexual activity: It is vital to abstain from intercourse for 12 weeks following your surgery. It is not uncommon to lose interest in sex. Your treatment may leave you feeling more tired, or you may feel shocked, confused or depressed about being diagnosed with cancer. Try to share your feelings with your partner, if you have one. If you feel you have problems with sex that aren't getting better with time, you may want to speak to a psychosexual counsellor.

Travelling abroad: Once you have completed your treatment, there is no reason not to travel abroad. Sometimes patients can experience difficulty in acquiring travel insurance, your local Macmillan Support and Information Centre and the Macmillan website will be able to offer advice.

Fatigue: Though fatigue is a common symptoms there are steps you can take to reduce or cope with this. Top tips include – take it easy, conserve your energy, maintain your energy & get moving.

Exercise: Try to gradually increase your daily activity, with the aim of trying to build up to four or more thirty minute sessions each week of activities that increase your heart rate. If you require further information to access any local programmes please speak to your CNS team.

Diet: Evidence shows that maintaining a healthy weight, avoiding excessive weight gain, and maintaining levels of physical activity is associated with an improved quality of life and enhanced recovery. Top tips: keep to your meal routines, chose reduced fat, walk off the weight, pack a healthy snack, look at labels, caution with your portions, think about your drinks & focus on your food.

Follow up

Following the end of your treatment you will begin a three year surveillance period, the aim of this is to ensure everything is going well and find out if you have any concerns. You will be stratified into one of the following methods of surveillance; this is decided by the MDT depending upon your final results.

Clinical follow up. Traditional Face to face appointments at the hospital with a doctor, during which you will be asked questions about your recovery and any side effects or symptoms you have been experiencing. You may also have an internal examination.

Supported self-management. Rather than face to face appointments you will instead be supported by a care navigator & your CNS to be in control of your own three year surveillance period. Through an education event and on online portal you will be provided with essential information to help you manage your own follow up and live well beyond cancer. Further information will be provided if this is your follow up method.

When to contact your CNS

It is important to remember you will still get coughs, colds, aches and pains and bowel upsets just like anyone else. Your GP will normally be happy to treat such problems. However if they are concerned about your symptoms when they see you, they can contact your CNS who can arrange a clinic appointment.

For most patients their treatment is effective and their cancer will not come back but sometimes people do have problems. We would like you to contact your CNS if you have any of the following symptoms and they persist for more than two weeks:

- New onset of bleeding or persistent discharge from the vagina
- Bleeding from the back passage and/or changes in bowel habit

- Persistent abdominal bloating
- Bleeding after sexual intercourse
- New problems with passing water
- New persistent aches, pains, discomfort or lumps in your tummy
- New lower back pain
- Unexpected weight loss without dieting or exercise
- Persistent loss of appetite or nausea
- New persistent breathlessness
- New swelling of one or both legs

It is important to remember that even if you have some or all of these symptoms it does not necessarily mean the cancer has come back, but we will arrange to see you in clinic to check you over. Do remember, however, that some of these symptoms can also be caused by other conditions that are completely unrelated to womb cancer, so please do not become unduly anxious while awaiting your review.

You can contact your CNS team Monday – Friday 08.00-16.00 using the details provided at the end of this leaflet. If you phone and they do not answer please leave a message and contact number on the answerphone and you will be contacted as soon as the CNS picks up your message.

Worries about cancer returning

It is entirely natural to feel anxious that your cancer may return and we recognise that this can make you feel very uncertain about the future and lead to difficulties in “getting on with life”. Should there be any cause for concern, you will be reviewed by the clinical team and appointments or appropriate investigations will be organised for you.

Ways to manage worry and uncertainty about cancer

- Learn to focus on the ways cancer has made you a stronger person.
- Talk to family and friends about your concerns
- Join a support group
- Write a diary about your fears and feelings.
- Get involved with an interesting hobby or other things you enjoy doing.
- Review your priorities towards interesting and meaningful activities.
- Remember that as time goes by, your worries can fade.
- If depression, anxiety or any part of the cancer journey becomes overwhelming seek advice from your CNS or GP

How to contact the Gynaecology Oncology Clinical Nurse Specialist team:

Monday to Friday 8am-4pm telephone 0151 702 4186.

If you get the answerphone please leave your name, date of birth, telephone number and a brief message. Your call will be answered within 24 hours, or on the next working day if it is a weekend or bank holiday.

Support Networks Available Locally

Further information, advice and support are available for yourself/partner and family from:

Lyndale Cancer Support Centre - Knowsley
Tel: 0151 489 3538
Email: support@knowsley-cancer-support.co.uk

Sefton Support Group
Website: seftonsupportgroup.org
Tel: 01704 879352
Email: hello@seftonsupportgroup.org

St Helens Cancer Support Group
Website: sthelenscancersupportgroup.org.uk
Tel: 01744 21831
Email: contact@sthelenscancersupportgroup.org.uk

Halton Cancer Support Group
Website: www.haltoncancersupport.org.uk
Tel: 0151 423 5730

Macmillan Delamere cancer centre
Tel: 01928 753502
Email: Whh.macmillandelamerecancercentre@nhs.net

Isle of Man
Lisa Lowe centre & Manx Cancer Help
Website: www.manxcancerhelp.org
Tel: 01624 679118
Email: info@manxcancerhelp.org

Liverpool Sunflowers
Website: www.liverpoolsunflowers.com
Tel: 0151 726 8934
Email: info@liverpoolsunflowers.com

The Holistic Cancer Centre (Wirral)
Website: www.holisticcancercentre.org.uk
Tel: 0151 652 9313

Maggie's: Wirral
Website: www.maggies.org/our-centres/maggies-wirral
Tel: 0151 334 4301.
Email: wirral@maggies.org

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