

## Care After Cancer of the Cervix

### Introduction

You have now completed treatment for cancer of the cervix 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 the aspects mentioned in this leaflet.

### Recovering from Cancer Treatment

After treatment, you'll probably be keen to get back to a sense of ordinary life. However, you may still be coping with the side effects of treatment and with some difficult emotions. Recovery takes time, so try not to be hard on yourself and you may find you have 'up' and 'down' days for a while afterwards.

### Recovering from surgical treatment for cancer of the cervix

There is very good evidence that by encouraging patients to return to normal as quickly as possible following surgery, reduces problems and complications. This is called an 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. We encourage you to try to do a little more each day and use self-awareness to determine what is right for you. Another factor in your recovery is the type of surgery you had. If you had a large loop excision of the transformational zone (known as LLETZ procedure) or a cone biopsy, your recovery should be quicker, and most women are able to do most things after a few weeks. If you had a larger surgery such as a trachelectomy or radical hysterectomy laparotomy and had your pelvic lymph nodes removed, recovery can take a while longer. Usually, this type of surgery can take several months for you to feel fully recovered. Information regarding your recovery will have been provided to you prior to your discharge from hospital. However, if you do have any questions, you can contact your CNS and cancer support worker.

Depending on your diagnosis, further treatment may be required, this being adjuvant (additional) chemoradiation. This is given to help reduce the risk of the cancer coming back. Not everyone needs adjuvant (additional) treatment after surgery. If the cancer has spread to your lymph nodes or if the cancer was close to the edge of the resected tissue. If required, we would aim to start adjuvant treatment approximately six weeks after your surgery. This allows time for recovery after your surgery.

## **The impact of cervical cancer**

Being diagnosed with cervical cancer, being treated, and reaching the end of treatment can have both an emotional and physical impact on you. For some it is a sign that things can start to get back to “normal”. Many women return to a state of normality or can find and be comfortable with a new normal, yet 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.

### **Emotional Impact**

Coping with a cervical cancer diagnosis and treatment can be hard. You may have many different emotions, from numbness, shock, or fear, to anger, guilt, or sadness. It may leave you feeling out of control of your life and future. It is often more difficult to deal with the unknown, so having the right amount of information and support may help you feel more in control. Your CNS is happy for you to talk through any concerns or questions when you have them. After treatment, you may feel relieved that it’s over but also nervous about the future. It is common to feel anxious that the cancer may come back. Knowing the risks and what options are available if this happens can help you to cope with any fears.

### **Physical Impact**

**Fatigue:** Though fatigue is a common symptom after surgery, radiotherapy and chemotherapy, there are steps you can take to reduce and cope with this. Top tips include – take it easy, conserve your energy, maintain your energy & get moving.

**Scaring:** Depending on the type of surgery you have; you may have some scars. These should fade over time. Some scars may cause localised numbness which should improve after a few months. If you have any problems with scaring speak to your surgical team and CNS.

**Lymphoedema:** Lymphoedema is more likely to develop after surgery that has involved the removal of pelvic lymph nodes and in women who have radiotherapy following cervical cancer surgery which included the removal of pelvic lymph nodes. Lymphoedema is when your leg, legs, pelvic area or both swell with fluid that struggles to drain on its own. Your lymph nodes job is to drain lymphatic fluid (waste fluid from cells) so it can be removed by your body. When lymph nodes are removed this can cause a build-up of fluid whilst your body compensates for the lymph nodes that have been removed. It is common that fluid can accumulate in the tops of your thighs following surgery and will improve over time, yet for some women this may be more persistent. There are ways to reduce the risk of lymphoedema and to manage it through exercise, massage, and light compression hosiery. If you are concerned about lymphoedema, speak to your CNS who can offer you more advice.

**Changes to your bowel or bladder:** After surgery and treatment, some people experience changes in how their bowels, bladder or both work. Sometimes these changes only last for a short period of time and eventually improve. However, for some people, these changes can be more persistent, may get worse after treatment or may only develop a while after treatment has finished, known as a late effect from treatment. If you experience bowel or bladder changes, it is important to speak to your CNS who can help you get the right support.

**Menopause:** If you have not already gone through menopause and during surgery you have your ovaries removed, early menopause may be triggered, known as a surgically induced menopause. Having radiotherapy may also mean you are more likely to go through menopause early.

Hot flushes, night sweats and mood changes are the most common menopausal symptoms, but many women also notice weight changes, sleep disturbances, vaginal dryness, and changes in libido. Hair and skin can become dry, and your joints may be painful. In time, low oestrogen levels can cause osteoporosis (thinning bones) and heart disease.

If you are suffering from vaginal dryness, vaginal lubricants and moisturisers can be prescribed.

Most women with cervical cancer can safely take Hormone Replacement Therapy (HRT) for the management of menopausal symptom and can prevent osteoporosis and there are many different forms of HRT available such as tablets, patches, and creams. HRT, however, may not be suitable for all women with cervical cancer so you should discuss taking HRT with your medical team or a menopause specialist. Alternatively, some women find changes to lifestyle, herbal remedies, and complimentary therapies such as acupuncture, hypnotherapy, massage, and aromatherapy helpful for their symptoms. Do tell your CNS or GP if menopausal symptoms are troubling you.

**Changes to your vagina:** the upper part of your vagina is removed as part of your surgery and does not usually have any impact on your sex life and relationships. If this affects, you sex life and relationships please contact you CNS who can support you with this.

**Changes to your sex life:** Following your surgery, it is strongly advised that you abstain from penetrative intercourse for 12 weeks. It is important that your internal anatomy, following the removal of your cervix, has time to fully heal. Your sex life may also change following your treatment for cancer of the cervix because of physical and emotional factors and, it is not uncommon to lose interest in sex and intimacy following your treatment for cancer. Treatment may have triggered menopause or caused vaginal stenosis and sex may be more uncomfortable. You may feel differently about yourself or your sexuality and have other physical changes such as scars and hair loss that affect your body image which may impact on your relationships. We encourage you to share your feelings if your feelings towards sex and intimacy have altered and take time to introduce intimacy if you wish to do so. You can discuss this privately with your CNS for advice. If you feel you have ongoing problems with sex and intimacy that are not getting better with time, you may wish to consider speaking to a psychosexual counsellor.

## **Other concerns**

**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, and some are listed at the end of this leaflet.

**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, choose 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.

**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.

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

## **Follow up after treatment**

**Clinical follow up.** Once you have completed your treatment, you will begin a five-year surveillance period. The aim of this is to ensure everything is going well post treatment and to explore any of your concerns. You will have traditional follow up appointments every 3-6 months. During your appointments you will be asked questions about your recovery and any side effects or symptoms you have been experiencing. You may also be offered a pelvic examination and internal examination. If you are experiencing problems or are worried about anything between your appointments, you are encouraged to contact your CNS team who can assess you and if needed, can bring you back in for a clinic appointment sooner.

## **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.

We would like you to contact your CNS if you have any of the following symptoms and they persist for more than two weeks:

- Bleeding from the vagina
- Bleeding from the bowel/ back passage
- Bleeding after sexual intercourse.

- Bowel changes, if this is new e.g., diarrhoea or constipation.
- Problems passing urine (if this is new).
- New aches and pains or lumps in abdomen.
- Vaginal discharge.
- Weight loss without dieting or exercise.
- Feeling generally unwell.
- Swelling of the legs.

It is important to remember that even if you have some or all 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 cervical cancer.

You can contact your CNS team Monday – Friday 8am – 4pm 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

Sefton Cancer Support Group  
Tel: 01704 879352  
[www.seftoncancersupport.org.uk](http://www.seftoncancersupport.org.uk)

St Helens Cancer Support Group  
Tel: 01744 21831

Warrington & District Cancer Self-Help Group  
Tel: 01925 453139

Widnes & Runcorn Cancer Support Group  
Tel: 0151 423 5730

Isle of Man  
Manx Cancer Help Association  
Tel: 01624 679554  
[www.manxcancerhelp.org](http://www.manxcancerhelp.org)

Liverpool Sunflowers  
Liverpool Cancer Support  
Tel: 0151 726 8934

The Wirral Holistic Care Services  
Tel: 0151 652 9313  
[www.wirralholistic.org.uk](http://www.wirralholistic.org.uk)

Maggie's Cancer support Wirral  
Centre Clatterbridge  
Tel: 0151 334 4301  
[www.maggies.org](http://www.maggies.org)

Jo's Cervical Cancer Trust  
Tel: 0808 802 800  
[www.jostrust.org.uk](http://www.jostrust.org.uk)

Macmillan  
Tel: 0808 808 0000  
[www.macmillan.org.uk](http://www.macmillan.org.uk)

Menopause Matters  
[www.menopausematters.co.uk](http://www.menopausematters.co.uk)

The Daisy Network  
[www.daisynetwork.org.uk](http://www.daisynetwork.org.uk)

**This leaflet can be made available in different formats on request. If you would like to make any suggestions or comments about the content of this leaflet, then please contact the Patient Experience Team on 0151 702 4353 or by email at [pals@lwh.nhs.uk](mailto:pals@lwh.nhs.uk)**

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