

Transforming Cancer Care in the Community



Positively managing your breast cancer

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This leaflet will guide you through the important questions and answers once your cancer treatment has been completed. Hinchingsbrooke Health Care Trust wants to:

- Do all we can to ensure you feel fully supported moving forward in life after cancer treatment
- Know what health issues to report, how, when and to whom?
- Know who to contact for non-health matters
- Have the opportunity to attend our varied well-being workshops
- Understand what happens about any follow up tests and results.

SUPPORT WHEN TREATMENT ENDS

Some patients are able to move forward on their own and require little or no on-going support after completing their cancer treatment, which can feel like a real achievement and relief. But for other patients, when that final session is over, the sense of relief you might have been expecting may not always happen. Many people describe the end of their medical treatment as a time when they feel very low, confused, vulnerable or alone. You might feel that family, friends and work colleagues expect you to get back to 'normal' and move on from your cancer experience, but we know this is not always easy and on-going help is important and essential.

If you have been focussing on getting to the end of your treatment, the seriousness of what you've been through and the effect it has had on you, your family and friends, may only impact on you once treatment finishes or many months later. After treatment has ended, the healing process could be linked to many questions including:

- Physical issues & fitness
- Weight management
- Coping day to day
- On-going side effects of cancer treatment
- Finances, debts and benefits
- Fear of recurrence and the 'What if' question
- Getting back to work
- Sexuality, relationships and emotional needs
- Self-image and body changes
- Lack of confidence
- Making a new start
- Changed life priorities
- Simply wanting to talk about your experiences

The issues above can take many months for the patient, partner and their family to resolve. Our role is to give the help and support to patients and families who need it, ensuring your experience of cancer services in Huntingdon is positive, enabling and responsive to your long term well-being.

TAKING CONTROL OF YOUR LIFE WITH SELF-MANAGED AFTERCARE

You have now come to the end of the main part of your treatment and may now be receiving tablets, such as hormonal therapy, or other drug treatment. We will now offer you a patient led follow up service known as 'Self-Managed Aftercare' which is an innovative form of 1-2-1 support and follow up help where you are able to take the initiative and be in control of moving on with your life after cancer treatment.

WHAT HAPPENED BEFORE SELF-MANAGED AFTERCARE?

Patients had regular follow up consultant appointments, but research has shown that it is rare that a recurrence of cancer is detected in this consultation. This form of follow up does not improve diagnosis or life expectancy and can cause unnecessary anxiety or hospital visits. Your progress has indicated that you no longer need to see a consultant as part of your on-going follow up or regular tests; instead your support will be delivered via the new Self-Managed Aftercare service

WHAT IS SELF-MANAGED AFTERCARE?

Self-Managed Aftercare has been successfully implemented in many other hospitals. Research has shown that by providing information, 1-2-1 support and prompt access to help when you have worries or concerns about your health, practical, daily living or emotional issues improves your sense of control, confidence and well-being.

General Questions and Answers

Q. I am perfectly happy that my cancer treatment has ended and currently I don't want any further contact, support or help.

A. This is absolutely fine but if in the months ahead you change your mind, something starts to concern you or you would like to talk to someone about yourself or family please phone the your Clinical Nurse specialist, GP or the Woodlands Centre. They will be more than happy to help or assist you in anyway possible. However, we would recommend that you may find it very beneficial to attend our Well-Being Workshops as part of your on-going recovery. The dates and times of these are available through the Cancer Support & Information Centre or your Nurse Specialist

Q. What can I do if I am worried my former cancer symptoms might be coming back or a new unexplained ache or pain is concerning me?

A. You need to phone your Clinical Nurse Specialist in the first instance who will continue to be an essential point of contact for any medical, health or complex emotional issues. If unavailable, please contact the Woodlands Centre who will do all they can to get a medically trained member of staff to talk to you. If further investigation is needed, you might be asked by your **Clinical Nurse Specialist** to have further tests, referred to your GP, a trained counsellor or consultant.

Q. What is the positively managing your cancer Workshop I will be expected to attend?

A. You will be given an appointment to attend a local well-being workshop with other patients who have cancer. This will give you an opportunity to hear about and discuss what to expect after treatment, normal aches and pains, medication, asking for help, managing day to day symptoms, signs of recurrence and the importance of healthy living

Q. What happens about my follow up tests?

A. You will be provided with a plan of when and what follow up tests will take place that will automatically be arranged by our administration team.

Q. How long will I wait for the results?

A. Dependant on the test, staff will be able to tell you when to expect the results and where to phone if you haven't heard within the time they tell you.

Q. Will I see my consultant or member of the medical team as part of any routine follow up tests?

A. You will not require face to face meetings with a consultant or member of the cancer team. However, we can assure you that all routine tests will continue to be professionally medically assessed and considered as part of our highest standards for monitoring your on-going well-being, medical needs and health.

Q. What if a test needs more investigation?

A. Very rarely, a routine test might require further investigation, you will be contacted as a priority with further information or for additional tests if required.

Q. If I need a consultant appointment as a result of my routine tests will it be delayed because I am not seeing them on a regular basis?

A. Absolutely **not**. Should there be a need to see a cancer consultant you will be fast tracked to ensure that there is no delay in obtaining a medical opinion if needed.

Q. What happens when I need to talk to someone during the weekend, bank holiday or out of hours?

A. Please phone:

- **999** if you believe it is an emergency
- **NHS Choices 111** (when you need medical help fast but it's not a 999 emergency)
- Contact your out of hours GP service
- Phone your ward if recently discharged.

Q. What if I find I need more help emotionally than a volunteer befriender can offer?

A. You may find it helpful to contact your Cancer Nurse Specialist who can offer advice and support.

We can also provide you with the opportunity to attend a course called **Helping Overcome Problems Effectively (HOPE)** which is a supported self-management programme for cancer survivors. The HOPE course is six weeks long, each session being 2.5 hours and is run by a trained tutor and or cancer survivor/peer. The core content may include:

- Instilling hopefulness
- Gratitude
- Goal setting
- Preparing for change
- Challenging unhelpful thinking
- Finding motivation
- Progressive muscle relaxation
- Communication with health professionals
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Course outcomes are assessed before the course, on completion of the course, and then six and 12 months after the course. At six months after the course, a range of patient reported Outcomes were measured and the results showed:

- Improvements in quality of life, in particular fatigue and physical pain
- Reduced distress over recurrence – a component of cancer related quality of life
- Increased confidence to meet goals

Following Treatment for Breast Cancer

Many patients ask us about what to expect after they have completed their treatment for breast cancer. This may include physical changes or side effects from treatment or the lasting emotional effects. Patients also ask us what sort of symptoms they should look for, or problems that we feel you should report to us. You will be given a pack called 'Moving Forward' which addresses all of the common issues for patients and how they can be addressed:

REASONS TO CONTACT YOUR SPECIALIST NURSE

1. Symptoms

Many women are cured of their cancer by the treatment they have received and live without any cancer related problems. You will get normal coughs and colds, aches and pains. You may have symptoms that cause you anxiety and concern. You may worry that the cancer has come back. The following symptom guide may help you to know which symptoms to seek further advice about. If you have any of the following symptoms, for more than four to six weeks, which are getting worse rather than better, then please contact your nurse specialist (key worker) if you experience any of the following:

- New changes/ lumps in your breast / breasts
- Swelling of the arm (lymphoedema)
- Unexpected vaginal bleeding
- Lumps around the collar bone (clavicle)
- Persistent back pain or pains in your bones which wake you at night
- Persistent shortness of breath, or cough

2. Side Effects of Medication

You may experience symptoms and side effects from the tablets that we are giving you. You will have been given a leaflet about the specific side effects of the tablets. However, you may have symptoms that you wish to discuss. These are often menopausal symptoms that the tablets cause by removing the effects of oestrogen from the body. You may have been given a leaflet about menopausal symptoms and how to cope with them. The main symptoms are hot flushes and night sweats.

3. Bras and Prosthesis

If you need advice on bras or breast prosthesis please contact your breast care nurses secretary to make an appointment:

4. Lymphoedema

Some patients may be at increased risk of lymphoedema (swelling of the arm or hand) due to the treatment they have had. If you notice any such swelling please contact your nurse specialist who can advise you and offer the correct management.

5. Psychological Support

We recognise that there will be times when you feel uncertain about the future. Reactions to breast cancer treatment are individual and varied and there is no right or wrong way to feel. It may take some time to feel that you are in control of your life. If you need additional support after treatment this too can be discussed with you at a clinic appointment with a nurse specialist, or your GP. The time it takes to recover from treatment can vary and again, this is an individual experience.

6. Media Reports

Every day, there are articles in newspapers and women's magazines, as well as radio and television discussions about breast cancer. Often myths and worrying facts make breast cancer seem something to be feared. Despite this, encouraging advances in the development of breast cancer treatment over the last decade have led to improved response rates and survival for women. If you are uncertain or worried about anything you have heard, or read, please feel free to contact your nurse specialist.

7. Consultant Consultation at end of treatment

It is helpful to come prepared for your follow up clinic appointment by writing down any questions or concerns you may have before coming to the clinic. It is important to us that when you leave you feel satisfied that your questions have been answered.

WHAT HAPPENS NEXT?

1. Mammograms

You will have regular mammograms for 5 years. The 1st mammogram will be about 1 year after your diagnosis.

- If you have had a wide local excision (lumpectomy) you have these once a year for 5 years.
- If you have had a mastectomy, you will have these at 1 year, then on the 3rd and 5th years.
- After 5 years you will be entered back onto the National Breast Screening Programme
- If, after 5 years, you are over 70 years of age you can self-refer into the National Breast Screening Programme.

After five years:

- if you are under the age of 50, you will continue to have annual mammograms until you reach the age of 50, then have three yearly mammograms within the National Breast Screening Programme
- If you are between the ages of 50-70, you will have 3 yearly mammograms within the National Breast Screening Programme
- If you are over 70 we advise you to have mammograms every 3 years.

2. Blood tests and scans

Blood tests are not routinely taken after treatment. This may cause you some concern, as you will have become used to having a blood test during your treatment. It is not necessary to take a blood test once treatment has finished, unless any unexpected symptoms you describe are causes for concern.

CT and bone scans are not done at the end of treatment or on a regular basis either, as they can cause unnecessary anxiety and do not show anything if there are no specific symptoms to investigate. If any new symptoms develop, the appropriate scan will be organised after you have been reviewed in the clinic.

Websites

www.macmillan.org.uk

www.breastcancercare.org.uk

www.breakthrough.org.uk

www.cancerhelp.org.uk

National support group(s)

Coping with breast cancer 0845 601 7152