

# Your breast cancer follow-up after treatment

# Information for patients

Follow-up is how we talk about what happens after you finish your treatment. This has been carefully planned for you and is called a personalised follow-up (PFU). This information explains your follow-up. If you have any questions, please speak to a doctor or nurse caring for you

Your breast care team has carefully planned your follow-up care. It includes information to help you become breast aware (in checking your own breasts), and to get support for your health and wellbeing. You can contact your breast care team at any time during your follow-up if you have any concerns.

# Personalised follow-up

After your treatment, you might be offered personalised follow-up (PFU).

PFU is sometimes called:

- personalised stratified follow-up (PSFU)
- patient initiated follow-up (PIFU)
- open access follow-up (OAFU)
- supported self-management (SSM)

You do not need to remember all these terms. They are all ways to describe planned care after treatment for cancer. We'll explain how things will work for you.

# What to expect during follow-up:

You will have mammograms as part of your follow-up. Mammograms (breast X-rays) will check for breast cancer recurrence (the cancer coming back). You will have mammograms once a year for 5 years. Your mammogram appointment will be sent to you in the post.

**If you are aged 50 or over**, your care will be moved from the hospital team to your GP and local NHS National Breast Screening Unit after 5 years. This is called being discharged. After you have been discharged, you will have your mammogram once every 3 years.

**If you are aged under 50**, you will still have a mammogram once a year until you are 50 years old. At 50, you will be discharged back to the care of your GP and local NHS National Breast Screening Unit and have a mammogram once every 3 years.

If you are aged 70 or over, you will have mammograms once a year for 5 years. After this, you might not be invited for routine screening, but you can have mammograms once every 3 years at your local NHS Breast Screening Unit. To do this, ask your GP for an appointment.

We highly recommended that you still ask for a mammogram to be arranged by your GP after 5 years

If you have had both of your breasts removed (a bilateral mastectomy), with or without reconstruction, you do not need to have mammograms. You do not need other routine scans, or appointments in the breast clinic, but you will stay on PFU for 5 years. This means that you can contact the breast care team (see contact details below) at any time if you have any worries or concerns. After 5 years, your care will be moved from the hospital team to your GP

# Mammogram results

After your mammograms, you will get your results as a letter through the post if everything is normal. If there are any concerns, your breast care team will contact you by telephone.

The effects of treatment (such as surgery or radiotherapy) can sometimes make it difficult for us to read the results. This means you might be asked to come back to the hospital to have more tests or scans. If this happens, you will be contacted by telephone. It is important to make sure the hospital has your correct address and telephone number.

If you do not get your results 4 weeks after having your mammogram, contact us through the breast clinical nurse specialist (CNS) helpline.

# Follow-up after hormone therapy

Some people have hormone (endocrine) therapy as part of their treatment. This can last 5 to 10 years, and your oncologist will plan this with you. After 5 years, your breast care team will contact you to decide the next steps. For example, you might stop having hormone therapy, you might continue this treatment, or you might need to have a different type of hormone therapy. If you are on hormone therapy you might also need to have a bone density (DEXA) scan during your follow-up. This will be explained to you by your oncologist and arranged by your GP.

### **End of Treatment Clinic**

After treatment, you will be invited to an End of Treatment Clinic to talk about your follow-up with your nurse. You will fill in a holistic needs assessment (HNA), to help your team develop a care plan. The HNA makes sure your needs are met, and you have all the support you need.

You will be given a treatment summary. This explains the treatment you have had, any possible side effects, signs of your cancer coming back, and information about medicine you are taking. We will send a copy of your treatment summary to your GP, and you will be able to keep a copy. Your nurse will support you to become breast aware and check your breasts if you have remaining breast tissue. They can also give your health and wellbeing support.

You will be given an information booklet called 'Moving Forward' to help you during your follow-up. If you do not have this booklet, please ask your breast care team for a copy.

# **Quality of life survey**

Measuring people's quality of life is about understanding:

- how cancer has affected them
- how well they are living after their diagnosis.

This includes people's emotional or social wellbeing, finances, and ongoing physical problems, such as tiredness and pain.

You will be sent a survey from NHS England by email or post 18 months after your diagnosis. Please complete the survey to tell us how cancer might have changed your quality of life.

The survey results will help us improve how we support people to live their lives as well as possible. Completing the survey can also help you to talk about the support you need with your team.

# When to contact your breast care team

You can contact your breast care team on the CNS helpline at any time during your follow-up. You can contact them to arrange a call back, or an appointment to talk about any new symptoms, treatment side effects, or worries or concerns you might have.

When you call the helpline, you can leave a message asking to be called back. A nurse will call you back by the end of the next working day. If they feel that it would be best for you to come back to the hospital, you will be given a clinic appointment.

### Contact us

If you have any questions or concerns about your follow-up, please contact the breast clinical nurse specialist (CNS) helpline, Monday to Friday, 9am to 5pm:

- King's College Hospital: 020 3299 3085
- Princess Royal University Hospital: 01689 863173

King's College Hospital offers a range of cancer-related information for patients and carers, available at www.kch.nhs.uk/services/cancer/

# King's Macmillan Information and Support Centre

King's Macmillan Information and Support Centre provides cancer support services. We have a drop-in information area and offer complementary therapies, psychological support and benefits advice for patients and carers.

The centre is in the Cicely Saunders Institute at King's College Hospital, Denmark Hill, tel: 020 3299 5228, email: <a href="https://kch-tr.macmillan1@nhs.net">kch-tr.macmillan1@nhs.net</a>.

# **Useful sources of information and support**

Your breast care team will give you information on the support available to you. Your GP might also be able to tell you about support in your local area.

**Breast Cancer Now** has information and support other people diagnosed with breast cancer, and breast care nurses, phone: 0808 800 6000, web: www.breastcancernow.org

**Cancer Research UK** has information for anyone affected by cancer. phone: 0808 800 4040, web: www.cancerresearchuk.org

**Cancer Care Map** helps you find cancer-related services in your local area. web: www.cancercaremap.org

**Cancer Wellbeing London** has information about health and wellbeing workshops, and support across London, web: www.cancerwellbeinglondon.nhs.uk

Citizens Advice Bureau gives free and confidential information and advice to help people with financial, legal and other issues, web: www.citizensadvice.org.uk

**Future Dreams House** is a national breast cancer charity based in King's Cross. They provide practical, emotional and psychological support. web: <a href="www.futuredreams.org.uk/">www.futuredreams.org.uk/</a>

**Macmillan Cancer Support** has practical and emotional information and support (online or over the phone), including financial information and support with work. phone: 020 3299 5228, web: www.macmillan.org.uk

**The Primrose Centre** offers Breast Cancer Support Centre Services in Orpington, near Bromley and Sevenoaks, Kent. web: https://www.primrosecentre.org.uk

**Shine Cancer Support** offers support for young adults in their 20's, 30's and 40's. web: www.shinecancersupport.org

**Trekstock** offers support for young adults in their 20's or 30's who are affected by cancer. web: www.trekstock.com

**Working With Cancer** helps employees, employers, the self-employed, job seekers and carers to manage cancer and work. They give coaching, training and advice. web: www.workingwithcancer.co.uk

### **NHS 111**

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day, tel: 111, web: www.111.nhs.uk

# **MyChart**

Our MyChart app and website lets you securely access parts of your health record with us, giving you more control over your care. Visit www.kch.nhs.uk/mychart to find out more.

# **Sharing your information**

King's College Hospital NHS Foundation Trust has partnered with Guy's and St Thomas' NHS Foundation Trust through the King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas' hospitals. King's College Hospital and Guy's and St Thomas' NHS Foundation Trusts share an electronic patient record system, which means information about your health record can be accessed safely and securely by health and care staff at both Trusts. For more information visit www.kch.nhs.uk.

# Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

### **PALS**

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. They can also pass on praise or thanks to our teams.

Tel: 020 3299 4618

Email: kings.pals@nhs.net

If you would like the information in this leaflet in a different language or format, please contact our Interpreting and Accessible Communication Support on 020 3299 4618 or email kings.access@nhs.net

**Networked Care** 

Corporate Comms: 3857

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