The Rotherham NHS Foundation Trust Secondary Breast Cancer Pledge

The standards of care and support you can expect and how to have your say
The Breast Team at Rotherham are already proud of the care they provide for Secondary Breast Cancer patients but recognise that there are always improvements that can be made and are committed to ensuring that the service given to patients is the best it can be. It has been a very positive experience working in partnership with our patients in developing this Pledge and we are looking forward to continuing to work together in the future to provide an excellent service.

The Breast Care Team
Your care at Rotherham NHS Foundation Trust

We’re working hard to make sure you are happy with the treatment you receive. However, we know from national research that sometimes people with secondary breast cancer don’t receive the support and care they need and that the way services are organised and delivered can sometimes be confusing and difficult to find your way around.

That’s why we’re working with Breast Cancer Now and Breast Cancer Care on our Secondary Breast Cancer Pledge. The Secondary Breast Cancer Pledge gives patients the opportunity to speak up about what matters most to you about your local service and help improve these things.

Where we could do better
With most things there’s room for improvement, and services for people with secondary breast cancer are no different. That’s why we’ve asked our patients to fill in surveys and talked to them about their experiences to help us understand what is important for them.

This booklet tells you what you can expect from Rotherham as well as the improvements we are making. It is based on both national guidelines and what Rotherham patients have told us needs to be improved.

Not all the improvements patients suggest can be done overnight, so on page 12 you’ll see a list of what we’re working on at Rotherham in the long term.

Talk to us
You’ve probably got your own ideas on what would improve your care. If you have, let us know. By telling us what you want, you’ll be helping to develop and improve the services we offer to patients with secondary breast cancer. See page 14 for how to get involved.
What you can expect from Rotherham Hospital’s secondary breast cancer service...

Someone to answer your questions
You will be able to contact a named clinical nurse specialist, at and from the point of your secondary breast cancer diagnosis onwards. They will be knowledgeable about the disease, treatment and support needs of people with secondary breast cancer. They will act as your ‘key worker’: co-ordinating your care, acting as your advocate and providing, or signposting you to, support and information.

This is someone you can call for support any time during working hours (Monday to Friday 8:00AM – 4:00PM). You will be given their name and contact details when you meet them. Outside of office hours you will be able to leave an answerphone message and your call will be returned within one working day. For other support outside of working hours please see page 11 for more information and contact details.

Your clinical nurse specialist is there to help make sure you get all the information and support you and your family want, so ask them if you need more. For instance, they can offer you counselling and, if needed, refer you to specialist services.

You can talk to your clinical nurse specialist in private if you are unsure about any areas of diagnosis, treatment or care. They can also talk to you about any family history of breast cancer you might have.

Your clinical nurse specialist is:

Name

Number
Your healthcare team
You will receive a multidisciplinary team approach to your care, which means that all healthcare professionals who contribute to the medical and nursing management of your care meet regularly to discuss your situation, so that you receive the best care for you. Your team includes members of the oncology and palliative care teams to ensure all aspects of your care are considered.

To make sure you get consistent care between the hospital and community services, communication between the hospital-based team and your GP (local doctor) will be as efficient as possible. Your GP will be informed and kept up to date about your condition and will be able to provide support and care when appropriate. You can decide whether you get copies of letters sent to your GP about your treatment.

Your treatment and care
You will be given timely information on all aspects of your treatment and care – both verbally and in writing. This includes a care plan and information about the purpose of your treatment, the side effects, and the potential impact on your wellbeing.

When any new treatment is proposed, you’ll get written information about its potential benefits, risks and side-effects, with time to decide whether you want it. Any treatment you have will be explained to you beforehand and you can ask questions.

Your information needs should be assessed on a regular basis and updated information provided about your diagnosis, test results and treatment plan, whenever any of these change. Support should be provided alongside all information given.
All the information you get should be right for you, whether that means it is in Braille, recorded, or in your chosen language. Your healthcare team will talk to you clearly and sensitively, using words you understand.

You will have access to all appropriate treatments and where appropriate, be made aware of the availability of clinical trials for which you may be eligible before treatment is started or changed.

You can be as involved as you want to be in decisions about your care and treatment. However much involvement you’d like, your options will be clearly explained and you’ll get the time, information and support you need to make your decision.

You can expect to be treated somewhere clean and safe.

Some medicines you might be taking could interact with your treatment. Tell your consultant about any medicines you are taking, including complementary medicines.

Your treatment plan has been designed specifically for you. If you have any concerns, please discuss these with the team caring for you before stopping or changing your agreed treatment plan. If you do decide to stop treatment, you can do so at any time and your decision will always be respected.

You can ask for a second opinion about your diagnosis and treatment. If you want a second opinion, you can talk to your clinical nurse specialist about how to do this.
Your appointments
Where possible, you’ll have a choice of appointments.
When you get to the clinic someone will tell you about any delays and when it’s your turn your name will be called clearly.
You will be seen somewhere comfortable where your privacy is respected. If students or trainees are there at your consultation, they will be introduced and you’ll be told why they are there and that you can ask for them to leave if you prefer. There will be time to ask questions and discuss the answers.

When you come to Rotherham Hospital
All the time you’re at Rotherham Hospital, you can expect to be treated with dignity and respect.

You will be told where you need to go for your treatment or appointment and how to get there with details on things like public transport and parking etc. If applicable, you will also be given information on how to reclaim travel costs.

You’ll be greeted when you come in and someone will tell you how long you’ll need to wait and why. And when you do get seen whoever treats you will introduce themselves by name and explain their role.

Whenever you’re examined, we’ll respect your dignity and need for privacy.
If you need to stay at Rotherham Hospital

If you’re staying, someone will tell you which bed you will be in and when it will be free. During a stay, you’ll share a sleeping area, toilets and shower facilities with other patients of the same sex. There will also be somewhere safe to put your things. You will get healthy meals and help eating if you need it. Our staff will do everything they can to make sure you get a good night’s sleep.

A doctor or nurse will discuss with you when you can go home and beforehand staff must make sure you have enough support at home and in your community.

When you’re discharged, you’ll be told who you should contact if you have any concerns.

Supportive and palliative care

You will have access to expertise in palliative care. This means specialist support with symptom control, such as ongoing management of troublesome symptoms and side effects. Your physical, psychological, social, spiritual and financial needs will be assessed and discussed with you regularly (Improving Supportive and Palliative Care for Adults with Cancer, NICE 2004). Information about end of life care should also be provided at a time you feel is appropriate.

We will let you know about any informal support services that are available both nationally and locally for you and your family.

Your emotional wellbeing will be assessed on a regular basis and you will have access to the appropriate level of psychological support. This should be when you need it, but particularly at diagnosis, if the cancer progresses, and when treatment changes.

Your family’s support and information needs should be assessed separately to your own by a healthcare professional involved in your care. They should be offered or signposted to information/support services specifically for them.
You can be as involved as you want to be in decisions about your care and treatment. However much involvement you’d like, your options will be clearly explained and you will get the time, information and support you need to make your decision.
Your other needs

We recognise that secondary breast cancer affects much more than your physical health. We’ll talk with you about other support you might need and where to find it, including:

- Complementary therapies
- Cultural support
- Employment advice, including your rights at work
- Exercise and healthy eating
- Financial support, including social security benefits
- Hair care services
- Local patient self-help groups
- Lymphoedema services and physiotherapy
- Occupational therapy
- Options for treatment closer to home
- Supportive and palliative care
- Prostheses
- Psychological, social or spiritual support
- Support available to partners, family, friends and children

If you’d like to know more about any of the above services or any other support you feel you might need then please ask your designated keyworker (the clinical nurse specialist within the team) who will be happy to help. Depending on the particular service we may be able to give you information, signpost you to someone who can help or make a referral.
We’re here to make it easier for you

If you have a concern about the care or support you are receiving
You can speak to one of the team caring for you or approach the Patient Experience Team on:
01709 42 4461 or email: yourexperience@rothgen.nhs.uk
You can also use our complaints procedure by contacting the Patient Experience Lead (Complaints Manager) at the above number and email.

For support after office hours
If you have a concern or question relating to treatment/chemotherapy please contact the Weston Park 24 hour helpline you have been given.

If your concern is regarding venous access/PICC line problems please contact A6 on 424208.

Hospice 24 hour helpline for emergency symptom control advice:
01709 428910.

If your concern is a general enquiry please contact your GP or District Nurse.

If your concern is support or information on psychological issues please contact your Macmillan Specialist Breast Nurse/Key Worker.

To find out if you are eligible to reclaim travel costs, please speak to your clinical nurse specialist.
Do your bit

Help us make sure you get the best possible treatment and help improve care by:

1. **Telling us as soon as possible if you need to cancel your appointment.** That way we can make good use of the time.

2. **Being patient.** We work hard to do the best we can for you, but please understand that you may have to wait for your appointment if those in front of you need more time.

3. **Telling us if your personal contact details change,** so we can always contact you about your appointments.

We’re working on it

Secondary breast cancer patients at **Rotherham Hospital** spotted these areas where we could do better. Here’s what we plan to do and when.

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<th>What you told us</th>
<th>What we’re doing about it</th>
<th>When we’re aiming for</th>
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<tr>
<td>You were routinely asked to change into a gown prior to seeing the doctor but often an examination wasn’t needed.</td>
<td>We will ensure doctors see patients fully-clothed first and if an examination is required they will step outside while the patient changes.</td>
<td>We made this change straight away by November 2015.</td>
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<tr>
<td>You are often left to wait for a long time in a small clinic room before the doctor arrives.</td>
<td>Patients will only be called through when the doctor is ready to see them. If unforeseen delays do then occur we will keep you informed.</td>
<td>We made this change straight away by November 2015.</td>
</tr>
<tr>
<td>What you told us</td>
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| You aren’t told about other support services or offered support if you have children or other caring responsibilities. | We will appoint a nurse practitioner to release the clinical nurse specialists’ time to support patients with secondary breast cancer.  
All patients will be offered a holistic needs assessment within a maximum of 3 weeks of diagnosis or any change of treatment. | April 2016.          |
| You weren’t sure who you should speak to about different types of problem or concern and were unclear about the role of your specialist nurse. | Clear written guidance will be given to all newly diagnosed patients at the point of diagnosis about who to contact in different circumstances, and how.                                                       | April 2016.          |
| Communication between the hospital and patients and between different parts of the hospital could be improved. | We will hold an annual patient forum for patients with secondary breast cancer.                                                                                                                                             | The first forum will take place by March 2017. |
Now tell us what you think

You wouldn’t be reading this booklet if our patients hadn’t given us feedback about our service. You can help too by telling us what you think about our services.

We hold an annual user group for patients with secondary breast cancer that you will be informed about and invited to.

Use your experience to develop Rotherham Hospital’s services for people living with secondary breast cancer. It’s a unique and powerful way to make life better for everyone affected by secondary breast cancer.
Breast Cancer Now

We’re Breast Cancer Now, the UK’s largest breast cancer charity – and we’re dedicated to funding research into this devastating disease.

At our heart we have a clear aim: to make sure that, by 2050, everyone who develops breast cancer will live. But it’s only by standing together with all those affected by the disease, and speaking together with one clear voice, that we’ll make it happen.

Right now, people all across the UK are giving their time to make sure our work can continue – whether that’s raising money, increasing awareness, making their voices heard or improving the way our society views and responds to breast cancer. And the more people who join us, the sooner we’ll stop women dying.

To find out more, visit our website: breastcancernow.org

Relevant Policy and Guidance


