Maidstone and Tunbridge Wells NHS Trust
Secondary Breast Cancer Pledge

The standards of care and support you can expect and how to have your say
The health care professionals at Maidstone & Tunbridge Wells NHS Trust responsible for the care for people with Secondary Breast Cancer believe that we already provide a good standard of care that we can be proud of. However, we recognise following the 2015 Secondary Breast Cancer Pledge that there are improvements that can be made.

We are committed to ensuring that our service offers the best care that it can to meet the health and social care needs of people with secondary breast cancer. Working in partnership with our patients, Breast Cancer Now and Breast Cancer Care in developing this Pledge has been a very positive experience, and we are looking forward to driving forward the service developments proposed.

Dr Russell Burcombe; Dr Rema Jyothirmayi; Dr Catherine Harper-Wynne; Claire Ryan Macmillan Nurse Clinician

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Breast Cancer Care  
Breast Cancer Now

Maidstone and Tunbridge Wells NHS Trust  
Hermitage Lane  
Maidstone  
Kent ME16 9QQ  
www.mtw.nhs.uk  
Maidstone Hospital: 01622 729000  
Tunbridge Wells Hospital: 01892 823535
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


Your care at Maidstone and Tunbridge Wells NHS Trust

We hope you’re happy with the care and treatment that you receive at Maidstone and Tunbridge Wells NHS Trust (Kent Oncology Centre and Tunbridge Wells Hospital). However, we know from national research that sometimes people with secondary breast cancer don’t receive the support and care they need. The way services are organised and delivered can also make life difficult.

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 them about their 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 Maidstone and Tunbridge Wells NHS Trust as well as the improvements we are making. It is based on both national guidelines and what patients treated at Maidstone and Tunbridge Wells NHS Trust have told us about services they have benefited from and what may need to be improved.

Not all the improvements patients suggest can be made overnight, so on page 12 you’ll see a list of what we’re working on at Maidstone and Tunbridge Wells NHS Trust 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 Maidstone and Tunbridge Wells NHS Trust’s secondary breast cancer service...

Someone to answer your questions
You will be able to contact Claire Ryan, who is a Macmillan Nurse Clinician responsible for care for people diagnosed with secondary breast cancer. She will act as your ‘key worker’ and is based at both Kent Oncology Centre and Tunbridge Wells Hospital.

Each person’s experience of secondary breast cancer is unique. For many people, the uncertainty of living with secondary breast cancer can be the hardest part. It is Claire’s role to be knowledgeable about your disease, treatment and support needs to help you live with your diagnosis, and receive the best care for you. She will be able to offer ongoing information and advice on the many treatment options.

It helps Claire to care for you effectively if you know what your concerns are, and what information you would like. Don’t be afraid to say what is on your mind. She can discuss any of these concerns with you, and the impact that they may have on you, and your family and friends.

Your healthcare team
You may be looked after by many health care professionals in both the hospital and community. Your health care team at the hospital will be led by a cancer specialist called an Oncologist. Other key professionals involved in your care may be your Consultant Surgeon, Breast Care Nurses, GP, district or community nurses, palliative care teams based at your local hospices, occupational therapist, social services and benefits advisers. You may also access care at local charity organisations.
Your oncology care will be led by one of the following consultants, while Claire Ryan works closely with all involved to coordinate your care.

Dr Russell Burcombe is a Consultant Clinical Oncologist and his practice is at Kent Oncology Centre, Maidstone. Clinics with Dr Burcombe are held on a Wednesday morning.

Dr Rema Jyothirmayi is a Consultant Clinical Oncologist and her practice is predominantly at Tunbridge Wells Hospital. Clinics with Dr Jyothiramyi are held on a Wednesday. However, you may be asked to attend Kent Oncology Centre for some of your appointments as well.

Dr Catherine Harper-Wynne is a Consultant Medical Oncologist and her practice is at Kent Oncology Centre, Maidstone. Clinics with Dr Harper-Wynne are Wednesday afternoons.

Claire works closely with your Consultant Oncologist, and has designated clinics at Kent Oncology Centre, Maidstone (Monday afternoon), and Tunbridge Wells Hospital at Pembury (Thursday morning). She may review you in clinic instead of your Consultant as she is an advanced nurse practitioner who has undergone specific training and education. By sharing your care with your Consultant Oncologist, they aim to ensure continuity and good communication.

Claire also works closely with the community health and social care teams and your GP, to ensure continuity of care between the hospital and community services. She can organise referrals to these specialist services such as the community nursing and palliative care teams, psychological support services, financial benefits clinics and Macmillan Information Centre.
Your treatment and care

The aim of treatment for secondary breast cancer is to control and slow down the spread of the cancer, relieve symptoms and give you the best quality of life, for as long as possible.

A number of different treatments are used to treat secondary breast cancer and your Oncology Consultant will talk with you about your options. Any recommendations for treatment will be discussed with you, taking into account your personal wishes. It’s therefore a good idea to have a list of questions ready that might help you make your decision. You may want to take time to discuss things with your family, friends or different members of your health care team.

As part of your treatment you may be asked if you’d like to consider taking part in a clinic trial. Your health care team will talk about what this would mean for you.

Please always ask your health care team about current trials, whether they are available at Maidstone and Tunbridge Wells NHS Trust or elsewhere.

When any new treatment is proposed, you will receive written information about its potential benefits, risks and side effects. 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 information you get should be in a format that is right for you, and your health care team should talk to you clearly and sensitively, using words you understand.
Decisions about treatment

You can be as involved as you want to be in decisions about your care and treatment. It may be helpful to think about what would influence your decision to have a treatment. For example, an improved quality of life by choosing not to have a particular treatment and experience its side effects may be more important to you than the possible benefits of that 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.

Some medicines you take, including complementary medicines, could interact with your treatment. Please tell your health care team about any medicines you are taking.

Once you have agreed your treatment plan with your Oncologist, it will be prescribed. If at any time you have concerns about your treatment plan, please discuss these with the health care team caring for you before stopping or changing the agreed plan. If you do decide to stop treatment, you can do so at any time and your decision will always be respected.

Your treatment and care may be reviewed in one of the Macmillan Nurse-Led Clinics. This clinic provides the opportunity to review patients receiving treatment for secondary breast cancer, and assess any symptoms and side affects you may be experiencing as a result of your treatment.

You can ask for a second opinion about your diagnosis and treatment. If you want a second opinion, you can talk to your Consultant or Macmillan Nurse Clinician about how to do this.
Specialist secondary breast cancer multi-disciplinary team meetings

You will have regular clinic appointments and intermittent tests and scans. Scans help the oncology team to see how well your secondary breast cancer is responding to treatment, and may also be performed to investigate new or worsening symptoms.

At Kent Oncology Centre we hold a weekly specialist Multi-Disciplinary Team Meeting, specifically for secondary breast cancer patients. This meeting is not national standard practice, but a locally driven service which your health care team believe will benefit your care planning.

Key health care professionals (your Consultant Oncologist, a Consultant Radiologist, Macmillan Nurse Clinician, Registrars and Research Nurses) review scan findings and discuss the best treatment for individual patients.

The meeting also facilitates timely reporting of scans and helps reduce the waiting time for results.

This meeting means that your health care team is well prepared for your clinic consultation and will discuss the outcomes with you so that you can be involved in the decisions about your treatment.

It is important that you let the Macmillan Nurse Clinician or your Consultant’s secretary know when you receive the date of your scan, so that your care can be discussed at this meeting.
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.

When you come to Kent Oncology Centre Maidstone or Tunbridge Wells Hospital
When you come to either hospital, you can expect to be treated with dignity and respect at all times.

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.

When you are due to see your Consultant Oncologist at Kent Oncology Centre, you will be seen in the “ABC” (Advanced Breast Cancer) clinic. This is a designated clinic for secondary breast cancer, also known as metastatic or advanced breast cancer.

We structure the clinics around the specialist needs of people with secondary breast cancer. Your appointment slots are longer than other clinics, as we are aware that your consultations may be complex because of your treatment or symptoms. We also aim to streamline your care as far as possible, to ensure we match the right length of consultation time and the right health care professionals for your needs.
Getting the most out of your appointment with a health care professional

Feeling comfortable with your health care team can make a positive difference to how you feel about your treatment and care. Some things can be difficult to discuss, but being prepared for your hospital appointments and knowing what information you need from them to make the most of your consultation may help.

1. Prepare for your appointment
Write a list of what you want to discuss. It may include how you’re feeling physically and emotionally, new symptoms, side effects and any questions that you may have.

2. Take support
If you are able to attend with a family member, close friend or someone you trust, they can support you. “Two pairs of ears are better than one”. They will be able to listen to the information you are given and make notes that you can revisit later.

3. Say what you want
It helps your health care team to care for you effectively if they know what your concerns are and what information you would like. Don’t be afraid to talk about what’s on your mind. As you get to know your health care professional team you will feel more comfortable doing this.

4. Make sure your questions are answered
If you don’t feel you have had an answer to your question, or you don’t understand the information you have been given, ask again.
If you need to stay at Maidstone and Tunbridge Wells NHS Trust

If you’re staying, someone will tell you which bed you will be in and when it will be free. There will always be somewhere safe to put your things.

During a stay at Maidstone Hospital, you’ll share a sleeping area, toilets and shower facilities with other patients of the same sex.

During a stay at Tunbridge Wells Hospital, you will be in a single room.

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.
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 Macmillan Nurse Clinician, Claire Ryan, 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.
Secondary Breast Cancer Pledge

The monthly meetings have been invaluable to me. It’s a unique chance to meet up with my fellow “warriors” and have open and honest conversations that we wouldn’t normally be able to have. All of us are in the same boat and we all help and advise each other. I have found the presentations and talks to be most useful and information as I find myself in an unknown and uncertain situation. Strangely, with a group of like-minded people and with expert support, we can normalise our situations and find that our individualistic domestic dramas turn out to be very common amongst us. It’s a huge relief to know we are not alone!

Other care and support
Some of your care may be delivered outside the hospital, for example by local hospice teams or charity organisations.

Living with Secondary Breast Cancer
This national service, established by the charity Breast Cancer Care, is available for patients in West Kent.

After a diagnosis of secondary breast cancer, people can feel isolated and have unanswered questions about living with the uncertainty of the disease. Whether facing an initial diagnosis, looking for tips about dealing with the day-to-day challenges or the side effects of treatment, talking openly with people who understand what it means to live with secondary breast cancer offers vital support.

Meetings are held on the first Tuesday of every month, and alternate months offer the opportunity to hear the most up-to-date information on topics that meet many of the health and social care needs for people living with secondary breast cancer.
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 our Patient Advocacy and Liaison Services (PALS):

Maidstone Hospital
Located in the EEMU Corridor on the ground floor
Opening Times are 10am-4pm, Monday to Friday
Telephone 01622 225119 or 01622 224960
Email: mtwpals@nhs.net

Tunbridge Wells Hospital
Located in the corridor to the right of the main reception desk
Opening times 10am-4pm Monday to Friday
Telephone 01892 632953
Email: mtwpals@nhs.net
Both PALS offices have an answerphone available when the phone lines are busy or out of office hours. Telephone calls are answered 9am-5pm and messages left are answered within one working day. They will also be able to advise you on our complaints procedure.

**During office hours:**
You can call your Macmillan Nurse Clinician: 01622 225011.

If unable to take your call because of clinical commitments or leave or absence, a message will always be left to signpost you to the appropriate point of contact.

**For support outside of office hours:**
If you are receiving chemotherapy and phoning about any of the health concerns highlighted on your red emergency card please phone: 07717 343134.

If you have a Community Palliative Care Nurse you can call the Hospice where they are based:

Hospice in the Weald: 01892 820509
Heart of Kent Hospice: 01622 792200
Molly Wisdom: 01634 830456

To find out if you are eligible to reclaim travel costs, please speak to your 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 Maidstone and Tunbridge Wells NHS Trust 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>As a new patient you wanted more information about who the Macmillan Nurse Clinician is and what she can offer you when first diagnosed with secondary breast cancer.</td>
<td>We will develop an introductory letter to give to patients explaining the role of the Macmillan Nurse Clinician (MNC) and give this to patients at their first new patient consultation.</td>
<td>December 2015.</td>
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<td>Some patients are not aware of the multi-disciplinary team (MDT) meetings for metastatic breast cancer, who attends them and what is discussed.</td>
<td>We will develop a leaflet to give to patients explaining the importance of notifying the Macmillan Nurse Clinician each time a scan is scheduled so that their case can be included on the weekly MDT meeting. This leaflet will also offer a mission statement of the role of the meeting.</td>
<td>January 2016.</td>
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<td>Patients at Tunbridge Wells and Maidstone hospitals do not have the same access to the Macmillan Nurse Clinician. While those in crisis get the contact they need from the MNC, patients who are more stable and visit less frequently can feel isolated.</td>
<td>We will present a business case to sustain funding of the MNC post beyond September 2016, and seek funding for an additional post (Clinical Support Worker Band 4) to provide support to the Macmillan Nurse Clinician. We will work to plan a streamlined ABC clinic for patients at Tunbridge Wells which mirrors the service at Maidstone so that the Macmillan Nurse Clinician can be present in clinics.</td>
<td>April 2016.</td>
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<td>More than half of patients were not offered appropriate services such as counselling or referral to a psychologist or emotional support from a palliative care nurse when they received their diagnosis. A number of patients have indicated that they have needed emotional support but have not yet received it. This includes support for family and carers.</td>
<td>We will launch local support that is specific to secondary breast cancer by partnering with Breast Cancer Care to deliver the Living with Secondary Breast Cancer service. We plan to continue the funding for the Living with Secondary Breast Cancer service through an annual application to Breast Cancer Kent. We will launch an Ear Acupuncture Service, prioritising patients with secondary breast cancer, to promote relaxation and encourage a sense of physical and emotional well-being. We will work with community and primary care organisations to deliver a family service that supports parent-child communication and other parenting needs relating to living with secondary breast cancer.</td>
<td>Already implemented.</td>
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<td>Some patients do not feel they are getting access to information on local and national support services.</td>
<td>We will work with a patient focus group to develop a “directory” of local services available for people living with secondary breast cancer.</td>
<td>January 2016.</td>
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<td>The Macmillan Information Centre (MIC) may not be in the right place for patients to access it easily.</td>
<td>We will identify an area for a “pop-up” information point in the main oncology seated waiting area. We will look at the feasibility of new patient group appointments specifically about the Macmillan Information Centre and sign-posting.</td>
<td>September 2016.</td>
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<td>A number of patients felt they did not get tailored information relating to where they are in their disease trajectory.</td>
<td>We will pilot the use of Information Prescriptions to identify tailored and relevant information for patients at each stage of their secondary breast cancer.</td>
<td>April 2016.</td>
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Now tell us what you think

You wouldn’t be reading this booklet if our patients hadn’t given us feedback about our service. Patients were sent a survey and invited to a focus group. Three Patient Representatives also worked more closely with us to help develop the improvement goals and ensure we’re keeping patients at the heart of any changes we make.

You can help too by telling us what you think about our services. The patient representative group would value your input and you can find out more about joining the group by contacting Claire Ryan on 01622 225011.

Use your experience to develop Maidstone and Tunbridge Wells NHS Trust’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 Care

We know that after a diagnosis of secondary breast cancer, nothing is ever the same again. That’s why we provide specialist support and information services for people who have been told their cancer can no longer be cured.

Our clinical expertise and emotional support network help women and men, their families and friends find a way to live with secondary breast cancer, making the most of every day. Across the UK we give people the chance to meet regularly with others with a secondary breast cancer diagnosis – face to face or online – to share experiences and support. To find out what’s available near you go to www.breastcancercare.org.uk/information-support/secondary-metastatic-breast-cancer or call our Helpline 0808 800 6000.

We want healthcare professionals to have enough training and resources so that they can meet the needs of their patients living with secondary breast cancer. To help with this, we offer training for breast cancer nurses and opportunities for them to share best practice.

Our information is used in breast care units across the UK, including our Secondary Breast Cancer Resource Pack. You can get free copies through our Helpline or order them direct from our website at www.breastcancercare.org.uk/information-support/publications

We want every person with secondary breast cancer to have the best treatment, information and support. So we press for improvement at all levels. To do this, we work in partnership with people affected by breast cancer, who are at the heart of and involved in everything we do.

For expert secondary breast cancer information and to find out more about our work, visit www.breastcancercare.org.uk or call our free Helpline for support and information on 0808 800 6000.