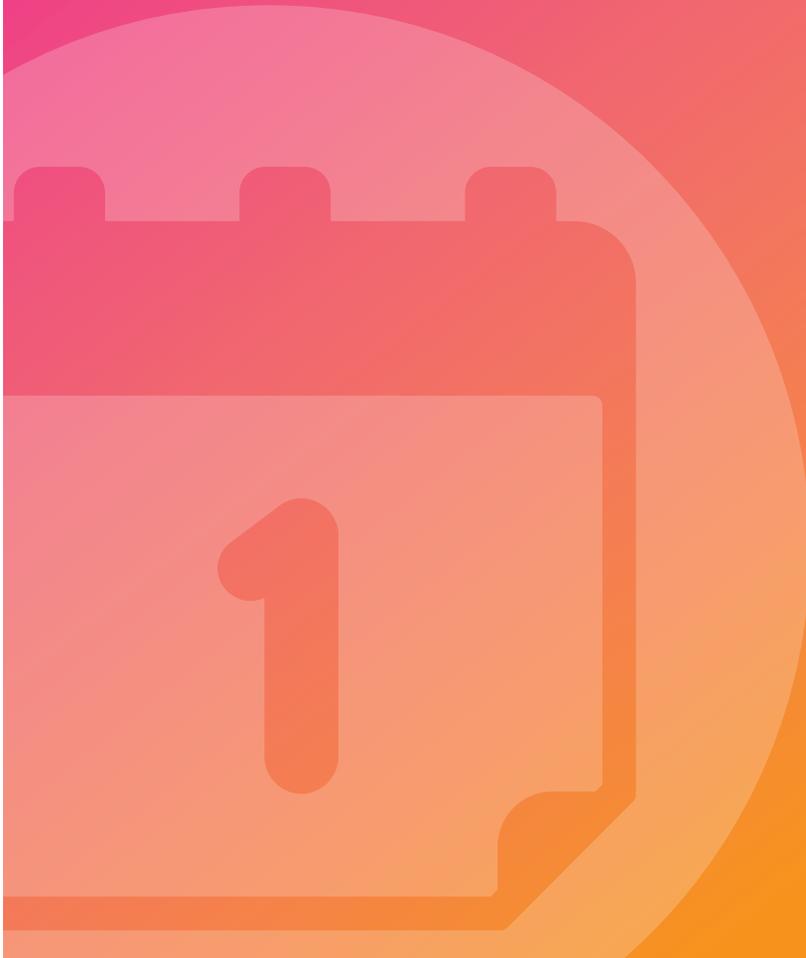


Personal organiser

breast
cancer
care

This organiser is for anyone with secondary breast cancer. It is part of the **Secondary breast cancer information pack**.



1

This information is by Breast Cancer Care.

We are the only specialist UK-wide charity that supports people affected by breast cancer. We've been supporting them, their family and friends and campaigning on their behalf since 1973.

Today, we continue to offer reliable information and personal support, over the phone and online, from nurses and people who've been there. We also offer local support across the UK.

From the moment you notice something isn't right, through to treatment and beyond, we're here to help you feel more in control.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **[breastcancercare.org.uk](https://www.breastcancercare.org.uk)**

The logo for Breast Cancer Care, featuring the words "breast", "cancer", and "care" stacked vertically. "breast" and "cancer" are in a pink color, and "care" is in an orange color. The font is a bold, sans-serif typeface.

breast
cancer
care

How to use this organiser

This organiser contains space for you to record whatever aspects of your condition, treatment and care that you want to.

You can use it to keep a record of:

- symptoms and side effects, such as pain or fatigue
- details of your appointments, what you want to discuss and any test results
- names and contact details of the people involved in your care
- needs and concerns that you would like to address
- general notes about your cancer and treatment

There's also a list of questions you may want to ask your specialist, which was put together by other people with secondary breast cancer.

Finally, there's a section to help you identify any new symptoms to report to your doctor or specialist nurse.

If you fill up the space in this organiser, you can order another copy at breastcancercare.org.uk/personal-organiser
You can also order another organiser by calling **0808 800 6000**.

Symptoms and side effects

Use the space on the following pages to keep a record of any symptoms of your cancer or side effects of treatment.

Describing your symptoms and side effects to your specialist team will help them suggest ways to control them.

What to record

Pain

It's useful to rate any pain you have on a scale from 1 (no pain) to 10 (extreme pain).

Record where the pain is and what it feels like. For example, is it aching, tender, sharp, burning, nagging, intense, stabbing, dull or throbbing? Is it constant or does it come and go?

You can also record how any pain relief you take affects your pain, and any side effects it causes.

Fatigue

Rate your fatigue level from 1 (no fatigue) to 10 (extreme fatigue – constantly tired, sleeping or resting most of the day).

Recording when you have treatment can also help you identify how treatment affects your fatigue levels.

Other symptoms or side effects

You may also want to record symptoms or side effects of your treatment such as:

- breathlessness
- nausea or vomiting
- diarrhoea or constipation
- poor appetite
- weight loss or gain
- problems sleeping
- menopausal symptoms such as hot flushes

Questions you might want to ask your specialist

The following questions have been put together by the Secondary Breast Cancer Focus Group at The Christie Hospital, as these are questions they asked their specialists.

You might find them useful to take along to your appointments. You might not want to ask them at every appointment but they may be useful from time to time.

- Can you explain the blood test results to me?
- What do the results mean?
- Can you show me the scan and explain what's on it?
- Can you tell me more about the tumours? Where are they? Have they changed size?
- What is the aim of my treatment?
- What sort of side effects will I get? What can I do to help manage these side effects? Will you give me something for these today?
- What other treatment options are available?
- Are there any clinical trials I can join?
- Who else can I speak to?
- Can I see a/my nurse specialist?

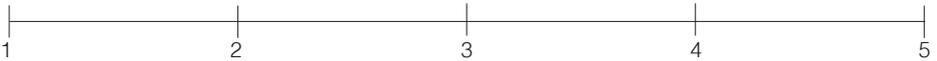
You can ask your specialist to go over your plan, repeat information or explain any new terms to you. What matters most is that you understand what's happening and why.

Appointment record sheets

Use the following pages to keep a record of your hospital appointments and anything you want to discuss.

Date of appointment

Emotional wellbeing over the last week (1 = low, 5 = good)



Physical wellbeing over the last week (1 = low, 5 = good)



Things to discuss

New symptoms (see page 32)

Questions (see page 9)

Blood test results

Scan results

Other measurements taken (for example blood pressure or weight)

Plan:

Continue with current treatment

Change treatment

Details of new treatment

Next clinic in _____ weeks/months

Other appointments to be arranged

Date of appointment

Emotional wellbeing over the last week (1 = low, 5 = good)



Physical wellbeing over the last week (1 = low, 5 = good)



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Other appointments to be arranged

Professionals involved in your care

You may find it helpful to record the names and contact details of the people caring for you.

Oncologist (usually contacted through their secretary)

Name _____

Telephone _____

Email _____

(Clinical) Nurse specialist/Specialist nurse

Name _____

Telephone _____

Email _____

Chemotherapy department

Name _____

Telephone _____

Email _____

Chemotherapy information/hotline number

Radiotherapy department

Name

Telephone

Email

Physiotherapist

Name

Telephone

Email

Palliative and supportive care nurse/doctor

Name

Telephone

Email

District nurse

Name _____

Telephone _____

Email _____

GP

Name _____

Telephone _____

Email _____

Social worker (in the community, hospital or hospice)

Name _____

Telephone _____

Email _____

Benefits/Finance adviser

Name _____

Telephone _____

Email _____

Local cancer information centre contact (eg manager)

Telephone _____

Email _____

Others

It can also be helpful to have a record of who to contact if you have an urgent query or problem during the working day or out of normal working hours.

Urgent contact (daytime) _____

Urgent contact (night time) _____

Urgent contact (weekends) _____

Your needs and concerns checklist

This checklist can help you identify your needs and concerns. It's based on the kind of checklist that's often used as part of a holistic needs assessment (HNA). See page 56 of the pack for information about HNAs.

Tick the boxes next to the concerns you want to discuss with your specialist team.

Physical concerns

- Symptoms are not well controlled
- Constipation or diarrhoea
- Indigestion
- Nausea or vomiting
- Hair loss
- Mouth and dental problems
- Mobility
- Weight changes
- Appetite changes
- Taste changes
- Pain
- Fatigue
- Personal appearance and body image
- Menopausal symptoms
- Skin and nail problems
- Cough or breathlessness
- Concentration and memory
- Lymphoedema
- Other medical conditions

Practical concerns

- My caring responsibilities
- Household duties
- Housing

- Transport and parking
- Bathing and dressing
- Changes to my independence
- Planning for my future
- Wigs
- Protheseses

Emotional concerns

- Sad or depressed
- Worry, fear and anxiety
- Anger, frustration or guilt
- Hopelessness
- Feeling different from other people
- Feelings about the future
- Explaining my feelings to others

Information concerns

- Amount of information I prefer
- How I prefer to receive information (spoken or written)
- Information about my illness, treatment or care
- Accessing clinical trials
- Accessing other support
- Getting copies of letters about me

- Involvement in decisions about treatment
- End-of-life care

Employment concerns

- Continuing to work
- Support from employers
- Adjustments to work, workload or environment
- Stopping work

Financial concerns

- Benefits
- Pension
- Insurance or critical illness cover
- Mortgage
- Debt
- Inheritance

Language and cultural concerns

- Preferred language for written and spoken information
- Aids to communication
- How my cultural background affects my care

Social concerns

- Travel and travel insurance
- Arranging special days out
- Not being able to go places
- Hobbies and interests
- Feeling lonely or isolated

Family and relationships

- Children
- Partner
- Other relationships
- Sex and intimacy
- Role in the family
- Effect of your illness on others
- Needing more help

Health and wellbeing

- Diet
- Exercise
- Alcohol
- Smoking
- Sleeping problems

Spiritual

- Access to religious/spiritual leader
- Change to faith or belief
- Loss of meaning/purpose
- Requirements to practise faith
- Restrictions related to faith or culture
- Regrets about the past

End of life

- Making a will
- Lasting power of attorney
- Guardianship of my dependents
- Worries about dying
- Legal and personal affairs
- Advance decisions

Signs and symptoms to report to your team

These pages show the areas breast cancer can most commonly spread to and the symptoms this may cause.

If secondary breast cancer appears in new areas of the body or spreads further at its current site(s), it's often said to have progressed. If your cancer progresses you may notice symptoms.

Lots of these symptoms can be caused by other things, such as treatments or different illnesses, so may not be due to a change in your cancer.

If you have new or worsening symptoms that don't go away and don't have an obvious cause, tell your specialist nurse or doctor about them.

BONE

- Pain in your bones, for example in the back, hips or ribs, that doesn't get better with pain relief and may be worse at night
- Symptoms of spinal cord compression such as severe or unexplained back pain, difficulty walking, numbness and loss of bladder or bowel control
- Symptoms of hypercalcaemia such as nausea and vomiting, fatigue, passing large amounts of urine, confusion and being very thirsty

LYMPH NODES

- A lump or swelling under your arm, breastbone or collarbone area
- Swelling in your arm or hand
- Pain
- Dry cough

GENERAL SYMPTOMS

- Feeling tired all the time
- Increased fatigue
- New symptoms making you feel unwell or that affect your daily/ quality of life

LIVER

- Feeling sick all the time
- Discomfort or swelling under the ribs on the right side or across the upper abdomen
- Weight loss and a loss of appetite
- Jaundice
- Hiccups

LUNG

- (Increased) feeling of breathlessness, either when exerting yourself or when resting
- A cough
- Pain in the chest or back when breathing

It's not possible to list all the symptoms of progression. Talk to your doctor or specialist nurse about **ANY** symptoms that are:

- **new**
- **don't go away**
- **don't have an obvious cause**

SKIN

Lasting changes to the skin on the breast or chest wall, particularly around your scar, or on the abdomen (belly) including:

- Change in the colour of the skin or a rash
- Painless nodule(s) of different sizes

BRAIN

- Headaches
- Dizziness
- Nausea or vomiting, especially when waking up in the morning
- Loss of balance
- Altered vision or speech
- Weakness or numbness
- Changes in mood or personality
- Fits



Four ways to get support

We hope this information was helpful, but if you have questions, want to talk to someone or read more about breast cancer, here's how you can.



Speak to our nurses or trained experts. Call our free Helpline on **0808 800 6000** (Monday to Friday 9am–4pm and Saturday 9am–1pm). The Helpline can also put you in touch with someone who knows what it's like to have breast cancer.



Chat to other women who understand what you're going through in our friendly community, for support day and night. Look around, share, ask a question or support others at forum.breastcancercare.org.uk



Find trusted information you might need to understand your situation and take control of your diagnosis or order information booklets at breastcancercare.org.uk



See what support we have in your local area. We'll give you the chance to find out more about treatments and side effects as well as meet other people like you. Visit breastcancercare.org.uk/in-your-area

We're here for you: help us to be there for other people too

If you found this booklet helpful, please use this form to send us a donation. Our information resources and other services are only free because of support from people such as you.

Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

Donate online

Donate using your debit or credit card breastcancercare.org.uk/donate

Donate by post

Please accept my donation of **£10/£20/my own choice of £**

I enclose a cheque/PO/CAF voucher made payable to **Breast Cancer Care**

Name _____

Address _____

_____ Postcode _____

Email address _____

Telephone _____

In addition, we'd love to keep you updated about our work and provide you with other opportunities to get involved with Breast Cancer Care. Please tell us how you would like to hear from us (by ticking these boxes you confirm you are 18 or over)

- I'd like to hear from you by email
- I'd like to hear from you by text message or SMS
- Please do not contact me by post
- Please do not contact me by telephone

We never give your information to other organisations to use for their own purposes. To change your preferences, or find out more information on how we use your data, please view our privacy policy at breastcancercare.org.uk or contact supporter services on 0345 092 0800.

Please return this form to Breast Cancer Care, Freepost RRRKZ-ARZY-YCKG, Chester House, 1-3 Brixton Road, London SW9 6DE



About this booklet

Secondary breast cancer: Personal organiser was written by Breast Cancer Care's clinical specialists, and reviewed by healthcare professionals and people affected by breast cancer.



For a full list of the sources we used to research it:

Phone **0345 092 0808**

Email **publications@breastcancercare.org.uk**



You can order or download more copies from **breastcancercare.org.uk/publications**



We welcome your feedback on this publication: **breastcancercare.org.uk/feedback**



For a large print, Braille, DAISY format or audio CD version:

Phone **0345 092 0808**

Email **publications@breastcancercare.org.uk**



When you have breast cancer, everything changes. At Breast Cancer Care, we understand the emotions, challenges and decisions you face every day, and we know that everyone's experience is different.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancercare.org.uk**

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