

PERSONAL ORGANISER



**BREAST
CANCER
NOW** The research &
support charity

2 Call our Helpline on **0808 800 6000**

HOW TO USE THIS ORGANISER

This organiser is for anyone with secondary breast cancer. It designed to be used with the **Secondary breast cancer information pack**.

It 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 to share with your treatment team
- 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 the cancer and its treatment

There's also a list of questions you may want to ask your treatment team, 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 breastcancernow.org/personal-organiser

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 treatment 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.

You can also make note of what else might help the pain or make it worse.

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.

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Other symptoms or side effects

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

- Breathlessness
- Nausea or vomiting
- Diarrhoea or constipation
- Poor appetite
- Weight loss or gain
- Problems sleeping
- Menopausal symptoms such as hot flushes
- Sore mouth and taste changes
- Numbness in the hands and feet

Date/time	Description of symptom or side effect and any medication taken to help with this	Rating (if appropriate)
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Date/time	Description of symptom or side effect and any medication taken to help with this	Rating (if appropriate)
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QUESTIONS YOU MIGHT WANT TO ASK YOUR SPECIALIST

The following questions have been put together by secondary breast cancer patients as these are questions they have asked their treatment team.

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 do I need to know about my new 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.

It's important to let your treatment team know what's on your mind and if you have anything specific you wish to ask or discuss at clinic appointments, as this can help them plan the most appropriate individual treatment, care and support.

Recording and reporting side effects to your treatment team means that they can monitor whether changes to your care and treatment are making a difference to your overall wellbeing. This organiser can help you do this.

For example, your secondary breast cancer diagnosis and treatment is likely to have an impact on any roles and responsibilities you may have, such as caring for others and financial and employment responsibilities.

What is important to you may not be the same as someone else with secondary breast cancer. But addressing any concerns or questions may help your treatment team signpost you to the appropriate support and improve your quality of life.

You can use the Holistic Needs Checklist on page 32 to help you think about what is most important to you.

Date of appointment

Emotional wellbeing since your last appointment (1 = low, 5 = good)

1

2

3

4

5

Physical wellbeing since your last appointment (1 = low, 5 = good)

1

2

3

4

5

What have been your main concerns?

New symptoms (see page 36):

Questions (see page 10):

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 appointment in weeks/months

Other appointments to be arranged:

Date of appointment

Emotional wellbeing since your last appointment (1 = low, 5 = good)

1

2

3

4

5

Physical wellbeing since your last appointment (1 = low, 5 = good)

1

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3

4

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Physical wellbeing since your last appointment (1 = low, 5 = good)

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Continue with current treatment

Change treatment

Details of new treatment:

Next clinic appointment in weeks/months

Other appointments to be arranged:

PROFESSIONALS INVOLVED IN YOUR CARE

The multidisciplinary team (MDT)

People with breast cancer are cared for by a team of healthcare professionals, each with their own expertise. This is known as the multidisciplinary team (MDT). They meet regularly and may discuss your care at the multidisciplinary team meeting (MDM).

You may find it helpful to record the names and contact details of the people caring for you. You won't necessarily have all the following involved in your care.

Oncologist (usually contacted through their secretary)

Name

Telephone

Email

(Clinical) Nurse specialist/Specialist nurse

Name

Telephone

Email

Chemotherapy department

Name

Telephone

Email

Radiotherapy department

Name

Telephone

Email

Therapeutic radiographer (radiographer who plans and delivers radiotherapy)

Name

Telephone

Email

Physiotherapist

Name

Telephone

Email

Occupational therapist

Name

Telephone

Email

Dietitian

Name

Telephone

Email

Hospital oncology pharmacist

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/financial adviser

Name

Telephone

Email

Local cancer information centre contact (for example, manager)

Name

Telephone

Email

Religious or spiritual leader

Name

Telephone

Email

Urgent queries

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 CONCERN 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). Any needs or concerns should be highlighted and discussed with your treatment team who can also go through an HNA with you.

See page 81 of the pack for more information aboutHNAs.

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

Emotional concerns

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

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

- | | |
|---|---|
| <input type="checkbox"/> My caring responsibilities
<input type="checkbox"/> Household duties
<input type="checkbox"/> Housing
<input type="checkbox"/> Transport and parking
<input type="checkbox"/> Travel to appointments | <input type="checkbox"/> Bathing and dressing
<input type="checkbox"/> Changes to my independence
<input type="checkbox"/> Planning for my future
<input type="checkbox"/> Wigs
<input type="checkbox"/> Prostheses |
|---|---|

Information concerns

- | | |
|---|---|
| <input type="checkbox"/> Amount of information I prefer
<input type="checkbox"/> How I prefer to receive information (spoken or written)
<input type="checkbox"/> Information about my illness, treatment or care | <input type="checkbox"/> Accessing clinical trials
<input type="checkbox"/> Accessing other support
<input type="checkbox"/> Getting copies of letters about me
<input type="checkbox"/> Involvement in decisions about treatment
<input type="checkbox"/> End-of-life care |
|---|---|

Employment concerns

- | | |
|---|---|
| <input type="checkbox"/> Continuing to work
<input type="checkbox"/> Support from employers
<input type="checkbox"/> Adjustments to work, workload or environment | <input type="checkbox"/> Needing to change jobs/ finding new employment
<input type="checkbox"/> Stopping work |
|---|---|

Financial concerns

- | | |
|--|--|
| <input type="checkbox"/> Benefits
<input type="checkbox"/> Pension
<input type="checkbox"/> Insurance or critical Illness cover
<input type="checkbox"/> Mortgage | <input type="checkbox"/> Rent
<input type="checkbox"/> Bills
<input type="checkbox"/> Debt
<input type="checkbox"/> Inheritance |
|--|--|

Language and cultural concerns

- | | |
|--|---|
| <input type="checkbox"/> Preferred language for written and spoken information | <input type="checkbox"/> Aids to communication
<input type="checkbox"/> How my cultural background affects my care |
|--|---|

Social concerns

- Travel and travel insurance
- Arranging special days out
- Not being able to go places
- Being able to continue or take up new hobbies and interests
- Being able to go out with friends
- Feeling lonely or isolated

Family and relationships

- Talking to my children about my illness
- Practical care of children
- Being a single parent
- Partner
- Other relationships
- Sex and intimacy
- Role in the family
- Effect of your illness on others
- Support for my family members
- Needing more help

Health and wellbeing

- Diet
- Starting to exercise regularly
- Returning to regular exercise
- Alcohol
- Smoking
- Sleeping problems
- Mental health

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 any new or worsening symptoms that don't go away and don't have an obvious cause, tell your specialist nurse or doctor about them. It may well be unrelated to cancer, but it is always worth checking out.

You can also call our Helpline on **0808 800 6000** to discuss any concerns.

GENERAL SYMPTOMS

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

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

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

Talk to your doctor or specialist nurse about ANY symptoms that:

- Are new
- Don't go away
- Don't have an obvious cause

LYMPH NODES

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

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

38 Call our Helpline on **0808 800 6000**

NOTES

ABOUT THIS BOOKLET

Personal organiser was written by Breast Cancer Now'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:
Email health-info@breastcancernow.org



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health-info@breastcancernow.org



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BREAST CANCER NOW

The research &
support charity

At Breast Cancer Now we're powered by our life-changing care. Our breast care nurses, expertly trained staff and volunteers, and award-winning information make sure anyone diagnosed with breast cancer can get the support they need to help them to live well with the physical and emotional impact of the disease.

We're here for anyone affected by breast cancer. And we always will be.

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

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Patient Information Forum

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