This booklet is for people who would like more information about medullary breast cancer. It describes what medullary breast cancer is, how a diagnosis is made and possible treatments.
Introduction

We hope this booklet helps you to ask your specialist team questions and be involved as much as you want in decisions about your treatment. We recommend that you read this publication with our Treating breast cancer booklet.

What is medullary breast cancer?

Medullary breast cancer (sometimes called classic medullary breast cancer) is a rare type of breast cancer. A pathologist (doctor who examines tissue removed during a biopsy or surgery) looks at the cancer cells under a microscope to see what type of breast cancer it is.

Medullary breast cancer and atypical medullary breast cancer (when some but not all the features of medullary breast cancer are seen under a microscope) are sometimes referred to as medullary-like breast cancer. Invasive ductal breast cancer (often called ‘no special type’ or NST) can also have medullary-like features. Together these account for around 3-5% of all breast cancers.

Medullary breast cancer is an invasive type of cancer, which means it has the potential to spread from the breast to other parts of the body, although this is not common with this type of breast cancer.

Medullary breast cancer can occur at any age but it is more often diagnosed in younger women. It is also more common in women who have inherited an altered BRCA1 gene. Our booklet Breast cancer in families has more information on the BRCA1 gene.

Men can also develop medullary breast cancer but this is very rare.

Although each case is different, the outlook for medullary breast cancer is often better than for some other more common types of invasive breast cancer.

How is medullary breast cancer diagnosed?

Medullary breast cancer is diagnosed in the same way as other breast cancers. Tests may include a mammogram (breast x-ray) and/or an ultrasound scan, followed by a fine needle aspiration (FNA) and/or core biopsy.

For more information, see our Your breast clinic appointment booklet.
How is medullary breast cancer treated?

Surgery is usually the first treatment for medullary breast cancer. This may be breast-conserving surgery (usually referred to as wide local excision or lumpectomy), and is the removal of the cancer with a margin (border) of normal breast tissue around it, or a mastectomy (removal of all the breast tissue including the nipple area).

The type of surgery you'll be offered depends on where in the breast the cancer is, how big the cancer is in relation to the size of your breast and whether it’s found in more than one area of the breast. Your breast surgeon will discuss this with you.

Sometimes further surgery is needed if the margin of normal tissue surrounding the cancer that was removed during the first operation contained cancer cells. This is to ensure that all the cancer has been removed. In some cases this second operation will be a mastectomy.

If a mastectomy is recommended, or if you choose to have a mastectomy, your breast surgeon will discuss the option of breast reconstruction with you. This can often be done at the same time as your mastectomy (immediate reconstruction) or months or years later (delayed reconstruction). For more information see our Breast reconstruction booklet.

Medullary breast cancer is less likely to spread to the lymph nodes (glands) under the arm than other types of breast cancer. However, your specialist team will want to check your lymph nodes, as it helps them decide whether or not you will benefit from any additional treatment after surgery. To do this, your surgeon is likely to recommend an operation to remove either some (a sentinel lymph node biopsy or sample) or all of the lymph nodes (a lymph node clearance).

Sentinel lymph node biopsy is widely used for people with breast cancer whose tests before surgery show no evidence of the lymph nodes containing cancer cells. It identifies whether or not the first lymph node (or nodes) the breast drains into is clear of cancer cells. If it is, this usually means the other nodes are clear too, so no more nodes will need to be removed.

If the results of the sentinel lymph node biopsy show that the first node (or nodes) are affected, your surgical team may recommend further surgery or radiotherapy to the remaining lymph nodes.
If the tests carried out before your breast surgery show that your lymph nodes contain cancer cells, the surgeon will usually recommend a lymph node clearance at the same time as your operation. For more information, see our Treating breast cancer booklet.

What are the adjuvant (additional) treatments?

After surgery, you may need further treatment. This is called adjuvant (additional) therapy and can include:

- chemotherapy
- radiotherapy
- hormone therapy
- targeted therapy.

Sometimes chemotherapy or hormone therapy may be given before surgery. This is known as neo-adjuvant or primary therapy.

The aim of these treatments is to reduce the risk of breast cancer returning in the same breast, developing in the opposite breast or spreading somewhere else in the body.

Chemotherapy

Chemotherapy is a treatment using anti-cancer (also called cytotoxic) drugs, which aims to destroy cancer cells. It is known as a systemic treatment as it treats the whole body. Whether it is recommended will depend on various features of the cancer, such as its size, its grade (how quickly the cells are growing and how different they are to normal breast cells) and whether the lymph nodes are affected. It will also depend on the oestrogen receptor (ER) and hormone receptor (HER2) status (for more information on this see our Understanding your pathology report booklet).

Some people are offered chemotherapy before surgery. This is called neo-adjuvant or primary chemotherapy. For more information see our Chemotherapy for breast cancer booklet.

Radiotherapy

Radiotherapy is a treatment for cancer that uses carefully measured and controlled high energy x-rays. If you had breast-conserving surgery (removal of the cancer and an area of normal breast tissue around the
cancer) you’ll usually be given radiotherapy to the remaining breast tissue on that side. Sometimes you may be offered radiotherapy to the nodes under your arm.

If you had a mastectomy (complete removal of the breast), you may be given radiotherapy to the chest in the area where you had your surgery. This is more likely if there is a high risk that cancer cells may have been left behind or if cancer cells are found in the lymph nodes under the arm (axilla). For more information see our Radiotherapy for primary (early) breast cancer booklet.

**Hormone (endocrine) therapy**

As the hormone oestrogen can play a part in stimulating some breast cancers to grow, there are a number of hormone therapies that work in different ways to block the effect of oestrogen on cancer cells.

Hormone therapy will only be prescribed if your breast cancer has receptors within the cell that bind to the hormone oestrogen (known as oestrogen receptor positive or ER+ breast cancer). All breast cancers are tested for oestrogen receptors using tissue from a biopsy or after surgery. When oestrogen binds to these receptors, it can stimulate the cancer to grow. If your cancer is oestrogen receptor positive, your specialist will discuss with you which hormone therapy they think is most appropriate.

Medullary breast cancer is more likely to be oestrogen receptor negative (ER-) therefore hormone therapy will not be of any benefit to you if this is the case.

Sometimes when oestrogen receptors are not found, tests may be done for progesterone (another hormone) receptors. As oestrogen receptors play a more important role than progesterone receptors, the benefits of hormone therapy are less clear for people whose breast cancer is only progesterone receptor positive (PR+ and ER-). Very few breast cancers fall into this category. However, if this is the case for you, your specialist will discuss with you whether hormone therapy is appropriate.

For more information, see our Treating breast cancer booklet or our individual hormone drug factsheets.
Targeted therapies (sometimes called biological therapies)

This is a group of drugs that block the growth and spread of cancer. They target and interfere with processes in the cells that cause cancer to grow.

The most widely-used targeted therapy is trastuzumab (Herceptin). Only people whose cancer has high levels of HER2 (called HER2 positive) will benefit from having trastuzumab. HER2 is a protein that makes cancer cells grow.

There are various tests to measure HER2 levels which are done on breast tissue removed during a biopsy or surgery.

Medullary breast cancer is usually HER2 negative. If your cancer is found to be HER2 negative, then trastuzumab will not be of any benefit.

For more information see our Trastuzumab (Herceptin) booklet.

Triple negative breast cancers

When breast cancers are HER2 negative, oestrogen receptor negative and also test negative for progesterone receptors, this is referred to as ‘triple negative’ breast cancer. This is quite common in medullary breast cancer.

If you have triple negative breast cancer, you may feel concerned that you are not able to have treatments such as trastuzumab or hormone therapy. However, people diagnosed with medullary breast cancer generally have a better prognosis (outlook) than people with some other types of triple negative breast cancer.
How you may feel

Being told you have breast cancer can be an anxious, frightening and sometimes isolating time. It can be particularly difficult to be diagnosed with a rare type of breast cancer such as medullary breast cancer, as you may not meet any other people with exactly the same diagnosis as you.

However, medullary breast cancer is treated in the same way as other, more common types of breast cancer so you may also find it helpful to talk to others who have had similar treatments to you.

Whatever type of cancer you have had, it’s natural to worry that it may return at some time in the future. There are people who can support you so don’t be afraid to ask for help if you need it. You can let other people know how you are feeling, particularly your family and friends, so they can be more supportive. Some people find it helpful to discuss their feelings and concerns with their breast care nurse or specialist. If you’d like to talk through your feelings and concerns in more depth over a period of time, a counsellor or psychologist may be more appropriate. Your breast care nurse, specialist or GP (local doctor) can arrange this.
Other organisations

Macmillan Cancer Support

89 Albert Embankment
London SE1 7UQ

General enquiries: 020 7840 7840
Helpline: 0808 808 0000
Website: www.macmillan.org.uk
Textphone: 0808 808 0121 or Text Relay

Macmillan Cancer Support provides practical, medical, emotional and financial support to people living with cancer, and their carers and families. It also funds expert health and social care professionals such as nurses, doctors and benefits advisers.
Helping you face breast cancer

If you’ve been diagnosed with breast cancer there’s a lot to take in. It can be an emotional time for you, your family and friends. Our free information and support services are here to help – on the phone, or online 24 hours a day.

Ask us
Calls to our free Helpline are answered by specialist nurses and trained staff with personal experience of breast cancer. They’ll understand the issues you’re facing and can answer your questions. Or you can Ask the Nurse by email instead via our website.

Free Helpline 0808 800 6000 (Text Relay 18001)
Monday–Friday 9am–5pm, Saturday 10am–2pm
www.breastcancercare.org.uk/ATN

Expert information
Written and reviewed by healthcare professionals and people affected by breast cancer, our free booklets and other information resources cover all aspects of living with breast cancer. Download or order booklets from our website or call the Helpline.

Talk to someone who understands
Our Someone Like Me service puts you in contact with someone else who’s had breast cancer and who’s been fully trained to help. This can be over the phone or by email.

You can also chat to other people going through breast cancer on our online discussion Forum. It’s easy to use, professionally moderated and available to read any time of day.

Find out more about all of our services for people with breast cancer at www.breastcancercare.org.uk/information-support/support-you or phone the Helpline.
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.

We want to be there for every person facing the emotional and physical trauma of a breast cancer diagnosis. Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

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

Donate online
You can give using a debit or credit card at www.breastcancercare.org.uk/donate

My details
Name __________________________________________________________
Address _______________________________________________________
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Postcode ____________________

Email address ___________________________________________________

We might occasionally want to send you more information about our services and activities.

☐ Please tick if you’re happy to receive email from us
☐ Please tick if you don’t want to receive post from us

We won’t pass on your details to any other organisation or third parties.

Please return this form to Breast Cancer Care, Freepost RRKZ-ARZY-YCKG, 5–13 Great Suffolk Street, London SE1 0NS
About this booklet

Medullary breast cancer 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 www.breastcancercare.org.uk/publications

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

Phone 0345 092 0808
Email publications@breastcancercare.org.uk
Breast Cancer Care is the only UK-wide charity providing specialist support and tailored information for anyone affected by breast cancer.

Our clinical expertise and emotional support network help thousands of people find a way to live with, through and beyond breast cancer.

Visit www.breastcancercare.org.uk or call us free on 0808 800 6000 (Text Relay 18001).