This booklet is for people who would like more information about borderline or malignant phyllodes tumours. It describes what they are, the symptoms, how a diagnosis is made and possible treatments.

If you have a benign phyllodes tumour, see our *Benign phyllodes tumour* booklet.
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
What is a borderline or malignant phyllodes tumour?

A phyllodes tumour is a hard lump of tissue that develops from the stroma (supportive tissue) of the breast.

Phyllodes tumours are grouped into three types:

- benign (not cancer)
- borderline (these have most of the same features as a benign phyllodes tumour but also have some abnormal characteristics)
- malignant (cancer)

They are grouped according to how they look under a microscope. Pathologists (doctors who examine tissue from a biopsy or surgery) decide this by looking at a number of things. For example, how quickly the cells are dividing, how abnormal the cells are and whether they are growing into the surrounding breast tissue.

Borderline and malignant phyllodes tumours are rare. They account for less than 1% of breast cancers.

Phyllodes tumours are most common in women between 40 and 50 who haven’t yet been through the menopause, although they can occur at any age. Phyllodes tumours can also occur in men, although this is very rare.

The outlook (prognosis) for borderline and malignant phyllodes tumours is very good.

Symptoms

Phyllodes tumours usually become noticeable as a smooth, hard lump, sometimes seen as a smooth bulge under the skin. In some cases they can grow quickly and become quite large.

Routine breast screening can often pick up changes in the breast before a woman notices any symptoms. Therefore some women who attend breast screening may be referred for further tests and are diagnosed with a phyllodes tumour without having any symptoms.
How is a borderline or malignant phyllodes tumour diagnosed?

Phyllodes tumours are diagnosed using a range of tests. This may include:

- a mammogram (breast x-ray)
- an ultrasound scan (uses high frequency sound waves to produce an image)
- a core biopsy (uses a hollow needle to take a sample of breast tissue)

In some situations a fine needle aspiration (FNA) may be done, but this is not commonly used in testing for phyllodes tumours. An FNA uses a fine needle and syringe to take a sample of cells.

Your specialist may also suggest you have a magnetic resonance imaging (MRI) scan. This uses magnetic fields and radio waves to produce a series of images of the inside of the breast.

For more information about these tests, see our Your breast clinic appointment booklet.

Phyllodes tumours are often difficult to diagnose because they can be confused with other breast problems, particularly a benign breast condition called a fibroadenoma. This means your specialist team may not be sure of the diagnosis until the whole tumour is removed and examined by a pathologist.

How is a borderline or malignant phyllodes tumour treated?

Surgery

Surgery is usually the main treatment recommended for a borderline or malignant phyllodes tumour.

You may be offered breast-conserving surgery or a mastectomy. Your specialist will discuss with you what type of surgery you need. Breast-conserving surgery, also known as a wide local excision or a lumpectomy, is the removal of the tumour with a margin (border) of normal breast tissue around it. A mastectomy is the removal of all the breast tissue including the nipple area.
If you have breast-conserving surgery, it’s important to have a clear margin of normal breast tissue when the lump is removed to reduce the risk of the tumour coming back (known as local recurrence). If there isn’t a clear margin then more surgery is usually recommended.

Unlike other types of breast cancer, borderline or malignant phyllodes tumours rarely spread to the lymph nodes (glands) under the arm (axilla), so these will not be routinely removed during surgery. However, your surgeon will look at your individual case and recommend the best surgery for you. You may want to read our Treating primary breast cancer and Your operation and recovery booklets for more information.

If you are going to have a mastectomy, you will usually be able to have breast reconstruction. This can be done at the same time as your mastectomy (immediate reconstruction) or months or years later (delayed reconstruction). If you would like more information please see our Breast reconstruction booklet.

If you are unable to have breast reconstruction, choose not to or have a delayed reconstruction, you may want to read our Breast prostheses, bras and clothes after surgery booklet.

The decision to have a reconstruction or wear a prosthesis (an artificial breast form) is very personal and some women opt to do neither.

**Are there any adjuvant (additional) treatments after surgery?**

Some people with breast cancer are given further treatments (such as chemotherapy, radiotherapy or hormone therapy) to reduce the risk of the cancer coming back. These are known as adjuvant (additional) treatments.

It’s unlikely you will need any additional treatments after surgery, even if you have a malignant phyllodes tumour.

In very rare situations you may be offered radiotherapy or chemotherapy. In this case it will be recommended that you see an oncologist (a doctor who specialises in the treatment of cancer) to discuss your situation.

Your specialist team will be able to tell you if there are any clinical trials that you could take part in.
Coping with a borderline or malignant phyllodes tumour

Being told you have a borderline or malignant phyllodes tumour can be a very anxious, frightening and isolating time. Having a rare type of breast cancer may add to your anxiety. However, there are people who can support you, so don’t be afraid to ask for help if you need it. Let other people know how you are feeling, particularly 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 feel you’d like to talk through your feelings and concerns in more depth over time, a counsellor or psychologist may be more appropriate. Your breast care nurse, specialist or GP (local doctor) can arrange this.

If you want to talk you can also call our Helpline on 0808 800 6000.
Notes
4 ways to get support

We hope this information was helpful, but if you have questions, want to talk to someone who knows what it’s like or want to read more about breast cancer, here’s how you can.

Speak to trained experts, nurses or someone who’s had breast cancer and been in your shoes. Call free on 0808 800 6000 (Monday to Friday 9am–5pm, Wednesdays til 7pm and Saturday 9am–1pm).

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.

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 breastcancercare.org.uk/donate

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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, Chester House, 1–3 Brixton Road, London SW9 6DE
About this booklet

Phyllodes tumours: borderline and malignant 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:

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Email publications@breastcancercare.org.uk

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

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

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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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