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#### Donations from the public make it possible for us to provide publications like this one free to people affected by breast cancer.

If you would like to make a donation, please send your cheque to: Breast Cancer Care, RRKZ-ARZY-YCKG, 5-13 Great Suffolk Street, London SE1 0NS. Or donate via our website at [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)

## About Breast Cancer Care

Breast Cancer Care is here for anyone affected by breast cancer. We bring people together, provide information and support, and campaign for improved standards of care. We use our understanding of people's experience of breast cancer and our clinical expertise in everything we do. Visit

[www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)

or call our free helpline on **0808 800 6000** (Text Relay **18001**).

Interpreters are available in any language. Calls may be monitored for training purposes. Confidentiality is maintained between callers and Breast Cancer Care.

## Phyllodes tumours: malignant and borderline malignant

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

We hope that this information helps you to discuss any questions you may have with your breast cancer specialist or breast care nurse.

## What is a malignant or borderline malignant phyllodes tumour?

Phyllodes tumours are smooth hard lumps of tissue that can occur anywhere in the breast. They can sometimes grow quite large.

Although they can happen at any age, phyllodes tumours are most common in women between 40 and 50 who haven't yet been through the menopause. Phyllodes tumours of the breast can also occur in men, although this is extremely rare.

Phyllodes tumours can be classed into three types: benign (non-cancerous), borderline malignant and malignant. They are put into these three categories according to what they look like under a microscope. Pathologists (doctors who examine tissue removed during a biopsy or surgery) look at various features when making this decision. This includes how quickly the cells are dividing, how abnormal the cells have become and whether there is a clear border between the phyllodes tumour and the breast tissue that surrounds it.

Malignant and borderline malignant phyllodes tumours are rare types of cancer that account for less than one per cent of breast cancers.

If you have a benign phyllodes tumour see our **Benign phyllodes tumour** leaflet, as the information will be more relevant to you.

## How is a malignant or borderline malignant phyllodes tumour diagnosed?

At the breast clinic you will usually have a mammogram (breast x-ray) and/or an ultrasound scan. A small sample of the lump will be taken using fine needle aspiration (FNA) or, more commonly, a core biopsy, where a hollow needle will extract a thin sample of tissue from the lump.

Sometimes your doctor may also recommend that you have a magnetic resonance imaging (MRI) scan which uses magnetic radio waves to produce detailed pictures of the inside of the breast.

Phyllodes tumours are complex and sometimes difficult to diagnose because they can be confused with other breast problems. Sometimes doctors cannot be sure of the diagnosis until the entire tumour is removed and examined by a pathologist.

## How is a malignant or borderline malignant phyllodes tumour treated?

Surgery is usually the only treatment needed for a malignant or borderline malignant phyllodes tumour. Your specialist will discuss with you the type of surgery you need.

The aim of the surgery is to remove all of the tumour and an area of healthy tissue around it (known as clear margins). It's important to have a clear margin of healthy tissue when the lump is removed to reduce the risk of it coming back because some cells have been left behind. If a clear margin is not achieved by the initial surgery then further surgery will usually be recommended.

You may be offered a lumpectomy (also known as a wide local excision) where only the lump and the margin of healthy tissue are removed. Or, in some cases, a mastectomy (the removal of all the breast tissue and nipple area) may be needed, for example if the tumour is large in relation to the size of your breast. If you would like to read more about having surgery for breast cancer please see our booklets **Treating breast cancer** and **Your operation and recovery**.

If you are having a mastectomy then you will usually be able to have breast reconstruction if you choose. There are many factors to be considered when thinking about breast reconstruction. If you'd like more information please see our **Breast reconstruction** booklet.

Unlike other types of breast cancer, malignant and borderline malignant phyllodes tumours rarely spread to the lymph nodes under the arm (axilla) so these will not be removed routinely during surgery. Your surgeon will assess your situation individually and recommend the most appropriate surgery for you.

## What are the additional (adjuvant) treatments?

A borderline malignant phyllodes tumour will not require any additional treatments after surgery.

This is usually also the case for a malignant phyllodes tumour. Unlike with other types of breast cancer, the benefits of radiotherapy are uncertain so it is not commonly used. Chemotherapy will not be offered for a malignant phyllodes tumour unless it has spread outside the breast. Hormone therapies, such as tamoxifen, are also not thought to be helpful in treating malignant phyllodes tumours.

They are used to treat other types of breast cancer where growth is stimulated by the hormone oestrogen. However, malignant phyllodes tumours, although occurring in the breast, do not tend to be stimulated by oestrogen. They are thought to behave more like another type of cancer of the soft tissues called a sarcoma.

## What might happen if it recurs or spreads?

Although in most cases a malignant or borderline malignant phyllodes tumour will be successfully treated the first time by surgery, sometimes the tumour can come back. A borderline malignant phyllodes tumour can come back as a borderline malignant tumour or a malignant tumour. In these cases, further surgery will usually be offered.

A malignant phyllodes tumour has potential to spread through the bloodstream to other areas of the body, although it is important to know that for most people this does not happen. If a malignant phyllodes tumour spreads (metastasises), the most common site for it to spread to is the lungs, although spread to other areas of the body, such as the bones, is also possible. If a phyllodes tumour does spread beyond the breast, chemotherapy or radiotherapy may be offered.

## Follow-up

Your follow-up care after treatment for a malignant or borderline malignant phyllodes tumour may vary depending on which hospital you are being treated at. Your consultant will let you know about the frequency of follow-up appointments but it is common to have an appointment about once a year at which you will usually have a mammogram and be examined by the doctor or nurse. If you have had a mastectomy you won't need a mammogram on the affected side but a clinical examination can still be done.

If you have any concerns in between follow-up appointments or develop any new symptoms that are worrying you, contact your GP, cancer specialist or breast care nurse who will be able to arrange for you to be seen earlier if necessary.

## Living with breast cancer

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

Remember 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 that 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 in more depth over a period of time, a counsellor or psychologist may be more appropriate. Your breast care nurse, specialist or GP can arrange this.

You may find it easier to share your feelings with someone who has had breast cancer. You can do this either one to one or in a support group. For more information on individual support or support groups in your area call the Breast Cancer Care helpline on **0808 800 6000** (Text Relay 18001).

## Further help from Breast Cancer Care

For further medical information, emotional support, and details of our services, call our helpline free on **0808 800 6000** (Text Relay 18001).

Breast Cancer Care's website has an email enquiries service called Ask the nurse, along with forums and live chat sessions where you can share your views with people in a similar situation. For more information about these services and other online support, visit **[www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)**

We run courses and activities for people with breast cancer, which aim to provide information and support and give people the chance to meet others in a similar situation. For more information about these events, call our helpline or contact your nearest Breast Cancer Care centre details (details on the reverse).

Breast Cancer Care also has a wide range of publications to guide you from diagnosis to living well after treatment. You can download and order our publications at **[www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)** or call our helpline on **0808 800 6000** for a printed order form.

## Other organisations

### Macmillan Cancer Support

General enquiries: 020 7840 7840  
Helpline: 0808 808 00 00  
Website: [www.macmillan.org.uk](http://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. Over the phone, its cancer support specialists can answer questions about cancer types and treatments, provide practical and financial support to help people live with cancer, and are there if someone just wants to talk. Its website features expert, high-quality information on cancer types and treatments, emotional, financial and practical help, and an online community where people can share information and support. Macmillan also funds expert health and social care professionals such as nurses, doctors and benefits advisers.

### Cancer Research UK

Telephone: 020 7061 8355  
Freephone: 0808 800 4040  
Website: [www.cancerresearchuk.org](http://www.cancerresearchuk.org)  
Patient information website:  
[www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)

Cancer Research UK is the world's leading independent organisation dedicated to cancer research. They provide a free information service about cancer and cancer care to people with cancer and their families.

### Rarer Cancers Forum

Telephone: 01227 738279  
Email: [contact@rarercancers.org.uk](mailto:contact@rarercancers.org.uk)  
Website: [www.rarercancers.org.uk](http://www.rarercancers.org.uk)

The Rarer Cancers Forum offers advice and information to people with rare and less common cancers and their families and friends. They put people in touch with others for support and sharing of experiences. They also work to raise awareness about rare and less common cancers and the needs of patients, provide educational resources and are involved in securing the best possible services for people living with rarer cancers.

## Notes

This factsheet has been produced by Breast Cancer Care's clinical specialists and reviewed by healthcare professionals and people affected by breast cancer.

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A large print version of this booklet can be downloaded from our website, [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk). It is also available in Braille on request. Call 0845 092 0808 for more information.