1. What is Paget's disease of the breast?
Paget's disease of the breast is an uncommon type of breast cancer that usually first shows as changes to the nipple.

It occurs in less than 5% of all women with breast cancer.

Men can also get Paget's disease but this is very rare.

2. Symptoms of Paget's disease
The most common symptom is a red, scaly rash on the nipple. The rash may spread to the darker area of skin around the nipple (areola).
The rash can feel itchy, or you may have a burning sensation.

The nipple may be pulled in (inverted).

Sometimes there may also be some liquid (discharge) coming from the nipple.

**Is it Paget's disease or eczema?**

Paget's disease can look like other skin conditions such as eczema. But there are differences.
For example, Paget's disease affects the nipple while eczema on the breast generally affects the areola and rarely affects the nipple.

Also, Paget's disease usually occurs in one breast while most other skin conditions tend to affect both breasts.

Your GP may prescribe a steroid cream first to treat the nipple rash if eczema is suspected.

It's important to stay breast aware and if you notice a change in either breast tell your GP as soon as possible.

3. Paget's disease and DCIS

Most people with Paget's disease will have an early form of breast cancer – known as ductal carcinoma in situ (DCIS) – under the nipple or elsewhere in the breast.

DCIS means that cancer cells have developed inside the milk ducts but remain within the duct (‘in situ’). They have not yet developed the ability to spread outside the ducts, either into the surrounding breast tissue or to other parts of the body.

Because it’s confined to the breast ducts, if treated DCIS has a good outlook (prognosis).

However, if DCIS is not treated, the cancer cells may develop the ability to spread from the ducts into the surrounding breast tissue and become an invasive breast cancer.

DCIS is graded as either low, intermediate, or high grade, based on what the cells look like under the microscope. High-grade DCIS is more likely with Paget's disease.

Although the size and grade of the DCIS may help predict if it will become invasive, there’s currently no way of knowing for certain if this will happen.

4. Can Paget’s disease be invasive?

Some people with Paget's disease will also have developed an invasive breast cancer.

Invasive breast cancer has the potential to spread from the breast to other parts of the body.

In many cases this will mean a breast lump has also developed in the affected breast.

Even if there's no lump, some people may still have an invasive cancer.

5. Diagnosing Paget’s disease
As Paget’s disease is rare and can look like other skin conditions, it’s not always diagnosed straight away.

Once your GP has referred you to a specialist, you may have several tests including:

- A mammogram (a breast x-ray)
- An ultrasound scan (uses high-frequency sound waves to produce an image)
- A biopsy – see below

**Biopsy**

You will usually have a biopsy to confirm the diagnosis.

A biopsy is the removal of tissue to be looked at under a microscope. Local anaesthetic is used to numb the area before the biopsy.

The kind of biopsy you have will depend on your symptoms. For example:

- A punch biopsy removes a small circle of tissue from the skin of the breast or nipple
- A core biopsy removes a small sample of tissue from the area of concern if this can be felt within the breast

If an area of concern in your breast can only be seen on a mammogram or ultrasound, you may have an image-guided biopsy. This is where samples of breast tissue are taken using a mammogram or ultrasound to help locate the exact position of the area.

The samples of tissue or cells are sent to a laboratory where they are examined under a microscope to make a diagnosis.

Find out more about the tests and procedures you may be having.

### 6. Treatment for Paget’s disease

**Surgery**

Surgery is usually the first treatment for Paget’s disease.

This may be breast-conserving surgery, also called wide local excision or lumpectomy, which is the removal of the cancer with a margin (border) of normal breast tissue around it.

Or you may have a mastectomy, which is the removal of all the breast tissue. For Paget’s disease, the nipple and areola (the darker area of skin around the nipple) will also be removed.
You may be offered a choice between these types of surgery, depending on the size and location of the area affected. Your breast surgeon will discuss this with you.

The breast tissue removed during surgery is examined by a doctor who analyses tissue and cells (pathologist). If any cancer cells are seen at or close to the margin of normal breast tissue, you may need more surgery or radiotherapy.

A mastectomy is more likely to be recommended if:

- A large area of the breast is affected by DCIS or invasive breast cancer
- It hasn't been possible to get a clear margin of normal tissue around the breast cancer using breast-conserving surgery
- There is more than one area of cancer in the breast
- The position of the cancer means breast-conserving surgery is not an option

If a mastectomy is not recommended but you would prefer to have one, you can discuss this with your breast surgeon.

**Localisation**

If you are having breast-conserving surgery for DCIS or invasive breast cancer, the cancer may need to be localised.

Localisation is when the exact position of the breast cancer is ‘marked’ for the surgeon, so the right area can be removed.

A technique called wire localisation is used. In the x-ray department or breast clinic, a mammogram or ultrasound scan will be used as a guide to insert a fine wire into the breast under local anaesthetic. The wire is then carefully secured under a small dressing and left in place until the operation to remove the area of breast cancer.

The operation is usually done under a general anaesthetic on the same day, and the wire will be removed during the operation.

Some hospitals are using a new localisation procedure. Instead of a fine wire, a tiny very low-dose radioactive seed (about the size of a grain of rice) or a small radiation-free magnetic marker (known as a Magseed) is inserted into the area of breast tissue to be removed. This can be done up to two weeks before your operation.

During surgery, a special probe is used to locate the marker and guide the surgeon to the tissue that needs to be removed. The marker will be removed during the operation.
Sometimes the operation is done on a different day. You’ll go home after the wire or seed has been inserted and come back to the hospital the day of your operation. If the wire or seed feels uncomfortable you can have mild pain relief, such as paracetamol.

**Breast reconstruction**

Most women who have a mastectomy will have the option to have breast reconstruction. This may be done at the same time as your mastectomy (immediate reconstruction) or months or years later (delayed reconstruction).

It’s possible to have the nipple reconstructed after surgery for Paget’s disease of the breast, whether you have breast-conserving surgery or a mastectomy.

Some women choose not to or cannot have breast reconstruction. They may use a breast prosthesis or may prefer not to use anything.

**Lymph node removal**

If you have invasive breast cancer with the Paget’s disease, your treatment team will want to check if any of the lymph nodes (glands) under the arm contain cancer cells.

This, along with other information about your breast cancer, 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 of the lymph nodes (a sentinel lymph node biopsy) or all of them (a lymph node clearance).

Usually the lymph nodes under the arm don’t need to be removed if you have DCIS. This is because the cancer cells haven’t developed the ability to spread outside the ducts into the surrounding breast tissue. However, surgery to the lymph nodes may be recommended for some people with DCIS, for example if you have a mastectomy.

Find out more about surgery to the lymph nodes.

**Adjuvant (additional) treatments**

After surgery, you may need other treatments.

These are called adjuvant (additional) treatments and are more likely to be recommended if the underlying breast cancer is invasive.

These treatments can include:
• Chemotherapy
• Radiotherapy
• Hormone (endocrine) therapy
• Targeted (biological) therapy
• Bisphosphonates

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

Some of these treatments may be given before surgery. This is known as neo-adjuvant or primary treatment.

**Chemotherapy**

Chemotherapy destroys cancer cells using anti-cancer drugs. It’s given to reduce the risk of breast cancer returning or spreading.

Whether you’re offered chemotherapy depends on various features of the cancer.

Chemotherapy may be used if the underlying breast cancer is invasive.

It’s not used to treat DCIS or Paget’s disease.

**Radiotherapy**

If you have breast-conserving surgery you will usually be offered radiotherapy to the breast to reduce the risk of the cancer coming back in the same breast.

Some people may also have radiotherapy to the lymph nodes under the arm or above the collar bone.

Radiotherapy is sometimes given to the chest wall after a mastectomy, for example if some lymph nodes under the arm are affected.

**Hormone (endocrine) therapy**

Some breast cancers use oestrogen in the body to help them to grow. These are known as oestrogen receptor positive or ER+ breast cancers.

Hormone therapies block or stop the effect of oestrogen on breast cancer cells.

Invasive breast cancers are tested to see if they are ER+ using tissue from a biopsy or after surgery.
DCIS may be tested but this is not done in all hospitals.

Find out more about when hormone therapy is given.

**Targeted (biological) therapy**

This is a group of drugs that block the growth and spread of cancer.

The most widely used targeted therapies are for HER2 positive breast cancer.

Targeted therapy may be used if the underlying breast cancer is invasive. It’s not used to treat DCIS or Paget's disease.

Find out more about targeted therapies.

**Bisphosphonates**

Bisphosphonates are a group of drugs that can reduce the risk of breast cancer spreading in postmenopausal women.

Bisphosphonates may be used if the underlying breast cancer is invasive. They are not used to treat DCIS or Paget's disease.

Your treatment team can tell you if bisphosphonates would be suitable for you.

7. **Follow-up after treatment**

You'll continue to be monitored after your hospital-based treatments (such as surgery or radiotherapy) finish. This is known as follow-up.

It's also important to be aware of any changes to the breast, chest or surrounding area. It can be difficult to know how your breast or scar should feel. The area around the scar may feel lumpy, numb or sensitive. This means that you'll need to get to know how it looks and feels so you know what is normal for you. This will help you to feel more confident about noticing changes and reporting them early to your GP or breast care nurse.

Having breast cancer in one breast means the risk of developing cancer in the other breast (a new primary breast cancer) is slightly higher than in someone who's never had breast cancer. Therefore it's important to be aware of any new changes to your breasts and to report these as soon as possible.

8. **Coping with a diagnosis of Paget’s disease**
Being diagnosed with breast cancer can make you feel lonely and isolated.

If you would like any further information and support about breast cancer or just want to talk things through, you can speak to one of our experts by calling our free Helpline on 0808 800 6000.

Many people find it helps to talk to someone who has been through the same experience as them. Breast Cancer Now’s Someone Like Me service can put you in touch with someone who has had a diagnosis of breast cancer, so you can talk through your worries and share experiences over the phone or by email.

You can also visit our confidential online Forum and join one of the ongoing discussions.

Find out more about coping emotionally with breast cancer.

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