Paget's disease of the breast

This factsheet is for women diagnosed with Paget's disease of the breast. We hope it answers some of your questions and helps you discuss your options with your cancer specialist or breast care nurse. We recommend that you read it together with our booklet Understanding Cancer of the Breast.

WHAT IS PAGET'S DISEASE OF THE BREAST?
Paget's Disease of the breast is an uncommon form of breast cancer, which first shows as nipple changes. This type of breast cancer starts in the breast ducts and spreads to the skin of the nipple and the areola (the dark circle around the nipple). It occurs in around 1% of all women with breast cancer. Men can also get Paget's disease but this is very rare.

WHAT ARE THE SIGNS AND SYMPTOMS?
The most common sign is a red, scaly rash involving the nipple, which may spread to the areola (the darker skin around the nipple). The rash can feel itchy or you may have a burning sensation. The nipple may be inverted (pulled in) and there may also be some discharge. The symptoms of Paget's disease can look like other skin conditions such as eczema or psoriasis. However, there are differences. For example, Paget's disease affects the nipple from the start while eczema affects the areola region first and only rarely affects the nipple. Paget's disease usually occurs in one breast, while other skin conditions usually affect both breasts.

Approximately half of patients with Paget's disease will also have an underlying lump.
Most of these will be invasive cancers, which means the cancer has the potential to spread outside the breast. Where there is no lump, most will be non-invasive or in-situ cancers. This means that the cancer cells are inside the milk ducts and have not developed the ability to spread either within or outside the breast.

**HOW IS A DIAGNOSIS MADE?**

Because Paget’s disease can look like other skin conditions, it can be difficult to make a diagnosis. Once your GP has referred you to a specialist, certain tests may be done to help make the diagnosis. They include:

**Mammogram**
You will usually have a mammogram (breast X-ray) to check whether there is any underlying cancerous tissue in the breast.

**Skin scrapings**
This involves scraping some cells from the skin of the nipple. The cells are put onto a slide so that they can be looked at under a microscope.

**Imprint cytology**
In this case an area of the affected nipple is pressed onto a slide. The cells on the slide can then be examined under a microscope.

**Biopsy**
You will probably have a biopsy taken to confirm the diagnosis. This means taking a small piece of skin and breast tissue from the affected area so that they can be looked at under a microscope. This is known as a punch biopsy and is usually done under local anaesthetic.

**WHAT TREATMENT WILL I BE OFFERED?**

**Surgery**
As for most types of breast cancer, surgery will be the first treatment. The type of surgery will depend on whether or not you have a lump and the extent of the cancer. If you have a lump or the cancer is widespread in the breast, then you are likely to be offered a mastectomy (removal of the whole breast). If the cancer is confined to a small area, a wide local excision (removal of the affected area and a section of normal tissue around it) followed by radiotherapy may be suggested. In some cases you may be given the choice.

The surgeon may recommend a specific treatment, or you may be asked, which treatment you would prefer. If you are given a choice, it means your doctor believes that both treatment plans offer you equal benefits. It is important to find out whether cancer has spread to the lymph nodes in the axilla (glands in your armpit). This means removing all the nodes (clearance) and will help to decide if you need any further treatment such as chemotherapy.

**Adjuvant treatment**
Adjuvant treatments are treatments given in addition to surgery and include chemotherapy, radiotherapy and hormonal therapy. The aim of adjuvant treatments is to reduce the risk of the cancer coming back either in the same breast (local recurrence) or elsewhere in the body.

If you have a wide local incision, you will probably be offered radiotherapy to reduce the risk of the cancer coming back in the same breast. If you have a mastectomy, you may or may not need radiotherapy. For further information see Action Breast Cancer’s Radiotherapy factsheet.

In some cases chemotherapy is recommended, for example if the cancer has spread to the lymph nodes. For further information see the section on chemotherapy in our booklet on Understanding Cancer of the Breast.

The surgeon may recommend a specific treatment, or you may be asked, which treatment you would prefer. If you are given a choice, it means your doctor believes that both treatment plans offer you equal benefits.

Information. Support. Research.
If your tumour is oestrogen receptor positive, which means it depends on the hormone oestrogen for growth, hormone therapy will usually be recommended. There are many hormone therapies available. For further information call the National Breast Cancer Helpline on freephone 1800 30 90 40.

COPING WITH BREAST CANCER

Being diagnosed with breast cancer can be a very anxious and frightening time. Having a rarer type of cancer may add to your anxiety. Remember that there are people who can support you so don’t be afraid to ask for help. You can let other people know how you are feeling, particularly your family and friends, so that they can be more supportive. It can also help to discuss your feelings or worries with your breast care nurse or specialist.

You might find it easier to share your feelings with someone who has had a similar experience to you. Reach to Recovery is a programme set up to help and support women who have recently had a breast cancer diagnosis. The programme works on the principal of personal contact between the patient and a Reach to Recovery volunteer (a woman who has had surgery for breast cancer). Carefully selected and fully trained volunteers are available to provide advice and reassurance at a time when a woman is most in need of both.

For more information on individual support or support groups in your area, call the National Breast Cancer Helpline on freephone 1800 30 90 40.

HELP FROM ACTION BREAST CANCER

Action Breast Cancer, a programme of the Irish Cancer Society, provides breast cancer information and support and funds breast cancer research. Our services are free, confidential and accessible.

For more information call the National Breast Cancer Helpline on freephone 1800 30 90 40 or visit www.cancer.ie/action
ORGANISATIONS

Action Breast Cancer
43/45 Northumberland Road
Dublin 4
Freefone Helpline:
1800 30 90 40
Email: abc@irishcancer.ie

Irish Cancer Society
43/45 Northumberland Road
Dublin 4.
Freefone Helpline:
1800 200 700
Email: helpline@irishcancer.ie
Website: www.cancer.ie

Quinn Healthcare
Mill House, Fermoy, Co. Cork,
Phone: 1890 700890
Email: info@quinn-healthcare.com
Website: www.quinn-healthcare.com

Reach to Recovery
43–45 Northumberland Road,
Ballsbridge, Dublin 4
Freefone Helpline:
1800 30 90 40

Voluntary Health Insurance
VHI House
Lower Abbey Street
Dublin 1.
Callsave: 1800 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

Hibernian Healthcare
Po Box 764, Freepost, Togher,
Co. Cork.
Phone: 1850 716 666
Email:support@hibernianhealthinsurance.ie
Website: www.hibernian.ie

USEFUL WEBSITES

Irish Cancer Society
www.cancer.ie
Breast Cancer Care UK
www.breastcancercare.org.uk
Cancerbacup
www.cancerbacup.org.uk
American Cancer Society
www.cancer.org
The Susan G. Komen Foundation
www.komen.org
Europa Donna
www.cancereurope.org/europa/donna
Lymphodema Ireland
www.lymphireland.com
Manual Lymph Drainage Ireland
www.mldireland.com

ABC – ACTION BREAST CANCER

Action Breast Cancer, a programme of the Irish Cancer Society, is the leading provider of breast cancer information and support in Ireland. Each year we reach over 25,000 women who are concerned about breast cancer or breast health. Our services are free and include:

- Patient care programmes – providing emotional support and practical assistance for those living with breast cancer.
- Health Promotion – providing community and workplace programmes on breast awareness and leading a healthy lifestyle.
- Advocacy – providing a voice for those affected by breast cancer in Ireland.
- Professional support – complementing the services offered by those caring for breast cancer patients.
- Research – funding vital Irish research that will have a significant impact on the diagnosis and treatment of breast cancer.

ABC is funded entirely by donations from the public. If you would like to support our work or make a donation please contact us.

Freefone Helpline
1800 30 90 40

First published by the Irish Cancer Society in November 2007
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