

Neurofibromatosis type 1 (NF1) and breast cancer risk

This leaflet is for women with a **moderate risk of breast cancer in association with neurofibromatosis type 1 (NF1).**

It gives information on how common breast cancer is, screening, genetic testing and how the risk of breast cancer can be altered. If you have any further questions, please speak to a doctor, genetic counsellor or nurse caring for you.

Contact details

Clinic telephone number: _____

Seen in clinic by: _____

Date: _____

What is a moderate risk of breast cancer?

Breast cancer is a common disease. In the general population about one in eight women in the UK will develop breast cancer.

Breast cancer affects 1 in 8 women



If you have a moderate risk of breast cancer this means that your risk of getting breast cancer is higher than the risk for women with no family history of the disease. You are still much more likely not to get breast cancer than you are to develop it.

Do women with a moderate risk of breast cancer need screening?

Yes. Screening for women with a family history of breast cancer is based on nationally recommended guidelines – these can be found on the National Institute for Health and Clinical Excellence website at **www.nice.org.uk**. A separate leaflet about breast screening is available.

Current guidelines recommend that women with a moderate risk of breast cancer have mammograms once a year from 40 to 49 years old.

There is no evidence that screening before the age of 40 is helpful for women with a moderate risk, even if your relatives have had breast cancer before this age.

Also some young women have breast tissue that is too 'dense' (tightly packed) for a mammogram to produce clear images.

Women aged 50 to 70 with a moderate risk of breast cancer are offered mammograms every three years like all other women in the UK. You will not need a mammogram more often than women in the general population because:

- breast cancer is easier to see on a mammogram after the menopause
- if breast cancer does occur, it is likely to grow more slowly in women aged 50 or over.

Women over 70 years old can request that breast cancer screening continues every three years if they wish. A separate leaflet is available which explains this.

All women are encouraged to be breast aware. Contact your GP if you notice any changes in your breasts. Please do not wait until your next mammogram.

Can anything alter breast cancer risk?

Yes – the following can alter the risk:

- the oral contraceptive pill and hormone replacement therapy (HRT) slightly increase the risk of breast cancer while a woman is taking it and for up to five years after it is stopped
- alcohol increases the risk of breast cancer
- pregnancy and breast-feeding lower the risk of breast cancer

- being overweight increases the risk of breast cancer for women after the menopause
- regular exercise lowers the risk of breast cancer
- eating plenty of fresh fruit and vegetables and lowering cholesterol intake helps lower the risk of cancer
- if anyone else in your family develops cancer, particularly breast or ovarian cancer, then this could alter your risk – if this happens please ask for a reassessment of your risk.

What about genetic testing?

Although breast cancer is common, it is quite rare for it to run in families. Only about 5-10% of all breast cancers happen because of an inherited tendency (also known as a genetic predisposition).

Currently genetic testing is not offered to families with a moderate risk of breast cancer associated with neurofibromatosis type 1 (NF1). This is because the chance of finding a genetic predisposition to developing breast cancer is low. This may change in the future as more is discovered about the role of genes in cancer.

Useful contacts

Breast Cancer Care

t: 0808 800 6000 www.breastcancercare.org.uk

Macmillan Cancer Support

t: 0808 808 0000 www.macmillan.org.uk

The Neuro Foundation

t: 020 8439 1234 www.nfauk.org

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Contact details

If you have any queries, please contact the NF department on the following numbers (9am to 5pm, Monday to Friday):

Appointments 020 7188 1029

Adult nurses 020 7188 0748/9976

Children's nurse 020 7188 9979

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints)

e: complaints2@gstt.nhs.uk

Language and Accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices – Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

t: 0800 731 0319 **e:** members@gstt.nhs.uk

w: www.guysandstthomas.nhs.uk/membership

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