

Headache awareness for neurofibromatosis type 1 (NF1)

This leaflet is for people with NF1 and covers how to reduce headaches. If you have any further questions or concerns, please do not hesitate to contact your NF1 nurse specialists.

How to reduce headaches

Headaches in NF1 are very common. There are simple lifestyle changes you can make to help reduce headaches and migraines.

Relaxation

Reduce stress and anxiety by trying:

- mindfulness
- meditation
- gentle exercise
- deep breathing
- writing a list of your worries before going to bed to clear your thoughts.

Sleep

- Learn healthy regular sleep patterns.
- Too much or too little sleep can cause headaches.
- Try to avoid caffeine after 5pm and alcohol and smoking shortly before going to bed.
- Don't use back-lit devices like televisions, phones, tablets and computers in your bedroom or before you go to bed.

Cut caffeine

- Try to drink fewer than three cups of tea, coffee or cola a day.
- Find decaffeinated alternative options.

Eat regularly

Lack of food can cause headaches:

- aim to have three meals each day at regular times
- aim to drink 6-7 glasses of water a day.

Reduce painkiller use

Overusing painkillers like paracetamol and codeine can cause headaches. Discuss with your specialist or GP and try to reduce your reliance on painkillers

Useful sources of information

The Migraine Trust

t: 020 7631 6970 **w:** www.migrainetrust.org

Nerve Tumours UK

Nerve Tumours UK provides information, support, and advice for people with neurofibromatosis and their families/carers.

t: 020 8439 1234 **e:** info@nervetumours.org.uk **w:** www.nervetumours.org.uk

Contact us

If you have any queries, please contact the NF department, Monday to Friday, 9am-5pm.

Appointments **t:** 020 7188 1029
Adult nurses **t:** 020 7188 0748 or 020 7188 9976
Children's nurse **t:** 020 7188 9979

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** 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, Monday to Friday, 9am-5pm

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 **w:** 111.nhs.uk

NHS website

Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing. **w:** www.nhs.uk

Was this leaflet useful?

We want to make sure the information you receive is helpful to you. If you have any comments about this leaflet, we would be happy to hear from you, fill in our simple online form, **w:** www.guysandstthomas.nhs.uk/leaflets, or **e:** patientinformationteam@gstt.nhs.uk

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