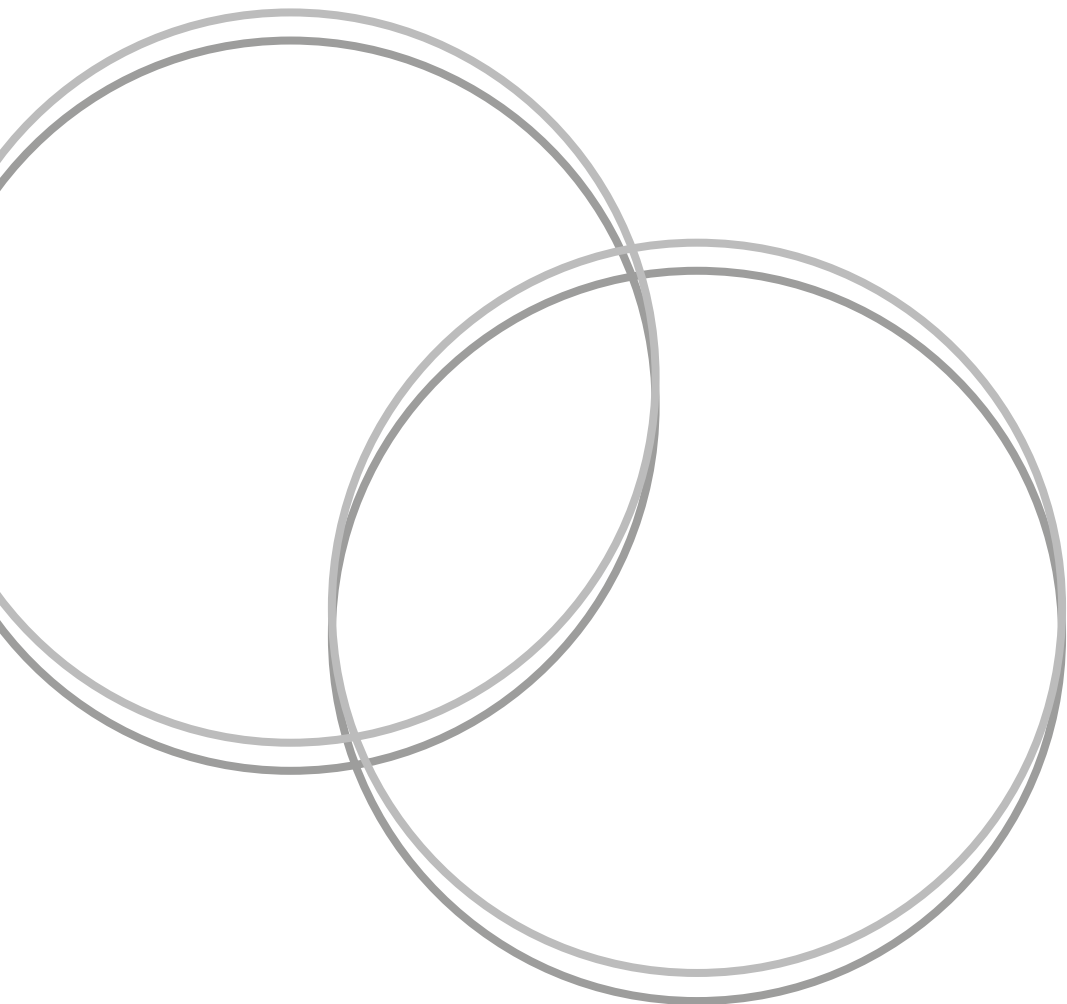




Oxford University Hospitals
NHS Foundation Trust

A Guide to NF2-Related Schwannomatosis (NF2) Care in Oxford

Information for patients



The NF2 Team

The Oxford NF2 team consists of health care professionals who work together to provide a high level of care to patients with NF2, their family and carers. Clinics are held in the West Wing building of the John Radcliffe Hospital in Oxford.

You may see all or some of these professionals when you visit the clinic. The Oxford University Hospitals NHS Foundation Trust is a teaching hospital and observers may be in clinic.

Please do let us know if you do not want this.

NF2 Specialists Nurses

The NF2 specialist nurses support patients, their families, carers and other healthcare professionals. They can provide help and support by phone, text or email, and can visit patients in the hospital or at home.

NF2 Clinic /Pathway Co-ordinator

The clinic co-ordinator will arrange your appointments and is the first point of contact if you have questions.

Consultant Neurologist

Neurology doctors look at how NF2 may be affecting you. They will take a full medical history, talk to you about your symptoms and examine you. Neurological examinations involve moving your limbs, looking at your co-ordination and testing your strength and reflexes.

Consultant in Clinical Genetics

Genetic doctors understand about our genes and will be able to explain how NF2 is caused. They will take a history from you about your health and also your family, including any illnesses or symptoms you or they have had, now or in the past. The Genetic doctor will examine you for features specific to NF2 such as lumps or marks found on the skin or underneath the skin. The Genetic Doctor will be able to tell you about genetic testing for you and your family and how this is done.

ENT (Ear, Nose and Throat), Neurosurgery or Plastics

You may see a specialist who will discuss any treatments or procedures that are right for you.

Clinical Psychologist

Psychologists help patients and their families manage emotions, behaviours and experiences. Having NF2 can affect people physically, emotionally and socially.

Genetic Counsellor

The genetic counsellor will provide you with information and help you to make decisions about the genetics of the condition. They may contact you before you are seen in clinic to find out about your family history. They can talk to you about how NF2 might affect other family members and discuss ways of sharing that information with relatives. They can also provide information around the options available when planning a family.

Audiology (hearing test)

You will have a hearing test as part of your appointment. The hearing therapist can advise and assess you on your hearing and aids.

Ophthalmology (eye test)

The eye doctors will examine your eyes. Eye drops may be needed to dilate the pupil and you should avoid driving for around 2 to 3 hours after this. NF2 does not always affect the eyes but these tests can pick up any early changes. It is important that you also attend your usual eye tests at the optician.

Physiotherapist

The Physiotherapist looks at balance issues, difficulty walking/ mobilising or maintaining your fitness.

They can assess and provide an individual exercise programme and help you to access treatment and advice.

Radiologist

It is unlikely you would meet the radiologist. They will look at your scans and discuss with the multidisciplinary team, to help plan the best care and treatment for you.

How to contact us

The Oxford NF2 team can be contacted by phone, text or email.

NF2 Specialist Nurses

The Clinical specialist nurses can be contacted from Monday to Friday between 8am and 4:30pm.

Direct Line: 01865 231 741

Mobile: 07747 795 588 or 07749 837 593

Via the hospital switchboard on: 01865 841 166

Email: nf2@ouh.nhs.uk

NF2 Clinic /Pathway Co-ordinator

Telephone: 01865 231889

Email: NF2@ouh.nhs.uk

Useful national contacts

Carers UK

Website: www.carersuk.org

Freephone 0808 808 7777

Email: advice@carersuk.org

General enquiries: info@carersuk.org

Department for Work and Pensions Benefits

(for claim packs and information) www.gov.uk/browse/benefits

Nerve Tumours UK

Website: Nervetumours.org.uk

Helpline: 07939 046 030 or 02084 391 234

Email: helpline@nervetumours.org.uk or info@nervetumours.org.uk

RNID - Royal National Institute for Deaf People

Website: Rnid.org.uk

Phone: 0808 808 0123

Email: contact@rnid.org.uk

Tinnitus UK

Website: [Tinnitus UK](http://TinnitusUK)

Helpline: 0800 018 0527

Text: 07537 416841

Email: helpline@tinnitus.org.uk

RNIB - Royal National Institute of Blind People

Website: www.rnib.org.uk

Phone: 0303 123 9999

Email: helpline@rnib.org.uk

Or say "Alexa, call RNIB Helpline"

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

Author: NF2 Clinical Nurse Specialist
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Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information



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