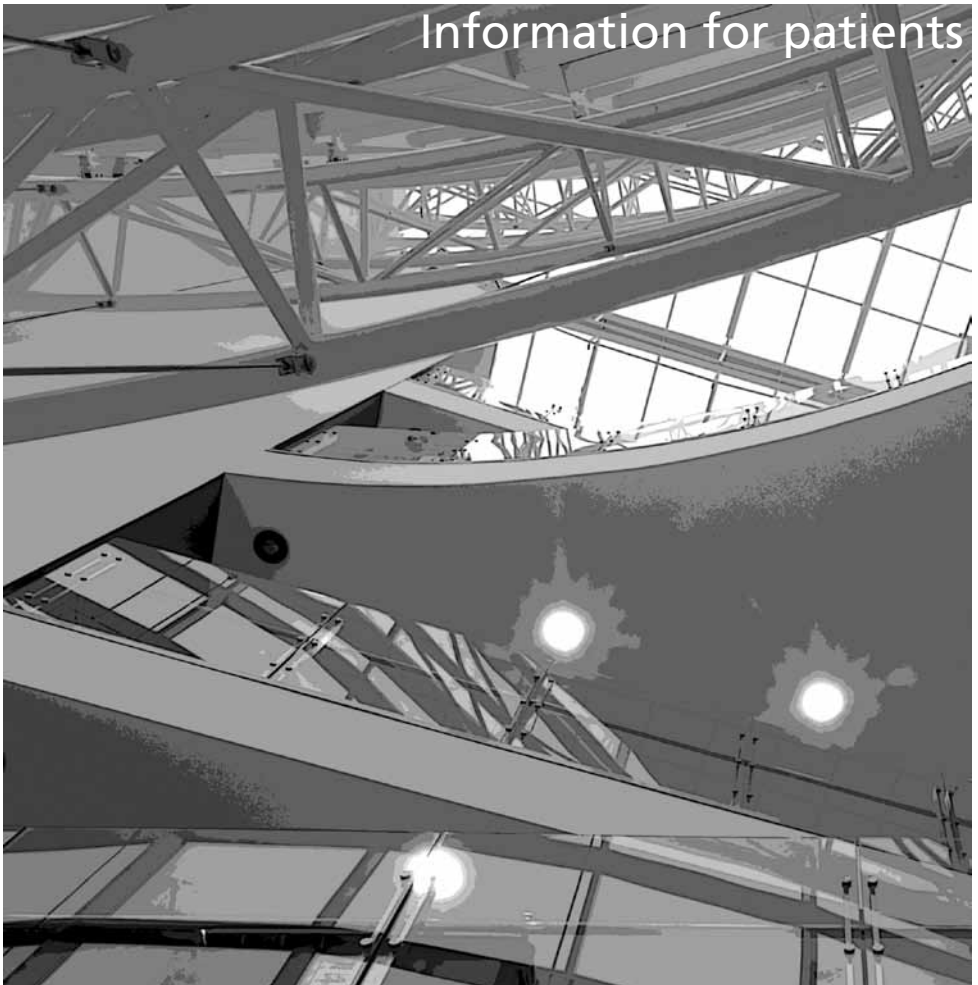


Department of Neurosciences

A guide to Neurofibromatosis Type 2 (NF2) care in Oxford

Information for patients



The NF2 team

The Oxford NF2 team consists of a variety of health care professionals who work together to provide a high level of care to patients with NF2 and their family or carers. Clinics are held in the West Wing building of the John Radcliffe Hospital in Oxford. The departments where your hearing or sight is checked are in the same building, but on different levels.

You may see all or some of these professionals when you visit the clinic. The Oxford University Hospitals Trust is a teaching hospital and observers, such as medical and nursing students, may be in clinic. If you feel you would prefer not to have observers present please let us know.

Consultant neurologist

Neurology doctors look at how NF2 may be affecting your nervous system. They will take a full medical history, talk to you about your symptoms and examine you in relation to these. Neurological examinations involve moving your limbs, looking at your co-ordination and testing your strength and reflexes. Dr Allyson Parry is the neurologist within the NF2 team.

Consultant geneticist

Genetic consultants understand about our genes and will be able to explain in as much detail as you would like how NF2 is caused. They will also take a history from you about your own health and that of your family, including any illnesses or symptoms you or they have had, now or in the past.

The genetic consultant will examine you for features specific to NF2 such as lumps or marks found on or underneath the skin and will discuss with you whether these features mean that you have the condition NF2.

If you have NF2 they will discuss the condition with you and what this means for you and your family.

They will discuss genetic testing with you and can also advise you about the chances of passing on NF2 to your own children. Should you wish, they will discuss techniques which can help a couple avoid passing on the condition to their children. The genetic consultant can discuss with you whether NF2 might be present in any other members of your family and suggest if any scans or other screening tests may be helpful for your relatives. Dr Dorothy Halliday is the geneticist within the NF2 team.

Genetic counsellor

A genetic counsellor helps you to look at and understand NF2 as an inherited genetic condition. They will ask for information about your family tree so, if you have this available, you may wish to bring it with you to your first appointment. The genetic counsellor will be able to organise genetic testing for you and other members of your family as appropriate. The counsellor is able to provide advice and support to all members of the family at what can sometimes be an anxious time. Sarah Durell is the genetic counsellor within the NF2 team.

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 any appropriate aids. Hearing tests are usually carried out annually so they can be compared from year to year. Mr Lee James is the audiology doctor within the team and Ellie Mace is the hearing therapist.

Ophthalmology (eye test)

The eye doctors will assess the structures of your eyes and your sight in detail. NF2 does not always affect the eyes but these tests can pick up any early changes. It is important that you attend your usual eye tests at the optician in addition to this. Mr John Elston is the ophthalmology doctor; he is assisted by Rachel Edminson, who is an eye care specialist.

ENT (Ear, Nose and Throat), neurological or plastic surgeons

You may see a surgeon who will be able to discuss with you any treatments which are available for the schwannomas or neuromas (benign/non-cancerous nerve tumours) that NF2 can cause. The surgical doctors will be able to explain procedures that are available which may be appropriate now or in the future.

Mr Christopher Milford is the ENT surgeon, Mr Richard Kerr is the neurosurgeon and Mr Henk Giele is the plastic surgeon within the NF2 team.

Radiologist

It is unlikely you would see the radiologist, however they will look in detail at any scans that you have had. They will give their expert opinion at the multidisciplinary team meeting, which all of the NF2 team attend, to plan the best available care and treatment for you. The NF2 radiologist is Dr Pieter Pretorius.

NF2 specialist nurses

The NF2 specialist nurses are available during the clinic day to support patients, their families, carers and other healthcare professionals. The specialist nurses can provide help and support by phone, text or email, and can visit patients in the hospital or at home. They liaise with other members of the NF2 team to ensure care and support is organised to suit your individual needs. The nursing team can also provide assistance in applying for appropriate benefits and grants.

The NF2 specialist nurses are Claire Mansfield, Wendy Howard (Oxford) and Carolyn Redman (Southampton).

Clinical psychologist

Psychologists specialise in helping people and their families manage the range of emotions, behaviours and experiences which can result from having a genetic condition such as NF2.

Having NF2 can affect people physically, emotionally and socially. Most people and their families cope with this very well, but lots of people have told us that it can be helpful to have additional support around worries or concerns. Sometimes people feel it helpful to talk about their worries regarding genetic testing, managing their feelings around a new diagnosis, surgical procedures or treatments and other difficulties that arise. Dr Jacinta Cordwell is the clinical psychologist within the NF2 team.

Physiotherapist

The physiotherapist can help with any walking or balance problems you may have. This may include appropriate exercises and strategies to help improve your balance. After an initial assessment, the NF2 physiotherapist can refer you to physiotherapists in your local area for ongoing therapy as needed. The physiotherapist working within the NF2 team is Kate Browne.

Secretarial and clerical support

The NF2 team are supported by a secretary who will make sure that your clinic letters are sent your GP and any other appropriate health care professionals. You will also be sent a copy for your records (please let us know if you would prefer for this not to happen). The secretary will organise for your medical records and scans to be transferred from another hospital if you are new to the Oxford clinic. The NF2 secretary is Linda Porter Goff.

The clinic co-ordinator will send out your appointment letters and is the first point of contact if you have questions about your appointment. The co-ordinator also keeps our website updated and collates the quality of life questionnaires that you may be asked to complete during your visit. The NF2 clinic co-ordinator is Steven Martin.

How to contact us

The Oxford NF2 team can be contacted by phone, text or e-mail.

Claire Mansfield and Wendy Howard – NF2 Specialist Nurses

Direct Line: 01865 231 741

Mobile: 07747 795 588

Via the hospital switchboard on 01865 841 166 – Bleep 6262

Email: claire.mansfield@ouh.nhs.uk
wendy.howard@ouh.nhs.uk

Carolyn Redman – NF2 Specialist Nurse in Southampton

The Southampton Specialist Nurse is part time and can be contacted from Monday to Thursday between 8am and 4:30pm

Direct Line: 02380 794 973

Mobile: 07747 837 593

Email: carolyn.redman@uhs.nhs.uk

Sarah Durell – Genetic Counsellor

Tel: 01865 226 021

Mobile: 07747 851 915

Email: sarah.durell@ouh.nhs.uk

Linda Porter Goff – NF2 Secretary

Tel: 01865 231 889

Steven Martin – NF2 Clinic Co-ordinator

Tel: 01865 231 742

Mobile: 07747 837 693

Email: steven.martin@ouh.nhs.uk

Useful national contacts

British Deaf Association

Tel: 01772 259 725

Textphone: 05603 115295

www.bda.org.uk

Carers Direct Freephone

Tel: 0808 020 202

www.nhs.uk/carersdirect

Department for Work and Pensions Benefits

(for claim packs and information) 0800 882 200

www.direct.gov.uk

Disabled Living Foundation

Tel: 0845 130 9177

www.dlf.org.uk

Hearing Link

Tel: 01323 638 230

Text: 01323 739 998

www.hearingconcernlink.org

NHS Direct

Tel: 0845 46 47

www.nhsdirect.nhs.uk

Neuro Foundation

Tel: 0208 439 1234

Minicom 020 8481 0492

nfauk.org

Tinnitus Helpline

0808 808 6666 (voice)

0808 808 0007 (text)

We hope that this booklet has been helpful.
We would welcome any comments and
suggestions for future editions.

If you need an interpreter or need a document in another
language, large print, Braille or audio version, please call
01865 221473 or email **PALSJR@ouh.nhs.uk**

Claire Mansfield, NF2 Clinical Nurse Specialist
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