



The **N**eurofibromatosis Association

Registered Charity No 1078790



THE ROLE OF THE Nf SPECIALIST ADVISOR

Neurofibromatosis Type 1 (Nf1) and Type 2 (Nf2) are separate genetic conditions that are unrelated to one another, although they share the same name. Both are complicated to understand and can vary in how they affect individuals of any age. Since people can often feel confused and unsupported after a diagnosis is made, the Neurofibromatosis Association (NfA) is investing £150,000 a year in a network of professional Specialist Advisors, who are regionally based within hospitals, to give support to anyone affected by Nf1 or Nf2. This support can be following diagnosis or at any stage.

The Nf Specialist Advisor can offer:

- Time to talk about Nf and what it means for you
- Accurate and up to date written information about Nf1 and Nf2
- Support and ongoing contact if and when you need it
- Information on other organisations that might be able to help
- Guidance on education problems, including talking to teachers
- Where possible the opportunity to link with others who have a diagnosis of Nf
- Information about events and activity based holidays for young people and adults with Nf
- Specific information for professionals
- Information on NfA and benefits of membership available

How can I contact an Nf Specialist Advisor?

Contact with the Nf Specialist Advisor is offered to you by telephone or at your clinic appointment, or if essential within your own home — or we can make other arrangements if you prefer. Overleaf is a map showing where our Specialist Advisors are based. Please contact head office if you are unsure which Specialist Advisor covers your area and we will put you in touch with your nearest one.

The service of the Specialist Advisor is free and confidential. Any information will only normally be shared with your permission. However, on those rare occasions when someone's safety is at risk, it may be necessary for the Specialist Advisor to seek advice.

Do I have to be a member of the Association?

Access to the Specialist Advisor is available to anyone with Nf but we recommend that you join the Association. Benefits include three newsletters per annum which will inform you of the latest developments in research, of fundraising and social events, summer camps, local news etc. You will also receive invitations to attend our Annual Get-together/ Information Day, which incorporates the Annual General Meeting.

The Neurofibromatosis Association is a national registered charity. The purpose of the NfA is to fund the network of Specialist Advisors, to fund research into both Nf1 and Nf2 and to provide information about both conditions.

THE NEUROFIBROMATOSIS ASSOCIATION SPECIALIST ADVISOR NETWORK



NfA Helpline 0845 602 4173
Monday and Thursday 9 am — 4 pm, Tuesday 9 am — 12 noon

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For more information and a full list of publications please contact:

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National Telephone Helpline :

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Mon — Fri 9am — 5 pm

0845 602 4173 Mon & Thurs 9am — 4pm, Tues 9am — 12 noon

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