



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. First established in 1991, Nerve Tumours UK is committed to investing jointly with the NHS, in a network of professional Specialist Advisors. Subsequently the network has expanded to reflect our aim of working towards national coverage and equal access to services across the country. The team has a depth of knowledge and understanding of Neurofibromatosis and related conditions which benefits individuals, families and professionals needing their expertise. Their varied professional backgrounds bring a complementary set of skills which can be constructively shared by the team. The value of the network is demonstrated every day in the unique and specialised work of our Advisors.

Each Advisor is a highly qualified professional with a background in either nursing, social work or occupational therapy. Our Advisors work from a hospital base and have links to regional genetics centres. They collaborate with the many other professionals involved in the care of patients with Neurofibromatosis.

The specific role of the Advisor includes:

- support for those newly diagnosed or in times of acute need (for example when facing difficult decisions).
- time to talk about the many aspects of Neurofibromatosis and what it means to the individual patient as well as to the wider family.
- on-going contact if and when needed.
- acting as a point of contact for health, education and social services to ensure that the best practical help and support is available.
- accompanying patients to clinic appointments and help to coordinate appointments if necessary.
- home visits.
- school visits.
- accurate and up to date written information about NF1 and NF2.
- information about other organisations that may be able to help.
- guidance on education problems, including talking to teachers.
- providing information about events for children, young people and adults.
- helping patients and their families to explore social support and activities that are available in their area.

Helpline Team
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Please seek further information from www.nervetumours.org.uk, or contact our helpline on the details above.

Nerve Tumours UK has taken reasonable care to ensure that the information contained in its publications is accurate. Nerve Tumours UK cannot accept liability for any errors or omissions or for information becoming out of date. The information given is not a substitute for getting medical advice from your own GP or other healthcare professional.

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