

PREPARING FOR YOUR NF1 MEDICAL APPOINTMENT



**Tumour
Foundation
of BC**

A QUESTION GUIDE FOR INDIVIDUALS, PARENTS & CAREGIVERS

Living with neurofibromatosis type 1 (NF1) can involve appointments with many different healthcare providers over time. Not all clinicians are familiar with NF1. This guide is designed to help you feel better prepared, organized, and confident before your appointment, whether it's for yourself, your child, or someone you care for.

You do not need to ask every question listed here. Use this guide to focus on what matters most to you.

BEFORE YOUR APPOINTMENT

You may wish to note:

- Any new or changing neurofibromas
- New or ongoing pain
- Headaches or vision changes
- Changes in mobility, balance, numbness, or weakness
- Learning, attention, or school concerns
- Emotional or mental health changes
- Sleep concerns or fatigue
- Any recent tests, ER visits, or new medications

MY MAIN CONCERN TODAY:

QUESTIONS I DON'T WANT TO FORGET:

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QUESTIONS YOU MAY WISH TO ASK

GENERAL QUESTIONS

- Are there any changes we should continue to monitor?
- Are there screenings or referrals we should consider?
- What symptoms would require more urgent follow-up?
- Should we see a specialist with NF1 experience?
- When should the next follow-up appointment be scheduled?

PEDIATRIC CONSIDERATIONS

Parents and caregivers may wish to discuss:

- Learning, attention, or behavioural concerns
- School accommodations or support services
- Growth and development
- Social or emotional wellbeing
- Pain, headaches, or mobility concerns
- Transition planning for teen or adult care

ADULT CONSIDERATIONS

Adults living with NF1 may wish to discuss:

- Pain or changes in daily functioning
- Work or accommodation needs
- Mental health and emotional wellbeing
- Family planning or genetic counselling
- Ongoing monitoring and screening recommendations
- Access to specialists or community supports

BEFORE LEAVING YOUR APPOINTMENT, ASK YOURSELF

- Do I understand the next steps?
- Are there follow-up tests or referrals needed?
- Who should I contact if symptoms change?
- Do I know when the next appointment should happen?

YOU ARE NOT ALONE

The Tumour Foundation of BC is here to support individuals and families affected by NF across British Columbia.

If you have questions about NF, need help navigating resources, or would like support preparing for appointments, we encourage you to contact us.

**No one with NF walks the journey alone.
We are here to help.**

CONTACT US