

Owning your transition to adult care

Managing neurofibromatosis type 1 with plexiform neurofibromas (NF1-PN) can be challenging as you move from pediatric care to adult care. Some people even choose to cope with their symptoms instead of continuing to seek medical care, but routine monitoring is an important part of staying on top of NF1-PN.

Taking an active role in your health and standing up for what you want can help you get the care you need.

Consider the following tips as you prepare to own NF1-PN as an adult:

- ✓ Practice talking to your healthcare provider (HCP) without the help of a parent or caregiver
- ✓ Talk to your HCP about aging out of pediatric care. Find out if they can provide a referral or if you'll need to find a new HCP on your own
- ✓ Become comfortable scheduling appointments with your HCP and other specialists
- ✓ Organize important medical documents in a folder so you have them all in one place
- ✓ Find out how your family's insurance works or if you need to sign up for your own plan
- ✓ Connect with advocacy groups to learn from others in the NF community
- ✓ Ask your HCP about considerations for significant life events, such as starting a family
- ✓ Continue learning about NF1-PN to become a better advocate for yourself



For more tips, read through *A Guide for NF Patients and Caregivers Transitioning to Adult Care*, by the NF Collective.*

Check out additional resources, including tools to find an HCP who is familiar with NF1, at NF1PN.com/resources.



Before I left for college, I wish my primary or other doctors would have prepared me and said, 'Hey, you need to make sure you get connected with a doctor.'

— Antwan, living with NF1-PN

*SpringWorks Therapeutics is providing this resource to help patients find more information about NF1-PN, but its inclusion does not represent an endorsement or a recommendation from SpringWorks Therapeutics for any group or organization. Any organization listed is independent of SpringWorks Therapeutics.



Once you're set up with a new HCP, consider discussing:

- ✓ Your treatment history and the current status of your condition
- ✓ If they have your complete medical history on file
- ✓ How you've been feeling overall
- ✓ Visible or noticeable changes to your tumor(s)
- ✓ Changes in the amount of pain you've been experiencing
- ✓ Changes to your mood and/or sleep patterns
- ✓ How often you'll need to schedule appointments
- ✓ Other specialists you may need to see to manage your condition
- ✓ Practical concerns, such as financial or travel limitations

Checklists are adapted from the NF Collective's *A Guide for NF Patients and Caregivers Transitioning to Adult Care*.



I stay on top of routine appointments because it's so important when you have a progressive chronic medical condition that can change at any moment.

— Krista, living with NF1-PN



Want to get the most out of conversations with your HCP? Download the *NF1-PN Discussion Guide* at NF1PN.com to help track your symptoms and prepare for visits.