

# Helping with the transition to adult care

As a caregiver, you play a pivotal role in caring for someone with neurofibromatosis type 1 with plexiform neurofibromas (NF1-PN). You've supported them in managing and learning to live with the condition, but over time the needs of your loved one will change. And so will the role you play.

As people with NF1-PN get older and transition from pediatric to adult care, managing the condition can become even more challenging. Some even choose to cope with their symptoms instead of continuing to seek medical care. As a caregiver during this time, your role changes from being a champion of their care to helping them become their own champion. You can help them take ownership of their care, while emphasizing the importance of staying on top of NF1-PN.

## Here are some tips to consider before your loved one ages out of pediatric care:

- ✓ **Make sure you both know if and when they'll have to find a new healthcare provider (HCP)**
- ✓ **Emphasize the importance of continuing care throughout adulthood**
- ✓ **Provide them with an organized and thorough record of their medical history**
- ✓ **Be a supportive resource while encouraging their independence**

## As they prepare to transition into adult care, consider helping them:

- ✓ **Feel comfortable talking to their HCP about their health without you present**
- ✓ **Learn how to check their benefits or sign up for new insurance, find a new HCP, and schedule appointments**
- ✓ **Connect with advocacy groups so they can learn from others in the NF community**
- ✓ **Ask their HCP about considerations for significant life events, such as starting a family**
- ✓ **Stay knowledgeable about NF1-PN so they can become a better advocate for themselves**



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](https://NF1PN.com/resources).



\*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 they're set up with a new HCP, remind them to consider discussing:**

- ✓ Their treatment history and the current status of their condition
- ✓ How they've been feeling overall
- ✓ Visible or noticeable changes to their tumor(s), pain, or mood/sleep patterns
- ✓ How often they'll have to schedule appointments
- ✓ Other specialists they may need to see to manage their 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*.



“ The way I built my NF care team was mostly through my mom. I really couldn't have done it without her help.

— Lindsey, living with NF1-PN



Want to help someone get the most out of conversations with their HCP? Download the *NF1-PN Discussion Guide* at [NF1PN.com](https://www.nf1pn.com) to help them track their symptoms and prepare for visits.