

Be prepared to get the most out of your appointments by tracking how you feel

When you are living with or caring for someone with neurofibromatosis type 1 with plexiform neurofibromas (NF1-PN), it can be difficult to explain how you or your loved one is feeling to your healthcare provider (HCP), especially if it's been awhile since your last appointment. Keeping track of how things are going can help you and your HCP notice if something has changed.

Remember, being open with your HCP can help them manage your care.



Take a look at the weekly tracker example below, then go to page 3 ("Start tracking") to begin filling out your own tracker. You can print and fill it out by hand, or fill it out electronically and print the results to bring to your next appointment.



Can't print? Download and save the tracker to your computer and email it to yourself before your next appointment.

Fill in the week here.

Check a box in each row to rate how PN's are affecting you on a scale of 1 to 5, with 1 being "not much at all" and 5 being "very much."

Week: 3/03-3/09

Rating						Notes
Rate how your plexiform neurofibromas (PNs) are affecting you	1 (not much at all)	2	3	4	5 (very much)	
Pain	☐	☒	☐	☐	☐	
Difficulty moving	☐	☐	☒	☐	☐	
Depression or anxiety	☐	☐	☐	☒	☐	
Sleep	☐	☐	☐	☒	☐	
Difficulty with daily activities	☐	☐	☒	☐	☐	
Other _____	☐	☐	☐	☐	☐	
Have you noticed changes to your PN's?	☒ No	☐ Yes	If yes , what kind of changes? ☐ Size ☐ Look ☐ Texture ☐ Number			Use this space to jot down any other symptoms or concerns you'd like to discuss.

Check any changes you've noticed in the PN's, including if they're bigger, look or feel different, and if there are new growths.



Being actively involved and openly talking about the symptoms you or your loved one is experiencing will help your HCP better know how to manage the condition. Visit NF1PN.com to hear real people with NF1-PN talk about how they own their care.

Questions to ask your HCP

What symptoms should I be looking for?

How will I know if my PNs are changing?

Who else should I be seeing to help manage my NF1-PN?

What should I do if I start experiencing a new symptom?

What can I be doing even if I'm not experiencing symptoms?

When should I plan to come for my next visit?

Write down additional questions here.



"Writing down the symptoms as they happen is helpful, so when you talk to your doctor, you remember what you want to say."

- Lindsey, living with NF1-PN

Start tracking

Included below and on the following pages are trackers for 3 months. You can print or save as many of these pages as you want to keep tracking how you feel over time.

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