

Coping with questions and staring



Coping with questions

We are all curious about the world, and make sense of it by looking and by asking questions.

Sometimes people with NF2 may look different from other people, and may experience staring or be asked questions about their appearance.

Here are some ideas for how to manage this, and respond, if it happens to you.

Some of these may suit you better than others; what is important is that you can respond in a calm and confident way. Try these out with a friend and add some of your own ideas.

NF2 affects people in different ways, and **you may never experience the symptoms described in these examples**. You can adjust the responses to fit in with your personal situation.

How to respond to comments / questions about the way you look

Talking about your medical history with a stranger feels different from sharing it with a friend.

Think in advance about how much you want to share, so that you feel comfortable having the conversation.

You might explain briefly that you have NF2, and ***reassure***

People may say things that are patronising or frustrating, even though they mean well. It can help to reassure them.

- “I have NF2, It can affect my balance when I walk, I’m OK if I take it slowly.”
- “I had an operation which affected part of my face: it’s OK, it doesn’t hurt.”

Or Give a **short explanation** and then **change the subject**

This way you can get to know the other person, and tell them about your own interests.

- "It's just my face muscles: did you see the football yesterday?"
- "My NF2 affects my hearing: have you lived in this area for long?"

Or deflect the question

- "I don't want to talk about it at the moment."
- "Thank you, I'm fine."

You will come across many people who are unaware of your NF2. Being prepared will help you to feel more in control

You might explain what they can do to support your conversation

- "I have NF2. It has affected one side of my face. My vision / hearing is better on this side."
- "I have NF2, which affects my hearing. I lip-read so it helps if you face me when you are speaking."
- "I am deaf; please can you write your question down?"
- "I have NF2; it can affect my speech at times. It's OK to ask me again, if you don't understand."

Sometimes people ask questions which don't consider your feelings.

A firm response indicates that a question is not welcome.

- "What you just said is impolite."
- "Please don't ask personal questions."

Coping with staring

People may never have seen someone with symptoms of NF2, and they may be curious and stare.

Often they are not aware that they are doing it, or trying to upset you; a simple comment or action can make clear that you do not want them to continue.

You may **ignore them** by walking away, looking away, or turning your body away. If you want to **let them know you have seen them**, and want them to stop, you could smile / nod or say:

- "I'd prefer if you didn't stare at me."

If they look friendly and you decide to talk to them, **think of their staring as an 'unasked question'** and respond.

- "I'm guessing you're interested in why I use a frame. I have a condition which affects my balance so the frame helps me walk."

Getting help from a Psychologist.

The Clinical Psychologists in the NF2 team can help with all of the strategies mentioned here, and can support you if you find people's reactions difficult.

If you have further questions, or would like an appointment, please contact us.

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If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

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