

What is it like living with nystagmus?

Preamble: I am part of a team finding out how nystagmus affects people's lives. This part of our research is to ask patients to say what matters to them: the good and bad things about having nystagmus, and whether you think it affects the quality of your life - in either positive or negative ways.

I have a list of things to ask you about, but we do not have to cover every question. It's important that I give you a chance to say what *your* life is like. So there are no wrong or right answers – just your experiences or opinions.

If you have questions about nystagmus, I can pass them on or arrange for you to talk to a professional about them at a later date. It's important that I tell everyone who takes part that I'm not meant to try to answer that sort of question in this interview. This session is for *you* to tell *me* about your life.

Check: information leaflet (go through this if wished, check whether participant has any questions about the research or what happens)

Check: OK to audiotape? We do this because it's important that we have things in your own words not mine; also I can concentrate much better on what matters to you if I do not have to write things down.

Anonymity: all identifying information will be removed when the recording is typed up. It will not be possible to identify the patient from the transcript nor any person that is mentioned in the transcript. For instance if you mention a nurse or doctor, or any other person by name, the typed version will just say 'doctor' or 'friend' etc, instead of the actual name.

Check whether there are any questions

If all OK, Sign consent to participate and consent to audiotape.

TOPIC GUIDE:

First, some general questions:

1. If you look back, would you say that nystagmus has been a **big part** of your life or a **small part**, or somewhere in between?
Tell me about it.
2. Do you remember when you **first knew** that your vision was in some way different from other people's?
Tell me about your thoughts and feelings when you learned about it.

Was anyone else involved in you finding out about it (e.g. parents, doctors, teachers, peers)? When was that? How were they involved? What did you think and feel about the way they were involved?

At what point did you or your family discover that your eye problems or symptoms were called nystagmus? Tell me a bit more about that

(Probe further about treatments that were offered – glasses, surgery etc)

3. If you look back, have there been any times when you felt **negative** about having nystagmus? Tell me about them. What led to that feeling (may be several, explore each one, if time).

For each:

Did anything make things worse for you at this time?
Did anything help you manage during this time?

4. And on the other side of the coin, have there been times when you felt **positive** about having nystagmus if you look back? Tell me about them. What led to that feeling?

Explore as above

Those questions involved looking back; now I'll ask about how things are these days

1. Some people say they have **good days and bad days** with their nystagmus. Is it like this for you? If so are there more good days, or more bad days, or does it vary?
2. *(If all days the same, ask what a typical day is like)* Could you describe what a **good day** is like? (probe different parts of the day eg getting up, eating breakfast, going to work, eating dinner, shopping, cooking, leisure activities etc) Any particular thoughts or feelings?

3. Now a **bad day** – what's that like? (Probe different parts of the day as above) How is it different? Do you have to change what you do? Would you say your thoughts and feelings are different on a bad day? Tell me more about it.
4. Do you think your typical days differs from those who don't have nystagmus?
5. Do you think that nystagmus is different from, or the same as other visual conditions, in the effects it has on your wellbeing or quality of life?
6. What **problems** – if any - are you encountering these days because of your nystagmus?
7. Where do the problems come from – for instance is it other people's attitudes that matter most, practical things, your own feelings ...
8. I hope you haven't had too many negative experiences but if you don't mind talking about it, is there anything or anybody that has actually been **unhelpful** to you, in managing nystagmus? (e.g. any people, any organisations ...)

(For each negative experience ask how much have been upset by the experience and if it had any impact/type of impact)

9. And now looking on the cheerful side, is there anything or anybody that has been **helpful** to you in managing the effects your nystagmus can have on your life (or other people's lives)? (e.g. any people, any organisations ...)

(If it is mentioned here about doctors/opticians probe further about treatment options that have been offered)

Before we finish, I have 12 cards here with some things that sometimes – but not always - cause problems in the lives of some people with nystagmus.

You have already talked about some (most) of them but can we just go through them, and you can tell me if each thing causes problems for you (now, or in the past)

On the other hand, if you think that some of the things do *not* need to be a problem, please say so.

So – for you, what sorts of problems, if any, do these cause - or don't they?

DRIVING AND GETTING ABOUT
SHOPPING
EDUCATION AND SCHOOLING
WORK (any work including unpaid work such as housework)
YOUR APPEARANCE
LEISURE OR SOCIAL LIFE
YOUR VISION
FRIENDSHIPS AND OTHER RELATIONSHIPS (FAMILY, ROMANCE ETC)
STATE BENEFITS, REGISTRATION AS PARTIALLY SIGHTED ETC
GETTING NYSTAGMUS DIAGNOSED OR TREATED
TIREDNESS, DISCOMFORT OR STRESS BECAUSE OF NYSTAGMUS
BEING A PARENT WITH NYSTAGMUS

Summing up questions:

1. Looking back, summarising the sorts of things we've talked about today, does nystagmus affect the **quality of your life (for better or worse)**? If so what are the main effects on your quality of life?
2. Is there anything you would say to young people with nystagmus that would help them? Anything you'd like to say to the NHS, or to schools, or to the government?
3. Do you feel that we have covered everything is there anything else that you would like to mention?

AT THE END:

Thank you very much indeed. We hope this will be very helpful in understanding what matters to people who have nystagmus. Over the next few years we plan to use these interviews to put together a way of assessing whether different treatments make a difference to people's quality of life.

If you would like a report that summarises what everybody has told us – not just you but a collection of all the things that matter to a wide range of people with nystagmus – I'll ask your permission to keep your name and address separately. We don't keep any identifying information with this recording because it's important that it is truly anonymous. All names and other identifying information will be removed when the recording is typed up as I explained at the beginning.