

How might you be feeling at this time?

Being involved in the Neurology Recall can be a stressful experience. Receiving information regarding the outcome of the Neurology Recall review processes can activate negative feelings from the past, as well as in the present. Your feelings may range from mild to very strong; this can be true even if there were no issues identified with your previous care.

There is no right or wrong way to feel. Different people react in different ways. A sense of uncertainty, and fears, are common. Thoughts and feelings change over time, and you may bounce between negative emotions for a while. These may include a sense of:

- Shock or disbelief
- Numbness, confusion
- Anger, frustration, guilt
- Sadness, feeling low
- Anxiety, fear

You may also experience thoughts, & concerns, such as:

- Illness-related worry & uncertainty
- Concerns about impact on others
- Adjustment stress to new health information or reminders of the recall
- Upsetting memories or thinking over past healthcare experiences
- Reduced or increased confidence & trust
- Relief at being able to address ongoing health concerns

What you might find helpful:

Take a moment to pause, and check in on how you are feeling. Notice your first emotions and first thoughts. Notice if you have questions, ideas, or images too, as your mind works to process the new information.

Outcome information provides you with new information. This may give you some answers, but there often will also be questioning thoughts, which you may not have an answer to. Some of these may be answered as part of other processes such as Independent Neurology Inquiry. Others may be questions to discuss with your doctor or to seek advice via the advice line.

If you feel overwhelmed, focus on simple practical coping, and looking after your basic needs. Recognise that this type of information is naturally difficult to process, and that you may require some time to process the outcome report.

It's ok to ask for help. Enlisting support from others is central to coping. Talking helps because it helps us think, learn, process and see other perspectives, and ways to get through. Talking is practical.

You might feel unsure or guilty about talking to others. Remind yourself, this is not your fault. Sharing can make a problem more tolerable.

Can I access psychological support?

There is a dedicated psychological support service delivered within the Belfast Trust for adults who have been affected by the Neurology Review process, and have been part of the patient recall clinics.

The service provides an external support for people experiencing the stress of being part of the recall process, or having to adjust to new information regarding physical wellbeing.

How might the service be helpful?

You might find it helpful to have an external one-to-one space to talk about your experiences. To help work through any difficulties, or challenges, that have arisen from being involved in the recall process.

The service can also help with accessing relevant information, and thinking about your current psychological, coping or mental health needs. If you have pre-existing or new psychological or mental health needs, the service can help review your issues, and if needed, consider onward referrals as part of your overall care.

Who provides the service?

The service is provided by practitioners with experience and expertise in supporting psychological distress and mental health concerns.

How/where will I be seen?

Due to the Covid-19 pandemic we have been operating telephone reviews (or video-call via MS Teams). We will make contact with you once a referral is received. If the date and time does not suit you, you will be offered another review date/time that suits you better. We have been returning to increased face-to-face appointments, and we will endeavour to provide these if you prefer. This is subjected to safely guidelines relating to Covid-19. The service is based at Level 9a, Outpatients Centre, Royal Victoria Hospital, Belfast Trust.

Is it Confidential?

We seek to ensure what you tell us remains private. We are required to keep notes on all contacts (e.g. reviews, telephone calls etc.). These notes are always held **separately** to your medical file. Sharing of relevant information to your care is important (e.g. liaison or summary letters to the medical team, GPs). These professionals are also bound by rules of confidentiality. Information sharing will be discussed with you, and you can typically choose not to have some private or personal information shared. In exceptional circumstances, like very serious concerns about your or others safety,

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we may need to take action to inform appropriate third parties (e.g. other professionals or agencies). In these rare circumstances, we will try to inform you of what we intend to do and why.

What does attending with psychological support services involve?

Support is person-centred, so will focus on your needs and circumstances. The first appointment typically involves an assessment conversation, and learning about your situation. The aim is to gain a shared understanding of you, and your unique experiences, in relation to your current and past health, family, life circumstances and impacts from the Recall. For some people, self-report questionnaires may be used to help gather more information. Following assessment, a summary of the main concerns and suggestions as to what might be helpful will be discussed with you such as:

- Providing you with information, especially if adjusting to a change in understanding of your neurological health, symptoms or treatments
- Discussing if further support sessions are needed or not
- Considering what, if any, feedback would be useful to the Neurology Team (e.g. regards symptoms, questions, concerns)
- Signposting to resources/ community supports which you may find helpful
- Possible onward referral to other appropriate services if you agree

Psychological Information: Support for those impacted by the Neurology Recall

Useful Contacts

Neurology Advice Line

0800 980 1100

The Neurological Care Advice Service

028 9504 2270 or email

neurocareadvice@belfasttrust.hscni.net

A friendly, free and confidential service providing information, advice and support for adults with neurological conditions, their families and carers.

Lifeline - 0808 808 8000

Northern Ireland 24 hour crisis response helpline service for people who are experiencing distress or despair.