

### *How might you be feeling at this time?*

This may be your first experience of being recalled, or you may be receiving information regarding the outcome of the review processes. Either way, being involved in a Neurology Recall can be a stressful experience. Your feelings may range from mild to very strong; this can be true even if there are 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 management
- 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.

There will often also be questioning thoughts, which you may not have an answer to. These can help with ideas of things to ask your medical team or the advice line.

If you feel overwhelmed, focus on simple practical coping, and looking after your basic needs. If required, booking in your review appointment can feel stressful, but knowing the date can help reduce sense of uncertainty, by giving a timescale. As worried thoughts arise, remind yourself you can raise these at your review.

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.

Should psychological, or neuropsychological, assessments be needed as part of your review process, your neurologist can also request this as part of your 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 are operating telephone reviews (or video-call via MS Teams). We will aim to make contact with you within 3-4 days once a referral is received. If the date and time we call does not suit you, you will be offered another review date/time that suits you better. If you have difficulties accessing tele-care for health or social reasons, we can look at other ways for you to safely access supports. 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, 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 or cognitive tests (tests of things like memory) 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](mailto: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.