

What is it like to hear life-altering medical news? Perspectives from health professionals

Breaking bad news to people with a life-altering disorder is never easy. In this article, Neil Bindemann shares some unique insights from health professionals who have themselves received such news and highlights key learning points to support clinicians with such conversations.

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Any disturbance (or interference) in the functioning of the nervous system can lead to an adverse effect on a person's wellbeing, where wellbeing is defined as the 'combination of feeling good and functioning well'¹ and 'focuses on assets in functioning, including emotions and psychological resources (e.g. positive affect, autonomy, mastery) as key components'.²

Furthermore, given that the sense of wellbeing is likely to be unique to the individual, when the disturbance to the nervous system is such that a diagnosis is reached, it is likely that **the same diagnosis will affect people differently**.

This supports the usefulness of **a more person-centred care approach**. Thus, it can guide services in a way that helps them to optimise a person's ability to perform daily-life activities, make considered decisions and effectively engage with life. Such an approach can also assist a service in identifying the support that may be needed as the person experiences changes in mental and physical functioning, including the planning of, and transition to, palliative care services.

Each of these outcomes and experiences can be traumatic events that could affect an individuals' quality of life. It should be recognised that **it can also be traumatic for the healthcare professional to inform an individual of their diagnosis**.

Box 1: Suggested guide to breaking bad news³

1. Establish an appropriate setting
2. Check the patient's perception of the situation prompting the news regarding the illness or test results
3. Determine the amount of information known or how much information is desired
4. Know the medical facts and their implication before initiating the conversation
5. Explore the emotions raised during the interview
6. Respond with empathy
7. Establish a strategy for support

There are many papers that offer a variety of useful steps on how to "Break Bad News" (see Box 1).

However, the Person-Centred Neurosciences Society's vision acknowledges the significance of **learning through lived experiences** and sharing this knowledge.

For this reason, this article takes a very different approach and brings together a collection of thoughts and learnings that come from a unique perspective of health professionals who have **received** life-altering news of having a particular neurological or psychiatric disorder.

A summary of key learnings is included at the end of the article.

'Receiving' versus 'hearing' news

Before introducing the health professionals' perspectives,

perhaps a first thought to offer comes from the careful and deliberate selection of a word in the introduction: **'received'**. Imparting bad news to someone is one thing, but it's another to know if a person is going to **'hear'** everything you tell them, once their 'fight or flight'/survival response has instinctively reacted.

To illustrate that point, let's take a well-trained pet dog. While the dog has his eyes and ears drawn to your attention, all is well. But not when it sees the likes of a squirrel! It's no longer listening to you; its brain has suddenly switched to **'fight or flight'/survival mode**.

So perhaps one of the very first steps to be taken is to **be prepared for such a reaction** from the person you are speaking to, who, in an instant, has had the undesired 'label' of patient pinned to them.

Perspectives from health professionals on giving and receiving bad news

The best words I have heard from a doctor telling a patient that they have a chronic health condition is 'We will work together on this'.

— Dr Jonny Acheson

Let's meet the first of our health professionals who has been at the receiving end of hearing bad news about his health: **Dr Jonny Acheson**, Emergency Medicine

Consultant, who was told in his 40s that he was living with Parkinson's. The following are thoughts from Jonny:

"The **best words** I have heard from a doctor telling a patient that they have a chronic health condition is "**We will work together on this**".

"I liked that because the clinician was taking **responsibility** but also placing responsibility and accountability onto the patient. It was also **realistic, honest**, and set them up to be on the right track. There is also a theme of not looking through rose tinted glasses, but it shows the importance of **determination** and **grit**.

"The **worst words** for a Parkinson's diagnosis are "It's Parkinson's, you will have five good years." [This is of course relevant to any progressive condition].

"There needs to be **hope**, something that the patient can identify with. When the diagnosis hits them it's like they enter a very long dark tunnel. Therefore, **carefully chosen words** at diagnosis are like handing them a torch."

Be prepared for the moment; be in the moment; live through the moment; give time for the moment; reflect on the moment.

— Dr Anita Rose

Giving that news to someone is a challenge and can be emotional for the healthcare professional. To recognise that important aspect, **Dr Anita Rose**, Clinical Neuropsychologist offers a few thoughts. Anita, lives with neurological deficits resulting from a Clinically Isolated

Syndrome [this is the prodromal phase of MS, and is not as widely recognised as 'MS'] and has a cancer diagnosis:

"Be prepared for the moment – even if you have only a few minutes take some time (in the loo if necessary!) to centre yourself, do a mindfulness exercise.

"Be in the moment – it can be very hard telling someone bad news but there is nothing worse than a distracted clinician looking at emails, acting as though you are one of many that day. Being in the moment allows for empathy to be shared.

"Live through the moment – be prepared to go in all directions as you will not be able to know how it will go because everyone is an individual (and that includes you).

"Give time for the moment – ensure you have time to be able to deliver the news.

"Reflect on the moment – after you have dealt with the situation reflect on how you are feeling, listen to your body and be kind to yourself."

Use of phrases such as 'patient' and 'sufferer' are unhelpful.

— Prof Alan Palmer

The next series of thoughts come from **Prof Alan Palmer**, who is a prize-winning biotech entrepreneur, visiting professor at the University of Reading, as well as Trustee of The Brain Tumour Charity, the Cancer Awareness Trust and the British Neuroscience Association. Professor Palmer, who lives with multiple sclerosis, has focused his career on brain disorders and their treatment.

“Given physicians often have very little time available to convey life-changing information, it is so important that, as much as possible, both the language used and the framing of the discussion leaves **room for hope** and some degree of agency over the disorder and that its description is not too deterministic/fatalistic.

“Emphasising **approaches to enhance brain health** needs to be encouraged, especially for modifiable risk factors of a specific brain disorder.

“Access to **psychological support** is helpful. For example, when I received my diagnosis of multiple sclerosis while a faculty member in the Department of Psychiatry at the University Medical Centre in the USA, my health insurance company covered the cost of several sessions with a psychotherapist, which was very helpful.

“Use of **phrases such as 'patient' and 'sufferer' are unhelpful**. The phrase ‘people with [INSERT NERVOUS SYSTEM DISORDER]’ is much less pejorative and so more acceptable.”

Linking in early with community-based health and social care professionals ... is very valuable.”

— Catherine Atkinson

A consultant neurologist may be tasked with giving the news, however it may not be the person the patient will see on a regular basis. As **Catherine Atkinson**, Consultant Occupational Therapist, explains:

“Often the **post-acute diagnosis support** falls to non-medical colleagues, if lucky, to the specialist nurse or Allied health professional (AHP) who can follow up and provide

more tailored, personalised diagnosis information and support to the person and their family. **Community therapists** often find this role sitting with them, which can be very helpful as they may have more awareness of the individual's personal and social context and environment, and have more time and functional awareness to help an individual deal with a diagnosis and provide relevant information over several sessions/episodes.

"Linking in early with **community-based health and social care professionals**, for example the local community neurological rehabilitation or therapy team, who may be able to offer holistic rehabilitation, information, signposting, self-management support, is very valuable. It also can empower the individual to know who to contact, how and when, rather than feeling isolated.

"Certainly, with more rapidly progressive conditions such as Motor Neurone Disease, therapists may often start a conversation, **introducing and preparing the person for potential future discussions that may feel uncomfortable**. This can be necessary to prevent delays in aspects of care such as major adaptations/equipment/local authority or Continuing Healthcare (CHC) assessment/Advanced Care Planning (ACP) etc. The pace of these sometimes difficult discussions should be tailored to an individual's needs, with an awareness that they may differ to those of the partner/family's needs. Adaptation to diagnosis, disability and end of life is impacted significantly by an individual's personal context.

"I like to use an **inverted International Classification of Functioning (ICF) bio psychosocial model**⁴ to help staff consider their approach with people living with long-term and complex conditions. The first things to consider are an individual's personal, social and emotional context – such as their prior reactions to and experience of illness/disability, hope, overcoming challenge and previously used engagement and coping strategies. Then consider their

current/future areas of life/death that are most meaningful to them in terms of roles and responsibilities, priorities and expectations. Finally, look at the impact of the diagnosis, activity limitations and participation restrictions. This enables a more person-centred approach to goal setting and intervention."

It's important that a sense of false optimism is not created, although a sense of hope is important.

— Clare Lindley

In this final section, Parkinson's/Movement Disorder Nurse, **Clare Lindley**, who was diagnosed with Parkinson's aged 30, outlines a few practical thoughts to be mindful of when faced with difficult conversations. Clare starts with what she has heard in the past:

"Do you understand?" This question is often used very broadly. From the person-centred viewpoint, they are very likely to think that question is about the part they just heard whereas you might be referring to something else in the conversation – it's therefore important to **be clear in how you use this question/phrase**. Giving clarity on which part you are asking about is very important.

"You may have a natural desire to comfort them by saying 'It will be ok'. However, it's important that a sense of **false optimism** is not created, although a sense of **hope** is important. I would rather be told 'It's going to be a difficult journey but with the right support our aim is to keep you as stable as we can'. Be **open** and **honest**, its ok to say something like 'I can't be sure of how things will go, but we will work together...'

"Breaking bad news is difficult in any circumstance. It doesn't

always need to start with 'I'm sorry...' (it's not the clinician's fault). Perhaps an alternative to consider is: 'There is no easy way for me to say this ...', which expresses your feelings without the 'sorry'. **Sorry adds a very negative tone** to the already challenging situation. Another approach could be 'I have some news which I'd like talk through with you.' This may help both parties as it helps to explain it may take some time to talk through the information.

"A question I've heard used by some clinicians, which is understandable as they are likely to be using it to check a person has been listening, is: '**Are you ok with what's been discussed?**' That sort of question may have been selected in a 'subconscious' way as the clinician may be keen to hear the answer 'Yes'. However, **it is very likely that the person is thinking 'No, my head is spinning!!'**

"The word '**grateful**' can sometimes crop into a consultation. Let's be realistic: **no one is grateful when receiving a diagnosis** of a long-term degenerative neurological condition. They may be accepting of the information, they have been given by a highly skilled clinician, but I would think never grateful. I think this is possibly the clinician's interpretation of the situation to help them manage this emotional environment."

Finally, it's important that words selected by a clinician shouldn't have any implications for the length of the consultation. An **open, honest, and secure** discussion should be encouraged from the start. A feeling of **ownership, control**, and a sense of being '**safe and secure**' is so important for us all. These relationships are life long, whether they are professional or personal.

Summary of key learnings

- Healthcare professionals should look after their own emotions. When breaking bad news, be prepared for the moment, be in the moment, live through the moment, give time for the moment, reflect on the moment
- A person receiving 'bad news' may not hear everything that is said:
 - Be prepared for such a reaction
 - Be clear in how you use the question 'Do you understand?' and what part of the conversation you are referring to
- 'There is no easy way for me to say this ...' or 'I have some news which I'd like talk through with you,' are better conversation openings than 'I'm sorry'
- 'Patient' and 'sufferer' can be unhelpful phrases. Consider using 'people with/living with ...' instead
- Be realistic and honest. Leave room for hope, but don't create a sense of false optimism
- Both the attending clinician and a person with a brain disorder should take responsibility for the path ahead, e.g. "We will work together on this"
- Linking in early with community-based health and social care professionals is very valuable and can empower the individual to know who to contact, how and when, rather than feeling isolated
- The person receiving a diagnosis of a brain disorder should be encouraged to have agency
- Emphasising approaches to enhance brain health needs to be encouraged, especially for modifiable

risk factors of a specific brain disorder

- Access to psychological support is key and empowering for the person with the condition

Back to top

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To learn more about the Person-Centred Neurosciences Society's work and the people behind this article, plus if you wish to support us by joining, please go to www.p-cns.org.uk.

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About the main author

Neil Bindemann is the Executive Director of the Person-Centred Neurosciences Society (P-CNS). He trained in both Immunology (BSc) and Neurobiology – nerve injury (PhD). Neil has worked with many leading professionals and stimulated and led the creation of various education initiatives including Primary care and Community Neurology Society (P-CNS) and The Lifestyle Health Foundation. Then in 2015, after a period of disturbing neurological symptoms, Neil's interest in neurology, mental health and healthcare communication took on a new, more personal perspective, when he was diagnosed with a very rare, slowly growing brain tumour – pineocytoma. It is the learning through this continuing lived experience which fueled his passion to become trauma-informed. That experience opened up his vision to recognise the importance of lived experiences and in 2021, together with new members of the steering committee, Neil launched a new more person-centred care vision and mission for the P-CNS.

Back to top