

The experience of hearing life altering medical news: Perspectives from health professionals

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Introduction

- Being diagnosed with a neurological condition can lead to an adverse effect on a person's wellbeing.
- Wellbeing is unique to individuals as is the experience of neurological change regardless of condition.

Therefore, we could hypothesize it is likely that the same diagnosis will affect people differently. Furthermore, it is argued that communicating life-altering diagnosis is a traumatic experience not only for the person receiving the news but also for the person giving the news.

Such hypotheses suggest the need for a more person-centred care approach when breaking 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

Aim

To gain perspectives and thoughts on what it can mean to be more person-centred to provide more person-centred care.

To generate some simple and practical guidance gained from capturing the thoughts and views from several healthcare practitioners (HCPs) who have received a diagnosis of a neurological condition.

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

"...the same diagnosis will affect people differently"

Dr Jonny Acheson, Emergency Medicine Consultant, living with Parkinson's
 Dr Anita Rose, Clinical Neuropsychologist, living with neurological deficits resulting from a Clinically Isolated Syndrome &
 Clare Lindley, Parkinson's/Movement Disorder Nurse, living with Parkinson's
 Dr Neil Bindemann, P-CNS Executive Director, living with a brain tumour



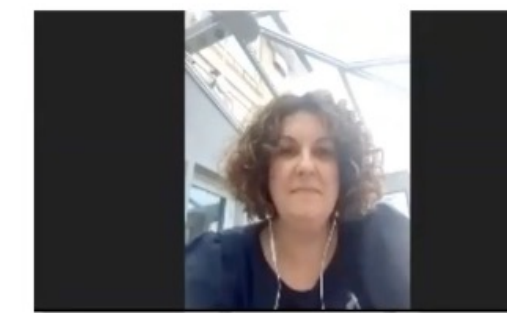
Method

A unique approach of inviting Healthcare Practitioners, diagnosed with a neurological condition, to a "roundtable" discussion held on zoom

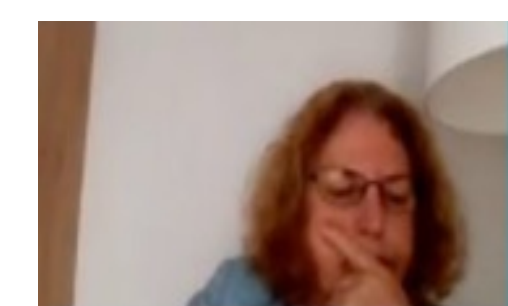
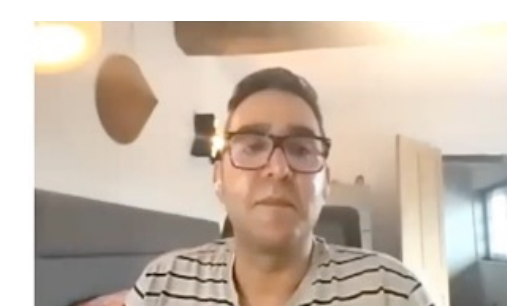
Participants were requested to reflect on their own experience of hearing life-altering medical news.

They were also asked to offer practical thoughts and suggestions to help with communicating life-altering medical news.

A qualitative interview approach was utilised, and the transcript was analysed for themes.

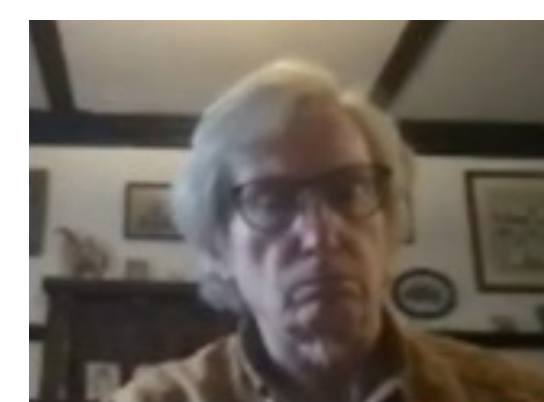


The participants, (clockwise starting top left):
 Nassif Mansour, GPwER Neurology, living with migraine;
 Clare Lindley, Movement Disorders Nurse, Living with Parkinson's;



Miguel Toribio Mateas, clinical neuroscientist, Living with ADHD;
 Anita Rose, Neuropsychiatrist, living with cancer.

The participants, (clockwise starting top left):
 Jonny Acheson, Emergency Medicine Consultant, living with Parkinson's;



Alan Palmer, Professor of Neuroscience, living with MS;
 Gareth Noble, Associate Prof of Medicine, parent of son diagnosed with Asperger's;
 Chris Freer, Mindset and lifestyle coach, living with secondary progressive MS



Lee Morgan, dietetics student, managing his diagnosis of epilepsy with the ketogenic diet



Neil Bindemann, Neuro-immunologist, diagnosed with a non-malignant brain tumour

Results

The major themes elicited from the discussion included.

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|---|--|
| <ul style="list-style-type: none"> • False Optimism • Hope • Language • Honesty • Shared Responsibility • Preparation | <ul style="list-style-type: none"> • Safe • Realistic • Time • Individualistic • Engaged • Empathy |
|---|--|

These themes occurred in both the experience of receiving and in giving bad news.

The following are practical thoughts that were generated from the roundtable discussion, for consideration when communicating the news of any diagnosis:

Suggested guide to breaking bad news

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

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

"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**.

Jonny goes on to explain that:

"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."

Anita Rose, from her living experience offers these:

- **Be prepared for the moment**
- **Be in the moment**
- **Live through the moment**
- **Give time for the moment**
- **Reflect on the moment**

To read the fuller explanation of these points please make contact using the email below or visit www.p-cns.org.uk.

Conclusion

The key themes along with the various practical recommendations offered, acknowledges the significance of learning from people, who have experiences of receiving and hearing life-altering medical news.

This knowledge will be invaluable in supporting both person in imparting and the person receiving the news

It's important that words selected by a healthcare practitioner 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 all. These relationships are life long, whether they are professional or personal.

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