



## PRACTICE

## WHAT YOUR PATIENT IS THINKING

# I feel I am missing a piece of the puzzle

Rhiann Johns describes what it is like to live with functional symptoms and how they affect her life

Rhiann Johns

For years I had experienced complex, unexplained symptoms. Symptoms such as frequent episodes of dizziness and vertigo, and trembling and pain that was concentrated in the legs. I had many tests, but none supplied answers. Often the symptoms were blamed on anxiety, or they were “all in my head.” Eventually I was given a diagnosis of functional neurological disorder. Functional symptoms cover medical symptoms when no physical cause is apparent. Although there is no physical evidence of the disorder, the symptoms are no less real and can be just as debilitating as symptoms with a known cause. I have tried anxiety management courses, deep breathing, and relaxation exercises—none had any effect.

What makes this condition so hard is living with symptoms that can't be seen, yet they are real to me. People's responses often make me feel that I am imagining the symptoms or making them up, which makes me think that I am failing or have done something to cause these symptoms.

## Unpredictable symptoms

I perceive my symptoms as scary monsters lurking in dark shadows. I am constantly aware of their presence, but I do not know how or when they will strike. Every day I am reminded about the unpredictability of my condition. Each new day I do not know which symptoms will occur or whether I will be able to get out of bed and function at all.

Functional neurological disorder can present in many ways. The symptoms I experience include pain and constant trembling in my legs. As my legs are often weak and give way with no warning, I rarely go out alone. I also experience continuous dizziness and regular episodes of vertigo and poor balance, which result in falls. Other symptoms include visual disturbances, such as double vision, and occasionally complete loss of sight. Some days I might only experience one or two of these symptoms. Other days I get the whole set.

## The missing jigsaw piece

I have yet to establish the triggers that bring on the symptoms, the things that make them worse, or what eases their severity. It is incredibly frustrating. One of the most difficult aspects of

living with functional symptoms is the unknowns. Why did it start? How should it be treated? Will I ever feel better?

Sometimes I think of my condition as a jigsaw puzzle with a missing piece that I can't find. If only I could complete the puzzle I might find some answers.

It has been hard to get my head around having a formal diagnosis of functional neurological disorder. It is a condition about which much is still unknown. Online resources have helped me to understand the condition a little, but the main thing I have learnt is that even though my symptoms cannot be seen or detected they are real to me and are life changing.

### What you need to know

- Although symptoms are functional, they are no less real than those caused by other conditions, and acknowledging this can help
- Being open and honest about the unknowns around conditions can help patients feel supported because information is often conflicting, which can be confusing
- Psychological support is important for patients with functional neurological disorder, but acknowledging that the physical symptoms are real is also important

### Education in to practice

- How can you provide patients with clear information about conditions when little is known about them?
- How could you help your patients feel that you are taking their symptoms seriously?
- How can you support patients in managing functional symptoms when no treatment is available?

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More information on functional neurological disorder can be found at [neurosymbols.org](http://neurosymbols.org)

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