

## Key Stages

# Future Pathway for Functional Disorders

Sneha Raman and Gemma Teal

Dec 2022

## Feeling heard

Ensuring that the person feels heard and validated and knows that their unique experience is understood and acknowledged by all health and care professionals right from the beginning and throughout their care journey.

People living with functional disorders often find it hard to articulate their symptoms or make connections between their condition and psychological factors such as trauma. A psychologically-informed approach and building a relationship based on listening, trust and respect will support the formulation of their experiences and story to inform a meaningful diagnosis and a tailored approach to care.

## Feeling held

Enabling coordinated care, whether through multidisciplinary working or a dedicated care coordinator, this part of the pathway aims to ensure that ongoing care is patient-centred and community-based, providing a sense of the person feeling held.

People living with functional disorders often feel let down or confused by not knowing who to turn to for informed and holistic support. This part of the pathway focuses on building trusted circles of care and education to support people to make sense of their condition and its impact on their everyday life.

## Feeling empowered

Acknowledging that the process of acceptance can be different for each individual and supporting people to explore options and choose ways to self manage that work for them. This part of the pathway aims to make them feel able to take control, while ensuring they can easily access health professionals at times when they need support.

People living with functional disorders often find it hard to accept their diagnosis due to a lack of clear distinction between different conditions with similar symptoms and go through cycles of questioning or accepting it. Empowering a person to make their own journey towards acceptance and self management requires a psychologically-informed approach to enable the person to make their own choices and develop supportive relationships with health and care professionals, third sector organisations, peers, family and friends.

## Feeling heard

Ensuring that the person feels heard and validated and knows that their unique experience is understood and acknowledged by all health and care professionals right from the beginning and throughout their care journey.

People living with functional disorders often find it hard to articulate their symptoms or make connections between their condition and psychological factors such as trauma. A psychologically-informed approach and building a relationship based on listening, trust and respect will support the formulation of their experiences and story to inform a meaningful diagnosis and a tailored approach to care.

### Evidence that supports this from the workshop with health professionals

*"It's nothing, which is what they hear, even if you say it in the best terms."*

*"...there's something about waiting well... a lot of people's functional symptoms will get worse... if you are feeling really stressed about 'what's wrong with me? People haven't heard me and they are saying it's in my head and is it in my head?'"*

*"...balance between an individualised approach that really allows the person to feel heard and validated and their unique experience to be understood. When equally, to see this in the context of something that has a name and other people have... who could do a psychological formulation, as there's a bit of debate because the reality... there's not millions of psychologists out there... And that's why it's a psychologically informed workforce – OTs, physios and things but being trained in that kind of approach."*

*"...for certain people it's more difficult to articulate what's going on for them. I suppose that's sort of health inequalities and also just the key bit of this... is trauma. So I suppose there's a significant proportion of people who perhaps have had difficult experiences in their lives, therefore find it more difficult to engage, to trust, not turn up for appointments, so there's something about an awareness there. So that little bit of that...I suppose psychologically informed but, yeah, just thinking about choice and empowerment."*

### Evidence that supports this from lived experience Interviews

*"...sometimes it felt that there was no point in going to the GP with the symptoms I was having and on at least one occasion one GP said to me 'it's all in your head', and statements like that."*

*"I felt like they thought I was making it up all the way along, especially the neurologist in the end and I think he wanted me to see a psychiatrist and the way he said it made me think, 'I'm not making this up, I'm not going loopy, I'm not nuts, this is happening!'"*

*"I knew there was something wrong with me and the doctor was like, 'No, it's this, try this', and then I was like, 'No, it's not that, it's something else', and then they give you tablets, tell you to go away and you'd be back a month later with the same problem."*

*"I couldn't get through to them that I was twelve stone heavier and I didn't have an inkle of the pain I've got now."*

*"...she [nurse practitioner] knows that I know myself... she [nurse practitioner] seems really nice and she's actually listening to me. And not just fobbing me off, she actually seems to be willing to help rather than, 'Here, have some more tablets'."*

## Evidence that supports this from the workshop with health professionals

*"The difficulty at the moment I think is sometimes with something like FND they'll get their diagnosis, and then whoever made the diagnosis will say 'we'll review you in a year', and they are sort of left to go and look at these resources."*

*"...And if they do refer to physio, to the likes of ourselves, we've got a waiting list, unless they are urgent, they are waiting at least six months to a year."*

*"...we see that very much in the pain service, which would include patients with fibromyalgia, sort of fosters the belief that there's going to be some fix at the end of that wait..."*

*"I think what we need to acknowledge as well is often it's the patients that drive their referral to secondary care. So they would see the GP and perhaps have some basic management... And then they would come back and say, 'but I'm no better', and 'I want to see somebody else, I've not found the right doctor just yet', or the right person, just yet. So, it is difficult to say the GPs need to contain all of this, it's very hard for them."*

## Feeling held

Enabling coordinated care, whether through multidisciplinary working or a dedicated care coordinator, this part of the pathway aims to ensure that ongoing care is patient-centred and community-based, providing a sense of the person feeling held.

People living with functional disorders often feel let down or confused by not knowing who to turn to for informed and holistic support. This part of the pathway focuses on building trusted circles of care and education to support people to make sense of their condition and its impact on their everyday life.

## Evidence that supports this from lived experience Interviews

*"And you form good relationships but once John retired, recently it was just anybody... I certainly think everybody should have their doctor."*

*"...there's my doctors here that don't even know what it is, they've heard of it but they don't know what it is. One will say one thing and another will say something else and I just want them to shut up because they don't have a clue."*

*"I think I had such a long period of time without going to the doctor to complain about it, I literally just got on with it and then I'm like, 'What's the point? Because they don't do anything'."*

*"I didn't have faith that if I went to see him that I would get any results and that just was frustrating and upsetting, so rather than have to deal with extra emotions on top, I'd just deal with things, which is not really how you should go."*

*"...you feel that... you are being passed around the departments and nobody is going to do anything about it."*

*"...that was a big weight off my shoulder because finally people who knew what I was going through, knew why."*

## Evidence that supports this from the workshop with health professionals

*"...acceptance isn't just an overnight thing, it's probably a back-and-forth thing, isn't it? And you almost just need to go away and think about it, and they need a bit of time and not pressure, 'maybe I can try that'."*

*"But there is something about empowering people and then investing in this because it's for them, rather than being told I should do it. Feeling that it's your choice, rather than... 'you must do it'..."*

*"...she'd been to the national pain programme and she [patient] said, 'they told us it's not going to go away. And we were like, [sighs]' but actually that was the most helpful thing that was empowering because we were no longer looking for a thing to fix it. We were then starting to think, well what can we do to live our lives well, with this'."*

## Evidence that supports this from lived experience interviews

*"...you absorb that information you kind of then started to question it..."*

*"I do have to plan a bit but I can – I'm getting better at regulating what I eat before that it isn't any of the FODMAP type things, so I am getting a bit better at managing it".*

*"I know myself that I have to lose weight and that will help it as well. But that wasn't the main situation of what she was telling us; she [Rheumatologist] was just helping us out to manage it, we can try different medications, we can try – she was giving us other options."*

*"If [neurologist] was to discharge me, I think I'd feel lost and scared. I think I'm very dependent on him because I know he gets it. Even the thought of that is causing me anxiety thinking about it! I think if the GP was here full-time, all year and never going to leave the job and all that, then maybe...but [name of neurologist] has been a constant in my FND journey."*

## Feeling empowered

Acknowledging that the process of acceptance can be different for each individual and supporting people to explore options and choose ways to self manage that work for them. This part of the pathway aims to make them feel able to take control, while ensuring they can easily access health professionals at times when they need support.

People living with functional disorders often find it hard to accept their diagnosis due to a lack of clear distinction between different conditions with similar symptoms and go through cycles of questioning or accepting it. Empowering a person to make their own journey towards acceptance and self management requires a psychologically-informed approach to enable the person to make their own choices and develop supportive relationships with health and care professionals, third sector organisations, peers, family and friends.