

Scott and Laura both live with persistent physical symptoms, and they have shared their thoughts and opinions of a few websites and phones apps below.

The Pain Toolkit - <https://www.pain toolkit.org/>

Overview:

Site with tools and resources for people suffering from chronic pain.

Reviews:

- Good general advice in very short video form – you can also hear from the kit creators own personal experience with each ‘tool’ too.
- Lots of further reading/other resources - the resources are easy to find.
- The seminars they run seemed interesting, kind of pricey - but I have booked a place in the internet café session they offer for just a donation to see what it’s like – at worst it’s £3.50 (it’s charged by donation so I went with the price of a coffee).
- I found the video ‘What is Pain?’ – linked on the first page of the pain toolkit website – a great visual for helping patients explain to family why doctors aren’t continuing more tests etc. a good resource against the ‘oh, you’re just being fobbed off’ opinion - it’s also available directly on YouTube, which might be less intimidating for some care givers than being given a list of web resources: https://www.youtube.com/watch?v=C_3phB93rvI
- I think this site is mostly of an emotional support benefit – it helps explain in basic terms ‘why’ you are doing something but not the real ‘how/why it works’ info. Helpful if you have issues remembering exactly what was said but you remember the key word like ‘pacing’ - it’s a handy refresher.
- It is a big site for people to work through. For me, with poor concentration & ability to hold information, I would need to refer back to it when needed.
- Costs: It’s a pity that you have to buy the accompanying booklets containing the pain toolkit - £7.95 hard copy, £13.99 from Apple Books for online copy. Run 2&1/2hr seminars for both medics & patients. Initial thought for me is that it’s a long time to sit through, add in costs of £45.75 for a patient or £65.14 for a medic & it all seems cost prohibitive for a lot of people.

Lorimer Moseley – Pain Revolution - <https://www.youtube.com/watch?v=oji2mfcjisk>



Professor Lorimer Moseley, 'The Pain Revolution', April 2017

Leading pain scientist Professor Lorimer Moseley explains the science behind 'Explain Pain' - and the good news for chronic pain sufferers. With fascinating examples and the latest research Lorimer explains how science is showing there are alternatives to drugs for many sufferers - and how it can be done. Produced by Help4backs - patient ...

www.youtube.com

Overview:

- Good explanation about how the pain system works and why you might get chronic pain.

Reviews:

- First slide gives instant validation: all pain is real no matter what is causing it. Fascinating from a scientific perspective but it's delivered in a way that focuses on the message that YOU can control your pain and improve your situation.
- Challenges beliefs & mind-sets. It does give hope.
- Follows on to other videos by same the person.

Live Well With Pain - <https://livewellwithpain.co.uk/>

Overview:

- A website for managing chronic pain.

Reviews:

- Seemed to have a good mix of information for both medics & patients attached & free which is always good.
- 10 steps very similar to pain toolkit but more comprehensive and better explained.
- Other resources are very accessible.
- I would recommend this over the Pain Toolkit.
- It is a lot of information but in small, concise steps.

www.Neurosymptoms.org –

Overview:

- Website providing patient information on functional neurological disorder.

Reviews:

- The first and only resource I was given by the neurologist who explained FND to me.
- I see its place and usefulness – it was overwhelming for me as a first port of call but it has been updated and is a much better layout now. It's still a lot but the user guide at the start is helpful.
- Free.
- Excellent starting point for patients, carers, medics et al.
- Lots of good information but it little dry reading and personally I find it geared more to professionals or those of a scientific mind-set – I have referred professionals to it before.
- However: for my symptoms it's still one of the best resources.

FND Hope & FND Action –

<https://fndhope.org/>

<https://www.fndaction.org.uk/>



HOME FND Hope - FND Hope International

FND Hope is a charitable organization promoting awareness and support for individuals and carers affected by Functional Neurological Disorder.

fndhope.org

[CLICK FOR CORONAVIRUS INFORMATION](#)

FND Action - Raising awareness of Functional Neurological Disorder and Non Epileptic Attack Disorder (NEAD) | FND Action

FND Action is a registered charity in England and Wales whose aim is to raise awareness of functional neurological disorder (FND) offering support

www.fndaction.org.uk

Overview:

- Charities dedicated to functional neurological disorder offering information and online forums for discussion.

Reviews:

- Both sites offer some help, some advice to a point.
- I personally have had bad experiences from both sites & associated/linked Facebook groups and forums so I leave others to make up their own minds but I personally wouldn't recommend them.
- Would recommend the basic site but not venture beyond that

The Spoon Theory - https://youtu.be/7_9Nis6JqLo

Overview:

- Story told by a woman who suffers from Lupus who is trying to explain to a friend why she can't socialise in the evenings. Good for understanding why, when you have chronic symptoms, you might need to pace and grade your activity, and how you might do that.

Review:

- Analogy simple enough to follow, but from personal experience from M.E in the late 1990s the analogy of the monetary budget is both easier to explain, comprehend & follow.
- Manage your energy levels like you would your money:
 - You have £70 per week to live on.
 - Do you spend/blow your £70 on Monday with nothing to live on the rest of the week

OR

- Do you budget a maximum of £10 per day & then further try not to spend the full £10 every day so at the end of the week you have a little saved over to add to next week's budget.

Understanding Pain in 5 minutes - https://youtu.be/C_3phB93rvI

Overview:

- Short 5 minute video explaining chronic pain and gives 5 simple targets for patients and doctors to work on together

Review:

- Good for professionals to use with patients in a normal consultation to provide information and start setting goals for treatment

myFND app -

Overview:

- App to log symptoms and triggers and work out what techniques might help to reduce the symptoms

Reviews:

- Very useful especially when learning personal triggers or when you feel changes in presentation.
- Private so you don't need to worry about someone else reading it.
- Easy to follow check-in screen.

Information for IBS - www.theibsnetwork.org

- Some free info but for full access you need to join - £24 per year online, £34 per year offline.
- Again, first thought was not everyone can afford that.

Podcasts/blogs

It's me it's me it's FND – Jake in Sheffield talks all things FND in 7min episodes about his experiences over the past 10 years and what it's like for him living with FND.

Hope Caitlin Treasures – Hope is a young person living with FND and often shares her unique perspective over on her blog – not a hugely information heavy page, but very encouraging for younger sufferers. <https://www.hopecaitlontreasures.com>