We need to talk about symptoms:
narratives and explanations

Information for health professionals on Persistent Physical Symptoms

For many health professionals, understanding and explaining the cause and nature of Persistent Physical Symptoms can be challenging. Patients may present with a range of symptoms and in some areas there remains a level of medical uncertainty as to how and why symptoms occur. Research[1] shows that patients report fewer symptoms and reduced health anxiety when health professionals are able to provide effective explanations for symptoms. Patients are also more likely to follow recommended treatment regimes when they consider the symptom explanations given to be resonant and meaningful. This leaflet, the second in a series of four on Persistent Physical Symptoms, provides examples of symptom narratives that can be used by health professionals, to deliver effective symptom explanations.

Explaining a symptom

Symptoms are the feelings we have when our body senses something may be wrong. The brain interprets, often with out us being aware of it, which feelings are a warning, perhaps of an illness, and which can be ignored.

When our bodies are working well, and in balance, our brain knows which 'alarms' can be ignored and which it needs to respond to. But if our systems are out of balance, our brains can be confused and treat both as if they are cause for alarm and action. Think of when a house alarm goes off. It could be because a cat has gone through the cat flap, or a burglar has come through the window. It is the same alarm, but the meaning and the consequences are different. Sometimes our brains get it mixed up.

The sections that follow present explanations and narratives for five common symptoms presenting in primary care.

1. Fatigue
2. Dizziness
3. Pain
4. Headache
5. Abdominal discomfort and altered bowel habit

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An effective explanation

Health professionals regularly underestimate the amount of information that patients require for a symptom explanation to provide reassurance. Effective explanations have been found[2] to be tangible, blame free and involving.

The three parts of an effective explanations are:

Tangible, credible and linked to mechanisms in the body: *"I think these symptoms are occurring because your balance system isn't working properly. Would it help if I tried to show you how the balance system works – how it communicates with your brain?"*

Blame free, reinforcing symptoms are real and not inadvertently blaming the patient: *"your brain has lost trust in your balance system" or "your balance system is no longer accurately telling your brain what is happening" rather than "you have become more sensitive to movement."*

Involving – moving from symptoms to action: *"how about downloading the vestibular rehabilitation leaflet from the Ménière's Society website and working to retrain your brain, so that it trusts your balance system again?"*

When developing explanations for use in consultations, this technique can be a simple check to ensure all three elements are included. The narratives are shown as examples, rather than scripts to be followed rigidly. It's important that each health professional prepares their own narratives and develops a confidence to be able to adapt and flex these to reflect the patient's symptoms and interests.

Underpinning the narratives are a core set of building blocks including:

- System dysfunction/dysregulation, systems get out of sync with each other (thermostat broken, handbrake on)
- Brain mis-interpreting signals or loosing trust in a system (false alarm)
- Sensitisation/hypersensitivity/Hypervigilance
- Fight or Flight response, pain cycle, panic cycle, stress cycle
- Reassurance that it's odd, painful/disturbing, but not dangerous
- There are practical activities that can be done to reduce the impact of symptoms

We have to be careful as clinicians to keep on the right side of scientific plausibility. But giving a 'good enough' explanation is better than safely 'doing nothing'
(GP)

Fatigue

There are lots of different systems in our body. Some control our 'get up and go'; others help us to remain calm, rest and digest. Sometimes these systems get out of balance with each other and don't work properly. One way this can happen is after a period of prolonged stress or anxiety, when the system that controls our reaction to stress, the hypothalamic-pituitary-adrenal axis (or HPA) axis which has been working hard, and functioning for a long time, gets stuck on 'max'. *In your case…(reflect the patient's symptoms here)*

It's a bit like when a thermostat breaks on a heater, and it keeps pushing out hot air even though the room is warm. So instead of your body resting at night, and recharging, your body, your brain and all of its systems are still switched on and working at maximum. Without this restful sleep your body doesn't have time to recharge, so when you wake up you still feel exhausted.

I can really understand that your fatigue means you don't feel able to do much at the moment. Sometimes making time to do something you enjoy can help 'jump-start' our systems. It's a bit like giving a car a push to start it on a cold morning, or when the battery is low. Once it gets going, it's able to tick along as normal, but it won't start with out a push. Maybe you could find some time for a bit of gentle exercise or meet up with a friend?

Dizziness

This symptom narrative is adapted from an explanation provided by Professor Lucy Yardley in the publication: *Controlling Your Symptoms How to reduce dizziness and nausea* **http://www.menieres.org.uk/files/pdfs/controlling-your-symptoms.pdf**

Our balance system relies on three different pieces of information:

1. Using our **eyes** we can see where we are and where we are going.
2. Using the sensors in our **body** we can feel where we are and how we are moving.
3. Using the **balance organ** in our inner ear (the vestibular organ or labyrinth) we can sense whenever our head moves.

Our brain acts like a computer, combining signals from these three senses to give us a stable picture of the world and control our head, body and eye movements. Sometimes these systems get out of sync with each other and don't work properly. *In your case…(reflect the patient's symptoms here).*

If any part of the body's balance system is giving out unusual or faulty information then you may feel dizzy, disoriented or unsteady. *[Tests such as the stepping test, Dix-Hallpike and stretched out arms can be used, and followed up with*] What you have just demonstrated to me is that that bit of your body is working, so perhaps there is a problem in the way in which your brain is interpreting the signals it is receiving. It's as if your brain has lost trust in your balance system.

The Ménière's Society website has a free to download vestibular rehabilitation leaflet. It has some exercises that you can do to retrain your brain, so that it trusts your balance system again. Something else that can help is keeping a note, a bit of a diary, of what you are doing when the dizziness is less obvious to you, less present, and what you are doing when you are more aware of it.

Pain

This narrative, and the accompanying pain cycle, are adapted from information that forms part of the pain toolkit **www.paintoolkit.org**

Pain starts as an unpleasant signal in the body, think of it as a warning sign. It is designed to grab our attention and keeps going until we sort the problem out. This is called a 'threat' response, so our brain downloads chemicals to make sure we take action:

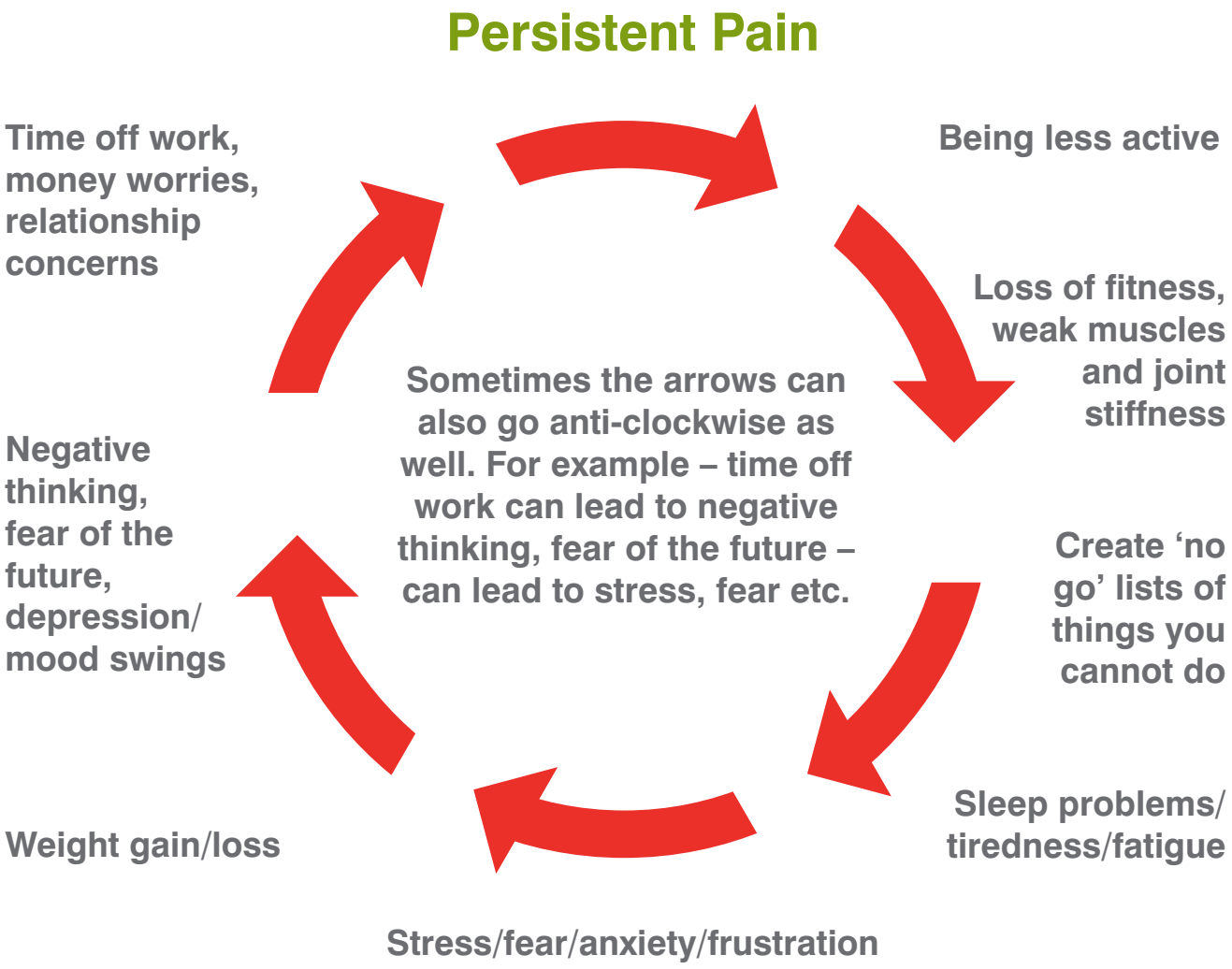
- muscle tension and protective chemicals to guard against further damage;
- worry and anxiety chemicals to find out what is wrong;
- stress chemicals to make us respond and get help.

Persistent pain is triggered when the nerves carrying unpleasant information become irritated and continue to react even though the initial cause has healed.

Sometimes the pain system stays switched on, perhaps after surgery or changes in posture. The threat chemicals continue to download, making the system fire again and again. This is known as the persistent pain cycle [share a copy of the pain cycle]. Your pain system can become wary of anything that makes it react, e.g. activity, inactivity or changes in weather.

Pain management is about helping the body produce chemicals to make the threatened system feel safer. Often the natural reaction to pain is to want to rest and avoid too much movement, but becoming a bit fitter can strengthen your muscles and increase the flexibility in your joints. It is important to remember that more pain does not always mean you are doing damage to your body. It may mean you are stretching muscles and nerves that are stiff and tight which is a 'normal' pain. Most importantly, find something that you enjoy. It often helps to do activities with friends.

The Persistent Pain Cycle



Headache

The central nervous system, the brain and spinal chord, act like a central computer interpreting information from our senses for example our eyes and ears and from internal organs such as the stomach. Headaches occur when the feedback loops of the Central Nervous System are functioning poorly, or if too little or too much input is occurring. The Central Nervous System can mix or confuse the direction of the messages coming from different organs, tissues and bones. Some headaches are the result of referred pain, which means pain is felt in an area away from the actual source of the pain. Modern medicine hasn't entirely explained the reasons behind referred pain, however, the most common theory is that strong pain messages running along nerves either "leap" or "overwhelm" adjacent nerves, causing pain to be felt where that series of nerves originates. At times referred pain can result in numbness, pins and needles or tingling in other areas of the body.

In your case…(reflect back the patient's symptoms and address their concerns).

It sounds like your headaches occur when your brain misinterprets signals from your Central Nervous System or when your Central Nervous System 'switches on' its pain nerves by mistake, when nothing is wrong. This 'system error' can cause other changes, for example to blood vessels and to the stomach, so you might find that light seems too bright, noises too loud or smells too strong. Over time, your brain has probably become wary of things that makes it react, for example stress, erratic eating, sleep disturbance, exercise or even unpredictable triggers like changes in weather.

It can be helpful to keep a keep a diary to try and identify triggers that your brain responds to (the National Migraine Centre /The National Headache Foundation websites have a free to download diary[3]). You can then divide your triggers into two groups – those triggers within your control you can do something about (missing meals, sleep disturbance, stress) and those which are out of your control (the weather, menstrual cycle, travelling/jet lag).

Abdominal discomfort and altered bowel habit

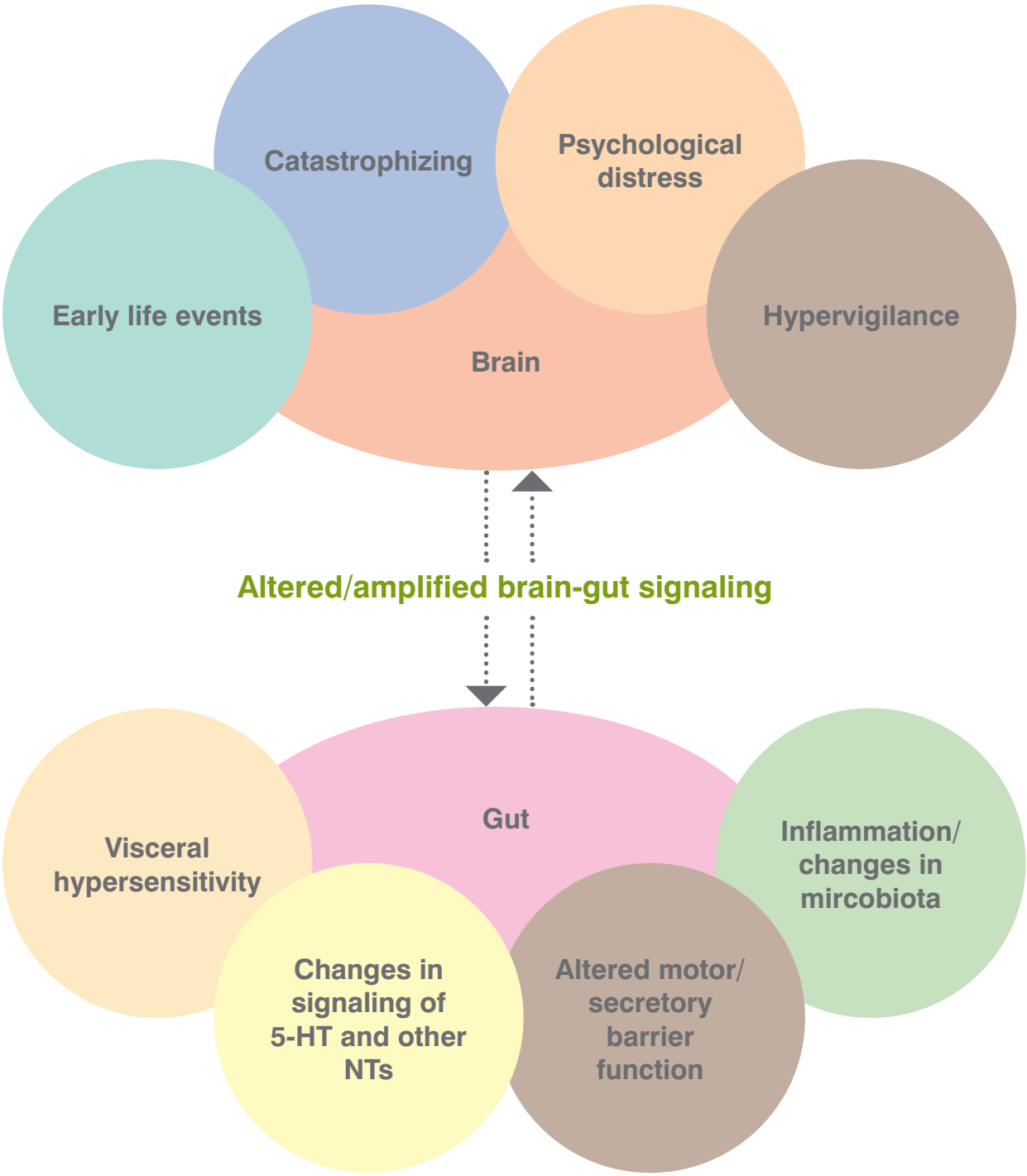
Lots of different systems in our body start to work when we eat, some mechanical, some chemical. When we put the food into our mouths the acid in our gullet breaks it down. A muscle wave carries the remaining food through our stomach and intestines where different nutrients and vitamins are adsorbed. Muscle contractions help us to pass the rest out. *Reflect back the patient's symptoms and address their concerns: for example if a patient has symptoms of heartburn or acid reflux, you should explain the role of the lower oesophageal sphincter.*

There are many different reasons why a person's digestive system might not work as well as it should. One cause is thought to be that the gut does not regulate itself properly. For example, if the brain produces and/or releases too much of a chemical, serotonin, people can experience diarrhea; too little can result in constipation. For other people, the intestines can become overly sensitive to stimuli for example food, smoking, hormonal changes, medication, worry and stress. A third cause suggests that after infections, for example food poisoning or gastroenteritis or prolonged stress, your brain loses trust in your digestive system and normal stimuli are interpreted as abnormal.

It can be helpful to keep a keep a diary maybe for two to four weeks, to try and identify triggers that your stomach responds to. It's important not to focus on each item of food you eat, or each bowel movement, but more on the day as a whole, how were you feeling, what was your mood, how severe were your symptoms. The BUPA website[4] has a free to download Irritable Bowel syndrome symptom diary. Having regular meals, following dietary advice, taking exercise, taking time to do something you enjoy, limiting the intake of fatty foods, alcohol, caffeine, and fizzy drinks, have all found to be helpful.

Work by Professor Hungin and colleagues[5] has led to the development of an explanatory model for IBS that focuses on impaired transmission and interpretation of brain and gut communications. Phrases from their research that could be included in explanations are:

- The brain sends signals in such a way that they are over-interpreted by the bowel.
- The bowel is receiving signals over-sensitively.
- The bowel is processing signals over-sensitively and this affects function.
- The function of the bowel is affected by the nervous system.
- The bowel sends signals in such a way that they are over-interpreted by the brain.
- The brain is receiving or processing signals too sensitively.
- The brain is misinterpreting normal signals from the body as signs of disease.
- Food, bacteria, or substances found in the gut can sometimes cause the gut to malfunction and trigger symptoms



Over to you!

Research with patients suggests consultations that deliver high levels of satisfaction are those where health professionals are able to effectively convey empathy and take time to offer a meaningful, resonant explanation of symptoms. This leaflet provides information, tools and techniques to support health professionals provide effective symptom narratives.

To get the most out of this resource, it is important that health professionals take time to rehearse and develop their own narratives. Why not dedicate some time in a practice meeting to share symptom narratives? Spending time looking up, writing and rehearsing the explanations you can give to patients could be a piece of reflective practice you could include in an appraisal or revalidation portfolio.

References

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5 Hungin, A. P. S., Becher, A., Cayley, B., Heidelbaugh, J. J., Muris, J. W. M., Rubin, G. & De Wit, N. J. (2015). Irritable bowel syndrome: an integrated explanatory model for clinical practice. Neurogastroenterology & Motility, 27, pp. 750-763.

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