Bodysymptoms.

Navigating healthcare with functional symptoms: a guide

This guide provides advice for those dealing with health challenges related to functional symptoms. The aim of this guide is to help you understand and navigate the healthcare system more effectively.

What This Guide offers: This guide recognizes that trying to navigate healthcare with functional symptoms can bring unique challenges.

You will be able to read about the experiences of others, as they looked for diagnosis, support and treatment. This guide aims to help you become aware of some common challenges. It gives general info and tips to help you find the support you need.

What This Guide Doesn't Do: This guide does not provide specific information about local health services. This is because healthcare (especially what is available when you have functional symptoms) is different everywhere.

It's Not One-Size-Fits-All: Remember, not everything in this guide will apply to you. veryone's journey through healthcare is unique, depending on factors like where you live, your symptoms, and the professionals you encounter. So, while it's good to be aware of potential difficulties, try not to expect problems before they happen. You might have a better experience than you think!

How to use This Guide:

This guide is divided into 5 chapters:

1. **Thinking About Seeing a Doctor:** This chapter might help if you are starting out, perhaps with new symptoms or a new healthcare team. It aims to help you understand what to expect during the assessment process.
2. **Understanding the System:** This chapter helps you map your journey and the options available.
3. **Making Decisions about Treatment:** This chapter helps you understand which types of treatments are effective for functional symptoms and which approaches might suit you.
4. **Understanding Confusing Healthcare Experiences:** This chapter might help things make more sense if you've already been to the doctor and felt confused or upset about what happened, and includes advice on how to avoid common pitfalls.
5. **Getting the most from your healthcare journey:** This chapter summarises some practical approaches that can be helpful.

There is a lot of information in this guide, and it touches some challenging subjects. If you have symptoms, it may be overwhelming to read it all at once. It is recommended that you focus on the part(s) that are most relevant to where you are in your health journey.

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CHAPTER 1: Thinking about seeing a doctor

It is not necessary to go to the doctor for every problem. Many people first ask for advice from family and friends, or the internet. If you have longer term symptoms, you may be comfortable managing certain things yourself. Many people with functional symptoms also choose alternative or complementary therapies.

These are all valid routes towards understanding your symptoms better and supporting healing.**However, mainstream healthcare also plays important roles when you have persistent symptoms:**

Role 1: To help you understand what is going on and what might help. When you're ill, it's normal to want to figure out what's happening. Doctors and other healthcare professionals know a lot about the body and can help you understand what's going on and how to feel better.

Role 2: To rule out other causes of symptoms and confirm a diagnosis.

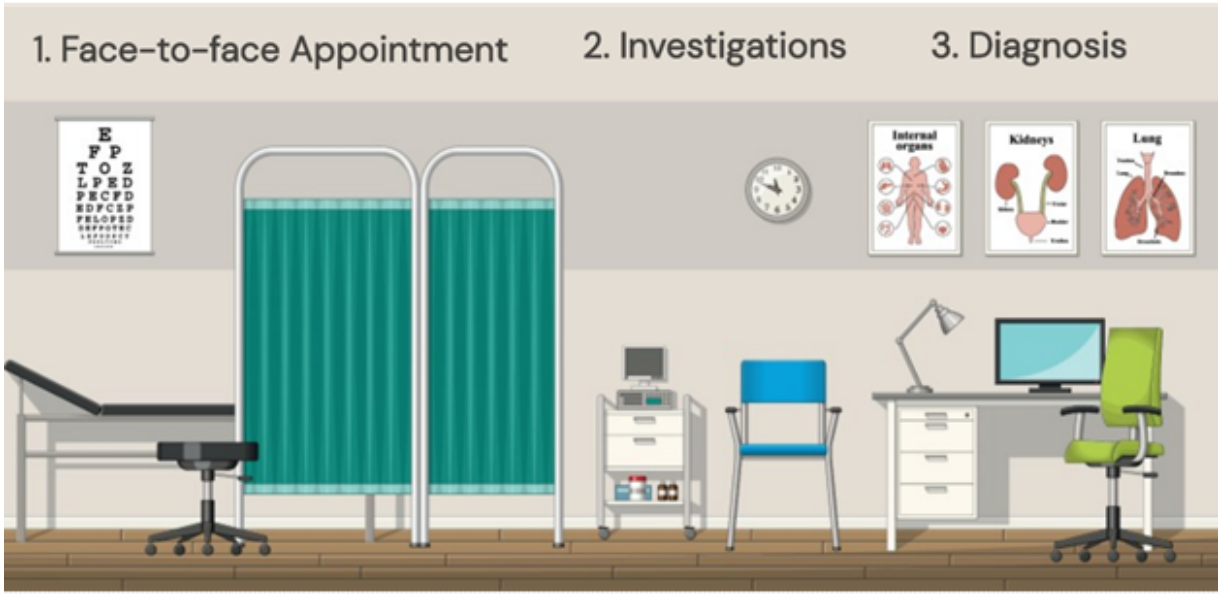
Most symptoms have many different potential causes. ven though in functional symptoms medical tests typically come back normal, investigating new or alarming symptoms this way can reassure you that other potential causes for symptoms have been considered.

Role 3: To access resources and support:

Seeing your GP / family doctor is often the first step to being referred to treatment and other services. There are times when you might need special help or benefits, that you can only access through health services. For example, you might need a doctor's note to take time off from school or work.

What to expect: assessment

The first step in most healthcare journeys is to make an appointment with a doctor. This will normally be your general practitioner (GP or family doctor). When you visit a doctor for the first time, they need to get a complete picture of your health. This process is called an assessment, and it usually includes the following steps:



When you see a new healthcare professional for the first time, they'll start by asking about your symptoms, medical history, and overall health.

The face to face appointment

This will involve a medical interview (sometimes called a 'history') and physical examination. If your doctor can only offer short appointments, or if you have a very complicated medical history, assessment might take place over several meetings.

Doctors usually want to know:

-A good **description** of your symptoms (including what they feel like)

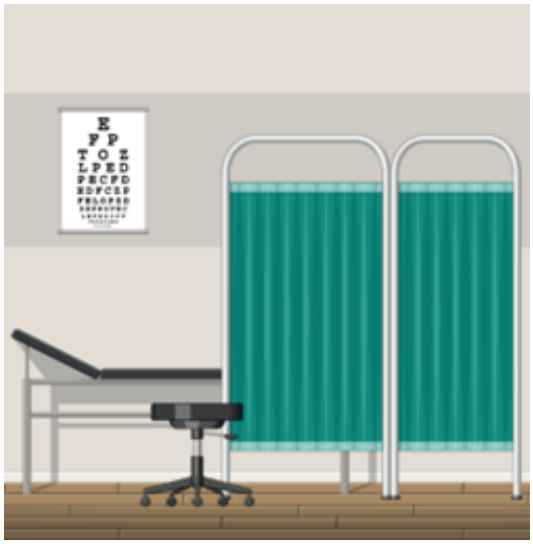
-Any **pattern** you have noticed in your symptoms. (e.g. specific things that trigger them)

-The doctor should ask about your **daily life,** and the impact of symptoms.

-They will **screen** for other symptoms, anxiety, and depression.

-They should review any **medication** you are taking and discuss alcohol and drugs.

-They should ask you if you have any t**houghts and questions**



Physical Examination:

You will usually get a quick check-up to help the doctor understand what's going on. If it would make you feel more comfortable to have a chaperone, then you can request one.

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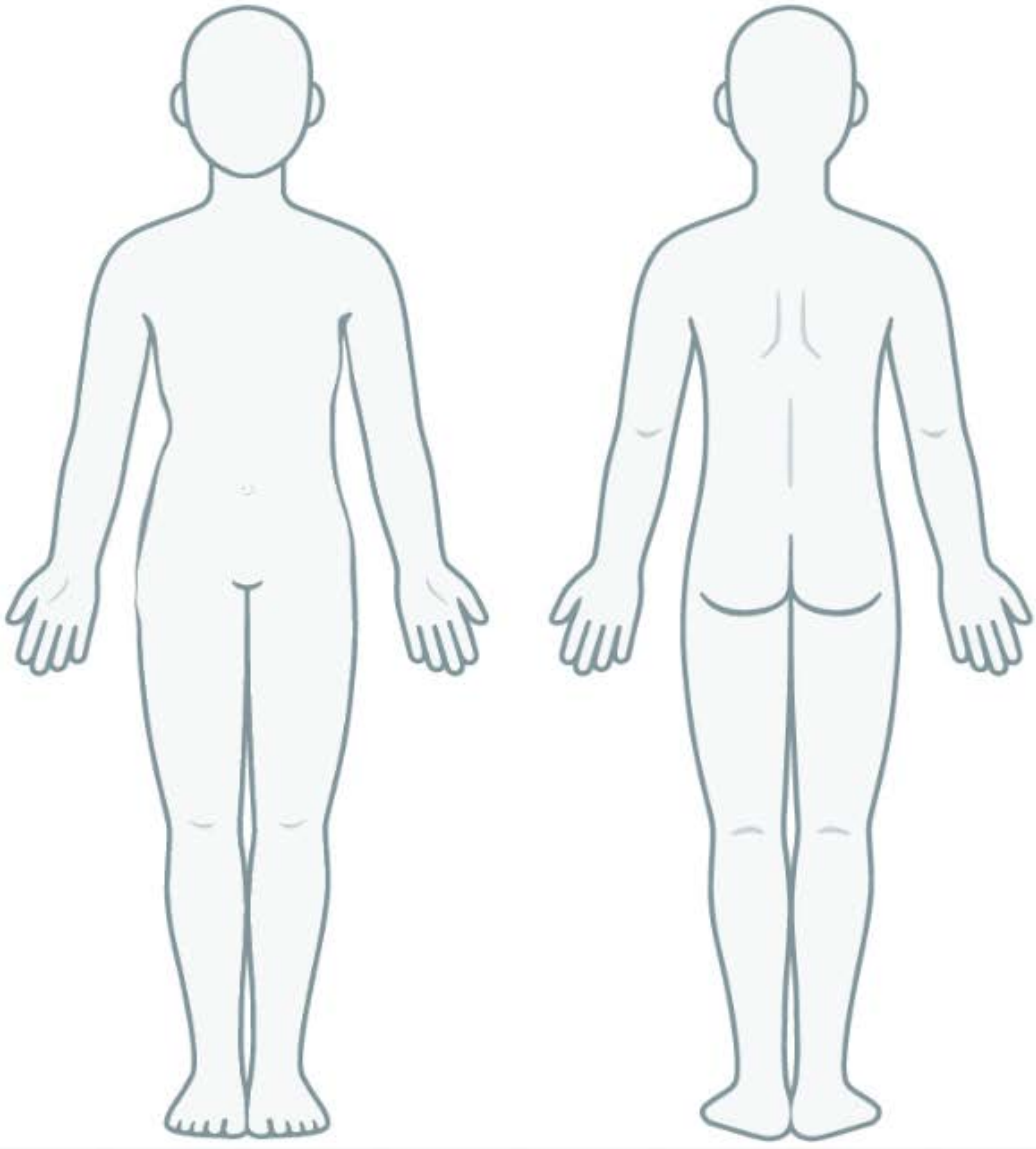
Draw a map of your body.

You can use the outline below, or draw your own. Include all your **symptoms on the map**.



Therapist tip.

It is important that you mention all your symptoms. If you have many symptoms, it can be helpful to take in a list or draw them on a body map. If the doctor is short on time, they might ask you to talk about your main issue. Be ready to explain if you think your symptoms are connected.

Possible outcomes from the initial appointment:

Sometimes, when symptoms are mild, short lived and don't have any worrying features, your doctor might suggest a**'watchful waiting' approach.** If they take this approach, they should explain why your symptoms are not likely to be dangerous and offer a plan of what to do in case things get worse.

When symptoms are more severe, last for longer than seems normal, or have 'red flag' features, your doctor might suggest they are **investigated with further tests.**

Maria G's experience

Note that this describes an ideal scenario. My experience has often been more frustrating.

For example, the doctor doesn't understand, does not take it seriously or is general unhelpful, for whatever reason. Rather than black and white, functional symptoms often involve a lot of different greys. This means the assessment process can be very difficult on an emotional level as a patient.

Therapist tip.

The assessment process can take time, especially if your symptoms are tricky. It's a good idea to stick with the same healthcare team instead of switching doctors too often. If you keep changing, you might always be in the assessment stage and not get the help you need for your symptoms.

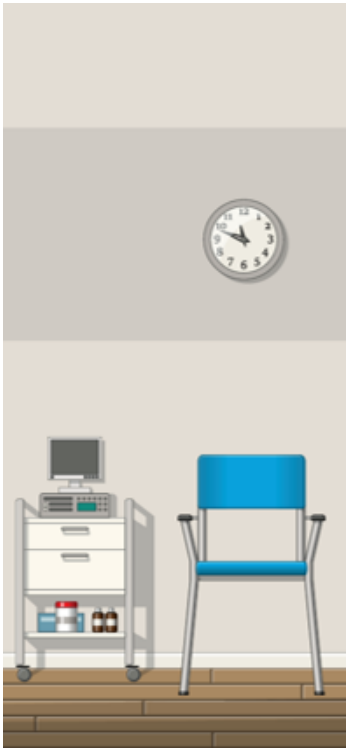
Investigations are tests or scans that your doctor orders to help them to understand better what is going on in your body.

Investigations

Good reasons to do investigations are:

1. to rule out diseases which are dangerous
2. to identify diseases where the root cause can be directly treated
3. to clarify a diagnosis and/or prognosis.

Your doctor should be able to explain to you why they are doing a certain test. It is also important that any results from tests are fully explained to you. With most functional symptoms, often very little 'shows up' on medical investigations, such as blood tests and scans. In medical-speak, this means that most investigations come back 'negative' 'within normal range' or 'non-specific'.



Negative test results usually signal good news. Medical tests are designed to rule out the most dangerous possible causes for symptoms.

Sometimes, however, positive test results are seen as the only form of evidence that a disease exists. This can lead some doctors to become very focused on 'finding' bio-markers that might explain your symptoms. Some patients can become focused on this hunt too.

Terence's Experience

In late September of 2022 I caught flu. There was nothing unusual about it. However, after a few weeks I still had a cough. In fact, the cough, together with bouts of fatigue, hot flushes, hoarse throat and heart palpitations would go on for the next 5 months. Some days, I'd feel like I was improving only for the symptoms to re-emerge.

By February, the mental stress of these symptoms really started to take a toll. I'd been in hospital several times at this point, to have my heart and lungs checked. I'd never had heart nor lung issues in my life. The doctors' conclusions were always the same, I was perfectly healthy and they couldn't explain my symptoms.

At this point I started to wonder whether I had a lifelong condition. My GP (family doctor) was sympathetic, but couldn't offer a solution.

Avoiding unnecessary investigations

Patients are often initially relieved to get a positive test result, but this does not mean the result is helpful in pointing towards treatment. Because no test is 100% accurate, all investigations can give 'false positives' as well as 'false negatives'. This means that, statistically, the more tests are done, the greater chance something will come back positive. Getting any test done means that the chance of acting on a 'false positives' (i.e. treating a disease you don't actually have), increases.

Because evidence shows that unnecessary tests more often cause anxiety than reassurance, guidelines advise doctors to avoid repetitive, especially risky investigations, that are only done to provide reassurance to the patient or themselves,

Why are my tests all negative? Some potential reasons

Medical tests understand the body by looking at small parts separately.

Functional symptoms are best understood by looking at how the body/person/environment is working together as a whole.

When things go wrong with bodily functions it may be a problem of timing.

Medical tests provide a snapshot or image frozen in time. Problems with timing, co-ordination, or communication between different body processes are often invisible in the lab.

Medical tests only show results which are outside of a statistical 'normal range'.

If bodily functions are dysregulated, measurements might all be within the normal range, but highs and lows might occur in the wrong situations, which can cause symptoms.

Symptoms could be memory traces.

We can wake up with a symptom today just because we had the symptom yesterday. If symptoms persist in this way, they can't be detected by looking at the body. Medical tests usually cannot "see" memory traces in the body or brain.

Remember

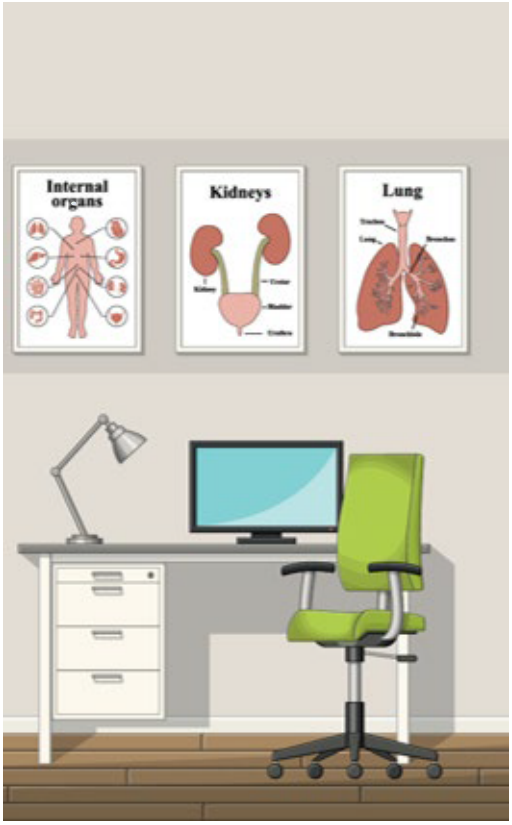
What is going on for you is no less real, and no more your choice or fault, just because it doesn't have a biomarker (positive test result).

A diagnosis is a label that your doctor uses to categorize your health condition. Getting to the best fitting diagnosis is one aim of the assessment process.

The diagnostic processs

A diagnosis is a tool that can help you understand your condition and find appropriate support and resources to recover. At the same time, it is important to remember that for conditions involving functional symptoms, the diagnostic labels aren't perfect..

There are two Stages of Diagnosis:



1. **Suspecting the Diagnosis:** Your doctor looks at the features of your symptoms to figure out possible causes and comes up with a list of possible diagnoses that would fit (this list is called a 'differential diagnosis').

2. **Confirming the Diagnosis:** Tests are done to narrow down the differential diagnosis by ruling in or out diagnoses on the list. This process usually starts with trying to rule out the most urgent or serious causes. The uncertainty during this process can be difficult, but keep in mind that negative test results are usually good news.

During this process, your doctor may already have a good idea your symptoms are functional and may even recommend treatment or rehabilitation strategies to help with these. In this instance they may still organise some tests to rule out other possible causes for your symptoms.

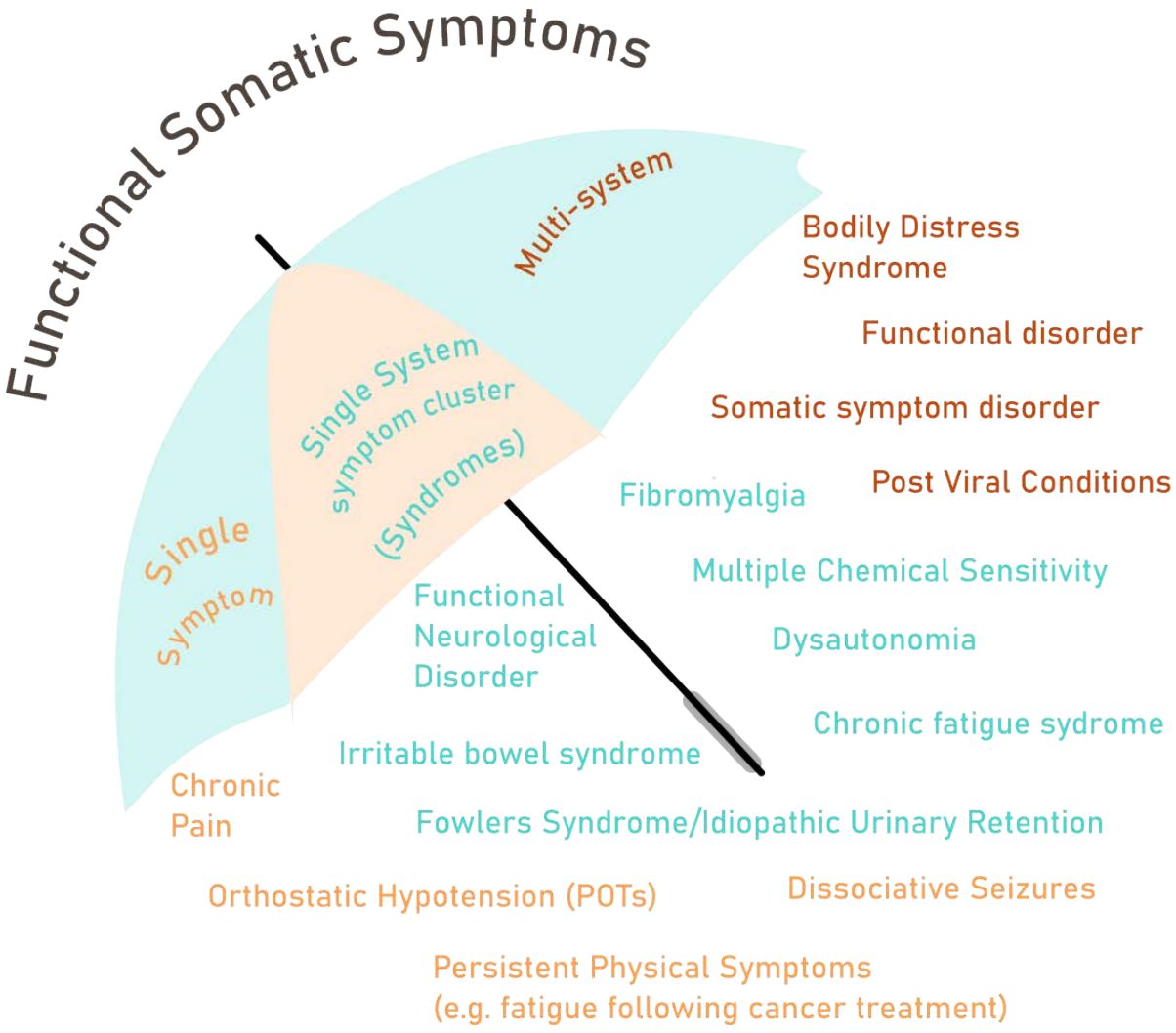
You can talk to your doctor about how they're trying to figure out what's wrong with you. This can help you feel more confident that they're addressing your concerns and not missing any rare or unusual causes of your symptoms.

If you want to know more about the diagnostic process, and how doctors make decisions, we recommend this series of blog posts: https://sciencebasedmedicine.org/clinical-decision-making-part-i/

The diagnostic process can take some time, often due to waiting lists or other delays in the system. There is no need to wait for a final confirmed diagnosis before starting to plan rehabilitation for functional symptoms. What you do to support the body to heal from functional symptoms will be beneficial for the body, whatever the cause of your symptoms ends up being.

What sorts of diagnoses are associated with functional symptoms.

Functional symptoms is an **umbrella term:** when you have functional symptoms you may be given one, or several, different diagnoses. There are many different diagnoses that fit under the umbrella, but the diagnoses overlap. They represent a spectrum of conditions that share many symptoms, causes and mechanisms, and treatment approaches.



Multiple terms and labels

The diagnostic systems in this area are far from perfect and can be very confusing..

Diagnoses are often based on the way the medical system is split up into specialties. Each branch of medicine has its own names. For instance, doctors who focus on the nervous system use the term functional neurological disorder (or FND) for symptoms referred to their clinic, rheumatologists typically see people for joint pains so are more likely to diagnose fibromyalgia.

So, in part, the diagnosis or diagnoses you get will depend on which clinic you are referred to for your most obvious or challenging symptom.

Of course, in real life, our body is not neatly divided like the different medical specialties. Functional mechanisms often affect many parts of the body at once. This is why people often get several different diagnoses for related problems.

If your symptoms effect multiple systems, you may get multiple diagnoses or you may be given a unifying diagnosis (such as functional disorder). This depends on the diagnostic culture within your healthcare service.

In addition, functional symptoms present very individually. Not everyone fits diagnostic criteria for a defined syndrome. The word ‘syndrome’ refers to a typical cluster of symptoms, that are assumed to have a shared underlying cause because they often co-occur. The most commonly diagnosed functional somatic syndromes include fibromyalgia, irritable bowel syndrome and chronic fatigue syndrome.

You can see a list of diagnostic terms and labels that are used to refer to functional symptoms and syndromes in Appendix 1.

To learn more about the diagnostic systems in this area, listen to the diagnosis episode of the‘Not so Invisible’ podcast.

Understanding diagnostic codes

In Europe, most doctors will use the World Health Organization's International Classification of Disease to assign a diagnostic code (current version: ICD-11). Functional syndromes (clusters of typical functional symptoms by organ system) are usually diagnosed within one of the different medical sections of the ICD, e.g., IBS in the chapter on gastroenterological diseases and fibromyalgia in the chapter on rheumatological diseases. Most Functional Somatic Syndromes have research diagnostic criteria, which define them, e.g., the Rome criteria for IBS or the criteria of the American College of Rheumatologists for fibromyalgia. Most classification systems just require that you experience a certain number of symptoms out of a set but don't say anything about severity, which means that different people with the same diagnosis will have different levels of illness and impairment.

In some healthcare systems it might be necessary for your doctor to assign a code so they can refer you to psychological treatment. In the mental health section of ICD-11 there is a diagnostic code for 'Bodily Distress Disorder', a relatively new diagnostic code, not yet widely used. In some European countries you might come across the diagnosis 'Somatic Symptom Disorder', which is similar to Bodily Distress Disorder, but is from the American Psychiatric Association's Diagnostic and Statistical Manual (DSM-5).

There are some local differences in coding practice. For example, in Denmark 'Functional Disorder' is an official overarching diagnostic category, and can therefore be given its own code. In the Netherlands, you are more likely to be given a code which refers to the each symptom you have (e.g. Pain, Vomiting) without specifying what causes them.

Functional symptoms and other diseases

Functional symptoms are very common when people have diagnoses of other chronic diseases.
For instance, many people who have treatment for cancer experience persistent fatigue and other symptoms long after tests confirm the cancer itself has disappeared. Another example is that people with epileptic seizures often develop functional seizures alongside their epileptic ones, creating a mix of different seizure types.
It's important to recognise when symptoms are maintained by functional mechanisms, even if they were triggered by other diseases. Like in Zoe's experience, when this happens, treating the primary disease may not make the functional symptoms go away.

Zoe's Experience

In hospital I underwent many tests. As I had just returned from South America, I had tests for different viruses and bacteria that live in those countries. But nothing was found.
Eventually, the medical team found something, a trace of Lyme bacteria in a blood test. The medical team decided to perform a lumbar puncture to see how widespread the bacteria was and found evidence that there was Lyme bacteria in my brain.
After being diagnosed with Lyme disease I had a 3-week round of antibiotics. Unfortunately this treatment didn't help my symptoms. I had less and less strength and more and more pain, there were days when I couldn't stand it and I felt completely exhausted.
My medical team decided to give me another second round of antibiotics through a central line on home admission. Once again, the antibiotic left me exhausted and I didn't feel any better.
The heavy antibiotics had cleared any trace of the Lyme bacteria from my body, but my symptoms did not miraculously go away. In fact, I was now in a worse state following the treatment, and there was little left that the medical system could offer me in terms of a cure

Remember

- There is not one single diagnostic category that covers all relevant dimensions for patients with functional symptoms.
- Diagnoses can be a useful starting point, but a diagnosis won't explain everything about your body.
- Your body's condition is constantly changing, and a diagnostic label should not determine what is possible for you in your life.

Some questions that you might find it helpful to ask when you get a diagnosis

Can you explain how you have made the diagnosis?

How confident are you this is the final diagnosis? Are there any other possible causes for my symptoms that still need to be ruled out?

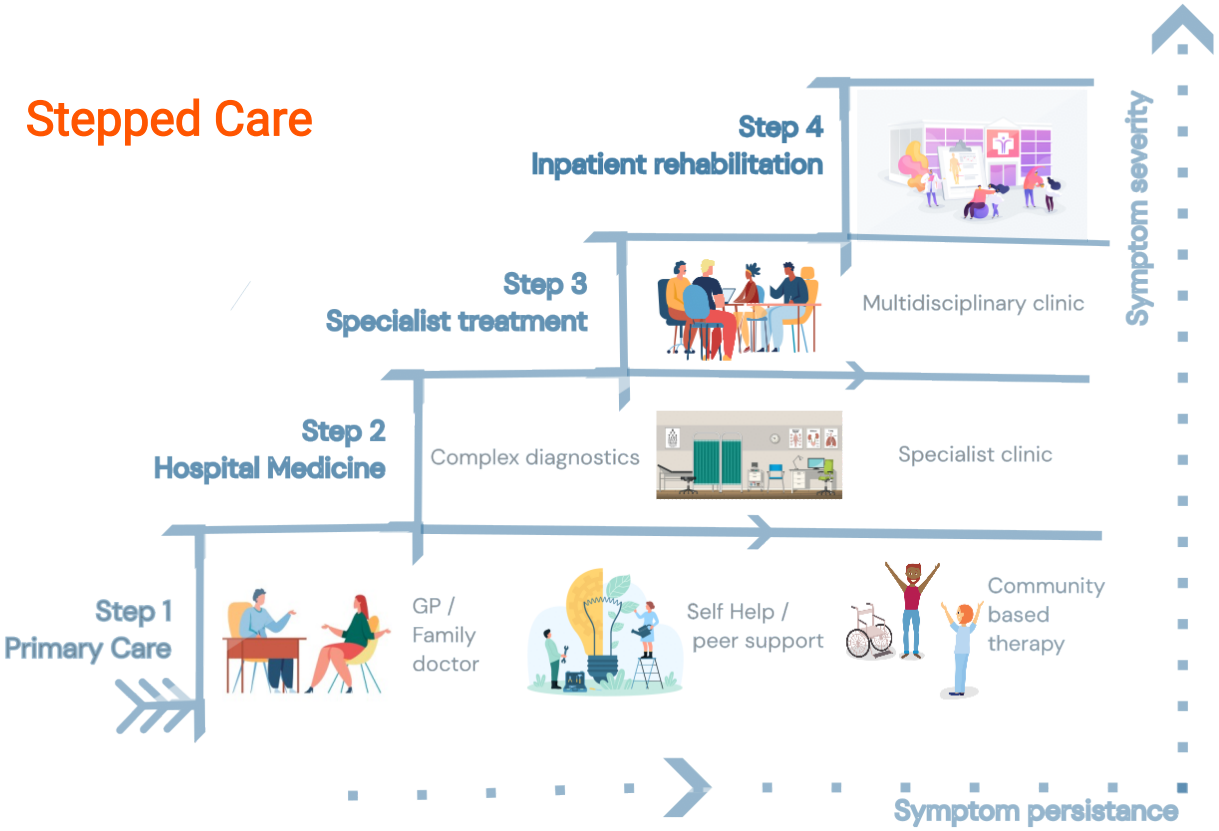
Can you explain what the diagnosis means?

Do you have any information or reading materials you can recommend about the condition?

What treatments are available/what can I do to help myself?

CHAPTER 2: Understanding the system

For many people, understanding the healthcare system is one of the biggest challenges of having functional symptoms. If you are seeking treatment, it can be difficult to know what treatment approach is right for you, which routes you can take through the healthcare system and how to find out what treatment is on offer.



What level of help you need with your health will depend on the nature and severity of your symptoms. Many healthcare systems use a 'stepped care approach' to try and match patients with the appropriate level of treatment. **This usually means you start with basic treatments and move to more specialized ones if the earlier steps don't help.**

Remember	We try to provide a road-map here, but the reality is that the type of support or treatment available and its quality differs a great deal. This means we are not able to describe exactly what sort of help you will be able to access. Often the best place to start getting an overview of what is available to you is by asking the question(s) to your GP / family doctor.

Step 1: Primary Care

The majority of functional symptoms are managed in primary care. Primary care is centred around your GP practice (family doctor clinic) and community treatment services, which may include physiotherapy or psychological therapy, social or occupational support.

Step 2: Hospital Medicine

If your GP / family doctor needs more input to help you with your symptoms, or wants to clarify a diagnosis, they might refer you to see a specialist, usually based in a hospital.

This might include endocrinologists (hormone specialists), gynaecologists (women's health specialists), neurologists (if FND is suspected), rheumatologists (if symptoms are predominantly related to pain and inflammation), gastroenterologists (bowel symptoms), or urologists (bladder symptoms). In fact, people with functional symptoms are referred to almost every specialty you can think of, as functional symptoms can appear to come from almost any of the organ systems.

Many hospital clinics can help with investigations and diagnosis, but not all specialty based clinics are set up to provide treatment for functional disorder. This means some people have the experience of not getting the help they need from the hospital.

Step 3: Multi-disciplinary team clinic.

Research tells us that being referred to a hospital clinic that is set up to involve teams of different professions that work together is most beneficial for people with functional disorders.

This set-up is called a multi-disciplinary team (or MDT) approach. If you are referred to a multi-disciplinary team clinic, usually your first meeting will be an assessment to get an overview of your problems. The assesment will help your team work out which sorts of professionals it would be most beneficial to have involved in your treatment.

Therapist tip.

Although it can feel frustrating not to be referred to specialist services straight away, being too focused on this could delay recovery.

Remember: the goal is to get your health back. It is usually a more promising approach to accept the foundational treatment or support that is available to you and start working towards recovery with the resources you already have.

The multidisciplinary team

The gold standard in treatment for functional disorders happens within a multi-disciplinary team. The team includes experts in the body (for example, medical doctors, physiotherapists, dieticians), experts in mind-body connections (for example, psycho-motor therapists, somatic psychotherapists, neuropsychiatrists, or liaison psychiatrists) and experts in thought processes and making changes (for example, psychologists, occupational therapists and social workers).

Typical members of the multidisciplinary team include:

Medical doctors

Usually a medical doctor will carry out the initial assessment and oversee your treatment. They will order investigations and will guide the diagnostic process.

They can help explain to you what they think is causing your symptoms and make a plan with you for further treatment and follow-up. They should work out if there are any other things going on that need to be taken into account, such as mental health difficulties, or social needs. Doctors are also usually the people on the team who prescribe, and can help you with questions about medication or side effects.

There may be different types of medical doctors involved in MDT's specialized in functional disorders. Typically, doctors who work in this area include general practitioners, neurologists, rheumatologists, and anesthetists (in some pain clinics). In some countries there is a medical specialty (psychosomatic medicine), with special expertise in treating mind-body problems including functional disorders.

Physiotherapists

Physiotherapists have a central role in the MDT. They are specialists in the musculoskeletal system and in rehabilitation. They can provide valuable therapy for a range of functional symptoms, including pain, dizziness, neurological symptoms and fatigue. Some physiotherapists are experts in functional disorders and can provide highly specialist input working with attentional, cognitive and emotional components of movement.

Aimee's Experience

It might just be my physiotherapist, but she in honestly amazing. She specialises in FND (functional neurological disorder).

She is the one who will turn around to me and say the exact right thing that helps. She makes me aware of things that I could not see by myself.

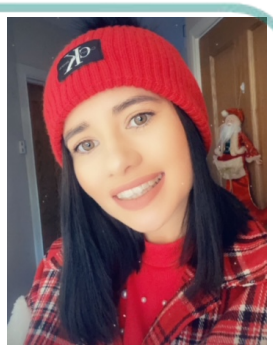
Dieticians

Dieticians are trained to understand the science related to food and nutrition. A dietician might help you to understand if you are deficient in any nutrients and how to change your diet and food habits so the nutrients you need are properly digested, absorbed, transported, metabolized, stored and discharged by the body.

Psychiatrists

Consultation-Liaison Psychiatry is the name for the sub-specialty of psychiatry that operates at the interface of physical and mental health care usually by providing psychiatric consultation in the general hospital. Some liaison-psychiatrists might have a special interest in functional somatic symptoms. Similarly neuro-psychiatrists are specialist psychiatrists that work at the interface of psychiatry and neurology, and typically have relevant expertise working with Functional Neurological Disorders.

Aimee's Experience



After many years of suffering and trying to find doctors to listen, understand and help me with my condition, I finally met my consultant in Liaison Psychiatry June 2022.

From the moment I met her she listened, I felt she understood me and I finally have some support. She will take time to explain why things are the way they are for me, and point me in the right direction if I need advice. She has also had my family in for meetings to teach them and help them understand my illness. Since I have met my consultant, I had the best year with my illness and I truly believe its down to her support and guidance.. I see my consultant once a week at the moment and as my illness calms down I will see her less often but I know I can contact her if I need to. I will always feel grateful for how amazing she has been.

Psychology

Some evidence suggests that treatments for functional symptoms are most effective when delivered by psychologists and psychotherapists. Health psychologists have a particular interest in helping people adapt to and manage chronic illnesses, and are a central part of many MDTs. Psychologists might offer different types of individual or group therapies. Depending on the psychologist's background and training these might involve the body (somatic psychotherapies), or look like more traditional talking therapies.

Occupational therapy

Occupational therapists (OTs) help people overcome the impact of symptoms through practical support to improve performance and satisfaction in activities of daily living. Occupational therapists typically help people with functional symptoms with things like routines, pacing, and sustainably increasing activity levels.

OTs also have a key role in supporting people with FND to manage their condition in the context of work and/or study. This might include helping employers and educators to understand your condition and work with occupational health departments to identify and advocate for reasonable adjustments to improve work performance and symptom management.

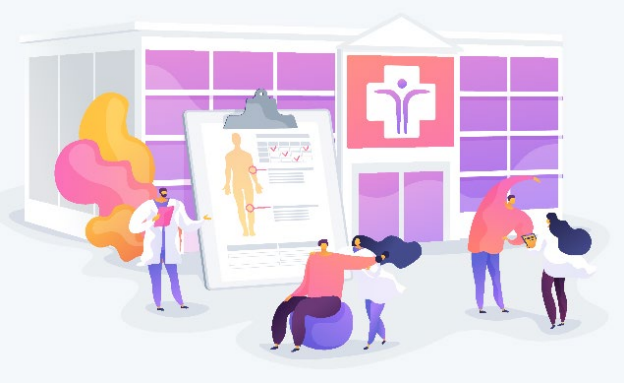
Social workers

Some people with functional symptoms have related social needs. Examples of this include people struggling to claim the benefits they are entitled to, or people who are under stress from unsafe or inappropriate living situations. To help with problems like these, social workers are sometimes part of MDTs.

Nurses

Specialist nurses are often part of the MDT, providing foundational care and support. For example, they might help take your blood pressure, blood tests, help you solve problems, or give health advice and counselling

Step 4: Specialist rehabilitation



If you've been unwell for a while, you might benefit from a more intensive treatment. Highly specialist rehabilitation does exist for these problems, but it's different depending on where you live and what your symptoms are.

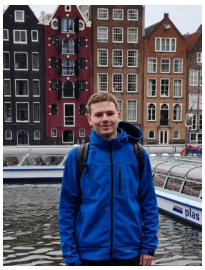
In some countries, there are specialist outpatient centres that help people rehabilitate from pain and other complex and chronic symptoms. Although services are set up differently everywhere, they usually involve a multi-disciplinary team which can support you to work towards a tailored plan to bring more freedom and ease to day to day life.

In other countries, people with the most challenging functional disorders may have access to specialist MDT treatment in a residential setting. The set up of these inpatient units vary considerably according to the type of health system.

For example, psychosomatic inpatient units exist mainly in Germany. They are centres which provide joint medical and psychological care, which would not be possible in mainstream hospitals, for the prevention and treatment of chronic illness, functional disorders, and job-related disturbances (such as burnout). They usually offer a range of therapies and other activities as Marc describes below.

Marc's Experience

I have had inpatient and outpatient treatment for functional somatic symptoms. My inpatient therapy took place in the psychosomatic department of the large university hospital in Hamburg in 2020.



A day at the clinic lasted from .15am to 6.30pm with different breaks depending on the day. The treatment plan included the following activities and therapies: exercise group, one-to-one sessions, art therapy, mindfulness, medical check-ups, depression group, yoga, breathing therapy, a group where patients could voice their concerns which were then discussed together, physiotherapy, social competence training group, and PMR (progressive muscle relaxation).

Most of the therapies have been fun and interesting. I liked all the sports therapies because sports have always been very important to me and I could block out everything else and focus on sports. I found the breathing therapy exciting because I had the feeling that I could effectively regulate my nervousness in tense situations, such as before a school assignment, by breathing rhythms.

Art therapy and progressive muscle relaxation, on the other hand, did not help me at all. Personally, I can't express my physical nor my emotional feelings with art. In progressive muscle relaxation, with my symptoms, I did not manage at all to first tense and then relax my different body parts. My body was so restless and shaky that I had to get up and move because I could no longer sit.

The most positive thing about the inpatient treatment was definitely the family atmosphere on our ward. My fellow patients all did their best to make sure that, despite the difficult situation, we all had it as good as possible, and I made some new friends.

Advocating for better services

In most European countries, there is currently inadequate provision of multi-disciplinary treatment for functional disorders. There are many professionals who find this unacceptable and are working hard to improve the situation for people with functional disorders. However, there is a long way to go. This is a long-term and often invisible problem, within healthcare systems that always seem to have a lot of urgent issues to respond to. These services will usually not be funded unless those with the power are made aware of the need. If you have the time and capacity, you could think about working with a patient organisation to advocate for better services where you live.

You can find a list of active patient organisations through the resource page of bodysymptoms.org

CHAPTER 3: Making decisions about treatment

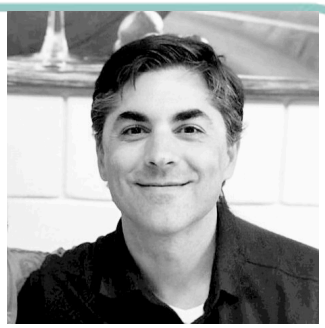
After getting a diagnosis of a functional disorder or syndrome, you will wonder what treatment is available and how it might help.

It is a general rule that there is no 'magic bullet cure' for functional symptoms. This means there is no pill that you can take to make the problem disappear, and there are no surgical interventions that have been shown to help.

Despite this, many people recover completely, even from severe symptoms. The reason for this is because healing is possible, even when 'magic bullet cures' don't exist.

This doesn't mean you have to be on your own with symptoms. In fact, recovery is much easier in connection with others. There are many health-professionals and therapists who have expertise in functional symptoms and there are evidence-based treatments that can support your recovery.

Javi's Experience



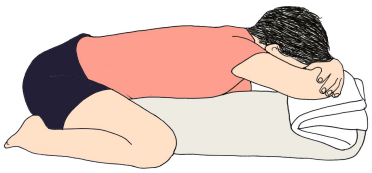
In 2019 I started a group course which was run by some doctors locally. The group met for one session a week for 12 weeks. It followed a curriculum to help us understand pain, how it works from the point of view of the neuroscience. For me, understanding that pain is not the same as damage was a sort of cognitive therapy.
Now I understand better how my pain is working. I know the logic of why, when I am out with friends and when I'm in certain situations I don't feel pain at all because. In relaxed situations, I don't need to get alarm signals from my brain. So, I understand how the pain is working, and this allows me to feel confident to know when to go against what my brain is suggesting.

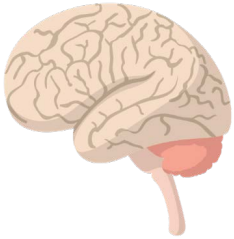
What does the evidence say about treatment for Functional Disorders?

There is moderately good evidence for the effectiveness of various treatments, which are offered within mainstream medical settings for functional somatic syndromes and functional disorders.

In terms of medication, there is evidence that some classes of antidepressants help some people with Functional Symptoms. There is best evidence for the effect of tricyclic antidepressants (such as Amitriptyline, Imipramine). However, newer antidepressants (for example, Duloxetine) or other medication that act on the central nervous system are often prescribed.

There is also established evidence for the effectiveness of a wide range of activating, mind-body therapies. Within this category, there is moderate to strong evidence for the effectiveness of multidisciplinary treatment, different forms of exercise training, different talking therapies, hypnotherapy and hydrotherapy. Mindfulness-based therapy, relaxation training and yoga-based therapies have all also demonstrated moderate effect in treating functional somatic syndromes..





Why is it difficult to evidence treatment in functional disorders?

It is clear that with functional symptoms, there is no 'one size fits all' approach to treatment. It is difficult to 'group' patients by diagnoses and expect them all to respond the same way to a set treatment. Instead, a tailored, modular, and personalised approach to treatment is most appropriate.

However, this fact comes with a downside: it is actually very difficult to provide evidence for personalised treatment approaches. Methodologies for evidencing personalised treatment are still relatively undeveloped. The more complex statistics needed can mean that studies lack power and can be seen as lower status by commissioners, or when guidelines are created.

This fact means it is reasonable to choose alternative and complementary approaches to recovery from functional symptoms. These are usually backed by different forms of evidence than the narrow approach to evidence- valued in western medical science.

The good news is it might be harder to collect evidence for treatments used in functional disorders but where evidence does exist effect si es (a measure of how effectiveness the treatment is) are comparable to other areas of medicine.

Medication

The most commonly used medications in functional disorders are described as 'centrally acting'. This means they work within the central nervous system (brain and spinal cord). They work by altering neurotransmitters that can have an impact on symptoms like insomnia, pain, or depression. You can read more about specific medications that are often prescribed in Appendix 2.

Therapist tip.

People have very different relationships to medication.

Some people are very anxious about medications and side effects, and are very cautious about trying any medications. Other people are happy to trust their doctors and take anything they are prescribed.

If you have health anxiety, you may want to consider whether or not to read about all the side effects of a medication before you take it.

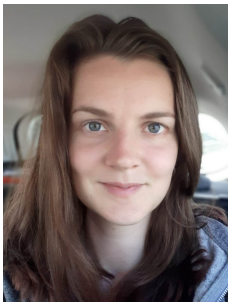
The same goes for reading the rest of this section, where we discuss some of the problems associated with medication in functional disorders.

If in doubt reading about experiences with side effects will be helpful for you, pause for a moment before reading on.

Side effects

All medication have side effects and should be used with caution. People with functional symptoms may be more sensitive to side effects than average. Your doctor might not be aware of this fact. As a general rule, a 'start low, titrate up slowly' approach to dosing is recommended.

Maria's Experience



In principle I think both Sertraline and Venlafaxine could have a positive effect for me if prescribed properly, but due to the dose being put up too quickly and switching directly between the medication, I got some really nasty side effects.

I had never had functional seizures before I was put on antidepressants, but ended up with a trip to the emergency room when I switched from Sertraline to Venlaflaxine. It started as violent tics, jerking my head and hands, then there were episodes where I sat staring blankly into space, not responding to others even though I could hear them perfectly well.

If you are prone to dissociation, be aware that antidepressants can trigger these symptoms in particular during tapering or switching. This is not necessarily something one's own doctor or psychiatrist is aware of, and not always clear from the side effect list.

I mention this because it has been both part of my own experience, but also because I subsequently found out that I was far from alone when browsing international internet forums with others who have functional disorders. It's not something I found from a scientific source, but there were enough similar experiences described independently that I felt it should be included here. As there are many aspects of functional disorders that are not fully understood or researched yet, I think it is worth taking into account patients' own stories when a pattern forms that has not otherwise been fully spotted by doctors yet.

I decided for myself not to try any more of that type of medication until all other options had been tested.

Skills guide: Navigating healthcare

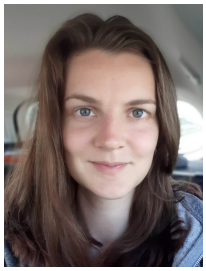
Polypharmacy

Unfortunately, some patients with functional symptoms end up being prescribed a large number of medications, with new prescriptions added in at a faster rate than old prescriptions are reviewed and stopped. This situation is called polypharmacy. Because combinations of medications are rarely researched, polypharmacy is associated with unknown health risks.

Polypharmacy usually builds-up gradually because many doctors put more focus on starting than stopping medication (it can feel more satisfying in a short appointment to 'do something' rather than 'take something away'), and because both doctors and patients tend to over-estimate the benefits of medications and under-estimate the downsides. If you are on a lot of medication, it is worth considering whether any of your symptoms could be due to medication side effects. For example, opiate medication can cause cognitive problems, sleep disturbance, and, if used in the longer term, exacerbate sensitisation and pain.

If you suspect that you are prescribed too much medication, or that any of you medication are exacerbating symptoms, it is a good idea to discuss this with your GP / family doctor. Coming off medication can be difficult, and for some medications requires gentle tapering under medical supervision to avoid withdrawal effects. You can get more information at https://deprescribing.org/resources/.

Maria's Experience



I would advise as far as possible, start or stop medication during a period where there is not too much else going on. It can be difficult to make sense of whether something is working or not if there is a lot of other change in your life, for example if you are starting a new job, moving house or other major changes in your treatment.

Javi's Experience

My experience is that drugs can rescue certain situations. Don't be too afraid of drugs.

There are side effects of course, and I do think a lot about quitting but also I think that it's not a big deal if I need to take some drugs during my whole life. I am still living with that dilemma, but I don't pay much attention to it.

In summary

- Medications can help some people cope with symptoms
- Overall there is limited evidence that long term prescriptions make a difference to outcomes.
- The best evidence base is for certain classes of anti-depressents ((SNRIs or TCAs))
- People with functional disorders are often more sensitive to side effects. Start, switch and stop medications gradually.
- Combinations of drugs should be reviewed regularly to see if any can be reduced or stopped.

Evidence based mind-body therapies

Psychosomatic medical research has advanced over the past decades, and although some people may still class the following approaches as 'complementary' or 'alternative' (to biomedicine), many mind-body treatment approaches now have an established evidence base for effectiveness in functional symptoms.

This makes it more likely you will be able to access these treatments within main-stream health-care (although this still differs from area to area).

Traditional talking therapies (psychological treatments) may be the starting point in some treatment settings, whereas in other treatment settings bodily focused therapies (such as physiotherapy) may be offered first.

Treatment approaches that work at the interface of mind and body are particularly promising for functional symptoms. These may include therapies that retrain the brain and bodies automatic responses.

Regardless of the training background of the therapist you are working with, ideally treatments involve the whole person, mind and body, equip you with tools to manage your symptoms, and work towards reversing some of the mechanisms that are maintaining them.

You can read more about some of the specific evidence-based mind-body therapies that you might be offered in Appendix 3.

How can psychological treatments help with physical symptoms?

The body is always affected by what is going on in the mind, emotions and habits. Problems like depression, anxiety, or past traumas are very common for people with functional symptoms and usually need to be addressed to give the best chance of recovery. Talking therapy helps you work through common problems such as around setting boundaries or improving your self-esteem, which also often need to be dealt with as part of the recovery process.

Even if your symptoms don't involve any obvious psychological mechanisms, it is helpful to make use of the therapy space to get to understand your condition better. Therapists can point out patterns in how we relate to and respond to symptoms, which allows for better ways to manage symptoms to become clear.

Complementary and alternative approaches

Complementary and Alternative Medicine (CAM) are a group of diverse medical and health care systems, practices and products that are not generally considered to be part of western conventional medicine. Many people choose to include CAM as part of their recovery plan, and many have good experiences.

CAM may also be part of a mainstream healthcare offering as part of a holistic approach to treatment. This varies considerably depending on where you live and your health insurance system.

It is important to keep in mind that CAM treatments can be less regulated than treatments available in mainstream healthcare, and you might have to pay for them directly. This means it is important to make sure you trust the practitioner you work with. It is usually a bad sign if someone is trying to sell you a lot of supplements, equipment etc.

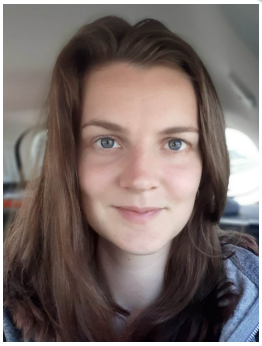
Drastic interventions that put the body under a lot of stress, or promise unrealistically quick results, should be approached with particular caution.

In Appendix 4, we list CAM treatment approaches that in our experience make sense, help people more often than not, and carry a low risk profile.

Trauma focused therapies

It is a little bit difficult to know where to put this group of treatments. Trauma is considered a ‘separate problem’ from functional symptoms in the scientific literature, which means there is limited evidence that these types of treatments help with functional disorders or syndromes. On the other hand, there are well established links between trauma and functional symptoms, and many people (even those not meeting clinical diagnostic criteria for PTSD) have experienced therapies with a trauma focus has also had a positive benefit on their physical symptoms.
We recommend trauma focused therapies that put the body at the center of the treatment, for example Eye Movement Desensitization and Reprocessing (EMDR) or Somatic experiencing therapy.

Maria's Experience



Totum body therapy is the type of therapy I have stuck with the longest. It is a combination of talk therapy and addressing the body at the same time.

Techniques from reflexology are used and part of it consists of a type of massage where you are gently shaken. It can be used both to calm the nervous system and to address some of the places where things build up. The conversation part includes finding out how trauma and stress have settled as tension in the body.
My therapist has been very understanding that some days I come in and everything hurts and my who,le body is shaking, so I just need to rest. Other days, when there is a little more surplus, we can address some of the things that might hurt a little but loosen up in the end.

Making decisions

There are many factors which will effect whether a particular approach to treatment works for you. As a rule of thumb: an approach is more likely to help if:

- It makes sense to you in context of how you understand your body.
- If you feel understood by the practitioner.
- If the treatment involves an active component (i.e. you are shown how to do something different yourself rather than passively receiving a treatment).

This section of the guide provides some advice on how to make sure your preferences are taken into account when it comes to your healthcare.

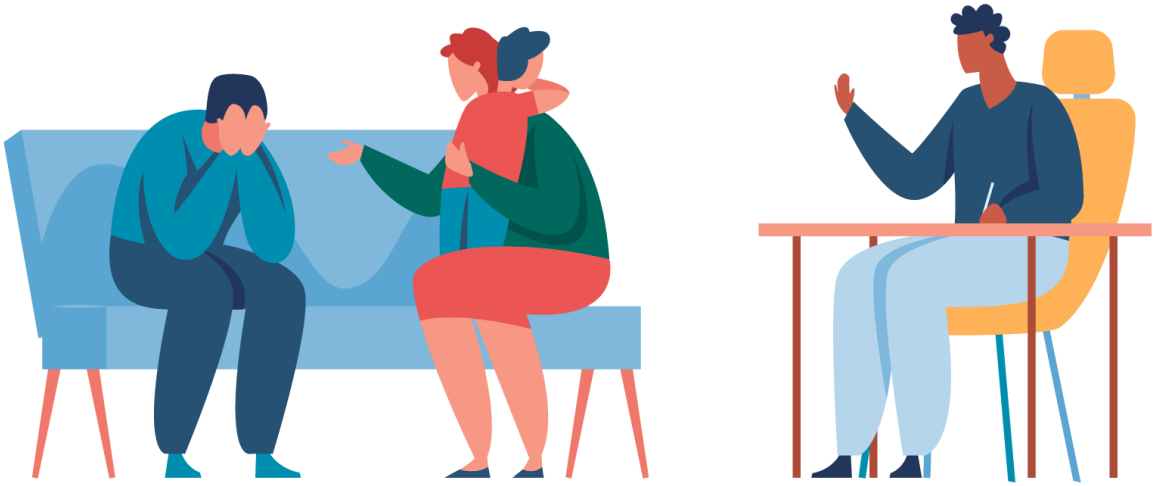
Shared decision making

Taking care of your health is a team effort, and you are a crucial part of that team. While your doctor is an expert in diseases and medicine, you know a lot how your body and mind work, what's important to you, and what's feasible in your current situation. Shared decision-making is a collaborative process that involves the patient and their healthcare team working together to reach joint decisions about care. Most modern healthcare systems aim for shared decision wherever possible.

Practically this means that when your doctor chooses tests and treatments, they should base their decisions both on evidence and guidelines, but also on your preferences, beliefs, and values. Without your input, key information will be missed.

In order to collaborate in shared decision making, it is necessary you understand the risks, benefits and possible consequences of different options that might be available to you. This means that you have the right to ask your doctor for this information about these things and expect to be given time to make up your mind.

However, it is all too easy to suddenly feel overwhelmed and passive when you step into the patient role.



Tips for getting the most out of treatment

1. **Invest in relationships.**
   Good, trusting relationships with your healthcare team and other members of your support systems can make all of the above easier. Try to reach a shared understanding about what caused and now maintains your symptoms with your healthcare team.
2. **Commit to being an active partner in treatment**
   This means setting goals and taking responsibility for seeing them through, prioritising time for homework, regularly practice of what you have learnt, etc.
3. **Be brave.**
   For things to change you need to be willing to take some risks, face up to some of your most challenging and deeply engrained habits and commit do some things differently.
4. **Be honest about and deal with any conflicting motivations.**
   This is likely the most challenging aspect on the list. Conflicting motivations are usually unconscious and can manifest on relational or emotional levels. When conflicting motivations arise, navigating through them can be quite difficult. Often it is only in retrospect that people realise how conflicting motivations were holding back their healing.

Remember

There are no hard and fast rules about who gets better from functional symptoms and who doesn't. Even people who have many symptoms and have been unwell for many years can recover with the right approach.

Some examples of conflicts that can hold back recovery:

- You're awaiting the outcome of a legal case or a judgment from the social system regarding your ability to work or access to benefits. This might cause a conflict where on the one hand you don't want to suffer, but on the other hand, you need to prove you are ill while the case is resolved.
- You might hold the unconscious belief that your partner is only staying with you out of sympathy, creating a fear of getting better in case they leave.
- You might have set yourself numerous goals to achieve when you're well, but this exposes you to the potential shame of not feeling good enough if you recover and lose the 'excuse' of being ill.

Avoiding harm from treatment

It is a natural tendency to want to do everything you can for your health. However, it is also the case that more health-care is not necessarily better health-care. In fact, 'doing everything possible' can often do more harm than good.

When people with functional symptoms enter the health-care system as patients, it has been observed that they are at particular risk of **iatrogenic harms** (harms inadvertently caused by medical interventions).

These types of harms most often result from over-testing or inappropriate treatments. This is driven by the combination of a general lack of understanding about functional symptoms and their appropriate management, and anxiety (on behalf of patient and/or the treating team).

Tips for avoiding harm in the healthcare system

1. **Treating functional symptoms is rarely an emergency.** It is easy to assume something is an emergency because you are in A+E or because everyone around you seems rushed and stressed, but this is not necessarily so.
2. If something feels like an emergency, some time and a calm environment will usually help things de-escalate. **You can ALWAYS ask for the time** to make decisions about interventions if you are feeling rushed or pressured.
3. It is important to **keep a sense of control**. Don't fall into the trap of letting things be 'done to you'. If your doctor truly believes that a treatment decision urgently needs to be made, they will let you know.
4. **Remember: more care is not always better care,** You always have the right to refuse treatment (do nothing and see what happens).

Some questions it is helpful to ask when you are offered a test or treatment.

What are the benefits?
What are the risks?
What are the alternatives?
What if I do nothing?

CHAPTER 4: Bruised or confused

Healthcare systems are far from perfect. They may feel impersonal, confusing, or simply too busy/overwhelmed to be able to give you time and attention. These challenges can feel even harder when your symptoms don't have a single, simple cause. This chapter is about some common challenges faced by people with functional symptoms when they need to navigate healthcare.

Problem 1: Feeling Like Your Symptoms Are a Mystery

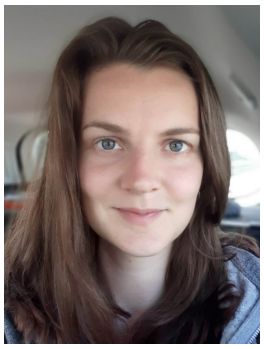
Functional symptoms are known to improve when patients feel understood by their treating team and when they find an explanation that makes sense. However, people who seek medical attention with functional symptoms, often have a difficult time getting a helpful explanation for their symptoms.

This can lead you to feel like your symptoms are a mystery. Mix that with a little anxiety and you are stuck in a loop, waiting for Dr House to come along and diagnose you with some rare and terrible condition.

The good news is, that most functional symptoms are not due to mystery illnesses. These kinds of symptoms have been around for as long as human beings. We know a lot about them, and there are many tried and tested routes towards healing and recovery.

However, there are problems. Healthcare professionals do not always learn enough about managing functional symptoms in their training, and how modern healthcare services are organized and structured, can be stacked against the sharing of this knowledge. Functional symptoms can be difficult to assess and explain in short appointments and many patients leave healthcare appointments without adequate explanations about what is going on in their body to cause symptoms, and no sense of the way forward.

Maria's Experience



The information I have been able to get both from my general practitioner, at the hospital, and on the internet has usually lacked something concrete to relate to. Many of the explanations I have received about my symptoms I found so vague that they often left me with more questions than answers. This created frustration, anxiety about what I could possibly do to feel better and, on several occasions, a sense of being abandoned.

I think it's a real shame that you rarely get the full explanation of how the body's systems work the way they do. I'm sure this is mostly because the doctors don't want to confuse the patient with long complex explanations, or because they're not 100% sure and finally don't want to say something that might be wrong. But treatment works better when you understand why you have to do what you have to do.

I personally find it hard to understand and work with symptoms when you are served an A→ F solution and then just leave out all the steps in the explanation in between A→ B→ C→ D→ F.

Problem 2: Being made to feel like you are the problem.

Sometimes, trust between patients with functional symptoms and their healthcare teams breaks down. This can happen when doctors feel pressured and can't provide all the help you need. They might feel bad about this and project these bad feelings onto you.

It is best if you are able to trust your healthcare team have your best interests at heart. But this is not always possible. Many people are forced to navigate healthcare within an atmosphere of distrust.

Unfortunately, some people with functional symptoms face stigma as well, as some healthcare professionals still hold old-fashioned negative views about the 'types' of people who struggle with functional disorders. There are various ways this stigma can show up, including as othering, denial, non-explanation, minimising, norm-breaking or (inappropriate) psychologising. This stigma can be worse if you're a woman, younger or older, have difficulties with your mental health, or face economic challenges. (i.e. groups that are already subject to marginalization.)

If this is your experience, we are sorry! It is overwhelming to be ill, and no-one should experience feelings of blame or stigma when they reach out for support. We hope it is helpful to understand this is not a personal problem, but a common experience shared by many people with Functional Symptoms. It is a problem that has many complex roots.

Takeaway

We hope stigmatising attitudes and belief structures are on the way out. You deserve to have a healthcare team that make a serious effort to understand your difficulties, and to help you with them.

Maria G's Experience

It was obvious to me over this time-frame that:

a) my medical history was becoming increasingly more difficult to describe

b) I had been labeled as 'difficult'. It seemed like a problem for the doctors if I simply talked back or asked questions.

I had an A4 bullet-point list with my symptoms, my surgical interventions, and my medication. Most doctors brushed it aside and treated me like a 'hysteric' who could only be making up such an extensive list. I felt condescended. Because I struggled to find anyone who could give me an adequate explanation, I saw many different doctors.

I can now clearly see I had suffered iatrogenic harm – I had several orthopaedic and gynaecological surgeries that were not needed, even my hip was replaced to no avail, and with life-altering consequences. I was told by two London doctors, (the ones from private, fancy clinics), that I should go home and take analgesics until I die. One evening, I was thrown out of a clinic and fell on the pavement, covered by the heavy rain. I wanted to die.

Although you are not the problem, there are things that you can be aware of that can help interactions with healthcare go a little more smoothly. We offer some advice at the end of this guide that can help you build and maintain helpful relationships with your healthcare team.

Problem 3: Fragmented care (Falling between the gaps)

Modern healthcare systems are (on the whole) split into specialties that deal with the diseases of a single organ system. Functional symptoms tend to effect multiple organ systems. Current practice about who should provide care for patients with functional disorders is mixed. In many places specialist services treating functional disorder do not exist and there can be very different attitudes and arrangements even within a single hospital.

Patients are often caught between services, or referred from one service to another, without a clear understanding of who is supporting them or why. This creates a sort of health limbo land, where you are constantly going for assessments and never getting answers, treatment or support.

Of course this situation is frustrating, time consuming, and sometimes feels personal (like rejection or abandonment). We hope it helps to hear that this is a structural problem in how healthcare services are organized, rather than something necessarily you are doing wrong.

Why functional symptoms fall between the gaps in modern biomedicine.

Functional symptoms show 'complex causality' because they relate to the functioning of the body, which is itself a complex system. This means functional symptoms have multiple interacting causes that occur in unique individual patterns.

In contrast, modern biomedical science has had its biggest successes developing cures for diseases where it is possible to identify a simple causal relationship (A→ B) between a biomarker and symptoms. Examples of this include infections or deficiencies, simple genetic diseases and cancers. These kinds of diseases are easier to study with laboratory science, and suit commonly understood statistical methods. They are also easier to develop drugs for and are therefore considered profitable areas for the pharmaceutical industry to invest.

This focus on diseases with 'simple causality' has led to a situation where functional symptoms, whichthat have complex causality, fall between the gaps at many layers in the medical system (including at the research and funding levels), despite being very common, and often treatable.

CHAPTER 5: Getting the most from healthcare

Reading the last chapter, you might be tempted to steer well clear of healthcare. However, there are some situations where it is wise, helpful, or necessary to engage with the healthcare system. Below is some advice that might help.

1. Plan ahead: when does it make sense to involve healthcare?

It makes sense to think carefully about which situations you want to involve healthcare. For example, if you are someone who experiences more dramatic symptoms, such as seizures, or fainting (where people tend to call an ambulance), it can help to have a plan in place for when you get exacerbations. Acute hospital admissions can be highly distressing and can usually be avoided, once your symptoms have been fully investigated and you are confident they are not life-threatening. I

f you decide it's better overall for you to manage things outside of hospital, this usually needs to be communicated with people who are close to you, the people with whom you spend time, and your healthcare team. In some situations it might be necessary to plan how you might communicate about your condition and preferences with paramedics.

2. Build a support team

Taking care of your health is a team effort. It's important to have people who support you through your health journey. It will take a while to build a team you trust. So, to start with, try to identify one person you trust, who understands your situation and is generally sensible/ knowledgeable around health issues.

It's necessary to choose someone you're comfortable with and willing to let into your treatment. Ideally they are both able to challenge you and support you when things get tough. Your helper could be your partner, friend, mentor, therapist, doctor, coworker, exercise buddy, a CAM practitioner, or anyone else you trust. Perhaps you could buddy up with someone from a patient support group.

Of course, the person you ask to be your helper, might have their own limitations as to the level of support they can provide, so make space for them to share these with you.

It is normal that someone might be able to fulfil some roles (e.g. attending appointments with you), but not others (e.g. joining you on daily morning walks). This is fine. In fact, it is a good sign if the other person is able to express their boundaries with you in this way. This provides an opportunity to think about who else you could ask to help in these roles. You are on your way to building a support team.

You might want to write down or draw a map of everyone you consider in your support team. This can help you see where you might have gaps in your support, prompt you who could reconnect with, and have a reminder of who you can turn to for help when things get tough.

3. Be aware of how shame effects your interactions with healthcare

Many people with functional symptoms feel intense shame. Although this area is not fully studied, various factors, including early life attachment trauma, may be related to both shame and symptoms. In addition, symptoms can bring up shame related to the body and its failings, and the stigma associated with functional disorders themselves.

Shame is a very intense emotion, that in itself can activate the nervous system and exacerbate symptoms. Unfortunately interactions within healthcare have many features that can easily trigger shame, including a focus on the body, which feels shameful for many people, and imbalances of power, which can trigger shame for others.

Be aware if shame is driving you to switch healthcare teams regularly, or preventing you from communicating openly all the information that is relevant for your healthcare team to understand and help you with your problems. One study suggested that in the Netherlands, over half of women with severe persistent fatigue did not mention the fatigue to their doctor, despite attending their GP/Family Doctor often. Other studies suggest that people with functional symptoms can hold back on mentioning patterns they have noticed in their symptoms, for example, when symptoms were related to stress, perhaps because they anticipated a negative reaction.

Of course, if you don't tell the doctor about your symptoms, it makes it harder for them to understand what is going on, and to help you.

Therapist tip.

Self-compassion, trust and openness are crucial for navigating this emotional landscape, but it usually takes some time to recognise and work through deep-seated emotions, like shame, which we usually do everything we can to avoid.

4. Be aware of the vicious cycle of having to prove you are a 'deserving' patient

It has been noted that there is a particular pressure that falls on people with functional symptoms. Since according to medical tests there may be 'nothing wrong', patients with functional symptoms can feel the need to work harder in their interactions with healthcare to become a 'credible patient'.

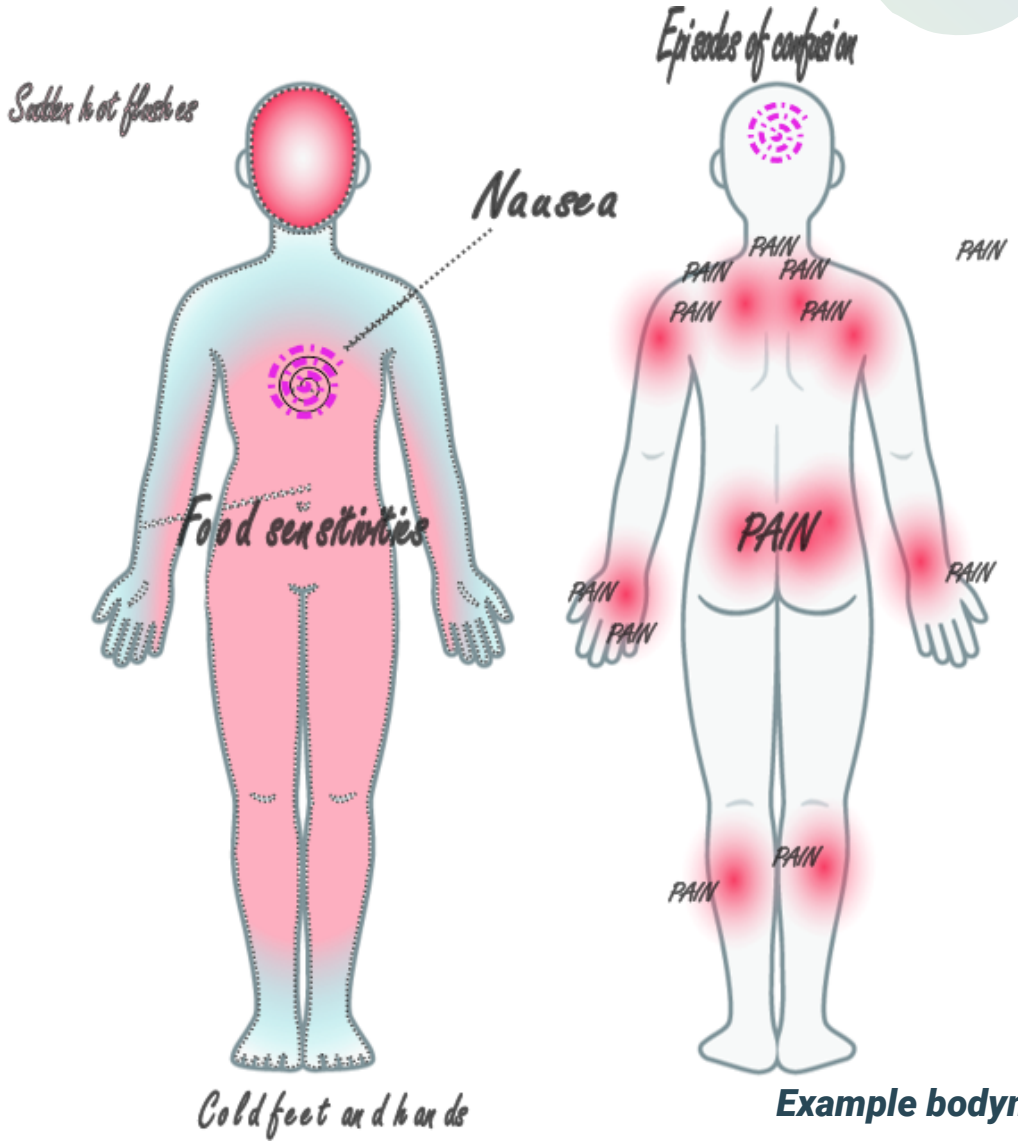
Perhaps you notice this as a sense of 'performance anxiety' before or after consultations, or that you find yourself spending lots of your appointments justifying that you are ill, and at the same time sane, responsible etc. Although usually not conscious, it can be helpful to recognise and interrupt this pattern. The need to prove either illness or blamelessness can hinder the healing process.

Being open, honest, and expressing vulnerability where you feel it, is usually a better strategy, but it can take time to establish this sort of trust.

5. Prepare to make the most of appointments

- **Know the reason for your visit and what you want to happen.**
- **Before your visit, write down 1-3 main issues or questions you want answered.**
- **If seeing a new team, it can help to bring a written summary.**
  This can include a timeline, with major life events, when symptoms started (and ended), diagnoses, treatments tried, and the impact of any treatments.
  If you are more of a visual thinker, it might help to sit down and draw a 'body map' of all your current symptoms (example below). You can show this to your healthcare provider, and use it as a prompt to make sure you don't forget to mention anything.
- **If the appointment is a follow-up it can help to keep a symptom diary for a week or two before your appointment.** You can show it to your healthcare professional to keep track of any progress, the impact of treatment or management strategies.
- **Bring someone with you**
  Have a conversation with them beforehand about what role you would like them to play at the appointment. For example, should they help you ask questions or take notes to help you remember what your provider tells you.

Bodysymptoms.



Example bodymap

Therapist tip.

You may have circumstances where you need to access a resource, support or benefit that is only available through healthcare. You might for example need a diagnosis to access social sickness benefits, or a doctor's note to approve time off work.

It is usually a good approach to be honest about this, if this is the main reason you have made a healthcare appointment. Being up-front saves both you and the professional time. Expect that you may need to be patient and respect the need for your healthcare team to complete a full assessment and follow any guidelines that they are required to follow when dealing with your case.

6. Don’t leave the appointment without a plan

You should expect to leave an appointment with a clear plan for the next steps. If the appointment is particularly busy or emotionally charged, it can be difficult to reach this point. It is always an option, 5 minutes before the appointment ends, to remind the healthcare provider that the appointment time is coming to its end, and it would be helpful to agree a plan together for the next steps.

- Write down the name and instructions for any new medicines, treatments, or tests.
- Also write down the instructions for any symptom management strategies instructions that are suggested (or where to find more information).
- Write down time-frames. I.e. how long should you try a medication/ symptom management strategy for before deciding it has worked or not.
- If you have a follow-up appointment, write down the date, time, and purpose for that visit.
- Know how you can contact your provider if you have questions.

Wherever you are in your healthcare journey, good luck.
We hope this guide has helped.

Some questions that you might find it helpful to ask at an appointment.

I think the symptoms are maintained by/related to (share your current working explanation)… But I am unsure about (…) What do you think?

Can you explain what the diagnosis means?

How certain are you about the diagnosis, are there any other investigations that are needed?

It is important for me that I am able to (…..share a goal)... Do you think this is realistic?

If a treatment is suggested:

- How long will it take for the treatment to work?
- What is the evidence for this treatment for my condition?
- What are the alternative treatment options?
- Why have you chosen this particular treatment?
- What are the possible side-effects - how common/ uncommon are they?
- Who should I speak to if I am having side effects?

Would psychological therapies be helpful?

Are there things I can do to help myself?

Do you have any information or materials you can recommend about conditions or treatments?

Do you know of any organizsations or services that could help?

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The rest of the document provides additional information in 4 appendices. This information might not be relevant for everyone but is included for for reference:

A) **An overview of diagnostic terms**

B) **Medications in functional disorders**

C) **Evidence Based mind-body therapies**

D) **Complementary and Alternative treatments**

Appendix 1: An overview of diagnostic terms

This table lists some of the labels and diagnostic terms that researchers consider refer to conditions characterised by functional symptoms.

Please note that some of the terms are contentious, and some are outdated. However, as they are all still used in some contexts, we include them for reference. We have indicated terms which we consider outdated or inaccurate with an asterisk*

Terms used to describe symptoms	**Functional** symptom or disorder e.g. 'functional bloating', 'functional neurological disorder'
	Persistent symptom e.g. 'persistent dizziness'
	Subjective symptom, e.g. 'Subjective shortness of breath'
	Chronic symptom e.g. 'Chronic widespread pain'
	Intolerance e.g. 'Systemic exertion intolerance'
	Sensitivity/hypersensitivity e.g. 'Reflux hypersensitivity'
	Dysfunction e.g. 'Dysfunctional breathing' or 'Temporo-mandibular dysfunction'
	Disorder e.g. Circadian rhythm disorder
	Dissociative symptom, e.g. 'Dissociative amnesia'
	Psychosomatic This is used to mean that both mind and body mechanisms are important.
	Centrally mediated e.g. 'Centrally mediated abdominal pain'
	***Medically unexplained** This is usually used to mean symptoms where medical investigations are normal.
	***Idiopathic** e.g. 'idiopathic overactive bladder'
	***Non-**organic e.g. 'non-epileptic attacks'
	***Psychogenic** symptom, e.g. 'psychogenic palpitations'
Functional somatic syndromes (Refers to defined clusters of symptoms, usually by organ system)	**Irritable Bowel Syndrome** (IBS)
	Fibromyalgia (FM/FMS)
	Multiple chemical sensitivity
Related to cause	**Post- '**disease/treatment' symptom, e.g. Post-chemotherapy fatigue; post-viral fatigue; Post-concussion syndrome; Post-traumatic complaint
	Chronic- 'name of infection or injury' e.g. Chronic Lyme/ Chronic Epstein Barr; Chronic Whiplash
	Repetitive **strain/overuse** injury
	Stress-related symptoms e.g. stress headache
Related to mechanism	Dissociative disorder
	*Conversion disorder
	Bodily stress

	(Disorders of) central sensitisation
	Disorder of brain-gut interaction
	Myofascial pain
	Microvascular, e.g. 'Microvascular Angina'
	Hyperventilation syndrome
Specialty specific	
Gastro-intestinal	Cyclic vomiting syndrome; Proctalgia fugax; Levator ani syndrome
Urological	Irritable bladder; Urethral syndrome; Shy-bladder; Interstitial cystitis; Fowler's syndrome; Hinman Syndrome
Neurological	Allodynia; *Stroke mimic; Tension type headache; Dysautonomia
ENT (Ear, nose and throat)	Glossalgia; burning mouth; bruxism; Persistent postural perceptual dizziness; tinnitus, globus
Cardiology/Respiratory	Orthostatic hypotension (POTS); Hyperventilation syndrome
Psychiatry	Bodily Distress Disorder (ICD-11); Somatic Symptom Disorder (DSM-5); *Somatoform (ICD-10), *Somatisation (Primarily used by psychologists)
Endocrinology/general	Adrenal fatigue, burn-out, pre-menstrual tension; *Neurasthenia/neuromyasthenia;

Appendix 2: An overview of commonly prescribed medications in functional disorders

Antidepressants

Duloxetine (an SNRI) and **Amitriptyline or Imiprimine (TCA/Tricyclics)** are types of antidepressants. There is reasonable evidence this group of medications can help functional symptoms, and they are commonly prescribed. These medications are thought to work centrally on the nervous system, to dampen down pain signalling, and boost neuroplasticity.

You usually need to take Antidepressants 2-6 weeks before they give full therapeutic effect. This is probably because they work through re-wiring neural pathways, which takes some time. It is helpful to undergo therapy or lifestyle changes alongside anti-depressant treatment, as this ensures the neural networks rewire in a helpful direction.

Sedatives and opioids

For syndromes characterised by chronic pain and central sensitisation, use of opioids and sedatives is **generally not recommended,** as although they provide short term relief, they increase sensitisation over time. T

his includes benzodiazepines., like **Diazepam.** Benzodiazepines have short-term muscle relaxant effects, so are sometimes prescribed for short term use when there is acute pain related to muscle spasms. It is easy to develop tolerance to these medications, so longer term use (for example anything above 3 days) is not recommended.

Peripherally (locally) acting medication

Overall, there is **little evidence** that peripherally acting molecules, such as **nutritional supplements, botulinum toxin, locally acting pain medication,** medications that interact with the immune system, like **anti-histamines,** or **antispasmodic medications,** make a difference to functional symptoms in the longer term. So although some individuals may get some **symptomatic relief** from such approaches, they should not be relied upon as a curative treatment.

Appendix 3: Evidence based mind-body therapies

Psychological treatments

A range of psychological approaches to therapy are known to help with functional symptoms. The main types of psychological therapy you might come across are described below.

Cognitive behavioral therapy (CBT)

CBT helps you become aware of your core beliefs and automatic thoughts. It helps you map out how these unconscious thought habits play into your behavior and experience. CBT usually involves setting up mini experiments to try out different responses in your day-to-day life, which helps your brain update unhelpful thought-behavior-experience loops.

Acceptance and Commitment Therapy (ACT).

ACT recognizes that our inner experiences (like thoughts, feelings or bodily sensations) are not under our direct control. ACT focuses on learning practical skills to relate to these experiences. The aim of therapy is to feel empowered to move away from control and avoidance as coping mechanisms, and move towards more acceptance and values-based responses.

Compassion focused therapy (CFT)

CFT was developed after it became clear that traditional CBT didn't work so well for people who had difficulties with self-criticism or feelings of low self-worth. The general idea is, if you feel a lot of shame, guilt, or negative self-talk, you might know all the right things to think and do, but you don't really believe that you deserve to get better. CFT therefore focusses on learning to relate to and speak to yourself with unconditional kindness and care.

Psychodynamic therapy

Psychodynamic approaches have been used for a long time in the treatment of functional disorders. Psychodynamic therapy is based on the idea that we repeat certain unhelpful patterns often without realizing what these are. The therapy itself provides space for these unconscious patterns to become clear, often through observing how the relationship between therapist and client evolves. Traditional treatments can be quite intensive and have the downside of taking a long time, which makes treatment expensive. Shorter, more structured forms of psychodynamic therapy for functional symptoms are currently being researched.

Emotional expression and awareness therapy

This approach pays special attention to emotional mechanisms, helping people to identify emotional responses in their bodies, and experience directly how emotional patterns effect symptoms. This awareness is the foundation for being able to be present in the body, develop interoceptive accuracy, and build a toolkit of emotional regulation skills that can also be helpful in symptom management.

Group therapy

Although not suitable for everyone, group therapy can be especially helpful for people with functional symptoms. The connections with others and the support this can offer, can be very beneficial during the recovery process. Group therapy might be based on one or more of the approaches above, or combine a mixture of approaches. Some groups combine education about the mechanisms of functional symptoms with more active exercises that allow participants to test out moving beyond current limitations in a supportive environment.

Physical Therapies

Exercise training/Physiotherapy

Movement remains one of the most powerful routes by which we can bring more freedom and ease to our bodies, and at the same time boosting neuroplasticity to bring about change in neural circuits. Additionally, exercise helps many functions of the body. For example, movement can regulate the circadian rhythm, the autonomic nervous system, the metabolism and the immune system. It is important to stress that, in illness, exercise training needs to be carefully tailored to your current symptoms and level of fitness, and build in intensity gradually, giving your body time to adapt.

Hydrotherapy/Balneotherapy

Hydrotherapy is another treatment that has been used for its health benefits for hundreds of years. It involves combinations of hot and cold water applied at various temperatures, pressure, duration, and site. Like exercise, hydrotherapy is a treatment that effects the functioning of the body in a range of ways, it can stimulate the vagus nerve, boost the immune system, and help with relaxation.

Psychomotor therapy (PMT)

Psycho-motor therapy is an experiential movement and body-orientated approach to therapy. It has strong traditions in some European countries, where it is integrated in the healthcare systems. It is most common in the Netherlands, Belgium, Denmark, Norway and Portugal. In PMT, the immediate experience is used as a basis to find new possible behaviors, cognitions and emotions.

Relaxation techniques

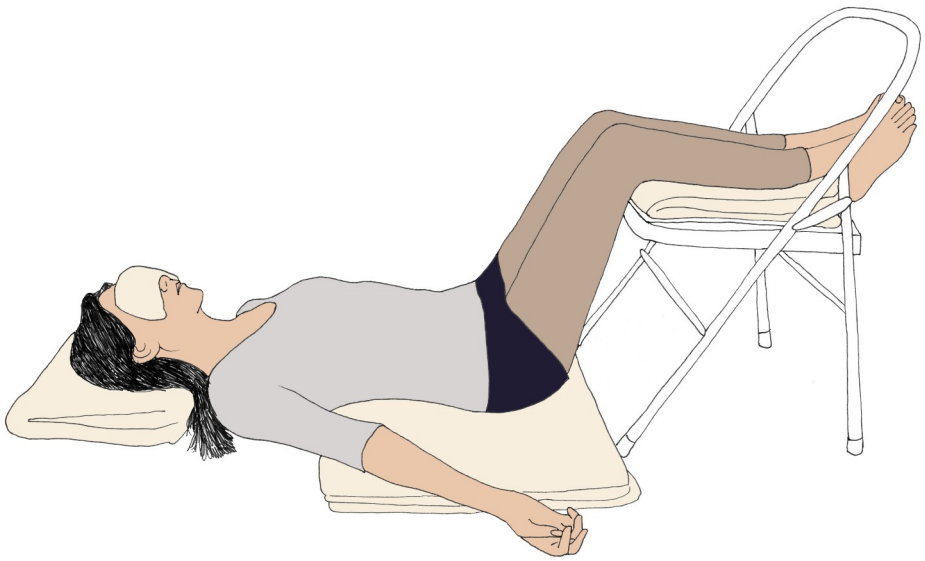
Relaxation techniques are helpful tools for coping with stress and promoting long-term health by regulating the body's autonomic nervous system and quieting the mind. There is good evidence that learning to relax the body helps with symptoms from various systems. For example, it is the most effective mind-body treatment for immune-related symptoms. Relaxation techniques are often incorporated into other therapies, like physiotherapy or psychological therapies. However, you might also be offered relaxation training as a standalone treatment, often as part of a group.

Mindfulness-based therapy

Mindfulness-Based Stress Reduction (MBSR), an approach based on a Buddhist meditation practice, is now used widely to relieve stress and enhance wellbeing.

Biofeedback

Biofeedback is the name for technology-assisted approaches to training interoceptive abilities. This can help you to learn techniques to self-regulate on a physiological level.



Hypnotherapy

Hypnotherapy uses an altered, relaxed state of mind resembling sleep, but one in which people can still concentrate, to help them change their awareness and intentions. In hypnotherapy, the therapist uses suggestion to put you into a trance. Hypnotherapy is often used to help people change habits and reduce pain and stress.

Massage therapies

Massage therapy has been practiced as a healing therapy for thousands of years in nearly every culture around the world. It helps relieve muscle tension, reduce stress, and evoke feelings of calmness by using touch to influence the activity of the musculoskeletal, circulatory, lymphatic, and nervous systems. Gentle types of massage are usually a better idea than deep massage, if you have been ill shortly before. Deep massage can set off so much in the various circuits that a lot of waste products that have been stuck are suddenly released. It can be hard for the body to suddenly have to process all at once. Manual lymphatic drainage, and myofascial release are approaches that can use slightly deeper (carefully applied) pressure, that can be helpful in functional disorders.

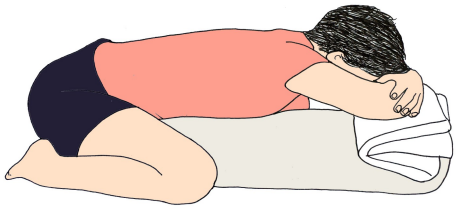
Self-massage

Self-massage is also a very good option, as it can bring many of the benefits of massage, but is free, available any time, and has the added benefit that you are able to control the pressure and can be sensitive to how deep to press. Tactile-induced catalepsy is a self-massage technique taught to patients in some specialist clinics, and is helpful in managing functional movement problems, like rigidity, tremor or problems walking. Hand and forearm massages can be very grounding for people who dissociate, and there are many other pressure points which can be used to relieve various symptoms, from pain to nausea. If you are starting out, the Kum Nye self-massage system is easy and safe to learn at home.
Kum-Nye: Tibetan Yoga, A Complete Guide to Health and Well-Being, 115 Exercises & Massages (2007)

Yoga therapies

Yoga uses physical postures, breathing exercises, chanting and meditation to improve health and wellbeing. Yoga has been used for healing in Ayervedic medicine for at least 6000 years. This means that there is a lot of accumulated knowledge about specific sequences of exercises can be helpful to manage particular symptoms or bodily conditions.

Western science has confirmed the effectiveness of yoga therapy for various functional conditions. However, it should be noted that yoga therapy should be carried out by an appropriately trained and experienced practitioner. Many 'high-street' (or online) yoga classes may be unsuitable for people with functional symptoms, as some exercises will need adapting to be carried out beneficially.



Appendix 4: Complementary and Alternative therapies

Acupuncture is a treatment within traditional medical systems. Acupunturists might be trained according to different traditions (for example Chinese, Japanese or Ayervedic). At the core of acupuncture is the notion that energy (or qi) flows through pathways (meridians) in the body. The proper flow of energy is thought to create health. Inbalances (too much, too little or a blocked flow) result in disease. Acupuncture needles are inserted at points along the meridians to restore balance and flow of the qi.

Ayurveda is the Sanskrit word for the science of life. Ayurveda is considered the oldest healing science and has been practiced in India for more than 5,000 years. The basic principle of Ayurveda is the prevention and reversal of chronic illness by maintaining balance in the body, mind and spirit through proper diet and lifestyle habits. It also uses yoga and massage therapies, and various herbal treatments.

Breathwork There are a variety of techniques through which you can learn to use patterned breathing to promote particular physical effects, including symptom relief and relaxation.

Dance/movement therapies use expressive movement as a tool for personal expression and emotional healing.

Feldenkrais

Feldenkrais is a therapeutic method involving gentle mindful movement based on principles of biomechanics, psychology, motor development, martial arts, and re-connection with how the body moves and develops. Feldenkreis can be delivered as a 1:1 therapy, or as a group.

Kum Nye

Kum Nye is a form of healing yoga from Tibetan traditional medicine. It is a therapeutic yoga and therefore is very accessible. It can be practiced safely by most people, including older people, and people who are unwell. Kum Nye works through interoception, breathing exercises, mindful movement, physical self-massage; and attention.

Meditation

Meditation refers to a myriad of practices that relax the body, calm the mind and help train attention. It can take a little time to find an approach that helps your mind settle. Repeating mantras (prayers or hymns), or using guided imagery or visualization, are types of meditation that might work for you.

Mindfulness meditation usually involves getting present, by observing an object: typically the breath, sensations in the body, or sights or sounds around you. As you develop your meditation you will be able to observe the mind itself, and see the patterns by which your thoughts and emotions come and go. This skill can help you not get caught up in thought patterns that might be involved in cycles that maintain symptoms.

You don't have to sit still to meditate. Walking/moving forms of meditations might suit you better than seated meditations if you are restless in the body. You can even meditate whilst you do the washing up.

Nature Therapy

Nature therapy takes advantage of the fact that our "primal" brains and bodies naturally respond powerfully and positively to natural environments. If you are confident enough, you can carry out your own ‘nature therapy’ by finding beautiful and peaceful places to visit, whether you prefer walking, bird-watching, mushroom hunting, wild-swimming, or forest-bathing. The "nicer" nature the better. For example,we like water, viewpoints and a lot of green because these are things that signal to the brain that this is a good place in terms of resources or safety.

Maria's Experience

When interacting with nature, it makes the most sense to take your time and not rush through the trip. It's also good to notice what's around you, and walks where you collect from nature's bounty, e.g. berries/fruits/mushrooms, can really get the brain away from complicated thinking and back to something that suits the human body.

Osteopathy

Osteopathy is an established system of complementary medicine that emphasizes the interrelationships of structure and function and works with the body’s ability to heal itself. Its underlying philosophy is to treat the whole person, not just the person’s symptoms.

Traditional Chinese medicine (TCM)

TCM is a complete medical system that has been used to diagnose, treat and prevent illnesses for more than 2,000 years. TCM is based on a belief in yin and yang (opposing energies), such as male and female, winter and summer, and happiness and sadness. When yin and yang are in balance, a person is energized. Out of balance, however, yin and yang negatively affect health and well-being. In TCM, this state of balance is achieved through the use of multiple approaches, including herbal medicines, acupuncture and qi gong.

Tai Chi

Tai chi is a gentle exercise program derived from the martial arts. A traditional Chinese medicine practice, tai chi is composed of slow, deliberate movements, meditation and deep breathing, which enhances physical health and emotional wellbeing.