What is functional cognitive disorder?

Functional cognitive disorder is a problem with memory or concentration that happens when the brain doesn’t work or function as we need it to. Functional cognitive symptoms are not caused by disease or damage to the brain, but they are coming from the brain.

What sort of problems do people with functional cognitive disorder have?

- Losing track while doing things – for example, walking into a room and forgetting what you went in there for
- Going ‘blank’ – for example, finding you suddenly can’t recall a PIN or phone number
- Mental fuzziness, sluggishness, or mental fatigue
- Losing track during conversations
- Frequently misplacing things like your keys or phone
- Forgetting periods of time even though you have kept going, on ‘autopilot’
- Forgetting details from films, books, or past holidays
- Forgetting a word that seems on the tip of the tongue

Some people may have relatively mild functional cognitive symptoms, sometimes alongside other health problems. For other people, memory symptoms are the main problem that affects their day-to-day life, and the term functional cognitive disorder is used. Functional cognitive symptoms can be frightening. They can make normal activities like working and socialising much more difficult.

Some people are concerned that their problems might be caused by a type of dementia, like Alzheimer’s disease, or might be related to damage after an injury.

Deciding whether someone’s memory and thinking problems are the result of brain disease or damage, or whether they are functional cognitive symptoms, requires careful assessment. However, it is possible to make a confident and accurate diagnosis of functional cognitive symptoms. Having a definite diagnosis can help people find ways to improve their symptoms.

This factsheet is designed to help share what we know about this condition and to give you some ideas to help make sense of what is going on.
How common are functional cognitive symptoms?

Functional cognitive symptoms are common. However, until recently doctors have described them using a lot of different terms, which can be confusing.

A study of patients attending memory clinics with suspected dementia found that 24% were most likely to have functional cognitive symptoms, rather than dementia

Functional cognitive symptoms can occur on their own. They are very common in people with other symptoms of functional neurological disorder (FND). FND is the name of a condition where people have a variety of neurological symptoms such as limb weakness or blackouts which are genuine and arise from a similar problem in nervous system functioning. They are also common in people with painful conditions, like fibromyalgia, and in conditions where people have severe fatigue. They can also be accompanied by anxiety and depression or sometimes be part of it. We will discuss this more later on.

What causes functional cognitive symptoms?

Functional cognitive symptoms can happen for several different reasons. Often, more than one underlying cause is present.

Functional cognitive symptoms can come ‘out of nowhere’, but can also start after an injury or traumatic event. Head injury or mild traumatic brain injury (sometimes called concussion) is a common trigger.

Most things that cause functional cognitive symptoms do so by interfering with a set of brain processes called attention.

One way to think about attention is as a spotlight, directing our brain’s processing capacity towards important information or the task at hand.

Another way of thinking about attention is as a filter which blocks out irrelevant or distracting information.
Although our capacity to learn and store information is enormous, our attention is limited. We can only focus on a small amount of the world at one time. If you cannot focus attention on new information, you won’t be able to learn and remember that information.

**Examples of things that can interfere with attentional focus:**

- Physical symptoms
- Pain
- Sleep problems
- Stress
- ‘Software errors’, e.g. getting stuck in involuntary thinking loops
- Experience of an injury or stressful event
- Medication

Some people become concerned about memory lapses that are common even in healthy people. Some worry that their memory problems are the first sign of dementia.

Watching out for memory problems causes a shift from using your memory in a normal, automatic way, to an effortful and tiring way. Involuntary activities like worrying about your memory, spending time thinking about or checking how well your memory is working, or using a lot of notes and lists, can all use up attention.

*All this effortful cognitive activity creates a vicious cycle which actually causes more memory problems*

This diagram shows how in functional cognitive symptoms, a switch from ‘automatic’ to ‘effortful’ thinking causes a vicious cycle, using up attention and causing more memory and concentration problems.
How is the diagnosis made?

The diagnosis is usually made by a psychiatrist, neurologist, or neuropsychologist.

The most important part of making the diagnosis involves finding out all about your symptoms.

People with functional cognitive symptoms can often give detailed description of the problems they have been having.

Hearing from other people who know you well can help. Often (not always) people with functional cognitive symptoms are more worried about their memory than other people are.

Cognitive tests are often used by doctors and psychologists to try to measure how serious memory problems are. Some people with functional cognitive symptoms do as well as normal healthy people in cognitive tests. However, some people with functional cognitive symptoms struggle with tests and can score quite poorly.

What’s the difference between functional cognitive disorder, dementia and “mild cognitive impairment”?

Although the symptoms of functional cognitive disorder and dementia may seem similar, they have different causes. In dementia, memory symptoms are the result of damage to the brain areas involved in memory, as result of progressive brain disease. In functional cognitive disorder, symptoms arise from changes in brain processing, and not due to damage or disease of the brain.

“Mild cognitive impairment” or “MCI” is a term which is sometimes used by doctors to describe patients with cognitive problems who don’t have dementia, but who may be at higher risk of developing dementia in future. However, “mild cognitive impairment” is only a description of symptoms and difficulties, and not a diagnosis of any specific disease.

Importantly, some people with functional cognitive symptoms might also be told that they have “Mild cognitive impairment”, especially if they struggle with memory tests. But people who doctors can clearly identify as having functional cognitive symptoms are less likely to develop dementia in the future than some other people with mild cognitive impairment.

It is really important for functional cognitive symptoms to be identified. This is because this changes the information that doctors will give you about your future risk of dementia, and because specific treatments might also be available that will help to improve your symptoms.
Am I imagining it?

Functional cognitive symptoms are real. They are not “put on”, “imagined” or “all in the mind”.

For some people, depression or anxiety can be an important factor that may contribute to the development of functional cognitive symptoms. Even for people who are not depressed or anxious in general, worries about the cognitive symptoms can worsen their symptoms and make it harder to recover. Many people with functional cognitive symptoms are not depressed or anxious, but it is important to recognise depression and anxiety when they are also present, as treating these problems can help the symptoms to improve.

You may worry that friends, family or health professionals think your symptoms are “all in the mind”. Functional cognitive symptoms are real, not imaginary.

Do you have confidence in the diagnosis?

It is essential that you feel you have the correct diagnosis. If you don’t, it will be hard to put into practice the self-management strategies suggested here.

If you don’t feel you have functional cognitive symptoms, you need to look at on what basis the diagnosis has been made. Usually it will be because the pattern of your symptoms matches the typical features of this condition. You do not need to be stressed to have functional cognitive symptoms. Perhaps the diagnosis didn’t make sense to you because the doctor suggested it was “stress related”? There may have been a misunderstanding if that was the case. We know that some patients do have stress as a cause of their symptoms, but many don’t. So, whether you have been stressed or not is not relevant to the diagnosis.

If necessary, go back and speak to the person who made the diagnosis. Find out why they made it and see if you can gain more confidence in it.
Self-help strategies

1. **Information**
   The first step in managing any symptom is to understand it better. Reading this factsheet is the first step. The more you understand why your memory isn’t working, the more you may be able to develop ways of coping better with memory lapses. If you have other neurological symptoms that are part of the same functional neurological disorder, reading about that on the neurosymptoms.org website may help you make more sense of what has happened.

2. **Manage any worsening factors**
   It is important to identify any factors that could be making your symptoms worse, so that you can try to change them where possible.

- Are you on any medication that could worsen cognitive symptoms? Many types of medication, especially painkillers, and sleeping tablets, can worsen memory symptoms. If so, ask your GP or consultant to review whether these could be adjusted.
- Is your sleep pattern good? If not, try to follow “sleep hygiene” advice to improve this. Exercise can also improve our sleep and general well-being.
- Do you have any depression or anxiety symptoms? If so, ask your doctor if you might benefit from treatment for these.
- Are you living with chronic pain? If so, you might benefit from learning pain management strategies. You could ask your doctor if there is a pain management programme in your area that you could be referred to.
- Do you have a healthy pattern of activity? People living with functional neurological disorder (including cognitive symptoms) sometimes get into a “boom and bust” pattern. This is where they push themselves so hard on good days that they then feel much worse for several days afterwards. It is better to try to “even out” your activity by doing a bit less on good days but a bit more on bad days. Once you have achieved this you can very gradually start to build up your levels of activity.
3. Keep in mind that memory lapses and forgetting are a part of normal experience

It is important not to set abnormally high standards for your memory. Lapses in memory, short gaps where we have been on ‘autopilot’, and forgetting names or unimportant details about past events are all entirely normal experiences. People who rely on their memory and concentration functioning at a very high level may be more likely to notice or feel worried about small lapses.

We asked 127 healthy young adults (average age 27) how often they experienced a range of memory lapses

At least once a week:

- 57% had difficulty finding a word
- 51% went into a room and forgot what they had gone in for
- 47% forgot to buy something when shopping
- 35% forgot an important conversation, an appointment, or an errand
- 28% forgot an important PIN or phone number
- 16% had a memory gap when they had been ‘autopilot’

4. Keep using your memory

Understandably, some people with functional cognitive symptoms start to avoid the tasks they find difficult. For instance, they might ask a family member to take over doing the shopping so that they don’t forget any items. Or they might avoid talking to groups of people because they are afraid of struggling to find a word in conversation. Usually this isn’t a helpful coping strategy in the longer term.

The more you can use your memory in ordinary situations, the more easily your brain can return to normal cognitive processing

Using memory aids, like writing lists and using alarms on your phone can be helpful for specific tasks. But try not to become too reliant on these, as it is better to use your memory in as close to a normal way as possible. Sometimes keeping lists etc can use so much attention that it can actually make the cognitive symptoms worse. You might need help to make fewer lists and become more confident in using your memory.
5. **Learn to change your own ‘automatic thoughts’ about your memory**
   
   Try to start noticing the automatic thoughts that spring to mind when you forget something or make a mistake. Challenging these thoughts can help your memory start to work in a more normal way.

   For example:

   **OLD THOUGHT**

   - Oh no! I’ve forgotten the name of that person I bumped into on the street who I hadn’t seen for 18 months
   - I ought to be able to remember a full shopping list without having to write it down
   - I must be getting dementia – these memory problems are getting worse every day
   - My brain isn’t working properly – I should rest it so I don’t cause more damage

   **NEW THOUGHT**

   - It’s very normal to forget names. Few people can remember everyone’s names easily
   - That isn’t normal at all! Few people can remember a shopping list without writing it down
   - People with dementia usually notice their symptoms less than others. Being so aware of memory problems makes it much less likely that I have dementia
   - Using my memory and trying to concentrate on things will help to train it to work normally again and can’t do any damage to my brain

**Further treatments**

Although some people can find these self-help strategies useful, we know it we know that it is often hard to make progress on your own without guidance. At the moment, we don’t have much evidence about what is the most effective treatment for functional cognitive disorder. We know that Cognitive Behavioural Therapy (CBT) can help people living with other persistent physical symptoms, like pain and fatigue. It may well be that this form of therapy could also help with functional cognitive symptoms, but we have more to learn about that.

It is not your fault if you can’t get better by using self-help, and it doesn’t mean you can’t recover. Some neurology or neuropsychiatry departments might be able to refer you for CBT. Ask the doctor looking after you what further treatments might help in your particular case.
Looking at the bigger picture

In some people, functional cognitive symptoms are part of a ‘bigger picture’ of ill health. Some people with functional cognitive symptoms also have other symptoms of functional neurological disorder (FND). Functional neurological disorders are common conditions which are the result of abnormal functioning of the nervous system rather than nerve damage (software, not hardware).

Some people with functional cognitive symptoms might also have anxiety, depression, or post-traumatic stress disorder. Sometimes depression and anxiety is a consequence of the stress of the condition itself.

Functional cognitive symptoms are common in chronic pain conditions such as fibromyalgia and complex regional pain syndrome.

Functional cognitive symptoms are also common in people with ‘post-concussion syndrome’ after a head injury. These people might also have problems with headaches, dizziness, and sensitivity to light and sound.

Many people who have functional cognitive symptoms have NONE of these other health problems so please don’t be put off if this section doesn’t apply to you. But if it does, it may be worth spending time with a health professional, such as clinical psychologist, neurologist or psychiatrist who understands these disorders to try and put things together for you.
Case Study 1: Josh

Josh is 28 and works as a teaching assistant in a special needs school. At work, he was accidentally hit on the head with a table that another staff member was moving into the hall. He was not knocked out, but felt dazed for several minutes after the injury.

For the next few days, he noticed headaches, dizziness and poor concentration. He was sensitive to bright lights and felt extremely tired. He took some time off work to rest. Over the next few weeks, the dizziness went away, his headaches reduced, and he was able to get back to work.

Back at work, he continued to struggle with his memory and concentration. He had previously had an excellent memory, but now found he was forgetting tasks unless he kept a list. After talking to a colleague, he would often realise that he had forgotten most of the details from their conversation. He sometimes called the children in his class by the wrong name, even though he knew them well. He had a sense of “brain fog”, as though he wasn’t quite himself. His thinking was slower, and everything seemed like more of an effort.

The symptoms were worse on days when he had slept badly, or had a headache, but he never felt completely well. By the time he got home from work every day he felt exhausted.

He found these difficulties very frustrating, and was worried about whether he might have damaged his brain in the accident. His GP told him the symptoms could be due to stress or depression, but he liked his job and did not feel depressed.

Josh saw a neurologist who explained that his symptoms were typical of functional cognitive disorder. He was surprised as he had been concerned that his memory problems had been caused by brain damage and might never improve. The neurologist explained that pain and poor sleep interfered the brain’s ability to focus. He got some helpful tips from a leaflet about improving his sleep. When they looked together at Josh’s activities, they noticed that he tended to ‘overdo it’ on the days when he felt ‘ok’, and this left him exhausted. Josh spoke to the school and negotiated some changes in his hours and responsibilities so that he could gradually build up his activity level at work without this “boom and bust” pattern. Over time Josh’s energy levels improved everything started to feel a bit easier. He still sometimes called children by the wrong name, but he noticed that everybody did this sometimes and he no longer felt worried or embarrassed when it happened.
Case Study 2: Jean

Jean is a 63 year old woman. She has had a hard few years caring for her mother, who died 6 months ago with Alzheimer’s dementia.

She first realized that something was wrong about 3 months ago, when she was at the bank machine and couldn’t remember her pin number. This had never happened before.

She started to ‘drift off’ during conversations and sometimes couldn’t remember things that her husband insisted that he had already told her. She began using a lot of lists, and notes, and reminders on her phone, as she felt sure that she was going to miss an appointment. If it hadn’t been for this, she felt sure she would have missed some appointments.

Every day, Jean would find that she had walked into a room and forgotten what she was there for.

Although Jean had never got lost when out of the house, she started to worry that this might happen. When she told her husband, he suggested that he should do the driving and that it would be better if they only went out together.

After letting a pan boil dry one evening, Jean stopped cooking and started to buy microwave meals instead, in case it happened again.

With everything that was going on, Jean was sure that her symptoms were the first sign of Alzheimer’s disease. She had trouble getting to sleep and would lie awake for hours worrying about the things she had to do the next day, and about how her family would manage as her dementia got worse.

Jean went to see her doctor but did not tell her family that she thought she had dementia as she didn’t want to worry them. It was stressful when the doctor asked her to do memory tests. Her doctor referred her to the memory clinic, where the psychiatrist told her that she did not have dementia. Jean did not feel reassured by this as she knew that something was very seriously wrong with her memory.

However, after another appointment to talk things over with the psychiatrist, she started to notice times that her memory was working very well. She also started to notice when her mind was starting to wander and worry so that it was hard to take information in. She stopped using so many notes and lists – she made a few mistakes with the shopping but not nearly as many as she expected. Jean started seeing her friends again and stopped planning for the worst, although she still sometimes worried about getting dementia in the future.
Further information

**www.headinjursymptoms.org**

Functional cognitive symptoms sometimes start after a head injury. This website contains information and advice about managing symptoms after head injury.

**www.neurosymptoms.org**

This website explains more about functional disorders and functional neurological disorder (FND) in particular, if that is relevant to you. There is also a “patient story” from someone with functional cognitive disorder.

**www.good-thinking.uk**

An NHS approved well-being service, with helpful information and resources on topics like sleep, stress, anxiety and low mood.

For a review of Functional Cognitive Disorder – see


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