MANAGEMENT FILE

by DR CHARLES SHEPHERD, our medical adviser

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STOMACH AND IRRITABLE BOWEL SYMPTOMS

BACKGROUND

A significant proportion of people with ME/CFS report that they also have stomach and bowel symptoms very similar to those found in irritable bowel syndrome (IBS). This Management File looks at those symptoms, how they should to be investigated, and what treatments are available.

SYMPTOMS

Symptoms that are suggestive of what doctors term irritable bowel syndrome (IBS) include:

- Abdominal pain, colic or discomfort – which is often located in the left lower abdomen and is typically relieved by having a bowel movement. This type of pain can also be triggered by eating.
- Bloating and stomach distension – often worse after meals, increases during the day and disappears overnight.
- Change in frequency or form of bowel habit. This can be either towards constipation - which is termed IBS-C; diarrhoea – which is termed IBS-D; or a mixture of both, which is termed IBS-M.
- Urgency – a sudden urge to have a bowel movement;
- A feeling of incomplete emptying and/or the passage of mucus.
- Non-bowel symptoms may include backache, gynaecological symptoms – painful periods/dysmenorrhea or pain during sex/dyspareunia; and urinary symptoms – urgency to pass urine, passing urine during the night.

Around 10% of population have IBS symptoms. They quite often occur in ME/CFS but do not form part of the list of key symptoms in most of the criteria that are used for diagnosing ME/CFS.

This is important because having symptoms such as abdominal pain, bloating, or a change in bowel habit may indicate that a completely separate gastric or bowel disorder is present.

Coeliac disease is a classic example of an illness that can present with chronic fatigue and irritable bowel-type symptoms and is sometimes misdiagnosed as ME/CFS.

Other possible explanations include an inflammatory bowel disease (IBD) such as Crohn's disease or ulcerative colitis, a chronic bowel infection such as giardia, lactose intolerance, or more rarely a problem outside the bowel such as ovarian cancer.

Some people with ME/CFS also experience nausea (feelings of sickness). Nausea is not a key part of IBS and there may be another explanation.

WHAT CAUSES IBS SYMPTOMS?

Unfortunately, from the point of view of treatment, there is no simple answer. The most likely explanation is that a number of factors, which may overlap, are involved.

Firstly, there are control centres in the brain that pass messages by way of what is called the autonomic nervous system to the heart, bladder and intestines. These messages either slow down or speed up the function of these organs. In the case of irritable bowel symptoms, disturbances in the way that nerves controlling the activity of the muscles in the bowel wall that propel food along may be partly responsible for symptoms such as colicy pain or changes in bowel habit – constipation or diarrhoea.

There is also a control centre in the brain for vomiting – so a disturbance here may account for why nausea is occasionally a very disturbing feature of ME/CFS.

Any form of stress or anxiety will affect these control centres, and this mind-body connection helps to explain why irritable bowel symptoms are often exacerbated during a period of stress or relapse.

Secondly, chemical transmitters in the bowels may be disturbed in IBS. One chemical in particular is serotonin – which is present in abundance in the gut. Changes in serotonin status have also been reported in ME/CFS.

Thirdly, there may be a disturbance in the membrane lining the bowel and the bacteria that are naturally present inside the bowel. This is particularly so where food allergy/intolerance is playing a role, or where irritable bowel symptoms clearly follow an episode of gastro-enteritis.

There is also evidence that antibiotics can trigger IBS and exacerbate pre-existing IBS.

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WHEN SHOULD YOU SEE YOUR DOCTOR?

If you have IBS-type symptoms, this should always be discussed with your GP to start with.

Symptoms that are not consistent with IBS, or suggest the possibility of another explanation, include:

- ❍ Family history of inflammatory bowel disease (IBD), colon or ovarian cancer.
- ❍ Symptoms suggestive of inflammatory bowel disease: mouth ulcers, eye irritation, joint pains.
- ❍ Fever.
- ❍ Weight loss.
- ❍ Severe or progressive abdominal pain.
- ❍ Persistent stomach bloating or distension – especially in women over the age of 50, where this could be a sign of ovarian cancer.
- ❍ Signs of food malabsorption.
- ❍ Persistent or nocturnal diarrhoea.
- ❍ Persistent loose bowels if you are over the age of 50.
- ❍ Bleeding from the back passage.
- ❍ Blood test showing any sign of anaemia.

Any of these symptoms or signs indicate the need to carry out a more detailed assessment and investigation.

INVESTIGATING IBS

If there are no clinical clues pointing to other possible explanations, investigations are normally limited to:

- ❍ Full blood count – to make sure there is no sign of anaemia.
- ❍ Thyroid function tests;
- ❍ Blood calcium level (to exclude hypercalcaemia).
- ❍ ESR or CRP (C reactive protein) test – to help exclude inflammatory bowel conditions. A raised platelet count is also suggestive of inflammation.
- ❍ Anti-tissue transaminase antibody test – to help exclude coeliac disease.

Other tests that may be necessary include:

- ❍ Stool test for infections such as giardia – a potentially chronic bowel infection, especially if you have been overseas.
- ❍ Stool test for blood (faecal occult blood).
- ❍ Blood test for ovarian cancer – the CA125 test – where this needs to be excluded. This can be arranged by a GP.
- ❍ Two new tests – faecal calprotectin (measures white blood cells in the gut) and lactoferrin – may help to distinguish IBS from IBD.
- ❍ Testing for lactose (in milk) intolerance.
- ❍ Colonoscopy for persisting diarrhoea.

HOW CAN IBS SYMPTOMS BE MANAGED?

As with ME/CFS, management of IBS is mainly based on trying to alleviate individual symptoms through a combination of approaches that may include diet, drugs (over the counter and prescription) and non-drug treatments such as hypnotherapy.

Once the diagnosis has been confirmed by your GP, mild symptoms can often be self-managed. If your GP requires further help with either diagnosis or management, you can ask for a referral to a hospital gastro-enterologist – who will be seeing plenty of people with IBS.

Irritable bowel symptoms often settle down over the course of time but have a tendency to return at a later date. Reassuringly, there is no link with cancer or serious bowel disorders.

IS IT WORTH CHANGING YOUR DIET?

When doctors first recognised IBS, they believed it was mainly due to lack of fibre in the Western diet. Consequently, people were advised to increase the amount of fibre in their diet by eating plenty of wholemeal bread, cereals and pasta, etc.

While this approach helped some, others found that increasing insoluble dietary fibre, especially bran, just made their pain, bloating, and bowel symptoms worse. So any change in dietary fibre needs to be carried out gradually over a few weeks to give the bowels time to adjust.

Increasing soluble fibre (eg oats) may help some symptoms and removing/decreasing insoluble fibre (such as wholemeal bread and high bran cereals) may help with diarrhoea and bloating.

With evidence that food intolerance/sensitivity plays a role in somewhere between one-third and two-thirds of people with IBS, it may be worth trying what is known as an exclusion diet.

This involves removing one of a list of possible 'culprit' foods on a rotating basis, as well as keeping a food diary at the same time – to see if any particular food makes the symptoms worse.

Food groups that are commonly implicated in IBS include wheat and dairy (cheese, milk, yoghurt), citrus fruits, onions, caffeine in coffee, cola drinks and tea. Other food triggers can include corn, beef and white wine.

This type of dietary experiment should be carried out with the help of a properly qualified dietician.

If wind or bloating is a problem:

- ❍ limit fruit to three portions per day and fruit juice to one small glass per day.
- ❍ reduce the intake of resistant starches – foods that are not completely digested by the body. Examples include oven chips; potato waffles; fried rice; part-baked breads such as garlic bread; ready meals containing potato or pasta; dried pasta.
- ❍ oats and golden linseeds may help.

If diarrhoea is a problem:

- ❍ replace lost fluids with water or non-caffeinated drinks.
- ❍ restrict fizzy and caffeinated drinks (coffee, tea, cola) to three cups per day.
- ❍ limit insoluble fibre intake from bran, cereals and nuts.
- ❍ limit fresh and dried fruit to three portions per day.
- ❍ limit intake of resistant starches.
- ❍ avoid sugar-free sweets (mints and gum) and food products containing sorbitol.
- ❍ avoid foods with a high fat content – eg chips, burgers, crisps and cakes.

If constipation is a problem:

- ❍ oats and golden linseeds (which can be added to breakfast cereals or yoghurts – up to one tablespoon per day) are good sources of soluble fibre. They help to soften the stool and make it easier to pass.
- ❍ ensure a good fluid intake – up to eight cups of non-caffeinated fluid per day.

It's also worth:

- ❍ eating small regular meals.
- ❍ taking your time when eating.
- ❍ not skipping meals or eating late at night.

Certain foods and fizzy drinks are also recognised to exacerbate 'wind' and feelings of distension. These include onions, carrots, sprouts, raisins, bananas, and apricots.

A more recent development is the use of what is called a FODMAP diet where intake of fermentable carbohydrates – oligo, di and mono-saccharide and polyols – is reduced. This may be helpful for diarrhoea and bloating but the evidence is not yet compelling.

NICE has recommended that more patients with IBS are referred for dietary advice. Linking in with this, the British Dietetic Association has produced some very helpful and more detailed guidance on the dietary management of IBS symptoms. This can be downloaded at: www.bda.uk.com/foodfacts/IBSfoodfacts.pdf

DRUGS THAT MAY HELP

Any good pharmacy will have a range of non-prescription drug treatments that can often help with individual symptoms. But there are also a number of prescription only-drugs that can be helpful if symptoms are more persistent or disabling.

◆ **Colicy pain and muscle spasms** Antispasmodic drugs such as mebeverine hydrochloride (Colofac), alverine citrate (Spasmonal) and peppermint oil capsules (Colpermin) may be worth trying for mild episodic pain and muscle spasms.

These drugs work by relaxing the muscle in the wall of the bowel and can be used when necessary or before meals. Another type of antispasmodic drug is hyoscine (Buscopan) but this has more side effects, including constipation. Conventional painkillers such as paracetamol and ibuprofen are NOT recommended for pain in IBS.

◆ **Constipation** Bulking agents such as ispaghula husk (eg Fybogel sachets or Ispagel Orange), methyl-cellulose and sterculia help by softening and bulking the stools. These are best taken after meals and with plenty of fluids. They may cause or exacerbate flatulence and bloating.

Osmotic laxatives cause stools to retain more fluid and increase bulk. Lactulose is best avoided as it can increase bloating and flatulence. Other osmotic laxatives include magnesium (Milk of Magnesia) and macrogol Movicol).

Laxatives containing senna, which irritate the bowel wall, are more powerful . Generally, they are best avoided.

◆ **Diarrhoea** Products containing loperamide (eg Imodium – available over the counter) will slow down the propulsive movements in the bowel wall and also help with urgency but may not help with pain. Loperamide works rapidly and can be very effective but needs to be used with care as it has a side-effects (dizziness, drowsiness) that people with ME/CFS may not tolerate. Codeine-containing drugs, which cause constipation and sedation, can lead to dependency.

◆ **Probiotics** These are 'friendly bacteria' that come in the form of yoghurt, drinks and supplements. They help to restore the normal balance of gut bacteria.

Probiotics may help with pain, flatulence and bloating in some people but the evidence so far is not of high quality. The key bacteria are bifidobacteria and lactobacilli. Products include Activia (contains bifidobacteria – for constipation and pain) and VSL3 (contains bifido-bacteria and lactobacillus – for flatulence).

◆ **Drugs to avoid** IBS symptoms can be made worse by non-steroidal anti-inflammatory drugs such as ibuprofen/Brufen.

◆ **Nausea** Simple remedies such as ginger (in the form of biscuits, root, sweets, tea) and acupressure bands (which are placed over a specific point on the wrist) are worth trying. A drug called cinnarizine (Stugeron) can be helpful – especially when sickness is travel-related.

WHAT ELSE CAN THE DOCTOR PRESCRIBE FOR IBS SYMPTOMS?

At present, there isn't a great more that doctors can prescribe. However, a number of drugs that act on chemical transmitters in the bowel are currently being assessed.

◆ **Antidepressants** A low dose (ie 5 or 10mg at night going up to a maximum dose of 30mg) of a tricyclic antidepressant drug such as amitriptyline can help to relieve pain. Tricyclics cause constipation so are more suited to IBS-D. SSRI drugs (which affect serotonin levels) do not cause constipation – so may be used for IBS-C.

◆ **Linaclotide** This is a relatively new drug that is sometimes prescribed where there is moderate to severe constipation. It also helps to reduce pain and bloating.

◆ **Nausea** Drugs such as metoclopramide (Maxalon) and prochlorperazine (Stemetil) need to be used with care in people with ME/CFS.

ALTERNATIVE AND COMPLEMENTARY APPROACHES

A wide range of alternative, complementary and nutritional approaches are advocated for irritable bowel symptoms – some of which are extremely dubious. There is no evidence that candida infection is linked to IBS (reference: *Postgraduate Medical Journal,* 1992, 68, 453-454), and some of the food allergy testing services on offer in the private sector are unreliable to say the least.

PSYCHOLOGICAL APPROACHES

One approach that does appear to work in some cases is hypnotherapy – which may even be available through an NHS specialist service.

Relaxation techniques should be helpful if anxiety or stress are playing a role in exacerbating symptoms.

FURTHER INFORMATION

More detailed advice and information on these topics is contained in *Living with ME*. Irritable bowel symptoms and treatments on pages 62-64; food allergy and IBS symptoms on pages 211-212; nausea on pages 65-66.

Some clues on how to bring IBS under control

by **SUE LUSCOMBE**, diet and nutrition adviser to the ME Association

Irritable bowel syndrome, (IBS), is very common with ME/CFS. Gut symptoms vary, but typically include abdominal pain, bloating, wind, diarrhoea and/or constipation.

It is very important to have IBS confirmed, thereby ruling out other possibilities, such as coeliac disease and Inflammatory Bowel Disease, e.g. Crohn's Disease.

If you are considering a gluten-free diet, because you suspect wheat upsets you, talk to your GP about a Coeliac blood test. For this to be valid, you must eat gluten (wheat) for six weeks before the test. Too many people start long-term gluten-free diets without being tested – yet Coeliac disease presents with similar gut symptoms to IBS.

If you are not tested, you will not rule out Coeliac disease and you could miss essential treatment and monitoring for this condition.

STEPS TO TRY FOR IBS

❍ Three regular meals a day. Smaller meals may be better. Avoid late night eating, or skipping meals.

❍ Cut down fatty processed foods like chips, pizza, cakes and biscuits.

❍ Keep a food and symptom diary to identify patterns and see if changes help. Make only one change at a time, so that you can tell what helped.

CHANGES FOR SPECIFIC SYMPTOMS

Wind/Bloating

❍ Limit fruit juice to a small glass daily.

❍ Avoid gas-producing foods, such as sprouts, broccoli, cauliflower, beans, pulses, sugar-free mints and chewing gum.

❍ Try one month on a low lactose diet, using lactose-free milk, yoghurt, cream and cheese. If nothing improves, add ordinary milk back in. If you continue on a low lactose dairy diet, take care to have an adequate calcium intake – this is important for long-term bone health.

CONSTIPATION

❍ Ensure a good fluid intake of two litres a day, (8 mugs/glasses).

❍ Increase fibre gradually, with wholegrain and more fruit and vegetables. Oats and linseeds are particularly helpful with softer stools.

❍ Try one tablespoon of linseeds with your breakfast cereal, soup, or yoghurt.

❍ Avoid extra wheat bran. This can make things worse.

DIARRHOEA

❍ Ensure a good fluid intake of two litres a day, (8 mugs/glasses).

❍ Limit fruit juice to a small glass daily.

❍ Limit caffeine from coffee, tea and cola drinks to maximum three a day. If you have sleep problems, avoid caffeine after 6pm.

❍ Choose white and lower fibre varieties of breakfast cereal and bread.

Medical information contained in this leaflet is not intended to be a substitute for medical advice or treatment from your own doctor. The ME Association recommends that you always consult your own doctor or healthcare professional about any specific problems. We also recommend that any of the medical information provided by The MEA in this leaflet is, where appropriate, shown to and discussed with your doctor.

- Try up to one month on a low lactose diet by using lactose-free milk, yoghurt, cream and cheese.

PROBIOTICS

If the actions above don't resolve your symptoms adequately, you may find probiotics helpful. There are many types and you should try them for about a month before seeing if they work. You may need to try more than one strain/ brand.

STILL NOT WORKING?

Speak to your GP about referral to a dietitian. They may suggest a diet to reduce fermentable carbohydrates, (the Low FODMAP diet). FODMAPs, (**F**ermentable, **O**ligo-, **D**i-, **M**ono-saccharides and **P**olyol**S**), are short chain carbohydrates, (e.g. fructans, galacto-oligosaccharides, polyols, fructose and lactose), that are poorly absorbed in the small intestine.

With all the information on Low FODMAPS on the internet, you may be tempted to try this yourself. However, it is not an easy diet and the first phase of cutting down FODMAPS for 6-8 weeks is only part of the treatment.

The second phase, and really important part, is to systematically test for toleration of the foods avoided. The Low FODMAP approach is complex and, if both phases are not carried out, your food choice may be more restricted than needed.

It is recommended that you follow this approach under a dietitian's care. It is important to avoid any unnecessary diet restrictions and potentially unwanted nutritional consequences, such as low calcium intake or weight loss which may compromise your recovery.

REFERENCES AND FURTHER READING

- British Dietetic Association *Foodfacts on Irritable bowel Syndrome*. Find it at https://www.bda.uk.com/foodfacts/IBSfoodfacts.pdf (accessed August 2015).
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Her interest in ME/CFS started over 10 years ago, when her daughter, aged 12, was diagnosed with ME. Living with a sometimes severely affected family member, has given her great personal and professional insight to some of the challenges.

Sue has her own private nutrition and dietetic consultancy. For more details, email: sue@hampdenhealth.com or phone 01525 888 552.

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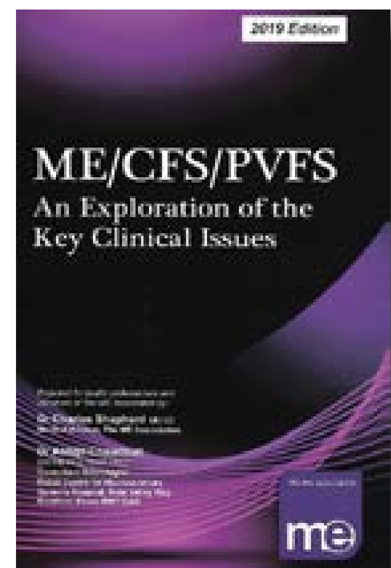

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