

INTERSTITIAL CYSTITIS

and ME/CFS

ME CONNECT HELPLINE: **FREEPHONE 0808 801 0484**

by **Dr Charles Shepherd**

Hon Medical Adviser to the MEA

INTRODUCTION

Interstitial cystitis (IC) is an important and very distressing condition that seems to be more common in people with ME/CFS.

Interstitial cystitis is a poorly understood bladder condition that causes bladder symptoms and long-term pelvic pain. It tends to first affect people in their 30s and 40s, and is much more common in women than men.

The main symptoms are pelvic pain that is felt below the bellybutton, sudden strong urges to pass urine and passing urine more frequently than normal – including during the night.

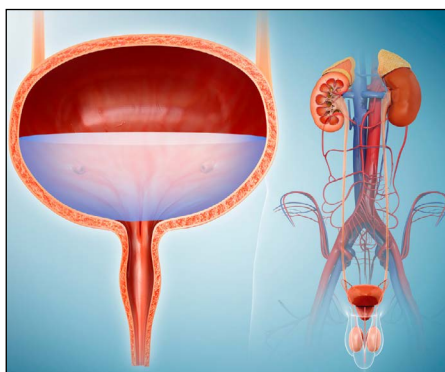
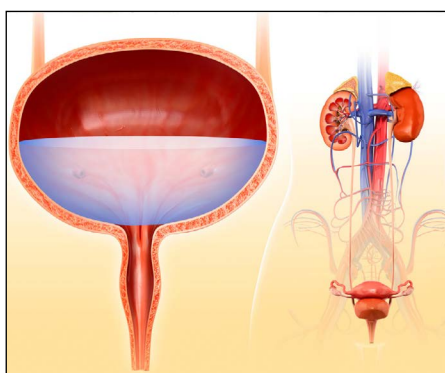
The pain may be worse when the bladder is full and may be temporarily relieved on passing urine. Pain may also be worse during periods or after having certain foods or drinks.

Symptoms often come and go in phases. So, there may be episodes lasting days, weeks or months where symptoms improve, followed by times when they are worse.

The exact cause of interstitial cystitis isn't clear. Unlike other types of cystitis, there is no obvious infection in the bladder - so antibiotics do not help.

Possible causes include damage to the bladder lining, which allows urine to irritate the bladder and surrounding muscles and nerves; a problem with the pelvic floor muscles that are used to control urination, and the body's immune system mistakenly attacking the bladder (an autoimmune component).

Interstitial cystitis can exist alone or as part of a more widespread problem - where it is associated with fibromyalgia, irritable bowel syndrome and lupus, as well as ME/CFS. Unfortunately, interstitial cystitis can be very difficult to treat.



There are a number of approaches that are worth considering.

No single treatment works for everyone and there's disagreement about how effective some of these treatments are.

So it may be worth trying several treatments to find which one works best for you.

LIFESTYLE, DRUGS AND SURGERY

Lifestyle changes that may improve symptoms include:



Interstitial Cystitis was written by Dr Charles Shepherd (pictured above), Trustee and Hon Medical Adviser to The ME Association.

© The ME Association, 2021
All rights reserved.

Reproduction, in full or in part, is not allowed without the written permission of The ME Association.

DISCLAIMER

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



■ **Stress reduction** - anything that helps you relax, such as regular warm baths, may help to reduce symptoms. Research suggests that mindfulness-based techniques, such as meditation, can also help.

■ **Avoiding certain foods or drinks such as tomatoes and alcohol** - but don't make significant changes to your diet without seeking professional advice.

■ **Stop smoking** - chemicals in cigarettes can irritate your bladder.

■ **Fluid intake** - reduce the amount you drink before going to bed.

■ **Plan toilet breaks** - taking regular planned toilet breaks may help to stop your bladder becoming too full.

DRUG TREATMENTS

■ **Over-the-counter painkillers** - such as paracetamol and ibuprofen/Brufen

■ **Over-the-counter antihistamines** - such as loratadine and cetirizine .

■ **Stronger prescription-only painkillers** - such as amitriptyline, gabapentin and pregabalin.

■ **Tolterodine, solifenacin or mirabegron** - drugs that help relax the bladder muscles.

■ **Cimetidine** - a prescription-only drug that may help by blocking the effect of a substance called histamine on cells in the bladder .

■ **Pentosan polysulphate sodium (Elmiron)** - may help to repair the bladder lining.

Some medications can also be passed directly into the bladder using a thin tube called

a catheter. These are known as intravesical medications or bladder instillations.

Examples include lignocaine (a local anaesthetic that numbs the bladder) and hyaluronic acid or chondroitin sulphate (medications that may help restore the bladder lining).

SUPPORTIVE THERAPIES

Supportive therapies and treatment include:

■ **Physiotherapy** - massaging the pelvic floor muscles may help reduce any strain on your bladder.

■ **Bladder retraining** - where you gradually learn to be able to hold more urine in your bladder before needing to go to the toilet.

■ **Psychological therapy** - to help you cope with your symptoms.

■ **TENS** (Transcutaneous electrical



nerve stimulation) - a small battery-operated device is used to relieve pain by sending electrical impulses into your body.

SURGERY AND OTHER PROCEDURES

Surgery and other procedures may be recommended if there are abnormal areas (lesions) in your bladder and other treatments don't work.

Procedures that may be carried out include:

■ **Cauterisation** - where ulcers inside the bladder are sealed using an electrical current or laser.

■ **Bladder distension** - where the bladder is stretched with fluid, which can aid diagnosis and may temporarily relieve your symptoms.

■ **Botulinum toxin injections** - where a substance called botulinum toxin (such as Botox) is injected directly into your bladder to temporarily relieve your symptoms.

■ **Neuromodulation** - where an implant that stimulates your nerves with electricity is placed in your body to relieve pain and reduce sudden urges to pass urine

Further information and support:

Support groups, such as the Interstitial Cystitis Association or Bladder Health UK provide more detailed information and advice about living with interstitial cystitis.

Bladder & Bowel Community: <https://www.bladderandbowel.org>

Interstitial Cystitis Association: <https://www.ichelp.org>

Bladder Health UK: <https://bladderhealthuk.org>



Become a Member of the MEA

For a small subscription you can receive quarterly issues of **ME Essential** magazine, keep updated with the latest information on ME/CFS and with stories from other members of the charity.

You don't have to be personally affected by ME/CFS to join the ME Association. Membership is available to carers, family-members, and anyone with a professional interest in the condition.

Annual membership costs:

£18.00 (UK residents and BFPO)

£24.00 (Mainland Europe including Republic of Ireland)

£30.00 (Rest of the World)

Find out more here:

<https://meassociation.org.uk/mea-membership/>





ME CONNECT

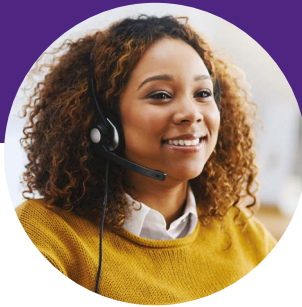
The Support and Information Service for people affected by ME/CFS/PVFS and Long Covid



Freephone
0808 801 0484

For opening hours visit:
meassociation.org.uk/me-connect

Contact ME Connect
3 WAYS TO GET IN TOUCH:
by phone, email
or social media private message



HERE TO LISTEN

We are here to listen, validate and empathise with any issues you might be facing.



VITAL SUPPORT

We are here to help you reach an informed decision.



SAFE ENVIRONMENT

We provide a safe, confidential and understanding environment where you can be heard and understood.

We're here for you!



MEConnect@meassociation.org.uk



[X.com/meassociation](https://x.com/meassociation)



facebook.com/meassociation



instagram.com/meassociation

meassociation.org.uk