

A PATIENT GUIDE TO THE HEALTHCARE JOURNEY WITH:

MEDICALLY UNEXPLAINED SYMPTOMS

Feeling dismissed, overwhelmed, lost or misdiagnosed?

You are not alone; it is not your fault!

This guide is intended to support and bring hope by helping you to:

- ✓ Understand if you are a person with unexplained symptoms.
- ✓ Feel more confident in medical appointments.
- ✓ Find trustworthy information and support.



What are medically unexplained symptoms?

- Often shortened to MUS, these are symptoms for which no diagnosable cause has yet been found, despite examinations and investigations by different doctors.
- MUS can be caused by a current or a past condition which is still having repercussions. This may be a rare disease or an unusual presentation of something common.
- Perhaps there are only few specialists with relevant expertise, or your test results are inconclusive or don't fit standard criteria - still, the symptoms are real and distressing.
- Sometimes no single cause can be identified.
- There can be many contributing factors alone or together for your symptoms (including stress, family issues, and mental health conditions) or none of these.
- Other terms for MUS include somatic symptoms or persistent physical symptoms.

Some common MUS:

- heart palpitations,
- muscle, joint, chest or back pain
- stomach or digestive issues,
- feeling faint, dizzy, fatigued, or having headaches.

What impact can MUS have on people?

- Often, a slow challenging journey with no clear plan.
- People feel frustrated, anxious, hopeless & exhausted.
- Sometimes, they don't know what questions to ask.
- Getting stuck in delayed 'referral loops' between GPs and specialists, often receiving limited explanation.
- Unnecessary, painful or invasive tests & treatments.

How can you take back control?

- Talk to family and friends. Explain how you feel. You may well discover people in a similar position.
- Ask for the same doctor. Continuity is important. You avoid repeating yourself and outcomes are better.
- Connect with MUS organisations or support groups.
- Look into specialised research programmes – ask about new tests and trials of treatment.

Consider other ways to feel better:

- Diet changes, exercise, physiotherapy and complementary therapies can be beneficial.
- Mental health care strategies, like stress management or talking therapies, may help.
- Often, a combination of tailored approaches with support from health professionals works best.

Find out about your other options:

- If unsatisfied, you can request a second opinion. Ask respectfully e.g. “this is a lot to take in, I want to be sure”.
- The medical journey does go wrong sometimes. If you consider this is due to poor care, you may wish to complain. Ask for a form or email address.

More information and links to resources are available on our website, forgottenpatients.org.

If you are carrying out your own research:

- ✓ **Do seek credible sources.** Well-known medical organisations, government websites and health journals are good starting points.
- ✓ **Do focus on evidence-based information.** Look for published research on relevant symptoms, diseases and treatments. NB Many symptoms do not have a serious cause.
- ✓ **Do consult healthcare professionals.** Discussing your research can clarify misunderstandings, reduce worry and might lead to new treatments.
- ✗ **Don't fall for misinformation.** Social media or unofficial websites may contain false claims or opinions. Be cautious about tools like ChatGPT - they can mislead, be inaccurate or may not be relevant to your situation.

Advocate for yourself

Remember you are your own expert:

- Keep a log of your symptoms, severity, and any possible triggers e.g. foods & medicines. Where relevant, take photos or videos. This evidence will shortcut the medical investigation process.
- Present all symptoms, whether you consider them relevant or not.
- Bring your full medical history, any medications (or supplements), and previous test results.
- Ask for the diagnosis or possible diagnoses? How sure is the doctor?
- Be honest, open and precise about how MUS affect your life.
- Ask for copies of your health records and test results.
- If there's something you don't understand, ask for clarification during the appointment.
- If you are unhappy, feel dismissed, unheard, or misunderstood, ask to meet the senior doctor or write a short polite letter/email.
- Bringing along a friend or family member can be very supportive.
- Above all, be confident in your own knowledge about your lived experience.

