

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 medically unexplained symptoms.
- ✓ Feel more confident in medical appointments.
- ✓ Find trustworthy information and support.



- 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.

What are medically unexplained 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 continuity of care if possible. You can avoid repeating yourself and outcomes are better.
- Connect with MUS organisations or support groups - helping those with similar problems.
- 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

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.



For more resources, visit **forgottenpatients.org** or scan:

A PATIENT GUIDE TO MAKING THE MOST OF:

YOUR HOSPITAL APPOINTMENT

- ✓ Approach your appointment feeling confident and well-prepared.
- ✓ Ask useful questions and prepare for any next steps.

Before the appointment, think about...

Getting there:

- Arrive a bit early. How will you travel? How long it will take?
- Research times and prices for car parks or public transport.
- Book assistance, like use of a wheelchair, an interpreter, or a chaperone.



Talking about health:



- List your symptoms, and any questions or concerns you would like to discuss.
- These may be about your health, tests, treatment options, or what comes next.

Describe your **symptoms** in simple, clear language:

- ? What do they feel like? How often do they happen?
- ? How do they affect your day-to-day life?
- ? Does anything make them better or worse?
- ? When did you first notice them?
- ? Is there anything you think might be causing them?

Try not to underplay or exaggerate how you feel.

On the day:

- First impressions matter: how you look, what you say, and how you say it are important.
- Wear loose, removable clothes and shoes in case you are examined.

Definitely do bring:

- The appointment letter.
- A list of your current medication(s) and dose.

Optionally, you can bring:

- A notepad and pen.
- A family member or friend to support you.



- It's normal to feel frustrated, but stay calm and polite. The staff are doing their best.

During the appointment, it might go something like this...

- First, you see a **nurse**, to measure your height, weight, and blood pressure.
- Next, you see a **consultant and/or another health professional**. They may want to **examine** you: taking blood pressure, heart rate, and so on. You can ask for their names and positions, so you know who you spoke to, if they are not on your letter.
- If you need blood tests or scans, you see **another nurse** or an **imaging technician**.
- There could be **students** observing. You can refuse if you are uncomfortable, and it won't affect your treatment.

Questions you could ask:

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Please explain the basis for this diagnosis. How certain is it? Could my symptoms be caused by something else?

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What does this mean for me now, and in the long term? What are my treatment options?

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Who should I contact if my symptoms get worse? What if I have any follow-up questions?

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After your appointment...

- Write down a summary of **what happened** and **anything important** you were told. If you forget something, ask whoever came with you, or a nurse if present.
- Pick up **prescriptions** and attend any **tests** or **follow-up appointments**.
- Keep notes of **your health** and updated **contact details** for your doctor.
- Be aware of your **patient rights**, like your right to get a second opinion.

The doctors may ask you for:

An explanation of your symptoms, GP visits or appointments you have already had, and any treatments you have tried.

Your detailed medical history, including:

- Previous diagnoses you have received.
- Medications you take, and the dosages.
- Any surgeries you have previously had.
- Your alcohol intake, smoking habits, and use of any recreational drugs.

What are the likely outcomes?

- Your doctor might organise more tests (bloodwork, scans, biopsies, or others).
- They may give you a treatment plan.
- They may discharge you to your GP for monitoring or refer you to a specialist.



A PATIENT GUIDE TO MAKING THE MOST OF:

This guide covers the essentials for success.

- ✓ Be prepared and explain yourself clearly.
- ✓ Understand the results and next steps.

Before your GP visit...

Make an appointment:

- It can be difficult if it's busy. Try calling, booking online, or in-person. Don't give up!
- Describe your problem – it may be treatable by a nurse or pharmacist instead.
- If you have more than one concern, you might need to book a double appointment.
- If you are uncomfortable or have an intimate problem, request a same-sex doctor.
- If you need help with English, ask for an interpreter or bring a fluent adult with you.

Be prepared:

- Arrive early. How will you travel? How long will it take?
- Wear loose clothes and shoes you can easily remove.
- Bring a list of your main symptoms, questions, medications, and any relevant letters.
- You may want to bring a notepad and pen, and a friend or family member for support.

My legs and feet are numb first thing in the morning.

I have a sharp pain in my back, several times a day.

Every time I climb stairs, my chest feels very tight.

A VISIT TO YOUR GP



Ask yourself:

What do I want from this visit? A referral?
A prescription? Tests?
What impacts me most?
What am I particularly worried about?

Think about how to describe your **symptoms**:

- ? What is happening? Where in your body is it?
 - ? Does it feel sore, numb, nauseous, stiff, tight, etc.?
 - ? How often does it happen? Does it affect your life?
 - ? Does anything make it better or worse?
 - ? When did you first notice it happening?
 - ? Is there anything you think might be causing it?
- Try not to underplay or exaggerate how you feel.

During your GP visit...

- Describe your problems - try to focus on what is worrying you the most. If you feel like something is not getting across, you can pause and start over again.
- Don't be embarrassed to talk about a personal issue – they have seen it all before!
- Don't be surprised if your doctor makes notes or checks things on their computer.
- It's normal to feel frustrated, but stay calm and polite. The staff are doing their best.

Your doctor may ask about...

Your detailed medical history, such as:

- Your health problems, including allergies.
- Your family history – anything similar?
- Any medications or supplements you take, and the dosages of each one.
- Any operations you have had.
- Any unusual activities or travel.
- Habits like alcohol, smoking, or using recreational drugs.

More general questions, such as:

- “Why did you make this appointment?”
- “Can you describe what your concerns are?”

They may also do physical tests, like heart rate, blood pressure, pain, and reflexes.

You have the option to ask for a chaperone.

If you are given a **diagnosis**, make sure you understand:

- what it means (in detail),
- the basis for the GP giving it, and how confident they are,
- your options for treatment.

If you need **further tests**, ask:

- what the tests are for,
- what is involved in each one,
- if there are any associated risks.

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If you receive a **prescription**, make sure you understand:

- what is being prescribed,
- how to take it and how long for,
- if there are any side effects.

Once your visit is finished...

- Write down the **main points** of the visit and confirm the **next steps**.
- Pick up any prescriptions and look at any recommended materials.
- Follow instructions about medication, tests or further appointments.
- Keep notes of **your health** and updated **contact details** for your doctor.
- If you are not satisfied with your care, you have the right to seek a **second opinion** - ask the reception or see our resources for advice.

