Guidance for Health Professionals on Medically Unexplained Symptoms (MUS)

KEY LEARNING POINTS

Making Sense of Symptoms
Managing Professional Uncertainty
Building on Patient Strengths

Medically unexplained symptoms are ‘persistent bodily complaints for which adequate examination does not reveal sufficient explanatory, structural or other specified pathology.’

» People want to be taken seriously: show your patients you believe them.
  – Ask yourself and the patient “Am I hearing and understanding what you are trying to tell me?”

» Doctors can make a difference to a patient’s well-being, even when their symptoms are unexplained.
  – Concentrate on helping to manage symptoms and improving functionality.

» Sometimes the only “therapy” needed is the strength of your doctor-patient relationship.
  Continuity of care can have a very positive impact.
  – Be pre-emptively reassuring, yet show you have an open mind and will continue to reassess.
  – Explain rather than just ‘normalise’.

» Be explicit about your thoughts, your uncertainties and your expectations of referrals to specialist care.
  – Proactively communicate with other clinicians.

Though GPs often have a strong suspicion that there is no serious medical condition in cases of MUS, they often worry about missing something crucial. Similarly, patients may feel unsupported and confused. This uncertainty often leads to extensive and unproductive investigations.¹

This guidance will highlight the importance of clinicians trusting, perhaps more than they do, their own psychological abilities and the strengths of their therapeutic alliance with their patients. This helps to achieve better concordance between addressing the patients’ fears and managing their own anxiety and uncertainty.²

“Our remedies oft in ourselves do lie.”

All’s Well That Ends Well, William Shakespeare
William Carlos Williams, (American Poet, 1883 -1963)

“...It is not what you say that matters but the manner in which you say it; there lies the secret of the ages.”

MUS cannot easily be ascribed to recognised physical diseases

There are three main types of MUS:
• pain in different locations
• functional disturbance of organ systems
• complaints of fatigue or exhaustion.

They might be caused by physiological disturbance, emotional problems or pathological conditions which have not yet been diagnosed.

What should alert me?

MUS should be considered in patients that have physical symptoms lasting three or more months that affect functioning and cannot be readily explained.

Risk/associated factors for MUS:
• Long term conditions with anxiety/depression
• Childhood adversity/abuse
• More common in women
• Patients with Personality Disorder (severe cases)
• Recent infection or physical illness.
• Severe illness or death of close relative.

Why is this important?

• MUS account for up to 20% of GP consultations.
• It is associated with 20-50% more outpatient costs and 30% more hospitalisation.
• The symptom complexes can affect all ages.
• Investigation causes significant iatrogenic harm.
• The annual healthcare costs of MUS in UK exceed £3.1 billion. The total costs are estimated to be £18 billion.

Outcomes for this group:
• 4%-10% go on to have an organic explanation for their presentation.
• 75% remain unexplained at 12 months.
• 30% (10% – 80%) have an associated psychiatric disorder (usually depression or anxiety) depending on how many unexplained symptoms are present.
• 59% of patients with lung symptoms suffer from hyperventilation.
• 25% persist in primary care for over 12 months.

In secondary care, 50% of outpatients fulfil the criteria for MUS with a wide range of disorders.

The following shows the % at 12 months:
• Gynaecology (66%)
• Neurology (62%)
• Gastroenterology (58%)
• Cardiology (53%)
• Rheumatology (45%)
• General Medicine (40.5%)

Effective interventional do exist:

Certain techniques enable doctors and nurses to make sense of the symptoms, offer credible explanations and appropriate support, and avoid behaviour that may worsen the situation. (See box on the left for what helps during consultation and what doesn’t.)

A mismatch – patients’ help seeking and GP’s care

Doctors often manage the symptoms by minimising (normalising) and treating empirically, whereas patients usually want explanations, emotional support, and for their symptoms to be made sense of.

Doctors and nurses, especially if they are unsure how to manage the situation, may assume patients want more than they do. The doctor may precipitate premature tests and referrals, perhaps to distance themselves from their patients, or because of perceived pressure to diagnose and cure.

Past health and psychosocial experiences may encourage some patients in order to minimise certain symptoms and over emphasise others to shift the doctor’s attention in a particular direction.

Patients want reassurance that the doctor has considered all the possibilities. They will usually accept that there is uncertainty now but will want assurance that their symptoms will be taken seriously and reassessed in future.

Therefore consider...

Medically Unexplained Symptoms are just that; medically unexplained. Patients will often present with symptoms that can be explained alongside those that cannot.

This is especially the case in those with long-term conditions including diabetes; respiratory, vascular, musculoskeletal and neurological disorders; severe mental illness; and, depression and anxiety.

Patients presenting with MUS to surgical clinics or assessment may need careful consideration given the often irreversible nature of surgery, which may not always help.

Oversimplified explanations and the use of unwarranted investigations may increase patient’s expectations of a surgical solution to a complex set of symptoms and problems.

The professional needs to consider multiple modalities and approaches and personalise care plans to include physical, medical, pharmacological, psychological (CBT, PDT) and spiritual.

So what helps?

Just being there

MUS is about the doctor having a number of hypotheses. Many patients with unexplained symptoms just need reassurance. Most people with MUS who see their GPs will improve without any specific treatment, particularly when their GP gives an explanation about symptoms that makes sense, removes any blame from the patient, and generates ideas about how to manage their symptoms.

Treat the Treatable

Advocate specific treatments that will help acute or chronic conditions; use pain ladders, control dyspnœa in COPD and angina in IHD. Remember to maximise treatment and symptom control of long-term conditions and pain, whilst balancing treatment with potential adverse effects.

• Consider altering medication; ask if it might be medication causing or aggravating the symptoms.

Positive Risk Management

For MUS, good practice consensus recognises that not investigating may be best for the patient.

Investigations and Referrals

• When referring, discuss the possible outcomes and their meanings; pre-empt normal tests results.
• Be clear with the specialist what the question is.
• Copy patients into letters and agree content and goals.
• 30-60% of people in chronic pain have depression. Depression is four times more common in patients with low back pain (in primary care). Treating depression can help with pain, including arthritis.
• Screen for depression and treat appropriately.
• CBT helps with MUS and with chronic pain. It also reduces fatigue in Chronic Fatigue Syndrome.
• Physiotherapy and exercise therapies help and should be encouraged.
• Communicate with other clinicians involved; consider a shared plan agreed with the patient and professionals.

Consultation techniques that help

**Connect:**
• Listen to the patient. Ask about their beliefs about the cause of their symptoms and any associated ideas, concerns and expectations (ICE).
• Ask open questions and let them tell their story fully: their experience; their family background; their worries.
• Go back to the beginning of the complaint – including previous health experiences. (“Drain the symptoms dry.”)
• Focus on the impact of symptoms and how the patient is affected.
• Acknowledge and validate the patient’s sense of suffering; acknowledge it can be frightening.
• Watch for signs that you are not “hearing” the patient; including repetition, new symptoms and amplified symptoms. If this occurs, try a different approach.
• Knowing the patient and the context, or even admitting you don’t know these things, can make all the difference.

**Summarise:**
• Let the patient recap their view of the situation.
• Summarise what you think you have heard, being open about your uncertainty and willingness to check your understanding.
• Use the patient’s language to offer tangible explanations of what is causing the symptoms; be clear on what is not wrong and why.
• Indicate how common their symptoms are.
• Use narrative and metaphor, linking to the patient’s own experience.
• Offer the opportunity to link physical with psychosocial.
• Certain ‘word-scripts’ have been shown to help. See website for examples.
• Show your interest with phrases such as: “I have spent a lot of time thinking about this.” “I would really like to learn more about you.”

**Hand Over:**
• Share the action plan with the patient, including goals and functional improvement. Suggest that the patient may monitor his or her symptoms to observe fluctuation.
• Agree that the goal is to restore function as well as minimising symptoms.

### It DOESN’T help to... >> IT DOES HELP TO...

<table>
<thead>
<tr>
<th>It DOESN’T help to...</th>
<th>It DOES help to...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus exclusively on a diagnosis</td>
<td>Focus on the symptoms and their effect on functioning</td>
</tr>
<tr>
<td>Give a diagnosis whatever</td>
<td>Talk about functional conditions, and being able to manage symptoms</td>
</tr>
<tr>
<td>Dismiss the symptoms as normal (normalisation) without matching the explanation to the patient’s concerns</td>
<td>Match your explanation using their own words</td>
</tr>
<tr>
<td>Give the impression that you think something is wrong by investigating, without sharing the likelihood of the normal test result</td>
<td>Share your uncertainty; discuss the possible test result and its implications</td>
</tr>
<tr>
<td>Treat symptoms with drugs whatever</td>
<td>Have a discussion about therapeutic trials and side effects</td>
</tr>
<tr>
<td>Assume you know what the patient wants</td>
<td>Share decisions; listen to what they want carefully</td>
</tr>
<tr>
<td>Judge the patient; be critical of their behaviours. Be careful not to oversimplify the explanation to one life event</td>
<td>Acknowledge the importance of the patient’s view and circumstances: they are important. Don’t attribute ‘blame’</td>
</tr>
<tr>
<td>Ignore or miss psychological cues</td>
<td>Sensitively accept them and let the patient expand on them</td>
</tr>
<tr>
<td>Enforce psychosocial explanations as this leads to defensiveness</td>
<td>Allow time and encourage the patient to make those connections. Accept that this might take a few consultations</td>
</tr>
<tr>
<td>Let your anxiety or uncertainty take over</td>
<td>Use “word scripts” to encourage a shared plan. Be clear about your uncertainty and open-minded, but reassure that a serious cause is unlikely</td>
</tr>
</tbody>
</table>

### Cautions and uncertainties
• By highlighting MUS, doctors may use it as a diagnosis, but this is best avoided. It is better to focus on the symptoms, the consequences and the functioning, not the name.
• Setting up MUS teams? The risk is that teams concentrating on MUS may label patients and encourage silo management – it is better to encourage collaborative care and increase skills within primary care and specialist departments. Improve communication channels.
• Reattribution training – whilst appearing to increase GPs confidence and improve the Dr-Patient relationship, it is unclear if it improves patient outcomes.
• The business case and medical offset costs – although it is likely that addressing MUS effectively will reduce both health and social costs, further research is required – the evidence that is available does show cost reduction.

“Sorrow which finds no vent in tears, may make other organs weep.”

Sir Henry Maudsley (c.1907)
Guidance for Health Professionals on Medically Unexplained Symptoms | June 2014 | 1.0

References