

Guidance for health professionals on medically unexplained symptoms (MUS)

Making Sense of Symptoms Managing Professional Uncertainty Building on Patient's Strengths

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

“Our remedies oft in ourselves do lie.”

All's well that ends well, William Shakespeare

Key learning points

- **People want to be taken seriously – show 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 the patient's well-being even when their symptoms are unexplained.**
 - Concentrate on helping to manage symptoms and improve functionality
- **Sometimes the only “therapy” needed may be the strength of your doctor-patient relationship – continuity of care and the long-term relationship helps.**
 - 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

Despite having a strong suspicion that there is no serious medical problem, GPs worry about missing something serious and are often left with a sense of dissatisfaction with such cases. Patients may feel unsupported and confused. Such 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 would help achieve better concordance between addressing the patients' fears and managing their own anxiety and uncertainty.²

MUS cannot easily be ascribed to recognised physical diseases

Three main types:

- pain in different locations
- functional disturbance of organ systems
- complaints of fatigue or exhaustion.³

They might be caused by physiological disturbance, emotional problems, or pathological conditions which have not yet been diagnosed.⁴

What should alert me?

MUS should be considered if you see a patient with

- Physical Symptoms
- For 3 months
- Affecting functioning
- Cannot be readily explained

Risk / associated factors for MUS

- Long Term Conditions with anxiety/depression.
- Childhood adversity/abuse²³
- More common in women
- In severe cases overlap with Personality Disorder²⁴
- Recent infection; current physical illness; severe illness or death of close relative.

Why is this important?

- Accounts for up to 20% of GP consultations⁵
- MUS is associated with 20-50% more outpatient costs⁶ & 30% more hospitalisation^{7,8}
- The symptom complexes affect all ages
- Investigation causes significant iatrogenic harm^{9, 10}
- Annual healthcare costs of MUS in UK exceed £3.1 billion. Total costs are estimated to be £18 billion^{11, 12}

Outcomes for this group

- 4%-10% go onto have an organic explanation for their presentation^{13, 14, 15, 16}
- 75% remain unexplained at 12 months
- 30% (10% – 80%) have an associated psychiatric disorder (usually depression, anxiety) depending on how many unexplained symptoms are present^{17, 18, 19}
- 59% with lung symptoms suffer hyperventilation
- 25% persists for over 12 months (in primary care)²⁰

In secondary care, 50% of outpatients fulfil criteria for MUS with a wide range of disorders.²¹

The following shows the % at 12 months²²

- Gynaecology (66%)
- Neurology (62%)
- Gastroenterology (58%)
- Cardiology (53%)
- Rheumatology (45%)
- General Medicine (40.5%)

Effective Interventions do exist:

Techniques enable doctors and nurses to make sense of the symptoms, offering credible explanations and appropriate support, whilst avoiding behaviours that may worsen the situation. (See box opposite for what helps in a consultation and what doesn't.)

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

William Carlos Williams,
(American Poet, 1883 -1963)

A mismatch – patients' help seeking and GP's care²⁵

Doctors often manage the symptoms by minimising (normalising) and treating empirically; whereas patients usually want explanations and emotional support – for their symptoms to make sense.²⁶

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

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

People want reassurance that the doctor has considered all the possibilities. They will usually accept that there is uncertainty now, yet want assurance that their symptoms will be taken seriously and reassessed in future.²⁷

Therefore consider...

Medically Unexplained Symptoms are just that – medically unexplained. People will present with symptoms that can be explained alongside those that *cannot*.

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

The professional needs to consider multiple modalities and approaches – personalise the plan – physical; medical; pharmacological; psychological (CBT; PDT); 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 for symptoms that makes sense, removes any blame from the patient, and generates ideas about how to manage their symptoms.^{28, 29}

Treat the Treatable

Advocate specific treatments that will help acute or chronic conditions – use pain ladders, control dyspnoea 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.
- 30-60% of people in chronic pain have depression.³⁰ Depression is four times more common in patients with low back pain (in primary care).³¹ Treating depression helps with pain, including arthritis.³²
- Screen for depression and treat appropriately.
- CBT helps with MUS³³ and with chronic pain.³⁴ It also reduces fatigue in Chronic Fatigue Syndrome.³⁵
- Physiotherapy and exercise therapies help and should be encouraged.^{36, 37, 38, 39}
- Communicate with other clinicians involved – consider a shared plan agreed with the patient and professionals.

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 – agree content and goals.

Consultation techniques that help

Connect⁴⁰

- Listen to the patient – their beliefs about the cause of their symptoms and their associated worries – ideas, concerns and expectations (ICE).⁴¹
- Ask open questions and let them tell their story fully their way: it's *their* experience; *their* family background; *their* worries.
- Go back to the beginning of the complaint – right back, including previous health experiences. (“*Drain the symptoms dry*”)
- Focus on the impact of symptoms – how it affects them.
- Acknowledge and validate the patient's sense of suffering – empathy; acknowledge it can be frightening.
- Watch for signs that you are not “hearing” the patient; repetition, new symptoms, amplifying symptoms etc, and then try a different tack.
- Knowing the patient and the context – or admitting you don't know these things – makes 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 such 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 – “*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 – around 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.
- Develop an individual personal health plan (similar to ones for other long term conditions); but not a pre-defined one.
- Reassure about long-term improvement and reversibility of symptoms, the ability of the body to recover.

It DOESN'T help to...>> IT DOES HELP TO...

Focus exclusively on a diagnosis	>>	Focus on the symptoms and their effect on functioning
Give a diagnosis whatever	>>	Talk about functional conditions, and being able to manage symptoms
Dismiss the symptoms as normal (normalisation) without matching the explanation to the patient's concerns	>>	Match your explanation using their own words
Give the impression that you think something is wrong by investigating, without sharing the likelihood of the normal test result	>>	Share your uncertainty; discuss the possible test result and its implications
Treat symptoms with drugs whatever	>>	Have a discussion about therapeutic trials and side effects
Assume you know what the patient wants	>>	Share decisions; listen to what they want carefully
Judge the patient; be critical of their behaviours. Be careful not to oversimplify the explanation to one life event	>>	Acknowledge the importance of the patient's view and circumstances – they are important. Don't attribute ‘blame’ ⁴²
Ignore or miss psychological cues	>>	Sensitively accept them and let the patient expand on them
Enforce psychosocial explanations as this leads to defensiveness	>>	Allow time and encourage the patient to make those connections; it may take a few consultations – accept that
Let your anxiety or uncertainty take over	>>	Use “word scripts” to encourage a shared plan; Be open about your uncertainty yet reassuring that a serious cause is unlikely, but stress that you will keep an open mind

- Introduce the idea that emotions can aggravate physical symptoms, being careful not to imply you disbelieve them.
- Believe in patients and their ability to manage this; encourage them; build on their strengths.

- health trainers; well-being teams; peer supporters; links to IAPT pathways. Communication is essential.
- Ensure doctor peer support to discuss thinking & management.

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

Sir Henry Maudsley (c.1907)

Safety Net

- Understand positive risk management and discuss that with the patient; share the uncertainty.
- Reassure the patient that they will always be taken seriously and any working hypothesis will be reassessed.
- Safety net in agreement with the patient.
- Inform and document about “Red Flag” symptoms and signs. Agree actions if the situation changes and in what timescale and encourage continuity of care.
- To address uncertainty in general practice on how to manage these symptoms, pathways of care should support alternatives to hospital referral

Cautions and Uncertainties

- By *highlighting MUS*, doctors may use it as a *diagnosis* – 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* training⁴³ – 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. ■

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Useful Resources

TRAILBLAZERS: several primary care mental health resources including those on the theme of MUS

www.trailblazers-uk.net

FORUM: Forum website has a number of useful primary care mental health resources

http://www.rcgp.org.uk/mental_health.aspx

If you would like further information, including information about “word scripts” or would like to comment on this guidance, please contact Dr Anand Chitnis, anand.chitnis@nhs.net or via the website www.trailblazers-uk.net

References

- 1 Ring, A. et al. The somatising effect of clinical consultation: What patients and doctors say and do not say when patients present medically unexplained physical symptoms. *Social Science & Medicine*, 2005 October; 61(7): 1505-1515
- 2 Burton, C. Beyond somatisation: a review of the understanding and treatment of medically unexplained physical symptoms (MUPS). *Br J Gen Pract*. 2003 March; 53(488): 231-239.
- 3 Henningsen et al. Management of functional somatic syndromes. *Lancet* 2007 Mar 17; 369 (9565): 946-55.
- 4 Hatcher S, Arroll B. Assessment and management of medically unexplained symptoms. *BMJ* 2008; 336:1124-1128
- 5 Simon, 2005 – Simon GE, Von Korff M. Somatization and psychiatric disorder in the NIMH Epidemiologic Catchment Area study. *Am J Psychiatry* 1991; 148:1494-500
- 6 Steven Reid, Simon Wessely, Tim Crayford, and Matthew Hotopf. Medically unexplained symptoms in frequent attenders of secondary health care: retrospective cohort study. *BMJ* Mar 2001; 322: 767
- 7 Fink P. The use of hospitalizations by persistent somatizing patients. *Psychol Med* 1992; 22:173-80.
- 8 Fink P. Surgery and medical treatment in persistent somatizing patients. *J Psychosom Res* 1992; 36:439-47
- 9 Kouyanou K, Pither CE, Wessely S. Iatrogenic factors and pain. *Psychosomat Med* 1997; 59:597-604.
- 10 Fink P. The use of hospitalizations by persistent somatizing patients. *Psychol Med* 1992; 22:173-80.
- 11 Extrapolation from Barksy A, et al. Somatization Increases Medical Utilization and Costs Independent of Psychiatric and Medical Comorbidity. *Arch Gen Psychiatry*. 2005 Aug; 62:903-910
- 12 Birmingham S, Cohen A, Hague J, Parsonage M. The cost of somatisation among the working-age population in England for the year 2008-09. 2010 (personal communication; in press)
- 13 Stone, J. et al. Systematic review of misdiagnosis of conversion symptoms and “hysteria”. *BMJ* 2005; 331:989 (29 October)
- 14 Morriss, R. et al. Turning theory into practice: rationale, feasibility and external validity of an exploratory randomised controlled trial of training family practitioners in reattribution to manage patients with medically unexplained symptoms (the MUST). *General Hospital Psychiatry*. July 2006; 28 (4): 343-351
- 15 Morriss, R. et al. Cluster randomised controlled trial of training practices in reattribution for medically unexplained symptoms. *British Journal of Psychiatry*. 2007; 191: 536-542
- 16 Carson AJ, Ringbauer B, Stone J, McKenzie L, Warlow C, Sharpe M. Do medically unexplained symptoms matter? A prospective cohort study of 300 new referrals to neurology outpatient clinics. *J Neurol Neurosurg Psychiatry* 2000; 68:207-10.
- 17 Escobar JJ, Waitzkin H, Silver RC, et al. Abridged somatization: a study in primary care. *Psychosom Med* 1998; 60: 466-472.
- 18 Kisely S, Goldberg D, Simon G. A comparison between somatic symptoms with and without clear organic cause: results of an international study. *Psychol Med* 1997; 27: 1011-1019.
- 19 Fink P, Sorensen L, Engberg M, et al. Somatization in primary care. Prevalence, health care utilization, and general practitioner recognition. *Psychosomatics* 1999; 40: 330-338.
- 20 Khan AA, Khan A, Harezlak J, Tu W, Kroenke K. Somatic symptoms in primary care: etiology and outcome. *Psychosomatics* 2003; 44:471-8.
- 21 C. Nimnuan, M. Hotopf and S. Wessely. Medically unexplained symptoms: how often and why are they missed? *Q J Med* 2000; 93: 21-28
- 22 Byng, R. A whole systems approach to MUS in Plymouth; NHS Plymouth, Personal Communication, September 2009
- 23 Hotopf, M. *Psychological Medicine* 2004; 34:2:195-198 / Hotopf M, Mayou R, Wadsworth M, et al. Childhood risk factors for adult medically unexplained symptoms: results from a national birth cohort study. *Am J Psychiatry*. 1999; 156: 1796-1800.
- 24 Bass C, Murphy M. Somatoform and personality disorders: syndromal comorbidity and overlapping developmental pathways. *J Psychosom Res*. 1995; 39(4):403-427.
- 25 Dowrick CF, et al. Normalisation of unexplained symptoms by general practitioners: a functional typology. *Br J Gen Pract*. 2004 Mar; 54(500):165-70.
- 26 Salmon P, et al. Primary Care Consultations About Medically Unexplained Symptoms: How Do Patients Indicate What They Want? *J Gen Intern Med*. 2009 Jan
- 27 Peters S, Rogers A, Salmon P, Gask L, Dowrick C, Towey M, Clifford R, Morriss R. What do patients choose to tell their doctors? Qualitative analysis of potential barriers to reattributing medically unexplained symptoms. *J Gen Intern Med*. 2009 Apr; 24(4):443-9.
- 28 Salmon P, Peters S, Stanley I. Patients' perceptions of medical explanations for somatisation disorders: qualitative analysis. *BMJ* 1999; 318:372-6.
- 29 Hatcher S, Arroll B. Assessment and management of medically unexplained symptoms. *BMJ* 2008; 336:1124-1128
- 30 Robert Peveler, Alan Carson, Gary Rodin. Clinical review; ABC of psychological medicine, Depression in medical patients. *BMJ* 2002; 325:149-152 (20 July)
- 31 Robin Waxman et al. Community survey of factors associated with consultation for low back pain. *BMJ* 1998; 317:1564-1567 (5 December)
- 32 Elizabeth H. B. Lin, et al; for the IMPACT Investigators. Effect of Improving Depression Care on Pain and Functional Outcomes Among Older Adults With Arthritis. *JAMA*. 2003; 290:2428-2429
- 33 Kroenke K, Swindle R. Cognitive-behavioral therapy for somatization and symptom syndromes: a critical review of controlled clinical trials. *Psychother Psychosomat* 2000; 69:205-15.
- 34 Morley S, Eccleston C, Williams A. systematic review and meta-analysis of randomised controlled trials of cognitive behaviour therapy and behaviour therapy for chronic pain in adults, excluding headache. *Pain* 1999; 80: 1-13.
- 35 Price JR, Couper J. Cognitive behaviour therapy for adults with chronic fatigue syndrome (Cochrane review). In: *The Cochrane Library*, Issue 1, 2001. Oxford: Update Software.
- 36 Department of Health, Physical Activity, Health Improvement and Prevention. At least five a week. 29 April 2004
- 37 Koes BW, Bouter LM, Beckerman H, van der Hiejden GJMG, Knipschild PG. Physiotherapy exercises and back pain: a blinded review. 1991; *BMJ* 302: 1572-6.
- 38 NA Singh et al. A randomized controlled trial of the effect of exercise on sleep. *Sleep* 1997 20: 95-101.
- 39 Pate, R. et al. Physical Activity and Public Health – A Recommendation from the Centers for Disease Control and Prevention and the American College of Sports Medicine. *JAMA* 1995; 273:402-407
- 40 Neighbour, R. *The Inner Consultation* 1987; Radcliffe Publishing Ltd; 2nd Revised edition (Oct 2004)
- 41 Pendleton, D. et al. *The Consultation* 1984; OUP Oxford; 2nd Revised edition (24 April 2003)
- 42 Salmon P, Peters S, Stanley I. Patients' perceptions of medical explanations for somatisation disorders: qualitative analysis. *BMJ* 1999; 318: 372-376.
- 43 Morriss R, et al. Cluster randomised controlled trial of training practices in reattribution for medically unexplained symptoms. *Br J Psychiatry*. 2007 Dec; 191:536-42.

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