

MEDICALLY UNEXPLAINED SYMPTOMS (MUS) IN CHILDREN AND YOUNG PEOPLE

**A GUIDE to assessing and managing
patients under the age of 18 who are
referred to secondary care**

**This Guide is endorsed by the Royal College of Psychiatrists (RCPsych) and the Paediatric
Mental Health Association (PMHA).**

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- [Contents](#)
- **Introduction.**
 - What are MUS?
 - When should I use this guide?
 - Confusions and disputes with terminologies and the label of 'MUS'.
- **Step 1: opening your mind to the possibility of MUS**
- **Step 2: beginning the conversation. ED settings vs inpatient settings vs outpatient clinics vs GP clinics**
- **Step 3: making sure you don't fall foul of under- as well as over-investigation**
- **Step 4: creating chronologies, linking with others, exploring psychosocial factors and safeguarding.**
- **Step 5: the management of MUS and retaining a longitudinal connection with the patient**
- **Step 6: managing your, as well as other staff members', feelings about this type of work**
- **Step 7: involving experts when necessary**
- **A final note**
- **A case study of MUS**

Appendix 1: Prognosis of MUS

Appendix 2: DSM 5 Terminology.

Appendix 3: Word script examples

Appendix 4: Support services.

Appendix 5: MUS flow chart.

Appendix 6: GP referral letter template.

Appendix 7: MUS patient leaflet.

Appendix 8: Bibliography.

Who is this guide for?

The following guide provides advice and helpful tools, primarily to secondary care doctors in the assessment and management of children and young people CYP with MUS. The aim of the guide is to minimise the risk of recurrent presentation, iatrogenic harm and destruction of the therapeutic relationship.

When should I use this guide?

This document will be most helpful to those involved in the identification and management of CYP with MUS, particularly those working without expert advice. Regardless of service set up, seeking direct input from senior paediatric colleagues, and, if available, under 18s mental health clinicians, is always advisable over sole use of this guideline

How should I use this guide?

This guide is designed to be read in sequence, as it covers a number of steps in the identification and management of MUS. So we would prefer you to read and think about it page by page. However, it may be that you need to use this guide in less leisurely circumstances.

If you are just about to see someone who you think might have MUS, go to step 2

If you are following someone up who is under investigation for unexplained symptoms, go to step 3

If you have someone on the ward or in clinic who needs managing, consider whether step 4 has happened, and if so, go straight to step 5

If you are thinking about how to organise services around these CYP, step 7 might help you

This guide is written by clinicians, for clinicians, and is designed to be a useful practical aid. So let us know if you find it helpful, or, more importantly, if you don't.

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Introduction

What are MUS?

The term medically unexplained a symptom (MUS) describes a broad range of clinical presentations, rather than a diagnostic condition in its own right. The symptoms an individual describes (from bodily pains through to a loss of neurological function) are not fully explained by physical examinations or investigations. However, the symptomatic experience is no different from that of an individual with a known pathology, and is certainly no less anxiety-provoking.

The experience of MUS is common and affects one in ten children. This can range from mild, transient physical symptoms to a severe, debilitating and enduring disorder. The symptoms should be taken seriously, and a range of services need to be available to children and young people with these problems.

N.B. MUS can occur alongside a physical disorder eg non-epileptic seizures in someone with epilepsy, or abdominal pain in excess of pathology, in someone with inflammatory bowel disease

What are the implications of developing MUS?

For some individuals, MUS will resolve spontaneously (see Table 1). However, some will develop chronic ill health and the mainstay of their treatment will be symptom control.

From research in adult populations, it is known that MUS cost the NHS significant amounts of money (£3.1 billion pa).

Primary care clinicians play a vital role in managing MUS and this work needs support and acknowledgement by those working in secondary care. Approximately 30% of individuals seek direct healthcare support, of which only 1% present to secondary care^{1**}. This subgroup present frequently, to multiple specialities and often undergo extensive and unnecessary physical investigations, leading to a significant risk of iatrogenic harm^{2**}.

For the purpose of this guide, the term MUS has been used to allow inclusion of all CYP who present with medical symptoms lasting three months or longer, where symptoms are causing a significant amount of distress, disability and help seeking. This includes:

- 1) CYP who require ongoing diagnostic work up for a possible underlying physical illness
- 2) CYP where an underlying physical cause has been sufficiently excluded but the symptoms persist and are causing significant disability
- 3) CYP who have a diagnosed physical illness in whom symptom levels are inconsistent with underlying pathology and / or who have additional unexplained physical symptoms in other body systems

For a more in-depth discussion about the various terms that are used to describe medically unexplained symptoms, please see Appendix 2.

** Statistics quoted refer to data collected from the adult population. At present there is very little data available exclusively relating to the under 18 population.

¹ Improving the Classification of Medically Unexplained Symptoms in Primary Care. Rosendal M., et al. 2007. 2007, The European Journal of Psychiatry.

² Therapies, Improving Access to Psychological. 2009. Medically Unexplained Symptoms (MUS): A whole systems approach in Plymouth. Plymouth: NHS Plymouth, 2009.

Step 1: Opening your mind to the possibility of MUS

Just as some patients and their families may be more inclined to perceive bodily symptoms as indicative of some underlying physical disorder, so too may some doctors. Recognising that you are someone who is more comfortable having conversations based on the known, rather than unknown, recognising that you are a doctor who prefers to say yes, rather than to say no, or recognising that you are a doctor who likes to feel that you are “sorting your patient out”, may all be a prompt to make yourself consider MUS early on in your assessment process. Doctors managing their own anxiety, or that brought to them by their patients, by ordering *another* investigation or referring on to a specialist is a well-recognised phenomenon in the NHS.

Think about MUS if:

1. Your patient has undergone an unusual level of investigations and/or been to a significant number of hospital specialists relative to their diagnosis (remember MUS can also occur in the context of organic pathology e.g. non-epileptic seizures alongside epilepsy)
2. You experience a high level of anxiety when seeing the patient and their family, and/or feel pressured into referring for investigations or to other specialists in a way that you don't experience with other patients in a similar clinic setting
3. You feel irritated with the patient or their family for not 'getting better'
4. There is a family history of MUS (drawing a quick three-generational family genogram and plotting all illnesses across the generations is never time wasted in any clinic setting)
5. There is significant absence from school as a result of symptoms that appear 'out of proportion' to physical investigations
6. You have an experience of a parent who appears overly-invested in their child's illness and loss of function

Step 2: Beginning the conversation

In an outpatient clinic, or inpatient setting, introduce the idea as early as possible that emotionally-driven mechanisms are often a key contributor to bodily symptoms. As you order investigations, prime the CYP and their family that results may prove to be negative, and that, even if they are, this doesn't detract from /invalidate their experience of pain/tiredness etc.

Provide plenty of informal (chatting away as you examine the CYP) psycho-education on the connection between body and mind e.g. that even at a cellular level our immunity goes down when we're sad and depressed^{3,4}. Equally that many of our figures of speech derive from this knowledge e.g. "I felt sick with shame", "It felt like a real kick in the stomach/guts" i.e. when something really disappointing happens.

During the consultation, explore the connection between the CYP's mood and their symptom severity. Get a feel for whether their symptoms are worse at times of stress, but also ask directly whether e.g. exams/fatigue worsen their symptoms.

You might feel it is your role to rule out a physical cause BEFORE addressing the mental health aspects of the case. However, as well as delaying the process of addressing the anxiety generated by the symptoms, this can create a very unhelpful dynamic. Two alternative approaches are illustrated below.

Figure 1:



Figure 2:



Communication tips.

-Share your uncertainties with the CYP and their family about their condition.

-Do not focus on finding a diagnosis.

-Listen to what the CYP and family wants; explore their concerns. They may not want investigation and may just require reassurance.

-Remain non-judgmental; the CYP is genuinely experiencing the symptoms.

-Pre-empt normal test results and explain what you expect to rule out.

-Explore early on how the CYP's symptoms affect their mood and vice versa.

-Normalise the impact that stress can have on symptoms e.g. muscle overuse/tension causing back pain.

In **figure 1**, the paediatrician finds themselves at the end of the line with investigations and an unexpected referral on to mental health can leave the family feeling fobbed off.

Figure 2 instead takes a more holistic approach from the start, helping to minimise the pseudo-separation between mind and body.

In one-off emergency settings, you may need to operate a little differently. If you note that the CYP has had multiple attendances, raise this with senior colleagues and make sure someone has talked with the CYP and their family about how bodily feelings are often an important communication about the state we're in i.e. about our emotions; tell them this is something you see a lot in the emergency department (ED). Warn them that frequent emergency presentations with unexplained physical symptoms can result in medical harm if staff aren't alert to the possibility of an emotionally-driven component to the CYP's symptoms.

Offer to connect them up with CAMHS, paediatric psychology or a paediatric liaison service, or simply offer to talk to their GP about needing to think a bit more with them about what might be contributing to these frequent presentations to the ED. If possible (and it may not be) offer to see the CYP and family with your mental health colleague. This makes it clear to the CYP and their family that you are seeking help with **your** understanding of their situation, and that you are not simply 'getting rid' of them to someone else. Most importantly they then see mind (mental health) and body (child health) working closely together in the same room and can begin to appreciate the connectedness between mind and body themselves.

Step 3: Making sure you don't fall foul of under- as well as over-investigation.

i. Performing relevant but finite physical investigations

Adult data shows that between 4 and 10% ^{5**} of patients who present with presumed MUS are subsequently found to have an underlying organic illness. With this in mind, it is important that all basic investigations are performed in any CYP who present with MUS.

The type of investigation will depend on the presenting symptoms, but should always include a full history, physical examination and routine blood tests. If these tests results are normal, then at this point you should consider whether any further investigation is required.

This can be a tough decision to make, which may be helped by considering whether there are any sinister signs or symptoms accompanying the presentation. Tables 2 to 6 give some examples, laid out by body system, with red flag symptoms and key diagnoses that may masquerade as MUS.

It is important to note that investigating MUS is a dynamic process. Symptoms may evolve or change over time. Don't be afraid to restart the process of reinvestigation, should the CYP's symptoms change and 'red flags' develop.

ii. Not investigating unnecessarily

Amidst the uncertainty and anxiety generated by MUS, many CYP fall victim to over- as well as under-investigation.

Doctors dealing with CYP with MUS often feel pressurised into performing unnecessary investigations by CYP and/or their families. Studies show that performing investigations where there is a low index of suspicion for underlying pathology does not reduce an individual's anxiety about their MUS ^{6**}. The only result is a small reduction in further visits to primary care.

Furthermore, sending off a battery of investigations may identify minor non-specific and insignificant findings that may impede rather than helpfully support decision making. One study looking at MRI findings in CYP with sickle cell disease identified that 6.6% yielded incidental intracranial findings.⁷

So, when considering whether to perform an investigation, consider whether the perceived benefit of the investigation (factoring in the pre-test probability) outweighs the associated iatrogenic harm, economic impact and possible delay in shifting the focus from diagnosis to symptom management. If you do decide to investigate further, rather than creating the impression that you expect to find underlying organic pathology, pre-empt normal test results and start to prepare the CYP and family for the possibility of MUS being the 'end point' of investigations.

If you continue to question whether further investigation is necessary, and / or you are experiencing pressure from the CYP or their family to do so, utilise the wider team and other colleagues for support and advice, and consider requesting a second opinion. It is important for doctors to protect themselves as well as their patients. Document clearly what you have chosen to investigate, why you have chosen not to order other tests, what you have told the CYP and family and record the absence of relevant 'red flags'.

**** Statistics quoted refer to data collected from the adult population. At present there is very little data available exclusively relating to the under 18 population.**

3 Dhabhar S.F. 'Effects of stress on immune function: the good, the bad and the beautiful' Immunologic research, May 2014, Volume 58, Issue 2-3, pp193-210.

4 Kiecolt-Glaser J. K. Glaser R., 'Depression and immune function: central pathways to morbidity and mortality'. Journal of psychosomatic research, Volume 53, Issue 4, October 2002. Pages 873-876

5 Chitnis A., Dowrick C., Byng R., Turner P., Shiers D. et al 'Guidance for health professionals on medically unexplained symptoms -MUS' January 2011.

6 Rolfe A., Burton Reassurance after diagnostic testing with a low pretest probability of serious disease: Systematic review and meta-analysis. C. 2013. s.l. : JAMA intern Med , 2013, Vol. 173 (6). Mar25;173(6):407-16.

7 Jordan L.C., McKinstry R.C. et al 'Incidental findings on brain magnetic resonance imaging of children with sickle cell disease'. Pediatrics. 2010 Jul; 126(1): 53-61.

ii, Common MUS presentations in secondary care and their associated 'red flags':

<u>Table 2: Neurology</u>	
<u>Symptom</u>	<u>Red flags</u>
-Headache	-Pyrexia
-Dizziness	-Anaemia
-Fits i.e. non-epileptic seizures	-Night sweats
-Faints i.e. LOC/collapse	-Absent tendon reflexes
-Amnesia	-Bladder/bowel dysfunction
-Visual disturbance	-Skin pigmentation
-Tinnitus	-Focal neurology
-Paralysis / going off their legs / muscle weakness	-Ear discharge
	-Hearing loss
	-Nystagmus
	- Papilloedema
	-Family history of neurological disorder
	-Neurocutaneous stigmata eg auxillary freckling, café au lait spots on examination

'Psychogenic non epileptic seizures' (PNES) and functional overlay in diagnosed physical conditions

Around one third of patients who present to neurology outpatient settings are felt to have a functional component to their presentation⁸. PNES are an especially common presentation and considered a form of conversion disorder (See **Appendix 2**).

The prevalence is felt to increase with age and general estimates vary between 1-9% of children with suspected epilepsy⁸. Due to the understandable anxiety that a seizure presentation can provoke in carers and professionals, the potential iatrogenic harm is significant. This again includes multiple investigations being performed, with many CYP spending years on antiepileptic medication unnecessarily before an accurate diagnosis is made. Interagency working (child health, neurology, family, school, CAMHS, paediatric liaison and possibly social care) is important to avoid mismanagement and a very serious misdiagnosis.

For a proportion of CYP with a diagnosis of epilepsy, PNES may also develop. This is often described as a functional overlay i.e. the presence of medically unexplained or functional symptoms in addition to known pathology in the same body system. This is frequently seen in many other long-term conditions such as sickle cell disease. In these cases, which are inevitably complex and challenging, it is important to identify and highlight the existence of this phenomenon to the CYP, family and professionals, and careful and collaborative interagency working is crucial.

⁸ Reilly C., Menlove L., Fenton V., Krishna B.Das 'Psychogenic nonepileptic seizures in children: A review' *Epilepsia*, Wiley online library. Volume 54, Issue 10, Version of Record online: 14 AUG 2013

<u>Table 3: Cardiology / Respiratory</u>	
<u>Symptoms</u>	<u>'Red flags'</u>
-Shortness of breath -Palpitations -Chest pain	-Dysphagia -Anaemia -Weight loss -Pyrexia -Night sweats -Loss of consciousness

<u>Table 4: Gynaecology/Urogenital</u>	
<u>Symptom</u>	<u>'Red flags'</u>
-Dysuria -Polyuria / incontinence -Dyspareunia -Dysmenorrhoea -Menorrhagia	-Anaemia -Pyrexia -Weight loss -Night sweats -Precocious puberty -Haematuria-micro/macrosopic -Abnormal vaginal discharge

Table 5: Rheumatology/ Musculoskeletal	
Symptom	'Red flags'
<ul style="list-style-type: none"> -Back pain -Joint pain -Pain in arms/legs -Persistent / recurrent fever 	<ul style="list-style-type: none"> -Thoracic spine pain -Pyrexia -Weight loss -Night sweats -Anaemia -Focal neurology -Joint restriction, persistent morning stiffness > 15 minutes -Overlying skin erythema, rashes or skin pigmentation on examination

Table 6: Gastroenterology	
Symptom	'Red flags'
<ul style="list-style-type: none"> -Vomiting -Abdominal pain -Dysphagia -Nausea -Bloating -Diarrhoea 	<ul style="list-style-type: none"> -Weight loss -Anaemia -Night sweats -Haematemesis -Pyrexia -Blood in stool -Tenesmus -Steatorrhea -Strong family history of pathology -Rapidly progressing symptoms -Skin manifestations on examination e.g. dermatitis herpetiformis, pyoderma gangrenosum, erythema nodosum, granuloma annular

Box 1. APLEY'S RULE

The further the abdominal pain away from the umbilicus, the more likely there is an organic cause.

iv. Identifying underlying mental distress and considering missed diagnoses

Make sure your own lack of familiarity with diagnosing / ascertaining particular conditions (e.g. autism, anxiety or depression) does not mean they get missed and left untreated. On average, 10-30%^{5**} of all patients who present with MUS have an underlying psychiatric diagnosis.

Always work alongside paediatric liaison, psychology or CAMHS colleagues if they are available. If not, consider using screening tools such as the RCADS

(<http://www.childfirst.ucla.edu/RCADS%202009.pdf>) or 'SDQ'

([http://www.sdqinfo.com/py/sdqinfo/b3.py?language=Englishqz\(UK\)](http://www.sdqinfo.com/py/sdqinfo/b3.py?language=Englishqz(UK))) and then referring on.

It is important to be mindful however that these screening tools are rather blunt instruments in this particular patient group. Patients with MUS tend not to report overt mental health symptoms precisely because their distress is expressed in bodily form (hence the term 'conversion').

A note of caution: separate work by off-site teams never tends to work as well as co-located work between child health (including physical therapies) and mental health, so make sure you work hard to maintain close links with each other, if colleagues are distant from your practice/hospital.

Step 4: Creating chronologies, linking with others, exploring psychosocial factors and safeguarding

i. Creating a chronology and linking with others

For all CYP who present with MUS, it is vital to take a comprehensive social history covering home and school life, as well as peer relationships. This provides a more contextualised understanding of the CYP's symptoms and their meaning within, and impact on, the family. Table 7 outlines various social stressors that are important to screen for early on in the assessment process.

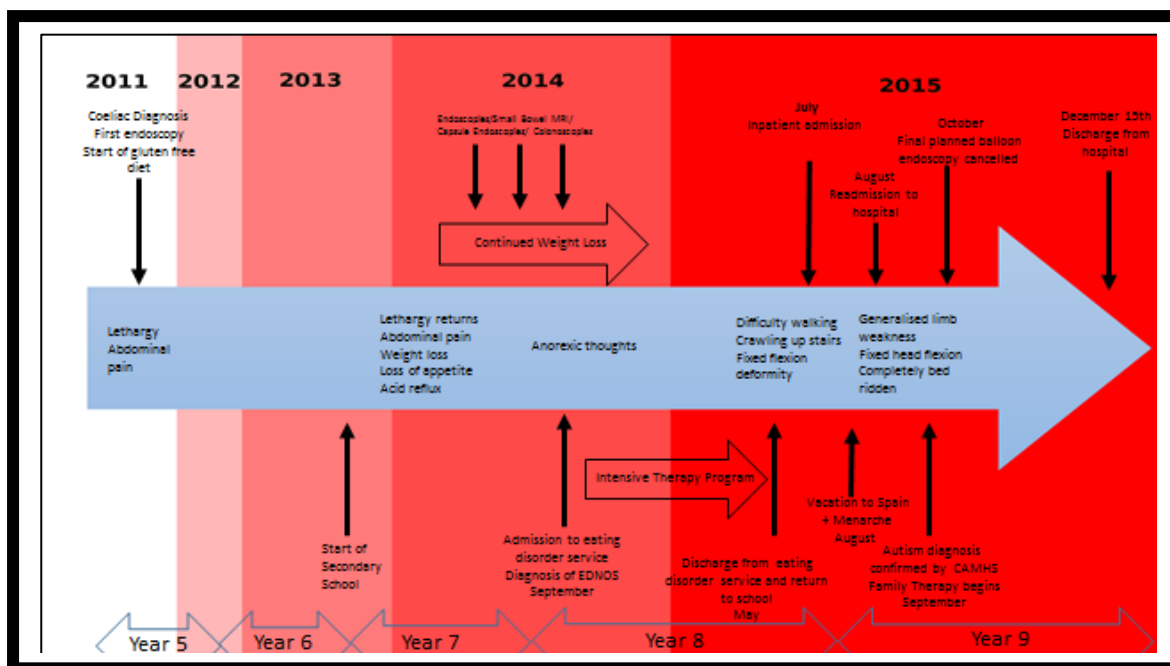
^{**} Statistics quoted refer to data collected from the adult population. At present, there is very little data available exclusively relating to the under 18 population.
⁵ Chitnis A., Dowrick C., Byng R., Turner P., Shiers D. et al 'Guidance for health professionals on medically unexplained symptoms- MUS' January 2011.

Table 7: Predisposing and precipitating factors that may suggest and contribute to a psychological basis for MUS.	
Child factors.	Family factors.
<ul style="list-style-type: none"> - Are social stressors present? e.g. bullying or strained family situation -Is the CYP sensitive to psychological events and social changes? -Does the CYP have a perfectionist attitude, leading them to work very hard at school and currently feel undue pressure? e.g. exams -Does the CYP appear unable to openly react to or communicate their distress? Consider both environmental and genetic factors such as emotional neglect, a learning disability and autism. -Does exacerbation of the symptoms coincide with stressful situations e.g. Sunday night/ Monday mornings or a parental argument? (Ask the parent to keep a diary). -Is there a history or evidence of physical, sexual or emotional abuse? - Does the CYP have a difficult temperament that may be challenging family dynamics and affecting parental relationships? -Are there symptoms suggestive of significant psychological distress, previous trauma and/or a possible underlying mental illness? 	<ul style="list-style-type: none"> -Is there a family member who suffers from MUS? -Is there a family member with mental illness (especially maternal depression)? -Is there evidence of emotional rejection in the family? -Is there evidence that a family member uses the CYP to fulfil their emotional needs excessively***? -Is there family adversity? e.g. divorce, parental discord or bereavement. -Are family members overly critical towards the CYP or is there evidence of taunting and belittlement? - Are family members intrusively overprotective? -Is there the use of threats of violence, abandonment or excessive guilt as a form of discipline? -Does the family impose inappropriate responsibilities or expectations on the CYP for their level of maturity? -Is there lack of parental authority and inconsistent discipline? - Has an in-depth and holistic family history (including potential trauma) been sufficiently obtained for three generations?

*** May be suggestive of possible factitious or induced illness. See table 9 for more details.

One of the most helpful things you can do if you are beginning to wonder if a significant component of the CYP's presentation contains MUS, is to plot all their symptoms over time, and relate these to school year, time point in the school year, onset of puberty and menarche and any other major events in the family's life e.g. divorce and separation, parental ill health or death, grandparental ill health or death, injury or illness in the child, peer difficulties or trauma. Note also any social care involvement, which often relates to psychosocial stressors in the whole family unit.

EXAMPLE OF A TIMELINE:



Once you've done this, liaise directly (preferably in person) with any other clinicians involved, both current and past, and ask them what they felt was going on at the time (don't just read clinic letters; they will tell you little about the real context). This tends to be far more time effective in the long run and allows for better communication and a shared understanding. Also request that colleagues document their views (e.g. in secure email or letter correspondence) if you feel the nature of the discussion and its implication warrants this.

ii. Exploring psychosocial factors in sufficient detail can prove challenging in a busy clinic setting, so you may want to explore using 'the BATHE tool'.

It provides a framework for rapidly exploring psychosocial factors that may be exacerbating the CYP's MUS. For some (particularly below the age of 11 or with learning difficulties), the tool may not be suitable or the questions may need to be adapted to be developmentally (age and stage) appropriate. However, it provides a basic structure to explore the psychosocial component of the CYP's presentation.

Table 8: BATHE Technique⁹.	Screening tool for assessing mental health.
B: Background	What is going on in your life?
A: Affect	How do you feel about it?
T: Trouble	What troubles you the most about the situation?
H: Handle	What helps you handle that?
E: Empathy	This is a tough situation to be in. Your reaction makes sense to me.

i. Safeguarding issues and possible FII (fabricated and induced illness)

For all CYP who present with MUS, fabricated or induced illness must be considered. Your index of suspicion should be higher for FII when the parent is the main complainant about the CYP's symptoms, speaks for the child, persists in requesting more investigations and a diagnosis, and does not accept a psychological approach to symptom management.

There are three main ways in which FII may present

- 1)** Fabrication of signs and symptoms by parental erroneous reporting. This may include the CYP's past medical history. This is the common form.
- 2)** More rarely, falsification of hospital charts/records and specimens of bodily fluids. This may include falsification of letters and documents.
- 3)** Very rarely, induction of illness in the CYP by a variety of means.

Table 9 outlines in more detail common presentations and associated red flags in the history and presentation which should raise your suspicions about FII

⁹ The BATHE method: Incorporating Counseling and Psychotherapy into the Everyday Management of Patients. Leiberman A. Joseph, Stuart R Marian. 1999. 1999 Apr: 1(2):35-38, s.l. : Prim Care Companion J Clin Psychiatry., 1999.

Table 9: When to consider fabricated or induced illness	
Red flags in the history and examination.	Common presentations by parental report (R) or rarely by signs in the CYP (S).
<ul style="list-style-type: none"> -CYP taken to numerous different hospitals -CYP vague about details of illness - CYP has unexpectedly extensive knowledge of disease, as if having read a textbook -Inconsistencies in history given by the parent -Parent hostile or antagonistic - Physical signs that are expected to accompany symptom description are not found - Acute symptoms and signs cease when the CYP is separated from the parent/carer or when CYP is observed constantly, even if parent/carer is present - Evidence that a family member uses the CYP to fulfil their emotional needs excessively 	<ul style="list-style-type: none"> - Fits (R) - BRUE (brief resolved unexplained episode) - Drowsy, coma (S) -Blood loss in vomit or rectally (R), (S) -Failure to thrive (S), feeding difficulty (R) -Bowel disturbance (R) -Severe asthma (R) -Vomiting (R), (S) -Skin lesions (S) -Disability (R) -False allegations of abuse (R) -Blood in urine (R), (S)

If erroneous or false reporting by the parent is found and the approach advocated here is obstructed by parental disagreement, referral to social services is needed. If you suspect FII, you should anyway be following the hospital safeguarding pathway. Depending on the severity of the presentation, an immediate hospital admission should be considered to prevent the CYP from significant harm or to separate them from the parent/carer to confirm the diagnosis. Further management will need to be decided by the multidisciplinary team. In severe cases, psychiatric intervention for the CYP may be required.

On a more general safeguarding level, you should be aware that CYP who present with MUS have a significantly higher prevalence of abuse and neglect than the general population, and the presence of MUS may be the only clue to the situation. You may need to involve social services early, with a clear statement about the nature of your concern.

The RCPH endorsed guideline on the '[Fabricated or induced illness by carers \(FII\)](#)' is a useful resource for more information.

Take away messages from steps 3 and 4:

On receipt of the referral to secondary care, many doctors find it difficult to shift their focus from investigation to management and symptom control.

The four key questions that are important to answer at this stage are:

- 1) Are there any red flags associated with the presenting symptoms which are suggestive of an underlying organic pathology?
- 2) Could the CYP have some kind of underlying psychological disorder?
- 3) Are there any factors in the school, home or peer group which could be contributing to the CYP's presentation?
- 4) Is this CYP at risk of harm?

If these avenues have been explored sufficiently by the MDT, then you should instead shift your focus to symptom control and on-going psychosocial explorations.

Step 5: the management of MUS and retaining a longer-term connection with the patient.

Once medical investigations are definitively completed - and there must be a firm line drawn at this stage - the focus can shift to understanding the CYP's symptoms in a different way, with the emphasis on investigations changing to that of symptom control.

It is important not to allow the CYP and their family to feel abandoned at this stage. Their symptoms are still present, feel just as bad and must be respected with just as much serious attention as they were during the investigatory stages.

Appendix 7 is a leaflet that should be given to every patient once the presence of MUS has been identified.

Create a simple management plan with the CYP and their family to help them manage the symptoms effectively. Table 10 outlines some examples of what management to offer.

With the exclusion of pathology and a simple management plan in place, it is appropriate to transfer the CYP's care back to the GP for on-going symptom management and review, ideally remaining in the background yourself. Your letter to the GP should note the absence of 'Red Flags', exclusion of relevant pathology and **that no further investigation is currently indicated**. In addition, caution about re-emergence of symptoms and your willingness to get involved again should this occur

'Red Flags' can develop at any time and 4-10% of patients with MUS will have an underlying organic cause^{5**}. Therefore, emphasising to the CYP and family, and mentioning in your GP letter that the CYP can be re-referred in the future should further investigation be warranted is an important part of your handover management.

Appendix 6 is a letter template that can be sent to the GP.

As well as communicating with the GP, it is important to update school and social services (if previously involved). Signpost them to online educational resources and advice that may help educate and support the CYP, as well as those working with them (See **Appendix 5** for an example list of support services).

Communication tips.

Don't focus on giving a diagnosis

Do focus on symptom management

Empathise with the situation and the frustrations the CYP and their family are feeling, especially if no cause is identified

Empower the CYP and family by involving them in creating the initial management plan

Use word scripts for difficult conversations - Appendix 3

Don't abandon the CYP and their/family with their symptoms after medical diagnoses have been excluded. Evidence your on-going concern by the co-creation of the care plan and carefully negotiating step down to primary care. Mention future review as a possibility

There are three **possible trajectories** for CYP who present with MUS.

- 1) **The spontaneous resolution of symptoms:** For a significant number of CYP their symptoms will resolve spontaneously over time. Table 1 outlines the prognosis of symptoms depending on the system involved^{2**}.
- 2) **The persistence of symptoms with adequate symptom control:** For a number of CYP, symptoms may persist but at a level where they do not impair function for a significant amount of the time. Reassurance and/ or simple management strategies (instead of diagnosis and cure) may be all that is required to cope with their symptoms and to ensure that a normal quality of life is maintained.
- 3) **The persistence of symptoms with inadequate symptom control:** For around 1% of CYP^{**}, symptoms will become chronic and poorly controlled. It is this group that are at the greatest risk of iatrogenic harm and cause the majority burden of MUS on the health service. They need careful management and support. For some, a referral for psychological interventions or to psychiatric services may be appropriate. For further information, see 'Step 7: Involving experts when necessary'.

Only time will determine which trajectory a CYP with MUS will follow, and unless one person holds an overarching view of the CYP's care, progress may be poorly judged and symptoms inadequately, rather than adequately, controlled.

Consider the management of MUS as a cycle. Symptoms can change over time and red flags may develop on the background of chronic symptoms. CYP who present with MUS may go on to develop a concurrent organic illness, so reinvestigation may be necessary at a later date. CYP also want to feel listened to and understood, and even CYP who are successfully managing their symptoms should have regular planned reviews to ensure an underlying illness is not being missed. Depending on the level of symptomatology, a single appointed lead GP or paediatrician is therefore best placed to be the long-term reviewing doctor for a CYP with MUS.

i. Exploring, understanding and appreciating a CYP and family's concerns

Family anxiety surrounding a CYP's MUS is natural and should be acknowledged and legitimised. It is almost to be expected that family anxiety will persist despite your reassurance and exclusion of underlying organic pathology. This is a normal reaction in concerned parents/ carers. This is why exploring and understanding the impact the MUS have on the CYP and their family should be considered a routine part of your management.

Table 11 outlines family factors that can increase the chances that MUS will persist rather than resolve spontaneously or become adequately managed. If such factors are present, and symptoms remain debilitating despite an adequate trial of management strategies, a referral for family psychological support i.e. family therapy should be considered. This setting offers the opportunity to think about symptoms in a different way i.e. to re-frame them in the family mind-set, the aim being to better understand what the symptoms are achieving (e.g. protecting the CYP from aversive experiences like a return to school, growing up, becoming more independent etc) and to help the family and CYP shift the focus from illness onto rehabilitation and symptom control.

Table 12 outlines the various psychological support services. Unfortunately, the demand for family therapy often exceeds the availability. Therefore, responsibility lies with all healthcare professionals involved with the CYP to approach and explore unhelpful family dynamics, including

predisposing, precipitating and perpetuating factors that may hinder recovery (see Tables 7 and 11).

<u>Table 10: Management strategies that should be trialled for up to six months.</u>		<u>Further management strategies for severe symptoms.</u>
<u>System</u>	<u>Simple management advice</u>	
Palpations, shortness of breath	Relaxation techniques	<ul style="list-style-type: none"> • Pain clinic • Fatigue clinic • Relaxation techniques • Psychological therapies e.g. cognitive behavioural therapy • Graded Exercise Therapy • Self-management strategies: see Appendix 5 • Psychological therapy e.g. family therapy if perpetuating factors identified • Support groups: see Appendix 5
Back/limb pain	Heat packs, physiotherapy, regular exercise NSAIDS, diclofenac patch, muscle relaxants Relaxation and distraction techniques Gradual increase in activity ie grading and pacing advice (after establishing a baseline) Sleep hygiene advice. NICE guidelines on Chronic Fatigue Syndrome	
Fatigue		
Abdominal pain	Heat packs, dietary modification, simple analgesia, antispasmodics, peppermint oil IBS patient leaflet , Stress management, relaxation and distraction techniques	
Headache	Avoid triggers e.g. lack of sleep/excessive TV use. Simple analgesia: paracetamol, ibuprofen, relaxation and distraction techniques Sleep hygiene advice. Exercise. Chronic tension headache leaflet	
Limb weakness	Consider amitriptyline/gabapentin. Graded exercise. Physiotherapy, OT	
Dysuria	Adequate fluid intake, avoidance of caffeine and alcohol. Overactive bladder syndrome patient leaflet.	

** Statistics quoted refer to data collected from the adult population. At present, there is very little data available exclusively relating to the under 18 population.

² Therapies, Improving Access to Psychological. 2009. Medically Unexplained Symptoms (MUS): A whole systems approach in Plymouth. Plymouth : NHS Plymouth, 2009.

<p><u>Table 11:</u></p> <p><u>Family factors that may contribute to persistence of MUS in a CYP.</u></p>	<p><u>Examples of systemic questioning allowing exploration of the family set up.</u></p>
<ul style="list-style-type: none"> - Are any members of the family particularly distressed about the CYP's symptoms and why? - Does this focus unnecessary attention on the symptoms? - Does the family always have a medical approach to illness rather than a psychological one? - Is there evidence of low emotional intelligence in the family? - Is there evidence of high expressed emotion in the family? - Are family members intrusively overprotective? Is the 'sick role' inadvertently encouraged? 	<p>What are the family 'beliefs' about the illness?</p> <ul style="list-style-type: none"> -When did it start? -What was 'going on' at the time? -How severe is it? Will it get better? -What would need to happen for it to get better? -Are there differences in these beliefs-why might they be important? <p>Who is most worried and why?</p> <ul style="list-style-type: none"> -What 'function' does the illness serve? -What would change in the family if it resolved? -And by extension, what is the illness maintaining? -What is not being thought about?

<u>Table 12: Different psychological support services</u>	
Counselling of CYP or parent/carer	<p>Sessions are non-directive, unstructured, and supportive and aim to help the CYP or parent (as adult patient) cope with difficulties not severe enough to require specialist psychological interventions</p> <p>Parental/carer counselling focuses on enhancing parental coping by allowing them to work through problems and find their own solutions</p>
Family Therapy	<p>Sessions involve various combinations of the entire household, as well as non-resident grandparents or other involved relatives. Work aims to detect and address dysfunctional family relationships that may be inadvertently contributing to persistence of the CYP's MUS</p>
Cognitive Therapy	<p>Sessions and homework are used to uncover and explore unhelpful thinking styles which may be driving negative feelings, beliefs about the self and associated behaviours</p>
Psychodynamic Psychotherapy	<p>Sessions tend to be more frequent eg at least once weekly and aim to explore in a more in-depth manner unconscious conflicts that may be driving the MUS</p>
Parenting Groups	<p>Sessions known as 'Parent Training' tend to be highly structured and deliver a course aimed at enhancing parenting receptivity to their CYP's positives, as well as building greater effectiveness in their parenting approaches to unhelpful behaviours</p> <p>Parent support groups – see counselling</p>
Behavioural therapy	<p>Sessions focus on eradicating specific behaviours that are felt to be both maladaptive and detrimental to a CYP's quality of life</p>

ii. Effective communication:

Poor communication risks destroying the therapeutic relationship and may lead to the CYP and their family losing trust in you and the medical profession. This can alienate the CYP, exacerbate their symptoms and lead to recurrent presentations to primary and secondary care in search of help, a diagnosis and a cure. By using the communication tips provided in every section of the guideline, along with word scripts for difficult conversations (**Appendix 3**), you should minimise the likelihood of your communications triggering hostility and defensiveness in the CYP and their family.



Top tips from a CYP/family perspective.

1. Please don't make us feel guilty for being an in-patient, especially when you haven't shared your suspicions about MUS with us. My child's pain and inability to walk was as real as any other medically explained child's symptoms.
2. Please be honest from the outset- explain that MUS doesn't mean that you don't actually know what's wrong with my child.
3. Please don't tell me that my child is making it all up, or that it is all in his head- this leads me to question my own sanity and then not be fit to support my child in their time of crisis.
4. Please spend time listening to the whole history, diagnoses offered, parent and CYP thoughts as well as the emotional state of the CYP and family.
5. Explain to me that the pain my child is feeling, despite not having a medical explanation, is still a genuine pain that hurts like any other pain.
6. Don't tell me that there is nothing more you can do for my child and send me home with a child, in a worse physical condition than when we arrived and with the prospect of very little outpatient support.
7. Make sure that you communicate between yourselves so that I don't get 3 or 4 different messages from different Drs, specialists or departments and so that I don't have to retell the history hundreds of times.

Step 6: managing your, as well as other staff members', feelings about this type of work

Work with cases involving MUS can stir up strong feelings in those caring for the CYP, as well as those providing clinical care. Some physical healthcare staff can really struggle to accept that these unexplained medical symptoms are genuine and can inadvertently make CYP feel like frauds (especially as they lie in a hospital bed / attend an outpatient clinic alongside another CYP with diagnosed physical illness). Such feelings, even if unexpressed, can begin to feel frankly aggressive towards the CYP and their family.

Equally, some staff can experience overwhelming, and at times almost disabling, feelings of failure and inadequacy. Healthcare is often about making our patients 'better' and everyone struggles when this is not happening. If you can remind yourself and your colleagues that it's precisely not about 'making' the CYP better, but about sticking with them as their body/mind dis-ease eases and they start to lose their symptoms/learn how to adapt to them and progress nonetheless.

Whoever is acting as lead doctor on the case will have to hold the hope / positive outlook. If this is you, you will need to remind everyone, staff, as well as the CYP and family, that the mainstay of all your approaches is to show the body that we mean to slowly, slowly get back to 'business as usual' ie that you and the team will be encouraging the CYP's body to function, as much as possible, and not necessarily all at once, within a daily schedule that is about as ordinary an existence as possible for someone of their age. This expectation needs to stay in place throughout recovery/into the chronic symptom management phase, and it can sometimes be one of the most difficult things that you will have to hold on to.

Communication tips.

-Don't force a psychological explanation on the CYP and family. Allow them time to make the connection in their own time

-Remain non-judgmental

-Reiterate and normalise the impact that stress can have on symptoms e.g. muscles overuse/tension causing back pain

-Acknowledge that the CYP is genuinely experiencing the symptoms and it is important to support them emotionally during this time

-Use word scripts for difficult conversations see page

Step 7: Involving experts when necessary

Involving experts in the right way and at the right time is essential. A 'gold standard' approach to the management of MUS involves collaborative care from the start.

A 'stepped approach' should be taken with different levels of intervention. The CYP's progression will depend on how well they respond to each level of intervention

STEP 1: Basic intervention:

All children with a presentation that has a component of MUS should be seen by a practitioner who understands MUS, can introduce and explain the possibility *at the first consultation*, and provide basic interventions. Senior paediatric clinicians should be involved from an early stage to facilitate this

STEP 2: Joint review/ mental health consultation:

At this point, basic interventions have been tried. Local mental health specialists should be involved. This may be at the level of consultation, or ideally via a joint review with paediatric and mental health clinicians. Screening for specific mental health conditions should occur at this stage.

STEP 3: Further specialist assessment:

Further assessment and intervention by mental health specialists.

Importantly, these stages are not fixed, or time-bound. If concerns are very high at initial assessment, then rapid escalation and specialist support may be necessary. A delay in appropriate management and support may cause the CYP to miss large amounts of school and social interaction, both of which are vital for healthy development.

Table 13/14 gives an outline of when a child/YP who presents with MUS should be referred to psychological or psychiatric services. It follows the general rule that a paediatric psychology or paediatric liaison referral is preferable when organic illness is under investigation or has been identified. A CAMHS referral is prioritised when an organic cause has been sufficiently excluded.

When discussing the wish to involve mental health colleagues in the CYP's care, it is important that you continue to acknowledge the serious impact of their symptoms and your own need for help in working out how best to help them. Families are likely to be understandably defensive if the decision to refer comes without warning or a pre-emptive discussion about the important interplay between mind and body. CYP and family engagement is generally better if a joint approach is taken rather than care being transferred from physical to mental health services. You should aim to remain involved with cases even after mental health intervention has begun for several reasons

- To avoid communicating to families and young people that the symptoms are no longer a concern to you / physical health.
- To remain accessible for overlooked or emergent pathology.
- For ease of access to further physical investigations and therapy e.g. physio.

However, despite their known efficacy, many hospitals do not have an in-house mental health liaison service and at best may have only one nurse to cover the entire inpatient and outpatient

department during office hours. Because of this, the threshold for specialist service involvement and capacity for collaborative care may be limited.

In order to achieve the 'stepped care' model in all trusts:

1. The case needs to be made by senior clinicians from both physical and mental health for the benefits of effective liaison services. In certain cases, support may also need to be commissioned from mental health trusts as well.
2. There should be joint leadership at a local level by child health and mental health, incorporating training of staff and agreement between both about protocols for joint work and referrals.
3. There should be minimisation of organisational barriers to joint work, including ready access to consultation, training and joint appointments. Co-location is also encouraged where possible.

A final note

Working with MUS can be challenging, with the navigation through various diagnostic investigations to the acceptance of symptom control (not cure) being difficult for doctors and patients alike.

At worst, diagnoses can be missed, and/or significant iatrogenic harm suffered. In particular, poor communication risks the destruction of the therapeutic relationship and may lead to the CYP and their family losing trust in the medical profession. Furthermore, this can exacerbate the CYP's symptoms and lead to recurrent presentations to primary and secondary care in search of help, a diagnosis and a cure.

By keeping an open mind, maintaining a degree of unconditional positive regard and seeking support from this guide and other professionals, you can help prevent destruction of the therapeutic relationship, minimise iatrogenic harm and lessen the economic burden of MUS. You can also increase your own confidence and satisfaction with work that you have previously found challenging and a significant source of stress.

A case study of MUS

- Age 13 at presentation
- Caucasian female
- Two parent family
- Older of two sisters (younger sibling 10)
- Attending non-selective girls state secondary school, Year 8/9 cusp
- Home counties residents, owner occupiers
- Both parents' professionals, mother not currently employed because of child's care needs

- 7 – 11 July admission to teaching hospital from the local eating disorders clinic with sub-acute deterioration. 'Struggling to walk 200m, lack of balance and dragging her left foot, reduced power in all four limbs.' Paediatrician noted fixed flexion deformity. Home via the local district general, after agreement that symptoms could be adequately managed at home. Diagnosis by physios: chronic fatigue with functional overlay
- 3 August admitted with acute deterioration in symptoms to teaching hospital, direct from a family holiday in Spain. During the holiday, she had undergone a rapid decline, with widespread weakness and extensive immobility. Unable to feed self or meet own basic care needs. Mother wanted to take her to a Spanish hospital but father insisted they wait to consult doctors when they got back to the UK

Background

- January of Year 4, started feeling tired a few days before school term started
- Year 4 "a write off". 90% attendance despite tiredness and abdominal pain
- July of Year 4 coeliac disease diagnosed. Symptoms resolved with diet
- September Year 5 all fine. Year 5 and 6 no issues
- October of Year 7, abdo pains "within weeks" of starting at secondary school
- Stopped PE by end of first half term because of "acid regurgitation when she ran"
- January of Year 7, mother asks GP to refer for ASD assessment (goes on waiting list)
- February of Year 7, now on a reduced timetable at school, with increasing time away from peers in student support

May of Year 7, five day admission to local DGH refusing to eat. Reporting feeling full after ever decreasing amounts of food. Sent home on ENSURE with referral to CAMHS. Seen July and referred to specialist inpatient unit within a paediatric setting

September of Year 8, specialist inpatient unit diagnoses atypical anorexia "it didn't seem off piste" said mother of this diagnosis and referred to the local eating disorders service. "I didn't feel I was in the same boat as the other parents" (in the ED service)

Year 9 starts an intensive day programme (including education) which runs all academic year

During the summer term of Year 9, during increasing periods of school reintegration, posture deteriorates and complaints of tiredness increase. Repeated visits to GP are met with the response "nothing's wrong". Mother experiences feelings of "utter helplessness". Intensive therapist queries conversion disorder, but X-rays raise concern about possible previous scurvy.

Overview of investigations

Endoscopies

- June 2011: OGD - consistent with coeliac disease
- May 2014: OGD and a colonoscopy - unremarkable
- July 2014: Capsule Endoscopy - unremarkable

Ultrasound

- April 2014: Abdominal ultrasound- unremarkable

Imaging

- July 2014: Abdominal MRI scan - unremarkable
- July 2015: Spinal X-Ray - unremarkable
- August 2015: Head and spinal MRI - unremarkable
- August 2015: Bilateral knee X-ray - Flexion deformity / slightly osteopenic/no effusions

Blood Tests

May 2014 - Faecal calprotectin - 476 (<51), June 2014 - 840, September 2014 - 281

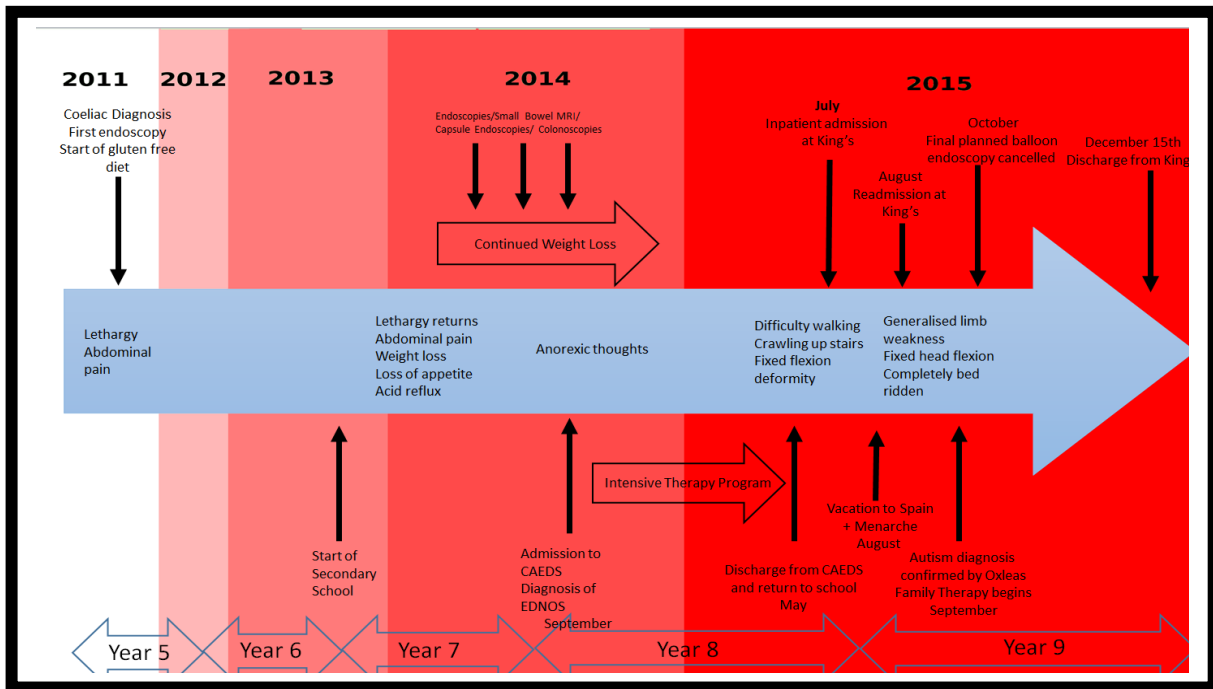
August 2015

- SM antibodies - negative
- Mitochondrial antibodies - negative
- Gastric parietal cell antibodies - negative
- Antinuclear antibodies - negative
- Anti-streptolysin O - negative
- EBV DNA - negative
- Rheumatoid factor - 7 (<9)

September 2015

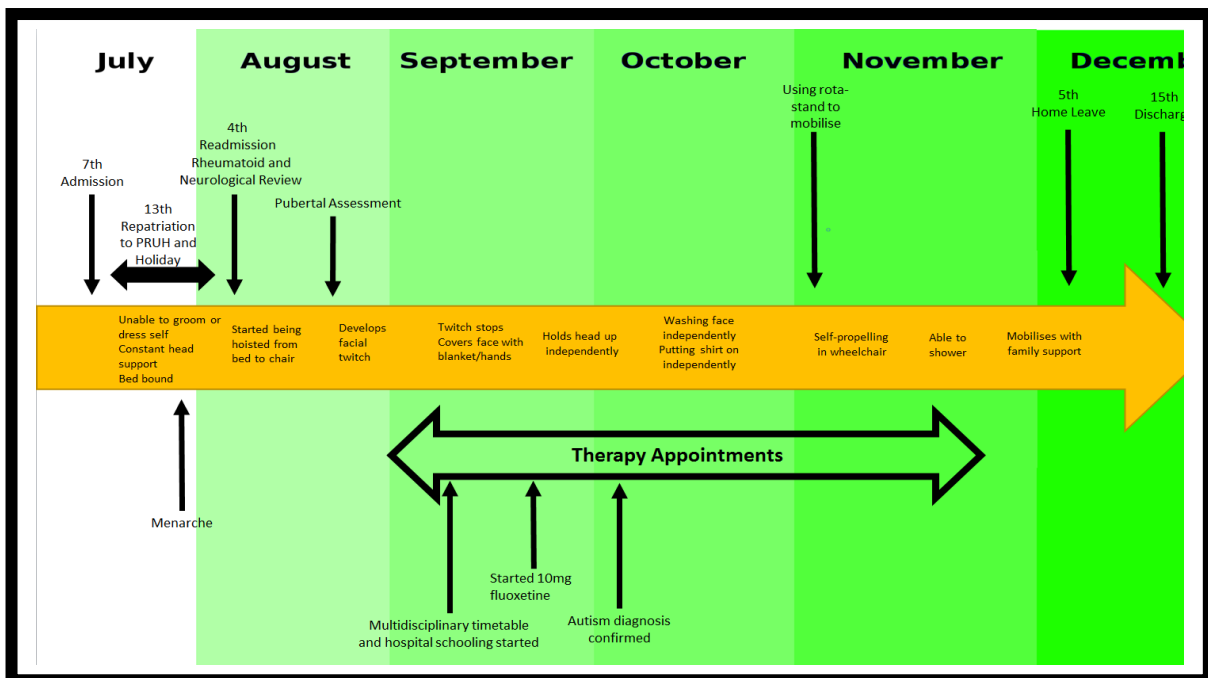
- ESR - 35 (<15)

Timeline of CYP journey



Treatment involved parallel working between nursing on the ward (in a manner that did not ‘indulge’ or give excess attention to the symptoms), week day physical therapies, week day education in the hospital school (a place to feel competent and not sick), psychological work with the family, behavioural work (exposure mainly) with the young person, regular appearances by the paediatric consultant alongside the paediatric liaison consultant (to embody concretely the joining of mind and body) and regular MDT work / communication to ensure that everyone was working in unison and pulling in the same direction (even those who struggled to accept the nature of the presentation, and understand that it was not fabricated or attention-seeking).

Timeline of treatment and recovery



Appendix 1

Table 1: Prognosis of MUS ^{2**}		
<u>System</u>	<u>Frequent MUS presentations.</u>	<u>% recovery after 12months</u>
Cardiology/ Respiratory	SOB, palpitations, chest pain	47%
Gastroenterology	Vomiting, abdominal pain, dysphagia, nausea, bloating, diarrhoea	42%
Musculoskeletal/ Rheumatological	Back pain, joint pain, pain in arms/legs	55%
Neurology	Headache, dizziness, LOC, amnesia, visual disturbance, tinnitus, paralysis, muscle weakness, PNES	38%
Gynaecology/ Urogenital	Dysuria, dyspareunia, dysmenorrhoea, irregular menstruation, menorrhagia	34%

**** Statistics quoted refer to data collected from the adult population. At present, there is very little data available exclusively relating to the under 18 population.**

² Improving the Classification of Medically Unexplained Symptoms in Primary Care. Rosendal M., et al. 2007. 2007, The European Journal of Psychiatry.

Appendix 2

Confusions and disputes about terminologies and the label 'MUS'.

The term 'MUS' can be confusing or controversial, especially if misused. It should not be used as a diagnosis, but as a description for the various symptom presentations which require common approaches to management. 'Body distress symptoms' can sometimes be an alternative, less confusing and more readily understandable term to use with CYP and families

The upcoming ICD 11 is likely to use the diagnosis 'Bodily Distress Disorder' to encompass all terms under F45-somatoform disorder (apart from hypochondriacal disorder) and F48.0-Neurasthenia, into a single category.

The emphasis within this diagnostic category is on the level of distress and disability associated with the bodily symptoms, and the resultant contact with health care providers. Much less emphasis is placed on whether there is or isn't a diagnosed physical illness.

Bodily Distress Disorder has been favoured by researchers, clinicians and patients alike partly because it simplifies and streamlines diagnoses, whilst dispelling some unhelpful connotations.

Similarly 'persistent physical symptoms' is another term utilised particularly in primary care which encapsulates long term conditions such as Chronic Fatigue Syndrome, Irritable Bowel Syndrome and Fibromyalgia.

However, unlike MUS, these terms do not allow for a single pathway to be followed from the point of presentation to the point of diagnosis or symptom management.

Some doctors dealing with MUS prefer the term 'Functional Disorder'. This description may be appropriate once physical illnesses have been sufficiently excluded.

Others mistakenly see the term MUS as interchangeable with Somatic Symptom Disorder (SSD), Factitious Disorder and Malingering (DSM5 terms). These are not the same as MUS.

Table 13 (below) outlines the specific diagnostic criteria for each of these disorders. SSD is the manifestation of a psychological illness through physical symptoms and requires at least a six month duration. A physical illness may or may not be present and instead the emphasis is on the degree of preoccupation the patient has with the symptoms, along with the subsequent effect on their functioning. Factitious disorder and malingering on the other hand are the intentional feigning of symptoms for either primary or secondary gain respectively.

Whilst CYP who present with MUS may later go on to be diagnosed with one of these conditions, it is inappropriate to diagnose any of these conditions until a full patient work up has been performed over time.

Table 13: DSM 5: Somatic symptoms and related disorders

<u>Somatic Symptom Disorder</u> (Formerly known as Somatoform Disorder)	<u>Conversion Disorder</u>	<u>Illness Anxiety Disorder</u>	<u>Factitious Disorder</u>	<u>Malingering</u>
<p><u>Criteria A, B and C must be fulfilled</u></p> <p><u>A:</u> One or more somatic symptoms that are distressing and /or result in significant disruption in daily life</p> <p><u>B:</u> Excessive thoughts, feelings and behaviours related to these somatic symptoms or associated health concerns: at least one of the following must be present.</p> <ol style="list-style-type: none"> 1) Disproportionate and persistent thoughts about the seriousness of one's symptoms 2) Persistently high levels of anxiety about health or symptoms 3) Excessive time and energy devoted to these symptoms or health concerns <p><u>C:</u> Although the symptoms may not be continuously present, the state of being symptomatic is persistent for >6 months</p>	<p><u>Criteria A, B, C and D must be fulfilled</u></p> <p><u>A:</u> One or more symptoms of attached voluntary motor or sensory function</p> <p><u>B:</u> Clinical findings demonstrate incompatibility between the symptoms and recognized neurologic or general medical condition (Eg. Hoover's sign of functional limb weakness)</p> <p><u>C:</u> The symptoms or deficit is not better explained by another medical or mental disorder</p> <p><u>D:</u> The symptom or deficit causes significant distress, psychosocial impairment, or warrants medical evaluation</p>	<p><u>A:</u> A preoccupation with and fear of having or acquiring a serious medical illness</p> <p><u>B:</u> Persists for > 6 months despite appropriate medical evaluation that excludes a medical disorder and despite reassurance</p> <p><u>C:</u> It is not better accounted for by depression or another mental disorder</p>	<p><u>A:</u> Intentional production of false or grossly exaggerated physical or psychological symptoms</p> <p><u>B:</u> The motivation for the behaviour is to <u>assume the sick role</u></p> <p><u>C:</u> External incentives for the behaviour are absent</p>	<p><u>A:</u> Intentional production or feigning of physical or psychological signs or symptoms</p> <p><u>B:</u> The motivation for the behaviour involves <u>external incentives</u></p>

Appendix 3

Word Script Examples:

The textbook of adolescent medicine:

'It is clear that you have been experiencing some difficult symptoms for quite some time. Our aim is to identify what is causing these symptoms. As you have had these symptoms for quite some time now it is unlikely they will go away very quickly so we need to put together a plan that reduces your symptoms so they don't interfere with your life so much.'

'We know that people who have to deal with these symptoms for a long period often start to feel down, do you think this is the case with you?'

'We also know that if you are feeling low or have emotional stress in your life that this stress can make your symptoms feel worse, so, it is important that we consider your emotional health as well as your physical health to try and improve things for you as much as possible' 'Some people find speaking to a member of our mental health team helpful in this situation'.

A whole system approach to MUS in Plymouth

NEGOTIATING A NEW MODEL OF UNDERSTANDING AFTER NEGATIVE RESULTS (REFRAMING)

Physiological imbalance

- "Often bowel symptoms can be caused by imbalances in the way the intestines work – pressure build ups cause pain and rapid transit diarrhoea"

Reaction to stress and strain / nervousness

- "I sometimes see such reactions in stressed people. DO YOU THINK THIS COULD BE THE PROBLEM IN YOUR CASE?"

Depression lowering pain threshold ("you're more sensitive when depressed")

- "When depressed the pain becomes more intense, because you are more sensitive. COULD IT BE SO IN YOUR CASE?"

Muscular tension in anxiety and nervousness

- "Stress(emotional) strain can result in muscular tension, I have seen this in many patients. I WONDER IF THERE COULD BE SUCH A LINK FOR YOU?"

Demonstrations:

Practical (hyperventilation, muscular tension)

- "If you go shopping and carry home heavy bags then your arms may start hurting. Likewise, a little tension in your muscles over a long time will cause pain. WHAT DO YOU THINK ABOUT THIS?"

"Here and now" (nervous about consulting the physician). Only use if they're obviously experiencing the symptom at that moment

- "I can see you feel bad when we discuss this. HOW DOES IT FEEL in your back (or different body part) RIGHT NOW?"

Normalising Explanation:

(Either)

- Temporary imbalance in their system that will right itself in time. Could be related to hormones, nerves, muscles.
- "The more you think about/touch the affected area, the worse it feels"

(Or)

- Give explanation relating physical symptom to psychosocial problems of lifestyle because of link in time or physiology. Examples:
 - "Stress at home causes muscles in your body such as your back to tense and muscles held tight for long periods ache"
 - "Frustration about not working leads to depression and depression lowers the pain threshold and makes you tired"

Hormonal Explanation:

Links emotions to the production of hormones that cause physical problems. Examples:

- "We currently know that there are some hormones, such as adrenaline, ... in the circulating blood that may increase this type of pain ... moreover, these hormones more easily affect people like you, who are responsible, hard workers, sensitive"

Adapted from TEFM model – Fink et al, 2002

A whole system approach to MUS in Plymouth

GOAL SETTING & RESTORATION OF FUNCTION

Moving the conversation towards positive goals after dealing with negative results can be a more productive end to consultations

- **Preparation for consultation**
 - Develop summary of problems and potential treatment plans prior to consultation
- **Educate the patient**
 - Evaluate the patient's understanding & illness beliefs
 - Discuss MUS and how problems associated with this diagnosis apply to the patient
 - Describe treatment options and the associated risks and benefits
 - Describe the prognosis of the illness
- **Treat anxiety, depression and any other mental health problems**
 - Medication
 - CBT Therapy or counselling
 - Referral to specialists
- **Collaborate with the patient and determine their preferences**
 - Determine the patient's goals for recovery
 - Determine the patient's opinion on priority of problems and urgency for treatment
 - Determine the patient's opinion on the recommended actions or options
 - Determine the patient's motivation towards, and identify barriers to, treatment
 - Obtain the patient's consent to the plan
- **Goal-setting**
 - Restoration of function is the main goal of treatment
 - Negotiate brief, measurable and achievable goals with the patient
 - Only 2/3 goals should be made at each consultation
 - Goals should be reviewed and updated at each consultation
- **Empower the patient for self-management**
 - Move the responsibility of patient improvement to the patient
 - Encourage a change in lifestyle, including exercise, diet & stress reduction
- **Implement the action plan**
 - Coordinate treatment / action plan activities
 - Establish a referral and interdisciplinary team approach, if indicated

Patient presents with MUS

Step 1: Performing basic investigations

Perform a full history, examination and baseline blood tests

** Type of referral depends on the support services available in each hospital

Step 2: Identifying an underlying illness and safeguarding patients

Are there any red flags associated with the presenting symptoms?

Is there evidence of significant social stressors, mental distress or an underlying mental illness?

Could the child be at risk of harm from themself or others?

Yes

No

No

Yes

No

Yes

Further investigation needed for underlying pathology

No further investigation needed at present
-Document the absence of red flags

1. Involve social services and school to obtain a collateral history
2. Refer to CAMHS or liaison services for further assessment **.

1. Involve social services for further assessment
2. Follow the safeguarding policy

Step 3: Creating a management plan

Create a simple management plan with the patient depending on their symptoms

Step 4: Making a referral

Does the patient have either of:
1. An unreasonable preoccupation with the associated symptoms
2. Symptoms causing debilitation in excess to what would be expected given the underlying disorder

Are the symptoms:
1. Poorly controlled?
2. Significantly impacting the patient's life?
3. Have simple management strategies been trialled for 6 months?

Discharge the Patient's care back to the GP
1. Send a discharge letter to the GP
2. Give the patient a patient leaflet

Refer to the Liaison Team **

Refer to the CAMHS team **

Step 5: Consider revisiting steps 1-4 if the patient's presentation changes at any point

Appendix 5:

Supportive Resources

- 1) Youth in mind: Online support website for stressed children and teenagers and those who care for them.
<http://www.youthinmind.info/py/yiminfo/Start.py?language=euk&country=uk>
- 2) MindEd: Online educational resource on children and young people's mental health. Includes a tutorial on unexplained physical symptoms. <http://www.minded.org.uk>
- 3) Royal College of Psychiatrists: Medically Unexplained Symptoms, information leaflet for patients, carers and young people.
<http://www.rcpsych.ac.uk/healthadvice/parentsandyouthinfo/parentscarers/medicallyunexplainedsymptoms.aspx>
- 4) Rethink: Online support website for everyone affected by mental illness.
<https://www.rethink.org/services-groups>

Self-Management Strategies:

- 1) Sleep management leaflet:
www.patient.co.uk/showdoc/27001301
- 2) Expert patient programme:
www.plymouthguild.org.uk
- 3) Tiredness leaflet:
www.rcpsych.ac.uk/mentalhealthinfo/problems/sleepproblems/tiredness.aspx
- 4) Pain leaflet
<http://www.painclinic.org/aboutpain-copingwithpain.htm>
Pain toolkit
- 5) Online CBT:
<http://www.beatingtheblues.co.uk/connect/>

Appendix 6:

GP Referral Letter

RE:
DOB:
NHS:

Date:

Dear Colleague,

I reviewed the above patient in my outpatient clinic today who presented with the following symptoms.

-

I have investigated them as far as is clinically indicated and no organic pathology has been identified. At the current time, no further investigation is indicated and the mainstay of treatment will be symptom control.

The following investigations have been found to be normal:

-

During our consultation, I created a simple management plan with the patient to aid their symptom control. I am discharging the patient back to your care and would be grateful if you could review them in one month to assess their progress and make any alterations to the management plan.

Should any red flags develop in the future, please do not hesitate to re-refer the patient for further investigation and review.

Yours sincerely,

Letter direct to patient and family

Date

Re patient details

Dear Parents / Young Person

Thank you for coming to see me in clinic today

As you know, I have been seeing... (child's name)...../you about his/her/your....(description of symptoms in plain English)

And as you also know, we now have back the results of all the investigations I arranged to make sure that we weren't missing any serious underlying illness. This is excellent news and means we were able to get on with planning what we need to do next to make sure that... (child's name)...../you can get back to business/life as usual as soon as possible.

We agreed that I would arrange for ... (child's name)...../you to

- Eg see my physiotherapy colleagues
- Eg Return to school on a timetable of increasing hours, starting with attending registration only for the first two days and then building up.....

I will review ... (child's name)...../you again in 's time on(date) / I have arranged for your GP to review ... (child's name)...../you after one month to check on progress with this plan

Please feel free to get in contact with me via my secretary if things crop up that make sticking to the plan difficult

Yours sincerely

Cc GP

Consider agreeing with CYP/family that school or other agencies are cc'd in eg physio

Online Resources:• **Sleep management leaflet:**

www.patient.co.uk/showdoc/27001301

• **Expert patient program:**

www.plymouthguild.org.uk

• **Tiredness leaflet:**

www.rcpsych.ac.uk/mentalhealthinfo/problems/sleepproblems/tiredness.aspx

• **Pain leaflet**

<http://www.painclinic.org/aboutpain-copingwithpain.htm>

• **Online CBT:**

<http://www.beatingtheblues.co.uk/connect/>

• **Relaxation techniques:**

<http://www.nhs.uk/conditions/stress-anxiety-depression/pages/ways-relieve-stress.aspx>

• **Non-epileptic seizure leaflet:**

<file:///C:/Users/lucyb/Downloads/Non%20epileptic%20seizures%20C0229%20A5%20col%206pp%20singles%20FINAL%20Aug16.pdf>

Support services:• **MindEd:**

Online educational resource on children and young people's mental health.

<http://www.minded.org.uk>

• **Youth in mind:**

Online support website for stressed children and teenagers and those who care for them.

<http://www.youthinmind.info/py/yiminfo/Start.py?language=euk&country=uk>

Medically Unexplained Symptoms (MUS)



Patient Information Leaflet

What are Medically Unexplained Symptoms?

If your doctor has given you this leaflet, then you or someone you know is suffering from medically unexplained symptoms (MUS).

MUS can also be described as 'functional disorders' and are abnormal bodily sensations which cause pain and disability by affecting the normal functioning of the body. Despite adequate medical testing, an illness cannot be found to be causing the symptoms and no underlying damage to the body can be seen.

They are common and affect 1 in 10 children.



Common Types of MUS:

- Tummy pain
- Chest pain
- Breathlessness
- Pain on swallowing
- Headaches
- Muscle aches/tiredness
- Difficulty walking
- Bloating
- Diarrhoea
- Vomiting
- Racing heart

Coping with MUS can be difficult and at times the symptoms may impact your whole life. However the symptoms are likely to resolve or improve over time

What Can My Doctor Do?

The doctor/s you have seen will probably have given you some advice on how to manage and control your symptoms. It can sometimes take a few months for a significant improvement to be seen.

You should be reviewed by your GP in around one month's time to ensure your symptoms are being as well managed as possible and for any alterations to be made.

If the symptoms persist beyond this it is helpful to schedule regular appointments to your GP for a review and further coping strategies to be considered.

What Can I Do?

Stress and exhaustion can often worsen symptoms so it is important to maintain a healthy lifestyle and look after yourself e.g.

- Do regular exercise
- Maintain a good sleeping pattern
- Eat regular meals
- Maintain a healthy diet.
- Minimise stress inducing activities.
- Look up coping strategies online (see back of leaflet).
- Visit support groups in the area (see back of leaflet).
- Consider complementary therapies.
- Relaxation techniques (see back of leaflet).
- Maintain a positive outlook



Appendix 8:

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