

Medically Unexplained Symptoms (MUS)

A whole systems approach

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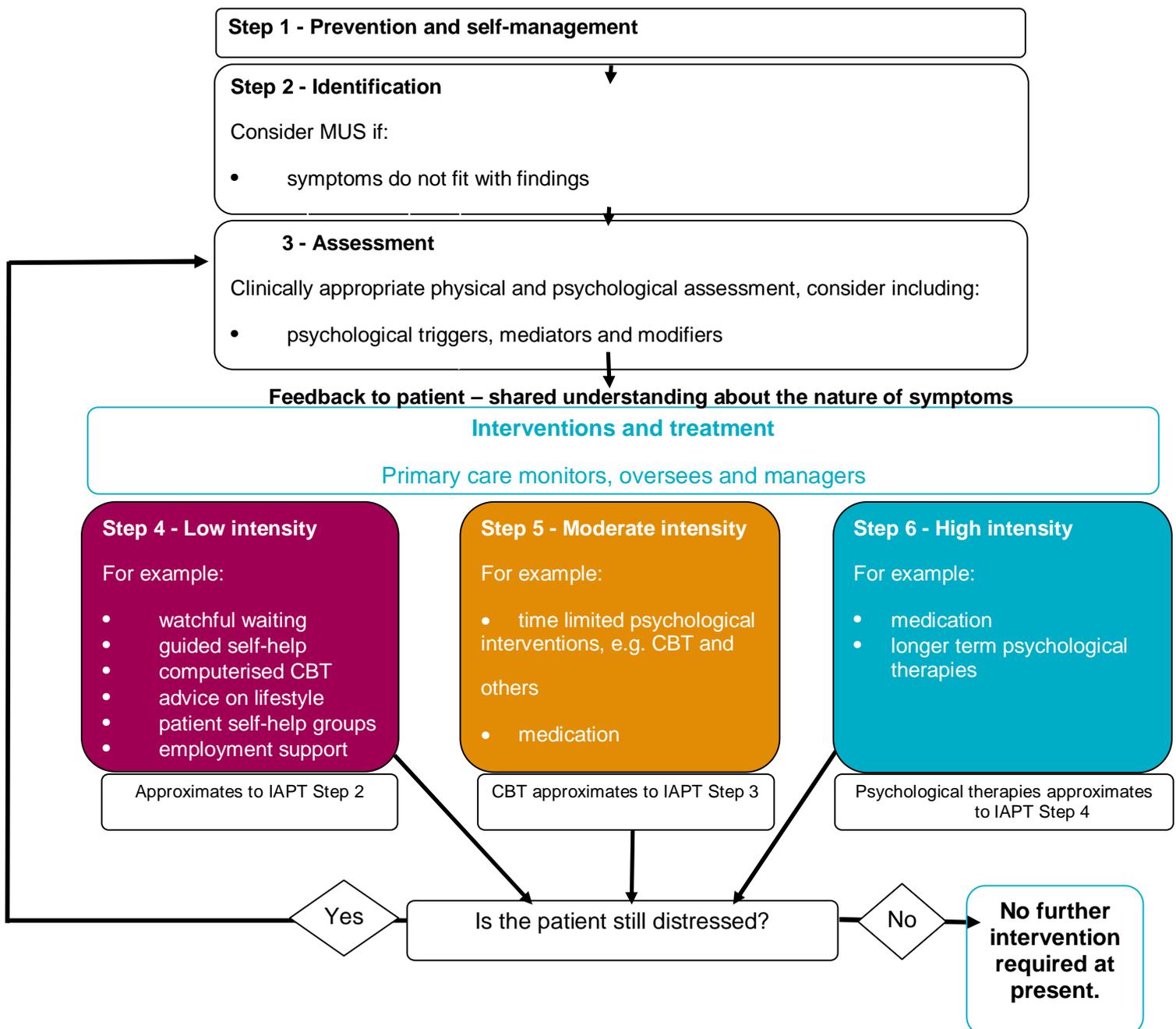


1. Introduction and purpose

- 1.1 These notes are intended to support the MUS case management approach and to provide best practice examples of service models along the whole of the care journey. They include the characteristics we would expect any commissioned service for MUS to include. See Figure 1 for the Model of Care
- 1.2 This section has been divided into seven different steps along the patient journey or pathway, providing detailed guidance to implement the model of care.
- 1.3 Integrated into each step are best practice examples of service models which are currently provided in the UK to deliver the pathway with descriptions of service modelling. Service models are meant to be illustrative, rather than prescriptive, to support commissioners and clinicians to work together to develop equitable services.
- 1.4 The model of care was designed by a representative group of stakeholders, including patients, clinicians from primary care, mental health and acute settings and mental health, primary care acute and practice based (PBC) commissioners. The service models were defined with input from this group and best practice examples were identified through a clinically led evidence based review and from stakeholder input. A list of stakeholders can be found in Appendix 1.



Figure 1 - Medically unexplained symptoms model of care



2. Background and Challenges

- 2.1 This integrated service model for people with medically unexplained symptoms (MUS) in London provides best practice information for commissioners and clinicians to commission and deliver effective and efficient services for people with MUS.
- 2.2 Although families and social networks are the foundation of support, and many people who present with medically unexplained symptoms find that their symptoms resolve of their own accord, health and social care services play a vital role in the treatment and care of people with MUS.
- 2.3 The model of care and best practice examples have been designed for all people who have medically unexplained symptoms.
- 2.4 Commissioners responsible for services and support for people with MUS in London face particular challenges. London is one of the most ethnically diverse cities in the world, with cross cutting inequalities related to age, gender, ethnicity and social deprivation which exacerbate problems related to MUS. All individuals accessing health services may face potential barriers. However, people from BME communities may face additional barriers involving ethnicity, culture, language or faith
- 2.5 The prevalence of MUS is higher amongst younger people, peaking usually before the age of 30 (Nimnuan et al 2001). However, older patients who experience chronic conditions may demonstrate MUS. MUS is more prevalent amongst women (e.g. Katon et al 1990).
- 2.6 MUS is ubiquitous and affects all cultural groups. Not only is MUS common in developed countries but somatic presentations of emotional distress are the norm in much of the developing world (e.g. Ustun and Sartorius, 1995) and migrants from these countries are likely to retain traditional illness models and to describe distress in bodily terms. Patients from BME communities in Britain with MUS face added barriers in accessing appropriate care. Community isolation may be a barrier for those who have moved to the UK more recently. These individuals may have little or no understanding of the services available in this country, including the wider health services. With a growing young population that is ethnically diverse, MUS is a key area for improving understanding and treating appropriately.
- 2.7 London commissioners also face challenges in commissioning services which deliver an approach which cuts across commissioning and service 'silos'. Commissioning of services which provide the whole of the MUS model of care will involve taking an integrated approach working across acute, primary care, practice based and mental health commissioning.
- 2.8 Therefore, it is recommended that PCT's establish a joint commissioning group to implement a MUS commissioning specification, which includes mental health, PBC, primary care and acute commissioners and clinicians. It is recommended that this group also includes other key stakeholders, such as patients and QOF leads.
- 2.9 Commissioners will want to assure quality in the delivery of the approach, which is likely to be provided across a wide range of service providers who will in turn face challenges in staff learning and development to achieve the significant behavioural change required to implement the model of care.



- 2.10 Some of this service change will rest with primary care and PBC commissioners, who will be required to ensure an integrated approach is taken to identifying and assessing people with MUS, and managing their care in primary care. One route to achieving this may be through commissioning a local enhanced service for MUS.
- 2.11 Some of this service change will rest with acute commissioners, who will be required to direct resources to achieve the routine identification of MUS and onwards referral and to ensure that an integrated approach is taken to ensure the management of patients with MUS rests in primary care. Acute commissioning vehicles (ACVs) will also need to ensure services provide an integrated approach to routine psychological input in gynaecology, neurology, cardiology and pain clinics.
- 2.12 Some of this service change will rest with mental health commissioners who are at different stages of commissioning services for improved access to psychological therapies (IAPT).
- 2.13 An integrated approach to commissioning for MUS is essential to commission service models which result in the successful implementation of the model. When an integrated approach is taken to commissioning, it increases the integrated functioning across health care settings. These complexities are best managed by a system that co-ordinates the work of different organisations, disciplines and staff across the whole scope of health care, from prevention and self management, to identification, assessment, therapeutic interventions, and recovery.
- 2.14 The best practice service models highlighted in this section provide examples of effective service models which deliver parts of the MUS model of care to achieve agreed outcomes.

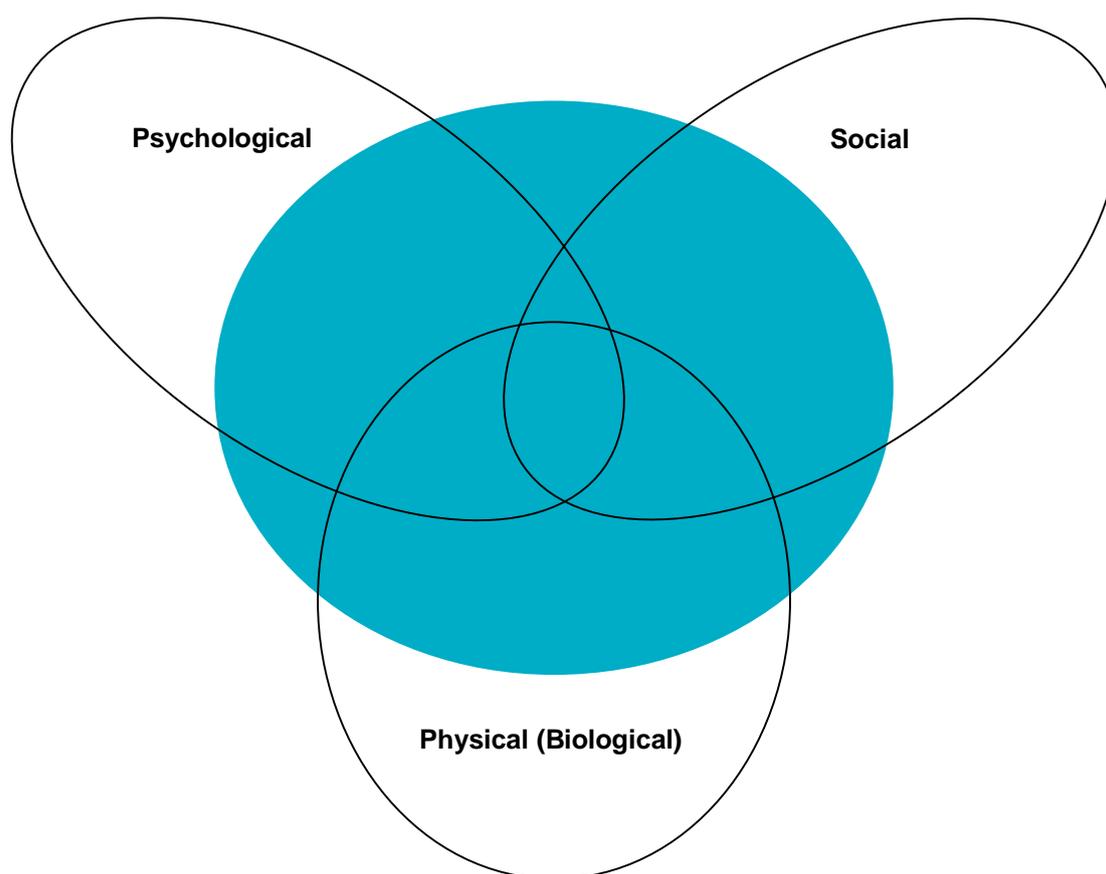
3. Overview of the Approach Underpinning the Integrated Service Model

- 3.1 The integrated service model is based on a person-centred, culturally responsive holistic value system, which is underpinned by a bio-psychosocial approach. The service model will require language appropriate services delivered in locations which are accessible to ethnic minorities.
- 3.2 The bio-psychosocial approach considers all biological, social and psychological aspects of a person's health. It works on the assumption that all factors are inter-related and not distinct from one another; social and emotional health impacts on physical health, and vice versa.
- 3.3 Fundamental to the model is a holistic construct of health and wellbeing and therefore a requirement for healthcare to reflect this construct. This represents a direct challenge to our predominant healthcare culture of dualism within which problems are perceived and treated as either mental or physical. The underlying philosophy is that there is no dichotomy between psychological and physical health - all presentations have components of both.



- 3.4 Values are highly important in this context. We know that if people feel disempowered and hopeless, this will tend to reduce their level of functioning and increase their symptoms and presentations. Evidence shows that if people feel involved in decisions about their care they are more likely to feel better.
- 3.5 Figure 1 depicts a network of care with the patient at the centre. The holistic response to an individual will be based on a continuum dependant on their needs. Individuals with MUS may manage their own symptoms and condition with little or no support. At other times they may require further support from their GP or specialist services and the wide range of services these professional can access. The rest of the paper describes how these services could be delivered.
- 3.6 The model is also based on the values of the co-production model of health, recognising that a collaborative relationship with dialogue and negotiation between patients and professionals can be achieved through individual and community capacity building (Morris, 2007; Needham, 2009).

Figure 2



4. Description of the Model of Care and Best Practice Service examples

- 4.1 This section in particular should be read in conjunction with the model of care for MUS. It takes each component of the stepped care model and provides best practice examples of service delivery.
- 4.2 The best practice examples provided below offer a multi-disciplinary, multi-agency, planned approach to the delivery of high quality care and support for people with medically unexplained symptoms.

5. Step 1- Prevention and self-management

Step 1 - Prevention and self-management

Improving the general public's understanding of how the interplay between the emotional, physical and social influences impact on health is a crucial task. Tools to enable this sea change in understanding will need to be wide reaching. Commissioning Support for London's Medically Unexplained Symptoms workstream is recommending an advertising campaign that in itself may include a drive to get the media to include examples in soap story lines, lifestyle/health/fitness magazines, posters on buses/bus stops.

Self Identification and Self Management

PCTs will be required to develop a directory of services with links to online self help tools, which will feed into NHS Direct and NHS Choices. Online tools do not exist at present and research will be needed to support their development. This work is part of the national recession response for mental health to provide support during the economic downturn.

Individually or collectively, PCTs might like to provide translated leaflets for distribution to GP surgeries, libraries, local pharmacies, faith and community organisations and other community venues. Additionally, leaflets would be distributed to specialist clinics, for example drug and alcohol units, GUM clinics to improve accessibility. These leaflets would highlight the link between psychological and physical symptoms. These could include explicit examples, such as:

- the link between anxiety and increased intestinal contractions, with an explanation that there is a very strong nerve supply to the gut from the emotion controlling part of the brain
- the role of mood on perception of symptoms and how stress can impact on health, i.e. headaches and muscle tension
- explicit explanations of the role that anxiety and depression (which may well be due to the symptoms) play in the reinforcing feedback loop that occurs and accentuates pain



- books on prescription, including books in community languages and audio books; culturally responsive and language appropriate patient self help groups, and other self help literature and/or workbooks

Further information on best practice models for primary prevention and self management can be found in the Department of Health's *New Horizons* proposals, located at http://www.dh.gov.uk/en/News/Recentstories/DH_097701

6. Step 2- Identification

Step 2 - Identification

Consider MUS if:

- symptoms do not fit with findings

Early identification of people who possibly have MUS is important as the more they are investigated and referred the more difficult it becomes to help them (Barsky, 1996). It is essential that we attempt to stop progression of MUS to the point where it becomes dangerous to the patient and this model of care is designed to do this at all levels of presentation.

Physicians will need to be particularly alert to mental and physical health needs amongst people with learning disabilities, and amongst people for whom English is not a first language, who may be overlooked because of potential difficulties in communication.

Identification via NHS Direct

Commissioning Support for London recommends that NHS Direct develop a system to identify frequent or repeated callers and to feed this back to primary care.

Identification in Primary Care

Many patients with MUS present first to the general practitioner or practice nurse. The general practitioner, as diagnostician, needs to be thoughtful about those patients whose symptoms may point towards this problem. It is important to note that only a limited number of medical conditions present with vague, non-specific complaints affecting multiple organ systems, which is the hallmark of the more persistent forms of medically unexplained symptoms. Typical MUS presentations include combinations of the following:

- the symptom does not fit with known disease models or physiological mechanisms
- the patient is unable to give a clear and precise description of the symptoms
- symptoms seem excessive in comparison to the pathology
- symptoms occur in the context of a stressful lifestyle or stressful life events
- patient attends frequently for many different symptoms



- the patient seems overly anxious about the meaning of the symptoms and has strongly held beliefs about a disease process causing the symptoms
- patient complains of pain in multiple different sites

The GP might like to consider actively searching for patients on their list using a computer system such as 'Corporate Radar' to search for a list of patients attending the surgery or A&E frequently or those being admitted frequently. This list can then be refined by including those with chronic pain, multiple pain, using opiates, gabapentin or pregabalin, or where all investigations have failed to show a cause for the symptoms.

Morriss (2009, unpublished) has developed a search tool that identifies people with a number of common factors which may give PCTs a calculation of the number of patients with MUS in a population. The factors are:

- age
- prescription of opiate analgesics
- presence of multiple pain sites
- chronic fatigue
- life stress
- a normal ESR

This tool was not useful on a clinical level to identify named patients but could be used by the patient's GPs to generate a list of patients with possible MUS, knowing that this tool will falsely identify some and miss others. The GP could then further refine the list to exclude or include those patients known to have this condition.

Please see the quality outcomes section of this document for further detail on identifying patients with medically unexplained symptoms.

Identification in Acute Health Settings

In addition to the above, the hospital doctor needs to consider MUS when initial investigations are negative and when the patient is not reassured after detailed discussion of the results of investigations. The hospital doctor needs to consider MUS when the patient has clearly been to other outpatient departments for the same symptoms and referred on.

Identification in Unscheduled care

A&E and unscheduled care departments should develop a mechanism for flagging up those patients who attend frequently with unresolved symptoms and feeding this back to the GP, as well as to their own staff, so that when the patient next presents, a more constructive and coordinated response can be taken.



7. Step 3 - Assessment

3 - Assessment

Clinically appropriate physical and psychological assessment, consider including:

- psychological triggers, mediators and modifiers
- misuse of substances including alcohol, illicit and prescribed

The model mentions a 'clinically appropriate physical and psychological assessment'. This assessment involves a truly holistic history taking. The clinician will need to:

- listen carefully to the patient, using interpretative services as appropriate
- gain a description of the symptoms (enabling an assessment of whether these are 'biological' or less clear cut)
- find out what the patient thinks the cause may be and what the patient is afraid the cause may be – think ICE
- find out about the patients' present life circumstances in terms of stressors, employment, family, etc.
- find out if particular situations make the symptoms worse or better
- find out how the patient is trying to treat and live with the symptoms and what their licit and illicit drug use is
- perform an appropriate physical examination focused on the organ system that the patient is complaining about
- look for signs rather than symptoms of disease
- identify any coexisting psychiatric disorder
- acknowledge patients symptoms as real
- understand the extent to which new symptoms are an emotional communication rather than a new disease
- empathise and begin by taking the patients' beliefs seriously – understanding how they have arisen (not contradict them) but develop a shared understanding and discuss the evidence for and against gradually with the patient



- for example, the patient may not believe a test result because a family member may have been given the wrong diagnosis and had a negative health outcome. A mistrust of western medicine and services by some people may increase the challenge of accepting a test result. It is important to avoid polarisation and keep options open in terms of beliefs.

Clinicians' interventions need to be carefully considered and evidence based. The use of diagnostic tests can become a problem when these are being used not to confirm a clinical diagnosis but to explore increasingly remote diagnostic possibilities or to provide reassurance to the patient or the doctor that 'nothing has been missed'. There is a statistical chance of around 5% that any test will report a spuriously abnormal result that will in turn leads to further investigations. This statistical chance increases the more tests are done. So, for example, a recent report of the cumulative incidence of false-positive results in repeated cancer screening found that after 14 tests, the cumulative risk of having at least 1 false-positive screen for cancer was 60% (95%CI 59.8-61.0) for men and 48.8% (5%CI 48.1-49.4) for women.

Furthermore, the risk of undergoing a potentially dangerous invasive diagnostic procedure prompted by this false positive test was 28.5% for men and 22.1% for women (Crowell, et al; 2009). The task of MUS management is to replace dependence on a technical procedure, for example, a laboratory test, or a corrective investigation, with a strategy that aims to help patients live with their symptoms rather than seeking to remove them altogether.

The use of diagnostic procedures to screen for unlikely diagnoses where the symptoms don't fit particularly is not evidence based and will result in false positives which in turn will lead to further investigations. Identification therefore involves the more skilful and appropriate use of diagnostics and statistics.

The thought process which involves 'I will first rule out anything *serious*' is not appropriate in primary care if or when the symptoms are not suggestive of a life-threatening condition. Clatworthy (2009) provides a useful discussion on managing and communicating uncertainty to patients and doctors.

There is value in continued reviewing to consider how physical symptoms develop, demonstrating that they are being 'taken seriously', and minimising the need to over investigate. Setting up brief, regular and planned review visits, for example, every 6-8 weeks initially, and gradually lengthening to much less frequent would be appropriate. The goal is not to remove symptoms but to help patients cope with them, which in turn often minimises their impact.

There may be value in using specific outcome questionnaires to assess the degree of co-occurring anxiety or depression (e.g. PHQ-9 and GAD-7), or to ascertain the impact of the condition on quality of life (e.g. EQL5D). There is also the Illness Perception Questionnaire (IPQ) that assesses beliefs about illness. However it must be remembered that not all patients with MUS have mental health problems (Burton 2003).

Feedback to patient- shared understanding about the nature of symptoms

This part of the approach is not listed as a 'step' but is crucial to the management of MUS. This process is therapeutic in itself and, in the majority of cases, a skilled handling of the process of feedback to the patient will enable the patient to manage their symptoms and in many cases, recover. In many ways, this step is about helping the patient to understand what is happening to them so that they can become an active partner in their own management and indeed, may be able to self-manage their condition. Clinicians can use the bio-psychosocial model (figure 2, page 7) with the patient to begin making a formulation of their problem.



Working on the distress resulting from the symptoms is often an acceptable way to start. The physician will need to work with the patient to co-create an explanation for their symptoms and consider what factors may influence them. In some cases patients will find a psychological contributing factor that they will be able to work on. In other cases the patient will not be able to find any psychological contributing factor, in which case the physician needs to help the patient work on ways of getting back function and quality in to their lives without expecting cure of the symptoms.

Several models of working with the patient to negotiate a shared understanding for the possible cause of the symptoms have been suggested. (Goldberg et al (1989) on reattribution; Morriss (2007); Dowrick (2004) on effective normalisation; and Fink's (2002) TERM model²). It has been demonstrated that these techniques can be successfully taught to General Practitioners and other clinical specialists.

These techniques can act as a bridge to help the patient to move to a position where they can access activities that will improve their functioning and quality of life but may not be enough on their own to produce symptom resolution (e.g. Morriss et al, 2006). They may also be helpful in preparing the way for more sophisticated interventions. Some will accept the offer of language appropriate CBT and other psychological therapies. Others will not be interested in this but can be helped through increasing functioning with exercise or distraction, e.g. occupational therapy techniques. The GP or hospital specialist can then ask the help of the IAPT workers to explore these options with the patient.

It is important to be open to the unknown. We know that psychological distress can cause symptoms and can make existing symptoms worse. We know that distraction techniques can reduce pain. It is less clear whether people who have fibromyalgia or chronic pelvic pain experience 'normal' physiological processes differently. It is less clear whether their pain thresholds are altered and whether they experience symptoms of emotional arousal differently. Decreased inhibition of afferent stimuli has been suggested by neuropsychologists (Miller, 1984).

It is also important to note that a review of the literature by Burton (2003) showed that many patients with medically unexplained symptoms had no definite psychological illness and, as mentioned early, these patients will be lost if it is implied that because they have MUS they have a mental health problem.

The reattribution model has been further developed by Per Fink et al (2002) to design a sophisticated teaching model for primary care physicians. However this model would require a degree of commitment on the part of physicians prepared to undertake the course. The information below attempts to extract the key actions from the various models. We would hope that if all physicians were able to master these techniques the progress of many of these patients along the existing journey could be prevented.

Key physician behaviours:

Physicians need to offer appropriate explanations for the symptoms and to negotiate a shared understanding with the patient of the possible cause of the symptoms. The following list has been generated from a number of sources including Rosendal et al (2005), Salmon et al (1999), Morriss et al (2006), Guthrie (2008), and Smith et al (2003).



Do's

- Understand the patient and the effect the symptoms are having on them.
- Show the patient you believe they have these symptoms.
- Be honest when a patient has an unusual symptom that fits no clear disease process – 'I don't know what this is but it doesn't fit any disease pattern I know of and I think we could afford to wait and see'.
- Think about how you can empower the patient (Salmon, 1999).
- Undertake only appropriate physical examination and, again only if indicated, simple investigations.
- Explain the links between physical and psychological stresses. Explain the link between the biological and psychological without any implication that the symptoms are 'in their head'. For example, make connections between fear causing nausea and sweating, tension causing stomach cramps, or depression causing pain in the face.
- Negotiate a culturally responsive explanation with the patient for the symptoms using the bio-psychosocial diagram, e.g. "Could your pain be influenced by the stress of your daughters divorce?"
- Normalise that all symptoms are influenced by bio-psychosocial factors. Explain to the patient that although you have not found a cause that is amenable to a simple biological treatment, the patient's symptoms can be helped.
- Explain that psychological stress (which may well come from the symptoms) can make the symptoms worse, setting up a negative feedback loop.
- Use examples to explain how there are techniques which could help. For example, 'people who walk on live coals have developed a psychological strength which enables them to do this. Your back is causing you great pain but it is possible you could develop similar psychological techniques to help you cope'.

Don'ts

- Tell them that you can find nothing wrong. There is something wrong.
- Tell them the symptoms are normal. They are not normal for the patient.
- Reassure repeatedly as this results in a never ending cycle of needing reassurance (Burton, 2003).
- Tell them there is nothing you can do to help. This is abandonment.
- Give results of normal tests and reassure and think that this will help. It won't. Lucock (1997) demonstrated that medical reassurance resulted in a very short term reduction in worry about illness. Furthermore patients want acknowledgement of their symptoms and an explanation rather than reassurance (Donovan et al, 2000) so reassurance alone is unhelpful.



The key to delivering this section of the model of care is ensuring the continuity of the physician with the patient (Simon et al 1999). Services should be commissioned for continuity.

8. Step 4 - Low intensity

Step 4 - Low intensity

For example:

- watchful waiting
- guided self-help
- computerised CBT
- advice on lifestyle
- patient self-help groups
- employment support

Approximates to IAPT Step 2

The simple interventions outlined in Step 4 would be offered largely by the GP or they may be offered by Low Intensity IAPT workers. They could take place in the surgery or polyclinic, as close the person's home and normal life routine as possible.

The list of simple interventions included can be expanded considerably to include OT input, physiotherapy, graded exercise, undertaking enjoyable activities, finding appropriate work and managing avoidance. It is important to understand that all these interventions can be used to support the initial shared explanation and understanding that the general practitioner and the patient have reached together.

Different interventions will suit different patients and, where they are needed, will need to be negotiated together.

- 'Watchful waiting' – MUS may be acute or chronic. Where it is chronic, it is essential that the physician supports the patient. This support needs to be structured and negotiated. There needs to be an agreement about how often the patient will be seen. It may be helpful to agree that once a year the physician will repeat a simple list of baseline tests. Long term follow up of patients with MUS shows that less than 10% of patients eventually develop a biological illness (Carson et al 2003, Crimsky et al 1998, Wilson et al, 1994). What is essential is that the physician keeps the symptoms and their diagnostic value in perspective. If the risk of the test is higher than the risk of the disease then this should be discussed honestly with the patient (see Clatworthy, 2009).
- Self-help materials and packages- This would include educational and self-management leaflets and recommended books, guided self help (self-management booklets based on CBT principles with advice from a trained worker to help people make the best use of the booklets) and computerised (CD-Rom and internet based) self-help packages. Available self-help materials need to include materials specifically on self-management of MUS as self-management materials for depression and anxiety are not always appropriate or acceptable for MUS patients. These materials are not available at present and would need to be developed.



- Advice on lifestyle, including posture, exercise.
- Patient self help groups. See below for AU's story, which shows how powerful patient self-help groups can be. Polyclinics may be good sites to establish such groups and increase accessibility. However evidence is conflicting and further research is required before London-wide implementation.
- Employment support – GPs can refer patients to an employment advisor, directly or via IAPT, for work retention support.
- Therapies, including occupational therapy.
- Patient choice – the process of the patient identifying what s/he thinks might help is valuable. Additional interventions, which may or may not be provided by the NHS can be found on the new IAPT directory, available on PCTs websites.from July 2009

Best practice service model example – primary care

A management strategy of one GP in the practice making regular appointments with the patient (every 1 – 2 weeks if necessary in first instance, decreasing to monthly or 6-weekly when consultation behaviour is in control, i.e. the patient is not attending out-of-hours services in between these regular appointments). The Patient is asked to hold on to concerns until their regular appointment and not seek consultation in between. At the regular appointment, the GP takes seriously the physical concerns of the patient and undertakes a physical examination, if appropriate, but refrains, unless clearly indicated clinically, from referrals for diagnostic procedures and outpatient appointments. The GP discusses the symptoms in bio-psychosocial terms, communicating that the patients symptoms and suffering are real, not 'all in your head', but the reasons for the symptoms are complex as human beings are complex bio-psychosocial organisms.



A Patient's Story

In 1977 at age 17, I underwent an operation to remove my ovaries.

Since then I have lived with various medically unexplained symptoms including depression, fibromyalgia, heart palpitations, kidney problems, urethral strictures, irritable bowel syndrome, chronic pain, chronic fatigue, migraines and fainting episodes.

For thirty-odd years I was shunted from pillar to post, visiting various specialists and staying in hospitals all over London.

I have seen countless psychotherapists, clinical psychologists and psychiatrists. They all seemed to have no interest in me or gave up because I was 'too complicated' – which only worsened my depression and feelings of isolation, and led to countless more symptoms. I have also attended various pain management clinics and support groups, but none of these helped in the slightest as my symptoms were still 'unclassified'!

I was told I was unemployable as my symptoms were too unpredictable. But, after attending an NHS Expert Patients Programme self-management course for people with long-term health conditions, I progressed from Volunteer Tutor with the programme to being fully employed as a Trainer and delivering and organising courses all over London.

My mission now is to help prevent anyone from going through what I did over the years, where the 'system' left me feeling severely let down. By empowering the patient to work with their healthcare professionals and helping them to manage their own symptoms this could be avoided for good.

AU, 2009

9. Step 5- Moderate intensity

Step 5 - Moderate intensity

For example:

- time limited psychological interventions, e.g. CBT and others
- medication

Approximates to IAPT Step 3

The actions described below will need to occur in primary and secondary care. They need to be incorporated in to the running of the primary care organisation or the secondary care outpatients.

The key interventions in Step 5 are:



Medication

The principles are to minimise the use of benzodiazepines and stronger pain killers, due to the risk of dependency, and to try to minimise side effects and interactions. TCAs seem to help more with MUS symptoms than SSRIs and in lower doses than used for depression (Guthrie, 2008). It is recommended that GPs use medication where appropriate.

Time limited psychological interventions

CBT is effective for the treatment of people with medically unexplained symptoms (Kroenke, 2007; Arnold, 2006). In some cases other psychological interventions may be helpful, including couple work, psychosexual counselling for gynaecology patients with chronic pelvic pain.

Some cultures or community groups may have little or no understanding of what psychological therapies are and what is involved in receiving these; this may create a barrier to accessing these services. Additionally, language appropriate services that enable the correct assessment of individuals in a supportive environment are essential to engage non-English speaking groups. Translated reading material about IAPT services will also raise awareness of the service and promote the use of interpreters and translators within the service.

An Occupational Therapy Approach to MUS

Patients with Medically unexplained physical symptoms can be effectively treated with physical interventions, with recovery via graded rehabilitation helping to legitimize both the problem and the resolution (Behr, 1996; Moene et al, 1998; Teasell and Shapiro, 2002). Physical therapy interventions with MUS, such as Occupational therapy and Physiotherapy, are based primarily on clinical and empirical evidence. Studies that have been undertaken, although of level B and C evidence, have found encouraging results (Behr, 1996; Moene et al. 1998; Teasell and Shapiro. 2002). Positive prognostic indicators for recovery of MUS include a short duration of symptoms and a short interval between symptom onset and engagement in treatment. (Crimlisk et al, 1998; Mace et al, 1996).

Early physical therapy interventions in the form of occupational therapy and physiotherapy using a restorative functional approach can therefore be effective in helping the patient to maintain function, enabling continued participation in daily activity and the maintenance of routine. Observation of occupational performance can identify incongruence between occupational identity and observed occupational performance and treatment can be targeted to bridging this gap by concentrating on functional outcomes rather than physical symptoms. The aim of early intervention is to limit a spiral of dependence and to prevent development of secondary symptoms. It is essential that these interventions are provided by therapists who have a developed understanding of MUS, in order to maintain consistency of approach within the context of the bio-psychosocial model.

Service modelling

The following core service models are key commissioning requirements of the MUS Model of Care.



All GPs will have access to sufficient psychological support for patients with MUS, explicitly including a low intensity (LI) or psychological wellbeing worker (PWP) to work with the patient on behavioural activation and a named psychological therapist to work closely with GPs reviewing patients and undertaking shared consultations where appropriate. This could be provided through IAPT or other primary care counselling and psychology services.

In secondary care departments, it will be necessary to provide multi-disciplinary teams with expertise in bio-psychosocial approaches, such as psychologists, to work alongside the consultants, as part of the department. In order for the team to work effectively, it is necessary for the secondary care physician to actively promote and support the work of the aforementioned bio-psychosocial experts, seeing them as an equally important part of the team. In doing this, the consultant is indicating that the psychological support is an important and valid part of the patient's treatment, so much so that it is part of the mainstream.

For this approach to be fully successful, we would envisage any patient contemplating certain operations (to be determined locally) to see the psychologist as well as the consultant, in order to explore what they think the benefits of the operation might be, what they want from this operation and whether these beliefs are realistic (see NRAC model on p. 21). The psychologist would work in out-patients with the consultant providing immediate discussion as outlined above. While it might not be possible or desirable to apply this step to every single operation undertaken, departments could discuss and agree which operations may be performed more frequently than is strictly necessary (e.g. revascularisation for ischemic heart disease – see example below) and target those.

It may be possible within the new polyclinic model that the routine of psychologists working with consultants would develop. Equally, they could work in hospitals in more structured ways such as a 'pelvic pain' clinic.

We would suggest that one consultant in each department should lead on this area of the work, helping other consultants to think about difficult presentations, ensuring patients can access the psychologist appropriately and reviewing the care of patients where no biological explanation can be found. At present, patients are referred back to primary care or on to another secondary care department, thus allowing the clinician to maintain the idea that medically unexplained symptoms are not part of their work.

It will be necessary for acute clinicians working in these clinics to code patients that they feel may have MUS. There are often no codes available to do this in these specialities. We would advise therefore that the ICD codes F44, F45 and F48 are used as 'catch-all' codes. These would include any situation where the clinicians felt there was an element of MUS affecting the patient and their management. This is necessary in order for outcomes to be quantifiable. These codes are to be used to monitor outcomes; clinicians can use the codes where appropriate, in conjunction with other codes.

Best practice service model example – National Refractory Angina Centre

Chester's (2007) study of angina patients found that when patients received appropriate psychological care, unscheduled admissions fell by 70%, while stress management reduced the number of patients requiring revascularisation by 70%. He calculated the savings to be, on average, around £17,000 per patient per year.

Chester also found that the majority of a cohort of 84 patients awaiting bypass surgery decided not to proceed after attending a group cognitive behavioral therapy programme.



Best practice service model example – A Multidisciplinary Chronic Pelvic Pain Clinic

There is growing evidence that interventions based on cognitive behaviour therapy can reduce chronic pelvic pain (CPP) and improve levels of functioning (Pearce, 1982; Kames et al, 1990; Peters et al, 1991) and that CBT is an effective treatment for chronic pain (Morley, Eccleston and Williams, 1999).

A novel service model for CPP which is based on a bio-psychosocial approach is a multidisciplinary one stop clinic at Guy’s & St Thomas’ Foundation Trust. A Consultant in Pain Management, Consultant Gynaecologist and Clinical Psychologist interview on average six patients per clinic with 20-25 minutes spent with each clinician, who provide assessment and psycho-education and a review with a range of options (e.g. psycho-education, bibliography, IAPT, referral to pain groups, referral to clinical psychology, further pain interventions). An audit of 30 patients found positive changes beliefs (emotional impact, control and cure and understanding of the pain) immediately after the clinic.

Comments from patients:

‘I found all the doctors helpful – seeing three different specialists was very useful as they discussed the different aspects of the pain. I feel more positive about managing my condition.’

‘Today has helped as I have now been given some more advice and new treatments. Hopefully this may make a difference.’

10. Step 6- High Intensity



Patients with severe and chronic MUS are often referred to medical and surgical clinics within secondary care. Such patients may also access secondary care by Emergency Department attendance, with some being admitted for further investigation.

Within local secondary and tertiary care there may already be services which offer assessment and intervention for some patients with MUS. Commonly these are Liaison Psychiatry and Clinical Health Psychology services based in general hospitals. Typically, Clinical Health Psychology will provide services for specific patient groups, e.g. patients with chronic pain. Liaison Psychiatry usually offers a generic service for all specialities.

There could also be a supervision training role provided by senior mental health professionals for each PCT for IAPT workers and to support GPs and an MUS network in each PCT to manage and support the structures.



Where such services do exist, they will require skills and expertise that could be used to inform and deliver the provision of specific MUS services, particularly within primary care. For example, a senior mental health professional such as a liaison psychiatrist or clinical health psychologist might join a multidisciplinary team assessing and managing patients with MUS, or they may provide support and supervision to GPs in the management for more complex cases. Without sufficient capacity, it will be difficult to provide the recommended interventions for this step. Examples of best practice service models are described below

Best practice service model example – Bio-Psychosocial Approach in A&E

Margalit and El-Ad (2007) demonstrated that a multi-disciplinary team, working with a 'high risk' MUS population by providing a comprehensive assessment and a bio-psycho-social approach, reduced visits to physicians and emergency wards, hospital days, diagnostic tests and total costs when patients were provided with CBT and pharmacological treatments.

The multi-disciplinary team was co-located in primary care and staffed with family physicians with expertise in the bio-psycho-social approach, a nurse and a social worker. The clinic, similar to a polyclinic, house sub-speciality consultants, laboratory and imaging services and thereby provided improved accessibility to additional diagnostics, if required. Consultants provided interventions, which consisted of a mean of 7 sessions over 1.5-12 months using short term family therapy in ambulatory care. This approach sought to gain insight into the patient's health beliefs, life story, context of the patient's health problems, their significance to the patient and others, and the patient's past difficulties with health providers. After a thorough review of the history and medical records was conducted, along with a physical examination, the patient and physician agreed a bio-psycho-social diagnosis. A management plan identified treatment options and responsibilities of the physician, patient and carer. These included, for example, advice on lifestyle changes, patient empowerment in self-monitoring medical regimes, medication reviews.

Weekly follow-up visits of 30 minutes supported the patient to shift their view from the physical symptoms to an awareness of their emotional consequences. Follow up plans were recorded.

Routine liaison between the consultant and primary care physician was maintained to eventually transfer the patient back to primary care. Primary care physicians were supported via remote supervision and recommendations on future management.

Over a two year period, the service model resulted in a reduction of the number of annual visits to acute consultants from 31.8 to 14.6, visits to hospital emergency wards from 33.5 to 4.1, hospital bed days from 112.7 to 6.5.



Best practice service model example – Neurology and Psychiatry

The Functional Neurology Clinic at King’s College Hospital

We have run a specialist functional neurology service at King’s College Hospital since the beginning of 2007. Referrals are accepted nationally, though the great majority come from neurologists in the South East. We do not take referrals for patients whose primary problems are pain, fatigue or seizures, but only because specialist services for those already exist within our directorate. What we offer is a multi-disciplinary assessment and diagnosis, with integrated feedback, and tailored management that is either delivered by the service or by local services in liaison with our specialists.

Patients are seen by a psychiatrist, by a neurologist and by an allied professional relevant to their problem (typically neuro-physiotherapy, but sometimes speech and language therapy). Assessments are held on the same afternoon, sequentially, followed by MDT discussion, formulation and feedback to the patient. This means that the patient gets the result the same day and by the entire team, allowing questioning of individual team members as they desire and minimizing divisions within the diagnostic message. The management plan is outlined to the patient and the letter generated goes to all involved, including the patient, so that a hopefully definitive diagnosis is established. Sometimes further tests are required, but typically these have already been conducted. Management is tailored to the patient, but commonly involves physiotherapy and/or CBT. Delivery of this is discussed with the patient and we either provide this at King’s, using specialist services, or liaise with local services, as determined by availability, the patient’s wishes and of course the PCT.

Best practice service model example – Inpatient Treatment Programme for Neurology

National hospital for neurology and neurosurgery (NHNN - UCLH NHS Foundation Trust)

Inpatient Treatment Programme

A treatment programme for Medically Unexplained Neurological Symptoms has been running at NHNN for over twenty years. Patients are admitted to Hughlings Jackson, a 12 bed ward which provides a National tertiary service for Neuropsychiatric conditions. The ward can accommodate up to four MUS patients on the four week programme at any one time.

The programme takes a multidisciplinary goal orientated functional approach to treatment and outcomes are measured on goal attainment. The MDT consists of a consultant neuro-psychiatrist, SPR in psychiatry, SPR in neurology, SHO in psychiatry, SHO in neurology, specialist nursing team (combination of RMNs and RGNs), cognitive behavioural therapy (CBT) physiotherapy (PT) and occupational therapy (OT). Nursing staff and therapists meet weekly with the patient to set functional and behavioural goals. Emphasis in treatment sessions is based on restorative techniques with graded reduction of previously adopted compensatory measures (e.g. equipment, reliance on carers). Patients are encouraged to take weekend leave during their admission to practice gains to their home environment; families are also encouraged to engage in the process.



MDT Assessment Clinic (2 clinics a month)

The MDT clinic was set up in 2002 in order to explain the programme to patients before offering in patient treatment. The clinic takes the form of a two part assessment, one by a consultant neuro-psychiatrist and clinical nurse specialist, the second by a CBT, OT and PT. Two patients are seen in each clinic. During the clinic, diagnosis is discussed and it is explained that the approach on the ward is based on an approach that takes into account the psychological and social, as well as the biological causes of their symptoms. Patients can also be given written information explaining this further. Emphasis is made on the belief in the patient's symptoms and the impact on their lives. Recovery is discussed in terms of bio-psycho-social and function gains, rather than reduction of specific symptoms.

Approximately fifty percent of patients seen at the clinic are not suitable for the programme for a variety of reasons including unclear diagnosis, non-acceptance of approach by the patient or co morbid conditions (either physical or psychiatric) where the team feel effective treatment can be provided in other environments.

Training

The need for training on somatoform disorders was identified from the high level of interest in the topic, specifically in relation to conversion disorders expressed in from other NHS inpatient and outpatient services as well as various professional special interests groups including NANOT (National Association of Occupational Therapists in Neurology), ACPIN (Association of Chartered Physiotherapists in Neurology) and AOTMH (Association of Occupational Therapists in Mental Health). Staff working on Hughlings Jackson ward are often contacted by healthcare professionals working in Mental health and Neurology for advice in treating clients with somatoform disorders . Also handovers to teams for this client group often involves some work in educating health and social care professions in the effective approaches to continue the gains made as an in patient.

Two courses have now run at the National hospital, primarily attended by OT's and PT's to address this. We hope to run another course next year and encourage attendance across he variety of healthcare professionals.

Longer term structured psychological therapies

Longer term structured psychological therapies may be helpful for some patients with MUS, although at present there is limited evidence on which patients might benefit. Where possible, such treatment should be provided within the context of a multi-disciplinary team that includes physical and mental health practitioners in primary and secondary care.

Personality Disorder and MUS

As with other mental health problems there is a high level of co-morbidity and so patients with medically unexplained symptoms have a higher incidence of personality disorders than the general population (e.g. Tyrer et al, 1997). This should not necessarily affect treatment of medically unexplained symptoms. However consideration should be given to whether the



patient would also need support and treatment for personality disorder and it is likely that this will involve step 6 level interventions.

Specialised MUS clinics

Specialised MUS clinics – virtual or real. These clinics could take place in GP practices or polyclinics allowing the specialists to support primary care and also being the most appropriate place for this work to take place.

Extended role of general practitioner

Continuity is important (Simon et al, Smith et al (1995) in caring for those patients who are very disabled by this condition, so we would expect the GP to demonstrate that they have a system for offering continuity. As the GP is the clinician most likely to have all the details of where the patient is going to seek help, the GP needs to coordinate their care. It is recognised that managing patients with MUS is currently part of the GP role. The practice would undertake to code patients that seemed to fall under the blanket of MUS. There is a Read code for 'unexplained symptoms continue' (16H) that could be used to code for 'medically unexplained symptoms'. The practice would undertake to review all patients with this code annually. The GP would under-take to review the most severely affected patients 6 monthly (or yearly) with a senior mental health professional. The GP would be the named doctor for the patient. The GP would keep track of any attendances at A&E departments, walk-in centres etc. The GP would watch for any new referrals from these points of contact in to secondary care and if they were for known conditions that the patient had been investigated for, they would halt the onward referrals. The GP would liaise with the local hospitals, ensuring consultants did not refer to secondary care colleagues unless appropriate. This is a considerable amount of work and would need resourcing, hence the enhanced service. However it would pay for itself. This model is close to the collaborative care recommended by the NICE guidelines with the exception that the GP is acting as a case manager (which in the collaborative model is a mental health professional).

Additional Primary Care Support for MUS Patients

Since the model of care and service models are likely to have considerable benefits to the PBC budget in the medium term, it would be sensible for PBC budgets to be used to support this service and for PCTs to support GP Practice Based Commissioners, where they wish to do this. The service has been described under step 6 but would also involve the GP performing the role outlined – i.e. an all encompassing role of coordination and consideration of the patient's predicament and tools to help the patient. The role would involve ensuring that the GP practice had a coordinated approach, as well between primary and secondary care.

In some larger general practices now, there is the possibility for patients to go from one doctor to another without any coordination, being referred repeatedly by new doctors over the years for the same symptoms. This is not beneficial to the patient and we would expect any practice offering this service to ensure there were systems in place to prevent this happening.

However, no current evidence exists to support the effectiveness of commissioning a local enhanced service. The recommendation above for an enhanced service is a pragmatic response for a common problem to managing patients with MUS, as there is evidence that the proposals contained in a local enhanced service can be helpful.



11. Step 7 – No further intervention required at present

Step 7
**No further intervention
required at present.**

Patients with MUS will not necessarily be ‘cured’. This condition should be understood as a relapsing and remitting condition. The patient may well need further help subsequent to apparent recovery. It is therefore essential that psychological or other types of help are not rationed and that the patient is not barred from further support once they have completed a therapy.

Throughout the patients journey the GP remains the significant person who provides oversight and review of the care provided to the patient. This relationship is key to effectively managing patients with MUS.



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13. Appendix 1

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