

MEDICALLY UNEXPLAINED SYMPTOMS (MUS): A WHOLE SYSTEMS APPROACH IN PLYMOUTH



In partnership with:

- Plymouth Hospitals NHS Trust
- Sentinel Healthcare Southwest CIC
- Southwest Development Centre

September 2009
FINAL REPORT

iapt

Improving Access to Psychological Therapies



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1 EXECUTIVE SUMMARY

Introduction

Medically unexplained symptoms (MUS) are common, associated with significant distress, and can result in unnecessary and costly referrals, diagnostic tests and even operative procedures. The current system is inefficient; resulting in unnecessary stress and dissatisfaction for both clinicians and patients in addition to the use of a disproportionate amount of time and resources.

Aims

The project aimed to take a systemic approach to developing solutions, including the role of the Sentinel CIC Referral Management Centre (RMC)

Objectives

1. To develop guidance for the management of MUS by GPs and specialists
2. To develop a commissioner led approach to MUS.
3. Pilot the development of 'care pathways' for MUS in the Plymouth RMC
4. To provide national guidance on MUS for commissioners and RMCs

Phase 1:

Method

- Literature review; consultation with experts and clinicians
- Mapping of current practice in Plymouth
- Stakeholder event

Key issues identified.

- The relationship between clinician and patient is crucial
- Patients with MUS fall within a range of severity from mild to severe.
- Each type requires a slightly different type of management
- Reattribution is a well-researched method but mixed evidence.
- Value in tackling all components of the system concurrently – patient, clinician and system
- In Plymouth there is no specific provision within psychology services for people with MUS except for those with some specific functional disorders
- Clinicians recognise need for training and tools to aid them in working with MUS patients

Objectives agreed at Stakeholder Event.

- Develop patient information
- Produce positive risk management guidelines to support whole system governance
- Produce clinical guidance
- Produce specialist psychological toolkit
- Focus on ENT specialty
- Instigate training for primary care
- Adapt Sentinel CIC referral to ensure MUS is highlighted

Achievement and Difficulties:

- Development of:
 - Positive risk management guidelines (Appendix A)
 - ENT Specialty (Tinnitus Pathway) (Appendix B)
 - Clinical Guidance (Appendix C)
 - Patient Information (Information leaflet) (Appendix D)
 - Specialist Psychological Toolkit

- Problems included:
 - Engagement Sentinel CIC which was setting up basic operational systems.
 - Poor data systems
 - Attempting to compress a whole system project into six months.
 - Governance barriers inhibiting patient involvement.

Recommended Next Steps

1. Adopt clinical, organisational and risk management policies across health care system
2. Develop training programme for primary and secondary care:
3. Develop MUS “franchise” model in secondary care:
4. Focus on commissioning of additional services to improve functional outcomes (e.g. balance therapy):
5. Consider how Practice Based Commissioning can mobilise greater GP involvement in managing patients in Primary Care.

2 INTRODUCTION

2.1 Project outline

- Set out to develop guidance for the management of MUS using a systems approach, with a particular focus on the role of the RMC (Sentinel CIC)
 - Project team: Dr Richard Byng, GP with special interest in mental health and GP Advisor Regional Development Centre, Nicola Bray, Lead Service Improvement manager, NHS Plymouth, Dr Rupert Noad, Clinical Neuropsychologist, and Caroline Maxted, project worker
 - Reporting to a steering group, comprising representatives from general practice, Sentinel CIC, mental health and psychological services, service users and commissioners
 - Funding of £24,000 from NIMHE Primary Care Programme for six months
 - Project sponsor, Dr Pete Williams, Sentinel CIC
 - External Advisors, Professors Richard Morris and Chris Dorwick
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2.2 Objectives

Original Objectives:

- To develop guidance for the management of MUS by referral management centres and associated GPs and specialists. To develop a commissioner led approach to MUS
- Pilot the development of 'care pathways' for MUS in the Plymouth Referral Management Centre (unlikely to be a specific MUS pathway but guidance on both best practice and on a range of appropriate pathways)
- To develop understanding about the critical and potentially generalisable elements of an MUS care pathway within referral management centres and other commissioning contexts
- To test the use of the MUS identification toolkit in a RMC context
- To provide national guidance on MUS for commissioners and RMCs

Predicted Risks:

- That Plymouth RMCs might not develop sufficiently quickly
- That the high workload of the RMC, as a newly-established company, may mean there is initially less time and fewer resources to allocate to projects such as this

3 PHASE 1: DESIGN AND PLANNING

3.1 Method: (Months 1-3)

- Review of literature
- Investigate and map current practice in Plymouth
- Consult with national experts
- Stakeholder event – to present plans for improvements to Plymouth system based on data and analysis.

3.2 Key Messages from Literature:

- MUS can be associated with significant distress and impaired functioning for patients, high stress levels for clinicians and high costs to the healthcare system
- The relationship between clinician and patient is crucial: the patient needs to feel listened to and understood
- MUS fall within a range of severity from mild to severe. Each type requires a slightly different type of management
- A consultation-liaison model is recommended but difficult to implement in practice
- Reattribution is a well-researched method, but has mixed results.
 - TERM: Danish group (Rosendal et al) developed a training method based on the reattribution model, including training and ‘scripts’ for use by GPs
 - However, evaluative studies have shown reattribution to be ineffective in terms of altering patient perceptions and costs
- Communication between components of the healthcare system is vital for a consistency of approach to tackling MUS
- NICE Guidelines should be followed for specific syndromes, where available

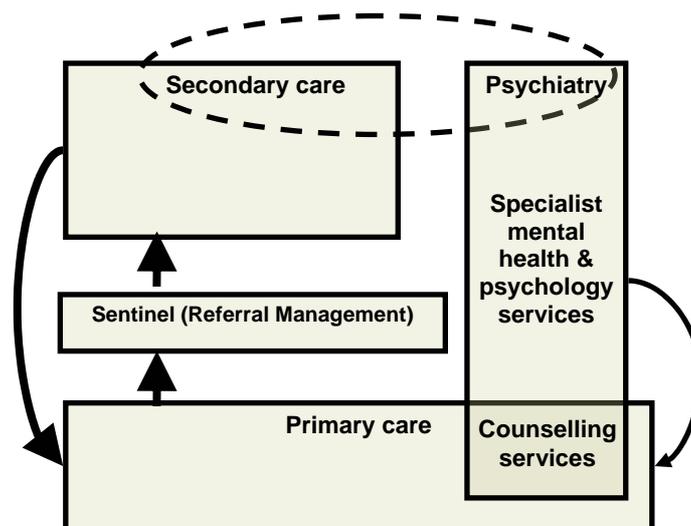


Figure 1: Representation of Plymouth Healthcare System

3.3 Plymouth Healthcare System:

The Plymouth system is depicted in Figure 1. A number of features were identified.

- Some specific services for particular functional disorders or co-morbid psychiatric disorders e.g. neuro psychiatric
- Patients with MUS are encountered at all tiers of the healthcare system
- Clinicians are generally amenable to the use of training and tools to aide them in working with MUS patients – particularly those newer to the NHS, who have not yet built up their own strategies

Gaps in Plymouth health system:

- Psychological assessment and therapy services for people with MUS
- Little community / primary care capacity for managing patients with longer term MUS
- Community based primary care accessible services to specific problems e.g. a dizziness clinic has been called for, bringing together a multi-disciplinary team consisting of consultant in neurology, ENT consultant and a physiotherapist.
- Liaison Psychiatry for MUS.

HEARING THERAPIST FOR TINNITUS.

Box 1

- **Brief description:**
 - One-on-one sessions
 - Involves diagnostic tests and a counselling-type approach
 - Helps patients to see the mind/body link
- **Positive points of service:**
 - Solution-focussed
 - Encourages self-management
 - One-on-one sessions with therapist
 - Methods consistent with literature
 - Validation of symptoms
 - Time given to patient
- **How accessed:**
 - Referrals from ENT specialty, GPs & specialist nurses
- **Scope for improvement:**
 - Use of clinical and patient-reported outcome measures and patient satisfaction measures
 - Enhanced CBT / counselling training for clinician

Positive Practice in Plymouth:

Despite, as across the UK, there being a relatively poorly developed health care system for people with MUS there were examples of good practice in Plymouth as outlined in boxes 1-3.

DERRIFORD PAIN MANAGEMENT PROGRAMME

Box 2

- **Brief Description:**
 - 7 week course: 3 hour sessions, twice a week
 - Standardised programme of group work including education, discussion, relaxation and exercise sessions
 - Provides education, strategies and encouragement for people with chronic pain, to take control of their pain, and learn to manage it
- **Positive points of service:**
 - Stresses importance of bio-psychosocial link and self-help
 - Run by a multi-disciplinary team
 - Wide range of outcome measures
 - Encourages self-management
 - Validation of symptoms
- **How accessed:**
 - Referrals from hospital consultants
- **Scope for improvement:**
 - May be better placed in primary care

PRIMARY CARE CONSULTATION FOR MUS

Box 3

- **Positive points of service:**
 - Emphasises maintenance of clinician / patient relationship
 - Many GPs are already conforming to good practice identified in literature
 - GPs build capability towards best practice through accumulated experience
 - Bio-psychosocial link made in many consultations
- **Identified scope for improvement:**
 - Need for training to ensure consistency of approach to people with MUS
 - Further support to reduce anxiety for clinicians considering not making referrals or ordering investigations they believe will be unhelpful

3.4 Towards a Whole-Systems Approach (3 stages of management for MUS)

From the Literature, discussion with experts and clinicians in Plymouth a three stage model for management of MUS was developed:

1. **Identification:** Common indicators of MUS:
 - Frequent attendance
 - Multiple symptoms with no obvious cause
 - Sleep disturbance
2. **Engagement & shared understanding:**
 - Acknowledge pain or physical symptom
 - Elicit concerns and expectations
 - Maintaining relationship – feeling heard
 - Managing and accepting uncertainty
 - Exploring the bio-psychosocial context

3.5 Shared action planning:

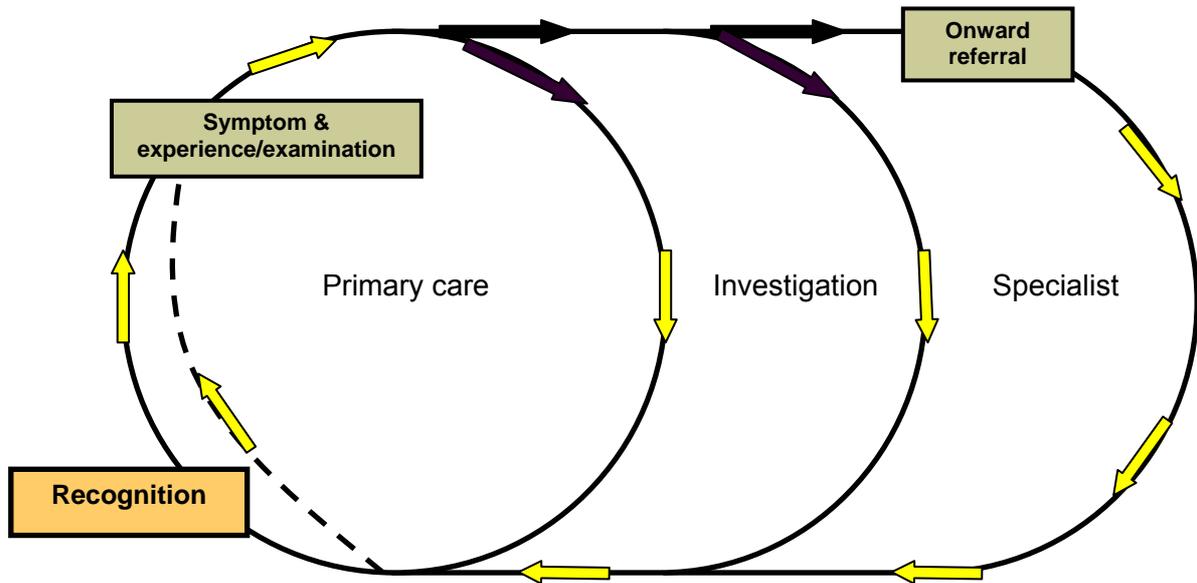
- Verbal ‘Scripts’ for use prior to examination, investigation or referrals during consultations
- Clarity of rationale for referral and plan in referrals and discharge letters
- Pathways/protocols for specific conditions
- Framing discussions about results – before and after
- Treatment of mental health problems – medication and/ or psychological therapies
- Make restoration of function the goal of treatment
- Medication – avoiding over prescribing
- Goal-setting (for improvement / restoration of function)
- Scheduling appointments
- Positive risk management

Figure 2 represents the pathways taken by individual patients being investigated and passing through primary and secondary care.

This loop is particularly detrimental if:

- It is mainly shifted to the right or specialist end.
- Multiple “trips” for invasive investigation or referral occur sequentially or simultaneously.
- Consultations are not focused on positive social, physical and emotional well being.

Figure 2: MUS Patient Loop



A pictorial representation of the loop that people with MUS can pass around

Stakeholder Event:

- Held mid-way through the project.
- Aims were:
 - To publicise the issue of MUS
 - To gauge level of interest from healthcare professionals
 - To gain feedback on our approach to the problem, and possible interventions
 - To discuss possible options for interventions

Outcomes of Stakeholder Event:

- 27 practitioners from eight different professional groups attended.
- Feedback:
 - Agreement that it is a common area of difficulty within GP practices and the wider healthcare community that needs to be addressed
 - A psychological toolkit would be useful for consultants in secondary care as this isn't emphasised in their training
 - Patient information would be useful to support consultations.
 - Agreement that a systems approach is a helpful way of viewing the issue, but that GPs are essentially at the centre of management
 - Need for more multi-disciplinary working
 - Risk management issues need to be addressed
- Support for action plan (see below)
- Further specification of objectives

Objectives for Phase 2 Identified at Shareholder Event:

Patient Information:

- List of available patient information
- Written information needed for increasing patient awareness of issues, backing up the GP, and reducing anxiety

Positive Risk Management Guidelines:

- Needed to reduce clinician anxiety

Clinical Guidance:

- Develop and pilot both general guidance and a range of specific guides supporting clinicians at all stages of pathway.

Specialist Psychological Toolkit:

- Psychological training for consultants and specialist teams.

ENT Specialty as a focus to test the approach:

- Chose to focus on Ear, Nose & Throat (ENT) specialty in order to get more specific knowledge and input
- Trial specialist psychological toolkit with ENT consultants
- Availability of care pathways/management advice for three pathways

Training across the system:

- Training needs identified for consultants and GPs
- To be successful, training needs to be:
 - Practice-based
 - Linked to guidance
 - Aimed at a large group

Referral Form and Referral Management (Sentinel CIC):

- Alter form to encourage open discussion of MUS issues but avoid 'labelling' MUS as a disease
- Making full, correct completion of referral form part of culture of how Sentinel works

Develop Whole-Systems Governance to support changes:

- Develop clinical guidelines
- Develop risk-management guidelines
- Gain PEC support
- Ensure ratification of guidance

3.6 Summary of clinical changes required

In order to improve deficits in the system it is envisaged that care shifts to have:

- Less investigations
- More primary care input
- A greater focus on attaining improved functional status (quality of life)

In order to achieve this key changes in clinical behaviour are required which will shift care to the left in figure 2 and towards primary care in figure 1. These are shown in Box 4.

BOX 4:

Summary of key changes required to clinical practice:

Changes to primary care consultations (as means of micro-commissioning):

- Empathise and acknowledge symptoms
- In MUS cases at low risk of disease, investigation and referral may not be required – clinicians can ‘share risk’ by discussing with patient, specialist or colleagues (and documenting)
- In suspected MUS cases, when referring for investigation or specialist opinion, patient should be informed of likely ‘negative’ results in order to manage expectations
- Inform specialists of likely MUS in Sentinel referral letters (rather than feeling need to justify referral but emphasising symptoms)
- Offer and explore, but don’t push, psycho-social explanation
- Focus on improving functional ability
- Recognise and treat co-morbid anxiety and depression

Changes to specialist consultations:

- In suspected MUS cases, when referring for investigation, patient should be informed of likely ‘negative’ results in order to manage expectations
- Once low risk of disease established further investigation may not be required – clinicians can ‘share risk’ by discussing with patient and/ or colleagues (and documenting)
- Discharge to primary care once investigations are complete with clear negative results
- Respond to GPs provisional MUS diagnosis and actively support it verbally to patient and in writing to GP
- Offer and explore, but don’t push, psycho-social explanation
- Recognise and treat co-morbid anxiety and depression

4 PHASE 2: IMPLEMENTATION

From the stakeholder day & design & planning stage, key items for action were identified (see section 5.9). The core team devised a work plan and based on the identified objectives and resources available. The following developments were achieved:

Positive risk management guidelines (Appendix A)

- Specifically addresses systems aspect of appropriate investigations & discharge
- Approved as an approach by Primary Care Clinical Governance Forum
Recommended as possible adjunct to training.

Clinical Guidance (Appendix C)

- Guidelines assist clinicians in preparing for, and dealing with, patients with medically unexplained symptoms:
- Evidence-based. Adapted information from Denmark, the U.S., and other sources of evidence
- To be approved by the health community as clinical guidelines for the management of MUS in Plymouth
- Trialled at two Plymouth GP surgeries during the development stage. Generally well-received. Feedback included:
 - Need to be shorter They didn't feel that they needed tools in the identification of MUS, as they were already well-skilled in this due to the frequency with which they saw these patients
 - Best delivered as part of training event rather than just distributed without implementation advice
- To seek approval as per above

Patient Information leaflet 'Managing Your Symptoms' based on several other leaflets for patients with MUS / LTC. (Appendix D)

- Developed in accordance with NHS guidance for the production of patient information
- Pilot version sent to local Recovery Champion for distribution to a number of service users to gauge opinion and acceptability
- Positive response amongst patient population. Changes made on the basis of feedback
- Process set in motion to have leaflets approved for use within the trusts

Specialist Psychological Toolkit

Compiled by clinical psychologists

- Based upon psychological tools for the assessment and handling of distress

Implementation

- Designed to be delivered to hospital specialists as part of a training event

ENT Specialty

Three Syndromes

- Focussed on three specific syndromes: tinnitus, globus pharyngeus and dizziness as examples of symptoms likely to fall under MUS umbrella.
- Discussed management with ENT GPwSIs and consultants
- Gathered referral management information for ENT syndromes

Tinnitus Pathway (Appendix B)

- Produced as an example of a care pathway that is consistent with MUS principles
- Produced in the form of an algorithm
- Agreed between ENT GPwSI and consultants ENT surgeons.

Training

- A training event as part of CPD framework for clinicians would be preferred

Referral Form from Referral management Centre (Sentinel CIC)

- After speaking with representatives from Sentinel, it was decided that correct and thorough completion of the form was more important than adding to it
 - Adding to the form could lead to labelling if not carefully worded
 - Thorough completion of the form should include psychosocial factors and suspected MUS anyway

Whole-Systems Governance:

- Clinical guidance document and Risk Management document submitted to the PEC and principles approved. Need to be approved by provider clinical governance groups.

Contribution to National Guidance

- The team was involved in the LTC/MUS special interest group for IAPT
- We contributed to the ensuing IAPT guide: 'Medically Unexplained Symptoms Positive Practice Guide' as an example of the positive research being conducted in the area.

5 LEARNING / EVALUATION

5.1 How we met original objectives:

To develop guidance for MUS for GP's and Specialists.

- 1) The guidance for the management of MUS has been well received (Appendix C). It will require further evaluation.
- 2) To develop care pathways for MUS in the referral management centre. To develop a commissioner led approach to MUS. The work involved the collaboration of the PCT commissioning manager and Sentinel representing PBC. PEC have agreed that MUS work should be led by the "Planned Care Group". However, MUS is not seen as a priority for 2009 work streams.
- 3) We have produced a care pathway for MUS as part of the toolkit, as well as a care pathway specifically for Tinnitus. The project successfully incorporated the priorities and concerns of a wide stakeholder group. It has taken on a whole system, approach. Generally however, due to the competing operational priorities of Sentinel CIC, there was less emphasis on referral management centres being a critical part of the pathway, than had originally been envisaged. The real potential of PBC and referral management centres in improving MUS care has not been fully developed.
- 4) To test the use of the MUS identification toolkit.
This referred to the toolkit that was at that time in production by Morriss et al. However, this piece of research has since changed its focus and did not emerge as a discrete tool for the identification of MUS as intended.
- 5) Contribute to National guidance. The output of the project - a local framework for the management of MUS – is a useful resource for others involved in developing care for MUS. It does not however constitute guidance issued by a national body.

5.2 Process and Problems:

This section outlines some of the barriers met by the project.

Sentinel:

- Although the initial focus of the project was the referral management centre, (Sentinel CIC), the initial consultation and pressures on Sentinel as a newly-created company with competing priorities led the team to adopt a more system view for Plymouth Healthcare as a whole.
- Attempts were made to gather data regarding the more well-known MUS syndromes but this proved to be challenging as systems are not yet in place to record these in Sentinel systems.

General Practitioners:

- Engagement of GPs was challenging but GPs both on an individual and at a practice level successfully engaged with the project. Their engagement might have been improved in sentinel had been able to offer higher visibility sponsorship of the project. Many of those GPs taking an interest had developed strategies for dealing with MUS which was incorporated into the guidance.
- There was general consensus that a small group of MUS patients presented particular challenges to GPs

- There is a need for greater support for GPs in the management of patients with MUS. Less experienced GPs who often feel less equipped when it comes to MUS patients and were able to articulate this as an educational need. Whereas some experienced GPs have often developed their own strategies for management, many of which mimic very closely those suggested by research. It may therefore be worth looking at the provision of training and tools at the training stage for GPs
- Reaching experienced GPs without an interest in MUS may be more challenging.

Patient Involvement:

- The Mental Health Recovery Champion was on the steering group and was consulted at several stages throughout the process.
- As MUS is not a diagnosis and many patients do not understand / agree with this description of their symptoms, it was difficult to identify patients. It is a sensitive issue for both patients and clinicians, so the issue of patient involvement throws up ethical problems.
- Patients were consulted regarding the patient information leaflet
- An MUS patient case study utilising medical records was undertaken to track journey through healthcare system, and better understand the issues
- It was originally planned to use Discovery interviews to gather patient experiences but further investigation revealed that implementation of this approach would involve a significant amount of development time / training etc and was outside the capacity of the project

The elusiveness of MUS:

- MUS is a difficult subject to redesign services for as it appears in such a wide range of services and individuals
- It was useful to focus on distinct ENT syndromes but many patients with MUS do not fall into any such distinct categories. Work therefore has to support both specific syndromes and generic issues.
- The project was never focussed on the role of mental health services for MUS. While there is a consensus that people with MUS and co-morbid depression and anxiety should receive mental health care, often through the new IAPT service, there is much less agreement about whether the IAPT service should provide CBT specifically for MUS. There is also no clear pathway for those particularly complex patients with co-morbid MUS and personality disorder.

General:

- The project statement & aims were broad at outset.
 - This was due to the difficulty in predicting what an MUS strategy might look like early on
 - This made decisions on implementation more difficult
 - However, it allowed for a greater flexibility of approach, and allowed changes to be made partway through in response to clinicians' input and local situation.
- The project was funded relatively intensively (a full time worker) but for a short life (initially six months). Engagement and ongoing involvement of key (busy) shareholders in a collaborate process was not possible in such a short time frame where there were competing priorities.

- As an externally funded project the PCT stakeholders were willing to support the project but it was not seen as its highest priority.
 - Healthcare professionals' response to the project was encouraging, although engaging them is difficult due to demands on their time
 - There was a shift from a focus on best practice to a focus on positive practice
 - This was to allow the inclusion of good practice already employed by clinicians
 - Also allowed for the construction of guidance that didn't necessitate the commissioning of new services
 - The continued success of the project relies on effective involvement of healthcare professionals, clinical leaders and managers.
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5.3 Proposed Next Steps for NHS Plymouth

- 1. Policy Development (for management of MUS):**
 - PEC to ratify strategy for whole system
 - Ratify guidelines as clinical policy for GPs (via Clinical Governance), PHT and Mental Health Provider services
 - Approve Positive Risk Management Guidance
 - Agree milestones and criteria for implementation and evaluation
- 2. Develop and deliver training programme across Health community:**
 - Key skills and knowledge for key PHT departments (Preferably in line / in conjunction with CPD framework)
 - Training in MUS and risk for GPs via mandatory clinical governance training (Concept already approved by Primary Care Clinical Governance Forum)
 - Dissemination of guidelines via practice meetings
- 3. MUS franchise model:**
 - Offer 'consultancy' service to PHNT departments
 - Develop care pathways for different MUS conditions,
 - Develop consultation-liaison model with health psychology and liaison psychiatry for PHT and primary care
- 4. Commissioning new services:**
 - Possibilities include: Symptom management group, liaison psychiatry, specialist 'training' service aimed at increasing capacity of health professionals (IAPT, LTC, planned care programme), specific interventions e.g. 'balance' for vertigo,
 - Could be taken forward once clinical policy has been ratified
- 5. Patient information and involvement:**
 - Already produced, conforms to patient information guidelines (Funding for 1st batch could be drawn from remainder of project funds)
 - Leaflet distribution should be integrated with training.
 - Need to develop more effective PPI.

6 Conclusions

The Plymouth whole systems MUS project has succeeded in engaging shareholders across the system to produce:

- Clinical Guidance for practitioners in the form of whole system pathway.
- Positive risk management guidance to support clinicians by gaining whole system governance approval.
- An outline for integrating educational interventions for patients and clinicians into a whole system approach.

The project also described key clinical changes across the system. Using practice based commissioning as a specific mechanism, in order to shift care away from investigation and hospitals, towards primary care and a focus on improved functional status remains elusive. The experience described and the products developed should be of use to others across the UK developing services for patients with MUS.

Selection of key references

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**Risk Management Strategies
For Medically Unexplained Symptoms (MUS) in Plymouth**

DRAFT FOR CONSULTATION

1. Background

Medically unexplained symptoms are common, associated with significant distress, and can result in unnecessary and costly referrals, diagnostic tests and even operative procedures. Studies on 'medically unexplained symptoms'(MUS), show that between 20% and 30% of those seen in primary care have no clear diagnosis, in Secondary Care this rises to an average of 52% of those seen in, Cardiology, Dental, Gynaecology, Neurology, Chest and Gastroenterology and Rheumatology outpatients. (Nimnuan, 2001)

2. Introduction

The management of patients with medically unexplained symptoms (MUS) is complex and clinical decisions often involve weighing up poorly defined positive and negative risks. While by definition patients with MUS are thought not to have life threatening or disabling diseases a very small proportion will go on to have specific diagnoses. Some studies have shown a low probability of MUS concealing physical disease but work in press by Morriss, is reported to show a 10% incidence of organic disease in those thought to have MUS (Morriss, 2008). On the other hand it is now well accepted that excessive investigation is associated with both physical harms and poorer psycho-social outcomes.

'They'll always be right in the end.'

Almost inevitably, all those patients, who have medically unexplained symptoms, passing through a rotation of out patient clinics or recurrent GP attendances will one day present with a life threatening condition. Practitioners are all too aware of the daily dilemmas faced in balancing the risks of over investigation with missed diagnoses. This document is designed to support thoughtful positive practice.

The guidelines below have been accepted by NHS Plymouth and Plymouth Hospitals Trust as being consistent with their policies on risk management. NHS Plymouth supports positive risk management as a means of achieving improved outcomes. This guideline should be read within the context of the following documents: e.g. PHNT risk policy, PCT risk policy, Plymouth MUS strategy.

3. Purpose

The purpose of these guidelines are to promote a positive approach to risk management within the Plymouth Health Community and to suggest strategies practitioners may employ

3.1 The aim of positive risk management is to:

- Improve the function and wellbeing of patients
- Protect clinicians and patients from negative risk
- Provide clinicians with a support structure when making decisions
- Provide a clear audit trail as justification for difficult decisions

4. Principles

Positive risk management involves the following principles:

- Making decisions on the basis of what is best for the patient rather than to protect practitioners and organisation
- Distributing responsibility for decision making between practitioners and patients
- Evidencing the rationale for decisions in order to support practitioners in this challenging work

5. A systems approach to risk management of MUS

Patients with MUS present and pass through primary and secondary care and in most specialties through the hospital as well in mental health services. Risk adverse practice is fuelled by patient and physician anxiety; advances in technology offer the possibility of diagnosing disease and further encourage invasive investigation.

6. Positive risk management in patients with MUS is particularly relevant when making decisions about whether to investigate, refer on, or continue to monitor in secondary care. Whilst sometimes necessary to rule out disease, referrals to specialists or for investigation can have the following negative effects:

- legitimising the patient's view of their symptoms as underlying a serious physical illness
- subject patients them to the risks associated with intrusive investigations
- have false positives or pick up on minor abnormalities that will worry the patient more

The Plymouth MUS risk management strategy aims to ensure that people do not receive unnecessary and potentially harmful investigation and follow up.

7. Practical strategies for positive risk management

The boxes below provide specific guidance on positive risk management for MUS.

The aim of positive risk management is to:

- Improve the function and wellbeing of patients
- Protect clinicians and patients from negative risk
- Provide clinicians with a support structure when making decisions
- Provide a clear audit trail as justification for difficult decisions

Avoid iatrogenic damage through unnecessary investigations, referrals and follow up:

- Use your clinical judgement – if you do not believe that there is any need for further investigations, then arrange to monitor the symptoms and to reassess after an agreed time, or if the symptoms change
- When making referrals or organising investigations for those with likely MUS let patients know that the results are likely to be negative

Communicate effectively:

- Start to open up discussions about potential psycho-social causes or exacerbation of symptoms – many patients have made the link already
- Listen to the patients concerns and ensure that the patient feels listened to
- Provide explanations of the symptoms that relate to their understanding and beliefs about the cause of their symptoms – either to support or refute harmful beliefs
- Communicate clearly with colleagues when referring that you expect a negative result and speedy discharge
- Ensure any relevant psychosocial factors which may be important to the assessment process are communicated fully
- Copy letters to all clinicians involved to ensure a shared understanding that the patient may have MUS

Document decisions clearly:

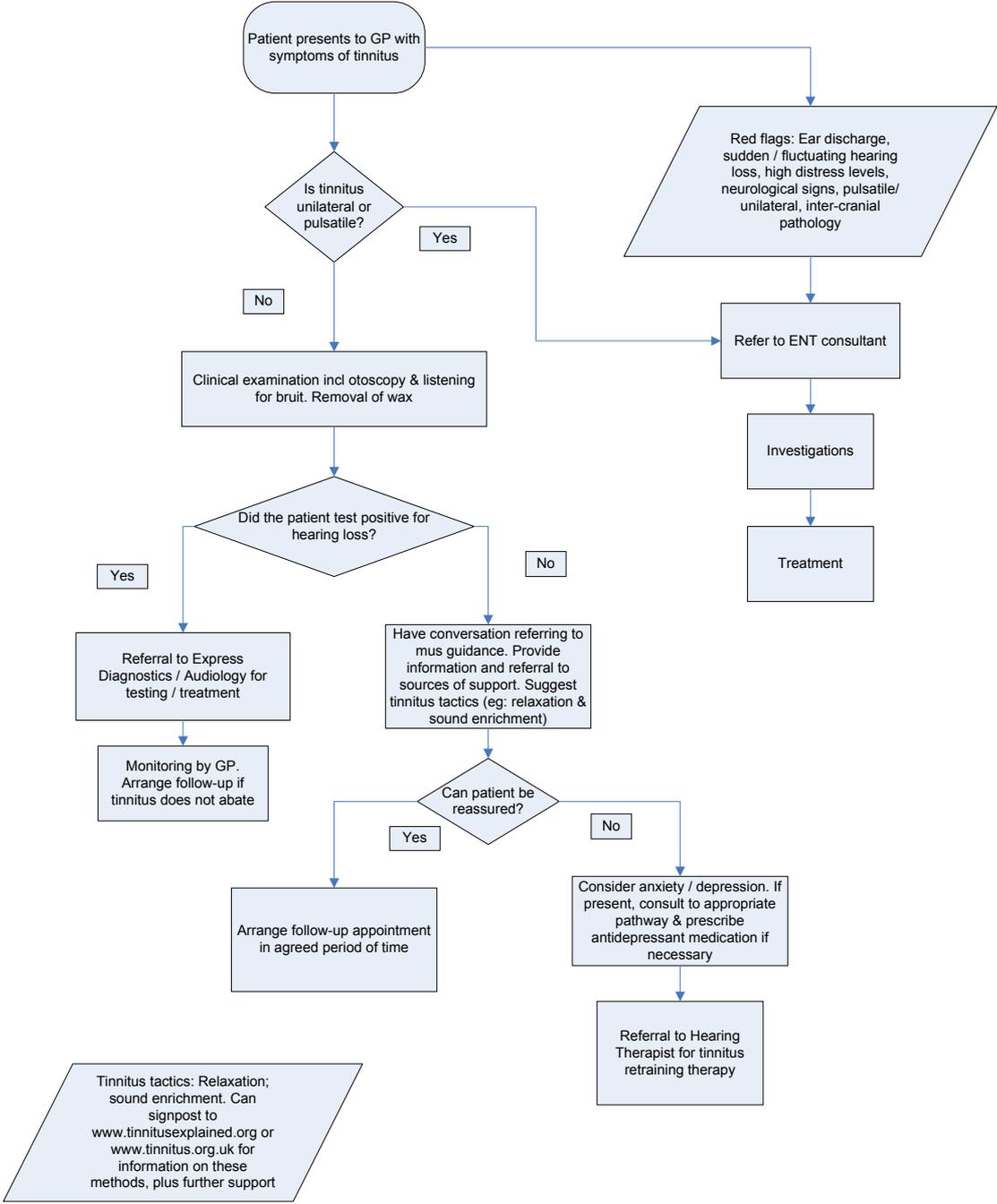
- Document all contacts with patients and any action / inaction agreed.
- Share any action plan with the patient
- Clearly document negative results and the absence of red flags
- All consultations should be documented with carefully wording to provide evidence for reasoned inaction or monitoring
- Document discussions and telephone conversations with colleagues and patients

Share risks:

- Discuss cases with GP or specialist colleagues
- Gain peer supervision / collaboration in formal clinical meetings or informal discussions to support difficult decisions
- Sharing risk with patient about why referrals are being or not being made*
- Share relevant Information with the patient so that they are able to participate in a shared decision making process
- Ensure 'safety-netting' by developing a contingency plan e.g. Inform colleagues about triggers for a further referral, inform patients about when they should re present

*NB. People vary in the extent to which they wish to share decision making with physicians

**ENT Pathway: Tinnitus
DRAFT**



Three-Stage Toolkit for the Management of Medically Unexplained

Risk Management Strategies to support avoidance of unnecessary investigation

- Communicate effectively with patient and other clinicians
- Document rationale for decisions clearly
- Share risk with other clinicians and patient (See p.2)

MUS identification in primary and secondary care

- Person with MUS** (Adapted from VA/DoD Clinical Practice Guideline for MUS, 2001)
- “(MUS) are physical symptoms that cannot be explained by organic pathology, which distress or impair the functioning of the patient” (Morriss & Gask, 2006)
 - The person has unexplained symptoms after an appropriate assessment and testing
 - May or may not have a psychological origin (See p.3)



Engagement and shared understanding

- The Bathe Technique** (Adapted from Servan-Schreiber et al. 2000):
- **Background:** “What is going on in your life?”
 - **Affect:** “How do you feel about it?”
 - **Trouble:** “What troubles you the most about the situation?”
 - **Handle:** “What helps you handle that?”
 - **Empathy:** “This is a tough situation to be in. Your reaction makes sense to me.” (See p.4)

- Negotiating a new model of understanding after negative tests (Reframing)**
- Link the explanation to the beliefs of the patient
 - If anxiety or depression is also present explain how it can contribute to the symptoms
 - Provide explanation for how symptoms may be caused by bio-psycho-social factors (See p.5)



Action planning

- Investigations / examinations: Making referrals & delivering negative results**
- Prepare patient beforehand for negative results
 - Explore possible psychosocial explanation before referral/investigation
 - Make expectations for referral and psychosocial factors explicit in written referral
 - Acknowledge reality of symptoms
 - Provide empowering explanation (See p.6)

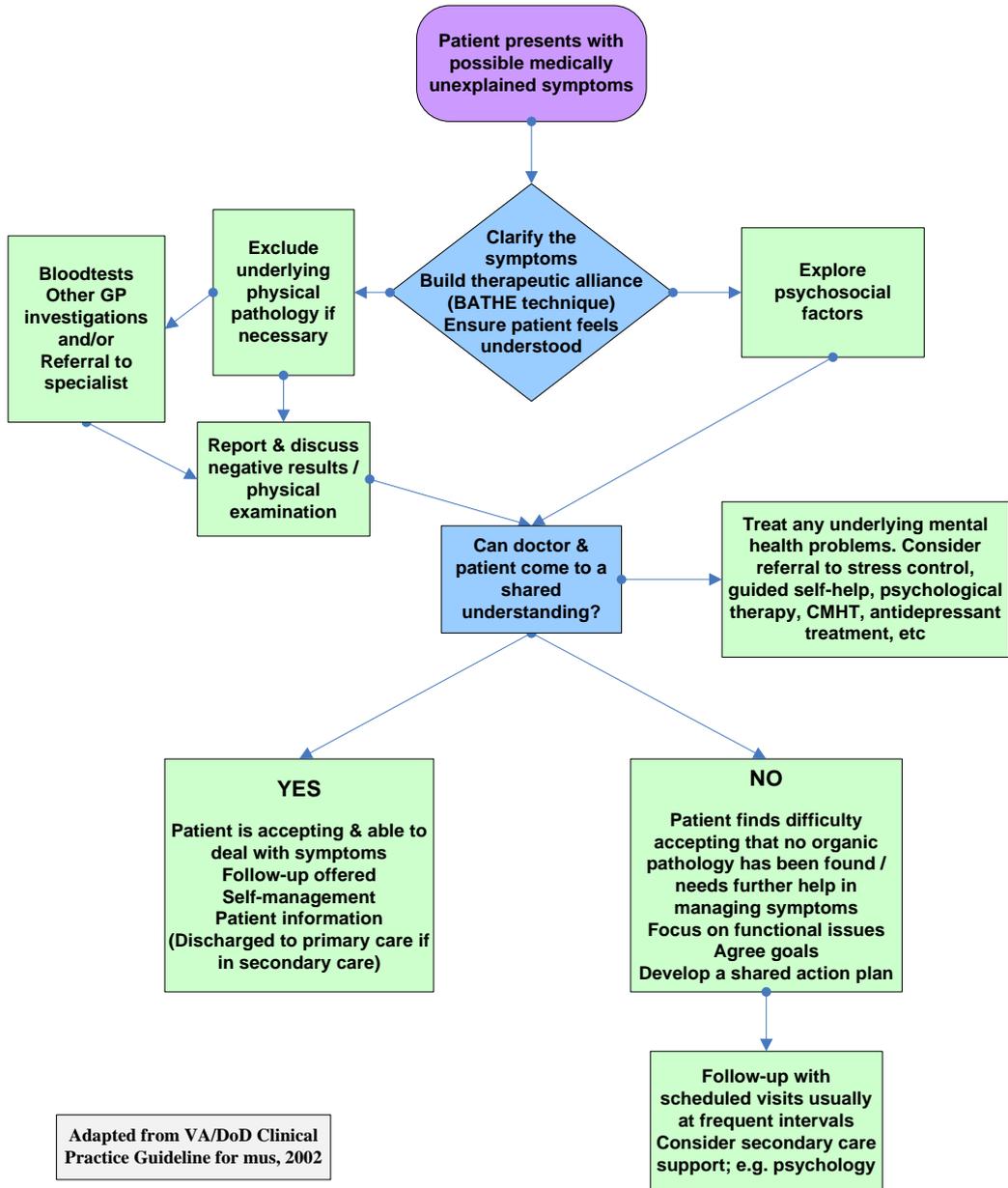
- Goal-Setting & Restoration of Function**
- Prepare for consultations
 - Collaborate with the patient and determine their preferences
 - Treat anxiety, depression and any other mental health problems
 - Set achievable, time-limited goals
 - Educate and empower the patient for self-management
 - Monitor impact of symptoms & effects of treatments
 - Assess patients for new symptoms suggestive of other diagnoses
 - Assess patient’s adherence to treatment and address any barriers to this
 - Assist the patient to take an active role in their recovery
 - Respond to any desire to change/re-evaluate the treatment plan (See p.7)

Follow-up Visits (See p.8)

Self Management Strategies (See p.8)

**Medically Unexplained Symptoms: Guidance Pathway
(For Functional Somatic Syndromes see appropriate pathway / NICE Guidelines)**

Positive risk management strategies



Introduction

GUIDANCE FOR THE USE OF THIS DOCUMENT

These guidelines are designed to support clinicians in the management of MUS to limit potential side effects and negative impact of excessive referrals, investigation and prolonged secondary care follow up; and to focus on improving functional status whilst utilising a sensitive, patient-centred approach.

The journey for people with MUS along the care pathway is not necessarily a linear one. The majority will only require clarification of their history and symptoms but there will be those who continue on to the end of the pathway. These guidelines can be used whether a person has been newly identified as having MUS or has been using the healthcare system for many years. They can be used by practitioners in any part of the system, whether in primary or secondary care.

The guidelines have been adapted from TERM (Per Fink et al. 2002) and VA / DoD Clinical Practice Guidelines for MUS, 2002

GUIDANCE SUMMARY FOR RISK MANAGEMENT STRATEGIES FOR MUS

Avoid iatrogenic damage through unnecessary investigations, referrals & follow up:

- Use your clinical judgement – if further investigation is unnecessary, arrange to monitor symptoms and reassess after an agreed time, or if symptoms change
- When making referrals or organising investigations for those with likely MUS let patients know if you think that the results are likely to be negative
- Discharge to primary care for follow up as soon as possible

Communicate effectively:

- Begin to open up discussions about potential psychosocial causes of symptoms
- Provide explanations of the symptoms that relate to their own understanding and beliefs; either to support helpful beliefs or refute harmful beliefs
- Communicate clearly with colleagues at the referral stage that you expect a negative result and speedy discharge
- Copy letters to all clinicians involved to ensure shared understanding

Document decisions clearly:

- Document all contacts with patients and any action / inaction agreed.
- Clearly document negative results and the absence of red flags
- All consultations should be documented, providing evidence for reasoned inaction or monitoring
- Document discussions & telephone conversations with colleagues & patients

Share risk:

- Discuss cases with GP or specialist colleagues – and document decisions
- Gain peer supervision / collaboration in a formal clinical meetings or informal discussions to support difficult decisions
- Where possible share risks with the patient explaining the disadvantages of investigation or referral*
- 'Safety-netting': e.g. developing a contingency plan for the worst case scenario e.g. advice about action in the case of changing or worsening symptoms

*NB. People vary in the extent to which they wish to share decision making

Identification

IDENTIFICATION OF PERSON WITH MEDICALLY UNEXPLAINED SYMPTOMS: (MUS)

Medically unexplained symptoms are physical symptoms are physical symptoms which doctors are unable to explain by organic pathology

Diagnosis of exclusion: unexplained symptoms after investigation.

- Repeat attendance with poorly defined symptoms
- May have one or more diagnoses that lack a well-defined disease explanation (e.g. chronic fatigue syndrome, chronic pain syndrome, globus, fibromyalgia, IBS).
- Usual clinical features include a relative lack of objective signs and a chronic symptom course often marked by exacerbations, remissions and reoccurrences

May be purely physiological imbalance, but often has psychological origin or secondary mental health diagnosis:

- May have history of abuse or trauma
- Screen for cognitive impairment in older people, for suicidal ideation and substance misuse
- Useful screening tools for underlying mental health problems: PHQ, GAD7, HADS - can be used as a way for patients to see their symptoms in black and white

Engagement

Some patients with MUS are very willing to consider psycho-social causes for physical symptoms, or that psychosocial factors have a role in exacerbating their symptoms. Others have strong beliefs that their problems are due to an underlying disease. Developing a shared understanding of the issues, which may include an agreement to differ, is critical to successful management.

THE BATHE TECHNIQUE

Provides a time-efficient way to address the impact of patients' symptoms on their level of function

Background:

- *"What is going on in your life?"*
- *"Do you have any specific expectations of what is going to happen today?"*
- *"Why do you think you're feeling this?"*
- *"How does it affect your everyday life / job / role as...?"*

Affect:

- *"How do you feel about it?"*
- *"You say everything seems confusing – try to tell me more about that"*
- *"Do you feel depressed / tired?"*
- *"Has anything happened in the past that may affect how you're feeling now?"*

Trouble:

- *"What troubles you the most about the situation?"*
- *"With these complaints, how do you manage at home, at work, with friends?"*

Handle:

- *"What helps you handle that?"*

Empathy:

- *"This is a tough situation to be in. Anybody would feel (down, stressed, etc.). Your reaction makes sense to me."*
- *"There is a lot of merit in being able to talk about these topics – it can help to make things a little clearer and easier to deal with"*

(Adapted from Servan-Schreiber et al. 2000 and TERM, Fink et al. 2002)

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 TERM model – Fink et al, 2002

Shared Understanding & Action Planning

INVESTIGATIONS / EXAMINATIONS: MAKING REFERRALS & DELIVERING NEGATIVE RESULTS

Making referrals:

Predict a negative outcome and make this explicit to the patient. This could be phrased in the following way:

- *“Your symptoms aren’t consistent with ... but as I can’t rule it out completely I’ll refer you for tests, but I’m 99% sure they’ll be negative.”*

Completing referral letters:

Clearly indicate:

- Your reasons for making the referral and expectations for the outcome
e.g. the purpose of the investigation is to rule out a specific illness and the patient should not be referred on to anyone else without prior consultation with yourself
- Relevant psychosocial factors
- Be clear about the ‘Primary Reason for Referral’
- Ensure you have filled in the ‘Relevant Past Medical History’ thoroughly including other MUS syndromes and mental health problems

Delivering negative results:

- Avoid the phrase “there is nothing wrong with you”. Instead, validate the patient’s symptoms and sympathise with their suffering
- Provide an empowering explanation for the negative results – e.g. one which provides a tangible psycho-physiological mechanism, removes blame, & provides opportunities for self help. Base this on patients’ own health beliefs
- Simple written materials may help

The following suggestions may help in terms of what to say to the patient:

Provide feedback on the results of the physical examination

- *“I have now examined/tested for.. I have found no signs of disease”*
- *“After my examination of / test for... I can inform you that it is not ... (according to the patient’s own illness perception)?”*

Acknowledge the reality of the symptoms

- *“BUT I have no doubt that YOU HAVE “the symptom!”*
- *“BUT I can SEE/FEEL that YOU ARE IN PAIN!”*

Discussion of next steps

- *“You have been examined thoroughly... and there is no indication of a serious disorder. No available medical or surgical treatment could help you. WHAT DO YOU THINK hearing that? COULD WE TOGETHER TRY TO FIND other explanations for your symptoms?”*
- *“Now we have excluded the possibility of ... (disease tested for) ... , we can now concentrate on managing the symptom itself”*

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

FOLLOW-UP VISITS

- **Follow-up visits:**

- Monitor severity & impact of symptoms, effects & adverse effects of treatments
- Assess patients for new symptoms suggestive of other diagnoses
- Assess patient's adherence to treatment and address any barriers to this
- Assist the patient to take an active role in their recovery
- Respond to any desire to change the treatment plan or behaviour that indicates a need to re-evaluate the treatment plan
- Use cognitive techniques to help patients learn to reassure themselves rather than continually needing reassurance from a doctor
- Scheduled visits can help reduce repeated attendance for minor symptoms
- Perform brief physical examination if there is concern about new symptoms or worsening of chronic symptoms

Interval between visits:

- This will vary depending on a number of factors:
 - Quality of patient/clinician relationship (i.e. new or established patient)
 - Distress of the patient
 - Need for refinement of the treatment/action plan
 - Presence or absence of psychosocial stressors
- This will gradually lengthen as symptoms remit / as the patient is able to sustain lifestyle changes having a positive effect

SELF-MANAGEMENT STRATEGIES

Consider signposting to sources of self-help. Some suggestions are:

Expert Patient Programme:

www.plymouthguild.org.uk

Sleep management leaflet:

www.patient.co.uk/showdoc/27001301

Tiredness leaflet:

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

Pain leaflet:

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

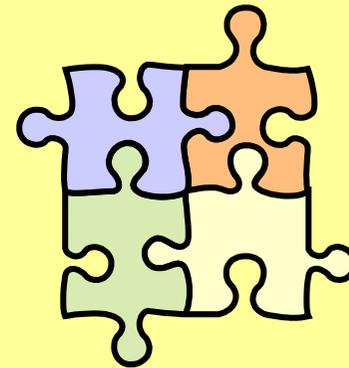
Online CBT:

www.moodgym.anu.edu.au

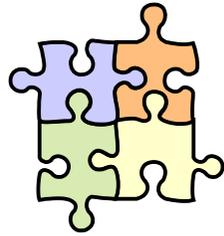
<http://www.beatingtheblues.co.uk/connect/>

Appendix D

Managing Your Symptoms



Patient Information Leaflet



This leaflet is intended for people who have symptoms that have been investigated, and no specific underlying medical cause can be found.

It is intended to provide you with information to supplement what you have already been told by your healthcare professional.

Why have I been given this leaflet?

You have been given this leaflet because you are experiencing a symptom for which no cause has been found. You may well have experienced one or more of the following:

- Repeated visits to your GP
- Referrals to specialist services
- Investigations / tests with no conclusive results
- Seen a specialist

From this, it seems that further investigations are not likely to find a cause for the symptoms you are currently experiencing.

About my symptoms

Sometimes people experience physical symptoms that can't be explained by a specific underlying physical cause. These symptoms are very real, and can have a major effect on a person's life, health and wellbeing.

Common unexplained symptoms can include:

- Headaches
- Fatigue
- Memory loss
- Sleep problems
- Skin rash
- Digestive problems
- Chronic pain

In some people, their symptoms can be grouped into disorders or syndromes. For example: numbness, nausea, loose bowels, constipation and abdominal pain are all symptoms of Irritable Bowel Syndrome. Your doctor will have told you if you have a particular syndrome.

Sometimes 'functional disorders', can be caused when the nervous system does not work properly, but not as a result of damage or disease. This can lead to symptoms such as limb weakness or heaviness and non-epileptic attacks.

they can be due to a complex interaction between physical, psychological and social factors.

Chances are that 10% of the general population has some sort of ongoing physical symptom like those listed above. As a matter of fact, studies show that a third of the time, when a patient seeks medical care, a cause for their concerns cannot be found. Whether or not a cause has been found, the focus will be on treating your symptoms.

What caused my symptoms?

The causes are not clear. The following are possible explanations that are currently being researched.

Sometimes people can be vulnerable to continued symptoms after an injury, illness or a traumatic event, when the nervous system has taken a hit and is more vulnerable to damage.

Often biological factors (illness, injury, physical symptoms), psychological factors (trauma, coping styles etc) and social factors (lifestyle, relationships etc) all interact, which causes a reaction or imbalance within the individual.

Being prone to these symptoms can also sometimes run in families. The reason for this is unclear, but, if there is a history of these

This is an area which has only recently become an important issue within medical science and, while new research and discoveries are being made all the time, there is no clear idea of how to deal with it, so different practitioners will approach the problem in different ways.

Your symptoms are very real and may be affecting your life in a big way. Whilst there is currently no 'cure', there are things that can be done to tackle both the symptoms and the cause, and your GP / healthcare professional will be working very hard to help you as much as possible.

What can my healthcare professional do for me?

- Listen to my concerns
- Fully explore my symptoms, including treatment for any background problems
- Share decisions about further investigations and treatment
- Help with managing symptoms such as sleep problems, pain etc
- Help with setting goals and coming up with an action plan, e.g. increase my activity levels by walking for 20 minutes three times per week
- Share information, such as this leaflet
- Signposting to useful services including counselling or cognitive behavioural therapy

What can I do for myself?

Try to lead as healthy a lifestyle as possible. This includes:

- Eating healthily
- Reducing stress-inducing activities
- Avoiding excessive drinking and smoking
- Increasing your activity levels as much as possible
- Maintaining a positive attitude
- Some people find that alternative therapies may help
- You may want to try the Expert Patient Programme, which supports people in managing their symptoms

Relaxation

You may find that relaxation techniques help with managing your symptoms. You could ask your GP for advice on the following:

- Deep muscle relaxation
- Distraction
- Visualisation
- The Devon Book Prescription Scheme

What happens now?

Your GP or healthcare professional will have taken a detailed history from you in order to understand your symptoms. It is important that you tell her/him everything that could be relevant so that you can work in partnership to tackle your symptoms. If you develop any new symptoms, you need to inform your GP of these so they can be investigated.

Your healthcare professional will arrange with you a personal strategy for managing your symptoms.

Often symptoms rectify themselves quickly, for others symptoms can last longer. In these cases it can be helpful to make scheduled appointments with your GP.

