Medically Unexplained Symptoms
A Practical Guide

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Lambeth PLT
09/03/17
“Dear doctor

Can you please see this patient? There’s nothing wrong with them.

Yours sincerely

.....”
Overview

1. **Background**
   - Terminology
   - The scale of the challenge

2. **Key facts**

3. **Approach to MUS**
   - What we’re teaching GPs

4. **The PRINCE Trials**
What are Medically Unexplained Symptoms (MUS)?

- Physical symptoms not explained by an underlying organic cause
Terminology

- Functional (eg. Functional neurological disorder)

- Medically unexplained symptoms (MUS) / Medically unexplained physical symptoms (MUPS)

- Idiopathic pain

- Bodily distress disorder (Fink & Schroder 2010)

- Somatisation

- ICD-10: Dissociative (conversion disorders); Somatoform disorders
- DSM-5: Somatic Symptom Disorder
One Syndrome or Many?

- Gastroenterology: Irritable bowel syndrome
- Rheumatology: Fibromyalgia
- Infectious diseases: Chronic fatigue syndrome
- Neurology: Headache / Non-epileptic seizures
- Hand surgery: Repetitive sprain injury
- Dental: Atypical facial pain
- Cardiology: Non-cardiac chest pain
- Gynaecology: Chronic pelvic pain
- Urology: Irritable bladder syndrome
Persistent Physical Symptoms (PPS)

• Survey of healthy population – preferred term was Persistent Physical Symptoms (PPS) (Marks, Hunter 2014)

• Survey of CFS patients in specialist clinic in secondary care – preferred term was PPS, then Complex Physical Symptoms (Picariello 2015)
Bringing together physical and mental health
A new frontier for integrated care

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March 2016
The challenge

- The King’s Fund: Bringing Together Physical and Mental Health Report (2016):

“People experiencing MUS are typically referred for multiple investigations and assessments, at considerable expense to the system and with little or no benefit for the patient.

The NHS in England is estimated to spend at least £3 billion each year attempting to diagnose and treat medically unexplained symptoms (Bermingham et al 2010).

Much of this expenditure currently delivers limited value to patients; at worst, it can be counterproductive or even harmful.”

- Joint Commissioning Panel for Mental Health (2017):

“MUS accounts for approximately 10% of total NHS expenditure for the working age population in England”
London Commissioning Guidance

Medically Unexplained Symptoms, A Whole Systems Approach, Commissioning Support For London:

“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.”
Local data

- In primary care between 20 and 40% of patients have PPS
- In secondary care this figure rises to 50% in many specialties

- Lambeth Practices:
  - Search tool developed for PRINCE trials
  - Patients attending 12 or more times in the last year with records indicating consultations for MUS
  - GP Practice 1, **289 MUS patients** (of 13038 total)
  - GP Practice 2, **174 MUS patients** (of 12021 total)
  - GP Practice 3, **200 MUS patients** (of 24061 total)
  - GP Practice 4, **194 MUS patients** (of 24061 total)
The impact

- PPS patients have a disproportionately high usage of health services including outpatient referrals
- Sufferers consume large amounts of health care and welfare benefits (Dirkzwager and Verhaak 2007)
- Left untreated, the prognosis of these patients is poor (Deary et al., 2006)
- Significant distress and impaired functioning for patients
- Around 50% of sufferers have co-morbid anxiety and depression (Nimnuan et al., 2001)
- High stress levels for clinicians
- High costs to the healthcare system
What works?

- **CBT is an effective treatment for health anxiety and MUS** (Barsky & Ahern, 2004; Kroenke, 2007)

  - Improves medical symptoms and associated symptoms of depression and anxiety (Greeven et al, 2007)
  - Medium to large effect sizes for more specific syndromes
    - Non-cardiac chest pain (Chambers et al., 2014; Johnsbu et al., 2011)
    - Chronic fatigue syndrome (CFS) (Quarmby et al., 2007)
    - Neurological symptoms, including non-dissociative seizures (Goldstein et al. 2010)
    - A meta-analysis by Kleinstauber et al. (2011) found similar results across studies (including 10 systematic reviews)
IAPT Pathfinder Evaluation Project: Phase 1

• 15 therapy teams selected to become IAPT LTC/MUS Pathfinders in February 2012.

• A diversity of projects, with innovative approaches to engaging and treating patients.

• All pathfinder projects developed some hand-outs, self-help manuals and training materials to support their intervention.

• Majority of patients received low-intensity interventions

• Phase 1 report published 2013

• “The quantitative evaluation, albeit based on a limited data set, indicated improvement in some of the patients, although the overall picture is one of no changes in the clinical and economic outcomes”

• “Assessment by practitioners, trained mainly for low-intensity psychological interventions, may miss complex psychological needs requiring more intensive work and deep-seated problems may not be amenable to manualised group courses”
MUS – 5 key facts

1. **Unexplained symptoms are common**
   - 20-40% of presentations in primary care
   - Can be up to 50% in secondary care clinics

2. **The symptoms are real and the distress is real**

3. **There is no greater risk of missing underlying organic pathology**
   - MUS is a stable diagnosis
   - Misdiagnosis rates are the same as other neurological disorders 4% at 5 years – Stone, Carson 2015

4. **MUS can and does get better + treatment is available**

5. **Overlap with pre-existing physical health conditions is common**
   eg. Epilepsy and non-epileptic seizures; Asthma and dysfunctional breathing; non-cardiac chest pain after MI
## A model of MUS

### Predisposing and Precipitating Factors

- Parental ill health during childhood
- Illness during childhood
- Childhood adversity / abuse

- Personality traits (negative perfectionism)
- Long term conditions
- FH of someone with LTC

The CBT Model for Medically Unexplained Symptoms: Deary et al. (2007)
A model of MUS

Predisposing and Precipitating Factors

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Possible Triggers

- Repeated and/or major stressful life events
- Viral infection
- Physical trauma
- Illness

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Viral infection
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Illness

Maintaining Factors

**Physiological**
- Autonomic dysregulation
- Central sensitisation
- HPA axis dysfunction
- Irregular circadian rhythms

**Behavioural**
- Avoidance of symptoms
- Avoidance of activity
- All or nothing behaviour
- Poor sleep management

**Cognitive**
- Attention to symptoms
- Catastrophic misappraisal of symptoms
- Intolerance of uncertainty/symptoms

**Social**
- Medical uncertainty
- Poor professional management
- Loss of role
- Unhelpful role of significant others

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Maintaining Factors

**PHYSICAL SYMPTOMS**

- Reduced activity
- Boom or bust pattern of activity
- Irregular sleep routine

**BEHAVIOUR**

- ‘This activity will make my symptoms worse’
- ‘This is a sign of something serious’

**COGNITION (THOUGHTS)**

- ‘This activity will make my symptoms worse’
- ‘This is a sign of something serious’

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*King's Health Partners*
Assessing MUS

- Timeline of symptoms
- Physical and / or psychosocial stressors
- Any triggering factors
- Impact
  - What is it stopping you doing?
  - Take me through a typical day
  - Work, Home, Social Life, Relationships
  - Sleep
- Co-morbid anxiety / depression
- What has been tried so far?
  - Both by health professionals and by patients
- Risk factors in FH, PMH, SH, Personal History
Investigations

- Physical Examination
- Height, Weight, Physical Obs
- Urine Dip
- Bloods: FBC, U&Es, LFTs, Glucose, TFTs, ESR, CRP, B12, Folate, Coeliac Screen
- Others may be appropriate depending on history
Treatment

• Positive explanation of diagnosis

• Step-wise approach:
  • Guided self help (resources on RCPsych website)
  • Cognitive Behaviour Therapy – IAPT
  • Referral to secondary care services – liaison psychiatry will be able to help re: local services
Explaining the diagnosis

- Stress that the symptoms are real
- Positive diagnosis of MUS
- Symptoms with no findings on tests are common
- MUS is treatable
- Joint working with medical colleagues can help
  - “Software, not hardware problem”
  - Physiological / mind-body explanation
  - Physical symptoms can persist when the trigger is long gone
  - “Putting you in control of the symptoms rather than the symptoms in control of you”
Treatment – 10 minute CBT tips

**Activity:**
- Achievable (SMART) goals
- Establish a baseline and gradually increase
- Avoid all or nothing behaviour
- Symptoms may get worse before they get better (like when we exercise after a long time)

**Sleep:**
- Set up time
- Bed for sleep and sex only
Case 2 – Ms S

- 57 year old
- Worked for a media firm, lives with her partner
- 2013 Road Traffic Accident, seatbelt injury to abdomen
- Since then she has had difficulties swallowing
- “Food gets stuck in my throat”, feels sick
- Poor oral intake, only eating soft food
- Low but stable BMI (19)
Case 2 – Ms S

- PMH: Irritable bowel syndrome diagnosed in her 20s
- Psych history: Nil else
- SH: Increasing time off work in the last year, now on long term sick leave
- FH: Mother suffered from anxiety
- DH: Minimal alcohol, non-smoker
Case 2 – Ms S

- Routine blood tests normal
- Referral to gastroenterology by GP
- One previous hospital admission due to poor oral intake; NG tube needed
- Endoscopy, Barium swallow NAD
- Referral to eating disorders service – concluded there was no eating disorder
- Low dose Mirtazapine to stimulate appetite has not helped
Case 2 – Ms S

- Ms S is admitted again, now on medical ward
- GP concerned regarding worsening oral intake over last few weeks, ?weight loss
- Prescribed cyclizine, hasn’t helped
- Team feel there are no further investigations requiring ongoing admission
- Ms S is requesting NG tube which helped last time
Ms S

- Positive explanation of diagnosis
- Joint working liaison psych and
- Avoid potentially harmful investigations / interventions
- Dietician input, stepwise approach to increasing oral intake
- Avoid prolonged admission
- On discharge, refer for CBT + gastro follow up
‘Rebranding’ – Persistent Physical Symptoms

- Chronic Fatigue Service, established up in 1993
- Chronic Fatigue Syndrome and Persistent Physical Symptoms (PPS) Care Team
- Terminology preferred by patients
  - Survey of healthy population – preferred term was Persistent Physical Symptoms (PPS) (Marks, Hunter 2014)
  - Survey of CFS patients in specialist clinic in secondary care – preferred term was PPS, then Complex Physical Symptoms (Picariello 2015)
- Avoids labels, unexplained/explained divide which can discourage patients
Who we see and what we offer

- We are an ageless service
  - Adults of any age
  - Adolescents over 11 years old
- Failure to respond to measures in primary care
- More than three months’ illness
- Disability and functional impairment
- Special circumstances (for example: young age, job at risk)

- Out patient CBT or Graded Exercise therapy
- Home based assessment and treatment for severely affected
- Family focused CBT for adolescents (joint working with CAHMS)
PPS pathway for local CCGs - Stepped care

- CFS / PPS
- Care Team
- IAPT
  - CBT provided by local services
- Primary Care
  - Positive Explanation of Diagnosis and Guided Self-help
SLaM PPS pathway

Inpatient Treatment
NHSE

CFS / PPS Home-based treatment, CCG
FiND Day Service, NHSE

Outpatient treatment
CFS PPS Service – CBT or GET, CCG
Neuropsychiatry Outpatients, NHSE

Outpatient assessment
CFS/PPS Service, CCG funded
Neuropsychiatry, NHSE funded

Referrals
- Primary Care – LSLC and BBG
- Secondary care, including rheumatology, gastroenterology, cardiology, respiratory, neurology, pain teams
- SLaM services – A&L teams, Lambeth Hub
- New pathways – occupational health, dieticians, eating disorders
- National referrals from primary or secondary care

No improvement – consider other SLaM services eg. Medical psychotherapy, CMHT

Recommendations can include
- IAPT
- Discharge back to GP
- Other referrals
- Other diagnoses

Severely affected or housebound

South London and Maudsley NHS Foundation Trust
What our patients say…

- From our latest PEDIC report:
  - The team are friendly and always helpful with any issues or questions I have. My sessions are always tailored to my needs and I always find them paramount to my recovery.
  - The team are very caring and friendly, and I feel like I am making personal progress in becoming well again.
  - We have consistently received helpful and constructive support.
  - Positive, understanding and very supportive.
  - ----- is wonderful and has been really helpful and all the staff are friendly.
  - I feel very very fortunate to be treated in this clinic.
What our patients say...

How likely are you to recommend our service or team to friends and family if they needed similar care or treatment?

- Extremely likely
- Likely
- Neither likely nor unlikely
- Unlikely

Are staff kind and caring?

- Yes, definitely
- Yes, to some extent
Our outcomes

- 30% improvement on the Work and Social Adjustment Scale 6 months after discharge (Quarmby et al, 2007; Stahl 2013)
- 30% reduction in fatigue on the Chalder Fatigue Scale at discharge (Quarmby et al, 2007)
- 20% recover from fatigue at one year follow up (White, 2013; Flo and Chalder, 2014)
- 60% of patients reporting feeling better or much better (Stahl et al 2013)
- Maintenance of improvement at 2.5 year follow up (Sharpe et al, 2015)
Outcomes

Fig. 1. Mean scores for RCT and clinic-based patients on the Fatigue Questionnaire (Chalder et al., 1993).

Fig. 2. Mean scores for RCT and clinic-based patients on the Work and Social Adjustment Scale (Mundt et al., 2002).
Family-focused CBT versus psychoeducation for chronic fatigue syndrome in 11 to 18 year olds

This graph shows the school attendance over time of patients who were treated using family-focused CBT or psychoeducation.

Chalder T, Deary V, Walwyn R (2009). Family-focused CBT versus psycho-education for CFS in 11 to 18 year olds: a randomised controlled treatment trial, Psychological Medicine
When to refer to specialist services

- Not responding to first line treatment (ie. IAPT)
- Complex picture
- Multiple persistent physical symptoms
- Co-morbid depression, anxiety or other mental health issues
- Risk of self-harm
- Employment / Education at risk
- Housebound / mobility difficulties
- Frequent attendance at GP, A&E or multiple referrals / specialists involved

Chronic Fatigue and Persistent Physical Symptoms Service, Mapother House, Denmark Hill, London, SE5 8AZ
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Resources

http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/medicallyunexplainedsymptoms.aspx

RCGP – Guidance for health professionals on MUS

www.neurosymptoms.org
Thanks and questions

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