Welcome!

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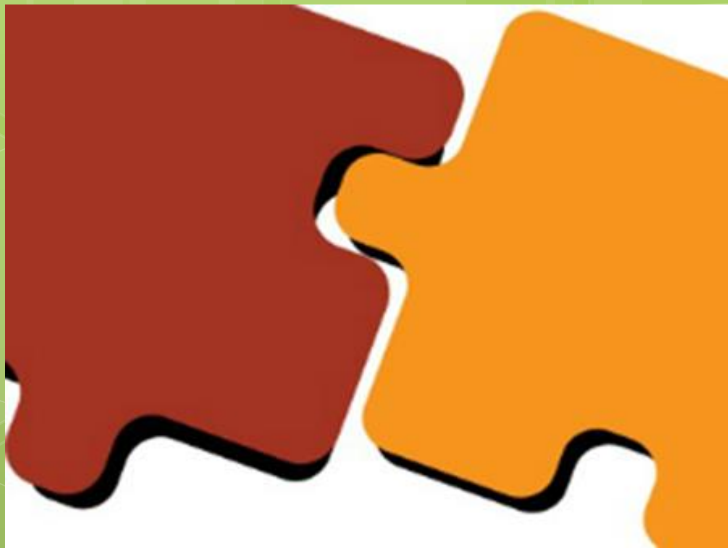
Hard-to-control unexplainable medical symptoms: Wellbeing for body and mind



Pathways 2 Wellbeing

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Overview

- Symptoms - prevalence, costs, what are they, do you have them and what is the treatment?
- Definition of terms, the problem & how it might feel to have these kind of symptoms
- What is wellbeing & The BodyMind Approach?
- P2W courses step by step & outcomes
- Break - for our bodies and minds
- Barriers to delivery of new service and strategies employed
- Supportive elements, drivers and lessons learned
- Transferability
- Questions

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Medically hard-to-explain symptoms

Those that just do not seem to 'fit' into a known diagnosis - How common are they?

- Primary care: 15-25% Reid et al (2002)
- Medical out-patients: 35-52% (mainly neurology, gastroenterology, rheumatology, cardiology, gynaecology) Burton (2003); Nimnuan et al(2001); Hamilton et al (1996); Jackson et al (2006 Kooiman et al (2000)

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Pain Unexplained

Up to two-thirds of all symptoms have no medical diagnosis, one study says. Some of the most common problems:

Headaches

Back Pain

Dizziness

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A major problem

- Very common LTC
- Associated with high costs
- Generally not well managed
- Associated with anxiety and /or depression
- Associated with medical illness

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Costs

- NHS: the **most** costly diagnostic category of out-patients - £3 billion per year rising to £18 billion if quality of life, benefits and absence from work is included Bermingham et al (2010) and **4th** most expensive category in primary care
- Netherlands: **5th** most expensive category
- USA: **5th** most frequent reason for clinic visits (60 million per annum) Cherry et al (2005); CDC US National Center for Health Statistics (2007)
- High cost to patient e.g. travel, parking, loss of income, time and emotional cost

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What kind of symptoms?

IBS
Fibromyalgia
Chronic Fatigue
ME
Chest/back pain
Head ache
Breathing problems
Skin conditions
Muscular-skeletal pain
Palpitations
Insomnia
And many more…………

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Bodily symptoms hard to explain and control?

- Does your GP send you for appointments for your symptoms which do not seem to help?
- Is it difficult to obtain a satisfactory diagnosis?
- Do you sometimes feel overwhelmed with the symptom(s)?
- Are you rather pre-occupied with the symptom(s)?
- Do they stress you out or make you feel low?
- Does your GP not seem to know what the problem is?
- Have you had the symptoms for over six months?

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Hard-to-explain symptoms

- **Definition:** they cannot be fully explained by any known medical condition, termed 'medically unexplained symptoms' (MUS)

Terms included in MUS:

- **Hypochondriasis** Pronounced worry about health and illness
- **Somatisation** High number of symptoms
- **Functional Somatic Syndromes**

(e.g. Irritable Bowel, Chronic Fatigue, Fibromyalgia)

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Other terms

- **Undifferentiated somatoform disorder** only need to have 1 persistent (> 6 months) symptom (DSM-4) totals 79% of MUS in Primary Care Lynch et al (1999)
- **Somatisation disorder** multiple physical symptoms unexplained by known medical condition (after full investigation) (DSM-4) totals: 1% primary care
- **Pain disorder**

Symptom Distress Disorder (SSD) is most likely term to replace above terms in new DSM-5 -associated with distressing somatic symptoms and marked health anxiety

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People suffering MUS may recognise this posture?

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How might it feel to have such symptoms?

- Pain (or any symptom) can get people down
- All alone with little hope of change
- Unsupported/not understood
- Fed up that all tests etc are negative
- Stressed that nothing has been found
- Dispirited of ever feeling any better
- Ask 'Am I the only person for whom the GP cannot find a diagnosis?'
- Want to come off (pain relief etc) medication yet remain pain/symptom-free but unable to do this

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What would people like to be able to feel/do?

- To feel understood and supported to live well in Body & Mind
- To feel less stressed by the symptom
- To feel more in control
- To feel amongst friendly faces
- To be able to stop/cut down on medication
- To be more active
- To manage their symptoms themselves
- To improve wellbeing in Body & Mind

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Wellbeing

What is wellbeing? Discuss in pairs

Definition of wellbeing:
It is a subjective feeling. A state of being comfortable, healthy or happy. It means people have:

- a sense of individual vitality
- can undertake activities which are meaningful, engaging, and which make them feel competent and autonomous
- have inner resources to help to cope when things go wrong & be resilient to changes beyond their immediate control
- feel a sense of relatedness to others -the degree to which people have supportive relationships and a sense of connection with others

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connecting

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Current Treatment

- GP care - little effect
- CBT for chronic fatigue/IBS but no better than sophisticated routine care for generic MUS Sumathipala (2008)

- However, CBT stigmatises/fails to address physical symptom/need for psych. mindedness
- Less than10% of patients receive specific psychological or antidepressant treatment Hamilton et (1996); Fink (2002); Mangwana et al (2009); Hansen (2001)

- No action/recommendation in 44% of medical out-patients Mangwana et al (2009)
- Limited patient choice
- Best practice treatment pathway in primary or secondary care yet to be adopted

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Pathways2Wellbeing (P2W): A solution

- A University of Hertfordshire spin-out company 2013
- Aims to help people with MUS in primary care to improve wellbeing in Body & Mind. Courses include:
- One to one consultations with group facilitator
- 12 x 2 hourly group workshops over 10 weeks
- Individual monitoring pre-group, post, 6 months FU
- A phase 2 of supportive contact to embody action plans over 6 months via text, emails, letters, option of self-help group thereafter

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P2W

- DH QIPP project refined processes and gave further practice-based evidence Payne (2014a; 2014b); Payne & Brooks (2015)
- Delivered 5 courses to date and gained a commission in two CCGs; discussions in several other CCGs
- Group Facilitators qualified to Masters level, with a health professional background, trained x 4 days CPD via P2W

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Improving feelings of wellbeing

- Finding a deeper connection with our bodies for empowerment & control
- Listening to bodily signals both sensory& self awareness, purposeful attentiveness, and enabling comfort
- Learning more about our symptoms in a group setting - making relationships
- Increasing vitality through movement/breathing practices
- Activities which are meaningful i.e. using arts to explore meaning of symptoms, perception of body
- Promoting inner resources by increasing coping skills and inner resilience, kind mindfulness

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The BodyMind Approach (TBMA)™

- P2W courses employ TBMA – the term emerged from patients' comments after their group experience employing aspects of DMP and mindfulness practices in a proof of concept research study Payne & Stott (2010)
- Market research study discovered GP views about the proposed clinical service Fordham; Payne (2009)
- Cost effectiveness study conducted to see whether savings for the NHS
- Facilitators deliver in NHS/privately in their locality
- Course workshops referred to as 'Symptoms Groups'
- Separate brochures describe the approach to patients and GPs

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What is it all about? Exploration and Learning through the bodymind

- Listening to and discussing with others
- Relaxation and breathing practices
- Making meaning, learning more about symptoms/self
- Hand - talk (creating the somatic metaphor)
- Discovering inner resources
- Mindfully moving/body awareness
- Exploring symptoms through creative arts e.g. images
- Being curious about the sensation of symptoms
- Opening to new perspectives on their nature/purpose
- Making action plans based on new-found knowing for sustained change

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Why a Group Approach?

There is evidence that:

- learning about symptom in a small, nurturing, non judgemental group people feel more in control
- facilitated groupwork with others who also have hard-to-explain bodily symptoms can promote feelings of connection and is a supportive setting
- people learn from each other about different coping strategies in this sharing, friendly community

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What will you do on the course?

- You cannot do it wrong!
- No one has to do anything feel uncomfortable about
- Easy exercises to learn how to listen to bodily signals
- Learn to find inward quiet/calmness
- Learn about our bodily symptom and its role/how it functions in our everyday lives
- Learn about ways in which we can cope better with our symptom through gentle movement
- Use body language, scanning and imagination to learn more about our bodies
- Learn how to nurture and take care of ourselves according to our bodily needs

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What does the pathway to wellbeing look like?

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The Steps on the Course

- **Step 1** – GP referral/complete & forward booking form
- **Step 2** - welcome pack including brochure/dates/times and travel/directions, GP communication
- **Step 3** - a telephone appointment with clinician for first individual monitoring
- **Step 4** - individual welcome appointment with group facilitator at venue
- **Step 5** – 'Symptoms Group' - weekends/residential or 10 weeks x 2 hours (first two weeks two sessions per week, thereafter weekly sessions). Max 12 per group
- **Step 6** - individual appointment with group facilitator to say goodbyes and confirm action plan

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The Steps on the Course Pathway continued

- **Step 7-** individual post group telephone monitoring appointment
- **Step 8** - letter written by yourself in last group session is sent to you 6 weeks post group
- **Step 9** - letter from facilitator at 12 weeks, nudges and supports you in sticking to action plan
- **Step 10** - text message to check email at 18 weeks - asks how you are getting on now to which you can respond with a comment
- **Step 11** - individual post group telephone monitoring appointment with clinician (this session will also take account of your response to the email question and can arrange for a self-help group follow-up if indicated)
- **Step 12** - end of course (in month 9-12 from referral date). Communication with GP.

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Outcomes

From the evidence so far:

Participants have **enjoyed** attending the groups (PEF)

Participant benefits include:

- Increased overall **wellbeing**
- Increased **activity** day-to-day
- Increased **self-management** of symptoms
- Decreased **symptom distress**
- Decrease in **feeling low**
- Decreased **stress levels**

Attendance is exceptional (5-10% absence)

Courses rated as excellent/very good

3 min break to stretch/stand up before sharing some perceived barriers to service delivery

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The barriers were not only what we could see!

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Barriers

- Tight budget constraints in NHS
- Re-organisation of NHS

- Change of personnel in NHS
- Other priorities e.g. critical care

- Reduced number of GPs - more pressurised
- Lack of awareness of the scale of the problem

- Lack of categorisation by GP for patients with MUS
- GPs indifference to the costs of these patients to themselves/NHS made referrals difficult initially

- GP culture- normally traditionalists, naturally suspicious, uncertain
- For private courses, although GPs accustomed to referring privately, and for social prescribing e.g. gym membership (they are private businesses) but they were unfamiliar with this particular service

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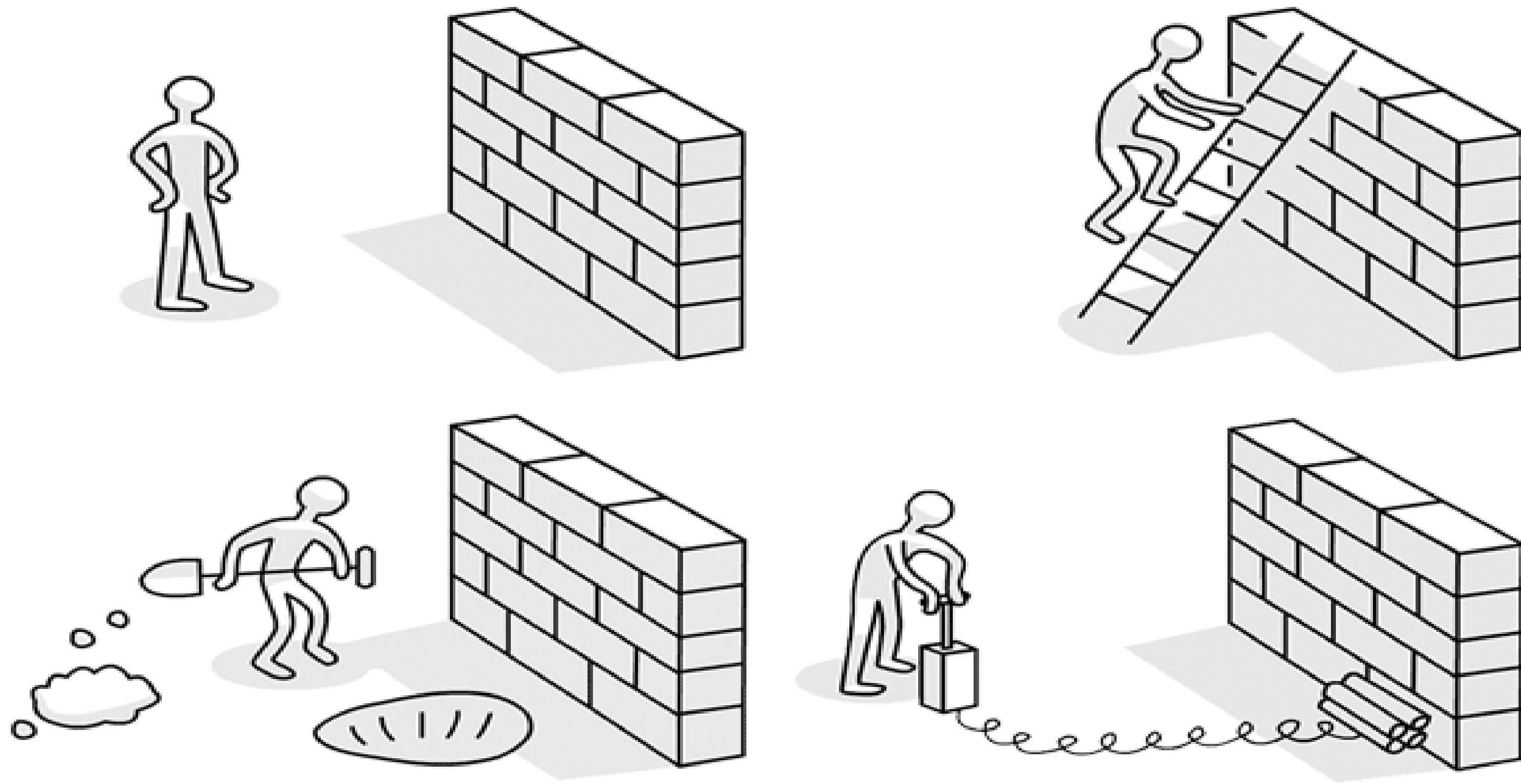
Overcoming barriers



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Strategies employed 1

- Presentations to GPs in localities, CCGs, practices
- Gathered feedback from GPs/patients

- GP Mental Health leads/commissioners letters to GPs
- Case Report Forms/self report demonstrates GP increased capacity/cost reduction

- GP/patient brochures at meetings/P2W website
- Narrative supports GP consultation with patients including how to refer and why - uncomfortable explaining no medical explanation/lack of confidence explaining service

- Screening tool assists GPs in identifying suitable referrals
- On-line GP registration for referrals & 2x5min videos on TBMA/referral process

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Strategies employed 2

- Discharge letter patient attendance/outcomes for referring GP
- Training GPs/trainee GPs

- NHS Information Governance security clearance at level 2
- Deferred to GP culture of paper-based referrals

- Awareness-raising for MUS sufferers/GPs via blogs, videos, articles in magazines, free talks
- Self referrals with patient permission GP confirms suitability

- Encouraged self referrals via messages - 'learn to live well with your bodily symptoms'; 'learn to improve your wellbeing' and residential, non residential, weekly courses
- Demonstrating cost effectiveness helped acceptance by GPs
- Selecting assessment tools reflecting those already used showed parity when evaluating outcomes comparatively

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Supportive elements

- Numbers of patients with MUS
- No pathway for treatment in primary care
- Many of these patient have a lack of interest in enrolling for CBT
- Patient choice Gonzalez et al (2005)
- 'No health without Mental Health' government initiative
- Avoiding stigma of mental health route/addressing patient pre occupation - the bodily symptoms
- Heath care professionals already aware of the Recovery Model e.g. instillation of hope; better quality of life; diminished symptom distress; more in control; happier; good health again, moving forward with life
- NHS agrees with the need to put patients at the centre of the system
- GPs require CPD e.g. PG medical centres/ practices at lunchtime
- NHS commissioner championing the inception of the service in primary care
- GP mental health lead promoting service to GPs

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Helpful Drivers

Increase in patient choice

Integration of Mental & Physical health LTC

P2W Service

Evidence-based practice

Reduction of costs NHS/ society

Reduction of wastage

LTC Self-Manage Reduce A&E visits

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Drivers

- Patients with MUS are a worldwide problem
- One third of medical outpatients MUS Bass (2003)
- Up to 25% of patients in PC are frequent health seekers with MUS Reid et al (2002)
- High prescription costs for MUS
- Unacceptability of psychological Allen & Woolfolk (2010); Gonzalez et al (2005)
- Need for more sustainability of heath & wellbeing
- Need for a gateway to psychological therapies

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Lessons learned

- To name the intervention to patients /GPs differently to enable access/referrals
- To liaise with IAPT to support patients who do not attend CBT to consider P2W courses instead, described to psychs as 'bodymindfulness'
- To explain the treatment is a 9 month course, TBMA group is one aspect phases 1 & 2 - value for money
- To recognise the need for GP CPD/training in MUS/referrals
- To ensure systems for referral fit with those traditionally used by GPs
- To gain GP's confidence via awareness-raising/sharing overall/individual outcomes

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More lessons learned

- built evidence base via PB evidence judged on efficacy
- developed acceptability/accessibility-specific terminology/course structure/delivery/content
- evaluated outcomes using known instruments
- reassured GPs it is ‘in addition to other investigations/treatment’ not an alternative
- supported GPs on how to consult re: missing diagnosis & possible legal ramifications

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Transferability potential

- Many of these above elements will be standard practice in other countries or could be adapted to embed P2W MUS Clinics
- These courses employing TBMA are a transferable model to most health care systems
- Currently exploring delivery in The Netherlands

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Questions/comments

?

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References

Bermingham, S; Cohen A; Hague J & Parsonage M (2010) the cost of somatisation among the working-age population in England for 2008-09. Mental Health in Family Medicine, 7, 71-84.

Burton C. (2003) Beyond somatisation: a review of the understanding and treatment of medically unexplained physical symptoms (MUPS). British Journal of General Practice, 53, 488, pp. 231-9

Cherry D; Woodwell, DA; Rechtsteiner EA (2005) National Ambulatory Medical Care Survey 2007 Jun 29;(387):1-39.

CDC National Center for Health Statistics (2007) Health, The United States.

Dimsdale J; Creed F (2009)Workgroup on somatic symptom disorders. The proposed diagnosis of somatic symptom disorders in DSM-V to replace somatoform disorders in DSM-IV- a preliminary report. Psychosomatic Research; 66;6:473-6

Fink P; Rosendal, M; Toft T (2002) Assessment & treatment of functional disorders in general practice: the extended reattribution & management model-an advanced program for nonpsychiatric doctors. Psychosomatics 43,2, 93–131.

Hamilton, J., Campos, R. & Creed, F. (1996) Anxiety, depression and management of medically unexplained symptoms in medical clinics. J Royal College of Physicians of London, 30, 18 -20

Hansen MS; Fink P; Frydenberg M; Oxhoj ML; Sondergaard; Munk-Jorgensen P (2001) Mental disorders among internal medical inpatients: prevalance, detection and treatment status. Psychosomatic Research, 50, 4, 169-204

Jackson J; Fiddler M; Kapor; N Wells A; Tomenson B; Creed F (2006) Number of bodily symptoms predicts outcome more accurately than health anxiety in patients attending neurology, cardiology & gastroenterology clinics. Psychosomatic Research; 60,4, 357-63

Kooiman CG; Bolk JH; Brand R Trijsburg RW; Rooijmans HGM (2000) Is Alexithymia a Risk Factor for Unexplained Physical Symptoms in General Medical Outpatients? Psychosomatic Medicine; 62:768–778

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References

Lynch DJ; Mcgrady A; Nagel R; Zsembik C(1999) Somatisation in family practice; comparing 5 methods of classification. Primary Care Companion to J Clin Psychiatry, 1,3,85-89.

Mangwana S; Burlinson S; Creed F (2009) Medically unexplained symptoms presenting at secondary care--a comparison of white Europeans and people of South Asian ethnicity. Psych in Med. 39; 1; 33-44

Nimnuan, C., Hotopf, M., & Wessely, S. (2001) Medically unexplained symptoms - An epidemiological study in seven specialities. Journal of Psychosomatic Research, 51(1), 361 - 367. 10.1016/S0022-3999(01)00223-9

Payne H; Fordham, R (2008) *Group BodyMind Approach to Medically Unexplained Symptoms: Proof of Concept & Potential Cost Savings*. Unpublished Report, East of England Development Agency/University of Hertfordshire.

Payne H (2009) The BodyMind Approach to psychotherapeutic groupwork with patients with medically unexplained symptoms: review of the literature, description of approach & methodology selected for a pilot study. *European J Counselling & Psychotherapy*. *11, 3,287-310.*

Payne H; Stott D (2010) Change in the moving bodymind: Quantitative results from a pilot study on the BodyMind Approach (BMA) as groupwork for patients with medically unexplained symptoms (MUS). *Counselling and Psychotherapy Research, 10,4, 295-307*.

Payne H; Brooks S (2015) Clinical outcomes and cost benefits from The BodyMind Approach™ for Patients with Medically Unexplained Symptoms in Primary Care in the UK: Practice-Based Evidence. Submitted *Arts in Psychotherapy*.

Reid, S; Wessely S; Crayford T; Hotopf M (2002) Frequent attenders with medically unexplained symptoms: service use and costs in secondary care. British Journal of Psychiatry, 180:248-253.

Sumathipala A; Siribaddana S;Abeysingha MRN; de Silve P; Dewey M; Prince M; Mann AH (2008) Cognitive-behaviour therapy v. structured care for medically unexplained symptoms: randomized controlled trail. The British Journal of Psychiatry, 193, 51-59

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Bibliography

- Payne, H (2009) Medically unexplained conditions and the BodyMind approach. *Counselling in Primary Care Review, 10,1, 6-8.*
- Payne, H (2009) Pilot study to evaluate Dance Movement Psychotherapy (the BodyMind Approach) with patients with medically unexplained symptoms: participant and facilitator perceptions and a summary discussion. *Int. Journal for Body, Movement & Dance in Psychotherapy. 5, 2, 95-106.*
- Panhofer, H; Payne, H (2011) Languaged and non languaged ways of knowing. *British Journal of Guidance and Counselling, 39, 5, 455-470.*
- Payne, H (2014) The Body speaks its Mind: The BodyMind Approach® for patients with Medically Unexplained Symptoms in UK primary care. *Arts in Psychotherapy, 42,19=27.*
- Payne, H (2014) Patient experience: push past symptom mysteries. *The Health Service Journal, 124, 6390, 26-7.*
- Lin, Y; Payne , H (2014) The BodyMind Approach™, Medically Unexplained Symptoms and Personal Construct Psychology. *Body, Movement & Dance in Psychotherapy, 9, 3.*
- Payne, H (2014a) The BodyMind Approach: the treatment of people with medically unexplained symptoms. *The Psychotherapist, summer, issue 57, 30-32*
- Payne H (2014b) Using the inter-relationship between the body and mind reduces symptoms and improves wellbeing for people suffering with IBS. March 2015, IBS Network
- Payne, H (2015) The MUS Clinic: A New Pathway for Patients in Primary Care suffering Medically Unexplainable Pain. forthcoming June 2015, Pain Concern Magazine

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