

Menstrual Matters Information Sheet

Summary:

Menstrual-Matters is non-profit research and information hub that aims to raise awareness about the role of the menstrual cycle, or hormonal medications, in ill health.

Our website is for three different audiences:

1. **Patients** can use our simple 'Check. Track. Manage. & Learn' approach to find out if their symptoms are cyclical or medication-related, and, if so, how to manage them through tried and tested dietary and lifestyle changes, before resorting to medications (which can cause unwanted side-effects).
2. **Clinicians** can make more informed diagnoses, and consider a wider range of treatment options, for a range of female-prevalent chronic ill-health conditions; simply by asking patients to track their symptoms over time (at least 2 menstrual cycles*). Clinicians can also keep up with the latest in menstrual cycle-related research developments by signing up to our newsletter.
3. **Researchers** can keep up with the latest in menstrual cycle-related research news by signing up to our newsletter. We are also developing the 'research' area of the website, where individuals will one day be able to share their work, collaborate with others, and access information on relevant funding opportunities and conferences.

* As advised by the latest (2017) RCOG (Royal College of Obstetricians and Gynaecologists) Guidelines on PMS [1].

The Problem:

A combination of social, economic, and political factors have resulted in an inadequate diagnostic process to differentiate between the symptoms of various female-prevalent health issues, and those triggered, worsened, or caused by the menstrual cycle (or hormonal medication).

For example, women of reproductive age are known to be disproportionately affected (at least 2:1) by chronic health issues that share many of the same symptoms as 'PMS' (Premenstrual Syndrome);

- IBS (Irritable Bowel Syndrome) 2:1 (80% symptoms are shared with PMS)
- Migraine 3:1 (80%)
- Chronic Fatigue Syndrome 2:1 (86%)
- Depression 2:1 (91%)
- Anxiety 2:1 (81%)

However, menstruating patients are not typically asked to track their symptoms over time (at least 2 cycles), to enable a fully-informed differential diagnosis.

Symptom	PMS/ Hormone- related	Anxiety	Depression	IBS	CFS/ME	Migraine
Difficulty concentrating/ Forgetfulness	Yellow	Dark Green				
Fatigue	Yellow	Dark Green				
Nausea/ Vomiting	Yellow	Dark Green				
Sensitivity to light, loud noise, alcohol or certain foods	Yellow	Dark Green				
Abdominal pain	Yellow	Dark Green				
Bloating/ Constipation	Yellow	Dark Green				
Diarrhoea	Yellow	Dark Green				
Excessive sweating/ Poor body temperature control	Yellow	Dark Green				
Headache/ Migraine	Yellow	Dark Green				
Irritability	Yellow	Dark Green				
Low mood/ self esteem	Yellow	Dark Green				
Muscle and joint pain	Yellow	Dark Green				
Sleeping problems	Yellow	Dark Green				
Anxiety/ tension	Yellow	Dark Green				
Restlessness/ Pins and needles	Yellow	Dark Green				
Backache	Yellow	Dark Green				
Dizziness	Yellow	Dark Green				
Low libido	Yellow	Dark Green				
Shortness of breath	Yellow	Dark Green				
Tearful	Yellow	Dark Green				
Abdominal (period) pain	Yellow	Dark Green				
Bladder urgency	Yellow	Dark Green				
Breast tenderness	Yellow	Dark Green				
Clumsiness	Yellow	Dark Green				
Dry mouth	Yellow	Dark Green				
Painful lymph nodes	Yellow	Dark Green				
Passing mucus (in stool)	Yellow	Dark Green				
Sore throat	Yellow	Dark Green				
Suicidal thoughts	Yellow	Dark Green				
Trembling or shaking	Yellow	Dark Green				
visual/sensory problems	Yellow	Dark Green				
% shared PMS/ hormonal symptoms	100%	81%	91%	80%	86%	80%

Symptoms as listed under each health condition on www.nhs.uk – retrieved 14 November 2016

Between 80-91% of the symptoms involved in a diagnosis of any one of these chronic ill-health conditions could potentially be caused/ affected by the menstrual cycle.

In fact, several factors have combined to effectively obscure the role of the menstrual cycle in triggering, worsening, or causing such symptoms;

1. The *menstruation* taboo (linked to the bleeding part of the cycle) can prevent doctors and patients from mentioning, or adequately considering, the menstrual cycle (i.e. changing levels of sex hormones) as a potential cause of, or factor in, ill health [2] [3].

2. PMS (Premenstrual Syndrome) and other female-prevalent chronic health issue symptoms are more likely to be misunderstood, disbelieved, or dismissed by others, including clinicians [4] [5] [6].

"I don't consult [a doctor]... I haven't bothered again- I don't feel they understand the problem and it's so hard to explain." - Research participant from menstrual symptoms help-seeking behaviour study [7].

"We have evidence that over half of our patients have to see three clinicians before somebody takes them seriously." -Lawrence Nelson, a gynaecologist at the US National Institute of Health (NIH) [8].

3. Time limited (and, therefore, economically pressured) appointments typically force a prioritisation of symptoms to inform a 'most likely' differential diagnosis, rather than allowing the clinician to understand the full range, and changing severity, of symptoms, as experienced over time i.e. in relation to the menstrual cycle [9] [10].
4. A clinical (and public) focus on the psychological causes and effects of PMS, obscures the role of the menstrual cycle in triggering, affecting, or causing numerous physical symptoms of ill health [11] [12]. Additionally, the lack of any medical specialisation in the menstrual cycle (other than in relation to fertility, or as a signifier of gynaecological disease or abnormality) undermines its role in chronic ill health [13].

So, patients may be misdiagnosed with a chronic health issue (or left without a diagnosis), when, in fact, their symptoms are related to their menstrual cycle.

A misdiagnosis, or a lack of diagnosis, of hormone-related symptoms can have a serious impact on patients and the healthcare sector; especially in terms of costs, health outcomes, patient well-being, and societal perceptions of female-prevalent chronic ill-health conditions.

Misdiagnosis can have a serious impact on patients [14]:

- Lack of efficacy of prescribed medication or treatment
- Prolonged inability to work, or maintain a social life
- Inability to understand, predict, or manage symptoms
- Poor well-being, low mood

For the healthcare sector, this can result in [15];

- Repeat consultation and treatment costs
- A loss of trust between patient and clinician/health service
- Incorrect clinical data
- Inappropriate resource allocation

What's more, cyclical symptoms are often quite simple to treat, without the need to resort to prescription medication. For example, it is possible to manage even severe cyclical symptoms through diet and lifestyle changes, alone.

Plus, there is a big difference between a diagnosis of a chronic ill-health condition, and one of 'cyclical symptoms', especially in terms of long term patient health and well-being...

Finally, by ignoring the physiological causes of symptoms, female-prevalent chronic ill-health conditions will continue to be dismissed as entirely 'psychological in origin' i.e. the *"it's all in her head"* mentality.

Studies show that female-prevalent health issues (such as IBS, anxiety, depression, migraine, chronic fatigue syndrome, fibromyalgia, and auto-immune conditions) are more likely to be dismissed as ‘not real’ or ‘exaggerated’ by sufferers [4] [5] [6], even if the patient is male.

Founder:



Sally King- Director and Founder.

In 2013, Sally started researching the role of the menstrual cycle in ill health after experiencing unexplained nausea and vomiting, and then developing asthma after taking hormonal medication to deal with this issue. The difficulty she faced in trying to find evidence-based and unbiased information on this ‘taboo’ topic led to the creation of Menstrual Matters.

Sally has over a decade’s experience as a professional researcher in human rights organisations, with a focus on gender equality. She has a Master’s degree in Research Methods (qualitative & quantitative) and is a massive fan of ‘Evidence-Based Medicine’. She is currently also doing a PhD on the topic of Premenstrual Syndrome at King’s College London.

For more information please contact us at info@menstrual-matters.com

References:

- [1] Green LJ, O’Brien PMS, Panay N, Craig M on behalf of the Royal College of Obstetricians and Gynaecologists. (2016) ‘Management of premenstrual syndrome’. *BJOG*
- [2] Low EL, Whitaker KL, Simon AE, et al. (2015) ‘Women's interpretation of and responses to potential gynaecological cancer symptoms: a qualitative interview study’ *BMJ* 2015:5
- [3] Nnoaham, K. E., Hummelshoj, L., Webster, P. et al. (2011). Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. *Fertility and Sterility*, 96(2), 366–373
- [4] Hoffmann DE., Tarzian AJ. (2001) ‘The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain’. *Journal of Law, Medicine & Ethics* 29:13-27.
- [5] Asbring P, Närvänen AL. (2002) Women’s experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qual Health Res.*; 12(2):148-60
- [6] Leston, S. Dancey, C.P. (1996) ‘Nurses Perceptions of Irritable Bowel Syndrome (IBS) and Sufferers of IBS’ *Journal of Advanced Nursing*, Volume 23, pp.969-974.

- [7] Scambler, A. & Scambler, G. (1985) 'Menstrual symptoms, attitudes and consulting behaviour' *Social Science and Medicine* 20 pp.1065-7
- [8] As quoted in an Al Jazeera news article 'How menstruation stigma puts women in US at risk', January 30th 2015, <http://america.aljazeera.com/articles/2015/1/30/menstruation-stigma-puts-girls-at-risk.html>
- [9] Heneghan C, Glasziou P, Thompson M, Rose P, Balla J, Lasserson D, Scott C, Perera, R (2009). 'Diagnostic strategies used in primary care'. *BMJ*, vol 338, pp 1003–06
- [10] Doust J (2009). 'Using probabilistic reasoning'. *BMJ* vol 330 pp 1080–82.
- [11] Freeman, E. W., Halberstadt, S. M., Rickels, K., Legler, J. M., Lin, H., & Sammel, M. D. (2011). 'Core Symptoms That Discriminate Premenstrual Syndrome' *Women's Health*, 20 (1), 29–35
- [12] Chrisler, J and Caplan, P. (2002) 'The Strange Case of Dr. Jekyll and Ms. Hyde: How PMS became a Cultural Phenomenon and Psychiatric Disorder.' *Annual Review of Sex Research* 13:274-306
- [13] King, S (2016) 'The menstrual cycle as 'matter out of place' within medicine' June 20th 2016, blog post on www.menstrual-matters.com
- [14] Studd, J. (2012) 'Severe premenstrual syndrome and bipolar disorder: a tragic confusion' *Post Reproductive Health* Vol 18, Issue 2, pp. 82 - 86
- [15] Reid S, Wessely S (2002). 'Frequent attenders with medically unexplained symptoms: service use and costs in secondary care'. *British Journal of Psychiatry*, vol 180, pp 248–53