WORK FOUNDATION

More than "women's issues"

Women's reproductive and gynaecological health and work

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June 2017

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Acknowledgements

The authors would like to thank those who shared their knowledge and experience with us in expert interviews, including colleagues from Endometriosis UK, Fertility Network UK, the All Party Parliamentary Group on Women's Health (via their secretariat PB Consulting), PwC, Royal Mail, and Unum. We would also like to thank Work Foundation colleagues David Shoesmith and James Chandler for their support with this project, and Professor Dame Carol Black for her support for the original idea.

This paper has been supported financially by grants from the British Safety Council and Napp Pharmaceuticals Limited who have had no editorial input.

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Executive summary

The role of women in pregnancy and post-natal care is often part of the discourse around work and inequality; the motherhood pay penalty is well known, and taking time out of the labour market to have children is key to the sharp increase in the gender pay gap from the age of 40. However, women’s reproductive and gynaecological health burdens in regards to work do not end there – indeed, there are challenges irrespective of whether one has children. In this paper we shed a light on the less talked about factors of female reproductive and gynaecological health which present challenges to working, all of which are under-recognised in the current debate. Indeed, despite affecting half of the population, these issues are rarely discussed out loud – women’s reproductive and gynaecological health is replete with whispered conversations and euphemisms. It’s time this changed.

Every woman of working age will experience some health related, physical and/or psychological, implications of being a woman. This occurs across the life-cycle from periods to menopause, and includes common conditions such as fibroids, endometriosis and pre-menstrual syndrome, as well as those which inhibit the ability to become pregnant or carry to term. Being pregnant may cause a range of symptoms (such as extreme morning sickness), exacerbate symptoms of existing conditions (including where pregnancy inhibits the ability to manage an existing condition), or lead to the development of health conditions, including post-natal depression. Many of these conditions manifest in emotional stress, poorer psychological health (often depression), fatigue and pain, all of which are known to have considerable negative implications for work.

In this paper we feature four areas of women’s reproductive and gynaecological health: **endometriosis**, **infertility**, **pregnancy and health**, and **menopause**; shining a light on what they mean in terms of work. We suggest recommendations for action to reduce the risk that a considerable number of employees are facing additional challenges in work merely due to being a woman. The point we seek to make is that these conditions and experiences are not just “women’s issues” – as they affect so much of the UK labour force, their effective management is important to the country as a whole. The issues we cover are:

- **Endometriosis.** A condition caused by cells similar to the ones lining the womb (uterus) growing outside the womb, endometriosis can result in excessively painful periods and chronic pelvic pain. Though estimated to affect 1 in 10 women in the UK (around of third of which experience severe symptoms), awareness among the public and health professionals is low; it takes an average of 7.5 years to gain a diagnosis. Time taken off work for investigation of the condition, the stress of not knowing and in some cases not being believed (with symptoms dismissed as common period pain) takes its toll on women and their ability to work, as do the condition’s symptoms of recurrent pain and fatigue. Many women report reduced productivity and absence, while others find themselves forced into part-time work, or unable to work at all. Often women feel unable to disclose their condition, especially due to managers of the opposite sex, due to stigma and a general low awareness of endometriosis, what it is, and what support women who have it may need to be supported to stay at work.
- **Infertility.** Wanting to have children but not being able to do so can be immensely distressing for both women and men, but often particularly so for women, likely

influenced by their social and biological role of carrying children. The stress of infertility can manifest in mental health conditions, with one study finding 90% of infertile women regularly experience feelings of depression. Feelings of social exclusion and of being a "failure" add to the psychological impact. Research has indicated that a large majority of women who experience infertility found it to affect their performance at work. Access to treatment (especially IVF) is restricted, and for those who are able to access it, there are likely further implications for working in terms of time off, which employers may not feel is justified; some employers regard IVF as a "lifestyle choice" rather than treatment for a medical condition.

- **Pregnancy and pre-existing conditions.** All women experience pregnancy differently, including in terms of maternal health. This is even more evident where the woman has certain pre-existing health conditions, which pregnancy can complicate such as those involving the heart, the metabolic system (such as diabetes), and mental illness. Pregnant women with such conditions may need more support at work than healthy pregnant women; there will likely be additional antenatal appointments to monitor the health of mother and baby, but also in terms of managing medication while pregnant where continuation presents risks to the unborn child.
- **Menopause.** This hormonal change is a natural part of the ageing process; usually affecting women aged 45-55 (though earlier in one out of 100 cases). Despite being a common experience in working age people, discussion of its impact on work and how this can be managed remains limited. As well as being a hugely emotional experience, women often experience a range of side effects, including hot flushes, fatigue, irritability, difficulty concentrating and sleep disturbance. These effects can last for several years. The work environment is often not conducive to effective management of the side effects of menopause; for example, high office temperatures can exacerbate hot flushes, causing distress and embarrassment. For many, the menopause remains a "taboo" subject, preventing many women from disclosing their normal, yet challenging, experiences to managers.

As we have seen above, there are a range of issues relating specifically to the female reproductive system which can and do impact on women's health and work; it is time we stopped dismissing them as "women's issues" and recognise and support them as workplace health concerns. These conditions and experiences involve both physical and psychological pain for women, and can cause great distress and fatigue, and as such should be seen alongside other workplace health priorities. Perhaps the greatest challenge is one of awareness; the relationship between these conditions and experiences at work is under-recognised and under-researched. We hope that this paper opens up more dialogue around women's health and work, improving recognition and understanding of the reality for working women, empowering women to raise these issues and access support at work to self-manage their symptoms, and driving the development of support where it is needed.

Recommendations for employers

- **Recommendation 1: Improve recognition of women's reproductive and gynaecological health in workplace policy and processes** – *Recognising that these are chronic conditions, sometimes severe, and need to be considered in sickness absence management, health and safety, Equality Act implementation and so on.*

- **Recommendation 2: Provide a pathway for female staff to access confidential work support** – *Due to the gender-specific nature of these sensitive issues, it may be helpful in larger companies to have a designated alternative to line managers who affected staff can speak with.*

Recommendations for the Joint Work and Health Unit

- **Recommendation 3: Improving access to evidence-based advice and support through government services and support** – *For example, the Government’s Fit for Work online advice service currently only has resources on menopause. Guidance needs to be developed collaboratively with government departments, patient groups, employers and health professionals – particularly general practice, gynaecology and occupational health.*
- **Recommendation 4: Review and improve clarity over legal status of conditions** – *Especially in terms of the Department for Work and Pension’s recognition of the disabling nature of severe endometriosis.*

Recommendations for the health system

- **Recommendation 5: Review clinical guidance** – *In terms of improving access to timely diagnosis, and addressing the implications of this delay, as well as more explicitly recognising self-management, peer support, and quality of life factors in NICE and other guidance.*
- **Recommendation 6: Recognition of work as a health outcome** – *Encourage consideration in the health system of quality of life issue, including work, in policy and practice of general practice and gynaecology healthcare professionals.*

Recommendations for further research

- **Recommendation 7: Building the evidence base** – *This is an under-researched area. In order to better understand the challenges many women’s experience due to these conditions, more good quality research needs to be commissioned. Research should focus on the challenges posed by these conditions, as well as the solutions.*

In developing this paper we have spoken to Endometriosis UK, APPG on women’s health, Fertility Network UK, vocational rehabilitation specialists at Unum, and colleagues at Royal Mail and PwC.

Contents

1. Introduction

The role of women in reproduction, and particularly in terms of pregnancy and childcare (women still take on the lion’s share of family, care and domestic responsibilities) is often part of discourse around work and inequality. The consequential gaps in working or reduced working hours may have implications for progression and promotion, and are likely to provide at least part of the reason why women (and particularly mothers) are paid less, and are less likely to be in senior roles than men.[1]

However, women’s reproductive burden in regards to work does not end there – indeed, there are challenges irrespective of whether one has children. In this paper we shed a light on the less talked about factors of female reproductive and gynaecological health which present challenges to working; all of which are under-recognised in the current debate. Indeed, despite affecting half of the population, these issues are rarely discussed out loud – women’s reproductive and gynaecological health is replete with whispered conversations and euphemisms. It’s time this changed.

Every woman of working age will experience some health related, physical and/or psychological, implications of being a woman. This occurs across the life cycle from periods to menopause, and includes common conditions such as endometriosis and Pre-Menstrual Syndrome (PMS), as well as those which inhibit the ability to become pregnant or carry to term. Being pregnant may also come with a range of symptoms (such as extreme morning sickness), exacerbate symptoms of existing conditions (including where pregnancy inhibits the ability to manage a pre-existing condition), or lead to the development of health conditions, including post-natal depression. Many of these manifest in emotional stress, poorer psychological health (often depression), fatigue and pain; all of which are known to have considerable implications for work.

That is not to say that health relating to reproductive systems only affects women; we recognise that male reproductive (and urological) health is also important; infertility, hormonal issues, and the male menopause may also have an effect on work outcomes. Further, a woman’s reproductive health concerns will have clear implications for their partner. The focus of this paper however is limited to the health issues relating to the female reproductive system; given the female role as carriers of children, and given the dramatic changes inherent in the female reproductive cycle within a woman’s working years.

In this paper we feature four areas of women’s reproductive and gynaecological health. This has been informed by the academic and grey literature, and by conversations with a number of expert interviews. Its purpose is to shine a light upon the implications for work, and how this might be managed to reduce the risk of women facing additional challenges in work merely due to being a woman. In looking at **endometriosis**, **infertility**, **pregnancy and health**, and **menopause**, we hope not only to directly identify ways to improve working life for women, but also more generally to push these issues into the spotlight, and get more employers, policy makers, health professionals and others talking with everyday working women to understand and help to solve challenges at work relating to female biology.

[1] TUC (2016). *The Motherhood Pay Penalty.*

2. Endometriosis

Endometriosis is relatively common among adult women, many of whom experience considerable, regular pain and fatigue. These symptoms, along with stigma and poor recognition of the condition can affect the ability to work productively or indeed to work at all.

2.1. What is endometriosis?

The experience of menstruation varies considerably across women. For some it passes by each month with minimal impact on daily life, but for others it is much more challenging. Many women experience pain and low mood associated with premenstrual syndrome (PMS), while others will experience rarer but much more severe symptoms, including premenstrual depression, or excruciating pain (dysmenorrhoea). In some cases, these symptoms are an indication of an underlying health condition, such as endometriosis.

Endometriosis is a chronic health condition that affects 1 in 10 women of reproductive age in the UK[2 3]. It is the second most commonly diagnosed gynaecological condition[4]. Endometriosis occurs when cells similar to those lining the uterus (womb) grows outside the womb, for example on the fallopian tubes, ovaries, bowel or bladder.[5] This can cause symptoms such as excessively painful periods, chronic pelvic pain, bowel and bladder problems and fatigue[6 7 8]. Although around 20-25% of cases are asymptomatic[9], an estimated 30% of cases are severe[10], with the severity of endometriosis increasing with age[11]. Those experiencing endometriosis symptoms are also at a greater of risk of poor mental health.[12]

One in ten women in the UK has endometriosis… Common symptoms include pain and fatigue

Endometriosis is frequently called 'the missed disease'[13] because of the prolonged length of time between the first onset of symptoms to an accurate diagnosis; on average 7.5 years in the UK[14]. During this time, women may be misdiagnosed with other conditions, or their symptoms not believed or taken seriously[15]. In one expert interview we were told that even where all healthcare professionals involved in a case believe the patient has endometriosis, it can still take months or even years to receive an actual diagnosis – due to delays in accessing a gynaecologist and subsequent referral for a laparoscopy.

Known as the 'missed disease' the average length of time between first symptoms and diagnosis is 8 years

There is no cure for endometriosis, and although some of its symptoms can be treated – including through surgery (sometimes multiple surgeries) – there is no guarantee that symptoms will not return[16]. The healthcare costs associated with endometriosis can be high; a survey across 10 countries found them to be comparable to those for other chronic conditions such as diabetes, Crohn's disease and rheumatoid arthritis[17]. Based on this research, Endometriosis UK estimate that endometriosis costs the UK economy £8.2bn a year in treatment, loss of work and healthcare costs.[18]

Endometriosis is a fluctuating condition, with recurrent, invisible symptoms which are hard to predict and to manage[19]. It affects the quality of life of many women who, along with the

pain, often feel frustration about delays to diagnosis, and anxiety around the uncertainty of their future in terms of operations and long-term treatments, and risk of relapse[20]. There will also be concerns about family planning and fertility; though the causative relationship with infertility is unclear, severe endometriosis comes with a higher risk of infertility, and women who are infertile are at high risk of having endometriosis.[21]

2.2. Implications for work

Endometriosis can negatively affect women in the workforce – in terms of their jobs, careers and economic prospects. Studies show that it is associated with absenteeism and presenteeism, and even women's capacity to retain full-time employment.[22] [23] [24] [25]

The impact on women in work is demonstrated by a ten country study of 1,418 premenopausal women, aged 18-45 years, which found that women with endometriosis experienced reduced work performance[26]. On average, they lost 10.8 hours of work weekly, mainly due to reduced effectiveness in work (presenteeism). Pelvic pain and disease severity were the major drivers of work productivity loss. The costs of lost productivity associated with endometriosis can also be considerable; that the costs of work absence and presenteeism associated with symptoms of endometriosis were estimated by the study to average out at €6,298 per woman annually, double the direct healthcare costs. The ratio of health to productivity costs is comparable to that found for musculoskeletal disorders.[27]

Endometriosis can have a considerable impact on work… it is associated with absenteeism, presenteeism, and even the capacity to retain full-time employment

Other smaller studies have identified similar associations between endometriosis, work productivity and absence, with women reporting that pain interfered with work substantially during the month, and this could mean a day or more of lost productivity during a week when symptoms were bad. Women also described physical and emotional barriers to working, reporting that endometriosis affected their mood, and highlighting the concerns many women feel about how others perceive their condition.[28]

Job loss is also a concern. Expert commentators explained that job loss was more common for women working in certain areas, such as the army or navy, due to difficulty managing symptoms in such a physical role. The risk to jobs was also identified in the literature, where a correlation between having endometriosis and job loss, unemployment and involuntary movement into part-time work was identified[29]. Qualitative data suggests that job loss is influenced by the need to attend medical appointments, by pain preventing women from doing their work, and from time off of work due to symptoms.[30]

> *"I left my part-time job because I was not able to work due to severe symptoms and undergoing two surgeries… Having two surgeries within a year – it's kind of hard to find a job if you think that that's going to be ongoing, not many people are going to employ you to have time off."*[31]

In this sense we see that endometriosis can have a significant financial impact on women.

> *"[The] Financial [impact]; [is] massive, because you're taking so much time off work.…There's no way you're getting out of bed that day and just not getting up and coming, not being able to pay those bills, it does put a massive stress on you."*[32]

The work barriers associated with endometriosis are driven not only by the pain, but also fatigue, and often co-occurring poor mental health. As we shall see, this is compounded by the attitudes of line management and employers and the poor recognition of the condition and how it should be treated at work.

2.3. Management and support at work

Difficulties with diagnosis and poor recognition of endometriosis in the medical community are reflected in the work environment; concerns around stigma, lack of understanding, and a reluctance to disclose were prevailing themes in the literature around women working with endometriosis. The gendered nature of reproductive and gynaecological conditions can make women (and similarly men) particularly wary and even unwilling to discuss them with managers of the opposite sex, and despite its severity, endometriosis is no exception[33]. With many symptoms occurring monthly, endometriosis comes with the same challenges as other fluctuating conditions[34]; and the awareness of the regularity of impact over such a long period of time makes its disclosure a considerable risk for many women.[35]

Expert interviewees suggested that the long delay in diagnosis effected women's ability to get support at work. Indeed, on a purely practical level, women who are waiting for a diagnosis will not have the official medical evidence of a long-term health condition to provide to employers to justify sickness absence or requests for adjustments – this was suggested to sometimes lead to endometriosis management at work becoming a performance management issue, rather than it being recognised as a health issue to be supported.

Further, even for those with a diagnosis, such a history was suggested to reduce women's confidence in disclosing at work. Not disclosing a health condition is a clear barrier to accessing support and employers will need to consider these cultural issues if they are to support employees with endometriosis to be more productive and happy at work. Based on findings from previous research, making small adjustments to work – particularly in the form of flexible working, allowing home working, and allowing extra breaks was often crucial for their retention[36], providing women with some time and space in which to manage their symptoms around their workload. As seen with other long-term conditions, the importance of having a supportive line manager who understands that time off might be required is essential. Indeed, unsympathetic employers that did not allow time off of work for what is often seen as "women's problems" was a widely reported negative experience in research findings[37]. Self-management was also found to be important in terms of managing symptoms at work, for example peer support, healthy eating, exercise, massage and acupuncture was also found to be helpful.[38] [39]

Endometriosis UK have produced some guidance to support employers and their employees at work[40], however, disappointingly, such guidance has not been reproduced on mainstream sources of occupational health information, such as the on the government's Fit for Work website.[41]

It is clear that endometriosis, where the symptoms are severe, should be recognised as a disability and protected under the Equality Act 2010 as a chronic, debilitating disease, which can and does affect the ability to work for a considerable part of many women’s working lives. Women experiencing severe endometriosis should be able to access the same support (including in terms of workplace adjustments and the right to request flexible working) as people with other long-term conditions. However, expert informants suggested that this was not always the case; with particular concerns about recognition of the severity of the condition being levied at the Department for Work and Pensions. One story, provided anecdotally, was of a woman in her 30s who became so unwell with endometriosis that she was unable to work, but was not seen as eligible to access welfare support, as the guidance used by the assessor stated that “endometriosis rarely leads to disability”. Further concerns have been raised about the potentially exclusionary wording of health and work-related policies where there is reference to a life-long condition, as endometriosis is not life-long, but primarily occurs during reproductive years (still as many as 40 years of a woman’s life).

Endometriosis is underdiagnosed, under-reported, and under-researched

Endometriosis is underdiagnosed, under-reported by those afflicted, and under-researched in terms of clinical implications, as well as in terms of broader social and quality of life implications, including its relationship with work[42]. The invisibility, complexity and poor recognition of this chronic condition in the work environment needs to be addressed. Given the high prevalence of the disease amongst British women and the extent to which it affects working lives, we believe endometriosis should be recognised as a work issue, and more attention should be made to improving understanding and developing solutions to enable women living with endometriosis to disclose their condition at work, and empower managers to give employees the support they need to manage it in work.

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[2] Berek, J.S. (2012). *Berek & Novak’s Gynecology. 15th edition*. Lippincott Williams & Wilkins, North American Edition.
[3] Berek, J.S. (2012).
[4] Rogers, P.A., D'Hooghe, T.M., Fazleabas, A., *et al.* (2009). Priorities for endometriosis research: recommendations from an international consensus workshop. *Reproductive Science*, **16**(4): 335-46
[5] NHS (2017). *Endometriosis*.See: http://www.nhs.uk/conditions/endometriosis/Pages/Introduction.aspx [Accessed 26 May 2017]
[6] Bulletti, C.,Coccia, M.E.,Battistoni, S. & Borini, A. (2010).Endometriosis and infertility. *J Assist Reprod Genet,* **27**(8): 441-447
[7] NHS (2017). *Endometriosis.*
[8] Culley, L., Law, C., Hudson, N., Denny, E., Mitchell, H.,Baumgarten, M. & Raine-Fenning, N. (2013). The social and psychological impact of endometriosis on women’s lives: a critical narrative review. *Hum Reprod Update,* **19**(6): 625-639
[9] Bulletti, C.,Coccia, M.E.,Battistoni, S. & Borini, A. (2010).
[10] Reported by Endometriosis UK
[11] Bulletti, C.,Coccia, M.E.,Battistoni, S. & Borini, A. (2010).
[12] Facchin, F., Barbara, G., Saita, E., Mosconi, P., Roberto, A., Fedele, L. & Vercellini, P. (2015). Impact of endometriosis on quality of life and mental health: pelvic pain makes the difference. *J PsychosomObstetGynaecol,* **36**(4): 135-141
[13] Overton, C. & Park, C. (2010).More on the missed disease.*BMJ*, **341**: c3727
[14] Hadfield, R., Mardon, H., Barlow, D. & Kennedy, S. (1996). Delay in the diagnosis of endometriosis: a survey of women from the USA and the UK. Hum Reprod, **11**(4): 878-880
[15] Fishwick, C. (2015, September 29). Endometriosis: Women discuss endometriosis: 'No one believed I could be in such pain from a period'. *Guardian online*. Available at: https://www.theguardian.com/society/2015/sep/29/endometriosis-experiences-women-period [Accessed 26 May 2017]
[16] Denny, E. & Mann, C.H. (2007). A clinical overview of endometriosis: a misunderstood disease. *Br J Nurs*, **16**(18): 1112-1116
[17] Simoens, S., Dunselman, G., Dirksen, C., Hummelshoj, L., Bokor, A., Brandes, I. & D’Hooghe, T. (2012). The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod*, **27**(5): 1292-1299
[18] Endometriosis facts and figures (n.d.). *Endometriosis UK*.See: https://www.endometriosis-uk.org/endometriosis-facts-and-figures [Accessed 26 May 2017]
[19] Steadman, K., Shreeve, V. & Bevan, S. (2015). *Fluctuating conditions, fluctuating support*. London:The Work Foundation
[20] Berek, J.S. (2012).
[21] Gilmour, J.A., Huntington, A. & Wilson, H.V. (2008). The impact of endometriosis on work and social participation. *International Journal of Nursing Practice,* **14**(6): 443-448

[22] Gilmour, J.A., Huntington, A. & Wilson, H.V. (2008).
[23] Nnoaham, K.E.,Hummelshoj, L., Webster, P., d'Hooghe, T. *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
[24] Fourquet, J., Báez, L., Figueroa, M., Iriarte, R. I., & Flores, I. (2011). Quantification of the Impact of Endometriosis Symptoms on Health Related Quality of Life and Work Productivity. *Fertility and Sterility*, **96**(1): 110
[25] Moradi, M., Parker, M., Sneddon, A., Lopez, V. & Ellwood, D. (2014). Impact of endometriosis on women's lives: a qualitative study. *BMC Women's Health,***14**: 123
[26] Nnoaham, K.E.,Hummelshoj, L., Webster, P., d'Hooghe, T. *et al*. (2011).
[27] Nnoaham, K.E.,Hummelshoj, L., Webster, P., d'Hooghe, T. *et al*. (2011).
[28] Fourquet, J., Báez, L., Figueroa, M., Iriarte, R. I., & Flores, I. (2011).
[29] Gilmour, J.A., Huntington, A. & Wilson, H.V. (2008).
[30] Moradi, M., Parker, M., Sneddon, A., Lopez, V. & Ellwood, D. (2014).
[31] Moradi, M., Parker, M., Sneddon, A., Lopez, V. & Ellwood, D. (2014).
[32] Moradi, M., Parker, M., Sneddon, A., Lopez, V. & Ellwood, D. (2014).
[33] Gilmour, J.A., Huntington, A. & Wilson, H.V. (2008).
[34] Steadman, K., Shreeve, V. & Bevan, S. (2015).
[35] Gilmour, J.A., Huntington, A. & Wilson, H.V. (2008).
[36] Irenicon Limited (2015). *An employer's guide to managing endometriosis at work*. London: Endometriosis UK. Available at: https://www.endometriosis-uk.org/sites/default/files/files/Endometriosis.pdf [Accessed 26 May 2017].
[37] All-Party Parliamentary Group on Women's Health (2017). *Informed Choice? Giving women control of their healthcare*. Available at: https://static1.squarespace.com/static/5757c9a92eeb8124fc5b9077/t/58d8c98b1b10e366b431ba06/1490602405791/APPG%20Womens%20Health%20March%202017%20web%20title.pdf [Accessed 31 May 2017].
[38] Gilmour, J.A., Huntington, A. & Wilson, H.V. (2008).
[39] Moradi, M., Parker, M., Sneddon, A., Lopez, V. & Ellwood, D. (2014).
[40] Irenicon Limited (2015).
[41] See: http://fitforwork.org/
[42] Gao, X., Yeh, Y.C., Outley, J., Simon, J., Botteman, M. & Spalding, J. (2006). Health-related quality of life burden of women with endometriosis: a literature review. *Curr Med Res Opin*, **22**(9): 1787-1797

3. Infertility and fertility problems

Fertility problems cause considerable emotional pain to those who experience them. The impact on women has been found to be more intense, often manifesting in stress and poor psychological health which is likely to have an impact on work. Treatment can also have complex implications for women's health and work.

3.1. What do we mean by fertility problems?

Fertility problems, where an individual or couple who are trying to conceive and carry a child to term are unable to do so, can have a profound impact. Experiencing problems when looking to have children is common, with fertility issues estimated to affect one in seven heterosexual couples in the UK.[43]

Fertility issues are estimated to affect one in seven heterosexual couples in the UK

There are multiple causative factors for infertility, predominantly physiological. For women, infertility most commonly relates to ovulation problems, with eggs not being released at all or not being released during some cycles. Other reasons include fibroids and endometriosis, as well as rarer conditions such as MRKH (Mayer Rokitansky Küster Hauser) syndrome wherein the vagina, cervix and uterus may be absent. For men, infertility is most commonly linked to semen quality and testicular issues. For both sexes, infertility can also be caused by the use of drugs or medications (such as chemotherapy). In 25% of cases it is not possible to identify any cause for infertility from either partner[44]. Age has a large influence on the ease of conception, with women's fertility declining particularly after the age of 35[45]. With the average age of women having a first child rising[46] (often cited as being due to financial, educational or career reasons[47]), age-related infertility can be expected to affect increasing numbers of working age women.

Half of women experiencing problems conceiving see coping with their infertility as the most upsetting experience of their lives

Treating infertility solely as a physical condition ignores the huge psychological toll. Whilst there is no doubt that within heterosexual relationships, both partners will experience distress and unhappiness when struggling to conceive, there is evidence to show that infertility can have a more intense impact on females; in a study of 200 heterosexual couples who had problems conceiving, half of the women saw coping with their infertility as the most upsetting experience of their lives, compared with around 1 in 7 (15%) of the men[48]. The greater resultant distress experienced by women is in part due to the societal pressures upon women to have children[49], and to differing coping mechanisms[50]. It is also understandable that, for a woman who seeks to have a child, the feelings of being let down by one's biology may be more pronounced due to their role of physically carrying the child.[51]

3.2. Treatment

Depending on the nature of the fertility issues there are a range of treatments, including medicines to address ovulation problems, surgical procedures for fallopian tubes or endometriosis, or assisted conception, including in vitro fertilisation (IVF)[52]. IVF is the process of fertilising an egg outside of the body, which is then implanted in the womb to

grow and develop. It is a recommended course of treatment for women under the age of 40 who have been trying to get pregnant for two years[53]. However, IVF is an expensive procedure, and as such is treated cautiously by the NHS, with some clinical commissioning groups placing additional criteria on eligibility[54 55], while some heavily restrict access to the process – such as Mid Essex CCG who only offer IVF in "exceptional clinical cases"[56]. The huge variation in the availability of IVF via the NHS was highlighted in a recent report by the All Party Parliamentary Group on Infertility[57]. Despite being recognised as a long-term condition by both the World Health Organisation and the Department of Health, discrepancies in treatment access imply it may not in practice be viewed in the same way as other long-term conditions. As such many women who can afford to do so choose to undertake IVF privately (fully or partially) sometimes costing tens of thousands of pounds[58]; potentially providing another source of stress, as well as introducing an inequality in provision. Parliamentary debates about inequalities in treatment have drawn attention to the lack of consideration of the mental distress associated with infertility on the national policy stage, and the impact on wider quality of life, including in terms of employment.[59]

3.3. Implications for work

For women who want children, fertility issues are likely to be a considerable source of stress[60]. Though work is not the cause of this stress, it is likely to affect it; stress is associated with a negative effect on employment outcomes[61]; it is the most common cause of long-term sickness absence and the second most common cause of short term absence[62], and the risks to work are often higher when someone experiences competing pressures and stresses both in and out of work.[63]

Infertility is associated with poor mental health; prevalence of mental illness among infertile women may be as high as 40%

Stress can cause a range of physical symptoms, including physical pain or difficulty concentrating, and it is also associated with the development of illness and disease[64], e.g. coronary heart disease, rheumatoid arthritis and depression. Infertility has been most strongly associated with mental health problems, with high levels of self-reported poor mental health (see Box A), and higher rates of mental illness when compared to the general population - one study found infertile women have a markedly higher prevalence of mental illness than the general population, as high as 40%[65], and have been found to be at a higher risk of committing suicide[66]. Another study showed high levels of anxiety and depression for women who wanted children but who were unable to have them. The effect on their health was considerable; rates of anxiety and depression among these women comparable to those experienced by women with life threatening conditions, including cancer, hypertension or HIV[67]. The impact of infertility on mental health is arguably the most pronounced effect of the experience on the quality of life of those experiencing it.

We must also recognise the importance of the social context of infertility in causing this psychological distress; involving as it does an inability to achieve a desired social role (i.e. to be a parent)[68]. For women who wish to have children, infertility can challenge core female identities. As one expert we spoke to suggested, despite being a medical condition, to many women "it feels like failure", and as such many can lead to a diminished sense of self-worth and damage to self-esteem[69], with the subsequent distress often manifesting in anxiety[70].

Infertility can often seriously disrupt life plans, representing a loss of control[71]. The "high social value" which is still placed on biological parenting can compound feelings of isolation and segregation[72], while the continuing stigma around infertility[73] further feelings of exclusion.

Box A: Health impacts of fertility problems: Fertility Network UK survey results

Respondents (mainly female) to a survey by the Fertility Network UK of people with fertility problems found:

- 90% reported feelings of depression, and 42% reported having had suicidal thoughts.
- Most reported feeling sadness, frustration, fears and worries, feeling out of control, and helplessness most or all of the time.
- Those who had unsuccessful treatment (who had either decided not to have more treatment or were undecided) reported greater distress as well as more frequent suicidal feelings.

Treatment for infertility, and in particular having IVF, can be both physically and emotionally demanding. It may require multiple attempts, and it not always successful. Along with the stress of the process, there are a number of side effects associated with the medication, commonly including hot flushes, low mood, irritability, headaches and restlessness. All of this is likely to have implications for work, and many women will require time of work for treatment, perhaps as much as a week off work during each treatment cycle.[74]

3.4. Management and support at work

There has been little research on the direct effect of infertility or its treatment on work. However a recent survey of female members of Fertility Network UK indicates that many women feel treatment affects their work (e.g. difficulty concentrating), and that it might, or even that it had already, affected their career. Those who felt that their treatment affected their work were more likely to have days off (in some cases over a month), and some had even reduced their working hours, while a small minority had left their job entirely.[75]

The survey implied that work can influence women's health and wellbeing during treatment – levels of disclosure at work were quite high in the sample, and those reporting greater support from their employers reported lower levels of distress and less frequent suicidal feelings[76]. Those whose employers had set some policies surrounding infertility leave (23% of the sample) were more likely to disclose their condition, and reported lower levels of distress.[77]

Where employers had set some policies surrounding infertility leave, women were more likely to disclose their condition, and reported lower levels of distress

Very little information is publically available regarding the extent of 'fertility leave' amongst organisations, implying that the issue is generally treated under the umbrella of other HR sickness absence policies. Expert informants raised concerns that the social and emotional aspects of infertility and infertility treatment are not always considered within this usual work support. The Fertility Network survey found that 75% would have liked to have counselling if it was free; only 44% did receive counselling and, of these, over half had to fund some of it themselves.[78]

Workplace policies regarding infertility treatment are also not common and there is no specific statutory right to time off work for IVF, however, employers should treat requests in

the same manner as other medical appointments[79]. In practice this does not always happen, and although many employers are supportive, expert informants suggested that some employers see IVF as a lifestyle choice and may not support employees.

Good practice does exist and we did identify some examples of employers who do provide specific support, for example; Bristol City Council offers paid time off for fertility treatment, granted to both partners, and ASDA allows up to three periods of paid leave for IVF, along with mechanisms to swap shifts to fit appointment schedules and the option for additional unpaid leave[80]. Though not necessarily having specific infertility policies, employers we interviewed in the development of this paper suggested that flexible working and additional sickness absence days were offered by employers who had an awareness of the impact of fertility issues on their employees, as part of comprehensive approach to employee health and wellbeing and inclusive flexible working policy. Such approaches were seen as positive by the Fertility Network UK, who shared with us examples of women benefitting from such flexibility, for example working through lunch in order to attend appointments, rather than having to take the entire day off.

What was clear however as that these were exceptions rather than rules, and many employers and line managers lack specific knowledge of how to support employees experiencing infertility and related treatment. Our expert interviews also spoke about how a lack of line management awareness of this issue is a huge barrier to effective management.

Indeed, this is an area in which the usual sources of information are lacking – a quick review of the Fit for Work service website, the government's occupational health advice service, found little of use. The Fertility Network UK is currently developing a resource for employers with the hope of providing better support to employees. Ensuring good quality information is available is essential to ensuring that work does not worsen what is already an incredibly stressful time, and the impact on and risks to work are minimised.

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[43] NHS (2017). *Infertility: Causes.* See: http://www.nhs.uk/Conditions/Infertility/Pages/Causes.aspx [Accessed 26 May 2017]
[44] NHS (2017). *Infertility: Causes.*
[45] NHS(2017). *Protect Your Fertility.* See: http://www.nhs.uk/Livewell/Fertility/Pages/Protectyourfertility.aspx [Accessed 26 May 2017]
[46] ONS (2017). *Statistical Bulletin. Birth by Parent's Characteristics in England and Wales: 2015*
[47] Comments from Rosalind Bragg, Director of Maternity Action. In: Batty, D. (2016, July 13).Fertility Rate higher among over-40s than under-20s for the first time since 1947.*Guardian online.*Available at: https://www.theguardian.com/uk-news/2016/jul/13/fertility-rate-higher-over-40s-than-under-20s-first-time-since-1947 [Accessed 26 May 2017]
[48] Harvard Mental Health Letter, May 2009. Harvard University Publications
[49] Peterson, B.D., Newton, C.R., Rosen, K.H. & Skaggs, E. (2006). Gender differences in how men and women who are referred for IVF cope with infertility stress. *Hum Reprod*, **21**: 2443-2449
[50] Peterson, B.D., Newton, C.R., Rosen, K.H. & Skaggs, E. (2006).
[51] Peterson, B.D., Newton, C.R., Rosen, K.H. & Skaggs, E. (2006).
[52] NHS (2017). *Infertility: Treatment.* See: http://www.nhs.uk/Conditions/Infertility/Pages/Treatment.aspx [Accessed 26 May 2017]
[53] NICE (2013). *Fertility problems: assessment and treatment*. See: https://www.nice.org.uk/guidance/cg156 [Accessed 26 May 2017]
[54] NHS (2017). *IVF.* See: http://www.nhs.uk/Conditions/IVF/Pages/Introduction.aspx [Accessed 26 May 2017]
[55] Currently, NICE guidelines recommend up to three cycles of IVF should be available on the NHS for women aged 23-39 with fertility problems. Some CCGS apply additional criteria to their funding eligibility i.e. that participants must be a health weight, and a non-smoker. Waiting lists for these treatments can be lengthy, and many CCGs are beginning to further restrict access to treatment in response to funding difficulties.
[56] Mid Essex CCG (2015). *IVF Consultation Statement*. See: http://midessexccg.nhs.uk/news/196-ivf-consultation-statement [Accessed 26 May 2017]
[57] House of Commons Library Debate Pack (2017). *Decommissioning of IVF and other NHS Fertility Services*.
[58] Payne, N. & van den Akker, O. (2016). *Fertility Network UK Survey on the Impact of Fertility Problems.*
[59] House of Commons Library Debate Pack (2017).
[60] Cousinea, T.M. & Domar, A.D. (2007). Psychological impact of fertility.*Best Pract Res ClinObstestGynaecol*, **21**(2): 293-308
[61] Bashir, U. & Ramay, M.I. (2010). Impact of Stress on Employees Job Performance.*International Journal of Marketing Studies*, **2**(1): 122-126

[62] CIPD (2016). *Absence Management*.
[63] Bank Workers Charity (2014). *Bank On Your People: The state of wellbeing and productivity in the financial sector*.
[64] Grimshaw, J. (1999). *Employment andhealth: Psychosocialstress intheworkplace*. London: The British Library.
[65] Chen, T.H., Chang, S.P., Tsai, C.F. & Juang, K.D (2004). Prevalence of depressive and anxiety disorders in an assisted reproductive technique clinic.*Human Reproduction*, **19**: 2313
[66] Kjaer, T.K.,Jensen, A., Dalton, S.O., Johansen, C., Schmiedel, S & Kjaer, S.K.(2011). Suicide in Danish women evaluated for fertility problems. *Human Reproduction*, **26**(9): 2401-2407
[67] Cousinea, T.M. & Domar, A.D. (2007).
[68] Greil, A.L., Slauson-Blevins, K. & McQuillan, J. (2010). The experience of infertility: A review of recent literature. *Sociology of Health & Illness*, **32**(1): 140-162
[69] Peterson, B.D., Newton, C.R., Rosen, K.H. & Skaggs, E. (2006).
[70] Klemetti, R., Raitanen, J., Sihvo, S., Saarni, S. & Koponen, P. (2010). Infertility, mental disorders and well-being – a nationwide survey.*Actaobstetricia et gynecologicaScandinavica*, **89**(5): 677-682
[71] Cousinea, T.M. & Domar, A.D. (2007).
[72] Cousinea, T.M. & Domar, A.D. (2007).
[73] Cousinea, T.M. & Domar, A.D. (2007).
[74] Payne, N. & van den Akker, O. (2016).
[75] Payne, N. & van den Akker, O. (2016).
[76] Payne, N. & van den Akker, O. (2016).
[77] Payne, N. & van den Akker, O. (2016).
[78] Payne, N. & van den Akker, O. (2016).
[79] ACAS (2017). *Employee Rights During IVF Treatment.*
[80] Fertility Network UK (2016). *Factsheet: Employment Issues*. See: http://fertilitynetworkuk.org/wp-content/uploads/2016/12/FACTSHEET-Employment-Issues-November-2016.pdf [Accessed 26 May 2017]

4. Pregnancy and long-term conditions

Some long-term health conditions are worsened by pregnancy, placing the health of the pregnant women and the child at additional risk. The combination of pregnancy and illness can have particular implications for work, often requiring additional ante-natal support or leave from work.

4.1. Pregnancy and health

In the UK, the majority of women experience pregnancy; an estimated four out of five women has had children[81]. The experience of pregnancy varies across women, with some having minimal health affects while others experience difficulties; in some cases this can affect ability to work. Pregnancy often comes with side effects, such as high blood pressure, fatigue and backache. Nausea and vomiting, common in early pregnancy have in particular been shown to affect ability to work[82], while a more severe, rare form of morning sickness, Hyperemesis Gravidarum (effecting up to 3% of women), can be hugely detrimental, sometimes requiring hospitalisation.[83]

4 out of 5 women have children, and 1 out of 3 have at least one long-term health condition

Pregnancy can take an even more significant toll on an individual and their working life if they have a pre-existing medical condition. With an estimated 1 in 3 women of working age having at least one long-term health condition, this combination of factors warrants exploration. In this paper we explore some examples of where this combination of factors might create additional disadvantages for working women: heart conditions, obesity, diabetes and mental illness.

Heart conditions: The additional strain on the heart associated with pregnancy means women with pre-existing heart problems may require extra health and work support. Though relatively rare, congenital heart defects are a recognised area of risk, due to inefficiencies in the heart's ability to pump blood. Whilst the health impact of this varies among individuals (an estimated two-thirds of women with such defects have no cardiovascular complications during pregnancy)[84], those in the high risk category are at significant risk of death during pregnancy and in the first month after birth. In most cases, both mother and baby will require close attention and monitoring by clinicians throughout. Similarly, for women with coronary heart disease pregnancy increases the risk of a heart attack. Though diseases of the heart and circulatory systems are more common in older women, 2.6% of all related deaths occurred in women aged under 54[85], while in women under 65 the prevalence of myocardial infarction (aka heart attack) is 1.2% and for stroke 2.9%.[86]

Obesity: Levels of obesity among pregnant women are a growing concern; in the US the prevalence of obese pregnant women is estimated to have increased by 69% over a 10 year period[87]. Around 15-20% of all pregnant women in England are obese[88] (BMI of over 30), and 5% have a BMI of 35 or over[89]. Maternal obesity increases the risk of preeclampsia, development of gestational diabetes, blood clots and heavy bleeding after birth, whilst reducing the likelihood of an uncomplicated vaginal birth. The risks for the baby are also high; an obese mother increases the likelihood of a premature or stillbirth, and foetal abnormalities.[90]

Diabetes: Related to increased prevalence of obesity, the number of pregnant women with pre-existing (not gestational) diabetes has also increased in the last decade. There are 3.3 million people diagnosed with diabetes living in the UK, a number which has doubled since 1996[91]; women who have diabetes form 2-5% of all pregnancies[92]. Women with diabetes who become pregnant may develop problems with their eyes or kidneys, or have other existing problems exacerbated. They are at a higher risk of having a miscarriage, developing pre-eclampsia and having a large baby – and a consequently more difficult birth[93]. In this situation, babies are also at risk of abnormal development in the womb or being stillborn[94]. To minimise these additional risks, diabetic women are offered multiple additional tests, including ultrasound scans and retinal assessments.[95]

Women who have diabetes form 2 - 5% of all pregnancies

Mental illness: Pregnancy and birth is a time of great change and upheaval that has a huge impact on anyone who goes through it, and may have particularly implications for people with mental health conditions, such as anxiety or depression. Those with a mental health condition, or who have had one in the past, are at a high risk of becoming ill during pregnancy and the first year after birth[96]. Severe mental health problems (such as bipolar affective disorder, severe depression and psychosis) can progress more quickly and become more serious after a birth than at any other time in a woman's life[97]. Many psychotropic medications which are prescribed for the management of different mental health conditions can, when taken during pregnancy and breastfeeding, pose a number of risks to the baby[98]. This is a difficult decision for an expectant mother as there are also risks associated with stopping medication[99]; around7 out of 10 women who stop taking antidepressants in early pregnancy becoming unwell again[100]. Best practice guidelines indicate that women with existing mental health conditions should be referred for pre-pregnancy advice at specialist services, with extra care taken by all their health team to monitor their mental health over the perinatal period and after birth. These appointments and related self-care may also require time off work but this is essential to reduce the risk of harms to both mother and baby in the longer term.

Around 7 out of 10 women who stop taking antidepressants in early pregnancy becoming unwell again

4.2. Implications for work

Pre-existing conditions can lead to complicated pregnancies. Complications, in whatever form, often have the same implications – more scans, more hospital visits, more appointments- resulting in more time needed off from work, greater difficulty returning to work after birth, and more stress. In some cases, for example where medication can no longer be taken, there may be considerable difficulties with working.

Pregnant women are protected under the Equality Act 2010 from being treated "unfavourably" because of pregnancy "or an illness relating to pregnancy", for the period from when she becomes pregnant until she returns to work (the protected period). Despite this, one in nine mothers report being made to leave their job during this period (dismissed, made redundant where others were not, or treated so poorly they felt there was no choice but to leave)[101]. Antenatal or other medical appointments are often integral to the health of pregnant women with long-term conditions. There are legal protections to enforce the right to

be paid for “reasonable” time off for antenatal appointments, though what is reasonable can be a grey area[102]. Indeed, 10% of mothers said their employer discouraged them from attending antenatal appointments; if scaled up to the general population this could mean up to 53,000 mothers a year[103]. There is no further guidance for employers on reasonable leave for women with pre-existing health conditions which are likely to be impacted by pregnancy.

1 in 10 mothers report their employer discouraged them from attending antenatal appointments

The type of employment that a woman is engaged in can influence the level of negative impact that becoming pregnant will have on her work. Often those working in “non-traditional” forms of employment (such as casual/agency workers and those on zero-hour contracts) bear the greatest brunt of disadvantage[104]; for example, lacking any entitlement for paid leave for antenatal appointments. This can lead to missed appointments, risking the health of both mother and baby. A pregnancy complicated by an existing health condition could, in many cases, be financially ruinous for a non-traditional employee. Certain job types are also less open to pregnancy related flexibility, with mothers working within male-dominated skilled trades such as chefs or mechanics being five times as likely to say they feel “forced out” of their roles then the average for women in all professions.[105]

Despite the strengthening of legal protections for pregnant women in the last decade, working (or seeking work) whilst expecting a child continues to cause significant problems for thousands of women each year. Recent research found 77% of women reporting at least one potentially discriminatory and/or negative experience at work whilst pregnant[106]. Worryingly, they found an increase on the levels of discrimination reported in a 2005 study, with more women being made redundant or being forced to leave their job than a decade ago.[107]

4.3. Management and support at work

We do not know whether or not pregnant women with health conditions experience further work disadvantage than women with either long-term conditions or women who are pregnant. However, combined evidence on pregnancy related discrimination and health related discrimination suggest this is a hypothesis worth testing. The EHRC identified that disability status had an influence in determining whether a mother reported a negative impact on opportunity, status or job security, albeit to a lesser extent than factors such as type of occupation, contract and whether they already had children.[108]

The additional time needed to attend medical appointments, or to manage the additional strain of an illness exacerbated by pregnancy, can mean that women with pre-existing health conditions may need to take more time off work. Whilst it is illegal for pregnancy related sickness absence to factor into an employer’s decision regarding a women’s employment, extra leave and poorly understood conditions could lead to employers gaining a negative impression of their pregnant workers.

There are limited materials which discuss how to better support pregnant women with long-term conditions at work. Royal College of Nursing (RCN) guidance suggests midwives and occupational health nurses have a key role in supporting working pregnant women with disabilities. They highlight the need for risk assessments and reasonable adjustments where

there are problems, in particular noting concerns around reduced mobility and physical and psychological hazards, and suggesting that developing strategies to manage these risks can be crucial to keeping women in work.[109]

The additional burden of having a long term condition must be taken into context of working while pregnant in the UK, with the associated loss of earnings and high potential for discrimination at work. A compounding illness may add extra complexity, and the "grey area" and gaps around enforcement of rights means that, for many women, the lack of a sympathetic and understanding employer could have an impact on the health of both the mother and her baby.

[81] ONS (2012). *Statistical Bulletin: Cohort Fertility England and Wales*
[82] Mazzotta, P., Maltepe, C., Navioz, Y., Magee, L.A. & Koren, G. (2000). Attitudes, management and consequences of nausea and vomiting of pregnancy in the United States and Canada. *Int J GynaecolObstet,* **70**(3): 359-365
[83] McParlin, C., O'Donnell, A., Robson, S., *et al* (2016). Treatments for Hyperemesis Gravidarum and Nausea and Vomiting in Pregnancy: A Systematic Review.*JAMA,* **316**(13): 1392-1401
[84] Wacker-Gussman, A., Thriemer, M., Yigitbasi, M., Berger, F. & Nagdyman, N (2013). Women with congential heart disease: long-term outcomes after pregnancy. *Clin Res Cardiol*, **103**(3): 215-22
[85] Data from Cardiovascular Disease Statistics. See: British Heart Foundation (2014). *Cardiovascular Disease Statistics 2014*. Available at: https://www.bhf.org.uk/-/media/files/publications/research/bhf_cvd-statistics-2014_web_2.pdf [Accessed 26 May 2017]
[86] British Heart Foundation (2014).*Cardiovascular Disease Statistics 2014.*
[87] U.S. data from 1992-2002. See: Leddy, M.A., Power, M.L. & Schulkin, J. (2008). The Impact of Maternal Obesity on Maternal and Foetal Health. *Obstetrics and Gynaecology*, **1**(4): 170-178
[88] Health Survey for England 1993-2013
[89] Centre for Maternal and Child Enquiries (2010). *Maternal Obesity in the UK: Findings from a National Project.*
[90] NHS (2017). *Overweight and Pregnant* .See: http://www.nhs.uk/conditions/pregnancy-and-baby/pages/overweight-pregnant.aspx [Accessed 2June 2017]
[91] Diabetes UK (2015).*Diabetes: Facts and Stats*
[92] Diabetes UK (2015).*Diabetes: Facts and Stats*
[93] NHS (2017). *Diabetes and Pregnancy.*See:http://www.nhs.uk/Conditions/pregnancy-and-baby/pages/diabetes-pregnant.aspx [Accessed 26 May 2017]
[94] NHS (2017). *Diabetes and Pregnancy*
[95] NHS (2017). *Diabetes and Pregnancy*
[96] Royal College of Psychiatrists (2017). Mental Health in Pregnancy. Available at : http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/mentalhealthinpregnancy.aspx [Accessed 2June 2017]
[97] NICE (2016). *Antenatal and postnatal mental health: Clinical Management*.
[98] MIND (2016). *Antidepressants*.
[99] NICE (2016). *Antenatal and postnatal mental health: Clinical Management*.
[100] Royal College of Psychiatrists (2017).
[101] Equality and Human Rights Commission (2016). *Pregnancy and maternity-related discrimination and disadvantage*.
[102] Equality and Human Rights Commission (2017). *Employers obligations during pregnancy: Antenatal care, breaks and travel*. See: https://www.equalityhumanrights.com/en/managing-pregnancy-and-maternity-workplace/faqs-employers/employers-obligations-during-pregnancy-3 [Accessed 26 May 2017]
[103] Equality and Human Rights Commission (2016).
[104] Women and Equalities Select Committee (2016). *Pregnancy and Maternity Discrimination Report.*
[105] Women and Equalities Select Committee (2016).
[106] BIS & EHRC (2016). *Pregnancy and maternity-related discrimination and disadvantage: Experiences of mothers*, March 2016: 38-39
[107] BIS & EHRC (2016).
[108] BIS & EHRC (2016).
[109] RCN (2007). *Pregnancy and Disability: RCN guidance for midwives and nurses*. Available at: https://www2.rcn.org.uk/__data/assets/pdf_file/0010/78733/003113.pdf [Accessed 26 May 2017]

5. Menopause

Menopause is a universal process, affecting working age women at some point in their lives. Despite this, the symptoms that it presents and their impacts on work – sometimes lasting several years – are poorly recognised by women and employers, with potential implications for the ability of older female workers to work happily and productively.

5.1. What is the menopause?

Menopause is a natural part of the ageing process for women. It is defined as the point when a woman has not menstruated for 12 consecutive months and typically occurs between the ages of 45-55, although around 1 in 100 women in the UK experience the menopause before 40 years of age[110]. Menopausal symptoms include hot flushes, poor concentration, tiredness, poor memory, feeling low/depressed and lowered confidence[111]. All of these factors have been linked to poor workplace performance, and as many women of this age are still in full-time employment[112], menopause will undoubtedly have an effect on work.[113]

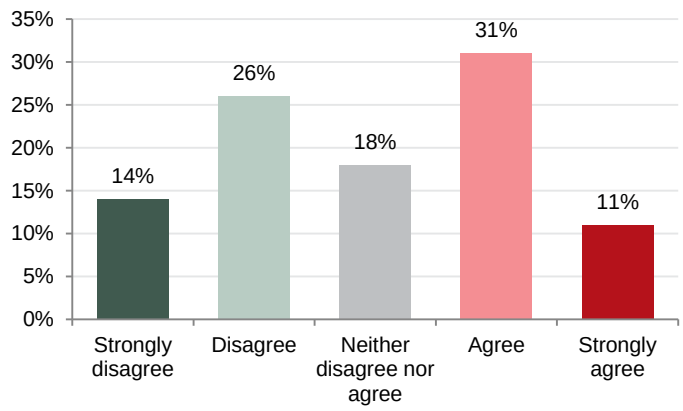
The average age of menopause is 52, but the hormonal change and related symptoms can last between 4-8 years

5.2. Implications for work

There is a growing body of evidence exploring how menopause effects work and life. A survey of over 900 women aged 45-55 found over half reporting it was difficult managing life during the menopausal transition. This was true also of managing work – 48 per cent reported they had some difficulties, while 5 per cent experienced considerable difficulty. Over four out of ten women surveyed reported that their menopausal symptoms negatively affected their job performance.[114]

Women often also reported that they had to work harder to overcome difficulties relating to having the menopause; of those women who felt that their work performance had *not* been negatively affected by menopausal symptoms, 36% said that this was because they worked even harder to overcome the difficulties, so to ensure they met their performance targets and job requirements[115]. Such figures imply that, for many women, there is a work penalty associated with the menopause.

Figure 1: Job performance negatively affected by menopause symptoms[116]



As all women experience the menopause, given its reported impact on work performance, it can be surmised that the menopause may also have a negative effect on business outcomes and performance. By improving our understanding of the menopause and its effect on working women, we can minimise this penalty.

The challenges of working with mood or cognitive-related issues

are well-documented, commonly identified in terms of mental ill-health, as well as part of the experience of a number of physical health conditions. More specific to the menopause are common side effects, such as hot flushes, which can be especially challenging for women and cause considerable distress[117]. Some 20-25% of women experience vasomotor symptoms (such as hot flushes and night time sweats) to the extent that it significantly affects their perceived quality of life, both at work and in the home[118]. The work environment itself can exacerbate menopausal side effects, as workplace stress may make the mood and cognitive aspects more difficult and high workplace temperatures and poorly ventilated work environments are frequently reported as causing problems for menopausal women[119]. Unsatisfactory or limited toilet facilities can also cause problems for menopause management in the workplace.[120]

Two fifths of women felt their menopausal symptoms negatively affected their work, while other reported having to work even harder to compensate

The visible aspects of the menopause can be challenging. Hot flushes and sweats can be particularly problematic at work when one finds themselves the subject of attention, such as in meetings or presentations[121]. Many women report embarrassment, or even disgust, about experiencing hot flushes and sweats, sometimes often leading to their avoiding social situations to minimise risk of this happening in public[122]. This reflects the persistent social stigma around the menopause and its symptoms which remains a *"significant source of distress"* for many women[123]. Indeed, despite being a normal life process, previous research has concluded that the menopause and its symptoms can represent *"a major challenge for working women, but one they are reluctant to discuss openly".*[124]

Stigma around even talking about the menopause at work prevents women from accessing the information they need to help them self-manage symptoms. A lack of management and HR preparation on this topic may be hindering women's ability to work to the best of their ability during this time[125]. Many women report wanting more information, help and support from managers, but felt that discussing the menopause was still "taboo"[126]. This lack of access to information through the workplace is likely a barrier to creating a workplace culture that is open to discussing the menopause.[127]

Three quarters of women had not discussed their symptoms with their line manager

Such concerns about disclosure may be warranted – many women have encountered criticism and ridicule about menopausal symptoms from co-workers and managers[128], with nearly a fifth of women believing their symptoms had had a negative impact on their manager's perceptions of their competence[129]. This lack of understanding can inhibit likelihood of disclosure and add to the stress. In one study, three quarters of respondents had not discussed their symptoms with their line manager, with the most common reasons for not doing so including 'privacy' (62%), 'line manager is a man' (42%) and 'it's embarrassing' (32%).[130]

There is poor awareness of the challenges around the menopause in women. This is perhaps compounded by a lack of knowledge among women themselves about what to expect from the menopause, with many reporting feeling unprepared[131]. The lack of training and awareness among managers is in stark contrast to the policies, practice and support

afforded to younger women in the workplace going through pregnancy and maternity leave[132]. One 2003 survey suggested that only half of managers recognised the problems associated with the menopause.[133]

5.3. Management and support at work

Unlike the other conditions we discuss in the paper, there is some guidance available for the management of the menopause at work (including from the Faculty of Occupational Medicine)[134], including on the government's Fit for Work website. Advocates call for better recognition of the menopause as an occupational health issue[135]. Efforts should be made in organisations to provide appropriate support for women who are experiencing this natural transition. Employers and managers need to be more aware of what the menopause means for their female employees, and how they can better support them, to reduce any negative impact it has on work, and on the women who are experiencing it.

Legally, under the Health and Safety at Work Act there is a duty to undertake regular risk assessments[136]; this should obviously include any specific risks to menopausal women if they are employed. The risk assessments must ensure that the working environment will not make menopausal symptoms worse. This includes attention to issues, such as temperature control, proper ventilation, and addressing general welfare issues, such as access to toilet facilities and cold water[137]. Employers might also include in their sickness absence procedures that they are flexible and can cater to menopausal symptoms within their sickness absence criteria. Women should not be discriminated against if they need time off of work, under sickness absence, due to menopausal symptoms. This requires employers to be flexible in their approach to sickness absence and time off of work, which in turn, should result in a decrease in workplace absenteeism.

The provision of the Act largely reflects the research evidence. A 2013 study identified four main areas for an organisation to better support employees experiencing the menopause.[138]

- **(i) Greater awareness among managers about menopause as a possible occupational health issue.** There is currently limited awareness of the implications of the menopause at work and what it means from an occupational health perspective. There also remains a high level of stigma. Improving managerial awareness about this common process and the challenges there in can help to normalise support.
- **(ii) Flexible working hours.** Flexible working can be an effective tool to minimise the effect of menopausal symptoms, for example, allowing an employee to start work later to compensate for night sweats and disturbing sleep. In one study, only a third of respondents reported having the ability to negotiate working hours to the extent required to help them deal with symptoms adequately.[139]
- **(iii) Access to information and sources of support at work.** Many women feel ill-prepared for the menopause, including in terms of the potential impact on work, where they might seek support, and what types of things might help. More information about the menopause may help and empower employers to raise this sometimes difficult topic with managers, as well as informing them as to what they can do in terms of self-management.
- **(iv) Attention to workplace temperature and ventilation.** Temperature control is important in terms of minimising the effect of hot flushes and sweats. Making efforts

to provide a ventilated environment can reduce some of the distress associated with these common symptoms.

A supportive employer should try to provide a work environment in which women are able to self-manage their symptoms; with self-management identified as important for helping women manage symptoms at work[140]. For example, allowing the use of fans to adjust the work environment temperature, permitting adjustment of work routines including flexibility around taking breaks, and making notes to aid cognitive problems[141]. Building on this, support from other women experiencing or who have experienced the menopause, e.g. peer support, has been identified as a valuable tool for women, as is the more general improvement of information about the menopause, increasing one's knowledge of the menopause for one's own edification[142]. However, there are difficulties in ensuring that line managers have the correct awareness; our interviews with experts in this field revealed that specific training around the menopause (as well as other reproductive and gynaecological issues), is almost non-existent.

As the menopause has been shown to affect women that are still of working age and negatively affects job performance, then supporting full employment of women with the menopause has clear economic and moral imperatives. By 2022, the number of people in the workforce who are aged 50+ will have risen to 13.8million[143], meaning that enabling older women who are of menopausal age to continue working full-time, as effectively as possible, will become increasingly important. A decline in labour force participation of older women will hit certain sectors very hard, so retaining women going through the menopause is crucial in some sectors – such as nursing –that rely on a female-dominated labour force and also have a larger proportion of older women workers[144]. Therefore, employer support is necessary to deal with an ageing female workforce that will eventually experience this process.

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[110] NHS (2017). *Menopause.* See: http://www.nhs.uk/conditions/Menopause/Pages/Introduction.aspx [Accessed 26 May 2017]
[111] Griffiths, A., MacLennan, S. & Vida Wong, Y.Y. (2010). *Women's Experience of Working Through the Menopause*. The British Occupational Health Research Foundation.
[112] 78% of women aged 35-49 are in employment, as are 66.2% of women aged 50-64. ONS (2017) Dataset A05 SA
[113] Griffiths, A., MacLennan, S. & Vida Wong, Y.Y. (2010).
[114] Griffiths, A., MacLennan, S. & Vida Wong, Y.Y. (2010).
[115] Griffiths, A., MacLennan, S. & Vida Wong, Y.Y. (2010).
[116] Griffiths, A., MacLennan, S. & Vida Wong, Y.Y. (2010).
[117] Griffiths, A., MacLennan, S. & Vida Wong, Y.Y. (2010).
[118] Annual Report of the Chief Medical Officer (2014). *The Health of the 51%: Women.*
[119] TUC (2003).*Supporting women through the menopause*.Available at: https://www.tuc.org.uk/sites/default/files/TUC_menopause_0.pdf [Accessed 26 May 2017]
[120] Unison (2016).*The Menopause and Work*
[121] Annual Report of the Chief Medical Officer (2014).
[122] Annual Report of the Chief Medical Officer (2014).
[123] Annual Report of the Chief Medical Officer (2014).
[124] Annual Report of the Chief Medical Officer (2014).
[125] HM Government (2015) *A new vision for older workers: retain, retrain, recruit*
[126] Annual Report of the Chief Medical Officer (2014).
[127] Annual Report of the Chief Medical Officer (2014).
[128] Annual Report of the Chief Medical Officer (2014).
[129] Griffiths, A., MacLennan, S. & Vida Wong, Y.Y. (2010).
[130] Griffiths, A., MacLennan, S. & Hassard, J. (2013). Menopause and work: an electronic survey of employee's attitudes in the UK. *Maturitas,* **76**(2): 155-159
[131] BOHRF (2011). *Changing attitudes towards 'The change of life'.*
[132] Fenton, A. & Panay, N. (2014). Editorial: Menopause and the workplace. *Climacteric*, **17**: 317-318
[133] TUC (2003).
[134] Faculty of Occupational Medicine (2016). Guidance on menopause and the workplace. Available at: http://www.fom.ac.uk/wp-content/uploads/Guidance-on-menopause-and-the-workplace-v6.pdf [Accessed 26 May 2017]
[135] Kopenhager, T. & Guidozzi, F. (2015). Working women and the menopause, Climacteric, **18**(3), pp. 372-375.
[136] HM Government (1999).The Management of Health and Safety at Work Regulations 1999. Available at: http://www.legislation.gov.uk/uksi/1999/3242/made [Accessed 26 May 2017]
[137] Unison (2016). *The Menopause and Work.*

[138] Griffiths, A., MacLennan, S. & Hassard, J. (2013).
[139] Griffiths, A., MacLennan, S. & Hassard, J. (2013).
[140] Griffiths, A., MacLennan, S. & Hassard, J. (2013).
[141] Griffiths, A., MacLennan, S. & Hassard, J. (2013).
[142] Griffiths, A., MacLennan, S. & Hassard, J. (2013).
[143] HM Government (2015). *A new vision for older workers: retain, retrain, recruit*.
[144] 88.6% of nurses are female, and one in three are set to reach retirement age within 10 years. Figures from Institute for Employment Studies (2016).

6. Conclusion and recommendations

As we have seen above, there are a range of issues relating specifically to the female reproductive system which can impact on women’s health and work. Though women are the ones directly affected by these conditions, they should not be dismissed as just “women’s issues"; the impact of these conditions and natural processes on health and to work of such a large part of the workforce should be recognised as important to the economy as a whole. The effect of reproductive and gynaecological health on work needs to be recognised, managed and supported in the same way that other long-term health conditions are. Indeed, the synergies between these conditions and other conditions which are regarded as public health priorities are clear – seen for example, in the fluctuating nature and pain of endometriosis, and the links with fatigue and concentration, and importantly the links to low mood and poor mental health and wellbeing.

In creating health systems and work environments which are supportive of all employees’ health needs, we can create a healthier, sustainable, and more efficient workplace (with better financial results) for all. A first step in addressing the barriers and difficulties around women working with these conditions is to amplify these issues and engage a consortium in discourse, which highlights the impediment on the quality of life and the work outcomes of a substantial part of the labour force – and in the case of the menopause – half of the population. These should be topics that women are able to discuss comfortably at work, and receive support for, to help them remain in employment and also to work productively.

Based on existing policy and academic literature and conversations with experts, we have developed a series of recommendations which we believe will help move this agenda forward. However, this is in the context of this topic being under-recognised and under-researched. Consequently, we hope that this paper opens up more of dialogue around women’s health and work, improving recognition and understanding of the reality for working women, and drives the development of support where it is needed.

The recommendations draw on all of the above conditions, and hopefully represent a broad spectrum of what is required to better support women’s reproductive and gynaecological health at work. We propose the following:

6.1. Recommendations for employers

Recommendation 1: Improve recognition of women’s reproductive and gynaecological health in workplace policy and processes

This is necessary to both provide assurances to women that they can raise their symptoms with managers/employers, and to provide managers/employers with tools to support them. We encourage employers to review their polices and processes around sickness absence, maternity leave, flexible working, health and safety and occupational health provisions to ensure that the issues we have discussed are being accounted for and women are not unduly disadvantaged in work. In particular, ensure that women’s reproductive and gynaecological health issues are recognised:

- and understood by human resources and occupational health providers/practitioners;
- in risk assessments, as per the Health and Safety Act; particularly in relation to menopause;

- in line management training where and as appropriate, alongside other health-related training. Managers should at least be aware that such conditions may be eligible for support under the Equality Act 2010 and provisions of the Health and Safety Act;
- in decisions around the flexible working requests (as part of right to request and as a reasonable adjustment) given the importance placed on flexible work for self-management for self-management;
- in sickness absence policies and processes. Such issues, including menopause, should be eligible for sickness absence and care should be taken to ensure that sickness absence and performance systems do not unfairly treat women in this context. Additional annual leave or compassionate leave may be appropriate in some circumstances;
- in reasonable adjustments decisions more generally; managers should be flexible in regards to their working policies and remain sensitive to requests, e.g. breaks, workplace temperature control, time off/leave, working from home, or even to reduce working hours temporarily, etc.

Recommendation 2: Provide a pathway for female staff to access confidential work support

There are clear issues with disclosure in the workplace and fears around stigma; particularly where there is a male line manager who may be entirely unfamiliar with the conditions. Although many line managers will be comfortable and adept at discussing a range of issues, others will not be; and for some, these issues are particularly uncomfortable to discuss. Non-disclosure of health conditions may lead to incidents being mismanaged or women not seeking support for their health condition, when with adjustments, they might be more productive or even be able to remain in work. We suggest employers:

- consider assigning a staff member (e.g. in HR or Occupational Health) as a gender-specific representative in the organisation for providing guidance on sensitive issues, or acting as a go-between or supportive presence for meeting with line managers.

6.2. Recommendations for the Joint Work and Health Unit

Recommendation 3: Improving access to evidence-based advice and support through government services and support

There is limited recognition of the importance of women's reproductive and gynaecological health in health and work policy, and limited evidence on what works in improving employment outcomes. Although there is a growing body of guidance around menopause and work, there is much less for the other conditions discussed in this paper. Having recognition of, and clear guidance from, the government on women's health issues and work may empower female employees to speak more confidently to employers about any challenges for working that their condition presents.

- Develop guidance on a range of women's reproductive and gynaecological health and work issues, including endometriosis, for use in occupational information sites, such as the Fit for Work website. Guidance should be developed in collaboration with (and preferably endorsed by) relevant patient groups, occupational health experts, and health bodies such as the Royal College of General Practitioner (RCGP), Royal College of Obstetricians and Gynaecologists (RCOG) and the Faculty of Occupational Medicine.

- Ensure that professionals involved in Access to Work and Fit for Work have knowledge and understanding of these issues to better enable them to support women.
- Raise awareness of the role of patient groups and peer support groups in terms of providing support inside and outside of the workplace.
- Encourage and support employers (e.g. via ACAS, CIPD) and organisations with a focus on women's health with the appropriate resources to host materials raising awareness of these issues and how to best support women experiencing them.
- Given the proportion of women who work part-time or in less secure jobs (including on zero-hours contracts), we must pay particular attention to make sure that all working women are able to access the support and advice they need to remain in employment.

Recommendation 4: Review and improve clarity over legal status of conditions

There is a lack of clarity as to the legal status of some of these conditions, which has been suggested to have implications for rights within employment and to related support.

- Department for Work and Pensions should update assessment criteria for welfare support to recognise the debilitating nature of some of these conditions; the case is particularly clear for severe endometriosis.
- Provide clarity over the status of women's reproductive and gynaecological health conditions, particularly severe endometriosis and infertility, under the Equality Act 2010 as a long-term, disabling chronic condition.

6.3. Recommendations for the health system

Recommendation 5: Review clinical guidance

Women can suffer from the effects of endometriosis for years without receiving a diagnosis; this poor recognition is the cause of much stress, and inhibits effective management of the condition at work. NICE guidelines on endometriosis are currently under review, but will hopefully address some of the challenges and reduce the average length of time to diagnosis.

- Take affirmative action to reduce the huge discrepancy in time of onset of symptoms and time of diagnosis for endometriosis.
- For those undergoing treatments and investigations for suspected endometriosis prior to definitive diagnosis, a presumptive diagnosis of endometriosis could be applied to support management of their condition in the workplace.

Further, there are concerns about the social and psychological implications for women experiencing other reproductive and gynaecological conditions, which we would hope to see addressed in clinical guidance.

- Include in clinical guidance reflections on the quality of life and psychological implications many women experience as a response to a hidden, chronic health issue, affecting all aspects of their life including fertility;
- Similarly, guidance on self-management (including pain management for women with endometriosis) as well as link to peer support will likely be beneficial for some women.

For further recommendations on women's healthcare, please see: All-Party Parliamentary Group on Women's Health: Informed Choice? Giving women control of their healthcare.

Recommendation 6: Recognition of work as a health outcome

The implications of these conditions on women's quality of life, ability to work, and to work well should be recognised in the health system. Work can be positive for health, and is often a sought-after outcome of medical care.

- Healthcare Professional's (e.g. GPs and gynaecologists) should be encouraged and supported to consider the challenges to the quality of life and to work presented by the conditions and/or their treatments. They should also consider these challenges in treatment plans and referrals for ongoing support. This should be reflected in Royal College of General Practitioner (RCGP) and Royal College of Obstetricians and Gynaecologists (RCOG).

6.4. Recommendations for further research

Recommendation 7: Building the evidence base

This is an under-researched area; additional work should focus on the challenges, as well as the solutions, facing women with health issues relating to reproductive and gynaecological health.

- In order to better understand the challenges many women experience due to these conditions – physically, psychologically and in terms of their ability to work – more robust quality research needs to be commissioned.

More information and support

For more information on these conditions and how to access support in work, please contact:

- **Endometriosis UK**: support and guidance for women with the condition. https://www.endometriosis-uk.org/
- **Fertility Network UK**: the national charity for anyone who has ever experienced fertility problems. http://fertilitynetworkuk.org/
- **Pregnancy Sickness Support**: charity dedicated to supporting women and their families experiencing Pregnancy Sickness and Hyperemesis Gravidarum. https://www.pregnancysicknesssupport.org.uk/
- **Equality and Human Rights Commission**: https://www.equalityhumanrights.com/
- **ACAS**: http://www.acas.org.uk/
- **Mayer Rokitansky Küster Hauser (MRKH) syndrome UK**: http://www.mrkh.org.uk/, **Global MRKH**: https://theglobalmrkh.wordpress.com/author/globalmrkh/

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June 2017