

Endometriosis and employment – Is this a contradiction in terms?

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Introduction

When I first decided to investigate this topic I put the words 'endometriosis and work' and then 'endometriosis and employment' into the BMJ search engine. Both searches came up with the article, '*Answering Death's Questions*'. Whilst this is rather amusing, it appeared that apart from Kapadia's work in 1996ⁱ, this topic has been little documented since this time. The National Endometriosis Society have carried out research into women's quality of life and endometriosis.ⁱⁱ

The aim of this study from the outset was to investigate whether endometriosis had any impact on a woman's career, and to what extent. I was interested in this area of work given my own personal history with endometriosis. I wanted to know whether I was a rare case or one of many whose work has been affected by endometriosis.

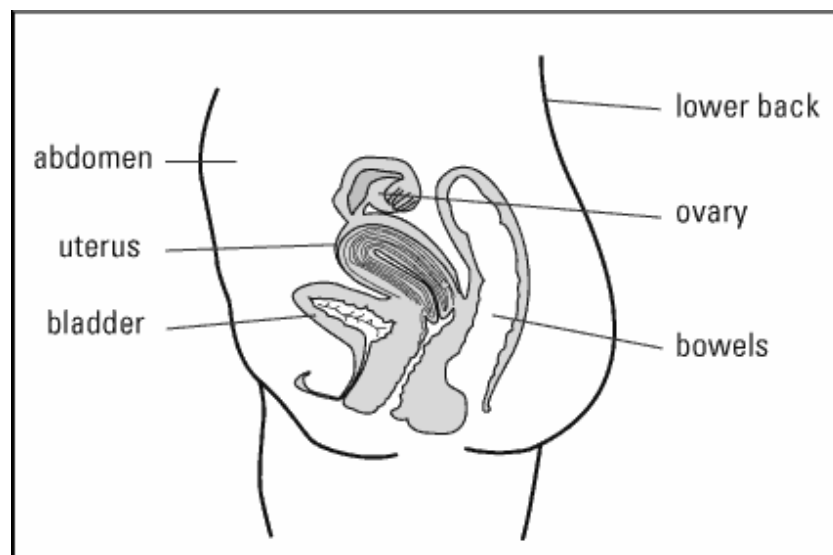
What is endometriosis?

Endometriosis is a condition in which the endometrium (the lining of the uterus) escapes into the surrounding pelvis and elsewhere.ⁱⁱⁱ It is a condition that is so far poorly understood. The shed endometrium cause pain and inflammation as the cells attach themselves to other parts of the pelvis and grow in response to the women's menstrual cycle. One of the likeliest reasons for endometriosis occurring was discovered by Dr Sampson in the 1920s, who developed the theory of '*retrograde menstruation*'.^{iv} More recent arguments to explain the causes of endometriosis include immune factors, blood and lymph transportation theories, genetic and pollutant factors.^v

The most common sites of endometriosis:

Endometriosis can be found in any area of the pelvis including the bladder and bowels. It can also be found (rarely) in the lungs, kidney and diaphragm^{vi}

The Female Reproductive System from www.4women.gov/faq/endomet



Symptoms of Endometriosis^{vii}

- Period Pain (Dysmenorrhoea)
- Painful intercourse (Dysparaunia)
- Painful ovulation
- Infertility
- Painful urination
- Painful bowel movements
- Back Pain
- Digestive complaints
- Fatigue
- Depression
- Psychological – poor memory and concentration

Some women will experience only one or two symptoms where others will experience a whole spectrum of symptoms.

Considering this range of symptoms it is not difficult to see why some women might suffer problems with work, but this must depend upon the severity of symptoms.

It has been widely accepted that the 'amount' of endometriosis a women has does not necessarily relate to the amount of pain that she experiences.

Diagnosis

The 'Gold Standard' (evidence level III) diagnosis for endometriosis is with a laparoscopy^{viii} The amount of endometriosis (if any) and its location can be found during a laparoscopy. If appropriate a surgeon may also remove any cysts or lesions that are found by laser or diathermy.

Images of Endometriosis



from www.emedicine.com

Management of Endometriosis

Endometriosis is often a complicated condition to manage so I am separating pain management from medical management.

Medical Management

Some women might find that they experience less pain after a laparoscopy particularly when they have had some treatment.^{ix} Some women might even find they can finally conceive. Both these are positive outcomes of surgery. For other women the symptoms of endometriosis can reappear again even quite a short time after surgery. This is because whilst normal menstruation continues, any remaining endometriosis, or new endometriosis continue to be fed by the woman's hormones during the natural menstrual cycle.

There are a few well-known methods and established drug therapies that can be used to medically manage endometriosis. One is through using the oral contraceptive pill sometimes tricycling packets (combining three months medication at a time) so that a woman has fewer episodes of menstruation^x. Another method is through use of Danazol a synthetic form of testosterone^{xi}. This method results in some unpleasant side effects.^{xii} Some women are treated using Depo-Provera, a form of progesterone, but again this also causes side effects and is less commonly used these days^{xiii}. Lastly, a group of drugs known as GnRH analogues are often used in the treatment of endometriosis. These work by reducing the FS (follicle stimulating) and LH (luteinizing) hormones and lead to lower levels of oestrogen^{xiv}. Since it is the oestrogen that 'feeds' the endometriosis, this means that its growth is inhibited. HRT is given in the form of 'add-back' therapy to minimise the pseudo menopausal symptoms incurred by this drug regime and to ensure that bone density is retained, as far as possible.

One of the problems with any of these drug regimes is that they cannot be used for indefinite periods. In particular the use of GnRH analogues is not usually recommended for longer than 6-12 months because of concerns about osteoporosis and lack of bone density. The long-term usage (continuous usage over many years) of GnRH analogues is something that is yet to be researched, as far as I am aware.

This all means that medical treatments for endometriosis are fairly short-term, so that even if a woman is experiencing good pain relief and improvement in her symptoms that just as she starts to possibly feel well again the drugs are often stopped. This can be very frustrating, especially if the treatment has been successful.

Pain Management for endometriosis

Pain management for endometriosis is difficult because of the wide range of symptoms that it encompasses. A range of analgesia may be used including paracetamol, aspirin, NSAIDs and codeine-related products.^{xv} Some women who are in severe pain are occasionally hospitalised and offered morphine related drugs.

The use of TENS machine has been helpful to some women with chronic pelvic pain and endometriosis^{xvi} Electrical stimulation on the skin via a TENS machine distracts the pain signals and can give relief.

A nutritious diet is also important. One high in fish oils and vitamins B and E, zinc and magnesium can help with the inflammation of endometriosis.^{xvii} Some women also find complementary medicine can be helpful in their management of endometriosis. The most commonly used therapies are herbal medicine, homeopathy and acupuncture.^{xviii}

When pain becomes chronic, as it is estimated by Latthe to be a prevalence of 38 per 1000 women aged 15-73, some women might need to be referred to a Pain Management team for further support^{xix}.

Some women with endometriosis find support groups helpful such as those run by the National Endometriosis Society, whilst others will find talking to helplines or website forums useful. These support factors are vital in managing what can often be a very lonely and isolating condition as many women find it hard to talk about gynaecological conditions.

The impact of endometriosis on a woman's life

Endometriosis can have a profound effect on a woman's life. In its' worst form it can cause infertility^{xx}. It can also have a very negative impact on relationships since many women suffer from painful intercourse, and for some the stress and pain can be too

much for a relationship to survive. The incident of relationship break-ups amongst women with endometriosis has not yet been documented.

This study is examining the extent to which endometriosis interferes with a woman's career.

Methodology

Advertisements were put online to SHE, National Endometriosis Society and Gumtree to recruit women to take part in the short qualitative data questionnaire. Responses were collated and analysed accordingly.

Questionnaire

Endometriosis Study:
 I am looking for any women who suffer from endometriosis to find out what, if any, impact endometriosis has on their working life.

Please e-mail me with your details. I am possibly looking to write an article about this, which I would run past the National Endometriosis Society.

I am particularly interested to find out:

- * How long you have had endometriosis?
- * Your age
- * Whether you have had time off work, had to leave a job, work part-time or no longer work because of your endometriosis
- * Whether you have had children or are trying
- * Your current treatment regime - e.g hormone treatment or hysterectomy etc

Results

Twenty eight women took part in this survey with an age range of 19-42 and a mean age of 31.5 although one did not complete her age and failed to respond to an email requesting it. The women were given a choice as to whether they would wish to remain anonymous or not throughout this study. In order to preserve the confidentiality of all, only initials will be used against age, when and where appropriate. It is also important to note that women's ethnicity, social status or education were not taken into account.

Results Table:

Primary reasons for absenteeism

Primary Reason*	Number	Percentage
No time off work	1/28	3%
Surgery	4/28	14%
Period/bleeding	6/28	21%
Pain	19/28	67%
Fertility treatments	1/28	3%
Drug side effects (e.g. drowsiness)	3/28	10%
Not working – multiple symptoms	5/28	17%
Considering a career change	3/28	10%

* some women gave more than one reason for taking time off work

Only one woman (1/28) said that she hadn't had any time off work at all besides for the laparoscopy. She writes, "*periods are painful but can be managed with solphadene max and hot water bottles.*"

Surgery was a sometimes a reason for taking time off (4/28). One woman who had laparoscopic excision surgery wrote that, "*I had five weeks off following surgery, other than that, just the odd day here and there.*" Another lady wrote that she took time off during her period, the most common time to take time off. She wrote that, "*I have a fair amount of time off, it varies depending on my treatment. Usually a few days a month over my period*". Surgery helped some women to be able to explain their symptoms to their employer. One woman wrote until her laparoscopy she was taking three days off each month, even though she was running pill packets together. She said, "*I was lucky and have an exceptionally understanding boss*".

The attitude of the employer was an important issue for some women in how they negotiated their condition. One woman wrote, "*I have had a few jobs in the past where I have had to give them up due to lots of time off with pain and bleeding. I still suffer pretty badly but I have to work and my female boss isn't the most sympathetic of people!*". On the more extreme end some women were sacked because of their condition. One woman wrote that, "*it stated in my contract that if I didn't contact work for 10 days and didn't turn up then they took it that I resigned – not that I would be given the sack. I knew they couldn't do this as they had been given sick notes signing me off for 2 weeks but I didn't physically or emotionally have the strength to do anything about it.*"

Another woman wrote that, "*about a month ago, I got fired from my job for going to all the appointments, for wincing in pain which they said was 'rolling my eyes' at another employee while he was giving a presentation (I truly did not), for clutching my stomach at work and showing signs of pain (promotes low company morale I was told!) and finally for missing so many days from the first of the year until now....The very same HR person who offered as many days as I needed, and the same boss who offered me paid holiday ended up giving me the sack because I was in pain.*"

In another case a woman wrote that until September last year she couldn't take time off for it. She writes, "*I would show up for work hardly being able to stand straight. Most of my day would be spent in the ladies doubled up in pain in tears. My boss thought it was 'silly women's problems' and didn't warrant time off. Once I did call in sick with it but I got such a telling off by my boss I went into work -it took me nearly three hours. Sometimes the cramps would start at around 1am and be so bad I'd throw up with the pain and/or faint, but I still had to go to work. If I had them at work I was completely useless but I put on a good act of looking busy*".

For all but a lucky few of us, work is necessary for financial reasons. Some women were stoical enough to forgo their social lives so that they could continue with work, or would arrange their periods to occur at the weekends. One woman writes, "*I arranged for my period to be on the weekends so that I no longer have to miss work. However it still stops me from doing simple things like the laundry at the weekends*". Another woman told me that she was, "*constantly taking time off – a couple of days every month and that she struggled with work and prioritised it so rarely socialised and slept at the weekends in order to cope*". One woman also wrote that, "*I generally have to take a day off each month with the pain, although if I was realistic I would have more, as I grin and bear a lot of the pain in a bid not to look like a malingerer*". It is significant I believe that many women continue to try and cope with their pain because they feel guilty about it and because they do not wish to 'go public' in their Companies with their condition. This leads to many women soldiering on and therefore often denying the severity of their condition. Such women are to be admired for their great courage and strength of

character, although not everybody can manage to successfully cope with this difficult condition.

Two of the women who completed the survey said that they were self-employed which possibly gave them greater flexibility to manage their bad days, but also meant a loss of income if they were unable to work. One wrote that she did need to take time off due to the pain, but didn't comment upon how much time. Another wrote that, "*moving her work about was sometimes possible when she felt very bad, but due to endometriosis she had not worked full-time in the past six years.*" One woman wrote that she worked a four-day week so that she could have a day off purely to rest and recharge. She writes that, "*I was struggling to get through the week so I have Wednesdays at home to give me a break to re-charge. I would not do this if it were not for my endo*". For many women, it is not just about the pain and bleeding, but the fatigue that this condition causes and the endless cycle of pain that mean essential breaks are a necessary coping mechanism.

Pain was the most common reason by far for taking time off work (67%). One forty year old woman, SC who didn't know why she was so ill until six years ago – the diagnosis of endometriosis as an adolescent had never been disclosed and was not disclosed until she was 34 years old. She wrote that, "*until six years ago I was literally a zombie due to the pain caused by something I wasn't aware that I had.*" Another woman wrote, "*I had to give up work six years ago due to endo – severe chronic pain all over my body not just pelvic pain*". For some women certain duties at work were compromised because of being in pain. One woman wrote that, "*my job is physically demanding and I have to at times avoid performing certain duties required of me because of the affect it will have on my pain level.*" Another woman wrote that, "*it (endometriosis) definitely debilitated my life in that I was constantly in pain at work. I would sometimes take a couple of days off around my period as I would be passing out*".

Only one woman specifically mentioned that infertility, a side effect of endometriosis was causing her absenteeism from work. She writes that, "*I had given up my full-time job six months before I was diagnosed with endo as I felt unable to cope and we were trying for a family.*" SC (above) also writes that fertility (or infertility) might have been an issue for her but was now a past issue given her age (40) and any probability of success.

For some women the side effects of painkillers and/or hormone therapies were enough to warrant missing work. One woman wrote that, "*I am a school science teacher. This means that even if the painkillers manage to control the pain they usually leave me feeling very drowsy and unable to cope with my work environment*". This is a safety issue and is particularly difficult if a woman has found a helpful analgesia but then is unable to take it because it compromises her work.

10% of the women who took part in this survey were considering career changes purely because of their endometriosis. One wrote of the need to certainly consider part-time work, whilst another wrote to that, "*There are times I have considered changing careers if I cannot find an effective way to treat this (endometriosis).*"

Finally 17% of the complete group (5/28) were not able to work at all given the severity of their condition. One woman wrote that, "*I still get awful pain, not all the time mind you, but it is enough to stop me working, and I have to take painkillers most days including a ready supply of liquid morphine for really bad days.*" Another wrote that, "*I gave up work in 2002 – I had so much time off work it was impossible to stay. I was a senior research fellow.*" For some women the decision is eventually forced upon them, which they understandably find difficult to accept. One woman wrote that, "*I was told that my contract would not be renewed when it expired owing to the number of absences I had had over the year.*" Another woman wrote that, "*I realised that I couldn't continue living*"

alone and making myself iller trying to do my job. This was a very painful conclusion to reach financially and personally. I felt that I had failed and let myself and the school down.” In the end such women are forced to leave because their illness permeates into their lives on such a regular and daily basis as to render any work impossible. This also leads to feelings of guilt and failure on behalf of the women who are forced or pushed to make this difficult decision. One woman wrote that her self-confidence is now shattered because she had lost jobs through endometriosis or been forced to resign. She wrote that, *“I really want to work, but given my health record no employer is likely to take me seriously.”*

Conclusion

Endometriosis and work – a contradiction in terms? For the 17% who are unable to work at all due to the severity of their symptoms, the answer has to be yes, yet many other women *were* able to work, even if it was part-time. Whether 17% as ‘unable to work’ would be typical of a larger cohort and would truly represent their endometriosis symptoms is questionable. From a recent NES Study^{xxi}, “36% had either lost or changed their job” so the numbers from this study are therefore lower than nationally suggested. Of the NES Study, “82% of UK women had lost time from work over the last five years due to their endometriosis losing on average 5.3 days a month”. This is costing our country hugely.

There is no doubt that an employer’s attitude impinges upon a woman’s ability to continue successful (or not) with her work. Those women with understanding, supportive and sympathetic employers were more likely to remain in their posts than women who did not receive a positive or helpful response from their employers. Women generally want to be upfront about their condition but find it difficult talking about gynaecological issues to either men or women. The most disturbing case I read about involved an employer deciding whether or not to hold a ‘return to work’ interview for a woman who had only had 1.5 days off sick in 18 months.^{xxii} This is a rather extreme example and was challenged on the ‘Workplace Law Network’

Everyone who took part in this survey wanted to work. One admitted that her fiancé had chosen to support her and wanted her to stop work so that she had a chance to recover and get well. This couple also wanted children. Guilt was often an emotion that came up in the course of the study – women felt guilty for letting themselves and their employers and colleagues down through a condition that was no fault of their own. Many women demonstrated great courage in continuing with employment when the situation was clearly exceptionally difficult.

In this study 67% missed work because of pain as opposed to 82% nationally (NES Study). Medically endometriosis can be supported through use of hormone treatments to minimise the number of menstrual cycles a woman has, but even this doesn’t guarantee women no pain, but perhaps less pain. There was no doubt that the highest level of absenteeism was likely to be around the menstrual period 21%. There was also a problem with some painkillers causing drowsiness and therefore being unsuitable to take whilst at work.

It seems that if a woman’s pain was mainly concentrated around the days of her menstrual period that she was more likely to manage to hold down a job, whilst if her pain encroached into other ‘non-menstrual’ days as well, she was less likely to manage to hold down a job, particularly if she was in pain on a more daily basis.

This study shows that for women who were on a hormone regime that suited them, or had endometriosis successfully treated by surgery, the chances of them being able to

work at least part-time was far greater than women who were not being hormonally treated, or had symptoms on the severe end of the scale.

Endometriosis and work is not a contradiction in terms, but there are factors that are going to lead an improved success rate in a woman being able to work successfully. These are:

- The amount of endometriosis she has/range of symptoms
- Using Hormone treatment that works for her
- Using Pain control that is suitable for her (especially at work)
- Understanding employers
- Supportive partners, friends and family
- Good medical care –a supportive gynaecologist/GP
- An ability to work part-time, or a slightly reduced full-time position with one day off in the week seemed a very successful solution for one person.

Women form a hugely significant portion of the workforce and improved understanding of endometriosis and the treatment thereof would benefit the economy overall not to mention the women's own personal incomes and work-satisfaction.

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I would like to thank all the women who took part in this study and for the many who continue to respond, so another, more detailed report might be available in the future.

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