

# Women with endometriosis need support, not judgement

March 3 2015, by Kate Young, Jane Fisher, And Maggie Kirkman

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One in ten women worldwide are thought to have endometriosis.  
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Known for years as the "[career woman's disease](#)" based on the idea that women without children develop disease in their reproductive organs, endometriosis is a painful condition thought to affect one in ten women worldwide.

The condition occurs when tissue similar to the lining of the uterus (that

is, the endometrium) grows outside the uterus. These tissues implant in and form lesions on organs such as the ovaries, bowel and bladder. The condition can only be definitively diagnosed through surgery and because people often don't believe the symptoms being reported by women, [diagnosis is often delayed](#).

There's no cure and the [cause of the condition is unknown](#). Treatments include hormonal therapy to inhibit growth of the disease and surgery to remove the lesions, but these often provide only short-term relief. And they have significant side effects, such as loss of bone density and the formation of scar tissue that can cause organs to fuse together.

In the absence of a cure and effective long-term treatment, we need to turn our attention to how doctors and loved ones can provide care and support to women with [endometriosis](#).

## **Living with endometriosis**

In a systematic review of studies [we published](#) late last year, we found the condition affects all areas of women's lives. All the studies we looked at used qualitative research methods to examine women's experiences of endometriosis. This kind of research, which involves interviews and focus groups, is useful for capturing experiences that numbers and statistics cannot.

Women spoke about the benefits of "taking charge" of the condition. They educated themselves about it and tried to destigmatise discussion of gynaecological health with their family, friends and [intimate partners](#).

Many took it upon themselves to manage symptoms with whatever resources they had. Some changed their diet, for instance, while others re-arranged their work and social commitments.

Women's accounts of their condition showed that the way endometriosis was acknowledged by other people, such as their doctors, intimate partners and employers, could influence their experience of it. This could be positive if, for instance, partners educated themselves about the condition and helped manage it.

Or negative if, say, family members refused to acknowledge the illness was real and not "just" bad period pain. And when little support was given, that made managing symptoms a bigger burden.

## **Economics of endometriosis**

Endometriosis is an expensive disease. One of the factors contributing to its cost is the delay in diagnosis, which takes an [average of five and a half years](#). In the meantime, women are often subjected to unnecessary investigations and treatments, all of which cost money. Then there's the cost of the surgery required for diagnosis, and further surgical treatment.

In our research, women highlighted the adverse impact of endometriosis on their ability to work. They spoke of the difficulty of performing certain tasks when under the effects of strong pain killers.

With symptoms such as intense pelvic pain during menstruation and at other times, heavy menstrual bleeding and bowel and bladder problems, including cyclic diarrhoea and constipation, it's not surprising that some women with endometriosis find it difficult to stay in paid employment.

So although health-care costs are substantial, income loss from this chronic – and, for some, disabling – condition is estimated at [almost twice as much](#). There's little published Australian data about the cost of the average annual loss of productivity. Calculations would need [to cover both](#) absenteeism and reduced productivity when at work.

And many women feel uncomfortable about having to explain a gynaecological condition to employers, particularly male managers.

## The right support

The accounts in our review show there are things that can be done to accommodate symptoms and support women's economic participation. Women spoke of the need for increased flexibility in the workplace, such as the option of working from home and the ability to arrange hours to suit medical appointments.

Our review also identified techniques clinical practitioners could use to facilitate better support for women with endometriosis from those around them. They could offer letters for employers, for instance, suggesting flexible workplace practices would enable women to fulfil the demands of their jobs as well as manage the condition.

For some women, sex is painful some of the time and clinicians could also offer to discuss the [effect of endometriosis on the women's sex life](#). Our review found few women reported their doctor asking about the effect of endometriosis on their intimate relationships and some were embarrassed to bring it up themselves.

While the idea of modifying social practices to improve the health and well-being of women with endometriosis may not have the glamour of a new drug or imaging technique, these are affordable, timely measures that women with the condition have identified as valuable.

Research into finding a cure or effective long-term treatment for endometriosis is important, but it shouldn't be our only goal. Rather, we should work together to create an environment that fosters [women's](#) agency in the face of this chronic illness.

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