

Endometriosis and Couples

Endometriosis can have a significant impact on quality of life, not just for women with the condition but also for those who are close to them including partners, family and friends. This leaflet is about the impact endometriosis can have on couples¹. It is aimed at both women with endometriosis and their partners. It describes the various ways in which the condition might affect couples, and offers some information and advice about coping with the condition as a couple.

It is important to remember that not all the impacts listed below will affect all couples, and that it is possible to have a happy, fulfilling relationship in spite of endometriosis.

How does endometriosis affect couples?

Endometriosis can have a negative impact on couples' quality of life in complex, multidimensional ways, including²:

Day to day life

- Endometriosis can have a considerable impact on day-to-day life including working lives, everyday tasks, social lives and childcare. This may create an extra strain on couples.
- There may be an impact on women's working lives. This is felt primarily by women but can have a financial and emotional strain on the couple unit.
- Endometriosis can have a significant impact on social lives. Feeling restricted and feeling a sense of loss can affect both partners.

Healthcare and treatment

- Couples may find that seeking an effective treatment is an ongoing battle – this can cause frustration for both partners.
- Couples may need to discuss if and how women would like their partners to help them make healthcare and treatment decisions. They may also need to discuss what partner's roles will be in consultations if they attend.
- Women and their partners may have differing views on how endometriosis should be treated and managed. For example, research suggests that men may be more likely to see endometriosis as something that needs to be cured, whereas women may be more likely to see endometriosis as something to be managed long term.

¹ This information sheet is primarily about heterosexual relationships, as this was the focus of the research study from which the leaflet was produced. However, it may be that some of the information will also apply to same sex couples.

² Information about how endometriosis can affect couples is drawn from the ENDOPART study which comprised in-depth interviews with 22 heterosexual couples (men and women interviewed separately). For further information and to access the study's report see www.dmu.ac.uk/endopart. Reference: Culley, L, Hudson, N, Mitchell, H et al. (2013): Endometriosis: improving the wellbeing of couples: summary report and recommendations. Leicester: De Montfort University.

Sex and intimacy

- Pain during or after sex (dyspareunia) is a common symptom of endometriosis. This can be very distressing for couples, and can result in a loss of intimacy.
- However, this pain is not the only factor that can affect sex and intimacy for couples. Sex and intimacy might be affected by a range of things including: bleeding during or after sex; general fatigue and feeling unwell; reduced sexual desire because of medication; low mood; the stress of trying to get pregnant; and loss of body confidence and desire.
- Both partners may experience feelings of guilt and sadness as well as feelings of loss associated with a lack of intimacy, closeness and affection. Partners may also feel hesitant and tentative, and may be reluctant to approach their partner for fear of causing pain.
- Women may face a difficult choice between avoiding sex or enduring painful sex in order to experience intimacy with their partner.

Emotions and support within relationships

- Both partners may experience a wide range of emotions. In particular, the woman with endometriosis may experience feelings of frustration, guilt, low mood and irritability, while partners may experience worry, helplessness and frustration.
- All couples need to work to support one another, but endometriosis may create additional support roles for partners. These may include practical support (e.g. attending consultations together, helping to make treatment decisions, providing care after surgery or taking on additional everyday tasks) and emotional support (e.g. talking things through, listening, sympathising, etc.).
- Some couples may find there is a mismatch between the support one partner needs and the support the other partner feels able to provide.

Planning for and having children

- Many women with endometriosis conceive naturally. However, endometriosis may be associated with fertility problems, although the cause is not fully established. Even with severe endometriosis, natural conception may still be possible.
- Fertility problems associated with endometriosis can be very difficult and distressing for both partners. This can cause a considerable strain on relationships. Endometriosis can also cause anxiety and worry for couples who are not trying to get pregnant, but would like children in the future – as they worry about the possible future impact of endometriosis on fertility.
- Couples may find their plans for having children are affected in a range of other, additional ways. For example, some couples might try to have children earlier than they would otherwise have done, due to worrying about how endometriosis may affect them, and not wanting to leave it too late. Some couples might decide not to have children because they want to concentrate on the woman with endometriosis getting better.
- Because hormonal treatment for endometriosis may act as a contraceptive, some couples may find they need to make a difficult choice between having children and accessing treatment for the woman with endometriosis. This might be especially difficult where each partner has different priorities.

Partners and endometriosis

- As is the case for many women with endometriosis, there is little support and information for partners. Partners are often marginalised and it is unusual for partners to be asked how living alongside someone with this condition impacts them.
- For male partners, research suggests that men try to be stoic and ‘stay strong’, try to remain calm and in control, and try to hide their emotions and in this sense, these experiences can reinforce ideas about masculinity. Endometriosis can also cause feelings of anger and frustration and as such some partners take on an assertive role in trying to advance treatment.

Strengthening relationships

- Despite all the potential difficulties, endometriosis can make relationships stronger as well. As partners may need to communicate and work together to address the impact it can have, these experiences can help partners to better understand one another. Providing care and support can help partners appreciate one another more. Dealing with the challenges and trying to find a way through together can bring partners closer and strengthen relationships.

How can my partner and I best cope?

All couples and individuals will cope in different ways, but there are some things you might do to better cope with the impact of endometriosis on your relationship:

- Communicating effectively is a key aspect of living with a long term condition. It is a good idea to set aside a specific time to sit and talk about your worries, frustrations and reflections. Within your discussions ask: ‘how can I better support you? What do I do that is and isn’t helpful?’ Be prepared to listen to your partner, and to answer the questions yourself (it might be useful to think about how you want to answer these questions in advance of sitting down and talking with your partner). If conflict arises, walk away, spend time alone calming down and revisit it another time.
- Don’t expect your partner to mind read. Tell your partner how you feel and what support you need.
- Extend kindness to yourself and your partner. Accept that endometriosis affects both partners (albeit differently).
- To reduce the impact of endometriosis, try to find practical solutions, as well as addressing your emotions and the way you think about the condition. Practical solutions might include things like changing treatment, changing work patterns, altering diet, etc. However, these solutions are not always possible or effective, in which case expressing emotions and changing the way you think and feel about the condition can be very helpful. This might include things like:
 - o focussing on endometriosis as something to be managed rather than cured;
 - o allowing yourself and your partner to express and talk through negative emotions;
 - o trying to feel more optimistic for the future or conversely trying to be more accepting of the situation and a new way of life.

Try to be open to finding a balance of both styles of coping (practical and emotional), and recognise that where there isn’t a cure or an easy solution, addressing how you think and feel about the condition can be very effective.

providing support, increasing understanding

- Do acknowledge and address the ways the condition affects you and your partner. Research suggests that in the long term it is better to acknowledge and address the impact of health conditions, rather than to deny or ignore this.
- Be aware that you and your partner might find some coping styles easier than others. For example, one partner might want to try to find practical solutions to the problem while the other partner might be more comfortable with addressing the emotional impact of endometriosis and the ways they think and feel about the condition. Similarly, one partner might be much more inclined to think positively, while the other is feeling very negative and pessimistic. Again, try to find a balance of thinking positively when it is helpful but also allowing yourself and your partner to voice more negative emotions when needed.
- Recognise that while communicating clearly and openly is often the most helpful approach, this doesn't come easily for some people. Try to be supportive and encouraging if your partner finds it difficult to share their emotions.
- Work to find a balance of time alone and time together that works for you (including quality time together).
- Even if it is difficult to have sex, don't underestimate the importance of continuing to show intimacy - by touching, cuddling, kissing, holding hands, etc.
- If difficulties can't be resolved, speak to your GP or healthcare practitioner about accessing psychological therapy or counselling as a couple or an individual.

Where else can I go for advice and support?

Endometriosis UK provides vital support services, reliable information and a community for those affected by endometriosis. Visit www.endometriosis-uk.org or call the helpline on 0808 808 2227. You can also watch a short film about endometriosis and couples, featuring real life couples and advice from a clinical psychologist, at <https://www.endometriosis-uk.org/endometriosis-and-couples>. In addition, a support group session entitled 'The impact of endometriosis on women and their partners: a session for couples', aimed at both partners, is being delivered at various locations across the UK – visit <https://www.endometriosis-uk.org/support-groups> to find your local support group and to enquire about this session.

Women being treated for severe or complex endometriosis may have access to a clinical nurse specialist with expertise in endometriosis. These endometriosis nurses can offer advice and support both to women and their partners. For more details about NHS services that offer access to endometriosis nurse specialists, see the British Society of Gynaecological Endoscopy website, which contains details of accredited endometriosis centres: <http://bsge.org.uk/centre/>.

You can find more details about the role of the endometriosis nurse specialist on the Royal College of Nursing Website: https://www2.rcn.org.uk/_data/assets/pdf_file/0007/611980/004-776-Clinical-nurse.pdf.

You may also find the following organisations helpful:

- Relate (relationship help) - 0300 100 1234 - www.relate.org.uk
- Fertility Network UK - 01424 732361 - www.fertilitynetworkuk.org
- Fertility Friends - www.fertilityfriends.co.uk
- Samaritans (emotional support, 24 hours a day) - 116 123 - www.samaritans.org

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To provide feedback on this leaflet, please email information@endometriosis-uk.org.

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