

INFORMATION SHEET

TALKING ABOUT YOUR ENDOMETRIOSIS WITH YOUR PARTNER



4 August 2021



ENDOMETRIOSIS AT A GLANCE

Endometriosis is a condition where tissue similar to the endometrium (the lining of the uterus) grows elsewhere in the body. This tissue responds to reproductive hormones where oestrogen stimulates patches forming superficial, lesions or endometrioma (ovarian cysts). Inflammation is generally present, and adhesions (scar tissue) can also form in response. Endometriosis within the muscle tissue of the uterus is known as adenomyosis, typically characterised by an enlarged uterus and heavy menstrual flow as well as pain at time of period.

Your partner will likely have questions about how endometriosis is impacting you and your relationship. To answer them accurately educate yourself first on the condition. You may also want to discuss with your doctor or specialist whether your endometriosis could affect your fertility.

Choose the right time to have the conversation with your partner. Find a time that you can be alone and without any distractions.

If you are comfortable about sharing your symptoms, and frequency of these, this can give an understanding of what you experience on a regular basis. Be honest with your partner about your pain, and what can trigger your endometriosis symptoms. Also consider sharing your treatment and management plan.

Be supportive and intently listen to your partner as they express their emotions, worries or any questions they may have. Acknowledge that endometriosis can have a major mental and emotional impact on those closest to you.

If you and your partner/spouse are struggling to cope, seek help from a professional who can help you both through this journey together. Encourage them to go with you to your next doctor's appointment to be involved in the conversation.

ENDOMETRIOSIS AND YOUR SEX LIFE

Every person is affected differently by endometriosis, but painful sex (known as dyspareunia) is a common symptom and experience. Painful intercourse can disrupt your sex life, result in a loss of intimacy and cause a strain on your relationship.

Experiment by having sex at different times in your cycle, incorporate other types of stimulation like touching massage or oral sex. Use a lubricant to make vaginal sex as comfortable as possible.

Sex and intimacy may also be affected by irregular bleeding, heavy bleeding, bleeding during or after sex, general fatigue and feeling unwell. Some medications may impact your libido, as well

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as low mood or the stress of trying to get pregnant. Some people also experience a loss of body confidence and desire.

Open communication is especially important when you are having sexual issues. Let your partner know how you feel and acknowledge how they feel.

Speak to your doctor or gynaecologist about possible treatments to overcome painful sex, such as seeing a pelvic floor physiotherapist. There is much that can be done, and asking for help is an important first step.

ENDOMETRIOSIS AND YOUR FERTILITY

Endometriosis may affect your fertility, and this may be a concern for you and your partner. Talk to your partner that having endometriosis may make it more difficult for you to conceive but treatment and management - alongside a healthy lifestyle for you both - can improve your chances of conceiving.

Fertility problems can be very difficult and distressing for both partners and can cause strain on the relationship. You may find that your plans for having children are affected in many ways, for example some couples might try to have children earlier than they would otherwise have done due to endometriosis. Some couples may decide to explore interventions such as IVF, or other options such as adoption or fostering, or may choose to not to have children.

Seeking information and support from fertility experts, loss and grief counsellors and fertility support groups can be helpful.

STRENGTHENING YOUR RELATIONSHIP

Dealing with the challenges that you may face due to endometriosis and trying to find a way through can bring you and your partner closer together and strengthen your relationship. The experiences of communicating and working together to address the impact endometriosis can have, can help you to better understand one another and by providing care and support you may appreciate each other more.

Everyone copes in different ways but there are some things that can help you and your partner to better cope with the impact of endometriosis on your relationship such as extending kindness to yourself and your partner and accepting that endometriosis can affect you both, though in different ways.


Try to find practical solutions, as well as addressing your emotions and the way you think about the condition. Practical solutions may include things like changing treatment, changing work patterns, altering diet etc.

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However, practical 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:

- Focusing on endometriosis as something to be managed rather than cured.
- Acknowledging and addressing the ways the condition affects you and your partner.
- Allowing yourself and your partner to express and talk through negative emotions.
- Trying to feel more optimistic for the future or conversely trying to be more accepting of the situation and a new way of life.

Communicate effectively by setting aside specific times to sit and talk about your worries, frustrations and reflections. Ask each other “how can I support you better? What do I do that is and isn’t helpful?” Be prepared to actively listen to each other and walk away if conflict arises, spend some time alone calming down and revisit the conversation another time.

Communication doesn’t always come easily. Try to be supportive and encouraging if your partner finds it difficult to share their emotions. Remember that good communication involves skills which can be learned and improved, so speak to your GP about accessing counselling as a couple or an individual.

Also remember your partner can’t read your mind, tell them how you feel and what support you need. Here are some ideas of how they could support you:

- Offer to go to appointments to support self-advocacy
- Help out around the house with cleaning or preparing meals
- Offer to go the chemist or shop to get anything they might need
- Be a safe place for them, be understanding, compassionate and kind
- Be there to listen to them when they need to vent or cry
- Validate their feelings
- Foot rubs, back rubs and head massages
- Run them a bath
- Prepare their hot water bottle or heat pack
- Remind them to take their supplements or medication
- Surprise them with thoughtful gifts such as flowers or small actions to brighten their day
- Lots of cuddles

For further information:

- Insight Endometriosis: Endo 101 Factsheet
- Insight Endometriosis: Endometriosis Symptoms Factsheet
- Insight Endometriosis: Talking about your endometriosis with your family and friends
- Insight Endometriosis: Talking about your endometriosis with your place of education
- Insight Endometriosis: Talking about your endometriosis with your employer
- Insight Endometriosis: Advcoating for Yourself Inforation Sheet

References:

- ENDOPART study: <https://www.dmu.ac.uk/documents/research-documents/health-and-life-sciences/reproduction-research/endopart/endopart-study-summary-report-and-recommendations.pdf>

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