

INFORMATION SHEET

TALKING ABOUT YOUR ENDOMETRIOSIS WITH YOUR FAMILY AND FRIENDS



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.

The people closest to you can sometimes be the hardest to talk to but it is important family and friends have a clear understanding of how endometriosis is impacting you, so they can have compassion for what you are experiencing and provide the support and practical help you need. This can include understanding symptoms, treatments, side effects from medications and how these are affecting your life, as well as lifestyle changes you would like to implement.

Your family and friends may have questions about endometriosis, to answer them accurately educate yourself first on the condition. Choose the right time to have an initial conversation, find a time that you can be alone and without any distractions.

You can start by explaining what endometriosis is and advise them of reputable websites they can look at for their own research and information. If you are comfortable sharing the symptoms and frequency of these this can give an understanding of what you experience on a regular basis. Also consider sharing your treatment and management plan.

Listen to your family and friends as they express their emotions, worries or any questions they may have. Endometriosis can have an emotional and mental impact on those close to you.

Support is everything. Sometimes the smallest signs of support go the longest way. Here are some ideas you can share with family and friends of what they can do to support you:

- Just listen, venting is therapeutic
- A simple hug goes a long way
- If you hear of any tips or tricks on how to manage endometriosis, let me know about them
- Understand what endometriosis is, that it's not just 'a bad period', that it's a long-term condition with no cure
- Be gentle and let me know you are here to support me

- Let me know how proud you are of me, acknowledge that living with endometriosis isn't easy
- Check in on me simply just to see how I am. Text, phone or visit
- Understand sometimes plans have to be cancelled or adjusted; unexpected flare ups can happen at any time.
- Assure me that our relationship or friendship is unconditional as is the love you have for me
- Ask them support your self-advocacy such as coming along to meetings with your health professionals, place of study and employer.
- Enlist their help with your lifestyle changes such as exercise and dietary changes

For further information:

- Insight Endometriosis: Endo 101 Factsheet
- Insight Endometriosis: Endometriosis Symptoms Factsheet
- Insight Endometriosis: Talking about your endometriosis with your partner
- Insight Endometriosis: Talking about your endometriosis with your place of education
- Insight Endometriosis: Talking about your endometriosis with your employer
- Insight Endometriosis: Advocating for Yourself Information Sheet

References:

- Insight Endometriosis Research Project: Developing community support services to empower the Waikato Endometriosis community
- The impact of endometriosis upon quality of life: a qualitative analysis:
<https://bmcwomenshealth.biomedcentral.com/articles/10.1186/1472-6874-14-123>

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