



JIGSAW OF SYMPTOMS

ABOUT INSIGHT ENDOMETRIOSIS

Insight Endometriosis is a community-based Charitable Trust working collaboratively to empower people with endometriosis (suspected or diagnosed). We are based in Hamilton but provide services throughout New Zealand, with a focus on:

- Improving access to quality evidence-based information.
- Connecting those affected by endometriosis to relevant support.
- Ensuring those affected by endometriosis are productive, feel valued in their workplaces, and nurtured to succeed in their places of study.
- Building a strong, connected community network amplifying the voices of those affected by endometriosis.
- Ensuring lived experiences of those affected by endometriosis informs policy development and health system change.
- Other relevant support and assistance.

ABOUT THIS GUIDE

The purpose of this guide is to empower you with knowledge about the symptoms of endometriosis and adenomyosis - whether you suspect you have endometriosis or adenomyosis, have a diagnosis of endometriosis or adenomyosis, or have a whānau member, friend, or someone in your life that is experiencing endometriosis or adenomyosis symptoms.

It is important to remember that each person's experience of endometriosis and/or adenomyosis is different and this guide provides evidence-based information.



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SYMPTOMS OF ENDOMETRIOSIS



Pain that stops you during or around the time of your period (dysmenorrhoea)



Pain in your pelvic region, lower back or legs



Pain during or after intercourse (dyspareunia)



Pain during or around the time of ovulation



Fertility problems



Painful bowel movements (dyschezia)



Cyclical bloated abdomen, constipation, or diarrhoea



Frequent urination or painful urination (dysuria)



Constant tiredness / fatigue



Premenstrual spotting



Immune system issues



Depression, low mood, PMS

You do not need to have all of these symptoms but the more you have, the higher the likelihood of endometriosis. While period pain that stops you from doing things is the most common symptom, you may have other symptoms that seem vague and unconnected.

What can symptoms be similar to?

- Irritable Bowel Syndrome
- Pelvic Inflammatory Disease
- Polycystic Ovary Syndrome
- Coeliac Disease
- Fibromyalgia Syndrome
- Ovarian Cancer

Our 'Endometriosis Related Conditions Information Guide' provides more information about symptoms, diagnosis, treatment, and management of the above conditions.

What are the impacts of endometriosis?

Some people are relatively unaffected by the condition, while a great many others suffer severe pain and distress from problems associated with endometriosis. It tends to be a progressive condition; left untreated it tends to worsen over time.

Endometriosis can have a significant impact on people's lives including on:



School



Study



Work



Relationships



Travel

What should I do if I have symptoms of endometriosis?

We have a range of tools that can help you determine what your symptoms are. These tools can help with the conversation with your GP or gynaecologist. You can find a checklist on page 13, visual jigsaws of symptoms and impacts on pages 14-16, and symptoms and pain tracker on page 17.

We also have an Information Guide 'Self-Advocacy with Medical Professionals' that provides guidance on preparing for appointments with your GP or gynaecologist and how to advocate for yourself during and after appointments.



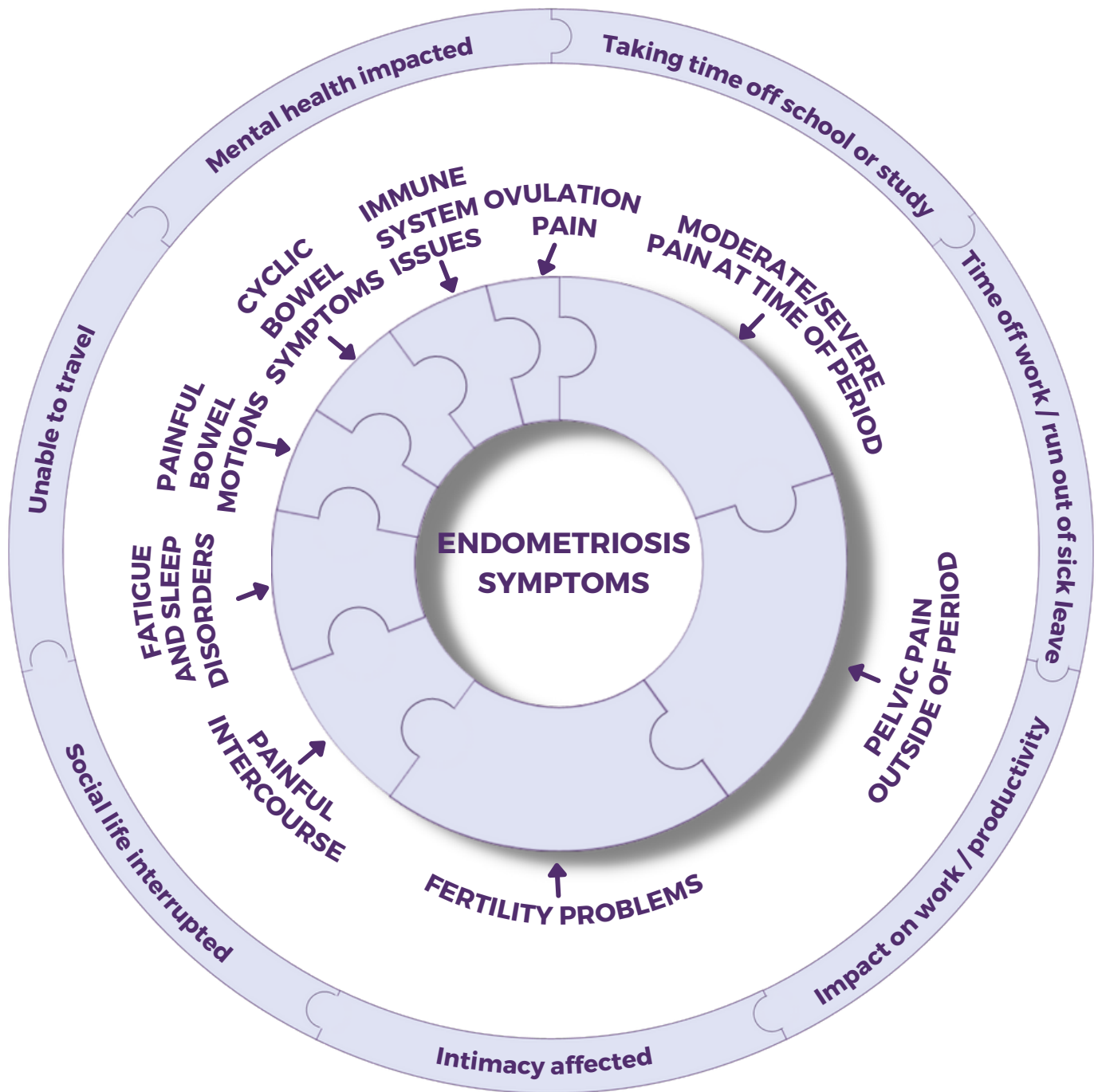
Use this checklist to help you decide if you need to seek medical advice:

- ☐ Do you take medication for pain at time of period?
- ☐ Do you need to take time off work or studies when you have your period?
- ☐ Do you need to rest when you have your period?
- ☐ Do you have pain during or after sex?
- ☐ Do you experience cyclical pain in your pelvic region, lower back or legs?
- ☐ Do you have pain midway through your cycle?
- ☐ Do you experience pain when you have a full bladder or when urinating?
- ☐ Are you, or have you, had fertility problems?
- ☐ Are your bowel motions painful, particularly around the time of your period?
- ☐ Do you experience cyclical abdominal bloating?
- ☐ Do you have diarrhoea or constipation related to your periods?
- ☐ Do you suffer from constant tiredness/fatigue?
- ☐ Do you experience cyclical depression, mood disturbances or PMS?
- ☐ Do you have premenstrual spotting?
- ☐ Do you experience heavy bleeding?
- ☐ Do you find smear tests painful?
- ☐ Do you have a grandmother, mother, sister, or aunt who has had similar symptoms or been diagnosed with endometriosis?

If you answer 'yes' to a few of these symptoms you may have endometriosis; the more you have, the higher the likelihood of endometriosis. Take this checklist to your GP or gynaecologist to discuss your symptoms.



ENDOMETRIOSIS JIGSAW OF SYMPTOMS AND IMPACTS



ENDOMETRIOSIS HAS A COLLECTION OF SYMPTOMS AND WIDE IMPACTS. COLOUR IN THE SYMPTOMS YOU EXPERIENCE AND THE IMPACTS ON YOUR LIFE. THE MORE PIECES COLOURED IN THE MORE LIKELY YOU ARE TO HAVE ENDOMETRIOSIS.

ULTRASOUND IMAGING CAN BE USEFUL, HOWEVER A NORMAL ULTRASOUND DOES NOT EXCLUDE A DIAGNOSIS OF ENDOMETRIOSIS

JIGSAW PIECE SIZING REPRESENTS THE MOST COMMON SYMPTOMS BASED ON RESEARCH

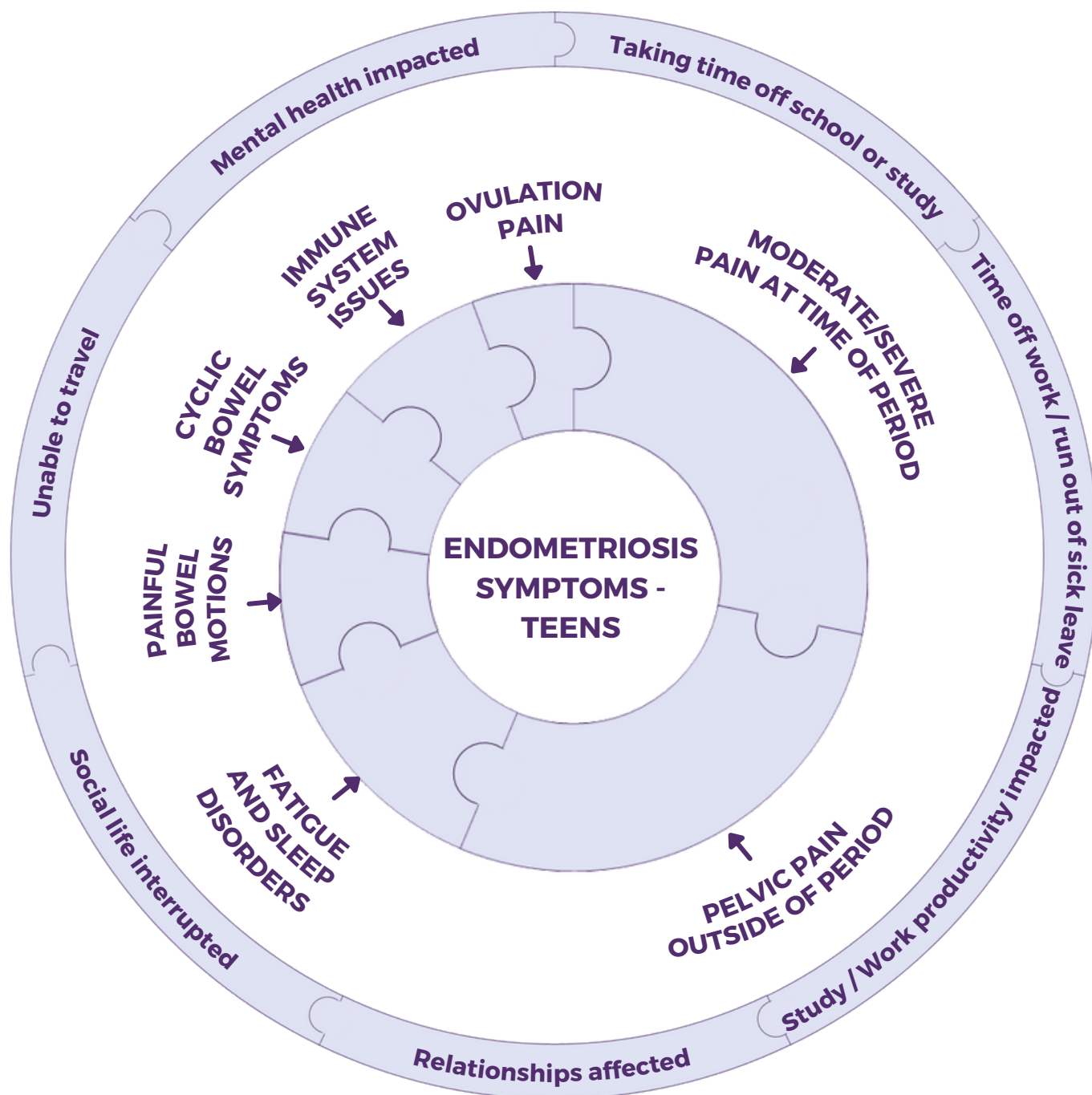
REFERENCES:

- <https://bmcwomenshealth.biomedcentral.com/articles/10.1186/s12905-020-01139-7>
- https://www.researchgate.net/publication/330190013_Clinical_diagnosis_of_endometriosis_a_call_to_action
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2939902/>

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ENDOMETRIOSIS JIGSAW OF SYMPTOMS AND IMPACTS - TEENAGERS



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ULTRASOUND IMAGING CAN BE USEFUL, HOWEVER A NORMAL ULTRASOUND DOES NOT EXCLUDE A DIAGNOSIS OF ENDOMETRIOSIS

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REFERENCES:

- <https://bmcwomenshealth.biomedcentral.com/articles/10.1186/s12905-020-01139-7>
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- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2939902/>

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SYMPTOMS OF ADENOMYOSIS

The common symptoms of adenomyosis include:

- Pelvic pain and cramping
- Enlarged uterus, bloated abdomen and pelvic pressure
- Heavy or prolonged menstrual bleeding and anaemia
- Fertility problems
- Pain during and/or after intercourse
- Leg pain

Other symptoms include bleeding between periods, back and hip pain, fatigue and painful cervical smear tests.

Adenomyosis is often present alongside endometriosis, with overlapping symptoms. The distinguishing feature is the enlarged or 'bulky' uterus which may show on an ultrasound and/or MRI and often causes pelvic pressure or tenderness in the lower abdomen or pressure on the bladder alongside heavy periods - which are not usual symptoms of endometriosis.

You do not need to have all of these symptoms but the more you have, the higher the likelihood of adenomyosis. While pelvic pain and cramping (period pain) that stops you from doing things is the most common symptom, you may have other symptoms that seem vague and unconnected.



What are the impacts of adenomyosis?

Some people are relatively unaffected by the condition, while a great many others suffer severe pain and distress from problems associated with adenomyosis. It tends to be a progressive condition; left untreated it tends to worsen over time.

Adenomyosis can have a significant impact on people's lives including on:



School



Study



Work



Relationships



Travel

What should I do if I have symptoms of adenomyosis?

We have a range of tools that can help you determine what your symptoms are. These tools can help with the conversation with your GP or gynaecologist. You can find a checklist on page 23, visual jigsaws of symptoms and impacts on page 24, and symptoms and pain tracker on page 25.

We also have an Information Guide 'Self-Advocacy with Medical Professionals' that provides guidance on preparing for appointments with your GP or gynaecologist and how to advocate for yourself during and after appointments.



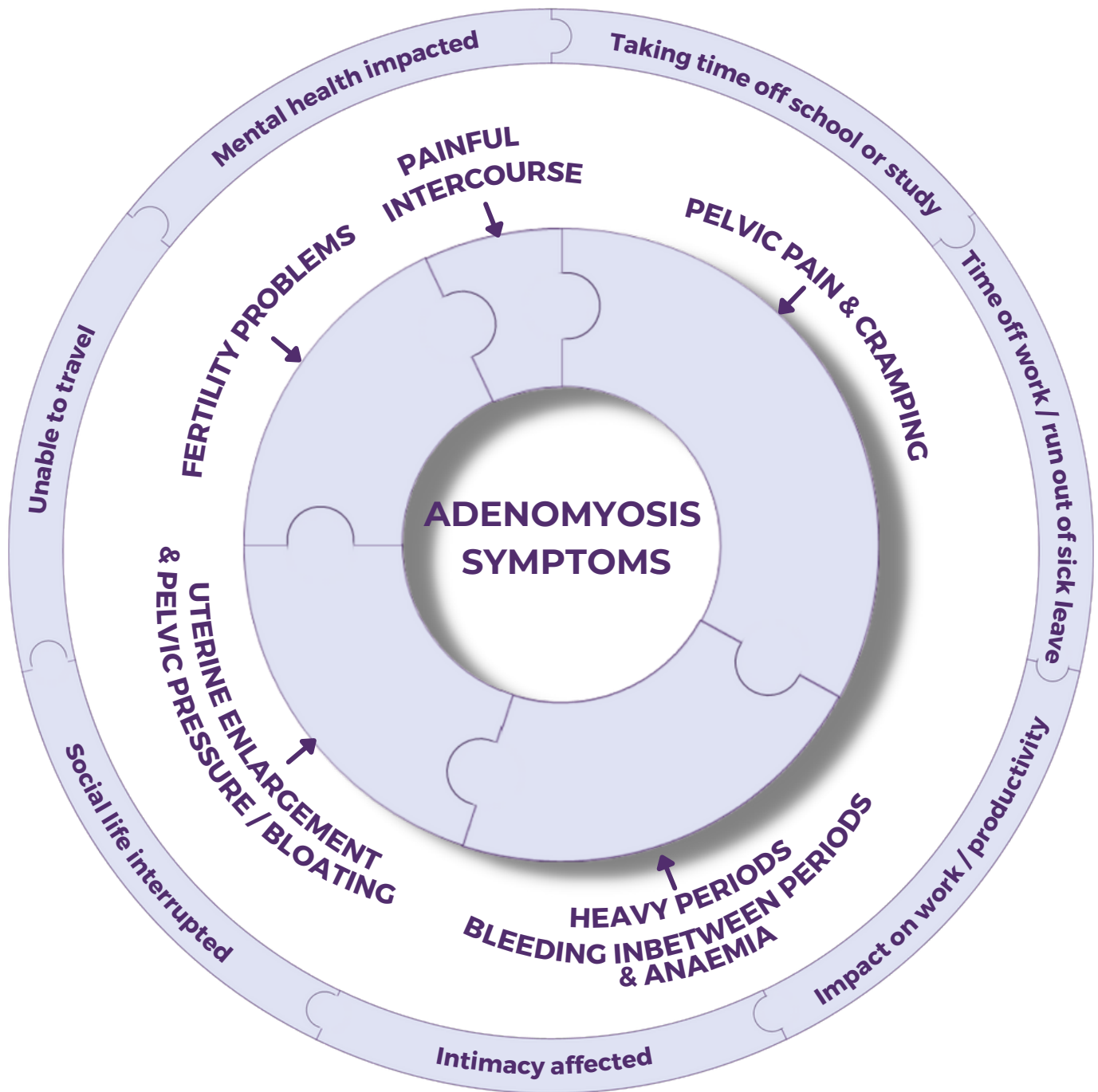
Use this checklist to help you decide if you need to seek medical advice:

- ☐ Do you experience a feeling of heaviness, enlarged or 'bulky' uterus?
- ☐ Do you experience cyclical pain in your pelvic region, lower back or legs?
- ☐ Do you feel pelvic pressure?
- ☐ Do you experience heavy bleeding?
- ☐ Do you take medication for pain at the time of your period?
- ☐ Do you need to take time off work or studies when you have your period?
- ☐ Do you need to rest when you have your period?
- ☐ Do you have pain during or after sex?
- ☐ Are you, or have you, had fertility problems?
- ☐ Do you experience abdominal bloating?
- ☐ Do you suffer from constant tiredness/fatigue?
- ☐ Do you find smear tests painful?
- ☐ Do you have endometriosis, or do you have a grandmother, mother, sister, or aunt who has had similar symptoms or been diagnosed with endometriosis?

If you answer 'yes' to a few of these symptoms you may have adenomyosis; the more you have, the higher the likelihood of adenomyosis. Take this checklist to your GP or gynaecologist to discuss your symptoms.



ADENOMYOSIS JIGSAW OF SYMPTOMS AND IMPACTS



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ADENOMYOSIS MAY SHOW AS A 'BULKY' OR 'ENLARGED' UTERUS ON ULTRASOUND

JIGSAW PIECE SIZING REPRESENTS THE MOST COMMON SYMPTOMS BASED ON RESEARCH

REFERENCES:

- <https://link.springer.com/book/10.1007%2F978-981-33-4095-4>

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Sinaii, Ninet et al. "Differences in characteristics among 1,000 women with endometriosis based on extent of disease." Fertility and sterility vol. 89,3 (2008): 538-45.

doi:10.1016/j.fertnstert.2007.03.069

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2939902/>

Real-world characteristics of women with endometriosis-related pain entering a multidisciplinary endometriosis program

<https://bmcmwomenshealth.biomedcentral.com/articles/10.1186/s12905-020-01139-7>

Clinical diagnosis of endometriosis: a call to action

https://www.researchgate.net/publication/330190013_Clinical_diagnosis_of_endometriosis_a_call_to_action

Differences in characteristics among 1,000 women with endometriosis based on extent of disease

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2939902/>

Adenomyosis Facts and Treatments

<https://link.springer.com/book/10.1007%2F978-981-33-4095-4>



DISCLAIMER

This guide reflects current evidence-based research from New Zealand and worldwide at the time of writing. While we endeavour to update as new information becomes available, Insight Endometriosis cannot guarantee or assume legal responsibility for the currency, accuracy, and completeness of the information.

This guide is for educational and support purposes only. It is not a substitute for professional medical or health advice.

A GP, gynaecologist, or specialist may provide new or different information that is more appropriate to an individual's needs and so Insight Endometriosis advises those seeking a diagnosis, medical advice or treatment to consult their doctor or an appropriate medical professional.

Insight Endometriosis is not responsible for the content of other parties that reference or are referenced within this guide; such references should not be construed as endorsements. Any links to external websites are for your information only, and Insight Endometriosis cannot guarantee their accuracy.

Nothing contained in this guide is, or shall be relied on as, a promise or representation by Insight Endometriosis.

We encourage the distribution and photocopying of the information in this guide to support those affected by endometriosis; please acknowledge 'Insight Endometriosis - Endometriosis Guide' as the source.

We support the Medical Council's statement that:
"... patients may need to be reminded that internet research cannot take the place of a face-to-face consultation."



INSIGHT ENDOMETRIOSIS INFORMATION GUIDES

Insight Endometriosis has the following information guides available on the website:

- Endometriosis Information Guide
- Adenomyosis Information Guide
- Diagnosing Endometriosis in NZ Information Guide
- Surgery and Hormonal Management for Endometriosis in NZ Information Guide
- Endometriosis Pain and Pain Management Information Guide
- Complementary Therapies and Lifestyle Changes for Endometriosis Information Guide
- Fertility and Endometriosis in NZ Information Guide
- Mental Well-Being and Self-Care with Endometriosis Information Guide
- Talking About Endometriosis with the People in Your Life Information Guide
- Self-Advocacy with Medical Professionals When You Have Endometriosis Information Guide
- Conditions Related to Endometriosis Information Guide

NEED MORE INFORMATION OR SUPPORT?

Visit our website to:

- Book a free/koha-based appointment with our Educator, by zoom, phone, or at our Hamilton office
- Register for a "Let's Talk About...." webinar session
- Join an Endo Meet-Up with other people with Endometriosis (suspected or diagnosed)

CONTACT US

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