TALKING ABOUT ENDOMETRIOSIS WITH PEOPLE IN YOUR LIFE INFORMATION GUIDE

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ENDOMETRIOSIS

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 INFORMATION GUIDE

The purpose of this information guide is to provide you with tips and tools that will enable you to talk about your endometriosis with people in your life - whether you suspect you have endometriosis or have a diagnosis of endometriosis. This information guide may also be useful if you are a whānau member, friend, or partner of someone experiencing endometriosis symptoms.

It is important to remember that each person's experience of endometriosis is different and this information guide provides evidence-based information as well as information based on other people's experiences.

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THE IMPORTANCE OF EFFECTIVE COMMUNICATION

Communicating with the people in your life about how endometriosis is impacting you is important so that they can have compassion for what you are experiencing and provide the support and practical help you may need.

What we say, how we say it, and what we mean by it are extremely important, and can be life-changing. There are skills and attributes which can be learned to support good communication. Two key skills and attributes are the use of ‘I Statements’, and Active Listening.

‘I STATEMENTS’

‘I Statements’ frame communication around owning your own feelings, reactions, and needs, rather than someone’s behaviour or comments. For example, compare and contrast these two statements, noting your emotional reaction to them:

- ‘You should get a Mirena, they’re great!’
- ‘I love my Mirena and would recommend them to others’

Which statement is easiest to hear?

'I statements' have fours parts to them:

I FEEL ____________________

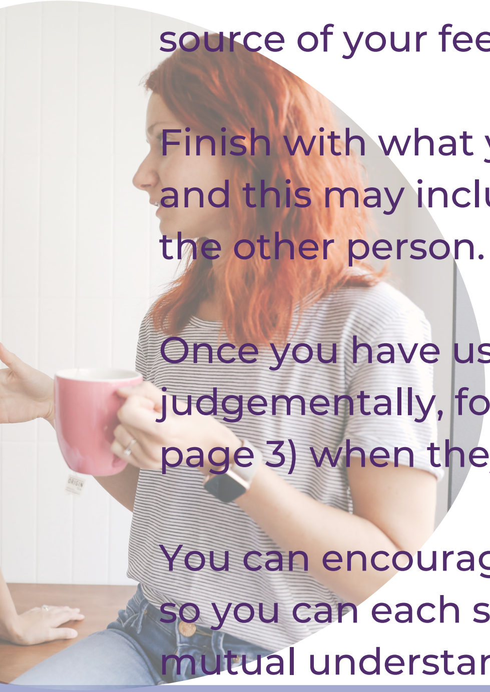
WHEN ____________________

BECAUSE ____________________

WHAT I NEED IS ____________________

Starting with how you feel when something is said, or something happens recognises the feeling that arose from your perception of events.

The 'when' part is the factual, specific statement of the situation. Continuing with 'because...' is helpful to clarify the source of your feeling.



Finish with what you need, being specific about your needs and this may include a change in behaviour from yourself and the other person.

Once you have used your 'I statement' wait, non-judgementally, for a response and utilise 'active listening' (see page 3) when they respond.

You can encourage the other person to use 'I statements' also so you can each state your needs and reactions to gain a mutual understanding.

ACTIVE LISTENING

Active listening is an aid to positive conversations which involves listening attentively while suspending judgment and advice.

The reference to active is important – this style of listening involves more than ‘listening passively’ and moves away from ‘critical listening’ which is judgemental.

Active listening is simple and very effective. Here are the steps:

- Pay attention to the speaker.
- Be fully immersed in what they are saying by suspending judgement, being patient and giving the speaker your undivided and empathetic attention.
- It is important to not ‘jump in’ with your opinions and ideas.
- Paraphrase and reflect back what is said – this step can be particularly useful if the points made were long or complex.
- Summarise what you think you heard, you can check and seek clarification or simply validate what they said.
- Use an ‘I statement’ such as ‘I think I heard you say...’ or ‘I want to check I understand....’ this is useful as it demonstrates that you are taking ownership of your part in the conversation.

ASKING FOR HELP

Asking for help can be hard, we fear that we will be turned down, laughed at, or revealed to be a fraud. Asking for help has social risks; rejection, vulnerability, diminished status and means that we are not in control. It's important to remember that these fears are unfounded and when you have a chronic condition asking for help is vital not only for your physical health but also your mental and emotional well-being.

Here are some tips to ask for the help you need, and get a yes response:

- Think about what you need and why - make sure you know what you need and why before you start a conversation with someone.
- Make it personal - ask someone who has the skills or expertise for the task and ask face to face or call the person. Studies show that face-to-face requests are more successful than over email or text. It's also easier for someone to say no over email or text. By asking someone who has the skills or expertise for the task you will make them feel needed and helpful, not just another person you can resort to for help.
- Don't apologise for asking for help - we all need help sometimes and there is nothing to be ashamed of. Apologising makes it seem that you are doing something wrong by asking and paints the task that you need help with in a negative light.
- Don't minimise your need - it suggests that the help is trivial and stops the person from feeling a sense of accomplishment from helping. Avoid phrases like "I hate to ask..." or "It's just a small thing..." or "Can you do me a favour?"
- Be concise and specific about what you need - describe what the task is, why it matters and how the person you're asking can contribute. Be willing to negotiate - let the person decide how much support they can offer and give and together talk about what works for both of you.
- Express your gratitude - take the time to express why their support not only matters to you but how it has impacted your life.

INSTEAD OF SAYING "I'M FINE"

We're constantly asked "how are you" in our lives, and often our response is "I'm fine" but when you have endometriosis or a chronic illness you often are not fine so how do you answer "how are you"? Here are some things you can say instead of "I'm fine".

♥ "Things have actually been pretty rough recently. When you have time to listen, let me know and I can share more" - this gives people a choice in when you share with them vs. 'emotional dumping'.

♥ “I'm not sure how to put my feelings into words at the moment. It's been a lot recently. I appreciate you asking, but I'm not sure how to talk about it now” – this lets people in and lets them know you are struggling but sets boundaries around the conversation.

♥ “I'm just taking it day by day. Small steps is what is helpful for me right now” – this shares that you are not doing 'fine' but doesn't give too much detail if you aren't comfortable sharing yet or at all.

♥ “Things have been better. I'm trying to be patient through this season of life” – this shares that you aren't doing the best but doesn't share too much detail

♥ “I'm not doing the best...I am open to talking about it but I would prefer a listening ear vs problem solving right now”- this clearly states what you need from the other person if you do want to share.

You also don't need to say anything and change the subject to something you feel comfortable discussing - It's normal to not feel like sharing, answering questions, or be comfortable responding to certain people. You can set conversational boundaries without being rude. Change the subject to something else that you feel more comfortable discussing, or ask the other person something about them.

WHEN PEOPLE IN YOUR LIFE TRY TO 'FIX' THINGS

It's natural for your whānau, friends, or partner to try and find practical solutions and want to 'fix' things for you. You may talk about changing treatment, surgical options, hormonal therapies, altering your diet, or changing work patterns.

However, practical solutions are not always possible or effective, in which case expressing emotions and changing the way you all think and feel about endometriosis 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 the person in your life.
- Allowing yourself and the person to express and talk through negative emotions.
- Trying to feel more optimistic about the future or conversely trying to be more accepting of the situation and a new way of life.

It may help to let the person know that you feel that they are trying to 'fix' things for you and that you appreciate that this comes from a place of care and love but it isn't helping as these practical solutions aren't possible or effective.

Let them know of ways they can support you instead.

TALKING TO FAMILY AND FRIENDS

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 whānau and friends may have questions about endometriosis, to answer them educate yourself first about endometriosis. You may want to look at the information on our website or have our information guides available to refer to during your conversation.

Start by choosing the right time and place to talk to your family or friend, a place where you can be alone and without any distractions.

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, share your symptoms, treatment, and management plan.

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

WAYS YOUR WHĀNAU AND FRIENDS CAN SUPPORT 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 about 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, and 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 to 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.

TALKING TO YOUR PARTNER

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.

Suspecting endometriosis or recently diagnosed

If endometriosis is new to you, 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.

Endo Fact

PELVIC PAIN SYMPTOMS HAVE CAUSED SIGNIFICANT PROBLEMS WITH A PARTNER FOR 67% OF PEOPLE IN AOTEAROA WITH ENDOMETRIOSIS

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.

Communicating effectively

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.

Communicate effectively by:

- Acknowledging that endometriosis affects you both in different ways
- Setting aside specific times to sit and talk about your worries, frustrations, and reflections.
- Asking each other “how can I support you better? What do I do that is and isn’t helpful?”
- Actively listening to each other and walking away if a conflict arises, calming down, and revisiting the conversation another time.
- Being open and honest about your feelings.
- Focusing on endometriosis as something to be managed rather than cured.

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 that can be learned and improved, so speak to your GP about accessing counselling as a couple or as an individual.

Also remember your partner can’t read your mind, tell them how you feel and what support you need.

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, resulting in a loss of intimacy, and can cause a strain on your relationship.

Experiment by having sex at different times in your cycle, incorporating 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 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 couple 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.

WAYS YOUR PARTNER CAN SUPPORT YOU

Here are some ideas of how your partner could support you:

- Attend appointments to support you and your self-advocacy.
- Help out around the house with cleaning or preparing meals.
- Go to the chemist or shop to get anything needed.
- Be a safe place, be understanding, compassionate and kind.
- Listen to you when you need to vent or cry.
- Validate your feelings.
- Provide foot rubs, back rubs, and head massages.
- Run you a bath.
- Prepare your hot water bottle or heat pack.
- Remind you to take your supplements or medication.
- Surprise you with thoughtful gifts such as flowers or small actions to brighten your day.
- Provide lots of cuddles.

ENDOMETRIOSIS AND YOUR EMPLOYMENT

As well as establishing a good relationship with your employer from the outset, it can help to understand employment law and best practice.

Applying for a job - your rights and responsibilities

When applying for a job, you must answer honestly and accurately any questions you're asked that are relevant to your ability to do the job. But if you don't have to volunteer any information if there are no questions raised about relevant health conditions or impairments.

For example it is inappropriate to be asked "do you have any medical problems of any kind" but you can be asked "do you have any medical problems or disabilities that could affect your ability to do the job?

If a health condition or impairment that you didn't mention does turn out to affect your ability to do the job, then the employer would deal with this as a performance issue. This means they need to give you a chance to improve, offering training or other support such as adapting to the work environment; they cannot dismiss you or otherwise discipline you for not telling them about your health condition or impairment.

Privacy

Your employer requires your consent to share information about your health with other internal and external parties. If you would prefer that they did not discuss your medical situation with others, advise them of this. Your employer may be obligated to inform others on a ‘need to know’ basis if your health presents a workplace health and safety risk to yourself or others but they still need your consent for this.

Employment Law
For further information about the legal aspects of employment, the Community Law website has quality up-to-date information (the website link is on the References page of this Information Guide on page 21)

TALKING TO YOUR EMPLOYER ABOUT SUSPECTED ENDOMETRIOSIS OR A NEW DIAGNOSIS

A good employer will be mindful of staff well-being. To ensure you are well and productive in your work, it may be helpful to talk to your employer about your endometriosis. Start by organising a meeting with your direct manager. If you are not comfortable speaking with your manager, consider speaking with someone else in the management team, someone from HR or your workplace health and safety team. If they need to know what endometriosis is, advise them of reputable websites including our own. It can be a good idea to take someone with you to support your self-advocacy.

If you are comfortable about sharing your symptoms and the frequency of these this can give an understanding of what you experience on a regular basis and the impact on your work. Also, consider sharing relevant aspects of your treatment and management plan.

Be clear that symptoms are different for each person and that at times of pain and fatigue you may find certain things challenging and you want to establish good communication to ensure you get the support you need to be productive in your role.

Respond openly and honestly to any questions they may ask but you need only share what you feel comfortable with. You don’t have to share detailed, personal information – rather, focus on symptoms or concerns that directly affect your role.

Communicate to your employer about any adjustments that may help you when you are experiencing endometriosis symptoms such as needing regular toilet breaks, being able to heat a wheat pack or hot water bottle, taking medication, being able to change from sitting to standing positions, being able to have regular breaks for gentle stretching.

There are going to be some days that you feel unable to attend work due to pelvic pain, fatigue or other endometriosis symptoms. Establish with your employer the criteria for staying home and what is tolerable and intolerable pain for you. If there is an opportunity to work from home on these days, discuss this possibility with your employer.

TALKING ABOUT YOUR ENDOMETRIOSIS WITH YOUR PLACE OF EDUCATION

It can be hard to know what to share with your teachers and place of education, but to make the most of your studies it's important to explain the impact of endometriosis and the support you need.

You may want to ask your doctor or endometriosis specialist to write your place of education a letter explaining how the condition can affect you and your life and use this to guide your conversation.

Here's how you can talk to your teacher:

- Meet with key staff at your place of education along with a support person who can help with your self-advocacy.
- Explain what endometriosis is, and advise them of reputable websites including our own.
- Be clear that symptoms are different for each person and that at times of pain and fatigue keeping up with classwork, homework, and assignments can be challenging and you want to establish good communication to ensure you get the support you need.
- If you are comfortable about sharing your symptoms and the frequency of these this can give an understanding of what you experience on a regular basis.
- Consider sharing relevant aspects of your treatment and management plan.
- Respond openly and honestly to any questions they may ask but only share what you feel comfortable with.
- Talk about what may happen when you are experiencing symptoms such as needing toilet and rest breaks, being able to heat a wheat pack, having access to medical care, taking medication on a timely basis, and having opportunities to study at home.
- Together make a plan to address absences and missed work.

To make a plan to address absences and missed work, here are some ideas that you can consider discussing with key people at your place of education:

- Have a person in each class who will be responsible for contacting you with homework and assignments if you miss class.
- Ask that assignments are given out in advance of any upcoming medical appointments so that work can be completed ahead of time.
- If needed, request extensions for when assignments are due.
- Ask your teachers to email you notes and what was done in class for the day, so you don't fall behind.
- Request a folder of homework and assignments to be kept in a central place such as a school office so someone could pick it up at the end of the day on your behalf.
- Understand the requirements to request an aegrotat consideration for an exam if needed.

Also discuss what may happen when you are experiencing symptoms such as needing toilet and rest breaks, being able to heat a wheat pack, having access to medical care, taking medication on a timely basis, and having opportunities to study at home.

There are going to be some days that you feel unable to attend your place of education due to pelvic pain, fatigue, or other endometriosis symptoms. Establish with your parent/guardian the criteria for staying home and what is tolerable and intolerable for you. Make sure you are getting good quality sleep and getting up early enough to get ready for school, have a sustaining breakfast, and take your medication.

Here are some other ideas to support you:

- A home tutor may help you keep up with missed work and ensure you are not overwhelmed.
- Keep an extra set of books at home to reduce your daily backpack load.
- If the distance between rooms is impacting, request extra time to get to class.
- Adjust your schedule to give you study or rest periods during the day and still meet academic requirements.
- Connect with Disability Support, Stress Counselling or other services at your place of study. They can help to co-ordinate support across your studies and help with your self-advocacy..
- For Secondary Studies, Te Kura offer quality distance education through to NCEA level 3. Find out more on their website: https://www.tekura.school.nz/
- Consider completing studies on a part-time basis: it might be better to complete studies over a longer period than to have to drop out and risk not completing them at all.

Notes

REFERENCES

Active Listening
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The impact of endometriosis upon quality of life: a qualitative analysis:
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Community Law
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The Centre for Young Women's Health https://youngwomenshealth.org/parents/endometriosis-school-concerns/

DISCLAIMER

This Information 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 Information 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 Information 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."

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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
- Self-Advocacy with Medical Professionals When You Have Endometriosis Information Guide
- Conditions Related to Endometriosis Information Guide
- Being a Teenager with Endometriosis Information Guide
- Supporting Students with Endometriosis Symptoms - A Guide for New Zealand Schools
- An Endometriosis Guide for Employers

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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....' session
- Join an Endo Meet-Up with other people with Endometriosis (suspected or diagnosed)

CONTACT US

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