

INFORMATION SHEET
ENDOMETRIOSIS AND YOUR EMPLOYEE

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WHAT IS ENDOMETRIOSIS?

Endometriosis (pronounced en-doh-mee-tree-oh-sis) is a condition where tissue similar to the endometrium (the lining of the uterus) grows in abnormal locations such as the ovaries, fallopian tubes, pelvic lining, bowel, bladder, appendix and other organs.

The tissue grows in response to reproductive hormones where oestrogen stimulates patches forming superficial, lesions or endometrioma (ovarian cysts). This can lead to symptoms being worse at certain times of the cycle, particularly at ovulation, prior to and during menstruation.

Inflammation is generally present, and adhesions (scar tissue) can also form in response, this is what causes pain. It is not simply a ‘bad period’ and pain is not just ‘period cramps’.

Endometriosis is considered a life-long condition with is no cure. Often described as an invisible chronic illness, many people with the condition experience symptoms every day and may not want to discuss what they are experiencing as it can feel embarrassing, demoralising and exhausting. It can be a particularly difficult topic to raise in a workplace.

WHO IS AFFECTED BY ENDOMETRIOSIS?

Endometriosis can affect people of all backgrounds and ages, including teenagers, transgender, non-binary, and gender-diverse people assigned female at birth. It affects 1 in 9, which will in turn affect many workplaces. While symptoms often start in teenage years, they can begin earlier as well as post-menopause, and can also affect those who have had hysterectomies. Rarely, it has also been found to affect those assigned as male at birth.

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

Symptoms vary from person to person – each additional symptom adds to the likelihood of endometriosis being the cause.

IMPACTS OF ENDOMETRIOSIS

While some are relatively unaffected, 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 pain and fertility problems, impacts on relationships and mental wellbeing, as well as absenteeism from school and work.

DIAGNOSING ENDOMETRIOSIS

Lacking the profile of other common conditions, endometriosis takes an average of 7-10 years to be diagnosed.

Those suspecting they have endometriosis are encouraged to keep a symptom diary and discuss with their GP and ideally a gynaecologist that specialises in endometriosis. A GP may be able to offer a clinical (tentative) diagnosis based on symptoms, medical history and family history, and may also suggest medical treatment without a definitive diagnosis to manage symptoms.

A definitive diagnosis is made by laparoscopic (key-hole) surgery with a biopsy of tissues suspected to be endometriosis. This is performed under general anaesthetic and may require an overnight stay or longer in, depending on the extent of the surgery and their recovery.

MANAGING AND TREATING ENDOMETRIOSIS

Treatments for endometriosis aim to reduce the severity of symptoms and improve quality of life. Appropriate treatments depend upon a wide range of factors including age, symptoms, clinical history, the extent of the endometriosis, any co-morbidities, cultural considerations, priorities including pain management and/or fertility, reducing risk of recurrence, and patient choice.

LAPAROSCOPIC TREATMENT

Surgery can remove patches and cysts, divide adhesions, and repair other damage caused by endometriosis (which may for example restore or improve fertility). Surgery is often an effective treatment method, and studies have shown that following surgery with a hormonal treatment on a continuous basis can significantly reduce recurrence.

HORMONAL TREATMENT

As endometriosis grows in response to the female hormone oestrogen, there are a variety of hormone treatments with a variety of attributes and side effects. These can be used on their own or in combination with surgical treatment and / or analgesics (pain relief).

PAIN RELIEF AND MANAGEMENT

There are a wide variety of pain medications and non-pharmaceutical management options which can help with symptoms, and these are often combined. Pain management techniques include using heat (such as wheatbags), TENS machine, aromatherapy, self-hypnosis, relaxation, meditation, pacing, distracting techniques as well as exercise and dietary modifications.

HELPFUL INFORMATION FOR LAPAROSCOPIC SURGERY

While considered minimally-invasive, laparoscopic surgery can be extensive and carries potential for complications. Surgery varies as to extent, length of stay, the skill of the surgeon, the response to pain as well as patient expectations. Recovery can range from several days to several weeks.

Following a laparoscopy for endometriosis a person may experience:

- effects of the anaesthetic, which can affect their concentration and cause fatigue
- pain at the incision points (there are typically four incisions depending on the extent of patches, cysts, adhesions and damage caused by endometriosis)
- shoulder pain due to CO₂ gas used during surgery to expand the abdomen and lift it away from internal organs
- nausea and short-term change in bowel movements such as constipation and bloating
- vaginal bleeding for up to eight weeks, and
- painful, longer or heavier menstrual cycles for 1-3 months

In the days or weeks after surgery, fatigue is common. Some people may find sitting down or standing for extended periods challenging; driving may be restricted for two or more weeks.

Emotions to do with loss and grief can run alongside recovery – perhaps crying more easily, or becoming anxious. The emotional recovery can be as important as physical recovery.

If you have an employee that requires laparoscopic surgery, take the time to empathetically discuss their surgery expectations and keep in touch through their recovery and return to work.

ENDOMETRIOSIS AT WORK

It's important to understand that people respond and cope in different ways. While for some their work may not be affected, for others endometriosis can affect productivity or require time off work; relationships with colleagues and managers may also be affected.

Challenges at work might include:

- Coping with a range of symptoms including severe pain and fatigue
- Taking time off work if they're feeling unwell, or for tests or treatment (including surgery)
- Feeling embarrassed or guilty about any absences, or that they've created an additional burden for their colleagues or manager
- They may feel distressed and find it a difficult topic to raise and discuss, particularly with the sensitive nature of symptoms.

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

SUPPORTING STAFF

Below are some steps you can take to support your employees:

1. **Build a supportive workplace culture** – Train managers to be supportive and react appropriately to concerns raised by employees. While a person experiencing endometriosis may be reluctant to disclose their condition, a supportive environment may them to share their health issues more confidently and enable managers to find ways to support valuable staff to stay engaged, comfortable and productive at work.
2. **Start a conversation** – While not everyone will want to discuss private health issues, people may be more open to participate in a conversation when it is introduced and conducted in a supportive manner. When discussing issues of a sensitive nature with an employee, be mindful not to ask for more information than necessary; questions should focus on helping them to perform their job.
3. **Medical certificates** – As a chronic condition, symptoms of endometriosis will often recur. You might want to consider accepting a medical certificate from their treating doctor which specifies ongoing expectations for a period of time. The advice of a health professional may also be useful as you work together on a support plan to reduce the impact on work.

4. **Flexible work arrangements** – An employee with endometriosis may be managing significant pain on a regular basis and/or undergoing treatment where they are required to attend multiple medical appointments for a period of time. You may wish to discuss formal or informal flexible working arrangements with them to support them during these periods. This could include a change in shift patterns or start and finish times, shorter hours, graduated return to work, an agreed period of paid or unpaid time off, or working from home.
5. **Job modifications** – You may wish to discuss job modifications to support someone with endometriosis such as changing responsibilities, reducing the pace of work, managing workloads or modifying workstations. Adjustments could also include regular or more frequent toilet breaks, being able to heat a wheat pack or hot water bottle, being able to change from sitting to standing positions. While not all proposed accommodations will work for your business (for example working from home as a retail worker), take time to consider reasonable and realistic options that work for you both.
6. **Policies and procedures** – Developing, implementing and promoting policies and procedures in relation to chronic diseases such as endometriosis, can assist in raising awareness and understanding, and mitigate the impact on productivity, engagement and culture. To be effective, policies and procedures need to be:
 - developed in consultation with employees and health and safety representatives
 - available and communicated to all employees
 - included in induction programs
 - discussed at team meetings, and
 - reviewed regularly.

Insight Endometriosis is available to provide information and support in developing workplace policies which can enhance productivity, staff engagement and culture.

EMPLOYMENT LAW

For further information about the legal aspects of employment, the Community Law website has quality up-to-date information (see reference below for details)

FOR FURTHER INFORMATION AND WORKPLACE SUPPORT

Insight Endometriosis has a range of information and factsheets available on their website; while aimed at those experiencing endometriosis symptoms, employers may find them useful. Visit www.insightendometriosis.org.nz/factsheets

We are also available to provide information and support in workplaces – please make contact to discuss how we can partner with you to support your valuable staff and ensure they continue to be engaged and productive.

REFERENCES

- Community Law: <https://communitylaw.org.nz/community-law-manual/chapter-17-disability-rights/employment-access-to-jobs-and-protection-against-discrimination/applying-for-jobs-what-you-do-and-dont-have-to-say-about-your-impairment/>
- Insight Endometriosis Fact Sheets www.insightendometriosis.org.nz/factsheets

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