

Condition Insight Report (CIR)

Endometriosis

Created in collaboration with
Endometriosis UK

11.10.22

[Slide 2 – Overview and common misconceptions](#)

[Slide 3 – Reliability](#)

[Slide 4 – Treatment, sensitivities and customer care](#)

[Slide 5 – Functional impact 1-3](#)

[Slide 6 – Functional impact 4-6](#)

[Slide 7 – Functional impact 7-9](#)

[Slide 8 – Functional impact 10-12](#)

[Slide 9 – Additional reading/ resources](#)

PLEASE NOTE: This is a document for internal use only and not intended for distribution.

Throughout this document you will find links to external websites. These links are being provided as a convenience and for informational purposes only and do not imply on the part of Capita, IAS, DWP or DfC any endorsement or guarantee of any of the organisations, opinions or information (including the right to display such information) found on their respective websites. Any comments or enquiries regarding the linked websites or their content should be directed to the owners of the website.

Overview

What is the condition usually called/ any abbreviations used?

Endometriosis

Brief overview of the condition

Endometriosis is a condition where tissue similar to the lining of the womb starts to grow in other places, such as the ovaries and fallopian tubes. It can affect women of any age and is a long-term condition that can have a significant functional impact on someone's life.

Presenting symptoms can include, but are not limited to:

- Pain – pelvic pain, lower back pain, leg pain
- Ovulation pain
- Painful periods (dysmenorrhea)
- Heavy periods (menorrhagia)
- Irregular periods or prolonged bleeding
- Pain during and/or after sexual intercourse (dyspareunia)
- Painful bowel movements (dyschezia)
- Bleeding from the back passage/rectum
- Symptoms of irritable bowel (diarrhoea, constipation, bloating)
- Pain when passing urine (dysuria)
- Fatigue
- Depression
- Anxiety

Common misconceptions and myth busting



'People with Endometriosis only have symptoms once a month.'

'Incorrect. Although symptoms may worsen during menstruation, symptoms of fatigue, pain and co-existing conditions such as depression, may be present in between the cycles.'



'Pelvic pain is the only symptom.'

'Pelvic pain isn't the only symptom patients experience. For an overwhelming majority of all people diagnosed with endometriosis, the condition initially manifests as a gastrointestinal issue. Bloating is common, as are diarrhea, constipation, painful bowel movements, and nausea. Endometriosis can also cause urinary urgency or frequency.'



Reliability

What specific areas should be covered to ensure a complete, reflective report?

SAFETY



Do they have any symptoms which could cause a safety consideration?

Consider if someone's mental health is impacted as a result of their Endometriosis, if they are safe to complete activities. This may be as a result of poor concentration or intentional harm to self.

TIMELY



For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?

People who have Endometriosis may suffer from fatigue which may impact how long it takes them to complete activities such as cooking, washing and dressing

ACCCEPTABLE
STANDARD



How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?

Someone may report they can complete activities, however, are not doing them acceptably. We must ensure the way someone has adapted to completing an activity is still unlikely to have a detrimental impact on their health.

REPEATEDLY

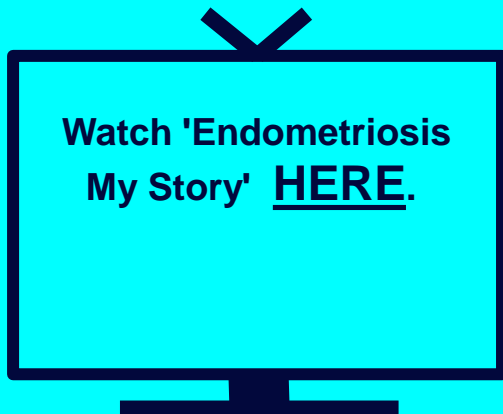


Are they able to repeat a task as often as required? Is this the same every day?

We must explore not only someone's ability to complete an activity, but how they feel after and if they can repeat it as many times as reasonably expected throughout the day. If someone experiences fatigue or pain secondary to Endometriosis, how does completing activities make them feel?

Common treatment

- **Analgesics** such as Non-Steroidal Anti-Inflammatories (Ibuprofen, Naproxen) , Opiates (Gabapentin, Buprenorphine) and Neuromodulators (Baclofen, Pregabalin).
- **Procedures** such as laparoscopy or hysterectomy
- **Therapy** such as hormone therapy
- **Nutritional changes** made to their diets.
- **Specialist involvement** such as Gynecology.
- **REMEMBER:** This may vary for every claimant and should not be used to negate a restriction simply because there is an absence of any of the above.



Sensitives and Customer Care



How is it best to ask about any sensitive topics and what are the common courtesies?

- Be empathetic, understand that endometriosis is a chronic and incurable condition.
- Demonstrate awareness around sensitive/personal issues specifically around, relationships.
- Show understanding of the complexity of the disease and how symptoms can differ for each individual.
- Allow the claimant the opportunity to explain their condition, listen to their symptoms and the impact this is having on their overall health and quality of life.

Allow the claimant to have someone present during the assessment process for support.

What areas might they find difficult to mention or perhaps understate the impact of?

- The effects on relationships/sexual relationships secondary to symptoms of pain.
- Infertility.
- Chronic nature of the condition, there is no cure for this disease and treatment options are to improve quality of life and symptom control.
- Awareness of the condition. It takes on average 8 years to receive a diagnosis, long term suffering and lack of specialist input may have led to chronic symptoms. Endometriosis may not be identified on scans.



Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

Preparing food may be affected during episodes of acute pain flares and they can leave individuals bed bound, nauseous and reliant on others to meet daily living needs.

Remember in PIP...

Can someone stand for long enough to prepare a simple meal? Do they have pain standing due to their condition? Do they have any difficulties chopping, lifting or peeling? If they are restricted, what is the reason for this?

Activity 2: Taking nutrition

Those with bowel endometriosis may require adjustments to dietary intake, certain food groups could trigger bowel irritable bowel symptoms secondary to the inflammatory process of endometriosis.

Remember in PIP...

Types of food are not considered within the scope of the activity. However, we must consider someone's ability to be nourished. Do they need prompting to eat due to their symptoms? Can they chew, swallow and bring food to their mouth independently?

Activity 3: Managing therapy and monitoring a health condition

Treatment side effects to medical options of management may also be troublesome leading to treatments being discontinued. Risk of recurrence of endometriosis following surgical removal, returning symptoms and disease progression.

Remember in PIP...

If someone is not taking medication or receiving treatment, explore the reason behind this. Absence of medication does not necessarily mean absence of restriction. If they do take medication, can they manage it themselves? Do they have any therapy in the home they require assistance with?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 4: Washing and Bathing

Washing and bathing may be affected during episodes of acute pain flares and they can leave individuals bed bound, nauseous and reliant on others to meet daily living needs.

Remember in PIP...

How are they bathing? How long does it take them? Can they reliably get in and out of an unadapted bath and shower? How do they feel after? Can they utilise aids or do they require assistance to wash?

Activity 5: Managing toileting needs and incontinence

Irregular and/or heavy menstrual bleeding, can lead to leaking. Bowel and bladder endometriosis may also impact toileting from constipation to incontinence. Bowel movements and urination may also be extremely uncomfortable. These symptoms maybe constant or vary in intensity throughout the menstrual cycle.

Remember in PIP...

Menstrual bleeding is not considered within the scope of the activity. If they have incontinence, how do they manage this? Is this on the majority of days? Can they sit and stand from the toilet and clean themselves after?

Activity 6: Dressing and undressing

Dressing and undressing may be affected during episodes of acute pain flares and they can leave individuals bed bound, nauseous and reliant on others to meet daily living needs.

Remember in PIP...

Can they physically dress and undress their upper and lower body on the majority of days? How long does it take them? If they are restricted, why is this? Does sitting down relieve their symptoms?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 7: Communicating Verbally

Although Endometriosis itself is unlikely to cause a functional restriction in this area, please consider any co-existing conditions that may impact their ability to communicate.

Remember in PIP...

A person needs to be able to both express **and** understand verbal information. Who do they speak to? Can they use the phone? Do they have any hearing problems? If yes, how do they overcome this?

Activity 8: Reading and understanding signs and symbols

Although Endometriosis itself is unlikely to cause a functional restriction in this area, please consider any co-existing conditions that may impact their ability to read.

Remember in PIP...

A person needs to be able to read and understand what they have read. Complex written information is considered anything more than one sentence. What do they read? Can they read a text message?

Activity 9: Engaging with others face to face

Endometriosis can have a negative effect on relationships and social activities if there are any associated mental health conditions. Symptoms can be debilitating preventing social interaction. Issues secondary to the condition can impact engagement with others. Individuals may become house-bound secondary to their symptoms of pain and/or to be in close proximity to a toilet. The condition may lead to social isolation.

Remember in PIP...

If they do report restrictions engaging, who can they engage with on the majority of days? How do they engage with unfamiliar people? If they report support is required to engage, who can provide this and why?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 10: Budgeting

Although Endometriosis itself is unlikely to cause a functional restriction in this area, please consider any co-existing conditions that may impact their ability to make complex budgeting decisions.

Remember in PIP...

Consider if someone reports low mood secondary to their condition, do they have motivation to manage their finances independently?

Could they manage change in a shop? How would they manage an unplanned bill/transaction? Can they plan for future purchases and do they manage the household bills?

Activity 11: Planning and following a journey

Acute pain symptoms may limit someone's desire to leave the home. Strong pain medication may affect focus and ability to plan and carry out journeys.

Remember in PIP...

Physical restrictions are not considered within the scope of the activity. Consider someone's ability to plan and follow a journey in relation to potential sensory or cognitive issues or the presence of OPD. How do they manage both familiar and unfamiliar journeys? Can they plan a journey? Could they manage a diversion? If anxiety is reported, does this meet the threshold of OPD? If so, could they leave the home on the majority of days with support?

Activity 12: Moving Around

Pelvic pain, neuropathic pain, lower back pain and bilateral leg pain are common symptoms of endometriosis and may impact a person's mobility. This can be either on a constant basis or during acute flares of symptoms.

Remember in PIP...

STAR is imperative, especially with conditions that may cause fatigue. How far can they walk? How long does this take? What pace do they walk at? Can they repeat this? Is this at the same or a reduced pace? How many times could they repeat it? How long does it take to recover? Do they need an aid?

Additional reading or other resources

EXTERNAL

Endometriosis UK - <https://www.endometriosis-uk.org/information>

NICE 2017 - Endometriosis: diagnosis and management. <https://www.nice.org.uk/guidance/NG73>

ESHRE 2022 – Guideline Endometriosis. <https://www.eshre.eu/Guideline/Endometriosis>

[Endometriosis - NHS \(www.nhs.uk\)](https://www.nhs.uk)

[Endometriosis - My Story | NHS - YouTube](#)

https://www.youtube.com/channel/UCm6hC9bouHzWOmSAfruF_yw/videos

Version Control