Canterbury
District Health Board
Te Poari Hauora ō Waitaha
CORPORATE OFFICE

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4 November 2021

9(2)(a) [redacted]

RE Official Information Act request CDHB 10720

I refer to your email dated 21 September 2021 which was revised on 23 September requesting the following information under the Official Information Act from Canterbury DHB. Specifically:

1. **Of all the patients with pelvic pain seen by a specialist in the last 12 months, what was the average wait time for that appointment?**
2. **Of all the patients with pelvic pain seen by a specialist in the last 12 months, what was the longest and shortest wait time for that appointment?**

The average wait time for people with pelvic pain seen by a specialist in the last 12 months was 98.5 days for that appointment. The shortest wait time for people with pelvic pain seen by a specialist in the last 12 months was 1 day. The longest wait time was 328 days.
Note: *there are a number of reasons for the long/maximum wait time for treatment including: a lack of capacity (SMOs) and needing to prioritise acute/non-deferable work. The longest wait time will always give an unrealistic perception of the data for how long people are waiting.*

3. **In the last 12 months how many patients have seen a specialist at the DHB for pelvic pain?**

There were 174 patients seen by a specialist at Canterbury DHB for pelvic pain in the last 12 months.

4. **In the last 12 months, how many patients have been transferred to another hospital to treat possible endometriosis?**

No patients have been transferred to another hospital to treat possible endometriosis.

5. **How many specialists does the DHB have available to diagnose and treat pelvic pain and possible endometriosis?**

We have 13 specialist Obstetrics and Gynaecology FTE who can diagnose and treat pelvic pain and possible endometriosis.

6. **Of the patients who had advanced laparoscopic surgery to treat suspected endometriosis in the last 12 months, what was the average wait time to get that operation?**

Laparoscopic surgery for endometriosis: (Laparoscopic diathermy of lesion of pelvic cavity, and Laparoscopic excision of lesion of pelvic cavity). Of the 83 total surgeries performed:

The average wait time was 72.7 days. The shortest wait time was 1 day, and the longest wait time was 244 days.

Note: *there are a number of reasons for the long/maximum wait time for treatment including: a lack of capacity (SMOs) and needing to prioritise acute/non-deferable work. The longest wait time will always give an unrealistic perception of the data for how long people are waiting.*

7. **Of the patients who had laparoscopic surgery to treat pelvic pain in the last 12 months, what was the longest and shortest wait time to get that operation?**

Of the 41 patients who had laparoscopic surgery to treat pelvic pain in the last 12 months, the average wait time was 73.1 days; the shortest wait time was 9 days and the longest wait time was 316 days.

8. **A copy of the DHBs clinical pathway to treat suspected endometriosis.**

We have attached for you as **Appendix 1** an excerpt from our HealthPathways* website and is available for use by Clinicians and Medical Professionals. *(This information is not publicly available).* Information which is publicly available can be found on the HealthInfo website www.healthinfo.org.nz;

**HealthPathways is designed and written for use during a clinical consultation. Each pathway provides clear and concise guidance for assessing and managing a patient with a particular symptom or condition. Pathways also include information about making requests to services in the local health system.*

Content is developed collaboratively by general practitioners, hospital clinicians, and a wide range of other health professionals. Each pathway is evidence-informed, but also reflects local reality, and aims to preserve clinical autonomy and patient choice. HealthPathways serves to reduce unwarranted variation and accelerate evidence into practice.

9. **Of the patients who saw a specialist with serious back pain, in the last 12 months, what was the average wait time for that appointment?**
10. **Of the patients who saw a specialist with serious back pain, in the last 12 months, what was the longest and shortest wait time for that appointment?**

Of the 86 patients who were seen by a specialist in the last 12 months for serious back pain (disorder of the back) the average wait time for that appointment was 91.6 days. The shortest wait time was 13 days and the longest wait time was 181 days for that appointment.

11. **Of the patients who had orthopaedic surgery to treat back pain, in the last 12 months, what was the average wait time for that appointment?**

Of the patients who had orthopaedic surgery to treat back pain ('disorder of the back') in the last 12 months the average wait time for that appointment was 51.3 days.

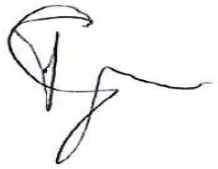
12. **Of the patients who had orthopaedic surgery to treat back pain, in the last 12 months, what was the longest and shortest wait time for that operation?**

Of the 27 patients who had Orthopaedic surgery to treat back pain (disorder of the back) in the last 12 months, the shortest wait time was six days and the longest wait time was 334 days for that operation. (**Note** 'disorder of the back' is the code linked specifically to our Orthopaedic Service'.)

I trust that this satisfies your interest in this matter.

Please note that this response, or an edited version of this response, may be published on the Canterbury DHB website after your receipt of this response.

Yours sincerely



Tracey Maisey
Executive Director
Planning, Funding & Decision Support

HealthPathways:

Endometriosis

See also:

- Chronic Pelvic Pain in Females
- Dysmenorrhoea

Background

About endometriosis

About endometriosis

Endometriosis has been defined as "an inflammatory disease process, characterised by lesions of endometrial-like tissue outside the uterus that is associated with pelvic pain and/or infertility".

Endometriosis is common, estimated to affect 5 to 10% of women of reproductive age. There is very little research on the diagnosis and treatment of endometriosis in Māori.

Clinical presentation is variable. Approximately one-third of women with endometriosis are asymptomatic, and so do not require any form of treatment. The stage or location of lesions at laparoscopy does not predict symptoms experienced.

The natural history of endometriosis is complex. Lesions have not been shown to progress over time in all cases, in some patients spontaneous resolution has been seen.

Historically laparoscopic diagnosis was considered to be the "gold standard" and was required before treatment was started. The wait for surgery resulted in long treatment delays, and internationally best practice is now aimed at managing the symptoms the patient presents with, and ensuring early medical management. Multiple surgeries may increase the risk of central sensitisation and chronic pelvic pain and should be avoided.

Adenomyosis refers to islands of endometrium buried within the myometrium and:

- can be diagnosed only histologically.
- is often associated with endometriosis.
- may cause increased dysmenorrhoea and management is as for dysmenorrhoea.
- is commonly suggested by ultrasound features yet this modality has a high false positive rate. Ultrasound is not indicated to diagnose adenomyosis.

Assessment

1. Consider endometriosis from menarche onwards for patients presenting with one or more of the following symptoms or signs:[1]
    - Dysmenorrhoea limiting daily activities and quality of life
    - Cyclical or non-cyclical pelvic pain
    - Dyspareunia (deep pain during or after sexual intercourse)
    - Abdominal bloating
    - Unexplained gastrointestinal symptoms, particularly when cyclical in nature and pain related to bowel movements including dyschezia
    - Unexplained urinary symptoms, particularly when cyclical in nature
    - Sub-fertility that is otherwise unexplained
2. History:
    - Take a careful history of the pain.

      Pain history

        - Pattern and severity of pelvic pain. Recommend a menstrual diary app that allows recording of symptoms, e.g. Period Tracker Lite, Flo.
        - Pain relief used
        - Any impact of period pain on quality of life
        - Yellow flags that increase the risk of developing chronic pain syndromes

          Yellow flags

          Yellow flags are psychosocial risk factors that indicate an increased likelihood of developing long-term pain, distress, and disability. They include:

            - an expectation that pain will persist and cause severe disability.
            - fear-avoidance behaviour (avoiding a movement or activity due to anticipation of pain), and resulting reduced activity levels.
            - high levels of catastrophic worry.
            - low mood, anxiety, and social withdrawal.
            - expectation that passive treatments rather than active participation will fix the problem.
    - Ask about:
        - gynaecological and obstetric history.

          Gynaecological and obstetric history

            - Age of menarche – girls may be symptomatic from menarche
            - Cycle frequency and regularity

        - Use of hormonal contraception
    - desire for fertility and how long they have been trying to conceive for, if relevant.
    - relevant medical and surgical history.

3. Check risk factors for endometriosis.

Risk factors for endometriosis

- First-degree female relative (mother or sister) with endometriosis
- Shorter-than-normal menstrual cycles (shorter than 27 days)
- Longer-than-normal menstruation (longer than 5 days)
- Low body mass index
- Early menarche
- Nulliparity
- Müllerian anomalies – abnormal anatomy that arises during the formation of parts of the female reproductive organs
- Outflow obstructions, e.g. cervical stenosis, a transverse vaginal septum, or an imperforate hymen

4. Consider using pain tools to obtain an accurate history:
    - Raising Awareness Tool for Endometriosis (RATE)
    - Canterbury DHB Pelvic Pain Questionnaire
    - A pain diary
5. Perform examination appropriate to age, maturity, and culture. Clinical examination in endometriosis is frequently normal.
    - Offer pelvic examination (including speculum and bimanual examination) unless the patient has never been sexually active.
    - Look for signs that may suggest endometriosis.

      Signs that may suggest endometriosis

        - A fixed retroverted uterus
        - Enlarged ovaries, which may indicate ovarian endometriomas
        - Palpable nodules on the uterosacral ligaments or in the pouch of Douglas
        - Endometriotic lesions visible in the vagina or on the cervix
6. Consider differential or coexisting diagnosis.
7. Investigation – Results are usually normal, but may be useful in the differential diagnosis.
    - Consider arranging CBC, STI swabs, and urinalysis.

- If history or examination suggests, arrange investigations for associated conditions or to exclude other pathology.
- If gastrointestinal symptoms form a major part of the presentation, consider investigations for bowel pathology.
- If a mass is found on examination or indicated by another pathway, e.g. Abnormal Uterine Bleeding, arrange pelvic ultrasound, preferably transvaginal (ideal) or abdominal (if the patient is not yet sexually active or does not consent).

  Ultrasound may identify endometriomas and some signs of deep infiltrative endometriosis, but a normal ultrasound does not exclude endometriosis.

Management

Practice point

Prioritise symptom control and sub-fertility

The priorities in the management of endometriosis are symptom control.

1. Manage the most distressing symptom first:
   - Sub-fertility – most women with endometriosis will conceive spontaneously. Discuss and prescribe contraception if they do not wish to become pregnant.
   - Dysmenorrhoea
   - Chronic pelvic pain
   - Dyspareunia
2. If endometriosis is the most likely diagnosis, start medical management to control pain and improve quality of life.
   - Consider hormonal therapy as per the Dysmenorrhoea pathway, unless the patient is trying to conceive. Inform the patient that:

     Hormonal therapy

     - Progestogen-only treatment may have benefits, but tolerance may be limited due to increased side-effects.
     - Progestogens may:
       - suppress the hypothalamic-pituitary-ovarian axis, leading to suppressed ovulation and decreased circulating estrogen levels.
       - cause atrophic changes to the endometrium and endometriotic lesions.
     - hormonal treatment can be effective in controlling symptoms, but it may not control disease progression.
     - approximately 50% of women will have recurrence of symptoms within 5 years if medical management is stopped.

- Consider prescribing:
    - a 3-month trial of a nonsteroidal anti-inflammatory drug (NSAID). Pain management with an NSAID may reduce pain levels.
    - a trial of a neuromodulator, e.g. amitriptyline, although there is little evidence of benefit. Short cyclical doses to coincide with menses are not likely to be helpful.
- Do not prescribe regular opioids for suspected endometriosis pain.
- There is limited evidence for complementary therapies.
- Manage associated conditions.

  Manage associated conditions

  - Irritable bowel syndrome (IBS)
  - Bladder pain syndrome

    Bladder pain syndrome

    Management is generally symptomatic and supportive.

    Advise the patient:

    - to avoid any irritants that may exacerbate symptoms, e.g. caffeine, alcohol, artificial sweeteners, hot pepper.
    - that there is some evidence to suggest that certain exclusion diets may help, but it is not conclusive. See Interstitial Cystitis Association – Least and Most Bothersome Foods.
    - that there is limited evidence for any oral medications, but medications for chronic pain, e.g. tricyclic antidepressants, could be considered.

    See:

    - HealthInfo – Interstitial Cystitis
    - Patient – Interstitial Cystitis/Painful Bladder Syndrome
  - Headache or migraine
- Encourage self-management.

  Self-management

  - Encourage the patient to learn more about endometriosis.
  - Provide patient information:
    - HealthInfo:
      - Endometriosis
      - How is Endometriosis Treated?

        - EndoActive – Endometriosis and Pelvic Pain [video, 30 minutes]
    - Give advice on self-management strategies.
    - Encourage the patient to keep moving or increasing exercise. If pelvic floor myalgia is felt to be a strong component of the patient's pain, advise that staying away from core-strengthening exercises may be beneficial, at least initially. Suggest physiotherapy or pelvic floor stretches.

3. If initial medication does not work, optimise medical management. Trial for 6 months.

    Optimise medical management

    Optimised medical management includes using medications, usually in combination and often with more than one hormonal method concurrently.

    More than one hormonal method concurrently

    - Mirena and norethisterone
    - Mirena and combined oral contraceptive pill (COCP)
    - Double dose of progestogen

4. If optimised medical management fails after 6 months:
    - Consider requesting non-acute gynaecology assessment. Include a completed pelvic pain questionnaire to allow accurate triage.
    - Discuss specialist management with the patient.

        Specialist management

        Specialist management may include:

        - further medical management, i.e:
            - optimising hormonal regimen.
            - considering gonadotrophin-releasing hormones (GnRH) to induce hypo-estrogenic medical menopause.
        - education.
        - self-management approaches and skills.
        - engagement with the multidisciplinary team.

            Multidisciplinary intervention

            An endometriosis multidisciplinary team (MDT) may include:

            - a gynaecologist with an interest in endometriosis or pelvic pain.
            - an appropriately trained advanced laparoscopic surgeon.
            - a physiotherapist.
            - a psychologist.

- a pain specialist.

- surgery (usually laparoscopic).

  Surgery

  Surgery is not considered first-line management and is not used to make a diagnosis alone. The general anaesthetic effect can temporarily relieve symptoms for 3 to 6 months after surgery. Therapeutic benefits for the first laparoscopy may include:

  - short-term (6 to 18 months) improvement in pain.
  - improvement in natural fertility. The conception rate for patients with stage 1 and 2 disease doubles in the first 6 to 9 months after the first surgery.
  - restoration of pelvic anatomy.

  Any patient who has had 2 or more laparoscopic surgeries previously, or who gained less than 2 years of significant benefit from a treatment laparoscopy, will not be considered for further surgical management without discussion at the pelvic pain multidisciplinary team meeting as non-surgical treatments are likely to be more appropriate.

  If the patient may be suitable for surgical management:

  - consider the benefits and risks.

    Benefits and risks of laparoscopic surgery

    - Benefits:
      - Excision and ablation may bring short-term improvement in endometriosis-related pain for some women.
      - Tissues are available for histology from excision of endometriotic lesions (but not from ablation).
    - Risks:
      - General anaesthesia.
      - Bleeding, port site wound pain, hernia, deep vein thrombosis (DVT).
      - Injury to neighbouring organs, e.g. bowel, bladder, ureter, nerves.
      - Worsening of pain or development of new post-surgical pain.
  - counsel the patient.

    Counsel the patient

    Counsel the patient that:

- a recent Cochrane review reported "Compared to diagnostic laparoscopy only, it is uncertain whether laparoscopic surgery reduces overall pain associated with minimal to severe endometriosis".[2]
- any abnormalities seen at laparoscopy may not be the cause of their pain, and surgery may not relieve pain if it occurs on most days.
- there is no correlation between endometriosis stages and pain severity.
- repeated surgeries risk complications, including central sensitisation. There is a "law of diminishing returns" with repeat operations being less effective.
- around 1 in 5 patients will get no improvement in pain or may have a deterioration in symptoms.
- 50 to 70% of women experience recurring symptoms within 5 years of surgery. Hormonal treatment, e.g. levonorgestrel intrauterine device (IUD), after surgery can lower this risk.

Hysterectomy does not "cure" endometriosis. Removal of both ovaries will decrease the amount of estrogen available and may improve some symptoms, but will precipitate surgical menopause with its associated issues including increased risk of all-cause mortality.[3]

For women with central sensitisation, chronic pelvic pain, or other overlapping pain syndromes, hysterectomy and bilateral oophorectomy is unlikely to completely get rid of the pain and risks developing a new chronic post-surgical pain syndrome.

- If the patient is taking cyproterone acetate, review the possible increased risk of meningioma before continuing it. Consider an alternative progestogen and discuss with the patient as part of shared decision-making.

5. If the patient has desire for fertility and has not conceived after 6 months of regular intercourse throughout the cycle, follow the Sub-fertility pathway.
6. If the patient has irritable bowel syndrome (IBS) symptoms, consider recommending a low-FODMAP diet.
7. Discuss the natural history of endometriosis after menopause.

   After menopause

   As endometriosis is estrogen-dependent, it is expected to improve after menopause.

   - An increase in estrogen, e.g. via menopause hormone treatment (MHT), could in theory contribute to a recurrence, however evidence for this is limited. Do not withhold MHT for this reason alone.
   - Consider using a Mirena with a low-dose estrogen patch.
8. Discuss that endometriosis is associated with a small increased risk of ovarian cancer (1.4 to 1.8 times that of the general population), particularly in women with a long-standing history of untreated ovarian endometriosis.
9. Request non-acute gynaecology assessment if:

- previously histologically diagnosed endometriosis and return of symptoms that have not responded to appropriate medical management.
- worsening symptoms and hormonal management is not appropriate because of wish for pregnancy.
- the patient is symptomatic and has signs of deep infiltrative endometriosis, or an endometrioma on examination or ultrasound.

Include the results of pelvic ultrasound scan, if performed, and a completed copy of the pelvic pain questionnaire with referral.

10. If difficulties with Mirena or Jaydess insertion, request non-acute gynaecology assessment, stating the nature of the difficulties and the service required (e.g. insertion only, need for sedation/general anaesthetic, further management of symptoms).

Post-surgical recurrence

1. If the patient has been discharged back to primary care after surgical management and there is no improvement or inadequate improvement following surgery:
    - check histology to establish if endometriosis was confirmed.
    - follow these pathways to optimise medical management as well as management of associated conditions:
        - Dysmenorrhoea pathway for cyclical pain
        - Chronic Pelvic Pain in Females pathway
    - consider seeking gynaecology advice, ideally from the treating surgeon.
    - consider involving the multidisciplinary team:
        - Pain services
        - Clinical psychology (private)
        - Women's health physiotherapy

    Any patient who has had 2 or more laparoscopic surgeries previously, or who gained less than 2 years of significant benefit from a treatment laparoscopy, will not be considered for further surgical management without discussion at the pelvic pain multidisciplinary team meeting as non-surgical treatments are likely to be more appropriate.

2. If there continues to be no improvement, request non-acute gynaecology assessment, ideally with the treating surgeon.

Request

- If optimised medical management fails after 6 months, consider requesting non-acute gynaecology assessment. Include a completed pelvic pain questionnaire to help accurate triage.

- Request non-acute gynaecology assessment if:
    - worsening symptoms and hormonal management is not appropriate because of wish for pregnancy.
    - patient is symptomatic and has signs of deep infiltrative endometriosis, or an endometrioma on examination or ultrasound.
    - no improvement following surgical treatment, despite optimised medical management.

  Include results of pelvic ultrasound scan, if performed, and a completed copy of pelvic pain questionnaire with referral.
- If difficulties with Mirena or Jaydess insertion, request non-acute gynaecology assessment, stating the nature of the difficulties and the service required.

Information

For health professionals

For patients

On HealthInfo

- Give your patient a HealthInfo card and encourage them to search using the keyword "endometriosis".

Printable Resources

- HealthInfo:
    - Endometriosis
    - How is Endometriosis Treated?

Patient Support Information

- Endometriosis New Zealand
- HealthInfo – Interstitial Cystitis

https://ranzcog.edu.au/womens-health/patient-information-guides/other-useful-resources/rate;

Pelvic Pain Questionnaire

WOMEN'S HEALTH

West Coast DISTRICT HEALTH BOARD TE POARI HAUORA A ROHE O TAI POUTINI

Canterbury District Health Board Te Poari Hauora ō Waitaha

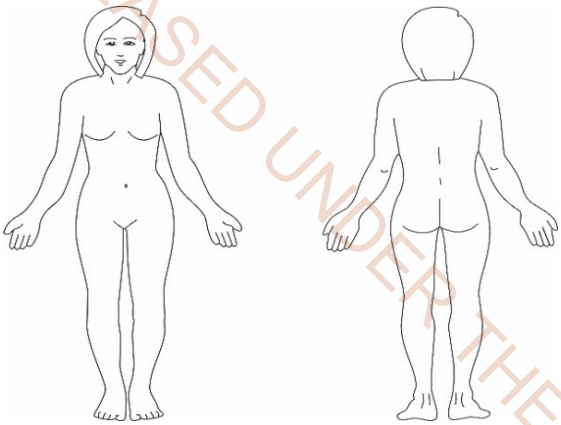
This questionnaire asks about different features of your pain and how it affects your life. It may seem a lot to fill in, but the information allows us more time in your appointment to focus on what troubles you the most.

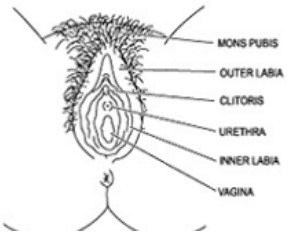
Read the questions carefully, but don't spend too long thinking about your answers. Your first answer is usually the best. There are no right or wrong answers. This is ***not*** a test of your medical knowledge.

If you find reading or writing difficult, please ask someone to help you fill it in. Make sure the answers are still your own and not those of the person helping you. It's your pain experience that we are interested in. If you need more space add another page.

Name:	Contact phone:	Age:
		NHI:
GP:	Who referred you here?	

1. **On the diagram below, shade <u>all</u> the areas where where you often experience/have problems with pain.**





2. **Mark the worst pain with an 'X'. How long have you had <u>this</u> pain?** _____weeks/months/years

3. **Overtime is <u>this</u> pain getting:** ☐ better ☐ worse ☐ no change/the same

4. **Please describe your pain(s):** _____

5. **What is your biggest concern/worry about your pain(s)?** _____

6. **What do you think is causing your pain(s)?** _____

7. **What treatment do you think you need for your pain(s)?** _____

_____

8. **In an average month how many days would you have pain?** _____/30

In an average month how many days would you <u>not</u> have any pain? _____/30

9. **Please rate your pain – where 0 is no pain and 10 is the worst possible pain:**

Your pain at its *worst* in the last week? _____ /10

Your pain at its *least* in the last week? _____ /10

Your pain on *average*? _____ /10

How much pain do you have *right now*? _____ /10 ☐

Has your pain been *typical* for you, *worse than usual* or *better than usual* for the last week? _____

10. **What do you notice makes your pain better?**

☐ meditation	☐ relaxation	☐ lying down	☐ changing position	☐ TENS unit
☐ sitting on the toilet	☐ pain medication	☐ massage	☐ ice	☐ heating pad/wheaty
☐ emptying bladder	☐ bowel movement	☐ nothing	☐ other:_____	

11. **What do you notice makes your pain worse?**

☐ exercise	☐ time of day	☐ lifting	☐ sitting down	☐ stress
☐ full meal	☐ full bowel	☐ bowel movement	☐ full bladder	☐ urination
☐ contact with clothing	☐ walking	☐ not related to anything	☐ other: _____	

12. **When you have your pain, do you also have any of the following symptoms?**

☐ heart racing ☐ sweating ☐ breathing fast ☐ tremor/shakiness ☐ dizziness
☐ anxious/panicky ☐ dry mouth ☐ irritability ☐ feeling faint ☐ feeling afraid

13. **Do you also have any of these problems?**

☐ vulval pain/vulvodynia ☐ lower back pain ☐ migraine headaches ☐ other frequent headaches
☐ fibromyalgia ☐ TMJ/facial pain ☐ chronic fatigue/ME ☐ irritable bowel syndrome (IBS)
☐ irritable bladder syndrome/ interstitial cystitis ☐ persisting pain problems in other parts of your body – where? _____

OTHER PRACTITIONERS CONSULTED

14. **Apart from your GP, who else have you seen for your pain?**

☐ public hospital gynaecologist ☐ private gynaecologist ☐ pain doctor / pain clinic ☐ physiotherapist
☐ chiropractor/osteopath ☐ psychologist ☐ sexual health clinic ☐ other _____

Please list names if you can _____

MEDICATIONS

15. **Do you have any allergies to any medications?** ☐ yes ☐ no

If yes, please list _____

16. **Please list medications you have *tried* for your pain, include ones prescribed by your doctor and ones bought at the pharmacy or elsewhere** *(use an extra page if needed)*

Medication/Dose	Currently taking	Did it help
	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No	☐ Yes ☐ No

SURGERY

17. **How many times have you had surgery for this pain?** Which year(s) _____

How much did the surgery(ies) help your pain: ☐ a lot ☐ a little ☐ not at all ☐ made it worse

How long did it help for? _____ Who was the surgeon/hospital? _____

PERIOD/MENSTRUAL

18. **Are you still having menstrual periods?** ☐ yes ☐ no

If no, why is this? ☐ have had a hysterectomy ☐ menopause/change of life ☐ other _____

19. **Are your periods painful?** ☐ yes ☐ no ☐ sometimes

If yes, how old were you when they first became painful? _____ years old

20. **Does your pain vary through the month?** ☐ yes ☐ no

If yes, is the pain worse: ☐ when I ovulate ☐ when my period/bleeding starts ☐ a few days before my bleeding
☐ other _____

21. Are you able to use tampons comfortably? ☐ yes ☐ no ☐ never use tampons for another reason

22. Do you experience sharp stabbing pains that shoot up into your vagina or rectum? ☐ yes ☐ no ☐ sometimes

23. Does your pain often radiate/spread down your legs? ☐ yes ☐ no ☐ sometimes

24. Have you noticed that when you pass urine the flow is slow to start, has a weak, stream, or you have to strain to pass urine? ☐ yes ☐ no ☐ sometimes

25. Is it painful to have clothes, pressure or touch on your belly? ☐ yes ☐ no ☐ sometimes

BLADDER

26. **Are you happy with the way your bladder works?** ☐ yes – go to question 24 ☐ no – please circle responses in table below

	0	1	2	3	4
How many times do you urinate during the waking hours?	3-6	7-10	11-14	15-19	20 or more
How many times do you get out of bed to urinate?	0	1	2	3	4 or more
Do you now or have you ever had pain or urgency to urinate during or after sexual intercourse?	never	occasionally	usually	always	
Do you have pain associated with your bladder in your pelvis (vagina, lower abdomen, urethra, perineum)?	never	occasionally	usually	always	
Do you still have urgency (strong need to go again) shortly after urinating?	never	occasionally	usually	always	
If you have pain, is it usually:	none	mild	moderate	severe	
If you have urgency, is it usually	none	mild	moderate	severe	

BOWEL

27. **Are you happy with the way your bowel works?** ☐ yes ☐ no ☐ mostly

28. **Since you have had the pain have you noticed:**

A change in how often you have a bowel movement? ☐ yes ☐ no

A change in the appearance of your stool/bowel movement? ☐ yes ☐ no

Does your pain change after a bowel movement? ☐ yes ☐ no

Do you notice that certain foods worsen your pain? ☐ yes ☐ no ☐ sometimes

Are you troubled with nausea or vomiting? ☐ yes ☐ no ☐ sometimes

Are you troubled with bloating? ☐ yes ☐ no ☐ sometimes

CONTRACEPTION/INTERCOURSE

29. **Are you trying to become pregnant at the moment?**

☐ yes How long for? _____months/years

☐ no What do you use for contraception/birth control?

☐ pill ☐ 'mini pill' ☐ Depo Provera/injection ☐ Jadelle/implant

☐ condom ☐ copper IUCD/ 'coil' ☐ Mirena/Jaydess IUCD/IUS ☐ hysterectomy

☐ sterilisation/'tube tie' ☐ vasectomy ☐ other _____

30. **Does the contraceptive pill help your period pain?** ☐ yes, a little ☐ yes, a lot ☐ no ☐ not tried

31. **Are you sexually active?** ☐ yes ☐ no – due to pain ☐ no – for another reason

32. **Do you have pain with intercourse?** ☐ yes ☐ no ☐ occasionally

If yes, do you feel this pain: ☐ inside your abdomen/belly ☐ inside your vagina ☐ outside/on your vulva

☐ on penetration ☐ on orgasm ☐ other area _____

SOCIAL

33. With whom do you live? ☐ alone ☐ partner ☐ friends/flat mates ☐ parents ☐ other_____

How do those who are close to you react when you are in pain?_____

34. Overall, how would you describe your mood most of the time for the last 3 months?

☐ good ☐ low/depressed ☐ angry ☐ anxious ☐ other _____

35. **Have you had any history of:** ☐ Depression ☐ Anxiety ☐ PTSD ☐ Other mental health condition _____

36. **Do you have any other significant stress in your life at the moment?** ☐ yes ☐ no

37. **Have you ever been the victim of physical or emotional abuse?** ☐ yes ☐ no ☐ prefer not to answer

38. **Have you had any unwanted sexual experiences?** ☐ yes ☐ no ☐ prefer not to answer

EFFECT ON YOUR LIFE

39. **What is your current work status?**

☐ full time work ☐ part time work ☐ home duties/parenting ☐ retired
☐ student ☐ reduced hours/duties due to pain ☐ unemployed due to pain ☐ other_____

40. **How many times in the last 3 months have you had to do the following due to your pain?**

Visit your GP _____ Visit the after-hours clinic _____ Go to the Emergency Department_____
Be admitted to hospital _____ Have a sick day off work or school _____ Spend a day in bed _____

41. During the past week, how much has pain interfered with the following? 0 is 'did not interfere' and 10 is 'interfered completely'. Circle the number that best describes:

	Did not interfere ... Interfered completely
Your general activity?	0 1 2 3 4 5 6 7 8 9 10
Your mood?	0 1 2 3 4 5 6 7 8 9 10
Your walking ability?	0 1 2 3 4 5 6 7 8 9 10
Your normal work (both outside the home and housework)?	0 1 2 3 4 5 6 7 8 9 10
Your relations with other people?	0 1 2 3 4 5 6 7 8 9 10
Your sleep?	0 1 2 3 4 5 6 7 8 9 10
Your enjoyment of life?	0 1 2 3 4 5 6 7 8 9 10

42. Rate how confident you are that you can do the following things at present despite pain. This is not asking whether or not you have been doing these things, but rather how confident you are that you can do them at present, **despite the pain.** Circle one of the numbers on the scale, where 0 = *Not at all confident* and 6 = *Completely confident*.

	Not at all confident ... Completely confident
I can enjoy things, despite the pain	0 1 2 3 4 5 6
I can do most of the household chores (e.g. tidying up, washing dishes, etc.) despite the pain	0 1 2 3 4 5 6
I can socialise with my friends or family members as often as I used to do, despite the pain	0 1 2 3 4 5 6
I can cope with my pain in most situations	0 1 2 3 4 5 6
I can do some form of work, despite the pain ("work" includes housework, paid and unpaid work)	0 1 2 3 4 5 6
I can still do many of the things I enjoy doing, such as hobbies or leisure activity, despite the pain	0 1 2 3 4 5 6
I can cope with my pain without medication	0 1 2 3 4 5 6
I can still accomplish most of my goals in life, despite the pain	0 1 2 3 4 5 6
I can live a normal lifestyle, despite the pain	0 1 2 3 4 5 6
I can gradually become more active, despite the pain	0 1 2 3 4 5 6

43. We are interested in the types of thoughts and feelings you have when you are in pain. Listed below are thirteen statements describing different thoughts and feelings that may be associated with pain. Using the following scale, please indicate the degree to which you have these thoughts and feelings when you are experiencing pain.

When I'm in pain …	**Not at all 0**	**Slightly 1**	**Moderately 2**	**Greatly 3**	**All the time 4**
a) I worry all the time about whether the pain will end	☐	☐	☐	☐	☐
b) I feel I can't go on	☐	☐	☐	☐	☐
c) It's terrible and I think it's never going to get any better	☐	☐	☐	☐	☐
d) It's awful and I feel that it overwhelms me	☐	☐	☐	☐	☐
e) I feel I can't stand it anymore	☐	☐	☐	☐	☐
f) I become afraid that the pain will get worse	☐	☐	☐	☐	☐
g) I keep thinking of other painful events	☐	☐	☐	☐	☐
h) I anxiously want the pain to go away	☐	☐	☐	☐	☐
i) I can't seem to keep it out of my mind	☐	☐	☐	☐	☐
j) I keep thinking about how much it hurts	☐	☐	☐	☐	☐
k) I keep thinking about how badly I want the pain to stop	☐	☐	☐	☐	☐
l) There's nothing I can do to reduce the intensity of the pain	☐	☐	☐	☐	☐
m) I wonder whether something serious may happen	☐	☐	☐	☐	☐

NPS MEDICINEWISE

MY PAIN DIARY

DATE AND TIME	DESCRIBE YOUR PAIN (e.g. how long it lasts, where it is, whether it moves, what it feels like – dull, sharp, stabbing)	RATE YOUR PAIN (0–10, see overleaf)	WHAT MADE YOUR PAIN WORSE?	WHAT HELPED YOU GET THROUGH THE DAY? (medicine and non-medicine such as meditation, exercise etc)	DESCRIBE YOUR ACTIVITY LEVEL AND MOOD (Has the pain affected your daily life, including sleep, work social life etc)	COMMENTS (e.g. problems with medicines, how your pain affects your daily life – sleep, mood, work etc.)

MY PAIN DIARY

What is a pain diary?

A pain diary is a written record of how your pain affects your daily activities. It helps you to describe to your healthcare team how your pain has been affecting you over time.

A pain diary also records how medicines, other therapies and your activities affect your pain levels throughout the day.

Why should I keep a pain diary?

A pain diary can help you and your healthcare team:

- understand what makes your pain worse and what helps to relieve your pain
- track your response to your pain management plan, including changes in your medicines or other therapies.

When should I use a pain diary?

Use your pain diary as often as recommended by your doctor or pharmacist. This may include when you have ongoing pain, changes in your activity levels or changes in your medicines.

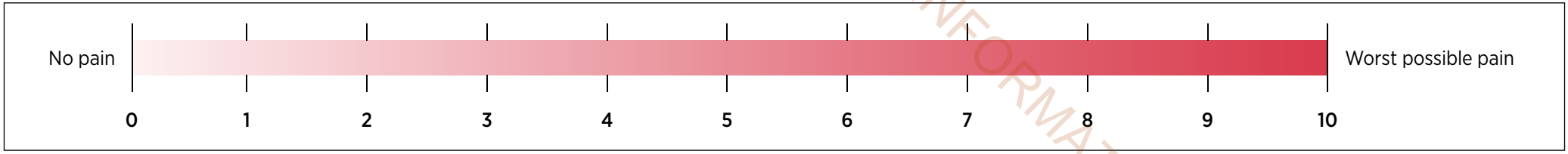
The information that you record will help you and your healthcare team prepare and guide your pain management plan. If your pain is under control you may not need to use the diary as often.

The more information you record in your pain diary, the more helpful it will be for you and your healthcare team.

How do I complete a pain diary?

Record all the information that is relevant to your pain in the diary over the page. You may not need to fill out all columns each time.

To complete the diary use the rating scale (below) to rate your activity. A zero (0) means no pain and a ten (10) means worst possible pain. Select the number that best describes your pain.



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NPS MEDICINEWISE

NPSE0992a

Complementary therapies for endometriosis

CAM use in Australian endometriosis patients

In a survey of a focus group of Australian women with endometriosis (n=61), all but one participant reported using complementary medicine to manage symptoms and obtain some quality of life. [i]

Available evidence

There is a paucity of good quality research looking at complimentary medicine in endometriosis management. There are a number of small studies using herbs, supplements, traditional Chinese medicine which either doesn't support its use or the level of evidence is weak.

An example of the type of research studies: a small RCT (n=59), Vitamin E 1200 iu and Vitamin C 1000mg, over 8 weeks, decreased pelvic pain in women aged 19-41 years, with endometriosis and/or fertility. There was a non-significant improvement in chronic pain in 43% of patients. Dysmenorrhoea and dyspareunia decreased in 37% and 24 % of patients respectively[ii].

There is some evidence to support the use of acupuncture[iii]

Dietary recommendations

- Increase fish and omega 3 polyunsaturated fatty acids
- Increase vegetables
- Reduce trans fats (fried foods, commercial cakes and biscuits/crackers, pies and pastries)
- Reduce red meat

Rationale:

A literature review showed that women with endometriosis consumed fewer vegetables and omega-3 polyunsaturated fatty acids and more red neat, coffee and trans fats[iv]. These findings were not consistently replicated.

Dietary fats:

Data from the Nurses' Health Study II showed that women who consume the highest fifth of long chain omega -3 fatty acids were 22% less likely to be diagnosed with laparoscopically confirmed endometriosis compared with lowest fifth of intake.

Conversely, those in the highest quintile of *trans*-unsaturated fat intake were 48% more likely to be diagnosed with endometriosis.[v]

Some small studies, have shown that omega-3 fatty acids reduced the symptoms of dysmenorrhea generally. In endometriosis and dysmenorrhea, prostaglandins (PGs) are thought to play a pathogenic role. Fish oils, a rich source of omega 3-fatty acids act as anti-inflammatories in endometriosis and dysmenorrhea, by reducing the pro-inflammatory PGs derived from omega-6 fatty acids, and the associated symptoms of endometriosis and/or dysmenorrhea. [vi]

Exercise

A 2014 systemic review concluded that there is inconclusive data regarding the benefits of physical exercise as a risk factor for endometriosis. Exercise may be protective against diseases that involve inflammatory processes as it decreases systemic levels of cytokines with anti-inflammatory and antioxidant properties. Exercise also reduces oestrogen levels. [vii]

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