

# Case Studies

Endometriosis: a discussion about diagnosis and treatment

Jean Hailes  
for Women's Health

jeanhailes.org.au



## Jessica's story

jeanhailes.org.au

1

2

### Jessica Chase

“ My name is Jessica Chase. I am 24 years old.

I started my periods when I was 13.

To begin with, they were irregular but when they would come they were heavy for 6-7 days and I would flood through pads and onto my uniform.

It was embarrassing.



jeanhailes.org.au

### Jessica Chase

I got a bit better at managing them and they settled to 6 days once a month when I was about 16-17.

However, in the last few years, they are also quite painful.

I get bloating, headaches, acne and crampy pain 2 days before my period and then really bad cramps for the first 2 days of my cycle.



jeanhailes.org.au

3

4

## Jessica Chase

I can manage with taking anti-inflammatories and a heat pack, but I did miss a lot of university for my period.

Now that I am working in my office it is hard to take days off work.



jeanhailes.org.au

5

## Jessica Chase

I would like my periods to be more manageable.

My mum and sister also had heavy and painful periods.

Mum said that maybe I should get checked out as she had trouble getting pregnant with me and my sister.



jeanhailes.org.au

6

## Jessica Chase

I'm not ready to have kids yet but I would like to someday.

I am worried that my heavy painful periods mean there is something wrong and I don't want to do anything that might impact my fertility long-term.



jeanhailes.org.au

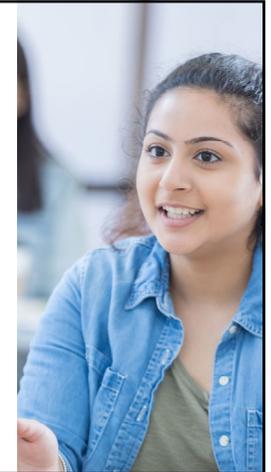
7

## Jessica Chase

I don't take any medication and don't have any other medical problems.

I don't smoke and drink alcohol only on the weekend.

I love dancing and netball.



jeanhailes.org.au

8

## Jessica Chase

I don't have a regular partner at the moment but I have had sexual health check ups and they have all been normal. ”



jeanhailes.org.au

## Heather's story

jeanhailes.org.au

9

10

## Heather Butler

“ My name is Heather Butler. I am 45 years old.

I have had debilitating period pain since the age of 14 and was subsequently diagnosed with endometriosis and adenomyosis.

I had laparoscopies every year between the ages of 14 and 27 to manage my symptoms and then another two more in my thirties.



jeanhailes.org.au

## Heather Butler

My pain always felt better after surgery even if they just found scar tissue and endometriosis wasn't removed, but my symptoms would always come back again some months later.

I am a single mother to an 18 year old son, Ben. I left his father due to domestic violence when he was young.



jeanhailes.org.au

11

12

## Heather Butler

It was a really difficult separation.

I have always had period pain but it has been progressively getting worse since Ben's birth.

I find myself in the fetal position almost every day, with really bad lower back and pelvic pain which radiates right down my legs.



jeanhales.org.au

13

## Heather Butler

Ben's birth has also left me with some other problems.

I feel like I need to go to the toilet frequently for both my bladder and my bowel and sometimes it's really painful to empty.

I have had ongoing weight problems since his birth as well and I'm now over 160kg.



jeanhales.org.au

14

## Heather Butler

I don't have any other medical conditions but I find myself on a cocktail of pain medications and drugs to help me sleep.

I am now finding the pain overwhelming but I have to cope with it for Ben's sake.



jeanhales.org.au

15

## Heather Butler

I'm so sick of taking hormone pill after hormone pill, they seem to make my weight gain worse and they really don't help me much in the way of relief.

I'm less focussed at work, I'm less motivated, I can't concentrate and sometimes I have really negative thoughts.



jeanhales.org.au

16

## Heather Butler

Ben's now having behavioural issues and I can't help but feel it's my fault - the pain and the challenges it has given me, make parenting a really huge struggle.

My GP recently ordered a scan which showed adenomyosis and both of my ovaries are now stuck.



[jeanhailes.org.au](http://jeanhailes.org.au)

17

## Heather Butler

I really don't know what to do.

I'm totally over it. ”



[jeanhailes.org.au](http://jeanhailes.org.au)

18



 Jean Hailes  
for Women's Health

Jean Hailes for Women's Health gratefully acknowledges  
the support of the Australian Government.

[jeanhailes.org.au](http://jeanhailes.org.au)

19

# Overview

Dr Pav Nanayakkara  
Gynaecologist and Advanced  
Laparoscopic Surgeon



Jean Hailes  
for Women's Health

jeanhailes.org.au

1

---

---

---

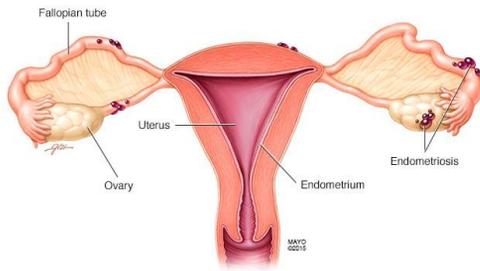
---

---

---

---

---



© MAYO FOUNDATION FOR MEDICAL EDUCATION AND RESEARCH. ALL RIGHTS RESERVED.

jeanhailes.org.au

2

---

---

---

---

---

---

---

---

one in    
seven women  
in Australia



**\$30,900**  
per person per year

jeanhailes.org.au

3

---

---

---

---

---

---

---

---

How do we know it is endometriosis?



4

---

---

---

---

---

---

---

---



5

---

---

---

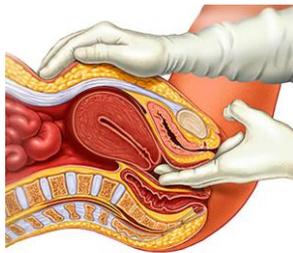
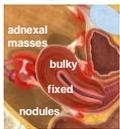
---

---

---

---

---



6

---

---

---

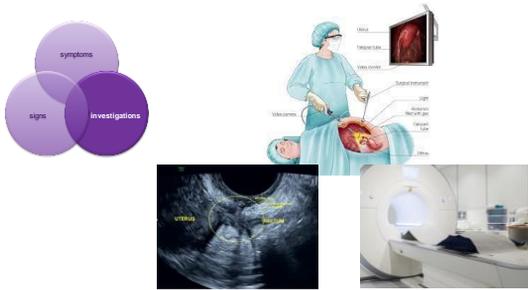
---

---

---

---

---



jeanhailes.org.au

7

---

---

---

---

---

---

---

---

---

---

**A plan for a working diagnosis of endometriosis**

Dr Sara Whitburn  
GP and Senior Medical Educator

Jean Hailes  
for Women's Health

jeanhailes.org.au

8

---

---

---

---

---

---

---

---

---

---

### What is a 'working diagnosis'?

*'Sometimes the most likely choice is designated to be the working diagnosis, meaning that it is likely, but hasn't been confirmed, and that other diseases haven't been ruled out.'*



Society to Improve Diagnosis in Medicine  
<https://www.improvediagnosis.org/processes/the-diagnostic-process/working-diagnosis/>

picture: <https://www.rush.edu/news/talking-about-pelvic-pain>

jeanhailes.org.au

9

---

---

---

---

---

---

---

---

---

---

### Why is a working diagnosis important?



- To decrease or avoid diagnostic delay which can lead to negative impact on quality of life (QOL).
- Recognise that the likely diagnosis is endometriosis.
- To start treatments in a timely manner.
- To refer appropriately.
- To empower and educate.

---

---

---

---

---

---

---

---

10

### Reasons for diagnostic delay

- Diversity of presenting symptoms, overlap with benign conditions, and a low index of suspicion.
- Frequent attendance with disparate symptoms may make diagnosis less likely as misdiagnosed as functional or psychosomatic cause.
- Cultural attitudes normalising painful menstruation.
- A lack of clinician awareness of updated guidelines.
- Concern over the invasive nature of laparoscopy.

---

---

---

---

---

---

---

---

11

### Recognising endometriosis

- Consider the constellation of symptoms and how/type of presentation.
- Need to ask directly about the defining and associated symptoms.
- Self-reporting of symptoms can help but consider health literacy and what tools may be most appropriate.

---

---

---

---

---

---

---

---

12

### Clinical history questions to ask

- **Ask** specifically about menarche, history of menstrual difficulties, details of pregnancies, and any difficulties with conception.
- **Ask** also about dysmenorrhoea, dyspareunia, pelvic pain throughout the cycle, and cyclical bowel and bladder symptoms.
- **Consider** asking people presenting primarily with irritable bowel syndrome (IBS) symptoms about their menstrual history.
- **Ask** about family history of symptoms and/or diagnosis of endometriosis.
- **Ask** about impact on quality of life (QOL), time off school or work, concerns about menstrual cycles, fertility plans.



13

---

---

---

---

---

---

---

---

---

---

### Helpful reporting resources (clinical history and interview)



- [endozone.com.au/](http://endozone.com.au/)
- Qendo app
- [rancog.edu.au/resources/raising-awareness-tool-for-endometriosis-rate/](http://rancog.edu.au/resources/raising-awareness-tool-for-endometriosis-rate/)
- Jean Hailes toolkit
- Pelvic Pain Foundation

Think pain, bleeding, GI symptoms, urination and food

Develop a pain plan Manage at home

Connect to resources Find information and communicate with your support team



14

---

---

---

---

---

---

---

---

---

---



**Any symptom which reliably worsens with the menstrual cycle should prompt consideration of the diagnosis**

jeanhailes.org.au

15

---

---

---

---

---

---

---

---

---

---

### Examination

- Physical examination
  - sensitive, trauma informed examination
  - palpation of abdomen for areas of tenderness or guarding
  - vaginal exam (if appropriate) for tenderness, uterine size, nodules, ovarian cysts.



16

---

---

---

---

---

---

---

---

---

---

### Investigations (diagnostic testing)



- Imaging (pelvic/abdominal ultrasound)
  - COGUS, bowel prep for deep infiltrating endometriosis (DIE).
- Exclude other causes of lower abdominal pain
  - sexually transmissible infection (STI), ectopic pregnancy, pelvic inflammatory disease (PID), ovarian torsion, IBS.
- Blood tests (if heavy menstrual bleeding present):
  - FBE
  - iron studies
  - thyroid function tests
  - Von Willebrands
  - platelet function studies.



17

---

---

---

---

---

---

---

---

---

---

### Initial treatment as part of 'working diagnosis'



- Consider a 3-month trial of NSAIDS with paracetamol for people who have pain with suspected or confirmed endometriosis.
- Offer menstrual suppression with hormonal options as a shared decision-making option.
- If these initial treatments are not effective then referral to gynaecologist for further investigation and management.



18

---

---

---

---

---

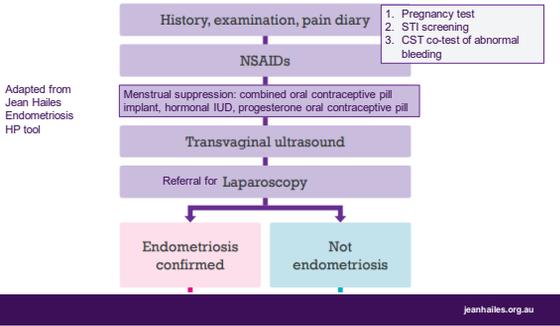
---

---

---

---

---



19

---

---

---

---

---

---

---

---

### Consider Jessica – applying our working diagnosis plan

- Ask about symptoms
    - dysmenorrhea
    - heavy menstrual bleeding
    - cyclical bloating, headaches, acne and crampy pain before period
    - cyclical menstrual pain
  - Ask about family history – Yes
  - Impact on QOL
    - had to take time off university and impacting on work now
  - Concerns and expectation
    - would like to manage periods
    - concerns about fertility
- What else is needed?
    - Physical examination
    - Diagnostic testing
      - sexual health is up to date
      - exclude pregnancy
      - confirm if co-test is needed (PMB/IMB)
      - imaging
    - Initial treatment as part of a working diagnosis
      - discussion of menstrual suppression
    - Referral

20

---

---

---

---

---

---

---

---

Jessica is likely to have endometriosis.

jeanhailes.org.au

21

---

---

---

---

---

---

---

---

# Management

Dr Pav Nanayakkara  
Gynaecologist and Advanced  
Laparoscopic Surgeon



Jean Hailes  
for Women's Health

jeanhailes.org.au

---

---

---

---

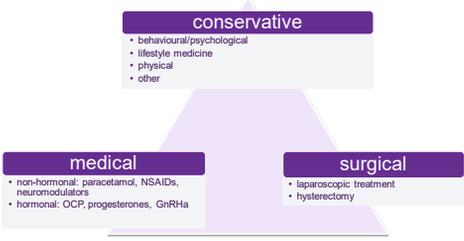
---

---

---

---

22



jeanhailes.org.au

23

**conservative**

- behavioural/psychological
- lifestyle medicine
- physical
- other

jeanhailes.org.au

24

---

---

---

---

---

---

---

---



---

---

---

---

---

---

---

---

**medical**

- non-hormonal: paracetamol, NSAIDs, neuromodulators
- hormonal: OCP, progesterones, GnRHa

jeanhailes.org.au

25

---

---

---

---

---

---

---

---

**surgical**

- laparoscopic treatment
- hysterectomy

jeanhailes.org.au

26

---

---

---

---

---

---

---

---

**conservative**

- behavioural/psychological
- lifestyle medicine
- physical
- other

**medical**

- non-hormonal: paracetamol, NSAIDs, neuromodulators
- hormonal: OCP, progesterones, GnRHa

**surgical**

- laparoscopic treatment
- hysterectomy

**Multidisciplinary team**

jeanhailes.org.au

27

---

---

---

---

---

---

---

---





### What is pain? – IASP revised definition (2020)



- Personal experience.
- Influenced by biological, psychological, and social factors.
- Pain and nociception are different phenomena.
- Individuals learn the concept of pain.
- A person's report of an experience of pain should be respected.
- Serves an adaptive role but can have adverse effects on function, social and psychological well-being.

jeanhailes.org.au

34

---

---

---

---

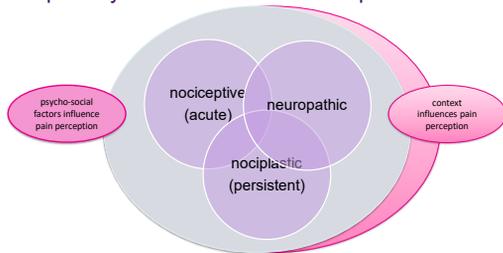
---

---

---

---

### Nociceptive system and endometriosis pain



jeanhailes.org.au

35

---

---

---

---

---

---

---

---

### Persistent pelvic pain (PPP) and endometriosis

PPP is:  
 'Pain in the area of the pelvis, present on most days for more than 6 months' (IASP 2020)

- the most common clinical manifestation of endometriosis (Arends 2017)
- most common reason for referral to women's health service. (Laine 2006)



jeanhailes.org.au

36

---

---

---

---

---

---

---

---

### Persistent pain and endometriosis

#### Co-morbidities of endometriosis



**IC/BPS**  
(70-80%)  
Chung 2005  
Tirlapur 2013

**IBS**  
(50-70%)  
Chiaffarine 2022  
Schomacker 2018

**Vulvodynia**  
Abdo-Pelvic myalgia  
Mc Namara 2021

**Fibromyalgia**  
Chung 2002

**Migraine headaches**  
Chung 2002

37

---

---

---

---

---

---

---

---

### How pain becomes persistent

- Brain interprets information from stimulus in tissues and combines it with past beliefs, experiences, current situation, physiological, behavioural, cognitive and social factors.
- Increased excitation and reduced inhibition of neural pathways over time cause cortical adaptations, CNS sensitisation.
- Inflammatory and immune changes enhance pain amplification, duration, area.
- Over-protective pain system results which remains even in absence of pathology.
- NB plasticity!

38

---

---

---

---

---

---

---

---

### Persistent pain – clinical presentations suggesting sensitisation of the nervous system - Heather

- Pain present most days - previously with periods-now most days
- Widespread pain - back and pelvic pain
- Hyperalgesia / allodynia - severe pain
- Co-morbidities/pain conditions - urinary/faecal frequency + pain
- Pain worsened by
  - stress  
pain overwhelming, Ben's behavioural issues, threatening experiences, difficult separation
  - cognitions  
negative thoughts, less focused/motivated at work.

39

---

---

---

---

---

---

---

---

### Persistent pain and endometriosis – the complexities of pain

- Central sensitisation of the nervous system may explain some endometriosis 'puzzles'

- discrepancy between disease burden and symptoms



- failure to respond as expected to lesion focused treatment.



jeanhailes.org.au

40

---

---

---

---

---

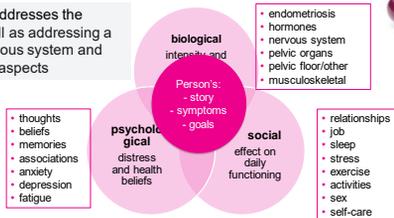
---

---

---

### BPS approach to management of EAP

Intervention addresses the tissues as well as addressing a sensitive nervous system and psychosocial aspects



jeanhailes.org.au

41

---

---

---

---

---

---

---

---

## Physiotherapy and endometriosis associated pain

jeanhailes.org.au

42

---

---

---

---

---

---

---

---

### The role for physiotherapy

Conservative therapies may be helpful in the management of EAP  
(Fraser et al 2023)



Interdisciplinary care may improve health outcomes and satisfaction  
(Clinical Practice Guidelines for Diagnosis and Management of Endometriosis (RANZCOG 2021)

---

---

---

---

---

---

---

---

43

### Physiotherapy treatment pain education – reconceptualise pain – why?

- Pain education changes pain levels more than any other treatment modality (Moseley 2004, Galagher 2010, Van Oosterwijk 2011)
- Understanding pain gives sense of control and empowers
- Neuroplasticity - offer hope
- Increases self-efficacy
- Reduces fear/uncertainty
  - fear avoidance behaviour
  - kinesiophobia

---

---

---

---

---

---

---

---

44

### Pain education concepts for PPP – what do sufferers want to know?



---

---

---

---

---

---

---

---

45

Physio treatment – downregulate the nervous system

- diaphragmatic breathing  
dailybandha.com/diaphragmatic breathing
- body scanning – jaw, shoulders, tummy, PF
- mindfulness/meditation (apps: Smiling Mind/Curabile/QENDO)
- management of anxiety/hypervigilance
- general exercise
- sleep
- encourage activities that enjoy.



46

---

---

---

---

---

---

---

---

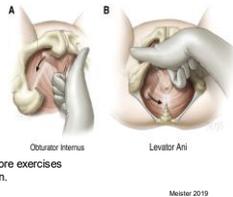
---

---

Physiotherapy treatment

Signs and symptoms that may suggest pelvic floor muscle dysfunction

- Pelvic floor muscles
  - stabbing pains in vaginal/rectum
  - generalised pelvic ache
  - voiding dysfunction symptoms
  - difficult defecation
  - painful sex
  - indrawn perineum, adductor spasm, vaginismus.
- Obturator internus
  - stabbing pain in iliac fossa
  - 'ovary pain'
  - referred pain to anterior thigh, back
  - agg by movement/prolonged positions/abdominal core exercises
  - eased with hot pack on lower abdomen/fetal position.



47

---

---

---

---

---

---

---

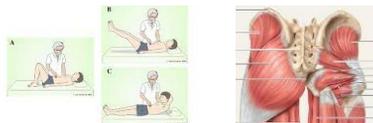
---

---

---

Other muscle involvement

- abdominal muscle myalgia (Yosaf 2016)
- positive Carnett's sign
- assess and treat other muscles around the pelvis.



48

---

---

---

---

---

---

---

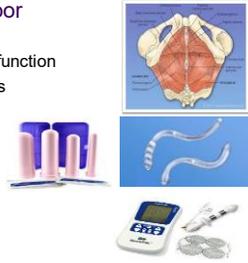
---

---

---

### Physio treatment - pelvic floor

- address pelvic floor muscle dysfunction
  - usually 'downtraining' exercises
- myofascial therapy
  - massage/trainers/wands
- biofeedback
- home program.



49

---

---

---

---

---

---

---

---

### Physio treatment - exercise and 'Speed Hump' tool kit

- Address fear of movement/deconditioning.
- Reduce fear avoidance
  - get them moving!
  - general exercise program
  - stretches; pelvic, neural
  - yoga (usually avoid Pilates).
- Pacing (avoid 'boom and bust' cycle).
- Pain relief tools
  - heat/cold
  - massage
  - TENS
  - stretches
  - diaphragmatic breathing.



50

---

---

---

---

---

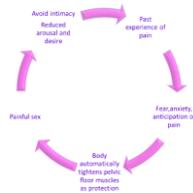
---

---

---

### Physio treatment - other

- Optimise bladder and bowel health.
- Educate and give tools to address physical responses to sexual dysfunction.



51

---

---

---

---

---

---

---

---



## Key messages

jeanhailes.org.au

52

---

---

---

---

---

---

---

---

### Key messages

- Pain is not a reliable indicator of tissue damage.
- Persistent pain can become the disease.
- Pain is always an output of the brain.
- A biopsychosocial approach to management is gold standard care.
- Pain education changes pain levels more than any other treatment modality.

53

jeanhailes.org.au

---

---

---

---

---

---

---

---




Jean Hailes for Women's Health gratefully acknowledges the support of the Australian Government.

jeanhailes.org.au

54

---

---

---

---

---

---

---

---

**For further information contact**

Jean Hailes for Women's Health  
PO Box 24098  
Melbourne VIC 3001

**Phone** 03 9453 8999

**Email** [hp.education@jeanhailes.org.au](mailto:hp.education@jeanhailes.org.au)

**Website** [jeanhailes.org.au](http://jeanhailes.org.au)

© 2023 Jean Hailes Foundation. All rights reserved.  
This publication may not be reproduced in whole or in part by any means without written permission of the copyright owner. Contact: [licensing@jeanhailes.org.au](mailto:licensing@jeanhailes.org.au)

Created September 2023