

pioneerpelvicpain.com.au



# ABOUT THE PROGRAM

The Australian Government is funding endometriosis and pelvic pain clinics in every state and territory in Australia as a pilot program. These clinics aim to

- improve access for patients to diagnostic, treatment and referral services for endometriosis and pelvic pain
- build the primary care workforce to manage this chronic condition.
- improve access to new information and care pathways.

Endometriosis is a complex and debilitating chronic condition that can be hard to diagnose, with those suffering waiting an average of 7 years before diagnosis. It is a progressive condition that can start at puberty and continue through to old age. In Australia it affects at least one in nine girls, women and those assigned female at birth.

# THE PROGRAM'S GOALS

The clinics will provide multi-disciplinary care with a focus on:

- improving the timeliness of diagnosis
- promoting early access to intervention, care, treatment options, and referral services for endometriosis and pelvic pain.

# PIONEER PELVIC PAIN CLINIC AIMS TO PROVIDE:

- Comprehensive and expert care
- Personalised treatment plans
- Pain management
- Emotional support

By focusing on the specific needs of individuals with endometriosis, we hope to play a pivotal role in improving the quality of life for our patients and ultimately reducing the profound physical and emotional toll this condition can take on those affected.

# The Pioneer Pelvic Pain Clinic is supported by:







Australian Government Department of Health





# PATIENT PATHWAY

#### Initial Appointment with Patient Support Coordinator

#### 60 minutes No cost

When you book a Pelvic Pain Clinic appointment, you will be prompted to complete an online questionnaire to be submitted prior to your initial appointment. Our Patient Support Coordinator, will spend time with you collecting information and arranging for any results or treatment reports to be sent to the Clinic in readiness for your GP appointment. They will also speak with you about what your priorities are in regards to your treatment plan. You will be assigned a treatment GP and your appointments will be arranged.

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#### First appointment with GP

60 minutes

With Medicare card	Standard	<b>Fee</b> \$300	<b>Rebate</b> \$197.90	<b>00P</b> \$102.10	No Medicare card
	Non-high school students	\$247.90	\$197.90	\$50	Out of pocket cost \$300
	High school students and concession card holders	Bulk-billed		\$0	

Using the information collected from your initial appointment, the GP will work with you to develop a management plan and liaise with other health providers that may participate in your care (e.g. Pelvic Health Physiotherapist).

#### Follow up appointment with GP

30 minutes					
With Medicare card	Standard	<b>Fee</b> \$159,95	<b>Rebate</b> \$82,90	<b>00P</b> \$77.05	No Medicare card
	Non-high school students	\$132.90	\$82.90	\$50	Out of pocket
	High school students and concession card holders	Bulk-billed		\$0	cost \$159.95

Follow up with the GP to review any results, discuss the progress of your management plan and review allied health involvement in your care.

#### **Further appointments**

Further appointments will be arranged as required

Video Consults with a Medicare rebate are available for patients who have had a face-to-face appointment at Pioneer Health in the last 12 months. However, all other patients will incur full private fees with no Medicare rebate applicable (due to Medicare rulings). Enquire with Patient Coordinator re fees.

# YOUR GP APPOINTMENT

Date:\_

Time:

We require at least 24 hours notice for a GP appointment cancellation. Patients will be charged a \$100 cancellation fee if they cancel within 24 hours of their appointment (or do not attend their appointment without notifying the clinic).

#### E: pelvicpain@pioneerhealth.com.au | T: 9842 2822



# SEVEN POINT PLAN FOR PELVIC PAIN MANAGEMENT

For suspected or proven endometriosis

#### 1 TAKING CARE DURING A PERIOD

Be kind. Go for gentle walks. Panadol, nurofen and a heat bag are effective tools. A mobile TENS machine is worth considering. There is little evidence for stronger pain relief.

#### 2 PERIOD CYCLE CONTROL

To prevent further growth of endometriotic deposits outside the womb. This can be: the pill, minipill, contraceptive injection, contraceptive implant or IUD. Sometimes we use two of these in combination for better effect at stopping disease process

#### 3 PELVIC FLOOR PHYSIOTHERAPY/YOGA

To encourage pelvic floor relaxation after years of pain, trauma and tension. Can be coupled with a mobile TENS machine or can be taught self trigger point release (pelviwand)

#### 4 DIETITIAN

Often a crossover with IBS, a dietician can help work on trigger foods that worsen bloating and bowel movements with each period cycle.

#### 5 **PSYCHOLOGY**

In recognition of living with chronic pain and its effects on daily life, psychology is recommended to assist with Acceptance and Commitment Therapy (ACT), to retrain your mind and pain pathways.

#### 6 CONSIDERATION OF NERVE PAIN MEDICATION

From years of monthly pain and trauma, these nerve endings are overstimulated. They begin to fire off without painful stimuli. We call this "neuropathic pain" or "nerve pain". These medications help calm the irritated nerve pain pathways and give the body a break.

#### 7 GYNAECOLOGY REFERRAL OR REVIEW

If proven endometriosis – could consider further discussion of pelvic floor botox or zoladex (to induce temporary menopause). If not proven, can work on planning for diagnosis with a good quality ultrasound. Formal diagnosis still needs to be with keyhole surgery to see and remove the deposits.



# Patient Resources



## These resources can also be accessed via our website

The resources listed herein are provided solely for general informational purposes and should not be construed as medical advice or an endorsement of their suitability or reliability by any entity or individual. No liability is assumed for any consequences that may arise from the use of these resources. Users are strongly encouraged to exercise their own judgment, verify information, and seek professional advice as needed when utilising the listed resources.

# WEBSITES

## **Endometriosis Australia**

#### www.endometriosisaustralia.org

Endometriosis Australia aims to raise awareness across various communities (medical, business and the general public) as well as provide educational programs and raise funds. Visit their website for info on:

- Diagnosis
- Treatment
- Fertility
- Pelvic Yoga
- Adolescents and endometriosis
- Complementary medicine
- Pelvic floor and perineum health



#### **Endometriosis WA (EndoWA)**

#### www.endometriosiswa.org.au

Coordinates and delivers programs, events and activities to provide quality services and support to people managing endometriosis and their families and carers. Endo WA provides accurate and up to date information on endometriosis in accessible and understandable formats.



## Endozone

#### www.endozone.com.au

An evidence based website co-created with people affected by endo. Funded by the Australian Government and Jean Hailes for Women's Health, EndoZone has been developed by researchers, health experts, Australia's endometriosis(endo) associations, and most importantly of all, you.

EndoZone learns what users want and responds to what they need.



## **Pelvic Pain Foundation Australia**

#### www.pelvicpain.org.au

A not-for-profit organisation formed to build a healthier and more productive community by improving the quality of life of people with pelvic pain. Website includes a number of resources including information about the PPEP Talk program (Periods, Pain, Endometriosis Program) which delivers fun, medically accurate and age appropriate information sessions to schools and other groups.



# WEBSITES

#### Jean Hailes for Women's Health

#### www.jeanhailes.org.au

Jean Hailes for Women's Health is a national not for profit organisation dedicated to improving women's health across Australia through every life stage. The website includes evidence based, easily accessible information as well as helpful external resources, many of which are available in different languages.

#### Endometriosis Australia Symposium

The Endometriosis Australia Symposium 2023 as part of Endo March is an educational symposium, designed for the public and health practitioners to better understand the debilitating disease that affects 1 in 9 women, girls, and those assigned females at birth.

Theme: The importance of research



# EXERCISE

## **Exercising with Endometriosis**

sarahlizking.com/exercising-withendometriosis-what-to-do-and-what-to-avoid

Exercise can reduce pain sensitisation, improve mental health and relax tight muscles.

This page explains how exercise can help with pain associated with endometriosis and includes information on the type of exercises that may help.



## **Online Exercise Classes**

The following are online exercise programs which you can subscribe to if you choose.



# EXERCISE

#### **Yoga and Mindfulness Session**

#### Instruction video for at home

#### https://pioneerpelvicpain.com.au/yoga-and-mindfulness-instruction-video/

If you would like to be able to do our yoga and mindfulness sessions at home, please visit our website via this QR code where you will find an

instructional video. This yoga and mindfulness practice has been designed specifically for people with pelvic pain but could be useful for anyone wanting to reduce pain or improve relaxation in their lives.





# RELAXATION

#### **Relaxation Methods / Sleeping**

www.endozone.com.au/self-management/ relaxation-methods

Understanding the link between endometriosis and sleep quality is important because sleepiness and fatigue can result in difficulty managing your daytime activities.

This page has a step-by-step guide to relaxation, including a voice track to listen to.



## **Sleep Hygiene: Fad or fiction?**

A Jean Hailes podcast by Denise Scott asking about Sleep Hygiene - what does it actually mean?



# MENTAL HEALTH SUPPORT

## **Head to Health**

#### www.headtohealth.gov.au

Head to Health aims to help all Australians access the mental health and wellbeing services that are right for them. Choose the most suitable care options, whether that's faceto-face, via phone, or online.

Whether you are trying to improve your own sense of wellbeing, looking for help with something that is bothering you, or helping someone you care about, Head to Health is a good place to start.



## **This Way Up**

#### thiswayup.org.au

Practical strategies for managing chronic pain, and associated low mood and anxiety. An 8-lesson program based on Cognitive Behavioural Therapy (or CBT), which is designed to help you lessen the impact of pain on your wellbeing and quality of life.



# **PRODUCTS**

## **TENS Machine**

A form of pain relief that delivers a small electrical current to the body through electrodes attached to the skin.



#### Wili Heat Bag - Pelvic and Back Wrap

Help with cramps, muscle pains and aches. 100% Cotton and hand made in South

Australia by an Adelaide-based family run business.

# **Spoonie Wrap** Around Heat Pack

Spoonie wrap around heat pack - small and large. Made in Melbourne, Australia.



A stool to promote correct posture on the toilet.





# APPS

#### Curable

#### www.curablehealth.com



Curable is an app which provides education to users on the neuroscience of pain and the factors leading to the development of chronic pain.

The co-founders developed a program using pain psychology strategies and made it accessible through this app (subscription required).

Curable describes itself as a "different approach to your pain".



## Qendo

#### www.qendo.org.au

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An free app for endometriosis, adenomyosis, PCOS, pelvic pain and infertility, developed by the community for the community and is available for download in Australia and New Zealand. The Qendo app includes a symptom tracker, allows users to develop a "pain plan" and facilitates access to education and connection within the community.



Matilda

#### Matilda

#### www.matilda.health

For access to expert holistic care from the comfort of your own home. Connect with other endo warriors in the Tilly Tribe community, sharing challenges and triumphs to keep you motivated and on track to success.



#### Frendo

#### www.frendo.co.uk

frendo has a real-time screening tool, to assist with your first step towards diagnosis and health tracker functions to help you notice patterns in symptoms and create a healthy routine.

The frendo social media community is a place to find others who know what it's like to live with endo.



# **HEAVY PERIODS**

## Jean Hailes - Heavy Periods

#### www.jeanhailes.org.au/resources/heavy-periods

About one in four women have heavy periods (heavy menstrual bleeding). A heavy period is when you lose lots of blood each period. The amount of bleeding can change at different life stages. For example, in teenage years or before menopause (your last period). Heavy periods are common in women aged 30 to 50.

## Jean Hailes - Heavy Periods Easy read

https://www.jeanhailes.org.au/resources/ periods-heaving-bleeding-easy-read

An easy read downloadable fact sheet.



## **RANZCOG - Heavy Periods**

A two page PDF explaining the difference between normal periods and heavy menstrual bleeding; symptoms; causes; tests and treatments.





# YOUTH

#### Headspace

#### headspace.org.au

Headspace is an Australian organization that offers mental health services for young people aged 12-25. It provides counseling, support, and information on various mental health issues. Additionally, it offers online and telephone support services and engages in advocacy and education to reduce stigma around mental health.

# Youth Support

www.pelvicpain.org.au/ppep-talk-schoolsprogram

PPEP Talk program (Periods, Pain, Endometriosis Program) delivers fun, medically accurate and age appropriate information sessions to schools and other groups.





## **Trans and Gender Diverse Teens**

www.pelvicpain.org.au/ppep-talk-schoolsprogram/for-trans-and-gender-diverse-teens

A FREE online Periods, Pain and Endometriosis (PPEP Talk) session focussing on Trans and Gender Diverse (TGD) teens and their families.

# BOOKLET

## **Pelvic Pain Education Booklet**

This is an excellent booklet written by Gynaecologist Susan Evans. It includes an introduction to a wide range of pelvic pains.

www.pelvicpain.org.au -> Tools and Resources for HP -> PPFA Resources to Support You -> Introduction to Pelvic Pain Booklet.

Introduction to Pelvic Pain



# **PIONEER PELVIC PAIN CLINIC RESOURCES**

# PODCASTS

## The Jean Hailes Podcast

Jean Hailes for Women's Health is a national not-for-profit organisation dedicated to improving women's health across Australia through every life stage.

## **This Medical Life Podcast**

Pelvic Pain And Endometriosis | More Than The Black Spots.

Although intended as a resource for medical practitioners, some patients will also appreciate this podcast as it presents a lot of information in a really helpful way.





# VIDEOS

## **EndoActive**

Endometriosis: Shared Perspectives.

This free series videos feature experienced specialists and a wide range of patient interviews. Topics include:

- Endometriosis and pelvic pain
- Physiotherapy and pelvic pain
- Early diagnosis of menstrual disturbance
- Endometriosis and the bowel
- The immune system, inflammation and endometriosis
- Ultrasound and MRI for endometriosis





# Other information

# 5 questions to ask your doctor or other healthcare provider before you get any test, treatment, or procedure

Choosing Wisely Australia has a webpage page dedicated to assisting patients in gaining pertinent information during medical consultations so that they can make informed decisions about their treatments.

Would you like to assist research projects by taking part in their studies?

Endometriosis Australia assists research projects with their Research Notice Board. Here you will find various research projects needing participants.



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