



# Endometriosis

## Shared Perspectives

### Video Series Resource Guide

**Endometriosis: Shared Perspectives** are award winning video resources produced by EndoActive for health care professionals, people living with endometriosis (endo), educators and students.

Endometriosis is a chronic painful disease. It can be effectively managed but requires varied interventions. These videos are evidence-based presentations by experienced Australian doctors and health professionals.

Most videos begin with short, themed patient perspectives on the specific topic. Hence the title, **Endometriosis: Shared Perspectives**.

**These videos are available for streaming, download or embedding on your own platform.**



For more information contact [info@endoactive.org.au](mailto:info@endoactive.org.au)

**EndoActive is a health promotion charity founded in 2014 by Lesley and Sylvia Freedman. We're committed to making a difference for women and girls and others living with endometriosis through Awareness, Information and Advocacy.**

**We convened the first two Australian conferences on endo for both health care professionals and patients, winning a Prime Award for Best Public Health Initiative for the first conference and these associated educational videos.**

The judge's citation reads:

*A unique approach to a great and largely hidden problem. We love the many facets of this campaign - advocacy (for treatment and awareness), education of both Health Care Practitioners and people with endometriosis, and a broad range of useful resources. What an accomplishment!*

EndoActive won the Prime Awards NGO of the Year 2019, recognised for our continuing contribution to raising awareness and providing information.

EndoActive is a member of the World Endometriosis Organisations (WEO), a founding member of the Australian Coalition for Endometriosis (ACE) and serves on the Endometriosis Advisory Group for the National Action Plan for Endometriosis.

#### **The Cost of Endometriosis in Australia Report**

produced for EndoActive by Ernst Young in 2019, estimates that endo costs \$7.4 billion annually in Australia. The full report is available here:

<https://endoactive.org.au/report/>



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## What is Endometriosis?

Endometriosis (endo) is a condition where tissue similar to the lining of the uterus, the endometrial stroma and glands, which should only be located inside the uterus, is found elsewhere in the body. Endometriosis lesions can be found anywhere in the pelvic cavity and, more rarely, in other parts of the body.

Endo affects approximately 7-10% of Australian women of reproductive age, with over 758,000 Australian women suffering from it at some point in their life.

Globally there is a diagnostic delay of between 7-12 years because of lack of awareness, normalising of symptoms and lack of menstrual education. Many women never get a diagnosis despite suffering symptoms.

The only way to diagnose endo for sure is during a laparoscopy, a surgical procedure. There is no cure for endo although treatments may alleviate symptoms.

## Symptoms

Pelvic pain is the most common symptom, often correlating to the menstrual cycle but a woman with endometriosis may also experience pain that doesn't correlate to her cycle. For many women, the pain is severe and debilitating.

The impact extends beyond the personal pain and distress experienced by the patient, affecting her partner, her family and community interactions, education and career, sexual relationships, fertility and mental and psychosocial health.

Endometriosis may also cause scar tissue and adhesions to develop that can distort a woman's internal anatomy. In advanced stages, internal organs may fuse together. Fertility may be affected – an estimated 30-40% of women with endometriosis may not be able to have children.

## Living with endo

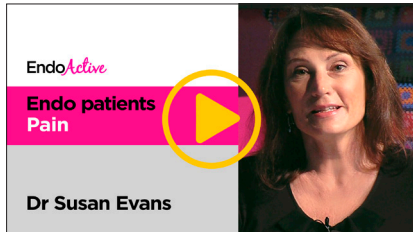
For many women, management of this disease may be a long-term process. If you, or someone you care about has endometriosis, it is important to research the disease as much as possible. Many myths and misconceptions about endo still persist, even in medical literature.

It is important for the patient to educate herself, take the time to develop a team of health professionals to manage her condition and consider joining a support group.

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**Endo patients: Pain** 1m 45s

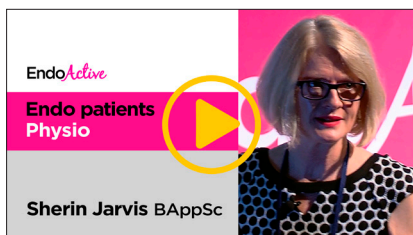
## **Endometriosis and pelvic pain** 29m 15s **Dr Susan Evans**

The 'big picture' of endometriosis. Pain and endometriosis don't always go together, but so often do – and it's not just period pain. Dr Susan Evans illustrates how 'lesions' can be seen in the pelvis and removed in laparoscopic surgery. What if pain is severe, yet only a small amount of

endometriosis is found? Are stabbing pains really due to lesions? Do lesions explain an irritable bowel, or food intolerance? How do headaches, fatigue, nausea, poor sleep, anxiety, low mood and dizziness fit in? What about an overactive bladder, painful vulval skin or painful intercourse?

**Dr Susan Evans** is a gynaecologist, laparoscopic surgeon and author of 'Endometriosis and Pelvic Pain'. She is a director of the Pelvic Pain Foundation of Australia [www.pelvicpain.org.au](http://www.pelvicpain.org.au) a not-for-profit health promotion charity that supports education and research in pelvic pain.

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**Endo patients: Physio** 0m 50s

## **Physiotherapy and pelvic pain** 19m 00s **Sherin Jarvis**

How can physiotherapy relieve the pain of endometriosis? Pelvic pain can result in reactive muscle contraction. The management of overactivity of the pelvic floor and external pelvic muscles aims to help patients with persistent pelvic pain. Addressing the sensitivity of the nervous system

explains the persistent pain experience and provides opportunity to reconceptualise pain for both the clinician and patient.

**Sherin Jarvis** is a clinical and research pelvic floor physiotherapist. She has post-graduate qualifications in Acupuncture; Continence & Pelvic Floor Dysfunction and Urodynamics. Sherin has pioneered research into the use of Botox for treatment of chronic pelvic pain.

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**Endo patients: Early diagnosis** 1m 20s

## **Early diagnosis of menstrual disturbance** 15m 10s **Melissa Parker RN**

When is period pain not normal? Melissa Parker RN addresses two main topics. Identifying and diagnosing endometriosis and other causes of pelvic pain - and the early treatment and long term management of endometriosis in teenagers. Early treatment is a stepped pathway to

identify and treat various causes and known contributors to pelvic pain, including endometriosis.

Most important is that women have the skills to self-manage their condition and take responsibility for their overall health.

**Melissa Parker** is the Endometriosis Nurse Coordinator and Researcher at the Canberra Endometriosis Centre at Canberra Hospital. Melissa has a Masters by research for her project entitled Menstrual Disorder in Teenagers, which surveyed over 1,000 Australian teenagers about their periods, published in the British Journal of Obstetrics and Gynaecology.

# Endometriosis Video Series Resource Guide



**Endo patients: Ultrasound + MRI** 1m 24s

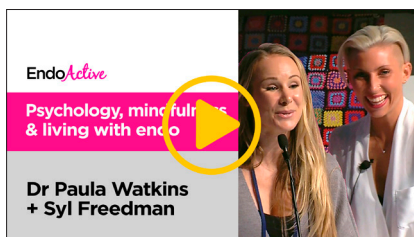
## Ultrasound and MRI 17m 30s Dr Kate Stone & Dr Natalie Yang

Can MRIs and ultrasounds detect Endometriosis? Do you need a scan before a laparoscopy?

**Dr Kate Stone** is an obstetrician gynaecologist with speciality qualifications in ultrasound imaging. **Dr Natalie Yang** is a consultant radiologist with sub-

specialty interests in women's imaging and MRI.

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**Psychology, mindfulness & living with endo** 26m 10s

## Dr Paula Watkins and Syl Freedman

Dr. Paula Watkins, a clinical psychologist and Syl Freedman, co-founder of EndoActive, outline a holistic psychological treatment programme for managing endometriosis. Dr Watkins describes how she worked with Syl, using cognitive-behavioural and positive psychology and mindfulness to help her cope with endo. Syl explains how that treatment has benefited

her in many aspects of her life.

**Dr. Paula Watkins** specialises in forensic and refugee mental health. Syl Freedman was diagnosed with Stage 4 Endometriosis in 2012. She and her mother, Lesley Freedman, co-founded EndoActive in 2014 to raise awareness of endo, provide information and advocate on behalf of people living with endo. **Syl** has a Bachelor of Communications in Social Inquiry, UTS and a Master of Health Communication from the University of Sydney.

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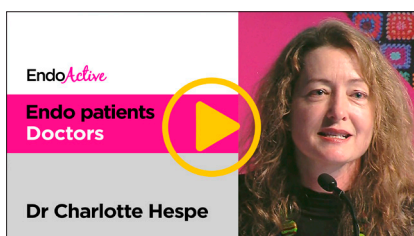
**The immune system, inflammation and endometriosis** 17m 00s

## Dr Alison Hey-Cunningham

Endometriosis is considered to be an inflammatory condition and autoimmune condition. Dr Alison Hey-Cunningham outlines immune aspects of endometriosis which can be harnessed to inform lifestyle and diet choices and reduce inflammation.

**Dr Alison Hey-Cunningham** is a research scientist at the University of Sydney with a PhD on the role of the pelvic lymphatic system in endometriosis. Her research aims to improve understanding of endometriosis, with the goal of contributing to improved management and a better quality of life for women affected by this common and complex disease.

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**Endo patients: Doctors** 1m 20s

## Endometriosis in primary care 18m 00s Dr Charlotte Hespe

What should you expect when being cared for by your GP? What are realistic expectations? What is a 'patient centred medical home' and what does this mean for 'me', my family and my doctors? Can we improve the timely diagnosis of endometriosis and access to evidence based care?

**Dr Charlotte Hespe** is a GP at the Glebe Family Medical Centre. She is Chair of Inner West Sydney Medicare Local and GP Synergy. She is also a board member of GPNsw and Deputy Chair NSW/ACT RACGP Faculty. She teaches medical students and is Head of General Practice and GP Research at University of Notre Dame, Australia.



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**Endo patients: Digestion** 0m 50s

## **Endometriosis and the bowel** 21m 20s **Dr Cherry Koh**

An overview of the risk factors, symptoms, diagnosis and treatment of endometriosis.

**Dr. Cherry Koh** is a Colorectal Surgeon and one of the clinical leads for colorectal research at Royal Prince Alfred Hospital.

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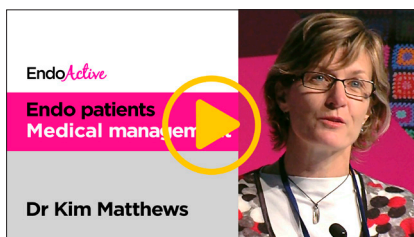
**Endo patients: Fertility** 2m 15s

## **Fertility fitness** 23m 45s **Dr Anne Clark**

Is endometriosis always to blame for infertility? Are women always responsible if there are problems? There are simple ways to improve your pregnancy odds.

**Dr Anne Clark** is an obstetrician and gynaecologist specialising in fertility and reproductive medicine. She is also Director of Fertility First.

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**Endo patients: Medical management** 1m 25s

## **Medical management of endometriosis** 16m 20s **Dr Kim Matthews**

Dr Kim Matthews discusses the medical management of endometriosis, a mainstay of treatment when used in conjunction with appropriate surgical treatment. The aim is for optimum quality of life whilst minimising the effect of the disease and the side effects of treatment. Progestins

(oral, depot, subdermal and intrauterine preparations), oral contraceptive pills (combined oestrogen and progesterone), GnRH Agonists, aromatase inhibitors and neuromodulators are discussed in detail.

**Dr Matthews** is a Fertility Specialist at Next Generation Fertility and a Visiting Medical Officer in Paediatric and Adolescent Gynaecology at The Children's Hospital, Westmead.

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**Endo patients: Pain relief** 2m 25s

## **Central sensitisation, pain and the brain** 19m 20s **Dr Meredith Craigie**

The neuroscience of pain and central sensitisation. How does chronic pain develop? Do opioids help?

**Dr Meredith Craigie** is a specialist pain medicine physician and a foundation member of the Pelvic Pain Foundation of Australia.

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**Endo patients: Laparoscopy** 2m 15s

## Laparoscopy and beyond 12m 40s Dr Susan Evans

Dr Susan Evans, gynaecologist, laparoscopic surgeon and author of 'Endometriosis and Pelvic Pain' explains laparoscopic surgery. What happens during a laparoscopy? Is surgery the only answer to Endo? What should you do afterwards?

**Dr Susan Evans** is a director of the Pelvic Pain Foundation of Australia ([www.pelvicpain.org.au](http://www.pelvicpain.org.au)), a not-for-profit health promotion charity supporting education and research in pelvic pain. She has contributed widely to education on pelvic pain in Australia and internationally.

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**Endo patients: Cannabis for pain** 1m 50s

## Medicinal cannabis and endo 20m 35s Justin Sinclair

What is medical cannabis? Could it provide alternative effective pain relief for Endo?

**Justin Sinclair** is a Research Fellow at the National Institute of Complementary Medicine at Western Sydney University and Head of the Australian Medicinal Cannabis Research & Education Collaboration.

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**Endo patients: What we wish for** 1m 30s

## Endo and the workplace 10m 00s Mia Freedman

How well is endometriosis understood in the workplace by employers and colleagues? Reluctance to discuss women's health issues at work can cause stigma and misperceptions for people living with endo.

**Mia Freedman**, founder, publisher and editorial director of Mamamia, offers a personal perspective on Endometriosis, speaking as an employer, a champion of women's rights and cousin of EndoActive co-founder, Syl Freedman.

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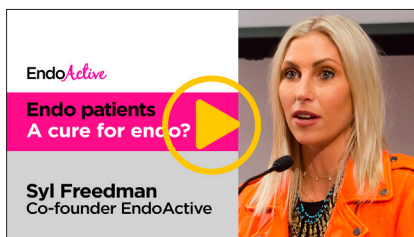
**Endo patients: Sex and endo** 2m 50s

## Sex, intimacy and endo 21m 00s Nina Booyen

Is sex painful for you? A candid discussion on ways to manage intimacy, pain and endometriosis.

**Nina Booyen**, a couples counsellor and accredited Clinical Sexologist, has a passion for helping couples who are battling illness, sexual dysfunction or struggling to remain in their relationships. She has trained in gender diversity and supports clients from the LGBTIQI community. Nina follows the Gottman Couples Therapy framework and utilises solution focussed, strengths based and cognitive behavioural techniques in her therapeutic approach. She is also trained in EMDR as a technique to assist clients who have suffered trauma.

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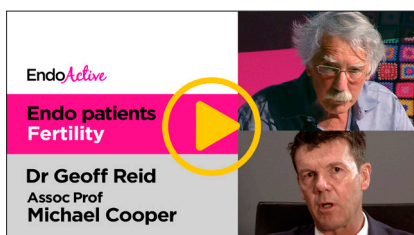
**Endo patients: A cure for endo?** 2m 05s

**Just go and have a baby?** 13m 38s  
**Syl Freedman, EndoActive**

Will getting pregnant cure Endo? Syl Freedman, Co-founder of EndoActive, examines the impact of this mythical advice on thousands of young women with endometriosis.

**Syl Freedman** was diagnosed with Stage 4 Endometriosis in 2012. She and her mother, Lesley Freedman, co-founded EndoActive in 2014 to raise awareness of endo, provide information and advocate on behalf of people living with endo. Syl has a Bachelor of Communications in Social Inquiry (UTS) and a Master of Health Communication from the University of Sydney.

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**Endo patients: Fertility** 1m 20s

**Ovarian endometriosis and fertility** 20m 05s  
**Dr Geoff Reid**

Professor Geoff Reid discusses the effect of ovarian endometriosis on fertility. Laparoscopic excision of endometriomas (ovarian endometriosis) has been regarded as “gold standard” treatment to improve symptomatology and natural fertility. The negative side is that excision of

ovarian endometriosis may actually cause irreparable harm to the ovary.

**Professor Reid** is a gynaecologist with a particular interest in endometriosis and infertility. He is the Director of Gynaecological Endoscopy at Liverpool Hospital and has VMO appointments at St Luke’s Hospital, St George Private Hospital and the Southern Highlands Private Hospital.

**Fertility - Associate Professor Michael Cooper** 12m 30s

A perspective on how endo affects fertility.

**Associate Professor Michael Cooper** is a Visiting Medical Officer and Head of Gynaecology at Royal Prince Alfred Hospital and Head of Gynaecology at St Luke’s Hospital. He is involved with ongoing research into endometriosis in collaboration with the University of Sydney and is part of the Sydney Women’s Endosurgery Centre team, training other surgeons.

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**Endo patients: What about diet?** 2m 25s

**Digestion, diet and endometriosis** 24m 30s  
**Dr Rebecca Burgell**

A gastroenterologist gets to the guts of endo, bloating and pain. Does diet make a difference?

**Dr Rebecca Burgell** is a consultant gastroenterologist with an interest in pelvic floor dysfunction and functional gastrointestinal disorders. Dr

Burgell works at Alfred Health and Monash University, where she is head of the Functional Gastrointestinal Disorders Service.

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**Endo patients: The pill and endo** 2m 00s

**Hormonal contraception and endometriosis** 19m 50s  
**Dr Terri Foran**

Busting the myths of medical management of Endo. How does the Pill affect Endo? Can stopping your period help or harm you?

**Dr Terri Foran** is a Sexual Health Physician with a special interest in contraception and menopause issues. Previously the Medical Director of

Family Planning NSW, she is now in clinical practice. Terri is also engaged in both clinical and research work at the Royal Hospital for Women in Sydney. She is a lecturer at the University of New South Wales in the School of Women’s and Children’s Health.