1. What are the biggest misconceptions about endometriosis among women’s health practitioners?

One of the biggest misconceptions is that ‘real’ pain should be visible. Other areas of medicine recognise that there is pain that can be ‘seen’ at operations or on scans, (for example, the pain of appendicitis), and pain that can’t be ‘seen’ such as migraine or phantom limb pain. However, for women with endometriosis, it seems expected that the lesions should represent the extent of her pain – and once these are removed that ‘real’ pain should resolve.

When I see endometriosis lesions at a laparoscopy, I do not consider that I am seeing the full extent of the women’s pain. I consider the lesions to be one, visible, common but non-essential, feature of pelvic pain syndrome. Her full pain picture may also include the symptoms of painful bladder syndrome, IBS, pelvic muscle spasm, central pain sensitisation, and menstrual migraine.

2. What are the difficulties health professionals face when diagnosing endometriosis?

A major difficulty is the lack of training in pelvic pain assessment and management. No health professionals currently leave their training with all the skills required to manage the needs of a woman with endometriosis, yet we are the ones women look to for their pelvic pain care.

It is imperative that gynaecologists either broaden their skills to manage a wider number of conditions themselves, or work within a team that can offer the range of care required.

3. Recently there have been many stories in the media about women’s struggle to obtain a diagnosis. Can you tell us about your experience of treating women who have had similar experiences?

Unfortunately, this experience remains common. Diagnostic delay is the norm, partly due to a delay in presentation for care, and partly to a lack of care after presentation. In 2017, the Pelvic Pain Foundation of Australia piloted the New Zealand-based Menstrual Education (ME) program in ten Australian schools: a program worthy of expansion throughout Australian schools. Increased awareness of normal menstrual symptoms allows girls to recognise abnormal symptoms promptly, and understand what help is available.

Difficulty obtaining a diagnosis of endometriosis is frequently followed by difficulty obtaining care for co-existing pains, and an over-reliance on laparoscopy. Laparoscopy has revolutionised the management of endometriosis. It remains crucially important when used judiciously in the hands of experienced laparoscopic surgeons. However, recurrent inexperienced laparoscopy, without consideration of non-surgical pain diagnoses risks surgical complications and increased central pain sensitisation.
4. What are some of the best ways for clinicians to support women to manage their pain? And what can women do to support themselves? What are your go-to suggestions to help in the short term?

With around 1 million Australian girls and women with endometriosis, many with complex pelvic pain symptoms, referral of all affected patients to a multidisciplinary pelvic pain unit is impractical. Clinicians caring for women with endometriosis have a responsibility to improve their diagnostic skills. To know when to, and when not to, operate: the hallmarks of a good surgeon.

To manage symptoms beyond dysmenorrhea, the Pelvic Pain Foundation of Australia holds courses for health practitioners who wish to broaden their diagnostic and management skills. For example, the gynaecologist who learns to recognise obturator internus muscle spasm, and can prescribe simple neuropathic medications, as well as offer expert surgery, has more to offer women with endometriosis and will be preferred by patients. The pleasure of providing effective care is one of the great privileges of medicine.

5. If you could give one piece of advice for clinicians who have patients with suspected or confirmed endometriosis, what would it be?

That stabbing pain on one or both sides – associated with difficulty walking or preference for the fetal position, that can refer to the back or front of the legs, and is helped by a heat pack – is commonly due to spasm in obturator internus. It improves briefly after surgery, possibly due to the muscle relaxant and change in activity, but then usually recurs. Endometriosis may have prompted the pelvic muscle spasm initially, but once established pelvic muscle spasm (commonly with a central pain component) may persist even after lesion removal.

6. With new government funding recently announced, what do you believe the future holds for endometriosis research and treatment?

The increased government attention is enormously welcome. It has been achieved through the combined work of interested politicians and the Australian Coalition for Endometriosis (ACE) – a collaboration of five peak consumer and advocacy groups. Endometriosis has been under-researched, under-recognised and under-managed for generations. The recent announcements are a beginning for a better future for girls and women.