

### **Chronic Pelvic Pain at Sydney's Royal Hospital for Women on the 17<sup>th</sup> of February 2011**

It was a privilege to be invited to speak at the meeting on Chronic Pelvic Pain at Sydney's Royal Hospital for Women on the 17<sup>th</sup> of February 2011 organised by Professor Thierry Vancaillie. There is now a greater understanding that the management of endometriosis requires more than just medical and surgical treatment. Some women respond well to these treatments alone, but for vastly improved health outcomes, the whole aspect of chronic or persistent pelvic pain must be treated with a multi-disciplinary approach.

“To have pain is to have certainty.  
To hear about pain is to have doubt.”  
E Scarry 1985

This quote will be particularly relevant to those women who have felt so disbelieved when relating their pain history. Sadly women still report a lack of validation for their symptoms whereas empathy, tolerance and broader management options should be the mainstay.

Pain medicine is a new specialty. As a result, there is a growing understanding of what happens in the brain when people suffer from persistent pain. Tissue damage causes nerves to send abnormal pain signals to the brain. Even when the damage has healed, these nerves may continue to send pain signals, with pain that continues long after the healing process is complete. Our responses and behaviour to pain are influenced by our beliefs, experiences, culture, memory and education. We therefore need to be looking at what that story tells us, as well as the disease (endometriosis) and from there work out the best holistic treatment approach to suit the individual woman.

Repeat surgery for endometriosis was noted as being a huge issue. A staggering 40% of women continue to have chronic pain following surgery, often with multiple laparoscopies that may not be effective at managing her pain. A US study showed that 70% will have yet another surgical procedure. It was noted that repeat surgery was not necessarily the most appropriate ongoing treatment as many pelvic pains do not respond to surgery. Surgery can only help some aspects of the pelvic pain pie.

The pelvis is a very busy area and other problems also cause distressing symptoms. For instance, one of the nerves in the pelvis often causing immense pain is the pudendal nerve which sometimes becomes irritated (pudendal neuralgia) or occasionally entrapped (pudendal nerve entrapment). This may follow a difficult birth or a surgical procedure, but may occur for no known reason. It often goes undetected.

Pelvic tissue and pelvic muscles can be traumatised not just with the lesions of endometriosis, but with the sum of all events and injuries a woman has encountered which can include surgery, pregnancy, C section, accidents involving the pelvis and even high exercise such as competitive and prolonged periods of cycling. All these factors can contribute to pain and can mean that tissue becomes sensitised and the body is on high alert for pain. The 'pain switch' in other words, doesn't learn to switch off.

Pain can be controlled medically. A first line of treatment is usually oral contraceptives and these were described as 'good medications'. They are cheap, non-invasive, have additional benefits and are relatively low risk. It was thought that GnRH medications may have some small role to play in helping symptoms and reducing recurrence. Though 50% will have side effects from progesterone, it may help reduce the recurrence of endometriosis. The levonorgestrel releasing IUS (Mirena) has improved symptoms and recurrence and is often well tolerated.

Research shows that there are major benefits from surgical resection of endometriosis. However it was also recognised that, to get the best outcomes, this surgery should be performed by gynaecologists practising advanced laparoscopic technique. It was also realised that this kind of surgery practised by highly skilled surgeons is unlikely to be get any better, so women who continue to experience chronic symptoms require further evaluation of the cause of their pain.

Muscle overload can arise from excessive exercise, direct trauma (like pregnancy) and neurovascular injury. In these cases the trigger points can be identified and pain can be treated with special injections (Botox) and pelvic physiotherapy. When muscles contract a lot they get bulky. This 'short muscle tension' reduces the range of movement and can cause chronic pain. Women are encouraged to do "squeeze, hold and let go exercises" rather than intense excessive exercise and should absolutely STOP all straining.

Emotional pain cannot be ignored in anyone suffering from chronic pain. In fact, emotional pain can 'turn' into physical pain. The trauma of experiences can rewire the brain – something changes and it becomes your life as well as affecting your personality. There are often lots of symptoms. A conversion disorder can develop (like avoidance, eg sex for instance) and in extreme cases some women find the 'patient role' is even comforting.

All the things which may have contributed to a woman's symptoms must be considered for best outcomes. Retraining the brain to have good experiences takes time, but is invaluable.

We can all learn from this meeting. It really was a reawakening in the way we think about endometriosis and pelvic pain. Education was high on the priority of best practice treatment services. It was said that a patient should not be treated in isolation. Learning how to live well with endometriosis and pelvic pain was essential for wellbeing.

There were 12 speakers at the meeting included Professor Thierry Vancaillie, Dr Susan Evans, A/Prof Milton Cohen, Dr Eric Bautrant, Dr Jason Abbott, Sherin Jarvis and Dr Joseph Dunn, . Presentations covered a variety of topics which included the current state of knowledge in chronic pain, endometriosis and chronic pain, chronic pelvic pain syndromes, pelvic floor physiotherapy, osteopathy and psychiatry.

A few do's:

- Set up goals.
- Understand your treatment and the timeframe.
- Ensure your condition, treatment and self-management options are well explained from a reputable source.
- Ask your gynaecologist and others involved in your treatment about what multi-disciplinary approach is available to you and how you can access it.
- Ask whether your gynaecologist is a recognised endometriosis specialist?
- Practice relaxation techniques and abdominal breathing.
- Exercise – choose 'old people's exercise at first. Walking is wonderful.
- Ensure regular bowel health and dietary changes if your bowel symptoms are troublesome.

- Avoid all straining – including toilet straining and exercise induced straining.
- Try to make sure your life is balanced with other activities and fun things so that you avoid being totally immersed in your symptoms and pain.

Endometriosis NZ can help. Services and programmes are peer reviewed and accepted as best practice. The services are available through some private endometriosis clinics in NZ and hospitals with the Patient Partnering Programme. You can find out more by contacting ENZ.

The book “Endometriosis and Pelvic Pain” Evans and Bush; is a must read and a real companion for recovery and learning to live well.

Mr Michael East, gynaecologist and ENZ trustee, wrote this many years ago and it absolutely fits with the modern view on best practice treatment.

*“TO PRACTICE MEDICINE WELL  
ONE MUST BE AWARE OF THE WHOLE PERSON  
PHYSICALLY, SOCIALLY, HISTORICALLY AND PSYCHOLOGICALLY  
TO PRACTICE IN ANY OTHER WAY  
IS TO COMMIT THE SIN OF OMISSION.”*

*Deborah Bush*

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