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SPEAKER SERIES

Early intervention for dysmenorrhoea and why it matters



Making Education Easy

2019

About the speaker



Deborah Bush
MNZM, QSM, DIP TCHG. LSB

Deborah Bush is the Co-founder and Chief Executive of Endometriosis New Zealand and has had a global influence on the promotion and prevention of endometriosis worldwide.

She has developed Innovative health initiatives and programmes for schools, workplaces, hospitals and CME. In 1997 she developed the world's first Menstrual Health and Endometriosis *me™* programme for schools which has significantly influenced early recognition of symptoms and timely intervention in adolescents.

Deborah was instrumental in developing a Task Force team with Medical Colleges and the New Zealand Government to develop new Clinical Pathways for endometriosis which will be implemented in 2019. Her private practice EPP (Endometriosis and Pelvic Pain) Coaching and Consulting integrates into treatment centres offering multi-disciplinary expertise.

Deborah presents frequently as key-note speaker at international academic conferences. Her many national and international awards reflect her achievements and contribution to the literature. She sits on the World Endometriosis Society Trust Board and in 2018, initiated the new organisation, World Endometriosis Organisations (WEO) and is Founding Principal.

Nurse Practitioners New Zealand (NPNZ) held their 2019 conference in Marlborough in April. Deborah Bush, co-founder and Chief Executive of Endometriosis New Zealand, discussed the early intervention for dysmenorrhoea and why it matters, at a breakfast session supported by Aspen.

Introduction

Dysmenorrhoea is the most common gynaecological condition, affecting between 45% to 95% of women around the world.¹ The condition has a huge impact on individuals, families, and fertility, and imposes a significant economic burden on society.¹ Dysmenorrhoea is associated with other conditions, especially endometriosis.¹ Unfortunately, few women with dysmenorrhoea seek treatment as they believe it would not help.¹

What is the difference between primary and secondary dysmenorrhoea? The main difference is that secondary dysmenorrhoea also includes other symptoms such as dyspareunia and nodules may be felt on pelvic examination and cysts detected on ovaries. Differential diagnosis is shown in Table 1.

Table 1. Differential diagnosis of primary and secondary dysmenorrhoea

Primary	Secondary
Onset shortly after menarche	Onset can occur at any time after menarche (25+)
Pelvic or abdominal pain usually associated with onset of menstruation and lasts 8-72 hours	Onset during menstrual cycle and varies in intensity
Abdominal pain, back and thigh pain, headache, diarrhoea, nausea	Abdominal pain, back and thigh pain, headache, diarrhoea, nausea and other gynaecological symptoms such as dyspareunia
No abnormal findings on examinations/tests	Abnormal findings on examinations/tests

Dysmenorrhoea in adolescence

Dysmenorrhoea has a prevalence of 25% to 93% in adolescent females, yet only 5% to 33% of adolescents seek GP advice regarding dysmenorrhoea.²⁻¹² In addition, the Menstrual Disorders of Teenagers (MDOT) study demonstrated that 25% of teenage females have marked menstrual disturbance, which includes severe pain, school absence, five or more symptoms, or moderate to high interference with life activities.¹¹ Globally, 20% to 31% of female adolescents miss school due to dysmenorrhoea,²⁻¹¹ which is in line with Deborah Bush's Christchurch study (*me™* programme) showing 27% of teenage females often or always missed school due to dysmenorrhoea every or most months (Figure 1).¹² "This is a quarter of our girls! When will that figure be important enough for the Ministry of Health to take notice?" asked Ms Bush.

Adolescent females with severe dysmenorrhoea experience disrupted development, interrupted education, missed job opportunities and emotional, psychosocial, physical and mental health outcomes – they can be frightened and anxious about getting their next period. Early recognition of symptoms and timely intervention is crucial. Raising awareness through education is the best screening tool (prevention) available and multidisciplinary treatment is key.

Figure 1. Dysmenorrhoea in adolescent females



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Why early intervention?

Endometriosis is the leading cause of dysmenorrhoea.¹³ While symptoms often start from the first menstrual period, endometriosis diagnosis can be delayed by more than 8 years.¹⁴ Endometriosis has the potential to develop into chronic pelvic pain,^{15,16} and also has a negative effect on fertility,¹⁷ and substantial personal, financial, and societal costs.¹⁸ For all these reasons, the literature and guidelines recommend early intervention for dysmenorrhoea.^{18,19} If nothing else, clinicians have an obligation to provide a duty of care.

Endometriosis is estimated to affect almost 200 million girls and women worldwide and 120,000 in New Zealand.²⁰ This means that globally, 1 in 10 women will have endometriosis. This is “a major public health issue too big to ignore”, according to Ms Bush. The condition is responsible for approximately 11 lost working hours per woman/week²¹ and over \$1billion in annual surgical and medical costs alone in New Zealand.²²

Symptoms of endometriosis

Symptoms of endometriosis are shown in Figure 2. Ms Bush pointed out that IBS type symptoms such as bloating, constipation, and diarrhoea are one of the leading symptoms of endometriosis.²⁰ Regarding tiredness and fatigue, iron deficiency is a hugely common and relatively hidden pathology for women of reproductive age.²³ Previous assumptions that only iron deficiency that leads to anaemia is the only scenario of clinical relevance are wholly incorrect; in fact, iron deficiency in itself can be significantly symptomatic and have substantial impact on quality of life - fatigue is the most prominent symptom, but there are others.²³ A number of clinicians are endeavouring to screen and treat iron deficiency and borderline iron. The new iron infusion ferric carboxymaltose has a much lower incidence of adverse events than ‘traditional’ iron infusions,²³ and Auckland Gynaecology Group is moving towards offering these infusions as a standalone service.

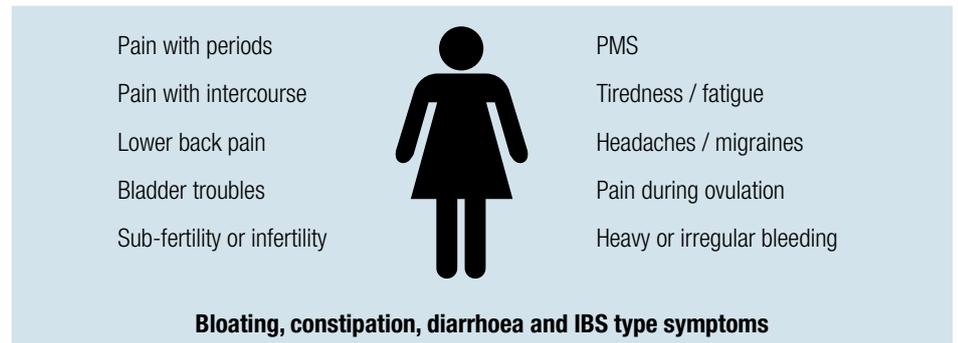
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Figure 2. Symptoms of endometriosis



The me™ programme in schools

The me™ (Menstrual Health and Endometriosis) programme is a New Zealand secondary school education programme endorsed by the World Endometriosis Society promoting early recognition of endometriosis symptoms and encouraging timely intervention.²⁰

The me™ programme research is now published in *The Australia New Zealand Journal Obstetricians and Gynaecologists*¹² and is the first piece of literature of its kind globally which examines the outcomes of a health education programme in schools and assesses whether it makes a difference. Data were collected from the education programme in Christchurch secondary schools and from the private Endometriosis and Pelvic Pain (EPP) Coaching Clinic.

Results showed that with consistent delivery of the programme, student awareness of endometriosis was 32%. Thirteen percent of female students experienced distressing menstrual symptoms and 27% (range 20% to 39%) of female students sometimes or always missed school due to menstrual symptoms.¹²

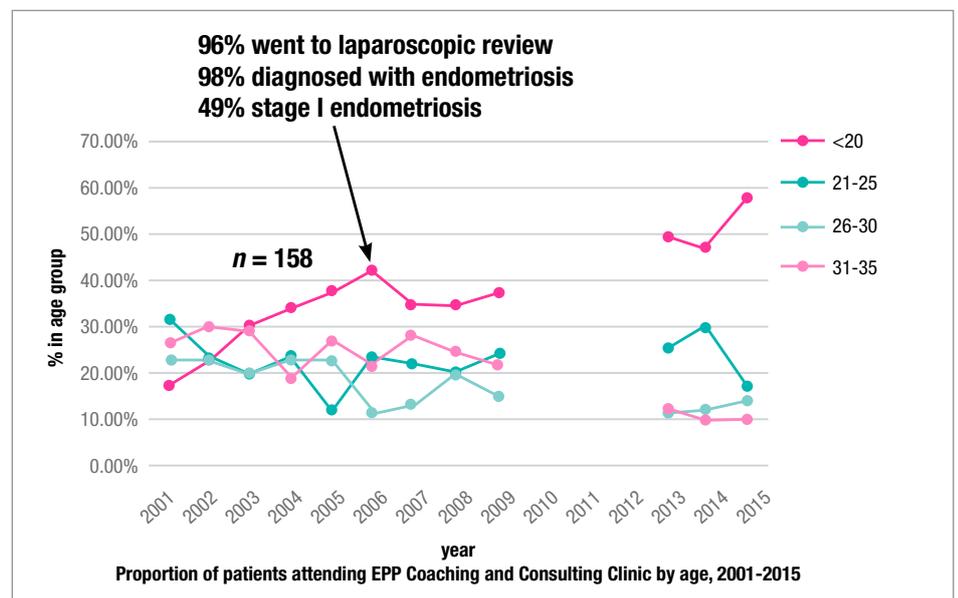
Are we seeing young women presenting earlier?

Has the me™ programme research translated to the clinical setting and are we seeing young women presenting earlier? In 2001, less than 20% of referrals to the EPP Coaching Clinic diagnosed with endometriosis were aged under 20 years (Figure 3).¹² That figure steadily climbed, to a peak in 2006 of over 40%. There is a gap from 2010-2013 where data were lost in the Christchurch earthquakes, then in 2015 almost 60% of referrals were aged under 20 years.

During the 2006 peak, 96% of women aged under 20 years underwent laparoscopic review. Their presenting symptoms were dysmenorrhoea, lower back pain, bowel symptoms (IBS), bloating and fatigue. Among these patients, 98% were diagnosed with endometriosis, and of these, half had stage I disease.

Ms Bush said these data show that if there is a suspicion for endometriosis – it probably is. Our young women should be treated and managed accordingly and referred to specialist care if not responding to first line treatments in primary care.

Figure 3. Proportion of patients attending EPP Coaching Clinic by age 2011-2015¹²

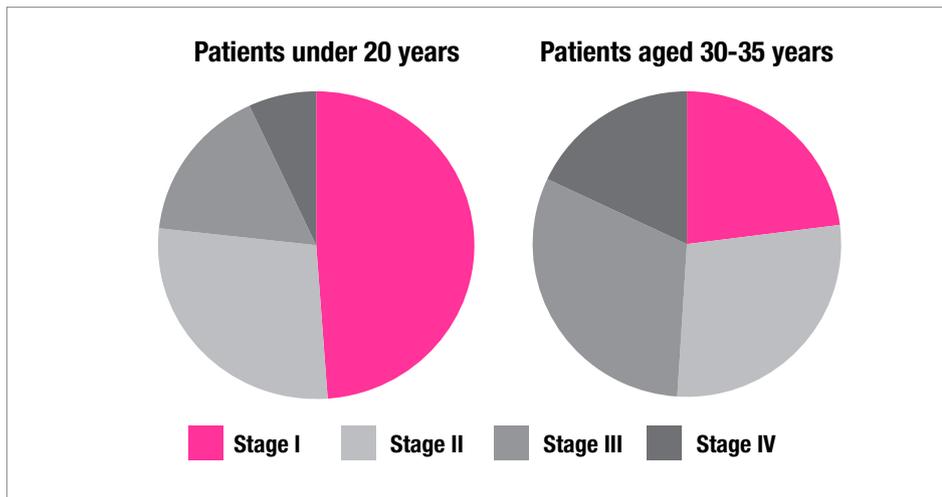




Early intervention is crucial

In 2006, patients under 20 years presenting to the EPP Coaching Clinic mainly had stage I endometriosis (Figure 4). These younger patients were treated with laparoscopic excision of endometriosis (gold standard), with or without Mirena or Jaydess placement. Management involved a multidisciplinary holistic approach specifically targeted to this age group. In contrast, patients in the 30-35-year age group had mainly later stage endometriosis and infertility. Thus, early intervention is crucial to stop the harm (including multiple sub-optimal surgeries) and significant impact of dysmenorrhoea and endometriosis.

Figure 4. Stage of endometriosis diagnosed in patients aged under 20 years versus 30-35 years



Case studies: Stage I versus stage IV endometriosis

Ms Bush discussed the case of 15-year-old Laura with stage I endometriosis, dysmenorrhoea and chronic pelvic pain, and 33-year-old Lisa with stage IV endometriosis, chronic pelvic pain and infertility. She said recognising symptoms early and intervening early, has the potential to stop progression of disease, significantly improve quality of life and avoid fertility being compromised down the track. Multi-disciplinary services and patient-centred care is key. Early intervention starts with educating youth as has been demonstrated in published research.¹²

New Zealand clinical pathway for the treatment of endometriosis 2019 (in review)

In 2015, Endometriosis New Zealand drove an initiative to bring about policy change for endometriosis. A Working Group was set up and is known as the 'Task Force to Improve the Quality of Diagnosis and Management of Endometriosis.'

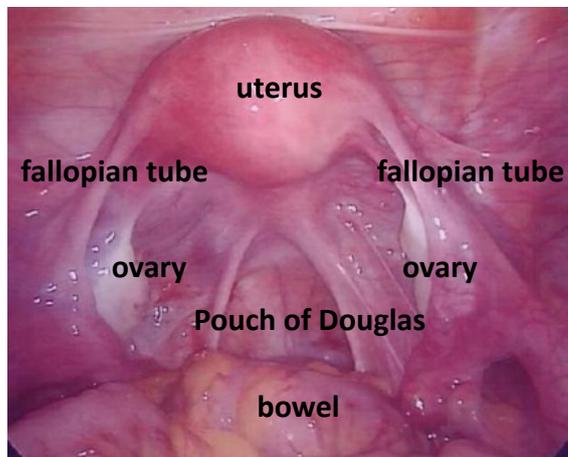
The group comprises representatives from Endometriosis New Zealand, RANZCOG, RNZCGP, Faculty of Pain Medicine, patients and the MOH. The Task Force was established to address:

- The high incidence of endometriosis and the impact on quality of life, productivity and fertility.
- The burden of endometriosis physically, socially, psychologically and economically.
- Early recognition of symptoms and timely intervention.
- Unnecessary surgical interventions.
- Inequity of access to care and reduce variability → major system improvement.

As a result, a new Clinical Pathway was developed which makes recommendations on recognising the disease and its management in primary care. It will recommend when to refer to secondary care and the expertise required. It will be a vital tool for doctors, hospitals and clinicians. At the time of presenting this talk, Ms Bush said the Clinical Pathway remains with the MOH for release and has undergone significant peer review.

Figure 5. Stage I vs stage IV endometriosis

Stage I endometriosis
Laura: 15 years old
Dysmenorrhoea & CPP

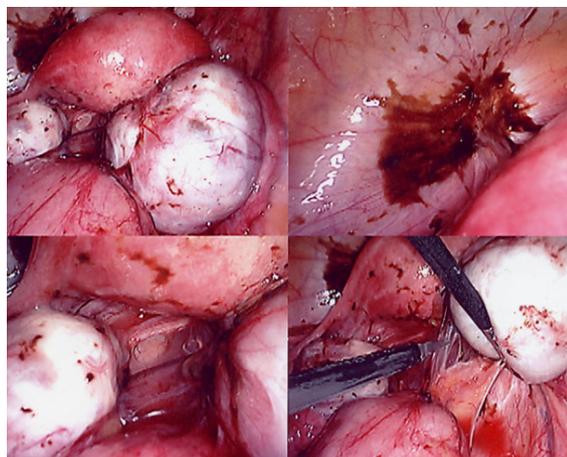


endometriosis



endometriosis

Stage IV endometriosis
Laura: 33 years old
Infertility & CPP





Take-home messages

Listen to patients

- Dysmenorrhoea is the most common gynaecological condition.
- Few women with dysmenorrhoea seek treatment.
- Endometriosis is the leading cause of dysmenorrhoea.
- Patients may have primary dysmenorrhoea symptoms, or symptoms that may have other causes (i.e. not endometriosis).
- Endometriosis diagnosis can be delayed by more than 8 years.

Treat appropriately in primary care

- Early intervention for dysmenorrhoea and endometriosis is key.
- IBS symptoms and fatigue are common symptoms of endometriosis.
- Treat iron deficiency and borderline iron levels.
- Endometriosis may lead to chronic pelvic pain, infertility, and substantial personal, financial, and societal costs.
- Watch for new clinical pathways.
- Focus on outcomes which matter to the patient.

Refer

- Gynaecologist with special interest and surgical expertise.

Educate

- Continuing Medical Education.
- Patient resources from Endometriosis NZ. Free downloadable eBook.
- Communities.
- Schools through me™ programme.

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