

Endo Info - correcting the misinformation

- Endometriosis Australia's Medical Director, *Associate Professor Jason Abbott*

During the week, [CNN](#) posted a story on Lena Dunham whose own battle with endometriosis and its impact on her career shone the media spotlight on her personal plight and the monster that is endometriosis. As part of that story, Dr Scott Sullivan from the University of South Carolina posted comments regarding endometriosis that were incorrect. I do think it important to note that Dr Sullivan is a specialist in feto-maternal medicine (high risk pregnancy) and not endometriosis and his views are commonly held views of many doctors who do not have specialist knowledge of endometriosis and it is unhelpful to continue these views with the modern, scientifically based information that we now have on this chronic and debilitating disease that affects 1 in 10 women.

It is worthwhile reviewing the misconceptions in this article, and whilst posting this to our Endometriosis Australia readers is like preaching to the choir, your shares, tweets and dissemination of the right information will boost the cause for endometriosis sufferers in Australia and around the world.

Problem 1. Endometriosis is just misplaced endometrium that behaves in the same manner.

Endometriosis tissue is not normal endometrium simply displaced into the 'wrong spot' that bleeds each month. Firstly, the tissue is not the same as that found in the lining of the uterus and its principle action is to cause inflammation in the sounding lining (the peritoneum) and adjacent organs (commonly ovaries, tubes, bowel and bladder). The normal endometrium responds to hormonal cycles in a known manner with growth of the tissue, then if a pregnancy does not occur the falling levels of progesterone causes the superficial layer of the endometrium to shed and menstruation results. This is the loss of the tissue (endometrium) and blood that women recognise as a period. This cycle is not occurring in the endometriosis deposits that do have similar structure to the endometrium (hence the name) but definitely not the same function.

The correction of this is that endometriosis is deposits of tissue with microscopic structures (glands and the supporting tissues) that leads to inflammatory changes through the rise and fall of hormones during a cycle. Controlling the rise and fall of cycles with a variety of medications such as the combined oral contraceptive pill or progesterone may help to reduce the inflammatory changes and control symptoms. It has also been shown scientifically that progesterones may actually reverse early endometriosis deposits and they do this by raising the levels of chemicals that heal damage to the peritoneum (technically they increase levels of TIMP - tissue inhibitor or matrix metalloproteinases - or MMP's. These MMPs damage the smooth cell layer of the peritoneum and make growth of endometriosis deposits possible). Once there is scar tissue and smooth muscle deposited into the tissues as well as the glands and supporting tissues, progesterones are not likely to work. Anti-inflammatory medications also work at this level to control symptoms.

Problem 2. Only 5-10% of women with endometriosis develop severe symptoms associated with endometriosis.

Whilst it is true that endometriosis may be asymptomatic both in terms of women having no pain and being able to become pregnant, these two primary symptoms (all types of pains that are often chronic and debilitating) and sub fertility (difficulty becoming pregnant compared to women without endometriosis) are huge, huge problems for women with this consuming disease. And more doctors need to listen and respond to what women tell them. It is estimated that 40% of women with infertility have endometriosis and 75% of women with endometriosis have severe pain. In addition, 80% of endometriosis will progress over time - although this may be a slow rate, it has also been reported scientifically that this can go from very minimal disease to severe disease in 6 months. It is important that chronic pain be addressed early to reduce the nerve changes that occur in the body which make it more difficult to alter the pain course over time. So whilst 95% of women will have period pain at some time of their life and 50% will have some period pain with each and every period due to the production of eicosanoids (the group of chemicals related to pain production that arise with the onset of menstruation) if these are not simply and easily controlled by physical measures (e.g. a shower, bath, hot water bottle or physical exercise) or simple analgesics (non-steroidal anti-inflammatory medication or paracetamol), then this needs to be addressed and endometriosis at least considered. Many women put up with severe pain for far too long before the diagnosis is considered and made. Trying to claw back from a chronic pain cycle is never easy, so early intervention for pain that stops you in your tracks is essential.

Problem 3. The 'common' way to diagnose endometriosis is a laparoscopy.

This is partially true since laparoscopy will diagnose endometriosis, however the statement needs to be much stronger than that since surgery with excision of the lesions and examination under a microscope is the only way to diagnose endometriosis. There is currently no blood test, scan or non-invasive method to make a diagnosis for endometriosis. Whilst it is not essential to have surgery should the symptoms suggest endometriosis as a likely factor, this is the only way to confirm that diagnosis. A laparoscopy is the insertion of a thin telescope (either 5mm or 10mm) through the umbilicus (belly button) that is attached to a camera. It is an invasive procedure and requires a general anaesthetic and carries risk. It is imperative that the surgeon doing the laparoscopy knows what it is they are looking for and has the skill to remove the lesions at the same time. This means that it is one surgery – one surgery done well will be a whole lot better than multiple surgeries with part treatment or biopsy only. This is not helpful for the woman with endometriosis.

Problem 4. Most cases can be treated using the hormonal birth control (combined oral contraceptive pill or OCP) and those that don't want to use the OCP can use strong medication called Gonadotrophin Releasing Hormone analogues (or GnRHa).

Firstly the OCP may be a useful drug for women with endometriosis. It may be used for a very long time, it has helpful effects such as reducing the total concentration of oestrogen in the pelvic cavity by more than 30 times (remember oestrogen drives endometriosis proliferation) and the constant rise and fall of hormones is controlled. But the pill is not for every woman – in fact 50% of women who are prescribed the OCP will not be taking it in any form 12 months later. The side effects may be intolerable (breast tenderness, headache, nausea or mood change to name a few) or women may want to become pregnant when no hormonal medications may be used at all. An alternative for long term management is a progestogen only – this is one of the hormones used in the OCP and may be given in many forms – a pill, an implant under the skin, a depot injection or a slow release form from an intrauterine device. Again, these may be used over a very long time and offer very good success but are not tolerated by all women and may not be used if a woman is trying for a pregnancy. It may be necessary to find the right combination of medications for you with the fewest side effects.

The GnRHa that are discussed in the article as an alternative to the OCP have a huge number of side effects and (this is a personal view from my experience over the last 20 years of treating women with endometriosis) they have a very limited role in the treatment of endometriosis. These drugs are frequently used in the USA and the problem with them is that they may only be used for 6-12 months at most. They do not reverse endometriosis although they may reduce pain symptoms since they make the woman temporarily menopausal. The downside to this medication is that the effects of bone-thinning may be permanent and the side effects including joint pains, hot flushes and sweats, hypertension and a host of other metabolic effects are debilitating and bring a whole raft of new issues for the woman with endometriosis. Mathematically, if you can only use this medication for 12 months in a 30-year reproductive life-span (which is conservative) then this represents treatment for only 3% of a woman's life, or alternatively, non-treatment for 97%. What we need is better non-hormonal medications and certainly a very judicious use of the very powerful agents like the GnRHa group that are used all too frequently and readily.

Problem 5: Hysterectomy cures Endometriosis.

No it doesn't. It never has and it never will. But it is important to think about why it doesn't. Endometriosis is a multifaceted range of diseases (it is way to simplistic to consider that it is only one disease) where there are variable presentations, locations, symptoms and severities. To think that removing the uterus – which may be normal in women with endometriosis will help solve the problem (particularly if the remainder of disease is left behind at surgery since it is 'too hard' to remove) does not make a lot of sense. It is true that some forms of endometriosis may involve the cervix, the ovaries and their ligaments, the front wall of the uterus to the bladder and even its surface where hysterectomy may help.



In addition, sometimes for women who have completed their family the abolition of menstruation with no more cyclic elaboration of those eicosanoids (the inflammatory chemicals) may provide symptomatic improvement. What it can't do is change the underlying genetics that lead to endometriosis, so if the uterus is normal then its removal will be of no value to the woman suffering the disease.

The uterus may also have endometrial glands and stroma within the muscular walls – a condition called adenomyosis which is a separate condition to endometriosis and is also relatively common with heavy bleeding and severe pain being common features. When there is no endometriosis, then hysterectomy may be curative for women with adenomyosis – but that is the subject for a separate blog....

An invitation to High Tea with Endometriosis Australia

So whilst it is always good to have information on endometriosis brought to the forefront of people's minds, that information must be factual. So followers of [Endometriosis Australia](#) help us to spread the factual word on this disease to those beyond the reading group. March is Endometriosis Awareness Month and Endometriosis Australia is hosting EndoMarch – high tea events on Saturday the 19th around the country with speakers, information, raffles, prizes and more visit the website for an event near you www.endometriosisaustralia.org. All of this so that Australia continues to lead the way with endometriosis research and awareness – factual and progressive information to tame the beast that is endometriosis.