

Endometriosis Association of Ireland (EAI)

Meeting with Joint Committee on Health, 28th June 2023 at 9.30am

Good morning, thank you chair and committee members for inviting the EAI here today. We are delighted to have this opportunity of opening a dialogue with you, hopefully the first of many, in discussing what can be done to help people suffering from endometriosis. I am going to start with an overview of the effects of endometriosis and then will speak about some of the progress that has been made to date, our view on current issues, possible solutions and then a bit about us as a charity.

Endometriosis is a chronic, progressive, inflammatory disease. It can manifest in many different ways, has been found on every organ of the body and it's effects are far reaching within society, I am going to speak about 5 specific areas;

1. Firstly, whilst not a menstrual disorder, endometriosis is usually triggered during teenage years, with the hormonal shifts that accompany the menarche. Young girls can experience intense pain, discomfort and heavy periods. Sufferers are frequently dismissed by doctors, and sent home with pain medication or oral contraceptives. However for most sufferers these solutions do little to help. This can end up leading people to self-medicate, and rely long term on pain medication, and we are all aware of the catastrophic outcome this can have
2. Next, is during reproductive years. Endometriosis often leads to fertility issues. For some, who don't present with pain, or for those on birth control, the diagnosis might only be triggered when seeking fertility treatment. Surgery is often performed to create a window of opportunity for conception, however, for some this may be too little too late, and there are cases where young women have lost their wombs or ovaries before they have even considered having a family, or simply those who are unable to have children, through the damage the disease has done to their bodies, and also through poor medical guidance. On top of this, there added anguish due to the inappropriate setting of endometriosis treatment, being primarily conducted in maternity hospitals
3. The third cohort are in the peri-menopausal or menopausal stage. The oestrogen dominance associated with endometriosis patients can lead to complications in prescribing the right combination and level of HRT. Some women who have undergone a hysterectomy describe having to fight to get progesterone as part of the HRT regime. The common medical guidelines are that progesterone is not needed if you do not have a womb. However, endometriosis exists in the body outside the womb, and progesterone can still be needed to help manage and control its symptoms long past menopause. These women can also face issues accessing the care they need as they no longer fit within the scope of gynaecological services
4. The next area is with regard to other related conditions – endometriosis is correlated to other oestrogen dominance linked conditions like PCOS, Fibroids and Adenomyosis. It is a complex condition with wide varying symptoms and unpredictable development. This can often lead to misdiagnosis and mistreatment. There are also some startling studies that suggest other worrying co-morbidities such as various cancers, autoimmune diseases like MS and inflammatory bowel diseases, asthma and allergic reactions, and cardiovascular disease. (<https://endometriosis.org/news/research/endometriosis-and-comorbidities/>)

5. The last area we will speak about today is with regards to mental health, and how this condition affects people's day to day lives
 - a. The hormonal imbalance associated with endometriosis can cause anxiety, depression and mood fluctuations in many patients
 - b. In addition to this, there is the emotional stress for those living with the debilitating pain endometriosis can cause. I use the word living, however is it even the right word to use? Are they really able to live or are they just finding ways to cope on a daily basis?
 - c. There are those living with the chronic fatigue associated with endometriosis, a fatigue that no amount of rest nor healthy behaviours alleviates fully
 - d. There are also those living with the destruction the disease has done to their bodies after years of misdiagnosis and mistreatment, and for some the turmoil of never being able to have children
 - e. For school goers there can be frequent absences, for those able to work, careers and performance can be impacted and worse still, some are not able to work at all as the daily stress the condition puts on them is too great
 - f. Also, the financial burden on patients spans decades causing additional stress

To summarise, endometriosis is a misunderstood, misdiagnosed and mistreated condition that has far reaching consequences for people assigned female at birth of all ages and socioeconomic backgrounds. The age with which menarche is starting is getting younger. The life expectancy of females is getting longer and women now represent more than 50% of the total population. Nationally, and globally, we speak about the need for gender balance in society, yet we lack an effective, cohesive women's health strategy.

The EAI and a host of independent advocates have been campaigning on behalf of the endometriosis community since 1987 and were invited here by Gino Kelly TD to present in the AV room in Dec 2019. We then met with the health representatives of the different parties throughout 2022. There has been some momentum since then, with the Coombe announcing its Enhanced Endometriosis Clinic, and the HSE funding an endometriosis clinic in Tallaght with plans for one in Cork, through the Womens Health Action Plan. We welcome the positive steps taken here and also with the development of the National Endometriosis Framework, however, we have concerns over how well understood endometriosis is and whether the needs of the patients have been fully considered, and welcome the opportunity to discuss it further this morning.

Fundamentally, there is still a long way to go and there are still many issues; long wait times for diagnosis and treatment persist. Factors contributing to this are the lack of skilled surgeons, with only a small number trained in excision surgery, and insufficient dedicated theatre time for endometriosis patients. For anyone in severe pain, even a month is too long to wait.

Women are still having to travel abroad to get the treatment they need, and while the cross border directive was put in place to help facilitate this, not everyone is eligible, there are up-front costs which leave it out of reach for many and those who do travel are faced with the distress, loneliness and complications associated with travelling abroad for medical treatment. The Irish healthcare system is letting these women down and adding to their burden emotionally and financially.

There are costs both to the individual sufferers and society. Patients on public waiting lists may end up needing to go private, to get the treatment they need, or abroad as just described. There may be

complementary treatments used to alleviate suffering, monthly prescription bills for medication to mask the symptoms or pain. As I mentioned earlier, there are some who cannot work at all, or cannot work full time, or need extended time off from work or school and this further compounds the personal and societal cost.

So, what outcomes are we hoping for endometriosis sufferers and how do we believe they can be achieved?

1. Education – to create awareness in young girls and empower them with the information they need to get the right diagnosis or treatment and continue to remove the stigma of talking about women's health issues. We need to ensure that there is awareness that it is not normal to have menstrual pain that impacts day to day life. This could be done through school programmes like the ones rolled out in New Zealand and France and regular awareness campaigns
2. Diagnosis - a reduction in waiting time to get a diagnosis. Early diagnosis and intervention is key to preventing long term damage and suffering. GP training through CPD and at undergraduate stage for medical students, training on imaging skills and how to identify the disease as it can often be missed or misread, and increasing the number of specialised surgeons in Ireland
3. Treatment – a reduction in waiting time for treatment in Ireland. We need, more trained endometriosis specialists, within accredited multi-disciplinary clinics to provide effective treatment pathways including aftercare
4. Research – the treatments available today do not cure endometriosis. They either suppress it through hormonal treatments, or surgical intervention which can provide varying degrees of temporary relief depending on the individual case. To understand this complex, multi-faceted disease, increased funding should be made available. Dedicated research staff within centres of excellence and collaboration with academia are also needed. This would provide critical mass in order to further research

We understand that this would require significant resources and funding, however the cost of not doing it in the long run would be far greater. It is still estimated that it takes on average 9 years to get a diagnosis. One in 10 women is thought to be affected, and given the disease affects women from age 8 to 80, the number of women affected is likely to be underestimated and will continue to grow.

I want to finish, with a little bit about the EAI. We do not receive any government funding. We are a small charity run purely by volunteers. We are either affected directly or indirectly by endometriosis so can speak first-hand about the issues I have described.

As a charity, we are now close to a full complement of board members, and, thanks to the generosity of our community we are in a position for the first time to be able to employ someone on a part time basis. We believe that this will go a long way to ensure that we are better equipped to deal with the volume of people who reach out to us for help, either directly, or indirectly through the HSE, expand our reach within the endo community, unite the voice of sufferers and advocates and to start having regular open dialogue with this committee or other stakeholders not here today, to ensure that collectively, we keep the patient voice at the centre of policy going forward.

Thank you.

