

Senedd Cymru
Y Pwyllgor Plant, Pobl Ifanc ac Addysg

Ymchwiliad i effaith argyfwng Covid-19 ar blant
a phobl ifanc yng Nghymru

COV 199
Ymateb gan: Endometriosis UK

Welsh Parliament
Children, Young People and Education Committee

Inquiry into the impact of the Covid-19 outbreak on
children and young people in Wales

COV 199
Response from: Endometriosis UK

I am responding on behalf of Endometriosis UK, the UK's largest charity supporting people affected by endometriosis. In Wales we run two Support Groups, a UK-wide helpline and Online Support Group, and an online forum to be there for those with endometriosis. We also support endometriosis research and work with Governments across the UK to raise the profile of endometriosis and ensure everyone has access to the right support at the right time.

Endometriosis is a condition where cells similar to the ones in the lining of the womb are found elsewhere in the body, usually within the pelvic cavity. It can be a debilitating condition affecting all aspects of a young person's life, including their physical and mental health, education, relationships and future career.

Symptoms can begin from the onset of puberty, with common symptoms including chronic pelvic pain, painful or irregular periods, painful bowel movements, pain when urinating and fatigue. The condition affects 1 in 10 women in Wales, and there is no cure. Treatment options are limited and can also come with side effects, and include hormone treatment, surgery and pain management.

There have been a number of challenges for young people with diagnosed or suspected endometriosis since the outbreak of COVID-19. The onset of the Covid-19 pandemic meant an abrupt change in healthcare provision in the UK. Whilst the primary focus was on the care of those infected with SARS-CoV-2 and public health measures to prevent transmission/identify those most at risk, individuals with chronic conditions saw their treatments halted, cancelled or changed with very little warning, little information available and extremely limited access to clinicians (in primary or secondary care). The impact of this on young people's physical and mental is huge, and areas of concern for the Committee and recommendations are listed below.

Education:

- The pandemic has put a huge strain on young people's education, and for those with diagnosed or undiagnosed menstrual health

conditions, this has only been heightened, with many already having missed considerable amounts of school prior to the outbreak.

- With many young people facing extra pressure due to missed school as a result of the pandemic, the pressure is only heightened for those with additional challenges such as living with endometriosis. Young people may be having to play “catch up” now schools have returned due to missed school, and for those still having to miss out on their education because of their menstrual cycle, the pressure and subsequent impact on young people’s mental health and education cannot be overstated.
- Menstrual wellbeing education should be taught in all schools across Wales, and be a mandatory element of the new Health & Wellbeing segment of the Curriculum for Wales Bill so that students understand what is normal for their menstrual cycle, and when and how to seek help if something isn’t right. This would also help ensure both teachers and pupils have a shared understanding of why some young people may need to take time away from school if they are suffering with their menstrual cycle or a menstrual health condition, without this, it will only add to the feelings of isolation heightened by COVID-19 for those with menstrual health conditions.
- A recent report in October 2020 by the APPG on Endometriosis found that often or very often 52% of respondents found it difficult to focus on their studies and 43% had to take time off school. The inquiry also heard from people who could not get into university due to the amount of missed school and the subsequent impact this had on their exam results, with some also who reached higher education also having to drop out. Without a known condition or access to support, young people are having to take time away from school and their education as they do not have access to the right treatment and support to help them manage their condition. At a time when young people have already had to take so much time away from school due to COVID, this is an even bigger concern for those who may need to take additional time off due to their endometriosis.
- We have also heard from some students who have benefitted in some ways as a result of home learning, with some stating that having regular access to toilets and easy access to menstrual products has helped them manage their condition.

Mental health

- The impact of endometriosis on the mental health of young people can be huge. The APPG report on Endometriosis from October 2019 found that of over 10,000 respondents: 95% said that endometriosis / the symptoms of endometriosis had impacted

their wellbeing negatively or very negatively, 90% would have liked access to psychological support but were not offered any, and 89% felt isolated due to their endometriosis. The impact of COVID-19 will have only heightened these feelings, with many people accessing our services stating that the pandemic and the halting of their endometriosis care has had a negative impact on their mental health and have felt feelings of isolation.

- Mental health support initially in the form of online resources and virtual appointments should be developed to provide prompt support, whilst longer term solutions are developed and put in place. Whilst this may require significant investment from health service providers initially, in the longer term it can only be beneficial for those suffering with endometriosis and may reduce the burden of their symptoms and the negative impact on quality of life including a young persons education.

Access to treatment and support for young people during COVID-19:

- Diagnosis for endometriosis takes on average 9 years in Wales, and with surgeries and appointments cancelled and delayed due to COVID, this is likely to only increase. Prior to COVID, in England 17% of patients were waiting 10 months or longer for their surgery, opposed to 32% in Wales. Waiting times for surgery and appointments is increasing, with the Cardiff Specialist Endometriosis Centre stating that some may be waiting up to 3 years for surgery. Lengthy diagnosis and long waiting times for surgery and appointments can have a huge impact on a young person's physical and mental health, as well as their education. It also means that for some, they may be suffering unknowingly with a menstrual health condition for their entire school life. Wales only has one endometriosis specialist centre, meaning many young people will not have access to specialist support. Instead, referrals may be to local general gynaecology, even for deep endometriosis which the NICE Guideline [NG73] 'Endometriosis: Diagnosis and Management' is clear must be seen in a specialist centre. The Welsh Government undertook a review of provision of endometriosis services in Wales, which recommended an enhanced service to provide good care for all those with endometriosis in Wales. The recommendation is currently being considered for implementation.
- The Welsh Government should make a commitment to reduce waiting times or ensure those with endometriosis are not left in the dark about when they can expect their care to resume, and encourage there to be continued communication with patients about when they can expect treatment to resume to help minimize the impact on a young person's education and mental wellbeing.

- The Welsh Government should commit to reduce average diagnosis times with targets of 4 years or less by 2025, and a year or less by 2030.
- Governments and NHS's in the UK in response to the COVID-19 pandemic need to recognise the scale of endometriosis, and commit the resources needed to diagnose, treat and manage the disease; acknowledging it is a chronic condition and long-term support is needed.
- Welsh Government should ensure the NICE Guideline [NG73] 'Endometriosis: Diagnosis and Management' is implemented so that young people have the right access to treatment and support; minimalizing the impact on their education and physical and mental health.