

Endometriosis support: How 18 years of misdiagnoses led to the creation of the Frendo app

It took 18 years for Dearbhail Ormond, CEO and founder of Frendo, to be given a diagnosis of endometriosis. Her harrowing experience led her to launch an app specifically designed to help endometriosis patients and those with suspected endometriosis symptoms.

Endometriosis is an inflammatory, chronic illness in which tissue that is similar to the lining of the womb grows outside it in other parts of the body. It affects around 176M women, girls, trans and non-binary people, but its impact isn't just physical. For people who have endometriosis, the impact on their mental and social wellbeing makes the condition even more upsetting.

"I had been battling with severe pain, erratic sickness and multiple misdiagnoses since young adulthood, and with every misdiagnosis, my hope for answers dwindled and subsequently my mental health suffered," said Dearbhail. "In the 18 years searching for a diagnosis, you wonder what is wrong with you and you question yourself constantly. You feel like you're a burden and almost a fake of sorts as you go to doctor after doctor to be told there is nothing wrong with you."

"The misdiagnoses, as a result of ignorance on endometriosis and reproductive

illnesses, only exacerbated my frustration. I found myself internalising my suffering, which put a real strain on my mental health and my personal relationships too. At a young age – when, as a young woman, you should be caring and loving towards your body – I felt like my body was going against me and it was quite a lonely period to navigate.”

When the long journey to getting a diagnosis finally came to an end, Dearbhail was understandably elated.

“Even though I was diagnosed with stage 4 endometriosis and you’re being told you have a chronic illness, there was such a sense of relief to finally have answers. I felt validated and I could put a plan in place to manage the pain. A weight had been lifted,” she said.

Shared experiences

The average diagnosis delay for endometriosis varies from seven to 11 years, with one in nine people who have periods experiencing the disease in their lifetime. Dearbhail’s frustration and anger at the health system’s lack of understanding of endometriosis was a key factor in the creation of Frendo, an app designed for endometriosis patients and those with symptoms.

“Going through misdiagnoses, facing dismissiveness from doctors and having my symptoms and concerns rejected makes endo a very isolating illness to live with,” said Dearbhail. “As a result, I wanted to create a support network where endo sufferers could connect with one another and share their experiences to know that they are not alone and what they are experiencing is valid.

“More than just a health app, Frendo is a lifeline allowing users to connect with similar people going through the same agonising and confusing experience of getting an endometriosis diagnosis. Frendo’s screening questionnaire is a key differentiator and one of the most important parts of the app – it’s the first step in getting answers and identifying your symptoms to help plan your next steps towards pain management.

“The health tracker is designed for endometriosis patients and those with suspected symptoms. Whilst there are other cycle trackers in the market, Frendo’s tracker is specifically designed for endo sufferers to track their pain symptoms and helps to provide users with credible resources on how to manage symptoms, find alternative treatment options, and how to talk to loved ones about endo, as well as improve their general wellbeing while living with a chronic illness.”

The Frendo app has a community feature, which allows users to share their endometriosis experience and positive lifestyle stories via a hub, providing a much-needed support network.

“The mental toll from battling endometriosis is just as impactful as the physical pain,” said Dearbhail. “The community aspect to the app has always been at the very heart of Frendo and throughout its development. I kept thinking back to what I wish I had during those 18 years of searching for a diagnosis. I know what would have helped me through some difficult times – knowing I wasn’t alone and that there were other people going through something similar.

“I wanted Frendo to be a place where people could share their positive lifestyle stories and tips with one another to empower endometriosis patients to live as well as possible with a chronic illness, and ultimately offer tools on how best to support wellbeing.”

Growth in rocky times

One of the biggest challenges Frendo has faced to date is overcoming the pandemic, like many other founders. Frendo was born in 2020 and Dearbhail and her team were all set to launch the app just as the pandemic hit.

“Initially, I was disappointed with the delay, but we tried to use the delay to our advantage,” said Dearbhail. “We used the time to listen to our community and noticed the real want for peer-to-peer connection to discuss those shared experiences and find comfort in knowing you aren’t alone in your endo journey.

“Another challenge is how users needed a means to be able to track and manage their disease themselves, particularly as appointments were either getting cancelled or rescheduled. As a result, we developed the tracker and insights features further, which are the components that allow the user to diarise their symptoms and push back helpful reminders and information to aid their illness on an ongoing basis. If anything, the pandemic gave us the time to delve into the features that were most important to sufferers.”

Despite the hurdles, Frendo had a successful private pre-seed funding round after operating on grants since ideation. The feedback has been positive, particularly concerning the tracker feature.

“We have had a 45% month-on-month user growth rate since we launched, which has all been organic,” said Dearbhail. “We are now very excited to be launching officially and building the awareness of endo and Frendo out to a much wider audience in our key markets of Australia, the UK and Ireland to begin with.”

Education and awareness

Awareness of endometriosis and its symptoms remains low in the UK both with medical professionals and the wider public, a shocking notion given the widespread nature of the disease amongst people who have periods.

“We need to hold our medical system accountable and force them to really educate themselves and the public on endometriosis and other reproductive diseases” said Dearbhail. “Endometriosis patients need to trust their instincts – if they believe something isn’t right, continue speaking up and make them aware of the trauma caused by dismissiveness and misdiagnoses as a result of the long diagnosis delays.

“We need endo sufferers to continue to open up about their experiences, and encourage others to get screened earlier and begin their road to diagnosis. There also needs to be more educational programmes on reproductive health in schools to improve awareness at a younger age. With such a delayed diagnosis time, I want Frendo to help young people with periods understand the warning signs to look out for and feel confident in speaking up and getting help.”

Looking ahead to what’s next for Frendo, Dearbhail is set on providing an educational platform that will both support and teach people about the impact of the condition.

“I believe education and awareness is the key,” said Dearbhail. “One of our goals is for education and screening of endometriosis and other reproductive health conditions to be included in school curriculums, third level colleges and universities so that we can start talking about the disease more openly and support sufferers with taking action early.

“Longer term, my objective is for Frendo to become a clinical trials partner with leading reproductive health pharmaceutical companies, working together with real world data to create better treatment pathways for endometriosis patients.

“I hope that Frendo will help people feel supported, get a timely diagnosis in order to break the cycle early and, as a result, reduce the progression rate of the disease. That’s certainly the end goal for us!”

Dearbhail Ormond is CEO and founder of *Frendo*.

