

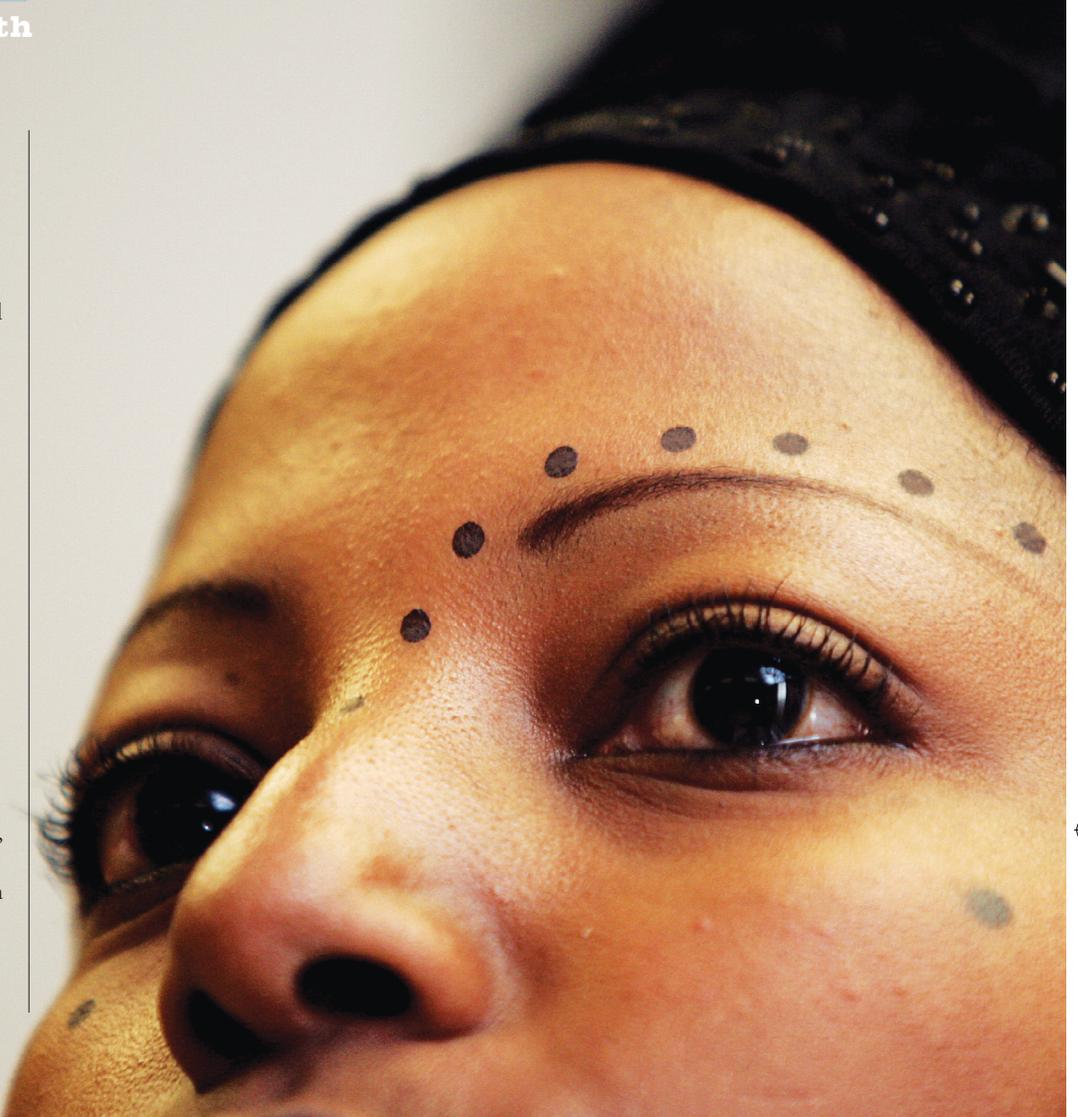


## Focus Women's Health

**A**delaide Damoah (*pictured far right*) is an artist of Ghanaian-British heritage. However, she has not always been a full-time artist. Damoah was doing well in her career in the pharmaceutical industry until endometriosis, a much misunderstood and little-known female medical condition forced her to take a break. Soon she would be compelled to give up her professional life due to the incapacitating condition she was battling. However, she redefined herself through her art when her illness became the basis of a mind-blowing series of heartfelt paintings, depicting her pain in a kaleidoscopic form. The negativity of her experience became the catalyst for her artistic expression. Today, Damoah is making a name for herself in the art world with her unusual artwork.

However, many women are not fortunate enough to be in Damoah's position. Based in the UK, she has access to some of the best healthcare in the world, providing treatment that will help reduce the crippling pain endometriosis inflicts on its sufferers. Damoah is also using her art to raise awareness about illness.

In other parts of the world, the stark difference is that they are still waking up to the devastating effects of endometriosis.



# Endometriosis silent, yet deadly

Endometriosis affects one in 10 women, yet little is known about the cause of this debilitating condition, which can also render its sufferers infertile. **Belinda Otas** talks to experts and some of its victims to shed some light on a neglected potential killer of women in their prime.

Described as a condition where tissue similar to the lining of the uterus (the endometrial stroma and glands, which should only be located inside the uterus) is found elsewhere in the body. Its lesions can be found anywhere in the pelvic cavity, ovaries, and fallopian tubes and in rare cases, inside the vagina, bladder, even in the lungs, spine and brain of the sufferer. Its most common symptom is pelvic pain but it could also have devastating implications for those affected, including infertility. At present, it is estimated 30 to 40 per cent of women affected by endometriosis may not be able to have children.

Dr Krina Zondervan, a genetic epidemiologist and fellow at the Wellcome



**“Adelaide Damoah redefined herself through her art when her illness became the basis of a mind-blowing series of paintings, depicting her pain in kaleidoscopic form. Today, she is making a name for herself in the art world with her unusual work.”**

Trust Centre for Human Genetics (WTCHG) and The Nuffield Department of Obstetrics and Gynaecology (NDOG), Oxford, England is currently leading a multidisciplinary research group working on understanding the epidemiology of endometriosis: its prevalence and impact across the world. She said, “In many countries, the condition is hardly recognised and many women never get a diagnosis. We know very little about the onset of endometriosis. What we have seen is that women who are more exposed to menstrual bleeding over their reproductive lifetime seem to have a slightly increased risk of endometriosis.”

Lone Hummelshoj is the chief executive

of the World Endometriosis Research Foundation (WERF). Founded in 2006, the WERF is based in the UK and the first of its kind in the world, is currently working with 32 centres in 20 countries including Egypt and Nigeria on the African continent. Her organisation’s aim is to foster research into endometriosis in order to improve knowledge and treatments in the hope that one day, no woman is crippled or prevented from having children by the disease. It also anticipates a time when endometriosis can be prevented.

A former sufferer, Hummelshoj explains that she suffered for 22 years and it took 11 years to get diagnosed and five surgical procedures to rid her of endometriosis.

**Left: one of Adelaide Damoah’s pieces of art depicting her illness. Her career in the pharmaceutical industry was cut short by endometriosis**

While there are no known causes for endometriosis, she adds that one of the reasons it takes a long time to diagnose the condition is because “Many women do not realise for cultural or societal reasons that distress with menstruation, for example, is abnormal. Discomfort is ‘normal’ but ‘distress’ is not. This means that most do not seek immediate medical help until the use of over-the-counter medicine has been exhausted. The second delay at primary level is that primary physicians dismiss menstrual distress or other cyclical pain and forget that the pain could be due to endometriosis. Hence, there is an added diagnosis delay before women are referred to a gynaecologist.”

According to Hummelshoj, in most countries, developed or not, endometriosis is still not well known at all and many millions of women suffer in silence and do not know that there may be treatments. Professor Hany Abdel-Aleem works at the Department of Obstetrics and Gynaecology, Assiut University Hospital, Egypt. He is a collaborator with the WERF and a participant in a new study recently commenced by the Foundation to assess the direct and indirect effects of endometriosis on society and women. He says to his knowledge, there is no documentation in Egypt about the number of women who suffer from endometriosis. Hence, its prevalence among women in the country is unknown. However, he encounters women with the condition when investigating infertility and cases of chronic pelvic pain.

Dr Bukola Fawole is a consultant obstetrician and gynaecologist to the University College Hospital, Ibadan. Like Professor Abdel-Aleem, Dr Fawole is also a collaborator with the WERF and champions the Foundation’s research in Nigeria. He said, “The study is the first research initiative in the country and the principal goal is to sensitise colleagues about endometriosis.” Dr Fawole says endometriosis has not received sufficient research attention among the African population and there is a lack of understanding about its existence in Nigeria. “The reason is primarily that of ignorance on the part of healthcare



providers. The training here does not give due cognisance to the condition. It is sad to note that many a woman with the chronic pelvic pain, for instance, would have passed through several doctors [while] being treated for pelvic infection.” He adds that there is lack of support for women affected by endometriosis in Nigeria. Due to the lack of understanding of endometriosis in women, misdiagnosis is rife in many cases. Dr Fawole gives the example of “a 17-year-old, who had acute lower abdominal pain and went to a private practice; she was misdiagnosed and one of her ovaries was removed. However the pain persisted until endometriosis was later diagnosed by the team. Its social impact on her life is that she was forced to quit school and encouraged to get married by her family as part of intervention for the debilitating pain.”

At present, most researchers agree that endometriosis is exacerbated by oestrogen. Hence, treatments currently available for

the disease aim to manage the production of oestrogen in the sufferer's body in order to relieve her symptoms. Though the WERF is currently undertaking a study to determine the socio-economic cost of endometriosis and the impact on the lives of sufferers, Hummelshoj says the foundation understands that “Some women with endometriosis either cannot work or need to reduce their working hours. Chronic pain also has an effect on relationships, and we do hear that relationships break up due to the illness the woman suffers from.” Dr Fawole adds that “Where infertility is involved, marriages may break up and social life may be non-existent.”

Hummelshoj, Dr Zondervan and Dr Fawole agree that the emotional, mental and physical pain endured by sufferers of endometriosis cannot be measured because “emotional and mental pain is so personal and it varies from woman to woman.”

**“In many countries, endometriosis is hardly recognised and many women never get a diagnosis. The way to help African women is to create awareness of the disease.”**

#### Specialist skills are needed to help diagnose endometriosis

However, they hope the study by WERF will shed more light on this area.

Dr Zondervan says in order for women in different parts of the world to gain a better understanding of their situation, they need to be informed and empowered with the right information. She added, “We need to raise awareness first, and then train gynaecologists with the specialist skills required for diagnosing and surgically treating the disease.”

Zondervan's point of view is reiterated by Dr Fawole who believes the best way of helping women in Africa to understand the disease is by “Essentially creating awareness among the populace and sensitising them about the common symptoms that may be suggestive of the condition, so they can seek care. African scientists must also begin to take interest in the condition and align with colleagues outside the continent in research into the condition. Ultimately, our health systems will have to invest in health technology that will avail our women of the necessary care for this condition.” ■NA