

**It currently takes on
average **9 YEARS** from the
onset of symptoms to
achieving a diagnosis of
Endometriosis.**

**People with Endometriosis **deserve
better!****

Trustee Report

January 10th, 2023 – January 10th, 2024

Charity Name

The Endometriosis Foundation

Registered Charity Number

1178525

Registered Charity Address

601 Prince Avenue

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Contact

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www.theendometriosisfoundation.org

hello@theendometriosisfoundation.org

About us.

Endometriosis can cause enormous suffering but remains understudied, under-funded, under-diagnosed and often misunderstood. **Our mission** is to create a future where endometriosis is recognised and understood. **Our vision** is a future where everybody with endometriosis receives the care and support they need without delay.

We believe everyone should have access to accurate, transparent, and trustworthy information, especially when it comes to making decisions about their bodies.

The Endometriosis Foundation is a not-for-profit organisation dedicated to raising awareness, providing trusted and transparent information, education, and support. One of the biggest challenges people with Endometriosis face is accessing the right information and care which is why we are dedicated to arming people with transparent, reliable, and trusted information to help guide them through their journey with Endometriosis.



Our mission is to create a future where Endometriosis is recognised and understood.

Our vision is a future where everybody with Endometriosis receives the care and support they need, especially those within the later stages.

Our goal continues to be to raise awareness of Endometriosis, providing reliable and trusted information. We continue to educate healthcare professionals and the public.

Our Story.

The charity's founder and CEO, Carla, suffered from most of the obvious signs of endometriosis from the age of just 13. Despite multiple visits to her GP and being under the care of a gynaecologist aged 14, along with several emergency admissions to A&E, for years, like most people with endometriosis, her symptoms were dismissed by doctors as well as being wrongly diagnosed with various other conditions.

Carla was officially diagnosed with endometriosis and infertility aged 25, over a decade after her symptoms started. Her late diagnosis impacted much of her adult life, resulting in multiple life-changing operations, including an unnecessary appendectomy, various hormonal regulating treatments, several laparoscopies, a laparotomy (open surgery), reconstruction of her bladder and ureters, bowel surgery – resulting in a temporary ileostomy (stoma), and a total hysterectomy – taking away the chances of her bearing her own child, forcing her into surgical menopause at just 29 years of age.

As a consequence of her suffering and having discovered there was very little awareness and understanding surrounding endometriosis, she decided to make a difference. First, she set up an online support group which now helps thousands of people.

Next, she began carrying out educational talks in schools which led to her campaigning for awareness among young people in education. She partnered with her local MP, the late Sir David Amess. Together, they managed to get endometriosis education on the school curriculum for the first time and later, went on to establish the endometriosis All Party Parliamentary Group (APPG).

Carla went on to launch The Endometriosis Foundation, now one of two leading endometriosis charities in the UK. For Carla, her goal for the charity is for it to become everything that she never had.

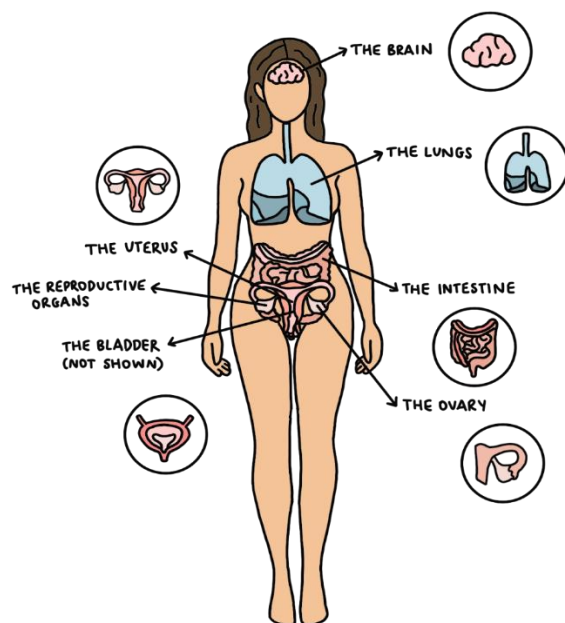


About Endometriosis.

Endometriosis is a common long-term health condition affecting more than 1 in 10 women and girls, and those assigned female at birth, usually of reproductive age (from puberty to the menopause). You may be more likely to develop the condition if a close relative, such as a mother or sister has it. It is a complex and often misunderstood condition that affects millions of people worldwide.

It can cause extreme pain, organ dysfunction, infertility, and numerous other physical and emotional challenges. Yet, despite its significant impact, the condition remains vastly under-recognised, under-diagnosed, and under-funded.

A diagnosis in the UK currently averages nine years. The causes are unknown and treatment options remain limited, with no definitive cure in sight.



What is it?

Endometriosis happens when cells, similar to those that make up the lining of the uterus (endometrium) are found growing and functioning in areas of the body they shouldn't be. These rogue cells are usually found affecting the lining of the pelvis, the ovaries, fallopian tubes, the urinary bladder and the bowel. However they can also be found further afield in places like the diaphragm (breathing muscle), chest cavity (thorax). Albeit rare, Endometriosis has been found affecting every organ within the entire body.

More about endometriosis

You can have one or few patches of Endometriosis in one area, or you can have multiple patches of Endometriosis in various parts of the body. These patches can be either on the surface (superficial endometriosis), deep inside the tissue and surrounding organ(s) or inside the ovaries forming cysts (endometrioma).

As Endometriosis develops, it can lead to the formation of fibrous scar tissue, causing organs such as the ovaries, fallopian tubes, the uterus, and bowel to stick together. This can distort the organs, jeopardising their function, leading to severe pain and sometimes serious medical problems. In its more severe form, this is known as frozen pelvis disease.

For information about Endometriosis, visit our website www.theendometriosisfoundation.org

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OUR YEARLY ACHIEVEMENTS.

Website

Our comprehensive website is now live, offering personalised information for everyone affected by endometriosis. Details about the condition, the signs, available treatments, referral pathways, and valuable nutritional and fertility advice.

Official launch

On March 7th, 2023, in conjunction with Endometriosis Awareness Week and 'National Be Heard Day,' The Endometriosis Foundation's official launch event was held at the House of Lords, UK Parliament. This momentous occasion marked a significant milestone in our mission and was attended by key stakeholders, supporters, and advocates who share our commitment to making a meaningful impact.

Partnership announcement

On the same day as The Endometriosis Foundation's official launch event, our founder's personal journey with endometriosis was prominently featured across all Holland & Barrett digital storefronts. This feature marked the beginning of an exciting new partnership between our charity and the renowned health and wellness retailer, aiming to raise awareness and support for those affected by endometriosis.

We hosted the BSGE webinars

Throughout the month of March, in honour of Endometriosis Awareness Month, The Endometriosis Foundation hosted a series of educational webinars in collaboration with the British Society for Gynaecological Endoscopy (BSGE). These webinars serve as a crucial platform to disseminate vital information about endometriosis, covering topics ranging from symptoms and diagnosis to treatment options and patient care. By bringing together leading experts and healthcare professionals, our goal is to empower individuals affected by endometriosis with knowledge, support, and resources essential for informed decision-making and improved quality of life. We are deeply committed to raising awareness and

fostering a better understanding of this often misunderstood condition through these insightful and educational sessions.

Endo Social events

The Endometriosis Foundation proudly launched its 'Endo Social' community events in collaboration with Holland & Barrett. These events aim to foster a supportive and informative environment for those affected by endometriosis. The 'Endo Socials' now take place regularly across the UK, providing a platform for individuals to connect, share experiences, and gain valuable insights into managing their condition. This partnership underscores our commitment to building a strong, informed community dedicated to raising awareness and improving the lives of those impacted by endometriosis.

Real Stories campaign launch

The Endometriosis Foundation has forged a meaningful partnership with Karl Storz, collaborating on multiple occasions to produce our Real-Stories campaign. Members from our support groups have participated in these sessions, courageously sharing their personal experiences on camera. These real-life accounts serve as powerful testimonials, shedding light on the challenges faced by those affected by endometriosis and highlighting the importance of awareness and support. Through this collaboration, we aim to amplify voices, inspire empathy, and foster greater understanding of the impact of endometriosis on individuals and their families. Together with Karl Storz, we are dedicated to raising awareness and advocating for improved care and resources for those living with this chronic condition.

Female Health Festival

The Endometriosis Foundation hosted its inaugural Female Health Festival at West Ham Women's Football Club. This groundbreaking event brought together experts, advocates, and the community to focus on women's health, with a special emphasis on endometriosis. The festival featured informative workshops, health screenings, expert panels, and interactive sessions designed to empower attendees with knowledge and resources. The collaboration with West Ham Women's Football Club highlighted the importance of supporting women's health in all areas, including sports and physical activity. This event marked the beginning of an ongoing effort to prioritize and enhance women's health and well-being.

Partnership announcement

The Endometriosis Foundation forged a meaningful partnership with OddBalls, uniting to raise awareness and support for those affected by endometriosis. This collaboration aims to amplify advocacy efforts through shared campaigns, educational initiatives, and fundraising activities. Together, both organisations strive to empower individuals with knowledge, promote early detection, and enhance the quality of life for those managing endometriosis. This partnership exemplifies a commitment to making a positive impact in the community and fostering greater understanding of this challenging condition.

Campaign launch

The Endometriosis Foundation launched its 'Our Fertility Matters' campaign, advocating for equitable access to treatment and comprehensive support for those affected by endometriosis. This campaign aims to address the significant barriers that many individuals

face in obtaining necessary medical care and resources. By highlighting personal stories, providing educational materials, and engaging with policymakers, the charity strives to bring about meaningful change in the healthcare system. The ultimate goal of 'Our Fertility Matters' is to ensure that everyone, regardless of their circumstances, receives fair and effective treatment options and the support they need to manage their fertility and overall health.

The Fertility Show

The Endometriosis Foundation made its debut at The Fertility Show at London Olympia. This significant participation underscored the crucial link between endometriosis and female infertility, as endometriosis is one of the leading causes of infertility among women. Our presence at the event provided a platform to raise awareness, offer support, and share valuable information with those affected by both fertility challenges and endometriosis. Building on the success of our first exhibition, the foundation proudly returned to exhibit at the 2024 show, continuing our commitment to education and advocacy within the fertility and endometriosis communities.

Sky News Documentary

The Endometriosis Foundation collaborated with Sky News on the acclaimed documentary, 'Endometriosis: My Search for a Cure,' which garnered attention and acclaim for its insightful portrayal of the challenges faced by individuals with endometriosis. This impactful partnership aimed to raise awareness and shed light on the realities of living with this condition. The documentary's nomination at the National Television Society further highlighted its significance in bringing important issues to the forefront of public discourse. Through this collaboration, both organisations continue to advocate for greater understanding, support, and advancements in the treatment of endometriosis.

Number 10 Downing Street

Our founder was honoured to join a pivotal round table discussion at Number 10 Downing Street, focused on the challenges and solutions related to endometriosis in the workplace. This high-profile meeting brought together key stakeholders, including policymakers, healthcare professionals, and advocates, to address the impact of endometriosis on employees and employers alike. The discussion aimed to develop actionable strategies to improve workplace policies, increase awareness, and provide better support for those managing endometriosis while maintaining their careers. This invitation underscores the foundation's commitment to driving significant policy changes and enhancing the quality of life for individuals affected by this condition.

Cambridge University: Endometriosis Workshop

The Endometriosis Foundation hosted its inaugural Endometriosis Awareness Workshop at Emmanuel College, Cambridge University. This milestone event brought together students, faculty, and community members to educate and raise awareness about the impact of endometriosis. Through interactive discussions, expert presentations, and personal testimonies, attendees gained a deeper understanding of the condition's challenges and treatment options. The workshop aimed to empower participants with knowledge and equip them to support those affected by endometriosis in their academic and personal lives. This

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initiative reflects the charity's commitment to fostering awareness, advocacy, and support within academic institutions and beyond.

The Endometriosis Foundation
12 months Accounts to 10th January 2024
Registered Charity Number 1178525

Income and Expenditure

10.01.24

INCOME

Fundraising	£13,632.39
Sponsorship	£1,000.00
Donations	£3,892.79
Grant	£20,220.00
Bank Interest	£733.29
Sundry	£93.90

Total Income	<u>£39,572.37</u>
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EXPENDITURE

Online Support Subscriptions & Service: including Email hosting, Web Support, data analysis, Dropbox, Adobe, Zoom & Marketing	£2,357.60
Phone Services	£152.54
Home Office Costs & stationery	£1,015.49
Accounting Costs	£25.00
Fund Raising Regulator	£50.00
Ansvar Insurance	£290.66
Fund Raising Platform	£179.70
Event Costs	£5,864.66
Educational Purposes	£1,590.72
Bank Charges	£9.15
Volunteer Expenses	£636.28
Consultancy Costs	£12,480.00
Postal Costs	£188.18

Total Expenditure	<u>£24,839.98</u>
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Excess of Income over Expenditure	<u>£14,732.39</u>
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The Endometriosis Foundation
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The Trustees declare that they approve of the Trustees' report above.

Signed on behalf of the charity's trustees –

Signature

A handwritten signature in black ink, reading "A. Cutner", is written inside a rectangular box.

Full name

Alfred Cutner

Position (Trustee, Secretary, Chair etc)

Chair

Date

8/7/24

Charity registration number 1178525