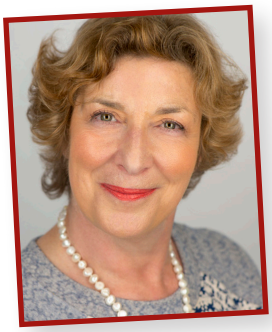
OUR STRATEGY

For 2025-2030

ENDOMETRIOSIS UK

FOREWORD


Liz Campbell


Emma Cox

For over 40 years, Endometriosis UK has existed to improve the lives of those affected by endometriosis. Together, with the support and hard work of our volunteers and supporters, we have transformed the way endometriosis is perceived: we've changed attitudes, increased awareness, and campaigned for change. Our support services, run by our incredible team of trained volunteers, continue to be a lifeline for those affected by endometriosis – as they have been since the very start of the charity.

We work directly with those with endometriosis, healthcare practitioners, like-minded charities, Royal Colleges, employers, educators, corporate partners and many others and are grateful to everyone who works with us to improve the lives of those affected by endometriosis.

Our last 5 year strategy saw us achieve a lot – more than doubling our income to £1.3 million which has enabled us to significantly expand our support services and campaigning. Our active volunteer network has grown to almost 200 volunteers, providing invaluable in person and online support groups, a helpline, webchat, and an online forum. We appointed our first staff members in Scotland and Wales, rebranded to make more impact, campaigned tirelessly for improvements to care across the UK, and made as much noise as we could to raise awareness. At the beginning of 2025 we were able to fulfil a long-held ambition, launching a nurse-led helpline, a step change in the way we provide information and support to the community.

But there is still so much more to do. At the time of launching this strategy, it takes on average nearly 9 years to get a diagnosis of endometriosis in the UK – an increase of a year since the onset of the covid pandemic, when gynaecology waiting times increased by the highest percentage of any medical speciality, and have remained unacceptably high since. Too many are left too long languishing on long waiting lists, suffering in pain, unable to access the treatment and management they need. Everyone with endometriosis deserves better, and the right to appropriate, high quality treatment regardless of background, identity, location or circumstance.

Building our new 5 year strategy has been an opportunity to evaluate our work, cement our determination for change, and identify our priorities for the future. Our new, ambitious strategy reflects the determination of everyone at Endometriosis UK – our volunteers, trustees, staff, beneficiaries and stakeholders. Those with endometriosis remain at the heart of everything we deliver, and we want to provide the best support and campaign for the best outcomes for those with the disease, at every stage of their lives.

We know that we must do more to identify the needs of all those affected by endometriosis to ensure all voices are heard; evaluate and develop our work and services to meet those needs; and undertake bold campaigns to secure necessary change. We will ensure that equality, diversity and inclusion are at the centre of our work as we take forward our strategic plan.

To achieve our mission, our 2025-2030 strategy continues to place those living with endometriosis at the heart of all our work. We will focus on four strategic goals:

1. **Diagnosis takes an average of a year or less by 2030**
2. **Access to high quality, effective management and treatment**
3. **Supporting everyone with endometriosis to live well, at every stage of their life**
4. **Providing hope for the future through supporting research**

We'd like to thank everyone who shared their views and helped us formulate this strategy - whether it has been through one-to-one interviews, meetings, workshops or surveys – your input has been invaluable, and we now look forward to working together to make our ambitions a reality.

Thank you to everyone who supports our work and helps us, together, improve the lives of all those affected by endometriosis.

Liz Campbell, Chair

Emma Cox, Chief Executive

WHO ARE WE

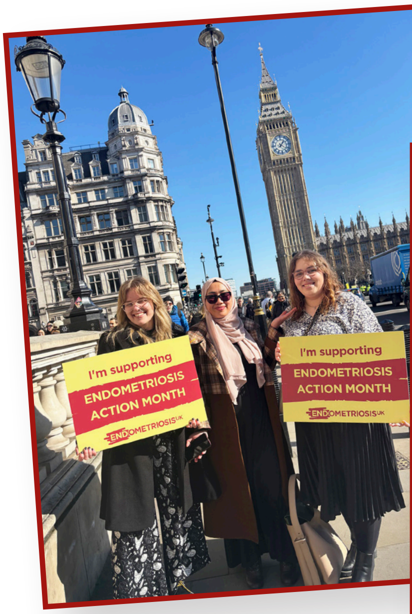
We are the UK's leading charity for all those affected by endometriosis, determined to ensure that everyone gets prompt diagnosis and the best treatment and support. Because many with endometriosis also have adenomyosis, our work will cover both diseases.

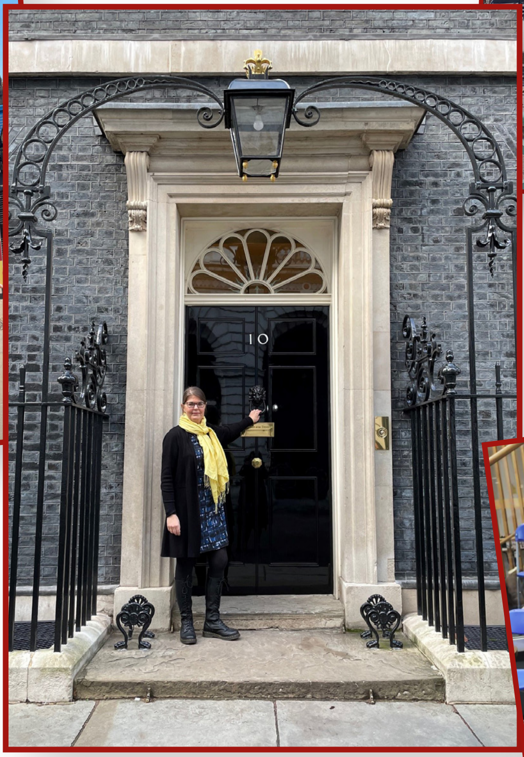
We work to break down barriers to access - wherever endometriosis impacts on lives. We are a powerful voice for those with endometriosis, driving up care standards across the UK.

The endometriosis community is at the heart of all we do. We lead collaboratively across our community, acting to inform, empower and advocate for all those affected by the condition.

We fight to make change happen for everyone with endometriosis, to end chronic menstrual related pain being brushed off as normal, and raise awareness of endometriosis and menstrual health with policy makers, employers and healthcare practitioners.

We are knowledgeable, inclusive, compassionate, bold and work with integrity. We live these, our organisational values, in everything we do, and expect everyone we work with to respect and uphold the same principles.





WHY WE ARE NEEDED

Endometriosis is a long-term health condition affecting 10% of women and those assigned female at birth from puberty to menopause, although the impact may be felt for life. That's over 1.5 million in the UK.

Yet it's a condition the majority of people have never heard of and do not understand. The cause of endometriosis is not currently known. Without awareness, pain and symptoms can be dismissed, brushed aside as 'normal' when they are anything but. It costs the UK economy around £8.2 billion every year in healthcare costs, loss of work and treatments.

Endometriosis is a spectrum condition. The impact of the condition can be minor for some people, whilst for others it can have a significant, sometimes devastating impact on all aspects of life: education, career, relationships, sex, fertility and quality of life. The wider impacts of endometriosis pain and symptoms can be seen and felt across both physical and mental health.

Adenomyosis has similar symptoms to endometriosis. If an individual has both diseases and only endometriosis is managed and treated, then symptoms may persist.

OUR MISSION

We believe in a world where endometriosis is recognised and understood, and where the disease does not limit people's lives.

We believe that everyone with endometriosis in the UK has the right to appropriate, high quality treatment regardless of background, identity, location or circumstance.

We believe everyone currently living with endometriosis should have the best care as a result of new developments in treatment, and that proactive research is vital to finding the cause and, one day, a cure.

We believe adenomyosis needs to be included in our work, as many have both diseases and symptoms are similar.

OUR COMMITMENT TO EQUITY, DIVERSITY AND INCLUSION

Endometriosis UK is committed to supporting and advocating for everyone affected by endometriosis regardless of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation.

Everyone affected by endometriosis needs to be acknowledged, and we know that we must do more to identify the needs of all those affected by endometriosis, develop, maintain and evaluate our work to meet those needs and advocate for necessary change and ensure all voices are heard.

We will ensure that equity, diversity and inclusion are at the centre of our work as we take forward our strategic plan.

PERSONAL STORIES

Debbie Cavalli,

Endometriosis UK volunteer:

> *It's empowering to be understood and still viewed as reliable, showing that my experiences don't limit my capabilities. Being in this space reminds me that I matter, and while being public about such a personal experience is new and vulnerable, it's also empowering and a chance to inspire others.*
>
> *I'm highly spirited on representation, so being part of an organisation which equally values this, makes me feel like I'm getting closer to drastically improving our quality of life.*

Jasmine Watson,

Endometriosis UK volunteer:

> *Volunteering at Endometriosis UK is being part of something meaningful. It's a way for me to give support to those who feel unheard or unseen, and to help raise awareness. Volunteering gives me a way to help break the silence, to offer empathy and to make all of our voices heard.*
>
> *Endometriosis UK has been invaluable in my journey. I can't quite explain how it felt on my training day, to be in a room full of people who understand and know my pain. Endometriosis UK have provided me with a community in which I am so grateful to be a part of.*
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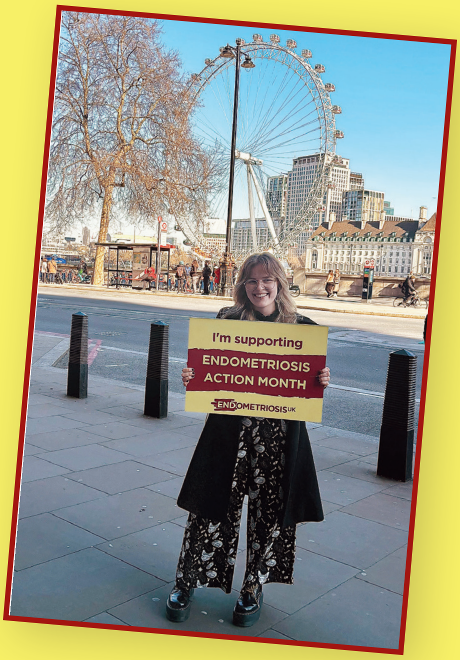
> *Being part of an organisation that's campaigning for a better future for those with endometriosis is both powerful and deeply motivating. It means I'm not just witnessing change, I'm part of it. I'm standing alongside a community that refuses to be silenced.*



To achieve our mission, our 2025-2030 strategy continues to place those living with endometriosis at the heart of all our work. We will focus on **four strategic goals**:

1. **Diagnosis takes an average of a year or less by the year 2030**
2. **Access to high quality, effective management and treatment**
3. **Supporting everyone with endometriosis to live well, at every stage of their life**
4. **Providing hope for the future through supporting research**

STRATEGIC GOAL 1:

DIAGNOSIS TAKES AN AVERAGE OF A YEAR OR LESS BY 2030

WHY IT MATTERS:

Securing a diagnosis is a crucial first step which enables those with endometriosis to make informed choices about the management and treatment of their condition. Without management and treatment, the disease may progress. Adenomyosis must be considered along with endometriosis, to ensure the best management and treatment.

Timely diagnosis gives the best chance of endometriosis being managed effectively and reduce suffering, and can save resources in the NHS. But despite this, getting a diagnosis for endometriosis is often a difficult and lengthy process, taking an average time of 8 years and 10 months in the United Kingdom. We know that it is possible – if symptoms are recognised, and management and treatment pathways understood – for diagnosis to take under a year.

Everyone who goes to a healthcare practitioners with symptoms should have the symptoms recognised as potentially being due to endometriosis and be told this is possibly what it could be along with other potential conditions depending on the symptoms. Healthcare practitioners should know the correct pathway for diagnosis, management and treatment, and support their patients through this process. Where applicable a 'working diagnosis of endometriosis' should be applied to help individuals secure the support they may need in education and the workplace.

To seek help from a healthcare practitioner, first you need to recognise that what you are experiencing may be symptoms and is not normal, and also be comfortable discussing menstrual issues. We believe effective menstrual health education in schools is key to support earlier recognition of symptoms, and overcome taboos and embarrassment in discussing these.

THE OUTCOMES WE WANT TO SEE:

- By 2030, endometriosis is diagnosed within an average of a year or less after symptoms are first presented to a healthcare practitioner.
- Healthcare practitioners have a better knowledge and awareness of menstrual health problems including endometriosis and adenomyosis and are willing and able to help secure a diagnosis. Medical schools, Royal Colleges and allied healthcare professional bodies have ensured menstrual health including endometriosis is embedded in curricula and ongoing continued professional development.
- Waiting times for endometriosis appointments and surgery in the NHS are reduced and prompt access is maintained, with the health systems across the UK are set up and resourced in a way which enables timely diagnosis and access to treatment.
- Gynaecology imaging is recognised as key to supporting diagnosis, and trained staff are available throughout the UK.
- Those with symptoms are informed, empowered and supported to seek a diagnosis from healthcare practitioners.
- Non-invasive diagnostic tests, evidenced by solid research results, are developed.
- There is good knowledge and understanding of menstrual health issues and endometriosis symptoms by the general public.

WHAT WE WILL DO:

- Campaign for reductions in diagnosis and gynaecology waiting times and prompt access to care and treatment for all those with endometriosis.
- Produce inclusive and accessible information and resources, and raise awareness of endometriosis and adenomyosis symptoms.
- Campaign for menstrual health education to be implemented in schools across the UK.
- Ensure healthcare practitioners have the knowledge and awareness needed to recognise symptoms and support those living with endometriosis from all communities.
- Investigate diagnosis times and healthcare experiences of diverse communities, and advocate for inclusive healthcare policies.
- Support the development and roll out of new diagnostic tools and techniques, where there is evidence of their efficacy.
- Grow our social media reach and public profile.

HOW WE WILL MEASURE IMPACT:

- Survey to show the average length of diagnosis times across the UK, at least every two years.
- Uptake and impact of our information resources and support services.
- Evaluate how our campaigning and influencing work is reflected in changes to policy and practice.
- Reach of our awareness raising activities through media coverage and our social media channels.

STRATEGIC GOAL 2:

ACCESS TO HIGH QUALITY, EFFECTIVE MANAGEMENT AND TREATMENT

WHY IT MATTERS:

Historically, the main forms of management and treatment for endometriosis have focused on surgery, hormonal medications, and medical pain relief. This needs to shift to a more holistic approach, supporting the psychological and social as well as physical impact of the disease for example non pharmacological pain management including pelvic physio, psychological support, fertility treatment and preservation, diet and exercise.

Being able to access effective management and treatment of endometriosis can have a huge impact on quality of life. Adenomyosis needs to be considered, otherwise symptoms may continue. But we know that people are not always offered the right management and treatment options for them, and there's a postcode lottery to get access to the medical support they need.

THE OUTCOMES WE WANT TO SEE:

- Everyone living with endometriosis has the information and support they need to make informed choices about the management and treatment options available to them.
- The NICE Guideline on Endometriosis is fully implemented across the UK; and a full review of the NICE Guideline has been undertaken.
- Effective management and treatment pathways exist within the NHS across the UK, and these are fully understood and implemented by healthcare practitioners.
- Healthcare services are adequately resourced at primary, secondary and tertiary levels to provide access to high quality management and treatment options in a timely way, for all those living with endometriosis.
- Healthcare Practitioners, including those in primary care, gynaecologists and in A&E, have a good understanding of which management and treatments options are most appropriate for endometriosis, and the care pathways to support their patients.
- Medical Schools, Royal Colleges, Nursing bodies and allied healthcare professional bodies have reviewed their curriculums and ongoing training, and they contain menstrual health including endometriosis.
- New, more effective management and treatment options are being developed which have the potential to further improve quality of life and help manage symptoms more effectively.

WHAT WE WILL DO:

- Deliver high quality information and advice on management and treatment for those with endometriosis, healthcare practitioners, Royal Colleges and Commissioners.
- Campaign for NHS to allocate the necessary resources, capacity and funding for effective endometriosis management and treatment across the UK. Within this we will highlight disparities and the experiences of those from diverse communities.
- Support the delivery of research studies which have the potential to lead to new management or treatment options, or a possible cure.

HOW WE WILL MEASURE IMPACT:

- Uptake of our information resources and support services for those affected by endometriosis.
- Update of our information resources by healthcare practitioners and Royal Colleges.
- The impact our policy influencing and campaigns have had on government policy and practice related to endometriosis, menstrual health and women's health across the UK.
- Being the go-to organisation for patient and public involvement in endometriosis research as evidenced by requests from the UK Endometriosis research network members.

STRATEGIC GOAL 3:

SUPPORTING EVERYONE WITH ENDOMETRIOSIS TO LIVE WELL, AT EVERY STAGE OF THEIR LIFE

WHY IT MATTERS:

Endometriosis is a long-term health condition; there is currently no cure. Symptoms vary person to person, from mild to severe and debilitating. Management and treatment options also vary in success person to person. Many with endometriosis also have adenomyosis, which can have some similar symptoms. The effect on physical and emotional health can have a profound impact throughout life - on education, careers, relationships and all aspects of life.

With access to the right practical and emotional support from the people around them, those living with endometriosis are more likely to be able to manage their condition and to live fulfilling lives.

THE OUTCOMES WE WANT TO SEE:

- Those living with endometriosis are able to understand and manage their condition throughout the life course – from the onset of puberty to menopause and beyond.
- Those living with endometriosis have the tools and support they need so that endometriosis does not stand in the way of building fulfilling social lives and personal relationships.
- Students living with endometriosis and menstrual health conditions are able to reach their full academic potential and are supported to manage their condition at school, college and university.
- Those living with endometriosis and menstrual health conditions can succeed in the career they choose and are supported to manage their condition in the workplace.
- Those unable to work due to endometriosis can access the welfare benefits and wider support they need.
- Partners, friends and family members have access to the information and resources they need to be able to support their loved ones.

WHAT WE WILL DO:

- Ensure that our information resources meet the diverse needs of all those with endometriosis through their entire life course and represent a range of cultures, identities and backgrounds.
- Provide access to peer support through our amazing team of trained volunteers who deliver support including through local groups, the helpline, webchat and online forums; plus our nurse led helpline.
- Provide employers with the tools they need to better support employees with endometriosis and menstrual health conditions.
- Campaign for better access to welfare benefits, and support for those who are unable to work due to endometriosis.
- Campaign for effective menstrual health education to be taught to all pupils in primary and secondary school. Develop endometriosis and menstrual health education for students at college and university.
- Produce resources for friends, loved ones and family members of those with endometriosis.

HOW WE WILL MEASURE IMPACT:

- Uptake of our information resources by employers, education providers and the public.
- Numbers receiving support through our support services.
- The number of employers signing up to our endometriosis and menstrual health at work offers.
- Evidence of the impact of our campaigning and influencing work on government policy on welfare benefits and employment law.

STRATEGIC GOAL 4:

PROVIDING HOPE FOR THE FUTURE THROUGH SUPPORTING RESEARCH

WHY IT MATTERS:

Research is where the endometriosis community see hope for the future. We need research to understand the many unanswered questions about the nature and cause of endometriosis, to lead to new and more effective forms of treatment and management and hopefully, one day, to a cure. We need to understand the similarities, and differences, with adenomyosis.

Despite this, there is a shortage of research on endometriosis alongside many other women's health conditions. For some communities in particular, the gap in our knowledge is even greater. Our role is twofold: to campaign for more funding to be awarded to endometriosis research, and to support the development and implementation of research breakthroughs by providing high quality PPI support, ensuring that diverse voices are heard.

THE OUTCOMES WE WANT TO SEE:

- High-quality academic and clinical research is being carried out which adds to our understanding of the nature of endometriosis for all communities, and how it can be better managed and treated.
- Those living with endometriosis are at the heart of research studies and clinical trials involve the voices of those with endometriosis right from the start.
- There is an increased awareness in the endometriosis community about current academic and clinical research studies.

WHAT WE WILL DO:

- Support members of the academic research community by sharing our expertise to shape research proposals, including those focused on issues affecting diverse communities.
- Continue to enable patient and public involvement (PPI) in research and clinical trials and promote the participation of those from diverse communities.
- Become a trusted source of information about PPI, key research projects and promising scientific developments in endometriosis; keeping the endometriosis community up to date with the latest developments.
- Campaign for more investment into research.
- Continue to monitor developments in Artificial Intelligence which have the potential to improve levels of awareness, diagnosis, management and treatment.

HOW WE WILL MEASURE IMPACT:

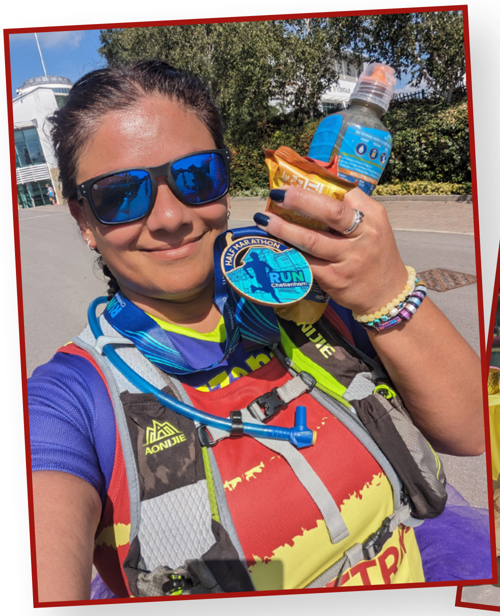
- Our involvement in UK academic research studies into endometriosis.
- How the UK academic research community feel supported by our PPI and other activities.
- Uptake of information on research developments and participation opportunities by our community.
- UK governments and related bodies invest in endometriosis research.

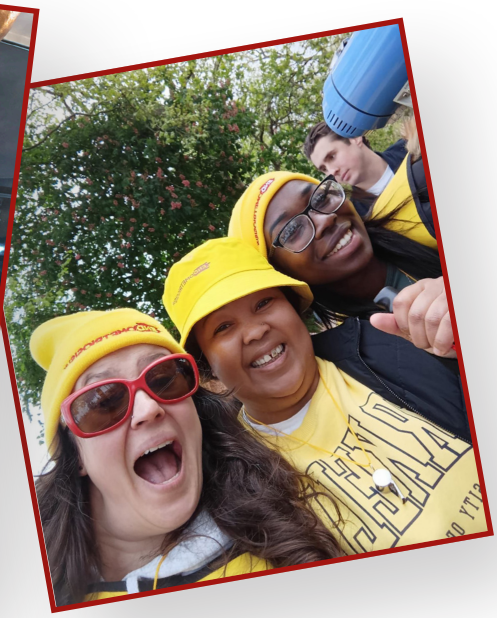
A STRONG, SUSTAINABLE AND GROWING CHARITY

To deliver our ambitious strategic goals for the endometriosis community, we need to build a strong organisation. We must grow, because there is so much more that needs to be done to drive down diagnosis times, improve management and treatment options, raise awareness, and support research. Our team of amazing volunteers are at the forefront of our support activities, and we want to provide a worthwhile volunteering experience, with training and support. We will prioritise the following goals to help us achieve our ambitions:

- Delivering high quality volunteer management and support
- Increasing our income sustainably, including the diversification of income sources
- Ensuring effective and efficient charity governance and management

Please note this is an outline of our strategy and is supported by an operational plan.





OUR ORGANISATIONAL VALUES

We embody our organisational values in everything we do. Our values guide the work we do to support, represent and advocate for the endometriosis community, and to achieve change.

We are knowledgeable

We strive to continually provide better information and enhance knowledge. We combine personal experience with healthcare expertise to deliver current, accurate and well-researched information. We acknowledge the diverse stages and unique paths individuals experience in their endometriosis journey through our work. We campaign for investment in research to find improved treatments, the cause and one day a cure.

We are inclusive

We are dedicated to inclusivity, representing all affected by endometriosis. Our goal is an inclusive and safe community where everyone is welcomed and respected and can access the information they need in the best way for them.

We are compassionate

We listen to those with endometriosis, as they are at the heart of everything we do. We make a difference through our support services, where lived experiences are acknowledged and treated with kindness. We recognise and understand those who support Endometriosis UK, and respect their courageousness in uniting voices and advocating for positive change.

We are bold

We are ambitious to drive change to reduce diagnosis times and improve access to quality care and support. We advocate for, and speak up on behalf of those with endometriosis, we passionately campaign for better outcomes and treatments. We proactively raise awareness as we want everyone to know what endometriosis is, its symptoms understood and believed.

We work with integrity

We commit to working with integrity. We are honest and transparent, placing the voices of those with endometriosis experiences at the core of our efforts. We are accountable and take responsibility for what we do, and we expect the same from those we work with.

WHAT WE DO

We CAMPAIGN	- saying "that's not good enough" - driving change and improvement - creating awareness, breaking down people's ignorance - so you're heard and believed
We EMPOWER	- because knowledge is power - helping you advocate for yourself - supporting, strengthening, amplifying voices and providing access
We CONNECT	- empowering, collaborating and promoting - ensuring diverse experiences and perspectives are heard - breaking down isolation - providing practical help and emotional support
We INFLUENCE	- policy and decision makers, seeking to change the status quo - employers, so understanding is there when it's needed - the research agenda and funding

THANK YOU

We would like to give our thanks to the supporters and stakeholders who gave their time to feed into the development of our strategy.

Our work is only possible through the generosity of our supporters.

Thank you for everything you have helped us to achieve, and we look forward to working with you over the next five years.

To get support, get involved, donate or learn more about any aspect of our work: **https://www.endometriosis-uk.org/**

Endometriosis UK
Registered Charity in England and Wales 1035810
Scottish Charity Registration number SC051651
Company number 02912853

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