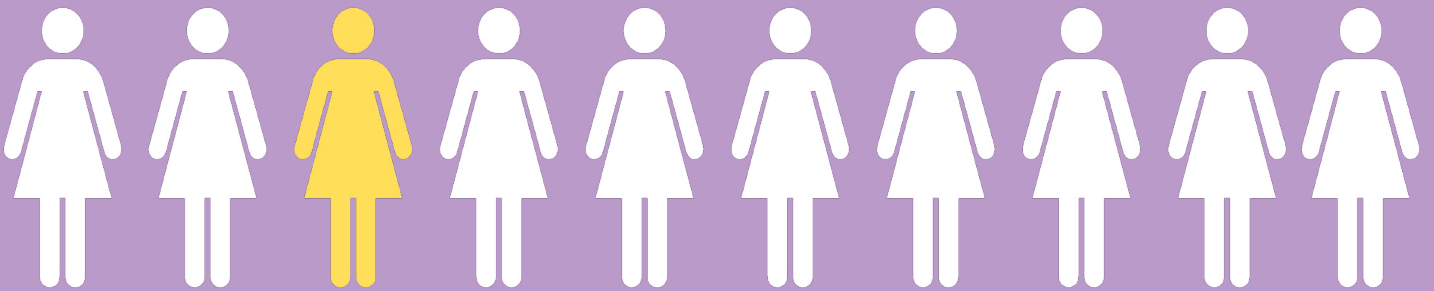


A plan for the one in ten.



Together, we can make a difference for women living with endometriosis.



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Meeting with Rachel Hall, Jemima Wharton and Becky Leigh, three women living with endometriosis in the Borders.

Foreword

Endometriosis is crippling the lives of thousands of people across Scotland. Estimates indicate it may impact 1 in 10 women.

But the truth is, we don't really know the extent of this debilitating condition. Many suffer in silence for years while struggling to get an accurate diagnosis. A recent Scottish Government insight report¹ on the condition noted: "We learned from participants that endometriosis is often spoken about as an "invisible" illness which can lead to a lack of understanding from people around those with the condition."

Awareness of this disease is so low that many people, including physicians, don't realise that they have it. A national survey² in 2019 estimated it takes an average of eight and a half years after the onset of symptoms to get an endometriosis diagnosis.

Even once a diagnosis happens, the pain doesn't end for a lot of women. There are some actions to help alleviate the disease. But in difficult cases, treatment options can be slow to materialise and, often, they don't help much. The condition can mostly only be limited, not cured.

One of the main problems is that we simply don't know enough about the condition itself. There is not enough data. It doesn't receive enough focus. More research must be funded to improve treatment options.

It's a stunning situation because so many women suffer from this condition - and it can wreck their life. In my own constituency in the Scottish Borders, I've heard heart-breaking stories from women who have had their lives upturned by this disease. Hearing about the pain they go through has brought tears to my eyes.

This cruel illness has meant that some have lost jobs, some have missed out on opportunities, some may not be able to have a family. It can cost them their health, their careers, their education and their relationships.

The government must intervene so that these women's lives are not held back by this devastating illness any longer. There is an opportunity for Scotland to be a world-leader in tackling this condition.

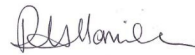
This policy paper will seek to kick-start a discussion about how we achieve that. It aims to improve treatment options, improve diagnosis times, and increase awareness of endometriosis. It will focus on improvements in three main areas: health, careers, and education.

The significance of dedicating resources to tackling this condition cannot be overstated. Better treatment would revolutionise the lives of those women who have had their lives upturned by endometriosis. It would also benefit society as a whole. It would advance Scotland's economic potential and improve productivity while saving taxpayers considerable sums. As it stands, hundreds of millions of pounds are lost each year in Scotland because endometriosis prevents people from working and advancing their careers.

In the pages that follow, I will set out a range of ideas we could progress immediately to make positive developments towards helping women suffering from endometriosis. These policies are neither left wing or right wing, unionist or nationalist, SNP or Conservative. They are solely proposals that would help improve the lives of women living with endometriosis.

So, regardless of your political beliefs or affiliation, I hope you will agree that women deserve faster diagnosis, better treatment, easier access to mental health and nutritional support and, above all, a chance to live without the daily pain of endometriosis.

Special thank you to Tao McCready, Becky Leigh, Rebekah Cockburn, Jemima Wharton and Rachel Hall for sharing their stories with me and helping to shape these proposals. In addition, thank you to CEO of Endometriosis UK, Emma Cox, Dr Lucy Whitaker and Professor Andrew Horne for their input.



Rachael Hamilton MSP



Tao McCready | Endo SOS

Endometriosis symptoms first hit me at 13 years old when I experienced chronic fatigue and migraines, not always around my period. But my GP didn't believe me. I was misdiagnosed with a bad back. Kidney infections. Irritable bowel syndrome. And even borderline personality disorder. For 17 years, I was misdiagnosed with other conditions. I was gaslighted for decades by the medical community, the very people we're supposed to trust to help us get better. They didn't believe me. They didn't listen.

Because I was left for 17 years with no answers, endometriosis affected my fertility. This breaks my heart and I struggle to speak about it, even now. I have had multiple miscarriages and symptoms that no one should have to live with for years. Medics even suggested I should 'get pregnant to cure my endometriosis', an outdated belief that is extremely insensitive to someone who has secondary infertility due to the condition. There is not one part of my life endometriosis hasn't affected.

Looking back, I can now see it had a huge impact in my school years, especially on my mental health. As well as medics, teachers also didn't believe my symptoms and led me to believe I was a 'drama queen'. After school, it damaged my working life. I had to give up my career as a bank manager due to the severity of symptoms. Even now, when speaking to potential employers, I need to be honest and explain to them that there are certain times in the month I am unable to work.

Endometriosis has greatly affected my relationship, mostly due to lack of knowledge. Despite the impact endometriosis has had on me, it was only when I went to speak about my fertility that my GP finally listened and I eventually started to get answers. At the age of 31, I was diagnosed with severe endometriosis and adenomyosis throughout my body including my arm, reproductive organs, bowel, sciatic nerves, rectum, bladder and POD. Even then, I was left without the help I needed.

I went for a private consultation and was told surgery would cost me £33,000. I couldn't afford that, not many people could, but the experience I received at the consultation was far better than my experience with the NHS. Being treated like an individual with compassion was a huge relief. I felt heard for the first time. I would love to say my story is unusual or unique. But it's not. After my experience, I felt I had two options: to get on with it quietly or to do something about it.

I chose to found Endo SoS, the first and only registered charity dedicated to helping people with endometriosis in southern Scotland. My team and I speak to hundreds of women weekly who all have similar stories to what I went through. Endometriosis affects 1 in every ten individuals. That equates to about 250,000 women in Scotland. That's 250,000 women who need more support and guidance. We have not been heard. That must change.

Endo SoS acts as the bridge between the medical community and patients with endometriosis. Knowledge is empowering. We have resources that are factual, relevant and up-to-date available on our website, which is being redeveloped for the end of March. We have resources ranging from webinars with medical professionals, to support sessions, to information on pre and post diagnosis, and much more. Please, use us!

But we cannot fix this on our own. Across society, we need to build a better understanding of this condition, from medical professionals to the general public, starting in schools and medical teaching settings.

We need more funding directed towards women's health. The diagnosis time in Scotland for endometriosis is sitting at 8 years and 10 months. That is terrible.

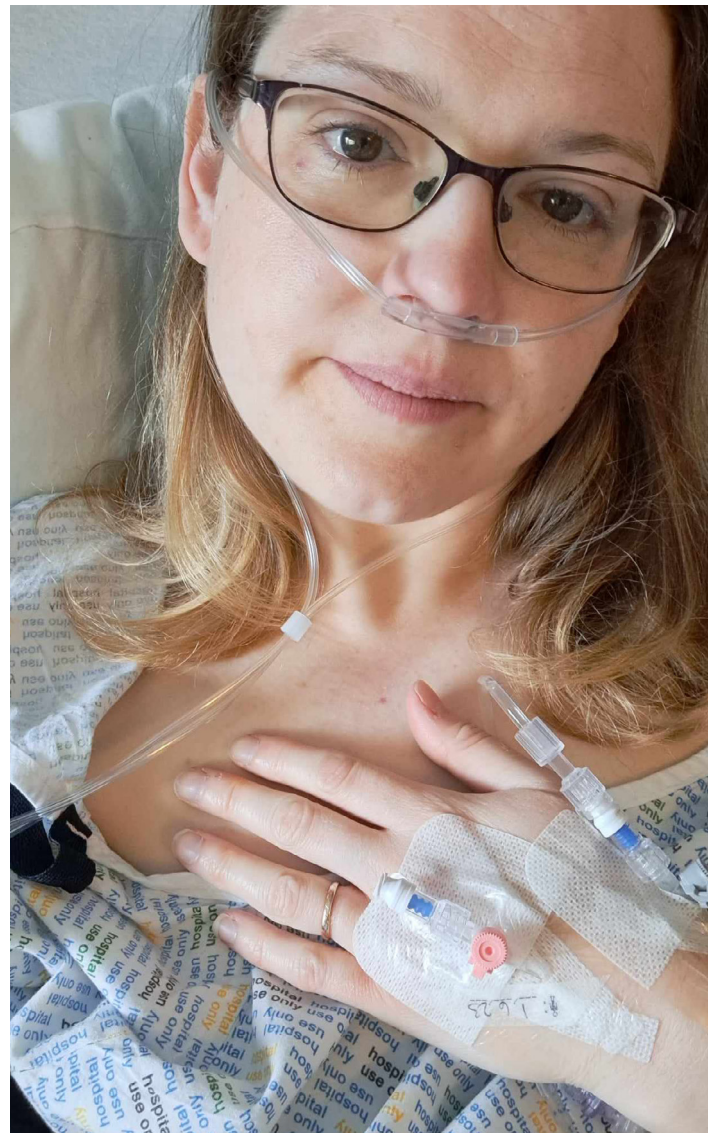
We need more local centres so people can get treatment and support when they need it.

At Endo SoS, we are working together for a better Scotland - but we cannot do that without the help of politicians. Scotland's politicians have the power to change what has happened for generations. They can make sure the next generation doesn't suffer in silence, like we have had to endure. It's time politicians took action and really focused on women's health.

It's time for change and together we can make a difference.

It's time that we were heard.

Tao McCready
Founder of Endo SOS



Becky Leigh | The Big Yellow Force

To live with endometriosis doesn't really feel like living at all.

It's surviving every day.

It's waking up and feeling immediate immense pain, that's if it even allows you to get any sleep.

Endometriosis is being betrayed by your own body, repeatedly and unpredictably.

It means you cannot plan ahead, you cannot live a 'normal life', except you look completely normal to everyone, hiding every painful step behind a smile because it is easier than having to explain your misunderstood condition to almost everyone you meet.

Endometriosis is not even being able to find a medical professional who can help, or that doesn't dismiss you altogether for the average of 8 years before diagnosis.

Endometriosis is having no hope for relief, filling its victims with anxiety.

Becky Leigh
Founder of The Big Yellow Force

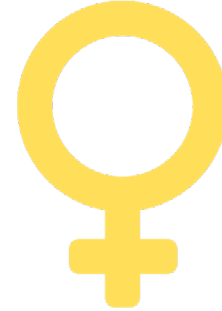


Executive summary

This paper will set out proposals for actions the Scottish Government could take immediately to help endometriosis patients. The policies are grouped into three main areas of focus: health, careers and education.

Health

- Improve treatment pathways and clarify NHS referral guidance for endometriosis.
- Ensure every health board has a specialist endometriosis nurse and work towards a specialist endometriosis clinic for every area.
- Ensure every patient has an individualised endometriosis plan, including integrated mental health support, a tailored nutrition programme, and improved post-surgery aftercare plans.
- Provide the NHS with funding to restart weekend surgeries for endometriosis.



Careers

- Ensure every public sector employer signs up for the 'Endometriosis Friendly Employer Scheme' and encourage private sector businesses to do the same.
- Guidance on handling endometriosis patients issued to all schools, colleges and universities.
- Develop a national training course which all organisations can access free of charge.
- Establish a national advice helpline for women with endometriosis who are at risk of losing jobs or education places.



Education

- Launch a national marketing campaign to raise awareness of endometriosis.
- Make endometriosis a core element of menstrual education in senior school classrooms.
- Work with the UK Government to launch a large-scale cohort study to research the risk factors and root causes that may contribute to or exacerbate endometriosis.



Background

Globally, endometriosis is not a well-known or extensively-researched condition. Very few places in the world treat it as effectively as it should be tackled, considering the reach and severe consequences of the disease. It affects a huge number of women. Estimates say it impacts 1 in 10.

The Scottish Government has taken some limited steps towards tackling endometriosis. Its Women's Health Plan committed to fully implement national guidance on the condition, develop new care pathways, and increase awareness of the disease, including at the school level and among GPs and hospital consultants. This is all welcome.

However, it is not anywhere near enough. Progress is slow and lacklustre. Women all over Scotland still face unacceptably long diagnosis times. In 2023, there are very few other conditions that take the best part of a decade to diagnose. But for endometriosis sufferers in Scotland, eight and a half years is the average from symptoms starting to the finalising of a diagnosis. **One in three patients wait more than a decade for a diagnosis.** ³

Specialist care is available for some women in Scotland. We have experts who are at the height of their profession. **But there are huge gaps in healthcare provision across the country, particularly in more rural and more remote areas.** The specialist clinics set up by the Scottish Government are limited to the largest urban areas. Although, even for many women who live around cities, there is a serious lack of access to the necessary network of multi-disciplinary specialist healthcare professionals.

Campaigners say that the level of knowledge of the condition is very low among the general public, employers, organisations and even those who may have the disease. Many chronic sufferers of endometriosis argue that the level of awareness is lower than it should be in the NHS too, which has been supported with compelling personal evidence and research from Endometriosis UK showing that many medical professionals are unclear about referral pathways. The World Health Organisation has also said that: "Patients who could benefit from medical symptomatic management are not always provided with treatments due to limited awareness of endometriosis among primary healthcare providers."⁴

This all must change - for the benefit of women and for Scottish society as a whole. The systemic failure to treat patients with endometriosis effectively means that GPs and other NHS departments are left overwhelmed. Our economy is not realising its full potential as lots of women don't get to have the careers they deserve.

The following policies could be commenced swiftly by the Scottish Government with a low initial investment and a high long-term benefit for those women living with endometriosis and for all of Scotland.



The bulk of the policies in this paper are proposals to improve healthcare for women with endometriosis.

1 - Improve treatment pathways and clarify NHS referral guidance for endometriosis.

The process of receiving an endometriosis diagnosis can be frustrating, exasperating and exhausting for many women.

A UK Parliament All-Party Parliamentary Group (APPG) report in 2020 found that 51 per cent of women had visited their GP more than 10 times with symptoms of endometriosis before receiving a diagnosis.⁵

Missed opportunities to diagnose endometriosis put a huge burden on the women affected. But they also place extra pressure on GP services and other areas of the NHS. Every time someone presents with symptoms and receives no diagnosis, valuable time and resources have been utilised without finding a solution.

There is no available estimate of the number of GP appointments that could be freed up if the diagnosis process was faster and easier. But, given that the condition impacts 1 in 10 women, combined with the fact that around 50 per cent of patients with endometriosis visit a GP more than 10 times, it is likely to be an enormous number. This will be putting a considerable added strain on already stretched GP services.

Therefore, it is clear that there is a pressing need to improve endometriosis treatment pathways, both for the patients living with this terrible condition and for Scotland's NHS as a whole.

Currently, the treatment pathways and referral processes for endometriosis patients are too complex and difficult to navigate for patients and practitioners alike.

The gold standard of care for endometriosis patients is widely recognised to be the guideline produced by National Institute for Health and Care Excellence (NICE). This NICE guideline outlines best practices for endometriosis treatment. It “aims to raise awareness of the symptoms of endometriosis, and to provide clear advice on what action to take when women with signs and symptoms first present in healthcare settings. It also provides advice on the range of treatments available.”⁶

The NICE guideline includes key recommendations on organisation of care, support for patients, the referral process, diagnosis of the condition, pain management and surgical management.⁷

A report by Endometriosis UK, Analysis of Endometriosis Service Provision in Scotland, uncovered many of the issues that must be resolved to fully implement these gold standard guidelines. The report states: “The provision of endometriosis care in Scotland does not currently align with the NICE guideline recommendations” and “the base level of care for endometriosis as outlined in the NICE Guideline is not currently being met.”⁸

That analysis, commissioned by the Scottish Government, found that half of all primary care practitioners felt only ‘somewhat informed’ about ‘when to refer a patient with suspected endometriosis’. Nearly 15 per cent also said

they felt ‘somewhat uninformed.’ It found that, among GPs, approximately half felt that ‘difficulties in referring to gynaecology and specialist services for diagnosis’ and a ‘lack of clarity on when to refer a patient with suspected endometriosis’ were barriers to endometriosis diagnosis. That report also identified ‘connections to other services’ and ‘access to endometriosis specialists’ as key barriers to implementing the National Institute for Health and Care Excellence (NICE) guidelines on treating endometriosis. It stated that: “Healthcare professionals reported that one of the main challenges in trying to implement the NICE guideline on endometriosis was meeting the requirement to set up a managed clinical network consisting of community services, gynaecology services and specialist endometriosis services. They explain that this was difficult because of the number of different disconnected services that had to act in unison with each other for the guideline to be fully met.”⁹

All of this evidence confirms that the problem is widespread throughout Scotland's NHS. That is why it is vital that the Scottish Government works with medical professionals to deliver much clearer guidance on treatment and referral pathways. They must also provide health boards with guidance on best practices for the integration of the various necessary aspects of endometriosis care, to prevent women from being bounced around from one service to another. As it stands, medical professionals are too often left without the necessary information on where and how to refer an endometriosis patient. If these processes were to be improved, women could receive a much faster and clearer diagnosis. We do, however, note that the Scottish Government has made small steps towards sharing best practices by developing an “Endometriosis Advisory Group made up of clinicians and service managers to understand barriers to service delivery, share best practice and advice on policy development.”¹⁰

The Scottish Government has started action to improve pathways. In their late 2023 insight report, they claimed to have “supported the Modernising Patient Pathways Programme to raise awareness of the Endometriosis Referral Care Pathway for NHS Scotland.” Their recent Women's Health Plan also includes as an aim to “Implement and raise awareness of current national guidelines on endometriosis and develop and implement further pathways for care where these don't currently exist—for example, endometriosis outside the pelvis.”¹¹ A separate aim includes an ambition to “strengthen collaborative working between regional specialist endometriosis centres, territorial and special NHS boards, and primary care providers, to drive improvement in patient pathways and achieve equitable access to care and treatment.” These are all welcome goals, but they must be backed up with more action. The current pace of progress is far too slow.

2- Ensure every health board has a specialist endometriosis nurse and work towards a specialist endometriosis clinic for every area.

Many women, particularly in more rural and remote areas of Scotland, have raised the difficulty in meeting with a healthcare professional who specialises in endometriosis care.

For residents of the Scottish Borders, and other regions outside of the central belt, it can be a long, complicated and frustrating process simply to see a specialist. In this sense,

endometriosis is an outlier compared to other conditions that impact large sections of the population. For other diseases, access to a specialist is a matter of course.

However, an analysis by Endometriosis UK of care provision in Scotland found that “there were no specialist nurses with expertise in endometriosis referred to outside of specialist endometriosis centres.” That review identified that a crucial issue was the difficulty in ‘recruiting gynaecologists with a specialist interest in endometriosis to rural areas.’¹²

Beyond simply having access to an endometriosis nurse, the Endometriosis UK report also outlined that the NICE guidelines recommend that endometriosis patients are treated by a multidisciplinary team of experts. It stated women should ‘have access to a gynaecologist with expertise in endometriosis, a gynaecology specialist nurse with expertise in endometriosis, a multidisciplinary pain management service, a healthcare professional with an interest in gynaecological imaging, and fertility services.’ However, they found that “there was no evidence that this has been systematically, if at all, implemented in general gynaecology services.”¹³

In discussions with women in the Scottish Borders suffering from endometriosis, it also became apparent that a bank of specialist nurses available online would be a step forward in the interim, until the specialist positions can be filled across every health board. Nurse availability by phone or online occurs for other conditions, such as Sepsis¹⁴, so there is a strong precedent to consider it for endometriosis in the short-term.

The development of a much wider network of specialist endometriosis clinics where women can receive help from experts would be a game-changer.

These centres are typically not physical buildings dedicated to endometriosis care. They are multidisciplinary teams of clinicians - including an Endometriosis Specialist Nurse, dedicated consultant lead endometriosis service, colorectal surgeon, urologists and pain management specialists - who offer an integrated care service within hospitals. Across the UK, there are approximately 63 centres. At the moment, it appears that just three are operating in Scotland.¹⁵

Access to these specialist centres can make all the difference between women receiving the care they need or continuing to suffer without hope. Once women receive access to these services, they are typically diagnosed and treated much more swiftly and effectively than otherwise.

However, access to these services is limited for many women. Most health boards in Scotland do not have one. The cost and difficulty of travelling to specialist centres also prevents many women from accessing this support.

The Scottish Government has accepted the case for these specialist centres. The recent Women’s Health Plan, referenced in the late 2023 insight report, stated that it was a government aim that “When required, all women will have access to a specialist endometriosis centre.” But it has not yet happened and there are too few identifiable actions towards achieving that ambition.

It is evident that there is a postcode lottery for those suffering endometriosis in Scotland. In more urban areas, treatment is more readily available, while in more rural areas, access to the necessary specialists is often not available. **Therefore, this paper recommends that the Scottish Government immediately sets up specialist clinics at every health**

board, they should bring in nursing availability by phone and online.

3- Ensure every patient has an individualised endometriosis plan, including integrated mental health support, a tailored nutrition programme, and improved post-surgery aftercare plans.

Alongside clearer guidelines and a network of specialist clinics and professionals, it is also vital that every patient receives a plan unique to their circumstances.

The Scottish Government’s 2023 Lived Experience Insight Report cited as one of the main things that people living with the condition hope to see is that they “ensure there are after surgery care plans that are patient centred” and “improvements to post-surgery consultations”.¹⁶

Endometriosis is a condition that impacts women in very different ways. National surveys estimate that 10 per cent of women suffer pain for a few days each month, 31 per cent suffer frequently each month, and 49 per cent were in pain most days.

In its examination of endometriosis services in Scotland, Endometriosis UK also found that “support at the time of diagnosis appears to be inconsistent and insufficient for patients. Three quarters of patients (75%) did not receive any written information on diagnosis. Of those that did, only a minority of patients were satisfied with the information they were provided with (17%) whereas over half (56%) were either ‘very dissatisfied’ or ‘dissatisfied.’”¹⁷

These points confirm the need for detailed, individual plans to be developed for each woman, rather than a one-size-fits-all approach to diagnosis. University of Oxford academic Professor Christian Becker, a specialist in gynaecology and endometriosis treatment, has put forward the view that “We need to rethink our classification and better distinguish different forms of endometriosis to individualise diagnostics and therapy.”¹⁸

Endometriosis has consequences for women beyond the physical pain and suffering they go through. A 2019 survey by the BBC of 13,500 women found that half of all women had suicidal thoughts due to their endometriosis. 13 per cent had these once, 30 per cent had these on occasion, and nine per cent had them regularly.¹⁹

It is critical that when the Scottish Government improves NHS treatment pathways, they also ensure that mental health support is a key component of this plan. The APPG on Endometriosis has also made a similar recommendation for the whole of the UK.²⁰ Every patient with endometriosis should be referred to a therapist. **Mental health support should be seen as a vital plank of individualised treatment plans.**

Additionally, women with endometriosis have spoken poignantly of the negative impact that the condition can have on personal relationships. As a result, it is vital that where applicable, mental health support should be extended to include the partners of those with the condition.

Individualised plans should also include a dedicated dietician and a tailored nutrition programme for each patient. Major studies have found clear links between certain kinds of food and the onset of endometriosis symptoms. Some of those studies have found alcohol, red meat and trans fats have a negative effect on endometriosis symptoms, while fish oil capsules and vitamin B12 have a

positive impact.²¹ Experts have noted that more research is fundamental to establishing clearer correlations between nutritional intake and endometriosis symptoms. However, there seems to be widespread consensus that a carefully managed diet plays a pivotal role in alleviating the condition, so it is vital that women can access a dietician to better inform their individualised treatment plan.

There is a pressing need to improve surgery aftercare and post-surgery plans for endometriosis patients. It is one of the key requests of those living with the condition. **The Scottish Government must urgently ensure every patient receives a tailored plan suitable for their needs. They must work with the recently established Endometriosis Lived Experience Forum²² to improve aftercare plans and gather regular feedback on the post-surgery patient experience.** Those insights should be collaborated and distributed on as local a level as possible so that each NHS health board fully understands the strengths and weaknesses in the delivery of its aftercare treatment. This could take the form of a Patient Involvement Network similar to the programme by Cancer Research UK.²³

4 - Provide the NHS with funding to restart weekend surgeries for endometriosis.

Surgery is the primary means to diagnose endometriosis and is also a common treatment to alleviate the symptoms of endometriosis.

In discussions with numerous NHS professionals, many identified the lack of weekend surgeries as a block on clearing waiting lists for endometriosis patients, which have been exacerbated by Covid. Endometriosis UK also found that there has been a “lack of available theatre space” post-pandemic for endometriosis patients, as a result of other surgeries being prioritised.

Endometriosis specialists say they could treat far more women if funding was delivered to restore weekend surgeries, which were paused during the pandemic.



5 - Ensure every public sector employer signs up for the 'Endometriosis Friendly Employer scheme'.

Endometriosis UK has established an Endometriosis Friendly Employer scheme to help organisations develop “a work environment and culture that enables employees with endometriosis to thrive at work”.

Membership of the scheme includes the appointment of an Endometriosis Champion, and also includes guidance and support on how to support those with endometriosis.

This scheme has the potential to raise awareness of the condition within workplaces and help women with endometriosis to maintain their careers.

The Scottish Government should ensure that every public sector employee is a member of the scheme and encourage private businesses to join too, where possible. They could base this approach on the Accredited Living Wage Employers programme, which is certified by the Living Wage Foundation²⁴, which has been successful in encouraging organisations to demonstrate they pay the living wage.

6- Guidance on handling endometriosis patients issued to all schools, colleges and universities

Currently, women have come forward with examples where they appear to be the subject of discrimination based on their endometriosis condition. This is evident in workplaces, where women lose jobs or opportunities because the disease prevents them from taking part fully as they would like. It also seems to be occurring in schools, colleges and universities, where the lack of awareness of endometriosis and its symptoms leaves many women feeling alienated and unable to continue their education.

The 2023 Scottish Government Lived Experience Insight Report acknowledged this is a substantial problem. It stated: “Several people spoke to us about the impact endometriosis has had on their career. Some had to drop out of university due to the condition and some had missed out on career progression.”²⁵

In order to prevent women suffering negative consequences through no fault of their own, the Scottish Government should provide national guidance on managing endometriosis patients to schools, colleges and universities. This should include information on the different ways the condition can impact students, the difficulty women have in receiving a diagnosis and obtaining treatment, and a detailed blueprint of how to manage a patient with endometriosis without subjecting them to discrimination on the basis of their health.

7- Develop a national training course which all organisations can access free of charge.

The Scottish Government could help employers and organisations meet the costs of increasing awareness about endometriosis by commissioning a national training course on the condition and establishing a fund to help organisations meet the costs of sending HR professionals onto the course.

The option to attend a national training course of this nature would gradually increase awareness of the condition and

educate organisations on how to help those suffering from it. Although it is not a directly comparable disease, major charities produce similar programmes to help organisations treat cancer patients with empathy and kindness. For instance, Cancer Support UK provide workshops to improve how organisations communicate about cancer.²⁶ Since awareness of endometriosis is so low among the general public, it may be necessary for the government to fund a third sector partner to launch a training course of this nature.

Many endometriosis patients also raised the need for a bespoke online tool kit to signpost individuals to mental health support and next steps. One local woman suffering the disease said there was “a lack of clarity once you are diagnosed”²⁷ which needed to be addressed.

8- Establish a national advice helpline for women with endometriosis who are at risk of losing jobs or education places.

There are some charities doing fantastic work to help people with endometriosis. Nationally, Endometriosis UK has been instrumental in raising awareness of the condition. On a local level, groups are emerging and thriving. For instance, in the Borders, Endo SOS (Endometriosis in the South of Scotland) launched in 2023 and has already established a large presence.

However, as a result of the lack of awareness about the condition, there is less support available for patients with endometriosis than many other diseases which are just as prevalent. Charities and third sector organisations do not presently have the resources to meet demand from women who need help to manage their condition and maintain their lives.

A national advice helpline could be set up by the Scottish Government in conjunction with third sector partners to act as a central point of help for women who need support beyond medical care. In particular, it could act as an advice agency when women find themselves at risk of losing jobs, placements on educational courses or are having difficulty dealing with employers who do not have any understanding of the condition.

As stated above, the 2023 Scottish Government Lived Experience Insight Report²⁸ recognised the impact that endometriosis can have on career progression. It also gathered direct evidence from one woman with the condition who said: “It’s financially had a massive impact on us. It’s eaten away at our savings, being off and not at work.” There is a clear need for the Scottish Government to act so that women do not struggle financially solely because of a health condition.

Awareness

9- Launch a national marketing campaign to raise awareness of endometriosis.

Knowledge of endometriosis is not high among the general public. As outlined previously, there are profound examples of women losing jobs and being kicked out of university and college places because of the lack of understanding of their condition.

There is a pressing need for marketing and awareness campaigns to inform the general public about the symptoms of the condition. These campaigns should be targeted at employers, public organisations, and higher and further learning institutes, since the condition impacts how women are able to work and study. These should be large-scale mass-media campaigns utilising well-known figures speaking candidly about the condition. As part of this, charities such as the Menstrual Health Project should be supported to spread awareness of key projects such as their Endometriosis Diagnostic Toolkit²⁹, the first in the UK.

In order to improve awareness of the disease among women who may have symptoms, targeted digital campaigns should also be developed involving influencers with a large reach among younger audiences. These campaigns are necessary so women who may already be experiencing symptoms do not continue to suffer in silence.

10- Make endometriosis a core element of menstrual education in senior school classrooms.

The Scottish Government should expand its campaign with Young Scot to improve awareness of endometriosis among younger people, which received £25,000 funding. While this funding is welcome, it is not yet clear that it is having a tangible impact.

Endometriosis education should be included as a core element of menstrual health classes in secondary schools. This was one of Endometriosis UK's key recommendations in their 2022 analysis of treatment of the condition in Scotland.³⁰

11- Work with the UK Government to launch a large-scale cohort study to research the risk factors and root causes that may contribute to or exacerbate endometriosis.

Clinicians regularly raise the lack of data and research on endometriosis as a key issue preventing the effective diagnosis and treatment of the disease.

Women with lived experience of endometriosis also told the Scottish Government in a December 2023 report that “more investment into endometriosis research” was one of the key changes they wanted to see.³¹

Janet Lindsay, Chief Executive of Wellbeing of Women, has said: “It is completely unacceptable that there have been no new treatments for endometriosis in 40 years. Too many women and girls are suffering from debilitating symptoms, such as chronic pelvic pain, fatigue and even fertility problems, and current hormonal and surgical treatments aren't suitable for everyone.”³²

Dr Susan Evans, an Australian gynaecologist, pain physician and founder of Alyra Biotech, has also said that she has been “disappointed over many years at the lack of real innovation in this space.”³³

However, there is evidence that the situation is starting to change. In March 2023, the largest ever study on the genetics of endometriosis was published.³⁴ University of Oxford researcher Dr Nilufer Rahmioglu described it as a “treasure trove of new information”.³⁵

It is positive that the Scottish Government awarded a University of Edinburgh research team £250,000 in 2023 to trial a potential new treatment for endometriosis pain management and provided funding of £299,000 for the ENDOCAN Project, also led by researchers at University of Edinburgh, which is undertaking a UK-wide trial to determine whether a cannabinoid can reduce endometriosis-associated pain.³⁶

There is clear acceptance from the Scottish Government that more must be done to increase the amount of research on this condition. The 2023 insight report mentioned that the government believes there is a need to “commission endometriosis research to find the cause of the condition, leading to the development of better treatment and management options, and a cure.”

However, progress must be accelerated. **The Scottish Government should work with the UK Government on a large-scale, long-term cohort study of endometriosis.** For other conditions, such as diabetes, studies of this nature have been conducted on a regular basis. The same level of focus must be applied to endometriosis.

There are numerous research avenues that could be explored with more funding, including ways that women may be able to help prevent the onset of the condition. For instance, one European expert, Professor Mette Nyegaard, of Aarhus University Hospital, Denmark, has said “We need to study the DNA and lifestyle from thousands of women with and without disease to identify the risk genes, because after that, we can importantly start identifying risk factors in the environment.”

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