Making the Case for Better Endometriosis Treatment in Wales

Report compiled by FTWW (Fair Treatment for the Women of Wales)

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Who we are

We are here as representatives of a relatively new online support group for women in Wales with endometriosis: FTWW, Fair Treatment for the Women of Wales. Despite our being in poor health ourselves, and the consequent lack of publicity given to the group, there are already 205 women and girls within it – all of whom are suffering terribly, finding it difficult to function normally, and who are not being able to access proper care. They represent the typical experiences of women across Wales.

What is Endometriosis?

For those unfamiliar with endometriosis, we think it is vital, first of all, that you are aware of its prevalence. One in ten women has this condition. That means approximately 150,000 women / girls in Wales are suffering with the disease. It is more common in women than either diabetes or asthma, yet recent research showed that 50% of people had never even heard of it (1). This means that the condition is shrouded in mystery, myth, and misinformation – a situation that seems to extend to medical practitioners in Wales, as well as patients themselves.

Endometriosis is a disease which can affect girls / women for most, if not all of their lives. However, to describe it as incurable would be erroneous. With proper, effective, surgical treatment, it can indeed be resolved, enabling women to go on to lead fruitful, productive, prosperous lives. The disease basically involves lesions, made of tissue similar to that lining the uterus, being present elsewhere in the body. These lesions cause bleeding, inflammation and pain, and over time they can become deeper and more invasive. This creates scarring and adhesions which impact upon other organs and structures, causing them to fuse together. This has implications for fertility and for normal organ function.

Up to 35% of women with endometriosis have severe disease, where endometriosis causes significant damage to other organs, including bowel, bladder, diaphragm, liver, kidneys, as well as the reproductive organs. At this point, highly complex surgery is required, with the involvement of a number of different specialists – for example, to remove part of the bowel if this has been damaged by endometriosis. It is vital that such surgery is performed by a multi-disciplinary team in order to fully remove disease, tackle its repercussions on the various organs, and avoid further complications. As it is, diagnosis takes an average of 8 years, with disease progressing throughout this period (2).

Treatment Options

It is now widely accepted that the best, most effective surgical treatment for the disease is excision – that is the cutting out of lesions. Excision should be the mainstay of endometriosis surgery; it focuses on actual REMOVAL of disease, leaving behind healthy tissue. If done properly, this surgical technique has the potential to be a CURE for endometriosis. Research shows that of those women receiving complete excision surgery, by a specialist surgeon who is fully cognizant of all appearances of endometriosis, the recurrence rate is around 7%, whilst for those women who undergo alternative surgeries, more than 80% of disease remains and will require re-operation (3). We have ladies in our group who have undergone up to 15 or more of these procedures and who are still not able to access the excision surgery that would potentially remove disease once and for all.
Currently, as far as we are aware, there are no surgeons utilising excision in North Wales, and only two individuals (in the University of Wales Hospital, Cardiff) in the South. In Wales, patients are referred, not to excision specialists or multi-disciplinary teams, but to regular gynaecologists who will perform burning – also known as diathermy, coagulation, fulguration, or cauterization – of disease. With burning, a low-energy heat source is used to disrupt the tissue. The heat spreads throughout a large area, often damaging healthy tissue. A recent study found that burning techniques leave endometriosis behind in 80 – 90% of cases (4).

Burning endometriosis has been likened to cutting the top of an iceberg; the vast majority of it remains untouched beneath the surface. Of those women who undergo this type of surgery (almost all women in Wales) their cases will become more complex as a result of the scarring and adhesions that burning of the pelvic cavity creates. In Wales, the answer to this seems to be to admit them for more identical surgery to repeat the process all over again. Disease continues to remain in-situ, causing damage to the organs, with the additional complication of scarring and extensive post-operative adhesions. Women in our group are being admitted for these surgeries year after year. It is not difficult to see how this can potentially ruin lives and cost the Welsh NHS millions. In fact, the current overall cost of endometriosis to the Welsh economy can be estimated to be around £400m per annum (5).

Both the ESHRE (European Society of Human Reproduction & Embryology) and NICE guidelines confirm that moderate to severe endometriosis should be treated in a BSGE centre. The British Society for Gynaecological Endoscopy currently offers accreditation for NHS specialist endometriosis centres, where the necessary multi-disciplinary team, integrated approach to care, is available. Specialists in these centres utilise excision as their primary surgical technique because it offers the best chance of non-recurrence. The centres are able to deal effectively with the range of medical and surgical problems caused by endometriosis, requiring the input of highly specialised gynaecologists, colorectal and urology surgeons, specialist endometriosis nurses, pain management, pelvic physiotherapists, etc. There are currently 45 BSGE accredited centres across the UK, and 9 provisional centres working towards accreditation. As we have mentioned, only one of those centres is in Wales. (6)

The Current Situation in Wales

With approximately 150,000 women in Wales suffering with endometriosis, it is plain to see that one NHS specialist centre to cover the whole country is hopelessly inadequate. In order to resolve this, women across Wales are simply not told about the existence of the centre(s); furthermore, individual health boards in Wales are very keen to ensure that their patients do not go ‘out of area’ for treatment. It is, therefore, incredibly difficult for patients across Wales to access the one centre capable of dealing with their problems.

For those women fortunate enough to live within the remit of Cardiff & Vale University Health Board, or allowed to access its care from outside of the area, the waiting time can be as much as 2 years, and even then they are not guaranteed an appointment with one of the two accredited specialists. Instead, they may be seen – and have their procedure performed – by a non-specialist, presumably in an effort to reduce the waiting time.
As we have already highlighted, non-specialists lack the complex skillset required to treat the disease effectively. This results in the need for repeated operations, none of which fully resolve/remove disease, and which frequently create additional complications. The non-specialist will frequently—and erroneously—recommend total hysterectomy (including removal of ovaries) as a ‘cure’ for endometriosis and, indeed, some women may report a reduction in symptoms as a result (usually because the bulk of their pain was due to uterine conditions such as fibroids or adenomyosis).

However, for the majority of patients, pain, bladder/bowel symptoms, and debilitation will continue, along with the added issues that surgical menopause and a dramatic change in pelvic anatomy can bring. This is because endometriosis secretes chemicals that cause inflammation, pain, and scarring independently of ovarian function (7).

Several members of our group report having had this radical surgery, only to find themselves with continuing, painful, endometriosis symptoms but no gynaecologist to treat them as they are now devoid of reproductive organs. Endometriosis should be treated by a sufficiently skilled excision surgeon (and team, if warranted) so that disease is removed, not healthy organs.

The Guidelines

Whilst the Welsh NHS is devolved from that of England, it still has obligations to follow European and NICE guidelines. The recent Welsh governance e-manual confirms (8) that the Welsh NHS agrees to abide by NICE guidelines pertaining to clinical guidelines, pathways, evidence, and best practice. However, with regards to endometriosis, this is not happening. Unlike NHS England, the Welsh NHS does not appear to publicise any guidelines pertaining to its treatment. Instead, the only resource available to patients is an online advice and information page provided by NHS Direct Wales (9). This internet page refers to the Royal College of Obstetricians and Gynaecologists (RCOG) as one of its main sources; a source which includes gynaecologists in Wales, and which is underpinned by the ESHRE (and subsequent NICE) guidelines. However, much of the information published on this page is problematic. There are inaccuracies and omissions, and it doesn’t reflect latest evidence of best practice:

1) the document claims that endometriosis is “incurable” – which, as we have established already, is not the case should proper, wide, excision be the modality used;

2) the document goes on to state that the “disease can be managed” using pain medications or hormone treatments (See Appendix 1).

This is an inaccurate statement. For some women, symptoms can be managed using various pain medications (although long-term use of pain medication has its own risks and should only be used as a short term strategy to provide relief until patients can access treatments that offer long-lasting improvement) or hormone therapies, including the contraceptive pill, the coil, or more significantly, GnRH analogues. With regard to the contraceptive pill, NICE has this to say, “Combined oral contraceptives are not licensed for the treatment of endometriosis, and there is only poor quality evidence of their effectiveness” (10).

Indeed, for a significant proportion of those using hormone therapies, there is no reduction in symptoms; for some, symptoms are increased or worsen – and for ALL women, neither pain relief or
hormone therapies will halt progression of disease (11). Subsequently, when women come off the contraceptive pill, for example, in order to try to conceive, they find their fertility has been severely compromised. 37% of all women undergoing IVF are doing so as a consequence of endometriosis. (12)

The routine prescribing of GnRH analogues is of particular concern to group members. Despite the manufacturers’ and ESHRE contraindications to taking these potent drugs, such as their not being suitable for women aged under 23 (13), not being used for more than 6 months in a lifetime, history of mental health issues, and so on, women AND girls continue to be strong-armed into taking them, sometimes for years at a time, and sometimes as an ‘alternative’ to surgery.

Many group members report having considerable and on-going side-effects, including depression and other psychiatric problems, issues with bones and teeth, extremely high blood pressure, severe headaches – and continuing pelvic pain. The ESHRE guide for professionals states that, “No evidence exists on the effectiveness of GnRHa for endometriosis-associated pain” (14). This underlines the dubious nature of these drugs as a ‘diagnostic tool’ – a purpose for which they are frequently appropriated, the theory being that a reduction in pain confirms the presence of endometriosis, whilst continuing pain excludes it.

There is also considerable concern about the serious, negative, and potentially permanent effects GnRH analogues can have on patients, including premature ovarian failure, increased risk of osteoporosis, reduced fertility, chronic headaches, and an increased risk of inflammatory bowel disease. In many case, the true long-term risk of hormone therapy is unknown, as it simply hasn’t been studied (15). The use of GnRH analogues in the management of endometriosis symptoms should, therefore, be reconsidered, taking the various guidelines and evidence into account, and be used with a lot more caution than currently is the case;

3) the NHS Direct Wales information refers to “heat, a laser, an electric current (diathermy) or a beam of special helium gas” (16) as being the ONLY surgical techniques employed in the treatment of endometriosis in Wales. The document is misleading because whilst it briefly mentions endometriosis being “cut out”, none of the methods it describes in order to achieve this are excision techniques. Burning and vapourisation (a technique which should be reserved for exceptional situations, such as the surface of the ovary, where excision would otherwise compromise fertility) are described, but not excision – the best, most effective method of disease removal.

Excision is an effective means of removing all areas of endometriosis and providing biopsies of diseased tissue. Unlike diathermy (burning) or vapourisation, it can be safely and effectively applied to more or less any area of tissue in the body and should, therefore be considered ‘best practice’ (17). The ESHRE guidelines state that, “Excision of lesions could be preferred with regard to the possibility of retrieving samples for histology. Furthermore, ablative techniques are unlikely to be suitable for advanced forms of endometriosis with deep endometriosis component” (18).

The ESHRE guidelines go on to recommend excision as opposed to diathermy for the treatment of ovarian endometrioma cysts, particularly because, “women with endometriomas almost always have disease elsewhere in the pelvis and are at an increased risk of deeply invasive endometriosis, including intestinal disease. Endometriomas are also often associated with adhesions, which can
make surgery more challenging” (19). It is therefore essential that women see a specialist surgeon with the necessary expertise to treat, and excise, severe disease.

Despite the clear evidence and guidance to the contrary, women in our group report that their endometriomas are routinely being treated with “drainage and coagulation” by diathermy. This is despite such an approach being associated with a far higher recurrence of both cysts and pain, and requiring further surgery.

The ESHRE guidelines go on to say, “performing surgical removal of deep endometriosis...reduces endometriosis-associated pain and improves quality of life” (20). The fact that women across Wales with “deep endometriosis” are instead being subjected to repeated burning (diathermy) is therefore wholly inconsistent with best practice;

4) All sources on which NHS Wales professes to base its own clinical guidelines and pathways (ESHRE, NICE, RCOG) state that all cases of severe endometriosis (See Appendix 2) should be referred to a specialist, multi-disciplinary centre:

“The GDG (Guideline Development Group) recommends that clinicians refer women with suspected or diagnosed deep endometriosis to a centre of expertise that offers all available treatments in a multidisciplinary context” (21).

All mention of the BSGE specialist centres is omitted from the NHS Direct Wales document.

The BSGE Accredited Centres

We have already established how all guidelines to which NHS Wales subscribe recommend referral be made to a specialist, multi-disciplinary centre for those patients with suspected or diagnosed severe endometriosis.

There is one accredited centre in Wales, within the Cardiff & Vale Health Board.

The BSGE website confirms that “severe endometriosis should be treated in specialist centres” (22) so, the fact that a Welsh board has sought and gained accreditation for a centre confirms that that board is in agreement with that statement and upholds the role of the centres in treating severe disease. Whilst there may be some degree of autonomy between boards, they are all ultimately governed by NHS Wales policy and principles.

To avoid discrimination by post code, the Public Services Ombudsman for Wales would undoubtedly insist that all patients with severe disease (suspected or diagnosed) should be able to access such a centre. Indeed, a precedent for this has already been set, with Hwyel Dda Health Board having to pay out damages to a female patient whose treatment was “mismanaged”, with doctors attempting and aborting a multi-disciplinary surgery because it was “so complicated”, beyond their expertise, and needed to be treated within a specialist centre (23). This particular health board claimed that it would, henceforward hold pre-operative meetings before attempting such surgery again. However, this is in direct contravention of the guidelines that state disease of this nature should be treated within a specialist centre. The fact that hospitals across Wales are attempting such surgery themselves could be considered to be causing harm to patients.
The GMC Advanced Training Skills module for advanced laparoscopic surgery for excision of benign disease states:

“This programme defines the training required to produce individuals with the skills required for the excisional treatment of benign gynaecological conditions using advanced laparoscopic surgical techniques. This is an advanced training programme... It is not covered anywhere else in proposed RCOG training. This programme requires two years intensive training... The trainee needs to assign at least 50% of their time for two years to be able to have the necessary skills at the end of training” (24).

The highly complex skills required of a surgeon undertaking excision of endometriosis, pelvic sidewall dissection and rectovaginal excision are then subsequently described in detail and demonstrate how these can only be acquired after completion of the rigorous training described above. This is also covered by the BSGE, but gynaecologists are bound by GMC standards. Therefore, any gynaecologist attempting to treat severe endometriosis without having undergone this training, or without routine access to the multi-disciplinary team available at the centres, would be in contravention of the GMC standards. Judging by the experiences of the women within our group, non-specialists are routinely attempting to treat severe disease, a situation which can again be described as ‘harmful’ to patients.

Cross Border Funding / Individual Patient Funding Requests

The 2008 RCOG guidelines state the following:

“To improve delivery of care for women with severe endometriosis, regional and national referral pathways should be developed for advanced laparoscopic procedures as the specialist centres emerge” (25).

In Wales, this is absolutely not happening. Health boards are unwilling to refer ‘outside of area’ and so women are not told about the existence of the centres – either in Cardiff, or across the border, in England. Not one of the women in our group was told of the existence of the BSGE centres by either her GP or gynaecologist. When pressed by politicians, health boards will pay lip-service to “correct referral pathways” but, in practice, these do not seem to exist or be followed.

Good medical practice requires all doctors / surgeons keep their knowledge up to date and follow guidelines and developments that affect their work. However, it seems that the vast majority of medics in Wales are ignorant to the existence of these centres and the clinical need for them. If women are fortunate enough to hear about them via word of mouth or internet support groups, for example, there then begins the tortuous process of getting either a referral to a massively over-stretched Cardiff centre or, for those for whom Cardiff is geographically far-distant, making a cross border funding application.

The cross-border (or out of area) Individual Patient Funding Requests (IPFR) are incredibly complex and are, again, something about which the vast majority of endometriosis sufferers are not informed. For a disease as commonplace as endometriosis and for which best practice treatment, as per the range of guidelines to which NHS Wales subscribes, is not available, this process seems entirely inappropriate, time-consuming (to patients, clinicians, and decision-making panels) and costly. It is also significant that there is no requirement for there to be any individual on the panel
who has a special interest in endometriosis. It is therefore unlikely that members will have any knowledge of the disease or its cost implications.

According to the All Wales Policy on Making Decisions on Individual Patient Funding Requests:

“IPFR are defined as requests to an individual health board or WHSSC to fund NHS healthcare for individual patients who fall outside the range of services and treatments that a health board has agreed to routinely provide. This can include a request for any type of healthcare including a specific service, treatment, medicine, device or piece of equipment. Such a request will normally be within one of the three following categories:

• a patient would like a treatment that is either new, novel, developing or unproven and is not within the health board’s routine schedule of services and treatments;

• a patient would like a treatment that is provided by the health board in certain clinical circumstances but is not eligible in accordance with the clinical policy criteria for that treatment;

• a patient has a rare or specialist condition that falls within the service remit of the WHSSC but is not eligible in accordance with the clinical policy criteria for treatment”.

Quite clearly, endometriosis and its treatment do not fit any of the above criteria:

• Excision, widely recognised as being the best, most effective surgical treatment of disease, is not “new, novel, developing or unproven”;

• The provision of excision and multiple specialisms within a BSGE centre is recommended by all clinical policy guidelines to which NHS Wales subscribes (and, indeed, Cardiff has one such centre);

• Endometriosis is not rare. It does require specialised treatment but this treatment is widely available in England, as per the clinical guidelines to which NHS Wales has subscribed. The surgical modalities currently being used throughout Wales are actively harming patients and the lack of information provided to patients contributes to this.

**ACTION NEEDED BY YOU:**

• Improve GP knowledge and understanding of endometriosis, including making both GPs and gynaecologists aware of the BSGE centres and their provision;

• Massively decrease diagnosis time, utilising a symptom check-list and patient diary;

• Recognise the limitations of hormone-based therapies, particularly GnRH analogues;

• Recognise excision as a vastly superior surgical technique to diathermy, both in terms of effectiveness and cost;

• Invest in training so that all women requiring endometriosis surgery in Wales are offered excision, regardless of stage of disease;

• Set up a national database to track the current surgical treatment of endometriosis in Wales, enabling the tracking of patients, recurrence of symptoms, and number of re-operations required (See Appendix 3);
• Implement and enforce an effective referral pathway to BSGE centres for all women with moderate / severe endometriosis in Wales, so that the onus is on clinicians to know about and refer patients to them, irrespective of location, without the need for IPFRs;
• Develop a comprehensive and up-to-date set of guidelines for the treatment of endometriosis in Wales; the NHS England Standard Contract for Severe Endometriosis should be seen as a template;
• Undertake a cost and benefits analysis of providing BSGE centres across Wales.

Appendices

1) The medical “management” of endometriosis, with pain-relief and hormone therapies assumes, first of all, that GPs actually diagnose the disease. With diagnosis taking in the range of ten years, clearly this is not happening in anything remotely approaching a timely manner.

During this period, women are being sent for numerous (and largely irrelevant) scans and tests, including blood and urine tests, ultrasound scans, colonoscopies, x-rays, barium enemas, CT and MRI scans, and routinely prescribed various inappropriate medications including repeated courses of antibiotics, IBS medications, ant-acids, and anti-depressants (implying that patients are in need of psychiatric care when, in fact, what they require is timely, effective treatment of a painful, debilitating disease).

In contrast, a diagnostic laparoscopy (performed on an out-patient basis) can absolutely confirm or exclude endometriosis as a cause of pelvic pain. It would be a good idea for GPs to have a simple tick-box symptom checker to make an immediate assessment as to whether a patient’s case warrants such a procedure. As a safeguard, they may ask patients to fill out a (printed) 3 month pain / symptom diary which could be used to confirm the potential diagnosis before being referred for a diagnostic lap. with a regular gynaecologist. Providing good quality surgical images and biopsies are taken during the procedure, it should then be made possible for women to access a specialist centre and for the surgeons there to have a good idea of the case before them.

2) It is vital readers be aware that the current treatment protocol for endometriosis in Wales ensures that more women eventually develop what can be categorised as severe disease: diagnostic delays and ineffective medicinal intervention allow disease to progress, whilst repeated inappropriate surgery fails to remove disease, causes scarring, increases adhesion formation, and can create additional complications. These factors subsequently count towards patients’ disease being re-classified as ‘severe’; several of our members report going from Stage 1 or 2 to Stage 4 (most severe) during their period of ‘treatment’ by the Welsh NHS.

3) In terms of migration, like Scotland, Wales has a relatively stable, consistent population, with relatively few people native to the region leaving. Demonstrating considerable foresight, Scotland established a national database of patients as follows:
“Every person registered with a general practitioner (GP) in Scotland is allocated a unique identifying number from a centrally maintained register called the Community Health Index (CHI). The CHI number is the unique patient identifier in all primary health care activities, and is now used in hospital based clinical information systems achieving 93% compliance. It is the key to linking health data for research purposes” (27).

It would therefore be useful to patients, clinicians, and health service strategists if there were to be a similar database in Wales; its use in assessing the re-operation rates for endometriosis sufferers would be invaluable in making a cost comparison between a (potentially) one-off excision surgery by a specialist, compared to numerous diathermy procedures performed by non-specialist gynaecologists, as the current treatment protocol in Wales dictates.

4) Document: Data pertaining to Excision of Endometriosis over Ablative Procedures (28)

If invasive endometriosis is left untreated, there is a significant risk that the patient’s symptoms will persist despite surgery with an ongoing impact on the patient’s quality of life and a need for further intervention. In order to address pelvic pain associated with endometriosis, minimize risk of recurrence and avoid a need for further surgery, all areas of disease should, therefore, be treated during the patient’s index surgery. Endometriosis may be treated surgically by destroying the lesions with thermal energy (fulguration/diathermy/cautery/coagulation and ablative vaporization) or by resecting the lesions to healthy margins (wide excision). Table 2 provides a comparative synopsis of the efficacy of these three surgical treatment modalities commonly used in the management of superficial (peritoneal) and invasive (retroperitoneal) endometriosis as reflected in the medical literature.

Table 2: Efficacy of treatment modalities in the surgical management of endometriosis.

<table>
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<tr>
<th>Treatment efficacy:</th>
<th>Peritoneal disease</th>
<th>Fulguration/diathermy/coagulation</th>
<th>Ablative vaporization</th>
<th>Wide excision</th>
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<tr>
<td></td>
<td>Research examining the efficacy of fulguration (mono-polar and bipolar coagulation) in the eradication of peritoneal endometriosis in female patients has found that disease persists despite treatment in 80.8% and 90.4% of lesions following monopolar and bipolar coagulation respectively. Fulguration is therefore not a reliable means of eradicating even superficial endometriosis. Fulguration does not allow for biopsy confirmation of the pathology of the tissue, it can only be consistently applied to small surface areas (not diffuse areas of disease) and to areas of disease that are not overlying vital structures, such as the ureters.</td>
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<td>Research examining the efficacy of ablative vaporization with the CO₂ laser in the eradication of peritoneal endometriosis in female patients has found that disease persists despite treatment in 28.9% of lesions. While ablative vaporization is considerably more effective than fulguration, many patients treated with ablative vaporization are likely to experience incomplete eradication of their disease especially given multiple areas of involvement are present in most cases.</td>
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<td>Excision is the only method of treatment of endometriosis that enables complete removal of the disease. The concept of wide excision is supported by the literature on the grounds that recurrence of disease most commonly occurs at or proximal to the sites of previous treatment, suggesting that the initial area of resection was not wide enough. By utilizing wide excision, the risk of leaving undetected endometriosis is minimized. Unlike, fulguration and ablative vaporization, excision allows the surgeon to assess the full extent of disease; the breadth and depth. Simply differentiating between peritoneal and retroperitoneal disease can be challenging without performing excision.</td>
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<td>Comparison of outcomes:</td>
<td>Peritoneal disease</td>
<td>Retroperitoneal disease</td>
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<td>No prospective clinical comparison studies exist between fulguration of endometriosis and other surgical techniques. Higher rates of post-operative adhesions have been reported in a rat model following treatment).³.⁴ As with fulguration, ablative vaporization does not allow for biopsy confirmation of the pathology of the tissue, and can only be consistently applied to small surface areas (not diffuse areas of disease).⁵ ²⁰</td>
<td>Excision of endometriosis has been found to be effective in both eradicating the disease, reducing symptoms across multiple domains, and improving quality of life.⁶ ²¹ In the majority of patients, the benefits of excision persist during long-term follow-up.⁶ ²⁶ Reoperation rates following excision are low and only a minority of patients are found to have disease recurrence despite long-term follow-up.⁶ ²⁸ When disease recurrence does occur, the disease is typically milder and subtler than at the index surgery.⁶² ³⁶ Excision can be applied to any area of the pelvis peritoneum regardless of underlying structures. It enables biopsy confirmation of the pathology.³ ²⁰</td>
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| Retroperitoneal disease | Unknown.⁵ No studies have yet explored the methodology, safety, or the efficacy of fulguration (diathermy, cautery, coagulation) in the treatment of retroperitoneal endometriosis. It is unclear how fulguration could be safely or effectively applied in the treatment of retroperitoneal endometriosis due to the effects of thermal spread on surrounding tissue associated with this technique and the proximity of vital structures to retroperitoneal endometriosis. Case reports have, however, been published of complications arising from undetected thermal injury secondary to fulguration of pelvic endometriosis.⁴ |

| Limited research has been undertaken into the efficacy of ablative vaporization in the treatment of invasive endometriosis. Of the research published to date, the findings have been mixed. While Jones and Sutton (2003) reported reduction in pain across all domains at 1 year post-op, a more recent study by Posadzka and colleagues (2015) found the benefits of CO₂-laser ablation to be limited to a reduction in dysmenorrhea while other forms of pelvic pain failed to show long-term improvement.⁷ Interestingly, Jones and Sutton (2003) found dysmenorrhea to be the symptom that responded least well following this intervention. On average, patients reported ongoing pain across all domains despite a degree of improvement. The results are further complicated by the fact that nearly a third of the patients in their study were receiving concurrent ovarian suppressive therapy. The efficacy of ablative vaporization in the treatment of invasive endometriosis therefore remains unclear. | Excision of deep endometriosis has been studied extensively.⁸ ⁴ ²⁵ ²⁶ It has been found to be effective in managing all aspects of retroperitoneal disease with low recurrence rates following complete excision.⁴ ²⁶ ²⁸ ²⁹ and acceptable complication rates given the complexity of the surgery and the severity of debilitation experienced prior to treatment.⁶¹ Unlike other approaches (fulguration and ablative vaporization), the approach to the treatment of retroperitoneal endometriosis via excision has been described in detail and is well established in the medical literature.⁶ ²⁴ ²² |
While endometriosis is a common disease, its effective surgical treatment poses significant challenges that require extensive knowledge and surgical expertise.

References

Citations

1) Endometriosis UK https://www.endometriosis-uk.org/endometriosis-facts-and-figures
2) Endometriosis UK https://www.endometriosis-uk.org/endometriosis-facts-and-figures
8) http://www.wales.nhs.uk/governance-emanual/nice-guidance
9) http://www.nhsdirect.wales.nhs.uk/encyclopaedia/e/article/endometriosis/
10) NICE, http://cks.nice.org.uk/endometriosis#!scenario:1
12) https://www.glowm.com/section_view/heading/Infertility%2520Aspects%2520of%2520Endometriosis/item/329
14) http://www.eshre.eu/~/media/Files/Guidelines/Endometriosis/ESHRE%20guideline%20on%20endometriosis%202013.pdf, page 34
16) http://www.nhsdirect.wales.nhs.uk/encyclopaedia/e/article/endometriosis/
18) http://www.eshre.eu/~/media/Files/Guidelines/Endometriosis/ESHRE%20guideline%20on%20endometriosis%202013.pdf, page 40
20) http://www.eshre.eu/~/media/Files/Guidelines/Endometriosis/ESHRE%20guideline%20on%20endometriosis%202013.pdf, page 44
22) http://bsge.org.uk/ec-requirements-BSGE-accredited-endometriosis-centre.php
23) http://www.bbc.co.uk/news/uk-wales-19817999 04/10/2012
27) http://www.scot-ship.ac.uk/overview.html
28) Hopton, Elizabeth, Vital Health Institute, California, 2016

Additional Resources

NHS England Standard Contract for Severe Endometriosis

NHS Wales Governance E Manual
http://www.wales.nhs.uk/governance-emanual/home

Royal College of Obstetricians and Gynaecologists

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