

# Endometriosis in Northern Ireland

## Position Statement as at 31 March 2016

### Introduction

Endometriosis is a long-term debilitating disease<sup>1</sup> that has no cure<sup>2</sup>. It affects up to two million women in the UK<sup>1</sup>, one in every 10 women of child-bearing age<sup>2,3</sup> and is more common than diabetes<sup>4,5</sup>.

Of those two million, a further 5-10% of women are diagnosed with the most severe form of the condition<sup>6</sup>, making it more prevalent than cancer of the uterus and cervix combined<sup>7</sup>.

Based on the 2011 figures from the Northern Ireland Statistics and Research Agency (NISRA), there were more than 250,000 women of child-bearing age in Northern Ireland<sup>8</sup>. That would equate to around 25,000 women with endometriosis and 1,500-2,500 suffering from the most severe form commonly known as Stage IV.

In 2011-12, there were 1,155 hospital admissions in Northern Ireland resulting from a diagnosis of endometriosis<sup>6</sup>. Despite its prevalence, there is no dedicated endometriosis centre in Northern Ireland or a fast-track referral pathway<sup>6</sup>. This is in stark contrast to the NHS in England, Scotland and Wales, where regional endometriosis centres and networks are a well-established practice<sup>9</sup>.

Since 2013, the Patient and Client Council (PCC) has been supporting women in Northern Ireland with Stage IV endometriosis – the most severe form - to ensure their voices are heard by decision-makers.

The aim of this paper therefore is to provide an overview of the current position on endometriosis services in Northern Ireland.

### What is endometriosis?

Endometriosis is a chronic condition<sup>1</sup> that behaves like cancer, although the abnormal tissue is non-malignant<sup>10</sup>. It occurs when tissue similar to that lining the womb or endometrium is found outside the uterus, which 'induces a chronic, inflammatory reaction'<sup>11</sup>.

It is most commonly found in the ovaries and fallopian tubes, the lining of the inside of the abdomen, and the bowel or bladder, although it can be found in other parts of the body<sup>1,3</sup>.



The size of the abnormal tissue (lesion) is not so much of a factor as its location within the body. A small amount could be more painful than a large amount<sup>1</sup>.

### **What causes it?**

Despite decades of research little is known about the causes of endometriosis, although it does not relate to lifestyle<sup>12</sup> nor is it caused by sexually transmitted disease<sup>13</sup>.

One theory suggests that it could be caused by 'retrograde menstruation'<sup>1,14</sup>. This is when small amounts of blood and tissue flow up the fallopian tubes during menstruation then leak out into the abdomen and pelvis.

Others believe that the uterine tissue is carried through the lymphatic system and blood vessels to other organs, that there are weaknesses in the immune system or a family history of the disease, while a more controversial theory is that it is caused by exposure to environmental toxins<sup>14</sup>.

### **How does it affect the body?**

As the abnormal tissue is similar to that lining the uterus (endometrium), it, too, reacts to the hormones oestrogen and progesterone during the menstrual cycle. As a result, cyclical, microscopic bleeding occurs from these abnormal tissue resulting in chronic inflammation. Over time, ovarian cysts (endometrioma), large deposits and adhesions (layers/bands of scar tissue) form within and outside the pelvis<sup>14,15</sup>.

### **Psychological and socioeconomic impacts**

Endometriosis is the second most common gynaecological problem<sup>16</sup> but despite this it is a seemingly invisible condition veiled in myths and misunderstanding.

Although the causes of endometriosis are still disputed, it is widely recognised that the disease can have a 'significant impact' on the physical, mental and social wellbeing<sup>2</sup> of those who have endometriosis, with 86% of women developing depressive symptoms and 46% classified as clinically depressed<sup>17</sup>.

It can destroy self-esteem, lead to severe depression, cause the breakdown of relationships and inflict financial hardship through loss of employment. It can even deny some women the chance of motherhood<sup>18</sup>.

Statistics show that approximately 25-50% of women with subfertility have endometriosis and 30-50% of women diagnosed with endometriosis have subfertility<sup>19</sup>.



It can be difficult to diagnose<sup>1,18</sup> and the symptoms can vary significantly from woman to woman<sup>1</sup>. Some have no symptoms at all<sup>1,3,18</sup>. That is why it has been labelled as the 'hidden epidemic'<sup>20</sup> or the 'hidden suffering'<sup>21</sup>.

Many women with endometriosis say the condition is misunderstood, even disbelieved by family, friends and employers<sup>22</sup>. Some have reported that their GP told them it was a normal part of being a woman<sup>23</sup>, that the pain was all in the mind<sup>24</sup> or that they were suffering from another ailment, leaving them feeling isolated and confused<sup>25</sup>.

Another socioeconomic consequence of the condition is that it has been estimated that £8.2 billion a year is lost to the UK economy through absences from work and costs to the health service<sup>26</sup>.

## Symptoms

The most common symptoms include: dysmenorrhoea (severe, painful periods), menorrhagia (heavy and/or prolonged bleeding during periods), pain in the pelvis, abdomen and lower back, metrorrhagia (bleeding between periods), dyspareunia (pain during and/or after intercourse) and difficulty getting pregnant<sup>1,3</sup>.

Other symptoms may include fatigue, discomfort while using the toilet, bleeding from the rectum or blood in faeces<sup>1,3</sup>. Most women with endometriosis initially experience pain and discomfort in their abdomen in a cyclical fashion but, in time, the symptoms become more constant, with difficulties in pain control.

As the symptoms are not exclusive to endometriosis, they can be misdiagnosed as irritable bowel syndrome (IBS) or masked by other conditions, such as cyclical intestinal complaints, ovarian cysts, musculoskeletal disorders, chronic constipation and chronic pelvic pain<sup>27</sup>.

Believing that they suffer from menstrual problems, some women will put off seeing their GP for many years<sup>18,28</sup> and it is this, along with other factors, that has led to an average diagnostic delay of eight years in the UK while in Germany and Austria that figure is 10 years<sup>18</sup>.

By this time, the endometriosis is likely to have progressed from the earlier stages to Stage IV - the more severe form of the disease<sup>6</sup>.

## Diagnosis

The definitive diagnosis is only made after referral to a gynaecologist for a laparoscopic inspection and/or histological confirmation<sup>1,3,18</sup>.



## The classification of endometriosis

Four stages have been identified:

- Stage I: Endometriosis is minimal and still very thin and 'filmy' so easier to treat;
- Stage II: Mild endometriosis, still on the thin side but is situated more deeply into the surrounding tissues;
- Stage III: Moderate endometriosis, denser, mixed with some Stage I or Stage II symptoms;
- Stage IV: Severe endometriosis, in this case the endometriosis is dense and deep<sup>18,29</sup>.

## How can it be treated?

At primary care level hormonal treatments and/or pain relief may be offered for a three to six month period. After that, National Institute for Health and Care Excellence (NICE) guidelines recommend referral to Gynaecology. The guidelines also recommend referral to Gynaecology in cases of subfertility<sup>30</sup>.

Other therapies should be offered in addition, such as counselling, pain management (including cognitive behavioural therapies) and alternative therapies.

At secondary care level, NICE guidelines recommend specialist hormonal treatments, add back hormone replacement therapy (HRT) or surgical treatments to remove lesions and adhesions through laparoscopic or radical surgery<sup>31</sup>.

## Prognosis

Around 20-50% of women will experience a recurrence of symptoms five years after medical or surgical treatment<sup>19</sup>. A significant proportion of women would also experience fertility problems.

In only a third of women, deposits can spontaneously regress after 6-12 months<sup>19</sup>. Furthermore, laparoscopic or radical surgery does not always guarantee long-term relief from the symptoms due to the progressive nature of the disease<sup>13</sup>.

## NHS services in England, Scotland and Wales

Following the 2003 world congress on endometriosis, it was recognised that UK gynaecologists needed to improve the surgical treatment of women with severe endometriosis, especially those with rectovaginal endometriosis.



The British Society for Gynaecological Endoscopy (BSGE) and Royal College of Obstetricians and Gynaecologists (RCOG) guidelines recommend that women with severe disease, or those with intractable symptoms, should be treated in specialist endometriosis centres<sup>32</sup> by a dedicated, multidisciplinary team. As a result, regional endometriosis centres and networks are a well-established practice in England, Scotland and Wales<sup>9</sup>.

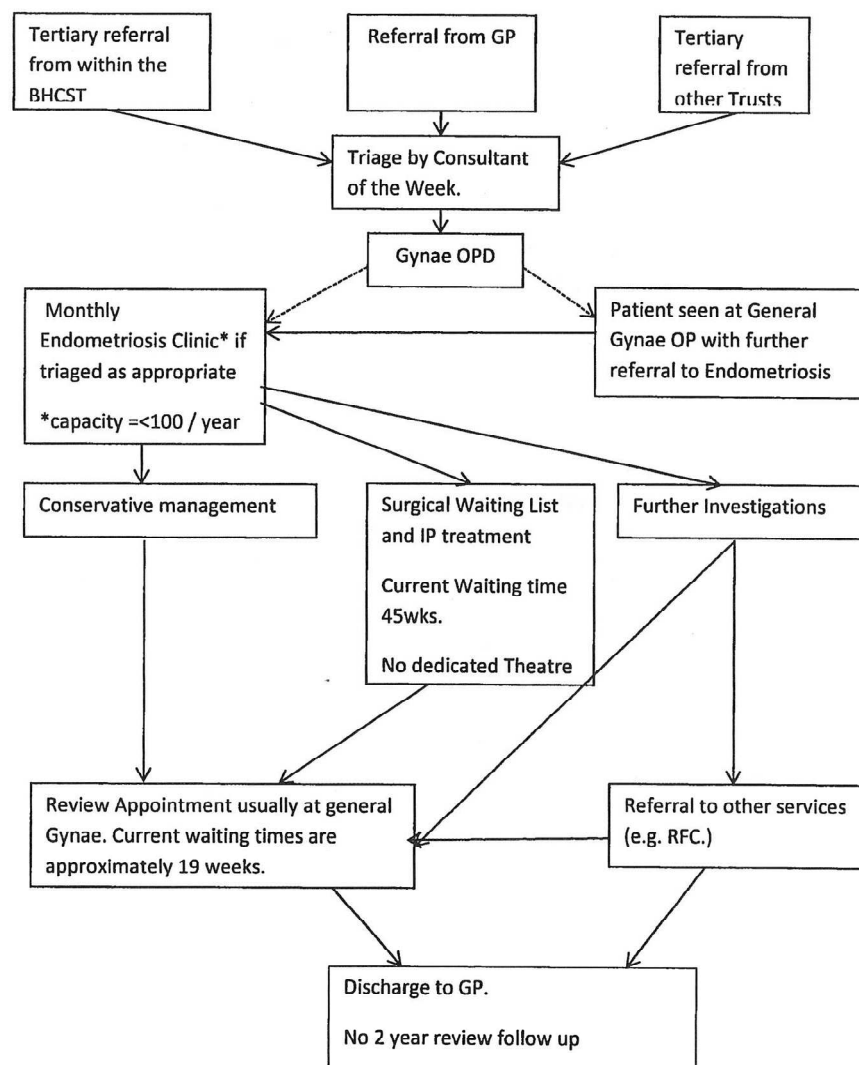
Long term data demonstrates that endometriosis centres improve treatment outcomes in much the same way as cancer treatment has been improved by the establishment of regional cancer centres<sup>6,8</sup>.

Additional funding has ensured that the service is sustainable, delivering a high quality, fast track referral pathway.

### Summary of services available in Northern Ireland

Figure 1 below shows the current pathway for endometriosis referrals in the Belfast Health and Social Care (HSC) Trust. It is both complex and inconsistent, and extremely difficult to ensure that patients are seen in a timely fashion.

**Figure 1: Belfast HSC Trust current pathway for endometriosis referrals.**



The Belfast service had been established, headed by a gynaecologist with a special interest in the management of severe (Stage IV) endometriosis, a colorectal surgeon and urologist with a special interest, fertility specialists, a radiologist and members of the pain management team<sup>6</sup>. The team has operated on an *ad hoc* basis, with a considerable degree of goodwill within the confines of the job plans of the consultant staff involved.

Demand for the service in Belfast has increased in recent years due to growing numbers of referrals from within and outside Belfast. Approximately 35-40% of the referrals suffer from severe endometriosis and the majority of the new patients are listed for surgery, having been referred for specialist treatment from other units throughout Northern Ireland. Access to operating theatre time is limited and waiting times for surgery are now up to 18 months<sup>6</sup>.

In June 2013, the Health Committee recommended an integrated endometriosis centre to the Northern Ireland Assembly based on a single site and offering the full spectrum of medical and surgical treatments alongside alternative therapies and counselling<sup>6</sup>.

The recommendations included dedicated staff including a specialist consultant gynaecologist, a pain management specialist, psychologist, colorectal surgeon, urologist, specialist nursing support, as well as research support<sup>6</sup>.

In September 2014, Belfast HSC Trust submitted a business case via the Women's Services Co Directorate. To date this business case has not been approved.

**No application has been made to have the Belfast clinic formally recognised as an endometriosis centre even though the caseload undertaken far exceeds that which is necessary to achieve official recognition<sup>6</sup>.**

This is due to the considerable administrative burden such an application would cause, as well as not being viewed as a priority within the confines of the current service provision.

As a result, while demand for the service has increased in recent years due to growing numbers of referrals from within and outside Belfast, the service is very under resourced and disjointed. It runs on an *ad hoc* basis, relying on considerable goodwill<sup>6</sup>.

### **The Patient and Client Council and endometriosis**

Since 2013, the PCC has been supporting women with severe (Stage IV) endometriosis to ensure their voices are heard by decision-makers.



In January 2014, the PCC hosted a regional symposium in partnership with the Pain Alliance Northern Ireland (PANI), which was attended by the Health Minister, decision-makers, patients and professionals.

The purpose of the symposium was to raise awareness of the condition, the need for a regional endometriosis centre, and a framework to care for and treat patients.

Additionally, the PCC has consistently advocated on behalf of the women at Health and Social Care Board (HSCB) meetings and at commissioner level. The PCC has also supported women to present personal testimonials on two occasions at public meetings of the HSCB.

In November 2015, the PCC hosted two group discussions between officials from the Public Health Agency (PHA), the HSCB and patients. At these meetings it was acknowledged that the current financial pressures meant that the business case for a regional centre was unlikely to be prioritised and funded by the HSCB and PHA in the immediate future.

It was agreed, however, that consideration would be given to:

- a) Prioritising the case for a clinical nurse specialist to support women and primary care clinicians, this has now been submitted to the Department of Health, Social Services and Public Safety (DHSSPS);
- b) The PHA would consider raising awareness of the condition among schoolgirls;
- c) The PHA and HSCB would also consider raising awareness of the condition at primary care level.

Subsequent discussions with the policy lead for the DHSSPS has confirmed willingness and a commitment to prioritise the need for a regional endometriosis centre.

### Conclusion and call for action

Endometriosis affects around 25,000 women aged 25-45 in Northern Ireland. Of that figure 1,500-2,500 suffer from Stage IV - the most severe form of the disease. This is, however, only a conservative estimate as diagnosis is difficult and many women delay seeking medical help for many years.

Demand for specialist treatment has increased in recent years, with referrals from HSC trusts across Northern Ireland but unlike all other regions in the UK there is currently no formally recognised endometriosis centre to care for those women with Stage IV of the disease.



While there has been a significant effort over the past three years on the part of patients, the PCC and PANI to increase awareness of the condition and the needs of the patients, there has been no betterment in terms of service delivery in that time. In fact, waiting times for both outpatients and inpatients have increased significantly which means that the situation for women with Stage IV endometriosis is actually worse than it was three years ago.

On the basis on our engagement with women who have suffered the impact of endometriosis the PCC is asking healthcare decision makers in Northern Ireland to make the following issues a matter of priority:

- a) The DHSSPS, HSCB and PHA should prioritise the need for a specialist endometriosis centre manned by a dedicated, multidisciplinary team to support women with Stage IV endometriosis;
- b) The PHA should undertake an awareness campaign on the condition among young women;
- c) The HSCB should provide information and raise awareness of the condition at primary care level;
- d) The Northern Ireland Medical and Dental Training Agency (NIMDTA) and Queen's University School of Medicine, Dentistry and Biomedical Sciences should include information on the condition during the training of doctors especially GPs.





## Glossary of clinical terms

**Adhesions:** Scars that connect two or more body structures together.

**Dysmenorrhoea:** Painful periods.

**Dyspareunia:** Pain during or after sexual intercourse.

**Endometrioma:** A benign, oestrogen-dependent ovarian cyst found in women of reproductive age. Also known as 'chocolate cysts' due to their dark, fluid-filled cavities.

**Endometriosis:** A condition where cells of the lining of the womb (the endometrium) are found elsewhere, usually around the pelvis and near the womb.

**Endometrium:** The lining of the womb (uterus).

**Hysterectomy:** An operation to remove the cervix and womb, carried out through a cut on the abdomen (abdominal hysterectomy) or the vagina (vaginal hysterectomy). The ovaries can be removed at the same time, if necessary.

**Irritable bowel syndrome (IBS):** A chronic disorder involving abdominal pain, bloating and changes in bowel habits, such as diarrhoea. It is caused by an overactive bowel.

**Laparoscopy:** Keyhole surgery involving up to four small cuts in the abdomen. A telescopic microscope (called a laparoscope) is inserted into the body to help diagnosis or treatment.

**Menorrhagia:** Excessive and/or prolonged bleeding during the menstrual cycle.

**Metrorrhagia:** Uterine bleeding at irregular intervals between the normal menstrual cycles.



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