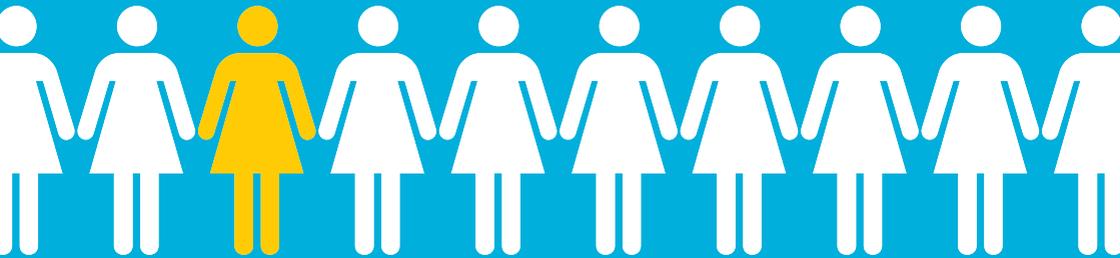


Clinical Nurse Specialist in Endometriosis



Endorsed by

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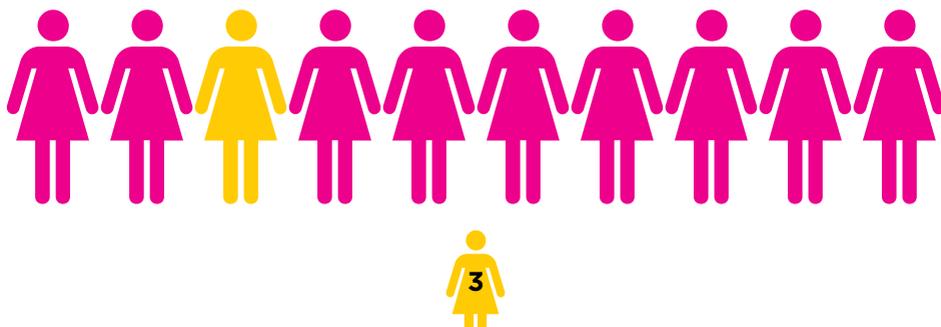
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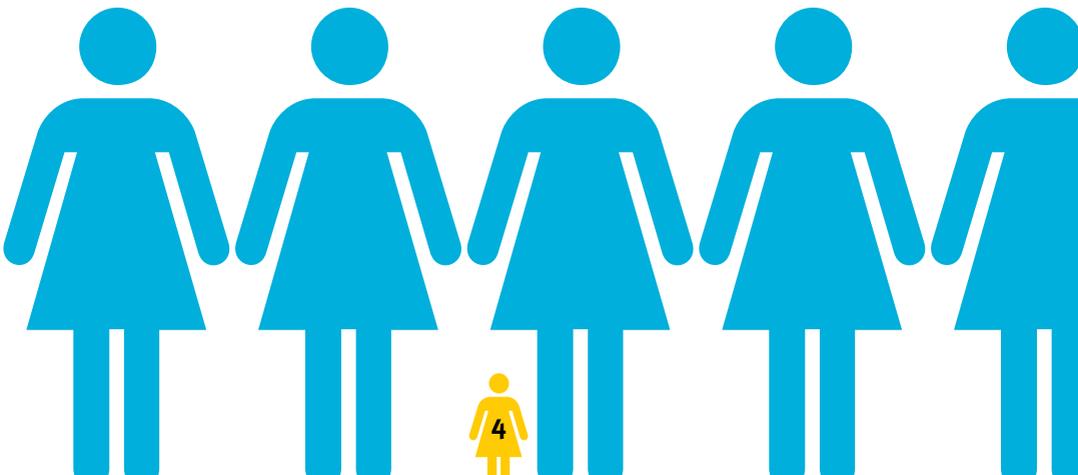
1 Introduction

Endometriosis is a life challenging disorder that affects over 1.5 million women in the UK – around one in 10 women from puberty to menopause. It is a complex illness that is often not quickly diagnosed when women first present with symptoms.

Evidence suggests that care can be delayed due to a lack of awareness and understanding of the disease amongst health care workers, which leads to lengthy diagnosis – it can take up to seven years for some women to receive a full diagnosis and access the best treatment for their condition.

Endometriosis is often misdiagnosed as irritable bowel syndrome, which can have devastating effects on the physical and psychological wellbeing of the women who have to live with this debilitating disease.

As a commissioned service within complex specialist care there are dedicated specialist centres which have been accredited by the British Society for Gynaecological Endoscopy (BSGE). As part of that commissioning review, it was confirmed that women attending these centres would benefit from improved quality of care by having direct access to an endometriosis clinical nurse specialist (CNS) and BSGE accreditation of specialist centres is now dependant on having an endometriosis nurse specialist in place. This role has been further recognised by the NICE guidelines (NICE, 2017), which expanded the role of the nurse supporting women with endometriosis or suspected endometriosis. This will have a future impact on the nurses who were originally employed to support complex cases.



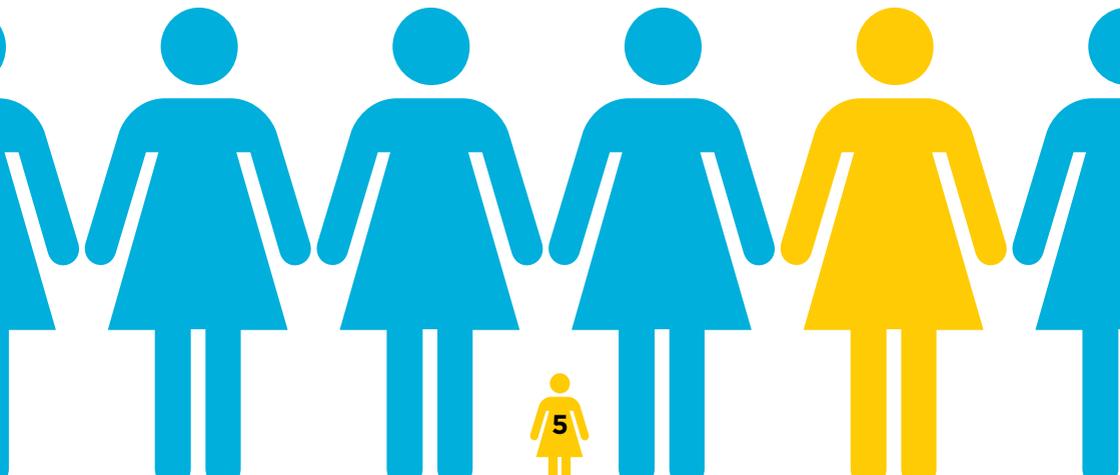
Recognising the lack of a national standard to define this role, the RCN Women's Health Forum, in collaboration with Endometriosis UK and the BSGE, initiated a project to devise a skills and knowledge framework that would inform and enhance local practice and establish a base line standard across the UK.

Defining the breadth and depth of the endometriosis clinical nurse specialist role will enhance career opportunities for nurses seeking to develop their own skills to become a CNS. It is envisaged that masters level academic learning should complement the development of this role.

It is hoped that defining the expectations will provide a clear direction for commissioners and managers when creating roles to support best practice in local service delivery. The clear definition of individual role components will not only ensure that the responsibilities of the endometriosis CNS is clearly understood but ultimately enable specialist centres to elevate the quality of care delivered for women.

When scoping the requirements for this project, the project team identified an urgent need for a simple yet effective information sheet that would enable nurses, and other health care workers coming into contact with women who may have endometriosis, to recognise the disease symptoms and support initial management of this condition.

The project team developed a generic fact sheet (see appendix 1) which provides guidance on how to recognise symptoms, sets out pathways of care and signposts useful online resources. It is hoped this resource will prove helpful to those nurses and other health care professionals who do not work directly within the field of women's health and will enable greater awareness of the disease.



2 Defining endometriosis

Endometriosis is defined as the presence of endometrial-like tissue outside the uterus, which induces a chronic, inflammatory reaction (NHS, 2013). While some women with endometriosis experience painful symptoms and/ or infertility, others have no symptoms at all (or may not recognise their symptoms as abnormal). The exact prevalence of endometriosis is unknown but estimates range from between two and 10 per cent within the general female population but up to 50% in infertile women (NHS, 2013).

Women of any age can have endometriosis however it is rare before the menarche (first menstrual cycle). Teenagers with painful periods, or who faint, collapse or miss school due to their menstrual periods may be demonstrating symptoms that indicate a possible diagnosis of endometriosis.

Endometriosis facts and figures

- One in 10 women of reproductive age (from puberty to menopause) in the UK suffer from endometriosis. 
- Ten per cent of women worldwide have endometriosis – that's **176 million** worldwide.
- The prevalence of endometriosis in **women with infertility** is as high as up to **50%**.
- Endometriosis is the second most common gynaecological condition (after fibroids) in the UK, affecting **1.5 million women** – a number that's similar to the number of women who are affected by diabetes or asthma.
- On average it takes **7.5 years** from the onset of symptoms to get a **diagnosis**.
- **Endometriosis costs** the UK economy **£8.2 billion a year** in treatment, loss of education, work and health care costs.
- The cause of endometriosis is unknown, but there are many different treatment options.

Endometriosis UK www.endometriosis-uk.org



3 The role of the clinical nurse specialist (CNS) in endometriosis

The role of the CNS in managing and supporting women with endometriosis has been defined to take account of the need to:

- lead and develop services
- ensure these services are linked with primary care
- support a better understanding of this condition among all nurses coming in contact with women.

Following the commissioning of complex gynaecology services, the care of women with complex endometriosis has been highlighted. Whilst minor and moderate cases of endometriosis can be managed in all gynaecology departments (with a specialist nurse who is interested in endometriosis), this service specification concerns only severe endometriosis, which has an annual incidence of around 5,000 new cases in the UK per year (NHS England, 2013). However, the RCN supports the need for all women with endometriosis to have access to specialist services to ensure the highest quality care which has been recognised in the NICE guidelines (NICE, 2017). However, this may be difficult to achieve in practice as centres tend to work to hours needed for each complex patient rather than focusing on the needs of individual women, regardless of their situation.

This document builds on this requirement and describes what a CNS might do, and encompasses the care of all women with endometriosis.

To become an endometriosis CNS, nurses will have had:

- extensive experience working within a gynaecology or women's health setting
- will have been educated to masters level and display masters level thinking and decision making
- have insight into the condition and all of the areas of management, including the wider social political dimensions of this condition.



3.1 Specialist commissioning for managing advanced endometriosis

For the purposes of specialist commissioning services, severe endometriosis is defined as either deeply infiltrating endometriosis or recto-vaginal endometriosis.

Deeply infiltrating endometriosis exists where the disease invades at least 5mm below the tissue surface and can occur in a variety of sites; this includes the bladder, pelvic sidewalls, ovaries, pelvic brim, bowel surface and diaphragm.

Recto-vaginal endometriosis is endometriosis which involves the recto-vaginal septum area (recto-vaginal septum; vagina; utero-sacral ligaments; rectum). There are many classification systems for endometriosis but none are universally accepted.

Removing the endometriosis involves complex surgery and national BSGE criteria (see www.bsge.org.uk) now exist which set out the standards of service and workload required to undertake surgical excision of advanced endometriosis.

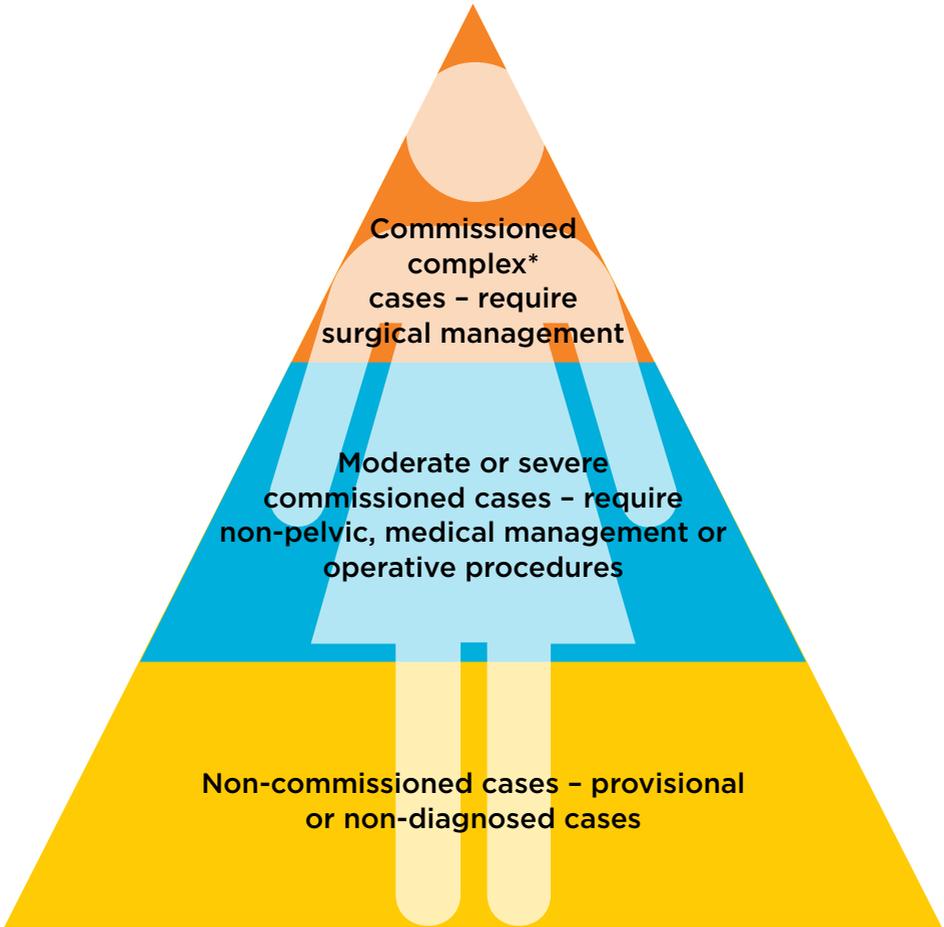
This is driving the establishment of endometriosis centres where such work can be undertaken by specialist multidisciplinary teams. Within the commissioning documents reference is made to an endometriosis CNS whose role is to liaise directly with women using the specialist service and provide women with support in the management of the condition.

The RCN supports recent NICE guidance (2017) that all women with suspected or confirmed endometriosis should have access to a gynaecology specialist nurse with expertise in endometriosis/CNS Endometriosis. At present it is more likely that only women at the more complex end of the spectrum of care will have access to these services (see figure 1).

The majority of the role of the CNS endometriosis will focus on women who do not necessarily fall into the specialist category. The majority of women who need support with their symptoms are those who do not fit into the severe category for surgery and those who have endometriosis outside of the pelvis; however these are women on medical therapy and will all need support from the CNS (NICE, 2017).



Figure 1 – Scale of need for women with a provisional and actual diagnosis of endometriosis



*Complex as defined by specialist commissioners (NHS England, 2013)

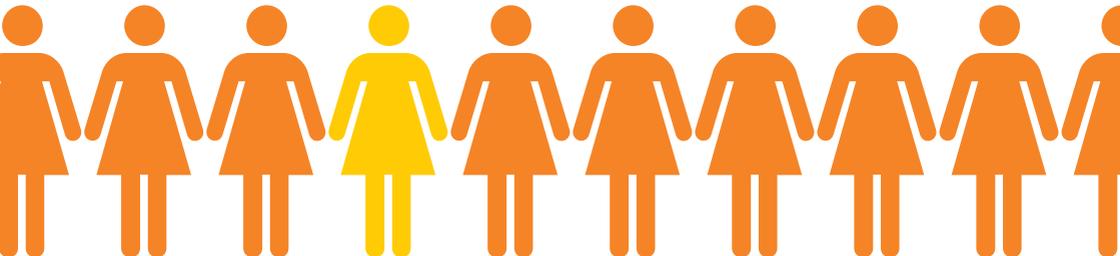
3.2 Specialist service centre aims

The primary aim of endometriosis centres is to provide woman-centered specialist care that helps improve the quality of life for women with severe endometriosis.

As these centres expand and develop, however, the CNS workload is set to evolve. At the present time, commissioning documents refer only to women with severe disease symptoms. In the future (and in light of the 2017 NICE guideline) the service may be extended to take into account the large number of women with endometriosis who do not require operations and receive non-surgical management and support.

The delivery of an excellent woman-centred service to women with endometriosis is achieved by:

- clearly defining and explaining the extent of the disease
- providing appropriate counselling and psychological support
- providing a nurse specialist to act as the interface between a woman and the specialist teams required to complete her care
- individualising care based on a woman's specific symptom complexity and preferences
- taking account of the woman's fertility needs
- providing high quality treatment and care to relieve the symptoms of endometriosis
- assessing quality of life before, during and after treatment.



3.3 Clinical nurse specialist responsibilities

The responsibilities of the endometriosis CNS within a specialist centre would encompass:

- elective outpatient follow-up at three months by a consultant and six months by a specialist nurse, with woman-related outcome measures (PROMs) including quality of life post-surgery assessments at six, 12 and 24 months
- working in a multidisciplinary team that includes a named colorectal surgeon and nurse specialist in endometriosis
- on their initial visit to the centre, women will be seen by the endometriosis specialist nurse and a full review of symptoms including completion of a quality of life questionnaire will be undertaken:
 - where investigations are incomplete or additional ones are needed these can be performed or booked
 - ideally the nurse should be able to organise or perform a pelvic and renal ultrasound if these are not supplied with the referral
 - detailed literature about all treatments including surgical treatment will be given to the woman and likely next steps discussed
 - if a diagnostic laparoscopy is required this will be organised directly by the nurse who will discuss each case with the doctor and multidisciplinary team.
- careful scrutiny of the referrals by the endometriosis specialist nurse will optimise this arrangement
- women will have contact details of the endometriosis specialist nurse and make contact if problems develop:
 - at six months the endometriosis nurse will review the woman and obtain a completed quality of life questionnaire
 - the same questionnaire will be completed at 12 and 24 months post-surgery and mechanisms for non-face to face consultations (telephone or website submission) need to be in place.



4 Clinical nurse specialist in endometriosis role: skills and knowledge

The role of the CNS endometriosis is complex and will demand a range of practice skills, alongside management and leadership insightfulness. This senior role will require the nurse to be able to:

- be clinically competent and confident in their own practice abilities
- be an inspiration and source of knowledge for others
- use audit tools
- enhance their own education
- consider the need for research to further enhance practice.

It is recognised that this is a developing role and that not all nurses will come with the full skills set required to fulfil all components outlined below.

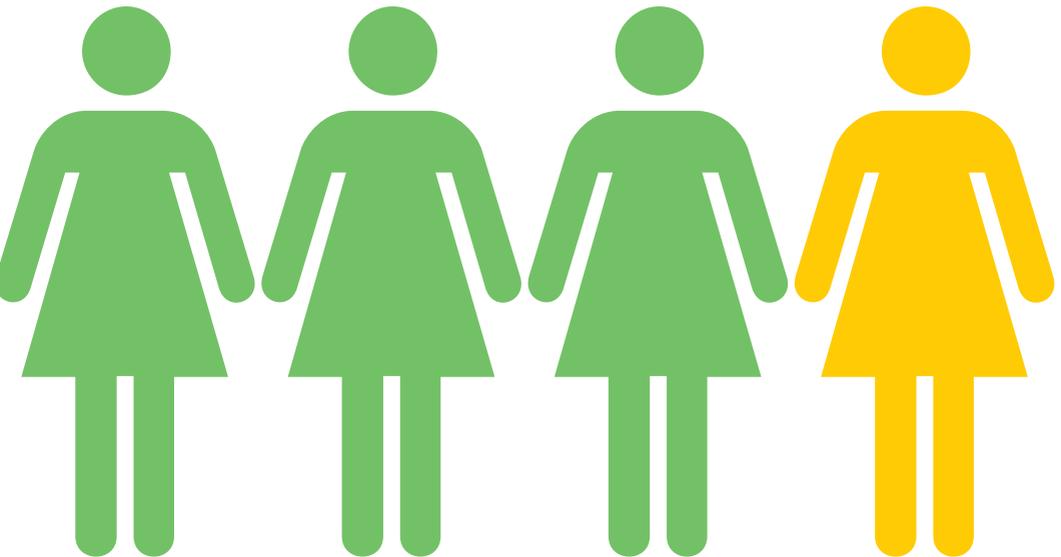
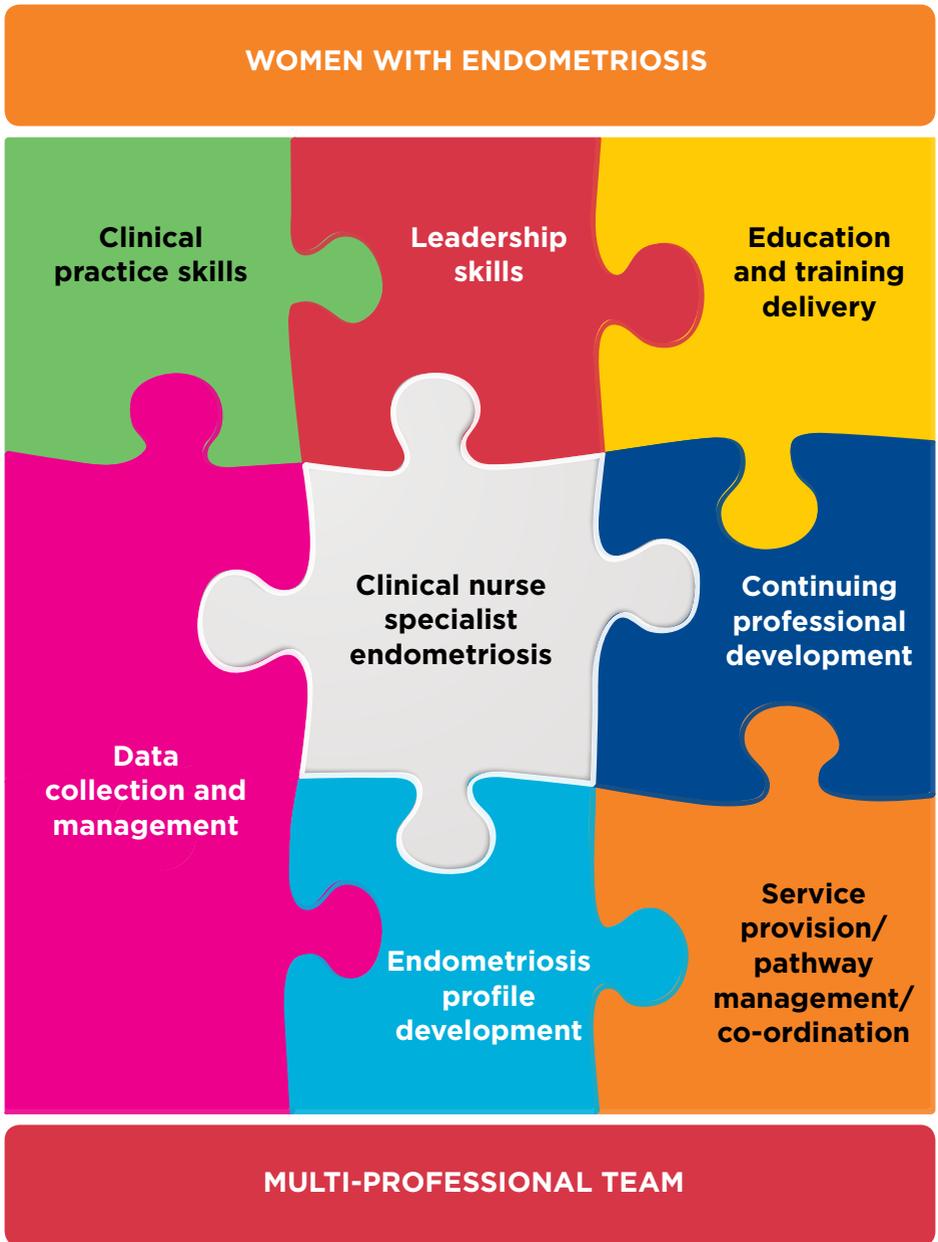


Figure 2 Overview of clinical nurse specialist skills



4.1 Clinical practice skills

- To have an expert knowledge of the condition, all treatment options (including associated side effects; complementary therapies) and be able to sign post if needed.
- Be able to communicate at all levels, to women, staff, primary and secondary care, written, verbal and phone, including good documentation.
- Be able to undertake consultations independently, which include assessment, history, physical and psychological assessment, for example, pelvic assessment. See also the RCN's 2016 publication *Genital Examination in Women: a Resource for Skills Development and Assessment*, which is available for download at www.rcn.org.uk/publications (publication code: 004 368) for further information on pelvic assessment.
- To be competent in the use of ordering and interpreting diagnostic tools – scanning, bloods, MRI (magnetic resonance imaging), and laparoscopy in conjunction with the multidisciplinary team.
- To undertake ultrasound or to be able to order and interpret results.
- To work with women who are inpatients, giving pre- and post-operative care and advice, co-ordination of any appointments on discharge, hormone replacement therapy (HRT) advice, follow-up phone calls.
- To hold own nurse-led clinics, both face to face and as a telephone service.
- To be a non-medical prescriber or work within patient group directives (PGDs) and have knowledge of drug regimes and side effects, including complementary therapies.
- To be able to undertake consent and give operative planning advice.
- To undertake counselling or be able to refer to the appropriate services.
- Undertake referrals – pain, fertility, investigations, psycho-sexual care/counselling, bladder and bowel care, counselling, menopause, mental health, and cognitive behavioural therapy (CBT).
- Advise on complementary therapies.

4.2 Leadership skills

- To be the woman's advocate in relation to surgery and treatment.
- To have the ability to work independently, as well as part of the multidisciplinary team, and to be organised.
- To be an autonomous practitioner while also working across and within multiple specialty teams.
- To be aware of the value and costing of the service by looking at the impact of the CNS on service users; for example, by user satisfaction ratings, number of consultations, number of women seen and number contacted, audit of appointment cancellations and audit of pathway in conjunction with management teams.

4.3 Data collection and management

- To contribute towards the collection and analysis of data, including quality of life surveys, own centre audit and research data.
- Service evaluation, including women's views on the service and individual women in relation to quality of life and symptoms.
- Informs research and uses research in practice.
- The assessment of individual women at each step of the pathway and the use of this data to inform the medical team/or consultant of a woman's progress, or if sooner follow-up is needed.
- IT skills should incorporate database, protocols, literature searching, audit, questions, research, word processing and spreadsheets (such as Microsoft Word and Excel packages).

4.4 Service provision/pathway management/ co-ordination

- Team work – this includes working with the multidisciplinary team to co-ordinate the care in outpatients, during surgical interventions and with other specialities.
- To ensure a streamlined service in all areas of care.
- To be the central point of contact for women.
- The co-ordination of services, for example medics, databases, outpatient appointments and surgery.
- Liaison with the colorectal team if dealing with a woman who has a stoma.
- The design and monitoring of care pathways.
- To be aware of women who have had a hysterectomy and are still experiencing problems – necessitating referral or liaison with the pelvic pain clinic or menopause clinic.
- Provide emotional support to women.

4.5 Education and training delivery

- To provide education to health care professionals, women and their partners in relation to endometriosis.
- To develop educational material for women or be able to find them.
- To educate nurses and medical staff within gynaecology and, if needed, to develop programmes with primary care.
- Work with practice nurses to identify women who may have the condition.



4.6 Endometriosis profile development

- To raise awareness among women in clinic and within primary care and to work with support groups to highlight the condition and provide support to women after a diagnosis.
- Create and enhance links with support groups.
- Understand the local and political landscape and providers and to actively find links in primary and secondary care.
- To provoke interest and engage with others about endometriosis.
- To conduct audits and consider opportunities for research to enhance practice.

4.7 Continuing professional development

- The education needed for the role is at masters level, with evidence of masters level thinking and problem solving.
- This could include for example non-medical prescribing, presentation skills, endometriosis module, evidence-based practice, advanced nursing practice, counselling, scanning, leadership, sexual health, contraception, advanced physical assessment skills.
- Manage effective support for self supervision, mentorship, buddying, utilising other clinical nurse specialists and the BSGE network.
- There is an expectation that a nurse within this role is given the opportunity to attend and maintain skills on an annual basis at appropriate national meetings.
- It is recommended that the endometriosis CNS becomes a member of the BSGE to extend good practice skills.

5 Conclusion

The clinical nurse specialist is a key post within the endometriosis team for women requiring care and support. The position represents an exciting opportunity for nurses to develop into a leadership role in a collaborative environment. It is recognised as a strategic leadership opportunity for nurses who specialise in an important aspect of woman's health care.

Recent research (due to be published shortly) on *The Role of the Endometriosis Clinical Nurse Specialist in British Society for Gynaecological Endoscopy Registered Centers*, is the first study to explore how the CNS endometriosis role aligns to the RCN skills and knowledge framework originally published in 2015 and identifies areas requiring further development. Conducted by Norton et al., (2018), this research has enhanced continuing collaboration by the RCN, BSGE and Endometriosis UK to further develop support for this role, and aims to ensure all CNSs can work to their full potential for quality effective care for all women who may have or be suspected of having endometriosis. Information on the progress of the project team can also be found at **www.rcn.org.uk/clinical-topics/womens-health/endometriosis**.

This role represents one of the first health service provision commissions to have stipulated that a service should have a nurse within the team and this development should be welcomed and celebrated as an attractive career opportunity for nurses.



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De Montfort University (2013) *The ENDOPART study. Endometriosis: improving the wellbeing of couples. Summary report and recommendations*, Leicester: DMU. Available at: www.dmu.ac.uk/research (accessed 23 October 2018)

Endocul (2010) *Endometriosis and cultural diversity: improving services for minority ethnic women*, Birmingham: Endocul Research Group. Available at: <http://cultureandcompassion.com/wp-content/uploads/2015/04/Endometriosis-and-cultural-diversity.pdf> (accessed 23 October 2018)

NICE (2017) *Endometriosis: diagnosis and management NICE guideline [NG73]*. Available at: www.nice.org.uk/guidance/ng73 (accessed 23 October 2018)

Norton W et al., (due to be published shortly) *The Role of the Endometriosis Clinical Nurse Specialist in British Society for Gynaecological Endoscopy Registered Centres*.

NHS England (2013) *NHS standard contract for complex gynaecology-severe endometriosis schedule 2 – the services a. service specifications*, London: NHS Commissioning Board. Available at: www.england.nhs.uk/wp-content/uploads/2018/08/Complex-gynaecology-severe-endometriosis.pdf (accessed 12 January 2015). Published by NHS Commissioning Board which is now known as NHS England.

Royal College of Nursing (2016) *Genital examination in women: a resource for skills development and assessment*, London: RCN. Available at: www.rcn.org.uk/professional-development/publications/pub-005480 (accessed 23 October 2018)

Useful resources

British Society for Gynaecological Endoscopy – see www.bsge.org.uk

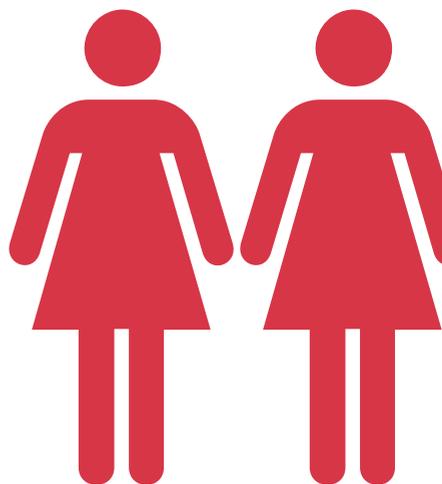
Endometriosis UK – see www.endometriosis-uk.org

European Society of Human Reproduction and Embryology – see www.eshre.eu

(ESHRE guidelines available at: www.eshre.eu/Guidelines-and-Legal/Guidelines/Endometriosis-guideline.aspx)

Royal College of Obstetricians and Gynaecologists – see www.rcog.org.uk

World Endometriosis Society – see www.endometriosis.ca



Appendix 1: Endometriosis factsheet

What is endometriosis?

Do you see female patients? Do they have painful periods? Pain pre or post their periods? Painful sex? Do they suffer chronic pain, which may be intermittent or constant? Do they have pain when passing urine or with bowel movements? Is it painful to place a speculum for a smear test?

Have you considered endometriosis?

One in 10 women have endometriosis and it takes an average of seven years for most women to get diagnosed. Endometriosis can often be confused with or misdiagnosed as IBS (irritable bowel syndrome). It is important that women receive an early diagnosis, or working diagnosis, of endometriosis even if hormonal treatments appear to be working, as women need to understand that they have a long term, chronic condition and the impact this might have on their future and their fertility.

What is endometriosis?

Endometriosis is defined as the presence of endometrial-like tissue outside the uterus, which induces a chronic, inflammatory reaction, and may lead to scar tissue formation.

While some women with endometriosis experience painful symptoms and/or infertility, others have no symptoms at all (or may consider their symptoms to be normal).

The exact prevalence of endometriosis is unknown but estimates range from between 2-10% of the general female population but up to 50% in infertile women.

NICE published new guidance in 2017, which details diagnosing and managing endometriosis, and should be consulted for further information.

You can find out more about the condition by taking a look at the informative website www.endometriosis-uk.org. Endometriosis UK is a charity that works to improve the lives of people affected by endometriosis and to decrease the impact it has on those with the condition and their families and friends.

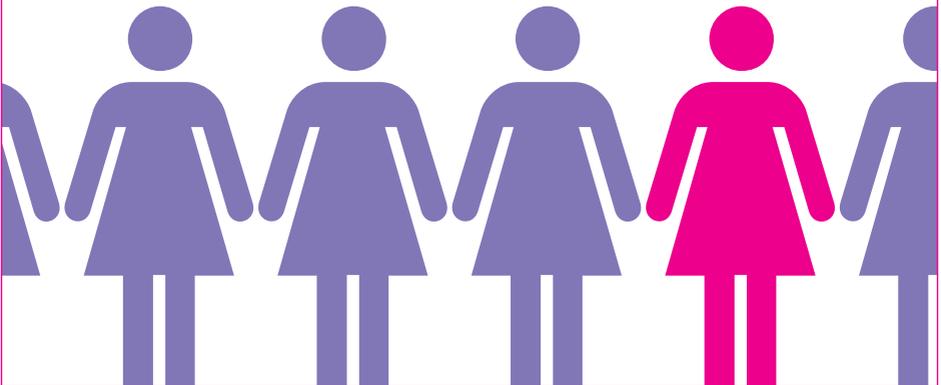


Some quick facts and figures about endometriosis

Facts and figures – from Endometriosis UK
www.endometriosis-uk.org

- **One in 10** women of reproductive age (between puberty and menopause) in the UK suffer from endometriosis.
- **10%** of women worldwide have endometriosis – that's **176 million worldwide**.
- The prevalence of endometriosis in women with infertility is as high as 50%.
- Endometriosis is the second most common gynaecological condition (after fibroids) in the UK.
- Endometriosis affects **1.5 million women**, a similar number of women are affected by diabetes or asthma.
- On average it takes **7.5 years** from onset of symptoms to get a diagnosis.
- Endometriosis costs the UK economy **£8.2bn** a year in treatment, loss of education, work and health care costs.
- The cause of endometriosis is unknown, but there are many different treatment options.

Information provided by Endometriosis UK



Who may be affected?

Women of any age can be affected by endometriosis but it is rare for the condition to manifest before a girl has her first period.

Teenagers who suffer with painful periods, experience fainting or collapse when having a period, or who miss school because of their period problems should be considered as possibly suffering from the condition.

What are the symptoms?

Symptoms may vary from woman to woman and some women may experience no symptoms at all (or may not recognise their symptoms as abnormal).

Typical endometriosis symptoms include:

- painful periods
- deep pain during sex
- chronic pelvic pain
- painful bowel movements, painful urination and blood in urine
- cyclical or premenstrual symptoms with or without abnormal bleeding and pain
- chronic fatigue
- depression
- a family history of endometriosis
- infertility
- painful caesarean section scar or cyclical lump
- back, legs and chest pain.



Endometriosis should be considered early in young women with pelvic pain as there is often a delay of between seven and 12 years from the onset of symptoms to receiving a definitive diagnosis.

Care management in primary care

Suspected endometriosis may be managed in primary care but consider referral to gynaecology or a specialist endometriosis centre if there is any suspicion or uncertainty over the cause of pain or if women are presenting with fertility issues. Women with suspected deep endometriosis involving the bowel, bladder or ureter must be referred to a specialist endometriosis service. All women should have as a minimum an abdominal examination and if appropriate a pelvic examination (quality standard 2018), and should be informed that endometriosis is being considered.

Treatments that can be tried in primary care include:

- **analgesics** – either simple or non-steroidal anti-inflammatory drugs (NSAID); these can be used in combination and especially around the time of the period
- **oral hormonal treatments** – combined oral contraceptive pills can be taken conventionally, continuously without a break, or in a tricycling regimen (three packs together); if women cannot have estrogen then the progesterone-only pill (eg, cerazette) could be used but it is important to remember that not all women will experience amenorrhoea so pain may persist; other alternatives include a course of medroxyprogesterone acetate (MPA) or norethisterone. If the initial course of hormonal treatment does not manage symptoms, the woman should be referred to a gynaecologist (quality standard 2018).
- **intra-uterine hormones** – an intra-uterine system such as Mirena IUS may provide relief from pain and is also a long-term treatment.

When to refer?

If you see a woman with the above symptoms, encourage her to see her GP or consider a referral to gynaecology. Be aware of local arrangements and seek advice from an endometriosis clinical nurse specialist:

- if there is uncertainty over the diagnosis
- if a woman requests referral
- if the woman has fertility problems
- if surgical and medical management of endometriosis is required

- if complex/severe endometriosis is suspected – for example, endometriomas or where endometriosis is affecting the bowel (Quality Standard 2018)
- if initial hormonal treatment for endometriosis is not effective, not tolerated or contraindicated (NICE guidelines 2017 and Quality Standard 2018).

Please note, a six-month timescale can be used to decide whether initial hormonal treatment is effective however a referral should be made before six months if it becomes clear that treatment is not effective.

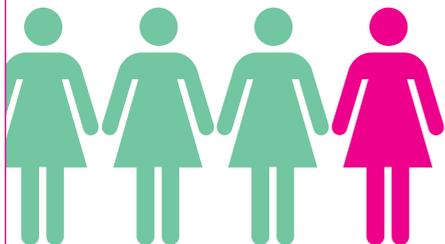
Care in secondary care and endometriosis centres

Women with endometriosis often need referral to secondary care for the diagnosis and treatment of the condition.

The investigations offered include ultrasound scan, although a negative scan or MRI does not rule out endometriosis, therefore the gold standard for diagnosis is laparoscopy. Laparoscopy can be diagnostic but more often this is combined with operative surgical procedures to remove the endometriosis.

Cases of severe endometriosis (or severe suspected endometriosis) should be sent to a specialist BSGE (British Society for Gynaecology Endoscopy) accredited endometriosis centre where women can access specialist gynaecologists and a clinical nurse specialist (CNS) who work in conjunction with general surgeons and urologists. These specialist centres also liaise with pain management teams and have links with a local fertility team.

A full list of accredited specialist endometriosis centres in the UK can be found online at the BSGE website at www.bsge.org.uk



Further information and resources

NICE (2017) *Endometriosis: diagnosis and management NICE guideline* [NG73]. Available at: www.nice.org.uk/guidance/ng73

NICE (2018) Endometriosis Quality standard [QS172]. Available at: www.nice.org.uk/guidance/qs172

Norton W et al., (due to be published shortly) *The Role of the Endometriosis Clinical Nurse Specialist in British Society for Gynaecological Endoscopy Registered Centres.*

To discover more about the condition or access additional information resources, here are some websites together with some topical research studies you might find helpful.

Endometriosis UK
www.endometriosis-uk.org

The British Society for Gynaecological Endoscopy
www.bsge.org.uk

Royal College of Obstetricians and Gynaecologists
www.rcog.org.uk

European Society of Human Reproduction and Embryology
www.eshre.eu

The World Endometriosis Society
www.endometriosis.ca

The ENDOPART study findings, published in 2013, provide a powerful insight into the emotional, sexual and relational impacts of the disease. See *Endometriosis: improving the wellbeing of couples – summary report and recommendations*. Available at: www.dmu.ac.uk/research

A 2010 study provides valuable indicators for providing care and services to women from minority ethnic groups. See Endometriosis and cultural diversity: improving services for minority ethnic women at <http://cultureandcompassion.com/wp-content/uploads/2015/04/Endometriosis-and-cultural-diversity.pdf>



Endometriosis

Please tear off this section and give it to women who you feel should seek a referral.



It has been suggested that I may have endometriosis.

Symptoms	Yes/ no	Notes
Painful periods		
Heavy periods		
Deep pain during sex		
Chronic pelvic pain (periodic or constant)		
Pain during bowel movements		
Painful urination and/or blood in urine		
Cyclical or premenstrual symptoms with or without abnormal bleeding and pain		
Chronic fatigue		
Depression		
Family history of endometriosis		
Infertility		
Painful caesarean section scar or cyclical lump in the scar		
Pain in back, legs and/or chest		

The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies.

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