RECOMMENDATIONS by AUDIENCE

NHS ENGLAND, WELSH GOVERNMENT, NORTHERN IRELAND DEPARTMENT OF HEALTH

ENDOMETRIOSIS AWARENESS

1

Raise awareness about endometriosis symptoms with the public and patients, highlighting that it is a chronic condition and how they can seek help.

Implementation supported by: *Royal College of Obstetricians and Gynaecologists, Royal College of General Practitioners, Royal College of Surgeons, Royal College of Emergency Medicine, Royal College of Nursing, Royal College of Paediatrics and Child Health, Department for Education, Endometriosis UK, Endometriosis Cymru*

RATIONALE and IMPLEMENTATION SUGGESTIONS

Improving awareness with the public may help reduce delays and improve care by earlier presentation to a GP. The following could be used:

- Social media campaigns on X, Facebook, TikTok, Instagram etc.
- Public health awareness posters
- Information on hospital intranets

See also: Endometriosis UK: Dismissed, ignored and belittled and NICE guideline CG138: Patient experience in adult NHS services: improving the experience of care for people using adult NHS services

ROYAL COLLEGE OF OBSTETRICIANS AND GYNAECOLOGISTS
ROYAL COLLEGE OF GENERAL PRACTITIONERS
ROYAL COLLEGE OF SURGEONS
ROYAL COLLEGE OF EMERGENCY MEDICINE
ROYAL COLLEGE OF NURSING
ROYAL COLLEGE OF PAEDIATRICS AND CHILD HEALTH
SOCIETY FOR ACUTE MEDICINE
BRITISH SOCIETY FOR GYNAECOLOGICAL ENDOSCOPY

2

Raise awareness with all healthcare professionals that endometriosis is a chronic condition and should be treated as such.

Implementation supported by: *NHS England, Welsh Government, Northern Ireland Department of Health*

RATIONALE and IMPLEMENTATION SUGGESTIONS

Endometriosis may mimic other conditions and patients may present to specialties other than gynaecology. Therefore, improving awareness with all healthcare professionals, including those not directly involved in the care of patients with endometriosis, may help reduce delays and improve care by earlier:

- Recognition of symptoms and referral – all pelvic pain, regardless of cause should be explored further
- Initiation of medical management
- Referral to supportive services to improve quality of life for patients and see specialists early in the condition's course.
- Re-entry into the care pathway for patients with recurrent disease

This may be aided using:

- Training modules
- Information on hospital/GP intranets

3

Improve training on the recognition of symptoms of endometriosis, such as pelvic pain and heavy menstrual bleeding.

a. **In primary care - to support healthcare professionals in the initial assessment, and any ongoing care of patients**
b. **In secondary care - enhanced training on endometriosis should be made available for all healthcare professionals who might care for patients with endometriosis.**

Implementation supported by: *NHS England, Welsh Government, Northern Ireland Department of Health*

RATIONALE and IMPLEMENTATION SUGGESTIONS

A pelvic pain lead could be responsible for upskilling staff at a regional level which would support with pathways to clarify where treatment is appropriate for primary care and what the thresholds for referral are. They could lead a team of primary and secondary care professionals with input by the MDT so that there is continuity of care but also be responsible for general awareness raising. This would enable earlier access to secondary care/specialist tertiary care/MDTs to help reduce delays.
It would also support the creation of more women's health hubs for the non-surgical treatments of endometriosis and as a home for the MDT.
For those working in secondary care, enhanced knowledge may lead to better treatment discussions and decision-making.

Those who may benefit from enhanced training would include:

- Primary care clinicians - GPs/practice nurses/physician associates
- Emergency medicine physicians
- Gastrointestinal physicians and surgeons
- Urologists
- Pain specialists
- Nurses, e.g. triage
- Sonographers

Women's health specialists would bridge the gap between the primary care and surgical care of this group of patients.

THE ENDOMETRIOSIS CARE PATHWAY

10

Formalise a care pathway for patients with or suspected to have endometriosis. This pathway should include implementation of NICE guideline NG73, the European Society of Human Reproduction and Embryology (ESHRE) endometriosis guidelines, as well as the recommendations from this report.

Implementation supported by: *NHS England, Welsh Government, Northern Ireland Department of Health*

RATIONALE and IMPLEMENTATION SUGGESTIONS

A dedicated pathway should cover the care of patients presenting with possible endometriosis, to the point of discharge following surgery and include the following steps:

a. Organisation of care
b. Information and support
c. Endometriosis symptoms and signs
d. Pharmacological management
e. Referral to support services to improve quality of life
f. Consideration of fertility intentions
g. When to refer
h. Diagnosing endometriosis, including imaging
i. Informed consent
j. Surgical management
k. Pain/chronic pain management
l. Psychological support
m. Follow-up care
n. Quality of life assessments

MEDICAL DIRECTORS, CLINICAL DIRECTORS, AND CLINICAL AUDIT/QUALITY IMPROVEMENT DEPARTMENTS

2

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HEALTHCARE PROFESSIONALS IN PRIMARY CARE AND SECONDARY CARE, INCLUDING PHARMACISTS

THE IMPACT OF ENDOMETRIOSIS ON QUALITY OF LIFE

4

Ask patients with endometriosis about the effects it has over and above physical symptoms, including its impact on their daily life and refer them as needed to support services (e.g. psychology/pain services), at all stages of the pathway.

Implementation supported by: *NHS England, Welsh Government, Northern Ireland Department of Health*

RATIONALE and IMPLEMENTATION SUGGESTIONS

It is important to consider all comorbidities when offering timely advice for the management of endometriosis. Physical health conditions as well as mental health conditions may influence the treatment decision and care provided.

A quality of life assessment should start in primary care and be repeated during any admission to hospital for endometriosis. The assessment should happen again at follow-up in primary, secondary or specialist care, and during any readmission for endometriosis. Endometriosis clinical nurse specialists would be ideally placed to carry out the assessments. The assessments should be linked to patient-reported outcomes following all treatment, including surgery. Tools include:

- World Health Organisation Quality of Life
- Consultation/pain questionnaire
- Generalised anxiety disorder assessment
- Patient health questionnaire

MEDICAL/PAIN MANAGEMENT FOR ENDOMETRIOSIS

6

Manage pain effectively for patients who have endometriosis:

a. Set a low threshold for the prescription of analgesia
b. Set a low threshold for hormonal treatment which may improve pain as well as other symptoms – while always considering fertility intentions
c. Refer to pain management services as needed
d. In parallel, refer patients for non-medical pain management e.g. physiotherapy

Implementation supported by: *Royal College of General Practitioners*

RATIONALE and IMPLEMENTATION SUGGESTIONS

Use of a stepped approach to analgesia, including simple analgesics and/or hormone treatment could be used.

7

Use interactions between patients with endometriosis and prescribing healthcare professionals to undertake a medication review.

Implementation supported by: *Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments*

RATIONALE and IMPLEMENTATION SUGGESTIONS

Any interaction with a healthcare professional, including pharmacists, is an opportunity to review medications, particularly pain medications and the long-term use of opioids, potential side effects and the efficacy of the medications.

DISCHARGE, FOLLOW-UP AND READMISSION

9

Provide patients with clear, written information at discharge following laparoscopic diagnosis/treatment of endometriosis, including who to contact and how to initiate direct access back into the endometriosis care pathway.

a. **Who to contact if they have any concerns, e.g. GP, endometriosis clinical nurse specialists, consultant**
b. **The follow-up plan and ongoing management of the endometriosis**
c. **The option of patient-initiated follow-up**
d. **Types and dosages of medication they are on at discharge, including analgesia and hormone therapy**
e. **The consideration of bone health for people with endometriosis on long-term hormonal medication, including nutrition, weight-bearing exercise and alcohol intake**

Implementation supported by: *Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments*

RATIONALE and IMPLEMENTATION SUGGESTIONS

A clear point of access and knowing who to contact should help patients avoid delays to readmission/re-entry into the care pathway. It would also reduce unnecessary GP appointments.

The use of patient passports could be considered, allowing patients to hold their data.

INTEGRATED CARE BOARDS, COMMISSIONERS, CLINICAL DIRECTORS AND EXECUTIVE BOARDS

ENDOMETRIOSIS MULTIDISCIPLINARY TEAMS AND CLINICAL NETWORKS

5

Ensure multidisciplinary teams/clinical networks are set up and utilised across all healthcare settings to help agree treatment plans and support women with confirmed endometriosis. Input from specialties should be proportionate to the patient's needs.

Implementation supported by: *Royal College of Obstetricians and Gynaecologists, Royal College of General Practitioners, Royal College of Emergency Medicine, Royal College of Nursing, Royal College of Paediatrics and Child Health, British Society for Gynaecological Endoscopy, Commissioners*

RATIONALE and IMPLEMENTATION SUGGESTIONS

Patient access to a multidisciplinary team or, as a minimum, established pathways for referral should be accessible from both primary and secondary care, not just specialist centres.

The use of pathways/ MDTs/clinical networks would support the patient and the clinical lead caring for the patient to ensure timely and appropriate referral back into the correct part of the pathway.

Consideration should be given to the fact that even minimal or mild disease can still cause painful symptoms and while a full MDT meeting may not be necessary, support from a wider specialty group may be helpful.

The MDT/clinical networks could include:

- Primary care - general practitioners/practice nurses/physician associates
- Endometriosis clinical nurse specialists
- Gynaecologists
- Pain/chronic pain/pain medicine specialists
- Pharmacists
- Radiologists
- Fertility specialists
- Mental health/practitioner psychologists/pain psychologists
- Pelvic physiotherapists
- Specialist surgeons when needed. e.g. colorectal
- Occupational therapists

This is consistent with NICE Guideline NG73 and British Society for Gynaecological Endoscopy (BGSE) accreditation

CONSULTANT SURGEONS, INCLUDING GYNECOLOGY, UROLOGY, COLORECTAL, AND GENERAL SURGEONS

CONSENT FOR LAPAROSCOPIES FOR ENDOMETRIOSIS

8

Provide patients with clear, written information as part of the process that allows the patient to give informed consent for the laparoscopic diagnosis/treatment of endometriosis. This should form the basis of a documented discussion with the surgeon before the day of surgery. Include:

a. **What the procedure involves**
b. **The purpose of the procedure e.g. to diagnose, stage, treat the symptoms of endometriosis, or a combination of these**
c. **What the patient's expectations are**
d. **The possible effects on endometriosis symptoms**
e. **Risks, benefits and limitations**
f. **The need for further laparoscopic/open surgery for recurrent endometriosis or if complications arise**

This is consistent with NICE guideline NG73

Implementation supported by: *Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments*

RATIONALE and IMPLEMENTATION SUGGESTIONS

Consent is a multi-stage process (or should be) that begins with an explanation in clinic and ends with signing a form. It is not appropriate to do all of that on the day of surgery but completing consent forms on day of surgery after prior explanation maybe appropriate.

To understand the benefits of any future procedures the operation note should include:

- how many prior laparoscopies the patient has undergone for endometriosis
- a comprehensive surgical description, with photographs
- a description of why any residual endometriotic tissue was left untreated and not removed
- comments about any difficulties performing the procedure which will underpin future decisions to operate.

GRANT-MAKING BODIES SUCH AS THE NATIONAL INSTITUTE FOR HEALTH AND CARE RESEARCH OR MEDICAL RESEARCH COUNCIL

FURTHER QUALITY IMPROVEMENT OPPORTUNITIES TO IMPROVE ENDOMETRIOSIS CARE

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a. **Collect surgical outcome data, including patient-reported outcomes, for benchmarking.**
b. **Review local practice against NICE guideline NG73, the recommendations in this report.**
c. **Undertake clinical trials to ascertain the efficacy of surgery for endometriosis-associated symptoms, especially for minimal or mild endometriosis.**
d. **Assess the use of pain medication, and the medical treatment of endometriosis.**
e. **Explore the use of imaging modalities in the diagnosis of endometriosis.**

Implementation supported by: Relevant Royal Colleges