BRITISH SOCIETY for GYNAECOLOGICAL ENDOSCOPY

Royal College of
Obstetricians &
Gynaecologists

BSGE and RCOG joint statement on Thoracic Endometriosis care in the United Kingdom

The thorax is the commonest location for extra pelvic endometriosis affecting up to 12% of those with pelvic disease. Thoracic endometriosis (TE) represents a spectrum of disease with endometriotic lesions being found on the diaphragm, pleural surfaces and / or lung parenchyma. The condition rarely occurs without pelvic disease. The main clinical manifestations include: catamenial pneumothorax, catamenial haemothorax, catamenial haemoptysis, and catamenial right upper abdominal or chest pain. There is limited evidence to guide accurate diagnostic tests and efficacious therapeutic interventions internationally (1).

The BSGE was approached by Endometriosis UK and patient representatives asking for a review of TE care in the United Kingdom (UK). The concerns raised included a lack of standardised treatments, geographical inequity in accessing care, and a lack of coordinated care nationally.

In response to these concerns, the BSGE conducted a survey of its members to establish their current practice and views on managing patients with TE. The survey results revealed low rates of screening questions being asked in clinic and low numbers of clinicians routinely looking for TE at the time of surgery (2). The majority of respondents surveyed felt that the care of patients with TE should involve a multidisciplinary team within centralised centres of excellence.

We believe that centralising the care of women with TE can improve clinical outcomes by allowing higher caseloads within a few specific units leading to greater experience and acquisition of expertise. Women with TE will benefit from better co-ordination of multidisciplinary care within specialist centres across the UK. Such an approach is in keeping with the aims of the Department of Health UK Strategy for Rare Diseases (3), enabling more accurate and timely diagnosis, and the potential for improved treatment outcomes. Concentrating care in this way can also facilitate research into the disease prevalence alongside the safety, effectiveness, and long-term prognosis of treatments.

In line with the recent All Party Parliamentary Group Report into Endometriosis Care (4) the BSGE supports:

- Working closely with BSGE members and patient representatives to understand the disease burden of TE.
- Working closely with patient representatives and funders in the development of a centralised pathway of care for TE.

References

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