

Acknowledgements

The RCN Women's Health Forum would like to thank the following members of the endometriosis project team for their assistance in the development of this publication:

Debra Holloway (Project chair), Nurse Consultant
Gynaecology, Guy's and St Thomas' NHS Foundation Trust and
Chair of the RCN Women's Health Forum Committee

Carmel Bagness (Professional lead), Midwifery and Women's
Health Adviser, RCN

Wendy Norton, Senior Lecturer, Faculty of Health and Life
Sciences, School of Nursing and Midwifery, De Montfort
University, Leicester and RCN Women's Health Forum
Committee member

Jane Hudson Jones, Chief Executive, Endometriosis UK (2015)
and Emma Cox Chief Executive, Endometriosis UK (2018)

Kay Logan, service user

Cathy Dean, Endometriosis Clinical Nurse Specialist, Royal
Cornwall Hospital

Tom Smith Walker, Consultant Obstetrics and Gynaecology,
Royal Cornwall Hospital and British Society for Gynaecological
Endoscopy (BSGE) representative



© 2018 Royal College of Nursing. All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means electronic, mechanical, photocopying, recording or otherwise, without prior permission of the Publishers. This publication may not be lent, resold, hired out or otherwise disposed of by ways of trade in any form of binding or cover other than that in which it is published, without the prior consent of the Publishers.

Contents

1 Introduction	4
2 Def ning endometriosis	6
3 The role of the clinical nurse specialist (CNS) in endometriosis	7
3.1 Specialist commissioning for managing advanced endometriosis	8
3.2 Specialist service centre aims	10
3.3 CNS responsibilities	11
4 CNS in endometriosis role: skills and knowledge	12
4.1 Clinical practice skills	14
4.2 Leadership skills	15
4.3 Data collection and management	15
4.4 Service provision/pathway management/co-ordination	16
4.5 Education and training delivery	16
5 Conclusion	18
References	19
Useful resources	19
Appendix 1: Endometriosis fact sheet	20



1 Introduction

women in the UK – around one in 10 women from puberty to menopause.

present with symptoms.

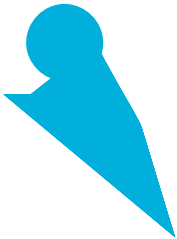
Evidence suggests that care can be delayed due to a lack of awareness and understanding of the disease amongst health care workers, which leads to lengthy diagnosis – it can take up to seven years for some women to receive a full diagnosis and access the best treatment for their condition.

Endometriosis is often misdiagnosed as irritable bowel syndrome, which 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

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

women with endometriosis or suspected endometriosis. This will have a future impact on the nurses who were originally employed to support complex cases.



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.

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.

commissioners and managers when creating roles to support best practice 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.

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 awareness of the disease.



2 Defining endometriosis



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

The role of the CNS in managing and supporting women with endometriosis

- 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

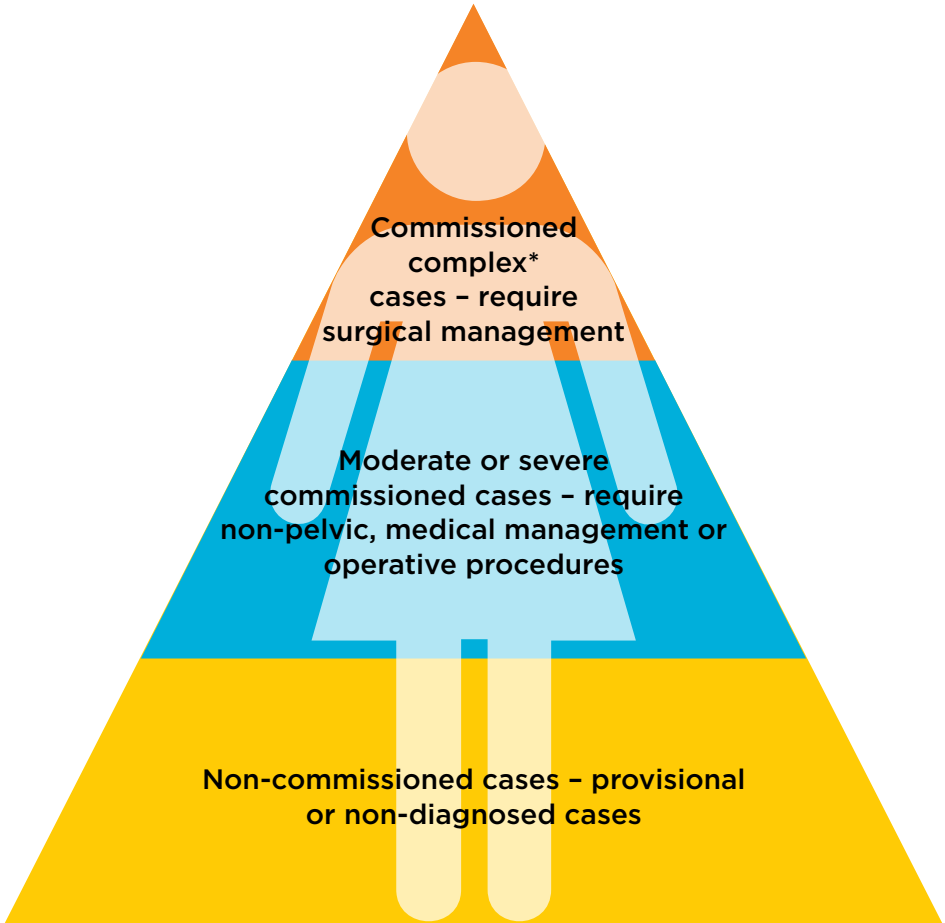


3.1 Specialist commissioning for managing advanced endometriosis

For the purposes of specialist commissioning services, severe endometriosis



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

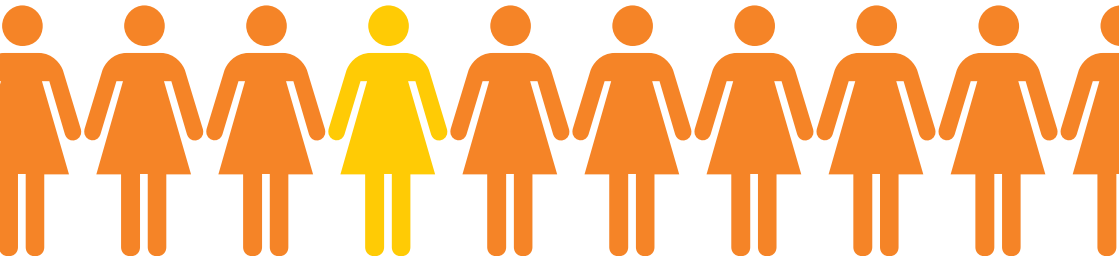
The primary aim of endometriosis centres is to provide woman-centered specialist care that helps improve the quality of life for women with severe endometriosis.

As these centres expand and develop, however, the CNS workload is set to evolve. At the present time, commissioning documents refer only to women

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:

-
- 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
-
- 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.





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 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

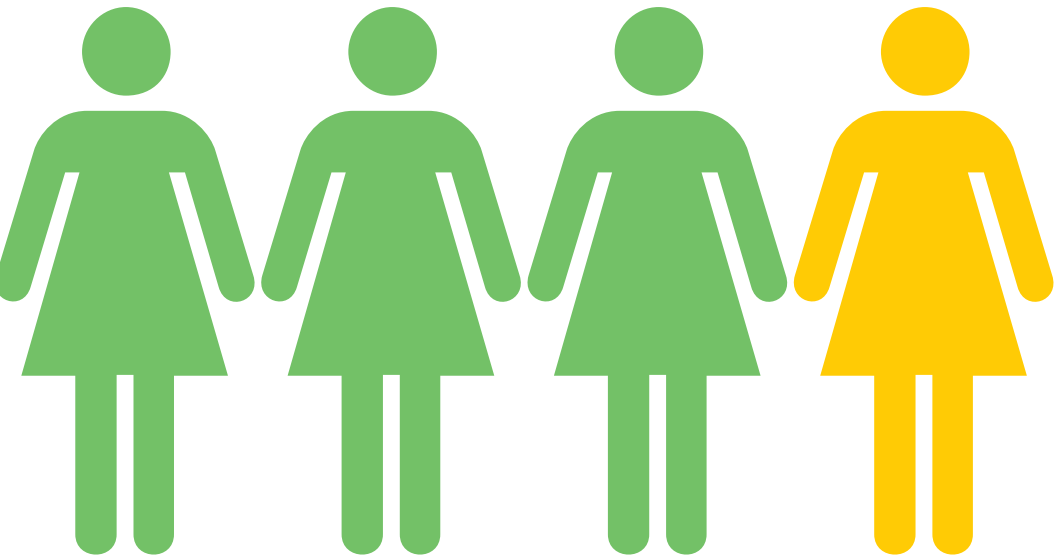


Figure 2 Overview of clinical nurse specialist skills

4.1 Clinical practice skills

- To have an expert knowledge of the condition, all treatment options to sign post if needed.
- 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 DEOH exaTjbeCN, fa, assement2, fuee also themen Ses045 or Sg

4.2 Leadership skills



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.
-
-



5 Conclusion

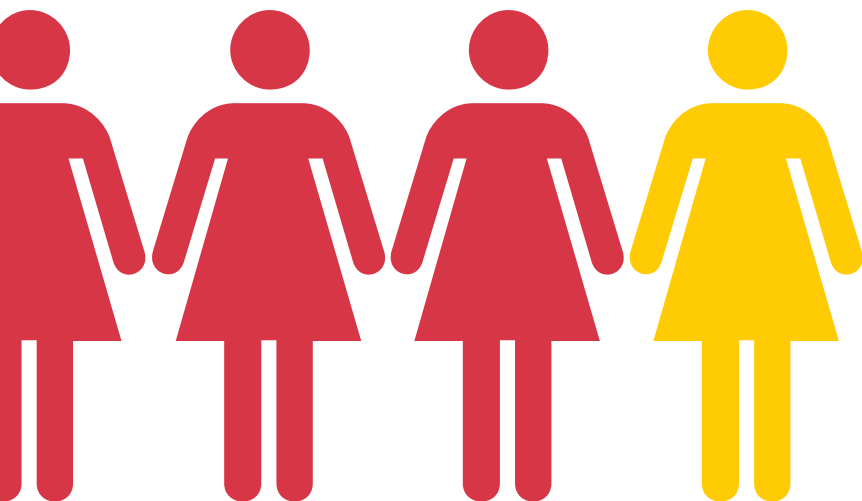
The clinical nurse specialist is a key post within the endometriosis team for women requiring care and support. The position represents an exciting opportunity for nurses to develop into a leadership role in a collaborative environment. It is recognised as a strategic leadership opportunity for nurses 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 how the CNS endometriosis role aligns to the RCN skills and knowledge

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

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.

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.



References

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)

Endometriosis: diagnosis and management NICE guideline

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 VHU YLFHV D VHU YLFH VSHFL & FDWLRQV, 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. 2010) Endometriosis and

Appendix 1: Endometriosis factsheet

Do you see female patients? Do they have painful periods? Pain pre or
SRVW WKHLU SHULRGV" 3DLQIXO VH[" 'R WKH\ VX HU F
LQWHUPLWWHQW RU FRQVWDQW" 'R WKH\ KDYH \$DLQ
ERZHO PRYHPHQWV" ,V LW SDLQIXO WR SODFH D VSHF

2QH LQ ZRPHQ KDYH HQGRPHWULRVLV DQG LW WDN
\HDUV IRU PRVW ZRPHQ WR JHW GLDJQRVHG (QGRPHW
FRQIXVHG ZLWK RU PLVGLDJQRVHG DV ,%6 LUULWDEC
LPSRUWDQW WKDW ZRPHQ UHFHLYH D HDUO\ GLDJQRV
RI HQGRPHWULRVLV HYHQ LI KRUPRQDO WUHDWPHQW
ZRPHQ QHHG WR XQGHUVWDQG WKDW WKH\ KDYH D OR
DQG WKH LPSDFW WKLW PLJKW KDYH RQ WKHLU IXWXU

(QGRPHWULRVLV LV GH¿QH DV WKH SUHVHQFH RI HQ
WKH XWHUXV ZKLFK LQGXFHV D FKURQLF LQÁDPPDW
WR VFDU WLVVXH IRUPDWLRQ

:KLOH VRRPH ZRPHQ ZLWK HQGRPHWULRVLV H[SHULHQ
DQG RU LQIHUWLOLW\ RWKHUV KDYH QR V\PSWRPV D
V\PSWRPV WR EH QRUPDO

7KH H[DFW SUHYDOHQFH RI HQGRPHWULRVLV LV XQNG
IURP EHWZHHQ RI WKH JHQHUDO IHPDOH SRSXOD
LQIHUWLOH ZRPHQ

1,&(SXEOLVKHG QHZ JXLGDQFH LQ ZKLFK HWDL
DQG PDQDJLQJ HQGRPHWULRVLV DQG VKRXO EH FR
LQIRUPDWLRQ

<RX FDQ ¿QG RXW PRUH DERXW WKH FRQG V Q E\ W
LQIRUPDWLYH www.ZimmerVet.co.uk (QGRPHWULRVLV
8. LV D FKDULW\ WKDW ZRUNV WR LPSURYH OLYH
HQGRPHWULRVLV DQG WR GHFUHDVH WKH LW W LW
FRQGLWLRQ DQG WKHLU IDPLOLHV DQG IUL



)DFWV DQG ¿JXUHV ± IURP (QGRPHWULRVLV 8.
www.endometriosis-uk.org

- **One in 10** ZRPHQ RI UHSURGXFWLYH DJH EHWZHHQ S
PHQRSDXVH LQ WKH 8. VX HU IURP HQGRPHWULRVLV
- **10%** RI ZRPHQ ZRUOGZLGH KDYH HQGRPHWULRVLV ±
176 million worldwide

‡7KH SUHYDOHQFH RI HQGRPHWULRVLV LQ ZRPHQ ZL
DV

‡(QGRPHWULRVLV LV WKH VHFRQG PRVW FRPPRQ J\O
DIWHU ¿EURLGV LQ WKH 8.

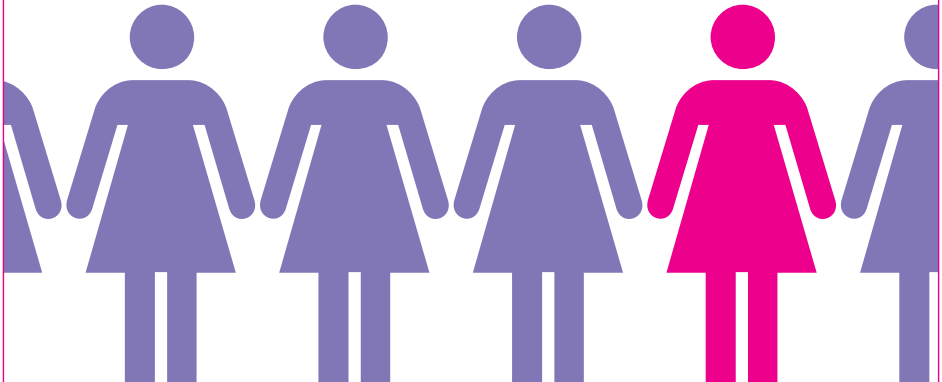
‡(QGRPHWULRVLV **1.5 million women** D VLPLODU QXPEHU
RI ZRPHQ DUH D HFWHG E\ GLDEHWHV RU DVWKPD

‡2Q DYHUDJH **7.5 years** DNHUP RQVHW RI V\PSWRPV WR J
GLDJQRVLY

‡(QGRPHWULRVLV FRVW **£8.2bn** D\HFURQ ROPWUHDWPHQ
ORVV RI HGXFDWLRQ ZRUN DQG KHDOWK FDUH FRV

‡7KH FDXVH RI HQGRPHWULRVLV LV XQNQRZQ EXW
GL HUHQW WUHDWPHQW RSWLRQV

,QIRUPDWLRQ SURYLGHG E\ (QGRPHWULRVLV 8.



:RPHQ RI DQ\ DJH FDQ EH D HFWHG E\ HQGRPHWULRV
FRQGLWLRQ WR PDQLIHVW EHIRUH D JLUO KDV KHU ¿U
7HHQDJHUV ZKR VX HU ZLWK SDLQIXO SHULRGV H[SH
ZKHQ KDYLQJ D SHULRG RU ZKR PLVV VFKRRO EHFDX
VKRXOG EH FRQVLGHUHG DV SRVVLEO\ VX HULQJ IURP

6\PSWRPV PD\ YDU\ IURP ZRPDQ WR ZRPDQ DQG VRPH
H[SHULHQFH QR V\PSWRPV DW DOO RU PD\ [[URW V XV

6XVSHFWHG HQGRPHWULRVLV PD\ EH PDQDJHG LQ SU
UHIHUUDO WR J\QDHFROJRF\ RU D VSHFLDOLVW HQGR
VXVSLFLRQ RU XQFHUWDLQW\ RYHU WKH FDXVH RI SD
ZLWK IHUWLQOLW\ LVVXHV :RPHQ ZLWK VXVSHFWHG GH

‡ LI FRPSOH[VHYHUH HQGRPHWULRVLV LV VXVSHFWHG
HQGRPHWULRPDV RU ZKHUH HQGRPHWULRVLV LV D H
6WDQGDUG

‡ LI LQLWLDO KRUPRQDO WUHDWPHQW IRU HQGRPHWU
WROHUDWHG RU FRQWUDLQGLFDWHG 1,&(JXLGHOLG
6WDQGDUG

3OHDVH QRWH D VL[PRQWK WLPHVFDQH FDQ EH XVH
KRUPRQDO WUHDWPHQW LV H HFWLYH KRZHYHU D UHI
VL[PRQWKV LI LW EHFRRPHV FOHDU WKDW WUHDWPHQ

:RPHQ ZLWK HQGRPHWULRVLV RIWHQ QHHG UHIHUUDO
GLDJQRVLY DQG WUHDWPHQW RI WKH FRQGLWLRQ

7KH LQYHVWLJDWLRQV R HUHG LQFOXGH XOWUDVRSQ
VFDQ RU 05, GRHV QRW UXOH RXW HQGRPHWULRVLV
IRU GLDJQRVLY LV ODSDURVFRS\ /DSDURVFRS\ FDQ E
RIWHQ WKLV LV FRPELQHG ZLWK RSHUDWLYH VXUJLFD
HQGRPHWULRVLV

&DVHV RI VHYHUH HQGRPHWULRVLV RU VHYHUH VXVS
VKRXOG EH VHQW WR D VSHFLDOLVW %6*(%ULWLVK (
(QGRVFRS\ DFFUHGLWHG HQGRPHWULRVLV FHQWUH Z
VSHFLDOLVW J\QDHFRRRJLVWV DQG D FOLQLFDO QXU
FRQMXQFWLRQ ZLWK JHQHUDO VXUJHRQV DQG XUROR
DOVR OLDLVH ZLWK SDLQ PDQDJHPHQW WHDPV DQG K
WHDP

\$ IXOO OLVW RIDFFUHGLWHG VSHFLDOLVW HQGRPHW
IRXQG RQOLQH DW www.66.org.uk HEVLWH DW

