

GUIDANCE ON LONG TERM CONSEQUENCES OF TREATMENT FOR GYNAECOLOGICAL CANCER

Part 1: pelvic radiotherapy

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How to use this guidance document

This document is aimed at UK gynaecological oncology professionals but will also be useful to anyone, including primary care professionals, involved in the care of women at any time before or after pelvic radiotherapy or brachytherapy (eg for cervical, uterine, vulval, vaginal, bladder, anal and colorectal cancers).

The main purpose of this document is to ensure that women diagnosed with a gynaecological cancer will be offered appropriate information on the signs and symptoms of long term consequences of pelvic radiotherapy and that they, and the professionals caring for them, are aware of pathways of care that should be available.

Alongside this guidance, NFGON recommend that nursing professionals consult the new *Caring for patients living with and beyond cancer: a Nurse Competence Framework*, endorsed by the Royal College of Nursing (RCN) and the UK Oncology Nursing Society (UKONS) and available to download at macmillan.org.uk/competenceframework

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Disclaimer: No reader should assume that this guidance represents the only management option. There are other reasonable care strategies and there is no duty of care for any health care worker to follow these recommendations. Each woman is an individual and holistic care is paramount and there may be many good reasons why this guidance may not be implemented. The guidance development group believes that all women at risk of developing consequences of pelvic radiotherapy are entitled to receive information that enables them to make informed choices about their cancer treatment and follow up care. The guidance development group accept shared responsibility for the publication of this guidance.

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'This guide is excellent and I wish that every recommendation in it would be followed by those who treat and support women who have had radiotherapy.'

Womb Cancer Support UK

1. Introduction

There are approximately 2 million people in the UK living with and beyond a cancer diagnosis and this is rising by 3% annually¹. Those who have completed treatment are often left with both short and long term side effects as a consequence of their cancer treatment.

Macmillan Cancer Support estimates that at least 25% will experience long term ill health or disability, and that these effects may last for 10 years or more, with some risks (eg second primary cancer and osteoporosis, lymphoedema) lasting a lifetime².

A woman diagnosed with a gynaecological cancer (cervical, uterine, vulval, ovarian, vaginal) will probably experience surgery, chemotherapy and radiotherapy, either alone or in combination. All of these treatment modes carry risks of long term consequences, which can impact severely on an individual's quality of life unless given the required attention to prevent or reduce them.

In the UK approximately 19,500 women a year are diagnosed with gynaecological cancer³, and it is estimated that 19% will receive pelvic radiotherapy. An estimated 67% of women survive more than 5 years following gynaecological cancer. The literature indicates that over 50% will experience some sort of long term problem⁴.

The National Forum of Gynaecological Oncology Nurses (NFGON), The Society and College of Radiographers (SCoR) and Macmillan Cancer Support identified a need to provide accessible

guidance, which signposts professionals to (a) ways of supporting women to self-manage and (b) key advice and source documents for clinical management. The latter is not in the expectation that nurses and radiographers would be required to follow all the guidance themselves, but rather to raise awareness that such guidance exists, therefore helping to change the culture around consequences of treatment, from "it's not really up to us to do anything" or "nothing can be done for this woman", to "I know how to work in an integrated, holistic way to ensure this woman receives the advice, support and treatment that meets her needs". As Kate Granger remarked in her blog⁵

'I think perhaps we should at least learn a little about the longer term consequences on the body as these are the things that a patient has to live with day in day out long after the treatment has finished.'

The guidance is in two documents. The first (this document) presents a compilation of existing guidance and other evidence on information and services that should be made available for women who are about to, or who have received pelvic radiotherapy (however long ago). The second (to be produced in 2015) will look at long term consequences following treatment

modes of surgery and chemotherapy.

This pelvic radiotherapy guidance covers good practice recommendations:

- Prior to pelvic radiotherapy
- Support for psychosocial issues
- Monitoring during and after pelvic radiotherapy - Pathways to identify issues/problems
- Management of symptoms due to long term consequences of pelvic radiotherapy
 - » Identified levels of intervention (dependent on expertise of practitioner)
 - » Management plan for levels of intervention
 - » Referral pathways for specialist level of intervention.

Level of interventions use the suggested Model of Care Pathway¹ and include supported self-management and a case management approach with more intensive support aimed at improving outcomes⁶. Practitioners should also take into consideration the RCN/UKONS/Macmillan nurse competence framework, which provides advice on how to build generic skills and confidence in managing consequences of cancer treatment.

 macmillan.org.uk/competenceframework

Guidance Development Group and Methods

Robust evidence for the management of consequences of cancer treatment in women before, during and after pelvic radiotherapy is lacking. This guidance was developed through the compilation of published guidance as of February 2014, and consensus opinion on best practice agreed by the expert group listed below. The guidance is endorsed by the Society and College of Radiographers and the UK Oncology Nursing Society.

The group welcomes all comments and suggestions for future editions via Tracie Miles (President of NFGON) at tracie.miles@nhs.net

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2. Consequences of pelvic radiotherapy (pelvic radiation disease)

Pelvic radiation disease (PRD) is a complex interplay of chronic symptoms that patients may experience following radiotherapy (RT) to the pelvis [Figure 1].

These consequences (late effects) of treatment include gastrointestinal symptoms, changes in bladder and sexual function, lymphoedema, hormonal changes, fatigue, infertility and pain that have been shown to have a significant impact on quality of life of those affected^{7,8,9,10} with evidence suggesting that the physical, psychological and social needs of many are not being addressed¹¹.

Gastrointestinal effects are among the most common, chronic complication following pelvic RT¹², with as many as 50% of patients reporting a worse quality of life^{13, 14, 15} and up to 90% of patients developing a permanent change in their bowel habit¹⁶. Although many of these will have mild/moderate symptoms which can be self-managed, a significant minority will have very severe effects and need specialist help.

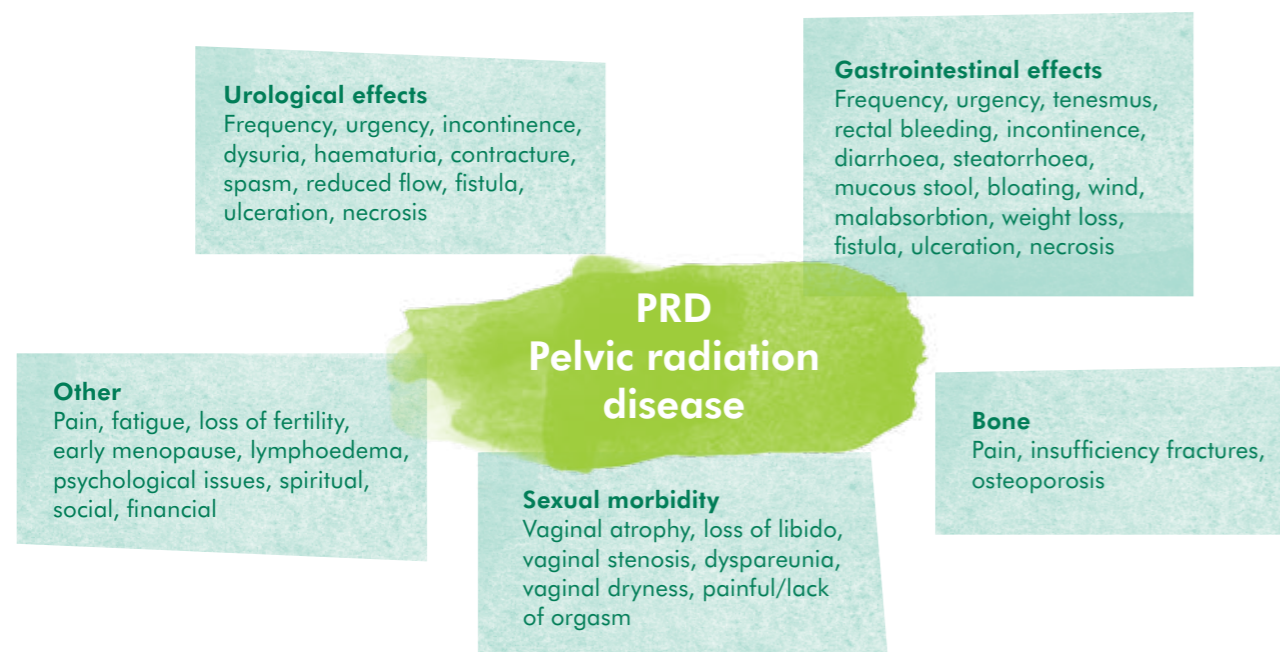


Fig. 1: Possible symptoms associated with pelvic radiation disease (designed by Lisa Punt)

Around 20% of patients will experience severe urinary adverse effects with up to 43% experiencing some change in their urinary function following pelvic RT¹⁷. Female sexual health morbidity has been poorly reported¹⁸, the incidence of sexual morbidity ranges from 1.2 - 88%¹⁹. Physical changes such as vaginal stenosis, along with hormonal changes (leading to loss of libido, atrophic changes to the vaginal/vulva/perineal area and an increase in vaginal infection/irritation) can result in a significant impact on sexual function. Carter identified women reported dissatisfaction with their overall sex lives (67%), pain during vaginal penetration (62%), and low levels of sexual desire (56%)²⁰.

Causes of PRD

(a) Tissue changes due to radiotherapy

The initial pathological change in the tissue begins directly after the first radiation exposure. However, the clinical symptoms and histological changes may not become apparent for several weeks, months or indeed many years after treatment^{21,22}. The initial damage caused by radiation to the mucosal lining of the organs in the RT field is characterised as inflammation or cell death. This may lead to an inflammatory process resulting in the 'acute' side effects that we see develop during RT and for up to 3 months after treatment is complete.

Once RT treatment is completed, the body will continue to produce chemicals that support tissue repair/healing and this may also cause tissue damage and scarring. The symptoms arising from this tissue damage may vary from mild to severe and may also be self-limiting or progressive. The rate of development of consequences of RT

treatment does not necessarily plateau over time^{15, 23}, indicating the potential to develop new symptoms many years after treatment, often when the patient is no longer involved in cancer follow-up. For example, surgery to the bowel or bladder may be needed - cases requiring a neo-bladder or stoma 15-20 years after RT for cervical cancer are rare but require early identification and highly specialist care. This timescale highlights the importance of women themselves understanding from the outset, and being regularly reminded of, the risks for long-term problems (for example by offering Macmillan booklets on pelvic RT²⁴) and, importantly, how to seek help if any concerns arise – however long ago treatment was. In addition, it is vital that the primary care team are made fully aware of all risks via the Treatment Summary⁶, which is also copied to the woman.

(b) Can PRD be predicted?

In some women, the acute symptoms can persist beyond 3 months, it has been suggested that cumulative acute symptoms are more predictive of late symptoms²⁵. A recent study concluded that this continuation of acute gastrointestinal and genito-urinary effects beyond 3 months are highly predictive of the development of long term problems²⁶ and suggests that "patients with greater and particularly longer non-healing acute toxicity are candidates for closer follow-up and possible prophylactic actions to reduce a high probability of long-term problems". The need for further studies including the role of chromosomes and genetic predictors has also been suggested^{27,28}.


Smoking has also been identified as increasing the risk of PRD²⁹.

3 Good practice recommendations

3.1 Good practice prior to treatment

(a) Information-giving prior to treatment

Women offered pelvic RT for a gynaecological cancer should receive and be guided to information on the potential side effects of treatment; ideally this should be given prior to consent being taken or before commencing radiotherapy. Provision of information should be tailored to the individual's needs, but should include (as a minimum):

 *Pelvic radiotherapy in women, managing side effects during treatment.* Macmillan Cancer Support, MAC13944. Available to order or download on be.macmillan.org.uk

You can find information, patient forums, and links to local patient support organisations and groups at:

 Macmillan Cancer Support
macmillan.org.uk
0808 808 00 00

 Jo's Cervical Cancer Trust
jostrust.org.uk
0808 802 8000

 Womb Cancer Support UK
wombcancersupportuk.weebly.com

For patient testimonies

 Healthtalkonline.org.uk

(b) Consent to treatment

The process of consent, and the consent form itself, should encompass the relevant risks of short term and long term side effects.

(c) Fertility issues

Women should be fully informed at diagnosis of the potential for ovarian or uterine damage caused by pelvic RT, together with the likelihood of early menopause and infertility. They should be given the opportunity to explore any possible fertility options available to them with a fertility specialist.^{30,31,32}

(d) Menopause

Pre-menopausal women should be fully informed of the likelihood of early menopause as a result of ovarian damage caused by pelvic RT.

(e) Prevention of consequences:

(i) Prevention of vaginal effects with vaginal dilators

During treatment, women should be offered vaginal dilators and receive both verbal and written information on the benefits of use and how they should be used.

Vaginal dilation information can be locally produced - adapted from the International Guidelines on Vaginal dilation after pelvic radiotherapy.³³

 nfgon.org.uk/?p=264

(ii) Prevention of vaginal effects with hormone replacement therapy (HRT)/topical HRT

Women experiencing treatment-induced menopause should be considered for HRT as long as it is oncologically safe to do so and there are no other contra-indications.

(iii) Use of vaginal moisturisers and lubricants

Can be combined with psychosexual education and information on dilators to maintain vaginal health.^{34,35}

(iv) Prevention of lymphoedema

Women should be advised on skin care, exercise and early identification of infection and/or limb swelling.³⁶

(v) Healthy Lifestyle choices

Women should be made aware of healthy lifestyle choices³⁷, including physical activity, healthy weight and diet, reducing alcohol and stopping smoking. Smokers should be signposted to an appropriate smoking cessation service.


'Good, helpful document covering all aspects of Pelvic Radiation Disease.'
Jo's Cervical Cancer Trust

3.2 Support for psychosocial issues

Macmillan has developed a wide range of resources on all aspects of living with and after cancer, including emotional effects, financial issues, work, physical activity and eating well. For more information visit:

 macmillan.org.uk


A short guide suitable for all patients is:

 *What to do after cancer treatment ends: 10 Top Tips* Macmillan Cancer Support, MAC13615. Available to order or download from be.macmillan.org.uk

The Recovery Package⁶ for patients at the end of treatment and has been developed to ensure that recovery from treatment is optimised, and provides the woman with information to support self-management where appropriate.

The key components are: a Holistic Needs Assessment³⁸ and a care plan (see below), a Treatment Summary sent to the GP and copied to the patient, a Cancer Care Review in primary care, and a Health and Wellbeing Event. Physical activity should also be encouraged.

 ncsi.org.uk/what-we-are-doing/the-recovery-package/

 *After Cancer Treatment: A Guide for Professionals* Macmillan Cancer Support, MAC14302. Available to order or download from be.macmillan.org.uk

Women should be made aware of local survivorship services, courses or Health and Wellbeing Events. Patient support groups, online forums etc may be available.

3.3 Monitoring during and after treatment

(a) Holistic Needs Assessment (HNA)

Women should be asked at the end of treatment, at each follow-up appointment/telephone follow up as well as during an HNA, if they have any new or persisting problems following RT. Whilst this gives patients the opportunity to express any general concerns (including pain, fatigue, sleep, diet and psychological issues), specific questions should include ALL of the following:

- Have you had any bleeding (vaginal, rectal or urethral)?
- Do you have any changes in your bowel habits since your treatment that are causing you any problems?
- Do you have any changes in your bladder function since your treatment that are causing you any problems?
- Do you have any discomfort (dull/constant ache) in bony pelvis?
- Do you have any new concerns with your sexual health? Do you have any new concerns with how you feel as a woman or with your sex life?'
- Do you have any changes/swellings in your lower limbs or pelvic region?
- Do you have any pain associated with any of the above?

(b) Detailed assessment of symptoms

Presence of symptoms and their severity can be assessed and recorded using instruments such as LENT SOMA³⁹ (a patient reported outcome (PRO) tool) or RTOG/EORTC Late Radiation Morbidity Scoring Schema⁴⁰ (a clinician-reported outcome tool), although these can be lengthy and are usually designed for research/clinical trials rather than routine clinical care. It is hoped that a simple pelvic RT PRO tool for use in clinical settings can be developed and implemented nationally, which will help to identify new or more troublesome problems and aid early intervention.

Women may wish to keep a symptom diary to aid self-assessment of symptoms to share with professionals or identify pattern of symptoms. Separate diaries to record bladder or bowel symptoms can be found at:

 bladderandbowelfoundation.org

(c) Follow-up assessment and on-going

Monitoring of symptoms is important to assess the effectiveness of interventions. Professionals may wish to keep a database of women who report symptoms and treatment outcomes for future audit purposes.




3.4 Symptom management

For each of the symptoms listed in this section, firstly identify the level of each problem for the woman and this will guide your decisions about signposting, referral or clinical management.

Secondly, ask whether they want to undergo further investigations/referral, as some women may not wish to proceed at that point in time. If the woman declines referral to specialist, ensure:

- 1 They have written information to help manage own symptoms
- 2 They know who to contact if they change their mind at any time in future
- 3 Their GP is informed that the referral was declined.

Women with symptoms should be offered the Macmillan booklet:

 *Managing the late effects of pelvic radiotherapy in women* Macmillan Cancer Support, MAC13826. Available to order or download on be.macmillan.org.uk

LEVEL 1
Mild symptoms, no significant effect on quality of life.

> Advice and self-help, re-evaluate.

LEVEL 2
Moderate symptoms, mild effect on quality of life.

> Advice and self-help, consider complex management.

LEVEL 3
Severe symptoms, quality of life significantly affected.

> Complex management (see links in this document).

(a) Bowel symptoms

- Ensure the woman has relevant information ie *Managing the late effects of pelvic radiotherapy in women* and/or discuss specific symptom advice.
- Offer other information as appropriate to support self-help. Identify latest information by use of Information Prescriptions, find at:

 nhs.uk/IPG

and signpost women to self-help groups and online resources/forums.

- Symptoms may include bleeding, pain, change in bowel function and reduced bowel control. General guidance includes:
 - » If bleeding - important to discuss this with a healthcare professional to assess severity and investigate possible causes, with several treatments available
 - » Making dietary changes can help modify bowel function accordingly eg adding in extra fibre in case of tenesmus and avoiding possible trigger foods, or reducing the amount of dietary fibre in case of mucus discharge, urgency and loose stool
 - » Using regular, small doses of anti-diarrhoeal medicines to slow the bowel down
 - » Strengthening with exercises the muscles used for bowel control.

- Inform GP of symptoms experienced by the woman – highlight British Society of Gastroenterology *Practice guidance on the management of acute and chronic gastrointestinal problems arising as a result of treatment for cancer*¹² and *Guideline: The Practical Management of the Gastrointestinal Symptoms of Pelvic Radiation Disease*⁴¹ (the latter due for publication in mid-2014).

If symptoms persist and their quality of life is significantly affected and the woman agrees, refer or ask GP to refer to gastroenterologist, ideally one who is known to have a special interest in gastrointestinal effects of cancer treatments. Key workers at the cancer unit or centre should be able to provide details of local services or signpost to central services.

The Pelvic Radiation Disease Association have information about gastroenterologists working in this field:

 prda.org.uk

(b) Bladder symptoms

- Check if the woman has a urinary tract infection and treat as appropriate.
- Ensure the woman has relevant information ie *Managing the late effects of pelvic radiotherapy in women* or provide specific symptom advice.
- Offer other information as appropriate to support self-help. Identify latest information by use of Information Prescriptions and signpost women to self-help groups and online resources/forums.
- NICE guidance⁴² should be followed for frequency (overactive bladder) or stress incontinence.

 [guidance.nice.org.uk/CG171](https://www.nice.org.uk/CG171)

However general advice would, depending on symptoms, include:

- » Drink about 2-2.5 litres a day; avoid caffeinated drinks, alcohol and smoking.
- » Offer verbal/written information on pelvic floor exercise/bladder retraining.
- The GP may consider anticholinergics.
- Inform the GP of symptoms experienced by the woman to ensure appropriate community support. Continence service referral if appropriate.
- If quality of life is significantly affected and the woman agrees, refer to a urologist with special interest in effects of pelvic radiotherapy.

(c) Bone pain

- Ask consultant or GP to arrange appropriate imaging to exclude recurrence or insufficiency fractures. Multi-disciplinary team MDT for management if positive investigations.
- If investigations negative, offer bone health advice, go to:

 **Bone Health**
Macmillan Cancer Support, MAC12169. Available to order or download on [be.macmillan.org.uk](https://www.be.macmillan.org.uk)

- Ask GP to assess for appropriate pain control and bisphosphonates to strengthen the bone.
- Diet rich in calcium and vitamin D can help pelvic insufficiency fractures to heal.
- Physiotherapy or occupational therapy referral.
- Referral to pain specialist if appropriate.

(d) Hormonal symptoms and sexual difficulties

- All health professionals should give women the opportunity to express any sexual health issues¹⁸.

Menopause symptoms

- Discuss appropriateness of HRT with Gynae oncology surgeon, oncologist or specialist oncology nurse and ask GP to prescribe if applicable.

- The effectiveness of HRT should be monitored as to whether acute symptoms are controlled and genital health is maintained.
- Highlight use of complementary therapies and lifestyle advice to help with symptoms of menopause. Signpost to support/self-help group such as:

 [The Daisy Network](https://www.daisynetwork.org.uk)
[daisynetwork.org.uk](https://www.daisynetwork.org.uk)

 [Menopause Matters](https://www.menopausematters.co.uk)
[menopausematters.co.uk](https://www.menopausematters.co.uk)

- Complex cases and women experiencing persistent distress associated with menopause should be referred to a menopause clinic.

Sexual difficulties

- Offer other information as appropriate to support self-help and identify latest information using Information Prescriptions if appropriate.
- Practitioners should recognise their level of competency and ability to explore sexual issues and offer support to the level they are competent. NFGON Level of interventions (presented at Liverpool⁴³) - see Appendix 1.
- Education tools for professionals include:
 - » Macmillan toolkit to help professionals talk to women about the issues surrounding sexuality and cancer, go to:

 [Learnzone.org.uk/courses/](https://www.learnzone.org.uk/courses/)


- » Cancer Australian National Centre for Gynaecological Cancers on-line learning resource for health care professionals - *The psychosexual care of women affected by gynaecological cancers* (reviewed and endorsed by NFGON Psychosexual sub-group), go to:

 modules.cancerlearning.gov.au/psgc

- Using the PLISSIT model⁴⁴ the practitioner should establish and maintain a safe relationship with women to allow them to discuss issues relating to sexuality, sexual function and body image.
- The CNS/Specialist Radiographer will use specialist knowledge and expertise to assess sexual function, analyse information to offer specific suggestions and if necessary interventions to address sexual dysfunction to women.
- Ask GP to refer (unless service available within centre/unit) for assessment to a psychosexual therapist when:
 - » Sexual difficulties are persistent despite appropriate interventions and where there are high levels of individual/couple distress.
 - » The woman has pre-existing sexual problems and psychological vulnerability prior to diagnosis.
 - » If there are dual sexual difficulties within the relationship.

(e) Lymphoedema

- Information should be given to women about lymphoedema and how to prevent it, prior to consent to the relevant high risk groups especially women who have undergone lymphadenectomy as part of their treatment.
- Information should be offered prophylactically prior to treatment or if women presents with lymphoedema using Information Prescription pathway or

 *Understanding Lymphoedema*
Macmillan Cancer Support,
MAC11651 Available to
order or download on
be.macmillan.org.uk

- Signpost woman to self-help groups such as The Lymphoedema Support Network

 lymphoedema.org

- Local service referral pathways should be available.
- A database of lymphoedema services is available on the British Lymphology Society website.

 thebls.com

(f) Further support

- Use of screening and assessment tools is advised³⁸ but can be adapted to suit the individual's practice.
- If the woman no longer has routine gynae-oncological follow up it should be reinforced and included in the Treatment Summary

and discharge summary that consequences or late effects of treatment can occur several years or even decades following RT. Advice on what symptoms to look out for, and who to contact should they arise should be given to both the patient and the primary health care team.

- Women who develop consequences or late effects can be signposted to supportive agencies including


 Macmillan Cancer Support
www.macmillan.org.uk

 The Pelvic Radiation Disease Association (PRDA)
www.prda.org.uk

 Jo's Cervical Cancer Trust
www.jostrust.org.uk

 Womb Cancer Support UK
wombcancersupportuk.weebly.com

 The Daisy Network
www.daisynetwork.org.uk

 Menopause Matters
www.menopausematters.co.uk

 The Lymphoedema Support Network
www.lymphoedema.org

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Appendices

Appendix 1

NFGON psychosexual sub-group levels of intervention

| Level | PLISSIT | Who | Aim | Rational |
|-------|-------------------------------|--|--|--|
| 1 | P Permission | All HCP Basic knowledge | Woman is able to discuss sexual concerns/ difficulties with a HCP. | First promoted when the woman is asked about her sexual concern or suggests that it is an appropriate topic for discussion. Gives the patient permission to have (or not to have) sexual feelings. |
| 2 | LI Limited Information | Experienced HCP | Woman is advised of the impact of treatment on sexual function to enable her to make informed choices about their proposed treatment. | Continues to convey willingness to discuss sexuality and provides specific factual information to clarify concerns and misconceptions and eliminate myths. |
| 3 | SS Specific Suggestion | Advanced CNS/HCP with appropriate skills and knowledge | To provide woman with specific suggestions promoting continued sexual satisfaction. Requires sexual history. <ul style="list-style-type: none"> • Suggestions include strategies for enhancing sexual expression. • Suggestions take into account the patient's and partner's values attitudes toward sex. • Referral for intensive therapy is indicated if sexual concerns remain unresolved. | Provided when support and limited information alone are inadequate. Follow-up is necessary to monitor effectiveness. |
| 4 | IT Intensive Therapy | Psychological or psycho-sexual therapist | Woman may need referral for more in-depth counselling if progress is not being made at other levels or if there are pre-existing sexual problems, dual dysfunctions or relationship distress. | Provides intensive therapy with appropriately qualified therapist to manage complex sexual and relationship issues that cannot be addressed at lower levels of interventions. |

When people have cancer, they don't just worry about what will happen to their bodies, they worry about what will happen to their lives. At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support people through. From help with money worries and advice about work, to someone who'll listen, we're there. We help people make the choices they need to take back control, so they can start to feel like themselves again.

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The National Forum of Gynaecological Oncology Nurses (NFGON) is available to all nurses and health professionals with any level of interest or expertise in gynaecological oncology. NFGON's aims include:

- To participate in, and disseminate research and evidence based knowledge advocating best practice.
- To influence at national and international level policies, protocols and guidelines in Gynaecological Oncology Nursing Management.

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