

## How charities and professionals are working together to support people after pelvic radiotherapy.



# WORKING TOGETHER

JANE NORRIS-JONES, LESLIE SMITH, SARAH JAMES, RICHARD SURMAN

**T**he use of cutting edge imaging and computing technology has enabled radiotherapy professionals to target the radiation dose to the relevant tissues more precisely than ever before<sup>1</sup>, thus reducing the severity of possible side effects as well as the likelihood of their occurrence, with potential benefits of improving outcomes and enhancing the quality of life of patients receiving radiotherapy<sup>2</sup>.

Despite these technological advances, many radiotherapy patients still experience unwanted side effects and for some patients these have a significant effect upon quality of life. For patients having pelvic radiotherapy these can manifest themselves as a chronic problem with a variety of symptoms which is known

as pelvic radiation disease (PRD)<sup>3</sup>. The symptoms that comprise this condition include:

- Gastrointestinal effects, eg bowel urgency and incontinence, diarrhoea, frequency, bleeding, flatulence.
- Urinary effects, eg incontinence, urgency, bleeding.
- Sexual difficulties, eg erectile dysfunction, vaginal stenosis.
- Other problems, eg pelvic insufficiency fractures, pain, fatigue, lymphoedema and menopausal symptoms.

There are also many patients today who have long-term side effects as a result of having radiotherapy in the past,

**PRDA** PELVIC RADIATION DISEASE ASSOCIATION

**WE ARE MACMILLAN. CANCER SUPPORT**

**FACTS about late effects of pelvic radiotherapy**

More than half of the 17,000 patients treated each year in the UK with pelvic radiation to cure their cancers are unable to enjoy their cure.

**WHY?**

Radiotherapy is highly effective in the treatment of pelvic tumours and there have been huge improvements in radiotherapy techniques and equipment over recent years. It is because of the very nature of the treatment, radiotherapy can affect tissue and other organs in the pelvic region.

Following pelvic radiotherapy, does your patient

- need to poo at night?
- need to rush to the loo, or not make it in time?
- have bleeding or
- have other GI symptoms that interfere with an active full life?

If the answer to any of these questions is **YES**, then a referral to a gastroenterologist is essential.

Further information can be obtained through our telephone service - **01372 744338**

The Pelvic Radiation Disease Association helps people suffering from late effects of pelvic radiotherapy with the help of donations and grants. Please support us at [www.prd.org.uk/donate-us](http://www.prd.org.uk/donate-us)

**PATIENTS AT RISK**

Your patients could be at risk of debilitating late effects of radiotherapy if they have had radiotherapy for bladder, bowel, rectal, prostate, anal, womb (endometrial), vaginal and vulval cancers.

**What other organs can be affected by pelvic radiotherapy?**

Radiotherapy also causes changes in other pelvic organs and patients may have some of these problems too:

- **Bladder** - frequency, incontinence, urgency, burning while passing urine, and bleeding.
- **Sexuality and sex life** - both men and women can experience a loss of desire and some men are unable to maintain an erection.
- **Bones** - sometimes radiotherapy causes tiny cracks which often cause pain.
- **Lymphoedema** - swelling of the legs caused by a build up of lymph can also happen if the lymph nodes (little filters) have been irradiated (or removed in surgery).

**NEED TO KNOW MORE?**

We have further information that may help your patients with onward referral and self-management of their symptoms.

Please visit → [www.prd.org.uk](http://www.prd.org.uk)

Or call → **01372 744338**

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▲ Figure 1.

**WE ARE MACMILLAN. CANCER SUPPORT**

**PELVIC RADIO THERAPY IN WOMEN – MANAGING SIDE EFFECTS DURING TREATMENT**

**PELVIC RADIO THERAPY IN MEN – MANAGING SIDE EFFECTS DURING TREATMENT**

**MANAGING THE LATE EFFECTS OF PELVIC RADIO THERAPY IN WOMEN**

**MANAGING THE LATE EFFECTS OF PELVIC RADIO THERAPY IN MEN**

▲ Figure 2.

Beating Bowel Cancer
Bowel Cancer UK
British Association of Urological Nurses
British Society of Gastroenterology
Jo’s Cervical Cancer Trust
National Forum of Gynaecological Oncology Nurses
National Network of Colorectal Cancer Nurses
Prostate Cancer UK
Royal College of General Practitioners
Royal College of Radiologists
Society & College of Radiographers
UK Oncology Nursing Society

▲ Table 1: Charities and professional bodies working collaboratively with PRDA and MCS.

**MACMILLAN TOILET CARD**

**LATE EFFECTS OF PELVIC RADIO THERAPY**

▲ Figure 3.



when it was not as sophisticated and precise as it is today. These patients are grateful to be alive, but some are living with problems that significantly impact on their ability to return to a normal life at the most basic day-to-day level.

In common with other people living with and beyond cancer patients with PRD are also likely to experience psychological issues and the effects that accompany them, such as the negative impact on relationships, their ability to work, difficulty in maintaining their financial income and their independence<sup>2</sup>.

## WHAT IS THE PELVIC RADIATION DISEASE ASSOCIATION (PRDA)?

Dr Jervoise Andreyev, Consultant Gastroenterologist in pelvic radiation disease at the Royal Marsden Hospital recognised that his patients and their families were feeling isolated due to their difficult symptoms. He inaugurated an annual patient group meeting which evolved into regular support group meetings. This in turn gave rise to the Pelvic Radiation Disease Association (PRDA)<sup>4</sup> in 2012. PRDA is a small but influential UK based charity with five trustees and an administrator. The principle aim of this charity is to publicise and increase awareness of PRD amongst both patients and professionals by:

- Improving awareness of the symptoms and impact of PRD.
- Providing direct support and advice to patients and carers.
- Providing telephone and email helplines which are supported by multi-disciplinary expert teams. Providing reassurance to both patients and professionals.
- It also aims to reach patients who have undergone their cancer treatment many years ago, as often their current symptoms are not recognised as related to radiotherapy undergone many years ago.
- Facilitating support meetings which are opportunities for experts to present on topics such as diet, exercise, self-help, sexual health and radiotherapy.
- Signposting of patients to professionals who may be able to manage and/or reduce symptoms.
- Promoting its own work at professional conferences across the UK, providing opportunities to network with professionals, patient and carers.
- Providing literature for patients and health professionals.
- Providing clear and simple advice to health care professionals about how to refer patients to specialist clinics.

The charity works with all relevant health care professions: therapeutic radiographers, cancer nurse specialists, dieticians, oncologists, gastroenterologists, gastrointestinal surgeons, gynaecologists and urologists.

## THE ROLE OF MACMILLAN CANCER SUPPORT

Alongside its reputable and well established patient support and information infrastructure including: telephone support helpline, website, patient information resources and online community forums, Macmillan Cancer Support (MCS)<sup>5</sup> recognised the need to develop specific guidance for professionals in managing the consequences of pelvic radiotherapy. It worked in partnership with key professional organisations to develop a series of guidance documents for diagnosing and treating gastrointestinal<sup>6</sup>, urological<sup>7</sup> and sexual problems<sup>8</sup> occurring in men and women as a result of undergoing pelvic radiotherapy. It is hoped that these

guidance documents and tool kits<sup>9</sup> will be adopted widely as part of the overall strategies to introduce the Recovery Package<sup>10</sup>, stratified pathways<sup>11</sup> and other initiatives, to improve the lives of people living with and beyond cancer.

Other resources produced by MCS include those focused towards primary care health care professions such as GPs and practice nurses in managing consequences of cancer treatment of their patients, as well as an online learning module facilitated by The Royal Marsden School<sup>12</sup>. This provides insight to health care professionals, as to how to diagnose and manage bowel consequences of pelvic radiotherapy in clinical environments.

## THE VALUE OF CHARITIES AND HEALTH ORGANISATIONS WORKING IN PARTNERSHIP

Both PRDA and MCS have worked collaboratively with a wide range of urological, colorectal and gynaecological cancer charities (Table 1) to both promote and improve awareness of PRD and to support those suffering from it.

In recent years, there have been several initiatives to improve care for PRD patients:

- Ensuring that all oncology teams are identifying patients with PRD at an early stage by using simple 'trigger' questions such as those used in the ALERT-Bi tool<sup>13</sup>.
- Developing streamlined local referral pathways to gastroenterologists once a patient has identified as requiring specialty services.

As part of an ongoing strategy to improve these patients' care, MCS and PRDA approached the British Society for Gastroenterology (BSG) in 2011, with the intentions of increasing the number of gastroenterologists prepared to manage bowel consequences of PRD. PRDA contacted every gastroenterologist in England, with the aim of raising awareness of PRD symptoms and asking if they were willing to accept patient referrals. As a result it is now estimated that approximately 120 gastroenterologists are able to accept patient referrals, using the published clinical algorithm as a tool for both diagnosis and treatment. Despite this growing number of gastroenterologists accepting referrals, there are many patients across the UK who do not have access to a gastroenterologist with an interest in PRD, and sometime even in locations where such services do exist, there remain inconsistencies with regard to patient referral rates and access.

In seeking to resolve these inconsistencies in care, PRDA wishes to continue promoting both the awareness of PRD and the care available for these patients, by working with the Society and College of Radiographers (SCoR). Both MCS and PRDA recognise the significant role therapeutic radiographers play in caring for patients with PRD. A publicity strategy has been agreed which includes newsletter and journal articles, and invitations to present at relevant professional meetings and conferences to improve awareness of PRD across the therapeutic radiographer profession, with the overall aim of achieving the objectives listed above.

## THE ROLE OF THE THERAPEUTIC RADIOGRAPHER IN SUPPORTING PATIENTS EXPERIENCING PRD

The role of therapeutic radiographers is well established across the entire radiotherapy patient pathway, at both advanced and consultant level practice, in managing and

caring for patients before, during and after their course of radiotherapy<sup>14</sup>.

A growing number of oncology centres have non-medical-led review clinics, where the appropriate health care professional is responsible for their patients' care. In particular, therapeutic radiographer-led on-treatment review clinics have been commonplace for a number of years<sup>15</sup>. More recently, radiographer-led survivorship clinics have also been successfully introduced<sup>16,17</sup>. The introduction of radiographer-led clinics has demonstrated their role as being instrumental in providing care, advice and support to both radiotherapy patients and to community health care professionals.

The introduction of a radiographer-led telephone follow-up service for patients who have received radiotherapy for prostate cancer has also proven to be effective and improved patients' experiences<sup>18</sup>.

The importance of these aspects of professional practice undertaken by therapeutic radiographers has been acknowledged by both MCS and PRDA and is one of the drivers behind working with the SCoR to improve awareness of PRD amongst the therapeutic radiography profession and influence change in service delivery and professional practice to the benefit of patients' care.

It has been recognised that in some circumstances it can be difficult to initiate the developments such as the non-medically-led clinics previously described, without wider stakeholder engagement. MCS also supports local multi-disciplinary educational events to spread best practice and encourage such changes in service delivery. Often, the inclusion of patients' testimonies at such occasions are a significant factor in changing hearts and minds towards the need to address the gaps in care for people with chronic symptoms of PRD.

### THE FUTURE

The number of people in the UK living with and after a cancer diagnosis is estimated to be four million by 2030<sup>19</sup>. This will lead to an unprecedented demand for services to assist with self-management of long-term effects of treatment and the need to identify those who need referral to specialist services. An effective working relationship between PRDA, MCS, SCoR and therapeutic radiography profession will become ever-more important, to ensure that patients experiencing PRD are offered the care and support they deserve.

### ABOUT THE AUTHORS

Jane Norris-Jones, Trustee, Pelvic Radiation Disease Association (PRDA).  
Leslie Smith, Consequences of Treatment Programme Manager at Macmillan Cancer Support.  
Sarah James, SCoR Professional Officer for Radiotherapy.  
Richard Surman, Chair of Trustees, Pelvic Radiation Disease Association (PRDA).

### REFERENCES

<http://www.sor.org//learning/library-publications/itp>  
This article has been prepared following local guidance relating to the use of patient data and medical images.  
To comment on this article, please write to [editorial@itpmagazine.co.uk](mailto:editorial@itpmagazine.co.uk)

### RESOURCES

The RCGP 'Consequences of Cancer' toolkit [www.rcgp.org.uk/coc](http://www.rcgp.org.uk/coc)  
Andreyev HJN, Muls AC, Norton C, Ralph C, Watson L, Shaw C, Lyndsay J O, Guidance: the practical management of the gastrointestinal symptoms of pelvic radiation disease. *Frontline Gastroenterology* 2015; 6:53-72. Also available as a PDF - [http://www.macmillan.org.uk/documents/aboutus/health\\_professionals/p215trmgibooklet\\_aw.pdf](http://www.macmillan.org.uk/documents/aboutus/health_professionals/p215trmgibooklet_aw.pdf) For hard copies go to [www.be.macmillan.org.uk](http://www.be.macmillan.org.uk) and use order code MAC15090.

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### HOW TO USE THIS ARTICLE FOR CPD

- Check that your radiotherapy centre is using a full range of materials to support patients at the relevant time points in their journey so that they understand the acute and long-term side effects of pelvic radiotherapy; eg booklets, symptom checklist, toilet cards.
- Establish whether your oncology team has a standardised method of identifying people with PRD (eg asking patients the questions in the ALERT-B tool).
- Meet with local gastroenterologists and dieticians to establish if they use the PRD bowel algorithm. Agree a PRD pathway, identifying what aspects of the pathway can be managed by radiographers, other oncology team members or the GP.
- Signpost patients to appropriate local and national support group and charity services offering help and support services for psychological, emotional, financial, social, sexual, urinary, lymphoedema, pelvic bone pain, fatigue and stoma problems
- Identify whether or not your radiotherapy centre educates local GP practices to understand the signs and symptoms of PRD, so that they can detect and manage them should problems arise in their patients in the future.

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