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RADIATION
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ASSOCIATION

The Pelvic Radiation Disease Association’s response to the All Party Parliamentary Group for Radiotherapy’s call for submissions on ‘Solutions to the COVID induced cancer backlog’

PRDA prda.org.uk would like to submit the following views and proposals:

In the short-term, PRDA proposes that:

1. **The Royal College of Radiologists’ new standardised consent forms should be rolled out as soon as possible**. This will ensure greater patient empowerment to make informed choices about their radiotherapy treatment and to ensure that they have the knowledge on how to self-manage or to get help should they experience any short-term or long-term side effects.
   This will help the cancer backlog by ensuring patients know how to get the help when problems first appear (for example from their GP, or dietetics or gastroenterology services or from a peer support charity such as PRDA), thus reducing demand on oncology teams. PRDA notes that the RCR’s document states that as well as improving patient care, ‘a reduction in unnecessary and wasteful duplication of work’ can be achieved which will prevent precious staff resource being diverted from delivery of radiotherapy treatments.

2. To further support patient self-management and reduce demand on oncology services, and in line with the recommendations in our December 2020 joint report with Jo’s Cervical Cancer Trust, **all radiotherapy services must provide timely End of Treatment Summaries** that give detail of how patients and their GPs can prevent and manage the potential side effects that are listed in the consent forms.

In the longer term, PRDA proposes that:

3. **The strategic direction of radiotherapy service development should fully incorporate prevention, minimisation and management of late effects** such as Pelvic Radiation Disease (PRD; defined here). However long ago a person had their radiotherapy and however ‘targeted’ pelvic radiotherapy now is, there will always be toxicity due to radiotherapy, and hence some people will always develop life-altering symptoms of PRD. These individuals deserve comprehensive and holistic care, rehabilitation and treatment so that their quality of life is optimised.

   The cost to the NHS and to society of ineffective management of late effects is huge. Covid recovery in the long term will be supported by reducing this cost.

4. The NHS needs to understand the effect of the Covid-induced delays in cancer diagnoses which are leading to later stages of cancer at diagnosis and thus potentially greater use of pelvic radiotherapy. **If more people are going to be treated with pelvic radiotherapy in the post-covid ‘spike’, there will be greater incidence of PRD and thus potentially greater demand on oncologists** to manage side effects. Services need to be ready for this demand.

5. In answer to the APPGRT’s question ‘What do cancer services need to look like in the future to improve survival of cancer patients?’, PRDA contends that the question must read ‘…to improve the survival **and quality of life** of cancer patients’.

It is not enough for the radiotherapy community to say that quality of life will be improved by new, advanced radiotherapy techniques that will reduce late effects for future patients. Not only does this ignore the large group of people* who have permanent radiation damage to their bowels, bladder, bones, nerves, blood supply and sex organs from past pelvic radiotherapy, but also ignores that physical side effects will still happen to some. Plus – importantly – it ignores the many psychological impacts of a cancer diagnosis and treatment.

Poor mental health often happens as a result of severe embarrassment, social isolation, pain, fatigue, inability to return to work and fear of cancer recurrence which can be caused by the symptoms of PRD (such as loss of bowel control or bleeding). Psychosocial consequences include poor quality of life due to loss of income, breakdown in relationships, or inability to spend time with family or friends.

People with PRD talk about how they are made to feel guilty for not being 'grateful to be alive', yet the long term effects on their mental health as they try to live with chronic poor health and poor quality of life is horrendous. These physical and mental consequences of treatment are not properly acknowledged or understood by the NHS, so patients and their carers have to fight for help at every turn, yet many are too debilitated to do so.

PRDA understands that NHS England is about to undertake work around how psychosocial support for cancer patients has been affected by the pandemic. **PRDA requests that the APPGRT exerts influence so that the outcome of this work is fully integrated into radiotherapy treatment and care pathways thus ensuring that people are offered the support for their mental health that they need at the earliest opportunity, through their treatment and also long after treatment has ended**.

*PRDA estimates 100,000 people in the UK experience ongoing side effects of pelvic radiotherapy.

Overall comment:

6. A good deal of effort is expended on communicating the role of radiotherapy in saving lives, which of course it does very well, and PRDA supports all efforts into improving access to the highest quality and effective treatments.

   However, these communications should be balanced with communications about how radiotherapy services are also concerned with quality of life, and in the optimal management of short-term and long-term side effects of radiotherapy. **As more and more people live longer after cancer treatments, more attention must be paid to supporting people to live with treatment side effects.**

   Radiotherapy may be able to develop a better image with the public if it shows itself to be a holistic service, that doesn't just aim to cure cancer/slow its progression, but to help every patient to live the best possible quality of life for as long as possible.

   This means provision of personalised care and support based on holistic needs assessments (as required by the NHS Long Term Plan), and far better prevention, diagnosis and management of late effects such as Pelvic Radiation Disease.

Contact: PRDA Office info@prda.org.uk