## 23 January 2018

# Notice to journalists / programme researchers the Pelvic Radiation Disease Association is offering expert opinion in relation to the House of Lords debate on 25 Jan 2018 on cancer treatments

On 25 Jan 2018, there will be a House of Lords debate on 'Evaluating innovative cancer treatments, making them available through the NHS and raising life expectancy for cancer patients'. (https://calendar.parliament.uk/calendar/Lords/All/2018/1/25/Daily)

The Pelvic Radiation Disease Association (PRDA) believes that a key issue in this debate is that the decision-making around new (and existing) treatments cannot just be about life expectancy, but also <u>quality of life for cancer patients.</u>

Some people cannot complete cancer treatment or only receive reduced intensity treatment because of the severity of side effects, while others experience long-lasting side effects, such that, even though they are able to survive cancer, they may live with a very poor quality of life<sup>1</sup>.

Gastrointestinal (stomach and bowel) problems are a common cause of poor quality of life during and after certain cancer treatments, such as chemotherapy and/or radiotherapy for cancers affecting the throat, stomach and pelvic area.

PRDA is seeking to ensure that NHS services are able to recognise, diagnose and treat conditions such as severe bowel difficulties due to Pelvic Radiation Disease. People can become house-bound due to the frequency and urgency of bowel movements, and experience many other problems (see Notes overleaf). Currently the NHS offers very few specialist services, and patients are often left to cope alone. With the increasing number of cancer survivors, the number of people needing help is only going to increase.

PRDA understands that one of the speakers in the House of Lords debate will be Baroness Rebuck, widow of Philip Gould, Baron Gould of Brookwood, who died of oesophageal cancer in 2011. Lord Gould funded research into gastrointestinal side effects of chemotherapy<sup>2, 3,</sup> and early results<sup>4</sup> show that it is often wrong to assume that these symptoms are untreatable.

This is a major issue affecting the quality of life of tens of thousands of people during and after cancer treatment, but has yet to get the attention it deserves.

PRDA is able to offer 2 spokespeople who are experts in the gastrointestinal side effects of cancer treatment:

- Richard Surman, Chair of PRDA and personally affected by the gastrointestinal symptoms of Pelvic Radiation Disease
- Dr Jervoise Andreyev, Consultant Gastroenterologist and leading expert and researcher on gastrointestinal side effects of cancer treatment.

# Contact

Please contact the PRDA administrator on <a href="mailto:info@prda.org.uk">info@prda.org.uk</a>
Telephone 01372 744338 or 07889 735673 during normal office hours

<sup>&</sup>lt;sup>1</sup> Macmillan Cancer Support. Cured but at what cost? 2013 <a href="https://www.macmillan.org.uk/">https://www.macmillan.org.uk/</a> images/cured-but-at-what-cost-report tcm9-295213.pdf

<sup>2</sup>https://www.standard.co.uk/news/london/philip-gould-fund-donates-300000-to-cancer-unit-at-the-royal-marsden-hospital-9280924.html

 $<sup>{\</sup>it ^3} \underline{https://www.royalmarsden.nhs.uk/news-and-events/news/new-study-combat-chemotherapy-side-effects}$ 

<sup>&</sup>lt;sup>4</sup> http://gut.bmj.com/content/66/Suppl\_2/A9.1

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#### Notes

Pelvic Radiation Disease (PRD) is a very debilitating and complex group of long-lasting symptoms that can occur after radiotherapy, mostly for cancers of the prostate, bowel, cervical and womb.

People with PRD often have serious problems with bladder and bowel control<sup>5</sup> and may also have their sex life, fertility, mobility and mental health affected<sup>6</sup>. People frequently report pain, swelling, bleeding and problems such as needing frequent, urgent access to a toilet, chronic fatigue, sleep disturbance and feeling unable to take part in normal life such as going to work or socialising.

The bowel symptoms are very similar to those for Crohn's Disease and Ulcerative Colitis, but people with PRD often have the added difficulties of bladder, sex life and other problems.

The knock-on effect on personal relationships and finances can be devastating.

Please see our website <a href="www.prda.org.uk">www.prda.org.uk</a> for more information and <a href="http://www.prda.org.uk/patient-stories/">http://www.prda.org.uk/patient-stories/</a> for patient stories.

<sup>&</sup>lt;sup>5</sup> J.Andreyev et al, Gut, 2012. <a href="http://gut.bmj.com/content/61/2/179">http://gut.bmj.com/content/61/2/179</a>

<sup>&</sup>lt;sup>6</sup> Jo's Cervical Cancer Trust. Long term consequences of cervical cancer and its treatment. 2017. <a href="https://www.jostrust.org.uk/about-us/our-research-and-policy-work/our-research/long-term-consequences-cervical-cancer-and-its">https://www.jostrust.org.uk/about-us/our-research/long-term-consequences-cervical-cancer-and-its</a>