

Review of dietitian service within the Pelvic Radiation Disease (PRD) late effects clinic

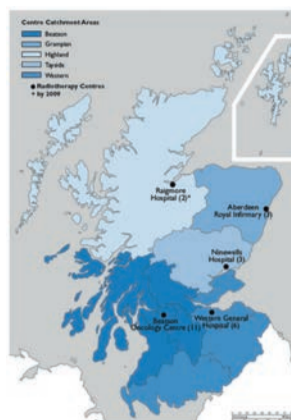
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The Pelvic Radiation Disease (PRD) Late Effects Team (LET)
The Beatson West of Scotland Cancer Centre (BWOSCC)
left to right; Carol Smeaton, Dr Sally Darnborough, Gina Giebner



The Pelvic Radiation Disease Association (PRDA) note approximately 100,000 people across the UK are impacted by PRD, with approximately 8,300 (8.3%) in Scotland (46% population service area) service area potential reach = 3,818.

Background

The LET (team capacity = 1.2 whole time equivalents) has been running since December 2018 and sees approximately 65-70 people with PRD per year. Macmillan funded dietitian Gina started May 2022.

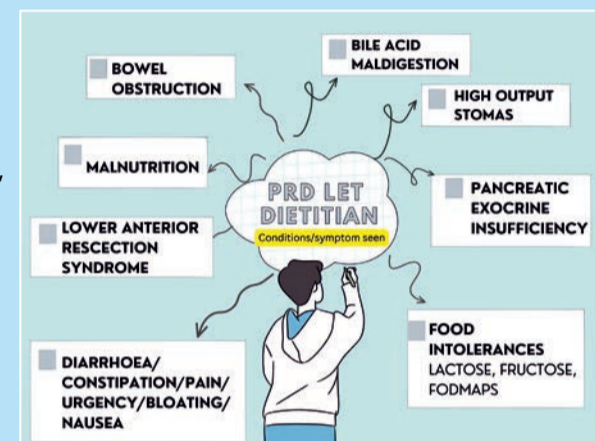
As a result of PRD Participants have noted a number of problems impacting on their daily lives.

For example;

- Isolation and stigma associated with symptoms
- reduced or very limited interactions with family or loved ones,
- their fear of 'accidents' [faecal incontinence] and subsequent reliance on quick access to toilet facilities leaving them 'housebound'
- the loss of employment or opting for early retirement.

The impact of these side effects of PRD on daily living cannot and must not be underestimated.

Having a dietitian on the team allows fully holistic dietary modification plans to be implemented. The aim of specialist dietetic input is to provide the best chance of success in improving PRD side effects and their general health. It also supports the LET team to work together improving communication between specialist roles thus enhancing the patient experience and compliance.



Aim

A service review was undertaken at 1 year to support continued funding for the Macmillan PRD LET dietitian. To continue to support LET service outcomes.

Methodology

An informal conversational approach using a structured conversation plan was used, followed by thematic analysis and report.

Results

- In total 24 patients were seen and discharged between May 2021-May 2022. All of the patients received holistic care plans and support to manage their condition/symptoms.
- 96% (n= 23) achieved full or part symptom resolution via dietetics support (diet, lifestyle and medication management)
- Total annual contacts = 267 (new and review) the 24 are within this plus others outside of the data.

Patient quotes from the review

Before

It's on my mind 24/7,
it's the first thing I think about,
it takes over your life [symptoms]

Terrified to go out
[in case of accidents]

I couldn't go out of the house,
had to stay near the toilet

After

It's been over two months since I've had the
[symptoms – nausea, vomiting, stomach pain]
the medication and diet changes
has helped hugely

I plan now [eating and drinking]
but symptoms have reduced that I can now
go out. I'm back to life, back to living

Definitely seen
an improvement
– it's a lot better now,
couldn't leave the house,
now I can

Themes from user review

Participants note that although unlikely to change their decision on treatment, being given comprehensive information about treatment related side effects would have been much preferred. This informed decision making process would have made participants aware of PRD and be prepared for side effects and ask for help, instead of multiple years of debilitating symptoms (for some 10+years after treatment)

Quotes

- Should have been given a choice
- very much relying on staff to give the full picture, not just bits

Participants were very supportive of the LET dietetics service

'wouldn't change a thing'

'the service couldn't be better,
it's priceless'

Recommendation for practice

From user review, without doubt participants view LET/Dietetics as a high-quality service with significant positive measurable impact/outcomes, it is a valued and most needed life changing lifeline.



Actions taken following user review/feedback.

- Feedback to LET on dietetics outcomes
- Video call consultations to start November
- Setting up an annual PRD support meeting
- Patient resource update including pre-treatment resources to improve user awareness pre cancer treatment
- Continue to work on improving service and exploring new evidence base for PRD
- Continued marketing and education about LET access/referral and awareness
- Continued review of service delivery and scope for development.