

**"I want my  
life back"**

**The long-term side-effects of radiotherapy: Gaps in recognition and resourcing leaving patients suffering without treatment.**

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## **John Webber, Chairman, Pelvic Radiation Disease Association:**

*“Thousands of people live restricted lives because of Pelvic Radiation Disease. More clinics and services would enable them to return to an active and productive life.”*

# Foreword

**Rebecca Shoosmith, Head of Information and Support Services,**

**Jo's Cervical Cancer Trust**

More people are surviving cervical cancer than ever before, with over half of those diagnosed living for ten years or more<sup>1</sup>. However, surviving is very different to living well.

Radiotherapy is a common, and highly effective, treatment for cervical cancer yet it can sometimes cause Pelvic Radiation Disease (PRD), a collection of symptoms affecting the pelvic organs following toxicity exposure during treatment. These symptoms include bowel and bladder problems such as frequent diarrhoea, incontinence, and difficulty passing urine. These symptoms can be chronic, leaving those affected unable to carry out day to day activities such as shopping, leaving the house, and employment. There is currently a systemic issue around PRD across much of the health system, with the condition vastly under recognised at all levels. As a result there is limited funding to support much needed training, treatments and clinics. Patients report ricocheting around the system, without getting the support they desperately need. Sadly we all too often hear from patients who have been told nothing can be done for them. This should not be the case.

One of the challenges is a lack of national guidelines for cervical cancer, or the late effects of pelvic radiotherapy, meaning there is no consistency in follow up care. PRD itself remains relatively unknown with no widely established standard for diagnosis and treatment. For patients presenting with symptoms, especially in primary care, there is often an inclination to treat the symptoms themselves instead of following diagnostic routes to establish the underlying condition. This can mean patients continue to suffer needlessly.

Services and specialists with the knowledge and resources to provide the holistic care required are scarce, an issue fuelled by limited funding at a national and local level. This ultimately creates a postcode lottery around who is able to access help.

Prevention and early intervention are evidently preferable and there is a pressing need for greater research to better predict those who may be at risk of PRD and identify them at the earliest possible stage.

This report includes the stories we hear through our support services, from 18 interviews with patients and from interviews with health professionals working within late effects and radiotherapy. We also issued Freedom of Information requests to NHS Trusts and Health Boards across the UK.

COVID-19 has put the NHS under a huge amount of pressure with many resources diverted to respond to the pandemic. We are now faced with the long term path to recovery of services. We started this report before the pandemic and were shocked by the stories we heard from both patients and professionals. In light of the additional pressures on the NHS due to the pandemic, we are even more concerned.

It should not be the case that treating a cancer is a box-ticking exercise. There is an urgent need for far greater understanding and recognition of the side effects caused by radiotherapy to the pelvis, along with consistent pathways to enable those affected to get much needed treatment and live as well as possible after cancer.

# About Pelvic Radiation Disease

There are over 3,200 cervical cancer diagnoses every year in the UK with around 49,000 living with and beyond diagnosis. Radiotherapy is a common, and highly effective, treatment for cervical cancer and around 40% of patients will receive it<sup>2</sup>.

As with many medical procedures and treatments, radiotherapy can have side effects. Short term side effects are common and often settle a few weeks after treatment finishes.

In order to treat all of the cancer during radiotherapy, surrounding tissue or body parts may unavoidably be included and affected. This means damage to internal organs or skin can occur leading to conditions such as radiation osteitis, pelvic insufficiency fractures, and exocrine pancreatic insufficiency. These in turn can cause many symptoms.

Pelvic Radiation Disease is defined as symptoms which start or continue three months, sometimes even decades, later. These can be progressive and permanent.

*“In September 2018 at 3 monthly clinic I was informed I’d be referred to gastroenterology due to persistent bowel problems. Saw them in November 2018 and was referred for a breath test in February 2019. This test came out as negative. Went back to gastro in May 2019 and was told there was nothing wrong with me. I became visibly upset as I felt these were symptoms I couldn’t cope with – given a prescription of Mebeverine and Peppermint Oil at this time as they believed I had IBS and was then referred to a dietician.”*

## Symptoms of PRD

- bowel and stomach difficulties (leakage or an inability to control the bowel or hang on, diarrhoea, need to rush to the toilet, bleeding from the bowel, poor appetite and malnutrition)
- bladder difficulties (such as leakage or lack of control, need to rush to pass urine, bleeding)
- sexual difficulties (such as painful intercourse)
- pain
- fatigue
- swelling (e.g. lymphoedema)
- poor mobility
- blood circulation disorders
- anaemia
- sore skin
- nerve damage
- bone fractures
- hormonal changes (such as hot flushes)
- infertility
- sleep disturbance
- memory problems
- psychological difficulties.

Pelvic tumours are treated with radiotherapy more than those in other parts of the body<sup>3</sup>. In addition to cervical cancer, this includes cancers of the colon, rectum, anus, prostate, testes, bladder, and womb, as well as patients treated with total body radiotherapy and radiotherapy in the pelvic area for other primary and secondary cancers.

*“No-one seems to be able to tell me if any of this is normal! My GP is helpful but has no idea whether these ongoing symptoms are to be expected or what to do about them.”*

As the number of people surviving cancer grows, so does the number affected by PRD<sup>4</sup>. The Pelvic Radiation Disease Association (PRDA) estimates that at least 100,000 people in the UK experience ongoing problems following radiotherapy to the pelvic region, with research showing 80% of patients develop a chronic change in their bowel function.<sup>5</sup> Our previous research<sup>6</sup> has found that 88% of patients living beyond cervical cancer have experienced at least one consequence of their treatment, with half reporting bowel or urinary problems. Even more concerning is that just 10% said they had received treatment for their problems.

## Lisa’s\* story



I was diagnosed with stage 2b cervical cancer in 2008 at the age of 27. I had to have 6-week course of chemotherapy, radiotherapy and brachytherapy.

My bowel habits changed during the radiotherapy treatment, which I had been warned about and was expected, and I had terrible cystitis immediately following the brachytherapy. It took a while for my bowel habits to return to a new normal, approx. 2 years. However I started to develop kidney infections once a year, which would come on suddenly with a fever and full body aches and I found that I was constantly chronically tired, again another symptom of long-term effects of radiotherapy I’ve been told.

In 2015, I began suffering with severe abdominal cramping with violent episodes of vomiting, symptoms similar to a bowel obstruction. I was hospitalised on a number of occasions and investigated for all sorts of illnesses, gall bladder stones, IBS, and porphyria to mention a few. However, no medical professional (to this day), could work out what was wrong with me and what the cause of this acute cramping and vomiting was.

In 2017, I was getting desperate and these flare ups and spasms were happening on a monthly basis, which was becoming debilitating. I had been referred to various other doctors, but everything was coming back negative. I’ve gone round in circles for years now, and still no one can work out exactly what is going on. These flare ups happen around the time I have my period and ovulate, so now it’s been suggested that I have keyhole surgery to investigate my abdomen for adhesions and possible radiation induced endometriosis. Depending on what is found the doctors may induce the menopause just to see if this stops these horrendous flare-ups. My scar tissue from my treatment is prone to infection and my bowels are very irritable now. There has been discussion to perhaps remove some of my small bowel if there are a lot of adhesions, but again this is depending on the results of the keyhole surgery, of which I am on a waiting list for.

While Googling, I came across the Pelvic Radiation Disease Association and decided to email my story to them. They gave me the name of a doctor at UCL who determined that the problems I was having were likely to be caused by long term radiation damage and that I had narrowing of the bowels overlapping with IBS and possible gynae issues.



**\*Name changed to protect anonymity**

## National guidance

National Institute for Health and Care Excellence (NICE) guidelines exist for the treatment or management of specific conditions. NICE guidelines provide a structured approach to managing a condition with robust measures, pathways, and justifications for service creation. This in turn is linked to funding and targets.

NICE guidance on bladder cancer<sup>7</sup> provides follow up protocols which includes two years after treatment, and the NICE guidelines for prostate cancer<sup>8</sup> include recommendations designed to support health professionals to identify effects such as urinary incontinence and radiation-induced enteropathy.

There is no national guidance for cervical cancer or the late effects of pelvic radiotherapy. The absence of which, for cervical cancer patients experiencing PRD, is keenly felt. Guidance on managing gastrointestinal symptoms of PRD<sup>9</sup> exists, however this is not national guidance and it is often overlooked.

*“If these symptoms are all caused by radiation damage, where is the guidance on how to live with that radiation damage?”*

The *British Gynaecological Cancer Society Cervical Cancer Guidelines: Recommendations for Practice*<sup>10</sup> highlights the wide range of late effects patients can experience and the need for patients to be fully informed on managing these. However the focus is very much on those under the care of their oncology team with little addressing care after this point.

While some patients may get referred back to oncology if they experience problems, if they no longer have cancer or are many years after treatment they can struggle to access appropriate care. Opportunities are often dependent on the understanding, and availability of resources, at the hands of the health professional they end up in the care of.

## Diagnosing PRD

Getting a diagnosis of PRD can be extremely difficult. There are a wide variety of symptoms, many of which can appear similar to other conditions such as irritable bowel syndrome. There is also the likelihood of symptoms presenting many years after radiotherapy has finished. A lack of recognition of PRD among health professionals, and minimal resources to support them, can mean joining symptoms back to the treatment can be overlooked.

Most people affected by PRD will be afflicted by more than one symptom<sup>11</sup>, therefore a holistic approach to diagnosis and treatment is needed to take into account the potential disruption to different bodily functions, structures, and organs.

Misdiagnosis is common. Symptoms such as diarrhoea, are often treated in isolation without identifying the cause, such as bile acid malabsorption.

*“No-one seems to be able to tell me if any of this is normal! My GP is helpful but has no idea whether these ongoing symptoms are to be expected or what to do about them.”*

Limited recognition of PRD amongst medical professionals is a big challenge and spans primary care and secondary care, where referrals can lead patients back to oncology or to services such as urology and gastroenterology. Unless clinicians recognise potential PRD and have access to diagnostic and treatment routes, the right care may not be given. Only 29% of clinical oncologists treating pelvic cancers in the UK say they would refer patients for specialist assessment, with 35% not having access to a specialist clinic<sup>12</sup>. A national survey of gastroenterologists<sup>13</sup> suggests low response rate to the research could “reflect the opinion that radiation-induced bowel toxicity is not a significant issue.”

*“I have mentioned my problems to my GPs over the years, and the fact they could be related to my radiotherapy treatment, but this has always really been brushed over, and no particular solutions have been offered. At no stage has there ever been any mention of the term Pelvic Radiation Disease. I feel I have very much been coping on my own.”*

Tools to aid identification of specific symptoms exist. The *Guidance: The Practical Management of the Gastrointestinal Symptoms of Pelvic Radiation Disease* clearly states that ‘managing patients with PRD requires a different approach to those with other forms of bowel pathology.’ It identifies when symptom presentation needs immediate intervention, for example a ruptured bowel, and can prevent conditions worsening.

The Assessment of Late Effects of Radiotherapy- Bowel (ALERT-B) tool<sup>14</sup> consists of three questions asking patients about bowel and bladder function and any impact on their day to day life. It aims to support referrals and treatments and can be used in a wide range of settings and conversations.

However, low awareness of PRD means such guidance is not used to full effect, if at all.

We issued Freedom of Information requests to Hospital Trusts across the UK asking whether they have a standardised method for identifying patients experiencing PRD.

The responses were varied, clearly demonstrating the need for more standardised guidance. Some reported using the ALERT-B tool or questions based on it, while others said patients would be referred to a specialist such as a dietician or gastroenterologist. Others do not use any standardised tool at all.

Just 23 NHS Trusts in England, six in Scotland, and four in Wales said they use one of the two tools above.

### Primary care

Patients with PRD may present while still in the care of their cancer team, however they are more likely to present in primary care. This is where many say they have reached a dead end. We often hear from patients who say they have been passed back and forth between general practice and different clinics, or simply told nothing can be done to improve their quality of life. This is all while diagnostic tools, pathways, and treatments exist.

There are many factors influencing quality of GP referral including low exposure to the condition, poor examination, low adherence to - or lack of – guidelines, and relying on patients' descriptions<sup>15</sup>. These are all relevant in the case of PRD.

*“I have mentioned my problems to my GP but these have always been brushed off. These problems became worse last year and I was referred to a gastroenterologist at Borders General Hospital and for colonoscopy. This process took nearly a year.”*

Supporting GPs to make the correct referrals is essential. In addition to training on PRD, better utilisation of the technology available could offer additional support. This could include flags in IT systems, such as EMIS, to identify patients who have had cancer with prompts to check symptoms at certain points and signposting to the appropriate course of action.

Treatment Summaries are a recommended tool<sup>16</sup> to facilitate consistent and joined up care. They provide patients with records of their treatment and information about what to do if they experience problems. Completing these in detail, ensuring GPs are sent a copy when patients leave radiotherapy, and adding them to patient's GP records is essential but does not always happen. Therapeutic radiographers are well placed to facilitate this process alongside an end of treatment consultation with the patient.



## Rhea's story

The effects after my treatment include peripheral neuropathy, bowel and bladder issues, and pain in my legs which has travelled up to my pelvis.

Early on, I would mention my long term effects of treatment to my gynae-oncologist every time I saw them. They would suggest things like cutting out caffeine, and a couple of basic medications of my bladder. I didn't tolerate them and they had awful effects on my bowel. I made lots of changes to my diet and lifestyle, increasing or decreasing fibre, cutting out red meat or figuring out workarounds if needed. I learnt to avoid certain things and just deal with it. Things like linseeds which worked well for a while seem to have stopped working.

My gynae-oncologist eventually referred to me to the bladder and bowel team, who gave me different medication for my bladder spasms and urgency. This helped with the frequency but hasn't got rid of the pain or the urgency. These are other things I've just had to learn to manage.

The gastro specialist I was referred to happened to have a special interest in PRD and was very thorough, investigating things to rule in or out. This meant that I got a diagnosis of bile acid malabsorption due to radiotherapy. They said that I was mild to moderate but on the borderline, so if I'm managing with lifestyle changes I should stick to that. It's only in the last few months things have progressed and they have advised me to get some medication. However, when I've been to my GP about them, they tell me that they will look into it but I've never received the medication. It might be a cost issue or a production issue which was caused by Brexit.

At my late effects clinic I had a really positive experience. I would love to see every single cancer service have this. There are amazing things developing in pre-hab - oncologists do amazing work - but most of the country has an enormous gap between 'you're NED' and living with all of these issues. You're no longer the remit of oncology because you don't have cancer, but all your side effects are from the cancer. Every cancer service should have a late effects clinic so that no matter how far you are down the line, you should be able to get some help.

I found my late effects consultant on social media. My oncology team didn't know it existed and I had to self-refer. It was a nightmare trying to sort out the funding as I was also out of the area, but they did take me on. It was incredible. The first appointment took 2.5 hours, it was extremely thorough. They talked me through loperamide and gave me options of taking it in a liquid form or a tablet. We discussed my lifestyle, my diet, medications, plus the next steps if I needed more invasive treatment. It was incredible to have so many options. I also had some mobilisation and manipulation which really helped, and some pelvic floor exercises.

The most eye-opening thing was seeing a CT scan of my pelvis and my spine, which showed spinal damage from the radiotherapy, which explained why I had so much leg pain and weakness. This experience was extremely validating and made me feel as though I wasn't crazy. There are many health professionals who still don't believe radiotherapy can cause effects years later and so can be dismissive of symptoms. At the late effects clinic, I didn't feel patronised or that anyone was condescending.

## Availability of services and treatment

While interventions and treatments exist for many symptoms, without the correct diagnosis many patients feel hopeless. We have heard from a number of patients who have resorted to private medical care or who have tried to self-manage their condition without medical interventions. Supported self-management is encouraged, for example being part of the NHS long term plan in England<sup>17</sup>, and can be highly effective, however it must be based on professional advice with the patient aware they can access support if they need it. This is backed up by research which shows giving a self-help booklet without any other intervention is not as good as the full intervention from a professional<sup>18</sup>.

Treatment for PRD may include physiotherapy, surgery, medications, and psychosexual support. However this should follow appropriate diagnostic tests and investigations, and for complex cases access to a Multi-Disciplinary Team should be supported and encouraged. With PRD being so underfunded and overlooked this is often not the case.

Without access to an integrated service supporting post radiotherapy, or a clinician with specialist knowledge of PRD, quality of life can be severely impacted.

While some specialist clinics for PRD exist, they are few and far between. Research shows 58% of clinical oncologists do not have access to a gastroenterologist or a gastrointestinal surgeon with a specialist interest in their area and most refer less than 50% of their symptomatic patients<sup>19</sup>.

Our Freedom of Information requests identified services at the following hospitals in England, with a further two who said they were planning clinics.

- Mid and South Essex / Basildon / Southend Hospital
- Royal Marsden
- Leeds Teaching Hospitals NHS Trust
- London NW University Healthcare Trust
- Cambridge University Hospitals
- Royal United Hospitals Bath NHS Foundation Trust
- Nottingham University Hospital Trust
- University Hospitals of Derby and Burton NHS Foundation Trust
- Taunton and Somerset NHS Foundation Trust
- Manchester University NHS Foundation Trust
- Lincoln County Hospital

Some are multi-disciplinary while others are more specific, such as focused on bowel. For patients outside of these areas, and even within, getting access is likely to require adequate funding and a clinician with the necessary understanding of their condition.

Having a clinician focusing on late effects within a hospital can also be effective as long as they have the adequate resources to deliver the service they need. For example, at The Christie:

*All patients are actively asked about their late effects including specific questions about bowel function along with bladder, vagina, sexual, bone and other general symptoms. This occurs at every follow up consultation every 3-6 months for 5 years following treatment for cervical cancer. Symptoms are managed within the team and also patients are referred on to specialist GI consultants with a specialist interest in pelvic radiation disease, urologists, lymphoedema specialists, dermatologists for vulval skin problems, psychologists with specialist interest in sexual health, endocrine specialists with an interest in bone health.”*

In Scotland the main specialist clinic is in Glasgow. Two specialist clinics were identified in Wales, and Freedom of Information requests pointed to follow-ups being delivered by the Northern Ireland Cancer Centre.

Funding was mentioned as an issue in several responses:

*“Unfortunately, this clinic has been run under the radar and has not been supported with investment from commissioning. So we are unable to advertise this clinic or expand capacity.”*

A Specialist Physiotherapist in Pelvic Health, Lisa McWilliams, ran a Gynae Oncology Physiotherapist Project from May 2018 to August 2019. During that time, 166 women were referred to the service, mainly from CNS.

*“I identified that patients undergoing radiotherapy were at a high risk of pelvic dysfunction. I met with clinical oncology in February 2019 and established a pilot referral pathway so that the women could be referred to physiotherapy four to six weeks post radiation. Pelvic health problems are embarrassing and have a huge impact on a patients mental and physical health and wellbeing; making it extremely challenging to discuss with anyone and seek help. At their physiotherapy appointment, the women were assessed in relation to bladder, bowel and sexual dysfunction with advice, exercise and treatment programmes delivered on an individual basis. The treatment outcomes collated showed significant improvements in symptoms and quality of life.*

*Women have told me that although they are grateful for the lifesaving treatments they have received they are not always living well with the consequences of those treatments and feel guilt over seeking help for these. Unfortunately funding ceased in March 2020 and we are currently exploring alternative funding options as it is essential that patients with pelvic radiation disease receive the treatment they deserve.”*

There is currently no centre of excellence in the UK, meaning no central hub for pioneering best practice, defining research priorities, and safely trialling treatments.

*“I attended Jos Trust Mini Meet in Glasgow in May 2018 two days before I started treatment and I attended the session on pelvic radiation disease. I was fortunate enough to meet a radiographer from the Beatson in Glasgow who advised of a new late effects clinic. When I realised I was having issues I called my cancer nurse specialist and asked for a referral. This was done quickly and with no issues. I am very lucky to have access to this.”*

## The funding gap

There is currently no tariff for late effects in the NHS. Without funding or incentives to commission or deliver services, these conditions are likely to be deprioritised. This issue is exacerbated due to existing pressures on services, and competition with other conditions that are funded with clear and resourced referral routes. Lack of targets or inclusion on tools such as Quality Outcome Frameworks further leads to lack of protection for this area.

We have spoken to many professionals who feel frustrated by the lack of recognition for this specialist area. Given the vast number of patients having pelvic radiotherapy each year, the number likely to be affected by PRD is equally large.

Services and clinicians report having to fight for funding and rely on charities, which do not always provide a sustainable model. We have heard from many clinicians who say it is often down to a passionate individual to add to their case load and make a case for resources.

Without appropriate payments or reimbursements for running late effects services, responsibility for the care and management of patients can be unclear. As a result patients may bounce around the NHS with no end or solution in sight.

## Jess' Story

I have suffered a lot of long term consequences as a result of my cervical cancer treatment, mainly changes to my bowel and bladder function.

Before I began my treatment, I was told I might experience some long term damage and was shown a model on all the different areas that could be affected. They were very honest with me and said they couldn't be totally sure if the damage would be long or short term.

Two weeks into my treatment, I began to experience some issues with my bowels and was given loperamide on prescription but was offered no alternative treatment. I have had diarrhoea every day since Christmas Eve 2016 but despite this have managed to gain ten stone. My GP has been of little help suggesting that I get a gastric band or just stop eating.

My problems with my bladder began about a year after my treatment. One day I was fine, the next I wet myself. It began to happen more regularly and then I started to have pains almost like I had an infection. I was initially given antibiotics for thrush but they eventually referred me to a bladder specialist who put me straight in for a day surgery so they could investigate with a camera. I was told that I had an over-reactive bladder due to scarring caused by my cancer treatment. I tried five different kinds of medication, none of which helped at all and I was even offered Botox in my bladder. I didn't like the sound of this as it meant I would have to self-catheterise three times a day. So, instead, I began a treatment called PTNS which is a nerve stimulation treatment. This didn't completely solve my issues but was improving things significantly.

But the pandemic put me back to 'square one' with my treatment.

The PTNS was stopped at the beginning of the pandemic and took until early August to be resumed. The day before lockdown, I saw my consultant who referred me for my bowel problems. This has taken quite a while to be referred, with my first appointment going ahead at the end of August. I was also due to have a six-month check up in the middle of lockdown which they tried to cancel. I cried over the phone and begged them not to cancel and, in the end, they agreed to see me.

I find leaving the house really difficult and I have to make sure I don't eat for two hours before I leave because I'm terrified that I'll need the toilet. It's become even harder during the pandemic because so many public toilets are closed.

I've also pulled away from friends and family as I struggle with panic attacks and feel like I have an emotional barrier preventing me from reaching out. My relationship with my husband, who is very supportive, is strained because I'm so tired all the time and the continence issues make it really hard for me to feel attractive.

## Gaps in research

PRD itself remains relatively unknown, being first defined in just 2010<sup>20</sup>. There are some fantastic clinicians trying to understand the condition better, but there are still many gaps.

The research that does exist often features small sample sizes. This means it can be difficult to make generalisations across the huge number of patients who may potentially be affected by debilitating symptoms after pelvic radiotherapy. Research is generally short term so does not clearly reflect the experience of those who are many years from treatment, when onset of symptoms may start. An understanding of the patient experience is also missing from the research that exists. By furthering this aspect we will be able to build a greater understanding of ways to manage the drop off of support post treatment, the type of support patients want, and how it should best be delivered.

Preventing the late effects of radiotherapy is preferential to treating them. A better understanding of how to identify which patients might be at risk from PRD will reduce the burden of the condition for many. This is in addition to better access to advanced radiotherapy techniques such as image-guided and adaptive radiotherapy, where treatment is tailored to an individual's anatomy on a daily basis leading to reduced doses to organs such as the bowel and bladder.

## Patient awareness

*“They didn't really talk about long term in terms of years later or even permanent damage, it was almost like they don't tell you as to not scare you.”*

When someone is diagnosed with cancer, there is lots of information to take in.

*“I think that because of the huge emotions linked to the diagnosis I did not understand what this meant. I certainly was not advised that complications could lead to a permanent catheter.”*

However it is vital that every patient has adequate information and access to resources to support them if they experience side effects.

The British Medical Association's consent toolkit<sup>21</sup> states that, prior to gaining consent for treatment, the patient should be made aware of “risks and potential side-effects, and adverse outcomes”. This enables patients to be fully prepared for anything they may experience, better able to identify symptoms, and therefore more inclined to seek help when experiencing them. It can also lessen the mental health impact of side effects such as incontinence and pain. Failure to gain informed consent means that patients may be unable to connect the cause of symptoms occurring later in life with the original radiotherapy treatment.

We often hear those living beyond cervical cancer feeling that they ‘should be grateful’ they no longer have cervical cancer, and resigning themselves to symptoms or believing that they are part of the price of having treatment. Anecdotally this is sometimes reinforced by healthcare professionals, creating further barriers to treatment.

*“I have tried to find ways to deal with all these problems without going to a GP as I didn't think there was any way that they could help me.”*

Among those we spoke to for this report, respondents recalled varying degrees of information provided about possible changes to their health following treatment. Some reported being poorly prepared and unaware of how to get help, with most feeling that increased communication or more in-depth information should have been provided.

*“There was no real mention of the long-term consequences of treatment. There was some discussion on whether I should have radiotherapy because of the impact on my ovaries, but I was directed towards having it as a ‘belt and braces’ approach.”*

This is where tools such as Treatment Summaries and information - both for patients and professionals - about charities such as Macmillan, Action Radiotherapy, Pelvic Radiation Disease Association, and Jo's Cervical Cancer Trust is essential.

## The cost of inaction

The late-effects of pelvic radiotherapy, coupled with the scarcity of available clinics and support, can have a profound impact on the physical, mental, and financial health of affected individuals. Loss of earnings, the cost of transport to appointments, and trialling non-prescription medicines can have a huge financial strain.

For those who find it difficult to leave the house, consequences can include having to drastically reduce or change working hours or stop working altogether. The impact on family and supporters can also be great.

High numbers of people have their employment status change following their cancer diagnosis and treatment<sup>22</sup>.

*“The after-effects of treatment have had a big financial impact. There’s all the hospital parking fees, transport and then having to leave work because of my health.”*

In addition to the costs to the NHS, there is an additional cost to the state when people stop working or work less because of ill health<sup>23</sup> as a result of lost income tax and National Insurance contributions.

\*Behind the Screen, Jo’s Cervical Cancer Trust, 2016

**Table 6 Loss in weekly earnings, salary, income tax and NICs when women reduce their working hours or cease working because they have cervical cancer, 2013**

	Median gross weekly earnings	Equivalent salary for full-time employee	Income tax paid per year	NICs paid per year
Full time	£517	£26,884	£3,377	£2,271
Part time	£160	£8,320	£0	£44

The cost to the state must also take into account the lost earnings of the partner or family member. We estimate that stopping work as a result of diagnosis and treatment costs the state over £9 million a year purely in lost tax contributions of patients and their families. This figure does not include other costs to the state, such as Universal Credit and Disability Allowance.

The earlier late effects are identified, the easier they can be treated. In turn this saves on costly surgeries, treatments, and consultations.



## Conclusion

Radiotherapy as treatment for cervical cancer is highly effective, however the burden of symptoms following treatment has long been overlooked, under researched, and sub-optimally managed. As a result of COVID-19, this is only likely to be exacerbated. Limited recognition of PRD in the medical community, out of date and inadequate research, the absence of standardised published pathways, and lack of funding means that thousands are currently living with highly incapacitating and lifelong conditions unnecessarily.

COVID-19 and long COVID are examples of the long term side effects a condition can cause. Specialist clinics and rehab have been developed for long COVID and so we know that it can happen.

We are concerned that there is a systemic failure across all parts of the health system when it comes to PRD. As a result, there is an inequality in opportunities afforded to those affected by debilitating symptoms which are severely impacting their ability to have a good quality of life after cancer. This disregard for people's quality of life cannot continue to be overlooked as the cost to the patient, to the NHS, and to the state is irrefutably high.

## Recommendations

- All patients to leave radiotherapy with a Treatment Summary, that is also issued to their GP, with details of their treatment, potential side effects, and where to access appropriate referrals and support if they experience them
- Centres of excellence for PRD to be established to support diagnosis and referral for patients, in addition to building the specialism through developing training across the workforce, trialling new treatments, contributing to the knowledge base, and providing a central resource hub for clinicians
- NICE guidelines on the diagnosis and management of the late effects of pelvic radiotherapy, or on the management of cervical cancer, to be developed, including follow up pathways for identification and treatment of symptoms following radiotherapy
- A tariff for the late effects of cancer treatment to be developed within the NHS to fund much needed clinics and services
- New research to be conducted to assess current understanding of PRD among professionals across primary and secondary care, in addition to long range studies looking at the experience of patients
- Professional bodies and societies including Society and College of Radiographers, Royal College of Physicians, British Society of Gastroenterology, and Royal College of General Practitioners to identify opportunities where teaching about toxicity following radiotherapy can be included in medical training, especially for primary practice and gastroenterology where patients may present with complex symptoms.

## Pearl's Story



I was diagnosed with stage 2b cervical cancer in November 2009. I had 31 days of radiotherapy along with chemotherapy and brachytherapy. I received excellent medical attention at Luton and Dunstable Hospital and then Mount Vernon. I was told before my treatment started that I might suffer some bowel problems- I had been constipated for some months but assumed that this would settle down eventually. I don't remember them mentioning anything about bladder problems. It's difficult to pin point when the symptoms started after treatment. My bladder problems were the first problem I noticed post-treatment. I couldn't make it an hour-long car journey without needing to stop at least once along the way. I put off going on holiday abroad. If I'm going to go on a long journey now then I limit my fluid intake to practically nothing and it means I'm drinking far less than I should.

In 2014, I went to a GP as I had heard there was medication that would help. After three visits, I was given two medications to try neither of which really helped. I went back to the GP who brushed me off and said there were no other treatments available. Regarding my bowels, I find that I have to go 2 or 3 times in the morning and sometimes ten minutes apart. In 2017, I went to the GP because I had rectal bleeding. I was fast-tracked through the system and had a colonoscopy. I had a few haemorrhoids and my 'rectum and rectosigmoid show minor radiotherapy changes with loss of compliance'. The procedure was very uncomfortable even though I opted for sedation. My bowels are narrower as a result of radiotherapy and less flexible so I sometimes experience bowel urgency. I find that drinking quickly or having anything cold or with ice in makes these problems even worse. I recently bought a Potette which is meant for toilet training toddlers but I know a few women that use them. This has actually made a huge difference to my life as it means I can travel greater distances without needing to worry.

Apart from when I visited the GP in 2014, I have tried to find ways to deal with all these problems without going to a GP as I didn't think there was any way that they could help me. I feel like I have been left to deal with these issues on my own and it's hard to not feel frustrated or angry at times.



## Support for you

If you are concerned or affected by any of the issues raised in this report, please get in touch with your GP or a specialist organisation.

### **Action Radiotherapy**

[www.actionradiotherapy.org](http://www.actionradiotherapy.org)

### **Jo's Cervical Cancer Trust**

[www.jostrust.org.uk](http://www.jostrust.org.uk)

### **Pelvic Radiation Disease Association**

[www.prda.org.uk](http://www.prda.org.uk)

### **Macmillan Cancer Care**

[www.macmillan.org.uk](http://www.macmillan.org.uk)

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