

# Living with the consequences

→ Peter McIntyre

Oncologists know well the fear and desperation of patients faced with a cancer diagnosis. They are far less familiar with the daily struggle to cope with functional impairments, pain or psychological damage that a significant minority of those same patients face once their treatment has ended. Here some survivors damaged by radiotherapy tell their stories.

**P**eople who have been damaged by cancer treatment often say two things – one, that they would feel better if they had been warned in advance, the other that when things went wrong, their specialist went into denial, sometimes refusing to speak to them about their pain, incontinence or loss of mobility.

It is understandable that doctors who do their best to save lives find it hard to accept that they may have offended against that key clause of the Hippocratic Oath which says, ‘never do harm to anyone’. No treatment is risk free, and a balance needs to be struck between maximising the chance of a cure and minimising the risk of long-term side-effects. Doctors have no magic solutions, but they can and must accept a responsibility to help their patients look beyond the immediate panic sparked by their cancer diagnosis, to consider and weigh up what the possible long-term damage from various treatment options could mean for their quality of life. There simply has to be a greater degree of honesty in warning the patient of possible bad effects and in facing up to harm afterwards.

The Patient Voice sections of this and the following issues of *CancerWorld* will look at the problems faced by survivors, and what can be done to reduce harm and to bring relief and comfort to those who have been harmed. Patients with severe damage represent a fraction of those who are successfully treated, but these are not very rare events, and some people’s quality of life has become almost indescribably bad. If the focus seems to be too much on the bad news, that is because it is too often ignored and denied.

This issue looks at some of the long-term damage that can be done by radiotherapy.

## THE RISING TIDE OF CANCER

The World Health Organization’s Cancer Research Agency, IARC, estimates that the number of people diagnosed with cancer in 40 countries of Europe rose to 3.2 million in 2006, a 10% increase over 2004. This is 1.5 million more people than died from their cancer in the same year. The incidence of cancer is still rising, but the number of people living with their cancer is rising much faster. IARC suggests that “around 20 million people” in these



Hitting the political agenda. Ten years ago, the campaign by RAGE helped to change the way that radiotherapy was delivered in the UK, making it safer for later generations of patients. *Yesterday's Women*, the story of that campaign and the women who led it, was launched at the Houses of Parliament in London last December

40 countries of Europe have had a diagnosis of cancer and are alive today (see box, p 62). These people are often referred to as 'survivors'.

When short-term survival was the only aim, the long-term effects of treatment – often known as 'late effects' – seemed relatively unimportant. As more people live five, ten, twenty and thirty years after diagnosis, the impact of the treatment on quality of life is ever more significant.

#### WHAT IS A 'SURVIVOR'? WHAT IS 'CURED'?

The term 'survivor' is used in several different ways, sometimes including anyone who has had a cancer diagnosis, and sometimes referring to those who have lived five or ten years after diagnosis and who are considered 'cured'. In the US, the term

has been extended to include all those whose lives have been affected by the cancer, including family members, friends and caregivers, which is perhaps not a very useful definition.

Survivorship has become a major issue in the US in a way that has not yet happened in Europe. In 2002, the Lance Armstrong Foundation and the Centers for Disease Control and Prevention (CDC) launched a *National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*. However, in 2005 the US Institute of Medicine still found that "primary care physicians and other health care providers often are not extremely familiar with the consequences of cancer, and seldom receive explicit guidance from oncologists."

## “The consultant almost reduced me to tears. I was ‘neurotic, arthritic’ and it was ‘all in my mind’”

Stella Kyriakides, President of the Cyprus Forum of Europa Donna, the European Breast Cancer Coalition, believes that it is misleading to describe people as cured if they live free of cancer for five years. “I think it is totally artificial. I have never advocated that there is life after breast cancer, but that you learn to live with breast cancer. That is the reality. You may finish intensive treatment and surgery and then have targeted therapy, and after that you have follow-up and are in contact with medical professionals and you may have side-effects that are the result of the treatment.

“I personally remember when I was diagnosed the cut-off point was two years, and for some reason I had this magic two-year mark in my head. The first time I started reading articles about five-year survival and ten-year survival it was hard to take. You learn to live with a cancer diagnosis. You need to be aware of everything that comes with it and all the quality of life issues that follow.”

### THE RAGE CAMPAIGN

It was the failure of doctors to inform their patients of the potential risks to their quality of life and their subsequent refusal to accept any blame that sparked a major campaign in the 1980s. The issue concerned women in the UK who were severely damaged by radiotherapy following surgery for breast cancer.

Two to five years after radiotherapy, the women started to suffer serious side-effects from radiation-induced brachial plexus neuropathy (BPN), afflicting the bundle of nerves that supplies power and sensation to the arm. The injuries were severe and irreversible. What began as tingling and numbness left many women without the use of their arm and living in terrible pain. Some had an arm amputated; others experienced damage to their chest muscles, which in some cases were fatal.

Some of these women formed the campaigning group RAGE and fought an unsuccessful 15-year battle in the UK for compensation (see box).

Listen to the words of one of the RAGE women who, in 1982, had a small breast cancer removed by surgery.

“I was then given an appointment for radiotherapy. There was no discussion on alternatives or possible risks, just an appointment. I had radiotherapy every other day for six weeks. I did not know at the time that this would involve a higher dose of radiotherapy at each session than if I had attended every day and that this higher dose involved a greater risk of injury.

“In August 1982 (about four months later), I began to have very severe tingling all along my arm, followed by pain, then complete loss of feeling in the arm, even though the pain persisted. In December, I told the surgeon about this. He just barked, ‘You are absolutely A1,’ and rushed out of the room.”

It took four years for her hospital to admit that she had been damaged by the radiation. “The consultant almost reduced me to tears. I was ‘neurotic, arthritic’ and it was ‘all in my mind’. My husband

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### RAGE PUTS RADIATION DAMAGE ON THE MAP

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In the 1990s, a group of several hundred breast cancer patients in the UK formed RAGE (Radiotherapy Action Group Exposure). They demanded compensation for the damage they had suffered following post-operative radiotherapy, and campaigned for changes in the way women are treated and kept informed.

Their compensation claims (fought by RAGE as a political campaign and by others in the courts) failed because the British courts and government argued that the treatment that inflicted the damage was not negligent, but standard practice at the time.

RAGE raised awareness of the risks of radiation damage nationally and internationally, and in many ways set a model for campaigning and self-advocacy groups. Their full story is told in a 2006 report researched and written by Bec Hanley and Kristina Staley and published by Macmillan Cancer Support. *Yesterday's Women, The Story of RAGE* can be found at [www.macmillan.org.uk](http://www.macmillan.org.uk) (search for: RAGE report).

was advised to ‘trade me in for one that doesn’t moan!’ In all this time, the pain had become unbearable and the arm progressively weaker and the dreadful anxiety of recurrence remained.”

In 1999, 17 years after her original treatment, an MRI scan revealed a new malignancy in her chest – a sarcoma induced by the radiation. Following treatment, she is left with the fear that it will return. “I try to push this to the back of my mind, but it comes back when I cannot sleep. Almost every day it is the first thing on my mind on waking. It has of course cast a great cloud of anxiety over our last years. Had this been inevitable I should have found it easier to bear, but it was not inevitable. It was caused first of all by excessive radiation, but most of all by the refusal of (the) hospital to admit the problem or follow me up.”

The plight of the RAGE women may reflect the standard of treatment of the early 1980s, but damage from radiotherapy is still happening today, and the attitudes of denial can still be found.

### COLORECTAL DAMAGE

Radiation of the pelvic area to treat gynaecological, bladder, prostate and rectal cancers can induce a chronic fibrotic reaction, causing damage to the bladder, sexual organs, and the colon and rectum (bowels). This problem was highlighted in the UK where the National Association for Colitis and Crohn’s Disease (NACC) commissioned a scoping study in 2006. The report, *Living with Bowel Problems Following Radiotherapy*, can be accessed at [www.nacc.org.uk](http://www.nacc.org.uk) (search for: Living with Bowel Problems).

Judy Wilson, who carried out the study, concluded that half of the 12,000 people given radical radiotherapy for pelvic cancers in the UK each year continue to have problems after radiotherapy treatment has been completed. For some the damage is permanent, causing diarrhoea or constipation, urgency, pain or rectal bleeding. One in five has long-term faecal incontinence.

Quality of life is severely damaged and patients are left feeling very isolated. According to the report, people felt their needs were not always of interest to cancer specialists, while family and friends found it embarrassing. Only about one in five people damaged in this way is referred to a gastroenterologist, who may lack the confidence and experience to manage their case.

### INFORMING PATIENTS

Patients and doctors need to be made aware of the risks and consequences of long-term damage. One example of how this is happening comes from the UK, where Cancer Research UK and Cancer Backup have published a pair of booklets entitled *Pelvic Radiotherapy: Possible Late Effects*, one for women and one for men. These act as handbooks for patients, identifying the problems they might expect, giving guidance on self-help and encouraging them to press for referrals if their problems do not improve. The booklets can be ordered from Cancer Backup at [www.cancerbackup.org.uk](http://www.cancerbackup.org.uk) (go to: Health Professionals/publications).

Many general practitioners are now reviewing all their patients who have had pelvic radiotherapy. If any of their patients are still having problems, the GPs are able to give them a copy of this booklet.

Cancer Backup has also prepared web pages to inform health professionals about managing the long-term side effects of pelvic radiotherapy. These can be found at [www.cancerbackup.org.uk/healthprofessionals/pelvicradiotherapy](http://www.cancerbackup.org.uk/healthprofessionals/pelvicradiotherapy).

Bette, a 57-year-old cervical cancer patient, had not been able to return to work following treatment. “You have to plan your life around the loo [toilet]. I don’t wander far from home now. I don’t stay at anyone’s house or go on holiday. I often can’t make it to the loo. I wash my hands and myself and my clothes, then sit down again and the same things happen.”

Tim, who was treated in his forties for prostate cancer, was left with faecal and urine incontinence and had to wear an incontinence pad. He felt that the focus had been only on curing the cancer, rather than on quality of life afterwards. “I still see my oncologist and my surgeon twice a year and neither of them are able to help. The surgeon could suggest the treatment for nappy rash. I have been told for the past five years that I am unique and the only one to have these symptoms.

“I do go to work but I often have to come home again. I commute on the train... but often don’t make it that far. If I didn’t have the treatment I would be dead, but if I had the choice again I wouldn’t have it.”

The figures in this study would suggest that, each year, worldwide 150,000 people are left with damage following pelvic radiotherapy.

Penny Vicary, from East Anglia in England, founded a patients’ group, Pandora’s Box, after she was damaged by radiation during treatment



GETTY IMAGES/STOCK ILLUSTRATION

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frightened about how they look or feel”

for gynaecological cancer and colorectal cancer shortly before her 35th birthday.

“I have damage of my bladder and my bowel, and because of the radiotherapy I have got severe narrowing of the vulva. I am more or less doubly incontinent.”

She says that her condition makes a close personal relationship very difficult. “I am concerned

about not being able to have intercourse and not being able to control my bodily functions. I would have to explain to somebody I might not be able to do the physical act, let alone things like how do you feel, do you smell, have you got leakage.

“My rectum makes it difficult for me to sit down and I don’t sleep very well because I cannot get comfortable. I cannot physically stand for long either.”

## “They said, ‘Don’t worry, this will disappear in three weeks,’ and I was stupid enough to listen to them”

Penny Vicary describes herself as ‘free spirited’ and ‘rebellious’ and says that this is what keeps her going. “But it is insidious. Only when I think about it, do I realise the enormity of the impact it has had on me and that every physical aspect of my being is affected. I don’t want to be a scaremonger, but I am not alone. There are hundreds of people out there experiencing the same things. I am grateful to be alive but some days... you just feel tired and you don’t feel you have a voice.

“People see a presumably healthy person. You don’t see someone constantly going to the toilet. You don’t see them thinking about that relationship, frightened about how they look or feel. After a while, what you are doing is hiding it. It is almost like a secret.”

### PROSTATE CANCER – NEEDLESS DAMAGE?

For many people treatment is an urgent necessity. However, that is not always the case. Louis Denis, Secretary of Europa Uomo, the European Coalition against Prostate Cancer, says that there is up to 50% over-treatment for prostate cancer detected by population screening and therefore a high degree of unnecessary damage.

Floortje Mols, based in Tilburg in the Netherlands, conducted a survey of patients treated for prostate cancer to see what they identified as major problems, and compared them with the general level of problems in a population of a similar age. The incidence of urine incontinence rose from 4% in the general population to 23–48%, and faecal incontinence was up from 2% in the population to 5–14%. Erectile dysfunction was put at 40–74% amongst prostate cancer patients, against 18% amongst men of a similar age.

Denis has a personal and professional interest in this. He is both Director of the Antwerp Oncology Centre and patient, having been diagnosed with prostate cancer more than 12 years ago. He points out that microscopic prostate cancer is already present at the age of 30. By the age of

50 around 50% of men have cancer cells in their prostate, and this rises to 80% by the age of 80. But in only one-third does this develop into clinical cancer and this process usually takes 20 years. Even then it usually takes another 15 years before they die from prostate cancer.

Because the current PSA test does not predict which cancers will develop into a clinical problem, Denis is firm advocate of ‘intensive surveillance’ for well-differentiated cancers.

“You track the progress of the little cancer. You check on the performance of the PSA velocity and doubling time. We take new biopsies one year later, five years later and ten years later to check on the histology for signs of poor differentiation. I followed the same scheme myself for 12 years before I got treated. The only problem is most people when they hear the diagnosis ‘cancer’, no matter what it is, go berserk and want to be treated. A lot of doctors and relatives feel that whenever you hear the word ‘cancer’ you should be treated.

“This is one of the big worries at the moment – reduce the over-treatment? yes or no? We have the same problem in breast, lung and colon cancer. In prostate cancer in 2006, we had 350,000 new cases in Europe while 85,400 die every year of the disease. As a consequence, there are more than two million men living with prostate cancer in Europe.”

Denis must be one of the best informed people in Europe about prostate cancer and treatment options, but this did not protect him. “I followed intensive surveillance for 12 years because I have studied prostate cancer for 50 years and I do what I preach. Then last year, after my fifth biopsy, I got a little bit chicken because the biopsies found a higher grade of cancer and my PSA was rising, and I said maybe it is better now that I have treatment.”

At the age of 72 he underwent radiotherapy. “Now my PSA is 0.3 so I don’t need to worry any more about prostate cancer, but my bladder function

## “What we have failed to address is the care of patients who are cured but are living with the consequences”

is gone, which is something I do not enjoy.”

He is angry with himself as much as with his doctors. He knew from research data that when radiotherapy doses rise from 72 to 80 Gy (7,200 to 8,000 rads), the side-effects rise by half, so he asked for the dose to be limited. “Nowadays, radiotherapists want to confirm that they are able to match the curative outcomes of surgery. So instead of giving 7,200 rads they give 8,000, saying that it doesn’t increase the side-effects. When I reached 7,000 rads I told them I wanted to stop, because I could not control my bladder. They said ‘Louis, don’t worry, this will disappear in three weeks,’ and I was stupid enough to listen to them and stayed on treatment.”

Strikingly, the first point in the manifesto of the patient group Europa Uomo is not survival, but “to find ways and means to promote quality of

life for prostate cancer patients and their families.” Denis believes that there is a fundamental gap in attitude and understanding between patients and doctors on this point.

He cites research from the Netherlands that shows that when patients understand the benefits (more chance of a cure) and risks (more chance of side-effects) of receiving 80 Gy of radiotherapy, they nearly always choose the lower dose.

His conclusion is blunt: “Patients should be correctly informed about the side-effects of treatment so that they are able to share in the decision on treatment in front of a multiprofessional panel.”

### RESEARCH AND REHABILITATION

Despite the problems with certain radiotherapy procedures that leave up to one in five patients with faecal incontinence, there is little research into the subject and poor referrals systems.

Jervoise Andreyev, consultant gastroenterologist at the Royal Marsden Hospital, is one of the few in the UK who specialises in helping people who have been damaged by radiotherapy. Writing in *The Gut* magazine in August 2005, he deplored the lack of research into these conditions.

“Of all the problems which can arise, new bowel symptoms have the greatest impact on quality of life. In addition, most have been cured of their cancer and many are young. ... [They] generally represent the fitter end of the spectrum for their age because they have been selected for – and survived – radical therapies.”

In that year, there was not one piece of research published on this issue. “Our understanding of how to treat these patients is equally dismally lacking an evidence base... We are becoming increasingly good at knowing how to cure cancer... The hospice movement has revolutionised the case of those dying from cancer. What we have still failed to address systematically is how best to care for the patient who is cured of their cancer but living with the physical consequences.”

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### GROWING NUMBERS OF SURVIVORS

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IARC estimates that in 2002, 2.8 million people in (40 countries of) Europe were newly diagnosed with cancer, and 7.3 million people who had been diagnosed with cancer within the previous five years were alive. Applying the same ratio to the current (2006) data gives a total of 8.3 million people in Europe living with a diagnosis of cancer received in the previous five years.

However, Jacques Ferlay, Informatics Officer at IARC, points out that while these are the best estimates available, they may be conservative, because they use out-of-date survival data. He has recalculated the figure, applying data from Finland, making the assumption that Europe is similar to Finland in terms of patterns of risk and survival. Based on an actual population count, he says that up to 9.2 million people are alive today who have received a cancer diagnosis within the past five years. If those who have lived with their diagnosis for longer than five years are also included in the estimate, Ferlay sets the total number of people in Europe living with cancer at “around 20 million” – 2.7% of the total European population.

IARC incidence estimates for 2006 can be found in *Annals of Oncology* 18:581–592 (the headline data were published in an IARC press release – [www.iarc.fr](http://www.iarc.fr) – on 7 February 2007)