

Me and my cancer

The power of a well told personal story

SIMON CROMPTON

Journalists who write about their own cancer journeys are able to convey important insights in a language that people understand – and are eager to read.

It is not surprising that a lot of journalists have written about their personal experiences of cancer: cancer is common; writers like writing about themselves; and they also know that real human experience and emotion engage readers like little else. It doesn't get much more real or emotional than having a life-threatening condition.

But some writers stand out from the crowd. In the UK in the late 1990s, John Diamond from *The Times* made a major impact with his weekly columns about throat cancer, and his subsequent book "C: Because cowards get cancer

too". Catherine Kalamis of the *Guernsey Press* won an ESO Best Cancer Reporter Award in 2006 for a powerful series of articles based on her personal experiences of neuroendocrine tumour.

And then there is Cassandra Jardine. A popular feature writer and interviewer for the UK's *Daily Telegraph* for the past 20 years, she died of lung cancer in May last year at the age of 57, having spent much of the last two years of her professional life writing about (among other things) her diagnosis of adenocarcinoma of the lung, getting on with life as a mother while having chemotherapy, the impact of her cancer

on her family, the itchiness of her wig, the power of a cosmetic makeover, and her highs and lows as she embarked on new treatment regimens.

She also spearheaded a national campaign to raise awareness of cancer symptoms. Just days before she died, she fronted the launch of an early diagnosis campaign 'Be Clear on Cancer', alongside celebrities such as comedian Ricky Gervais and football manager Alex Ferguson, who both lost parents to the disease.

Eulogies from colleagues pointed to Cassandra Jardine's good humour, compassion, lack of self-pity, supportiveness



CLARA MOLDEN

of others, professionalism and diligence. Readers commented on her warmth as a writer, her wit, her pragmatism – how they felt they had come to know her and became involved in her story.

But for the cancer community, her lasting contribution may be something more specific and unusual. She communicated in an accessible and involving way the reality of clinical trials from a patient perspective – how they work, their positives and negatives, and most of all, how it feels to be part of them. Journalists don't tend to cover this subject: it sounds too dry for editors, and patients themselves can't always be relied upon to

“I don't enjoy being a guinea pig but I want that vaccine.” This photo of Cassandra Jardine was used to illustrate one of many articles she wrote for the *Daily Telegraph* that gave her readers insight into the pros and cons of clinical trials and how it feels to be part of them

provide the emotional insight and clarity about the issues that newspapers and magazines require. Whether for good or ill, it takes a journalist writing about their own experience to bring such difficult issues to the fore.

Just four weeks before she died, Cassandra Jardine submitted three of her cancer articles dealing with her experiences of clinical trials to the ESO Best Reporter Award. In her supporting statement, she said these articles were those

of which she was most proud: “I hope they combine clarity on scientific topics with an ability to engage and touch the widest section of the public – whilst still drawing respect from the experts involved,” she wrote.

She said she wanted to convey the human experience of cancer not for its own sake, but to get information flowing forwards to patients and public, and backwards from patients like herself to professionals and scientists.

“Patients can be useful sources of subtle information that can be fed back into the research and development pool”

Making science accessible

“I feel we need to find new ways to combine an ability to express medical language so that non-scientists can more readily understand,” she wrote. “But I think we need to also remind scientists that these are not just statistics, that there are individuals out there who aren’t just passive recipients of therapies but who can be useful sources of subtle information that can be fed back into the research and development pool. It’s not a simple case of modern patients deserving to understand fully where they are with their own health (and control it where possible); but of how they can accumulate and utilise that information – together with their consultant – to constantly improve all patient pathways. And, to be frank, outcomes.”

In many countries, clinical trials of new cancer treatments are becoming more and more significant in the lives of people with cancer and the clinicians treating them. The UK has seen a five-fold increase in the number of patients being recruited into clinical trials in the past 10 years. Yet public understanding is still poor, with many potential subjects confused about the process – how randomisation works for example – or the potential dangers of new treatments. The need to air such complex areas beyond bedside conversations, formal information sheets and consent forms did not escape Cassandra Jardine.

In her article “I don’t enjoy being a guinea pig but I want that vaccine,” she charted her emotional highs and lows as she enrolled on a trial of the vaccine Lucanix in an attempt to delay her cancer’s return. In the process, the article corrects misconceptions that can deter patients from joining trials (see Editorial). It also addresses concerns that too many trials are now for drugs that are likely to help a lot of patients a little bit, rather than a few patients a lot.

“I found myself in the unusual position of being able to give a rare inside view of that perennial story which dominates headlines – Is X or Y a cure for cancer? It was a good chance to help explain to the public what a trial is, the difference between phases 1, 2 and 3 – and all the time from a personal perspective which I hope helped make it readable.” This piece also explained that many trials test a new treatment against a standard treatment, not a placebo. For severely ill patients, worried that they may be merely given a ‘sugar pill’ if they enter a trial, such knowledge can have real psychological implications. “This is the sort of nugget we cancer patients need to hear – but it’s not one the consultant may remember to offer.”

Like many others, Cassandra Jardine craved such nuggets. She suspected from the start of the trial that she was on the control arm of the trial because she experienced no side-effects. She knew

that standard treatments stood as much chance of helping her as a sugar pill (given the advanced stage of her cancer), but she still wanted to complete the two-year trial: “Helping medical research feels good,” she wrote in her article.

Ten months later, in April last year, she wrote the last of her articles she submitted for the Best Cancer Reporter Award. Entitled “Worse? Now that’s what I call good news”, she presented the paradoxical situation that, as her health deteriorated, so she became eligible to try a promising targeted therapy called crizotinib. She described how, with other drugs failing to control her lung cancer, her oncologist tried to get her the drug on compassionate grounds, or as part of the trial.

“For seven months, he got nowhere,” she wrote. “The researchers wanted either a new outbreak of cancer or a minimum 20% increase in the existing sites. And then, in March, we got there. Never has bad news about cancer been more gratefully received.”

She described how, in a peculiar euphoria, she invited friends to her house for homemade sausage tortelloni while she took her first dose of a drug that she hoped might not just control but reverse the spread of her cancer. Her hopes had been raised by earlier conversations with the lead researcher into the therapy from Denver, Colorado.

And at the end of the piece, Cassan-

“This is the sort of nugget we cancer patients need to hear – but it’s not one the consultant may remember to offer”

dra Jardine described the very human responses to taking a new 'wonder drug' that clinicians rarely glimpse: the initial fear that it was having no effect; the tentative hopes that it was working once she started to experience sickness, the elation of the growing conviction that she was getting well and could consign the rest of her medications to the bin.

"I am on a drug that has a positive effect," she wrote. "It has taken a while to absorb this small miracle, but, four weeks on, I am more energetic, I can walk and work. I am back. It just took me a while to notice."

Cruelly, ironically, the words were published just six weeks before she died. In her submission to ESO's Best Cancer Reporter Award, which was one of the last things she wrote, she said: "I'm sure most doctors and scientists would agree that there is nothing like a human record of how treatment works out of the lab and in the human body. By opening myself up to become that living petri-dish-cum-diary, I hope I have contributed to research and development in oncology. I hope I have also brought comfort to others in my situation."

She received a Special Merit Award in the ESO Best Cancer Reporter Awards because she succeeded.

A tricky area

This is not to say that her pieces are impervious to criticism. Like all good journalists, Cassandra Jardine was shamelessly accessible, writing to be read. That brings its risks. The judging



The Daily Telegraph

panel was not unanimous in its praise for Jardine's articles. Were some of her articles likely to raise false hopes about some of the treatments she described? Did they give the impression that clinical trials offered 'miracle drugs'? Did they devote sufficient time and space to weighing the risks against the potentially small benefits provided by many experimental treatments?

These are common concerns with all popular health journalism, indeed in all

An ability to engage. This article – one of three Cassandra Jardine submitted to the Best Cancer Reporter Award – described what the opportunity to try out experimental therapies means to patients like her who are running out of options and out of time

types of journalism. As Alan Yentob, the controller of BBC1 said, "It's a tricky area, this idea of marrying issues with human interest, human stories, the stories of people's lives... if you do it properly and effectively it makes for good journalism."

The problem is especially acute in the case of personalised, professional health journalism. By making stories

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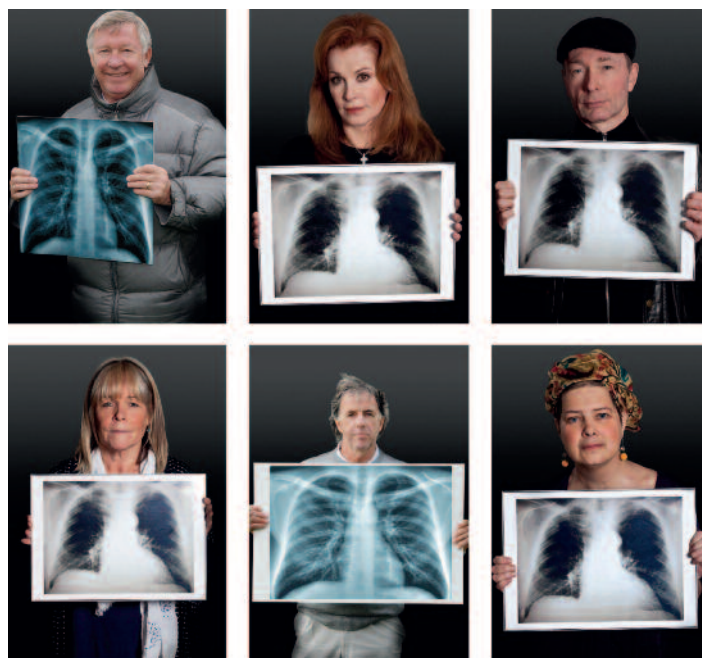
“I looked forward to reading her words telling us about her cancer in a very down to earth way”

about life-threatening conditions highly subjective, they can lack rational assessment of the benefits of approaches to populations, and fail to acknowledge the infinite variables of cancer pathology, physical make-up, personality type and environment that inform complex decision-making between patients and oncologists.

There’s another problem with journalists writing about their own cancer experiences: it can appear self-indulgently morbid. Brendan O’Neill, editor of the influential online magazine *Spiked*, recently described the glut of journalists writing about their illness as a “sick publishing phenomenon”. What turns writers “rational myopia” into something more macabre, he said, “is a public appetite for details of decay.”

But alongside these difficulties, comes the considerable benefit: impact. Well told stories of real people, involving real experiences, are read by millions. Cool, rational assessments of the benefits and risks of cancer treatments are not – in fact, they are rarely published in the mainstream media of many countries such as the UK, simply because editors judge that they will be ignored.

The net effect of the best mainstream, accessible health writers can be, in the end, far more positive than the worthiest of articles that remains unread. In the past, the effect of confessional



Spreading the message. Shortly before she died, Cassandra Jardine joined other well-known faces to front *Be Clear on Cancer*, a national campaign that aims to improve public awareness about the early signs of the disease

cancer writers may have been most strongly felt in breaking some of the taboos of discussing cancer in public. Today, their impact lies more often in providing a coherent patient perspective that makes other patients say “Yes, that’s what it’s like” and prompts clinicians to ask “Is that what it’s like?”

ESO recognised this complexity when it established the Best Cancer Reporter Award in 2006. It was launched to promote intelligent and critical coverage of cancer, recognising the media’s pivotal role in shaping public knowl-

edge and beliefs about cancer. But it has always acknowledged the challenges journalists face – how they must strive for readability while resisting the pressures to sensationalise and distort.

It is the best argued, best written, and most evidence-based journalism that wins the annual prize. But the award scheme also recognises impact, so this year Cassandra Jardine was specially commended by the BCRA judges for the tremendous effort she made to demystify lung cancer.

As Kathy Redmond, editor of *Cancer World* and

a member of the judging panel, said, “She demonstrated just how powerful it can be when journalists who are also patients use their skills to convey important messages to the public about issues that have a huge impact on cancer patients.”

Perhaps one of Cassandra Jardine’s regular readers in the *Daily Telegraph* put it best: “Having read and enjoyed her articles for years and followed her life coping with cancer, I have the most utter respect and praise for her... I felt that I learned so much from all she wrote. I looked forward to reading her words telling us about her cancer in a very down to earth way, making us aware of the importance of early signs. I know that as well as her beautiful family and countless friends, there will be many readers who will miss her.” ■

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