

## Reporting cancer from the inside

Catherine Kalamis of the *Guernsey Press* won a Best Reporter Award 2006 for a series of articles based on personal experiences of living with cancer. Below we reprint *A life-changing moment*, where she explains why good information is so vital to patients and she sends out a message about turning a threatening change into something positive.

**L**ast week, a chapter closed as I left the staff of the editorial family that is the *Guernsey Press*. But a new, exciting one starts. I was recently told about a man diagnosed with cancer who decided to ditch his old, safe life and instead live for the moment. He has since travelled the world and experienced many of the challenges he had previously only dreamed about.

I feel a bit like that. This is something that cancer does to you. It still has the power to change the way you feel about life, relationships, faith, self and the part that is frequently entwined in your essence as a person – work. While a growing number of cancer patients can still retain some health and actively live with their disease – which is happening more and more because of improvements in cancer treatments – so more people ‘with a diagnosis’ are deciding they want a change of direction in their life.

Until now my usual work has been my ther-

apy, giving me grounding during an emotionally rough time. Holding on to that has been important to steady myself in the new world of uncertain futures. It’s important for employers to be understanding during this phase and, fortunately, mine has been. But now the time has come to

make a change, to break free from the safe, or the ‘same old, same old’. So I am now fulfilling a goal to achieve something meaningful for cancer patients.

Three of us are launching a brand new patient foundation for people diagnosed with neuroendocrine tumour [NET], the little known and relatively rare form of cancer I was diagnosed with last year. It sounds a simple idea but

already it’s proving quite a mammoth task, with 48 pages of admin to plough through, a business plan to prepare and a legally binding governing document to write before we can apply for registration with the UK Charity Commission. And that’s before the really demanding work begins. But why, when there are hundreds of other



Good news. As a patient, Catherine Kalamis has used her own cancer diagnosis as an opportunity to refocus her life. As a journalist, she has used her pages in the *Guernsey Press* to tell her readers about the experiences of patients and their families, and to send out a message of hope: there is life after a cancer diagnosis – and it can be pretty good

HEALTH

## A life-changing moment

There is no doubt that a cancer diagnosis changes lives. But sometimes it can be positive and life-enhancing and takes you in a totally new direction.

By Cathy Kalamis reports

**L**ife is a journey, and sometimes it is a journey that leads to a new destination. For me, that destination was a new met of work, following the lead of many others who have been diagnosed with a shattering illness and yet found a way to move forward positively.

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**THE CANCER CLUB**

cancer charities? There is a simple answer. My experience showed me that there is currently very little information 'out there' about NETs.

I found a lack of general, lay information when I was eventually diagnosed with a NET in February 2004, three months after first falling ill. There is some to be found on specialised medical websites, or those created by drug companies. There is a bit more info about a specific type of NET called carcinoid tumours, which are the most common of the group – there is even a New York based group called the Carcinoid Fighters – but there is no centralised information about neuroendocrine tumours as a whole.

I have discovered in the past year that although this type of cancer can affect children, there are no paediatric specialists in the country and no specific information for parents. And there are only 12 consultants in the UK who have an interest in the disease, but they also do a lot of other work. My experience is not unique. I have since met many others who were presented with a shattering diagnosis but found it

hard to access solid, meaningful information, especially at a time of great distress and anguish.

Then there were family and friends. None of mine had ever heard of neuroendocrine tumours and all of them expected me to have the 'traditional' treatments of chemotherapy and radiotherapy because they heard the word 'cancer'. They still ask me about my treatment when, at present, I am not having any. I had to find out bit by bit and use my own words to explain that these tumours are, generally, slow-growing cancers even when they have metastasised to other sites in the body, which is what has happened in my case.

And chemo and radiotherapy, although useful for some patients with aggressive disease, might not always be the first-line course of treatment immediately after diagnosis. There are, however, other treatments and it's a judgment as to when they are brought into play. None of this is very easy to explain to someone who just asks about your welfare. Every clinic I have attended has been oversubscribed and it is common in

## One of the real issues affecting NET

### patients is a feeling of isolation

the UK that the doctors don't have much time to go through everything, or repeat it until it is fully understood.

NETs can become more aggressive, so patients need continual monitoring with scans, blood and urine tests to watch for the signs. Another peculiarity is that tumours can express high levels of hormones, but it's not always that straightforward, and some types don't. Although around 2,000 new cases are diagnosed each year in the whole of the British Isles, it is thought there are many people who have a NET but don't yet know it. I could have had mine for a decade or so already. If only there was some way of detecting them more quickly, then patients could have surgical intervention and perhaps even a cure. But the vast majority of patients who seek specialist referrals have metastatic and often inoperable, and therefore incurable, disease.

Speaking to other patients waiting in the NHS [National Health Service] clinic in London, I learned that it had often taken them years before getting a proper diagnosis. The common story was that GPs [general practitioners] or even specialists had dismissed their vague symptoms as irritable bowel syndrome or, in one alarming case, as being 'all in the head'. So the more I discovered about my disease the more the gaps in information, awareness, and understanding became acutely obvious.

A dynamic specialist NET nurse has had the same thoughts for years. She had been dreaming of providing more information for patients, but she was simply too busy, with some 550 people on her books. Then I met another patient, who coincidentally had just given up his job in medical PR at a time when I was considering taking my own 'gap year' to regroup and rethink. The three of us spoke many times on the phone and we even had a two-day meeting here in Guernsey.

In September [2005] I took the bull by the horns and approached a world-ranking sportsman – the snooker player Paul Hunter – who had publicly revealed he was suffering from the same disease. At the RAC club in Pall Mall, London, we all met and talked. He has since offered us several thousand pounds from his charitable resources to start what by now we had named the NET Patient Foundation. From there we have not only had his offer of help to publicise NETs, but also the first public fundraising event (when he switched on the Batley Christmas lights and a street collection was held for the foundation), and there is the possibility of a celebrity ball in September, the organisation of which may be filmed for TV with all proceeds coming to the foundation.

We shall see how this translates, but it looks and sounds promising. Suddenly the words and ideas have turned into something real. And now the hard work begins. From a starting position of nothing, we have enough for phase one of the foundation's plans, to obtain charity registration in the UK, approach and appoint trustees and a high-profile patron and begin to put together accurate, impartial and, hopefully, empowering information.

The NET Patient Foundation aims to have a new magazine for sufferers and their families that will not only explain the disease, but offer many practical ways to live positively with it. We want to build a state-of-the-art website and launch a moderated patient forum where patients from across the country – later Europe, we hope and who knows, globally – can talk to each other. One of the real issues affecting NET patients is a feeling of isolation. Unlike breast cancer patients, you probably won't find a large number in your town or village – here in Guernsey there may have been three or four in the past few years. But you could be talking about a larger regional number, and so the

foundation aims to organise a national road show, setting up regional patient support groups with the support of the specialist consultants who, we hope, will back us.

And then there are future campaigns that need to be organised – to raise awareness in the general population about the disease as well as front-line health professionals. And to support patients who find they are subject to the ‘post-code lottery’ for drugs prescribed to control hormonal surges that some tumours can produce. In some areas of the UK, health trusts refuse to pay for these injections even though they immeasurably improve the quality of life for some people.

This has all come about because of my own diagnosis of a life-threatening illness for which there is no current cure. It brings matters sharply into focus. It has become clear that living ‘in the now’, for the minute and the moment, is what should be important, and following your dreams and ideas, however large or small, should always be a possibility. I am not going to totally give up writing for the *Guernsey Press* – writing for newspapers has been my life for 30 years and it’s a hard drug to give up – but I will have more flexibility and it may not be quite so often.

But I shall be moving to a new sort of work, following the lead of many others who have been diagnosed with a shattering illness and yet found a way to move forward positively. Lance Armstrong and Jane Tomlinson\* are two such examples although I would never hope to aspire to what they have achieved. My goals are more modest. Armstrong, the Tour de France champion who has overcome a terrible cancer prognosis, has become a champion for cancer ‘survivors’ and is devoting himself to spreading the word about living well with a diagnosis. Briton Tomlinson, who has terminal breast cancer, has raised a million for charity and taken on the most gruelling sporting challenges. I am not quite in their league, but they show that things can be done even when you have disease.

However, I do want to use my experience to

hopefully help create something positive for other cancer patients. It’s a bit like the people caught up in the Boxing Day 2004 tsunami.

They also want to ‘do their bit’ and are highly motivated, perhaps because it is a way of coping, of dealing with what has happened: all that sadness, death and destruction.

Similar things happen to many of us in the cancer club who can still function, it seems. With cancer there always seems to be someone in a worse position than you but who is coping magnificently and bravely in the face of real adversity. Behind it all is a motivation to improve things for others who come along behind, because of our own, perhaps rather poor, experience.

Look at the Pink Ladies [a Guernsey breast cancer support group] and the work they have achieved locally. Jo Allen is one of the five founding members. She said: “The group has grown bigger than anyone could have expected and now has over 90 members. I was privileged to be actively involved in running this support group from its inception until May this year. I cannot express how important this support is to so many women: we’re not just talking about emotional support and the benefit of others’ experiences, but also the financial help we provide with complementary therapies and so many other helpful items.”

She has found her involvement extremely beneficial. “Why did I get involved? Well because it gave me a great sense of satisfaction knowing that what the Pink Ladies did made a real difference and that the road could be somehow easier for those who were diagnosed after me. I’m also at my happiest when I’m helping others and the Pink Ladies gives the ultimate opportunity to do that.” Until you have been through something like this, you cannot understand what it is like. “A diagnosis of any form of cancer really does give you the opportunity to re-evaluate your life and to live for now and that’s what this wonderful group of women do, whilst encouraging others in the process.” I think that says it all.

\* Jane Tomlinson tells her own story in *What's brave about having cancer?* p 60  
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