



## BREAST CANCER

### A look at the effects of Breast Cancer from the viewpoint of a carer

#### One Carer's Journey

I've tried numerous times to start this, wanting to keep it positive, which is not easy when faced with the current situation. Just over eighteen months ago my wife was diagnosed with breast cancer. A niece had already died from the disease, so the fear and distress it can cause weren't new to us. Despite being aware that these things don't just happen to someone else, the news still came as a shock. It seemed to me that we were about to enter a strange place of which we had little knowledge and no experience. Judging by the look on Ruth's face at the time, we were already there and someone had locked the door behind us.

Like so many others, I wished for the illness to pass over to me. I loved my wife more than I did myself and I felt sure that I was better equipped to shoulder the burden. After all, being a man, I was supposed to be a member of the "stronger" sex. Had I known then what I do now, I would have been satisfied to accept my lot as carer, for it would prove far more difficult and stressful than I could have imagined. In order to remain positive, I needed something to cling to and tried to regard it as another challenge, albeit the most important I had ever taken up. As Ruth's best friend and champion, I was determined not to let her down.

Those first days were eye-opening. We were both suffering from our respective levels of shock. Ruth was stunned and bewildered, while I felt as if we were free-falling, close enough for our fingers to touch, but no more than that. The forces which surrounded and controlled us were too powerful to permit any meaningful contact. There was something else too: a growing concern that everything we treasured, the point in our lives that we had reached, especially our confidence in a bright future, all had become suddenly redundant. Even personality and attitude needed re-shaping in order to cope. Being soul-mates, we had prided ourselves on being invincible as long as we were together, able to handle anything life threw at us. If ever there was a true test of faith, we were about to face it.

As soon as Ruth was diagnosed, she was on the system and someone pushed a button. Offers of help and support began to roll in. I am eternally grateful now because, in hindsight, "The Journey", as it is often called, would have been almost impossible to bear without the amazing level of kindness and understanding shown. At the time, however, it was overwhelming, suffocating. Ruth had always been strong, a consummate individualist who would ordinarily have welcomed the confusion and tackled it with confidence. Not so any more. I had to watch as she withdrew behind a veil of fear and uncertainty. My natural instinct was to go on the offensive, but I too was frightened, and not just for my wife and what she was going through. I was sure any show of anger or bitterness on my part would upset her even further. In effect, I was afraid of being myself.

They call it a life-changing experience, and truer words were never spoken. Roles reversed, I accepted the fact that I would have to be chauffeur, plus chief cook and bottle-washer, and be there for moral support whenever needed; but I never realised how much Ruth did that I had always taken for granted and that would now become my responsibility. I was to find out that filling in forms was a National pastime, that government departments operate on the "box" principle which people like us don't fit into, and that compassion and consideration take second place to practicalities. As for insensibility, officialdom wears it with pride. In short, if a person happens to get seriously ill, the onus is on them to prove it beyond a shadow of doubt, then wait

to see if anyone believes!

Perhaps I'm being over-critical, but it was the way I felt at the onset. When we had been enjoying life so fully, to be suddenly confronted by a possible death-sentence was a shock to the system that bred self-pity and paranoia. Angry that no-one seemed to understand my wife's plight, or mine, except in a matter-of-fact kind of way, I had to bite my tongue a lot in those early days. In retrospect, I believe it made me a better person, able to be more tolerant of others, one certainly less inclined towards knee-jerk reactions.

I'm not sure if Ruth took it as personally. Having to cope with the side-effects of chemotherapy was enough in itself and no mean task. Maybe it helped with her focus, taking each day as it came, concerned only with her current discomfort and what to do about it, rather than worrying over what came next. And because that particular kind of treatment made her susceptible to infection, we shut ourselves away from society. With the exception of medical appointments, we saw very little of other people, relatives included, thus shielding Ruth from secondary illness and the embarrassing attention of the curious mind. That was to come later.

Once the radiotherapy started, the worst, it seemed, was over. The treatment was less painful with fewer side-effects. Appointments, though, were more frequent. Every day, five days a week for six weeks, we drove to the clinic. We joked about it initially. Ruth claimed it took longer to undress, then put her clothes back on than the few minutes the actual treatment lasted, never mind the hours sitting in traffic. Sometimes, I talked with other patients while I waited for Ruth, often with their carers. I believe it was there in the oncology waiting room that I realised "The Journey" had barely begun.

I heard stories of couples who had been diagnosed with cancer within months of each other; admissions that "it" was a genetic thing which kept popping up in the family; some patients were on their second, or third round of treatment because the disease kept recurring; and there wasn't just one type – apart from breast cancer, sufferers had prostate, lung, throat, skin, and so on. All this new information could have been so distressing, had it not been for the honesty and courage with which those people casually viewed past, present and future. They were under no illusions about their prospects, yet were more than prepared to be as happy as their illness would permit.

Determined that I would not disgrace this new "club" I had been impressed into, I saw no reason why, once the cancer had been banished, we couldn't go back to a normal life. Months later, I realise the naivety of that hope. It isn't the fact that there are no guarantees of the cancer returning, nor Ruth's reluctance to plan too far ahead, not even the lingering physical and mental side-effects of the treatment. These are the kind of issues we are used to dealing with. It is the complacency of society in general which is hard to take.

Cancer is not a cut that can be stitched, healed and forgotten. Over time, the scars may be less-obvious, even unnoticeable in some cases, but they remain nevertheless. Unfortunately, because Ruth now looks well and seemingly able to function normally, those who haven't known her, or what she's been through, expect far more than she is capable of. Assumptions made in this regard are deeply hurtful to the patient and frustrating for carers. I ask myself: why are people so lacking in compassion? Why can't they understand that appearances deceive and the person before them is merely putting on a brave face because it's the only way they can cope? How can they be considerate one minute when sufferers are undergoing treatment and wearing a bandanna, but so apathetic and unforgiving a few months later when the hair has grown back and they look the same as everyone else?

I believe I know why – they have only glimpsed cancer in passing; it hasn't attacked them personally, or changed their lives as it has ours. I would ask those whom it hasn't yet touched to be sympathetic and considerate towards cancer sufferers, their carers and their families. The pressure on this ever-growing section of the community to "get back into the swing" is enormous and continuous. Attempting to comply places extra strain on relationships, jobs, daily routine and financial stability, all of which have been sorely tested and may even be at breaking point. Support groups and associations provide invaluable help during and after treatment, but without the understanding of ordinary people, the eventual return to normality will be difficult for most, impossible for some.

The post-cancer syndrome is particularly hard to appreciate unless it is experienced first hand. And even then there can be misunderstandings. I was lucky in that I was able to retire early to look after my wife full-time. Now the medical part is over, Ruth has taken back many of her former chores and we are beginning to enjoy life once again. It must be remembered, however, that we were already planning our retirement from the work-force. It just happened a little sooner than we'd hoped. But I know it isn't the same for everyone. Younger sufferers, especially those with families, will find it harder to recover than us.

Jobs have been put on hold, changes have been made to find the extra time for medical appointments, social commitments have had to be deferred or cancelled. No matter that the increased burden was anticipated and hopefully allowed for, the stress of meeting the challenge must inevitably take its toll. Employers and workmates will be growing tired of making sacrifices to accommodate the unlucky victim and their carer, both of whom have had to take time off. Children are starting to resent having to miss out on attention and being themselves when, in their eyes, everything is back to the way it was before Mum got cancer. Even the dedicated carer's ability to cope is wearing thin.

Families going through this level of crisis desperately need the help and understanding of everyone around them. From associates at work, to friends, extended family and especially institutions and government departments which may have an on-going interest in the affairs of those affected by cancer, all need to be more sympathetic than might be deemed reasonable. Victims want to return to the way they were before. They will probably claim to be ready and perfectly able to take up where they left off. But it isn't that simple and will be much longer than even they themselves believe before they can cope as well as they did before cancer changed their lives.

Let's remember that they never asked for the illness in the first place, and that they are unlikely to beg for consideration from others because of what it has done and is doing to them. So, it is up to all of us who can spare a thought, not to judge, not to pressure, just to continue our support of these courageous people who have as much right to happiness as anyone else.

Please consider – it could easily happen to you, or someone you care about.

**Focus F23: Book Review of “Take My Hand” by Jo Wiles – the inspiring stories of 14 McGrath Breast Care Nurses.**

For information and support assistance:

<b>Australia</b>	<b>Cancer Council Australia</b>	<a href="http://www.cancer.org.au">www.cancer.org.au</a>
<b>UK</b>	<b>Cancer Research UK</b>	<a href="http://cancerhelp.cancerresearchuk.org">cancerhelp.cancerresearchuk.org</a>
<b>USA</b>	<b>American Cancer Society</b>	<a href="http://www.cancer.org/">www.cancer.org/</a>

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