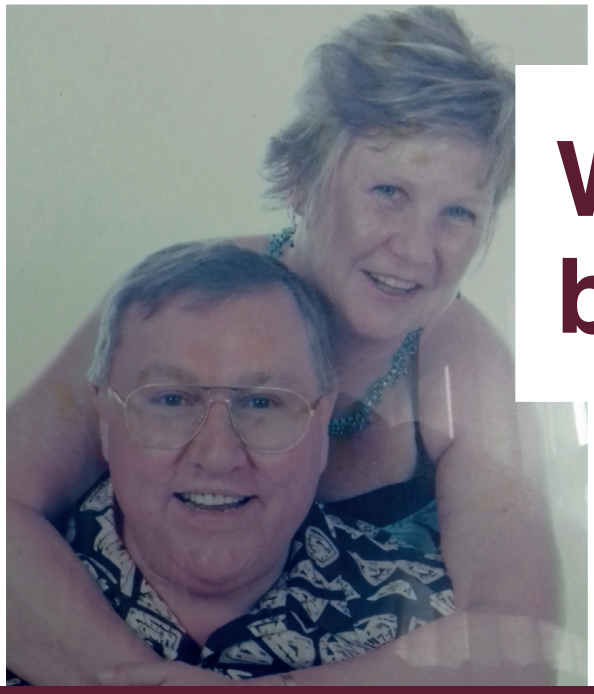

When does a carer become a carer?

Derek gives an in-depth account of his carer's journey, asking important questions along the way.

I'm fine... The Swallows
Frustated • Isolated • Neglected • Emotional
Shaping the future for carers

It is not my intention to talk to you about the 'ROLE' of the carer but instead I thought I would share my journey and experiences with you and allow you all to decide for yourselves what (if any) help or assistance we should be considering and more importantly delivering to carers during this extremely stressful and emotional time whilst they support the patient through their cancer treatment.

I'll start by posing 2 of the many questions that have been uppermost in my mind since I became directly involved with Head & Neck cancer as a carer:

1. When does a family member of a cancer patient become a carer?
2. What triggers a change of mind set from gently supporting the patient, accepting the situation as it is, to one of direct action?

I guess the answers to those questions are different for all of us as we embark on our individual journey down the cancer treatment highway.

So, here is my story, told briefly and entirely from my perspective (as the carer) and recognising that mine and Jane's personality may be completely different to yours, thereby, possibly causing you to opt for alternative solutions in similar circumstances. Both mine and Jane's personal strengths and weaknesses had a huge influence in the choices we made and the manner in which we went about achieving our aims. I make no claim whatsoever that my decisions and actions to the circumstances I faced are right or wrong, they are just the choices I made at a time, when emotions and stress levels were inevitably at an all time high.

I cannot, in any way, be described as a 'natural carer', I have to work really hard at the softly, softly approach, I am much more comfortable in an all out action, sort of 'Geronimo' style. Fortunately, I am reasonably well domesticated, so running the home, shopping, cooking, etc, was not going to be a problem. All these things, along with driving my wife to and from appointments just replaced all of my social activities.

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So . . . My answer to the two questions I posed at the start of this story?

> **"Well, it is, I believe simply, at the moment the diagnosis is confirmed!"**

Until that time arrives, you desperately hope that it will not be cancer and I spent most of my time talking to Jane, gently of positive outcomes and minimal life impact, whilst inwardly and silently planning for the worst possible result and the potential necessary actions.

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So, here is the first problem we carers have to balance:

> **Displaying a cool, calm, supportive exterior to our patient whilst dealing with a volcano of emotions internally which are constantly spewing out a lava of nightmare scenarios, not least of which may be the loss of our spouse/partner/ parent/child or friend.**

From the moment of confirmation (in Jane's case, it was mouth cancer) I took control of our daily lives.

I managed our diary (there were going to be lots of appointments) and I would be along side her at all of them. I also took on board a lot of household chores which had previously been abdicated to my wife.

However, I was also trying to keep her active and stop her from negatively dwelling on her own situation, so it was important (in my view) to keep her involved in as much 'normality' as possible, for as long as possible.

And of course I became her cancer related emotional comfort blanket, taking on board and dealing with the worst of her fears and concerns, whilst suppressing my own, certainly in her presence.

Problem number 2 now rears its ugly head - **who do I turn to with my worries and concerns?** I can't help feeling that my issues are insignificant compared to hers, and of course (rightly so) all the medical contacts are focused on the patient and their needs. An occasional 'and how are you coping?' thrown in the direction of the carer, usually in the company of the patient can only illicit a standard carer response of, **"I am ok thank you,"** when what you really want to share is the emotional turmoil you have found yourself thrown into by this terrible diagnosis.

You also find that your loved one is not always being straight-forward when asked questions by medical staff, that they are minimising what you (as the carer) see at home in a mistaken effort to not add unnecessarily to the burden of the overworked medical staff and that you feel you cannot speak freely in front of the patient from fear of increasing their already heightened emotional and stress levels. The carer needs some 'alone time' with the medical staff to discuss these issues, and the medical staff need to recognise that they are not treating just one patient with cancer but two or possibly more!

When planned treatment is cancelled there is an inevitable feeling of, at best disappointment and at worst despair. I found myself in a scenario of 3 cancelled surgeries (2 on the day of surgery after being fully prepped) and as time went by (we lost over 5 weeks from the first planned surgery) the tumour continued to grow - visibly, on the inside of my Jane's face. I felt I had to take some positive action. I could no longer accept waiting at home for a telephone call, that seemed to never come, offering us that new date for surgery.

I was being drained of my energy reserves, by constantly having to reassure my wife 'that it will be soon,' when I truly believed we had been abandoned. I had no one to share these thoughts, worries and concerns with, so I developed the ability to compartmentalise these negative issues and only share the positive one with Jane. All of my negative feelings were channelled into an action plan primarily directed towards the system that seemed ok with our plight.

> **Our lives were on 'hold' and time was fast running out for us!**

Make no mistake, I was angry, I felt crushed by the lack of interest from the hospital in Jane's worsening condition. I had exhausted all the normal channels of action and my anger and frustration was at boiling point. I needed to vent. I made the decision to contact the press and arranged an interview in regard to this intolerable and unacceptable situation and 2 days later, our story was front-page news.

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It took the hospital less than 24 hours after publication to arrange an appointment for my wife to be re-assessed by a different surgeon who did indeed recognise the need for urgent action and a date was confirmed with both the surgeon and senior administrative staff for early January 2019. During this meeting, I worked very hard on my self-control as I knew these people held our future lives in their hands. I wanted to rant and rage at them but it would not have achieved our goal.

I was massively relieved with the result of that meeting and Jane, who had been slowly sinking into despair, visibly and mentally responded positively to the news, although I still could not shake off that feeling that too much time had been lost and all our plans and hopes for the future were in jeopardy. Despite a positive result, I was left with nowhere to target and discharge my anger and frustration and so I once again compartmentalised it and took it home with me!

Our journey from then on followed a path that I am sure many of you will be familiar with, daily and sometimes twice daily 30 mile round trips to the hospital (Jane was an in patient for 29 days) and planning for the radio therapy treatment which would follow discharge after giving her time to recover from the massively invasive surgery she had already undergone.

Before radiotherapy could commence, we had to deal with infection issues which required further hospitalisation for 4 days and a poorly fitted peg feed which did not function correctly and had to be changed. Throughout this time I spoke only of a positive outcome and how we would look back on this time as one of life's great hurdles which we had successfully cleared.

All of this activity, whether, good or bad, helped keep me focused and stopped me from falling into a black hole of despair although my emotional compartments were fast filling up and it would soon be time to empty the trash.My nagging fears that this had all taken too long, I pushed into one of my compartments, labeled, over sensitive issues, to be deleted at a later date.

30 sessions of radiotherapy were planned, confirmed in the diary and an appointment made to 'fit' the face mask for which a scan was required.

> **"It was this scan result that shattered my entire world; a second tumour had developed very close to the location of the original tumour and as a result was diagnosed as both inoperable and terminal."**

I heard all the words being spoken but was having a massive problem assimilating them. I needed to ask all sort of questions, I needed more information, I needed to know why this had happened, I needed to deal with this but not right now, the shock was too much and certainly not with Jane sitting next to me.

I needed a future opportunity to discuss with the doctors how we had arrived at this point and where we went from here but instead we were almost in haste shuffled out of the room and told to go home and await contact from the District nurses. I was too stunned to resist, all the fight had drained out of me, I felt like I was ethereal, watching myself in theatre production from a distance, not comprehending but somehow understanding that this production was about to lower the curtain for the last time.

> Quite how I managed to keep the car on the road during that journey home, I do not know but by the time we made it home, I had a new anger building inside me and one that would keep me focused until the day I held Jane's hand in the hospice and she suddenly, but gently retired from life and I hope started a brand new adventure.

I am still dealing with my own issues resulting from Jane's diagnosis and passing, but I find the Swallows monthly meetings a great comfort, not from any morbid sense but from the hope that by giving another carer the opportunity to open up, share some of their deeper thoughts and frustrations, which under normal circumstances they may feel unable to speak out aloud, together, we might make a small but positive difference to the quality of both our lives.

Derek

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