

July 2011

An invitation to 'tell your story' on the Pelican website - www.pelicancancer.org

The Pelican Cancer Foundation is currently developing its website, aiming to empower and support patients by providing a forum for patients' own accounts of their experience with pelvic and liver cancers.

These stories from a patient's perspective will form part of a range of patient resources, where patients or their family members can read more about these cancers and treatment.

We would welcome your contribution to this patient-oriented resource, if you would like to 'tell your story'. An example of one patient's story (submitted for our 'bowel cancer' patient resource section) is attached just for your information. There is no set format, and it can be as long or as short as you wish. It would be useful if you could include a brief summary of your diagnosis, the treatment you received, with what results.

Some things you may wish to consider:

- Is there anything you wish you'd known, or known sooner, when you were first diagnosed?
- What questions do you wish you'd asked before or during your treatment? What aspects of your diagnosis or treatment were surprising?
- What is the single most important thing you wish to convey to anyone newly diagnosed?
- Your observations or lessons learned through your experience.

Ideally, we would like to feature an accompanying photograph with each story, OR you can make an anonymous contribution if preferred - please just let us know if you would rather not be named/pictured in the text. If you are providing a photo, please send a close-up, 'head-and-shoulders' image of yourself if possible- thank you.

Please note that all submissions will be reviewed and a version for your final approval will be sent to you before being posted online. You can withdraw your 'story' from the Pelican website at any time.

If you would like to submit your 'story', please complete the details below, and send your account either by post to: FREEPOST RSHX-YYKY-UKBK, Pelican Cancer Foundation, The Ark, Dinwoodie Drive, Basingstoke, RG24 9NN

Or by e-mail to: admin@pelicancancer.org

Many thanks!

Pelican Cancer Foundation is all about saving and improving cancer patients' lives. We are dedicated to curing bowel, liver, bladder and prostate cancers by advancing precision surgery. Pelican achieves this by sharing life-saving and life-enhancing knowledge and skills with surgeons and cancer teams. We develop and run training courses on the latest procedures and best practice. Pelican also leads vital clinical research aimed at extending and improving patients' lives today.

Registered charity number 1019311



Name:

Address:

Telephone number:

E-mail:

Please note I wish / do not wish to remain anonymous. (please delete as appropriate).

My story:

An example of a patient story – for information only

Cheryll's story – rectal cancer

As a patient from the vintage year of 2003, I am living testimony to the vital work Prof Heald continues to pioneer around the world.

I was diagnosed with rectal cancer in February 2003, after a routine examination for IBS. I was then referred to a consultant, who opened the conversation with 'How much do you know about this cancer?' - to which I replied, 'Not a lot actually'. He said, 'Well it ain't good news', and proceeded to tell me that muscles would probably be damaged, which would mean a permanent colostomy bag, and he then moved to fatality percentages. I could not take it all in but managed to stay composed until I reached my car and then – flood gates! I telephoned his secretary and asked if he could call me that evening, as I had not understood all that he had told me. He rang back and I asked one question: 'Are you telling me that I need to put my house in order?' to which he simply replied, 'Yes – I think I am'.

I thank goodness for this man's honesty, as he knew that his knowledge and general surgery were not going to be enough, on this occasion. I duly followed the trajectory of waiting for the appointment at Guys Hospital in London for the 'unavoidable' chemo and radiation. I still bear the tattoos from this - but I never started the treatment, as I was about to be re-routed!

My journey to recovery actually began with some literature sent to me by a girlfriend regarding alternative treatments for cancer. From this, I telephoned a doctor in Tunbridge Wells to find out more about oxygenation treatment, but he said to me, 'Don't come and see me - make a telephone call to Basingstoke Hospital. I do not know exactly who you need to speak with, but I do know you will have a 40% better chance of survival'. I made the call the next morning very nervously. The Welsh girl on the other end listened patiently whilst I relayed my story. I asked 'Do you know with whom I need to speak?' to which she replied, 'Oh yes – it is Professor Heald. Would you like me to make an appointment for you?' She then told me that she was the Colorectal Macmillan Nurse.

I asked my surgeon's permission to transfer to Basingstoke, and if he would release my scans and medical papers from Guys. He was more than delighted and we gathered all of this and I presented for my appointment with Prof Heald.

My prognosis in the main stream was not good, and I still remember Prof Heald's words to me, 'Well, the bad news is, you have cancer. But the good news is, I will perform a curative operation, with hopefully no chemo or radiation. I will just need another scan to confirm and then we will book you in for the operation. You may have just a temporary 'bag' whilst you heal.' I believed every word - and from that moment on I had absolutely no doubt that I had been given a prescription – it simply read 'Life'.

I then had to 'take on' the NHS for funding. This delayed the operation for a few months, whilst I waited for the wheels of bureaucracy to turn! My GP was fighting my case for the funding to be transferred but one day, I rang and asked them to give me the telephone number and I would pursue. The guy that picked up the telephone listened and then quietly said to me, 'Ms Woods, I cannot understand why you wish to go to Basingstoke, when you can have the treatment locally'. I took a deep breath and explained, 'If I stay in the main stream, I am to have chemo and radiation, which will surely destroy good organs/tissue, and then an operation that will leave me incontinent. If I transfer to Basingstoke, I am to have an operation with no chemo or radiation and no colostomy. Now, tell me – which would you choose?' He replied 'You have the funding'. I cried...

Professor Heald operated in November 2003 and kept every promise he made to me. He attended my operation and even found the time to visit me after in the ward. It was three days later when Nikki, the wonderful Macmillan nurse, came to see me and asked if I had looked at the 'bag', which I dreaded the most. I asked her to look first and when she announced 'No bag', I was elated! Not even a temporary bag was quite an achievement and so aided my recovery. I was back in my home town of Bexleyheath within five days, mentally ready for the journey of recovery. An angel guided me to Prof Heald, and I pray for this same angel to watch over this wonderful humble man.

I remember, when I was diagnosed, thinking, 'Oh my goodness, how am I going to tell people that I have rectal cancer?' I felt 'dirty', but I soon realised that it was my absolute duty to shout from the roof tops: 'I had rectal cancer and I know a man that has the knowledge to change lives!'

Prof Heald is pioneering surgical techniques that will save lives, and every bit as important as this progress toward a cure is that this news must be carried around the world, so that every person has a chance for life.



Written by Mrs C W, March 2011