

For my "NET" friends - a story with pictures

My name is Carole Shaw, but many of you know me as Carole Wickets, sorry - and there is a reason for this:

The forum we had, back in 2012, when I was first diagnosed, was on the old NPF website, I used my real name, and I made many friendships.

Sadly, at around this time, my personal facebook account had been very badly scammed: the host I used for my own website for our Ryeland sheep, sold it on to criminals.



The forum on the old NET Patient Foundation website was also targeted, by a Russian heavy metal rock band !!

...and so, the charity created the members only facebook groups, as a more secure platform for us, and become what they are today. . . Neuroendocrine Cancer UK Support Group (is one).

We are so very lucky to have these closed/private groups and our NCUK team, . . .



I didn't join the new facebook sites for ages, . . . because of the association with my own name being scammed. . . Then I saw a way around this, so, now I am Carole Wickets!

I was soon remembered and recognised by some of you, I think because of my interest in taking photos of the sky, and the world around us . . . I remember being asked, have you re-married!

I went to a few of the original "Natter" meetings run by Cathy Bouvier (NCUK Co-founder & CEO) and another lady from the charity, they were well attended.



Then the Natters were started here in Staffordshire, by Kevin and his wife, initially at the library in Hanley, Stoke on Trent, (now in Barlaston) again well attended, we made many more friends.

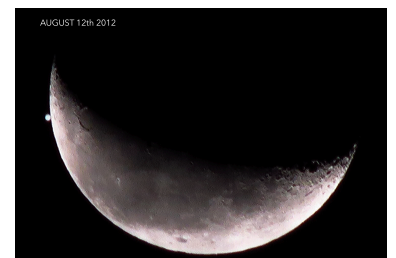
I went to every meeting with my husband, he was always by my side.

My journey . . .

I was fast tracked to The Royal Stoke Hospital, back in August 2012, after feeling, 'just awful'.

They x-rayed me, and told me that I had pancreatic cancer, which had spread out of my pancreas,

... only a few months to live. . .



It was after this news, they asked me to go for a biopsy: *they put you to sleep for this, as they have to go through your tummy, to get to the pancreas.*

The nurse said I needed to stay for a couple of hours before we went home, in case I had some bleeding. . . When she came back, she said the surgeon wanted to see me, after he finished his appointments . . .



He came, and said 'it is inconclusive'!

I remember saying to him, I could eat a pork chop!

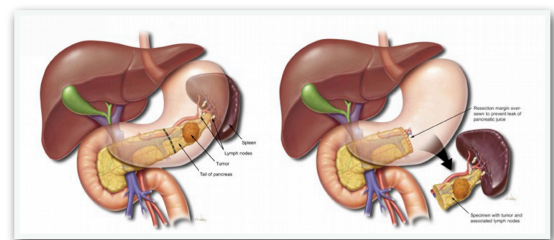
. . . why I said this, I will never know!!

. . . but he replied that he would not recommend this.

I returned the following week to see my consultant/surgeon and he was smiling as we entered the room. He said "we can operate' - it's pancreatic neuroendocrine cancer, and we wish to perform a distal pancreatectomy: we can give you five years/ten years, possibly even fifteen"

My reply was, " I will be happy with five!" [you don't forget these conversations!]

I was quickly booked in, and they debulked the cancer, removing the body and tail of my pancreas, my spleen, and part of my tummy.

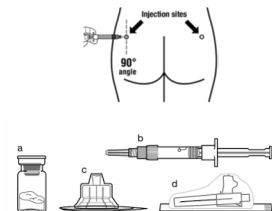


After surgery, I was treated, with monthly Sandostatin injections, at The Royal Stoke until 2015, when the lovely Dr xx referred me to the Prof at the Christie. My first appointment was 14th August, 2015, when I was entered into a trial for the gallium 68 pet scan, I was looked after by one of the trial team nurses.

I have been on the monthly Sandostatin since 2012



Select play to watch this short video about the types of scans you may encounter.



I had my next gallium 68 pet scan on 8th October, 2021.

In January 2022, Prof. telephoned me, he wished to try me without the monthly injections, as comparing the two pet scans showed no sign of growth.

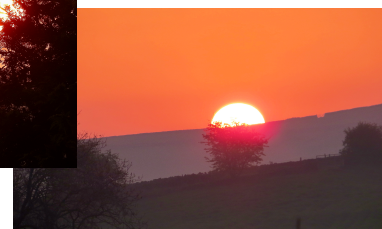
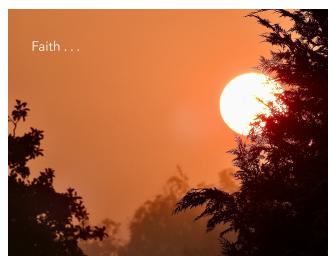
I think the company would have been extremely pleased with my results, after having these injections for so long!

I carried on having six monthly CT scans, and bloods at the Christie: I had my most recent CT scan on 22nd June, 2023.

After this, I had a telephone appointment with one of the Oncologists, it was "good news", there was no sign of any growth!

Yes!

I have a strong faith, and do believe in miracles . . .



but then he said he wanted to discharge me, ...

I felt scared, lots of emotions that I have never encountered before...

He added, "if you have any further problem, you can go to your GP."

... after all this time - more than 10 years ... it was good news ... wasn't it?

... and yet, I felt lost and lonely ... **"What do I do now?"**

I am still me ...

I have lived with this cancer, day and night, for the past eleven years, being given a death sentence in the beginning, and then, every single day has centred around my NETS, so, yes, what do I do now?

I am scared,

... I am still feeling I have a PNET, I lost parts of my body, I will always take four penicillin each day, I will still have to take enzymes with everything I eat, I will still need to use the loo urgently, ... I still have NET,

...but, thankfully, and most important of all ...to me, ... I will still be part of a huge family, the wonderful friendships I have formed over the last eleven years, will never change, I will always have the charity, now NCUK, and I know they will never let me down, ...



Monday mornings are very special to me, just knowing I have so many friends all over the world, just to say, hi, at the beginning of the week, all made possible because we have 'our forums'. our cancer may be rare, but it has become a family, now with whom we can share our problems, seek advice, support each other and share our journey through this cancer.

But what do I do? ... what did I do? ...

I got in touch with Nikie, at NCUK, who completely understood how I felt, and suggested I contacted the nursing team at the Christie, and discuss how I felt, ... Christina understood too ...

... my own oncologist was away, but they said they would get back to me ... ,

and they did, ... with a date for my scan, next July, an appointment for my telephone consultation two weeks after. I was asked to get my bloods done at my GP surgery two weeks before the scan, ...

... wow, I belong, ... I'm not forgotten - abandoned, ... and I know I am not alone ...

I have written this because I hope that it gives you hope too, ... I take huge comfort from this community, and NCUK .. and hope we will always have our (NCUK) team, whatever the problem, ...

With my love, as always, Carole, xx