

## **May 2014**

I was officially diagnosed with locally advanced adenocarcinoma of the pancreas in September 2013, just before my 56th birthday.

In October 2012 I was having a lot of abdominal discomfort, and thought it may be my remaining ovary causing problems, my GP organised an ultrasound but my ovary was ruled out. I continued to feel unwell and had problems digesting certain foods, I thought it was bread/carbs but in hindsight it was fat. I had to give up my Friday night pizza treat.

I went back to my GP in December 2012 feeling terrible, exhausted and depressed. Subsequent blood results showed low vitamin D and that I was not taking enough thyroid medication (had been treated for underactive thyroid for many years). We also agreed I needed to lose some weight, review in a month.

I diligently set about losing weight and taking the vit d along with the increase of thyroid medication. I lost around 4 kilos and felt much better, reported back to my GP at the end of January 2013.

Around February 2013 losing weight was becoming suspiciously easy, I was losing my appetite and not finishing my meals. I had had heartburn off and on for years but at this time it was very bad. I would often feel nauseous after eating. I found the smell of cooking, especially frying intolerable I would walk out of cafes if they smelt of fried food

March 2013 was the next phase of symptoms, I started to need to pass stools as soon as I got up in the morning which was very unusual for me. Not long after nocturnal diarrhoea started, usually around 3 am and I would go 4, 5 or 6 times over a period of a couple of hours. This would happen about every 3 days. Sometimes mid-morning, back to my GP, weight loss was about a kilo a week.

Stool sample tests proved negative. Food intolerance was considered so I modified my diet for a couple of weeks with no improvement and continued to lose weight. My stools were not normal even when I did not have diarrhoea and they smelt terrible.

April 2013 I had an endoscopy and colonoscopy, other than some evidence of damage from the heartburn there was nothing else obvious. For some weeks I had a stitch like pain in my left side which got severe 2 days after the endoscopy so was referred to Accident and Emergency. I had a CT scan and ultrasound but all they could find was a small amount of fluid on my gall bladder, stayed overnight and the pain subsided over the next few days after a course of antibiotics. Food intolerance was still considered and I modified my diet accordingly, this continued for weeks and I was then referred back to the gastroenterologist in August 2013. She concluded from my blood tests that I had developed pancreatic insufficiency and prescribed me Creon enzyme replacement and sent me for a CT scan. I was called back for the results early so knew it couldn't be good.

She told me I had cancer but that I did not present in the classic way, the scan did not show an obvious solid tumour more a misty area with lymph node involvement so I was referred for an endoscopy ultrasound and biopsy. The doctor who performed this told me my pancreas looked fine and he did not biopsy it but did biopsy a small tumour in my abdomen near the aorta, two more weeks dragged on with me being told that my blood results showed no elevated cancer markers and the biopsy was inconclusive. By this time I had lost 16 kilos and was still working, totally washed out. He suggested he either repeated the endoscopy or referred me to an oncologist. I took the second option.

September 2013 I saw the oncologist who without beating about the bush told me I had cancer and that the full biopsy results confirmed adenocarcinoma. He said it was almost definitely not operable but he referred me to a surgeon to confirm. I saw him the next morning and indeed not operable. At this stage both my husband and I thought I had very little time left. However when we expressed this fear to the surgeon he said that was not the case and with chemotherapy it could be many months. I started putting all my affairs in order and started chemotherapy on September 12th 2013. I was hugely impressed with the speed my oncologist got things moving and I was sad but relieved that at least I had a diagnosis, my husband said, this thing has had it all its own way for months, now it is

time for us to fight back!

I started on Gemcitabine, 3 weeks on, one off. My emaciated body coped well with the regime, helped by the caring staff in the oncology unit and my naturopath who my oncologist was fine with me seeing as long as he had a list of the supplements she was giving me. 3 month scan in December show no growth or spread, a good result for this cancer. Two weeks off and then another 3 month round. Scan in late February 2014 again showed no growth or spread. The oncologist wanted to give me a rest from chemo and will monitor me.

May 15th 2014 my blood test were reviewed by my oncologist and showed no cause for concern, nothing had changed so in 5 weeks I will have another blood test and a CT scan and take it from there.

It is now 9 months since I was told I had pancreatic cancer and well over a year since the most severe symptoms started. Such a sneaky cancer, my only real symptom was the night time diarrhoea and weight loss which could be put down to the diarrhoea anyway. I had no pain or jaundice and it was not seen on the CT in April at A&E but it must have been there. Even now cancer markers in the blood tests are relatively low. I had a general blood test through my GP to check thyroid function, vit D, glucose etc etc. They were all excellent, if she did not know my issue there would be no red flags in the results.

My biggest problem has been the diarrhoea, psychologically and physically and the lack of medical support in helping me deal with it. I was told by two senior doctors that it is not a symptom of PC. As a result of this advice I went on a bit of a wild goose chase. I had food intolerance tests (referred by gastroenterologist) that concluded I had fructose intolerance and a small intestinal bacterial overgrowth (SIBO). I was put on low dose antibiotics and had to follow a restrictive diet, a nightmare for someone with little appetite and now mildly anorexic as I was scared to eat because of the consequences. I was also told by the gastroenterologist that there was no point in increasing my dose of Creon as it would just go through me. All this time I am losing more and more weight and scared to go out without incontinence pants on. Lots of time spent on Google and I increased my dose of Creon per meal and guess what, I went 6 days without diarrhoea. My GP asked me to see a specialist dietician who confirmed by properly listening to my symptoms that it was fat in my diet causing the diarrhoea and Creon was the answer. It is not perfect, it is sometimes hard to judge the amount but it is way better.

I know you have to die of something, that is life but with all cancers early detection is important, PC is so hard to detect, so many of my symptoms could have been related to something else, no family history of it, although other cancers. By the time it is found it is often too late. To be honest I don't think I would have had the Whipple operation even if it had been an option, too much pain with too little gain and such high odds of it coming back quickly.

I feel lucky that I have had so much time, I have a wonderful oncologist and GP and I know they are doing their best for me, they both make things happen quickly when necessary. I am also lucky I have private health cover and a great oncology unit team that make me feel very comfortable

I hope this account is some help for your project, you never know, I may be able to send you an update in 12 months' time!

Regards, Jane  
Elizabeth Jane Clements.  
14/09/1957

### **19<sup>th</sup> May 2015**

My last comment that I may be able to send you an update in 12 months' time. Well here it is. In September 2014 my routine scan showed enlarged lymph nodes and elevated tumour markers in my blood tests, the tumour itself had not changed but my oncologist advised me to go back on chemotherapy, the same as before. I had a couple of rounds of Gemcitabine and during this time Abraxane which had been approved for use in other cancers, not Pancreatic, was approved for use

on the PBS. I started this in November along with Gemcitabine. My last scan showed no change in the tumour but my tumour markers had decreased. I am due for another scan to check progress in early June.

My constant problem before and after diagnosis is digestive issues. My weight has stayed at a skinny 58 kilos for a number of months now. For that I am grateful but it does not seem possible to put any back on. I have been seen by another gastroenterologist who conducted a number of tests and confirmed my pancreatic function is rather poor and that I am not digesting fat despite a relatively low fat diet. The conclusion is the enzyme replacement therapy, Creon, is not working for me, increasing the dose does not have any effect and there is no answer for this. I find this so frustrating, the oncologist has done a fantastic job of keeping me going with a good quality of life for all these months balancing the chemo to keep me stable but not making me feel so ill I want to give up. But a major piece of the puzzle is still missing. I wonder what is so special about me that the Creon does not work?

It is now over two years since I got sick and I suspect the symptoms I had six months before that were related. I believe the overall survival rate of one year for PC is now 6%. It seems I am one of those on the other side of the bell curve that has not had a Whipple procedure.

### **February 2016**

Well, yet another update I am still here. I went through Abraxane for 6 months and my tumour then became resistant to it. I then went through Folfox and was given time off for good behaviour. In August 2015 I presented myself to Emergency with a bowel blockage. The tumour had pushed up against my duodenum and stopped food leaving my stomach. I was lucky enough to be able to have a bypass operation rather than a stent as it was considered the cancer had not spread sufficiently to indicate end of life treatment. Shortly after this the pain started in my back. So far I had been extremely lucky with pain. Only mild and nothing that a couple of Panadol or Panadeine would not shift. I was put on strong pain killers in September 2015 which worked for a couple of weeks. My oncologist kept increasing the dose and also suggested I go on a novel chemo, the last one in the bag of tricks. This chemo was the worst ever. The others had bad side effects but I think my body was just not able to cope.

April 2016