

Shirley's journey

Things to come

The year had started pretty badly with Shirley having to spend Christmas Eve in the A&E Unit of Middlesex Hospital with an uneven and racing pulse. She was discharged as OK and we put it down to the excitement of helping our daughter and son-in-law move into their new house. The early part of the year saw us both get nasty chest infections. But by the spring things were looking better and we were looking forward to getting out and about. Until...

Yellow belly

On Sunday morning, 13 April, Shirley came out of the bathroom and uttered those immortal words, "Do you think I'm yellow?" Well, yes she was. We hesitated a bit, had a laugh, and then decided to call NHS Direct. Their advice was to call the emergency doctor (it was Sunday). This took us back a bit but we made the call. By pure chance the doctor was in the area and he arrived within ten minutes! He examined Shirley and pronounced cheerfully that if he were a betting man then his money would be on gall stones, advised us to see our GP as soon as possible, then jumped in his smart sports car and left.

We saw our own doctor next day who offered no diagnosis and arranged for Shirley to have an ultrasound scan later in the week at the local hospital. In the meantime I had a look on the Internet about jaundice and what I saw was not reassuring. However, Shirley had the scan and the man said that it was too muddy to be sure what was going on and to arrange to see our GP in two weeks to get the full results. In retrospect, of course the only thing that was muddy was the need to confirm what the radiographer had seen.

Incidentally, our dear daughter and her husband Richard were visiting at the time and, in our kitchen we have a board and dry wipe pen for shopping lists. Blissfully unaware of what was in store for us, Richard, who was in the habit of drawing daft pictures on the board, wrote, "Shirley has a yellow belly!" It was funny at the time.

Jaundice

Shirley then started to get the classic symptoms of jaundice, intense itching and bowel problems and she started to lose weight.

Unwilling to wait the specified two weeks for the ultrasound results, before seeing our GP we contacted the practice after seven days to be told that the results had arrived. Various completely unfair threats gained us a same-day appointment which resulted in a visit to Good Hope hospital to see the specialist the same week. The jaundice was doing its worst by now and each day was a torment for Shirley. The visit to the specialist was not without incident as, on arrival, we were told that no appointment had been made. This was no help at all and a very distressed Shirley and myself were accommodated in a back room whilst the problem was resolved; they were looking at the appointments of another specialist!

We returned to Good Hope later that week for blood tests, and the following Monday Shirley had an endoscopy during which a tube was fitted to allow the gall bladder to function properly and a biopsy was taken. The doctor told us that there were no gallstones present but offered no other reason for the problem. We came home assured that the jaundice would now subside. However, the jaundice did not subside and resulted in several home visits by our GP.

Shirley then developed one of several infections of where the tube had been fitted and on this occasion we were visited by a lady colleague of our own GP. Taking me into our lounge she said that she had seen Shirley's notes, she did not know why she had seen them, but asked me if I was aware that this could be "something nasty." I said that I was but for some reason we did not continue the conversation and she went upstairs to see Shirley. This, I think, was the first official indication of how severe the problem could be.

Diagnosis

Things thankfully moved quickly, for Shirley was very ill with jaundice and infections and within a week she had a CT scan at Good Hope, followed just over a week later with an appointment with the specialist who, in confirming that Shirley had cancer of the pancreas, expressed surprise that we did not expect it. He explained that a major operation was the best option and made immediate arrangements for us to see the specialist team at the Queen Elizabeth Hospital.

We saw the team at the Queen Elizabeth the same week and we were grateful for the refreshingly honest way in which they approached the issue, setting out the options and the risks involved and providing information leaflets and contact telephone numbers. For the first time we knew what was ahead of us and that alone was a help. Again, an immediate date, four weeks hence, was set for Shirley's admission to the Liver Unit and an operation was planned for the day after.

Back at home we tried to settle down for the four-week wait before the operation, but it was not to be. Shirley, already suffering from jaundice (the tube inserted during the endoscopy was having no effect) was taken ill very suddenly during a visit to her brother and we drove back directly to our GP's surgery where an ambulance was called and she was admitted to Good Hope Hospital with another infection.

Ward Nine woes

The next few days were probably the low point of Shirley's illness. She was in a four-bed ward, the other three beds occupied by ladies who were much older than Shirley and needed much more personal attention. This they got in varying degrees and it caused Shirley much sadness when their needs were not fully attended to.

The good news was that the antibiotics controlled the infection and she had a second endoscopy when a second tube was fitted and this quite quickly reduced the jaundice.

The fact that Shirley was not happy there was noted in that the hospital took the unusual step of allowing her to come home on the Saturday morning on condition she returned the following Sunday evening. This concession was followed by discharge on the following Tuesday. We then really did settle down to prepare for the operation.

Here we go

Shirley's birthday was on 1 July and she was due to go into hospital the next day with the operation on the day after.

About lunchtime on her birthday, the phone rang. It was Queen Elizabeth Hospital asking to speak to Mrs Griffiths.

"Not a delay?" I asked. "Au Contraire," was the answer, "come today!" The timetable had been brought forward one day and we were to go to the hospital immediately. What a birthday present!

We had been warned previously, that Ward West 3 Liver Unit of Queen Elizabeth Hospital was a transplant unit and that, naturally, liver transplants always took priority. We were not prepared for what happened next.

On two consecutive mornings Shirley was prepared for theatre only for her operation to be cancelled at the last minute on both days for liver transplants. She was now getting desperate.

However, the third morning came up trumps and she had a three-hour operation, called a Whipples operation, in which the tumour and several bits of surrounding organs were removed.

Shirley's only memory of going to theatre was thinking what a large number of people were standing round her bed!

Getting better

Once she had come round and settled down, the surgeons saw Shirley and told her that operation was successful and that the tumour had been removed cleanly and the outlook was good.

Shirley stayed a few days in the High Dependency Unit, bristling with tubes which were progressively removed as she was transferred to a ward. She was soon up and about and, Shirley being Shirley, had made friends with every nurse, doctor, patient, and ancillary worker on the ward! God help them!

During her stay in the ward Shirley became good friends with Gill in the next bed. Gill had had the same operation and Shirley still talks of the strength she drew from the positive support Gill gave her during their bed-to-bed chats. We are still friends and if there can be positive aspects to these dreadful events, then the friendship of Gill and husband Ken has been one of them.

Coming home

About ten days after admission Shirley was discharged from Ward West 3 and sent home on a glorious summer's day with a large bag of medicines. We had a celebratory glass (or two) of the best champagne ever and settled down to ward off the continued influx of cards, phone calls and visitors. It was brilliant.

The district nurse removed the thirty-two staples and drain tube a week later and our GP was super in the support he gave us. Shirley, who had always been fit, gradually began to do more and more normal things as we approached the next milestone, which was her first appointment with the surgeon since the operation and to hear the pathologist's report.

Chemotherapy trials and tribulations

We arrived at the Queen Elizabeth Hospital for our appointment with the surgeon only to find, to our delight, Gill and Ken there and about to go in. Gill came out and said that she had been asked to join a voluntary clinical trial involving chemotherapy.

Apprehensively, we went in for our appointment. The news was good! There was no evidence of cancer in the surrounding tissues, although the possibility of recurrence and the associated odds were reiterated in the honest and straightforward way typical of all the consultant staff involved.

Shirley was then offered a place on the same clinical trial as Gill. "Offered" was probably the wrong word. The consultant left us in no doubt that his personal goal in life was to get as many patients as possible on the trial. The specialist nurse gave us all the details and we came home to consider.

The trial, ESPAC-3, allocated the participants, randomly, into one of three groups:

- Chemotherapy with gemcitabine
- Chemotherapy with fluorouracil and folinic acid
- or no treatment at all

There was no choice really, and Shirley duly signed up. The nice news was that Gill had also agreed to go on the trial and she was allocated the same treatment. The chemotherapy regime consisted of six four-week cycles. We saw the oncologist and had blood test on Friday and then attended the chemotherapy day room from Monday to Friday of the following week for injections of fluorouracil and folinic acid.

We then had three weeks off, during which the side effects of the treatment took their toll before the cycle began again. During this time we have the full support of a trials nurse who is on call at any time and looks us out whenever we visit the hospital.

We have now settled down into the four-weekly cycle with the side effects being well controlled by medication, although Shirley has by now started to lose her hair and eyebrows.

During this time Shirley and Gill have regular telephone conversations comparing symptoms. They go something like this:

Shirley: "Help, Gill! I've got this pain in my side."
Gill: "That's OK, I've got the same pain."
Shirley: "Oh, thank goodness for that!"
Gill: "How's your wind?"
Shirley: "Really good today."
Gill: "So's mine."

And so on...

Its good fun, but the benefit from the support that they give each other is incalculable.

The future

It's getting near to Christmas, which we are looking forward to even more than usual. Even more so, we are looking forward to 2004. Shirley has her last cycle of chemo in January and then it's all systems go! We will have a holiday; perhaps two or three.

The Queen had her "annus horribilis" a few years ago; 2003 was ours. The great thing is that we are actually looking to the future with a confidence that six months ago we would not have had. Cancer of the pancreas is not something you forget, however successful the operation and the subsequent treatment. It will always be at the back of our minds. To think otherwise would be a delusion.

What we do know is that the care and treatment Shirley received was of the highest order and that, for the time being, will do. Shirley's Journey may not yet be over but we face the rest of it full of hope.