

TO HAVE AND TO HOLD



Foreword

I am Andrea, wife of Stephen, and what follows is a tale of the unexpected.

Of how a perfectly ordinary couple fell in love and saw ahead a perfectly ordinary life of work, home, family, no doubt with the occasional bump in the road but cruising along our comfortable middle-class pathways.

Stephen was educated at St George's Chapel School (Windsor Castle) and then at Sherborne, his parents sacrificing a great deal to give him this expensive education. He then went to Newcastle University to study Civil Engineering, and where he spent far too much time sailing.

I went to a nondescript small private school, where I got away with murder, but refusing to go to Slough High School for A levels, as I would have needed to get up early, and take two buses instead of cycling gently to school, seeing my adopted horse on the way.

We met at Bourne End Sailing Club and the rest is, as they say, history.

We made no grand plans, had no burning ambitions, which with hindsight I see as a great blessing. How frustrated and devastated we would have been when life took the course it did.

What follows is my account of those "ordinary" lives.

ONE STEP AT A TIME

Our first “solo” dialysis performance took place in a Nissan hut attached to the Lymington Mortuary. Stephen was in the starring role, and I was the non-glamorous and somewhat nervous assistant.

But I seem to have got ahead of myself.

How on earth did we end up in this somewhat precarious predicament?

I will start at the beginning of our journey together.

Stephen and I were married in 1965. He was 27 and I was 20.

Our first home was in the delightful village of Thorner, a few miles to the North of Leeds. Stephen was working for Wakefield County Council and designing and building bridges on the M1. I was still at Leeds College of Technology training to become a Dietitian. We bought a typical Northern three bedroomed, stone built, terraced house built in 1876 and complete with cellars and set about doing it up.

My elderly diehard Yorkshire neighbours took me in hand and between them taught me all sorts of housewifely essentials, such as making Yorkshire Puddings and the shortbread for which this house is still renowned!

The next event of note was the birth of our daughter, Clare and life seemed set fair.

We came home from the rather bleak Victorian style Armley Hospital and my mother came to give support. The midwife came daily for about a week.

Things went along quite smoothly and then when Clare was about 15 months old, I had some sort of instinct that something strange and intangible was amiss in the household. I have absolutely no idea what prompted this, but



decided both Clare and I were in rude health and suggested Stephen should go to the Doctor.

Three weeks later he was in Leeds General Infirmary and diagnosed with idiopathic hypertension and so began our difficulties. But at that time, we, perhaps fortuitously, didn't have any idea what this would lead to.

Stephen was started on anti-hypertensives and continued on them in some shape or another for the rest of his life.

1968 sees us in Guisborough, North Yorkshire and it was here that our son Robert was born in the cottage hospital.

We lived in the square at the top of the high street, next to the Church and with views of the Priory from the upstairs windows.



We had our work cut out to make the old, Georgian style house into a comfortable home. as it had been, until then, a bed and breakfast establishment. In fact the vendor offered to sell us 10 beds!

We had moved in the Autumn and Robert appeared on the scene on December 23rd meaning that I spent an exhausting time in Guisborough Cottage Hospital over Christmas,

enduring endless visits from worthy local groups determined that we should not miss out on the Christmas Festivities!

We managed to persuade the Sister to let me go home on New Year's Eve.

She was concerned that we were hell bent on wild celebrations, the North being 'big' on New Year revelries, but we just wanted to get home and establish ourselves with our new addition.

The snow was deep on the ground and it was very cold. The journey home made me realise why our visitors to the hospital were sometimes late and

full of excuses, mostly blaming the weather. Being cocooned in our cosy ward and totally absorbed in feeds and nappies we were totally oblivious to the outside world.

Robert was established in the “Nursery” on the second floor of the rather cold old house. My Mother duly arrived to assist and was the one to work out why the new addition was so quiet and docile. She realised the poor child was probably really rather too cold. She was right! We brought him down a couple of floors and he burst into life!

In Guisborough we had a really excellent family GP who treated us as a unit and over time saw us all.

He was the one who laughed uproariously when I realised that I had lost my medical notes, entrusted to me to take to the hospital, when labour took hold.

Guisborough has a very long High Street. We lived right at the top end and the surgery was at the bottom. Setting off for an ante-natal appointment I had bundled Clare into the push chair, collected up the Christmas cards to be posted and set off. Arriving at the surgery the somewhat stern receptionist asked me to hand her my medical notes.

“Sorry I can’t”

“Why not?”

“I seem to have posted them”

“Who to?”

“No one in particular”

She was not amused.

The Doctor, however, found it hilarious and there was a surprising and happy ending. By the time I got home the notes were awaiting me on the doorstep!

On a more serious note, it was he who told me that if Stephen’s blood pressure was not brought under control, I would probably be widowed by the time I reached my forties. I was 23.

Still, and perhaps fortunately, no great alarm bells rang and we carried on, with Stephen taking medication and appearing to be OK.

By 1970 we had moved to Rudgwick in Sussex, a village near Horsham. I should perhaps explain that Stephen was a Civil Engineer and most contracts

were for two to three years duration, which is why the moves were necessitated.

Here the GP soon realised that something serious was afoot and referred him to a consultant. An IVP was performed to check his renal function. Problems with kidney function are often associated with hypertension. But this test showed nothing abnormal and no further action was taken.

We met, and made, some very special friends in Rudgwick. Amongst them the Garthsides, Tony and Vida and their identical twin boys, Paul and Phillip, aged three when we arrived. At this time Clare was also three and Robert eighteen months. The three “big ones” were at the same nursery and soon there was a lot of intermingling. I was once asked in the village shop where my other two children were! More often than not, either Vida or I had all four.

1974

Sussex wasn't altogether to our liking, a bit too posh for us, and so we welcomed a move to the wonderful city of Newcastle, Stephen starting in August 1974 and us catching up with him in the October, having sold the house.

1975

Stephen's new job in Newcastle was working on the construction of an innovative enclosed dry dock enabling ships to be built under cover and thus speeding up the process. It was located at South Shields.

With both children now at school I also got a job. I worked part time as a Dietitian at the Newcastle General Hospital. The General was an old and somewhat outdated hospital and parts of it threatened with closure even at that time. When I was last in Newcastle, about 2010, some of it was still operational!

It was here that the children suffered yet another embarrassing moment with their mother. We went into town to buy new school uniforms and walked to the end of the road to catch a bus into town. All fairly simple. Not so coming home. Not being familiar with the bus station, I had to ask, where

to get the bus home. My ear was not attuned to the local accent, and having asked, I was, unfortunately still none the wiser. Realising my predicament, he helpfully took me by the hand and led us to the correct stop.

More red faces.

Later I felt triumphant when I went to the Fish Market in South Shields, and understood enough to buy a box of fish for the freezer!

We lived on a very nice, polite, estate called Melton Park as did Stuart Hunter, the paediatric cardiologist at the General and he often gave me a lift to work.

This was the time when Stephen's health became a real concern. His blood pressure spiralled out of control. He had frequent visits to the GP. One was on a Friday evening and he recorded a reading 240 over 170. Really rather alarming and we did not agree with the GP's opinion that this could be put down to having it taken at the end of a busy week. Perhaps he was trying to play it down to reassure us?

I related this to Stuart on the way to work one day. He was horrified and agreed with me that this was hardly normal, spoke to a colleague and in very short order, Stephen was referred to the Cardiology consultant at the Royal Victoria Infirmary.

The only other entry in my extremely scanty diary says "December 12th Stephen to hospital." My guess is that was for his first Outpatient appointment there.

1976

By May of this year, Stephen had been referred to the Renal Department at the Newcastle General Hospital. He attended on May 13th, May 20th and June 10th. I guess these frequent visits suggest that Dr Wilkinson, the Renal Physician was trying to sort him out. A significant step on our journey, but the penny was still only dropping slowly or were we just burying our heads?

After that there are regular visits as an Outpatient to the hospital and then in October, we had a bit of a worry when Stephen was made redundant. We were very worried that his health problems might affect his job prospects.

He was eligible for Unemployment Benefit which we claimed and he set to job hunting, but then in December we hit another problem.

On the evening of the 21st December, Stephen became, suddenly, really rather poorly and we were sufficiently worried to decide to call the Doctor. A doctor from the deputising service came. By this time, it was the middle of the night and we were imagining all sorts of frightening scenarios as Stephen had, among other things, pains in his chest.

The poor doctor simply couldn't understand why we were so overjoyed when he diagnosed pneumonia! I think I almost jumped for joy. We had been expecting a heart attack at the very least! He is probably wondering to this day, why two people were so excited, on a cold December night, to hear his somewhat serious diagnosis. He was taken there and then to hospital, not ideal timing, just before Christmas with Robert's birthday 2 days away.

Our kindly neighbour, Mrs Thompson, was roused and came to hold the fort whilst I accompanied Stephen.

A complicated bureaucratic situation then arose. Stephen, as I said, was receiving unemployment benefit. On being admitted to hospital, it became apparent that he needed to change from unemployment benefit to sickness benefit. This necessitated me going, the next day, to a rather run-down area of Wallsend, where the Social Security Office was located to try and arrange this.

This proved to be one of the most unpleasant experiences in my life. There were queues and queues of desperate looking people and it took ages and ages for the queue to move forward. So long that I began to think I wouldn't be back in time to collect the children from school. Bearing in mind that the children had woken that morning to find their father gone, I thought they might be slightly alarmed if they got home to find their mother had disappeared as well. I went up to one of the windows and tried to explain, through the very thick glass, my plight, and to ask if I could use a telephone to call my neighbour.

"No, there is a Public phone down the road but if you leave the building on return, you'll have to go to the back of the queue". So helpful!

That is the nearest I have ever come to hitting someone and believe me, it was a close-run thing. I came to understand why they sat behind strong glass!

However, I somehow managed to contact Mrs Thompson and she nobly came to the rescue again.

A further complication over these few days was Robert's birthday – the 23rd December, as I mentioned before. Once again kind people came to the rescue, this time in the guise of my work colleagues, who collected up Robert, Clare and friends and took them skating. Such kindness.

It looked as if Stephen would be in hospital for Christmas so we made up his stocking on Christmas Eve and went to visit him but “ Tidings of Great Joy”, they said he could come home. A very fierce ward sister came up to me and reeled off a list of the many, many tablets Stephen was to take. My mind was in a whirl, and I remember her being very annoyed with me when I asked her to write it all down.

We had a quietish Christmas but Stephen managed to carve the turkey, albeit it in his pyjamas.

During this time Stephen had indeed, found a new job. This was with Halcrow in Swindon, and so involved yet another move.

Dr Wilkinson, on hearing this said that if, for any reason, Oxford (the nearest Renal Unit) couldn't take Stephen for dialysis treatment we could go back to Newcastle and his care.

This was the first-time dialysis had been mentioned and, at last, focussed our minds somewhat.

This was in 1977 and dialysis was still fairly uncommon and places and facilities limited.

1977

And so, we headed South in April 1977, buying a new build house in Lechlade and Stephen was referred to Oxford. So began our long association with the Renal Unit at the Churchill Hospital.

Also, at this time my mother was very poorly with pancreatic cancer. She was desperately ill but managed one trip from Bucks to Lechlade to see us safely established in our new home. She died in the July after being cared for at home by Pa and a wonderful nurse, Halina. It was a hard time as Stephen's health and the distance made frequent visiting difficult.

All the time Stephen's kidney function was deteriorating and his blood pressure remained alarmingly high.

As the kidneys fail their ability to excrete the waste products of metabolism falls and there is a build-up of toxic products such as urea, creatinine, and uric acid among others.

At this time the patient is pretty ill, with all measurable parameters regarding kidney failure heading in the wrong direction but not yet considered bad enough to start the actual dialysis treatment.

Stephen was feeling rotten, looked increasingly yellow and had to put up with a very strict diet together with severe fluid restrictions. Fortunately, as I had trained as a Dietitian, I was not so bemused by these strictures as other people must have been.

A diet of low sodium, low potassium and very low protein, together with the fluid restriction is not easy and the products available, for example low protein bread, which came in tins, were not exactly appetising. Fortunately, since then, great strides have been made in the palatability and choice of products for patients needing restrictive diets such as these.

However, we soldiered on, with increasingly frequent visits to the Renal Unit at the Churchill Hospital.

My diary records the following: -

April 4th Arrive Lechlade

April 15th Stephen to Oxford

May 13th Stephen to hospital

May 20th Stephen to hospital

As we lived in Lechlade approximately 25 miles away from Oxford (i.e., a 50-mile round trip) travelling took quite some time and the traffic, even then, going into Oxford on the A40, could be very slow.

This was a bad period with Stephen going increasingly downhill health wise, and so, bearing in mind the words of the GP in Guisborough, we decided it was time I set about getting a job. I decided to give medical repping a go as all the reps who came to see us at the NGH said I would be good at it! Also, with no specialist services at our local Swindon Hospital, such as were

available in the teaching hospital in Newcastle, I thought I probably wouldn't find a Dietitian's job there very stimulating.

After a couple of false starts, I was asked to go for an interview with Eli Lilly. This was to take place the week after mother died. I, who had never done anything like this before was rather dubious about the timing, but they said they would provide tissues.

There was a fair amount of rushing hither and thither but amazingly, after several interviews, I got the job.

The next challenge was to be going to Basingstoke for 6 weeks for an intensive training course, staying away Monday to Friday. I would have to cross that bridge when I came to it.

In the meantime, I remember, and it seems incredible now, with the worries about Mother and Stephen, who were both causing such concern I became so thin my father bought me outers on Mars bars, i.e. twelve at a time, to try and fatten me up!

As can be seen by the frequency of Stephen's trip to Oxford, they were obviously quite concerned about him.

At the Renal Unit the consultant in charge was a lovely giant of a man, Des Oliver, who peered at you over half specs and missed nothing.

Our outpatient visits to the Renal Unit were, as I learnt years later, seen by the medical staff in three distinct categories defined as follows: -

Stage 1 More or less normal and okay if Stephen went on his own

Stage 2 Rather more trying if he was sent with a list of questions from me

Stage 3 Evidently, if accompanied by me. Run for the hills!

And from our point of view, we realised that the situation was not too bad, and that some other patients had more problems than we did, if, on that particular day, you got through on a nod.

I do remember very clearly one particular occasion when I had been "repping for some time and knew various reps from different companies.

Stephen's blood pressure remained alarmingly high despite everyone's best efforts.

He was started on a drug called Minoxidil. It was made by Upjohn but not to be found in any of the usual reference material, e.g. MIMs. I knew the Upjohn rep and asked him what he could find out for me. Nothing. He thought it must be a drug undergoing final trials.

So, on the next outpatient excursion (both attending and therefore stage 3 on the scale of Draper visits) I asked Des Oliver about it and why it was not documented, and not on general release.

Des, probably fed up with our endless questions, peered over the half glasses and said

“It kills rabbits”

Silence at last from our side of the desk.

Home we went, silent all of the way until we reached Stephen’s favourite view of the Cotswolds, overlooking the Windrush Valley and Burford when I said

“Are you thinking what I’m thinking?”

“Yes, I’m obviously not a rabbit!”

Eventually it was withdrawn from trials, not because of lack of efficacy but because it had the side effect of making the patient extraordinarily hirsute. Stephen was a fairly hairy individual, and after a short time, his hands began to resemble those of a gorilla. He was certainly not a vain man, but found this hard to bear so was not sorry when it was stopped.

Minoxidil never made it as an anti-hypertensive but is used by ageing people, like me, as a shampoo or solution to help prevent the hair thinning of old age and baldness in men!

Outpatient visits were sometimes challenging for us as well in another respect. I am not sure that the Doctors realised that if they said something new and worrying, one failed to take in any further information after that, and in my defence, sometimes having us both present improved the chances of retention.

Further information from the diaries tells me that I started with Eli Lilly in the October, somehow surviving the six weeks of a gruelling, intensive, residential training course.

Stephen had a couple of spells as an inpatient at the Churchill in August, .. I don't know what for, but obviously things were not good.

1978

I have no diary for 1978 but I suspect it was a bit dismal. Stephen's renal function would have been deteriorating all the time but not yet severe enough to meet the parameters for dialysis.

It was in 1978 that Pa announced he was to marry again, scarcely a year since mother died. This came as a considerable shock to my sister and me, especially when we realised the character and actions of his intended, were a million miles away from the principles that we had been brought up on.

Just to paint a picture of my upbringing. For example, when I decided, after A levels, that I thought I would like to study dietetics, and thought Leeds seemed to be the place to go, I asked Pa if he would take me there for the interview.

The reply came from deep inside the Telegraph

"If you can't get yourself to Leeds and back (from Buckinghamshire) you shouldn't be going to College."

But maybe his attitude served me well in our troubles. Two pieces of his philosophy still remain with me: -

If you think life's going to be fair you may as well give up now

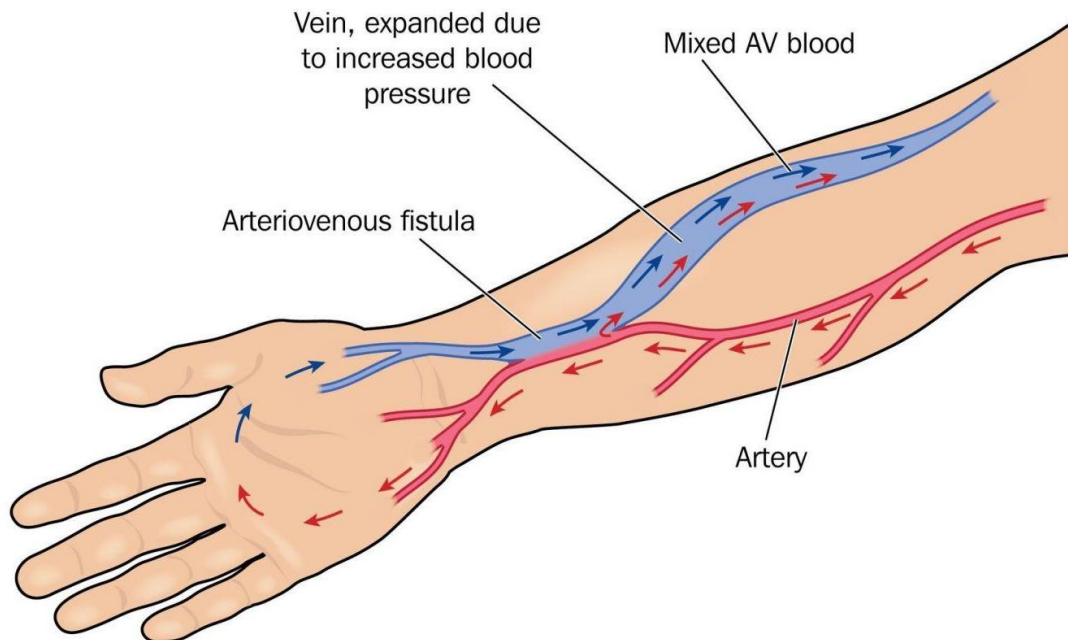
And

Never why me? Why not me? I was young, vaguely intelligent and relatively capable. (And I desperately wanted Stephen to be with me)

1979

This year saw the start of the dialysis treatment for Stephen and in January there were many visits to the Churchill, I guess for the close monitoring of levels of all those poisonous metabolites.

In June Stephen was an inpatient and had an operation to create an AV fistula in his arm. This forms the access points to connect the patient’s blood supply to the kidney machine so that it can be ‘cleaned.’



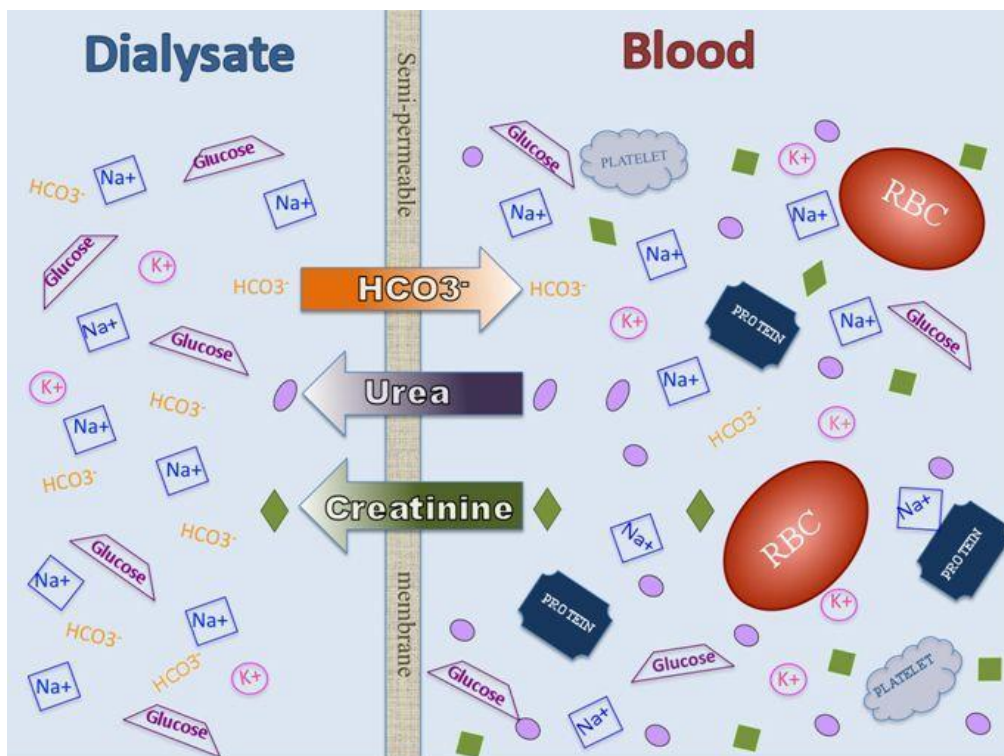
Reference 1

An artery is connected to a vein in the patient’s arm. Once formed, 2 access needles can be utilised, one above the other. The arterial line, removes the contaminated blood, which passes through the dialyser and is cleaned before returning via the venous access in the fistula, to the patient.

It sounds so simple but, of course, is not. There are dozens and dozens of checks and balances to be observed. The blood passes through the dialyser which has the cleaning fluid, or dialysate passing through it, and this carries the poisons away. Factors which must be considered are numerous and include rate of flow, the PH (acidity/alkalinity), and the temperature,(so that the blood is returned at body temperature), the electrolyte concentration along with many other factors. The process for someone of Stephen’s build took 5 hours. I should also perhaps point out that the treatment was a “two-person” procedure, a helper was required to assist with the “putting on” and “taking off” processes and to be on hand in case problems arose.

The purpose of dialysis, as stated, is to remove from the patient the accumulation of waste products of metabolism that the kidneys remove in

healthy people. The principle of dialysis is comparatively simple and is achieved by separating the unwanted elements in solution by diffusion across a semi-permeable membrane.



Reference 2

Haemodialysis, at this time, took place via the dreaded Kil Machine, a heavy contraption, the size of a coffee table, used to house the membranes through which the waste products passed and were washed away.

The semi-permeable membrane used in those far off days was made of a sort of cellophane, very like clingfilm. This material was relatively porous to fluid and solute but did not allow large molecules (albumin, vitamin B12) to pass freely.

There were 3 boards and 2 sheets of the membrane were sandwiched between each pair of boards. Grooves in the plastic boards directed the blood between the layers of membrane.

The dialysate solution flowed outside the membrane envelop and in the opposite direction to the blood.



Reference 3

The plan was, once we had mastered the necessary technique, we would dialyse at home with support and back up from the unit.

At this time home dialysis was organised in such a way that the machine and equipment was housed either in a portacabin adjacent to the house or in a specially adapted room within the house, in order to ensure that everything was kept as sterile as possible. We were able to opt for the latter.

In the “engine “room at the Renal Unit, there were 8 to 10 machines of varying makes and each “station” could process 2 patients a day, one overnight.

The whole process took upwards of 7 hours, the 5 hours of actual dialysis and at least half an hour preparing the machine and the same coming off and cleansing it ready for the next use.

This performance took place three times a week.

Added to this, the Kiil could only do a few treatments before it was necessary to dismantle it to replace the “cellophane”. More on this later.

At the beginning of July Stephen was going alone to hospital for treatment, learning his side of the process. He drove himself there and back. He must often have felt exhausted by it all, but just got on with it in his usual calm way.

Once I was familiar with the procedure I was to learn how to become “the helper”.

On reflection I realise we must have had incredibly supportive employers as it took several weeks to reach a safe level of competency, but I guess we also had to take holiday as well.

After a couple of weeks, we ran into the school summer holidays which complicated life somewhat. It meant we all had to be up and out early so as to arrive at the unit at about 9 o'clock.

It went like this. All up and off to Oxford. The children had to hang about until Grandpa or some other relation came to collect them and take them off for the duration of the treatment, and then drop them off at the hospital when we had finished, and then we all went home. I remember Pa being particularly brave about doing this as he was one of those people with an aversion to hospitals. It was a long time for them to have to fill and they seem to have quite a good knowledge of the various pubs in the vicinity!

Stephen's parents were also on hand but finding it all difficult to come to terms with. Stephen was a precious only child so it was very hard for them, but they supported us well.

The sister in charge was the wonderful Margaret. I'm afraid after a while she was known by us as "Big Margaret" and the children particularly loved her trendy outfit of rather short "Greens" and then a gap to her pop socks!

Whilst Stephen prepared the machine, I had to lay up a tray with all the things needed, such as clamps, cotton wool, micropore and many other necessities.

Clare meanwhile was deputed to make tea for one and all. (All the patients arrived at roughly the same time and gasping for a reviving cuppa, so this was quite some task).

I often made a mess of laying up the tray, while Clare made the most diabolical tea. This was quickly resolved by Margaret who shrewdly initiated a role reversal. And though I soon got the hang of the "tray" Clare still makes a lousy cup of tea.

I soon discovered that clamps seemed to be right-handed. I am very strongly left-handed. As a medical rep I spent a lot of time driving and whilst driving down the M4 would be practising clamping and unclamping.

Another day that stands out in this "learning" period and still comes up on family occasions at the point where everyone is reminiscing and in a mellow

state. Aunty Jan, my sister, came to take charge of the children along with her two, Amy and James and they all went down to the river Thames for a picnic. I have never really got to the bottom of it, especially as I am only told about it when everyone is in that silly state, but it appears to involve Amy falling into the Thames and Clare rescuing her, thus necessitating a trip into Oxford to purchase dry knickers! The telling of this story by the participants always results in great merriment all round.

Stephen took all that was happening to him in his usual stoical manner but even he was somewhat stunned when a doctor rushed up all excited to say that they thought they had a donor match and a transplant could be on the cards. You can well imagine what a successful transplant would have meant to us, health wise, family wise, work wise and time wise. Unfortunately, only a short time elapsed before they realised the match was not good enough and within a few hours, came back to say it was no good.

Back to the drawing board.

As we were judged to have had reached a reasonable level of competency, and as we were still in school holidays, thoughts turned to a getaway break for the family. After all the preceding dramas, this seemed to be a good idea. And so, this crazy plan was hatched. The Unit informed us that there was a dialysis facility attached to Lymington hospital, utilising the same machine we were learning on and supplied with the same products and equipment we were familiar with.

The facility was attached to the Hospital Mortuary. This seemed to us to be highly amusing if a trifle macabre. Our first “solo” treatment in a mortuary! Our rather tasteless comments were soon hushed by Margaret!

We would take a house in the New Forest for two weeks together with my sister, Jan and her two children, James and Amy. Her husband, Simon, would join us at weekends.

And so D Day arrived and Stephen and I duly set off for the Mortuary.

In fact, and to our great relief, we found that the dialysis was actually to take place in a Nissen hut adjacent to said Mortuary.

And to our, and possibly everyone else’s surprise, we managed the whole procedure without a hitch but we were incredibly slow and the whole thing

took hours. We were pretty tired and emotional by the end, but also pleased and relieved to have come through it all unscathed.

This then was our first “holiday” though I am not sure Jan would agree, minding and entertaining four youngsters, cooking, shopping etc. isn’t everybody’s idea of relaxation. Jan a “star” as always. Here again this episode gives rise to ridiculous reminiscences as when, on a particular picnic, and in a howling wind, a full, large bottle of Coke took off from the picnic table completely of its own volition!

Back home, technicians from the Unit came and installed all the necessary equipment and carried out the adaptations to the room. We were fortunate to be able to extend the house over the garage and convert a small bedroom into a dialysis room.

The room needed a large sink, horrible strip lighting, a lot of electrical sockets, a telephone and it had a special, thick, waterproof floor which came a few inches up the walls in case the Kiil should flood, plus shelves for all the chemicals and necessary equipment. A rather stark and inhospitable space to spend so many hours in.

The Kidney machine, a Kiil, and all the vast quantities of “stores” arrived in September and thus began this next part of our journey.

My diary says Monday 3rd September, machine here and

13th September Dialysis

And, horror of horrors,

14th September Kiil building

And then

17th September Dialysis again so I guess we managed it!

Stephen dialysed in a reclining chair and anyone else had to perch on a folding garden chair.

We did manage to include a small TV to help while away the hours, and there was plenty of heating to prevent that strange coldness Stephen (and perhaps others?) experienced during the treatment.

One of the rooms in the new extension became a sort of “Rumpus” room where we could sit close by and this meant that Stephen was not isolated alone upstairs.

The treatments were carried out three times a week. We tried to keep to a routine, Tuesdays and Thursdays, so that other parents knew we could not do the “fetching and carrying” of children on those nights but could do our share on the others.

We usually did the weekend treatment on the Saturday. By getting up at six we could be finished by lunchtime and have the rest of the weekend free. Dialysing three times a week does allow for a little flexibility, for example the weekend one could be changed to Sunday if something important was happening on the Saturday.

BUT THEN THERE WAS KIIL BUILDING!

Even thinking about this brings me out in a cold sweat. I was **ABSOLUTELY USELESS** at it.

You started by dismantling the whole thing which had been sterilised at the end of the last treatment. And then you started to rebuild the thing.

You began by laying a sheet of the membrane on the bottom board. This had to be done with absolutely no holes, snags or air bubbles. One person stood at one end and the co-worker at the other. Between them they laid the said membrane, (which to all intents and purposes, resembled “Clingfilm”) smoothly across the board. Then you laid the next board on top followed by the next sheet of membrane and finally the last board. Then it was all bolted down and you tested the apparatus with a pump to make sure “it held”. If it did it was a miracle and if it didn’t, you had to start all over again!

This had to be done every fortnight and we usually did it on a Sunday morning. It took quite a time even if it worked first time. And if it didn’t, I would start fretting about the state of the Sunday lunch. For Stephen it must have been like trying to put up a tent or assembling flat pack furniture with somebody all thumbs -a situation fraught with difficulties. As time went on, and for the sanity of the family, it became more usual for Stephen and a “child” to undertake this operation.

I think if I’m honest the root of the problem may have been that I rather resented this intrusion into a “non- dialysis day”.

(What's more I still frequently get in a dreadful muddle with Clingfilm)

Another time-consuming chore was the checking of supplies and then ordering the required amounts for the next delivery. These were very bulky, heavy to manoeuvre and took up a lot of room. They were stored carefully in the garage.

As time went on, we became more confident and adept, and hence, a bit quicker at managing the procedure. Life got easier for Stephen because as the fistula develops and toughens with use the needles are easier to insert. (The patient is the one trained to insert the needles).

If you ran into real trouble the system was that you rang the Unit, and there was always a technician on call to try and rectify machine hiccups, also, of course nursing and medical back up.

I remember one of the first times we rang and a soothing voice said "now, first, have you made yourselves a nice cup of tea"

No, but we've had a sherry!



They could usually sort us out and as time went on, we needed their input less and less. The calming way they set about helping was invaluable.

The technicians came if necessary, for emergencies and also to service the machine regularly. Flooding was always a bit of a worry but this only happened once.

The normal dialysis routine went like this. We were both working full time. Stephen would often get home first and start preparing the machine and I would get home as early as I could, to assist in getting him on, before starting on a meal for all and evening chores.

The arm with the fistula had to be kept still along the arm of the chair (in his case the right arm as he was left-handed) but his left hand was available and often put to good use. He was also a captive sitting target for helping with

homework, listening to flute practice and doing things like planning our holidays.

Two people in the Unit were on hand to make our life run as smoothly as possible.

They were Molly, a really lovely lady, the home dialysis organiser, and George who was a peripatetic dialysis nurse and an absolute Godsend to us.

According to my diary he first came to “process” Stephen that November while I attended a Sales Conference. He was ex forces and a great guy and did everything, served the meals I left and so on, and he and Stephen got on really well.

With us both working full time we were worried about Clare,13, and Robert, 10, being alone until one of us got home from work. One night I was at the Doctor’s for some forgotten reason and got talking to a lovely lady, Christine Berry, whom I had never met before. Burbling on as ever my worries spilled out as I explained our predicament.

“Oh!” she said. “Julie can cover that”. And so, it came about that Julie, who was 16, and at the same school as Clare and thereby travelled on the same school bus, would come and mind the children until one or other of us appeared.

This was all arranged by Christine without her feeling it necessary to consult Julie! Fortunately, Julie seemed happy to go along with this – I guess we paid her something but I really can’t remember.

Julie was a very special youngster and they all got on splendidly. The arrangement worked well, and we arrived home to a happy household homework done and the children fed. This arrangement went on for several years.

Our association with the Berry family goes on, but it was a bit of a blow when Julie married an American Airforce man and went to live in California.



As time went on, we enlisted others to help us. In Lechlade it was a lovely man called Mike. We met him at a party and when he learnt what we were up to he volunteered to help. He was in the RAF and did tours of duty, and then had maybe a couple of months at home. We trained him up, and I would put Stephen on and he would come at whatever O'clock later. I let him in and he would take him off so I got an earlier night. One of the men in my life who rarely saw me dressed!

We also asked the children if they thought they could learn to take Stephen off the machine in case some crisis arose.

They both said yes and could do this competently- Clare somewhat reluctantly, but Robert didn't mind and would do it voluntarily every now and then. Fortunately, Clare was only called on once in an emergency situation. This was when I dropped a teapot full of boiling hot tea on my foot carrying it upstairs. Clare took Stephen off the machine acting under his instructions. He was then able to drive me to Cirencester Hospital A and E.

The Wrefords, Jan and Co, were always ready to have the children for weeks in the school holidays and worked round us at busy times such as Christmas, often coming to stay and help with the festivities.

Another tremendous source of back-up was the Davies family. I had known Carol and we had been great friends since we were about 15. Carol married the lovely Frank and they had two children, Christopher and Kate.

They had our children for a week nearly every school holiday.

Sadly, Carol died in 2011, at the age of 64, from a brain tumour – she is sorely missed -one of my greatest and totally thoughtful and dependable “backups” gone.

On the whole we didn’t tell people about our somewhat complicated lifestyle, I think because we thought it unnecessary and also if we did, they probably wouldn’t fully realise the implications and life changing adjustments involved, and nor, indeed, did they need to.

Things went along relatively smoothly as we gained in technique and confidence, all the while hoping a transplant opportunity would come our way.

1980

Stephen started attending the Six Counties Kidney Association Meetings to keep abreast of developments and went pretty regularly according to the diaries.

Various possibilities were discussed and implemented.

One such proposition was put forward by the widow of a recently deceased patient.

The widow, whose name I forget, had moved to France where she had bought a house with a sort of cottage in the garden.

The proposal was that the cottage would be



renovated and made suitable accommodation for a renal patient and family to utilise for holidays.

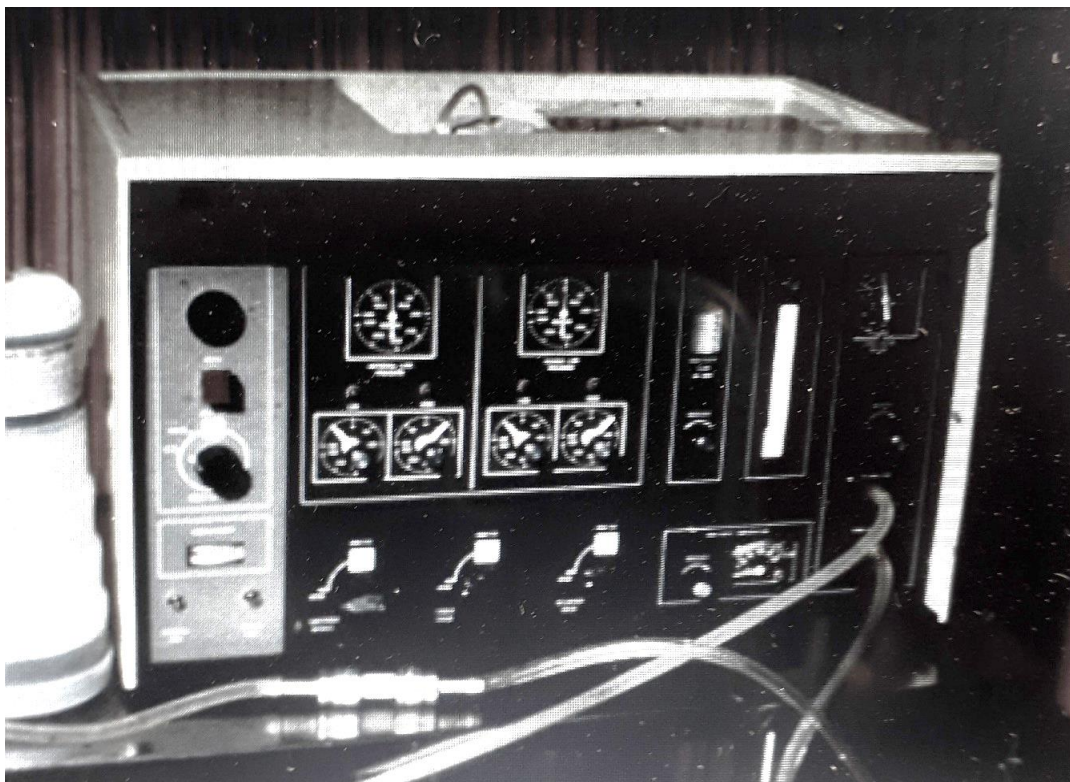
The visiting patient would take a portable kidney machine with them and she would ensure that the necessary water and electricity supplies were adequate. She also said she could act as the “helper” on occasions to give the usual accomplice a break.

The renal unit would arrange for the very bulky supplies to be delivered direct to the destination. We would travel with the portable dialysis machine and everything necessary for us to perform two treatments, in case of any hitches.

We were to be the guinea pigs in this marvellous opportunity. Sounded too good to be true. What could possibly go wrong?

The first thing to do was to learn how to use the portable machine. This went under the name of a “Redy”. A misnomer if ever there was one!

And so we went to the Churchill a couple of times to familiarise ourselves with this curious equipment.



Reference 4

This machine was somewhat rudimentary and not as efficient as our usual method of dialysis, and thus only suitable for short term use. However, it had certain advantages as the parameters needed for successful dialysis could be adjusted by the helper quite simply. The acidity was tested using a litmus paper then some suitable action was taken, (sloshing in some extra liquid? I don't remember what) and another adjustment was made, when necessary, by me turning something with a small screwdriver. (Again, I don't remember what this adjustment did). However, all quite simple and judged to be within our capabilities.

We decided to go for three weeks in the August school holidays and planned an overnight stop on the way down, thus arriving in good order fairly early on the second day, ready to perform a treatment.

We were provided with various documents from the Unit, for example the contact numbers for the "Redy" Technician for that region in France, letters for the local hospital in case of an emergency, and we also had our E111 medical cover forms.

Clare was now 13 and Robert 11. This would be our first family foreign holiday and so all very exciting.

We would leave on Friday night after work and take the overnight ferry from Portsmouth to St Malo.

Packing the car was quite a challenge, the machine taking up most of the boot with the bulky cylinders and fluids behind.

Going somewhere hot meant we didn't need too many clothes, but we were packed to the gunnels and Clare, who was learning the flute, decided it had to go with her, and she had it on her knee for the entire journey.

We dialysed on the Friday afternoon, squeezed the final bits into the groaning firm's car and set off for the Portsmouth to St. Malo overnight ferry with some trepidation. All day the News was about the strike of ferry workers and the effect it was having at the ports at the height of the season. Not a very auspicious start, nevertheless, we set off and on approaching the ferry terminal hit queues and queues of traffic held up by the strike. To our great relief, our carrier, Brittany Ferries, were still operating but the holding area had to be seen to be believed. We were soon packed in like sardines, row after row, and there was very little movement anywhere on the

quayside. I had a “bit of a moment” and said “what if we need to and can’t get out”?

“Never mind” says Stephen “there’s an ice-cream van over there with a generator, we can plug into that.”

“Many things, Stephen, I have done for you and would do, but dialysing on a quayside is not going to be one of them.”



Eventually, and to our huge relief, we started moving. Because of all the other cancellations, Brittany Ferries were trying to pack as many vehicles onto our ferry as possible. We were so tightly packed that we all had to scramble out of the one car door.

Despite all this it was exciting to be on our first cross channel ferry as a family; we settled into our cabin and then went to find something to eat, and so began the custom of always having those delicious, great bowls of, oh so French, “Frites” as a nod to the realization that the French holiday was really beginning. I’m not sure anyone got much sleep but sailing into St Malo that Saturday morning for the first time is a treasured memory.



The Barrage

We were one of the first cars off the ferry and as we set off, quite a few cars followed us, hoping we would lead them to the nearest motorway network. Little did they know that we were heading for the Barrage de Rance, the pioneering tidal hydraulic power station and a tremendous feat of Civil Engineering that Stephen was very keen to see this and had it all planned. Imagine their surprise when we stopped and made this the place to have our picnic breakfast of kedgerree! How sophisticated!

We took our time travelling South, enjoying the new sights and experiences. I don't remember where we stayed overnight. It rained the first day which was a bit disappointing, and slightly worrying, with so little space in the car, our very few clothes were all only suitable for the hot weather we were expecting. However, on the second day the weather cleared and we arrived at our destination early on the Sunday afternoon.

Now remember this was the carefully selected accommodation organised by the Unit in all good faith. It was in a hamlet near to the town of Sauveterre de Guyenne in the Gironde region and 42 kms from Bordeaux.

Great excitement and relief as we drove up and found our hostess.

I shall never forget the sight that greeted us.

The cottage was there, true enough, but every bit of furniture was in the garden and there were several workman milling about, (on a Sunday afternoon?) looking busy. But it was painfully obvious that the place was nowhere ready for occupation, and certainly not ready for the dialysis treatment which Stephen, was, by this time, in need of.

Added to this our hostess, who was bare armed, was covered in bites, (? flea bites). She was VAST, and I remember thinking if it was a flea, it must have died from exhaustion by the time it covered her wrist to her elbow.

Our collective faces fell but we were assured that it would all be ready if we were to go away for a couple of hours and then return.

Stephen and I walked down the lane and had a team talk. We decided there was no way this building site could be ready in a couple of hours, or even a couple of days and that it really didn't seem a viable possibility that we could stay there at all. So, explaining our fears to the children we set off as if we

were going to return as suggested, but in actual fact to try and find alternative accommodation.

Here we were, on a hot day in rural France on a Sunday afternoon when most things are shut, tired from our day's journeying and wondering what to do next.

Fortunately, the Tourist Office in Sauveterre was open. We had a bit of difficulty explaining that we had a kidney machine with us and that there were certain requirements needed to operate it. This being August she could not come up with much but suggested one possible accommodation.

We were slightly worried by this time, but with few options, so set off to find the property. The owners were a Monsieur and Madame Jourdes. Once again we tried to explain our predicament and that what we needed most were reliable water and electricity supplies.

The Jourdes were a fairly elderly couple, and their house did not inspire much confidence in us. However, we persevered and followed Madame across a paddock.

I shall never forget Clare's face as she stopped at a ramshackle shed and opened the door; what a relief to find that this was just to pick up a key!

Not that the gite was a lot better- basic in the extreme- however it was clean, and Stephen promptly tried the tap. The pressure seemed okay and Madame assured us the electricity was reliable.

There was only one bedroom and a sofa in the living room and the whole place was very dark, but we decided to take it.

The Jourdes did not provide linen, and we had none with us, but Madame rallied round when we managed to explain what had gone wrong with our plans, this being quite tricky, they having no English at all and our French being pretty basic.

She was delighted to hear that the neighbouring English Madame was "non propre" and set off to find bedding, returning shortly with Monsieur and something else. She said she thought that in England at about this time we would drink tea so they had brought us "Thé Francais" – homemade white wine. It certainly blurred the worried edges. We could have this wine free and also anything they grew in the garden, except lettuces, for which we had to pay.

We settled ourselves in and it was decided that Stephen would go back to the unsuitable cottage to collect the supplies delivered there for us, and tell the “Non propre English” lady that we would not be staying there. We thought that if he took a child with him, she could not be too unpleasant. Stephen set off with Robert. Clare and I stayed and unpacked. Their visit went okay, nothing had changed in more than two hours so we didn't feel too guilty.

When they got back, Stephen was understandably keen to open the supplies that had been delivered there, and check that all was well.

Quelle horreur! The wrong supplies had been sent. Never mind, we had brought supplies for two treatments. Time for another quaff of “Thé Francais”.

We managed to get ourselves together and set up the Redy successfully and the much-needed treatment went smoothly. When it was finished the machine had to be sterilised ready for the next go. This had to be done using formaldehyde and we hadn't reckoned on the appalling smell it gave off. The poor child who had to sleep on the couch had this to contend with – it really was overwhelming, but we all survived till morning.

Glorious weather greeted us, thank goodness, and the first task was to get the supply situation sorted out. So off we go to Sauveterre bright and early and partook of a delicious breakfast of coffee and croissant whilst waiting for the Post Office to open. Sitting in the sun in the attractive square soon lifted our spirits somewhat. As soon as the Post Office opened, we were on the case. With only slight difficulty we managed to convey the need to call England and Oxford. Stephen got through to the Unit. A worried sounding Molly came on the line.

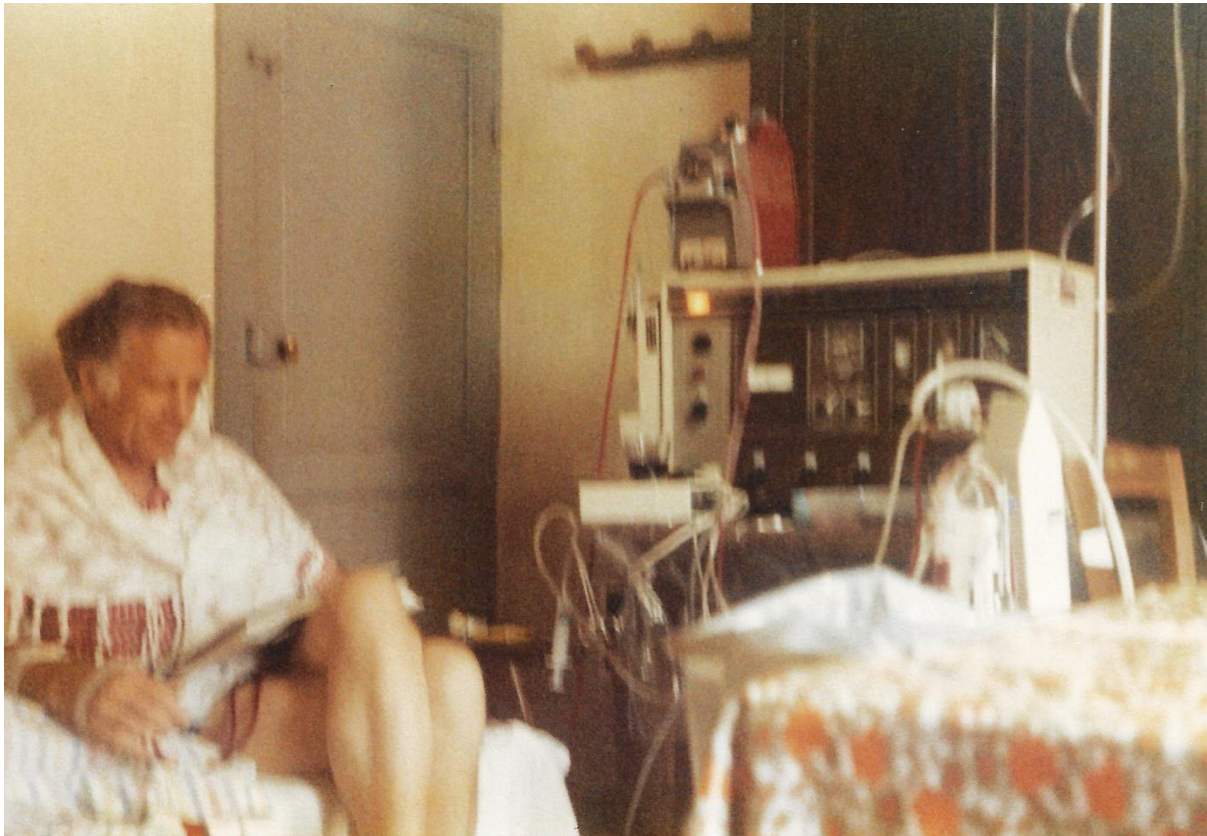
“Stephen, you're meant to be in France” (probably hoping we were out of sight and out of mind for three weeks!)

“We are. Only a couple of problems; the accommodation wasn't ready and the supplies the French company have sent are wrong”.

Poor Molly. She had tried so hard to organise a very special holiday for us; like us she was disgusted with the owner of the accommodation who was, theoretically, au fait with dialysis needs, and had promised so much.

We were to phone Oxford again when the correct supplies arrived. This happened pretty quickly and back we went to sleepy Sauveterre, where the telephonist took one look at us and said, “Oxford” with the most glorious intonation, and then another delicious breakfast in the sun.

Stephen stoically sat in a not very comfortable chair and endured the hours of dialysing. He, as always, got rather cold – I have no idea where the shawl came from!



Once all was sorted, we got down to the serious business of enjoying our holiday.

France had one of its hottest summers that year – a bit of a trial for me as I really don’t do heat. I seemed, from photos, to have been wearing the same cool dress the whole holiday. I suspect copious amounts of Thé Français didn’t help my cooling mechanisms!

The Jourdes were great, very friendly, with a son who had some challenges in life. When Monsieur learnt that Clare had her flute with her, he brought his trumpet over, and dreadful music was made and they also brought homemade champagne (free) – yet another challenge to be reckoned with!

They had lived through the war just South of the Maginot Line and a lot of their friends and neighbours were North of it and life had been pretty difficult. I guess we were lucky that on arrival they didn't take us for Germans.

When we came back from our days out, I set about preparing a meal and gathering together the necessary ingredients.

Robert was sent across to the Jourdes to practise his French and ask for the fruit and veg we needed and to pay for the lettuce. After about a quarter of an hour, and no sign of Robert, Clare was sent to see what was happening, another quarter of an hour and still no sign of returning children, so Stephen went to sort it out, again nothing. Eventually across I go, and there they all are sitting in their shady arbour on swinging seats enjoying yet more "The Francais".



There was a lake nearby for cooling off in the extremely hot weather. We also visited Bordeaux, where it rained and cooled me down so I could actually walk without thinking I would collapse in a heap. (In fact, I only did that once).

Whilst exploring Bordeaux, we tried, what was to us, the new type of public toilets, situated on the edge of the pavement. We thought we “girls” would be clever and go in together, and were somewhat taken aback to be suddenly exposed to all passers-by in Bordeaux and virtually ejected. Our time was up!



We also visited St Emilion, arriving as typical tourists in the heat of the day, with all the village sensibly inside away from the glare of the midday sun. The only other living thing we saw was a camel tied to a phone box! Never did discover why.

On the return journey North we stopped in Beaujolais country and bought as much wine as we could hide behind the Redy, filling the space in the boot where the stores had been on the way out. We bought from a Monsieur Siffert, who was mesmerised by our very blond teenage daughter, and recognised her, if not us, on a subsequent visit a couple of years later.

Those were the days when there were limits on the amount of alcohol you could bring back to the UK.

Approaching St Malo, we were flagged down by two gendarmes, probably because the car was so obviously carrying a heavy load. So out we get and

open the boot as requested. They were a bit baffled by what they saw, and when we explained what the machine did and why we needed it they were none the wiser but waved us through rather than get in any deeper.

So back to reality and both back to work, Clare to Farmors comprehensive where she had started the previous year, and Robert started at Rendcomb College, where he had been awarded a scholarship and started boarding.

My diaries are scant in the extreme but there are some interesting entries by Stephen in December.

They are

15th D

18th D

20th D

22nd D

24th D

27th D

And this was us planning treatments to fit around the Christmas Festivities.

1981

This year our holiday was to a cottage in Norfolk. The cottage was lovely, in an old mill on a fast-flowing stream, and the weather was kind. However, we soon realised that the disadvantage of holidaying in Britain was the fact that we had to take 2 cars to accommodate all the paraphernalia for the Redy, plus all the clothes necessary to contend with any of the variety of weathers that an English summer might throw at us.

I only remember one rather unfortunate happening. We decided to go to a remote stretch of beach as we don't really do crowds. It proved quite a trek from the car park, carrying all the gear we considered essential. Suffice to say it turned out to be a nudist beach and bearing in mind our attractive blonde daughter it wasn't quite as peaceful as we had hoped!

There are quite a lot of entries this year where Stephen attended the Six Counties Kidney Association meetings.

At this time there was a move afoot to change the mish mash of differing types of Kidney machine prevalent in the unit, and change them all to one of the newer models, the latest Cobe being the one chosen. This would simplify training, maintenance, stores and all manner of things. But the greatest benefit to the likes of us was the fact that these machines would run with disposable 'kidneys' (dialysers).

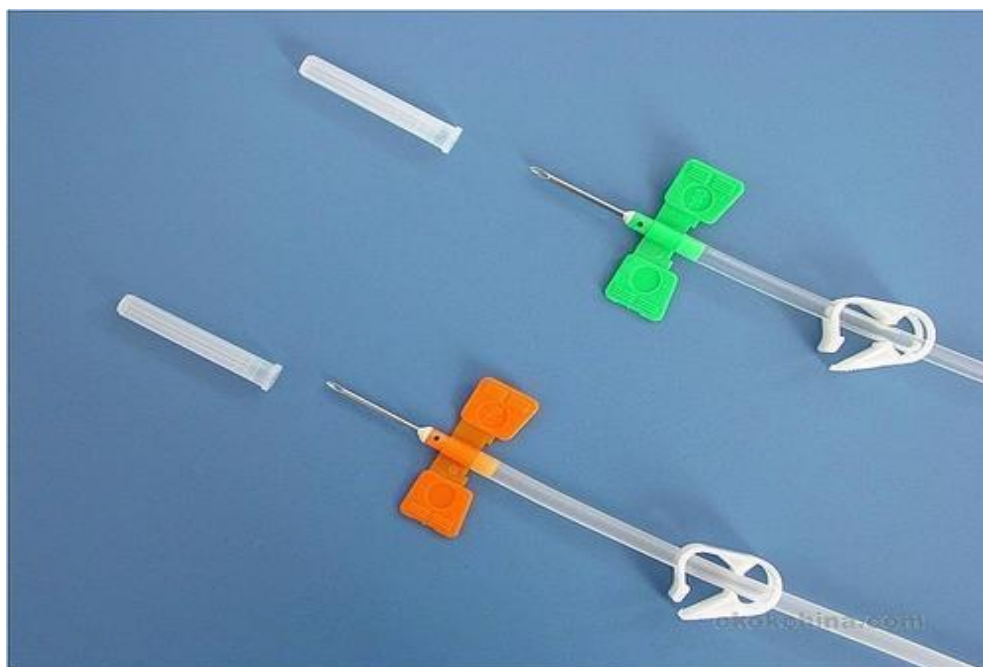
Death to the Kiil! What a huge relief and think of all those free Sundays!

Surely too good to be true and of course there was a snag to be overcome. We needed to fund raise £5000.00 to help cover the cost of our new Cobe machine.

Great! Stephen flatly refused. He had no wish to be the object of other peoples' charity. Time went by but he did eventually swallow his pride, and knowing the huge advantage and relief it would be for us all, decided we should crack on.

We thought we would try and raise the money with one big event and settled on a sponsored walk. A date and route were chosen and the walk was to be about 5 miles around the picturesque Coln Valley between Lechlade and Cirencester. To publicise this, we carried out various activities and in July I gave talks to the Womens' Institute, who agreed to be in charge of refreshments on the day, and to the Lechlade Probus group who said they would help by acting as Marshalls on the day.

I also gave a talk to the science students at Clare's school. It took place in the lab, with the students sitting on stools at the benches. It all went quite well until I, perhaps rather foolishly, got out one of the rather large fistula needles whereupon a girl fainted and fell off her stool. I didn't try that again!



Reference 5

I was by this time well into my repping job and knew a great many doctors and pharmacists in Gloucestershire and beyond. These were shamelessly tapped for sponsorship. Most gave very readily, but two incidences stand out vividly in my memory even today.

One was a call on a pharmacist who I got on really well with. I did my spiel and rather expected he would be fine with it. Instead, he hesitated and asked me to go back at 2 o'clock that afternoon. I, of course, did so and he had meanwhile, been back home to talk it over with his wife. The upshot was that he handed me a cheque for several hundred pounds!

Not so good was the reaction in one surgery I visited. I had finished my work and having coffee in the staff room which was, as I remember it, pretty full with Doctors, Nurses and all manner of staff. I stood there and explained the situation re raising money for the updated dialysis procedure, whereupon the senior GP stood up in a real fury saying "I have never heard anything so ridiculous in all my life" and stormed out. Silence. I packed up and slunk out.

Sometime later we received a substantial cheque from all at the surgery. It transpired that the GP was absolutely furious that we were having to raise this money ourselves.

The day in September dawned fair and we managed, with the help of a great many walkers, to raise the £5000 in one fell swoop – thank heavens for that! And thank you to all the Marshalls and helpers too!

You can't imagine what a difference the new set-up made – no Kiil building and the dialysis itself more efficient in its action.

The other really major event to take place in 1981 was the amazing news on October 5th that the Unit had a donor kidney, a match for Stephen and could therefore offer him a transplant. Imagine the excitement!

Stephen had the operation, and the actual procedure went well. The operation was performed by Professor Peter Morris, transplant surgeon to the Unit.

I remember Robert wanting to know how the offered kidney had been transported and he was intrigued to hear that it had been rushed from A to B by a blue light police motorcyclist.

At this point the procedure was, once operated on, the patient was isolated and in solitary confinement in a special room adjacent to the dialysis unit. This was because the drugs given to prevent the body rejecting the new kidney compromised the immune system. Stephen was barrier nursed and only allowed one visitor.

Hopes were high for a successful outcome. What a difference it would make to the lives of us as a family and our earning capacities and hence tax contributions to the state etc and also stop us being such a drain on the NHS.

However, after a promising start, things began to go downhill. It was not the half-expected rejection but a gradual loss of the new kidney's functioning. After the operation Stephen's blood pressure went back to its default setting of virtually uncontrollable and afterwards, I always thought that this defeated the new kidney before it had a chance to get established.

Stephen became increasingly unwell and it looked as if we might end up going back onto dialysis which would be hugely disappointing

He remained in solitary confinement with only me allowed to visit. A challenge in itself for the patient when you reflect that solitary confinement is regarded as one of the harshest punishments handed out to criminals.

I visited daily and at weekends took the children who had to stand on a box outside his room and speak through the glass.

It was a worrisome time and at some point, I was meant to go to a sales conference with Eli Lilly in Brighton which involved a couple of nights away.

I discussed this with my bosses and said I really didn't think I could go. They were very understanding and helpful.

They came up with a plan to "Help" me. I would visit Stephen in Oxford and then meet up with the Oxford rep, who would take me to Brighton, saving me the stress of the journey. We would do the same in reverse on the way home.

On arriving back at the Renal Unit, I had a nasty shock. Stephen had deteriorated rapidly. I was somewhat taken aback at his appearance and after this visit, arrived home tired and emotional.

On this occasion George and Edith, Stephen's parents, were minding the shop in Lechlade. They were often ready to be slightly critical and I felt Robert did me no favours as, when I got home, totally exhausted and worried to death, he opened the door, and with Granny Edith at his side, took one look at my face and said "Ah! A whisky night I think!"

The weeks dragged on with various relatives helping out. My days went like this; work all day around Gloucestershire, rush home, eat and set off for Oxford 30 miles in the opposite direction. At least we were allowed a bottle of sherry in the room! I arrived, chucked Stephen off the bed, had a sherry, chatted, sometimes watched a bit of telly together. My Aunt Jean kindly came down from Scotland to hold the fort for a while. I remember Brideshead Revisited was being shown on Television, (such a desperately sad story) and on a Thursday night we would watch that, and then after an hour or two of rest on Stephen's bed, I drove 30 miles home. All in all, I was driving nearly 1000 miles a week.

Tony Garthside was very supportive at this time. They now lived near Dorking and he had quite frequent business trips to Burton – on -Trent. He would call in and see us in Lechlade on the way home for a brief visit to see if we were okay, and then set off for home, often via the Churchill. Quite some detour.

Eventually the “new Kidney” was removed, and Stephen was released onto the Renal ward to continue his recovery. I remember one of the technicians, seeing him walking around, said “Well Stephen now I know there’s life after death”.

Then the inevitable chest infection struck, setting him back even further.

Prof Morris came round and said “Stephen, we haven’t half bugged you about – is there any thing you’d like?”

“Yes” says Stephen “Friars Balsam.”

This was speedily supplied and Stephen came home after 17 weeks in hospital, weighing just about 9 stone and incredibly weak.

It was wonderful to have him home again but of course desperately disappointing that we were back to square one. Not that you ever heard Stephen ranting or raving about it all. He was amazingly stoical though, of course, when we were alone, we had some reflective moments.

One of the consequences of the situation was that Stephen was so weak he couldn’t insert the dialysis needles into his arm. As time goes on the fistula gets tougher and it needs a bit more pressure to position the needles. At this juncture, it was simply beyond his strength to perform this function.

So, it was decided that I would have to do this until Stephen regained his strength. I don’t know who was more appalled by this prospect. I was terrified lest I missed or mucked it up and one can only imagine how Stephen felt watching his left-handed (Cack handed?) wife advancing with a huge needle.

As I said, I was repping around Gloucestershire, including the Gloucestershire Royal Hospital. Here there was a Surgeon called Mike Gear, whose wife was also on Dialysis and under the Oxford Renal Unit. One afternoon I presented myself to the Theatres and asked if I could see him. He agreed and I explained my predicament and asked if he had any tips. To my complete surprise he said he would come over one night and help us. Bearing in mind he was a busy surgeon and we lived quite a way away in Lechlade, this kind offer was so very generous.

So over he came on a dialysis night. We began by drinking sherry in the lounge to relax us all. Then upstairs and the lesson began. He said to abandon the use of the tourniquet to get the veins to stand out and use the

blood pressure machine cuff. Then to get the anglepoise, (provided) and shine it across the area, making things much more obvious – such a help.

He said using this method you could gain access at almost any point including a vein in the neck! Stephen's face was a study of pure horror at this suggestion, and fortunately we never had to resort to this!

Thank you so much Mr Gear, it was such a help and it worked! And Stephen was soon able to do it himself as usual.

I think at some point I must try and describe Stephen's character to you. He was a highly intelligent and well-educated individual, determined and stubborn with wonderful blue eyes and a divine speaking voice. He had very definite ideas on things and one of the things he hated most was the way people, doctors included, treated him (in his opinion) like an idiot the minute he was in pyjamas. He worked hard at his Civil Engineering and enjoyed the designing side. He often pondered over the fact that he did endless calculations to the nearest centimetre and then relied on a man with a digger to set it out!

Stephen was very "grounded" and not overly impressed by those trying to outdo one another. For example, we were once at a party where the conversation was going "Oh isn't it dreadful flying into Hong Kong – one thinks one is going to land in the sea" and so on. After a few minutes of Cotswold braying in this mode, Stephen said apropos of very little "Did you know that Black Faced sheep can jump three foot six?"

Fortunately, we were not very inclined to contemplate our navels and basically, we rarely had time to stop and indulge in deep thoughts. But this does not mean we never had occasional wobbles and New Year's Eve was usually tinged with worries over what the coming year would bring.

1982

There are only a few notes in the diary for this year.

One is that we acquired Jill, a rescue Dalmatian who took over the role of psychotherapist from our grumpy old spaniel, who had to be put down after biting Clare.

And then in June, Edith, Stephens mother, died. She had several times said, on visiting elderly friends in hospital who had become ill, that she would rather die than end up in a geriatric ward. Thus, when she had a fairly major

stoke, and came to in hospital, she looked round, didn't like what she saw and died a couple of days later.

She was cremated at Slough Crematorium and the ashes were to be buried, at a later date, in the hamlet of Turkdean, about 3 miles from Northleach in Gloucestershire. This is where our branch of Drapers came from. It is a beautiful spot and there are two rows of Drapers buried there.

This was to be a family gathering and all to come back to Lechlade for tea.

Stephen went to work in the morning and was to be home for lunch. I was at home baking and preparing for tea afterwards when the phone rang.

"This is Mr Sleigh" (the undertaker) "She hasn't arrived".

"What?"

Evidently, she was being posted from Slough to Mr Sleigh in Northleach and hadn't arrived as expected. What to do?

Mr Sleigh said he would go back to the Post Office and check again.

I phoned Stephen at work, who said helpfully "She was always late for everything".

I began to concoct a rather bizarre plan in my head. I won't elaborate!

Eventually another phone call from Mr Sleigh –

"I've found her".

By chasing around after every Post Office van in the neighbourhood he managed to locate her!

(Stephen had been determined to go to work for half a day as he had had to give up his very full on job as his health deteriorated and had just started less taxing employment).

August sees us in Meribel in the Swiss Alps where we had been lent a chalet by my brother-in-law's brother. This turned out to be very lovely and vast. We only used part of it so that we didn't have too much cleaning before we left. Still it is the only place we have ever stayed when after a week Clare suddenly announced she had found yet another bathroom!

Once again, we took the Redy which, though we were pretty rude about it, was great for holidays as there was not too many things that could go wrong and even those were easily fixed.

The family had been going there for years and had many friends there. One day, one such friend of theirs breezed in to make our acquaintance and was brought up short on finding Stephen churning away on the machine.

This was Clare Hohler, married to Arthur, and they were there with their four children down for a summer break in their chalet, their main residence being in Dreux in Northern France. On learning that we were planning an overnight stay on the way home they kindly asked us to stay with them. Clare(H) asked a lot of questions about dialysis and did Stephen have any dietary restrictions and if so, what could he eat. Stephen, with a twinkle in those blue eyes said "Guinea fowl and champagne".

And that's what we had amid great merriment!

Once on dialysis the patient's diet is not quite so strict as during that awful period leading up to the start of dialysis. Stephen could have such treats as cheese or ham on dialysis nights, so with careful menu planning, life was very much better and easier, and a lot pleasanter for Stephen. (Remember I had trained as a dietitian so not too difficult for me to manage).

One feature of Stephen's character was making sudden announcements, such as 'I've got a new job. We are moving'. It sounds ridiculous, but as I would have followed him to the ends of the earth, it didn't really matter! On one occasion I did say "what if I don't want to go?"

"Well (again that big twinkle in those blue eyes) "I guess you'll have to stay behind'. I went.

Around this time, in September 1982, Stephen announced he was going to start an evening class in Burford to do silversmithing.

I remember being a trifle peeved about this, selfishly observing that dialysis took up 3 nights a week and now yet another evening was taken up. But it was wonderful therapy for Stephen, and a great outlet for his creativity,

It was an example of his determination to carry on a normal life, -to put a lot in and to get as much as possible out.

Silver was bought, at great expense, from an accredited supplier in the Birmingham Jewellery Quarter. This was exciting stuff but I was massively

disappointed when the package was opened to reveal a small square of metal resembling the inside of a baked bean tin.

Stephen, a complete novice, fashioned this into wonderful objects. His piece de resistance was an incredible cruet set which he designed and made.

I was massively impressed with this beautiful creation and suggested, that for a Christmas present, I could buy him his own personal hall mark. To register this, it was necessary to send the finished piece to the assay office in Birmingham. I was very pleased with myself for suggesting this and off it went. A few days later Stephen told me that if the silver did not come up to scratch the whole thing would be scrapped. A nervy week or two and then back it came. Whole and hall marked.



This is one of the most precious objects in this house today – and when Clare married, I took the set to a jeweller in Cirencester and asked if their silversmith could make a copy. The assistant said he would ask but that he would only co-operate if he approved of the piece. He made it. I did the same for Robert on the occasion of his marriage, this time taking it to the Birmingham Jewellery Quarter. Here the man I approached simply couldn't

believe it was designed by a complete amateur and suggested I should patent it – no thank you.

That September, Clare joined Robert at Rendcomb to study for her “A” levels, having gained highly respectable GCSE results.

I think at about this time in the early eighties, there was a lot of hype in the media about the rights and wrongs of life support systems. I became concerned that dialysis could be seen by some in that light and that people could question its long-term use. I turned to the Renal Unit for advice and arranged a meeting with one of the doctors. We sat across what seemed a very large desk and I explained my concerns. The sensible young doctor, Tim Dornan, who I had not met before, heard me out and then said

“What are your options?”

I replied “I don’t think I’ve got any”.

“Exactly”

and then came what has been brilliant advice and used subsequently on many difficult occasions, and still used, when necessary, to this day -

“Well Andrea, you’ll have to have ‘don’t think’ days.” Brilliant!

Nowadays I have also added another mantra and have the occasional “be nice to Andrea” day when I do exactly as I please.

The only other thing in the 1982 diary is the Christmas planning!

December 13th D, 16th D, 18th D, 20th D, 22nd D, 24th D.

(There was always the added complication of Robert’s birthday on the 23rd!)

We evidently had an “Open Day” at home in December – I can only guess it was to show people what we had acquired through their efforts in our fund raising. I have no recollection of this whatsoever, but Clare assures me it happened.

1983

Early this year I had a career change and went to work for Cow and Gate in Trowbridge. They had been taken over by Nutricia of Holland who marketed a range of enteral feeding systems. My job was to recruit and train a team of

Dietitians to sell these products. A big challenge and change for me, but interesting and rewarding.

Another project was underway. For some time, the Six Counties Kidney Association, in conjunction with the Unit, were exploring a new scheme for holidays in France.

The proposal was to buy a mobile home on a campsite that was under construction in the South of France.

Fortunately, we were not required to raise money for this enterprising idea. The original plan was for a smallish home and this would be equipped with the standard machines and supplies that we all now used. We thought this was a great idea, but Stephen thought that we should go for the largest mobile home available and in a prime position as this would maximise the use long term. And this was what happened. We had a large mobile home with three bedrooms that comfortably slept four and could accommodate more if sofas were converted to beds.



The site was in the South of France, a short distance inland from the Mediterranean and quite high up. The actual caravan was right by the perimeter fence and looked out over the forest. It was also well shaded

which was a blessing on very hot days. The site had tennis courts, a restaurant, and other facilities and we looked forward to visiting.

Our first holiday there was in the July of this year, and it was a great success. We had an overnight stop on the way down with no dramas and enjoyed a relaxing time exploring the South of France, and visiting the nearby beaches.

On the way back we had a detour to the Beaujolais region and, once again, bought Moulin a Vent wine.

I am reminded by the diaries that we led a full life beyond the confines of the dialysis regime.

Such things as French exchanges for the young went on and this year we had Julian from Annecy and Robert had a return visit there

Again, In Stephen's handwriting there were dates for dialysing to accommodate Christmas. It was a good year, with no dramas.

1984

In early 1984 Stephen had a second chance of a transplant. Great hopes and expectations again. The actual operation was once again successful and this time, as practices and knowledge had moved on, no isolation and no solitary confinement. We asked if it would be OK if they just went for "the best-known outcome method" i.e. not go into any trials, something the Unit were always taking part in.

However, disappointingly, the result was the same and the kidney was removed and back to dialysis.

On this occasion the time in hospital was nowhere near so long but the disappointment greater as I don't think anyone could countenance another try.

But once again Stephen recovered and went back to work as soon as possible.

It was one of those tense years academically with Clare doing "A" levels and Robert "O" s, but despite the difficulties at home they acquitted themselves admirably.

Our holiday that year was to a Gite near La Rochelle, once again taking a portable machine.

But before we went, Des, always keen to innovate, had been looking into alternative types of portable machines, and asked us to go over and try one which he thought was an improvement on the Redy.

It was called a “Suitcase” model. Humph! And yes, it was the size of a fairly compact suitcase BUT all the many “Pipes” and lines had to go in to all the right spots on this relatively small surface. When set up it looked like spaghetti junction. We were asked what we thought. I remember saying I wouldn’t have a clue what went where after a glass or two of wine. Furthermore, all the waste water borne products passed into large plastic containers which I had to empty when full. They weighed a ton. I was not impressed and said so. Des said I was no fun anymore! The suitcase model did not appear again.

We took the Redy.

Not our best holiday! We took a gite near La Rochelle. It was not brilliant and in the middle of rather flat and uninteresting countryside. It was however enlivened by the completely unexpected arrival of Tim and Hilary Lane. Tim being a master at Rencomb. All very strange and never really got to the bottom of this and how they knew where we were.

But I have been eternally grateful ever since, as Hilary took the most wonderful photo of Stephen which she subsequently gave to me and is, again, a most treasured possession.

As all hopes of a successful transplant were abandoned, we set about thinking of ways we could improve the dialysis side of life.

‘I know, we’ll move!’

Not as daft as it sounds. We were pretty fed up with night after night in our sterile treatment room with its strip lighting and general discomfort. But the greatest benefit we felt we could achieve was due to the fact that the ideas on home dialysis treatment had moved on. If we found the right property, we could set it up in such a way that Stephen could have the treatments more in the body of the family. The rigours of sterility had been relaxed, although great care was still required, and with the improvement in the machines the risk of flooding was greatly reduced.

And so, we set about searching for a house that could accommodate the machine more sociably. In the Autumn we saw a house in a hamlet called

Winstone, situated just off A417, between Cirencester and Birdlip. It was called New Inn Cottage and was currently the village Post Office, having formerly been, as the name suggests, the village pub. It was structurally sound but very neglected and in quite a state. But we looked forward to doing improvements and Stephen, being DIY savvy could get stuck in to quite a lot of the refurbishment.



New Inn Cottage

When we first saw the house the post office's bullet proof screen and safe were still there, with a side entrance for customers. The screen was taken away by the Post Office but the safe was quite something and firmly attached to two walls and remained as a feature in what became our dining room.

The Unit were fantastic in supporting this scheme. The cottage had an open plan kitchen/ living room arrangement, the living room having an open fire with an alcove either side, and wonder of wonders, the perfect size in which to house the Cobe. There was also room for shelves above to house the necessary accoutrements.



Stephen felt he could design a folding door to hide the works when not in use and this was eventually constructed to match the new kitchen units.

We put our Lechlade house on the market and it sold quite easily. Our offer on the cottage was accepted, and on we went.

However, it took a bit of time to sort things out.

1985

Eventually, on a freezing cold day in February 1985, and in deep snow, we left our modern, cosy house in Lechlade and set off to the top of the Cotswolds.

The house was on a single track, no through lane, so nowhere for the huge van to park off the road. The house had a wall with iron railings on top and the snow was packed to the top of the railings! And all about the railing, inside and out was masses of ghastly looking rubbish, left by the 'dear departed'.

The day was perishingly cold. When the removal men saw the state of that place compared with what we had left behind I'm pretty sure they thought we were completely mad. The doors had been open all the day before while the vendors moved out and the house was damp. The temperature, even indoors must have been well into minus figures.

Never mind, on we go and try and light the ancient solid fuel range. There was a boarded-up fire in the living room. We ripped the boarding away and lit the fire praying it would work. I remember asking the men to look up at the chimney as they went in and out to check if smoke came out – it did and the fire worked really well. There were the most dreadful curtains at the living room window, I simply couldn't bear to look at them, so took them down and added them to the enormous rubbish pile outside against the railings.

Once the van had left, we were able to shut the doors and try and get warm. Our new neighbour, Pam, who we had never met, had taken pity on us and had sent round hot coffee and cake, mid-morning, which was a life saver. My Father, who had nobly come to help was muffled up in a scarf and hat the whole time.

I had made a shepherd's pie to heat up for supper, fortunately we had our electric cooker installed and working, and I tried to make the place look less gruesome with a candlelit supper. I got very annoyed with Pa who refused to take either the scarf or hat off for this very special occasion.

Suddenly the front door was flung open and a strange female came down the hall announcing "I've come to feed the goats". I think at this point Pa was

about to give up and we were more than a little bemused. It transpired that because of the bad weather the previous owners had been unable to move these animals. They were evidently living in the field we now owned, and would be collected tomorrow. She grabbed a bucket of water and disappeared back into the snowy night.

The next morning, again unbelievably cold, the most pressing task was to try and get the place cleaner before we had to dialyse.

It took roughly an hour to clean a radiator but the biggest challenge was the bathroom. We took it in turns to try and unblock the basin waste. Father with a glass of whisky and the Jeyes fluid was on the first shift, then Christine did a stint and finally, me, and eventually after several “shifts” we triumphed.

In the midst of the chaos the “old” owners came back to collect the goats. The wife (don’t remember their names) said she could see that we had taken down the curtains so could she please have them. Help! A surreptitious trip to the rubbish heap to retrieve them was successful.

We had the Redy for the first couple of treatments and all went well and very soon we had the Unit’s equipment in its rightful place with the drainage and all the necessary operations in place.

But what a wonderful thing it was to have Stephen in his reclining chair churning away and me in an easy chair opposite with a roaring open fire between us.

Thank you so much Oxford and the NHS. It transformed our lives in so many ways. It meant on dialysis nights we were all together as a family, and even better, we could give Stephen even more things to do! For example, preparing vegetables, including doing sprouts for 10 one Christmas (Needless to say, I got my come uppance as usual, when one year, as he was writing the Christmas cards, he decided to ask everybody who lived in a 2-hour driving radius to a party, about 60 came!).

We gradually got things put to rights and enjoyed the process and Stephen came into his own with DIY projects, such as tiling the bathroom, plus many others, and gradually the house became a really lovely home and we had happy occasions such as the “opening” of the newly refurbished bathroom with lovely tiling done meticulously by Stephen.

When the weather improved, we could set to outside where we had a couple of acres to lick into shape. Removing all the corrugated iron constructions (for the goats) was a challenge. At one point I became really very poorly and went to the doctor who diagnosed a giardia infection. They asked if I had been abroad, for instance to Russia. No, only to Bristol and Oxford. Eventually we learnt that there is evidently a strong association between giardia and goats! We bought a little tractor, for some reason called Eustace and Stephen got the grass into some sort of order.

We also demolished the "Post Office" entrance. So very therapeutic knocking seven bells out of something.

We had great times there and many parties and Pa felt rewarded one night when we had an "Out of Africa" party in the "orchard." It was such an unbelievable summer's night when in complete contrast to that first evening, we were outside till late at night and as Pa remarked the smoke from the candles actually went straight up, the air being so still.

A memorable evening.

It was also a great house for Christmas, which were mostly spent chez nous, Dialysis took place on Christmas Eve, and then we could have 2 days off. We made trestle tables that could seat fourteen. A lot of work but happy memories.

Also, this year I left Eli Lilly and went to work for Napp Laboratories, tempted by higher pay. A strange company and a move I came to regret.

This year we had, as far as I can tell, an uneventful holiday in the caravan in the South of France. We arrived home to find that Stephen's father, Grandpa George, had died. He had been in a home in Cheltenham for some time, which had worked well as I could pop in and out when I was repping around there and he could come to us in Winstone for the day.

My Father was staying in Winstone whilst we were away and had gathered up the young and they had dealt with the preliminaries. They had decided not to get in touch with us as we were, by that time, on our way travelling back North.

His funeral and interment went somewhat better than Granny Edith's, and he too, was returned to Turkdean, a place which was very dear to him.

After his death we set about clearing the house ready for its sale. This was a mammoth task. What Slough sewage works made of copious amounts of dubious home-made wine I can't imagine. And one does wonder why there was still jam, found in the attic, that was made in the war.

We were still working away trying to get the house in order, and in October and November were arranging for a lovely new fireplace to be built in the lounge, to accommodate a wood burner, made with stone from the local Farmington Quarry. We were also awaiting some new windows and for a Rayburn to be fitted, major steps to make the house both more welcoming and warmer.

Sometime in late November Stephen had a "bit of a do" and ended up in hospital. I can't remember the exact circumstances, or what symptoms prompted this but I know we drove over late at night and left him there, in good hands. He was kept in for a few days and dialysed there to try and sort out the problem.

I think this may have been when they found his potassium levels had suddenly gone off the scale. Anyway, a treatment sorted things out fairly easily and I remember a young doctor saying to Margaret the next morning "I don't know why they brought him in". Margaret replied "If the Drapers felt they needed help, they most certainly did". Thank you, Margaret.

But as they were not quite sure what had caused the problem, they kept him in. But on the Saturday Stephen pleaded with them to dialyse him on the early shift, as Robert was starring that evening in the school play at Rendcomb as Lysander in a Midsummer Night's Dream.

Fearing that Stephen would not be able to come Pa and Stella came to support us. Fortunately, Stephen's wish was granted and the call came that I could go and collect him.

So, home he went, far from well and we had a meal and set off. Thank goodness we made it. It was Robert's one and only foray into acting and he was brilliant. The cast were magnificent in hired costumes, and we were grateful to Stella, who had the presence of mind to bring a camera. Pa and I had never thought of such practicalities, we were more worried about parking as near as possible etc. and hoping Stephen could stagger in and get through the evening. She took a great picture and had it blown up to poster size and we still have it.

Then, in the diary, comes one of my famous lists

Things to do before Christmas

Curtains

Fireplace

Tiles (a lot of the downstairs had to be tiled in case the kidney machine flooded)

It was this autumn that our dear dog, Jill, a rescued Dalmatian, had to be put down. Robert said he wasn't coming home from school unless there was a dog there! We decided on a Pointer and found Zebedee, (kennel named Pipe away a Saint I ain't.) He must have been OK as I am now on my third pointer, all of them beautiful dogs but rejects for one reason or another. They have all come from excellent breeders. The latest one allowed to come to me because he would lean lovingly against the judges in the ring!

By the time Christmas came we were exhausted and very pleased to go to the Davies family for some R and R and Frank's wonderful gravlax, Carol's fantastic cooking and a great welcome from all!

As time went on, Stephen's health gradually deteriorated. Constant dialysis puts a strain on the heart and some of the necessary drugs have nasty side effects long term.

Because the initial cause of his problems was the raging hypertension his already damaged heart started to become a real concern. He became less able to do things and we adapted with some role reversals, for example, me gardening whilst Stephen cooked, very good he was at it too.

But life is a bit fraught when you have to keep doing "double takes."

For example, we had a large and energetic dog who needed exercise and walking has always been one of my chief joys and a time to reset in times of stress. So sometimes I wanted a really good walk but didn't like leaving Stephen, but then again, would Stephen feel worse if he knew he was preventing me having the exercise I craved? This dilemma was sometimes sorted by Stephen dropping me off somewhere and he would then drive round to the other end of the walk to collect me, and maybe even walk a little bit to meet me. Thus, I did quite a lot of new linear walks and often there would be a pub at the end.

We were always willing to do what we could for the Renal Unit and I remember one such trial Stephen was asked to participate in and, of course, said he would.

Some bright Oxford spark came up with the notion that long-term dialysis patients lost some of their colour vision.

Possibly not high on our list of worries. However, off we go to the Radcliffe Eye department for a jolly afternoon.

The test involved putting, what seems liked dozens and dozens of grey tiles of differing shades of grey (50?) into order from lightest to darkest.

Stephen, being determined not to have anything else wrong with him, and being a bit of a perfectionist and somewhat stubborn, was determined to get this right. Ages and ages went past! Why on earth didn't they put a time limit on it I shall never know!

1986

This year sees Clare studying in Newcastle and Robert at Rendcomb.

By the beginning of this year Stephen began to experience some rather more serious medical problems.

Early in the New Year we had a somewhat frightening incident. One Saturday morning, with snow on the ground, we went to Tesco in Cirencester where Stephen collapsed, and dropped unconscious, into the horrible slush in their car park.

I had just started to do a First Aid course, and had done the first lesson which was on resuscitation. Fortunately, it was all at very fresh in my mind. I did as I had been told and called for a first aider to assist me and was greatly relieved when a man stepped up to help. He put his ear to Stephen's chest and said he was dead. I was incandescent with rage as my lesson had just taught me never to say this at this juncture. I was so angry I gave a great thump to Stephen's chest and he came back to us!

Cirencester has a hospital staffed by local GPs and he was taken there. The doctor on call did an ECG and can't be blamed for being completely

bamboozled by it. I told him not to worry about it but just to get him to the Oxford Renal Unit, where he was well known.

Stephen went off in an ambulance and I went home to pack a bag for him and then set off for Oxford. Because of the snow, I also phoned Robert's school, which was only a few miles away, explained the situation, and asked if I could collect him en route. The weather was dire and as the snow was quite deep, and with my life-long loathing of snow, I felt I could do with some support.

The school said he was playing in a hockey match so I said I would collect him after it had finished and that was agreed on.

Whilst at home the telephone rang and Des Oliver is on the line and saying "Where are you?" (But not quite so politely as that).

I explained the plan and said I would be there a bit later. "You're to come now". Terrified, I rushed and got Robert and we set off. By the time we got there they had discovered his potassium level was off the scale again and were dialysing him, and he was recovering.

High Potassium levels, or hyperkalaemia, can occur where kidney function has failed and can be exacerbated by certain drugs. This can cause the heart to malfunction.

He was kept in, and I visited him, only missing so I could carry on with my evening first aid lessons. When I visited after the next class, he asked what he could do next – I said "You can break a leg" but, fortunately, he decided he didn't fancy that!

The snow was really bad but I was back at work, and Pa came to provide moral support and to mind the dog. I went off to work but arriving home I found a trail of blood in the white snow leading up the steps into the house. Now what?

Father had dutifully walked the dog who had somehow managed to cut himself rather badly. I think I have previously mentioned that Pa didn't do hospitals and he certainly didn't do blood. He had, however managed to get the dog into his basket and wrapped his paw in one of his handkerchiefs. Father had a restorative whisky to hand and as the paw was no longer bleeding we decided to leave it at that. He was completely exhausted and

very white and looking back I realise this must have been at the start of his very aggressive leukaemia.

Stephen had another similar “Turn” and we rushed him to hospital in the middle of the night. Once again dialysing corrected the raging potassium level, he recovered and came home.

On our next visit I was somewhat peeved when it was suggested that I had given him the wrong foods. Being a dietitian, I did menu planning each week working out which meals could be had on which nights depending whether it was a dialysis night or not. (On dialysis nights the diet was less stringent). However, on this second occasion, when the same thing happened again “Big Margaret” came to my rescue and said “Andrea wouldn’t make a mistake like that, and certainly not twice”. Thank you again Margaret! After that they must have worked out the cause and adjusted his medication accordingly and we didn’t have that particular problem again. (I guess one of his many pills, or a combination of some of them caused the dangerous rise in potassium levels.)

But by this time Stephen was definitely becoming more and more incapacitated. The side effects and strain of dialysis on the body were taking their toll. The large swings in fluid balance over the period of a treatment sometimes caused problems and Stephen would start to drift away towards passing out. A rather sharp “Stephen, come back” usually did the trick and on we went.

Quite some time after this Stephen was rather more, and uncharacteristically, pessimistic about the future which worried me.

I decided to go to Oxford to seek advice. I ended up meeting, for the first time, the new Senior Registrar, Tony Raine. This was sometime early in July. Tony and Stephen got on tremendously well and he later became a great champion on our behalf. On this occasion I saw him in his office, he one side of the desk, me the other.

My opening gambit, as I now realise, was probably rather disconcerting for Tony: -

“Stephen thinks he’ll be dead by Christmas”

Tony eyed me up and down, and after a considerable pause replied

“I think he’s probably right”

Fortunately, we were both wrong! We should have realised that Stephen's determination and sheer stubbornness would win through.

Another holiday and this time it involved a dramatic change in our modus operandi. Stephen was in charge of organising holidays whilst churning away on the machine. He decided on the Bordeaux region of France, and in a Hotel! How would this work? A posh holiday for us! I don't remember the name of the hotel, but it was very lovely, and run by a very jolly mine host, Monsieur Nebout. He was short and round and had an infectious laugh which seemed to start in his toes and rise up until it burst out his mouth. We had a room on the top floor where we would not disturb other guests if we were dialysing late into the evening. We had the trusty Redy with us and it behaved impeccably, which was a relief.

We enjoyed visiting Beaune, especially the Hospital there and exploring the surrounding vineyards. Monsieur Nebout sent us to local vineyards to try Givry, a delicious but lesser known red wine – lots came home, and still a favourite.

As time went on and Stephen became more unwell, we were referred to a cardiologist at the John Radcliffe who was fortunately very experienced, and not taken in by Stephen's rather overly optimistic replies to his questions. Just to get him there, I dropped him at the door as he was unable to walk very far, and even then, he had to have a pause between the door and the outpatient's department.

I think it was the only time I lost it in front of a doctor.

On being asked how far he could walk Stephen replied "A mile"

And how many pillows do you use at night "One"

I asked him very crossly, "What was the point of coming if you don't tell the truth?"

This bravado, didn't deceive.

But sadly, there was little that could be done to reverse the damage to his heart brought about by the initial hypertension and exacerbated by the strains of years of dialysis.

1987 started with a bang!

This was the result of Stephen writing the Christmas cards and inviting everyone who lived within 2 hours driving time.

About 60 folks came, all suitably attired, for it was a Last of the Summer Wine party. So many Compos, Nora Battys and some brave Marinas. A sausage and cider party and all good fun.

But pretty soon we then ran into a really rather serious situation.

Apparently, the many years of dialysis treatment has detrimental effects on other metabolic processes. One such is the effect on the parathyroid gland. The function of this gland is to control the level of Calcium in all fluids, cells, organs and bone. In some patients, in order to prevent excessive deposits of calcium in the body the gland needs to be removed. This involves a major and complicated operation.

We went together to the Unit to discuss this with Des. It was put to us that it was a major decision in Stephen's case because of the poor state of his heart.

In fact, we were told, that if he had the operation, he had a 50 -50 chance of coming out of it alive.

Next question - What did we want to do?

In my case, go home for a stiff drink.

It was of course, for Stephen to decide. I would back whatever he decided.

We were very quiet on the long way home but after some consideration Stephen decided to go ahead and take his chances.

Des, however, was of the opinion that it was not a good idea, too risky, and was against it. Tony Raine, thought it should be countenanced, if we wanted to proceed, partly on the basis that we were relatively young with two youngsters to bring up.

The major problem was that Stephen's heart was not expected to survive the rigours of the long period of anaesthesia necessitated by such a complicated operation. Thus, the Professor of Anaesthetics became involved, along with Prof Morris and the Renal Unit. To assemble all these illustrious persons in the same place and at the same time took quite some organisation.

The idea proposed by the Consultant Anaesthetist, was that they would, as far as I could understand, basically almost kill him with opioids and then resurrect him once the operation was over. This would be a new technique to attempt and as such, would be something innovative to explore and in the interest of a progressive medical technique, Des gave his assent.

I realised that if he survived, Stephen would need some support when he got home. I asked my employers, Napp, if I could work three days a week for a short time and be paid pro rata. Not possible it would appear. I was given three options:

Take six months off with no pay

Take 1 month's holiday and then 1 month with no pay

Join the OTC (over the counter) division – not so taxing but paying a lot less

I rejected them all and eventually went off sick for a couple of weeks when the time came.

The operation took place in February. I remember taking him to the John Radcliffe the night before the operation, and leaving him in a bleak treatment room, as there was no bed available for him. A grim farewell and so home. Thankfully, Clare came home from University to be with me on that dreadful day. The weather was cold and wet and time passed very slowly, and the only thing to pass down our No Through lane to the Church, was a funeral cortege. But eventually the news came through that he had survived thus far and we could go and see him.

We set off in the dark in unbelievably foul weather and eventually arrived and rushed in.

Stephen was in Intensive Care, wired, intubated, and connected to every conceivable piece of equipment, or so it seemed. He was conscious, but very dopey and unable to speak because of the tubes. The kind nurse handed him a board and pencil so he could communicate with his somewhat stressed wife and daughter.

This is what he wrote -

“Have asked Tony Raine to dinner!”

The same old Stephen was back with us!

And this spirit and tenacity was perhaps why all those medics took up the challenge.

All was not quite such smooth sailing after this. The operation was successful and their method had worked, but back on the Unit, and trying to dialyse him a couple of days later proved problematical. He was so “shut down” they couldn’t get access to perform the treatment. Things were pretty dire. I sat there for what seemed like days with Stephen wrapped in tin foil to try and get his temperature up. At some point Peter Ratcliffe, a senior registrar on the Unit came and looking very grave, he asked how I was and I said I thought I might go home as I was pretty exhausted.

He scared the living daylights out of me by saying “You’re staying here”.

(Apropos of this I was very excited in 2019 when Peter was awarded the Nobel Prize for medicine. Knowing how thrilled the unit must be, I contacted Chris Winearls to congratulate them all. Chris sent me a lovely picture of them drinking champagne and it was great to see him smiling. For some reason he was always rather serious when around us!)

However, Stephen won through again, and was soon home and back at work, though considerably weakened.

By April he had contracted shingles, no doubt something to do with his weakened state, and he was really quite poorly again.

And then in May, Pa died after a short but extremely distressing illness, made worse for us because he was quite a way off and we couldn’t visit as often as we would have liked. His last words to me were “If I were a dog, they would have put me down by now”. A great loss and another of our support back-ups gone, and still sorely missed.

We had another holiday arranged, for May. This time to Brittany, taking the Redy and going by ferry from Portsmouth and to stay in a gite.

Stephen was by no means 100% and we considered cancelling but decided to press on, hoping a holiday and change of scene would be beneficial.

In readiness I decided to cut all the grass, even though it was rather too wet for this. The upshot was that whilst trying to free the sodden grass from underneath the mover I succeeded in slicing off a fair portion of the middle finger on my left hand.

And so, a trip to Cirencester hospital, with me dripping blood everywhere, where they tried to patch me up. Unfortunately, it was not the sort of nice clean injury that could be stitched and which would have made recovery a lot easier and quicker.

We still thought we could manage the holiday and got the Redy a bit early to see if I could manage my part one handed. To help in this enterprise, Stella, (stepmother) came to help get us off. She was somewhat worried about the whole thing but we assured her Pa would have told us to get on with it and that is what we did. Stella helped by washing my hair for me and she also did the clothes packing.

We set off for Portsmouth, me with my left hand having to be kept up and still having a tendency to bleed, so Stephen was at the wheel. About half way down the A34, en route to Portsmouth, Stephen, still weak from the shingles, had had enough, so we swapped seats and worked out a system where I did the steering and pedals and Stephen operated the gear stick. Problem solved.

The gite was all good and dialysis went OK but my finger was not making any progress on the healing front and changing the dressings was only bearable with a glass of whisky at my elbow. Also, Stephen was still rather weak, and we looked like the walking wounded as we struggled round France.

I particularly remember a trip to a supermarket where we took it in turns to lean on the trolley for support!

I also found that Stella had been somewhat over enthusiastic with the packing and buttoned up all shirts and folded them neatly, not a bit like my usual throw in a case and hope there is an iron handy when you get there, if necessary.

The only other thing I remember is a visit to a rather nice restaurant where I, foolishly, ordered mussels. Mine host was one of those rather superior French madams, who didn't have a very high opinion of the English and their appreciation of food.

As I made a right mess of the mussels she came over and gave me a lesson on how to eat them. Sadly, it needed two hands and as I only had one in use the lesson was a bit of a failure. We did nothing to improve her opinion of Les Anglaise!

That summer Robert did “A “levels and then set off to a Camp America experience, Clare, I think was working having left Uni in Newcastle.

September saw us off on another holiday, this time to Italy, just Stephen and I with a much updated and superior, Redy. The Chianti region was chosen by Stephen as he had discovered Chianti was allowed on his diet sheet. This was all very exciting as we were going to put the car on the train from Lille to Nice and then drive around the corner to an hotel near Barge in Northern Italy. This had a cottage in the grounds which we rented. All went well and it was great to get on the train in grey Lille and wake up in the sunshine on the Riviera.

I was a bit nervous about this expedition as Stephen was nothing like so well as when we had last set forth on our travels. I said “What if you die over there”

“That’s what Embassies are for”.

And there we were, lovely weather, able to use the Hotel swimming pool, and restaurant, and enjoying the fascinating towns and countryside and generally being tourists. We dialysed outside, with Stephen under a large umbrella and enjoying the thought of taking loads of Chianti home.



All was going extremely well until the wonderful, modern Redy displayed a fault saying “computer failure”. A far cry from the litmus paper and screwdriver fixing of our former friend. Deep Joy. We contacted the local Redy technician, whose particulars we had been given, but he was not overly thrilled with the idea of coming to sort it out and fixed for us to go to a satellite dialysis unit in Barge.

The Italians, it would appear, were ahead of us in this matter, Oxford had been trying to get a satellite unit in Swindon for quite some time.

We arrived, presenting our supplies and relevant paperwork and dialysis began. Suddenly a very important looking personage appeared and he was evidently a Renal Consultant from Florence. We showed him the list of what were “normal” SI units for Stephen and when he saw the “normal” for Potassium, the expression on his face seemed to say

“Whatever possessed you to attempt such a foolhardy expedition?”

and who could blame him?

But all in all, it went well and was quite a break for me, for when Stephen was safely dialysing for 5 hours, I was free to go exploring or to simply relax.

Stephen said he was simply terrified when approached by a male nurse, built like a heavy weight wrestler, to help him onto the machine!

It was terribly hot and Stephen not always so good. In Florence I noticed they had a lot of ambulances waiting around, presumably, I thought, to rescue wilting tourists. I made a point of smiling at them. I also remember climbing to the top of the Duomo to take a photo of the view whilst Stephen sat in the cool below!

He found the Uffizi quite challenging and we invented, in our minds, a sort of wheel chair with caterpillar wheels which could manage the endless steps and with a reclining seat so you could look up at the amazing ceilings without getting a crick in your neck.

He only actually fell to the ground once, in Pisa, but quickly recovered.

Arriving home our lovely neighbours came and helped to get the wine stored under the stairs – and no doubt enjoyed it with us at a later date.

Clare’s Graduation took place in Newcastle in October of this year and we all went. Stephen and I stayed with “Osmotherley Mike” and Angie on the way

home and dialysed in their large kitchen (the Redy was with us). Stephen became very cold, so an electric blower was found and aimed at him. He was sitting in a metal, folding type, garden chair. Later Angie found strange marks in the cork floor; the metal of the chair had got so hot it had melted them! They are still there, a lasting memorial to Stephen and that visit.

In the midst of all this I was being “hassled”, in the nicest possible way, by a dear friend of mine, Ian Brown. I met him through my repping career and was always bumping into him. He had become a Hospital Rep for Bayer, quite a prestigious position in the repping world. He was about to have a change and go to a training role at Glaxo. He was utterly disgusted with the way Napp had treated me and set about trying to persuade me that I should take up his position in Bayer when he left.

I resisted this knowing that it would mean extensive training courses away from home and then learning a new role and territory, let alone having to undertake several interviews with me not necessarily feeling at my best. I simply didn't see how I could do this even if I wanted to.

In November we had the dinner party Stephen had invited Tony to. We invited all the special people who had helped us through that terrible experience, from our solicitor who made our wills, just in case, to those who had advised and supported us. It was known as the “Resurrection Dinner Party” and everyone signed the table cloth which I still have.

Quite a year!

1988

Another incident that is quite vivid in my memory, occurred early on in this year.

It is winter, and with snow deep on the ground, Stephen is on the machine and becoming worryingly ill, fading away, but not necessarily responding too well to the usual measures. Realising that we needed help, and because of the weather, we decided to call on our GP, thinking he might be able to influence things if we needed an ambulance.

Dr Coffey managed to get to us. He was quite elderly, and an old school GP.

(He was also the school doctor for Rendcomb College attended by both our young. Once I visited him as a rep and he saw me and said “Draper! I’ve just seen a Draper child”

“Oh, male or female”

“Female”

“What’s wrong?”

“She fell up a wall”)

On seeing the kidney machine, he was flabbergasted, he said he didn’t know how he could help, but he could see that Stephen was in a bad way and was able to ensure an ambulance came quickly.

The ambulance was soon with us and off we went into the snowy night.

When we got to the roundabout at Burford, on the A40, we found the road was totally impassable. (Stephen by this time was completely out of it and wrapped in a foil blanket, there being no heating in the patient part of the vehicle, and I was soon shivering with the cold.)

The ambulance driver took stock of the situation. It appeared that the police were at the far end of the road, by the next roundabout, and with the help of a snowplough were trying to operate a system whereby it ploughed a way one way with a few vehicles following and then when it got to “our” end turned and made its way back. What now? The ambulance men said they would put on the “discos” and hope the police would see us and send the plough to rescue us.

“What if that doesn’t work?” I asked.

“We’ll send for a helicopter”.

Luckily, they came and rescued us and we proceeded on our way, and eventually reached the Churchill and Renal Unit, me by this time very cold indeed.

Stephen was quickly taken care off and I suddenly realised I had no way of getting home. Ambulances are allowed to take a relative to a hospital, but not to take them home. However, in the circumstances, and with no hope of getting home by any other means because of the raging blizzard, they agreed to take me back to their base in Cirencester.

I didn't like leaving Stephen not knowing what had gone awry but knowing he was in good hands I had option but to go with them. Once again, I was in the "cold" compartment!

We had a very slow journey back but no mishaps and they dropped me off in the centre of Cirencester where I learnt that the A417 up to Winstone had been closed.

Taking stock, I went into the Feathers Hotel to find a restorative drink. Into the bar I go, possibly looking a trifle distraught, and asked for a double whisky which was downed at quite some speed. Goodness only knows what they thought of me as by this time it was fairly late on an evening when most sensible people were safely by their firesides. I then decided to ask if I could have a room for the night.

On being shown the room I found it was perishingly cold. Asking if it would be possible to have a hot water bottle, I got that kind of unhelpful British replies one dreads

"We don't do hot water bottles".

This, to me, was the last straw, whereupon I lost the plot and stormed out. I took myself to the Police Station and explained my difficulties and said I really needed to get home. Here they were rather more helpful and said they had people on hand with four by four vehicles who were willing to turn out for those in distress.

A lovely Canadian appeared in a huge 4x4 truck with a powerful spotlight on the roof and we set off up the A417 which had indeed been closed. Even this gallant chap was not prepared to venture down our lane from the main road but dropped me off at the junction and I trudged wearily on through deep snow. Never was I so glad to get home! though very worried about Stephen.

I don't remember what the particular problem Stephen had encountered on the occasion, but he bounced back. (well to be truthful he was by this time not really bouncing at all)

Although really worried about Stephen I couldn't get to see him because of the weather but I do remember that at the end of the next and rather trying day I went to a supermarket for a few provisions.

I got to the checkout and it appeared I had bought something that entitled me to a coupon. This coupon, if I was lucky, could win me a holiday in the Caribbean, but the checkout lady had run out of vouchers. I told her not to worry, I wasn't bothered about it. All I wanted was to get home at the end of a difficult day, but she insisted and it took all the self-control I could muster not to scream loudly whilst she left to get it. The chances of winning were negligible, and the prospect of going even if we won even more fantastical.

A memorable few days.

I had hated snow all my life and decided all this was the final straw. When the young subsequently went skiing, they would send me postcards of "Meribel by night". Very thoughtful!

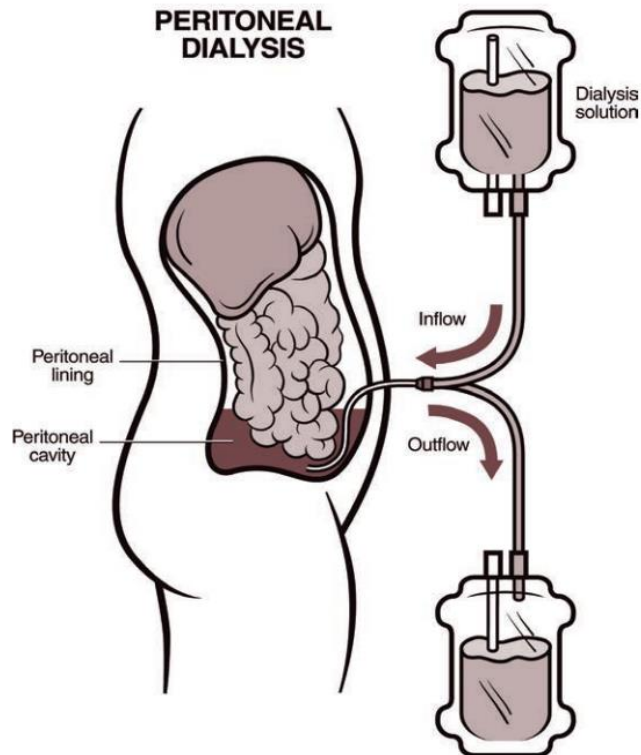
I still loathe snow, but also hate being confined to barracks, but I have discovered wonderful things "Winter Tyres".

In February Ian Brown had another go at persuading me to join Bayer, who he was sure would treat me better than Napp. This time I was quite cross with him for harassing me again in this way. By March he informed me he had arranged for me to have an informal meeting with his boss in a local hotel. I could scarcely refuse and duly attended only to be offered the position. And so accepted the post of Hospital rep with Bayer and started my new career and role in May.

Another blow hit us in April. Stephen's failing heart could no longer take the rigours of lengthy dialysis sessions and the only way forward was to change from three times a week to every other day but for a shorter period each treatment. It is hard to describe the detrimental impact this had on our lives. The "three times a week" routine allowed a certain flexibility, as previously explained. Quite a blow and we found this new regime very hard to come to terms with. Fortunately, we found Jane, a State Enrolled Nurse at the Gloucester Royal Infirmary, who came and helped to put Stephen on when her shifts allowed.

At some time during these hard times our young neighbours, who were living lives so different from ours, but who were very caring, also learned the ropes and occasionally helped us out.

After a short time on this excruciating routine, it was suggested that Stephen should consider the more recent dialysing technique known as CAPD, or Continuous Ambulatory Peritoneal Dialysis.



Reference 6

This was very much cheaper from the Hospital's point of view and many patients found it more acceptable and less complicated than learning the ways of a machine. The process could be done anywhere where a clean space could be utilised. The other great advantage being there was no need for an assistant.

The objectives are the same, the removal of waste products and excess fluid.

The advantages were:

The patient can control their own schedule

There are less stringent dietary and fluid restrictions because the slow, continuous therapy means the rapid changes in blood chemistry and fluid levels, associated with haemodialysis, are reduced and the process is altogether gentler, with less severe effects on the patient's cardiovascular

system. This was very important in Stephen's case, with his compromised heart.

The principal of dialysis is the same but with CAPD it is accomplished using the patient's peritoneum as the membrane across which the waste products cross from the blood stream and are then flushed out.

A catheter attached to a soft plastic tube is inserted into the lower abdomen. The catheter sits in the pelvic cavity while the soft plastic tube remains outside the body. Dialysate fluid is introduced through this and after a few hours of drawing excess water and waste products from the peritoneal blood supply through the peritoneal membrane, the fluid is emptied out and replaced with fresh.

So, once again Stephen went into hospital to have the necessary procedure whereby the tube was inserted for accessing the peritoneum.

The process of filling and emptying the abdominal cavity, via the catheter, is known as an "Exchange" and needed doing 5 times a day, in Stephen's case.

By this time Stephen was really quite poorly, but still working full time, so this meant doing a couple of exchanges at work. Okay in theory, but not great in practice.

Stephen quickly came to realise that this method was impractical if he were to go on working. He also really disliked having the tube hanging out of his abdomen. He felt the treatment impacted on his life even more than the machine - 5 times a day and never a day off. He soon came to hate it.

Eventually he drew up a chart which compared haemodialysis with CAPD and presented it to the unit, showing that by his reckoning he spent more time doing CAPD than he did doing Haemo, and that the risk of infection was greater and that there was never a day off.

When I pointed out he had not included *my* time in the man hours he asked what else would I be doing! I'm not sure my answer is printable but in truth carting all the equipment for CAPD about and worrying about finding suitable places to perform the procedure as well as the hours spent every day was not easy and we soon reverted to our old tried and tested, if gruelling regime.

About this time, I went once more to see Tony Raine at the Unit as I was so worried about Stephen driving on his fairly lengthy journey to and from

work. But on he went, getting increasingly incapacitated but determined to continue working.

Life was pretty difficult but we thought not worth living unless we carried on as normally as possible and so began to plan a holiday.

At first, we thought we would take the Redy and go to a gite somewhere in France. Robert was about to return from having done another spell teaching sailing on the Camp America scheme. We asked if he would be prepared to come and be a general dogsbody, doing the shopping etc. He agreed and then said could his great friend Tom come as well. Fine by us. Clare said if Robert and Tom were going, why couldn't she come too? Then she thought why couldn't Peter, her newish boyfriend come as well? This proposition was put to Peter over a rather nice dinner arranged for us to get to know him better.

Poor Peter, who at this point in time knew nothing at all about dialysis, had never seen a kidney machine, turned a little white and said "I think if I'm going to be left in the middle of nowhere in France with Stephen on the machine, I'd like to know a little bit more about it!" Bless him! We assured him that I would, at all times, be in charge of the machine!

At last sanity prevailed and we decided that perhaps an unknown gite was a trifle ambitious, so we decided to go to the dialysis caravan. Clare and Peter would sleep in a tent and the rest in the van and all would be easy. We had to take two cars and have an overnight stay on the long journey South.

The planned overnight stop was to be in Fuisse, in Bordeaux, a very favourite village of ours; we would rendezvous the two parties in the square. (No mobile phones at this juncture). We had, however, made a rather basic error. It was the vendange and not a bed to be had at any price. Plan B, we four (Stephen, Andrea, Robert and Tom) would set off to the fairly large town of Macon, to try and find accommodation, but even here things were not much better and by this time we were a trifle weary. In desperation we took a room that, with the addition of the camp beds for the tent, would take all six of us!

Rob and Stephen set off to try and find Clare and Peter. Tom and I were left organising the room and blowing up inflatable mattresses. The whole thing became a trifle hysterical and causes great merriment when recollected.

Stephen and I had a double bed, as did Tom and Rob, Peter was in a single bed and Clare in a cot!

There followed a rather jolly and very memorable holiday with many silly incidents and a mad rush back to the ferry, something we had always vowed never to do – and then finding we had very little money and gathering together every piece of “Shrapnel” to pay the peage!

Once safely back home things went steadily downhill and Stephen ended up in hospital for a couple of days in December. Nevertheless, once again, party invitations went out with the Christmas cards for a date in January.

Just before Christmas or thereabouts Stephen told me he didn't think he could go on much longer and that he was thinking of stopping his dialysis.

Next question – what did I think? I said it was his decision and I would go along with it but asked if he would go to the Unit one more time to see if there was anything else they could possibly do. They said the only possible action was a heart transplant and I don't think any of us thought that was a feasible option.

So, on we go, celebrate Christmas and feel pretty dismal at New Year as the coming one didn't look too promising for us.

1989

The New Year started with the party Stephen was so keen to have.

I later realised that this was Stephen's farewell to one and all and I can see in my mind's eye Tony Raine and Stephen in deep conversation on the sofa.

Stephen still kept on going to work. I spoke to Bayer and told them of my predicament and they allowed me a mobile phone, not usual in 1989. The only two contact numbers I had on it was Bayer and Stephen's work.

On the 19th of January, as I was working at the Radcliffe, Oxford, at 2 o'clock, the phone went off. It was Stephen's work. Although I knew almost certainly what it meant I ran at full pelt to a ward where I knew the staff well and made that call.

Stephen and his boss, Morris, had gone to get sandwiches for lunch and when Morris got back to the car, Stephen gave out a long sigh and died.

One last anecdote.....

When a near neighbour heard the news, she rushed round and asked if we would like to have the wake in a nice sort of garden room they had on the side of their house. We declined, opting to having it at New Inn Cottage. Determined to help, she offered to borrow a tea urn for us and this she duly did and brought it to us.

The day following that sombre occasion was as grey, dreary and cold as only January days on top of the Cotswolds can achieve. We were at a complete loss wondering what to do with ourselves. However, dogs need walks, so we wrapped up, gathered up the dog and looking very scruffy and feeling totally miserable, set off to return the tea urn.

This, we found, involved driving up a very long and imposing drive and drawing up outside a rather grand old Cotswold house.

We shuffle out the car with said urn and ring the bell. To our horror, this was opened by a butler, in full uniform. What he made of us I can't imagine but with impeccable politeness asked us in.

No, no thanks we just want to return the Urn.

Please wait there a moment.

And we stand there, a forlorn little group and he duly returns.

Mrs B has been very ill, but she is up today and downstairs, and would very much like to see you.

Horror strikes and we demur, but he ushers us in and we stand there looking like a group of ne'er do wells out of a Dickens novel.

Mrs B is reclining gracefully on a day bed and says graciously

“Did you have a lovely party?”

We shuffled out.



STEPHEN DRAPER

1938 -1989

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