

Chapter 2

All My Trials

“So, how did it all begin?”

... You ask ... how it all began?

I remember how it started ... *how could I ever forget?*

It was exactly two years ago. Two years ago to the day. The 2nd of June. I was in the shower.

Water on.

I can see the bar of soap ... there it is.

I have scorched into my memory the image of the bar of soap grasped in my right hand and pushed into my left armpit. The image of the soap seems to me to this day to carry with it around its edges sinister fluorescence, bubbling bursts of violent flames. And as it moved into my armpit the soap bumped up against this ... thing.

And I froze.

And I looked down. Raised my arm.

There it was.

The thing.

In my armpit, there in my left armpit.

It was the size of a golf ball. Hard and round.

And I whispered,

“Fuck it”

I should have shouted,

“FUCK it!”

It would have been a more appropriate response.

I sensed immediately that the lump was a very big deal.

I just knew that something completely horrible was up.

I felt sick. My hands shook. My heart raced. I was scared shitless ... I just ... well ... I just ... absolutely panicked. An army of ants rampaged in my guts.

And the lump throbbed.

It seemed to be telling me that it was important.

Golf ball, wish it had been a golf ball.

So my next thought after the fuck it thought, was the what to do thought. But the what to do next thought got muddled and forgotten and I dropped the soap. I felt in my right armpit. There was nothing there. Shower still on, I passed my hands over the rest of my body looking for anything strange, anything unusual. But there was nothing else alien to be felt. I washed off the bubbles and got out of the shower.

And then I remembered the what to do next thought.

And the answer was pretty straight forward and that was to go to my GP.

I didn't bother phoning the surgery. Would have been just told that I could have an appointment in ten days time. I didn't do ten days. I have always done now. So I went there ... it's my way just to do things, just to get on.

I didn't go to work ... just went straight down the road and into the GP's surgery. I remember almost in freeze frame, pushing open the door to silence. It was as if the volume control had been switched right off. And then the sound came back again arising in a big bubble that welled from a small crowd of shrieking kids and fretful mums. I went straight to the reception desk ... which was more of a keep away barrier than a desk.

The receptionist peeped over a stack of patient notes and stared at me peeking out from between the ferns,

"Have you an appointment?" she asked.

And I said,

"No!"

She peered over her half moons at me as if I was the fly in her soup, glanced at her computer screen as if she was the original model for the drag queen bank clerk in Little Britain and said,

"Not sure if doctor will see you without an appointment".

And so I told her that I thought he would, as I was very worried that I might have a very serious problem.

"I'll wait until he has a space to see me," I said.

Not waiting for her reply, I sat down and waded through the curly cornered copies of *Hello* magazine, with a nonchalance that said that I could wait all day if necessary and I am not going until you sort me out, whilst the legions of fully armed panic continued to have their way with my flesh. I was brazening it out with that gorgon receptionist and I wasn't going to look up from the marriage of Gavin and Colleen to give her the satisfaction of a chance to tell me that the doctor wouldn't see me.

After an hour's wait, at the end of the morning's list, the doctor came out of his clinic room. I watched him as he walked along the corridor and he saw me staring at him. He came into the waiting room, smiled a hello and said,

"We don't usually have the pleasure of your company at the surgery, why not come in and have a chat?"

My doctor is a little chap with glinting John Lennon glasses and one of those droopy moustaches that were in fashion in the late 60s. He's very decent and I bet he's the sort that doesn't send his kids to private school even though he can afford it.

So I followed him into his room for a chat.

Chat? Hardly! It wasn't about girls, the football or my Beemer! He asked me what was wrong and then examined me. I showed him the 'thing', pinching it between my fingers, and he felt it too, pushing at it with his finger tips. He became quiet, seemed to think for a bit and then he told me as I got dressed, that he thought that the lump was a lymph node, the sort of thing that lay people call 'glands'. Then he explained that glands like the one that I had in my armpit can come up when there is infection, but from the look of him when he said the word,

'Infection.'

I knew that there was no chance that he really thought that the gland was due to an infection. But what he did say was that the node was there and shouldn't be there.

Then pausing for a moment he tipped his glasses up the slope of his nose with his finger, scratched his head and then asked me some very strange questions. Well they were strange to me then, but nowadays, they are not strange at all, they are most familiar. Almost every doctor asks me the same questions. I have had the questions so often repeated that they are almost friends.

He asked me if I had had any night sweats, temperatures, or had lost any weight or had alcohol related pain or skin itching.

The answer was 'No' to all of his questions.

Nowadays I understand why it is that the doctors ask me these questions ... it's to find out if I have any specific symptoms caused by my tumour. You see the tumour makes peculiar chemicals that cause fevers and weight loss ... how weird is that then?

"Look," he said when he had finished with his probing.

"I think we better get you seen at the hospital. The 'thing', as you call it, in your armpit, well, it's a lymph node, as I have said and in my opinion it shouldn't be there. So if it's OK with you I am going to refer you to a surgeon.

"I should warn you, though warn is probably the wrong word, that the surgeon will want to take it out.

"I'd like to get you sorted out, so I'll fax a letter to the surgeon today and you should get seen within the next couple of weeks."

Then he paused again. I think that my GP specialised in pauses.

"Tell you what ... I'll phone him now and see if we can get you seen as soon as possible. If you'd like to wait outside whilst I give him a ring please?"

Not that I did like waiting outside, it felt as though I was being dismissed, not allowed to hear the real truth about my lump, a truth that the big boys were party to, but I was not. I wanted to know what they really thought about me!

I shuffled off whilst he made the call. It was back to the magazines in the waiting room. Not for very long though, not long enough to get to the bottom of the Gavin and Colleen

affair. But come to think of it, even though I did feel excluded from the medical chat, I don't think that I was in any state to hear any horrible words at the time. I realise that it was actually very good of him to make the call. Very good indeed.

So my appointment to see the surgeon was issued for the next day. The fact that the appointment had been issued so promptly worried me more than a little. But at least I was getting sorted out quickly.

I went by myself to the hospital, had neither friend nor lover to keep me company. I wished that I had someone to talk to, someone to remind me of what had been said, someone to give just a little comfort. Wished I had someone. On and off it's been a lonely business this illness. And life had been so good up to then, great job, great flat ... too busy though with the work, hence ... the ... you know ... lack of friends.

I say on and off a lonely business. Funny thing is that it's not lonely in the hospital; it's almost fun being sick and in hospital. How bizarre is that ... but when you think about it, maybe it's not so bonkers, because in hospital you are cared for and safe. And that's the paradox, because even though you might be mortally sick there's the camaraderie and community, there's always someone to ask how you are and share your troubles, always a whole bunch of people fighting for you trying to get you better.

The surgeon was brilliant though, brisk, as they are, and to the point as they are ... He said,

"We could mess around sticking needles in, trying to get a core biopsy ..."

And I had no idea what he meant by a core biopsy so I just nodded,

"It will save a lot of time if we just take it out. We'll get the answer without faffing around. It'll be a day case. You won't need to stay in. Any questions?"

The way that the surgeon put things made it all seem very simple and I really didn't have any questions.

So the next day they injected some local anaesthetic in my armpit and cut the lump out. Not much waiting around,

sorted, I thought. I thought that it was all over then because they didn't issue me with any outpatient appointment for review. I assumed that was it. All over and carry on as though nothing at all had happened or could happen. Silly, silly, innocent little me. They did tell me to go to my GP to get the stitches taken out, so when the nurse was doing just that in the GP's surgery, she asked me just by way of conversation, when I was going back to see them again.

"What, no appointment?"

She soon got me an appointment for the hospital for review.

So it was the surgeons again.

"We've got good news for you. It's all out and we're going to refer you to an oncologist."

I asked them what it was that they had got out.

"Oh it was a lymphoma, nothing to worry about. Professor Andrews will tell you everything that you need to know. It'll all be sorted out. Don't worry at all."

I can still hear those words echoing down the years ... Don't worry at all.

Mind you if I had any sense I would have followed their advice. You see there really wasn't any point in worrying at all. Worrying really doesn't help.

Professor Andrews. What a professor he was. Wherever he was there was noise. Red faced. Blustering. Pin stripe double breasted suit. Posh.

The nurse showed me into his room. He was sitting behind a big desk. There were two medical students there. They looked badly frightened. I am sure that he terrified them. He looked up as I came into the room, stared at me as if sort of summing me up and then without any ado just said,

"You could die from this you know."

Oh the shock of it. And then,

"But I am going to do my best to see that you don't."

And then he just went straight in with the business end.

"You have got a high grade lymphoma. It's a type of cancer. Can be nasty. You are going to have to have chemotherapy. The treatment will make you feel bloody awful. It could

possibly kill you. You will lose all your hair. You'll be frightfully sick. But at the end of it all you'll probably be all right ... Actually."

I wasn't too sure about the actually. But I did like his bluntness and directness. I knew that he cared and was on my side. In a funny way the bombshells didn't hurt, they felt good. His words were inspirational in a weird way. It was as if he understood me and would be fighting for me. It was as though it was us against the lymphoma, him and me, not just me, alone and unsupported. He was in my team and my team was going to win.

At the time I had been going through an awful phase, I'd become angry, really cross with everyone and everything.

Why me? I'd thought.

"Now," said Professor Andrews,

"You're probably thinking, why me?"

And I thought ... that man can read my mind. And he looked at me, as if he was hearing my thoughts, so I nodded. I'd been doing quite a lot of nodding at doctors.

"It's a phase you go through. If you weren't thinking that we'd be worried about you.

"It's what happens, if you are lucky. There are classical phases in the process of coming to terms with any life event of significance, phases that you go through as a patient facing profound illness. The first phase is called 'Denial'. It's when you fail to engage emotionally with the fact of illness. You carry on as though nothing at all has happened.

"The next phase that you pass through emotionally in dealing with the burden of your illness is the 'Why me' phase. You graduate to thinking about what it is that you have done in your life that has caused the lymphoma, you search for reasons ...

"But let me tell you that, actually, there is nothing that you have done. It's just all down to bloody bad luck. Beastly bad luck in fact."

I said to him and I remember it well,

"That's me professor. I'm there. I'm there in the bad luck phase."

“Yup! Let me tell you ...”

And Professor Andrews started to wag his finger at me.

“There’s nothing, actually, that you have done wrong. There’s no relationship to diet, bad behaviour ... anything.”

I had wondered about the bad behaviour!

“It’s likely to be in the genes but what it is in the bloody genes that’s caused the lymphoma we really don’t know. And to tell you the truth we don’t really care about that at the moment. What we do care about is getting you bloody well better.”

I was amazed at his language. But it was funny; funny odd, how strange that his words and manner gave me such assurance. It was inspiring to hear him talk in such a confident way. It was wonderful.

“Anyway, the next thing that that you will experience emotionally is anger. You will get bloody well cross at everybody and everything. Mind you they probably deserve it. So go for it!

“Then after that there comes acceptance. Bit hippy’ish that, mind you. Peace and love and all that nonsense. Some people get fixed at one stage in the process of coming to terms with illness and that’s not good emotionally.

“Anyway I digress. Here’s the point.”

Professor Andrews’ discussion about emotions seemed to be coming to an end and it was on to the real business, the practical stuff.

“You’ll be needing scans and a bone marrow test. Bloody hurts the bone marrow test. So don’t be a little girl about it. Take it like a man.”

I would try. I wondered whether he told the girls to take it like a man?

“All right? Any questions?”

I had none. No questions at all. He waved a few forms at me and I was dismissed, off to get my CT scans, blood tests and bone marrow assessment.

The CT scans were fine. Simple really, just a lot of lying around.

Then I had to have a whole lot of special blood tests done to characterise my blood group and look for genetic changes in my white cells. They asked if I would mind giving extra

blood samples for their research and I was pleased to be useful, so of course I agreed to do so but what a lot of blood they took. They made me sign my consent to having the samples taken for research. I found that odd. It was as if what they were doing in their research was somehow questionable.

It was a huge amount of blood.

“Don’t worry!” the doctor said, “You’ve got pints of the stuff!”

Next thing for me was the bone marrow test. I had to lie down on a bed. They didn’t really explain what they were doing, just told me that there would be an injection of local anaesthetic and that I would feel a pushing sensation. The local anaesthetic was injected under my skin and on the top of my pelvis ... just here ... over my hip at the side. I could feel the needle scrape the bone. And then the lady doctor leant on me, she leant her elbow on my thigh! And as she leaned she pushed a huge needle in to my side. The needle sank straight down on the bone. Wow ... was that painful or what? Then she seemed to screw the needle into the bone turning it around and around until with a little thunk it entered the bone marrow cavity. Oh that really hurt! Just thinking of that first marrow test still makes my eyes water ... and I can feel my legs cross involuntarily.

I was told later that the doctor hadn’t waited long enough for the local anaesthetic to work. It’s like the dentist ... if the dentist waits after the injection of local, then the anaesthetic has time to have an effect and the filling is painless.

The hurt got worse. The marrow test hurt most when she said, “I am just going to draw out another sample.”

Eeek.

There seemed to be a great sucking and pulling and a terrible aching, but then suddenly the test was over.

She turned away from me and fussed around with some slides, spreading out my bone marrow on the glass. She swilled out her needles and syringes into an assortment of glass bottles, smiled at me and then swooshed away. It was all over, and then it was time for me to get off the bed and limp home. The marrow test ache lingered around for days.

It was clinic time again, and I saw Professor Andrews, who told me that although the,

“Scans were clear ...”

You know they always seem to start with the good news ... and I know now to wait for the ends of the doctors’ paragraphs.

“... the marrow is involved.”

The doctors use words like ‘involved’ thinking that they aren’t being technical but they are of course being technical and what they think is lay language, is frequently incomprehensible jargon to the lay people that they are trying to inform. The words that they consider to be simplified descriptions are almost as incomprehensible as the grossly arcane technical terms that they reserve for their own conversations.

But I got to know just exactly what ‘involved’ meant as soon as Professor Andrews explained that the genetic tests had shown the lymphoma cells to be in the marrow.

What did that mean to me? Well it defined my treatment path, my journey.

Professor Andrews continued with his explanation, leaning forward and staring at me as if to emphasize the point that he was about to make; it was clearly an important one for him.

“You know this is a teaching hospital don’t you?”

I found this statement puzzling as it seemed an open ended observation whose relevance to me and my illness could not be discerned.

“So ... it is our duty to try and advance medicine ...”

I still had no idea what he was getting at.

Ah ... so this is what he was getting at ...

“So ... as I am sure you can probably understand, at this hospital we are involved in clinical trials in which we compare a new with an older treatment, hoping to show that the new treatment is actually better than the old.”

He saw that I was balking at the words ‘Better than the old.’ And I was doing just that, the words worried me. I wanted to have the best of all new treatments not some old fashioned rubbish.

“Don’t worry.”

And do you know, I felt as though I just wasn’t going to worry because he had told me not to worry. I felt myself relax and calm down.

“The old is pretty bloody good. In fact your chance of getting better is actually about 80%.”

But I thought that 80% was a pretty hopeless chance. 80% to me, meant that my chance of dying, and this was the first time that I had said the word ‘Dying’ to myself ... was 20%. It didn’t cross my mind for one single moment that my chance for living was 80%.

“So ... we are trying to get results ...”

So I was a ‘Result’?

“... better. You know if it hadn’t been for the trials of new treatments that we have actually been involved with at this hospital, we wouldn’t have available what we bloody well do have now ... the standard treatments for this illness.

“So ... what we would like you to consider ... is being involved in a clinical trial of a new treatment for your lymphoma. It could be the future standard, no bloody guarantee mind!”

And then, strangely, he laughed.

Professor Andrews turned to nod at a nurse who was sitting beside him. And bizarrely, such was my level of concentration on the professor, that I hadn’t really noticed her presence. Well of course I had seen that someone else was in the room but I had paid absolutely not the slightest bit of attention to what or who that person was.

But at the nod I did pay attention.

Well she was nice ... nice and smiley. And she was very pretty. Kind of a bob haircut, brown with blonde streaks and sparkly blue eyes, roundish face and lovely figure. About 5’ 5”. My age. I know that I should really have been concentrating on our professional relationship ... but what the heck, she was very nice looking ... and she did have a really lovely figure.

“Caroline, will you explain what we are trying to do?”

“Of course Professor Andrews. We’ll go next door. You’ll be wanting to get on with the next patient.”

The idea that Professor Andrews could have other patients apart from me seemed an outrage. I was his patient and he shouldn't have any others. He should be concentrating on me alone, not wasting time on other relationships. He wasn't to be allowed home until I was better.

Caroline and I sat in the counselling room talking about what would happen next. It was a windowless space cluttered with too many old fashioned pink plastic covered recliner chairs.

"Are you OK so far with what's been going on?"

I was OK. I felt pretty much up to speed with things but I thought that I would pretend not to be so that I could get as much information as possible on board. Also I was pretty worried that I hadn't been told the truth so I thought that Caroline might let me know some of the things that had been kept from me.

"So is it true that that I really have a 20% chance of dying from this or are the odds worse?"

"He's told you the truth. He always does. He's amazing. He's so honest. Too honest sometimes. And he's such a good doctor. You are in the best hands."

Intuitively I had known this, but it was great to hear it confirmed. I thought that I should just sit back and listen to Caroline, and so I did.

Caroline scraped her hair back from her face and pushed towards me a sheath of papers, sliding them across the glass topped coffee table that separated our two Parker Knolls. She crossed her legs, leaned back, and explained that she had given me two sets of information sheets about the lymphoma. The first set she said explained the nature of the illness and its treatment and the second set detailed the clinical trial that I might be involved in if I gave my consent.

"It's a pretty scary document you know. It's written by American lawyers so it doesn't spare the detail! It says at great length what might happen in the worst of eventualities. It really goes over the top. It's put quite a few people off. It's so freaky!

"You really should read it though. And think about things. You must be sure that you want to take part in the study.

“Now ... if you agree to be in the study then you will have to sign your consent to take part.

“But ... you can only sign after about a week has gone by so that the lawyers can say that absolutely no pressure has been brought to bear on you to be in the trial. And ... that you have agreed with full time for thought.”

Caroline uncrossed her legs. I remember that she was wearing blue and black striped tights and that her legs were ... lovely.

I also remember being really puzzled by the fact of having to sign consent. It seemed to me as though people might be covering themselves in case they were sued by the patients in the trial. It made me think that there were doubts that the treatment was effective. It also seemed to me that it was probable that the new treatment might have terrible side effects which the lawyers and doctors knew about and were worried about.

I was faced with a sudden loss of confidence in the system that I was in.

I remember being really worried, until Caroline said,

“The clinical trial has been approved by the regulatory authorities.

“And ... they’ve been scrutinised by committees of lay people and doctors. They’ve ... made sure that the trial is safe and is being carried out in an ethical fashion.”

The worry started to ease a little.

But then I thought ‘Why on earth should the ethics of the study have to be considered ... is it because the study is actually unethical?’

“This is how it is nowadays. It’s all very bureaucratic. But ... it’s good in a way. Makes sure that everything is above board.”

‘Above board ...’ I thought.

“Anyway ... you take all the papers away and read them. If you have any queries at all you can ring me on the number on the card.”

She handed me a card with her contact details.

“They’ll be seeing you in clinic next week to go through things and arrange your treatment. Meanwhile ... I’ll weight and height you.”

I didn't like the idea of being weighed and measured. It was as if I was being fitted out for my coffin.

"And ... I'll book you in to the Chemotherapy Day Ward for treatment."

I began panicking that next week was a long way away and that the delay to treatment might mean that I would die but my thoughts were interrupted by Caroline who said,

"It's all pretty standard for the moment. Do you want me to explain what treatment involves? Or ... would you like to take things a bit at a time?"

I thought that I'd heard enough for the moment. It was about all that I could take on board. I wanted to talk about things to someone who wasn't in the hospital ... and paradoxically, I also didn't want to talk. It was an odd situation really. To talk or not to talk, that was the question, or was it? I really didn't know; I was all in a muddle.

But who to talk to? The one person that I really didn't want to talk to was my Dad. We'd lost touch with Mum. She'd run off with someone all those years ago and never got back in touch with us. Dad had brought us up. He'd been a star, always around for us. Sort of put his own career on hold until we'd left home for college.

No I definitely didn't want to talk to him about anything, didn't want to worry him about me until things were sorted out. Just didn't seem fair.

So, as you can imagine, the lymphoma was preying just a little on my mind. And I really did need to chat to someone. And it never seemed the right time to chat or the right place or person until it just sort of flooded out in a splurge. Came spewing out when I was chatting with Keith, our milkman. I live in a bit of an old fashioned area. Although my flat is in London, the place that I live in is sort of friendly and not at all 'big city'. My neighbours chat, the postman asks how you are, and we have a milkman who does the rounds. Keith the Milk is quite a character. He's about 75 years old, small, skinny and very weather wizened. He's dead conscientious about his deliveries. Never misses a day, unlike our postman who I think has been hoarding our mail for the last six years ... there must be some reason why I never get letters.

Keith is a really nice man. Gives sweets to the kids. He's a menace on that float though. Quite oblivious to the traffic. He'll park his milk cart in the middle of the road, ignoring the hooting horns of the yummy mummies' 4 by 4s. They can wait and they can wait in a line. Keith won't move over. Keith has to deliver the milk.

So Keith and his float pulled up as I was walking down the garden path to get a little fresh air. There was a screech from his handbrake and there he was, walking towards me clinking the red tops. And I said,

"Hello Keith!"

And he said,

"You at home then mate?"

Well of course I was at home and it all just came out in a great avalanche of words as I explained the reason for being off work.

"Oh!" he said, putting the milk bottles down in the middle of the path to our front door.

"You'll be all right mate. Doesn't sound too bad. Where are you being treated then? Where they looking after you?"

I explained.

"It's a good unit there you know, world famous, mate. They'll look after you good and proper. They will. They looked after me brilliant."

I wondered at that.

"Yeh. Had colon cancer, didn't I? They chopped it out and after the op I had no trouble at all. It's been ten years. See. You can get better. I did. You'll be fine mate."

And then off he went and I felt better again.

And do you know that I thought,

'Well, if he can do it I can do it too. Look at the old bugger! He's delivering the milk when by all rights he should be long retired and off clapped up in a nursing home in his dribbling dotage. Best gird up the old loins and get on with things.'

So I did. I got on with things. I started by stocking up with books and downloading piles of stuff onto my iPod. Then I got my washing done. I specialised in stockpiling washing so that kept me out of trouble for a while. I read the stuff about

the clinical trial. The explanation was very difficult to understand as it dealt so extensively with the problems that might complicate treatment ... so much so that it was almost impossible to work out what the trial was all about.

And before I knew it ... well it was clinic time again and Professor Andrews was explaining the treatment to me. Caroline sat in on the consultation.

"They'll put up a drip and give you injections. Then you'll go home. Actually, you should be fine."

I was very puzzled at his brevity. He hadn't brought me up to speed at all. He hadn't talked to me about the treatment and he hadn't explained the trial. It was all quite a mystery

At that point Caroline took over, thank goodness. She waved some booklets at the professor and said ...

"Professor, you need to go over the inclusion and exclusion criteria and get him to sign consent."

"Bloody Hell! All right ... what do I have to bloody well do then?"

"You show me. I can never understand the blasted things."

"Just sign here.

"Tick the boxes professor,

"And then hand it over for him to sign.

"You have read the document? Is there anything that you would like to discuss?"

I had read it of course, and wanted to go through with the trial which offered me standard chemotherapy treatment for lymphoma followed by a transplant programme in which I got more chemotherapy plus or minus a new antibody to suppress my bone marrow. I did have a question for Professor Andrews.

"I understand that the trial is randomised so that I may or may not get the new antibody. I also know that the only way to really find out whether or not the treatment works is to carry out the sort of 'randomised controlled trials' that you want me to take part in.

"But what I don't understand is why it is that if you are randomised to the placebo treatment that you have to go

through all the same processes that you would have to go through if you had been randomised to receive the new drug?"

"Bloody good question. I agree with you actually. But that's what the Drug Company asks us to do. The thinking is that if you didn't go through the same processes then other factors might come into play that would affect outcomes. Everyone has to be treated in the same bloody way to make sure that there can be no technical criticism of the result. Got it?"

Needless to say that I sort of got it but didn't get and I signed the consent form anyway.

Caroline smiled and said,

"We've booked you in for treatment tomorrow.

"I'll take you down to the Day Ward and you can meet the team and get an idea of what's going to happen."

So Caroline ushered me out of Professor Andrews' consulting room and into the adjoining Day Ward. It was a ward in the miniature, and divided into two sections. One section contained half a dozen beds lined up against a wall with high round porthole windows. There were patients occupying two of the beds and they ... the patients, not the beds ... looked pretty gaunt and poorly. I hoped to Hell that I wouldn't end up looking like that.

I walked quickly through the bed section of the Day Ward trying not to stare at the patients. The other half of the ward was crowded with recliner chairs, a TV and a nurse's station. There were slightly more lively looking patients in this section, and they were sitting in the recliner chairs. They were linked up to drips and were either chatting with each other, or reading magazines or staring at a muted TV screen.

The nurses were bustling around checking on the drips, laying out treatments, making calls.

"This is Sister Jackie."

Caroline introduced me to a tall woman in a blue nurse's uniform. She smiled at me and shook my hand.

"I hear you are for R-CHOP tomorrow."

This was news to me.

"Yes ... he's for R-CHOP," said Caroline.

“I ... haven’t gone in to all the details ...”

“Don’t worry. I’ll go through things with him. Come and sit down.”

So I did as I was bid. Sat down with Sister Jackie who quietly explained that I would come in tomorrow to the Day Ward, have a drip put up and then have my treatment given through the drip. She explained to me that the drip was up for a couple of hours and that I should be prepared to wait around for most of the morning as the drugs needed to be made up in Pharmacy following the Day Ward order. She told me that people used to be very sick with the sort of chemo that I would be given but that nowadays there were marvelous drugs that stopped the sickness and I should be all right.

“Only trouble is that the anti-sickness drugs can make you pretty constipated.”

It all seemed pretty straightforward.

“Oh ... by the way ... have they explained about neutropenic sepsis?”

She peered earnestly at me.

I had absolutely no idea what she was talking about ...

“About seven to ten days after chemotherapy you can get infections. It’s because the chemo affects the bone marrow where your white blood cells are made ... you know ... they’re the cells that are part of the body’s defences against infection. Chemo stops all cells in their tracks ... you know ... sort of stops them being made. So if you have no white cells then you can be very poorly with an infection that your body would have no trouble with dealing with normally.

“So ... what happens? Well! You’ll feel as though you have the most terrible flu, with a sore throat, temperature and muscle aches. Point is that if this happens then you need to come into hospital and get sorted ... you know. We’ll treat you with antibiotics and you’ll be fine. But just remember ... if you ignore the symptoms then you can die. So don’t you do that ... PLEASE!”

And Sister Jackie wagged her finger at me in a most friendly way and me ... well ... I got the point that it was important not to bluff it out if I was unwell.

“So, call us if you are poorly.”

Sister Jackie gave me a little information booklet with contact numbers and my chemotherapy detailed. The side effects of my chemotherapy were outlined in brief with a clear outline of what to do if I had any trouble.

She then asked me to give my signed consent to treatment, which of course I did.

‘What are the alternatives?’ I thought and was surprised to find myself laughing.

I didn’t sleep at all well that night before chemo. I had a terrible dream in which I was floating out of control on a bobbing raft battling with brutal white waters and tumbling down high waterfalls. I really felt those waterfalls. I was drenched in the flume, smacked by the waves. I writhed in the rapids in fear for my life. The water was wild. I banged down into the cold waves, and was thrown up against razor rocks. The dream physically shook me. I was there, it was real. My muscles throbbed with the effort of clinging on to the raft.

I woke with my hands clamped around the mattress hanging on for dear life ... and that I suppose in retrospect, that was exactly what I was doing.

The day went quickly. A tiny prick and the drip was up. I was given three injections into the drip.

Sister Jackie explained,

“Some of these injections are to stop you feeling sick and one of the injections is chemo.”

She then turned to the drip stand and swapped the bag of clear drip fluid for another bag of equally clear looking fluid which had a big white label stuck to it.

“It’s the first bit of your chemo.”

The clear fluid felt cool running through my veins, a very bizarre sensation. The fluid was dripped in over a period of about an hour. Then the drip bag was changed and a sinister looking bag of red fluid was exchanged for the clear fluid. I didn’t like the look of it, it looked evil. Sister Jackie noticed my anxiety.

“It’s called adriamycin.”

I really hated the look of the red drug.

“Then, the ‘Rituximab.’”

I clearly must have looked very confused.

“It’s an antibody against a molecule on the surface of your lymphoma cells. It targets them, knocks them off and improves on your chance of getting better. We didn’t use this a few years ago. Clinical trials have shown us that patients have a better chance of surviving if they have the antibody and now it’s pretty much a standard add on to the chemotherapy of lymphoma.”

I remember thinking ...

‘Surviving! I like that word. Better chance ... I’ll go for that then.’

Then it was over and with smiles from the nurses I was off, clutching my bag of anti-sickness drugs and the steroids that were part of my treatment that was to continue for the next 10 days.

I thought that I might be able to make it to the office but it wasn’t possible. I just felt a bit stuffed. My GP called me in for a chat. Kind of him, and then he signed me off work for the next couple of months, which was dead nice of him, but that really worried me because it made me think that I was going to get to be like the poor people in the beds in the Day Ward.

So, I took my anti-sickness drugs for the next three days and Sister Jackie was right, they did make me very constipated. Almost worse than being sick I thought. And part of the recipe to control the sickness was a drug called dexamethasone, which made me feel as though I was on speed. I could hardly sleep. Still the drugs did the job: I wasn’t sick. It was a triumph of modern medicine! I was really, really relieved that I wasn’t too poorly. Made me feel that perhaps I would be able to cope on my own. I managed to get out of the flat and buy the newspapers. Not that I read them. And some ready meals. Not that I ate them.

So, all was going hunky dory, and maybe, I was getting a little cocky because I was thinking to myself that perhaps a week had gone by since chemo and maybe I could get down the road to the pub.

Uh huh.

There was someone up there sitting on a rain cloud wagging his finger at me and ... saying ...

‘NO, NO, NO.’

I woke up with a really sore mouth. There were ulcers on my gums and cheeks. The corners of my mouth were cracked. Then before I knew it, my arms started to quiver and shake. I felt hot and then very cold and started to sweat.

I knew that was what I had been told to look out for. My white cells were low and I had to get back to hospital.

I called the Day Ward and they told me to go to Casualty, and expect to be admitted. I was to tell the nurses in Casualty that I was an Oncology patient and was expected for admission.

I was amazed at the Casualty experience. They were waiting for me. They took my temperature, blood pressure and pulse, and then they got a doctor to come down to see me within about 20 minutes. I was booked in by the doctor, had blood tests and an X-ray, and within an hour of arriving I was sitting in the ward having had injections of intravenous antibiotics.

What a service; it was Rolls Royce.

And do you know I felt better, until the nurse booking me in to the ward said,

“Next of kin?”

That got me thinking.

“We need to know who to contact in an emergency.”

There was nothing for it but to tell the family. Not my Dad though. It would have to be Jenny, my sister.

We’d been so close in childhood, thrown together by the divorce, made to rely on each other for comfort and company. But then she’d got a boyfriend and I was just the little brother who was sort of in the way and a bit of an embarrassment, and next thing she was gone from my life ... she was off to university.

We’d kept in touch of course but it wasn’t the same. I really missed the loss of our *closeness* ...

“Jenny King.”

There, it came out.

“And her contact details please?”

I gave them.

The nurse looked at me enquiringly.

“Would you like me to tell her you’re in ...?”

That wouldn’t have done at all.

“It’s OK, I’ll call her”

I did call her. It was one of the most difficult conversations of my life. It made me cry. Not sure why. She was cross with me. Of course I understood that.

“You should have told me,” she said,

“I’ll come right away.”

She came in about 30 minutes and sat in the ward by my bed looking, well ... just beautiful I thought. Wearing a sort of a mix of styles that gave her ... her own unique style, lots of bracelets, Blackberry clutched in her hand, short skirt, beaded thrift shop cardigan, huge mass of hair, all the shades of blonde and brown.

“How are you?” she said.

“Fine. You’re not to worry ... they’re sorting me out.”

“Tell me again what’s wrong.”

I told her.

“I’m going to be alright. 80% chance. Honest.”

“Have you told Dad?”

“No. Didn’t want to bother him.”

“Are you completely crazy? He’d be so upset ...”

“Do you need anything?”

“I forgot my iPod.”

“Give me your keys and I’ll get it for you.”

So she did. And after a couple of days of antibiotics my mouth started to heal and the fevers died away. My appetite seemed to belong to a wolverine because of the steroids that I was taking as part of the chemo. And no matter how gross the hospital meals were, I still wolfed them down, gobbled up the boiled potatoes and sweetcorn, food, designed it seemed, to put a normal person off eating. Weird drugs those steroids.

There were ward rounds twice each day, parades of the doctors who went through my results and checked my charts. Didn’t seem to be much continuity of medical care because the doctors were always changing shifts. Apparently it was all

to do with the European Work Time Directive which laid down conditions of work. The juniors weren't allowed to work for more than 48 hours each week. I was amused to learn that the Directive didn't apply to the seniors though!

"Time to go home big boy."

This from a rather cool junior doctor, a George Clooney clone. I liked him.

"You've got your appointment for your next treatment?"

I had been issued my appointment for my next chemo course from the Day Ward. Well ... I can tell you that I was off and out of there, very, very, very, smartly. I had jumped out of bed and was getting dressed before he'd completed his sentence. I was out of bed before he'd had time to draw the curtains around me so that I could dress without making my neighbours on the ward feel inadequate.

Back on the bus to find that my flat had been invaded. There was a feeling that wasn't quite right that greeted me as I turned the Chubb. It was the smell. Everything seemed fresh. I prowled into the sitting room. It was tidy. The windows sparkled and the flat seemed brighter. The flat was warm. There were anemones in one of Keith's milk bottles on my dining room table and about ten get well cards. There was food in the fridge. The get well cards got me. I found myself blubbing. Hadn't thought anyone cared for me.

There was a note taped to the TV.

'Love from your big sister. Beeeeeeg kiss.'

And an impression of bright red lipstick lips endorsing the love.

There were another ten days until my next chemo. The days passed. My sister phoned every day and texted twice a day. Every other day she'd pop in after work. Dad called and then came over. We hugged, something that I hadn't done, I realised, since Mum left.

I found it good to have noise around me. I had the radio on a lot, and the chatter and music distracted me from any morbid thoughts. Believe me there were plenty of those. I seemed locked inside a closed circuit of questions that had answers that looped back to the questions.

There was the ‘Will I have to be admitted again with an infection?’ question motor racing circuit. The answers to this question were:

1. ‘Yes’,
2. ‘No’
3. ‘Maybe’.

If in my mind the answer was 1, ‘Yes’, I would enter the motor circuit to encounter three stage points. They also had numbers. There was the:

1. ‘What happens then if I am admitted’ starting grid ... which took me to the ...
2. ‘What will happen in the ward the next time, will I die of infection, hope not?’ black flag waving all the cars to a halt point at the crash at the chicane ... which brought me to the ...
3. ‘Probably be OK’, chequered flag and then round again to the ...

‘No’ sequence or the ‘Maybe’ sequence, all of which were really sticky questions because their answers led on to more and more curling chicanes of confusion. So, when I got stuck I would put the radio on and try and drift off on Desert Island Discs or Gardener’s Question Time or good old brainless XFM.

But still the musings continued. Particularly in the night. Horrid, just lying in bed thinking. The worst of all of the musings was the ‘Am I going to get better?’ question circuit. This is one that that if I went into, I would find that I had no numbered answers for. I would just freeze. This was a circuit that I couldn’t move around. I would get stuck.

About two weeks after the first treatment day I woke to find masses of hair on my pillow, a thousand spiders on the sheets and pillow slip. What a shock. Of course I knew that I would lose my hair, they’d told me that I would lose it all. But it was still a shock. The hair on the pillow didn’t look like my hair. It was as if it had been left there by an old lady. A dead thing, dry and wriggly.

The worst thing really about the hair was that it was evidence of illness. It seemed to tell me that I actually was sick. It was evidence that was incontrovertible and could not be denied. Needless to say that I dumped the evidence pretty quickly. I wasn't going to have that sort of thing hanging around the house. I bought a beanie. It was grey and ribbed, and had the letters 'A & R' printed on it. Looked cool funnily enough. I looked sort of tough. Went out and got the matching hoodie.

So it was treatment time again. I liked the nurses in the Day Ward. And there were a few familiar faces amongst the patients. Most of them were much older than me and I took comfort from the,

'How are you love?'

And the ...

'How's it going then?'

It was as if I had another support group in addition to the Professor Andrews and me support group.

So chemo time again. Good-oh.

I knew the ropes, I was an old hand. It felt easier.

Sister Jackie:

"How's things?"

"I'm OK."

"Have you got your appointment for the re-assessment bone marrow test?"

"No, should I have?"

"Sure. I'll check. Hold on there and I'll be right back to you."

Now normally when I hear the phrase 'I'll be right back to you' I'm on the line to a call centre and no one gets back to me. But good old Sister Jackie got right back to me and the appointment for my next marrow test was there written on my appointment card. It was booked for the week before the start of my third treatment cycle.

The second cycle didn't have any complications and the haematologist taking my bone marrow test waited long enough for the local to work so that it wouldn't hurt. I was amazed that it didn't hurt at all.

“It’ll take about a week or so to process,” she said.

“We’ll be in touch with the results.”

I didn’t like the sound of that at all. Seemed almost ominous. And anyway what results was she talking about?

I was in the Day Ward receiving my third lot of chemo when Professor Andrews swept in with an entourage of about 20 doctors and medical students. Jenny was keeping me company. She was sitting next to me as the chemo was going through the drip.

The professor was wearing a very old tweed jacket with leather elbow patches, the sort of patches that weren’t an affectation, but were needed to cover proper holes. There was a gold watch chain looped from his lapel button hole into his breast pocket, and in his breast pocket there was the sort of paisley handkerchief that had been popular between the world wars.

Professor Andrews hung on to my drip stand and leaned over me. He swayed backwards and then he swayed forwards. He smelt of red wine and a six cloves of garlic lunch.

“You’re all clear. No clone. Bloody good news. I’d go and have a few jars on that.”

And with that he strode off, the entourage struggling to keep up.

Jenny tugged at the sleeve of my jumper. She looked anxious.

“What does he mean?”

“I have no idea,” I said.

But Sister Jackie knew.

“The lymphoma has cleared from your marrow. You are in remission. That’s the first big hurdle cleared.”

I got a big sloppy kiss from Jenny. She stood up smiling and zoomed off to buy a huge tin of Quality Street from the hospital shop. She gave it to the Day Ward nurses. She made me sign the ‘Thank You’ card.

Time went by, it’s funny how time goes by, and the things that seem so terrible at the time, well you get used to them and they are just how it is, a way of life; so much so, that the fact that I went through four more chemo courses seemed to me something that was almost humdrum. It was my new way of life.

I didn't get back to work during treatment. I couldn't make it. Just didn't want to go. It wasn't that I felt too ill to work. My GP understood, bless him. I told him the truth. He signed me off long term sick. I felt no loyalty you see to my work ... I hadn't got a single card from work, nor even a call, spoke to nobody at all after that first telephone conversation with the office when I told them that I was a bit poorly.

I took the time to think about the nature of my work and what it meant in the grand scheme of things. And my conclusion was that it didn't mean very much dealing in stock options ... not in the grand scheme of things, life and death, which is what I was trading in at the time ...

So that was six courses in total; all done, and I was booked in to clinic again to see the professor.

"You're still on for the trial?"

That from Caroline. My, she was even prettier than I remembered. What must she have thought that I looked like? Goodness knows. Face fat with steroids, hairless and pale. What a sight. Sometimes I looked in the mirror and couldn't recognise who was standing there looking back at me.

I remember my answer ...

"... Let's go for it."

"Great. Any questions?"

And then I said ...

"I'll take it as it comes ... A step at a time."

"Great."

So she gave me a typed program that laid out the day to day arrangements of my involvement in the trial. I was particularly interested in the end of the program sequence of 'Recovery' and 'Home'.

But before 'Recovery' and 'Home', there was the marrow priming and then there was the peripheral stem cell harvest and purge and the Hickman line and the high dose chemotherapy. Those bits of the program didn't seem like much fun.

"Could be worse!

"You might have had to have a matched unrelated donor graft with long term immunosuppression."

I told Caroline that I was glad that ‘we’ weren’t going there, and she laughed.

“Right!”

The marrow priming, harvest and purge.

Why was all of this needed? It was needed because high dose chemotherapy would wipe out my bone marrow. The prime, harvest and purge were carried out before chemo and would provide me with bone marrow cells which would be given to me after chemo to re-populate my empty bone marrow and allow me to make blood cells again. Without marrow cells I would make no blood cells and die.

The prime and harvest were a doodle compared with what I had gone through. The prime ... a soupçon of chemo which got all my marrow cells into the same point in their growth cycle. Next, I had to wait a few days for an injection of a bone marrow stimulating drug. The stimulating drug fires the starting pistol for my lined up marrow cells to burst into an exuberant growth phase and spill out into the circulating blood. At that point came harvest time when they drained me of a large amount of blood.

The purge. The harvest had separated out the marrow cells from normal circulating blood cells. These circulating marrow cells have the potential to reform and re-populate normal bone marrow wiped out by chemotherapy, and are called stem cells. Trouble is that some of these stem cells can potentially develop into lymphoma cells. So in the laboratory the next step was to purge the stem cells of lymphoma impurities, using an antibody that sticks to any remaining lymphoma cells and kills them.

“Your cell count is fine ...” they announced after the harvesting.

By that they meant that there were enough of my own harvested marrow cells in the blood that they had taken, that if given back to me, would home into my bone marrow cavities, and re-populate my bare as bones empty marrow cavities, cavities that had had all life blasted away by the purge of the high dose chemo.

So why were they giving me more chemo? They hoped that this would eliminate all residual lymphoma cells from my bone marrow. I didn't quite understand this as I thought that they had all gone. Apparently it was a just to make sure sort of thing. Quite a big just to make sure sort of thing I thought.

The Hickman line insertion. That was surprisingly OK. The Hickman line is a plastic tube which has a metal needle in its core. The needle and surrounding tube is pushed through the skin on the front of the chest, threaded through a tunnel of tissue underlying the skin and then poked along into one of the big blood vessels just under the clavicle. Then, with a bit of a pull the needle is removed and the tube is shuffled along through the connecting blood vessels to the right atrium which is the first chamber of the heart. The atrium is the receiving room of the heart ... it's where all venous blood drains.

The Hickman line is inserted in the X-ray department. The doctors use an X-ray screen to see where the tube is going. You see it's pretty important that it sits in the right atrium and isn't curled up in some other part of the body. It can sidle off into the great vessels of the neck and we wouldn't want that, no we wouldn't want that at all.

So marrow harvested and purged, Hickman line in place, I was admitted to the ward for high dose chemotherapy, a whole galaxy of potions that stomped into my Hickman line. The mix of drugs came in over a five day period.

I was in the cancer ward and my bed neighbours were young men like me. They had leukaemias or lymphomas. They were from all sorts of backgrounds, two came from Afghanistan and Iraq, but the rest were just plain Essex boys. They were either getting chemo, or in the ward because of infections complicating their treatment. We had quite a nice thing going between us. There was a very pretty lady doctor who did the rounds and we had fun with her.

"Doc, I've got tummy ache."

And my neighbour, a white van driver from Chelmsford, pointed at his belly and asked to be examined.

The curtains were drawn around his bed and the belly examined but the doctor found nothing at all strange in the van driver's abdomen.

The doctor drew back the curtains and marched to the next bad boy lying moping in his bed.

"It's my tummy doc!"

Although the fruit and veg market trader from Basildon complained of belly ache, the grin on his face was evidence against any serious pathology. She twigged after that.

On the second day of my admission the ward cleaner stopped mopping the ward floor to contemplate my drip. He put the mop into his bucket and leaned on the handle.

"You get the green medicine, man?"

"No," I said.

"That good. I like you man. Get green medicine you die."

And then off he went on his ward round, with his bucket and mop to check on his patients.

I was sent home after the high dose chemotherapy. Had a couple of days off for good behaviour. They said that I would be in for about two or three weeks all together so I should get a break from the hospital. I just spent the time quietly. Jenny and Dad came over. It was nice.

Then back in. It was just before Christmas. I was admitted to my own room with a shower and loo en suite.

'Posh!' I thought, 'I must be special.'

But I wasn't any more special than any other transplanted patient. I was actually in isolation and all visitors to my room had to dress in surgical gowns, gloves, hair net and masks. They looked just like surgeons. Caroline came to see me to check off a list of questions that were to do with the trial. I was disappointed about that: had hoped she'd just come to see me for ... well ... you know ...

Christmas in the workhouse, I remember thinking.

Next thing? Well the stem cells that had been harvested from my marrow were re-infused. No big. The bag of cells were linked up to my Hickman line and dripped into me. No huge deal. Just a funny smell of sulphur. For a brief moment I thought that we were having a visit from the stinking Devil

and his host of fallen angels, but the truth was rather less dramatic than that. Apparently the stench was from the stuff that the cells had been mixed with to stop them clotting.

And next?

A day or so later ...

I forget the precise sequence of events because at that time things got a bit blurred but I think that I had the infusion of the experimental antibody. It came through the Hickman line like most of the drugs that I had been given.

I immediately became very hot and flushed. I was light headed and felt faint. I remember looking up from my pillow to a ring of faces that seemed intent and anxious. Apparently I was having an allergic reaction. They sorted me out though pretty quickly ... gave me more steroids and some I.V fluids and I was fine. Came around with a big thumping headache but I was OK.

They seemed very keen on counting my days and doing blood tests. My observation charts had the days from the high dose and days from the re-infusion of my stem cells marked on them. The blood tests were usually once but sometimes twice daily.

At about the fifth day from chemo my blood count started to dip. The lady doc told me that,

“... We'll support you with platelets ...”

Apparently if my platelet count got below a certain level I was at risk from spontaneous internal bleeding. They had to keep my count up artificially,

“Otherwise ...”

Well I didn't much like the sound of 'Otherwise' and so I asked her to be economical with the details.

The platelets were given to me every day for the next week or so. Professor Andrews came in to see me about twice each week during the early phase of my transplant.

He was just wonderful. So enthusiastic and positive.

He would always have some probing question for the juniors ...

And then there would be trouble ...

“What are the increments like?”

He turned to the junior doctor and stared at him balefully.

“Not bad.”

“What do you bloody well mean ...? Not bad?”

His face seemed to go purple with rage. He smacked at my charts and then threw them against the wall.

“What the Hell do you mean? They are terrible. When are you measuring the increments?”

A certain incomprehensible mumbling issued from the junior’s face mask.

“That’s appalling. You should be measuring levels at 20 minutes post infusion.

“And how are you giving the platelets?”

More mumbling.

“...Intravenously I hope.”

The junior shuffled uncomfortably. Nobody laughed.

“Give them as a rapid bolus otherwise they’ll be sequestered in the liver. There’s a one pass effect.

“Got it?

“I should bloody well hope so.

“Who’s examined him today?”

Professor Andrews glared at all of the doctors.

“Are you all completely irresponsible?”

Professor Andrews asked to examine me. I took off my pyjamas and lay on the bed in my Calvin Kleins. He stared at my skin, front and back and pointed out little red dots on my shins that none of the juniors had seen. Well they wouldn’t have seen them because they only looked at the results; they didn’t take time to look at me.

“Ophthalmoscope please Sister.”

He peered into my eyes.

“Retinal haemorrhage at 7 pm.”

He turned to the juniors.

“You can’t learn to be good doctor watching bloody ER. I expect a better standard of care. Got it?

“Well I bloody well hope you get it.

“I want to see the bloody increments ... I want you in my office with the blasted results ... at 5.30.”

And with not a word to me he stomped off. I liked that. I was sure that it was an act, an effort at setting standards of care, all done to make certain that the lessons given would never be forgotten by the juniors.

My mouth got really sore. It was just like when I had been admitted during the first cycle of chemo but ... a thousand times worse.

It looked as though I had florid cold sores. The sores spread from my mouth to around my nostrils. They were crusted and painful. It hurt to open my mouth and when I did my lips split. It hurt to breathe.

They gave me pills for thrush, which is what, apparently I had, but the pills didn't work. They gave me mouthwashes and they didn't work either.

The nurses took swabs from my mouth and started me on cocaine mouthwashes to numb the pain.

My white count went so low that they almost couldn't find a single cell in my blood.

At Day 8 after the first day of high dose chemo my temperature suddenly went sky high, and I felt even more unbelievably shitty than I had been feeling. I started to shiver and shake. They took blood cultures and they started me on antibiotics through the Hickman line.

I couldn't believe that it was possible to feel so frightful. There I was sores all over my face, covered with little red spots, shivering and shaking, just utterly wretched.

Professor Andrews came to my bedside.

When I saw him come into my room I thought that my number was up because it wasn't his official ward time. I stiffened in the bed.

Red faced and leery he loomed over me.

"Told you you'd feel bloody awful.

"Told you that you might bloody well die.

"Well you might. I said MIGHT ... Not WOULD.

"But actually you are not going to die.

"And if you have the bloody nerve to do so then I would personally be bloody cross.

"You wouldn't want me to be cross, would you?"

He checked the charts and looked me up and down.

“What’s the Chest X-ray like?”

He turned to the juniors.

“Well bloody get one done then.

“I want to see the bloody film and I want to see it in the next hour. Got it? And get ready to treat with anti-fungals.”

And off he stomped.

The X-ray was taken in my room because I was too sick to go to the X-ray department. My fever had got to 40 degrees and I was shivering, sweating and shaking. I couldn’t move from the bed and so the nurses came in to help me pee into a bottle. They washed me, turning from side to side to swab at my bits. One held me and one washed me. It made me feel cared for. I loved their touch. It was soothing and calming. They rubbed me gently with flannels and dabbed me dry with towels. I was a baby again.

So another couple of days passed. The doctors were anxious about my blood counts. They wanted the white count to come up. But it didn’t come up, it stuck stubbornly at about zero. Recovery was the word that I often heard but there was no recovery and the days went by.

“Why are you waiting for the count to come up?” I asked, as I was being helped by a nurse to get on to the bed pan.

“Because it means that your marrow has engrafted.”

There were question marks all over my face.

“That means that the transplant has taken and you are getting better.”

I understood. But the marrow hadn’t recovered and I was still needing platelets and antibiotics and mouthcare and anti-fungals and the occasional transfusion of red cells too for good measure. It seemed like I was being treated with just about every drug known to man.

It was Christmas Day. Dad and Jenny came up to have Christmas lunch with me. Dad had bought me a present. I couldn’t unwrap it because I felt too weak and my finger tips were all chafed.

Jenny unwrapped his present for me.

“Gloves. Thanks Dad.”

“They’re for when you’re better and out of here. Won’t be long. It’s been snowing and you’ll need them.”

I doubted that I’d need them. The way that I was feeling, the only thing that I thought that I’d need was a coffin.

“This is from me”

Jenny’s gift; Christmas cake and a glass vase.

“For your flat! When you get better you’ll need something proper to put your flowers in.”

She cut the cake. I couldn’t manage it but Dad seemed to hoover most of it up.

“Eating for the family, son!”

My skin started to itch and flake away, dry scales crumbling into my pyjamas and onto the sheets.

And then the itching worsened and my poo turned pale.

“You’re a little bit jaundiced,” they told me.

‘Little bit ...’ I thought.

‘... You’re either jaundiced or you’re not jaundiced.’

“So we are starting you on higher doses of steroids and another drug to help damp down the rejection process.”

This appeared an evil bit of news to me. I neither liked nor loved the idea of rejection.

Christ, the drugs made me feel sick. And I got belly ache which ended in them whisking me off for something they called an OGD. They stuffed a big tube down my throat and looked in my stomach. The tube made me gag. They found thrush and a generalised irritation of the lining of my stomach and gullet. More drugs for me then to help damp down the belly ache.

‘Serves me right!’ I remember thinking as I was wheeled back from the endoscopy suite.

‘The pretty doctor’s vengeance for us conspiring to get her to examine our tummies!’

The porters pushed me through the hospital corridors, on my way back to the transplant ward. I was draped in surgical scrubs, and had a face mask tucked tight around me. I remember the stares of the people in the hospital corridors: they stopped walking to gawp at me as I was wheeled back to the ward. It seemed as though they were scared by me. Believe

me I was scared by me as I caught a glimpse of my face in the mirror as I was lifted back into bed.

If I had looked weird on steroids in my beanie, during the early days of chemo, what did I look like now? I was at the next stage, beyond Auschwitz, skeletal, puffy faced, the whites of my eyes green, a stick like person, pale and poorly.

I lay on my bed, sobbed, and then fell asleep to be woken in the night by a nurse taking my temperature.

It was a good moment to wake.

She was Filipino. And she was smiling.

"No fever!" she said and drew a cross on my chart just below the latitude of normality.

'No fever ...' I thought ... didn't take much notice and fell asleep again.

I slept through to morning. When I woke up I noticed that my mouth was feeling better. The ulcers were gone and the soreness had lessened.

It was a morning like any morning. They took my blood. Same, same, processes. Drugs delivered and taken. Nursing observations made and registered.

'Goodness,' I remember thinking.

'I fancy a nice cup of tea.'

And I had one. It was a nice cup of tea.

There was a shuffling outside the door.

Then a knocking.

'Funny?' I thought.

'...They never knock.'

It was Professor Andrews. He walked in followed by his entourage of doctors. He sat on my bed and said,

"Told you that you would probably be all right didn't I?"

He looked strangely pleased with himself.

"Said you'd be bloody ill, didn't I?"

I wasn't sure what this was leading to.

And then I noticed.

The doctors weren't wearing surgical masks and scrubs.

Professor Andrews extended his hand to me to shake, and I grasped it.

"The marrow's taken ...

“You’ve engrafted.”

I couldn’t help it. I started to cry.

Professor Andrews shuffled awkwardly and coughed.

“You are going to bloody well be OK ...

“And if you don’t bloody well mind I’ll have my hand back, thank you very much.”

They all shuffled off then and I went home.

“ ... And do you know ... since then I’ve been OK, well I say OK, but I’ve not been ... you know ... right in my head.”

“I see!” And the therapist leaned forwards in her chair, face cupped in her hands, waiting, listening ...

“ ... Just not myself, just kind of hanging around ... you know ... waiting.

“The illness was a full time business, there was always something to do, something to fill the time.

“I had a community then ... and now ... I am alone.

“And ... there’s nothing. I can’t get started again, can’t work, don’t want to go out. I’m just well sort of ... waiting. Silly really.

“So I’ve come to see you about that and I wonder if you can help me. You know ... massage therapy, acupuncture, aromatherapy ...

“Can you help me?

“Please ...?”

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