

*The Journal of  
Claire Shelisa Khan*

### **Saturday June 3rd**

This probably should be renamed rantings of the terminally confused. I'm not exactly sure what's going on, only that I'm stuck in hospital with Cushing's Disease. I know basically what that is, but I still have 101 questions. What's the effect on my metabolism? Mainly after the operation what will happen, the swelling should disappear, but what about my weight etc. etc. I'd also like to know how long I'll be in here.

### **Monday June 5th**

Well, its 4:10 a.m. and I'm wide awake. I wouldn't mind so much if I was awake with pre-exam nerves, but no, I'm awake because I'm stuck in hospital. I feel so lost. All my life I knew I was going to study and go on to university now that's only postponed, I know but I still feel lost. It's almost like I'm in shock and I feel the whole world's still functioning around me but I'm not part of it. I can still converse, have a laugh, but it's like I'm functioning in this dream state, always removed. I've studied so hard I don't know what to do now.

I don't know how long I'm in this place for but I'll ask the Dr. when he comes round later. This may help because at least then I can start to make some kind of long term plans. Also, Mrs Cusworth is going to visit and maybe once I've seen her it will also be easier because she can help me plan the academic side of my life. Really I don't feel confident enough to go to university in September anymore because what would happen if I got ill again? I'm probably best seeing if I can have an illness free year so then I'm certain in my own mind I can go and cope and be really well. Another year in Doncaster won't be so bad. Lee, Diane, Jane (probably) at least are all going to be here as well as Neil and everybody. In fact, apart from Clare Humphrey and to a lesser extent Emma Rawlins there is no one really out of my year at school going to university that I'd have written to really. I'll see them when they come back for holidays but I won't particularly miss them, look at what's happened between Joanne and I. Once the invincible duo, now hardly a letter, people grow apart.

What I'd like to do in the next year is go back to school in September, sit Economics and any others if possible in November. Hopefully I will have done all right in General Studies, and even if I haven't I won't have to go to lessons to resit that, I can just be entered. When I find out how many hours I'm doing at school, I can work out what else I'm going to do. I'd like to work at the Salutation. School isn't going to be full time, so I could work lunch times and do my Tetley Diploma. In today's job market, the more strings you have to your bow the better. I also wouldn't mind seeing what courses the college have on offer. I feel maybe I ought to do some kind of IT course and I'd like to learn Spanish. If I can pick up a language it'd probably be useful.

If I can do these things this year when my life properly starts I'll have given myself the best advantages. I'll have academic qualifications (A-levels) to do my degree with but then I'd also have practical qualification in my work for Tetley and if I could learn a language, with the EU and everything the tourism trade is booming and a language is useful. Plus I'd like to travel Europe without looking like an ignoramus.

If dropped in France, I could probably survive on the little French I know but I couldn't elsewhere. It makes me feel very ignorant knowing that. I'd like to travel round Europe and pick up the odd job as I go so to do that although not entirely necessary now I think I ought to know at least some of the language.

The IT comes in because I'm fed up of being semi computer illiterate when they are now so important. If I can find a decent course and one that incorporates shorthand it would be great. A shorthand course is the first one I wish to find as it'd be invaluable for lectures.

Well I think I've just about written myself out of my mood. I can't say much more until I've seen Mrs Cusworth and the Doctors.

13:10. Doctor's been and said nothing. Strangely however, I'm feeling quite good. Should know more tomorrow.

## **Tuesday June 6th**

Its 4:30. I'm getting to be quite an early riser but never mind. Yesterday I had loads of visitors and that was great. It actually gave me some focus. I've found a parallel to how I'm functioning. It's like those crappy Halloween films where the camera is Jason or whoever, I can see myself moving and doing stuff, but its not really me. When I look in the mirror I don't see me. I don't look like that or at least I didn't use to.

At the moment there is no Claire Shelisa Khan. This may seem like a strange statement but it's probably the truest thing written. At first I thought this lack of knowing who I was because I was 'dieting. I thought that once I'd lost the weight I'd feel better, because I'd go shopping, reassess what I look like and feel better. It's not true. I genuinely don't look like me and if I didn't know it was the Cushings I'd swear I'd have gone mad. Looking in the mirror is a nightmare and I hate the reflection staring back. I no longer look like me. The sooner this nightmare is over the better. Only trouble is when you don't look like you, reality is a hard concept to grasp. I keep wanting to scream how can you all function? Come into my world. I watch the world from some dreamlike state, taking part but not really being part of it. Yesterday even Haagen-Dazs had no taste. I ate because it was there, but the enjoyment wasn't there, it was just ice cream. I don't want to leave the ward because I don't really want to be seen as I look awful. I don't know what my friends must think when they visit. I tell them all though that I'll shrink after the operation which is the truth, by how much and all the details I don't know.

They hope to have some test results this morning that should help. Being diagnosed as having Cushing's has at least explained one mystery - why I didn't lose weight with the Grave's Disease. I wish I'd known a) so it could have been treated earlier and b) so I could have controlled my bingeing sooner. Grave's Disease was making me constantly hungry and Cushing's Disease had me swelling. There is no doubt I added to the problem by going into depression so binge eating, but its nice to know its not all me.

The hard part is I'm going into the unknown. What happens after? I know I'm going to look different again after treatment - but how and to what extent. I will return to Swimming Club and I know I can diet, so once I'm healthy if there is some weight to lose, which there probably will be, I know I can do it with ease. I'll have to carry on exercising but that's no loss, its just having no time span.

I know while I'm in here I ought to switch off. If I could do that, then it'd be better, just concentrate on getting well but I can't, its in my nature to look forward, it would seem on this occasion intelligence isn't a virtue. I think I have to see myself as taking a sabbatical from life that will resume again after the summer when the possibilities are endless. Really I have so much to do and so much time in which to do all that I'm whinging on no account. However, as a means of catharsis this is keeping me sane. In 'Shadowlands' it was said "we read to know we're not alone," this is a very true statement but I'm also writing for the same kind of effect. I think I need to list my options which will hopefully give me some focus. Financially, I'm more than fortunate:

Finance:	£750	Cello Fund
	£250	Present from Uncle Cliff
	£200	Mum owes
	£45	Standing Order

There's something cheery about colour, although I'm actually in the 'black' and not the 'red'. I'll use Uncle Cliff's present with the 'Cello fund. That's my first goal achieved. I'll have my £1000 for my cello.

GOAL 1 - SAVE £1000 for Cello - Done !!

My next goal has to be to get a job.

### **Claire's goals and aims.**

- 1 Get a job
- 2 Learn to drive
- 3 Pass A-levels (in November if possible)
- 4 Save enough money to go to Canada
- 5 Keep exercising
- 6 Reach target weight
- 7 Enlist at college
- 8 Reapply through UCAS
- 9 Go to University.

It would be good if I could take all my A-levels in November, as then I'd have practically a completely free year. There is no way I'll go to university the Sept/Oct no matter what because I just don't feel ready. However if I take my A-levels in November and then get a job, I can earn enough to learn to drive and go on a brilliantly long holiday which I feel I deserve.

Really some good has happened. , I've been given an opportunity to "find" myself and at an age where I can call on all the support I need to help me on my way. A year to find what's important and if necessary, start again. There is always a positive side.

19:30. I have answers, in fact a lot of answers. I'm probably moving to surgical tomorrow. They are going to operate to remove the tumour from my adrenal gland cortex. Then there will probably be a course of radiotherapy. I could be out of here in a couple of weeks. The radiotherapy kind of drags out the whole procedure but it is going to be quicker than I thought. The quicker the operation, the quicker I can return to exercising.

Today was a good day. I'm still operating in a dazed state, but I enjoyed my food. The 'delirium' should correct itself eventually. The potassium levels are the main cause. I can't wait to get out of here. Aunty Jacqui's computer will be invaluable. I'm going to plan my holiday on it, just to be swotty. The planning will be half the fun.

When I'm feeling up to it, I'm going to have a complete sort out. To start with, I'm going to blitz my wardrobe. After that, I'm going to have a finance. Then I'm going to start saving, as I'm going to travel. When I get back to target weight I'm going to go to 'Visage' and pull Mark.

### **Wednesday June 7th**

6:45. I move to the surgical ward today. I hope I get a single room. Nothing against anyone, but as Mum carted the TV to the hospital, I've got rather attached to it, and I don't think they'll let me keep it on a four bedder. Take today for instance. I was watching 'Four Weddings and a Funeral' at 3:50 - not possible really in a four-bedder.

I have a whole host of things to do today. I must remember to ask Mum to arrange for Mrs. Cusworth to visit. I feel the need to talk to her personally. I won't feel completely settled until I have done. I didn't realise but this is actually my sixth day in this place - doesn't time fly when you're having fun.

I doubt I will get a room on my own on the surgical ward because I would presume they are for the poorer patients. I can cope, I've been in four bedders before, but having my own room is much better. Also with all my family visiting, it's probably advisable. The day room on the surgical ward is grim and people get sent to bed. I may miss E.R !!? (ahem!)

Just seen a nurse, she says I'll probably be moved this morning so I'll have to ring Mum. First, however I'm going to take a bath.

7:30 I really enjoyed that bath. I feel clean and refreshed - if I'm moving to surgical today my operation must be fairly soon. Hopefully it will be before the end of this week. If so I could be out pretty soon. I recuperated fairly quickly and the sooner I can return to exercising and rubbish the better. The only fly in the ointment is Granddad. When I'm discharged I'm going home to recuperate. I don't want him being a pain.

I know I probably sound spoilt, but its a shame my Nanny's going on holiday because if she wasn't I'd move back in with her. I still might when she gets back. Thing is, I'm not sure how long she's going for, so I don't know when she's going to be back.

When I get out I intend to be slimmer, I'd like to be no more than 2 stone off target weight when I return to slimming club. It is going to cost me £10 to rejoin. I wonder if they'll let me use my advance payment vouchers.

After the operation I will have lost weight, for several reasons, fasting and the operation should remove the cause of my swelling. I don't expect to go to sleep and wake up thin, don't get me wrong, but at least it will give my diet a kick start. Once the radiotherapy (if I need it) finished, my body will be my own. There is no way I'll ever be fat again, or if I am it won't be from over-eating. Anyway, time to ring Mum.

13:00. If I could measure human kindness I'd be here for weeks. Only six days in here and I've had eleven get well cards, 1 Bunny, 2 teddies, 3 lots of flowers, loads of books, magazines and just lots of time and well wishes. Truly it's all overwhelming. The latest is a really nice basket of flowers from my slimming club. Imagine that, a bunch of people I've known only a few weeks being kind and considerate enough to send me a bunch of flowers. It's just brilliant.

The ward 24 sister, Sister Gray has the reputation of a battleaxe, but she has been lovely with me. Maureen (trainee Healthcare Assistant) also a great person came in today to ask if I had blue eyes. Reckons I could charm birds out of trees. I don't know why everyone is so nice to me, I don't want to sound twee but I don't deserve it. I'm stuck for an adequate way to say thank you to everyone. Dave will find some chocolate I know but I need something more personal.

Someone from school is due to visit in fifteen minutes, it must be Mrs. Cusworth. Somebody else who has given up precious time I can never truly repay.



This is my honours list:

Maureen, Mrs. Cusworth, Sister Grey, Lee Adcock, Emma Rawlins, Stewart Edgar, Clare Humphrey, Diane Duffle, Mark Taylor, All my relatives, Mum's staff, Mr. Ward, Mr. Van Eijk, Mr. Davis, Mr. McVey. The list is endless.

I can see a trip to Argos looming. I think the best way to say thank you is to hold a dinner party for those friends who have visited me. H. Samuel silver bracelets for Clare + Emma. The trip to Argos is a flat warming present for Lee + Diane. What to get Stewart is the big thing. It looks like it will end up being a pen set. I must ask Mrs. Cusworth if Stewart is going to the leaver's do. If she is she could give him the pen set as part of the alternative awards.

### **Wednesday June 7th Cont.**

9:35 New ward, new page.

I feel very disorientated and unsettled again. Something doesn't feel right, but I'm hoping that's just because I've moved. I'm in a four bedder with 3 nice but strange old women. I've rung Lee, Clare + Mark to let them know.

There is a prisoner on this ward and that is bizarre. Also everything feels backwards. Talking to Mark has actually made things worse. They'd forgotten to enter him for Politics. I was nearly crying by the time he'd told me. Anyway I'm going to go, will probably write later.

11:00. I could cry. I look in the mirror and I know that is my reflection but at the same time it looks nothing like me. Moon face, more like cow face. Never mind, operation on Monday, only five days to go. I have some serious questions for that doctor tomorrow. The only thing is I find Mr. Jacob hard to talk to.

Everything has changed since this morning. I can only definitely take Economics in November. I've got to attend Mrs. Cusworth's E.Lit lessons. I don't know about Politics yet.

After I get out of here I'm going to pick up the study as I want a near perfect set of notes by September. I can't write any more because its all too much. I'm just babbling.

### Reflections

Mirror, Mirror on the wall, Who is the  
fairest of them all? Isn't that how it  
goes? Isn't that the Ultimate  
Question?

What does a reflection really say. At the moment mine's wrong. I don't even look like me. Who do I look like? I don't know but it sure as Hell isn't me. It's all right saying I have classic Cushing's Symptoms, but it doesn't make me feel any better. I look in the mirror and there is some ugly cow staring back and the worst thing is I don't know how long the ugly cow is going to remain. The operation is on Monday but how long after I'll see any change I don't know I just want it all to be over so I can reclaim my life. I want to swim and exercise, diet, reach target weight, pass my A-levels, travel, go to university. All these should be natural everyday things, but not with my body. I intend to rejoin life in September, maybe then my reflection will reflect me.

### **Thursday June 8th**

7:35. Today I feel more positive. Also less disorientated. I've decided to make no major decisions or do anything major till after Monday. My plan for today is very simple. I'm going to ring Mum and Joanne, eat breakfast and have a bath. Another day doing little. I have no choice but to go through de-tox. From Sunday, Monday's the operation. After that it is back to a low fat, healthy diet. Then as soon as I feel fit I'll pick up the exercise and get back on course with my diet. I'd like to rejoin at twelve stone, just two stone to target weight. I don't know what weight I will leave here at but I imagine it will be lighter than when I came in. However till I start fasting on Sunday, buggger calorie counts and diets.

I need to ask the doctor about the H.D.U. and how long before the swelling goes down. What kind of recuperation period there is.

It's strange but I'd rather speak to Dr. Lupton than Mr. Jacob. Well we will see what happens.

Breakfast should be here soon and to tell you the truth I can't wait. The only question is I don't know what I'll get. Anyway, they are here to do my obs. Will write later.

8:05. Was going to watch "The Big Breakfast" but the lady across the way has just stuck her radio on. Never mind its radio two so that's not too bad, also they're currently playing jazz. It does mean I will have to ask Mum for the headphones. I can't have a single room because there are some men coming in that they are having to use the single rooms for. I've given up buying a paper. Don't know why I just wrote that. I'm starving I wish breakfast was here. Not only that but my meal choice card so I can see if it's necessary to ask Mum to bring in any food. I am going to ring Aunty Jacqui. It would be nice if she came in for the day. With food and videos.

Breakfast is a write off. I know because I'd transferred there may be a problem but some battleaxe service assistant just banged a bowl of porridge in front of me and stormed off. Ignorant cow. So I've had a banana and a cup of Hot Chocolate. I was really hoping for a bread roll. On twenty-four, someone would have asked what I wanted and gone and found something. Everyone else is all right just this sullen cow. She doesn't smile and ignored everyone. She definitely won't get chocolate when I leave. Today could be a very long day. The nurses on the ward are nice it's just this one service assistant. She doesn't even acknowledge people. Menu's, arrived and its grim but I've used the vegetarian menu. 9:00 time to take a bath and start the day.

9:20. Doctors been but Mr. Jacob is going to come round this afternoon and explain the plan of action. Definitely going to have to ring Aunty Jacqui.

9:30. Aunty Jacqui is coming round with movies and food. Mr. Jacob is coming this afternoon and so is Mum. Today may be better than previously expected.

The lady opposite me is going to have an operation on Monday but she might be able to go home for the weekend and come back.

### **Friday June 9th**

2:36. Fell asleep around 20:30 so now I'm wide awake. My brain's on overtime so I'm attempting to watch Grumpy Old Men. It's actually a very funny movie but I'm just really not in the mood. This Cushing's Disease is getting more and more complicated by the minute and I'm in a bit of a quandary as to the exact meaning of it all.

As it stands the operation on Monday is an adrenelectomy i.e. I have a swelling of the right adrenal gland so they are going to remove it. That bit I get I have no problem with that. I'm a bit squeamish about the pain aspect afterwards but I think I can even cope with that. I don't even mind that depending on how things go I could end up in an I.C.U.

Guess what some nice nurse just brought me. Hot Chocolate. They must be really used to erratic sleepers on this ward. She's also said Dave rang earlier because he was worried. He rang while I was asleep and was shocked. Thing is earlier it was easier to sleep and I'm glad I did because it's made me more lucid. I wanted to write earlier but I just couldn't function.

The bit that gets me is the talk of cancer. Tumour is the name for any abnormal swelling but now there is a chance mine could be malignant and have spread. They won't know till about Wednesday, Chances are all will be fine but it sounds scary. Dr. Lupton says they won't really know anything till the operation and then they send all they remove to pathology who run tests.

Then they will know and depending I may have to see the Cancer specialist at Sheffield. Mr. Jacob was useless and didn't say or do anything. Mum asked him a question and he was so distracted that after rambling on about nothing he actually said "sorry, what was the question?"

I'm glad Dr. Lupton came round later to explain exactly what was going on.

I know I'm going to get better, its not like I'm going to die or anything but at eighteen you don't really expect people to start discussing the possibility of cancer and chemotherapy.

I'd really like to talk to Diane about it all because if, and that's a big if, it is cancer (malignant tumour) I'll want friends I can really count on and I know they will be brilliant. The only question is whether it is fair to burden her with the news. I'm not too worried now, personally I think its all going to be okay. Look at Mum and Nanny. Mum had cancer of the stomach and went on to have Lucy afterwards. No one would ever know. Nanny has also had cancer. Basically medical science can cope. I just needed to write it all down to get it clear in my mind.

The edema and swelling will take months to reduce, but I should see some improvement in the time I'm in here but the whole swelling will take about fifteen months to disappear. There is an upside, my legs and arms will be normal and thin very quickly, so with some clever dressing and a healthy diet I can still look slimmer. Any improvement is an improvement on how I look now so that is a bonus. My operation date is June 12th so hopefully my release date will be June twenty-second.

Release date, that sounds awful like I'm in prison or something. There is little or no chance I will go to the leaver's do but if I can get a lift there and back and sit down I might go to the leaver's service on the Twenty-ninth because I recuperate well - usually.

The other thing I'm going to do is study nutrition. Aunty Jacqui, although a complete flake, does know about some things. Anyway she was mumbling about saccharine being a carcinogenic. I didn't know this, and there is probably about another 100 things like that that I ought to avoid. I'm not going to go mad, but I'm going to find out how to improve my diet so I don't keep on getting sick and to give myself the best possible chance.

I think that is about it. Basically I can make no major decisions till after Wednesday at the earliest. Most can't be made till after August 19th when I get the decision of A-level grades. Now I'm just playing a waiting game whether I like it or not. After the operation it will be better because of course I'll know more. Till the health issue is sorted nothing else really can be.

However, that's just an unfortunate fact of life at the moment. At least I know I'm not going mad or a complete hypochondriac. It's always my worry that I seem like a complete hypochondriac. However, I am definitely seriously ill.

6:10. They'll be along to take my blood sugar soon. That's a new development. They are still concerned about my potassium and blood salt levels before the operation. The doctors think I'm spectacularly fabulous. My medical records are huge because they have run that many tests and things to find the cause and look at all my bits and pieces.

The only thing I didn't like, I don't have a problem with it, I was just a little uncomfortable, was the photographs. Because of the way it was done I felt a little exposed. I know that the only people to see them will be the medical profession so they should understand but I do have some pride and I did wish when he was taking the photographs that I was slimmer! This is really stupid as he was trying to photograph swellings and stretch marks. They're twenty minutes late coming to test my sugar. What a pity, I'm gutted. Drinks are on their way round now I think, I've just heard someone. They may test my sugars now. I don't know I'll ask whoever is doing this.

Well I've just had a visit from a nurse but still no test. I think a quick memory jog may be in order. I don't really want to but it is a necessary evil.

6:33. Done it. there you go. I've also made a decision. I know I said I wouldn't make any but I need to plan I need to know what I'm doing. I can't just drift. Anyway they say "life's what happens when you're making other plans". This plan takes no account of chemotherapy or cancer or any of those bad words that will keep me in Doncaster. It revolves on it being a nice benign tumour.

Talking about it being a nice benign tumour, I've decided to call it Fred.

If this sounds bizarre don't worry, it is, but psychologically it is a great help because who can have harm inflicted on them by something with a wussy name like Fred! It's as simple as that.

Anyway back to the plan of action.

- 1 By September complete Politics )  
Economics ) folders  
History )
- 2 Also in September, return to school
- 3 November- sit Economics + if possible Politics
- 4 Christmas, Birthday
- 5 February 2nd,- If well enough, get on a plane to Canada or if possible take advantage of the Round the World trip you've won. Date of return unknown but at the latest one week before you actually sit History and if necessary English Lit. i.e. you can travel for all of February, March, April, and most of May probably.

The thing is I don't want to wait 18 months to travel but even I can wait eight months for 101 days of travel at the least. Hopefully my S.T.A. travel guide will get here shortly and I can really start to plan. On the nearer scale is Nigel's graduation. Hopefully I will be well enough to go. By then, some of the edema should have gone and I'd like to wear my cream dress that I bought for Nazarene + Richard's wedding last year but couldn't. This means I need some cream leggings and I want a pair of cream pumps. Also I will make a trip to the Principle's shop for a decent jacket to go with it and then I'm going to buy a hat. I also really must make a hair appointment. The hair has to be done before the hat.

School can't object to me taking off before my A-levels because I haven't completed the syllabuses once and if I am extremely fortunate I will only be sitting one, three at the most. If I return two weeks before I'll have a week to recover from the jet lag and a week at least to read through the notes.

If Fred isn't a Fred but a Darren, you know big Daz the \*\*\*\* shit from Wheatley we will have a rethink but actually it may change nothing. I will be able to get away for some part of the time. I still want a list of college courses as I still want to do an IT course and language course. I will have the time because despite what they say I'm not going to school full time because I will die of boredom.

I need to go to English Lit. probably and a selected few History lessons but I've done sixth form once and I don't really feel the need to do it again. However, I would like to do a sixth form play and basically I have the time to organise it.

The other thing is I am going to learn to drive. It is now another necessary evil. How I'm going to fund everything I don't know but I am.

7:34. Bit of an interruption while I was waylaid by the lady in my old four bedder. She thinks I'm cheerful and optimistic in outlook. Maybe I am but I don't think I'm overtly optimistic, I'm just getting on with life. The nurses think I'm always writing, well it keeps me sane and that the important part.

10:00. Visiting hours. Diane should be here soon. I've decided to tell her. I hope she gets here soon before a) I lose my nerve and lots of other people arrive as well. This ward works really early, I've already seen the doctors and everything. I also need to ring Mum for some rice pudding and bananas. I can't think of anything else I need but I'm not sure.

21:17. Things have changed again. There is to be no operation on Monday. I had a scan today which showed the tumour may have spread to the liver. I have to go to Sheffield Hallamshire on Wednesday for some tests there. The outcome of this determines whether they will be able to operate here or whether I will be transferred to Birmingham for the operation to happen there.

Everybody keeps expecting me to fall apart. I don't want to or actually feel the need to. The truly weird thing that happened today is that Nigel gave me his Marvin Martian dogtags. If ever anyone expressed they truly cared that did it.



Its lovely but I won't tell him. I know someone giving me Marvin Martian dogtags seems irrelevant but I know the inner meaning and depth behind it. It's hard to explain, Nigel loves these dogtags and he knows I've coveted them for ages. Anyway Nigel parts with nothing especially if he knows I like them. It is his way of showing how much he cares, it is poignant in a really non-twee kind of way. I can't explain well it's just an emotion I know and its great.

Lee and Diane know everything and are being absolutely brilliant. In fact everyone is being superb which is probably why I can remain relatively calm. I can take everything in my stride, not only that but I suppose you cope just as you have to and I have to. It is as simple as that. This thing is happening, there is no changing that, so why fall apart. It will be later I'll fall apart, that's usually the way I work. The only thing I feel bad about is being unable to repay everyone for their kindness and support.

### **Saturday June 10th**

8:40. "Cool Runnings" is a brilliant movie and very funny. Mr. Jacob says I can leave the hospital for a few hours if I want but I think if I did that I really would lose it.

I still feel disorientated at times. It's only really been the last two days when I've started to feel like me. I didn't really want to ruin that. Not only that but I look so terrible.

It must sound mad the fact that I am willingly staying in hospital but after all that has happened, leaving here for a couple of hours knowing I had to return would just be too much. I may as well just wait. The only time I might consider it is if I am still in here but well enough I might go to the leavers service but I doubt it. Anyway the way my luck is going I'll be in Birmingham.

It's difficult not having or not being fully compos mentis. With lucidity only just returning I don't want to upset the balance. It was too scary before. Sometimes I wasn't sure where I was or where I'd been.

I'd start to drift and shake. I was functioning on a different 'reality'. Today I don't feel like that and that makes me happy.

I don't need to go anywhere anyway. Everyone visits, I have a decent T.V. and Video and of course this journal.

Today is my ninth day in hospital which really is quite a long time, but I'm not going stir crazy yet! 'I will ask Mum to buy me some leggings out of the money she owes me. Also, to bring in my DM's and a couple of big shirts in case I ever decide to go to the coffee shop. Basically I need leggings, my big shirt, cash, DM's, bras, a copy of 'Passage to India', more videos and visitors.

Today I have been crafty and organised it so Mum and I can have lunch together.

### **Sunday June 11th**

8:40. Yesterday I lost and became a crying gibbering mess. However I then found someone on the ward who'd had Cushing and now I'm fine in fact I'm the best I've been in a long time. Mum has brought in some clothes, jeans, jumper etc. so I can go to the coffee shop. What I've decided to do is buy nothing from the trolley but go to the shop down the stairs for my paper. Not as effective as working out but it is some form of exercise. Even though the fluid retention isn't my fault I really ought to do something. Also we are going to return as far as possible to the healthy eating kick. Mum is going to Tesco so I'm going to ask that she buys fromage frais and I'll ask if I can put them in the fridge.

I may not be able to lose weight in here but I don't have to start binge eating again. I've really let things get on top of me and although I suppose it's excusable to a certain extent it definitely isn't the long term healthy option.

Today is DAY TEN and Sheffield is DAY THIRTEEN so its not too long now. Good intentions out the window already. Well according to what I've ordered for my meals anyway.

I've ordered nothing keepable so I either eat at meal times or not at all which is good because like last night I ate things I'd saved but didn't want Just because they were there.

Everyone always asks what I've ordered and I've ordered:

Lunch- Beef & Tomato Soup  
Wholemeal Bread Roll V  
Burger  
Creamed Potatoes Eve's Pudding  
and Custard

I have no doubt I will have people around to help me eat it.

Tea: Veg. Soup  
Wholemeal Roll Spaghetti  
Bolognese Strawberry Ice  
cream

I'll probably just eat the main course, that is what's been happening but even if I don't I have an excuse. I'll just take things as they come. No hard and fast rule. The only thing I am going to do is write down for Jo exactly about Cushings. It just makes it easier to explain.

I have to fast on Wednesday. Its not the food its the lack of drink I'll miss.

9:50. Been for my walk to the shop. It was shut. It's left me a little disorientated but not too bad. I can cope. My jeans felt tight again so its returned my will power to do something about the fluid retention. I'll be all right once I get out of here but I am determined not to turn into a complete couch potato.

## Monday June 12th - Day Eleven

9:05 Vital Information 1st.  
Coffee Shop Opening

Times:

Mon-Fri 9:15am - 4pm

17:45-8pm

Saturday 11:30-16:00

17:30-20:00

Sunday 14:00 - 20:00

W.R.V.S. Opening Times

Mon-Sat 10:00-20:15

Sunday 13:45-20:15

Lee is coming today any time after 13:00. Aunty Jacqui is coming this morning with clothes and Pulp Fiction.

I'm trying to wait to go to shower till she comes so I can see what clothes she brings. When I get weighed yesterday it had gone down. Long may that trend continue. It ought to because I'm not eating a lot. I had my banana sandwich yesterday for breakfast, 1/2 Veg. burger for lunch, soup and a few mouths full of spag. bol. for tea. However I consumed a lot of calories from Hot Chocolate, mints, Smarties, Fruit juice and crap like that.

Today I've eaten

1 banana sandwich

4 Mint Imperials

3 Glasses of Fruit Juice

I could calorie count if I was feeling really self righteous but bollocks to that. Richard Hill has just found out he can go home. He's really nice.

No doubt I'll encounter him again because he and his family are involved with the Rugby Club. Also he is the equivalent of my year at Hall Cross.

Back to my weight. I get weighed here every Sunday and Wednesday. Even if it doesn't go down I know that any fat loss can be completely masked by fluid retention. As fluid retention is a known symptom of Cushings, I'm not too concerned. Also I'm on steroids, Cushings causes too many steroids in the body so most of my body weight I should lose. It may just take longer than originally planned but I have more days ahead of me than behind me.

Having said that I have to have chemotherapy. I'll get thin, but that is a drastic option even for me. I still don't want to go back to the slimming club till I'm at least 12 stone. Also when I go I will need to explain fully to Diane about my illness and explain I may hit the odd plateau. Thing is, once I'm out of here and can return to a 'normal' routine, I can go back to losing inches.

If I drink plenty of water, eat plenty of green salad and exercise, I can help control the fluid retention. Also there will be an improvement after the operation. In eighteen months, I should look like a 'normal' person.

I got a great present today; a Purple Ronnie mug off Gary Thompson. I'm not sure who was more impressed, me or Mum. I think Mum hopes there will be romance in the air. I've only met the bloke once and had one telephone conversation with him. Having said that, receiving it did give me a buzz.

The lady on here who had Cushings was discharged today. She said she never returned to being slim because of the steroids she's on but her treatment was over 20yrs ago, she was nearly 10 yrs older than me and she didn't look the athletic type.

Well, its only 10:30 and already I've seen 3 doctors, the phlebotomist and numerous others. I have to do another 24hr urine collection which is a pain. I'm in the day room at the moment because they are thoroughly cleaning my room.

I've had a visit from Male Greenwood. I mean it is now 10:45 and I've written very little but done loads. Including visiting the toilet 40 million times. Having said that it's good that time has passed so quickly. Aunty Jacqui should be here soon, which means I can get dressed. I need the loo again! Been and I've just sinned and eaten Mrs. Khan's rice pudding but it's lovely and isn't going to kill me

11:00- Rice Pudding

My weight yesterday was 86.5kg, which is down but up on what I was before but it keeps going down. I'll be fine and it should do if I'm sensible. My first target area is my legs. I can shape those. I'll just keep walking those stairs. I wish Jacqui would get here, I'm beginning to get really bored.

The way they do the 24hr urine collection on this ward is better. They keep the container in the sluice, so I don't have to have it in my room like last time. That's more private because I don't have to pour it from the jug to the container publicly. I'm tempted to ring Jacqui but I don't want to seem pushy.

I've just had 3 cards delivered. From the Hickman/Baines, Nanny and Sue Worth. People really are lovely. I am incredibly spoilt.

This really is a journal of drivel. I can't even bring myself to read what I've written previously so God forbid anyone should read it. It is just something to do which keeps me sane. Writing down what is going on and happening. It isn't soul searching like my last journals though. It's not really anything, just the ramblings of a slightly dazed eighteen year old.

11:30. No sign of Jacqui. I think I'm going to do Helen's puzzle. Dinner will be here in half an hour. That will give me something to do but I'm not hungry, I'm was ever stupid enough to take laxatives, I might as well just live in the bath room. At least if this carries on I will noticeably lose weight.

I admit defeat, I'm going to watch "This Morning".

12:25 - Still no sign of Jacqui, I wonder if she's poorly. I've just had dinner - 2 vegetable samosas. They were really nice. Spicy, which surprised me. I must remember to order them for Mum.

16:20. Went to the coffee shop and ate sausage roll and chocolate cake, 2 sticks of colts foot rock

20:40. Today has been a good day. Watched "Hocus Pocus" with Lee and Diane. Then Mum, Mrs. Wildey, Anne Holden came. Now I'm just going to kick back and relax. I won at Scrabble. I've eaten like a pig though.

Total food intake has been

Banana Sandwich, Rice Pudding , 4 Mint Imperials

2 Veg Samosas, 3 Glasses Fruit Juice

Sausage Roll, Chocolate Cake

2 sticks colt foot Rock, 2 cups of Hot Chocolate

Tomorrow Eoin and Jacqui are arriving at 10 to watch Pulp Fiction. Having people here influences what I order for lunch and means I can eat less as there will be someone else to feed. My plan for tomorrow is to get up, shower, have breakfast. At 10 precisely I will go downstairs for a paper, its nothing much but it is some exercise. I hope Eoin + Aunty Jacqui don't bring food. Having said that, Dave is coming so he will help them eat.

It is hard to vet how much to eat as I don't know what my metabolism is doing because of the illness. I think the trick is to eat only when hungry. I want out of here though so I can exercise off the fluid.

## **Tuesday June 13th - Day 12.**

8:30. I had a branflakes for breakfast. They were nice. I rang Mum and she said I had post, thinks its my S.T.A. brochure. I hope it is because then I can enter that competition. Eoin, Aunty Jacqui and maybe Dave should be here in an hour and a half. Mum is coming after school and then going to Slimming.

Its A-level British History today, I hope all goes well for them. I still feel bad- about Stewart's notes, but I've got him a nice pen set. I'll write him a letter to go with it, just explaining everything and send it with Lee.

Nearly time to go for a paper. Highlight of my day, a trip up and down the stairs. I've ordered fish pie for lunch and vegetable samosas for tea.

I'm just watching now for Pete the phlebotomist, also in 3hrs my 24hr urine collection will be over. M.R.I, tomorrow, I'm going to have to fast after breakfast, so I intend to eat well at breakfast so I don't get too lightheaded during the day. It's not the lack of food but the lack of drink that will be hard. At least they are not making me fast today or Friday. Having said that, I can't make any plans for Friday, but I don't want to miss Fish & Chips again, or Fish and Boiled potatoes anyway.

I'm still dying to go swimming. Thing is, I'm so Bruised and look so ikky I ought to wait till after the operation.

When I go down today, I must see if the foyer shop opens before the W.R.V.S. shop, because then I can go down before 10 which coincides with the

When I go down today, I must see if the foyer shop opens before the W.R.V.S. shop, because then I can go down before 10 which coincides with the beginning of visiting. I'll check it out when I go downstairs. I'll soon have this hospital sussed and then I'll probably be moved to Birmingham.

Birmingham pretty much seems to have been accepted as a foregone conclusion. However, there is no point being defeatist before the event. I reckon it was just a shadow on the scan and the tumour hasn't spread.



Not only that but its going to be benign.

Even if the tumour is malignant it is completely treatable. I'm a firm believer in miracles and I don't even need one of those because medical science is going to have me sorted very soon. 9:30 and Pete hasn't returned like he said. Oh well I'll just sit here and wait, but I am going to have to go at 10 to the shop because I won't get another chance and I need that walk on the stairs.

In eighteen months I will be thin healthy and at university if all goes well. I can't wait. Yesterday in the coffee shop Lee, Diane and I made some plans for when I get out of here but that seems such a strange concept. I can't quite grasp the concept of being out of hospital at the moment. My grasp on reality has become very warped. We are going to have a pizza day. We are going to meet at the supermarket in the morning and buy stuff for pizza then make our own pizzas - base and everything. We are then going to spend the day watching videos and playing silly games.

**20:45** Food Intake; Branflakes

BananaSandwich

Vegetable Samosa

Fruit Juice

2 cups of Hot Chocolate

1/2 brown bread bun

I got this really insensitive letter from Joanne today. It was really depressing. Fortunately I had lots of visitors and was feeling good enough about myself to pass it off but really it is horrendous.

I got lots of other things today, a teddy, lots more cards. Pulp Fiction was cool and it was nice to see everyone. Gary Thompson came at 10:15 and stayed until 19:00. He is also wanting to come back, tomorrow - very strange.

Tomorrow I'll get an early breakfast but then I'm fasting. We leave at 13:30, but my appointment isn't till 15:00. I can cope without food, but no drink for at least nine hours!! I think I will be as anti-social as possible and sleep. Lets hope its something nice for tea when I get back.

I used the charge card to ring my friends today which feels a little mean. I only rang Sarah and Jo, but it's all money. Mum bought me a new pair of leggings for tomorrow.

### **Wednesday June 14th**

9:25. Day 13 has finally arrived. Today is the day of the M.R.I. Been weighed. Lost 3.3kg which is another 6.6lbs. Apparently now I don't have to fast which is good news. Mandy has just gone to get me some breakfast. If I'm not fasting I can feed Mum which makes life easier. She should be here soon and I haven't showered or anything.

I've got my new black leggings and T-shirt to go in and I stick my big red jumper over that. It's been a funny morning so far. I'm still not fully awake. Change again, I can now have breakfast but not dinner. I'm fasting after that. Bit of

Had breakfast. Branflakes, wholemeal bread roll. Only 3 1/2 hours till I leave. My weight's still up but its going down

Food Intake: Branflakes

Wholemeal Bread Roll

Salad

Chicken Chow Mein.

### **Thursday June 15th DAY FOURTEEN**

7:25. Yesterday was all right. Mum came at 10:00 and sat and read. Gary came and he and I played Scrabble. Time was passing pleasantly and then they came to say the ambulance was here. Because of the nature of the trip to Sheffield, it took 2 hours as we had to pick up others on the way.

We got to Sheffield Hallamshire and they were running late. As I was wheeled in two girls started laughing at me and its really unnerved me. I'm not sure what they were laughing at but its really made me uneasy. I don't even want to go to the shop because of it. The M.R.I, was all right, I was able to lie still successfully, the only problem was the noise gave me a bit of a headache afterwards. It also turns out I didn't need to be fasted.

I got to come home in the car. Then I had Chicken Chow Mein form the Chinese but I could only eat a few mouthfuls. I also had some salad. Mum and Dave left about 19:00 and I went straight to sleep. With little exception I slept till 6:30 this morning so now I fell all right.

It's nearly time to ring Mum. I need underwear, pyjamas, bath stuff and bananas. I could also do with finding out exactly what she wants to do about being here for my test results and things.

Rang Mum and had breakfast - Branflakes. This is the most boring part of the day. This is when I get bored. I am going to go to the shop - why should I let two insensitive girls from yesterday who don't know me or anything about me dictate what happens in my life. Thing is, I don't' think there is anything I need from the shop.

Should have been sitting Economics this afternoon. I hope it all goes well for them. I don't really know how I feel, yes , its a shame I'm not sitting the exam because that would indicate some sensed normality. As the question goes though- what is normal? Hospitals and tests have become my reality. Getting out of here is going to be the strange thing. Yesterday, being in the car felt good. Being somewhere else with Mum and Dave then coming back in the car has helped re-establish my feeling of reality.

Today I've ordered for my meals:

Lunch – Minestrone Soup, W/meal bread roll. chicken salad, treacle sponge and custard

Supper - Vegetable soup, W/meal bread roll Sausage, mash and green beans and Banana custard

In other words, Chicken Salad Sandwich for lunch and then a nice big tea. There is always someone around to eat the soup and the pudding. Tonight it will be Dave. I'm not sure about lunch. You never know, I may feel like eating them.

After I get the test results, I'm going to write to Narry, Naz, Granny and explain what's what. I can hear Mr. Jacob on the ward, but he won't want to see me.

After I get the test results, I'm going to write to Narry, Naz, Granny and explain what's what. I can hear Mr. Jacob on the ward, but he won't want to see me yet, as I doubt he will have the results for a few more hours at least. It's not even 9:00 yet.

Birmingham means more Doctors and Nurses. I hope they let me go in the car. If I have to go, I don't know how to begin to organise it as I'll need to pack. It'll be strange leaving my room here, because as I said, I feel settled here. I know that sounds strange but I do. Of course I want to be well and at home among 'normal' things, but there is no doubt about it, I've slipped into the hospital routine.

I think the reason is I feel safe and in control. Maybe that is because I'm feeling better. I get delirious less and am far less tearful plus there is always someone on hand who knows what is wrong and that I am not going mad. It's not perfect, I do still lose it, but these periods are getting less. The pins and needles have subsided, and generally I feel better.

It must be worse for Mum, because I know how I feel, she can only try and empathise. I know it makes it hard for her not being here so she can't see me. I want to reassure her I'm fine. I think she is getting better as she realises I am getting better.

The truth is I am getting better, I feel better. Chances are the tumour is benign so this will all soon be over. By the time term starts in September things will be back on an even keel. Even if the tumour is malignant, it's treatable and in eighteen months everything should be sorted.

## **20:20**

Food intake: Bran Flakes

Strawberry Split

Chicken Roll + Salad sandwich

Treacle Sponge and Custard

Banana.

Test results didn't come through which of course was disappointing, but should know tomorrow. Ate a strawberry split ice cream because it was cold. Made me feel sick but I enjoyed it. It would seem I enjoy the branflakes for breakfast but that's it all day unless it is ice cold. However now I know downstairs sells ice cream, I'm fine. I could just eat breakfast and ice'lollies!! *Really healthy diet !!* I haven't got an appetite. I've just been eating the food because it has been there.

Gary came again today. I beat him at Scrabble again. He even had help because Mark Taylor came. Which reminds me that I forgot to remind Dave about the dictionary. I also didn't give Mum my post. Tomorrow is Friday, fish for dinner! If I'm not hungry which is a possibility in the morning I won't eat breakfast and see if I can work up an appetite for lunch. Unfortunately, in here I'm so damn inactive. Today, I went up and down the stairs twice but that's nothing, except it is because I've done very little in such a long space of time.

This is the best case scenario I can hope for, operation here on Monday, ten days recuperation and the go home for Thursday June 29th, which coincidentally is the day of the leavers' do and would be my 28th day in here. That is the best case scenario. That also includes the tumour being benign so I don't have to come back. It could all be over by June 28th. With just convalescence time at home. That is the date I'm going to concentrate on.

That day has been an important date for so many reasons. I am scared writing it down in case its tempting fate, but I need an aim and my aim is to leave Doncaster Royal and Montagu hospital on June 28th or possibly but not realistically before, a healthier woman with only an out- patients post op. appointment. "No news is good news", isn't that the saying?

unfortunate that the tumour will be malignant, but I don't really believe that, the majority believes its called Fred and its benign. I would just like to know 100%, that is all. There is no expressible worst case scenario because so much can go wrong, so I have to focus on the best. I have a tumour and they won't know if it is malignant until a few days after the operation, and they can't operate until they have test results. The test results didn't come today, tomorrow is Friday and because tomorrow is Friday, no affirmative action will probably take place till Monday.

Even if they can do the operation here, I'm not guaranteed to get on Monday's theatre list, although I should. Thing is, my operation was initially scheduled for the previous Monday and I should have been looking forward to going home now as I would only have had approximately another week if everything went to plan, and I should have had the results of whether the tumour is benign or malignant.

I know I said I wouldn't dwell but it is difficult. I could have a malignant tumour and need chemotherapy. That is the worst case scenario. Having said that, even that is copeable with because I'm not going to die simply because I refuse top give up. As I said, I believe in miracles, look at Tim, Chris, Mum, Nanny and all those people, all who were and still are much iller than me. Mind over matter is the key. There are plusses to chemotherapy - I did definitely want curly hair again! Also, weight loss definitely won't be a problem. Anyway, as I said, the tumour is going to be benign, its called Fred.

Fred is going to be removed at D.R.I; on Monday and Claire is going to leave here on June 28th a little less of a woman but healthier. She is then going to bum around for the summer, and life will resume on September whatever with the first day of school. Life will be different but fun. Academically, life will be easier and the hours less. Financially there are no worries.

The person I really feel sorry for is Martin Stanley. He is such a driven person. To be unable to take his A-levels now must be killing him. What Clare said about at least I had prior warning hurt and was a little insensitive, but she was right, whereas for Martin its been sudden, but I suppose he must have had some indication within himself something was wrong. I really hope he is all right.

He deserves so much more. I hope he doesn't lose his sponsorship and everything as he really deserved it and it would be such a shame.

I've just had a disturbing thought about the 'Cello. There is no way on God's green earth I am going to Saturday Symphony Orchestra, I may consider Beechfield, except they'd never consider me but not S.S.O. I'll just have to play for pleasure and at school.

Nothing else really, I'm just rambling now for the sake of it.

### **Saturday June 17th - DAY ONE**

7:00. New journal, new era because I am back at home temporarily. The scenario is thus; the tumour has spread to the liver so the operation has to be in Birmingham. I have an outpatients appointment with Dr. McArthur at the Queen Elizabeth on Wednesday at 10:30. He will then arrange the operation to remove most of the tumour. It can't all be removed without a liver transplant, but 95% of my liver is healthy so the rest is going to be treated with chemotherapy either at Birmingham or Sheffield.

There seemed to be no point in me remaining at D.R.I, because I can take tablets here at home. It's nice to be back and I feel quite lucid. It will be nice to be 'normal' for a while. We are counting till Wednesday, DAY FIVE, for now. It isn't that far away, and hopefully the operation will follow very quickly. After that, who knows. that far away, and hopefully the operation will follow very quickly. After that, who knows.

Mum is discussing the possibility of me going away for the summer, in between the operation and the chemotherapy starting.

I'm not making any decisions like that. Not just yet, everything can all be booked and done last minute in that respect depending on how I feel.

I'm not going to the Slimming Club yet, but I am going to monitor for a while at least what I eat, weigh and measure. The reason I won't go to slimming is because I'm on steroids, Cushings causes fluid retention, so I don't know what my weight is going to do and I don't want to feel under outside pressure to lose weight.

Currently, I weigh 13st, am 5 foot 7 inches. My statistics are H= 43.2". W=32.8" B=38" T=19.6" C=16. I am bloated after being stuck, inactive in hospital for fifteen days. I'm back to being a size 16-18, so it is time to start exercising again. Not today though, because I don't want to jump back in too quickly. If I still feel all right later, I'll do some Rosemary Conley. Thing is, today I am going to the supermarket, and if I work out now and exhaust myself Mum will worry, I won't have a good day and I'll be cactus by the time Nanny gets here. I've found this twinset I want Nanny to knit me but I need to decide what colour. I thought Navy would be nice, but I already have a Navy blue cardigan. Cream and brown fleck would be nice, it would go with my jeans. I could also smarten it up with the cream trousers I'm going to treat myself to when I lose weight. Purple might be nice, I just can't decide. Nanny has to say yes first. I know she will, but I am taking advantage because she has already knitted me two jumpers, and will probably insist on paying for it like she did with the other two. Also because I'm ill she will probably be even more insistent. I want this set and ill or not, Nanny would probably knit the set, but I don't want to take advantage of people. They have all given so much already, and I give back so little.

Today I've eaten Virtually Fat Free Strawberry & Vanilla Fromage Frais - 48 calories I need a new food diary, but I can pick that up at Tesco's. That leaves me 952 calories. I think with my current level of inactivity, the speed at which I want to lose weight, my underactive thyroid gland, the steroids and everything I ought to be able keep to 1000 calories a day. Also it is going to be very low fat eating.

Today I have to inventory the freezer, then sort out the recipe/slimming folder. I am actually hungry, but it is only 9:00. Having said that, I have done stuff today already. Well, I can hang on a while .longer.



I'll go take a bath in a minute and make a start on the stuff I have to do. By that time, Mum will be up and we can go shopping. Then we can cook. I fancy pasta and sauce for lunch. I can use the free sauce - pesto I think its called, or even have the tomato soup I made. Having said that, I've also got those Quorn burgers at 60 cals a burger. It would seem I am now a person who needs breakfast. I did say in hospital though, the one~ food I really appreciated was the branflakes in the morning. Today is going to be a very foody day.

Talking of foody days, I'm hoping to have the pizza day on Friday. 00:05. Technically, I ought to start a new day, but I haven't been to bed yet so that isn't going to happen. After today we have to completely reassess. It would seem unwise to calorie count, but I will mainly out of curiosity as to how much I am eating. Also, I shouldn't undercut 1500. Today I probably haven't because there are hidden calories like grapes, pork and salad. Tonight, things started going wrong. I started swelling, cramping, being in pain. I need to talk to Dr. Wright on Monday and get things a little clearer in my mind.

Things probably won't be better till Wednesday, when I should know more. Day 1 is just about over and Day 5 starts early so it isn't so bad.

sore, my knees hurt. I'm bruised and generally feel like crap. Tomorrow, I'm just going to be mellow, eat consciously and carefully, go to Matalan and just take it easy. Then, before you know it, it will be Monday and I can speak to Dr. Wright and find out the basic do's and don'ts. Monday night I'll go to the cinema then its Tuesday, and before you know it, it's Wednesday - day five and Birmingham. Banana on toast or rice cakes for Breakfast I think. However, I always change my mind about what I fancy. I must ring Karrie-Ann tomorrow, also Lee about pizza for Friday. Hopefully, tomorrow will be a better day and I will feel better. I felt all right before. I will probably feel better after talking to the Symptom Control/Macmillan nurse on Wednesday. I want to do everything just right, I am going to take no risks. I intend to help myself in every way possible. I'll listen to others, but I'm not going to accept every half-baked theory as everyone has an answer but knows nothing.

Dr. McMasters, the Birmingham consultant will probably be able to help more, I hope he's nice.

### **Sunday June 18th- Day Two**

8:30. Bran is on overtime again. I want to know everything and I want to know now! I want to know why yesterday was so bad, should I be exercising, what should my weight be doing, what should I be eating, what exactly are the medicines I'm on doing and why, when I swell what is the best course of action, how do I deal with the cramping, why do my knees hurt.

How soon after the op. will I see an improvement in the swelling, how does all this affect thyroid function, what is going on with my eyesight, but mainly how can I best help myself.

I will ring Dr. Wright before surgery on Monday to talk to him and also the Macmillan Nurse - Karen Neil. I know I probably still won't know much till Wednesday, but it will be a start at least. Then hopefully I will feel better about going out Monday night. When I spoke to Karen Neil, she was introduced as the Symptom Control Nurse, its only on her business card it says Macmillan Nurse. Seeing the words Macmillan Nurse is what brought home the fact that what I have really is a form of cancer. It is but it isn't, its all a big grey area.

I wish our house would get up the same time I do, it'd make life so much easier, I'm bored but I want to do all the bits and pieces planned for today now. However, it is only 8:50 and Sunday morning. I want Dave to wash my hair, get dressed, eat breakfast with the family before the rest of the family descend and go to Matalan.

10:45. Dave is just taking Granddad to church, then he's going to wash my hair and I've got a surprise coming. Well it was a surprise, he's just told me Helen is arriving at 12. That'll be nice and she can come to Matalan with us. Till Dave gets- back I'm just going to read. No doubt I will write later.

11:25. Today was a good day, especially after a visit from Lynn and Chris from \*\*\*\*\* Lindsey. Chris taught me a lot. He was given 3 days to live well over a year ago. Also, he kind of cleared up the food thing. No calorie counting. I'm going to eat 3 sensible meals a day, common sense I know, but when your brain is all over the place for other reasons, its hard to rationalise. Also, my tablets are to be taken with or after food. We eat to survive and I need to eat well. It's hard because I'm fed up of not knowing what I'm going to look like from one day to the next, because I don't know how much fluid I'm going to retain. Seriously, at present, I'm not eating enough to get fat or the right kinds of foods to really put on weight. I just have to be patient and wait. Okay, so now even my legs swell, but that's not me and it will go away eventually.

Some people consciously make themselves look bad, but mine is not my fault and I have to remember that. The weight I'm carrying now isn't a true representative of me and as long as I don't start binge eating again I will be fine

and it will go away eventually. Some people consciously make themselves look bad, but mine is not my fault and I have to remember that. The weight I'm carrying now isn't a true representative of me and as long as I don't start binge eating again I will be fine because the edema should begin to go after the operation. As for the exercise question, I'm just going to do what I can when I can. That aspect really has to be discussed on Wednesday as to what is safe and what isn't. Lynn said to pack a bag because there is always the chance they will admit you there and then. This is because they like to do their own tests and will probably start again, discounting most of Doncaster's findings so they know exactly what they are dealing with. Fortunately we went shopping today and I bought 3 nightshirts.

Tomorrow I shall scour the house for all the decent underwear - sorry Mum. Mum also bought me this cool dress that will fit despite the swelling to go in, and a new bra that hopefully will fit on the day and I have decent knickers. I will look all right on Wednesday if nothing else. I can't believe it is nearly day three already. I am certainly better off at home.

Lynn and Chris bought me this really cool bath bag with a Tesco toiletry set in it and Aunty Linda also came and she is going to give me money so I can buy what I need for the hospital. I'm a little overwhelmed to say the least by everyone's generosity in time, energy, support and financial in gifts.

Today I actually enjoyed what I ate and felt like a normal person. Maybe the pain killers this morning when I felt pre-menstrual helped, well I know they did, but today was definitely a good day and the visit from Lynn and Chris was the highlight.

Aunty Jacqui was bearable and pleasant, Nanny just lovely as always, Nigel, Dan and Dave were pissed and very funny. It was just great.

Everyone was just relaxed and happy and even though aware of the seriousness of the situation, we all had a great day which I thought was doomed. Right now I can cope with just about anything.

Tomorrow I will sort out what I'm taking to Birmingham. Also Nanny, Ellie, Mrs Cusworth are all coming. Not only that, but I'm going to the cinema tomorrow night.

### **Monday June 19th- Day Three**

7:45. Plan for today, exercise, shower, dress, ensure washing is done, sort out stuff for Birmingham, go to cinema. Also I have lots of visitors coming. If there is time, which I doubt, I'll do some school work. Ring Lee about Birmingham and Friday. Friday would be a good day to do pizza for lunch. Today I'll do the planning. I want everyone to leave so I can get up and exercise, because I can't do it with everyone here because they will worry. Daft, because I feel great and was\_ functioning before okay. Also I'm not going to do more than I can manage. I'm not completely devoid of brains.

I've decided to say thank you to the staff at D.R.I. I'm going to make macarons, ginger biscuits and chocolate chip cookies tomorrow. I thought it was the nice personal touch. I will spend today organising a shopping list. I can't see I will need much as we have loads in.

Day three is planned and day four then its Day Five and Birmingham. You never know, I may be admitted and even if I'm not, I've got Friday to look forward to. Its 8:30 and Mum and Lucy are leaving, but Dave is still here. I want him to leave so I can start the day. I've loads to do and it may take me ages to get ready for the

9:10. Did it - 20 mins, Rosemary Conley Whole Body Programme 1. That's enough. Tomorrow we will try number two but now it is time for breakfast and tablets. Then Jean will be here and I can go get showered.

#### **Tuesday June 20th - Day Four**

7-30. I've done Rosemary Conley, steamed my face, eaten breakfast, taken my tablets, wrapped Stewart's present and its only 7:30.

Yesterday was a good day, Ellie, Gary, Nanny, Jo, Mary and Lisa came. I went to see 'Jack and Sarah' with Margaret Wildey and also cut my hair and I had this really nice meal that Adrian cooked. It was also bizarre food wise. I know every day is bizarre food wise with me, but yesterday I wasn't hungry all day, breakfast made me feel sick, then all I had was 2 carrots, but then I had tea at Margaret and Adrian's. I wasn't hungry still and left some, despite that it was lovely but I don't know what it did to my body, but after that that all I craved was dairy products. I had a frozen yoghurt bar at the cinema because of the coldness of it, but when I came home I made a real pig of myself. I had a real craving for cheese and calcium + dairy products.

#### **Wednesday June 21st - Day Five**

21:45. I'm at home, so the counting continues. Yesterday was strange and stressful, hence the short entry. It's a bit of a blur really. I was grotty, felt busy and fell asleep fully dressed.

Birmingham was good, inconclusive but good. I have to go in for a few days next week for tests. After that we don't know. However, I should feel better after these tests. I'll start at the beginning. Arrived at Birmingham and immediately felt at ease. Mr. MacMaster's so eager to deal direct with me and is 100% straight which is cool. Originally he said he was going to have a case conference with the radiologist etc. at dinner time and would see me again in 2-3 weeks. After the case conference he personally rang me at home to say could I come in next week for more tests and to see an endocrinologist. That's fine, I'm quite pleased to see an endocrinologist, as hormones are his/her speciality. I also met a nice professor who specialises in chemo. and a lovely nurse. Basically the aim is to make me better before they operate to make the operation safer as with the thyroid gland.

I feel the Cushing's is getting worse not better despite the Metapro, but I will know more with the tests in Birmingham. The main problem is not the tests but the time span. I want to be able to tell Mum she can go on holiday but I can't. Its easier for me in many ways, because I know how I feel, she can only guess. I feel all right - I just want to get on with my own life. The only trouble is I can't till I look better because my self esteem is rather low.

I know I shouldn't care what I look like and just go out and have a good time, but I can't. I'm over conscious and over sensitive about the acne, the hairiness and the swelling. I remember every comment people have made and they are so insensitive. Some, make that most, people have been great, but I never realised how little comments can really hurt and remain longer than the rest. I always knew, but never really knew. People need to be more sensitive, I'm not talking about this over the top, overtly P.C. society but people definitely need to be more thoughtful.

Knowledge is power, I've just caught a very guilty looking Granddad making himself a cheese sandwich. Helpless, can't do anything Granddad - it's all an act!! Cheese and milk craving is back, that's what I was doing when I saw Granddad. Don't know what triggers it though. Earlier today, Dave's cheeseburger made me feel nauseous and chocolate is still a major turn off. The only food I feel I can face

Cheese and milk craving is back, that's what I was doing when I saw Granddad. Don't know what triggers it though. Earlier today, Dave's cheeseburger made me feel nauseous and chocolate is still a major turn off. The only food I feel I can face is noodles, wholemeal pasta shells, bean sprouts wholemeal pitta normally. I'm nearly out of milk, but I hate asking Mum for stuff. However I will, but I feel like I'm taking advantage because I know she wants to give me everything because she feels so bad for me. Why Chicken Chow Mein usually or cheese has become what I crave I don't know. Hormonal imbalances really suck the big one.

Tomorrow I intend to try to do some of the Hip & Thigh workout, plus Gary might come. If I keep busy and cool I might feel like the barbecue tomorrow night because it would be nice to make the effort for Lucy. Thing is, I just don't know how I'm going to feel.

#### **Thursday June 22nd - Day Six**

6:30. I did twenty minutes hip and thigh followed by 50 squeezes with the thigh master.

My room needs cleaning again. I ought to do that now. If I stay active today and maybe even do another twenty minutes exercise later, I may keep the swelling down, and feel hungry, maybe making it worth a trip to the barbeque.

I will go if I can get away with wearing my jeans. No, that's not fair on Lucy. I don't know what I want to do. I'm exercising and eating healthily, by rights I should be nearly down to target and feeling great. However, I'm a fat blob with acne. Maybe I should just give up and not care, after all most of it is due to illness. Thing is, people aren't going to look at me and think, 'oh, poor her, she must have Cushings,' they are going to see a fat spotty blob.

I've twenty-five days to Nigel's graduation. If I shape up my legs I can wear my long cream dress open over cream leggings. I will also buy a nice jacket from the Principles shop. What I will need is a big floppy hat with a huge brim to take away the emphasis from my huge face.

The collar on the dress will go part way to covering the buffalo lump. However, hopefully I should be slightly better by then, because that is the aim of the tests and stuff next week. I'll get Kerry-Ann to drop of the Callanetics video tonight and do that while Mum and Dave go to the, barbeque. It'll be back to wearing forty layers. The key is going to remaining active in hospital as exercise does help fluid retention.

I know I may not even get to Nigel's graduation but I need to work towards something. Fluid retention can mask fat loss and that is what happens to me because I'm keeping my fat count down. I probably won't get my own room in" Birmingham so exercise may be hard.

10:30. Woozy and tired. Didn't go to the barbeque, slept instead. Today was bizarre, computer arrived but I haven't used it yet. Also John Major resigned. Will have to buy a paper tomorrow.

Plan for tomorrow

Wake Up

Clean Room

9:00 Exercise

Breakfast

Tablets

Bath

Dress 11:00 Ring Neil and Lee

Vegetate.

Neil is a nice easy guest and no trouble. I'll make vegetable chow mein for him, Granddad and 1. Nanny is working, Gary isn't coming and Jacqui, Glynn and Yvonne can please themselves. It looks like I am going into Birmingham on Tuesday. I should get the details tomorrow or Saturday. Its difficult because they have said a few days, but how long is a few days? It's not too bad though because the plan is Mum is still going to work and travel through. This is because if they are just running tests all I will want to do is sleep so I'll probably be oblivious to her presence. I can always ring if there is a problem.



Birmingham is only 1 1/2 hours away. Nigel is coming tomorrow, I must check that it is all right me using his case.

I know this sounds mean, but apart from someone to drop off my tablets, I hope only Neil comes tomorrow. He is a really easy nice guest and just about all I think I can put up with. I hope tomorrow goes to plan (some hope!) Thing is, it makes me feel better if I've planned because then at least I feel as if I've got some control. I know lunch will be late on, well about 14:00 because Neil has a 12:15 diving lesson so that won't finish till at the earliest 1:15, then he has to get here and I have to cook. Haven't quite worked out what I'm doing cooking wise, Mum has bought chicken satay but when that is for I don't know. I may as well work out a vegetable chow mein recipe because I think I can do it low-cal.

#### Vegetable Chow Mein -

Noodles

Bean Sprouts

Peppers

Soy Sauce

Jean will be here tomorrow but that's not a major problem. She cleans upstairs on a Friday.

I have lots of questions for when I go to Birmingham. I'm pleased I'm seeing the endocrinologist. Hopefully I will be feeling better soon, or at least know more. I don't feel bad now, but the uncertainty and waiting around are a bit dodgy. There is no point asking time span questions because they currently change daily, but I do want to know how I can best help myself. I want to know what I should and shouldn't be doing, everything.

Questions: - What and how much should I be eating? If, What sort of exercise should I take? What proportion of my body is fluid retention? In playing with the treatment, what's my weight/swelling going to do? How can I best help myself? After treatment, what can I expect?

Tomorrow, I will have been home seven days, a whole week, I will have before Birmingham spent 10 days at home. Today was dodgy, but its been good, and better than D.R.I.

### **Friday June 23rd - Day Seven**

6:50. I'm pissed off, fed up an severely unimpressed with life. Life is complete bollocks. Who was I kidding, I'm not going to the graduation or to get in shape. I weigh 13 stone, wobble like the go-lightlies, have terrible acne, facial hair and feel like crap. What did I do to deserve this.

I don't want to see anyone and I'm not going anywhere. Okay, I could get up now and exercise - Wow, I'd only swell up again in an hour or two. Nothing helps really.

12:50. Feeling better, feeling more positive. Granddad's stuffed up. I told him to tell me if Neil rang so I could tell Neil not to come. Neil rang, Granddad told him I was sleeping, but to come around after his driving lesson and he would wake me then. All I want to do is nothing. The less I do, the better I feel. This morning I was definitely just over-tired. I need to be fit as the rowdy bunch move in this weekend.

Instead of trying to kill myself exercising, I'm going to borrow Yvonne's Slender-tone thingy. Basically I'm going to take it easy.

21:30. I feel strange but okay. I have some pain and disorientation, but mentally I'm okay. Birmingham rang to say they want me to go in on Sunday. I have to ring in the morning to confirm I have a bed, but I should do all right, I have faith. I'm just going to take everything as it comes.

Mum is going to help me pack tomorrow because my brain is just not functioning. That's it really. Don't know anything else to say.

## **Saturday June 24th - Day Eight**

7:00. Feeling nauseous again, but apparently this is a side effect of the Metapropene, which is like a mild form of chemo. trying to suppress Fred. I can cope.

I woke up a quarter to one this morning craving a cheese and salad sandwich and a glass of milk. I had this and a strange conversation with Nigel and Dave, who were slightly merry. Then Nigel and I watched 'Pretty in Pink' and I finally came to bed at three a.m.

Mum is going to help me pack today. This way, she knows what I've got and where everything is because how long is a few days? On a really positive note, how do I know that after the chemo, they may not decide to operate there and then, get it over and done with in one go and not discharge me at all! I'll just pack for a few days and leave supplies available. After all I'm only going to Birmingham, not" the Outer Hebrides.

The plan is to drive down tomorrow and get me settled. Mum will come back, go to school Monday, come back down, spend Monday night at Joyce and Stafford's, Tuesday in a hotel and I'm not sure after that.

I'm just going to take it as it comes, which right now involves going back to sleep.

18:30. Feeling bizarre, slept just about all day. Now not hungry, not thirsty don't know what I want to do. I don't feel nauseous although I feel a little strange. I still need to pack for Birmingham, but I'm due to wait for Mum after camp.

I thought Nanny might have visited and I could have played Scrabble with her. I'm feeling better now. I'm bored, for the first time in weeks I'm bored. Gladiators is crap. I need to do something but what? Things make little sense anymore.

18:20. Arrived a Birmingham. Nice enough place for a hospital. I feel settled, but will probably go for a walk later to orientate myself better.

The bizarre thing is the day room is off ward. Normally, anything off ward I'd get dressed for, but I'm not getting dressed every time just to go to the day room.

I have to have 4/hrly. obs. Pee in a container. However, they are going to do something about the swelling.

Don't know the houseman's name but he seems nice. It's all very relaxed and informal. Tomorrow I'm going for a scan a Vena Carva which involves X-ray dye - whoopee!!

You're not allowed fresh flowers on this ward. That makes sense though, because of the transplants. However there is a cool balcony and its the nicest four bedder I've ever inhabited. It's more like a dorm than a ward, because its an actual room. The woman in the next bed is from Sprotborough, the woman across the way from Bristol. Can't really say much more as I don't know much more. This is just another one of those bitty entries.

It's better here, in that there are two ward rounds, you get iced water, use of a fridge, and the people are friendly. 19:00, nearly time to take a walk and orientate myself I think. Trip to the bathroom on the way. At least if I do it now while it's fairly quiet, I can decide the clothing aspect of what I need and I've got four hours to kill before I have to ring Mum at 23:00.

When I get out of here its going to be a Balti and then Special curry from Yvonne's Chinese when I get back to Doncaster. Last night, playing Jenga was great. I've decided I really like Tony, he's a genuinely decent bloke.

Getting weighed was good, - 12 stone 6, only 2 stone 6 to go to target weight, no appetite, some of that is swelling which they are going to help. All I have to do is be sensible.

I'll ring Nigel in a minute just to let him know I'm fine and doing well. I think visiting finishes at 20:00, but I'm not sure. However, I'll wait till after I hear the bell and give people a chance to leave before I go exploring and see what's where, and how the land lies, as it were.

It's nice that I feel settled straight away, despite everything. There are no worries. Also I know I'm in here till at least Wednesday, I will probably be here longer, but discounting today that's only 3 more days- easy. Even if I have to come back at a later date, that is no problem either. This is a very positive place.

*May write later - doubt it*

### **Monday June 26th - Day Two.**

8:00. Things around here seem to start at 7:00 which is a reasonable hour. I want cheese again. I've rung Mum. Milk seems to have a similar effect to cheese, let's hope fromage frais will. What I need to do is get some tangerines. The only problem with this place is the milk is full fat. I must consider the possibility of getting Mum to bring me in some long life skimmed milk.

11:35. Seen Endocrinologist - Nice man.

- not recommending surgery
- Destroy Adrenal gland through drugs - Mitatane (?) may cause nausea (chemo)
- Gone to talk to Prof. Kerr and Mr. MacMaster
- Need more blood tests
- Will return
- Could go home soon?
- Will have to remain on steroids like with the thyroxin
- Self Medding
- Filling own forms
- Self Medding
- Filling own forms

13:30. I like the freedom of this hospital. Self Medding is better because now I don't have to eat till I want to, well not when but I can take my tablets with the meals and not have to snack. Lunch was nice, I hope tea is just as nice.

There is a vending machine on the ground floor. I doubt I'll need to use it but its nice to know its there. My hair is growing like a bush and needs trimming again. Unless it starts to fall out, I'll have to go see Margaret for tea again soon.

I'm up, dressed, and bored. I'm actually a little sleepy now I'm dressed. That has to be Sod's law. Going to ring Mum.

15,45. There is a ward round at four. Mum should be here for about six - tea time. About 2 1/4 hours to fill. Today has gone quite quickly and been suitably bizarre. When Mum comes, I'm going to go for a walk with her and Dave, find where everything is and stuff. Located the kitchen. Found out that Kim across the way owns and ostrich farm in Zimbabwe, I bet that's fabulous.

During the next year I want to visit Dubai, Sydney, Toronto, under my own steam and Jerusalem at Easter and Montserrat next summer with the family.

17:20. Scan thing next week now when specialist returns.

### **Tuesday June 27th - Day Three**

21:30. Not much to say. After a dodgy start to the day, feeling sick, it's ended up pretty well. Feeling fine, now have anti-nausea tablets that work. Went across to Nuffield House with Mum. Vena Carva not going to be done. Enjoyed food, took tablets. Spoke to the Macmillan Nurse - lovely woman made me feel good. Written to all the relevant people.

Nothing happened, but it should tomorrow, so I may as well leave this diary entry till then.

### **Wednesday June 28th - Day Four**

6:50. Lets hope more happens today and things start to get moving. My questions are written down, lets hope the answers can be written down also. Weight is down, getting there slowly. I do 'need to get out of here and exercise though. Legs and face are looking a right mess. A trip to the bathroom and moisturiser seems in order.

Don't feel nauseous this morning which is a nice start, although I do feel a little shaky. Hopefully though once I've had breakfast and a bath, that'll sort itself out. Blood sugar levels and weight went up yesterday, today weight was down and hopefully my BM should do the same.

8:35. Had breakfast and made a good discovery. I can order wholemeal bread and then use the toaster in the kitchen - marmite on toast or banana on toast is calling. The only thing I'm concerned about is my fibre levels are high, but I've not had my bowels open in four days. There is no pain pr anything and I'm peeing regular, but with everyone else around discussing it you begin to wonder. Barbara (next bed) is in great discomfort due to constipation and of course once attention is brought to something you think about it yourself.

Because I'm not eating a lot but drinking more, I'm probably passing most of my waste production in fluids. I don't feel constipated and bunged up so its obviously not a problem. Weirdest thing that, just talking about it and I had to go - definitely not a loose bowel movement though, so got a glass of Ribena + Fibre.

driving round Birmingham - freedom. Made a lost of clothes I want. This isn't too bad. 18:30. Nothing medical to tell. Went shopping to Mark One. Bought two lovely dresses. Soon be slim enough to wear them I think. (?) I know that sound bad but in the shop I was hot, swelling, felt ill and was a bit confused. Had a nice, calories laden (?) natural choice lunch. Mum took Mexican and cheese.

I took the natural choice however it was still probably laden with calories, and I did dip my spring roll in sour cream, eat loads of other junk today. I'm just consoling myself in the fact that at least I was active.

Tomorrow is no apparently D-Day. The spring roll was wholemeal and not fried. The thing that has got me is that I've eaten when I've not been hungry or wanted anything or even in a good cause. Never mind, we just write off today, start again tomorrow and be sensible.

We are not going anywhere tomorrow and we already know what we're eating - Banana on toast, Spinach + Lentil curry, Veg. chilli jacket potato. Nice sensible healthy eating, low fat, low calorie, high fibre diet.

For a person with no appetite I'm food obsessive, but now not only is it for the calorie count, but its to keep healthy. I wouldn't actually mind fat counting instead. I even know how to work Summer's World. Opened my bowels again - God, I hope no one ever reads these journals - so that's a good side effect of today.

I'm becoming healthy life style obsessive -1 even gave away a huge bag of chocolate without having any. When I get home, I plan to take over the cooking again. I've cut out as far as I can tell the saccharine, fromage frais will replace sour cream, pasta salads for lunch, all that kind of thing.

#### **Thursday June 29th - Day Five**

9:50. Today, things are a little more lucid, if not a little slow. This is how things stand: The tumour or the nature as to whether it is benign or malignant is still unknown, I think it is benign as if it is benign as if it was malignant I'd know instinctively. I'm still on the same tablets though that will change shortly.

I don't know if I'm going to change wards, I think I will be to the chemo. ward soon. Haven't had a blood test this morning.

Probably won't see a doctor till after lunch - lied, just seen one and they will be back at 11:30. Going to change to Mitatane.

Going to take a bath after lunch, ring Mum, go across to Nuffield house + the shop. The Macmillan nurse is coming.



Discovered how to control my disease, or at least help it. Looking back, I know this is common sense when you think about it, but the less I do the better. I feel I have an overactive adrenal gland, so if I stimulate that and hey presto, swelling, pain, delirium, its like going into a diabetic coma. In order to stay well, I need to stay calm, cool and fairly inactive for a while. I've been looking at nutrition (quelle suprise) and ways to eat healthily. I can have a healthy life style and eat out no problem. After Visage - Salad filled pitta.

Tomorrow, if I get visitors, depending on how I feel, I wouldn't mind going to the Natural Choice for lunch, but that is it and T.J.I. Friday's on Sunday. However, only if I have transport there and back.

When I get home, I'm going to ring Moira, explain about the leaver's do and also to ask about the hats.

When I get home, I'm going to ring Moira, explain about the leaver's do and also to ask about the hats.

12:30. Situation so far, Scenario 1 - Start tablets tomorrow.

2 - Start I.V. tomorrow.

3 - Go Home, return Monday, start I.V.

4 - Go Home, stay, take drugs, give in weekly urine samples to Doncaster.

Will know when Justin returns later. Mr. McMaster's would still like a Vena Cava, but concerned as legs still swollen.

Aim at 14:10 - Scenario 4.

5:30. Went for an ultra-sound and hence missed the ward round and Justin. However, he did leave a note, so here is the current scenario. Aim of treatment - shrink tumour, stop extra hormones Treatment - Drugs, not I.V. Course length - unknown

Go home in between, monitored by urine samples Not sure of the time span before I begin to look like me. Side effects: ' Nausea

Diarrhoea

Depression rare=

1) Eye Symptoms ' '

2) Blood in Urine

3) Skin Rashes (usually transient)

Hope to start drug tonight.

He actually wrote all over Mum's questions in my note book which is a little embarrassing, but never mind. Just had my B.M. done - 1.8 (oops) don't feel bad though. Forced to drink 180mls of full fat milk - yuk. Said they will return after tea to try it again. Joy of joys. Anyway, Tea is here.

17:35. Today has just been a farce. 'Nothing wrong with my B.M. - machine needed cleaning. Had to give 4 t.ms. Mitatane here, only need 1/2 tablet, 4 X day. Only problem is tablet won't break and as it atotoxic (cell destroying) only I can touch it. Ice maker is bust.

What went wrong today,

Understaffing: wait in X-ray 2 hours

missed ward round

No visitors

Didn't get to go home

Tablet didn't break

Faulty / Dirty B.M. machine give 4 B.M tests + had to drink full fat milk.

Ice maker on blink

Pen ran out / got nothing done However its not all doom and gloom. Treatments have started, a least 'soonest startest, soonest mendest'. Information is all written down so it was easy to tell Mum. Tomorrow is Friday and I know I'll get visitors Saturday.

9:05. Can't get the Discman to work, so stormed off in a huff to find comfort food, only to find there was nothing I wanted. I bought 4 Ryvita from the clock tower (and a Bounty I threw away). They didn't sell Marmite. I'm angry and I'm not sure at what. Actually I'm beginning to feel better now, just need to relax and calm down. Made an executive decision. Just written off, today will start again tomorrow!

### **Friday June 30th - Day Six**

6:50. I feel all right this morning. Today will be easier and I can get more organised. The B.M, machine read low again, but this time I knew what was happening, so we sorted it. In approximately two hours and ten minutes everything should be clearer, I should have had breakfast, then I'm going to get up, get dressed and start the day as I mean to go on. I don't feel nauseous. Now I've got an hour to kill before I ring Mum etc. Then another hour till nine so if I break it down into 2 its not so bad.

16:00. Feeling okay. Latest scenario.

- Mitatane started 4 X 5 / day
- Get ready for major hormonal imbalances.
- Have tablets till Tuesday -,
- May be able to go Monday '
- As I stands now I think my chemo. survival kit has to be on the food level at least.

Reduced fat cheese slices

Rice cakes

Skimmed milk

Tangerines (ribena and fibre?)

Bananas

Feta cheese flat breads (?)

I'm going to start Yoga on a Thursday night as soon as I'm out of here - Positive thinking is the key and I can do that.

20:30. Just spent ages in the bath, so feeling wonderfully relaxed. Barbara is in pain again after a good afternoon, which is a shame. Have skimmed milk, cheese, ryvita, pasta salad, ribena + fibre, 2 bananas, the only thing I don't have is tangerines. I even have MARMITE. Instead of tangerines, the new Ribena + Fibre I have may do the trick for now, as that's fruity. I've been making plans.

Macmillan Nurse – Wig

The trick is not to play the martyr to get home quicker, because if I get home and something goes wrong, Mum will panic. Feeling a little tired. Think I will read for a bit, then ring Mum and fall asleep listening to Vanity Fair. Nothing strenuous.

From Tomorrow, I will also write down tablets, as I really don't want to start forgetting those.

### **Saturday July 1st - Day Six**

7:20. Still feeling okay this morning if not a little shaky, but that's okay, these things are to be expected. With my blood sugar levels up and down, and my hormones in a tizz, it's just one moment to the next, but I'll get there eventually. Dr.

7:20. Still feeling okay this morning if not a little shaky, but that's okay, these things are to be expected. With my blood sugar levels up and down, and my hormones in a tizz, it's just one moment to the next, but I'll get there eventually. Dr. Stewart was very good again yesterday. When the ward round comes today, I must explain about Doncaster's ineptness.

10:30. Feeling great, so bored rigid.

The problem being that I am tempted to boredom eat, however what I crave isn't so bad, as its marmite. Thing is, I don't want to slip back into bad habits and I'm not really hungry.

This is why I need to be at home, because there is a thousand things I could be doing. Got a lovely letter from Karrie-Ann. She really is a brilliant friend.

### **Sunday July 2nd - Day Seven**

12:15. I have osteoporosis. Not good news, but not particularly devastating.

Discovered this falling over this morning. \*\*\*\*\*

18:10. Stiff, sore, in pain + sleepy.

23:00. Feeling more comfortable, had a good sleep, and eaten. Salad nice, ate about 1/3 but I'll make my own for school. It's cheaper.

2:50. Still laid flat out. Currently in no pain as such. Going back to sleep.

**Monday July 3rd -Day Eight Tuesday**

**July 4th - Day One**

**Wednesday July 5th - Day Two**

I don't know what I'm doing, Mum got me all flustered last night and now I can't function. Tried doing Paul McKenna, didn't help.

I'm not coping anymore. I don't want to take anti-depressants, but I'm just not coping. Everything scares me, and right now I can see no future. Everything is shaky and I'm in pain and keep crying.

**Thursday July 6<sup>th</sup>**

**Friday July 7th**

Morphines making me wappy. \*\*\*\*\*

**Friday July 14th**

12:50. Today is definitely a more lucid day. Was even out of bed and into the weigh chair. Still grotty and light headed, but nowhere near as bad as the morphine is now I.V.

**Saturday July 15th**

**Sunday July 16th**

**Wednesday July 19th**

Claire died on the 27<sup>th</sup> July 1995 in Birmingham