

## Jacky Pickles - My Dairy

**10/01/02**

Before the phone call today I had past through every emotion since Monday "only three days ago".

This morning I took on the invalid role, having difficulty in performing simple tasks like collecting the washing. Then I needed to be near to someone, Gary was at work, Sean was asleep - I was frightened, I laid on the bed with Sean, (top and tail) because I was scared of the phone ringing with my test results. Sean hugged my toes and we fell asleep until Gary telephoned at 10.30 - still no news.

Life went on, Sean went to sit his exam and Gilly sat with me. Gary came home early at about 2.30. Sean came home early from his exam also.

For the first time since yesterday, I began to feel that the news I would receive was going to be good news when the clock was ticking by - I became little complacent. Then at 5.40 - BANG my world and the people's world around me changed.

My emotions were not of anger and fear or self-pity like I imagined I would have felt when reflecting on a scenario like this throughout my life. Instead my feelings are concerned with protection for Gary and especially for Sean. Sean said he feels betrayed by God and Gary says he feels numb.

My first thoughts were to tell Gary and Sean that life goes on, and we must make the most of the time together and be happy. I had already spent this morning telling Sean that I will live on, within him, that his values and outlook on life which he displays now that are good come from Me and his Dad and whatever happens He must remember the good values we have taught him. I want him to be happy and if he becomes a doctor then that's great, but whatever he becomes I will always be proud of him. Sean shows his emotions, not like Gary who feels as much as me and Sean but says little. Sean said tonight - "Your not just my Mum, you're my best friend" - Well best friends always look out for one another so if I do die and am chosen to be a guardian angel then I'll guard Sean and look over Gary.

Gary had to ring Josie for me cause I didn't have the strength - cowards way out.

Then Josie had to break the news to the rest of my family. Soon I'll speak to them.

Gary's mum and dad responded similar to what I thought they would - one of disbelief then one of support.

There have been loads of tears shed today, even Joe (Sean's friend) "blubbered"

What I want most is for Gary, Sean and I to live the rest of my life as best friends and enjoy the good times - moaning might appear to make time together longer, but it just makes people miserable.

**11/01/02 06.45hrs**

Emotion now - frightened. Today we see Ann Cuthbert (haematologist) to discuss things and treatment. Sean and Gary are asleep; I don't want to wake them to talk because I don't know what to say. I have had very little sleep - I think I will have to rely on night all more.

**11/01/02. 09.15**

Sean read his thoughts to me. He is so expressive, - my baby - my ray of sunshine.

Gary is talking more and crying more - I'm glad he isn't bottling things up.

Life could be much worse - I could be alone in the world - but instead God has given me two strong wonderful men to help me through - I know they'll always be there for me. But when things become tough I want them to accept any help that people and hospitals (manor lands) provide.

**12/01/02 00.30am**

What a difference 48 hours makes - I still feel I am on an emotional roller coaster.

Yesterday we went to see Ann Cuthbert and after talking to her, I felt really positive - I have everything going for me to be in the 20% bracket.

I rang work this morning crying and irrational and told Sandra (ward clerk) so now

work knows. However, in the afternoon I was much calmer and was able to talk to John, Josie and my mum. Debbie responded well when we told her the news. We went out to Haworth to the Old Hall in the evening with them. I felt very positive.

I don't know why I feel so "together". I am shocking myself with my calmness, let alone others. Sean and Gary have been great. Yesterday I decided that I wanted a laptop to write my diary on and today Gary, Sean and I went to PC World and after some negotiation bought one - then we went to the Karachi for dinner. When we got home all three of us worked out together how to use it. It's great I can do everything on it, but it doesn't make meals!! - Never mind. I can record my voice so I can leave special messages for my Boys and can get on with writing my diary instead of lying in bed writing on paper, which is what I am doing now (it's about 12.30 am).

I feel life has totally changed and in a way for the better. As a family we say what we want with feelings instead of being sharp with each other at times or having mini arguments. Were not exactly like the "Walton's", but we appreciate each other more. When Sean said that I was not just his Mum but his best friend it touched me so much - What a beautiful compliment a Son can give to his Mum.

Knowing you have an illness can bring families closer and this is 100% in my case. Gary and Sean are my rock - both are showering me with real love and making everything easier to cope with - Because I am so well in myself its still unreal but as long as Gary and Sean continue to love me and be sensitive to each others needs then I think I will be able to cope.

I buried the hatchet with my Dad today - He was very emotional.

Today has been one of the best days that I can remember for a long time - if my life continues like today then I will cope.

We (Gary, Sean and Me) watched Bridget Jones Diary together on my new laptop, cause it's got DVD. It was peaceful, the three of us eating Doritos after dipping them in Salsa dip. I cannot remember the last time we watched a video together.

I have talked to Gary and Sean about big issues today -i.e. Gary finding a partner when I am not around. Sean understands and knows I am happy for Gary to have another partner - Gary says that I will always be here so he doesn't need anyone

else, but if I aren't He knows that he has my full blessing in finding someone. BUT - she cannot change my choice in wallpaper - I don't want to see any stars and stripes if I can return!!!

Bradford university sent me a beautiful inta-flora bouquet of flowers and a card which read "Dear Jacky, we're with you all the way, love from your friends in the division of midwifery" - beautiful, thoughtful words.

We were invited out tonight by Gary's mum and dad and Stewart and Shirley to the Roebuck for a meal. - I was happy to go but Gary didn't want to go. After prompting him he said that he didn't want to share me - but felt selfish.

**14/01/02 20.00 hrs.**

Another two days have gone by since I have put pen to paper. My positive ness and acceptance to myeloma has changed. Yesterday I had 14 visitors and lots of phone calls, all wishing me well. I was taken on with the atmosphere everything was surreal. Gary, Sean and I ate pizza and played pinball. I slept all right waking up at 2am with stomach gripes, then at 4am and 6.30am because my mind was working overtime.

**Hospital admission at 08.00hrs.** Still my mood was positive; Gary and I took it all in our stride. Small issues started to get to me, like when I read the myeloma booklet looking at stage myeloma and prognosis. I mentioned it to Ann Cuthbert, who said not to think too much about staging and talked positive about me as a person, not general statistics.

Having the Hickman line in was the worst experience that I have ever experienced, not only was I frightened but I felt all this tightness next to my throat - I thought it was in the wrong place and that I might die on the operating table and I wouldn't see my boys again - but it was just paranoia as I am still here writing this diary. I am still not 100% sure that it's in the right place (paranoia). The insertion of the Hickman line has brought out the reality of everything. Gary has been great saying the right things at the right time, but reality has hit home. I feel why me. People have rang up saying I am too nice a person for this to happen to, but as Gary says it's indiscriminate. Having the chemotherapy was scary. Prior to today I said to Gary to go to work because I can cope with today's events, but I tell you now I don't think I could have survived the day without Gary by my side, telling me nice things and saying I'm still

sexy with tubes hanging out of my chest. For the care you shown today Gary - I love you more.

We have had seven calls in four hours from well wishers. I am very tired but will probably not sleep. Sean appears to be coping well, I hope he is. I hope I am more positive tomorrow also.

**17/01/02 14.05 hours.**

Three days have gone by since I have written this diary - I feel this is a positive step. Treatment wise, all is going much better than I thought. Not one side effect as yet, however, I forget to ask anyone at the hospital if side effects build up or just happen. I'll put it on my question list that I have prepared for tomorrow. I am doing my own dressings - easy peasey. Well the phone still resembles a hot line from well-wishers, Ruth, Jo Harrison, Debbie, Chris, and Suzanne, not forgetting family also. Yesterday I had a few tears at teatime feeling sorry for myself, but since then I have felt very positive.

I am little concerned with Gary, cause he isn't sleeping well, but hopefully things will change. Sean appears to be coping better. He, Ruth and Kirstey have gone to Manchester to see Incubus. Then he informs me that it's studying time over the weekend - I hope so.

Tonight I think Gary and I will have a Chinese (I will cook my own rice though) - paranoia again - I think I will get every infection going.

I am extremely well in myself; yesterday I did the biggest pile of ironing you have seen. Today I have vacuumed the dining room, tidied up and phoned the university to arrange for Step to send me two workbooks so I can complete a workbook now making marking easier when I do them. I am doing lots of organising, sending books back to library, via Julia P-Morrell. I have also looked into finance issues.

Gary and Sean are continuing to be my rock, but I also feel life is having some sense of normality again. I am a bit nervous of getting my X -ray results - but we will take each step at a time.

**20/01/02 15.30.**

Things are a changing as they say. Lots have happened over the last three days. Alison Pickles/ Brown came to see me who was nice and we had a good chat. I am still getting flowers, cards and phone calls from lots of friends.

On Friday Gary and I went to the hospital to have my pump discontinued, there were no problems and Dr Cuthbert was available to answer questions that I had written down. The problem is now that I cannot remember the answers to the questions. I will put it down to nerves and not dementia.

After the hospital, Gary and I went to Harry Ramsdens for dinner and sent my sick note to Bradford. Sean came back from Manchester / Liverpool after having a good time.

John (big brov) came to see me in the evening with my mum and ending up staying until about 21.30 hours so instead of cooking a meal like we planned, we all (Gary, Sean and Me) ate pizza. I still felt well and was more or less symptom free.

Saturday has brought about many changes. A major change to me is the irritation of constantly tasting salt in my mouth. Anything I eat or drink appears to be laced in salt +++++.

Sue Williams, Chris T and John made up my visitors today. Gary went to football and Sean was at home with me.

Another twist in my life events is that my Dad has admitted to being an Alcoholic after all these years, so at this eleventh hour has sought treatment and in now an in-patient on ward four (Psychiatric unit). He has been there two days feeling suicidal.

Gary seems not to be coping as well. Maybe reality has sunken in. He is not communicating and is becoming eaten up over trivial issues. This is causing me some stress. It's starting to feel like I have to tread on eggshells because I don't know what he is upset about. Two incidences have occurred over the past twenty-four hours, which have been blown up out of proportion. Gary has gone out to Angles' but prior to leaving there was an atmosphere. He says that it's because Sean didn't help out - however, we were all lazing around and then, Gary decided to move, because Sean didn't respond the same Gary was mad. O.K but he didn't explain anything; he

was just going to not speak to either me or Sean and leave. This type of behaviour to me is not conducive to positive thinking. Gary must tell me more about what he wants and not create an atmosphere.

I feel quite negative today. I know that when Gary reads this he will see things differently

**23/01/02 09.30 hours.**

Again time has elapsed since I have come to write this Diary. Three days to be precise. I ended on a negative note last time feeling confused and unhappy. But today is another day and plenty of talking has changed a lot. My main concern was Gary's mood swings which after talking the issues through with him, but Sean was also listening things changed quickly. Gary shared how he felt, confused, head buzzing, too many things in his head, but not able to focus on anything particular, feeling some anger, but didn't know whom towards. All parts of "Elizabeth Koubler - Ross", identification process, which I understand well as I have been taught it throughout my nursing and midwifery trainings and facilitated within teaching sessions. I feel Gary will now try his best to share his feelings more, but at times will lapse, hopefully for fleeting periods only and quickly get back on course.

Sean appears to be coping with the situation very well. He has a very good understanding of the DNA structure and feels that if children are cured of Leukaemia then I can live forever with Myeloma, with appropriate treatment. He feels this is achievable and not denial.

John has spent a lot of time with me, between visiting my Dad and keeping my Mum sane. He has taken her out for meals and probably made this painful time for her easier to cope with. John went back to Portsmouth.

I cannot believe all the cards and phone calls I keep receiving from friends. At work, Andrea, Luisa, Val, Geraldine, Maureen D, Cath B, Sheila and Ruth and Jo H have all sent cards or phoned which I am touched with greatly.

On Saturday night we went to Debbie and Grahams, which was difficult probably for them as I was in a moaning mood. Gary and I had not resolved the issues at that point and all I did was moan about a salt taste in my mouth. I must apologise and

show them how different I am in a more positive light. As for the salt taste it's much improved. Ann C feels it's linked to the methalpregnisolone treatment. If this is so then I can cope with it for two to three days every three weeks.

Yesterday Gary, Sean and I went to get my x-ray results, which I was very, very frightened about receiving. Monday I in my fit of life goes on the same so I don't need to change anything I decided to move a small cabinet in the bedroom. No sweat for me a semi-professional removals woman. However, as I was pulling it around the bedroom I felt an almighty crack in my lower back and a pain surged through that area. Fear gripped me. I throw myself on the bed and quickly checked my leg movements to see if I had the full range of movements, but I was paranoid that I had caused permanent damage. The phone was next to me and my immediate action was to ring Gary or even the hospital. No one was in the house. I calmed down and just protected my back all day, to the extent that I was moving around like a cripple. I dare not take any painkillers in case there interacted with my C-VAMP therapy. When I went for my blood taking with Sean, Aden reassured me that taking simple paracetamol is fine, so with this information I gave in.

So results time. Gary, Sean and I were present. Ann C and Aden also. Results = good news. Small degenerative changes to D7, Myeloma?? Posture and age and some artefacts in the skull, which could be to do with normal ventricle blood flow, or minimal changes with myeloma. Ann C was more than happy with the results, adding to her previous assumption that we couldn't have caught the myeloma any earlier - so aren't I lucky!!! I at that second in time felt I had won the pools cause I was so lucky. In reality I am probably very unlucky to have myeloma. Sean quickly worked out that I had about a one in a  $\frac{1}{4}$  of a million chance of getting myeloma - how lucky is that!!!

Yesterday I also had my C treatment. It is quite frightening when the solution is been put in, although I have total faith in Aden. I feel like I might die as it is going in as my head becomes light and I cannot feel in control over this happening. I also had to drive home afterwards which again was scary, but eh I managed. I went into a deep sleep when I got home for about an hour and a half, then afterwards I felt fine, but just looked extremely waxy. I suppose I will get used to these new phenomenons, which are a small price to pay for effective treatment.

Today I have written a lot, cause it's all I have done for the past two and a half hours,

in-between answering the phone (Jason and Josie), oh and eating some breakfast with Sean.

Well a busy girl has to move on, so I will leave my thoughts for now.

**27/01/02. 13.30 hours.**

Four days have elapsed since I wrote. Thursday brought about visits from Alison and Jackie Haigh which were both enjoyable. I felt well and therefore did the ironing. Friday's day started with Sean and I getting up early to take the car in for a service, then we picked up Josie as she cleaned that day. Josie was upset, when I attempted to find out why, she said she felt I was blocking her out and she really felt annoyed with John because he is racist. I explained to her that I was not shutting her out and that I couldn't get excited over John's personal opinions. Josie said I was just like my mum, at times shutting my ears to issues. I suppose I feel I have enough to deal with without making waves. Josie seems annoyed with things she cannot control but wants to. I feel happy with life at the minute and don't want to reflect on major issues at present.

Ruth came and we chatted ++++++ about Myeloma mainly but anyone and everyone also. It was stimulating.

Friday evening Gary and I went to M&S to buy some hats cause the hair dropping out is getting nearer. Anyway I was not feeling too well, symptoms were feeling heavy headed, then every now and again my head went very hot which made me panic a bit. When we reached M&S I felt worse, and inside the shop I thought I might faint so I decided to sit down with no chair near I sat on a display stand. The only problem was that the stand was on coasters - hence it just slipped away from me. A concerned Gary helped me to my feet, led me to a chair and went to get me a sugary drink. He was very concerned at the time, however, 24 hours later told Family about the trauma with humour. Sean says he will still come shopping with me even if I am prone to showing him up.

On Saturday, Gary and I went Skipton and Keighley and I didn't show him up. We bought a light shade for the wine room. At night early on we went to the Turkey and had a glass of wine (tasted salty) - but I felt I might catch something - I don't know if I am paranoid or sensible. We went to Bizzy Lizzy's for fish and chip supper in the car.

I feel very positive still, Gary says I am the bravest person he knows, but I don't feel brave at all in fact when I cry I feel very scared.

Today Gary has gone to football and so Sean and I are pottering about making meals. I have learnt how to make bread in the bread maker, I have just made a shepherds pie and Sean has made a curry. I am becoming extremely domesticated. I have even steeped the towels that changed colour last week when I washed.

I have spent most of my morning compiling a letter to work, trying to make it informative, humorous and serious - I don't know if I achieved this but it reads OK. Again I end on a positive note. I feel there's plenty of life in this old soul at the moment.

**01/02/02 17.00 hours.**

It has been five days since I wrote this diary. A lot has happened over the last week. Monday 28<sup>th</sup> - I went for my blood test (by myself), nipped to town and Chris T came over for a coffee in the evening. At about 7pm the phone went, it was Ann Cuthbert asking how I was. I felt fine until she told me that my Hb came back at 6.8, it was 10.6 one week earlier. I panicked, felt ill and was not able to sleep, because I thought that if my Hb has dropped so drastically then how much more will it drop overnight. I had to attend HODU at 09.00hours on Tuesday, which is what I did. My Hb was rechecked and came back at 9.0. So the scare was over and I had my normal treatment. Gilly came for me after my treatment as I find it traumatic and don't want to drive home. Sean had driven me to AGH at nine. All day Tuesday afternoon I was in and out of sleep. The actual treatment this time was not as bad as before maybe due to the fact that the Maxalon was swapped for a different anti-emetic and also I sat on the couch instead of the chair. I will try these changes next time. In the evening Gary Sean and I went for a meal at the Turkey - which was nice.

Wednesday was a good day, Julie Morris and Angela Murray called and we all had a good chat, mainly about work and all the people who work on delivery suite. Also Tanya Trowers called, but as I had company, said she would call back Thursday. Suzanne also called. She was asking me about my medication - so I showed her my boxes of tablets and realised I had not taken the right amount of Co-trimoxazole, I had been taking one instead of two. Overall my mood was positive.

Thursday I had organised to go somewhere quiet with Josie, I had explained that I didn't need her to clean every week, as I spent most of my days cleaning and also money wise I had to be a bit more careful. Josie and I had been to Scar top and then decided to go to Ponden Mill and visit the Café. We had just finished our breakfast, when I touched my hair and about a dozen strands came off in my hand. I again panicked and had to come home. Josie came home with me and then I rang Linda the wig lady to organise collection of my wigs (Friday 1<sup>st</sup>). Josie went at half one, Tanya came at half two for a couple of hours. Throughout the evening I cried a lot, mainly because of my hair loss but also I felt exhausted with all the visitors I have had recently. I know everyone means well, but at times I feel I can not get on with making the tea etc, as I am constantly entertaining. Sean and Gary tried to lift my mood, joking about my hair loss, but I was still very down in mood. Gary went to his Saxophone lesson and then went to Sainsbury's. He brought me a Thornton's cake back, which cheered me up a bit. We all shared it, it was delicious. I was so tired when I went to bed that I slept like a log for the first time in ages.

Today I feel much better, probably because I have slept so well. I had a bath, and then gingerly washed my hair - a lot came out, but it just looks thinner at present, not clumpy. I picked up two wigs today, Gary came with me. It was just another hurdle that we have to get over. We showed the wigs to Gary's Mum and Dad and Sean. They were all positive about them. Sean had one wig on and I the other messing around. I am very concerned about how my hair will come out; it is causing me more concern than I anticipated.

The cards are still flowing, I have over 30 now. I also received a bouquet of flowers from Jacqui Gerrard and the Management Team. Gary is bored at this minute in time and wants to go somewhere, but I find it difficult to go places, due to the risk of infection (I have just found out that Duncan-James has Glandular fever and Alison called twice over the past two weeks - Ahhhhh) and because my hair looks thin and I feel unattractive. I have said that he must organise things like a curry with Gilly and his Dad or go to pub. I am not trying to push him out, but feel that he may become bored with my life on Chemo. The weather is bad so we cannot go out walking at present. I know I am not the life and soul at this minute in time, but things should get better. Sean seems fine and says he isn't bothered about my hair falling out.

My back has been giving me some jip, I'll have to keep an eye on the pain and if it

continues see about an X-ray.

**03/02/02 08.10 hours.**

Up early aren't I. I have had a very emotional, traumatic couple of days. My hair is falling out all over, you just have to touch it and about 15 / 20 strands will appear between your fingers. Its very upsetting, I spend quite a bit of time bursting into tears about my hair. Gary is telling me that I am sexy with or without hair - I wish I could borrow his eyes for a while. Sean and Gary have a lot to put up with at present, I don't like crying and feeling sorry for myself but it just happens. Their continual support is helping a lot, and for that I am grateful.

My back is uncomfortable at present; it may be how I have slept, so hopefully it will feel better soon. I have had to take paracetamol over the past couple of days, (only two a day).

Yesterday Gary and I went to Skipton to shop in the open Market; it was raining, but nice. We spent time looking at prices of things, instead of just chucking items in a trolley in Sainsbury's. It's amazing the mark up on things - deodorant was over a pound cheaper. Gary and I planned to go out in the evening, but I didn't feel up to it.

I put my wig on for Chris T, cause she called in after looking at a house in Laycock (imagine Chris living in Keighley after her slagging it of all these years - I told her I'd buy her some white scuffed stilettos and black leggings, cause she says that's how Keighley folk dress).

My mood on Friday night was very mixed up. It was the first time I became angry and sobbed, stating why me and feeling that I couldn't believe this was happening to me - I wasn't a bad person. I felt my face contort with the pain and emotion that I felt and that moment in time. Gary was there to help me see things in a different light. I have probably moved in and out of all Elizabeth Koubler Ross states of emotions, Denial, anger, bargaining, acceptance, the last if I can remember is death, and although I have talked about it, hopefully it's a long way off. Gary and Sean is my crutch, which I try not to lean on so much, but at the moment I feel I cannot walk without a crutch at either side holding me up. Lucky I have two men in my life.

I have just taken down my cards 37 in total; I am looking for a special box to keep

them safe in. Today we are going to a Garden Centre; hopefully we can buy some bulbs that may make spring feel nearer, because at the minute the weather is very windy and raining most of the time.

### **06/02/02 15.45 hours**

Today I feel like making time to write this diary. My emotions have been all over the place lately. Sunday evening, after Gary came home from football, we all had a bought curry. I was still upset about my hair loss, but I wore my wig all day so feel better about my appearance. Monday was a good day, Julie put my curtains up they look beautiful. Also Shirley came and we had a good chat. It was a very positive day.

Tuesday I went to town by myself in my wig and no one appeared to stare. I went to small office supplies and the woman made a comment on how nice my hair was - I let her in on the secret. Mary came for lunch and again my mood was positive. Gary's' mum and dad came to see the bedroom in the evening, and we all had a good chat. When we were alone, Gary was staring into space, so I asked him what he was thinking about, He said I was thinking that when your not here anymore, I don't think I'll remarry, because I don't think I will find anyone with your qualities, intelligent, good company, good looking - no-one will measure up to you. It made me cry, him placing me so high on a pedestal.

Gary and I were going to go away for my birthday to the Lakes this weekend, but what with my hair falling out all over the place, having double treatment Thursday and bleeding heavy from my period, I have decided to give it a miss. I will take a rain check on it and go when the sun shines. I also thought about somewhere else that I wanted to go - on the "London eye", I think it's called that, in London. I would love our own carriage, but don't know if that's possible.

Today, Wednesday, I went to the dentist and she was able to stick my gold crown back without drilling, again the dentist said my hair was nice - Sean chose well with the wigs. I received a beautiful arrangement of ivy and ferns from ward 21 and Alison M is coming to see me any minute. Sean has swept and bleached the back, which looks much better and is now picking up my medication from HODU. I have been for my sutures out and a blood test today. I feel that I might be anaemic, due to my heavy period, we will see tomorrow. Sean is taking me for my treatment tomorrow. My back hurts a lot less that it did so hopefully its getting better. It now aches more

than hurts and I seem to stiffen up as the day goes on. I'll end now as Alison M is just coming up the path.

**08/02/02 05.15 hours.**

On Wednesday I talked lots to Alison M about issues relating to having Cancer (She has undergone chemo and radiotherapy for breast cancer and is now in remission. We talked about issues relating to treatment, hair loss, family and what it feels like having cancer. She helped me tremendously, especially when trying to think of exactly what it felt like having the weekly treatment. I tried before to express how I felt, but Alison hit the nail on the head when she said that she felt claustrophobic - that's precisely how I felt. I feel the maxalon had a lot to do with this feeling, so now that they have substituted this for a similar anti-emetic I should lose the claustrophobic feeling.

Wednesday night I was in agony with my back - Both Gary and Sean looked really concerned. I tried to hide just how bad I felt, but they both saw through me. I put it on my list to asked if it is normal to feel more pain in the evening as oppose to similar pain at all times.

Yesterday Sean I and went for my treatment loaded with questions to ask. I asked simple nurse type questions about my Hb etc, which was surprisingly 10.1 and my nutrefils were 1.2. This is low, but I was still able to receive treatment, less than 1.0, interferes with giving full treatment. Sean asked much more biochemical questions about the treatment. He needed to know how the chemo was reacting to cells within my body. I was mega impressed with his knowledge base and more especially how he spoke on a level with a staff grade doctor (Dr Levy). Sean is an extremely intelligent boy with a wonderful questioning mind - I am so proud of him and all his life's achievements so far. I was petrified of having the weekly treatment, mainly due to the claustrophobic symptoms, which I felt with the initial two treatments and the thought of the hickman line, been so close to my heart and lungs. Sean had said previously that he thought the hickman line laid in a vein in my neck, but I thought it was nearer to my heart. Well need I say who was right, Sean again. To try and allay my fears both the nurse and Dr Cuthbert explained how hickman lines work and how the treatment is safe. Both said I need to trust them and the treatment more, so this is what I will work at, placing all my trust in them and stop panicking. My Globulin is 54/55 now, which pleases Dr Cuthbert. I was informed by Dr Levy that the plan is to

give me 6 three weekly treatments then reassess plans, things that were mentioned was my own or sibling bone marrow stem transplant, interferon injections and thalidomide medication as possible ways forward. But at present no line of treatment has been advocated.

When I got home I expected to feel tired and fall asleep, but that feeling did not happen. Instead Sean and I shared memories. I showed him my letters that Gary and I wrote to each other when we were going out with each other - cheesy. And we looked at old photo, reminiscing. Then Sean and I went through His memory box. What struck me was Sean memories centred around little meaning full times in his life with Ruth featuring strongly in most memories and laughs with friends etc. He never spoke of material things, just special moments. He is such a thoughtful person with strong emotions; to me his emphasis on life is about friendship and fun instead of materialistic gain. If nurture plays a part in how your children view life then Gary and I have NOT failed Sean. Today I realise just how thoughtful and sincere our Son is which again makes me so proud of him. He was telling me how he saw our mother son relationship, our closeness and special relationship and how difficult it was to be in his position seeing the person he loved most in the world going through Cancer and the treatment - He said he would change places with me, but then felt maybe not, as he did not know what I was going through but felt that what he was feeling he would not wish on me. I said if it was him who had my diagnosis I don't thing that I could cope. Losing Sean to Cancer would tear me apart. I cried a lot, but didn't see this negatively, more about sharing deep emotional feelings.

Gary came home from work early, the place was a mess, but he understood the need to reminisce was a greater priority than the need to clean. Dr Levy felt me progressive back ache was contributed to doing too much like vacuuming and ironing and to cut back on these chores.

Sean went out with Ruth to a poetry evening in Bradford while Gary and I stayed in with pizza and a glass of wine. We also spoke a lot about our feelings about the past and future, any regrets etc.

As you might have worked out the insomnia had kicked in as a side effect of the steroid Methalpregnisolone. I have been awake since 02.30 reading and trying to induce sleep but gave in to breakfast at 05.00 hours, then decided to write this diary. Its now 06.30 hours so I am going to go back to bed and see if sleep happens.

**10/02/02 17.20 hours.**

Friday was spent talking to Josie while she was cleaning up and Sean while he was getting organised to go to school. Josie was impressed with my wig and Sean went quiet when he read the latter page of this diary, but he said he liked it. In the afternoon I went to Julie Morris', we had a laugh talking about work and a couple of serious moments discussing treatment, and then Julie cut my hair, to a number 3. I was really scared and wouldn't stay still, but when she finished I was extremely glad she did it. We laughed lots cause I would not sit still; she said that if I was in labour and acted like that she wouldn't want to deliver my baby as I probably wouldn't keep my bum on the bed. Julie house was just what I imagined, stencils, antiques, Victorian style I really enjoyed the afternoon.

Friday evening Gary went upstairs on the Internet. He came down and I asked him what he had been doing. He told me he had just ordered me an extra birthday pressy. After prying more he told me he had bought me a star, and named it "My Darling Jacky", another message said "I will love you forever, until this star burns out". I cried a lot, but with tears of joy. How thoughtful and loving Gary is.

I have been deep in thought lately, thinking about having a big input into organising my own funeral. This may seem morbid to some, but to me it's practical so I will open another file with thoughts about my latter life and funeral arrangements on it. I don't think I'll die soon or anything like that, but I just want to be organised.

Saturday was odd job day. Gary and I went to town to get some new cutlery and paint to touch up the study. I received a beautiful spray of flowers from Aunty Carney and a card saying that a Mass will be said for me on 18<sup>th</sup> Feb at 09.00 hours. In the evening Gary and I went to his Mum and Dads for tea. Sean went to see a tribute band to the "Who", he said they were good. The salt taste is very bad at present, but I know it will pass in a few days, so I not too worried about it.

Sunday Gary, his Mum and I went to Granary Wharf; it was a nice day out.

**16/02/02 13.00 hours.**

The last entry on my diary was cut short, probably because someone called. It has

been six days since I have had time to write this diary, mainly due the amount of visitors I have been having and therefore I have not been able to spend time alone to think about writing down my thoughts. John and Trish together with the older boys visited every day for 4 days, which was tiring, but I understand his need to visit, as he isn't around much. On my birthday I was not without visitors from ten on the morning until ten at night, constantly making coffees etc. I would have moaned if no one came but to tell the truth I was shattered. The phone is ringing less often but visitors are still plentiful. I had a nice couple of hours with Andrea and Jane Morgan on Wednesday - they brought me some wonderful gifts from work, I was really spoilt. A watch, earrings, necklace and basket of flowers. Monday saw gasmen at the house three times because we had a gas leak. Mum and Dad came Monday so less people were around Tuesday on my birthday. Thursday was treatment day, I was suppose to go with Chris T to Louise's' for a look around her house then Chris and I were going for my treatment, but due to feeling tired with visitors and not wanting to be around children I cancelled. Instead Sean and I went, and then we went to AGH canteen for dinner.

Weekly treatment is much better since they switched maxalon for another drug. I no longer feel claustrophobic, and I feel happy to go for my treatment alone, however, as yet I have not gone alone, maybe next week. I attend for the blood tests alone. I am not as worried about the hickman line and read somewhere to view the chemo as a friend which helps irradiate the cancer cells. This is my aim and I feel I am getting there.

I have not cried for three days now, so emotionally I must be getting stronger. The last tear that I shed was not anger tears or pity tears but tears of proud ness and emotions which incorporated love for my Son when he gave me my birthday card in which he wrote "To my best friend and Mum. I will always love you forever and be there in times of need". All my love always Sean xxxx. What mother could ask for more? He is such a sensitive person. Gary also got me a beautiful card saying "To my darling Jacky on your 40<sup>th</sup> birthday. I'm sending all my love to you this day and every other day for ever and ever Love Gary".

The treatment at the moment is making me feel unwell at times. I feel that my digestive system is stripped due to the heartburn and excessive wind and excoriation of skin around my bottom. Also when I eat I have some referred pain around my right shoulder and down the top of my arm, which could be something new, but is probably

referred wind pain. But I cope OK.

Yesterday I did far too much. I went to town with Debbie for three hours and then in the evening I went to the Shimla Spice with Jo and Ruth. A combination of doing too much and eating rich curry foods had exacerbated my heartburn type pain, so now I have decided that a bland diet and a day pottering might help.

The salt taste has disappeared, it seems to build up with the Methalpregnisolone medication and then last two to three days after treatment then reduce. Now I know there is a pattern I can cope better. I will end now as Gary has just come in from work.

### **27/02/02 19.00 hours.**

Its eleven days since I last wrote this diary. I feel it is a good thing that I was able to leave it so long since last writing, but Gary feels I have a tendency to write when I am feeling more negative and he wants me to record both negatives and positive things. Cards and flowers are still coming. In fact I want the flowers to die and I want to get the cards down as these things remind of illness and I feel I want to move on now. I have had plenty of visitors, Viv and Geeta on 18/02/02. We laughed about work issues and gossiped about anyone who wasn't there. Julie Morris came on 20<sup>th</sup> and brought me a cupboard that has gone in the utility room. Chris and Howard came for drinks that evening. I went to Ponden mill with Josie on 21<sup>st</sup> to get towels for Debbie's birthday present and I bought a bed spread cover, which looks really nice. Gary went out in the evening for a curry at the Karachi.

On Friday I went to the university to hand in the feedback sheet that I had composed earlier on in the week. I stayed for lunch and caught up with gossip. Angela Guest called with flowers in the afternoon.

Friday was also Debbie's party, and what a party it was. Gilly came with us and Sean bobbed in with his friends for an hour. Debbie was drunk and was being suggestive with Gary; at one time she was baaing like a sheep. Sean danced with me to "Jimmy Mac". Sean looked really nice in his Jacket. Gilly and Gary laughed most of the night at people. I danced to a few songs, as my back now is 100% better. There was one song that made me and Gilly cry, the last song, "Can't live if living is without you". We really enjoyed the night and stayed until the end at 00.30 hours. There is

another party that we are invited to next Saturday, Craig's party, which will be as different as chalk and cheese. Craig has spent months organising his party. He has booked a DJ, band and karaoke and has a 70 / 80's theme. Outside caterers have been booked, unlike Debbie's party, who catered herself.

On Saturday we went to Debbie's to give her her present as I forgot it on the party night. She said that she remembered everything that went on at the party. However, when I reminded her that she was doing press ups on the dance floor, she could not recollect this.

In the morning Gary and I sorted out fancy dress gear for Craig's party. Gary has an Afro wig, pink frilly shirt and white flares. I look like a fat Beryl from Liver birds. I have A pink hat, a green flowery blouse with a big collar and pink flowery pants. I also invested in some pink heart shaped glasses to look the part. I'm looking forward to the party on Saturday.

On Saturday evening Gary and I went early doors to the Bella Napoli. It was really nice to do normal things, like go to a restaurant. Then we had an early night.

Sunday was spent performing DIY duties. B&Q and then Gary installed the new radiator in the study while I started to rub down and wax the cupboard doors in the utility room. Gary's mum and dad called in the evening. Gary is full of cold so doesn't feel well.

I have started to have a cold so on Monday 25<sup>th</sup> I went to HODU for antibiotic cover. Kath Nolan, Sheila and Viv were supposed to call but I cancelled them, as I did not know how long I would be at HODU. In the afternoon I painted the inside of the utility cupboard. I am proud of my DIY. We have asked Gary's dad to come and sort out and decorate the utility room. It is the last room in the house to complete.

Today, Wednesday 27<sup>th</sup>, Gillian, Geraldine and Justine came from work. It was nice cause they not only brought gossip, but also then supplied lunch with wine. Gary and I went to D-Jet and bought a cupboard and worktop for the utility room. Gary's dad is coming tomorrow to make a start on the room. Gary has gone to the quiz with Graham so I am all alone. Sean has gone to quid's in at the Royal.

I still cry most days, often with Gary, but feel stronger overall. I am frightened of dying

even after Sean has explained his chemical reaction theory. Tomorrow I will be getting my cassette on, so I will be looking forward to tasting salt ++++ on Saturday for a few days. Last week I got my Para-protein results, I have reduced from 40% to 21%. This is positive result that I must remember when I start talking about dying. I have been two hours writing this so I will end now.

Last Tuesday I had a terrible experience with my eyes. I was watching television when I noticed there was a small area of the TV that was difficult to visualise as I could see a glittery area and was not able to read the writing that appeared at the bottom of the screen. Both eyes were as bad each other. I waited for 15 min and by that time the area was much larger taking up half of the room. I decided to bleep Ann Cuthbert. She reassured me that this is a typical side effect of the Steroids. It might turn into a migraine but its nothing to worry about. After half an hour the symptoms disappeared and they haven't returned.

**02/03/02 16.30 hours.**

Today started horrible. Yesterday morning I could not sleep due to the steroids so I got up at 6am to iron and make bread. Gary got up so I put the kettle on but carried on ironing. He was mad cause his cup of tea was not ready. Therefore this morning he decided to repay me by not making me my Weetabix. I was very upset because I did not feel that it was the same I was busy ironing I had put the kettle on and I have a lot on my plate. What upset me most was Gary saying I was self-centred. These were cutting words that I feel were below the belt.

We are going to Craig's party tonight and the salt taste is pretty bad which make me feeling low in mood. I hope I enjoy myself cause I have been looking forward to tonight for a long time

**08/03/02. 18.15 hours.**

We had a great time at Craig's party. Gary and I quickly made up from our disagreement. I danced a lot and then when a bit of soul music came on I tried to dance more but my back began to hurt so I had to pace myself. Steve (Pam's husband) was drunk but before he left he told me that when he has been ill he asks the angels to help him. He made me promise that when I felt I needed help, and then I was to turn to the angels. I said I would. We took a few pictures, so the camera will

revel how hideous our 70's outfits were. Everyone at the party seemed to get into the 70's spirit. This made it a night to remember. It was a complete opposite party to Debbie's last week. Craig had outside caterers, a band, karaoke and a DJ. I didn't drink due to the salt taste been horrible (cassette in situ) but Gary made up for me.

We didn't do much on Sunday; Gary sorted the cupboard for the sink in the utility room. Sean, Gary and I had a meal. The day was spent just pottering about.

Gary is back on call today (Monday). It is only 3 weeks since he was last on call; this is due to new rotas. So we will not be doing much this week. Gary's Dad has started to decorate the utility room. I don't much like the mess but it's the last room in the house to be done. We are trying to decorate it so it looks good but not too expensive I hope we can achieve this. I got my cassette off (04/03/02), so the salt taste is at its worse, which leaves me feeling pretty uck. I have also noticed that my teeth are very stained so I have an appointment with the Hygienist tomorrow to see what she can offer. I went to Chris T in the evening for a coffee and to pick some Anne Geddis pictures for the bathroom. She recons that she will be moving Easter week. Sean went to see a band (A) in Leeds with some friends. Sean drove there. He has more confidence than me with driving.

The hygienist was very good sorting out my teeth. She felt it is the mouthwash that is staining my teeth. I decided to put some washing in, but prior to that I had been messing about with the sink cupboard that Gary had built. When the washer began to spin I heard water running. I ran in to see the utility room floor soaked in water; this was because I had moved a pipe that was connected to the waste. After spending time trying to dry the new cupboard before the wood swelled due to the water, I decided to leave plumbing to Gary Heaton.

The pressure in my back and hotness throughout my veins reappeared Tuesday evening. I couldn't move in bed due to the increasing pressure. I took co-proxamol but it had little effect. Gary is always concerned when I am upset due to the pain but there's little he can do.

Wednesday my back was even worse. I went out to Colne with Julie Morris and Angela Murray, I tried my best not to whinge and to look like I was enjoying myself but I was crippled in pain. I apologised to both of them for being so quiet, they said it was normal to have good days and bad and not to apologise. I went to my Mums

after being at Colne as today it's her 60th birthday. She knows something is happening tonight but doesn't know what. We have all booked to go to Dynasty. We have got her a cake and a few little presents, but she wants money for her birthday so she can send it to Myeloma Foundation. It will probably not help me in my quest, but it may help the next generation of Cancer sufferers.

Yesterday (Thursday) I went alone for my treatment but was very low in mood and upset due to the pressure pain in my back. I explained all my symptoms to Denise and Dr Levy who listened but then offered me anti-depressants and Morphine. I explained that I had pressure pain but I didn't feel that this was the answer. She agreed with me but said that medication is available if I change my mind. She feels it's a personal side effect from the cassette. I need to make note of when the symptoms occur it make sure that it is connected to the cassette. It happened one day after the cassette was removed and lasted 3 days. I have severe backache now, but I feel this is due to doing the ironing and cleaning mirrors.

Clare Simmonds and Helen Darrell came for coffee and cake Thursday. I was going to cancel them as I felt horrible with the pain, but I didn't have a contact number, but by the time they arrived I felt a little better.

In the evening Gary and I went to the Co-op. On the way back, Gary said we will read the Keighley News, half each, have a horlicks and then an early night. I said we sound like 70 year olds as oppose to 40 year olds.

Today Josie has been doing the cleaning and Gary's Dad decorating. My aim today was to do the ironing and make pizza for tea. I achieved my aims but at the expense of now having severe backache, which is different to the pressure pain that I had from Tuesday to Friday. Sean is getting ready to go out and Gary is on call so I will just have a few minutes to myself.

I read out to Sean what I wrote about Sean that I want reading out at the funeral. I don't know if I am morbid but I need to put my feeling down on paper.

**19/03/02 15.45 hours**

Eleven days has past since I last wrote this diary. This to me is viewed as a good thing as I feel life is getting back to normal, whatever normal is.

Well what's happened since I last wrote. Gary and I had to invest in a new washer on Saturday 9<sup>th</sup> March, as ours was leaking and causing some damp in the utility room.

Sunday was mother's day; Sean made me a card and bought me a book *The Green Mile*. I went to Josie's because Mum was there to give her a card and chocolates. In the evening Gary's Mum and Dad came up for tea. I didn't enjoy it, as my back was hurting +++++. It was worse on the Monday, so bad that I rang HODU for stronger painkillers and to ask for an X-Ray as I was convinced that my back was getting worse. Gary was concerned about me so came home from work. Work said they would pay him, which was good of them. I managed to see Ann Cuthbert at 13.00 hours, who said that she felt that anxiousness was probably the main contributing factor to my back pain. The X-Rays showed there were no real changes to my back. I commenced DF118 tablets.

Tuesday and Wednesday I relied on the medication and also had breakthrough pains. I did manage to go to town and buy a new top with Josie on Tuesday.

Wednesday was a nice day. Gary, Sean and I went to Manchester to look around the University. I felt like an invalid at times when we were walking around and I could not keep up and then my back played up a lot. But nevertheless we had a good day. Sean decided that Manchester would be his first choice, as he liked it so much. In the evening Gary and I went to the quiz at the Turkey. We had tea there as well. It was really a good day.

Thursday when I woke I decided not to take the DF118's and to try breathing techniques to help if the pain was due to anxiety. Also constipation was beginning to be a problem, which was connected to the DF118's.

Gary's Dad has been decorating the utility room all week, so I have not had full run of the house. But I will be glad when the room is completed.

Friday was a day of getting things off our chests. Sean said he had started to think more seriously about school work because he really wanted to go to Manchester so he needed 2B's and a C. Gary was upset about Sean's alcohol consumption. Sean at first was mad at Gary. He then began to think and worked out his alcohol consumption, which was below the average if he went out twice a week and just

above when he went out three times a week. I am really glad that Sean is beginning to take schoolwork much more seriously. Gary and Gilly went out in the evening to Bullies night do. I drove them there and back. They both appeared to have a good time.

Sean had friends up in the evening to show off his new optic. He then went to Rios with Ruth and co.

Saturday I was invited to Paul Skinners 40<sup>th</sup>. But I had back pain again, not the pressure type pain, just the back pain. Therefore I didn't go. Gary said lets go out to the Turkey or somewhere cause he was bored. I explained that I was too tired and had pain so I didn't want to go anywhere. Gary was annoyed at me for a few minutes. I explained that things would get worse in time and I was upset that I had no energy. I wanted to get up and party, but my body cannot do it, as I am at times energy less. Gary soon changed and said he was sorry and understood how I must feel.

Sunday was tip day again. We took the filing cabinet to the tip and chucked out 3 bin liners of rubbish out from the study. I composed a letter to IMF and sent the money £275.00, that my Mum raised from her 60<sup>th</sup> birthday. I also sent for further information about Myeloma. In the evening Gary went to Football and I received a phone call from Marie, a Myeloma woman. It was good to talk to someone who had gone through the same treatment and was now back working full time. She inspired me. Marie has been diagnosed now for over two and a half years. I am going for a coffee on Wednesday to Marie's house. She is ten years may elder and had drop foot for over six months so her illness took longer to diagnose than mine. I feel life is really getting back to normal, I know I have already said this but, feel it's worth another mention.

Yesterday, (Monday), Maureen and Karen came to see me and Diane rang me Sunday. We had a good chat about work and Diane gave me some tips about treatment. The car wouldn't start today so Gary's Dad took me for the taps for the utility room. Gary got the car working it was something and nothing. Gary Heaton sorted out the sink and washer plumbing. Another job done. It was Gully's birthday so we all went up to Angie's. When Simone was going to bed I let her kiss me. She must have thought about kissing me because she was told she couldn't hug or kiss me. Then she said, with her finger out to me, "so have you still got Cancer". We laughed; it's amazing what goes on in a child's mind.

Today I went to Scar Top to get some floor jars for the utility room and use my tokens up. Josie came with me. I am now attempting to make steak casserole, veg and mash. Gary is due in at six o'clock and it's now twenty to six so I must move and put the tea together. Bye.

**27/03/02 16.20 hours.**

I am still on an emotional roller coaster at times, but feel life is beginning to take shape again. Last week I went to see Marie. She really inspired me when we were chatting. She made me realise that most of the symptoms that I feel, she felt also, therefore I am normal and not "over anxious". Marie said she saw a psychologist and was told she was over anxious also. Sometimes Health Care Professionals make jib remarks and think no more about them, but to us "Patients", we chew things over, trying to make sense of the remarks.

This week I have had my 4<sup>th</sup> cassette, so I have had to put up with the horrible salt taste that happens. My Para protein was 20 - after the 3<sup>rd</sup> cassette, which I wanted it to be a little lower, but at least it's still reducing.

I still couldn't get my head around the searing pain that occurs after the cassette comes off, and then all of a sudden, my questioning mind worked it out. The liquid in the cassette is infiltrated at 0.5ml per hour, probably due to its potency. However, when I am disconnected in clinic, they flush my hickman line, which has about 5 - 6mls of fluid still in the tube. No wonder my veins spasm, or my muscles react. I knew I was not been over anxious or making the pain up. Today the pain is apparent, but I try not to take analgesia unless I am desperate.

I have started marking the workbooks this week, which makes me feel normal and worthwhile, instead of just cooking and cleaning. Some of the students are lazy, filling in only half of the books or copping straight from Miles, but that's students for you. At least I am glad to be marking and doing paperwork again.

Gary and I went out for a curry with Ruth and Jo and Hubbies last night. I enjoyed the evening but could taste much, never mind. Gary was up most of the night with indigestion, curry and booze just didn't mix well.

The utility room is near completion, apart from the tiling that Gary's Dad said he would do for nothing in the evenings. I love the colour; I might even paint the kitchen the same colour. Today I treat myself to a washboard for the utility room. We have also just bought the tiles so hopefully the room will be finished soon.

Sean is making up his mind regarding whether to put Manchester as his first choice or not. He is getting on with course work and is thinking about revision.

Sean has helped me mark the genetics part of the workbooks. We went to Debbie's today to commiserate as Bethan was rejected from York.

I am still getting lots of visitors, Ellen O'Connor telephoned me and she's coming to see me on Friday. It will be great to see her again after about 11 years. If I had not been diagnosed with Myeloma, I may have never seen Ellen again. Good does come out of bad.

The sun has been shining over the past two days, which makes you perceive life differently. I feel that life is becoming more normal, not like the nightmare I felt two and a half months ago.

Well tomorrow's treatment day again. Gary has asked me to see if going to France in late May is an option. Obviously treatment comes first.

**11/04/02 14.45hours.**

Two weeks has gone by since I wrote this diary. A lot has happened, good and bad. The good things are that Ellen O'Connor visited me with her daughter Molly. We had a wonderful day catching up on a whole decade. Ellen is a H grade for a drug and alcohol unit. Also another good thing for me was the completion of 24 student workbooks which I personally took back to the university and stayed there for about five hours grading the workbooks with the set assessment criteria. Others may think that marking is a negative side of my life, but to me it brings a sense of normality and structure to my life.

Gary and I went to Blackpool overnight, Saturday to Sunday. We stayed in a boarding house with a sea view. We people watched mainly, in Yates Wine Bar and when walking on the front. We also had a nice meal in the Cross Keys Pub. Sean

stayed at home and had a party. The house was still in one piece, thank God. The Sunday before Gary and I together with Debbie and Graham went for a walk down the main street in Howarth. I bought a couple of items for the utility room which is near completion. I am looking forward to going to Jenny Anderson's house tomorrow. There's about eight of us going.

Gary, Gilly, Taffy and I went out for a curry. We had a good evening. Gilly said Taffy was astonished with our verbal relationships. Gary saying he is going to have a motorbike when I die and them taking the mickey out of my cancer. Some people don't understand that being serious about cancer can wear you down, but making fun of events is easier to deal with.

What else is good? The way Gary cares for me when I am upset or in pain, the nice things he says to me, like he will never find anyone that will match me and yesterday he said a song came on the radio, Rod Stewart - "your in my heart", I don't know if that's what its called, but he said the words really fit our life and what he thinks about me. Both Gary and Sean try and reassure me when I panic about treatment or side effects and they put up with me getting upset at the drop of a hat. For that I am extremely grateful and feel honoured to have two people who love me so much.

I expect it's a good thing that I have just today commenced my 5<sup>th</sup> treatment (cassette), and although I have had new problems (clots), my treatment has still continued. I was sat in HODU last week listening to two other patients who could not have their treatment because their bloods were out. Then I realised that I was lucky with my treatment. I have to remember this when I am mixing and drinking the methalpregnisolone or injecting fragmin into my leg. By the way Gary and Sean inject me if they are in, if not I have to do it myself.

I had mixed feelings about the school reunion party for my year. It was nice seeing people that I hadn't seen since I left school. However, I saw how confident people were with there lives mapped out, and felt a bit resentful, that my life has changed so drastically over the past three months.

Bad things that have happened over the last two weeks have been feeling unwell and frightened on Saturday 30<sup>th</sup>. I had dropped beats and my pulse was 120bpm. On the Wednesday following my left arm was swollen and discoloured. Ann Cuthbert saw me and sent me for an ultrasound Doppler. It confirmed that I had two blood clots in

my veins, one in my axilla and the other in the subclavian. Therefore I had to have my Hickman line removed and commenced fragmin. Sean came with me and stayed when Ann Cuthbert took out the line which was not painful. The problem is when the line goes back in. I stated that I wanted a GA when the line was re-sited. Yesterday I had my line put back in under GA on ward 18. Gary took the day off work to hold my hand. Because I was a good girl; I was taken to McDonalds for a treat.

Ann Cuthbert said yesterday that she and Leeds had flagged up the end of May as the time for me having my bone marrow stem transplant. Josie had her HLA tested yesterday. Ann couldn't get blood from Jason and John is making appointments for his HLA being tested. Things are moving pretty fast at the moment treatment wise.

Today I had a swollen eye which really worried me, I thought it may be connected to all the drugs I am on. In reality it was probably a hair or some dust in my eye, but when it's happening I can not look at it objectively. Both Gary and Sean reassured me and now I feel a bit of a fool, thinking that my eye might fall out or something daft like that.

Gay is on call again this week. These on call weeks seem to come around very quickly.

I spoke to Marie yesterday. She seems to have had a many problems if not more than me while she was on her chemo, so she gives me confidence that I will get through and be like her in a couple of years, well and at work.

I have got a few things booked to look forward to. Next Tuesday Gary, Debbie, Graham and I are going on the Turkey's treasure hunt. I am going for lunch at Tanya's on Wednesday. Thursday I am going to see Edwin Star with Chris T in Bradford and Friday we are going for a curry at Ruth's. That is Me, Gary, Jo and Simon. So I have to stay well because life's too busy to be ill. I don't know how I'll fit in the cooking and cleaning. Good job that Josie's coming to clean tomorrow. I will close now as I have spent one and a half hours writing this today.

**23/04/02 16.30 hours.**

Today I have decided to write this diary. I am sat here with very mixed emotional feelings. I have a bit of a headache, which I have just taken 2 paracetamol for. I am

thinking am I normal having a headache, which most people get or is this another side effect of all the drugs I am on? Who knows!

Since I last wrote I have had times when I am low on mood - feeling sorry for myself, but I suppose I have been through a rough patch, with the replacement of the Hickman line, fragmin administration and attending the warfarin clinic twice weekly. Also I have had my 5<sup>th</sup> cassette, which always makes me low in mood.

Friday 12 April I went to Jennie Andersons with Andrea, Geraldine, Gillian, Justine, and Jill. We all had a good day, eating lunch and looking around a show house. We were being very daft pretending that it was Gillian's house and she took lots of pictures of us sat around the table etc. I remember being very out of breath a lot of the time. This had been going on for a couple of weeks. Looking back, my coagulation must have been way out, as now my breathings much better.

Monday 15<sup>th</sup> April, I made a Myeloma reference folder for HODU. If they are looking after me they need to be updated. I also sent more information to Marie. I have read a lot about sibling stem cell verses my own stem cell. At present I can not see too many advantages with sibling stem cells. I plan to get results of Josie and Johns HLA and then if one of them are a match, I, with Gary and Sean need to discuss options with Ann Cuthbert. If they are not a match, then it's no good discussing issues as that option will not be available.

Tuesday 16<sup>th</sup>, Gary and I, and Debbie and Graham did a Treasure Hunt organised by the Turkey. We had a good evening, collecting clues and eating pie and peas.

Wednesday 17<sup>th</sup> I went for dinner to Tanya's. We just sat chatting and chilling out. It was really relaxing. I thought how nice it was for Tanya to recover me after my GA last week.

When I went for my treatment on I was nutropenic 1.25 and my white cell count was low. I was advised not to go to see Edwin Star, so I did not go. I was not upset as I was tired. I say yes to too many people then either have to cancel or become too tired. I need to look after myself more and say no more.

Gary went to organise joining the fitness first gym. He says he is joining as he has to look after his own health. He says he needs to be healthy to look after me when I

need him. He says that he will be no good to me if he dies of a heart attack. I felt touched by this analysis.

Friday Gary and I went to Ruth's for a curry night with Jo and Simon. Although Gary was not looking forward to it, he appeared to enjoy himself and we didn't leave until after midnight.

Sunday was Gary's mum's birthday. There was a family party, all attended, Duncan and Alison included. I enjoyed the day, but had terrible stomach ache. It settled after about two hours. Gary went to Burnley's last match - they missed out on the play offs, but Gary did not seem too upset.

Yesterday, I went to town to get material for Julie to make curtains for the utility room. Today I have been to the university to send back some more workbooks. I had a word with Julia about the poor quality of the work. She felt that I needed to put my concern in writing to Mary Law, but also to feed them more and maybe drop my standards. I explained that I felt I could not drop my standards any more. I feel that I might as well write them for them.

Today I asked Sean how long he thought I would live - he said 8 years. I feel that I need to organise what I want out of life. At the moment I don't know what I want from my life.

**15/05/02. 21.15 hours.**

It has been 3 weeks since I last wrote this diary, and lots have happened. I have been too busy to write.

Treatment wise - I underwent a bone marrow biopsy on 25<sup>th</sup> April. It was very painful, but Gary and Denise were there with me to ease the pain and wipe away my tears. I then had to wait two weeks for the results. On 9<sup>th</sup> May I saw Ann Cuthbert and she gave me the results. The results showed that John was not a match, and Ann felt Jason would not be a suitable donor at this time, therefore the way forward now was stem cell transplant using my own bone marrow. Results show that my bone marrow plasma cells have reduced from 12.6% down to 7.5%. I always thought that you had to get down to 5% prior to having stem cells. However, Ann feels that it is right to start organising this treatment now. I have also had a further cassette since these results so I might be less than 7.5% now. Ann also organised a chest X ray as a

small plural effusion had shown up on a previous X ray.

On the Warfarin front I appear to be stable and am sticking to 5.5mgs.

I found out that I have IgA Myeloma. I asked Ann Cuthbert about prognostic factors - She stated that my B<sup>2</sup> was normal, as was my CRP and serum creatinine. These are all good signs when looking at prognosis.

Ann Cuthbert is sorting out an appointment with Dr Child prior to June 10<sup>th</sup>. This is the day that I am prepared for stem cells with very strong Chemo at AGH. On June 17<sup>th</sup> I am probably going to Leeds to start treatment. I need a femoral line sitting for the treatment, which will be sited at AGH by Dr Silverton. I feel good that the time has come for my stem cell, but also a little apprehensive.

Ann Cuthbert also wrote a letter of mitigating circumstances for Sean. This has been taken to school for Mr. Davis to send on to appropriate organisations.

Today I have bought chocolates and sorted out some wine for HODU staff that I will take on Thursday, as my treatment with them for now is coming to an end. They have all been wonderful with me, but Denise I particular has been great.

Sean and Angie took part in the Abseil at Harrogate on the 27<sup>th</sup> April. Together they raised over £760 for Cancer research. Both sides of the families turned up to watch and also aunty Mary, uncle Terry, Karen and Chloe arrived to watch them abseil. I was really proud of Sean raising money for cancer research.

So what social events have happened over the past 3 weeks, well I watched a school production (Oliver), with Debbie and Graham which was OK. Gary and I went out for a meal to a Mexican restaurant with Sue and Craig which was good. Sue and I along with Kath and Alison had a girly curry night at Kath's that we all seemed to really enjoy.

Gary and I went to the Turkey for a drink when it was the beer festival and Sean was working voluntarily that evening for Harry. We also went to Harry Ramsdens one lunch time Debbie and Graham came for a meal at our house. We had a good evening. Debbie and I spent time chatting about two young cancer patients on ward

14, one 39 years old and one 37 years old, both very ill.

Gary, Sean and I watched the green mile video. John Coffey touched both our hearts. But John Coffey was a character and not real. Gary and I have been to Bella Napoli for a meal which was very nice and relaxing.

Emotionally I feel strong at present. Although I still fluctuate a lot. I feel I am strong as I have a plan of care to look towards, some structure to my disease. Yesterday Sean and I had a deep meaningful chat about how I will be when the Myeloma progresses. Sean is not frightened of death at all, unlike me, although I feel better about it than I did prior to diagnosis. Sean feels that the humiliation of not been able to care for yourself will be difficult to deal with and doesn't know how he will cope seeing me in pain. I told him about PCAS pumps that will be readily available when I need them, at home or if Gary can not cope with me, then at Manorlands. I am glad we talked, but it was emotionally draining - we couldn't do that level of deep emotional conversation often.

I am not upset that John or Josie is not a match. Maybe I am naive but I feel a 20%+ risk of death from the actual stem cell process is a big risk that I feel I could not take at present.

I have been to make a will which was emotionally taxing. I explained that I wanted Sean to not lose out on what I consider his share of the house if Gary remarries or has a long term partner. The solicitor appeared to understand what I wanted and is now organising the will which will include a special clause. It will name Sean as a trustee of my half of the house. Everything I have, including the house will go to Gary, however, if Gary remarries or had a common law wife, the house will be valued and Sean will receive half of the value of the house. Gary can buy Sean out and continue to live there if he wants.

Yesterday I spoke to Marie, asking her about what happened when she had her stem cells. She filled in a few gaps for me and reassured me I would be fine. It is two years since she had her stem cells and she is fit and well at present. She is my inspiration.

Sean has given up his job at AGH so he can study more! He has had some work from the catholic club. His intension is to get a full time job for three months in the

summer prior to going to university.

On the work front - Diane Farrar came to see me for a couple of hours. We had a good chat about work and Cancer. She reflected a lot on her sister's cancer (Karen). Jacque Gerrard and Anita from personnel paid me a visit. I found out that I will be going to half pay on June 1<sup>st</sup>. I can claim incapacity benefit when sick pay stops, which I think is the middle of July. Geta rang me to tell me she had got the Antenatal Screening Job, I was pleased for her. I also spoke to Tina Mori, who wished me well.

Today I went to Bradford University to hand in Intake Two's workbook. I spent all last Monday changing bits of the book to make it more student user friendly. If I make it anymore user friendly I might as well fill it in for them. I also picked up more work books to mark. I am watching videos for the university as a side line - I hope I am receiving monetary gain.

Josie and I went to Drop Farm for our dinner which was nice. Josie is coming to clean tomorrow, but I have told her that tomorrow will be the last time until I return to work. She understood.

Gary is on call this week which is not much fun, but never mind, we will have to make up for it next week.

**14/06/02. 20.00hrs.**

It's been one month since I last wrote this diary and again lots have happened.

On the work front. I went to see colleagues at work on 3<sup>rd</sup> June. It was good to call in and see people. Also Andrea and Pauline have booked to see me next Friday. Wednesday 5<sup>th</sup> Gary and I took videos and workbooks back to the University. I put in a claim form for the work I did watching the videos. I am been paid £32 per hour which is good news. I am down to half pay now so every little helps. Today I received forms to fill in for disability allowance, so ill be busy this weekend with them.

On the house scene, I got the house valued last month - £115,000. This was pleasing to me. Julie made and put the curtains in the utility room on 20<sup>th</sup> May, so that's another room finished. Josie cleaned for the last time on 16<sup>th</sup> May, I can not afford such luxuries now.

Before I cancelled Josie we had a meal out at drop farm. It was nice. I bought some duck eggs and cooked them at home. After Sean and I ate them, Gary came home and told us how duck eggs and salmonella go together; Sean and I were waiting for symptoms which never happened.

On Monday 27<sup>th</sup> may I helped Chris to move house. The house she was moving into was really dirty I was glad to go home and leave the muck. Steve and Rachael called for coffee on 19<sup>th</sup> May. On 22<sup>nd</sup> may Gary and I went out for tea to the Turkey prior to taking part in the quiz with Debbie and Graham. They also called up on Sunday 2<sup>nd</sup> June prior to us going to France. On 25<sup>th</sup> may Gary and I went for a drink to the Turkey then bought supper.

Gary and I went to turner and wall to sign the will on 5<sup>th</sup> June.

I booked the holiday to France on the internet. It cost £232.00 return. We are going on 6<sup>th</sup> June to the 12<sup>th</sup> June, flying for Liverpool to Nice. When we got to Nice I went to organise a bus to Frajus, but the bus had just left, next the man rang the bus driver who turned around and came back for us. When we arrived in Frajus we tried to get a taxi, but there was no drivers. Next thing some French people asked us where we wanted to go then told us to get in the car and they would take us there. We were both amazed that strangers would go out of their way for us. They took us to the camp site, and wouldn't take any money from us. Gary and I went into the club house in the camp to surprise his mum and dad. They were stunned that we were there. We spent 6 lovely days touring France. We went to St Tropea, small villages and Monaco. At Monaco we had to walk up lots of steps, I found it really difficult to breathe when climbing the steps. Gary was very concerned; he told me later that he was concerned that I may have lung cancer. We played boules one evening and then took part in the celebrations, me on the karaoke and Gary performing a dance. The weather was good most of the time, but one day it rained and continued all night. One evening we all went out to a French restaurant for a meal.

Treatment wise I am continuing with my Thursday treatment until I have my harvest on 24<sup>th</sup> June. Gary and I went to Leeds to see Dr Child. We had to wait for hours which didn't please Gary. Dr Child explained procedures to us. He said that the treatment may add a further year to my life. This straight talking upset me, but I was glad that he was straight with us. I have my itinerary- on the 17<sup>th</sup> June I will attend

HODU for high dose Chemo, and then start growth hormone injections. I stop my warfarin on 20<sup>th</sup> June, ready for my femoral line insertion on the 24<sup>th</sup> June on ward 20. The ward clerk said that I was in the diary for admission which read - Jacky Pickles, side room, Dr Cuthberts special patient. This made me feel special.

Sean is seeing Kay again. He travelled to Winchester to visit her on Saturday 1<sup>st</sup> June and returned on the Wednesday prior to Gary and I going away on the Thursday. He is in Winchester now with Kay. I hope he has done enough revision, cause his exams start in three days. He says he wants to go to Bradford University now not Manchester. Sean left school on Friday 31<sup>st</sup> May, so on the Thursday he arranged a dazed and confused party, which was very good. He organised two barrels of beer from the turkey and food. All who attended enjoyed the event.

Emotionally although the treatment is intense I feel quite stable. I cry less and worry less. I have just found out I have a paralysed diaphragm but it doesn't bother me much. I have met another girl with Myeloma, called Janice; she is 55 and lives in Cowling. I speak to her about treatment, she was diagnosed in March, and so I am two months further on than her. I am going to attend a conference in July 6<sup>th</sup> with Gary all about Myeloma in Leeds.

Gary is on a works night out at the moment in Bradford.

He shows me lots of love and supports me when I am upset which I appreciate lots.

**08/07/02. 13.00 hours.**

I am at present sat in HODU having two units of blood as my Hb is 8.8 g/dl. I have been here for four hours laughing and joking with patients who are in a similar position to me. Its great being part of this positive attitude circle. The power of positive thinking goes a long way, and I usually subscribe to this. However, sometimes I am taken off guard and cry, usually when Gary is around. I try not to cry in front of Sean. Since writing this diary I have had my Harvesting. Prior to harvest I had to undergo a day of high dose chemo, which was horrible to say the least. I felt and was sick in the night. On the 24<sup>th</sup> of June I was an in patient in ward 20 for three nights. Throughout the day I spent two days going to Seacroft hospital for harvesting. They needed 2 of bone marrow, however I gave them 3.4. They were very pleased with my harvest. Prior to my harvest I had to inject myself with some growth

hormones to stimulate my bone marrow to spill over into my blood.

On 19<sup>th</sup> of June, Gary, Sean and Gilly went to the quiz. We didn't win, but had a good time. Sean, Gary and I had tea at the Turkey. I also went to the Turkey on the 21<sup>st</sup> June with Pauline Wintridge and Andrea Massey for Lunch (they paid).

Over the last seven days I have had a packed life. Monday 1<sup>st</sup> July was spent finishing marking intake ones workbooks. Now I am waiting for intake twos master pieces. Thursday 4<sup>th</sup> July evening I went out to the Balti House with the Group Practice Midwives. We had a good time. Friday Gary and I went to Debbie and Grahams for Chinese and a game of scrabble. Saturday Gary and I went to a Myeloma Study Day at the Hilton Hotel in Leeds. I really enjoyed the day, meeting other people who are in similar positions. I had subscribed to a patient support group. Gary came with me on the day, but didn't get that much out of the day, at least he attended.

Last evening Gary and I went to Chris', he put lights up for her. I was therefore surprised that my Hb was 8.8 as I seem to have enough energy for a packed week.

I am keeping busy by watching video's for the University and auditing them. Gary has finished the wine room, tiling the floor. It looks good.

I have been liaising with the DSS in an attempt to get incapacity benefit; however, due to my second job I am having difficulty getting payment.

**15/08/02 13.30 hours.**

Today Sean received his A Level results - Biology = B, Chemistry and Physics = D's. We are so proud of him as it has been such a difficult seven months for him. He says he is going to be a Doctor!!!! At the moment Sean is working at Toby Grill which is the Beaches Hotel. He is partying lots and has met new friends, Emma and Adam. He appears happy thank god. Gary and I have been busy socialising. I don't feel there are enough hours in a day, god knows

**03/09/02 12 noon.**

As I wrote previously, there are not enough hours in a day, this is why I have

neglected my diary, but now as I am in LGI with nothing better to do I thought I'd catch up on it.

Well, on the social scene, lots have been happening:

- Gary and I went for a curry with Ruth, Jo and Co on 10<sup>th</sup> July.
- 13<sup>th</sup> July - Gary and I went to Snooty Fox to see Soul Fish, who were OK
- On the 14<sup>th</sup>, Gary and I went to Harewood House to see a Jaguar display. It was a lovely hot day and in the evening we went to Chris T for tea.
- 15<sup>th</sup> we went to Simone's birthday party - a barbeque, again the weather was beautiful.
- 20<sup>th</sup> evening Gary and I went to the Turkey and met up with Chris and Harry and G Mum and Dad.
- 21<sup>st</sup> Gary and I had a day out in York. It was a lovely day, coming home we went through Borobridge in an attempt to find the caravan site where Janet and I stayed as teenagers, but we were unable to find it. We called to Dick Hudson's for tea.
- 25<sup>th</sup> July, Gary and I went for a free meal to Toby Grill with Debbie and Graham. Sean had to work, but managed to sit with us for 10 min.
- 2<sup>nd</sup> August Sean and I went to town. In the evening Gary and I went to the Turkey, for a change.
- Saturday 3<sup>rd</sup> was Gala day, what a flop it was. The precession was very poor. I watched it with Mum and Chris and Naomi. I never went to the Fair at all. It must be a first! In the evening Gary and I went to Toby Grill for evening meal, Sean was working there. It's a bugger that to see our Son we have to attend his work place.
- 4<sup>th</sup> - Gary's Birthday. He got a Camera from me and a camera case from Sean. Again Sean worked all day, while G mum and Dad, Gilly, Angie and Simone came for a bought curry at our house, Gilly made Gary a cake.
- 9<sup>th</sup>, Gillian and Geraldine came over for a couple of hours. I forgot to mention that work sent me a basket of flowers which was nice as it showed they hadn't forgotten me.
- 10<sup>th</sup>, guess what Gary and I went to the Turkey.
- 13<sup>th</sup> Gilly and I went Bilberry picking with Simone and then Gary made a apple and bilberry pie when Chris and Harry came for a meal that evening.
- Wednesday Quiz night
- Friday 16<sup>th</sup> Yes you guessed Gary and I went to the Turkey.
- Sunday 18<sup>th</sup>. The previous week I made contact with Michelle Hargreaves. We

talked lots on the phone and then Gary and I went to see her. It was wonderful to see her and catch up on seven years gossip. It was also great to see her twin boys. We made a promise not to lose touch again. On they way home from Michelle's Gary any I went to the Angel of the North and Horden. It was a wonderful day and we got back in time to see the last "24 hours".

- 20<sup>th</sup>, Gary and I went for a meal upstairs in the Turkey with Chris and Harry. Again we had a good night. Through the day Mum and Josie and I went to Toby Grill for dinner and saw Sean.
- 22<sup>nd</sup> Sean went to Leeds Festival - he had a good time with lots of tales to tell.

### **06/09/02 13.45 hours.**

This is the first time since I had my stem cells back that I can concentrate for a short period of time.

I came into hospital last Monday. Gary's Mum put a tea on and invited all the family which was nice on the Sunday, but all I did was cry when people were nice to me. By the time I arrived in hospital I had no more tears left. When Gary left me he had a little tear. Monday was spent talking to others in my position. I made friends with Rose and Sandra who both have Myeloma. Sandra has had it for nine years. Tuesday I had my Melphalan drip. Initially I had no side effects from it but after approx 12 hours I knew about all the side effects. Wednesday I had my stem cells back. Since early Wednesday morning I had eaten little, approx 2 slices of toast. I feel sick and wretch most of the time and then when that settles for a short period of time I feel so exhausted I can not keep my eyes open or if I do my concentration is zilch. My day is taken up trying to drink enough without been too sick so I don't need a drip putting back up.

Sean has telephoned me each day, he appears concerned about me. He says that he will come to visit, but I don't feel I am any company. I have told him not to come for a while. He says it's quiet at home without me.

Gary is my strength at the moment. He has to put up with me crying lots, people asking him how I am and juggling work and the house with visiting me. I know it's hard and he won't accept help from others, I wish he would.