

The
Thoughts
and
Worries
of a Pullthrough Patient

I was asked a while ago to collate the emails that I posted to the group mainly for the members who are not on the Internet. The result is this long document which I hope might give you an insight into how your kids are feeling and will cope once it is over

I have thought about whether or not I should complete this task. Some of the thoughts are very personal. I hope that it is not vanity that has made me publish this on the web. It was not my reason, just a hope that it will give an insight into what I went through and therefore some of the problems your children will experience.

This covers a period of going on 2 years. A lot happened in that time, so please excuse the length of it.. I have lost some of the first posts that I made, about how I was feeling before the pull through and immediately after. If anyone has these, could you please send me them.

I think that a good starting point is the letter that I wrote to my consultant, then he was only a Mr and not Professor. I wrote this at a low point for me to try to get sorted out more speedily as sometimes over here the wheels of the National Health Service can grind very slowly

Dear Mr Nicholls

Sorry about writing to you but I wanted to bring you up to date with what has been happening to me since you last saw me. I think that I can explain it better and clearer if I write it down instead of trying to tell you on the day of my appointment.

I have now been off work now for 6 weeks. I had become very run down physically due to my bowel problems. I get tired very easily and feel more tired during periods of not being able to pass a motion even of this period may only a few hours. Because of being run down I then became run down mentally and was showing signs of depression. I was on my way to work and found that I just had to turn around and go home. I could not go on any longer. My GP has put me on Prozac, one per day.

Over the passed few months even though my bowel motion is very loose it has been getting harder to pass. About 2 weeks ago I stopped going altogether and found that it was accumulating in the top part of my colon and my stomach was swelling there.

My GP then put me onto Senokot tablets. It worked wonders and cleared me out. Even though it worked, from the time of me feeling that I had to pass a motion it would take a few hours before I could. Over the passed few days this period has been getting longer and even though the motion can be very soft and in some part watery. I am now having to force it out. I started taking around 2 tablets in the morning and 2 in the evening, now it is up to 3 and 3. I am also losing weight, not great amounts, about 4 lbs in the past month and 2 notches on my belt. I am also finding that I feel the urge to go shortly after eating, as soon as 30 minutes after eating but as compensation my desire to eat is also decreasing. During this period of needing to go I find it hard to get around. Today things seem different, yesterday I did not eat a great deal and today so far not much. I have passed two motions with problems, neither of which were of great quantity but very loose and I am feeling full in the colon. I just feel that as the days go by my bowel is having a harder and harder time to work at all. I am due to see my GP on Friday and will ask him about the medication.

I had a word yesterday with work about returning on a part time basis, maybe 3 days a week. They were of the opinion that as it had not been confirmed yet exactly what the problem was nor what the eventual course of action was going to be and that these two things would be determined on the 17th when I see you, that I should remain off work until at least then. After that date my return will depend on what you recommend but there was no danger of me losing my job because of it. In principle they are not against me returning part time but they were concerned as to whether or not that would be in my best interest. When I get tired then I can become depressed again. Another concern was that if I returned and then in a week or two found that I could not manage then the job that they had created for me would have to be re-allocated causing more disruption to the company.

If the end result is as I feel it will be, that is that I have to have at least part of the colon removed could the wheels of this be put into motion quickly. I understand that the likelihood of it being done soon after our meeting is unlikely, I just want to point out that I feel that my being able to function properly and hold down the job that I had previously will be very small. What I am also thinking about is that when I do have the operation I have been told that I will be recovering for around 2 months and it could take a full year for me to be fully recovered. These past 6 weeks off work has been of great benefit and I do feel mentally much better but I do feel very bored now. I do not have the strength to do much to occupy myself and another 4 or 6 months of this will be hard to say the least.

Thank you for listening to me and I hope that you did not mind me writing to you

The letter worked as I was put on the urgent list. I had the operation on the 12th January 1998. As most know the rectum and lower part of the colon were removed this time, around a foot. I had to have an ileostomy for a few months while the colon healed. Having one of those was my worst nightmare but I thought that as it was only for a few months then OK but at the back of my mind was always the thought, what if and it had to remain. I had heard tales of the temporary ones stay for years. Must say the operation did not hold many fears for me, don't really know why maybe I just wanted it so much..

They had a problem in finding a place to fit the stoma because of the scars from my previous battles. The stoma Nurse started to come round to show me what to do, how to empty it and change it, to pick the type of bag that I wanted. She was very nice but I did not want that thing hanging off me. She came to help me change my bag after she and the other nurses had changed it for me for a few days. I did not remember this part but she did and mentioned it when I went in for the reversal. When I tried to change it I tried to do it without looking. I had seen this gross thing sticking out of me pumping stuff out. Me handle it, wipe it to. get off. Then with patience she got me to do it and accept it until in the end at home I would not be too bothered by it, swear at it when it kept on working while I was changing the bag that I had to do each day. I can never say that I liked having it but I was learning to live with it and it allowed to me eat Indian Curries which I had not been able to do for a while (and have not tried since its going, yet!!).

Well that was my stoma, thinking about the worst part was the Saturday before my reversal I went to a football match (yes football again sorry) and the car broke down. We got towed off the motorway and had to wait for the tow truck to take me and my daughter home. We were left on a housing estate and my bag was getting fuller and fuller and not loos pubs or anything in site. I kept on wandering off but did not want to leave my 14 year old daughter too long on her own.

Lucky enough I found a Working Man's Club that allowed me in to use their loos to empty it. It was getting very close to bursting point and I was thinking of all kinds of not very nice ways of emptying it.

In April the big day arrived for the reversal. I think that I was more nervous about this operation than the first. I know that it is meant only to be a small one but for me it was the big one. What would I be like after it would my bowels work or would I not have any control over them. I was pretty nervous the evening before hand and when they took me down. I was even wondering whether or not have the operation, was I daft. I had learnt to handle the stoma and if I had the operation was I opening a bag of worms for the future. Better the devil you know?

For the first couple of days things were OK not eating and therefore nothing to pass but wind and I was told that that was a good sign. Then on about the 3rd day the earth moved or at least my bowels did 3 times in 45 mins. and no real problems, yes the operation had been a success and all was well with the world and me. For the rest of day nothing, started to wonder!!! Next day 12 times, hell will it ever stop and it starts to hurts. Is it wind or a BM, can't tell so have to go just in case and if wind what else will come out? Asked the doctors how long this will go on for, could not help as each case is different but it will calm down in time, thanks! Walking is very painful because of the side wound, yes we don't tell you that it might be a small operation but painful, thanks again!! They are ready to let me go home on the Wednesday, a week after my operation. The night before I start bleeding when I go, the nurses don't seem to bothered about it but want a sample. Why did I let then take the bag off me (this is me who would not look at it). The doctors in the morning don't either but want to scope me just in case. So in the middle of my bacon sandwich they call for me, what timing. They looked and poke around and say I'm find and bye. Time to go, I feel good going home and the road to recover but also find some of the nurses that helped me though both time and give them a big hug. St Marks is that type of hospital the nurses are great and the doctors also first name terms for all except for the Prof. of course. All very friendly and helpful despite some of my !! and will always be very grateful to them all.

So now home and this is where my emails take over.

24/4/98

Hi all

Well now had time to settle in and thought that I would get in touch again

The last op might of been the major one but this one has its own 'delights'. I forgot that the stoma was in a muscle and that having to be stitched and heal is very painful.

My bowels are starting to calm down now, the second day that they started I went about 15 times but I give up counting. It does hurt when I go, well hurt is not the right word more sting and uncomfortable. I also bleed a little. That started the night before I was meant to go home. Halfway through breakfast the docs came around and scoped me. What a pleasant breakfast that was, almost put me off my bacon butty (eating well). They could not see much but they were quite happy with the healing and I am also. I still have not figured out yet what is wind and what is others so I try to keep it all in, much to the relief of the family. Mind my control is not yet perfect but pretty good, not major mishaps only staining so that's not bad. If I did try to find out

and it was not just wind then I am not sure if I would have the proper control, so airing on the side of safety :)).

I get my stitches out on Monday by the local nurse, something really good to look forward to. The wound is healing fine just hurts :))

For those who don't know me well. I like to go into detail of how I feel to try to help you in some small way understand how your kids are feeling, also it as and Ad says over here " Its good to Talk".

25/4/98

Thanks for the welcome back messages, nice to hear from you.

No Kim I have not yet been down the pub wish I had but yesterday got a high temperature. Got the doctor out and everything look find, soft tummy, wound fine etc, so maybe just a viral thing. Its OK this morning and I am not hurting as much. Tempted to go down at lunchtime for a half (pint tomorrow maybe) of Abbots Ale, nice brew but unsure if I dare. Had two minor accidents today with control and when I went down the shop, standing there trying to make up my mind about lunch I had 3 waves of urgent need to go. Unnerving standing there with that happening and no where to go :) I did manage to control it pretty well but it was hard work and made me wonder how a child would of been able to handle it.

Thanks again for the messages and maybe I will follow my hospital doctors advise, one day he told me to go for a 5 mile walk, could take it via the pub.

27/4/98

Morning all

On a joyous sunny morning I had to wander over to the doctors to have my stitches removed. Not a pleasant experience but after they came out I feel better. The wound area dose not hurt as much at all.

I seem to be getting better control, not perfect but better. It was hard this morning when one of my daughters spent about 45 minutes in the bathroom. I had to go walkabouts which I find can help but not stop the urges. So far not found any food to be avoided but then I have on purpose not tried hot food like curries (Asian Indian) and the like. That will come and the very good news beer seems OK also :).

Mind as I am sat hear writing this I have had about 2 urges but they are becoming more controllable. The difference today is that I am finding it hard to sit on chairs, my bum does not hurt so much as aches and therefore restless. Gives me a good excuse for lounging on the settee.

30/4/98

Don't know if it just one of those days but not feeling as perky as usual today. Maybe it is because the sun is not shining, the football team (round type) may miss out on promotion or just that today has a TH in the day. Getting feed up with having to run to the loo, wondering if I will

make it, sitting holding myself in hoping that it will work. The stinging when I do go and the feeling when I have finished that I need to again but then I think of all the discomfort that that will involve so I say na I will try to wait. Usually I can wait, never had to much of a mishap so what's the big deal, must be my team Sunderland. When we win on Sunday and the other team loses and we gain promotion then I will be back to my old self.

Thought that I would have a word with my local GP so seeing him at 2pm today(that was a suprise that I was able to get an appointment so quickly). See what he has to say about the bowel control and the stinging and slight bleed when I go. I have even started to use nappy rash cream to see if that will help. It does stop it afterwards but not during.

Thanks for listening and sorry to those who have no interest in football of the non American kind :))

On a lighter, remember baby John, well I have not seen him for a few weeks but my wife June just has. His mum was telling her that John is now trying to turn over and crawl. That should be fun with his storma bag, his mum is not looking forward to the burst bags.

4/5/98

Hi

Well I did go to the football, was worried about how the team would do and how I would do. Well 'the lads did great', we won 2-1 played really well but I am afraid so did the team we call the Scum or people call them Middlesborough. We have such nice names for our rivals on this side of the pond :)) That means that go up we have to enter the lottery called the play off and win 3 games. It was a good game and even though we away there was so many Sunderland supporters felt like a home game. Lots of singing cheering jumping up and down etc. Really good time.

The point to the above ramble is two fold, one I have been asked to keep some people informed of the progress of the team but more importantly to the group is that I left home at 11 in the morning arrived home at 5.30 in the evening and had no problem at all. No urges to go, no clenching of the teeth and other area even during the drives there and back. The only problem was my wound hurting me and a pain killer on the drive there and going back sorted most of that. The jumping up was hard and even though you are meant to sit in the seats here by law at this game no one did which was hard also.

This is making me think that maybe things are going to be fine. I am not healed yet they will be pit falls along the way but the path ahead looks good ahead.

I just wonder why have I been so lucky when some of the kids in the group have such a hard time of it, both this time and when I was a baby.

This time around it helped being an adult and 40 odd years experience of coping with your bowels and their moods. In a way you know what they are telling you and how to handle them and why things are happening. AT times may want to make you scream and you do. You wonder as to if things will ever go right. If you have the right consultant then you put your faith in them and say well they believe it will so hang on in and see.

Well rambled enough for now.

Thanks of all the help and advice that you have sent me it helps greatly to know that so many people are looking out for you. It helped last week especially when I got low.

6/5/98

Hi

Thought that I would post an update on my progress. Well up and down is the best way to describe it but more ups than downs.

After having such a good weekend and being away from home with no problems at all maybe I got too cocky. Yesterday I was going out to the shopping centre, just before I left I felt the urge and like prat I ignored it. Forgot my own words 'listen to your body'. When I got up there it was starting to get painful so I had to get to the nearest 'descent' loo. Don't know about the public ones your countries but he the male one's often are not nice. So I headed off to a department store. It was touch and go whether I would make it or not but I did. Maybe one day I will learn, but then again at 46 maybe not :)

One thing I will mention don't quite know if it is of any relevance but I have always even from a kid, had a phobia about going to the loo near people and that also means public loos, I mean for BM's. Don't know quite why I feel that I need the privacy, maybe a reaction against all that time that I spent in hospital as a kid and the lack of privacy in that area then or maybe sometimes the straining that I had to do at times and the thought that other people could hear me. Just a thought about how some of your kids maybe thinking. It is not something they would really tell you.

For a few days I stopped bleeding but started again yesterday, still don't think that it is a problem. The stinging has stopped which is good but it can still be painful when I go, I think that it is pressure in the annual area. One of the problems is that I am now starting to have to work to clear myself. That means putting pressure on my stoma wound so that area is now starting to play up again more of a ache than a pain. Glad that I don't have to push to hard as I know I would not be able to do it. What it does mean is that I may have to go a second time when only once would of done.

Going to see my GP tomorrow morning to see when I should go back to work. I feel fit enough and I think the bowel control is getting there, only if I listen to it. One of the problems is that I have around 1 hour 45 min train journey into work. I had the same fear with when I had the stoma and managed even when we got stuck in a tunnel for well over an hour so I think I will be OK now. So maybe back to work sometime next week.

9/5/98

Hi Folks

In the middle of a beautiful weekend, sorry to say I felt compelled to wear shorts. I like May it is a lovely month.

How do I feel? Not an easy question to answer. Inside I fell great and it leads me to my natural leaning to say me ill nah, just got to be careful or that is what I say most times.

I am still bleeding when I go slight worry and when I put the cream on my anus I felt a sharp bit, odd. The stinging that started a few days ago and kept me up most of the night is going. Why it started and why the nodules on my anus swelled???? but they are going down and things getting better.

The worst part is my side wound, where the stoma was. This is hurting more, I was out most of yesterday, went to the supermarket today on my own, that hurt. Also as I mentioned before I am having to work harder to clear myself. This is putting a greater strain on my wound as that always seems where the pressure is greatest. SO most likely it is a combination of things, as always. Me doing to much (will I change, doubt it) and the straining.

A strange thing happened in the car coming home from the supermarket, driving doesn't help either we don't as a rule have power assisted steering or automatic cars so it is turning the wheel often and changing gear. I digress as normal, I was driving along and the sun was out and I thought about beaches and swimming pools and then what can I wear and the new scars on my stomach. The January one is the largest I have had. Never really bothered about them before, I think and I started to feel sorry for myself and almost started to cry while driving. Strange how the oddest thing can bring on a bout of self pity. Did not last long and after I put the shopping away went over the local and had a cider, lovely in warm weather. Remember that with you kids it maybe hard to understand what caused it, with me it was the sun coming out and the pain in my side. Not a combination you would think of.

Well I will depart for now.

Gerry McGregor

Adult 46 with HD

Sun 28/06/98 07:39 PM

It has been a while since I last posted how I was getting on. The answer is I'm not 100% sure. I think that the operation has been a success but there are a few things that I am not happy with. Isn't that always the case though.

Firstly I am having to take more laxatives than I thought that I would do. Maybe I was naive to think that I would not have to take any but I now take around 2 senna tablet and 10 mls of Lactaloe in the evening and 1 senna and 5 mls of lactalose in the morning. It can be 2 of each in the morning depending on how I feel. When I take the maximum I am very loose but that I do on purpose as if I have to strain then my side where the stoma was gets very very sore. Also if I don't go often the I feel as if I am backing up. I tend to have to go around 2-3 before leaving home in the morning, which can make it awkward seeing as I have to caught a train, for some reason they don't wait for me. If I can't manage this then I have to go on the train or hurry to the office when I get off the train. Bowel control is kind of Ok I have never really been caught short but stains are becoming more common place.

Secondly I am also starting to get those feelings in the neither regions when I need to go, making it difficult to walk again. Because of this I have cut down my medicine in the morning to one of each but this is kind of making me feel full. I will wait and see what happens. I have two humps on my stomach. The first at the top left side where I was accumulating before the operation. The second is underneath where my stoma was. I think that these could be accumulations but I will see when I go back to the hospital a week on Monday for my check up.

Those things aside I must say that I am feeling good. Work is being good and tell me off when they see me lifting things. So far no regrets about having the operation. I must admit just before the reversal I was wondering if I was doing the correct thing but as I said no regrets.

I have started to come off the Prozac. Thought that as the operations were over and I am back at work I should try. Don't really need them now or so I think :)) Also as my PC seems to be almost back to normal and in some ways better that stress is over with.

Thu 06/08/98 07:15 PM

Suie

I know from my own experience that the time comes when the loose motion will just not come on its own and the straining begins. As an adult I can tell you it was hard. I wanted to push but could not as my stoma area still hurt like h*** when I did. I had to teach myself how to push but not too hard and keep the stoma area out of it. I then had to arrange my diet and medicine so that I was kept loose. In the end I ended up too loose but did not realise it, but it was easier on me to have it that way. I'm 46 and found it hard work sorting it all out, for a lad of 12 months approx heck you just have to admire how they get through it. John who is not as old as your lad found it odd and frightening when he started to have BM's. Now he has accepted them but still with a little wonder.

Mon 31/08/98 10:02 PM

Your doing such a great job in replying. I admire how you can express things. Must say the phrase Garden variety surgery does not ring any bells with me. I can't find the start of this chat so I will pick it up half way through.

I can say confirm from my point of view that 'normal' in our sense does not exist. When I went about 10 times in the first hour of me 'going' after I was joined up again, I asked the doctors what is normal and they said 'what is normal?' This is from the premier adult hospital in the UK and therefore in the world for adults with colon problems.. This is not a criticism by any means, they were great, just a statement of fact. After we are joined up the colon reacts in different ways and really your son, Joanne needs to feel his bowels. People may have heard me say this but that is the only way I can describe it. I started to control my own laxatives at about 12. From my own point of view that I was taking them so long into my twenties, I feel did me no real harm. I was able to control my life, do things that I wanted. I left home at 16 to go to college to take school exams, I was living in the Scottish Highlands and schools in the local area ended then.

So you can say that from then 16 until now I have been looking after myself. Yes I made mistakes, ended up in hospital because I was completely blocked and needed help but I have been my own master and not the HD being my master.

To some this may show arrogance but to me not. I have been fine, it would of been so much harder to live my life looking over my shoulder. I don't go mad, if I am loose the I am careful in what I eat but then that is not often. Other time I will eat, do what I want and go where I want.

Lately my underwear has been more stained, maybe due to my arrogance. Maybe, I have cut down on the laxative front, but increased the fibre I now don't need to go 3 times before leaving for work etc. This has given me more confidence maybe too much. Maybe now I leave it to long and so the hurry sometimes at the end. Despite the biting of lips etc, famous last words, I have never been caught short, nearly, the amount that passed has been slight but I can tell you felling it is not nice. You tend to assume the worse and when you have just got off the train and have another 15 minutes into work it can feel bad but how can I say this without sounding 'dirty'. You learn how much you pass and therefore that what has come is of no importance. You think it is huge amounts then look when you get to work and look its nothing. Don't get me wrong, you should not pass anything if you can help it but if it cannot be helped it may not be as bad as it first seems and if it does happen then as it may not be as bad as you think and then you will have time to recover the situation. I have thought about taking spare underwear but then thought how many? I am 46 so maybe I can understand better but it will come, the weighing up of situations will come. Not the best answer but not from my point of view it works. When it does not then I will be the first to tell.

Just read this and one thing I can stress is that I personnel hygiene is important but since my last pullthrough I have learnt to accept the realities of life but badly soiled under would be abhorrent to me, stained I have learned to live with.

This is not an answer to the question, sorry

Wed 02/09/98 02:54 PM

Sherri

That reminds me of when I had just recently had my illeostomy earlier in the year. We went for a day trip over to France, waiting in the departure lounge for the ferry home, about 8 at night, I emptied the bag. Went to the cafe, sat down had a coffee and about 15 mins later put my hand into my shirt pocket where I found the clip for the bottom of my bag!!!! Rushed to the loo holding the bottom on my bag through my toursers, must of looked odd. Found that the bag twisted upwards so nothing could escape. If it had what could I done so far away from home late at night??

Mon 12/10/98 06:37 AM

Hi

It has been a while since I last told you how I was getting on. Well as they say no news is good news.

I basically have been getting on with my life, trying to learn how to handle my new bowel. It is new, not like my old one but maybe I was foolish to think that it would be.

At present I am taking Milpar in the evening and Fibergel in the morning, although for the past couple of evenings I have missed out the Milpar. I also try to have a high fibre breakfast, with some fruit like prunes or figs in it. That is all that I am doing to try to regulate myself via diet.

I am finding that my control is quite good, not as good as it was but I have not had too many accidents and if I do they are not serious and I can manage to recover from them even if I am not at home. The biggest danger is when I am sitting down, that is when I have least control and the largest accidents happen. The sensation to go is very different to how it had been. It is hard to describe but now it is more nerve based. I become very uncomfortable, with the nerves in my lower part starting to tingle and feel so uncomfortable. Sitting becomes a problem, this can be hard on a packed train into work and the route to the loo is blocked with people. Also if your in a meeting, you cannot just up and go to the loo, or at least I have not yet found the nerve to do that so I tend to sit a squirm. At this point my usefulness to the meeting becomes not great :)) Trying to learn that I should try to go as often as I can before these kind of things so that I can last and also if there is a convenient break then try to go then even if at that point you don't want to. The other thing is the pressure that wind can cause in the lower part of the bowel. This is not the cramping pain or the sharp wind pain but the pain is near the anus and hurts. A stretching pain and as that is where my join is, unnerving at times. You cannot just pass the wind as 7 out of 10 time is it not just wind. Being able to work out if it just wind or not is difficult and also to have the nerve to find out is very very hard.

One of the other feeling that I have and this becomes more so when I have wanted to go but not been able to do so for a while is that my legs get affected, I find walking harder. This happened to me before the operation and then I described it as shuffling like an old man. Once I manage to go then I am back to normal. By not being able to go I can mean as short a period of time as half a day or even less. Generally I have to go twice before going to work, if I don't then I know definitely I will have to on the train in (it takes me about 1 hr 15 - 1hr 30 minutes to get to work). The during the day about 6 -8 times. It is funny how very soon after eating I need to go, it can't be what I have just eaten as it is too soon afterwards. It need not be much that I have eaten, just a snack.

As I said at the beginning, I am trying to learn how to handle my new bowel and generally I am. I am going out on a Friday evenings with 'the lads', a week ago it went on a lot longer than I thought and so consumed a few beers and then went to the local Indian for a curry. This did not cause me too much problems except for the hangover in the morning and feeling more uncomfortable when I went. A month or more ago I drove upto Yorkshire and back in a day, a round trip of about 400 miles without any real problems. Why I am saying this is to try to say that I am living an almost normal life again. I live not by ignoring my HD and the resections that I have had but not letting it rule me. I will be sensible to a point but then every so often I forget about sense. I have to, that is how I always have been and I hope will be in the future.

Am I glad that I had the operations, yes. I am so much better in myself, still can't do everything that I want with the two hernias that I have. Don't often feel them but they let me know they are there every so often. Am I glad that I have the stoma reversal, yes I am. Although I do have to be more careful about judging when to go etc. that is something I can live with and deal with. The accidents that I have had, before the op would of horrified me but not now. I don't class them as normal and would prefer not to have them but they are a part of me now, I can accept

them. I don't expect them to get worse and may improve as I learn how to handle situations better.

For those of you who are new, I have been writing my feelings and experiences down during the progress of my treatment in the hope that it will give you a better insight into what you children are feeling and therefore an understanding of how they are feeling. While doing it it has also been therapeutic for me, helping me understand what is happening to me and also helping me come to terms with it. Thanks for listening and helping me. Not sure if this something I should say but I did say that I would be honest with you and me being one of the few males on the list, I think I should make you aware of this. A few weeks ago my wife and I separate for good. I am living at home with the kids and they still have a lot of contact with their mother and that is how I want it to remain. Not always is no news good news, but mainly is. The only comment I will make is that the separation has made me more relaxed and therefore happier in myself which has also lead to a happier atmosphere in the home for the kids.

Gerry McGregor
Adult 46 with HD

Wed 18/11/98 10:47 PM

Hi

I kind of know how he feels. For years I hated passing BM anywhere apart from home.

Don't know why as it seems as if I had to perform often in the open. The wards in our hospitals at that time were not single rooms and we all had 'potty' time together. Maybe that was why.

It was not until recently when I had to go in public toilets after the pullthrough as needs must :))

Now I have got over my fear mostly but still feel easier at home.

I would not worry about it too much except if holding it in is making him constipated.

Gerry McGregor
Adult 46 with HD

Thu 17/12/98 11:02 PM

Subject; Guardian:RE: {PT} Blank Memory

I can confirm about how much your kids will remember about there time in hospital.

I basically spent by far the first 5 years in hospital, it was my second home if not my first. At weekends the nurses sometimes took me to their homes. This was the 50's when thing were more relaxed. Of that time I remember next to nothing and my memories I wonder how much I 'think' I remember due to what people say happened to me. The best example is that it seems as if when I had drips and feeds into both arms and legs, I kept taking them out so they tied my hands and legs to the bed, nicely :)) I can now vaguely remember that but can I?? There are only two real memories that I know are true. The first is when I was older about 5, I was upset

because I felt an outsider, I had come in for a few days and in MY hospital I was the outsider amongst the kids. The other was earlier in my life. I was put on a trolley and wheeled to the xray room, although I did not know where I was going. When I got into the room this big thing came over me. That was it, if I was knocked out or just forgot what happened next I don't know.

So as you can see the operations, the stretching etc that went on for years. I cannot remember, yes I think deep down they are still there and they have helped to form me but nightmares no, fears of hospitals, no, fear of needles, yes.

Of my pullthrough almost a year ago, the same is happening there too. The memories are getting vaguer. It seems to be by defence against it but what I do know is they have made the person I am today, even last year's episode. In a strange way I am glad, they have made strong in certain ways, but I will admit sensitive also, in certain way venerable but I know that what ever is chucked at me I will come through it, not unscared but not fatally wounded either. Just slightly stronger or more prepared for the next time.

I would not wish any child to go though what me and your kids go though, that they should have a normal childhood but as I said my illness has made me what I am and without it would I of achieved all that I have today?

Gerry McGregor
Adult 46 with HD

Mon 04/01/99 09:25 PM

Hi

I went to outpatients today at the hospital. One expected thing happened and one unexpected thing happened also.

The first was that I am scheduled for an operation to fix my two hernias. I will be going in in 3-6 months time. That was expected.

The second although minor in comparison affects me more, silly I know but such is life and fears made up of small things. You know that I have had problems with my bum breaking up and sweating. Well the Prof. thinks that it is related to my going so many time and that I seem not to be evacuating my bowels properly. I am going in-between 6-10 times a day. I went about 15 mins. before my examination. They tried to scope me but failed as I still had too much left inside of me. So for the next 3 week I am to have suppositories. That is the problem, I have a dislike of them. When I was a kids I had them when they first seemed to come out instead of enemas and don't ask me why, I would prefer the enema. I hate the feel of them going in and then waiting for the effects to happen. If I remember rightly they never really worked and maybe were a prelude to other procedures. I don't really remember just that I did not like them. The feeling of having to insert them just now brought the memories back.

Most likely it will be like the, bag hated it at first could not look at my stoma but then after I while handled it like a pro and I only have to have them for 3 weeks.

Don't know when you will get this due to the list being down but as I promised you I would let you know how I felt warts and all.

Tue 05/01/99 06:41 AM

Mmm

Well that was a good night, was up and down most of the night, heard that England lost ANOTHER test match, no gloating from our Antipadean members please - cricket for our American brethren . Although I had a disturbed night not much happened for the amount of discomfort and that discomfort is still happening. I have grave doubts as to if this is going to achieve the results that the Prof. was expecting, that is to empty my colon and therefore make me go less. Maybe part of the problem is that as it is me inserting them I cannot get them high enough up the colon and so it is all in the bottom are. If I remember that was the problem was I was a baby.

I will try it for another couple of days and see if it improves but not that convinced. Don't normal ignore doctors advice but got a feeling that I will not finished the 3 week course of treatment.

Wed 06/01/99 07:01 AM

Just a quick reply on my way out to work.

Sounds like a good idea forming that 'hate' group and a curry a day, boy that should do something :)) Nice to have something to vent your feelings on and suppositories seems a good thing to do it too.

Running late as I spent I long time on the loo this morning with no results just to have to leave the shower early for some results, vent, vent at them :)) Only woke twice during the night so maybe more human today but then again maybe not.

Like you all I can think of other ways of doing it and have two big bottles of Lactalose here plus a large number of sennkot tablets which will work from higher regions. We will see.

Well the dark but very warm morning calls and I hope that maybe a train or two will arrive at the station for a change. This winter is really strange, the weather is so warm, yes it is the UK. Mind you places further north are no having it so nice.

well can I ever do a short note?

Bye

Gerry McGregor
Adult 46 with HD

Sat 30/01/99 10:06 AM

Hi Folks

Been a while since I had a whinge. The last time was when I was put of these suppositories to clear out the lower part of my colon. At the time I was saying how I would not last long as it I hated them. I joined the sub group here of 'We hate suppositories'.

So how has it gone? Well I am coming to the end of them thank goodness. I still hate them but they seem to of had some effect. They are clearing out my lower part and in the benefit of this has been it has cleared up my 'nappy rash'. I still have to use creams and things but they now have a chance to work. I am going less than I used to, average I think about 6 times a day instead of the 10. Those are the plus sides, the down side is I take 2 at about 8.30 about 30 minutes after eating. It should be longer but time does not allow it. From then on I am really out of the running for doing anything really. You feel so uncomfortable and you lie there for a while, usually make phone calls then. It can take from around 30 - 1 hour for them to work. Sometimes I can keep them in othertimes I have to run. They mess up the feelings in the lower part of my body. Even this morning as I am sat here (9.55am) my nerves around there feel funny, messed up. When the urge to go comes, as it becomes more urgent, I start this shuffling again. This can happen even if the urge is not urgent but just there. If I had to take them for ever, well I just could not or would not. Famous last words :))

What I am finding slightly worrying is why am I taking them, what will happen when I stop? If the lower colon is working 'normally' should I have to take them?

The problem about over here is trying to get these answers from your Consultant. We don't have the contact with them that you do in the US. I am seeing my GP on Tuesday but he will not be able to answer the question. As my operation for the hernias is now 2-5months away, if it sooner rather than later then it will be OK to wait and ask then if not then maybe have to try to force a visit to him.

Well time to chase the girls and take them to ice staking while I do the supermarket run. Fun time :))

Gerry McGregor
Adult 46 with HD

Wed 10/03/99 08:51 AM

Just got into work and started sneezing my head off, I think the hayfever season has started here but the weather, frosty dull overcast. You don't think the two go together.

For some reason the sneezing brought back memories of a year ago and what happened when I sneezed then. Agony!!!! my stoma would feel as if it was going jump out, holding onto the top part of stomach and most other places where the wounds were still healing, nasty. I must also of looked quite a sight :))

Its great how time heals things, now when I sneeze I just feel as if my head is going to blow off, I sneeze hard. Time passes, things heal and

Sun 28/03/99 11:09 PM

Yesterday I was thinking that Easter will soon be here. That got my mind back to last Easter and how the reversal of my stoma was due. I thought that it was an apt time to have the reversal, a new beginning. Well, did not realise how new it was going to be.

I promised an update a few months ago but events kept on taking my time. Things in my life are starting to calm, so here are my thoughts and progress over the passed year.

Just as a brief resume of what went on with me before. As a baby I had 2 resections for HD, then started to live normally upto a few years ago. They thought that it was Colitis, was either having diahorra, constipation and both at the same time. Due to this I went down hill and eventually I had to stop work as I was so run down physically that I was run down mentally too. Anyway had my rectum and part of my colon removed Jan. '98 and a illeostomy for 3 months. From October '97 until the reversal I was not able to work. The reversal and the 'new' life, a new start.

When I went in for my reversal, yes I was scared, was I doing the right thing? My stoma was working well, I had learnt to look at it, touch and look after it, love it, no well that might be going too far. I was eating what I liked, drink what I wanted, going out to the pub, curry house etc. Would this operation make me incontinent, why chance it? Boy did the reversal hurt, and then the waiting for something to happen, had to wait a few days then success. Can't remember how many time in 45 minutes that I went but I did not move far from the loo. Simple little me, my bum started to hurt and has hardly stopped since. Did I not read your emails properly or was it me being an adult, would not happen to me. Well it did!!! Then as quickly as my motions started they stopped again and it was a day or so before I performed again. The doubts in my mind were still there but at least I was going and seemed to have control so life might not be so bad.

Went home and started to learn how to control my bowels again. Had a few mishaps, got to confident at times and had to run, sometimes could not run or else. And sometimes the 'or else' happened. The big day arrived, back to work. I work about 1 hour journey into London which I do by train. At that time I had to go about 3 times early in the morning. managed to fit that in, make my sandwiches, and catch my train, get into work just in time to go to the loo. Once or twice, I remember walking slowing across the concourse at Euston Station thinking would I make it into work. Once or twice I didn't but the accidents were minor, so cleaned myself up when I got to the office and life carried on. Meeting used to be a problem, sitting on the chair squirming wondering how much longer are they going talk Will I last? Always did.

Gradually things got better, control got better but as if just to remind me not to be too complacent I would have a mishap. Yes they did get me down, wondered if they ever would stop and allow me to have full control again.

I went to see the hospital in January and as I was not clearing properly and my bum was getting very sore, sometimes walk was very painful, because of it they put me on a course of suppositories. I thought they were mad, going about 10 times a day, they would make me go more not help me. My views might of been influenced that since childhood I hated them, give me a enema instead, over much more quickly. Anyway two per night for 3 weeks!!!! Fools, why should I take them, well try them for a few days and then say they were making things worse and stop. Silly little me again, my bum started to heal my motions went down to about 6 per day, felt awful in the evening and the morning because of them but mmm well maybe I should just finish the course.

I did and within a few days my bum was getting sore again, feeling slightly blocked, things were not right?? Went to the GP and asked to be referred back to the hospital. It was not working properly, not being able to clear myself properly and so the acid as building up. Then over the next few weeks things improved, the motioned stayed normally 3-6 times a day, the bottom so long as I kept creaming it was fine.

So Easter is coming, the year is nearly up. Has it been, the new life? Well in October split with my wife and started to learn how much pressure the bad marriage had put me under, my eldest brother developed and died of cancer. The strain of trying to piece my life back together has not helped my recovery. The strain that I was under I am now sure was one of the causes of my bowel becoming unusable. Were the past two years worth it? No doubt in my mind yes, I may not of reached the end of the tunnel yet but it is getting lighter. I has started to accept that their are things in my marriage that I don't want to know about, it was bad but best now behind me. The pain is not over but is getting less frequent. The colon is progressing nicely and I feel very positive about. My motions are under control, accidents don't happen now (famous last words). My control is not as good as it was but it is good enough.

The next hurdle is the operation in June to fix the hernias. What they may do to my bowels, don't know. Should not effect them but it is a big a operation. They will be putting a mesh across my tummy and the upheaval might make thing odd but only for a while.

If I had the choice again what would I do? Well nothing different. The resection was worked, the reversal of been painful but now I have full control and a life in which I can start thinking about me.

The one very big plus is that because of it I have found all of you. You have given me the strength to overcome all that has happened to me. When I had the stoma, my nurse put me in contact with John, Glenda and Michael. I was meant to help them and support them though the operations that John was having and they have ended up become lovely friends and more. Glenda even washed my clothes today (broken washing machine). If I had not become ill, would I ever of had the strength to as my wife to leave? Odd thing to do but when you have gone thought what I had though my HD then it makes you revalute your life, what is important and what is not.

If you ask me was it all worth it then yes and I would do it all again to get where I am today, pain hurt and a great amount of love.

Thank you all for that love that you have given me in the 2 years that I have known some of you.

I have just changed the subject of the email, added that last bit on. yes I do ramble but that is me :)))

Gerry McGregor
Adult 46 with HD

Sat 01/05/99 10:59 PM

Maybe I should be writing this tomorrow after a good nights sleep. For the passed few weeks, my bowels have not felt right. Can't make up my mind really why, feeling more bloated, yes I am eating well, maybe too well but I am slowly losing weight, nothing drastic. Maybe losing weight is not quite correct it fluctuates but a gradual trend of down. Over the passed week, motions getting loose but still don't feel empty. Needing to go but only wind comes out quite a lot of the time.

Yes, I am maybe not looking after myself as I could no. had a quick drink after work last night, caught the 2am train home and a late Friday night last week. Don't get the wrong idea, this is abnormal behaviour. Maybe I should be more careful with what I eat. I have lived all my life not having to bother about HD, maybe the time has come when I should think a little more but that to me seems a defeat. What might of upset me was on Wednesday woke up at about 3.30 feeling myself starting to go to the loo. This was the first time that it happened when I was asleep. Even after the last pullthrough it never got that far. I was very loose for the rest of that day but then for the next two got very slow.

Could be that the next operation is getting close, only a month away and I am also trying again to come off the Prozac. Maybe to soon to try but after 18 months on them I want rid of them.

Just got this fear inside of me that maybe just maybe things are not quite right with the bowel or maybe it is just that coming of the Prozac is making me anxious or just tired and need a few good nights sleep or a little of all. - what about maybe reaching the grand old age of 47

Just don't really know.

it.

Gerry McGregor
Adult 47 with HD

Mon 03/05/99 09:25 AM

My post the other evening was slightly unclear so thought I would try to put my thoughts down more clearly. For those just joined the group, I have doing a series of emails on my progress from pre pullthrough in '97 through the operation and the reversal of my illeostomy.

You may of gathered that on Saturday night I was low, the break up of the marriage has hit me harder than I ever imagined it would. They say time is a healer and yes it is but for me as time goes on it gets harder.

Thinking about it was foolish of me to try to come off the Prozac, they have a job just as my other pills and atleast until after my operation next month they should stay.

Right, the bowels. I am starting to get the feelings back that I had pre pullthrough. My muscles in the lower regions getting upset, the feeling of wanting to go but not being able to. The difference is that the not being able to go is temporary and I do during the day. Last night I was just going up and down stairs to the loo for a few hours. I am starting to get very uncomfortable feelings in the lower colon, would be rectum if I had one. It is the pressure, wind builds up there

and makes it very uncomfortable to sit. I now sit alot on the side of my buttocks or lying down. I squirm alot when I sit, previously that was when I felt I wanted to go but could not for various reasons, in a meeting, on a train home, driving, etc. My tummy is a lot more bubbly to and I get stress pains but that could be the hernias and the strain on them of me going and having to push harder than I want to sometimes.

Why is this happening? I don't know, maybe as I said the other night my diet and lifestyle. Maybe the time has arrived for me to take it more seriously. I think that I will try to eat better, less fried and fatty foods, see how that goes.

On the bright side, feeling slight more like my old self, until things improve mentally (was they will) some list things might take me longer than normal so bear with me.

Thanks for the kind messages that you have sent, it just proves what a wonderful group this is

Gerry McGregor
Adult 47 with HD

Tue 11/05/99 09:40 PM

Don't quite know how I am feeling except worried. Maybe it is the nearness of the next operation but I feel things are not right.

Not had proper movements for two days, I have been but still did not feel right. By lunchtime felt like some action so bought fruit from the market and pigged out. Just had to leave to go but still have that bloated feeling, still seems so much left there. The other area of worry is the pains. I have two types, one is sharp pains of short duration from the lower part of the stomach, that is most likely the hernias getting a little more active, shall we say. That does not worry me too much as they are going to be fixed.

The other lying in between the two hernias, the one across the top of the stomach and then on left is a dip where the stoma was and the hernia under it. The deep pain come of where the stoma was. My worry is based on no fact is the where the stoma was joined there is a slight blockage. These type of things tend to come into your mind when you feel the pains and don't really know why.

Most likely it is the hernias having their finally fling and everything is Ok but the nagging pain in the old stoma wound won't go.

Gerry McGregor

Thu 13/05/99 05:11 PM

I am having a day at home today. You may of gathered from my last couple of emails that I am getting a little anxious about my colon and how it is functioning. Well yesterday I called the hospital and have an appointment to see them on Monday afternoon. They also advised that I

see my GP this morning for an enema. He give me these micro enema's, my how things have changed since I was a baby and it was 1 pint or two of soapy water :))

Took my first a few hours ago and it did have some effect, will have another this evening. I was never worried about being able to get moving again but the reason behind it. Are things going wrong again as it does feel like the early stages of it. The sickness, tiredness, the nerve feelings in the lower part of the body, slow walking etc. One thing that I now understand that I did not last time was that some of these could be caused by the emotional strain that I am also going through.

I felt that I needed to be seen as there is no point in having my hernias fixed while having to strain to have a BM.

Will let you know how things go on Monday.

Gerry McGregor
Adult 47 with HD

Mon 17/05/99 10:32 PM

I had my appointment this afternoon at the hospital.

As normal some good news some Ok, some uncertain..

When he examined me internally he found that my muscles were in very good shape. Also my colon looked very healthy.

After the operation and the length of time one episode of this is not too unexpected. He advised me to continue with the micro enemas each couple of days until the operation.

Not totally convinced about there explanation but neither was I last time and I was proved wrong :)) Yust wonder kinda why they said that I would go back to one motion per day and now what I am having is 'expected'.

I think deep down hat things are OK but will never be normal again. On the bright side as I have said before I have ha 30 odd years of normal life, is that bad !!!! The next 30+ years may not be quiet so good but I honestly don't believe that they will be that bad. It is just like all of us we get disappointed, expect too much too quickly and when it does not happen wonder why :)))

Night

Sat 19/06/99 08:02 PM

Just realised that I have not really told the group how I got on.

The reason for the operation was due to me having a big incisional hernia. It was the colon that was being forced out. The expected that the colon had adhered to the muscles around the

hole. The operation took around 3 hours, luckily I was first one down. Prefer that you miss the rest of the room eating and drinking to much. I was in a room of 5 beds, in the UK only people that pay get single rooms. I must say that I think that I prefer a small room, gives you people to chat to and the advantage of this hospital is that everyone else has bum problems to.

The operation went well except that the surgeon told me that he did not want to fix it again as the hole was so big and might not be able to do it a second time. They put in a mesh to give it more strength.

For the first couple oday and half I was full of drips and cathode's so could not get up and no real urge to have BM. Was not eating of course and only the lolop mouth sticks for that time. That was lovely, one of the part of the operations that I really like, a mouth like a

When I did start to move around my bowels did not feel like join with me and as the hernia was at the top of my tummy I felt very very unsure about using force. Usually when I eat I like to go soon after but I had the feelings but nothing and once or twice as the waves went down the colon so did the pain. That then shut be down totally, BM's mean pain thought my brain so no BM;'s no pain. That is what it thought, I had to stop eating as the wind just built up in me and I felt bloated and sick This improved when they started on the fleet enemas, they did not move me but did release the wind. I ended up on a fleet in the morning and evening and picolax during the day. I felt like hell after a couple of days of that. Don't know if yours is called Picolax over with you but it the bowel prep to clear you out from the top down.

That started to do something so they reduced the procedure to one fleet a day plus all of my laxatives with senna tablets.

The hardest part was each day for breakfast I would order bacon and each day sent it back then the morning arrived then I felt that I could have breakfast and what happened, only half filled in my menu, left the bottom part off and that was where the bacon was !!!!!

Gradually my bowels started to work on there own and so the fleets ended. That was the first time I had had proper enemas since I was about 11 so I suppose 36 years without them was not bad going.

I was having spiking temps. A sign of an infection somewhere but they give me an ultrascan and could not find any and my wound seemed fine until one day I stood up and noticed that my front was all wet. The problem area and said hi to us. so after slightly opening the wound area and then placing a baby stoma bag over it for drainage I was starting to feel more like my old self. Was odd having a bag on me again :))

They let me free last Friday and Glenda and Michael thankful came to bring me home, thanks to them again. What I would of done then and since without them I don't really know, real friends and I shall return the thoughtfulness I hope in August when the new member to their family arrives.

I go out each day for walks, I think I am getting stronger but two things have made me think I am not as strong as I thought. One was when Glenda picked me up and took m round to her place. John was being John and I came home shattered :)) Today went to the supermarket, can't drive for a couple of weeks yet so took taxi there and back. I took Kris as bag carrier etc but when I got back slept for about an hour and still feel dead so early night for me.

The wound is healing fine had my stitches out for a week now. Look like a slimline version of myself but need to lose some more weight. My BM's are still fine, better than before I went in, maybe slightly too loose but still afraid to push too hard.

Too keep myself out of too much mischief I have been working on my web site and added lots and lots of pictures of me, the areas that I lived in etc. even more since I posted that message a few days ago.

Thanks for those that have sent me messages asking how I was.

Hope this answer most questions. I was thinking of going back to work at the end of next week but as today has knocked me so much maybe have an extra week off. I have a 12 hour day including travelling time.

Bye for now

Gerry McGregor
Adult 47 with HD

Sun 29/08/99 01:14 PM

Yesterday and today I think was a bit of a landmark in my recovery process. Might sound odd but yesterday was the first time in about two years that I felt able to cut the grass. Maybe I could of done it earlier but I felt not able to. It was 2 years ago at the end of next month that I had to stop working for around 7 months until I had my bowel resection and stoma reversal. After that the hernia that I had prevented me from any heavy work, ah what a shame that was :)) In between times my marriage went belly up and my mind went belly down kinda as most of you know.

I was told that at the start of September that my tummy would be at its strongest. The garden needed me to find out. yesterday I cut the front lawn. Today spent an hour or two pulling lots over over growing shrubs that are taking over the garden. No ill effects at all, no pain etc and in spirits feeling really good, nope not been down the pub, well not yet at any rate.

I feel now that the worst is over. No more operations on the horizon, my bowls seem to be behaving themselves. I am keeping myself loose, feel happier that way. Maybe be too cautious but I feel better going too much than too little. My weight is coming down nicely, that large distended belly that I had for years is going, don't know thought if was a beer belly or not. OK might not be mister slim and definitely not Mister Universe - thank goodness but feeling much fitter than I have for years.

So my health is better than it has been for a long time. The personnel life I feel is getting better, learned to accept what has gone before and looking forward to the future. No one on the horizon yet but I am sure there will be one day, any offers considered :)))

I think that one of earlier posts was the 'Beginning of the End', well I feel I have moved to the phase of 'the end of the beginning' and now onto the start of the rest of life. I knew that I would get to this part, it was a long and hard path but worth it.

Life is good again and learning to live it

Gerry McGregor
Adult 47 with HD

Sorry it's so long but you must know me by now why write a page when I can write six. Thanks for listening, as I was writing this I started to think and remember what it was all about . It does you good to get your thoughts out. This has been a long, painful period in my life. I never realise how ill I was until I started to get better which was fairly soon after the first operation. That was another reason for wondering about he removal of the stoma. In myself I felt so much better and would the reversal if it did not work put me back to how I was?

Well it is till early days yet and sometimes when I have the mishaps I wonder about that bag still but no I will make it and all of the anguish and pain will of been worth it. Other things have come out of it. The people that I have met, the group but also the others people in hospital, the guy with cancer who had to have his whole colon and rectum removed and within a few days was up and joking and heading up tot he 6th floor for a smoke. The nurses both at St Mark's and the storma nurses here who have helped me and encouraged me. Meeting John and his parents, and then the wonderful people on the list who have put up with my never ending messages and things. They have seen me through the bad time as well as the good, where my problems seem so small when I look and hear about their wonderful kids.. Thanks to you all and I will stop now, promise.

This last paragraph was written early 1999 but the sentiments as the same now as then
January 2000