

Paula's Story

THE PREGNANCY

It was April 1999 when I learnt that I was pregnant with my son. The pregnancy was exhausting and along with other social problems, my GP diagnosed me with depression and I was prescribed an antidepressant. Part way through the pregnancy my husband and I decided to move house, and my new GP immediately refused to prescribe any more antidepressants. I stopped medication without any medical support, and was living in an area where I didn't know anyone. I choose to concentrate on planning for the arrival of my baby but there were no proper organized antenatal groups to attend. I attended a one hour evening class where the midwife asked us questions like, "How do you know you are in labour?" and that was all. Issues such as pain relief, positions, etc were not mentioned at all. When one mum-to-be asked about the benefit of breathing correctly she was told that, "the body will do what's natural at the time". Hence, when I went into labour I had no idea what to expect, except for what I had read about in books or seen on TV, and had no idea what I was supposed to do.

THE LABOUR

I arrived at the labour ward at 11am (Thursday) and was checked by a midwife who then put me in the lounge room as there was no bed available for me. I asked for gas and air and a portable unit was bought to me, but I was not shown how to use it. After some time another midwife came to see me and took me into a bay to examine me. I was dilated 3cm and the gas and air ran out, which took some 20minutes for staff to fix. I was told to expect an estimated 8lb birthweight baby.

My husband and I were dumped in a delivery room and left on our own with still no instruction of how to use the gas and air. I had my waters broken as I had been in labour for over 15 hours and the labour had barely progressed. I was told that a student midwife would be present at the delivery of our baby. We were checked on infrequently and I felt that the incorrect use of gas and air made me very drowsy. The midwife removed the external monitor that monitored the baby's heartbeat, complaining that my bump was the wrong shape!

I was left on my own until, at 9½ cms dilated, I was given pethedine, a mistake which sent me in and out of sleep. A drip line was put into my hand, and being so drowsy it was impossible to push to give birth. I remember the midwife slapping me on the face and shouting at me for not pushing right, and being terrified because I knew that I should feel pain and did not. I began screaming to try and get someone's attention but no-one spoke to me. I was expelling faeces throughout this time and became petrified. I seriously thought that I was dying.

A doctor was called to assist, also a paediatric doctor in case my baby was affected, and the two midwives remained. The labour was not progressing well, I was screaming as I was in and out of conscious and no one was talking to me. I remember trying to get someone's attention and being told to shut up by the midwife. The doctor decided to use ventouse (an assisted delivery) and with little consultation with me cut me and used the ventouse to drag my son out of my body. I remember the paediatric doctor looking horrified at me but thankfully my son was born ok. I was scared that he would be born dead as his heart rate hadn't been

monitored.

I was given an injection and barely had time to touch my son as the doctor tried to stitch me up. I felt every stitch going in and had to beg for anaesthetic as it was so painful. I was told that I couldn't feel any pain, and was told to use gas and air (to shut me up, I'm sure). The doctor seemed to take forever to stitch me up. She was moaning under her breath and it was apparent that as she stitched me up she was hitting capillaries so that I was bleeding further, requiring more stitches and experiencing more pain. She took the best part of an hour and a half or so to stitch me up, and the midwives complained of the mess of blood everywhere all over the room. One of the midwives even slipped on the floor on it. My husband has since said that it looked like someone had been murdered. It certainly felt like it. The hospital had to take a blood sample and after nine failed attempts from my arm by a nurse, the doctor returned to take blood from my hand which was painful too. My son weighed 9lb 12oz!

Afterwards I was left feeling in a lot of pain and dizzy. My husband went home and I remained in the labour ward as there were no beds available in maternity. In the night a midwife offered to walk me to the toilet and on the way there I collapsed in a heap on the floor. I lay shaking feeling cold in some sort of fit. I was left on the floor as it subsided, I was given no blanket, only one midwife stayed with me and she looked terrified at my collapse. I believe she too was a student. I felt terrified. I was then helped back to bed and had a temporary catheter fitted. I was distraught and cried most of the night.

In the morning (Friday) I felt no better. I was moved to maternity where they fitted a permanent catheter. This was agony and as I screamed my husband arrived and held my hand. My skin was now grey and I couldn't sit up in bed without fainting. Since Michael had been born I had had no food in hospital for over 24 hours, so it was hardly surprising that I felt so ill. I asked for help breast feeding and was tutted at so my nipples bled and wept pus as I couldn't feed Michael properly. I screamed with pain every time I tried to feed him. Later in the day I was told by a male doctor I needed a blood transfusion of three units as my bloods were about 7mg instead of the normal 12-14 mg. I was told I may get Hepatitis or HIV. In the day I had fluids via a drip and in the night I had the blood transfusion.

I was not brought any breakfast the next day (Saturday) and I asked the lady bringing the coffees to fetch me one, and was told to get it myself from the lounge down the corridor. With a catheter and drip I could not carry a tray and eventually persuaded her to bring me something to eat. There were five women on the ward and yet we barely saw midwives, they were too busy watching TV in their private lounge. After eating I started to feel a little better, and was able to have my curtains open for the first time. It was past lunch before I was able to get out of bed and walk (aided by a nurse) to the (filthy) bathroom. I was very shaky and dizzy and a number of people commented on how ill I looked. I felt awful and carrying a catheter around was difficult and very painful. I had to have further blood samples taken by doctors as nurses failed to draw blood. My arms were well bruised by now, I still felt faint and tired.

On Sunday I signed out of hospital. My bloods were around 9mg instead of the normal 12-14mg and I was prescribed iron tablets, but was told to come back for them as the pharmacy was shut. I heard a doctor mutter that I should have started taking them earlier. I stopped breastfeeding due to painful bleeding breasts. Despite

my known history of depression I was not given any emotional support by the hospital to help me deal with the horror of childbirth.

It was at this time that I noticed that physically things weren't quite right. I experienced breast pain and was told by midwife to just wear a tight bra. I noticed changes with my bowels. I was in mild pain and bleeding although the stool was soft, I also had to get to the toilet quite quickly. My Health Visitor dismissed this as just piles and got me a prescription for anusol from my GP. I had no previous health problems with my bowels and did not receive a physical examination to confirm the diagnosis. It was suggested that I was making a fuss about nothing and my health visitor only did the one home visit. I went to see her at the surgery every week (a painful ½ hour walk) to complain that I wasn't feeling well. I felt unsupported by her.

PROBLEMS BEGAN

I experienced heavy vaginal bleeding which required medication from my GP. I felt depressed with the physical problems, and had no support at home. At this time my in-laws decided to tell me that they hated me, and my husband was ordered to choose between us. The on-going abuse that I was subjected to (which has never stopped) obviously caused a lot of distress at this time. I saw my GP who told me to "Face up to your problems and get on with life" so it was several months before I felt able to return to see my GP and ask for antidepressants. I knew that I felt unwell and needed treatment to avoid getting more depressed, but felt that I had to argue with my GP in order to be taken seriously.

My bowel problems continued but with no regular pattern of symptoms. Picking up my son Michael left me in pain, I bled, and was in a lot of pain if I had to hold on to get to the toilet, and I was soiling myself. Any comment made to my health visitor or my GP was met with the diagnosis of piles and yet I was never physically examined. In June I eventually persuaded my GP to prescribe the antidepressants cipramil again.

Going to the toilet was so painful that my diet gradually changed to consist of mostly fruit and vegetables. My weight had dropped drastically to about 9 ½ stone and I was quite bowel incontinent. I asked my GP for a prescription of the mini-pill that I had taken prior to pregnancy, and had to argue with him that I could not use the combined pill due to previous problems with high blood pressure whilst using the combined pill. I was refused my prescription and given one for the combined pill. I had to see another GP who gave me the mini-pill without argument. I was also experiencing diarrhoea, abdominal pain, wind and bloating but was given no support for this.

My bowel problems then appeared to increase significantly. Going to the toilet was agony and I had to bite into a towel and scream, holding the radiator to steady myself. I bled afterwards for several minutes and had to wash myself down with the shower as toilet paper was making me so sore. I was incontinent and going to the toilet up to 7 or 8 times a day and experienced severe abdominal pains. On occasions the pain was so bad that I passed out and fell down the stairs. I made an appointment to see my GP who was away, so I saw another doctor. I complained of vaginal soreness and bowel problems. He refused to examine me and told me that it was normal to have problems after having a baby and that if I wanted my health, I shouldn't have had a baby. I was told that it was all my own fault I felt ill, and that I was making a fuss. Hence, I made an appointment to see another GP, a woman, who

examined me and did a hospital referral at once for the bowel problems.

MEDICAL TREATMENT

My son was 11 months old before I visited and was given an internal bowel examination, which was agony. I was then told that I needed to be seen under anaesthetic and should, "Be prepared for the worst", then refused any more information. I obviously went home rather upset, particularly as a cousin of mine died from bowel cancer at a similar age and I was aware that some of my symptoms were consistent with cancer. I couldn't sleep much due to the bowel pain I experienced and the next day I had to telephone my GP to beg for painkillers as my bowel was in so much pain I could barely move. I had the agony of the ½ hour walk with a pram to get it and was also told that I would not be prescribed any more antidepressants, so I stopped taking them. Again, this meant being on antidepressants for a very short space of time so that they barely had time to take proper effect.

Two days after my son's first birthday (which was highly traumatic) I attended Day Surgery at hospital to have my vagina re-stitched and a bowel examination. I was not told what the examination would involve or side effects. I woke up in agony in the bowels and begged for pain relief. I was initially told off as I had been given morphine but staff checked with a doctor and I was eventually given painkillers. I felt dizzy and the nurse attending me grabbed my hand and hurt it, despite me telling her not to touch it as I had a bad bruise from the anaesthetic. I was given painkillers to take home and some ointment to use on the bowels but was not told what it was for. I was told that I would be contacted to be seen within a few weeks for an ultrasound.

I made repeated calls to the hospital as I received no letter for an appointment, and received a list of excuses. My bowel problems continued and were affecting my lifestyle quite severely. I was in almost constant pain, movement such as picking up my son hurt like hell, I was soiling myself a lot and could rarely go out, or only with very careful planning. I questioned the consultant's secretary if attending A&E would make a difference to my case and I was told that if I went into A&E I would be stealing an appointment from a cancer patient, and that would make me a bad person. At least I finally knew that my problems were probably not cancer.

I contacted the Patients Services Dept. at the hospital who were hopeless. It was 7 months before I attended hospital for an ultrasound, again not knowing what it was for. I undressed with a colorectal nurse present and was then told to wait back in the normal waiting room full of people (with just a gown on!) again as my notes had gone missing. Some 40 minutes later I entered a room with the consultant who said he would do an ultrasound which just meant inserting a long tube rectally. He said he would do a pencil test which was inserting a balloon and expanding it until it hurt. I was not told what they were looking for. The ultrasound was ok but the pencil test was agony. I shouted "That's the pain I keep getting all the time" and was crying with the intense pain. I was told that having a baby had caused my problems and that I needed surgery. I was crying and asked how long I had to wait, to which he replied, "About a year". I cried that I couldn't cope with the pain, that I was finding it difficult to take care of my son, that this was ruining my life and in particular my career as I was too ill to work. He said I could go private and simply told me to leave.

I wrote a number of letters to the hospital to try and find out what was wrong with

me but was never told. The consultant said I had a 'defect' which meant nothing to me. It was a further two months before my name was even added to the waiting list for surgery. My son was aged 2 years, 3 months and 4 days when I finally had corrective surgery. That's a long time to be in pain and be incontinent! During this time I had felt quite depressed and wished I was dead, or wished that I had cancer as people would perhaps be more supportive of me. I felt that I had become a social outcast; who wants to be friends with the mum who soils herself in public?

On the day of surgery, an anaesthetist saw me and said that I was having an episiotomy repair. A nurse came and performed a bowel wash which was agony, especially as she did not say what she was doing. The consultant simply said I would go for surgery soon and told me that if the surgery did not work other options would have to be considered. I awoke from surgery in pain and had the full dose of morphine. In the night my bowels opened slightly, making a bloody mess, and it was about 16 hours before I could eat or drink without being violently sick.

I was woken up about 6am and ordered out of bed and given a wash by a nurse. The consultant visited me and looked at the rectal area, commented on how clean I was and said I should try to stick my finger into the bowels when I bathed. This was the last time I saw him. Another doctor said that I could go home as I looked ok but I refused, scared that I would go to the toilet at home on my own, tear open and die bleeding on the floor. I was not advised on how to take care of myself post surgery or what side effects to expect, so I made sure that I stayed put for 6 days! I had baths twice a day but was not given medications or a special diet.

I had no aftercare when I got home. I attended the nurse at my GPs to have my stitches removed but she could not find a discharge letter from the hospital explaining what she was to do or how many stitches to remove. She removed what she could see. I saw a consultant at hospital for a check up and was told that I should have been having daily dressings by a district nurse. I told her that the operation had not been explained to me so she drew a sketch to illustrate how I had had an anal sphincter repair where the muscle is overlapped and sewn. I attended my GP Surgery and asked the secretary for the surgery follow up that they had failed to provide so far. I had to tell her in front of a full waiting room what my surgery had been and felt humiliated. I arranged for a district nurse to see me at home.

As time went on I began to hurt on my left bowel area and could feel a lump developing. Sitting was painful. My district nurse and GP thought that a stitch had been left in by mistake and refused to remove it in case they caused problems which could result in damage. I had to wait before I could get a hospital appointment for a consultant to remove the offending stitch, which was causing me to tear open again. My symptoms of diarrhoea, abdominal pain, wind and bloating had also increased again. Eventually the rectal bleeding and incontinence started to improve and my final check up was 6 months after surgery. The consultant was running late and checked my bowel had healed then left the room. I did not realise that my 30 second appointment was over until a nurse told me to go home. I had no opportunity to discuss pains and I was not offered any further advice about keeping well.

8 months after surgery I was having major problems again. I was experiencing rectal bleeding and in a lot of pain going to the toilet. I had an agonising smear test and was referred to my GP. She said that she thought I was just depressed again and just making a fuss. She refused to examine me physically and suggested that all my bowel problems were in my head. I told her that I had had a history of bad bowel

problems for three years, but she refused to listen to me, telling me that she did not want me back in the surgery for at least three weeks. Despite not feeling that I needed it I took the antidepressant but it made me very ill. I blacked out and spent the day being violently sick with disturbed vision. I did not feel safe in charge of my son. The bleeding was getting worse and I had to bite into a towel when I went to the toilet, and found it hard to sit down or walk. I saw my GP again who insisted that I was just depressed and told me to take a different antidepressant. She took a vaginal swab but did not examine the bowel area. She insisted that the pain and bleeding was all in my head.

At home I was in absolute agony with my bowel. Very sore, bleeding lots, not able to sit down, couldn't sleep because the pain was so bad. I found it agonising to walk and spent a lot of time leaning against a wall as that was the least painful position. I found it very difficult to care of my son. I saw another GP as an emergency case and was examined. I was told I had a fissure and a thrombosed pile, and was immediately sent to hospital and seen at A&E before being admitted to hospital. The doctor wanted to treat me with laxatives and be examined under anaesthetic. After being moved to the ward I was seen by another doctor who did not examine me but checked the details of why I was admitted and commented on how "miserable" I seemed. She said that it was obvious that I was in agony and had had enough, particularly as I could not sit down on a chair or lie down comfortably on the bed to be examined. She said I was not to eat or drink after midnight so that they could examine me under anaesthetic the following morning. I was offered morphine by nurses but not given any.

In the morning I was seen by a team of doctors, one senior one was very concerned about the pain I was in but said he wanted someone from the bowel team to see me as they seen me previously. Later a male doctor and his team from this department arrived and examined me. He thought it was a major chronic fissure. He commented on how this was the result of "a bad delivery" and "you will have bowel problems for life". I was told "Things will never be the same as how you were before having a baby". He seemed shocked that one baby had resulted in my problems. Despite my obvious agony he wanted to avoid surgery if possible as there was a possibility of bowel incontinence. I was discharged from hospital with lots of painkillers and an ointment, glycerol trinitrate, and told to use it externally only and return in 4 weeks time. I was advised a high fibre diet. I was told that if things did not improve "Other options would be considered".

I went home with 17 tablets a day to take but was still in agony. My GP prescribed laxatives and an anaesthetic cream. This was the first time that I had been given a prescription for proper pain relief in over 3 years! Unfortunately my son became petrified of the bathroom as he has seen me so ill and went back to wetting and soiling himself badly. For 6 months I went back and forth to hospital on a fortnightly basis to be monitored, and lived a highly restricted lifestyle. I was given ointments and, to my horror, an anal dilator to try and reduce the spasm of the fissure. I was prescribed suppositories and a new ointment called anoheal. I felt so dirty and hated the treatments, and eventually persuaded the consultant that this was not working. My son also saw a specialist to help him cope with his soiling problems.

After being in agony for 8 months I had more surgery. Prior to surgery the consultant said if things felt a bit better, she would leave things and told me to go home! I had to insist that things still did not feel right and that I would not go home without treatment. She offered to do an anal dilation if no fissure was found, in the

hope that this would stop the problem from reoccurring. After surgery I was given extra pain relief and was told me they had found a fissure and performed a sphincterotomy, so that I had an internal stitch that would dissolve by itself. She gave me lactulose solution, fibrogel and ibuprofen to take home and explained how to take them. On leaving the hospital I bumped into the consultant who commented that I was the only patient she hadn't come to see. She said she had found a small fissure that was not yet healed at the front of the rectum and performed a sphincterotomy. Apparently there was scarring suggesting that I had experienced several chronic fissures that would not have healed without surgery.

At my check up I was given further prescriptions of what I needed, and finally felt that I was being listened to. Unfortunately, a year later I developed another bad fissure but was able to control this with anoheal ointment and laxatives from my GP. A few months later I was agony again, felt very swollen and sore and bleeding heavily. I could barely sit down again and saw a GP who thought it was just piles. I insisted on a hospital appointment and was so glad that I did! Yes, I needed more surgery. All of the rectal problems had caused large painful skin tags to develop so I couldn't clean myself after going to the toilet or sit down properly. The surgery went really well and I was seen in just a week!

NOW AND THE FUTURE

Well, I still get bowel problems. I get fissures (think I have one at the moment) and going to the toilet can be rather uncomfortable some days, but I have learnt to manage my health better. I have to watch what I eat and feel I am constantly eating, which had resulted in unwanted weight gain. I still have IBS symptoms and sometimes find myself in agony, but it is less frequent than what it used to be. I find bloating is the worse symptom. The internet has a lot of useful information and I am planning on some dietary changes to make things better. I find anoheal is a useful ointment and taking 'bum baths' in my son's baby bath really helps with discomfort and relaxes the bowel to avoid/aid fissures. I drink 20 to 30 glasses of water a day, more when taking laxatives. I have learnt to eat fruit and vegetables, whether I like them or not. My son, who will be 6 in January, is funny about fruit and vegetables as he seems to associate them with being ill. He is still funny about toilets.

I expect that I will need further medical treatments and surgery in the future and am dreading this as I feel that I have not been listened to or respected by doctors. I feel that this had developed into a slight phobia. When my son was 3 years old and I was ill I began to experience severe joint pain and restrictive movement. When I saw my GP I was told to stop making a fuss about being ill, and was given no medical support. I was too afraid to go back (and was getting sick of doctors too) and have coped with stiff joints in my own way. I have fibromyalgia written on my medical notes, and I believe that stress could have contributed to this problem. I have also made attempts to get some counseling via my GP but because I did not like the CPN that I was introduced to (she spoke down to me like my mother does) I was told to go away and pay private. Hence, I still experience bouts of depression, although not as severe as when my son was born. I think I have learnt to be kinder to myself in that respect.

I admit that the horror of my son's birth still haunts me and I still cry when I think of it. My intense fear of childbirth would suggest PTSD and this makes the possibility of having another baby very difficult. My son constantly asks for a baby but I go from thinking, "Yes I can do this" to a state of panic, so he may have to wait a while or

remain an only child. People have not been kind or supportive of my ill health and relatives no longer speak to me because of it. My husband and I still have some marriage problems but I expect that what he has seen must have traumatised him too. I have recovered a good relationship with my son who knows a bit about 'mum's poorly bum' and he is fantastic at helping me after surgery. However, his birthdays are still quite painful for me. I felt that I was dying during his birth and I still think that part of me did that day.