
Action on Puerperal Psychosis News

Volume 7 Issue 2

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CHANGES IN THE TEAM

There have been some big changes in our research group since the last newsletter.

Professor Nick Craddock has left the University of Birmingham to become Professor of Psychiatry in the Mood Disorders Research Group at the Department for Psychological Medicine, at the University of Wales College of Medicine in Cardiff. This will allow him to devote much more of his time to research rather than administration. He will continue to work closely with the research team in Birmingham to further research into puerperal psychosis. **Katherine Gordon-Smith** who is remaining in Birmingham will be beginning to visit some of you in connection with the molecular genetic research. As a result of Nick's move much of the laboratory work following on from her visits is likely to be done in Cardiff.

Dr. Emma Robertson has travelled even further afield. She is now at the University of Toronto, Canada where she will be carrying out research into "Women and Depression". She also travelled to Australia last month as she was invited to present a paper concerning her research into puerperal psychosis to a meeting of the Marcé Society. The Marcé Society is an international, multidisciplinary society for all those interested in research into pregnancy related mental health.

After finishing her PhD, Emma was very busy writing papers based on her research to submit to scientific journals. She has submitted 2 papers to journals, one concerning the in depth interviews she conducted with 20 of you and the other concerning genetic research. A third paper is in preparation concerning the risks of suffering further mental illness following an episode of puerperal psychosis. We hope to bring you more details of the results of this

research following publication. Unfortunately, the rules governing the publication of original research in journals are so strict that giving you details of the research before publication would result in the journals refusing to publish on the grounds that the research was already published.

Jessica Heron has rejoined the Department after spending some time travelling. One of the places she travelled to was New Zealand where she was able to meet with some women who have experienced puerperal psychosis and who have contributed to our Molecular Genetic studies, thus bringing a more international element to our work. Over the next three years she will be working towards a PhD. She will look at, the range of mood symptoms experienced by women in the early postnatal period and whether there is a link with later postnatal depression, the relationship between mood symptoms and mother/infant bonding and the role of the hormone, oxytocin, in postnatal mental illness

YOUR STORIES

This issue, we have two accounts by women of their experiences. The first is from a Japanese woman. Puerperal psychosis is a condition that affects women from all cultures and it is interesting to see how much we have in common.

The second is from a woman who experienced two severe episodes 23 and 20 years ago with her first two children and was not ill at all with her third or since. I found her experience very moving and was heartened by the way in which she has been able to put it in perspective and feel stronger as a result.

We have a number of other accounts ready for publication in future newsletters. We would still be very interested in receiving accounts from others of you or your partners or families and

friends. Anything that expresses your own experiences in your own words would be welcome. You need not write everything down. You may prefer to write poem or just select one aspect of your experiences.

A JAPANESE EXPERIENCE

I now have four children--an-eleven-year-old girl, an eight-year-old boy, and three-year-old twin girls. I suffered from puerperal psychosis when I gave birth to my first baby. It was an expected, much desired pregnancy, and I was almost totally happy until the third trimester. I kept working, went to a maternal swimming class, and longed for the day I would meet my baby. I wrote "almost totally happy" because I had one concern--my mother was in hospital due to depression at the time I became pregnant, and she did not really recover from it after she returned home--my husband and I were living with my parents then. I guess this is an important information--my mother had been depressed more than a few times in her life. I remember she had had at least one very brief manic episode, caused maybe by medication, but for the most part of her life after forties, she was depressed and unhappy.

It was not until the last hospital visit before the delivery that I was told that my birth canal might be too narrow so I might need a Caesarean section. It made me feel so uneasy. When I went into labour and my husband and I went to the hospital, I heard an elderly nurse tell my husband that it would be a very hard, tough labour and it would take a long time. That upset me. They sent me back home, telling me to soak myself in the bathtub because warm water would ease the labour pains. I did so for a couple of hours (during the night), but it tired me. Then I withdrew into a room in my house (my husband was so busy then that I did not want to disturb him) and kept breathing hard (maybe too hard). I sweated so much as if I had run a marathon! The next day I went back to the hospital as the contractions became stronger, but it took me another whole day to let my baby out. I was almost exhausted. The funny thing then was, that I felt re-energized after my baby came out, talked loudly with my doctor about my experience of the first labour. I was so

happy, excited, and somewhat euphoric. Really, I became talkative and felt that I did not need much sleep. The third day after the delivery, when I saw TV news reporting that a volcano had erupted in a western area of the country, it suddenly occurred to me that the world was soon going to be over, as the Bible had predicted that volcanoes would erupt before the doom's day. When my baby cried, I thought that only she knew that something serious was to happen. Of course I thought back later to find that making such associations were a totally ridiculous illusion of grandiosity, but somehow, I made that short-cut connection at that point. At night I called my husband and told him that the world would be over pretty soon although few people knew it (I am sure he was startled, but he was just listening). I stayed wide awake till wee hours, expecting something terrible would happen, but of course nothing happened. Next morning I woke to realize that I was totally confused, behaving oddly, unable to organize my thought. I realized that I had been psychotic and the word (Wochenbett Psychose--the German expression equivalent to puerperal psychosis--I remembered learning about it at university) occurred to my mind. I told a nurse that I had developed a psychiatric disorder and needed treatment. The nurse of the obstetrical ward put me on a minor tranquilizer but I could hardly sleep. I thought I was being watched by nurses in the nurse station through the window. When I heard some nurses talking outside the room, I thought that they were talking about this stupid psychologist who went crazy. I had some clouding of consciousness and when I went out the room, I was unsure about where I was. I got confused about how to use a telephone. When I saw through the window a young lady standing on the rooftop of the building across the street, it occurred to me that she might jump to the ground and kill herself. I thought that this was an unrealistic idea, but I could not dismiss it.

I was referred to a psychiatrist of the hospital. He told me that I had puerperal psychosis (so I confirmed that I was right) and would recover in two weeks (this was not true). First I could not believe that I was in a state of depression because I did not feel sad or depressed. But I

did feel immense fatigue and was deprived of sleep. It was after I received the diagnosis that I became tearful and desperate. I was put on psychoactive drugs (sleep pills, a major tranquilizer and an antidepressant) for the first time in my life. It did not seem to work any, but after approximately two weeks' stay in the obstetrical ward (in Japan, an average hospital stay after normal delivery is five to seven days), I was discharged, on condition that my husband and his mother (she had come up all the way from home to help us) would take care of my baby around the clock.

I was so anxious to take care of my baby. Never did I think I did not like her. She was adorable. But I could hardly keep holding her for five minutes. It was then such an exhausting job to me. My husband, his mother, and my father took turns in the baby's care. For the first few days after I came back home, I was tortured by what was later found out to be side effects of the drugs. I could hardly speak, walk, and I looked exactly like the schizophrenic patients I had seen in mental hospitals. It upset me so much because my doctor had not explained about such effects. Then there was my mother--who was also depressed and was suffering from the same depressive symptoms and similar side effects. We held each other and cried.

The trouble is, my mother and I ended up reinforcing each other's anxieties. I could hardly stand hearing her speak endlessly about her worries. I started to avoid her.

Approximately two months later, my mother died in the same house, without my noticing that. Though it was due to a sudden heart attack, it seemed so tragic that I developed PTSD-like symptoms--flashbacks, avoidance, and worsening of sleep disorder. For that, my doctor had to augment the dose of my medication. The symptoms lasted for at least a month.

Somehow, I got back to work in a little more than three months. I had take my baby with me and ride a train and a bus to the hospital where I was then working for, so that I could leave her in the daycare attached to it. Only that required a lot of energy. But my boss and colleagues

were quite supportive and allowed me to start from working half time. Gradually I rehabilitated. I had lost confidence in my abilities and was quite unsure whether I would be able to see my patients as I used to. Once I came across in a bookstore books on cognitive therapy for depression, and that was a big turnaround. For the first time, I learned that being depressive, thinking pessimistically was "wrong". That actually helped me a great deal.

I was on medication for six months. It was my greatest regret that I had to give up breastfeeding because the psychoactive drugs would be transferred to breast milk. But eventually, I was freed from depressive thoughts. During my second and third pregnancy, my husband feared a relapse. So he stayed with me through the whole process of labor and delivery. I felt I was prone to depression when I stayed home with my children, cut off from the exciting outside world, but I somehow controlled myself: by getting enough sleep, by talking with my friends (sometimes by e-mail) and by correcting my pessimistic ways of thinking. Of course difficulties abounded when I gave birth to the twins and I did need a lot of support. But there was always somebody somewhere, my family and others to offer me help. Also, I had learned to manage, learned how to save up energy, and how to prepare for the worst.

I think back and having that experience of puerperal psychosis was a grace, a gift that very few people can receive. As a psychologist, it has been a great advantage to know by experience what it is like to be psychotic, depressed, or to lose ability to think and act normally due to clouding of consciousness (or brain damage). I also learned how to manage through various difficulties and gained some flexibility. All mothers learn from childrearing, but I did receive special lessons, thanks to the puerperal psychosis.

THE ANGELS I WENT THROUGH HELL FOR

I was a very timid child all through school leading onto my teenage years, not socialising much but that didn't bother me. I was a loner preferring to observe than be part of life's goings on. At eighteen years of age I got a job as a checkout operator after failing my life's ambition of wanting to work with premature babies because of health problems. Thankfully, the job was the making of me because suddenly I began speaking to customers and other members of staff and got a little bit of confidence.

In May 1976 I met Ted, nothing romantic just walking to my grandparents and he happened to follow me there and back. In 1977 we were married and on March 19th I gave birth to my beautiful daughter, Keeley Louise weighing 5lb 15 oz. I had only left work on 10th March but Keeley decided to arrive two weeks early. I was the picture of health all the way through my pregnancy. When I first saw Keeley I couldn't believe that something so perfect belonged to me. I watched her every move, fascinated with her, but I couldn't sleep. I thought it was just excitement and adrenaline. I felt exhausted as the seventh day drew nearer when I was to go home with my new baby. I told one of the nurses that each time I looked at the radiators on the ward they were going all wavy, but she said it was probably the heat on the ward making me feel that way.

I went home and muddled through for one week. Ted, Keeley and myself lived with Ted's mother because we couldn't get a council house straight away. We still had the old coal fires so each morning I had to light the fire before getting Keeley up. I struggled along for another week feeling more and more exhausted and angry. Because there was such a drastic change in my life and suddenly from being a total perfectionist everything was becoming a shambles, I was ashamed other mothers were brilliant and here I was, couldn't even look after a baby properly and run a home.

Keeley was just two weeks old and one night her dad and grandmother had gone out and

Keeley started crying non-stop from 11.00 pm. I tried everything in the textbook and more if that's possible. Keeley must have sensed I was stressed. In the end I got a large blanket, pooped it over my head and lay on the settee to drown the noise of this wailing baby out and I cried with frustration for her and for me.

The next evening I visited my parents and I was like one huge shivering jelly. I just couldn't control this cold shaking feeling so my mother made me go to bed for a couple of hours while she looked after Keeley. Then I went home but I felt really strange.

I got worse the next day and the doctor was called out. He told Ted's mother I had puerperal psychosis and I was to be admitted to a mother and baby unit in the local psychiatric ward. On arriving there it was very sparse. It had only recently been opened. There was bare floorboard with three beds and three cots at the side of them.

I clung onto my mother-in-law's coat and begged her not to leave me. People were banging doors, screaming, shouting and sobbing and I was really scared. At the time I didn't realise they were mentally ill also but with different reasons.. We were all mixed together. Some later became good friends while I was in there but others you learned to avoid.

Over the next few days I had nothing to do with my daughter, Keeley. Pointing to the electric street lamps outside, I told everybody I hadn't got a baby that it had died and that the lamps outside were its gravestones.

I was incapable of looking after myself never mind a baby so two nurses had to bath me. The bathroom contained two baths so two patients could be bathed in the same room but with a large shower curtain around each bath. I was convinced I could see a giant tarantula the size of the bath next to me but obviously the nurses couldn't. While they were trying to wash my hair I was convinced they had made a plan to drown me.

If anybody came near me such as a smoker with a match or a cigarette, I thought they were going to set me on fire and I wouldn't enter a room that smokers had been in either as my sense of smell was so strong.

For my own safety, after being such a laid back, placid person, I was sectioned. I was locked in a padded cell and in frustration I smashed a set of drawers up so I finished up with just a mattress on the floor. I had a plan that I would ask for a drink of milk, and when the nurse came I would throw it into her face. I would then try and escape because they wouldn't believe me about the spider and were, I thought, planning to kill me and keeping me against my will.

I could see a man in a large black donkey jacket through the barred windows. I thought this man was my husband, Ted. I would cry and shout for him, saying I was sorry as I thought he had put me in there for punishment. I was sorry but I later found out it was the local grounds man Graham doing the gardens dressed the same as Ted.

Because the drugs weren't working I had to have six sessions of Electro-Convulsive Treatment and then I was fine. I was allowed home for weekends on my own which was very upsetting with no baby, but better than nothing. At a later date, I was allowed home with Keeley for the occasional weekend visits finally being discharged in December when Keeley was nine months old.

When Keeley got to nearly three I decided I didn't want her to be an only child so we decided to try for another baby, being a calm laid back person and putting all the past behind me, The dreaded puerperal psychosis struck again. I had another beautiful daughter, 6lb 6 oz with no complications, no pain relief just the same as Keeley. She even arrived on the date the hospital gave me. We named her Laury Marie

By this time we our own council house and, luckily, a gas fire. I was convinced that we had a gas leak so I was walking Keeley up and down the garden getting her to chant bah, bah black sheep with my other daughter held in the crook of my arm. I eventually went to friends and told her I didn't feel very well, but she said she had to go to work. Obviously she didn't realise how ill I was as I had still kept my composure, so I went to my parents who I found had just gone out to the cinema.

Panicking by now thinking my children were going to be blown up I made my way to the local hospital and the realised straightaway what the problem was.

My husband and parents were sent for and a doctor calmly said, "It's puerperal psychosis. She'll have to be admitted to a psychiatric ward but the previous one's mother and baby unit has closed down so her children will have to go into foster care". I don't swear but when he said that I shouted, " My f.. kids aren't going in no foster care." and stormed out of the room and waited in the casualty department situated outside this room. I was scared to stop out there because there was a drunk man showing off and I felt so vulnerable but was too angry to go back into the room because of the mere suggestion being made after what I had been through and was still going through.

Again I was in for 6 weeks and in that time I can remember looking at a plant and it went from full bloom, withered and then came back to life before my eyes. I told people I could read their minds and tell them what they were thinking and going to say before they said it but they didn't believe me. One day I was staring at a young nurse when all of a sudden I saw her stomach swell from normal size to nine months pregnant and then go back to normal. I told the nurse, " you're pregnant aren't you?" She looked at me, shocked and said, " how do you know?". When I told what had happened, she explained that she had just taken a test that day and hadn't even told her husband yet.

As well as the nice things I also saw frightening things. Passing a room one day, I couldn't believe my eyes when I saw four or five she-devils in a room, one of them feeding my daughter Laury and all snarling at me.

I remember sitting chatting with my family, husband, daughters, parents, brother and sister. I started walking down the corridor leaving them behind in the distance and hearing them sobbing but I felt peaceful and curious about this white clinical place I was heading for.

I would walk up one corridor on the ward and it would warm with all laughing children and memories and if I went up the other corridor

there would be evil spirits and skeletons and it was so cold like winter.

I had to learn all my colours as I had forgotten the names of them. Somebody had to lead me down for meals as I didn't know my way about and couldn't follow instructions. I was a hopeless wreck most days but the Electro-Convulsive Treatment got me through again and when Laury was four months old at Christmas time I was discharged fully.

Thinking my family was fully complete now when my daughters were nearly ten and just turned six, I found I was pregnant. On telling the doctor, he gently broke the news that usually he was all for saving lives but in my situation I must have an abortion. I sobbed in front of him, what a situation I was in, another baby would be lovely after such a big gap but to risk my mentality a third time was like Russian Roulette. I was sent to the locale hospital with a letter and the consultant advised me to see a lovely psychiatrist named Dr Ryan. Dr Ryan explained if I was going to get puerperal psychosis I would get it after giving birth or after an abortion because it was my hormones that went back too fast for my body to cope with. I had already made the decision before I saw my family doctor. On the 28th July our third beautiful daughter, Stacey Vaun, was born. After 5 days I went home and I never looked back. I'm glad I have no sons as people would have said with the change of sex you didn't suffer the dreaded puerperal psychosis.

My third daughter was born with the tiniest freckle on her thigh and as she grew it grew with her. I always used to tell her it was where the angels kissed her before they let me have her and even now I call her "my special angel". All my daughters are special to me. I feel chosen to have them. Keeley, now 23, is full of confidence and in a good job. She's learnt to drive and travels all the country with her job. She's so witty and thoughtful.

Laury now 20 comes across as loud and confident but she isn't really, she's got a heart of gold and would give you her last penny. With Graham, my son-in-law, they've given me my first grandson.

Stacey's now 13 and she's so adaptable with having older sisters and then being an aunty at 10. She can get on with any age group and she's got her life planned years in advance even though she changes from month to month.

I'm now 43, I began self defence lessons on reaching 40 and have gained my orange belt in the Aikido style. I do voluntary work down at the local secondary school. I listen to the 11 year olds read and encourage them so they can catch up with other pupils in their year. I have recently done two first aid courses and a maths and English course. The best thing of all is being a good understanding listener to other people who have problems, I consider that my gift.

There is a life after puerperal psychosis, even if at the time you don't think there is. Always look forwards but remember that notch in your life made you the stronger person you are today and you may be needed by another person equally as scared as you were many years ago.

Lesley Austin

FURTHER EPISODES - THE RISKS

In view of Lesley's story above I am repeating the information we published some time ago concerning the risks of suffering further episodes of puerperal psychosis.

If I have already had an episode of puerperal psychosis, how likely is it that I will have another episode following another pregnancy?

It is important to say that we still have a great deal to learn about puerperal psychosis and it is difficult to be very precise in answering questions, particularly about the exact percentage risks of illness. That being said, the studies which have been undertaken show that if a woman has one episode of puerperal psychosis, the risk of her having a further episode in a subsequent pregnancy is in the region of 20-25%. This figure is an average across studies and the true risk for an individual woman is likely to vary depending upon other factors. For example, the risk of puerperal psychosis in a subsequent pregnancy seems to be increased if the first episode of puerperal psychosis was puerperal

mania and the risk also seems to be higher if the woman has already suffered two previous episodes of puerperal psychosis. The risk is known to be particularly high if the woman has suffered an episode of puerperal psychosis and has also experienced at least one episode of mania unrelated to childbirth (i.e. a non-*puerperal* episode) in which case, one American study suggests the risk may be close to 100%. Most studies have looked at the risk of puerperal psychosis following a full-term pregnancy, but there is also evidence that risk of illness is elevated following a termination.

Although some of these risks seem high, it is worth emphasising that for a woman who has had a single episode of puerperal psychosis the risk is in the region of 20-25%. This means that the likelihood is 75-80% that in a subsequent pregnancy the woman will *not* suffer with puerperal psychosis. Furthermore, if the mother and her family are aware of the potential risk, it is possible to recognise symptoms early and nip subsequent episodes of illness in the bud. There is also some evidence that taking Lithium immediately following delivery, may lead to reduced risk of puerperal psychosis and Professor Brockington is currently undertaking an important study of Lithium in this situation to obtain better evidence about its effectiveness.

What can I do to prevent puerperal psychosis recurring after a subsequent pregnancy?

As stated above, there is some evidence that taking Lithium immediately following delivery may reduce the risk of puerperal psychosis recurring. This evidence is not strong enough for us to be able to make firm recommendations and that is why we are involved in a clinical trial of the effectiveness of lithium as a prophylactic. Researchers based in London are looking at the effectiveness of oestrogen in preventing recurrences. Other researchers are currently looking at taking anti-psychotic drugs to prevent recurrences.

Progesterone injections have been advocated as a preventative measure. There is no convincing scientific evidence to support this.

If you have suffered puerperal psychosis, and are pregnant or thinking about having another a

baby, it is important to liaise with your psychiatrist so that you can agree how best to monitor your mental state. You may also wish to raise any concerns you have about the type of treatment you would receive if you became ill again. It would also make sense to rope in as much practical support as you can get from family, friends, social services or hired help around the time of the birth so that you and your family can be looked after and supported.

SCOTTISH INTERCOLLEGIATE GUIDELINES NETWORK - NEW GUIDELINES

In last Newsletter we mentioned that SIGN was preparing a new clinical guidelines for the treatment, diagnosis, screening and prevention of postnatal depression and puerperal psychosis. These were published in June 2002. The guideline can be viewed on SIGN's web site at www.sign.ac.uk

COULD YOU HELP APP?

I have been co-ordinating APP for 7 years now and have greatly enjoyed my role. The University has been paying me to work for 5 hours a week. Last December I took another unrelated job for 3 days a week and may soon be working full time elsewhere. I hope to be able to maintain some involvement with the running of APP. however, someone will be needed to take on some of the work of keeping in touch with new and existing volunteers a producing and sending out the newsletter and updating the web pages. You would need to be within reasonably easy reach of Birmingham. At present the post is funded until the end of August 2003. We will be seeking further funding for the future.

We could also do with some voluntary help around April and October when the newsletter comes out in stuffing envelopes and sticking mailing labels on them.

If you are interested in either role, please contact Jackie Benjamin.

CONTACTS

You can write to Jackie Benjamin or any other member of the team at

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Our web page is at <http://www.bham.ac.uk/app>



Telephone 0121 678 2361 You can leave messages on this number. Please be patient. Although we will try to get back to you, Jackie is employed part time and has another job in addition to working for APP.

We are sorry that we are unable to give advice on individual cases.

Our project aims to further research into puerperal psychosis. For details of organisations that can offer support, please see our web site.

CHANGES OF ADDRESS

Please let us know if you change your address or telephone number.