Cynulliad Cenedlaethol Cymru / National Assembly for Wales
Y Pwyllgor Plant, Pobl Ifanc ac Addysg | Children, Young People and Education Committee
Iechyd Meddwl Amenedigol | Perinatal Mental Health
PMH 16
Ymateb gan: GXXXXX and TXXXXX
Response from: GXXXXX and TXXXXX

Our Story

1) We first became aware of the existence of Post-partum Psychosis soon after the birth of our son FXXXXX in November 2015. It manifested itself the day after his birth but it was on the ward on day three that TXXXXX noticed a change in GXXXXX and alerted a nurse.

2) GXXXXX had had very little sleep after her admission to hospital, with the excitement of the birth, adjusting to looking after baby FXXXXX, struggling to breastfeed and settle him to sleep. The midwives tried to help GXXXXX to feed him and despite struggling she was determined not to give up as it was pushed at pre-natal classes that 'Breast was best' and suggested that bottled fed babies would not be as healthy.

3) During the first night GXXXXX became unsettled. She fretted when she failed to feed and settle FXXXXX that she was disturbing other patients on the ward. This was reinforced by hearing threatening comments made by a father to be in the next cubicle. The next morning GXXXXX heard further comments between patients on the ward so she spoke to the duty midwife. She wanted to bottle feed FXXXXX so he would not be 'starving'. The midwife was very understanding and moved GXXXXX to another ward. FXXXXX had a bottle that morning but the midwife urged GXXXXX to continue breastfeeding, FXXXXX would be fine.

4) Later that afternoon the audio hallucinations began. She 'overheard' patients conversing with a midwife who asked them to monitor GXXXXX and report any concerns about her parenting and behaviour. GXXXXX heard positive comments but after evening visiting hours this changed. FXXXXX was crying and unsettled, he would not feed or sleep. The comments became negative and critical, judging her on everything she said and did whilst looking after him. They said they "couldn't believe she had done that" and "that she was a horrible person." GXXXXX didn't know what she had done and was scared but did not tell anyone in case FXXXXX was taken away.

Later, a Midwife took FXXXXX to the Nurse's station overnight so that GXXXXX could sleep. GXXXXX was very unsettled. A stream of hallucinatory running commentary reported on every move she made, it was as if they could read her mind and they kept criticizing her in a monotone voice.

5) GXXXXX hallucinated that FXXXXX was rushed into theatre she had hurt him. He died. She was devastated and terrified but she was sure she hadn't hurt him. Had he really died? She asked a nurse who checked on her if FXXXXX was okay the nurse reassured her that he was fine and offered her sleeping tablets. She refused she could not say what she had 'heard' or why she was so scared and thought there was a conspiracy to stop her from escaping.

6) The running commentary altered to reading an online live stream reporting all of the 'terrible things' GXXXXX had done in her life, how 'horrible' she had been to people and what an 'evil' person she was. Many of the things being 'reported' were untrue.

7) GXXXXX hallucinated that TXXXXX and her Mother had been called to the hospital, she needed to see them, to explain she was innocent. They walked past the ward. She tried to find them but could not so she returned to bed. She saw two policemen walk past they would arrest her TXXXXXorrow. She could not confide in anyone. The commentary began to report the deaths of close family members including her husband and mother who could not cope with FXXXXX's death and what GXXXXX had 'done.' The voices suggested GXXXXX would be better off dead after all she had done. Her life was ruined. She knew she was innocent. What if this scenario was not true? She could not die, she had to remain strong. GXXXXX spoke to the on-call psychiatrist who spoke to her and prescribed sleeping tablets. It was the longest and worst night of her life.

8) The following morning the Midwife returned FXXXXX but before she entered the ward a hallucination caused GXXXXX to hear the Nurse say that he wasn't her baby they had found a look-alike to briefly place in her care. They would monitor her to see how she handled him and if she could have hurt FXXXXX. The baby was FXXXXX but GXXXXX was unsure after the hallucinations and checked with the Nurse. That morning GXXXXX was visited

by members of the psychiatric team who she believed were police officers trying to obtain evidence to arrest her. The audio hallucinations continued throughout the day. She received messages from TXXXXX and her mother but believed it was the police were texting her.

9) That afternoon GXXXXX spoke to the Psychiatric Liason she didn't tell her about the voices or the 'events unfolding.' TXXXXX arrived whilst GXXXXX was talking to the Psychiatric Liason. The nurses did not tell him until he asked, where GXXXXX was, who she was with or warn him that she had a bad night. GXXXXX returned to the ward and wanted to believe it was TXXXXX she was speaking to but she was unsure after the hallucinations. She tried to speak and interact with him normally but the voices were criticizing her saying that he was not her husband but an impersonator. GXXXXX told TXXXXX he was not her Husband, he was not really TXXXXX. TXXXXX immediately informed the Nurse who contacted the Psychiatric Liason. This time, knowing that something was wrong, GXXXXX revealed all before being sedated. TXXXXX stayed to do the night feeds.

10) GXXXXX spent ten days altogether on the Maternity Ward at Glan Clywd Hospital. Eight days of which were in a private room. During this time she received daily visits from members of the Ablett Unit staff who spoke with her and monitored her physical and mental state. For four of these days she received anti-psychotics and sleeping tablets. She began to separate hallucinations from reality but the confusion, fear and distress remained with her. TXXXXX stayed for seven nights at the hospital doing the night feeds and worked during the day. Travel expenses were costly and he was physically and emotionally exhausted but insisted on being with GXXXXX and FXXXXX.

11) On the day of discharge TXXXXX, GXXXXX and baby FXXXXX met with the team who had devised the care plan that would follow. They included; the community Midwife, the Health Visitor, a Social Worker, the Psychiatric Liason representing – the Psychiatrist and Home Care team; the Ward Manager and the Duty Midwife. They found the meeting very daunting. They were both exhausted and felt overwhelmed, they just wanted to get home. All the professionals present at the meeting were very helpful but they were too many in number.

12) The care plan consisted of an initial visit from the Community Midwife, visits by the Health Visitor and daily visits from the Home Care team. Initially, this was quite intense but as GXXXXX's condition improved the frequency of the visits reduced and some were replaced with phone calls. One facet that GXXXXX found unsettling was the inconsistency of visitors from the Home Care team. There were many different faces depending on who was on call and available as sometimes the one appointed for that day could not visit. Also, they were sometimes late. It was disruptive to family life. However, the members of the team were both friendly and helpful.

13) After around 3 months GXXXXX was transferred from the Home Care team to the local Community Mental Health team based at the Nant-y-Glyn Centre, Colwyn Bay. This was not a smooth process due to staff shortages and a reluctance by the Home Care Team to transfer GXXXXX to the Nant-y-Glyn Centre. Eventually, a Community Psychiatric Nurse was assigned she made regular visits which decreased over time as GXXXXX's condition further improved. GXXXXX found this was a great help as she was able to see the same nurse and build a rapport. The nurse was also very helpful and reassuring and offered groups related to Depression, Anxiety and Mindfulness that GXXXXX could attend at Nant-y-Glyn if she wished. GXXXXX considered this but found the idea daunting.

14) During the early weeks after her discharge, GXXXXX attended some Mother and Baby groups but she was exhausted from motherhood, managing her condition and found socialising difficult, as some elements and lack of sleep would trigger minor sympTXXXXXs making her ill at ease.

15) GXXXXX had two constructive appointments with Doctor Bugelli the on-call Psychiatrist who had stayed with her case. One was in February 2016 and the second in May 2016 when GXXXXX was discharged from Glan Clwyd. She was later discharged from the Nant-y-Glyn centre in September after monthly follow up telephone calls. Although, GXXXXX has recovered, Post-partum Psychosis changed her life, she is learning to live with it but eighteen months on the memories still remain. GXXXXX and TXXXXX have worked together to avoid stress, sleeplessness and other triggers which could cause relapses or further depression and anxiety.

Our Reflections

16) Reflecting upon the whole process we feel that there should be information about Post-partum Psychosis included in all pre-natal courses. Every maternity ward should have its own Mental Health Midwife who is on call and specialises in perinatal psychiatric conditions. Apart from being skilled at spotting the signs and acting swiftly such a person could be the perfect liaison and a consistent face which we feel is vital and was so lacking during GXXXXX's time at Glan Clwyd hospital. We also believe that there should be better communication between ward staff and partners of patients. If the patient has had a difficult night with their consent, their visiting partner should be informed and notified immediately if they have been referred to psychiatric professionals.

17) Our experiences inspired us to create 'Serenity – The North Wales Post-partum Group' to provide a social drop-in support group, campaign for better services within the community and raise public awareness of Post-partum Psychosis. GXXXXX found that although she could attend mother and baby groups if the topic of the birth arose she could only say so much about what happened before a group leader would steer the conversation away to avoid upsetting other group members. This meant even if she wished to she could not speak freely about her experiences to other mothers and often felt excluded. Whilst issues such as breastfeeding, baby behaviour, adjusting to motherhood and baby blues were fine, as so often more serious mental health conditions and traumas were taboo.

18) 'Serenity's' drop-in sessions will provide an outlet where mothers can speak freely about their experiences and not be excluded or shut down for it. We feel that such drop-in sessions should be expanded across Wales. So many women suffer for years with the effects of Post-partum Psychosis or Postnatal Depression / Anxiety and remain unheard. Many parts of Wales are rural and often women live in isolation and have no contact with others who share their experiences. We also feel there must be more support for fathers who have had to care for mothers and babies after traumatic births as currently there is very little for them. Obviously phone support lines run by

the Samaritans etcetera and limited social media outlets are available but no support groups where such conversations would not be taboo.
19) Another factor we believe needs addressing is the promotion of breastfeeding as the “Gold standard of baby nutrition” both at prenatal classes and within the healthcare system in general. Although, ‘Breast is best’ nutritionally for the majority of babies it is not always best for their Mothers who naturally want to do the best for their children and may feel pressured to continue breastfeeding even when it is pushing them emotionally and physically to their limits. This is especially true we feel with first pregnancies. We believe if midwives or other health care staff recognise that there is an issue with breast feeding after the patient has sought help and been given advice they should act to do what they feel is best for both the mother and baby. This is where a Mental Health Midwife would be invaluable. If a mother develops a mental illness the baby will be affected as the mother may not be able to care for the child as efficiently. If the mother is medicated she may not be able to breastfeed anyway. While there is a stigma against public breastfeeding conversely, not breastfeeding also has a stigma attached to it. Some Mothers feel more pressurised to conform rather than to bottle-feed. Public perception and repeated social media posts reinforce this Many babies growing up on formula milk and are as healthy, clever and able as their breastfeeding friends and not at any disadvantage.

20) We thank you for reading our report and ask you to consider the points within to reach the best possible solutions and implement the best possible measures for everyone.