

# Perinatal Mental Health Maternity Service User Feedback Report September 2016



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## **1 Background**

GROW was commissioned through Rotherham Clinical Commissioning Group to undertake a Perinatal Mental Health Service User consultation to help inform the Perinatal Mental Health Pathway.

The Royal College of Psychiatrists state that Postnatal Depression (PND) is a depressive illness, affecting between 10 to 15 women in every 100 having a baby.

## **2 Methodology/Approach**

It is important to acknowledge that this consultation has been carried out with a dual purpose of raising awareness of PND and promotion that it is an illness/condition, and also collecting the experiences/views of Rotherham women who have experienced either diagnosed or undiagnosed PND.

Contact has been made with women through established groups, women accessing the GROW service, and through community contacts. The majority of the groups have been visited on more than one occasion to build a trusting relationship with the women. Any 'live' issues have been responded to and women offered support to access relevant services.

The Outreach Worker also visited the Maternity Ward at Rotherham Hospital and was able to appropriately approach women on the ward. This provided a positive approach as the women welcomed an opportunity to share their experience and also promoted positive wellbeing and self-awareness.

Women have also had 1:1 meetings/interviews to discuss their experience in more detail and depth. The women were giving space to share their story in their own way, at a pace managed by them. The interviewer took care to ensure the ending of the session was a way to close down any outstanding emotions or concerns. If appropriate follow up meetings were arranged to ensure they were OK.

Workers completing interviews and contacts have done so with an awareness of the sensitivity regarding PND. They have also used a non-judgemental, compassionate approach to encouraging women to feel safe and also not to further stigmatise or collude with PND not being recognised as an illness.

### 3 Group Consultation

As part of the consultation four groups have taken part:

- MUGS – a women’s support group based at the Chislett Centre in Kimberworth Park. This a long established GROW support group which in the last year has become semi-independent. A GROW volunteer facilitates the weekly meetings. Women attending the group do so in response to local advertisement and word of mouth. Women do not attend the group as a result of being supported through a GROW project, but maybe supported as a result of attending the group.
- Butterfly – is a GROW recovery/support group based at GROW. The group has been developing over the last 10 months. The group meets weekly and is facilitated by a GROW Project Worker. The age range of the women attending this group is 18 – 25 years old, they all have had babies. Two of the women have had babies removed, 1 of which is in a court custody ‘battle’, and the other woman has had 2 babies removed. A third woman as a result of Domestic Violence had to leave two very young toddlers with her ex-partner. All of the women have been ‘victims’ of abuse, child sexual exploitation and sexual and domestic violence.
- A Reason To Like Mondays – parent group. The group has been set up by two mums just over 6 months ago, it is based in East Dene/Clifton and runs term time only with weekly meetings. Numbers are very low still.
- Bumps and Babes, Central Children’s Centre – a GROW Outreach worker attended a number of sessions. The group is for pregnant women and those with new babies. This type of group operates in the majority of Children’s centres and some have baby clinics operating alongside the group.

The more specific service user feedback has been included in the next section. Group consultation has often been generalised, with the Outreach Worker identifying individuals in the group to speak to in a ‘side’ conversation. Responses and engagement in the consultation have been more successful when multiple visits have taken place and when the group appear to be more comfortable with the Outreach Worker.

The MUGS group have also been consulted with regarding the development of a Post Natal Depression support group. They have offered insight into ways to attract women to attend and also the language used. A particular example of this was the term ‘baby blues’, which those who had experienced PND vehemently challenged.

*‘it’s not baby blues it doesn’t describe what it really is and actually it makes it sound like it something minor, it’s not.....’*

*“my family said this to me (baby blues) and it just made me feel worse..... I couldn’t understand why I couldn’t ‘snap out’ of it like they told me I should ..... I started to not say anything, I was so unhappy”*

The experience of the women attending the Butterfly Group differs as a result of the social complexities, past and present. In their view previous babies being removed has been an injustice, with only a few accepting why this had happened. For those who don’t accept decisions it is hard for them to come to terms with emotionally.

Many women in this situation are instructed they need to have therapy and or counselling to address their abuse before a final decision can be made regarding custody. However no-one supports or guides them on how to access the services, how to deal with or bypass long waiting lists, or how to deal with conflicting views between mental health specialists and Social Care.

Ante-natal anxiety affected members of this group significantly, with an added fear of saying they weren’t feeling OK and asking for medical support, which would then be logged in their parenting ability assessments.

#### **4 Service User Feedback**

Encouraging women to speak about their pregnancy/birth experience is more often an easy conversation and there is a genuine willingness from women to share their story. Women have sometimes become upset if they had experienced a difficult birth for example but are still willing to share their experience.

However asking women about their experience of Post Natal Depression and the atmosphere changes and for some there is a visible change in how they sit and the volume of their speech.

Women who felt they had ‘moved past’ the episode and had agreed to answer questions about their personal situation, have stopped in the midst of an interview and shared they were feeling anxious about discussing things and that it was taking them back ‘to a dark place’.

One woman when asked about why she had begun to almost whisper about how she had felt answered that she ‘felt so ashamed and embarrassed that she couldn’t cope’. She thought others mothers would judge her, and from what she shared she had experienced she had been judged. Not just by other mothers but family members and friends couldn’t understand why she ‘couldn’t just pull herself together’.

This consultation only involved speaking to women but a couple of the women briefly spoke about the impact on partners and their relationship. Some women said their partners and family hadn’t been aware at all, they talked about ‘putting on a front’. Others said it wasn’t that a partner or family didn’t know something was wrong, it was they didn’t ask.

One woman disclosed that during her second pregnancy 6 years ago, she had been in such distress she had actually thrown herself down the stairs while she was pregnant. She required a stay in hospital and significant treatment for her physical injuries. What she found most alarming now looking back was that no one asked her about her emotional wellbeing. She doesn't know whether she would have said anything but feels it was a wasted opportunity for her to get help. Fortunately the fall and the treatments didn't affect the baby, he was born healthy and without any concerns. This was the first time she had told anyone about the incident.

Two women who took part in the consultation shared they had experienced Post-Partum Psychosis. Although they knew this had happened and some of the detail, one woman in particular found it difficult to recall how the care package had actually worked for her. She was aware that it was when the psychosis was past and it had moved to PND that she found that there was less support, especially in the local community. When asked what would have made a difference she struggled to answer this, she knew something could have and maybe that was a support group but then felt this would have had to have been when she was in the final stages of her recovery.

Ante natal classes were suggested as an opportunity to raise awareness of the risk of PND and Psychosis, the signs and the symptoms, who to speak to if you are concerned for yourself or your partner. Women stated that 'baby blues and hormones' were discussed but this in no way reflected what they experienced. There was a general sense that it wasn't about scaring women but raising awareness of these 'illnesses' had to happen.

Next pregnancies have caused great anxiety for many women, this has been especially so for those who had not had a full recovery from the PND due to little or no support, or medical intervention. For those known to Mental Health services some felt as a result there was a positive care plan, and genuine compassion and care from the midwives, especially their community midwife. Where this wasn't the case it had been due to multiple midwives being involved in the community care, and not seeing the same GP at larger practices.

The experience of engaging with GP's ranged from 'they were great', to leaving women confused about whether they should still be taking anti-depressants, and some being told to stop without being offered any alternative care. Some women expressed how difficult it was to get an appointment with the GP 'who listened' in the practices with multiple GP's.

A small number of the women consulted had Social Care involvement and of these some had had a previous baby removed shortly after the birth. They felt they had been abandoned, whether their mental health state is classed as PND and/or grief was irrelevant to them. They were judged and their new baby had been removed. The aftercare they required was not

available unless they sought it out. GROW has historically found that some women self-medicate using drugs and alcohol, and their lives spiral into chaos.

*A had a complex background although at the time she was only in her early 30's she already had experienced four young children being removed permanently, one baby dying shortly after the birth, one baby being removed within hours of being delivered and within a year another pregnancy and birth.*

*Between baby number six being removed and the seventh pregnancy, A experienced a significant mental health breakdown, which led to suicide attempts and an inability to function. The situation became so critical that on one occasion the police had to send out the helicopter to locate her. A was hospitalised on a number of occasions but only after the interjection of A's lawyer.*

*It was only after the situation had become so severe that mental health services were able to intervene. There was inevitability around this case and how A's mental health would be compromised, this had not been picked up ante natal until the seventh pregnancy when a comprehensive care package was implemented. The outcome of this is that the baby was after a few months placed in A's care with a reducing support package in place.*

*T experienced post-natal depression with her second child, she accessed both her GP and Mental Health services for support. In T's view she never felt she fully overcame the PND and after a few months the input from health fell back to GP care.*

*When T became pregnant with her third child the ante natal anxiety this created was immense. She was so fearful of experiencing PND again, T became overwhelmed. T was encouraged by her Support Worker to seek help while she was pregnant by talking to her GP and Midwife. Although T's was still anxious, medically a care package was in place. T felt she could have been supported more if she had received more contact, even someone 'just to phone and ask how I was doing' on a weekly basis.*

*T shared she found it hard asking for help as she felt ashamed at not being able to cope. On reflection T doesn't understand why previous PND hadn't been picked up automatically on her third pregnancy.*

*T's third child is now three years old and until recently she was receiving intervention from RDaSH in the form of group therapy. At every attendance she has required someone to go with her, almost coaching her to attend. She did not complete all the sessions as she felt 'it was all too much'. T feels she just needed someone to talk to where she can 'off load without feeling judged'.*

## **5 Common Themes**

There still seems to be a lack of acceptance amongst a number of women that Post Natal Depression is an illness, and not a failing on their part to be a 'good mum'. There was a general consensus that if they had asked for help or pushed more with a GP who was telling them that it was just 'baby blues', someone might have taken their baby from them which increased their anxiety.

It appears those who were more at the acute point – psychosis; felt they received very good care, as did the women where previous PND had been recognised as a potential risk factor for a future pregnancy.

When previous PND hadn't been recognised or hadn't been diagnosed, it relied on the woman to bring this to the attention of the health professionals. This situation is then further impacted by the anxiety and depression, social factors surrounding the case and the 'fear factor' some of the women experienced.

A number of women raised that 'having someone to talk to' on a regularly/weekly basis could, they feel, have made a difference, this didn't have to be in person but could be via the phone. Women didn't feel this had to be a mental health specialist, just someone to ask how they were 'really' doing without fear of being judged as a failure.

BME women shared very little about their experience of PND, this could be for the same reasons outlined in the previous section which are then further affected by cultural expectations and restrictions. It has also been shared that the word depression does not translate well and can be interpreted as someone of weak mind.

## **6 Conclusion**

It is not easy for women at a time of emotional distress to be able to articulate what their needs are and how things could be improved.

Recently TV soaps have featured significant story lines relating to PND, which it is hoped have increased awareness but also encouraged women to seek help and support.

The experience of care appears to be 'patchy' and affected by numerous factors including:

- Recognition of being at risk of PND
- GP's response to prescribed medication
- Consistent midwife care

There appears to be a disconnect between how Mental Health professionals and colleagues in Social Care respond to PND, and also the expectations and understanding of the latter in relation to socially complex cases including victims of Child Sexual Exploitation.

## **7 Recommendations**

- It is acknowledged that in the main contacts were made through existing networks known to GROW and numbers consulted were relatively low. Future consultations would need to involve contact with RDaSH and Maternity Services prior to commencement of the consultation exercise to seek advice and aid access to those who have recently experienced PND/accessed services.
- Include feedback from non-health professionals relating to their experience of supporting women and families affected by PND.
- The Perinatal Mental Health Pathway needs to be shared with women in a format that is clear and practical. As one women said “how do you know if you have had a good service when you don’t even know what is available to you”.
- Guidance for partners, and family members on what to do if you have concerns about ‘mum’.

## **8 Questions**

How does Rotherham compare with national figures?

Which of the NICE Guidance recommendations (2014/15) are being adopted by Rotherham?

Does the new PNMH Strategy/Pathway recognise the impact of ‘social complexities’, and also the need for cultural awareness?