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How the Welsh Government can improve services for mothers, babies, fathers and families affected by Postpartum Psychosis.

About APP

- Action on Postpartum Psychosis (APP) is a national charity for women and families affected by Postpartum Psychosis.
- Collaboration between women & families with personal experience, specialist clinicians, and leading academic researchers.
    - Facilitates research
    - Develops patient information & resources
    - Runs an award winning peer support service
    - Trains health professionals in the care and management of PP
    - Campaigns for improved perinatal mental health services and raises awareness of PP in the general public.
- Largest network of women with PP in the world (with over 800 members with lived experience in the UK, and over 1400 peer support forum users.)
- Research team has conducted the most research into PP in the world (based in Birmingham & Cardiff Universities).
- APP is the only charity in the UK providing specific support and information for this population.
- We have Regional Reps that work hard to improve things in their local areas. Sally Wilson and Sarah Dearden will be attending today from N Wales.

Specific issues for the safe care of women who develop Postpartum Psychosis

- Postpartum Psychosis is a severe and frightening form of postnatal illness that develops, often out of the blue, in the days and weeks following childbirth, after 1-2 in every 1000 births.
- PP must be treated as a psychiatric emergency. Confusion, delusions, hallucinations and unusual behaviour escalate rapidly, at a time when women are responsible for a vulnerable newborn.
- Suicide is a leading cause of maternal death; the majority due to Postpartum Psychosis.
- Delayed treatment causes risk to the safety of the mother and newborn; longer and more severe episodes; and impacts on the woman’s and her families’ recovery.
- With the right care and support, women can make a full recovery and have fulfilling family lives.

Addressing the following 3 areas of service provision would greatly improve the situation for families affected by PP in Wales.

1) **Mother & Baby Unit provision in Wales**
2) **Health professional training in PP & development of PP appropriate care pathways**
3) **Provision of specialist peer support & information**

1) Mother & Baby Unit provision in Wales

We expect around 50 cases of PP in Wales each year. Almost all will need admission to a specialist Mother & Baby Unit. There is currently no provision, causing heartache to families and potentially poorer outcomes for Welsh families.

APP's survey of 218 women with PP found that, compared to those admitted to general psychiatric units, women admitted to MBU: are more satisfied with care; have shorter time to full recovery; feel safer; feel better informed; feel more confident in staff; feel more supported with their recovery; feel more recovered on discharge; and feel more confident with their baby. Our qualitative work shows that some women feel lifelong anger and trauma where treatment required separation from their baby.

Some women who develop PP in Wales are admitted over the border in England. Our research shows that women admitted to a MBU a long way from their home, felt that they were in the right place for treatment, but had concerns about the lack of continuity of care on discharge, the impact upon their partner, and isolation - many were in hospital for several months, and the distance made it difficult for partners, friends and relatives to visit.

MBUs ensure patients have access to: specialist medication knowledge; specialist facilities; appropriate physical postnatal care; and support with bonding and parenting skills.

Our Wales Regional Reps suggest that 2 MBUs are needed, one in North and South Wales, given the difficult access between N & S Wales.

2) Health professional training in PP & development of PP appropriate care pathways

Health professional and general public knowledge regarding Postpartum Psychosis is limited.

All staff that come into contact with pregnant and postnatal women should be aware of early symptoms of PP, risk factors, how, why and when to access help. Care pathways that are appropriate to meet the needs of women who develop Postpartum Psychosis are needed in each area.

Care pathways set up for the treatment of bipolar and psychosis at times unrelated to pregnancy tend to be too slow and lack consideration for the needs of mother, baby and wider family. Care pathways set up for the treatment of more common maternal mental health issues tend to be inappropriate to the needs of women developing PP.

General preventative strategies designed to improve the wellbeing of pregnant & postnatal women and address mild to moderate forms of postnatal illness are unlikely to have any impact on cases of Postpartum Psychosis (few psychosocial factors are involved in causing PP)

Specialist pre-conception advice (such as the excellent service provided by Dr Ian Jones at Cardiff & Vale) is essential for those at high risk (e.g women with a previous episodes or a history of Bipolar Disorder) however, half of all cases are to women with no previous mental illness history.

APP provide specialist workforce training in Managing Postpartum Psychosis, jointly delivered by clinical experts and those with lived experience, giving staff cutting edge, reliable information as well as a greater awareness of the importance of their good practice for real women & families.

Feedback from sessions run in England show health professionals rate the training highly and believe it will change their practice. The lived experience sections are rated as particularly important and powerful (importantly speakers have support, quality assurance and safeguarding provided by APP). These could be provided to each of the 7 Health Boards at a cost of £3120 per session.

3) Provision of specialist peer support

Recovery following PP can be a long, hard, isolating process, often taking 3 years. Often episodes are followed by anxiety, depression, and difficulty in coming to terms with the episode of PP.

There is limited information available on recovery from PP: APP has written a freely available guide to the recovery process.

PP mums are among the most stigmatised members of society. The media has portrayed them as ‘unnatural’, ‘dangerous’, or ‘unfit’ mothers, and families have hidden the illness. Women live with a sense of guilt, shame, fear and loss, lasting many years.

Our qualitative research shows that women have a strong need to talk to others with similar experience, and attending more general support groups aimed at those with depression and anxiety can leave them feeling more isolated and unusual.

Research into APP's peer support service shows that it increases feelings of support, reduces isolation, increases access to information, improves ability to talk to family members and health professionals, reduces feelings of stigma, and saves lives. In the words of one beneficiary

"Peer Support has been life-changing for me. I don't feel isolated at all… I feel proud to be part of this unique community of amazing, strong women and proud of everything we have been through. It has been so healing to give and receive support. It has helped me to recover more fully, to really fully come to terms with the experience, to deal with the grief, shame, sadness, trauma of the experience."

For around £2000 per affected woman, APP can provide an initial face to face visit in hospital / at discharge, patient information guides, one to one email support with a trained peer supporter – which normally lasts around 12 months, and online peer support forum membership – which means volunteers are there for lifelong support for any issues relating to PP, and membership of a regional PP social group.

APP's Peer Supporters are carefully selected, trained, well supported, and, crucially, have access to world leading clinical and academic advisors.

APP also provides information, one to one email support and forum support to partners and wider families affected by PP.

Providing access to such a service for those affected by PP in Wales could help to reduce PP related deaths, adverse outcomes, long term trauma and family separation.