



Insider Guide

Recovery after Postpartum Psychosis



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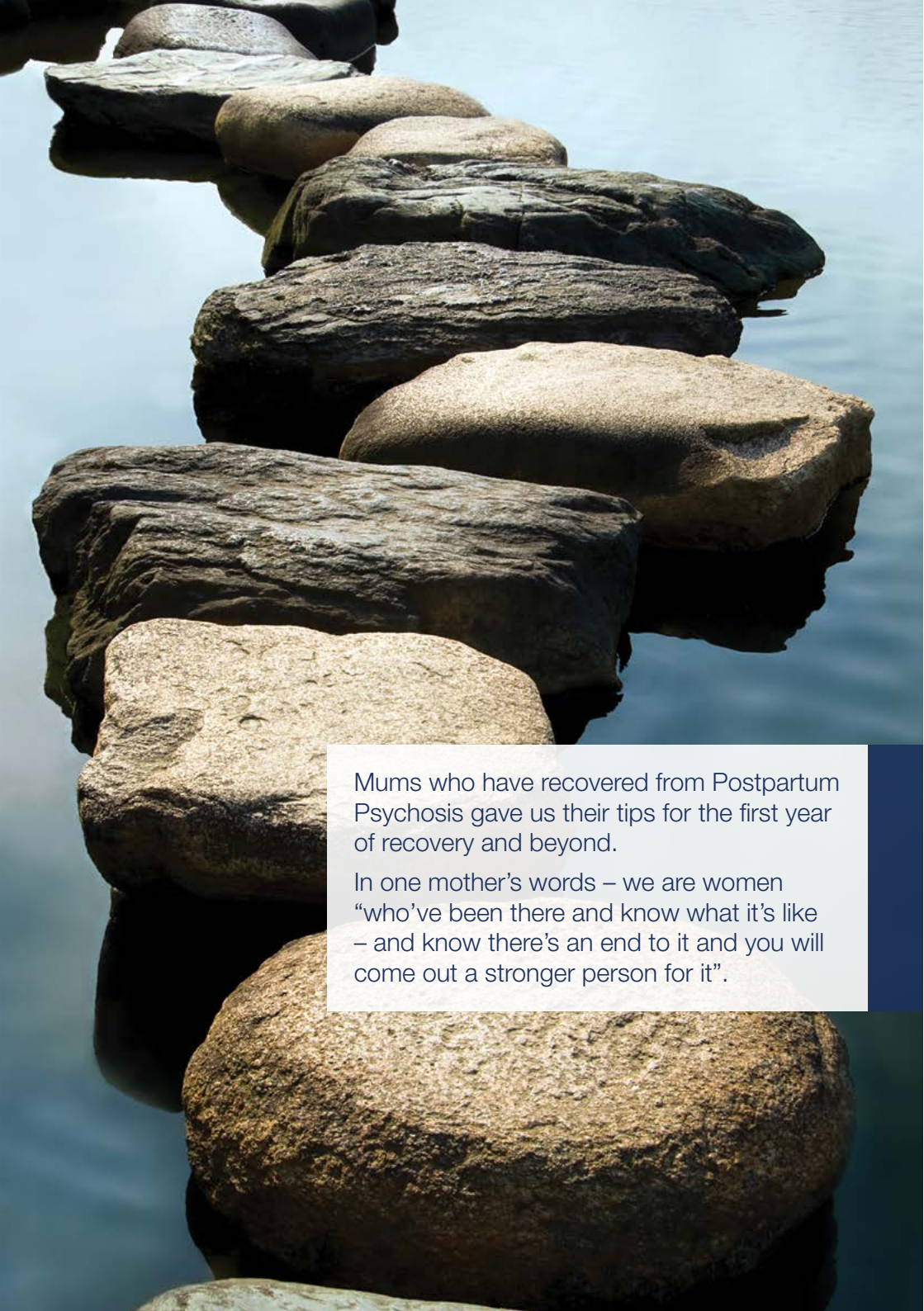
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Mums who have recovered from Postpartum Psychosis gave us their tips for the first year of recovery and beyond.

In one mother's words – we are women “who've been there and know what it's like – and know there's an end to it and you will come out a stronger person for it”.

Section 1

Early days – the first couple of months after diagnosis

Your feelings

It's normal to feel a whole range of emotions when you begin to recover from Postpartum Psychosis (PP). Below are some common emotions:

- Shock
 - Embarrassment
 - Why me?
 - Anger
 - Exhaustion
 - Guilt
 - Worry (bonding, your relationship, your future health)
- Read other women's stories – ask a friend to look on the APP website (www.app-network.org) and find encouraging stories for you. Be wary of googling before you are up to it as some web content can be upsetting.
 - Come to our PPTalk support forum at www.app-network.org/pptalk or request email support from a mother who has recovered from PP at www.app-network.org/peer-support

Making sense of what has happened

In the early days after being diagnosed and/or receiving treatment in hospital you may feel a sense of confusion about the events of your baby's birth and your illness. Many women find it hard to remember the exact sequence of events from becoming unwell to getting help. You may also feel let down or unhappy about the way treatment was started, especially if you had to go to hospital under a section of the Mental Health Act. You may want to understand more about Postpartum Psychosis, or you may not feel ready to deal with detailed information yet. Some of the following ideas can help:

- Ask your Mental Health Team for a summary of events and your treatment.
 - Talk to your partner or family about what happened – but some people find this very hard and need time to recover first.
 - Write your story in a private diary.
 - Use photos or memories to put together a time-line. This can help you look back on your baby's first days even though they weren't how you expected them to be.
- ### Coming to terms with shocking or traumatic behaviour
- Many women behave in ways that are really out of character during an episode of Postpartum Psychosis. It may help just to know that these experiences are usual symptoms of the illness. It is very common during PP to become angry, excitable, use inappropriate language, be over-familiar with strangers, or believe you have special insight or powers. Distressing thoughts about harming yourself or your baby are also common, though very upsetting. It is very normal to feel embarrassment or shock at the things you did when unwell. These ideas can help:
- Ask your Mental Health Team for information about common symptoms of PP.
 - Remind yourself that these were symptoms of the illness and not a permanent change in you.
 - Talk through upsetting symptoms with your partner.
 - Ask to speak to a health professional (e.g. a support worker, specialist midwife, community psychiatric nurse, or another member of the Mental Health Team) about how you feel about your symptoms.
 - A psychologist or counsellor (particularly one with specialist knowledge of postnatal illness) may be able to help you talk through your experiences.



Feeling knocked in your confidence as a Mum

Most women who have experienced Postpartum Psychosis find their confidence takes a huge dip. This can be especially true for doing daily things with your baby. The first weeks at home after hospital can be daunting and it's important to have practical help with your baby. You will also need time to rebuild your own self-belief. It's helpful to keep going with nappy changes, dressing your baby and feeding – as often as you can. Remember your baby knows you are Mum and has a special bond with you already built from before birth. Some ideas to help:

- Going to mother and baby groups might feel a bit daunting at first. If so, use your Health Visitor, or Mum-friendly websites for baby care advice.
- Ask for practical tips for playing with your baby if you are anxious about how to interact. At first it might feel like you are going through the motions, but in time your confidence will recover.
- Remember that all new Mums are anxious about whether they are doing it right. Keep taking it gently. You will get there.
- If you can, accept help from friends and family. Be clear about the help you would like, so that they resist the urge to take over.

Exhaustion

In the first few weeks of treatment, you might continue to feel quite energetic and 'buzzy' if you have experienced mania as part of your illness. However, most women find that as medication begins to take effect, and recovery begins, they feel physically and emotionally drained. Try and remember that all new Mums feel exhausted, and make sure you get as much rest as possible. As well as a new baby, you have also had a serious illness so it's really important to sleep, rest, and don't put too much pressure on yourself.

- Rest or sleep when your baby sleeps. The housework will wait!
- Seek out practical help in the house – friends, family or a volunteer from Home Start www.home-start.org.uk
- Take short buggy-walks in the daytime if you feel drained when baby is unsettled.
- Share responsibility for night feeds if you possibly can.
- Talk to your Mental Health Team about how you are feeling. Taking medication at bedtime might reduce sleepiness in the day.

Anxieties about the future

Recovery might feel like a long way off at the moment. Remember that you will get there. Almost all women who have PP recover fully. Many say that it has made them understand better what's important in life, and has made them stronger in the long term. There are no known adverse affects of having an episode of PP for the development of your baby.



Here are some quotes from women describing their feelings in the early days:

Shock

"It's such a shock and at the time that you were expecting this to be such a wonderful time."

"I think he was as shocked as me really, you don't expect that kind of thing to happen after you've had a baby at all, it's just not on your radar."

Embarrassment

"That's psychologically stayed with me, being outside in my pyjamas. It's like the ultimate image of a mental patient."

Why me?

"It took a long time to kind of rationalise what had happened to me and why this had happened to me... could I have done anything better, and all this stuff."

"Consequently, I wasted a lot of time and worked myself into a depression pondering the 'why me?' question and trying to understand why my brain had not functioned properly for a period."

Anger

"I just feel very bitter, and angry about the whole experience."

Guilt

"All these feelings of guilt because you missed out, or not being there for your new born baby, and guilty, because you left your husband to deal with it all when it's the first time for him as well."

Exhaustion

"I just thought once I was out of hospital, and the really delusional bit had gone, I thought 'I'm out of the woods' you know... 'yeah it's all going to be fine', and then actually the depression afterwards, the deep, deep depression afterwards, was just such a blow, such a double whammy."

Worry

"I worried about interaction. I worried that I'd never get better from the depression because it was very cyclical. I really, really worried about the impact on my child because I'd read about Mums who have mental health problems affecting their kids, I worried about the genetic side of it. What didn't I worry about? I worried, I worried for my marriage, all sorts of stuff like that really."

"I was terrified, absolutely terrified, that I wasn't doing the right things with her. I thought she wasn't gonna learn to talk or do anything because I wasn't interacting with her right."

Treatment

Medication

Most women who have recovered say that taking medication was vital to their recovery. Medications help bring the symptoms of psychosis under control and to stabilise mood. You may feel, however, that medication only helps with half the problem – symptoms but not self confidence. It is important to use more active recovery methods along side medication to help with self confidence and the social side of recovery.

In the first 6–12 months of recovery, it is likely you will still be taking medication of some sort. You may have been prescribed an antipsychotic, a mood stabiliser, antidepressants or sleeping tablets. MIND have produced excellent medication guides which give detailed information:

www.mind.org.uk/help/medical_and_alternative_care

Many medications used to treat Postpartum Psychosis have some side-effects. Here are some tips for managing side-effects:

- Keep talking to your Mental Health Team and/or GP about monitoring your dose. Higher doses of antipsychotics particularly can make you very sleepy and demotivated, but doses that are too low can delay recovery.
- Don't be afraid to remind professionals prescribing your medication that you have a young baby and you want to be able to do as much as you can to care for your baby.
- Talk to your Mental Health Team about altering the time of day that you take your medication. Some women find that taking medication at bedtime reduces sleepiness in the day.
- Give yourself plenty of time to get going in the morning wherever possible.
- Try longer walks with a pram or sling, or taking your baby swimming to help with fatigue or weight gain associated with medication.

Professional support

During recovery, most women will continue to receive support from mental health services. This may be from a specialist perinatal Mental Health Team, but in many parts of the country this is more likely to come from a community Mental Health Team or an Early Intervention in Psychosis team. You may have outpatient appointments with a Doctor or have a Community Psychiatric Nurse that visits you at home.

Support is also available from your GP, Health Visitor or specialist postnatal support workers. When you leave hospital, a plan should be put in place to provide support for you while you are at home. You can contact your GP or Mental Health Team to discuss what support is available locally or visit NHS Choices

www.nhs.uk/Pages/HomePage.aspx

Visits or appointments with professionals can seem intrusive, and you might worry that your 'performance' as a Mum is being monitored. It is really normal to feel like this, and OK to talk to your Health Visitor or midwife if you need reassurance. It is also OK to ask for specific advice to help you bond more with your baby – for example planning realistic daily activities that will be good for both you and your child. Some areas of the UK have courses or classes for parents who have experienced mental ill health, or Mums' groups for women with similar experiences. You could ask your Health Visitor to help you find out what is available locally.

If you find that feelings of anxiety or low mood are overwhelming you or you have concerns that you are relapsing, don't wait for your next appointment. Ask to see your psychiatrist at the earliest available appointment.

Daily life as a Mum

Rest

Resting is easier said than done with a small baby. However, it is essential in recovery from Postpartum Psychosis. Some things to try:

- Get into bed or put your feet up on the sofa at least once a day when your baby is asleep.
- Listen to gentle music when holding or feeding your baby.
- Put a time limit on essential jobs like laundry – after 15 minutes of tasks, reward yourself with a hot drink or magazine break.
- Accept as much hands-on help from friends and family as you can.
- Try low lights, minimal TV or Internet searching, and a slow pace in the evening to relax you for bed.
- Use ear plugs if you are sharing the night feeds with your partner so that you don't get disturbed.

Bonding

Bonding is a big worry for most Mums who have been through Postpartum Psychosis. There can be a lot of focus on breastfeeding and skin-to-skin contact in the very early days of newborn life, and you may feel as though you have missed out on this chance. It's normal to feel really sad about this, but important to know that bonding is an ongoing process and just spending time with your baby as you recover will strengthen your bond. Things to try:

- Copy your baby's facial expression when you are cuddling.
- Look at simple picture books together, especially faces.
- Talk about what you are doing even if it feels silly – your baby loves to hear your voice.
- Hold your baby close, facing your body during feeds even if bottle feeding.



Don't fancy baby & toddler groups?

It's normal to feel very different from other Mums at baby and toddler groups. Sometimes the conversation about babies' weight and nappy contents can feel a bit irrelevant after the shock of a serious illness. Depending on your personality, you may or may not feel OK about discussing your experience of Postpartum Psychosis. Many of the Mums we interviewed found activity groups easier going as there was a focus on learning something new together. If you would like to attend a group but find it daunting, see if you can take a friend or health professional for the first time – or ask the class tutor about buddying up with another attendee. Some good groups for 0–6 months:

- Baby massage
- Baby yoga
- Baby Sign Language e.g. Sing and Sign or TinyTalk
- Nursery rhyme/story sessions at local libraries

Section 2

Rebuilding Confidence – the first 6 months to a year

Your feelings

The ups and downs

Many women find the first year of recovery is marked by significant ups and downs in mood. It can feel like a real setback if you have been feeling well and gaining confidence, but then have a period of low energy or depressed mood. Try to remember that all Mums of young children have good and bad days. You may also find it worrying if you have periods of sleeplessness and high energy. It is really worth talking to professionals about any concerns you have. In the first year, it can be important to adjust your medication slightly or try different medications to help stabilise your mood. Tips to help with the ups and downs:

- Try keeping a regular weekly routine of activities for you and baby.
- Set yourself small goals and monitor your progress. Setbacks can make you feel like you are back to square one, but it is important to be able to see how far you have come.
- Keep a mood diary to help you see whether there are triggers for low or more energetic times – get to know yourself and what helps to keep you feeling level.
- List activities that make you feel happy or energised and try them when you feel low. Do the same for activities that make you calm and relaxed and try them when you feel stressed or high.
- Using a mood chart can help you explain your ups and downs to your psychiatrist: e.g. <http://bit.ly/Vf1EM8>
- Don't feel guilty about asking health professionals to talk through any concerns.

Depression

Sadly for many Mums, symptoms of depression do occur after an episode of Postpartum Psychosis. You may experience tearfulness, lack of pleasure in anything, loss of motivation, poor sleep and negative thoughts about yourself. This can feel like a real double-blow after the energy and elation common in Postpartum Psychosis. Firstly it's important not to feel guilty. Depression is a common reaction to a traumatic experience, and can also be caused by the disruption to your brain chemistry following psychosis or mania. These things can help:

- Ask about treatment to reduce symptoms of depression as soon as you can – talk to your Health Visitor, GP or Mental Health Team.
- Mood stabilising medication, antidepressant medication and talking therapy, such as Cognitive Behavioural Therapy (CBT) are effective treatments for depression. Ensure you speak to your Mental Health Team or GP immediately if you begin to feel very agitated or have thoughts of suicide whilst having treatment for depression.
- Keep doing as much as you feel able to with your child, even if it feels a struggle. Playing or reading a book with your baby can provide some distraction and temporary relief.
- Treat yourself – even though you might not feel you 'deserve' it.

Good times

During your baby's first year there will be special times to remember as you recover. It can be easy to miss out on enjoying the first smile, milestones like reaching for toys or sitting up. You could invest in a baby record book to put in important dates and photos – even if you are low at the time it can feel really important later to look back on these and see how much your baby has grown up. Ask your partner or family to take lots of

photos if you go on holiday or a day-trip. You could try painted handprints or footprints, or putting together an online album of photos. For many Mums who have experienced Postpartum Psychosis, your baby's first birthday is a very special and poignant time. You will probably still feel some sadness, but also relief and pride at making it through a tough first year.

Treatment

Medication

In the first 6–12 months of recovery, it is likely you will still be taking medication such as an antipsychotic or a mood stabiliser. You may have been prescribed an antidepressant and something to help with anxiety or sleeping problems.

See www.mind.org.uk/help/medical_and_alternative_care for more information

Although most women feel that taking medication regularly was very important in their recovery, many medications used to treat Postpartum Psychosis have some side-effects. Here are some tips for managing side-effects:

- Keep talking to your Mental Health Team and/or GP about monitoring your dose. Higher doses of antipsychotics particularly can make you very sleepy and demotivated, but doses that are too low can delay recovery.
- Don't be afraid to remind professionals prescribing your medication that you have a young child and want to be able to play and interact with your child.
- Talk to your Mental Health Team about altering the time of day that you take your medication. Some women find that taking medication at bedtime reduces sleepiness in the day.
- Give yourself plenty of time to get going in the morning wherever possible.
- Exercise can help with fatigue or weight gain associated with medication.
- Regular walks or an exercise class with a crèche can be helpful.

Thinking of counselling?

In the first year of recovery, you may feel you want to talk to a counsellor about your experience of Postpartum Psychosis. Going through such a serious illness can have an impact on your sense of self, your relationship with your partner, and especially on your confidence as a Mum. It's a very personal choice about if and when you feel ready to open these things up to a professional.

Accessing 'talking treatments' – particularly on the NHS can be difficult – but there are a number of options to think about.

- Your GP or psychiatrist may be able to refer you for a talking treatment, such as Cognitive Behavioural Therapy (CBT), which can be particularly helpful for depression, changing your thoughts about yourself as a Mum and coping with anxiety (usually 6–12 sessions).
- Relate www.relate.org.uk offer counselling for individuals and couples about managing the impact of illness on your relationship. See also Relate for parents: www.relateforparents.org.uk
- Private counsellors can be expensive, but can offer longer term therapy to talk about the trauma of illness, and explore change in your sense of who you are. Look for a BACP accredited counsellor here www.bacp.co.uk
- Remember, if you do not get on with the counsellor you have been given – try someone else. A counsellor with a different approach, level of knowledge, or personality might be more beneficial.

Getting back into Mum-world

Sharing your experiences

As you begin to recover, you may really want to talk to other Mums who have experienced mental health problems and understand some of what you have been through. One of the best ways to make these contacts is through web forums:

- APP has developed a peer support network specifically for women who have experienced PP, run by other women who have been through the experience. To get in contact with another Mum who has recovered from PP, email APP (app@app-network.org) or visit www.app-network.org/peer-support
You can also visit our online community, PP Talk, where you can ask questions and discuss issues with other mothers who have been affected by PP www.app-network.org/pptalk
- You may want to write your story on a forum such as Mumsnet – but do take time to consider the emotional impact, and it can be helpful to use a different screen name to protect your identity.
- Forums are generally very supportive and encouraging but take good care of yourself if you are also writing to support other women in distress.
- Some women find that they want to read as much information as they can about PP. Our FAQ www.app-network.org/what-is-pp/faq

section can help locate useful information. Free searching the web can throw up some distressing and unhelpful pages. Ask a friend to search for information for you and screen out anything that is not helpful.

Meeting local Mums

Lots of Mums who have experienced Postpartum Psychosis find their confidence is knocked in terms of socialising and meeting other Mums. However, knowing other parents can really help if you feel isolated, and many local Mums will still be there in the far-off days of the school run!

- Use Mumsnet www.mumsnet.com/local to find out what is going on for parents and babies in your local area.
- Invite Mum-friends to cafes with soft-play areas so you can have time to chat.
- Try activity groups like Sing & Sign www.singandsign.co.uk
- Gymbabes www.tumbletots.com/programmes.php?ID=3 or baby yoga
- If your partner, babysitter or family can look after the baby once in a while, meet up with friends for a film or a quiet drink. All Mums need time out too!



Section 3

Moving On – living life to the full after PP

Your feelings

Life with a toddler

Parenting a toddler is exhausting at times for any parent, but it can feel especially challenging as you recover from Postpartum Psychosis. It can be easy to worry that tantrums or wilfulness are a sign that you haven't bonded properly, or that your child is upset with you because of being unwell. Try to read as much as you can about normal toddler behaviour and reassure yourself that their testing of the boundaries is a good sign and not your fault! Useful resources for toddlers

- Mumsnet www.mumsnet.com/toddlers
- Relate for Parents: www.relateforparents.org.uk
- Cbeebies website, especially songs and games www.bbc.co.uk/cbeebies
- Combat boredom by borrowing from your local toy library www.natli.org.uk

Sadness and loss

It takes most Mums at least a year to begin to feel confident in their recovery. After the first year, your mood may feel more stable and you will have some experience of the challenges of motherhood under your belt. However, it is still really normal to feel a sense of loss of the first months of your child's life. It can be hard to come to terms with not enjoying your baby as much as you wanted to, and thinking about the tiny baby stage may still make you feel quite sad. It's important to allow yourself to grieve for this loss, and also to celebrate what you have achieved in recovery.

Reflecting on surviving Postpartum Psychosis

Some women are able to look back on their experience of Postpartum Psychosis and reflect on how it has made them stronger, or helped them value their loved ones even more. However, this is not the same for everyone, and you may still be dealing with the impact of illness on your relationship, work life or self-confidence. It can be really helpful to look back and admire yourself for courage and determination to work through your recovery, whatever your circumstances. You may want to talk your recovery through with someone professional – see Section 2: Treatment: thinking of counselling.





Planning for the future

Bring about something positive

For some women, after recovery, it is important to move on with life. For others it is important to come to terms with their experience by trying to bring about something positive. These are all things that have helped women to come to terms with their experiences: helping other women who are at an earlier stage in recovery, helping with a research project, organising a fundraising or awareness raising activity, campaigning for improved services, using their experience as a person with 'lived experience' to advise on research or healthcare panels, talking to a healthcare students or health professionals to educate them about PP, and reflecting on the positive changes in life and relationships that have come about since the illness.

More children?

It can be really upsetting when friends begin to announce second or subsequent pregnancies. It can seem such an easy decision for other families to make, and yet is much more complicated having been through Postpartum Psychosis. It is OK to feel sad or jealous – give yourself time to adjust. You may have decided definitely not to have any more children, or be undecided and unsure of what sort of gap would be best. Talk to your partner as openly as you can about your concerns and hopes. Read the detailed information here: www.app-network.org/what-is-pp/faq/#FAQ7 to help you make informed choices.

Returning to work

As for all Mums, deciding to return to work or starting a new job is daunting. It is a very personal decision whether you tell your employer that you have had Postpartum Psychosis. Sadly stigma and discrimination can still affect employment prospects. However, discussing your experience with an employer or occupational health service could enable you to make sure you are well supported at work, and able to discuss relapse prevention openly.

The Rethink website has comprehensive advice on going back to work after experiencing mental illness:

www.rethink.org/living-with-mental-illness

Looking after your wellbeing at work

- Consider a phased start if possible, increasing your hours over a few weeks.
- Have lunch and screen-breaks away from your desk when at all possible.
- If stress or low mood does build up, talk to your boss or occupational health department as soon as you can.
- Book in good stretches of annual leave to spend time with your child.
- Find a special reminder of your child to take to work – maybe something they have made – to help put work in perspective.
- Take a look at MIND's guide: Five Ways to Wellbeing at Work: www.mind.org.uk/employment/mind_week_2011/employees/five_ways_to_wellbeing



Relapse planning

The long term outcome after an episode of PP tends to be very good. However, some women who have had PP will go on to have further episodes of illness after childbirth or unrelated to childbirth.

The most important thing is to be able to monitor your own moods and your sleep, so you can catch early warning signs and access treatment. Before you are discharged from community support services or your psychiatrist, ask your team to help you put together a plan of action in case of illness. This type of plan could be written during pregnancy together with your midwife and Mental Health Team if you decide to have more children.

A plan could include:

- Triggers that you know might make you more vulnerable such as stress or bereavement.
- Any early warning signs to look out for such as sleeplessness.
- Which medications have worked well for you in the past, and at what doses?
- Any medications you would prefer to avoid.
- Where you would prefer to be treated if you had to go into hospital.
- The telephone numbers of any health professionals or services you might need should you relapse.
- Activities you have found helpful for your wellbeing and recovery.
- Downloadable Wellness Recovery Action Plan (WRAP)
www.workingtogetherforrecovery.co.uk/recovery_library.htm

Further reading

A copy of these articles can be obtained from the APP office.

For further information about this project, see: Heron, J. et al (2012) Information and support needs during recovery from Postpartum Psychosis. Archives of Womens Health 15: 155–165. <http://bit.ly/14NicRz>

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