



Insider Guide

Planning pregnancy: a guide for women at high risk of Postpartum Psychosis



Contents

What is Postpartum Psychosis (PP)?	4
Symptoms	
Causes	
What are my risks of developing PP	
Deciding whether to have a baby	
Planning for a baby	7
Preconception planning	
Medication – things to consider	8
Congratulations – you're pregnant!	9
Booking with your Midwife	
Telling friends and family	
Your feelings	
Developing a care plan for pregnancy and birth	
Congratulations – You're a mum!	13
Looking after yourself after the birth	
The first few weeks at home	
Further support and information	15

Contact Information

Action on Postpartum Psychosis

Tel: 020 3322 9900

Email: app@app-network.org

Website: www.app-network.org

Twitter: @ActionOnPP #PPTalk

Facebook: www.facebook.com/ActionOnPP

PPTalk Online Community:

www.app-network.org/pptalk

One to One Email Support:

www.app-network.org/peer-support

APP Director: Dr Jessica Heron

Senior Research Fellow in Perinatal Psychiatry

University of Birmingham

Email: jess@app-network.org

APP Chair: Dr Giles Berrisford

Consultant Perinatal Psychiatrist

Birmingham Perinatal Mental Health Service



Women with Bipolar Disorder, or with experience of Postpartum Psychosis, talked to us about the issues they faced when planning for a baby.

This guide brings together advice from professionals and families about getting the support you need during pregnancy and birth.

What is Postpartum Psychosis?

Postpartum Psychosis (PP) is a serious mental illness which usually occurs in the first few days or weeks after childbirth. Women with a history of mental illness such as Bipolar Disorder are at particularly high risk of developing PP, however half of all women who develop PP have no history of mental illness. The symptoms of PP can get worse very quickly, so it should be treated as a medical emergency and usually requires hospital treatment.

Symptoms

Women with Postpartum Psychosis may be:

- Excited, elated, or 'high'.
- Depressed, anxious, or confused.
- Excessively irritable, agitated, or changeable in mood.

Postpartum Psychosis includes one or more of the following:

- Strange beliefs that could not be true (delusions).
- Hearing, seeing, feeling or smelling things that are not there (hallucinations).
- High mood with loss of touch with reality (mania).
- Severe confusion.

These are also common symptoms:

- Having trouble sleeping, insomnia or not feeling the need to sleep.
- Being more talkative, sociable, or on the phone an excessive amount.
- Having a very busy mind or racing thoughts.
- Feeling very energetic and like 'super-mum' or agitated and restless.
- Behaving in a way that is out of character or out of control.
- Feeling paranoid or suspicious of people's motives.
- Feeling that everyday events, or stories on the TV or radio have special personal meaning.
- Feeling that the baby is connected to God or the Devil in some way.

For more information on possible symptoms and experiences, visit: www.app-network.org

The symptoms of PP can be very distressing for women and their families. However, the good news is that with prompt treatment in hospital and medication, women can and do make a full recovery.



Within days of being at home, after two sleepless nights at hospital, I started accelerating into mania, but very different to episodes I had experienced before. I was very anxious and irritable one minute, singing and laughing the next; unable to sleep or relax; becoming paranoid and hallucinating... it was several more weeks before I felt 'well' again.

A mum with Bipolar Disorder



What causes PP?

Unfortunately, very little is known about the causes of PP. There are likely to be many factors that lead to an episode of PP. Research points to genetic factors and biological changes around the time of pregnancy and childbirth. You are more likely to have PP if a close relative has had it, or if you have Bipolar Disorder or Schizoaffective Disorder. Changes in hormone levels and disrupted sleep patterns after giving birth may also be involved, but more research is needed to fully understand the causes. PP is not your or your partner's fault. It is not caused by anything you or your partner have thought or done. Relationship problems, or the baby being unwanted do not cause PP.



What are my risks of developing PP?

Postpartum Psychosis affects around 1–2 in 1000 women after childbirth. However, research shows that some women are at higher risk due to: genetic factors, a history of certain mental illnesses, or previous episodes of PP.

The risks outlined below are 'best estimates' based on research. Each woman will have an individual risk based on many factors. It is good to have an idea of your own chance of developing PP compared with the general population, so that you can talk to your health care professionals about this before you try for a baby and during your pregnancy.

I have a diagnosis of Bipolar Disorder or Schizoaffective Disorder

If you have Bipolar Disorder or Schizoaffective Disorder your risk of developing PP is around 1 in 4 (250 in 1000). This risk rises to 1 in 2 (500 in 1000) if your mother or sister has had PP. Your risk of developing PP is significantly higher than the general population, so it is important to talk to health professionals about your care, ideally before you start trying for a baby.

If you have Bipolar Disorder, there are a number of factors which could increase or decrease your individual risk of PP. An episode of PP may be more likely:

- after a first baby. If your first pregnancy is unaffected, then you are at lower risk of PP in subsequent pregnancies.
- if you have had several previous manic episodes (no matter how long ago these were).
- if you have a family history of PP.
- if the pregnancy is unplanned.
- if you experience mood symptoms during pregnancy.

It is important to be aware that you will also have an increased risk of Postnatal Depression (depression without psychosis) following childbirth.

I have had a previous episode of PP

If you have had an episode of PP before, your risk of another episode in a subsequent pregnancy is around 1 in 2 (500 in 1000). This risk may be as high as 7 in 10 (700 in 1000) if you also have had episodes of Bipolar Disorder, Schizoaffective Disorder or Schizophrenia unrelated to childbirth.

My mother or sister had PP

If your mother or sister has had an episode of PP, and you have not had previous mental health problems, your risk of developing PP is around 3 in 100 (30 in 1000). This is higher than the general population, so it's important for your Midwife and health professionals to be aware of, but you are still at relatively low risk. Ensure that you, your partner and health professionals know the early signs of PP. Your risk of developing PP is significantly higher if you also have a mental illness.



Deciding whether to have a baby

The decision whether or not to have a baby is a very difficult one for women who know they are at risk of PP. You, your partner and your wider family may have lots of concerns about your wellbeing during pregnancy and birth.

There is no 'right' or 'wrong' decision and what feels right for one couple may not for another. You and your partner will need to talk through your decisions carefully. Ideally you should seek advice from a specialist such as a Perinatal Psychiatrist before you start trying for a baby (see preconception planning).

You may find it helpful to talk through your concerns with other mums and dads in our online community forum: www.app-network.org/pptalk

Knowing you are at risk of developing PP will enable you to work closely with health professionals throughout your pregnancy and birth to reduce the risks of relapse. Planning well for PP can help you and your partner accept that, although an episode is a possibility, you have the best support and treatment plan in place. This will ensure that, if you do develop PP, everyone around you is prepared, and you can get early treatment and recover much more quickly.

If you do decide to try for a baby, the most important thing you can do is make sure that all of the health professionals involved in your care know about your risks of developing PP. You will need to ensure that care plans are put in place for pregnancy, birth and the early postnatal weeks.

The next section of the guide takes you through preconception planning, making decisions and developing a care plan for your pregnancy and birth in detail.

The care you can expect to receive prior to and during pregnancy is detailed in the NICE Antenatal and Postnatal Mental Health: www.nice.org.uk/Guidance/Lifestyle-and-wellbeing/Mental-health-and-wellbeing

The Royal College of Obstetricians and Gynaecologists publish a guide to good practice: www.rcog.org.uk/management-women-mental-health-issuesduring-pregnancy-and-postnatal-period

The Scottish Intercollegiate Guidelines Network's useful good practice guidance is available here: www.sign.ac.uk/guidelines/fulltext/127

Planning for a baby

Preconception planning

If possible, you should seek specialist advice when you are planning your pregnancy. Your GP or mental health team can refer you. You should see a Perinatal Psychiatrist if there is one in your area. This is a doctor who specialises in the care of pregnant and postnatal women with current or previous mental health problems or a family history of PP. If there is no local Perinatal Psychiatrist you can see a General Psychiatrist for advice. You will be able to discuss:

- Your individual risk of developing Postpartum Psychosis.
- Risks and benefits of medication in pregnancy and after birth. This will mean you have the information you need to make decisions about your treatment. (See Medication – Things to Consider).
- The type of care you can expect in your local area. Which health professionals will be involved in your care. Whether there is a Perinatal Mental Health Service or a Specialist Midwife in your area and how the health professionals will work together with you and your family. (See Developing a care plan for pregnancy & birth).
- Any concerns you and your partner have about trying for a baby, looking after yourself during pregnancy and recognising early warning signs of PP.

Specialist advice

Most Mother & Baby Units (MBU's) offer specialist preconception counselling for women at high risk of PP thinking about having a baby. Visit our website for a map of the locations of UK Mother & Baby Units: www.app-network.org/what-is-pp/getting-help/mbus

Other areas of the country have a Perinatal Psychiatrist or a specialist Perinatal Mental Health Team. See the services available in your area: www.everyonesbusiness.org.uk/?page_id=349

If your GP is not able to locate a specialist, you can post on our PPTalk forum for help finding out what is available in your region: www.app-network.org/pptalk

Cardiff University Psychiatry Service

If you are unable to access specialist advice locally, Cardiff University offers a Psychiatry Service which your GP or Psychiatrist can refer you to for specialist advice.

Prof Ian Jones, a Perinatal Psychiatrist and expert with APP, is happy to see any woman at high risk of PP via this service. More information can be found at this website: www.medicine.cf.ac.uk/psychological-medicine-neuroscience/cups/cups-second-opinion-clinic

Choosing when to try for a baby

It can be difficult to determine 'the right time' to start trying for a baby.

- If you plan to stay on medication, try to ensure that you are stable on one that is recommended for use during pregnancy before you start trying for a baby.
- To avoid overloading yourself with worries, it can be helpful to think about avoiding times when you will have other stresses in your life such as moving house or changing jobs – and ensure that you are as well as possible.
- Try to find a time that you will be able to get extra rest and sleep, particularly during late pregnancy.
- Think about how you can reduce job stresses or unsociable hours.
- Try to plan so that you will have adequate support from your partner or family members after the birth.

Medication – issues to consider

For women at risk of PP, there are often difficult decisions to make regarding medication. You will need to work with your health professionals (ideally a Specialist Perinatal Psychiatrist or specialist team) to weigh up the risks and benefits of stopping, changing or taking your regular medication during pregnancy. If possible, have this conversation before you start trying for a baby.

For all women at risk of PP, you will need to discuss your options for taking medication after the birth, either immediately as a preventative measure or if early warning signs of PP appear. There is also the option of starting medication late in pregnancy which some may favour.

You should also discuss your preferences for breastfeeding, and the impact of taking any medication on breastfeeding.

The Choice and Medication website has excellent advice on specific medications, their side-effects and whether they are safe for breastfeeding: www.choiceandmedication.org/ncmh

Taking medication during pregnancy

Many medications can be safely taken during pregnancy with a low risk to your baby. Some medications may carry a higher risk to your baby, but may be important in maintaining your own mental health during pregnancy. Balancing the risks and benefits of medication and deciding whether to continue, stop or switch medication is a difficult process and you will need support from your own doctor and ideally a Perinatal Psychiatrist or specialist team. Health professionals can advise you, but the final decisions will always rest with you and your partner and there is no 'right' or 'wrong' decision – it's important to go with what feels the most comfortable decision for you personally.

Stopping medication when trying for a baby or when you become pregnant

Many women prefer not to take medication when they are pregnant or trying to conceive as they worry about the risks of medication causing harm to their unborn baby. However, stopping medication suddenly can increase the risk of you becoming ill. For this reason, even if you find yourself pregnant unexpectedly, it is best not to stop any medication before discussing this with your own doctor, and ideally also with a Perinatal Psychiatrist.

Some medications such as Valproate (also known as Epilim or Oriect) do have a known risk of causing birth defects so your doctor may recommend stopping these medications gradually and possibly starting to take an alternative medication. It is important to discuss all changes in medication with your doctor.

Taking medication as a preventative measure

Women at risk of PP can opt to take medication (often an antipsychotic or a mood stabiliser) in the third trimester of pregnancy and/or immediately after birth to help prevent symptoms of PP developing. Some women prefer to 'watch and wait' for early warning signs before they start to take medication. Again, it's worth talking through this decision with your partner, your care team and a Perinatal Psychiatrist. You can ask to be issued with an advance prescription so that your medication is ready to take on the postnatal ward when you need it.

Medication and breastfeeding

Many women with PP decide to stop breastfeeding due to small amounts of medications passing to their baby in breast milk. However, some women do breastfeed on certain medications. You should talk through your options with a Perinatal Psychiatrist or specialist team if you are keen to breastfeed.

Congratulations – you're pregnant!



Congratulations on your pregnancy! You might be feeling both excited and anxious – it's natural, as a mum at risk of PP, to have mixed feelings when you find out you are pregnant.

Booking in with your Midwife

As soon as you know you are pregnant, you can arrange your first appointment with your Midwife, known as the 'booking in' appointment. Your Midwife should ask you three general questions about your mental health as part of this appointment. If you have a diagnosis of Bipolar Disorder, Schizophrenia or Schizoaffective Disorder it's important to tell your Midwife at this appointment and to discuss who will be supporting you with your mental health (your own Psychiatrist or a Specialist Perinatal Psychiatrist) and any medication you are taking. If you have a family history of PP or have had an episode of PP before, it's also important to tell your Midwife at this appointment.

If a Specialist Perinatal Mental Health Team or Specialist Midwife is available in your area, your Midwife can arrange to refer you. Make sure that your Midwife refers you as early as possible, as there can be long waiting lists.

If you are taking medication, the Midwife may also arrange for you to be referred to an Obstetrician to monitor you and your baby's health more closely during your pregnancy. You can discuss with your Midwife what extra support you will need during your pregnancy and who can provide this.

If no specialist service is available you may want to think about being supported by a Community Mental Health Team or a General Psychiatrist.

If you have a family history of PP and no personal history of mental health problems you are most likely to be supported by your own GP and possibly a specialist Midwife.



I decided to have a second baby when my eldest daughter was 5. I was very well supported in this pregnancy – but as my due date loomed I was definitely more nervous. Being thoughtful about my own wellness helped me to recognise 'early warning' signs and put my plan into action.

A mum with previous experience of PP





Telling friends and family

If you have had PP before, it can be particularly difficult wondering how friends and family are going to react to the news of your pregnancy. You may decide to give yourself and your partner a few weeks to let the news sink in for yourselves. In general though, remember that your family and friends will feel just like you do – a mixture of happiness and concern for your wellbeing.

Your feelings

Finding out you are pregnant can bring a mixture of joy and apprehension when you know that you are at risk of developing PP.

APP's online community "PPTalk" is a great place for asking questions and getting support from other women who have been in a similar

situation. Talk to others about: what their care plans included; their experiences with medication; and how they managed their anxieties during pregnancy. Visit: www.app-network.org/pptalk

It's important to remember that other expectant mums feel nervous at times about their pregnancy too. Give yourself permission to enjoy your pregnancy as much as you can – think about nice things you could do for yourself or your baby. Your Midwife might be able to advise you on local antenatal yoga or relaxation classes.

You may find it helpful to talk through your feelings and concerns with a health professional. Your Midwife or GP may be able to recommend a counselor, or you may be able to speak to someone from your Specialist Perinatal Mental Health Team.

Developing a care plan for pregnancy & birth

It's likely that a number of health professionals will be involved in supporting you during your pregnancy and birth. For this reason it is very useful to have a written care plan which can be kept at the front of your maternity notes so that everyone knows your preferences, and what to do if you do become unwell. Your partner and family members could also have a copy of your care plan.

Your care plan could include the following:

- Which health professionals will be involved and how/when they will be involved.
 - Midwife
 - Perinatal Psychiatrist (if available)
 - Specialist Midwife (if available)
 - Psychiatrist
 - Community Mental Health Team
 - Obstetrician
 - Health Visitor (some offer a pre-birth meeting)
 - GP
- What medications you would be willing to take during pregnancy, if necessary, and which medications you would prefer to avoid.
- Where you would ideally like to give birth, e.g. at home, Midwife-led unit or hospital.
- Your plan with regards to who will look after other children during labour and birth, if applicable.
- Your preferences for the birth, e.g. pain relief, measures to avoid a long labour.
- What arrangements you would ideally like for postnatal care, e.g. single room, the option for your partner to sleep in with you.
- Whether postnatal ward staff will assist with nights so you can sleep, or preferences such as going home as soon as possible so that others can assist with the nights.
- Details of any medication you have opted to take after the baby is born.
- Whether you will be breastfeeding or bottle feeding (which may be dependent upon medication).
- Details of early warning signs of PP. For information, see: www.app-network.org/early-symptoms
- An overview of what happened in your previous episode of PP (if applicable).
- Action to take if symptoms of PP do develop – contact numbers of your Psychiatrist, Crisis Team, Hospital Psychiatrist.
- Medications you would be willing to take if symptoms of PP develop and any medications you would prefer to avoid.
- Your preferences for hospital treatment if you do develop PP, e.g. Mother and Baby Unit if one is available locally.
- If you have older children, your preferences for who will take care of them while you are being treated and what they will be told about your illness.
- Who you would like to make decisions on your behalf should you become too unwell to make them for yourself, e.g. your partner.
- Voluntary organisations who could support you at home such as HomeStart.





Pre-birth planning meeting

Ideally you should have a pre-birth planning meeting at around 32 weeks of pregnancy. This meeting brings together you, your family and everyone involved in your care (e.g. mental health professionals, Obstetrician, Midwife, Health Visitor and GP). This is an opportunity to share and agree your care plan and ensure that everyone is clear about what to do and whom to contact if you do become unwell.

Your pregnancy and birth plan will evolve and change as you work in collaboration with your health professionals. Remember that you might need to be flexible with some aspects of your plan, but it is useful to have thought through your preferences.



I came off my lithium and had a healthy pregnancy, but this time I was ready to start taking it as soon as I had delivered my son – I felt it was better to try to stay well than risk problems again by breastfeeding. I also went home within hours of delivery, and I had first my sister, then a cousin look after the baby 24/7 for a fortnight. This meant I could relax and get a proper amount of sleep. This worked for me!

A mum with Bipolar Disorder and previous PP



Congratulations – You're a mum!



Looking after yourself after the birth

Getting as much rest as possible after your baby is born is really important. This can be tricky if you are on a busy postnatal ward and you are balancing the demands of feeding and visitors. This section looks at how you can prioritise your well-being in the very early days after birth.

Getting enough sleep

If you haven't requested a single room in your care plan, it's not too late to ask! If you find yourself on a noisy postnatal ward and are finding it difficult to get any sleep, talk to the midwifery staff on the ward and see what they can arrange. If there isn't a single room available, it is worth asking your partner to bring in some earplugs or headphones so that you can give yourself the best chance of some sleep.

In your care plan, you may have requested that the midwifery staff have your baby overnight and bring the baby to you for feeds, or feed your baby overnight. Again, if you find you are not sleeping well with your baby next to you, it's not too late to ask if the midwifery staff have any capacity to support you in this way. You can refer to the importance of sleep in your care plan if you need to.

If it is a possibility, you may want to arrange for your partner or a family member to sleep in with the baby. They could bring the baby to you for feeds, or give the feed themselves if bottle feeding.

Equally, you may find that you sleep better with your baby close to you, so give yourself the freedom to do whatever will support your sleep the best.

Feeding your baby

There can be a lot of pressure on mums to breastfeed, but if you have chosen not to or are not able to breastfeed, don't feel guilty. The most important thing is that your baby is fed and you are rested.

Establishing breastfeeding in the first few days can be very tiring and stressful. Make time for rests – your partner could take the baby for a little walk around the ward, or around the block if you are at home while you have a nap.

If you are bottle-feeding don't be afraid to ask for help from your partner, family or the midwifery staff. Your partner could take the night feed for you so you can sleep, and others can help with sterilising and making up bottles once you are home.

Visitors

Try to keep visitors to a minimum and visits short in the first few days. You can ask your partner to explain how important it is for you to get adequate sleep and rest, if you feel a bit awkward. If you need to rest, your partner could always take the baby to the family room on the ward, or into another room if you are at home, for your friends and family to have cuddles!

The first few weeks at home

Professional support

The first few weeks after childbirth are the highest risk time for PP, so you will need to ensure that your mental health is carefully monitored during this time.

You will have regular routine visits from your Community Midwife to check your baby's health and to check how you are healing after the birth. Midwives visit until your baby is 10 days old and then your Health Visitor will take over. It is worth arranging for a mental health professional, such as your Community Mental Health Worker, or someone from your Specialist Perinatal Mental Health Team to visit you regularly in the first few weeks after birth to assess your mental health in more detail.

When you come home from hospital, make sure you have a copy of your care plan and that you, your partner and any family members know who to call if you have any early warning signs or symptoms of PP. Contact numbers could include: your local Crisis Team, your own Psychiatrist or Perinatal Psychiatrist and your GP.

Things you can do

- You might find it helpful to keep a mood diary in the first few weeks after the birth to monitor any early warning signs. Visit: www.app-network.org/early-symptoms for more information about early warning signs. Examples of daily mood charts are available here: www.app-network.org/moodcharts
- You might find it helpful to have friends or family to stay to help around the house. Don't be afraid to give people jobs to do!
- You might find it helpful to arrange a schedule of visitors so that you're not overwhelmed.
- Some women employ a private Midwife, doula or a maternity nurse to support them with looking after their baby in the first few weeks.
- Take time to rest whenever possible, and enjoy plenty of cuddles with your baby.
- If you have older children it can be difficult to get the rest that you need, so do ask friends and family to help out with childcare whenever possible.
- Find out about voluntary organisations, such as HomeStart, that offer practical and emotional support to families.



If you do become unwell

- Don't feel guilty – PP is not your fault and can happen even with the most careful planning.
- Don't struggle on at home – remember that symptoms can get worse quickly so put your care plan into action.
- Contact your GP, Mental Health Team, or Crisis team as soon as possible.
- Remember that you will get better. With early, well-planned care, you are likely to recover much more quickly.
- Recovery following PP takes time, so get as much support from family and friends as you can with practical things such as cooking meals and doing laundry.
- You are not alone. Use APP's peer support forum or one-to-one peer support email service: www.app-network.org/peer-support



I guess the tough thing is that nobody can promise you won't become unwell again. However what you will have is a great team of professionals and your partner around you, the knowledge to get treatment straight away and also the reassurance that you have recovered before.

A mum with experience of two episodes of PP



Further reading

Visit our webpage for information, personal accounts, and a health professional learning module on Bipolar Disorder and pregnancy: www.app-network.org/what-is-pp/getting-help/bipolar-disorder-pregnancy

Academic journal articles written by members of the team can be obtained from the APP office.

The following leaflets are available to download at: www.app-network.org/what-is-pp/app-guides

APP Insider Guide: Recovery after Postpartum Psychosis.

APP Insider Guide: Postpartum Psychosis – A guide for Partners

APP/Bipolar-UK Leaflet: Guide to Bipolar Disorder, Pregnancy and Childbirth

Royal College of Psychiatrists Leaflet: Postpartum Psychosis – Severe Mental Illness after Childbirth

Find useful links and organisations at: www.app-network.org/useful-links

Acknowledgements

This guide was developed by women with experience of planning high risk pregnancy, health professionals and academic experts. This work was funded by The Big Lottery. Action on Postpartum Psychosis (APP) receives charitable donations from members of the public and grants for its research work. APP is hosted by the University of Birmingham and Cardiff University.

This Insider Guide has been written for Action on Postpartum Psychosis by Naomi Gilbert, Clare Dolman, Dr Jessica Heron and Prof Ian Jones. We are grateful to: Ruth Blamey, Dr Giles Berrisford, Andrea Lambert, Stewart Johnson, Regine Wilber, Heather Heron, Nicola Muckelroy, Jenny Stevenson, Ceri Rose, Sarah Spring, Natasha Kearney, Anna Jones, Michelle Bell, Hannah Bissett, Emma Odell, Sarah Dearden, Lucy Vernall, Sue Blamire, and Louise Bennett.



UNIVERSITY OF
BIRMINGHAM

NCMH
National Centre for Mental Health

Action on Postpartum Psychosis

Tel: 020 3322 9900

Email: app@app-network.org

Website: www.app-network.org

Twitter: @ActionOnPP #PPTalk

Facebook: www.facebook.com/ActionOnPP

PPTalk Online Community:

www.app-network.org/pptalk

One to One Email Support:

www.app-network.org/peer-support

Registered Charity Number: 1139925

Company number: 7466643

© Copyright 2014 • Printed March 2018



www.app-network.org