

APP

Action on Postpa



Having a baby is a major event in the life of any woman. For those with bipolar disorder (formerly called manic depression) there are even more issues to think about.

When considering having a baby, women with bipolar disorder and their families have many questions but can find it difficult to get the answers they need. In this leaflet we will attempt to address some of the questions including:

- What are the risks around pregnancy for women with bipolar disorder?
- What can I do **before pregnancy, during pregnancy, and postnatally** to reduce the chance of becoming unwell?

Each woman's experience and circumstances are unique. It is not possible to give answers that will apply to every woman – instead, we will raise some of the important issues, and emphasise the importance of discussing them with both the professionals involved in your care and the key people in your life, like your partner and family.

Despite the important issues discussed in this leaflet, we do not want to give the impression that women with bipolar disorder should avoid having children.

Many women with bipolar disorder are very glad that they have had a family and make excellent mothers.

Indeed the majority of women with the illness thinking of starting a family, when presented with all the relevant information, make the decision to try for a **baby**.

"There's a good chance now that I know and understand the condition so much better that I might stay well, and yes there is a strong chance that I could get ill, but at least if I do we'll be prepared."

Mother with bipolar disorder
considering her 2nd pregnancy



Many women with bipolar disorder make excellent mothers

Bipolar disorder and pregnancy: what are the risks?

Women with bipolar disorder may become unwell during pregnancy but are at a particularly high risk of becoming ill following childbirth. Episodes of postpartum psychosis (see below) occur after approximately 25% of births to women with bipolar disorder.

This is several hundred times higher than for women who have not had previous psychiatric illness. Postnatal depression follows a further 25% of births. Therefore, about half of women with bipolar disorder stay well after having a baby and about half may have an episode of illness.

Two groups of women with bipolar disorder are at even higher risk: those who have had a previous severe postpartum illness, and those with a mother or sister who have suffered a severe postpartum illness. For these groups the risk of suffering postpartum psychosis may be over 50% (greater than 50 in 100).

Women with bipolar disorder must therefore think very carefully about these risks. Even if you are currently well there is a real chance of becoming ill again shortly after the baby is born.

What are postnatal depression and postpartum psychosis?

Both high (manic) and low (depressive) episodes occur around childbirth in women with bipolar disorder, and can be severe. Mood symptoms like elation, irritability and depression are common. Psychotic symptoms such as delusions and hallucinations can also occur.

When such symptoms are severe, it may be called an episode of 'postpartum psychosis' or 'puerperal psychosis'. Other mood episodes at this time may be labelled as 'postnatal depression' or 'postpartum depression'. Women experiencing postpartum psychosis or severe postpartum depression usually require admission to hospital, but often do very well with treatment.

Although postpartum psychosis is thought to be the more severe illness, some episodes of postnatal depression can also be very severe - particularly in women with bipolar disorder.

In women with bipolar disorder it is often difficult to say whether an episode is postnatal depression or postpartum psychosis. All postpartum episodes in women with bipolar disorder must be taken seriously.

There are many different ways a postpartum episode can start. Women often have symptoms of depression or mania or a mixture of these. Symptoms can change very quickly from hour to hour and from one day to the next.

Most commonly postpartum psychosis begins in the first few weeks after birth. Often, symptoms begin in the first few days after having a baby. Less commonly, the illness starts later – several weeks after the baby is born. Postnatal depression may start up to 6 months following the birth.

Symptoms

- Feeling 'high', 'manic' or 'on top of the world'.
- Feeling low in mood, tearful and unable to enjoy anything.
- Feeling irritable or anxious.
- Feeling confused or as if you're in a dream world.
- Finding it hard to sleep, or not wanting to sleep.
- Feeling paranoid, suspicious or fearful.
- Seeing, hearing or feeling things that aren't really there (hallucinations).
- Experiencing odd thoughts or beliefs that are unlikely to be true (delusions).

You may not be able to look after yourself as well as you would when you are well, and your symptoms may make it very difficult for you to look after your baby. If you have a postpartum episode you may not realise you are ill. Your partner, family or friends may recognise that something is wrong and need to ask for help - make sure they have the phone numbers for your mental health team or crisis service to hand.

What makes some women become ill at this time?

Research has learned a lot about the causes of bipolar disorder. We know that it can run in families, and that there are lots of factors that can trigger episodes. But while we know that women with bipolar disorder are particularly vulnerable to becoming ill following childbirth, we don't fully understand what it is about childbirth that triggers the illness. It may be related to hormones, sleep disturbance or simply the fact that the arrival of a new baby is a major life event.

By doing further research, we can learn more and use this knowledge to help with prevention and treatment. This is why it is helpful for pregnant women with bipolar disorder to get involved with research. There are details on some research projects looking for volunteers later in this leaflet.



If possible, discuss pregnancy with your psychiatric team and GP before trying for a baby

What can I do to lower the risk of becoming unwell?

Planning a pregnancy

Ideally, it is best to discuss your thoughts about getting pregnant with your GP and psychiatric team before trying for a baby. Some psychiatrists and other mental health professionals have a special interest in pregnancy and childbirth (sometimes called Perinatal Psychiatry). In the UK there are a number of excellent Perinatal Mental Health teams but unfortunately many areas of the country are not covered.

Ask if you can be referred to a Perinatal Mental Health team – they would usually prefer to see you as early as possible, ideally before you become pregnant, and not just if you become ill.

Many Perinatal Mental Health teams are attached to “Mother and Baby” units (MBUs), which can admit unwell mothers with their baby.

If there is no local service, it may be possible to see a perinatal psychiatrist further away or there may be a specialist Mood Disorder Service in your region.

Even if these options are not available, all women with bipolar disorder should ideally see a psychiatrist for advice if they are planning a pregnancy, even if they are not currently under the care of psychiatric services.

You will be able to discuss:

- How to make sure you are as well as possible when starting pregnancy.
- Your risk of developing postpartum psychosis or postnatal depression.
- 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.
- The type of care you can expect in your local area. For example, how professionals will work together with you and your family. Also whether there is a perinatal mental health service, a specialist midwife or a mother and baby unit near you.

"We knew that we would want to have children at some point, so we very early on investigated what it would mean to my diagnosis and being on Lithium, how it would affect pregnancy."

Woman who discussed her medication options with her psychiatrist in advance of becoming pregnant

During pregnancy

In reality, many pregnancies are not planned. In this situation, let people know as soon as possible, and **do not stop taking your medication suddenly before getting advice.**

It is important to let all those involved with your pregnancy know that you have bipolar disorder, and that there is a risk of becoming unwell again following delivery.

Your midwife, your GP, your health visitor and your obstetrician should all be made aware of your illness, and your mental health team need to be told about your pregnancy. You may want to show them this leaflet.

Addressing other issues known to increase the risk of becoming ill may be important. This could include trying to reduce other stressful things going on in your life and paying attention to your sleep in late pregnancy and after the baby is born.

It is also helpful to think about your “early warning signs” of becoming unwell so that you, and those close to you, can watch out for them.

Some women, for example, start to get up very early in the morning, stop eating properly or become much more argumentative than usual.



Sleep loss can be a warning sign of an episode

“We had lots of open talks about it and he’s watching out for any signs of me changing behaviour.”

Mother describing how her husband had prepared for any changes in her mood after birth of their baby

What medications are safe to take if I am pregnant?

Most women would prefer not to take medication when pregnant and the decision about taking any particular medication is always difficult. For some medications used to treat mood disorders the risks are thought to be low. For others the risks are higher, but in some circumstances it still may be appropriate that medication is taken. In these circumstances the benefits of taking medication may outweigh the risks.

The balance of risks and benefits will vary between medications and will be different for each woman. Any risk from taking medication must be weighed against the risks for you and your baby of becoming ill. It is also important to realise that unfortunately 2 or 3 in every 100 babies are born with an abnormality, even when the mother has not taken any medication.



In some cases the benefits of taking medication while pregnant outweigh the risks

For women who are not taking medication or who have stopped taking medication because of the pregnancy, there is the option of starting medication in late pregnancy or after the baby is born to reduce the risk of becoming ill. Many women who have responded very well to a mood stabilising medication previously may decide to resume taking it to reduce their chances of a postpartum episode.

It is important to discuss these options with your doctor - ideally before you become pregnant - but the ultimate decision to continue, stop or change your medication will rest with you and your partner.

What care should I receive during pregnancy?

If you have bipolar disorder you should have specialist care in pregnancy. If there is a perinatal mental health team in your area you should be referred when you find out you are pregnant (or when you are thinking about getting pregnant).

Otherwise you should be seen by a general mental health team.

Ideally everyone involved in your care will be aware of the bipolar disorder, and know about your risk of a postpartum episode.

A written care plan should include early warning symptoms and a plan for the pregnancy and the postpartum period. It is good if you are given a copy of the plan, and there should be details of how you and your family can get help quickly if you do become unwell.

Care on the maternity unit

Your maternity care in labour will depend on what you and your baby need. The midwives will support you with feeding and caring for your baby. If you have any symptoms of mental illness a psychiatrist will see you when you are in hospital. The care you have will depend on how unwell you are.

You may see a psychiatrist or mental health nurse before you leave hospital even if you are well.

They can check the plan made at your pre-birth planning meeting and make sure you have any medication you need.

"So we worked on the plan with the perinatal psychiatrist looking at the different possibilities and that was all written up and circulated to the midwives and to the GP and to the postnatal ward."

Mother who stayed well after the birth of her daughter



The maternity care you receive will depend on what you and your baby need

Care when you go home from hospital with your baby

The first few weeks after your baby is born are a high-risk time for becoming unwell, and being deprived of sleep may be a trigger for some women. Getting enough sleep with a new baby is obviously difficult, but it may be possible to get your partner or family to help with some of the night-time feeds.

Your mental health should be closely monitored. Your midwife, health visitor and mental health nurse should visit you regularly in the first few weeks after your baby is born. If you become unwell this can be picked up quickly so you get treatment early.

You and your family should have emergency contact numbers for local crisis services. You can use these, see your GP or go to A&E if you, or your partner or family, think you are becoming unwell. If you think you are becoming unwell don't wait. It is better to be seen quickly as symptoms can worsen rapidly.

If you need admission to hospital, this may be to a Mother and Baby Unit (MBU) where you can be admitted with your baby, or a general adult psychiatry ward.

"I think being on the Mother and Baby unit was good for me and good for my daughter... we weren't separated."

Mother with experience of being on an MBU

If there is not an MBU near you it is possible that you can be admitted to a unit some distance away. This may involve some travelling for your family, but getting the specialist treatment you need is important.

What about breastfeeding?

Most women with a postpartum episode of bipolar disorder need treatment with medication. It is possible to breastfeed whilst taking some medications. Your psychiatrist can discuss the risks and benefits of medications in breastfeeding with you.

It is possible that you won't be able to breastfeed. There are several reasons for this:

- You may be too unwell.
- You may be admitted to hospital without your baby.
- You may need a medication which is not safe in breastfeeding.

Some women feel guilty about being unable to breastfeed, but you should not feel this way. If you have a postpartum episode it is not your fault. It is important for your baby that you have the treatment you need so that you get better.

Will I be referred to Social Services?

Some women will be referred to Children and Families Social Services. You may be referred in pregnancy because of your high risk of a severe postpartum episode. You may also be referred if you develop a postpartum episode.

Sometimes women worry that this means that people think they cannot care for their baby. This is not usually the case. The reason for assessment is to check the support you have from family, friends and professionals.

It is also to make sure there is a safe plan for your baby if you are too unwell to care for him or her. If referral is needed, this should be discussed with you (unless you are too unwell).

Some women and their partners worry that if they seek help for symptoms of mental illness, people may think they can't care for their baby. On the contrary, seeking help and having treatment means you are doing the best for your baby. This will be seen as a positive thing.

You may need extra help from family members. If you have no support from family or friends Social Services may be able to help.

Social workers can find a temporary carer for your baby if you need to come into hospital and there is no MBU bed.

Although it might take a while, most women recover fully and become good mothers. It is very rare for babies to be removed from women with bipolar disorder.



Only 10% of children who have a parent with bipolar disorder develop the condition

If I have bipolar disorder will my children get it too?

Many illnesses run in families. This is true for diabetes, heart disease and asthma, but also for psychiatric conditions such as bipolar disorder.

There is good evidence that both genes and a person's experiences are important in making some people vulnerable to becoming ill. A large number of genes are likely to be involved – each perhaps only affecting vulnerability by a small amount.

Although the children of people with bipolar disorder may be at a higher risk of becoming ill than people in general, it is important to remember that they are more likely to remain well.

Only around 10% of children who have a parent with bipolar disorder develop the condition, so 90% do not experience this illness (although other mood disorders, like depression, are also more common).

"We thought if our children were to inherit bipolar disorder, that at least we'd be in a good place to actually help deal with it"

Parents discussing the possibility of their children having bipolar

More information and support

Action on Postpartum Psychosis (APP)

This is a charity run by a group of women who have suffered with the illness, clinicians and academic researchers. Their website provides support and information for other women in a similar position and their partners. It includes a forum where women who have experienced the illness answer each other's questions and provide support.

APP are also keen to hear from women with bipolar disorder who are pregnant or considering pregnancy, so they can keep them informed of research projects which might interest them.

You can join for free and receive occasional emails about the latest news and research. The APP website also contains advice on recovery, personal stories and details of a Peer Support Network using trained volunteers who have recovered from postpartum psychosis themselves.

app-network.org

Bipolar UK

This is the national charity for people affected by bipolar disorder including families, carers and loved ones. They provide a range of services across England and Wales including self help groups, and regularly run workshops on the issues facing women who have bipolar disorder and want to start a family.

There is also a thread on the charity's web-based forum, the eCommunity - **bipolaruk.org/e-community** - where these issues are discussed and women can support each other.

bipolaruk.org

Help with our bipolar disorder research

The National Centre for Mental Health (NCMH) is working to better understand bipolar disorder. The aim of our research is to improve diagnosis, treatment and support for the future.

But to do this we need **your** help.

Helping with our research is easy, and all information we collect is stored confidentially. Taking part involves:

- an informal interview with one of our trained researchers, either at your home or in a local clinic
- providing a small blood or saliva sample
- completing and returning some questionnaires

For more information about our research and how you can help, visit our website (www.ncmh.info) or contact us:



info@ncmh.info



/walesmentalhealth



029 2068 8401



@ncmh_wales

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