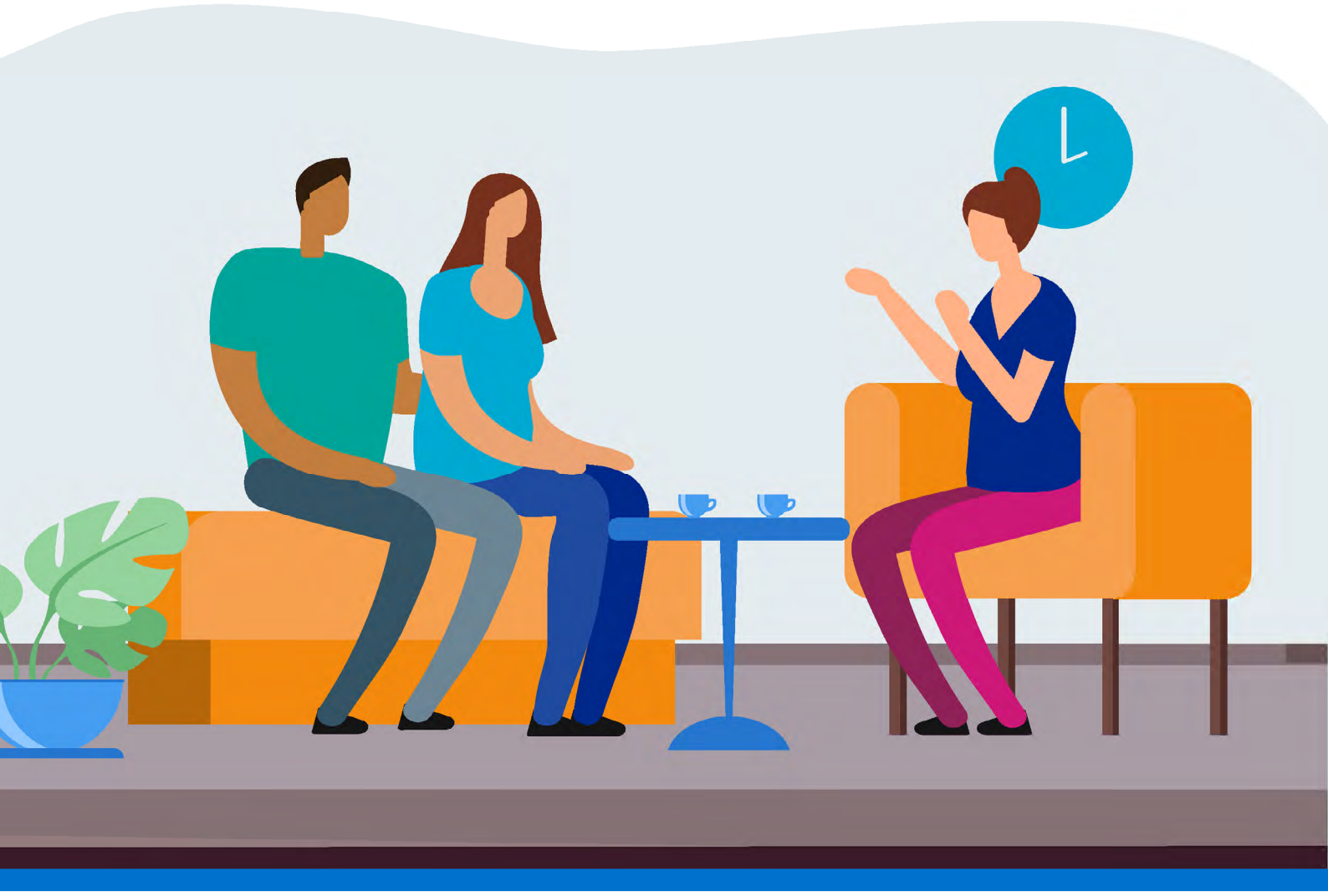
Delivering preconception care to women of childbearing age with serious mental illness



A guide for healthcare professionals involved in the care of women with serious mental illness (SMI) in primary and secondary care, including: general adult psychiatrists, mental health nurses, care coordinators, GPs, health visitors, physician's associates, non-medical prescribers, healthcare staff in obstetric care who work with women with serious mental illness and perinatal psychiatrists

NHS
Public Health England
King's College London
Tommy's

Accessibility

This guide can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages upon request. Please contact england.perinatalmh@nhs.net to request such formats.

Equality and health inequalities statement

Promoting equality and addressing health inequalities are at the heart of NHS England and Improvement's values. Throughout the development of this guide, we have:

- given regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it
- given regard to the need to reduce inequalities between patients in access to, and outcomes from, healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

Information governance statement

Organisations need to be mindful of the need to comply with:

- the Data Protection Act 2018
- the EU General Data Protection Regulation (GDPR), the Common Law Duty of Confidence
- Human Rights Act 1998 (particularly Article 8 – right to family life and privacy)

This resource has been authored by Professor Louise Howard, Abigail Easter and Katie H Atmore at the Section of Women's Mental Health, Institute of Psychiatry, Psychology and Neuroscience, King's College London, De Crespigny Park, London SE5 8AF

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Contents

Introduction

Preconception health impacts on pregnancy and birth outcomes, maternal mental and physical health and longer-term developmental health and social outcomes for mothers, children and families. (WHO 2013)

The World Health Organisation defines preconception care as "*the provision of biomedical, behavioural and social health interventions to women and couples before conception occurs aimed at improving the health status and reducing behaviours and individual and environmental factors that could contribute to poor maternal and child health outcomes*".

This guide provides the latest evidence to support health care professionals having informed conversations on the considerations regarding mental and physical health for women of childbearing age with serious mental illness (SMI), **whether or not they are planning a pregnancy**. It should be used along national clinical guidance and associated updates.

In this context 'SMI' covers a range of needs and diagnoses, including but not limited to; psychosis, bipolar disorder, 'personality disorder' diagnosis, eating disorders, severe depression and mental health rehabilitation needs, some of which may co-exist with other conditions, such as frailty, cognitive impairment, neurodevelopmental conditions or substance use.

SMI is associated with a higher prevalence of unplanned pregnancy than the general population, and extra risks for mother, fetal development and long term child health. This means the principle of **making every clinical contact count** is exceptionally important for women with SMI of childbearing age. Health professionals should not wait until women with SMI raise the topic of conception. Embedding high quality preconception care into existing conversations will mean that if pregnancy occurs, women and babies will have the best chance of being healthy.

Women with SMI who are actively planning a pregnancy will require more detailed preconception care and where possible should be referred to specialist perinatal mental health services.

NOTE: it is important to ensure that interpreters and BSL communications are available for patients and partners where needed during conversations.

Who is this guide for?

This guide is for all healthcare professionals involved in the care of all women who are of childbearing age with serious mental illness (SMI) in primary and secondary care, including general adult psychiatrists, mental health nurses, care coordinators, GPs, health visitors, physician's associates, non-medical prescribers, healthcare staff in obstetric care who work with women with serious mental illness.

More resources

For more extensive information and resources on the topic of specialist preconception care, the London Perinatal Mental Health Clinical Network has developed a resource ***Preconception advice, a best practice toolkit for perinatal mental health services.***

The ***Having a family: my plan*** resource at the end of this document to support informed preconception discussions with women is supported by the evidence base in this guide.

The ‘think family’ approach

All women have the human right to have a family at a time that is best for them. (Freedman LP et al 1993, UN Assembly 1948). Women with a SMI may become a parent at some point in their lives (even if it seems unlikely for a particular woman at a certain point in time); therapeutic optimism includes never saying never to family life. Women report that being told not to become pregnant ever is very distressing (Dolman C et al 2016).

Mental health professionals therefore need to: respect a woman’s right to have a child; provide information to women about how pregnancy and childbirth could affect them; and develop care plans that include sexual and reproductive health, and plans regarding motherhood, which may be perceived as central to their lives.

A ‘think family’ approach to potential unplanned pregnancies

As unplanned pregnancy, and modifiable risk factors for poor pregnancy outcomes such as smoking and domestic abuse are common among women with SMI (Matevosyan NR 2009, Firth et al 2019).), a long-term holistic approach to preconception care, especially targeting modifiable risk factors, is essential.

> **“We just didn’t feel at all supported. We felt that we were made to feel that we were being irresponsible in thinking about it [having a child] and that it would all end badly.”**
>
> Mother reporting conversations with her psychiatrist and CPN about having a baby

A “think family” approach helps engagement and is an essential component of care planning. As sex and relationships are an important part of life, it can be helpful to involve supportive partners, family members or other significant sources of support where possible.

A preconception review is beneficial even if the woman reports that she is not planning for a baby at the moment. It involves providing a safe environment to explore fears and expectations, as well as empowering a woman to make an informed decision about pregnancy and parenthood.

The review should include:

- information/psycho-education about the risk of postpartum psychosis (especially

for women with bipolar disorder as they are at particularly high risk of postpartum psychosis)
- contraception advice
- support with modifiable risk factors (see page 7)
- and referral for more specialist medication advice provided by a specialist perinatal mental health team if needed.

Views of any partner should be sought and explored, especially any concerns they may have for the mental health of the woman if she were to become pregnant, and for their own mental health.

Advice may include delaying pregnancy where appropriate to optimise physical and mental health before pregnancy and parenting.

"I encourage the partner to come [to appointments] too because I find sometimes the partners have not been around before when the woman's been ill and they may have unrealistic expectations, or no knowledge at all and the woman is doing this by herself, so I really like both to buy in to whatever we're talking about'.

Perinatal psychiatrist

Questions and statements to start a conversation

1. Can you tell me about your family?
2. Have you talked with your partner about having (more) children?
3. There is lots of help and support for women in pregnancy as well as before and after pregnancy.
4. Planning and readiness for pregnancy is about your physical and mental health. Even if you are not thinking about pregnancy now, this healthcheck is important for you.

Extract from *Having a Family: my plan* a full printable resource available at the end of this document

Be aware of potential domestic abuse

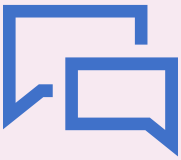
Having intimate and family relationships is a human right. However not all relationships are supportive. Do not assume a relationship is supportive (Oram et al 2017). Sex might not always be planned or may be transactional or non-consensual. All service users need to be asked specifically about domestic and sexual abuse. Remember that ex-partners may continue being abusive.

Validate any experience of rape or other forms of abuse by showing that you believe the disclosure and can offer support, including referral to a local Sexual Assault Referral Centre.

Note that the risk of domestic abuse may increase if the woman becomes pregnant.

More resources

LARA-VP A resource to help mental health professionals to identify and respond to domestic violence and abuse: This is an evidence based resource on how to ask and respond to domestic abuse safely.



Questions to detect domestic abuse

1. How is your relationship with your partner and ex-partner(s)?
2. What happens when you disagree? What is the worst that has happened? How did this affect you?
3. Are you afraid of anyone close to you?
4. Have you ever been hit? Slapped? Physically abused in any other way?
5. Have you ever been forced to have sex when you didn't want to?
6. Have you been insulted, called names or been sworn at?
7. Have your emails or texts been monitored?

Embedding healthy preconception conversations

As unplanned pregnancies are more common and can be more challenging for women with SMI of childbearing age, it is important to embed preconception care topics (eg family planning; modifiable risk factors such as smoking) whether or not they are planning a pregnancy.

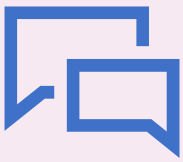
How to have regular 'healthy conversations'

Changing health behaviours can be challenging, but starting the conversation is important. Having regular "healthy conversations" within routine appointments can help empower women to modify unhealthy behaviours.

A healthy conversation can take place opportunistically or at annual reviews and involves encouraging individuals to consider their lifestyle and health and identifying small but important changes) (PHE & RSPH 2015, Barket et al 2018).

These 5 principles of healthy conversations can help:

- Identify and create opportunities to hold healthy conversations
- Use open-ended ('open discovery') questions to support women to explore issues, barriers and priorities
- Reflect on your practice and conversations
- Spend more time listening than giving information or making suggestions
- Support individually derived goals through SMARTER planning (**S**pecific, **M**easurable, **A**ction-orientated, **R**ealistic, **T**imed, **E**valuated and **R**eviewed)



Examples of 'healthy conversation' questions

1. We are talking to everyone about weight and diet at the moment; would you mind if we have a chat about that today?
2. Are there any aspects of your physical health that are concerning you that you would like to talk about today?

Family planning

Women need support to ensure safe, healthy sexual relationships as part of their care. Women may decide that they want to have a child but this may not be the right time to do it. Family planning and contraception information is therefore an essential part of the conversation.

Family planning services

If you do not know where local family planning services are, find out at **www.fpa.org.uk** so you can make an appointment and, where possible, accompany vulnerable women needing support.

Ideas for starting a family planning conversation

1. How would you feel if you were to become pregnant?
2. If you don't want to get pregnant are you using contraception? What is it?
3. Using a contraceptive such as the new long acting contraceptives can remove the worry about getting pregnant.
4. There is a range of contraceptive methods available – would you like me to help you access them?

Physical health

Public Health England states: *'As highlighted by the NHS England Five Year Forward View 7, health services can help improve the physical health of people with SMI by bringing together mental and physical healthcare. Mental and physical health conditions are often connected.'*

A review of SMI and physical health, including resources healthcare providers can use to improve physical health care can be found here: https://www.gov.uk/government/publications/severe-mental-illness-smi-physical-health-inequalities/severe-mental-illness-and-physical-health-inequalities-briefing

Physical comorbidities are common among women with SMI and holistic discussions about their physical health needs can help women improve or better manage their physical health before pregnancy occurs (Catalao R et al 2019). This can involve targeting known modifiable risk factors that are more common in those with mental illness, such as obesity, smoking and alcohol use (Firth et al 2019).

Weight management

Obesity

The risk of weight gain and obesity is higher among those with SMI and can be exacerbated by some psychotropic

Ideas for starting a physical health conversation

1. It is important for you and your baby that your physical health is as good as possible.
2. What support do you need to improve your physical health?
3. Are there any aspects of your physical health you are concerned about?

medications. A healthy weight (BMI 18.5-24.9kg/M2) before pregnancy reduces the risk of pregnancy complications. Women with a high BMI should be supported to help lose 5-10% of their weight. This would have significant health benefits and increase their chance of a healthy pregnancy.

Reaching a healthy weight takes time to achieve and should be discussed early regardless of pregnancy intention (Stephenson et al 2018). Applying the principles of 'healthy conversations' and goal setting can help empower women to reduce their weight in a realistic and time-bound way, while avoiding feelings of 'weight stigma'.

Eating disorders

Conversations about weight and diet can be challenging for women with a history of an eating disorder. Being weighed can be particularly distressing for some. Warning messages about the impact of eating disorders on fertility may also have unintended consequences and increase disordered eating practices in this group. Discussions about physical health should therefore consider the specific needs of these women and be co-ordinated with specialist eating disorder services where appropriate.

Nutrition

Folic acid: Folic acid 400 micrograms daily should be taken by women at normal risk for a neural tube defect (NTD). Women at high risk of an NTD (ie obese, diabetic, sickle cell anaemia, thalassemia, family or personal history of an NTD, or anti-epileptic medication) should take folic acid 5 milligrams daily 2 months prior to pregnancy until 12 weeks after conception (De-Regil LM et al 2015).

Ideas for starting a conversation about eating or weight

1. How would you describe your eating in a typical day?
2. Do you or anyone else have any concerns about your eating or weight?

Vitamin A should not be taken during pregnancy as high levels may cause birth defects and women should be able to get enough vitamin A from their diet.

Vitamin D deficiency is associated with pregnancy complications and is disproportionately found in black and minority ethnic groups, overweight women, and those with chronic illness. Vitamin D supplements in pregnancy may reduce risks of low birth weight, serious bleeding, preeclampsia, and gestational diabetes. (Palacios C et al 2019, Mumford SL et al 2018) Vitamin D levels should be checked and supplemented if needed. (This should be routinely checked during pregnancy.)

Alcohol/substance misuse

Alcohol exposure during pregnancy is associated with Fetal Alcohol Syndrome Disorders (brain damage and growth problems) (Popova S et al 2017). There is no amount of alcohol that is known to be safe during pregnancy, but higher levels of alcohol exposure are more likely to lead to fetal alcohol spectrum disorders. It is important to minimise alcohol use in the preconception period, as well as pregnancy, refer to specialist substance misuse services where needed.

Calories from alcohol are 'empty calories' and have no nutritional value. Alcohol intake can therefore increase weight gain and obesity, and impact on pregnancy. Alcohol and drugs may be used by women as a way of coping with their mental health.

More resources

There is also useful advice on nutrition here: http://www.eatingdisordersandpregnancy.co.uk/nutrition-leaflets-women/

If women are dependent on drugs and alcohol extra support will be needed to find healthier ways of coping as they reduce their intake. Other substances of abuse (eg cannabis, cocaine, heroin, amphetamines) are also associated with adverse pregnancy outcomes and should be stopped in the preconception period to reduce the risk (Gov.uk 2017, NICE 2011).

There is clear evidence that psychotropic medication in pregnancy is safer than alcohol or illicit substances.

Smoking

Stopping smoking could potentially reduce the risk of infant death by 5% and low birth weight by 10% (Floyd RL et al 2008). For women with schizophrenia, smoking is the variable that explains most of their elevated risk for prematurity and small for gestational age babies (Vigod SN et al 2019).

Screening and brief intervention by healthcare workers can have an impact on smoking behaviour. Referral to local smoking cessation services and providing women with information on the harm of smoking and effectiveness of smoking cessation services can improve birth weight and prematurity risk.

Discussing fertility, sexual health and pregnancy

In addition to the conversations above for everyone, there is specific information that needs to be given when a woman of childbearing age with SMI tells you she is considering having a child.

Risk of relapse and pregnancy timing

Pregnancy ideally needs to be at a time of wellbeing and no recent relapse; pregnancy and postpartum relapses are more likely if there has been a significant episode of illness, eg one that resulted in admission, in the last 2 years (Taylor CL et al 2018).

Maternal age

Increasing age is associated with an increased risk of miscarriage, chromosomal abnormalities and obstetric complications.

Spacing of pregnancy

There is evidence to suggest a pregnancy interval of 18-59 months is safer in terms of pregnancy outcomes and the risk of schizophrenia may be elevated in children conceived following a pregnancy interval of less than 6 months due to folate or other micro-nutrient deficiencies, (though in addition, if women are mentally unwell after a pregnancy they should be advised to wait 2 years before conception if possible (NICE 2018).

More resources

Preconception advice and management: https://cks.nice.org.uk/preconception-advice-and-management

Preconception care after the delivery of a baby (sometimes called interconception care) is also increasingly seen as an important time for preconception interventions as mothers are likely to have more than one child; this should take place early, for example before discharge from an MBU/CRT postpartum care.

Fertility

Of 100 couples having regular intercourse without contraception, more than 80 will conceive within 1 year.

Some psychotropic medications (eg risperidone) reduce fertility (largely due to increases in prolactin), so women need information about the impact of treatment on fertility (as well as in pregnancy and breastfeeding).

Women previously using progestogen-only injections for contraception may have a delay in normal fertility (for up to 1 year).

Sexual health

Sexually transmitted infections are associated with a higher risk of adverse

Ideas for starting a sexual health conversation

1. Have you thought about a sexual health check-up for you/your partner?
2. Sexually transmitted infections may not have any symptoms, so it is worth having regular check-ups.
3. Would you like support with this?

pregnancy outcomes and can be symptomless. Women may need support to attend local clinics.

Tetanus and rubella

Preconception vaccination against tetanus reduces neonatal deaths. Check rubella vaccination status, as rubella can cause a range of fetal abnormalities.

Medication

As pregnancies may be unplanned, women of childbearing age need to be prescribed medication that could be continued in pregnancy (McAllister-Williams et al 2017). Annual reviews are an ideal opportunity to review medication during which pregnancy can be discussed.

However even when women start to plan pregnancies, they describe difficulties in accessing holistic individualised advice. For example, women with bipolar disorder have described seeking advice regarding psychotropic medication when planning pregnancy as "*banging my head against a brick wall*" (Dolman et al 2009).

> **"I'm very fearful about reducing or coming off my [medication] …I'm fearful at the possibility that I would suffer with postpartum psychosis ... God actually I can barely even think about that."**
>
> Woman with history of psychosis

Be open to advising on medication that can be used in pregnancy and after birth and be aware of up to date evidence base. Where medication risks and benefits are complex, referral to specialist perinatal services is advised.

NICE Antenatal and Postnatal Mental Health CG192 Quality Standards of relevance for preconception care include:

- **QS1**: states that valproate must not be used in women and girls of childbearing potential (including young girls who are likely to need treatment into their childbearing years), unless other options are unsuitable and the pregnancy prevention programme is in place.
- This is also the position stated in **Medicines and Healthcare products Regulatory Agency** (MHRA) guidance on usage of valproate medicines (Gov.uk 2018) : **https://www.gov.uk/guidance/valproate-use-by-women-and-girls**
- **QS2**: Women of childbearing potential with a serious mental health problem are given information at their annual review about how their mental health problem and its treatment might affect them or their baby if they become pregnant (Howard et al 2014, NICE 2018).

More resources

- Information on prescribing before/during pregnancy and breastfeeding are available in the Maudsley Prescribing Guidelines (Taylor DM et al 2018). This can also be discussed with your local perinatal psychiatrist. As the evidence base changes rapidly, details are not given here.
- BUMPS - best use of medicines in pregnancy **http://www.uktis.org/html/info_patients.html**
- A position statement from the Royal College of Psychiatrists (RCPSYCH) provides alternative treatments to valproate **https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/position-statements/ps04_18.pdf**

Discussing risks and benefits of medication

Discussing benefits and risks of taking medication for a future pregnancy is important. This includes prophylaxis for the increased risk of relapse postpartum (particularly for those with bipolar disorder but also for other psychoses).

Be aware that discontinuation of medication just before or during pregnancy can lead to relapse (and therefore potentially larger doses of medication to treat an acute illness with more fetal exposure (Taylor CL et al 2018)).

Around 40% of women with bipolar disorder or non-affective psychosis (Taylor DM et al 2018) and around 60% of women taking antidepressants stop their medication in the first trimester (Benard-Laribiere et al 2018). It is striking that although the same medications are used in pregnancy for both bipolar disorder and epilepsy - both life-threatening conditions - discontinuation is much more likely in women with bipolar disorder. Staying well is equally important for all pregnant women with SMI.

An increase in the risk of relapse could adversely impact on the pregnancy (increased risk of prematurity, stillbirth and neonatal death) and has been associated with maternal morbidity, suicide and parenting difficulties (Howard LM et al 2014, Jones I et al 2014, Stein A et al 2014). Suicide is one of the main causes of maternal deaths in the UK and is associated with lack of active treatment, active intervention and engagement for SMI (Khalifeh H et al 2016).

"I think it's very important ... to help women think about how they might weigh up the risks and benefits in their own individual case and very much individualise it looking at their own history of illness and the medications that they've been on: what they have and haven't found helpful - think about risk of relapse."

Perinatal psychiatrist

Avoid using the words “high-risk” when discussing the risk of relapse and risks of medication. Women find this terminology unhelpful and anxiety-provoking (which itself could be a risk factor for relapse). Remember that observational studies identifying increased risk cannot address residual confounding (ie other factors that cause the adverse pregnancy outcome). Give absolute risks wherever possible – eg around 3 in 100 pregnancies in the general population have a congenital malformation.

Include a discussion about risks and benefits of breastfeeding while taking medication. Preconception medication needs to be appropriate for pregnancy, breastfeeding and parenting (eg it should not be too sedating). Where appropriate seek specialist advice and/or refer for preconception counselling available from your local specialist perinatal mental health service.

“The doctors were good, they were looking at it quite realistically and it wasn’t wrapped up in cotton wool, it was straightforward ...these are your options, we can change your medicine but on the other hand it might not be a good idea; how it will affect the baby in the first trimester...it was pretty matter of fact… and it was really good to have that advice”

Woman with history of psychosis

“I am usually very clear that [the choice of treatment] is the woman’s decision and I am there to help provide information and think through the issues.”

Perinatal psychiatrist

As mentioned on page 12, valproate should not be prescribed to women of childbearing age other than in exceptional circumstances.

Women with bipolar disorder also need to be informed about the increased risk of relapse in the weeks after childbirth.

Postpartum psychosis is particularly serious and rapid in onset and perinatal care plans need to include close monitoring by

the woman herself, her family, maternity and health visiting staff and mental health professionals.

Making advance decisions and care plans

Many women may benefit from writing an advance statement or directive detailing care preferences and the involvement of their loved ones, particularly in the care of the baby. Such statements can be agreed with their clinician and signed by all parties to provide guidance if there is loss of capacity.

For women planning a pregnancy, advance decision documentation could include medication preferences once women have been counselled regarding benefits and risks (Einarson AP et al 2001).

Discuss with the woman whether she has considered documenting advance decisions, in the event of relapse and loss of capacity, (see for an example the short video on Bipolar UK website https://www.bipolaruk.org/Pages/FAQs/Category/women-and-bipolar.

In addition, a relapse prevention plan can be drawn up to reassure women that support will be available during pregnancy and after birth. Perinatal psychiatrists can help with this as part of a preconception counselling appointment. CBT can be helpful for relapse prevention for women with affective disorders.

"We now have a plan …which is incredibly clear and I've been able to give that to the midwife, the GP and a copy's gone to the CMHT …so now I feel like everybody's singing from the same hymn sheet."

Expectant mother with bipolar disorder

"I would talk to people about what happens if they are ill and I make a very detailed plan about that. What do they want to happen and who will look after their other children? So they can have as much involvement in a plan, if they do become unwell, as possible and make as many decisions while they are in a good position."

Specialist Perinatal Community Psychiatric Nurse (CPN)

Additionally, contingency planning can be done to agree what will happen if relapse does unfortunately happen. This can include actions that the woman and her network will take in the event of a crisis, as well as potential responses from services.

Safeguarding children

Women with serious mental illness, like other women in the general population, often experience motherhood as central to their lives (Dolman et al 2013). There is good evidence demonstrating that most women with SMI can parent very successfully. However, if the patient has had experience of childhood maltreatment, or if their illness has led to sustained functional impairments, help with parenting may often be necessary.

Women with mental illness can be very fearful of social services as they can assume that disclosure of difficulties and stigma will lead to loss of custody. As social care may be involved in families where

"I was terrified of seeking help. I thought if I revealed how I felt she would have been taken into care."

New mum on mental health charity e-forum

Ideas for starting a conversation about parenting

1. Being a parent can be stressful. How are you feeling about being a mum?
2. We want the family to stay happy, which means getting the best support possible. If you are referred to social care, it is because people want to support your family so you can parent in the best way.

there is a parental mental illness, mental health professionals need to support women so that they can engage well with services and optimise their parenting and the safety of their children as a result. Explore what the woman thinks parenting is and assess how much this matches the reality of parenting.

A referral to Children's Social Care needs to be made where children are at risk of being harmed emotionally or physically, unintentionally, or otherwise. This process involves a social worker discussing the needs of the child and reasons for the referral with parents, family and social network and key mental health professionals where further help is indicated an assessment will be made which involves a home visit and observing / speaking to the child.

A Children Social Care assessment explores whether parents can prioritise the needs of the baby above their own, the heavy physical and mental demands of parenting (eg sleepless nights, developmental needs of the baby), and the need for social support eg from partner to share this level of responsibility if at all possible. Children Social Care will always consider if an Early Help service would be more appropriate for the family.

"I think that's very important, to say that you think they need to be referred, explain why and be clear that referral doesn't mean I think you shouldn't have care of a baby."

Social Care Practitioner

Read more

MindEd. *Being referred to children's social care:*
https://mindedforfamilies.org.uk/Content/childrens_social_care_referral/course/assets/e56ed6b1a6fa5ea49904c6c95024f48b5f598162.pdf

Reflective practice

As practitioners working with people, some of whom will have mental illness, it is important to be constantly aware of our own biases. We need to be able to be reflective on the judgements we hold and understand the impact that our experiences and thinking can have on our discussions with clients. This is relevant when discussing preconception care with our clients. It is vital that women who are accessing services are encouraged and supported to think about their preconception needs.

As practitioners we must be honest about the impact SMI can have on pregnancy and parenting; the language and assumptions we have about women with SMI can get in the way of these conversations, which can then increase risk and reduce the chance of early help and support.

"I've met quite a few people who think that just because they have a diagnosis people are going to perceive that they shouldn't be having children. I think that's a worry – whether it leads to them being less likely to be honest about things and soon".

General adult psychiatrist

"What women find difficult is when they feel that the attitude from the health professional is that they are being irresponsible: "You shouldn't be having children. I'm not prepared to discuss this with you".

I want my patients to know that I see them as a whole person not just their mental illness, and if they want to have a family there is extra support that we'd really like to give. I think you can do it very easily in a human way, not in a stigmatising way."

General adult psychiatrist

Jenny's story: a case study

Jenny was first treated for mental health problems at 28 and diagnosed with bipolar disorder three years later by which time she and her husband Henry were already thinking about having a family and how best to approach it.

She was stable on her medication and had successfully made a career change from lawyer to portrait artist but it would be a further 3 years before they were able to try for a baby. "It felt like a very long time because we didn't know whether we'd ever have children, that was the hardest part," she says.

Initially, the health professionals they consulted for information about the possible risks and the teratogenicity of different medications were not able to help them; getting information was "like banging my head up against a brick wall".

"*The key turning point was getting to see the right person, which was the specialist perinatal psychiatrist, because the team I had been under locally didn't have that expertise. They had told us you can't get pregnant on lithium and you can't stop the lithium because it's not safe so we felt 'Are we ever going to be able to have kids?*"

In the preconception consultation, "*the perinatal specialist was able to say 'these*

are the options, these are the risks' and to have that conversation with her was the most amazing thing and made us feel we were being given hope and empowered to make informed decisions".

As a result of the advice they received, the couple decided Jenny should taper off the lithium whilst continuing with quetiapine, which is not teratogenic. Jenny also used a mood management programme called True Colours to help her to self-manage her mood and prepare for pregnancy.

"*I also had a really brilliant care co-ordinator*

who helped us pull together a plan of how to cope during the pregnancy, birth and afterwards. Part of it was a sheet with phone numbers which had on it all the different people who would be involved in my care: the GP, psychiatrist, care co-ordinator and the obstetrician, that was very helpful". The plan also helped all the professionals involved co-ordinate her treatment more effectively.

Jenny stayed well after the birth of her first child, a son but, when her daughter was born 2 years later following a lot of stressful events during the pregnancy, she suffered a postpartum psychosis.

"*I was lucky enough to get into an MBU and keep my baby with me but I didn't get home for over 6 months and it was a long journey back to full health. But you do come out the other side and I've got two wonderful children and I wouldn't be without them. I'm very well now and we both feel really blessed to have them*".

Jenny emphasises how important it is for women with serious mental health conditions like bipolar disorder to see a perinatal specialist.

"*That hour we spent with her really changed my life and I don't say that lightly. Having hope that we could have a family made such a massive difference.*"

Having a family: my plan

Pre-conception plan for women with serious mental illness

This plan is to help you think about your reproductive and preconception health, whether or not you are currently planning a pregnancy. The plan can be used to help you explore fears and expectations about pregnancy and parenthood and provide you with information and support to make the best decisions for you

Preconception care involves thinking about several aspects of your care and health, including contraception and relationships as well as medication and symptom management. Planning and readiness for pregnancy is about your physical and mental health, and even if you are not thinking about pregnancy now, this health check is important for you.

1 *Things to consider*

Even if you are not currently planning a pregnancy, it can be useful to think about the following things…

- Fertility
- Contraception
- Relationships and sexual health
- Medication and symptom management
- Physical health
- Weight and nutrition
- Smoking
- Use of drugs and alcohol
- Parenting

Do you have any questions or concerns about these, or anything else in relation to planning a family?

2 *My priorities at appointments*

1. This is what I would like to prioritise in today's appointment

2. This is what I would like us to come back to in future appointments

3. Could we also spend some time together to talk about…

3 *Your plans for a family*

1. Can you tell me about your family?

2. Do you think it is possible that you might become pregnant in the next 5 years?

3. How would you feel if you became pregnant now?

4 My Action Plan

Setting small, realistic ‘stepping-stone’ goals can be a helpful way for you to change behaviours and get more support if you need it. It can be especially helpful to achieving long-term goals, such as weight loss or giving up smoking.

What is my goal?

How will I know if I’ve achieved it?

When can I realistically achieve this by?

When can we go over this together?

5 What support will I need?

Finding support can be tricky, but there are services and groups out there that can help you to achieve your goals.

The following groups or services are available to me to help me achieve my action plan…

What help do I need accessing these?

6 Review

Resources

For health professionals

Summaries of information available for preconception care for women in the general population (but also applicable to women with serious mental illness) are available here https://cks.nice.org.uk/preconception-advice-and-management#!scenario:1)

Domestic abuse

A downloadable resource to help mental health professionals identify and respond to Domestic Violence and Abuse. *LARA-VP: A resource to help mental health professionals identify and respond to Domestic Violence and Abuse* (DVA) [https://www.kcl.ac.uk/psychology-systems-sciences/research/lara-vp-download-form]

Medication

MHRA Valproate Guidance

UKTIS
Resource for health care professionals regarding maternal exposures from UK teratogen information service

For women and their families

Autism

Ambitious about Autism

Mums on the spectrum facebook group

National Autistic Society

NHS autism guide

Postpartum psychosis

Action on Postpartum Psychosis (APP)
Information and support on postpartum psychosis, online chatroom, peer support network.

Bipolar disorder

Bipolar UK
Information and support, local groups and an online chatroom for people with bipolar

disorder.

Bipolar UK resource for women and families during pregnancy and childbirth

Maternal OCD

Maternal OCD

General mental health

Eating disorders and pregnancy

Nutrition leaflets for women

MIND

Mental health charity providing information, support, local groups and an online chatroom

Mumsnet

Although they do not provide advice Mumsnet has a very supportive mental health forum.

Rethink

Supports people across England to get through mental health crises, to live independently and to realise they are not alone. **Find a support group in your area.**

Royal College of Psychiatrists

Includes information leaflets on pregnancy and mental health.

RCPsych Leaflets for Patients:

- **What are perinatal mental health services**
- **Perinatal OCD**
- **Mother and Baby Units**
- **Post-partum psychosis**

Samaritans

Confidential service offering emotional support to those in need.
Call them on 08457 90 90 90.

Social Care Referrals

A comprehensive description of what happens after a social care referral for parents.

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