

"I was diagnosed HIV positive when I was pregnant,
many years ago and I wish I had all this information
at that time!"

The Pregnancy Journey...

when you are living with HIV

Recommended reading:

Guide to HIV, pregnancy and women's health, www.i-base.info
The Swiss Statement, www.aids.ch/e/fragen/pdf/swissguidelinesART.pdf
BHIVA guidelines, <http://www.bhiva.org/ClinicalGuidelines.aspx>

For further advice or to talk to a mentor mother please call Positively UK on
020 7713 0444 or visit www.positivelyuk.org

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If you, or your partner, is HIV positive and you want to get pregnant, or you are pregnant or were diagnosed HIV positive during pregnancy, this leaflet is designed to help you find out information to have a healthy, happy journey through pregnancy to baby and beyond.

We have compiled a selection of some of the many questions that are asked by women living with HIV who are planning to have a baby or are pregnant.

At Positively UK we have a team of women we call 'Mentor Mothers' who are women living with HIV, many of whom have experienced pregnancy when HIV positive, all of whom have been trained in dealing with pregnancy as a positive woman.

This leaflet was produced by the project "From Pregnancy to Baby and Beyond" at Positively UK in partnership with clinicians to help women make informed choices and decisions around pregnancy, birth and the care of your baby. Your HIV clinic, midwife, GP and the team of Mentor Mothers at Positively UK are all there to help and support you on your pregnancy journey.

There is not space to give all the detailed information in this leaflet, but it covers the most frequent questions that crop up around HIV and pregnancy. You will have your own unique circumstances and questions, but remember: You are not alone!

"When I was diagnosed with HIV I thought that meant I could never have children. After I spoke to the doctor I realised it was ok. I called him four weeks later to say I was pregnant!"

Disclosure

Talking about HIV

If your friends and family are not aware of your HIV status, pregnancy can be a stressful time as everyone asks you so many questions. Talking to women who have been in the same situation can help you work through any worries and also give you ideas how to answer the questions we are all asked such as – why are you having a C-section? Why aren't you breastfeeding?

Do I have to disclose my HIV status?

It is important to inform your GP you are HIV positive so that they can treat you more effectively. Your doctor, midwife and health visitors can take care about what they write in your notes in order to maintain your confidentiality.

Disclosing your status or telling someone that you are HIV positive can be difficult; Mentor Mothers have all gone through the experience of disclosing to health care providers, and partners. Some have older children to whom they have started to talk about HIV. Talking to other positive people in support groups, or even on the phone, can help you come up with strategies to tell the most important people in your life.

For further advice please call Positively UK and ask to speak to a Mentor Mother on 020 7713 0444.

What do I need to consider after delivery?

You should consider your own health too! Your baby needs a healthy mum.

Make sure you:

- Attend all your appointments
- Continue to take and adhere to treatments as advised
- Continue to use contraception and have safe sex
- Eat well
- Stay healthy

Testing other children

If you find out you are HIV positive after having children then it is recommended that that you have your other children tested. It is vital that HIV is identified as early as possible so they can be treated where necessary and can stay healthy.

Before you start

Many women are concerned that having HIV means that you might pass the infection on to your baby. However, in the UK today if you are diagnosed in good time, the risk of this happening can be reduced to 1% or less. **There is no reason why having HIV should mean that you are not able to have a healthy baby.**

How is HIV transmitted from mother to child?

There are a number of ways HIV can be transmitted from mother to child.

- **During pregnancy:** HIV transmission while the baby is in the womb is rare as the placenta protects the baby from HIV. However, certain factors can increase the risk of transmission:
 - Presence of high viral load, a low CD4 count and an advanced HIV related illness
 - Presence of other Sexually Transmitted Infections (STIs)
 - Exposure of the baby to the mother's blood through invasive procedures
 - Exposure to mother's blood through trauma such as domestic violence
- **During labour.** A protracted or long labour can involve the use of birthing aids such as ventouse and forceps – these may rupture baby's skin
- **After birth through breastfeeding** – breast-milk contains the HIV virus

What percentage of HIV negative babies are born to HIV positive mothers with or without interventions?

- Without anti-retroviral medication and with breastfeeding – 70%
- Without anti-retroviral medications and without breastfeeding – 85%
- With anti-retroviral medication, a managed delivery and without breastfeeding – 99%

What things do I need to consider when thinking about having a baby?

- Discuss your plans with your HIV specialist doctor. Make sure they know you are trying to get pregnant as some ARVs might not be suitable
- Start taking folic acid – this is recommended for all women planning on having a baby
- Have an STI check-up for any sexually transmitted infections and cervical smear test
- Have a blood test to check your viral load, especially if your partner is uninfected
- Know when your fertile time is i.e. when you are ovulating – you can find out when you are ovulating with an ovulation kit. Some HIV clinics provide these free of charge, alternatively you can purchase a kit from all good chemists

- Check your general health – it is advisable to stop smoking, drink less alcohol, check your weight (being over or underweight can affect your chances of conceiving), avoid recreational drugs
- Remember you should continue practicing safer sex once pregnant

Conception

How should we conceive?

This is dependent on which of you is HIV positive. Please discuss your options with your HIV consultant.

If both partners are HIV positive

You can conceive naturally: when you have worked out your fertile time of the month you can have timed unprotected sexual intercourse (see The Swiss Statement*). When your fertile period is over, you should go back to having safe sex. Timed Unprotected Intercourse is advised as regular unprotected intercourse may increase the risk of acquiring other sexually transmitted infections and/or acquiring drug-resistant strains of the HIV virus.

If the woman is HIV positive and the man is HIV negative

You can conceive through DIY artificial insemination or you can try and conceive naturally as long as you have an undetectable viral load and you follow the conditions of the Swiss statement. Please see below for more information on the Swiss Statement*.

DIY artificial insemination involves getting your partner to ejaculate into a pot then using a plastic syringe to insert the sperm inside you. Your clinic doctor can advise you on this.

If the man is HIV positive and the woman is HIV negative

To prevent transmission of HIV you need to undergo assisted conception which involves either:

- Sperm washing is when cells are harnessed and placed into centrifuge to purify sperm from seminal fluid which contains the HIV virus. The purified sperm is then inserted into the woman using IUI (Intra Uterine Insemination) when she is ovulating or
- IVF (In Vitro Fertilisation) which is where egg cells and purified sperm cells are harnessed and put in dish to fertilise naturally, the fertilised egg is then implanted into uterus or
- ICSI (Intracytoplasmic Sperm Injection is when a purified sperm cell is injected into an egg cell and then implanted into the uterus)

After Care

Can I breastfeed?

In the UK the current recommendation is that a woman living with HIV should not breastfeed. If a baby is born HIV negative and you do not breastfeed the risk of transmitting HIV to the baby is zero.

For a woman whose viral load is suppressed and who is on treatment, the risk of transmitting HIV to her baby is reduced but, there is still a small risk of transmitting HIV to the baby through breastfeeding. **The safest recourse is not to breastfeed at all.**

If you cannot afford formula and feeding equipment, you may be able get it free of charge. Please check with your midwife, doctor or hospital.

Some women find it difficult to explain not breastfeeding. Again we have compiled a list of feasible explanations:

- You have cracked and painful nipples
 - You have a nipple infection
 - Your milk dried up
 - You have to go back to work soon
- Again there are many more...

If you find you haven't stopped lactating you can use a tablet called cabergoline, talk to your doctor or midwife about this.

Will my baby have to take medication?

Your baby should have two daily doses of an ARV in syrup form for four weeks after birth.

What tests will my baby have?

Your baby will undergo a blood test (a PCR test) which looks for virus in the baby's blood. Usually babies are tested the day they are born, at one month and at three months. If all these tests are negative then your baby is HIV-free. Babies share their mother's antibodies, so an HIV antibody test will show up positive until they lose their mother's antibodies at about 18 months.

So, make sure you:

- Have your baby tested for HIV
- Continue with baby's treatment as advised
- Do not breastfeed

Delivery

What delivery options are available to me?

You have two options for delivery: C-section (Caesarean-section) or vaginal delivery.* There are advantages and disadvantages associated with each.

C-section

A C-section is quick and there is little exchange of fluids so the risk of infection is reduced. It is however major surgery and requires a longer recovery period.

Vaginal delivery

Vaginal delivery is natural, there are usually less complications and recovery time is shorter. However, vaginal delivery can be a long process and there is an increased risk of infection transmission if certain interventions such as forceps or ventouse become necessary. Women having a vaginal deliveries can be advised to have a C-section if labour is not progressing easily to reduce the risk of infection .

Some women find it difficult to explain opting for a C-section. We have accumulated a few tips and strategies to explain having a C-section:

- You went into premature labour
- There were complications at birth
- You were advised to have a managed delivery

There are many more...

*"Positive women, who choose to have a vaginal delivery, should be treated in almost the same way as any other pregnant woman in labour. However for all women with HIV intervention in labour is kept to an absolute minimum and labour is encouraged to progress naturally. Should we need to help labour along, we would use the same methods we use for all women.... However, should an assisted delivery be indicated, the mode of delivery will be discussed with yourself and the safest method for you and your baby will be carried out."
HIV specialist midwife

Pregnancy

So you're pregnant. Congratulations! Now what?

Make sure you get the right care and information!

Is there more chance of me having a miscarriage because of my HIV status?

In general, the vast majority of pregnancies turn out fine. But, **as with any other pregnancy in women without HIV**, there is a small risk that all may not go well, and a small minority of babies may be born with abnormalities.

There are many other medical conditions which can result in difficult pregnancies, yet many women still plan to go ahead with pregnancies in these circumstances. Please speak to your doctor or specialist midwife if you have any concerns.

The Swiss Statement*

If you intend to try natural conception with or without PREP and PEP you must follow the guidelines set out in The Swiss Statement:

- You must have had a suppressed viral load for at least six months
- You must be on HAART and with 100% adherence
- You have be regularly tested for and there must be no presence of STIs
- You should have counselling and form an agreement with your partner as a couple

PREP (Pre Exposure Prophylaxis) and PEP (Post Exposure Prophylaxis) refer to anti-retroviral drugs to be taken before or after potential HIV exposure in order to reduce the risk of HIV infection. Talk to your HIV consultant about PREP and PEP.

Treatments

What treatment is recommended during pregnancy?

Anti-retroviral treatment during pregnancy and delivery depends on your own medical circumstances and it is important to get good advice from your specialist HIV consultant. Your HIV consultant will follow the latest BHIVA (British HIV Association) guidelines on the management of HIV in pregnancy.

There are the general guidelines if the woman is not on treatment for her own health and is asymptomatic, has a low CD4 count and a low viral load:

- ARVs from week 20
- Vaginal delivery if viral load is undetectable
- C-section if viral load is detectable just before delivery
- ARVs for the baby for the first four weeks
- Formula feed

What if I am already taking ARVs when I find out I am pregnant?

The current guidelines state that if you are already on ARVs and you find out you are pregnant you should continue taking your ARVs.

Are there any treatments you should avoid during pregnancy?

There are a two points to consider:

- During the first 12 weeks the foetus is most vulnerable to any toxic drug effects treatments should be avoided if possible. **However if you are already on treatment you are advised to continue taking your treatment and you should therefore not stop during the first 12 weeks.**
- There is very little data available on effects of ARVs on the foetus in early pregnancy

If you have any concerns about the ARVs you are taking should discuss these with your HIV consultant.

Other Considerations

What other tests are offered during pregnancy?

- Blood tests
- STI tests
- External ultrasound
- Foetal monitoring
- Amniocentesis – general advice is to avoid invasive procedures during pregnancy however this test can be carried out in extreme circumstances, but only if the woman is on ARV treatment and has an undetectable viral load

What tests or procedures should I avoid during pregnancy?

- Any invasive procedures that allow mother/baby blood exchange
- Internal foetal monitoring
- Foetal scalp sampling
- Percutaneous umbilical cord sampling
- The use of forceps at delivery

"When you are positive and pregnant you can feel very vulnerable - you can talk to a Mentor Mother about things that are difficult to say to anyone else - they understand..."