

# Planning for PARENTHOOD



For many people, choosing whether or not to start trying for a family can be a difficult decision to make. Having a chronic or life-limiting condition can make the choices about becoming a parent even harder. Because of advances in medicine, people with a range of chronic conditions are living healthy lives for longer. As a result, more people are choosing to become parents. Being a parent can be a joy and lots of fun in many ways, but any parent will tell you that it is hard work and involves constant demands on your emotional, physical and financial resources.



This toolkit gives you and your partner some information about things to consider and support that is available both in making your decisions about parenthood and coping along the way, should you choose to try and start a family.

### **Can I have a baby biologically?**

Depending on your condition, your ability to have children biologically may be affected. If this is the case, you may need to undergo specialist fertility treatment in order to have a baby or may wish to consider other options available to you, such as fostering or adoption. Additionally, for women other factors such as your weight and general health may affect your menstrual cycle and whether you can get pregnant. It is important to talk to your medical team early about your plans so that you get their support and the best outcome for yourselves.

### **When is the best time to have a baby?**

Many people wish to become pregnant when they are as well as possible, which may tend to be at a younger age for those with a chronic condition. It could be tempting to rush into pregnancy because you do not know what the future might hold. However, there are a number of factors to think about in planning the best time for a pregnancy:

- Your health
- The strength of your desire to have a baby
- Your natural hope to have as long as possible with your child while you are well
- The stability and permanence of your relationship with your partner

- Your child's need for a strong relationship with both of their parents.
- Only you and your partner can decide whether to go ahead and have a baby, taking all of these different factors into account.

### **Am I well or fit enough to have a baby?**

This depends on a number of factors related to your condition and your health. The risks of pregnancy will be different for each individual, so it is important you discuss all the medical issues with your specialist doctor and be assessed by them as early as possible.

### **How will pregnancy affect my health?**

During pregnancy, a woman's body undergoes many changes to provide for the growing baby. These changes place additional demands on a woman's body and energy reserves, which can make any health difficulties or tiredness even worse for women with a chronic health condition. In some conditions, pregnancy may also have some long-term effects on your health beyond when your baby is born. You also need to check if there are any medications that you should stop taking while you are pregnant, to keep your baby safe.

Your healthcare team will be able to talk to you about how your health is likely to be affected throughout the course of your pregnancy and in the long-term. You may benefit from additional support or monitoring throughout your pregnancy to ensure you stay as healthy as possible. This may include the use of vitamins and supplements and changes or additions to your normal treatments.

### Will my usual treatments/medications affect the baby during pregnancy or breastfeeding?

This will differ across conditions and depending on what treatments you are receiving. It is important to discuss this with your doctor as early as possible when you are thinking about pregnancy. If you will need to stop some of your treatments in order to get pregnant or breastfeed, this may have implications for your own health.

### Could my child inherit my condition?

Different chronic and life-limiting conditions have different causes. Some conditions have a genetic cause. This means that the condition is caused by a mutation in your genes (which is a section of your DNA code). Sometimes other members of the population can be a 'carrier' of this genetic mutation, meaning that they have the genetic mutation but do not

display the condition. This means that your partner may also 'carry' the genetic mutation without knowing.

A child could inherit a genetic condition through their DNA. For some conditions, the child can only inherit the condition if both parents have the genetic mutation. In these cases, genetic screening is often available to determine whether your partner also carries the genetic mutation. Sometimes tests can also be offered during fertility treatment, during pregnancy, or shortly after birth to see whether your baby has inherited the condition.

### Will I need extra help once the baby is born?

The physical side of parenting can be demanding and quite tiring. You may need to pace yourself or ask for extra help with childcare. You will also need to be a good organiser to take into account your own healthcare treatments, appointments and generally staying well, alongside your child's needs. Prioritising your own treatments can be a challenge when you are looking after a child, but it is important that you stay as well as possible.

Additionally, some conditions require considerable expense to remain well. Likewise, children cost money – extra food, heating, clothing, equipment, toys; and

you or your partner may have to take time off work to care for them. Sometimes people need to move house to make room for their growing family or to be near to good schools. It is important to think about whether/how you will manage the practical aspects of starting a family, and how you will afford the cost of both looking after your child and maintaining your own health.

### **Being an in-patient**

In-patient stays can bring their own parenting challenges. For example, who will help you when you have in-patient stays? Your hospital team wants to help you stay as healthy as possible so that you have energy for your new life as a parent, so it is important to find the right support so you can come into hospital if you need to.

### **Telling your child about your condition**

For some families, talking openly about your condition will feel comfortable and normal, because some families feel able to talk about the issues that affect their lives. For others, this part of parenthood may feel particularly hard and distressing, especially discussing 'end of life' concerns. You might want to think with your partner about how much you want your children to know about your condition and treatments, and when you will tell them.

Your healthcare team can support you in thinking about how you have these conversations with your family, and answering any questions your children might have.

### **Planning for when you might not be around anymore**

It is important to talk to your partner about the implications of him or her losing you, and then bringing up your child without you. You might want to think about who else will be around to support your partner with childcare, how they will manage financially without your income or if they need to stop work, and how they will help your child to remember you and know about you when you are no longer around.



# Top tips and strategies

Here are some techniques that you can try to help plan for parenthood.

1

**Talk to your partner about the decision to have a baby.** Use

this leaflet to help you think about all the different factors to consider when choosing whether to start a family.

2

**If you are considering having a child, it is best to discuss this with your healthcare team** before you start trying to get pregnant, especially for women. Your team can help you think about:

- Aspects of your health
- The risk of pregnancy for you as an individual
- Help you might need to get pregnant
- The likelihood that your child may inherit your condition
- Making your pregnancy as safe as possible for you and your baby

3

**If you have a genetic condition** and want to know whether your partner is also a carrier of the genetic mutation, speak to your GP to find out what genetic testing is available.

4

**Your GP can also give general advice about fertility,** and can refer

you to a specialist fertility clinic if you are likely to need fertility treatment to conceive a baby.

5

**Talk to your family and friends.** Think

about who would be available to offer support to your new family, especially in difficult times such as when you are unwell, when you have an in-patient admission, or if your illness gets the better of you and you are no longer around. In particular, think about who might be there to support your partner if they lose you and have to raise your child alone.

6

**Think together with your partner about the other important things in your lives** – activities you enjoy and goals you have. Regardless of your decision to have baby, it is important to have other goals in your life too.

7

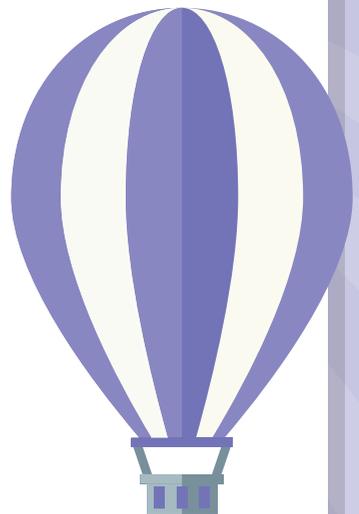
**If you decide not to have a baby, you might feel sad, or you may feel a sense of relief at having made the decision.**

You and your partner might choose to spend your time and energies on pursuing other goals instead.

If, on the other hand, you decide to have a baby you will be a much more interesting and stimulating parent if you have had as wide a variety of life experiences as your health and resources allow. Sometimes it takes a while to achieve a pregnancy for a number of reasons. Becoming obsessive about wanting to conceive at the expense of other activities and interests is likely to delay success even longer – and you might well take a lot of the fun out of your sex life too!

Your relationship with your partner is very important so try to think and plan with him or her some activities and interests that you can share together. If you are well enough, try and continue to work or study for as long as possible. Make the most of the freedom to go out together. If you can afford it, enjoy holidays and outings, visit friends and relatives and pursue lots of hobbies!

There can be a lot more to life than a single interest of getting pregnant, although it may be hard to remember this if conception doesn't come easily. It is important to recognise this and to enjoy the best quality of life for as long as possible.



# WHAT SUPPORT IS AVAILABLE?

Your healthcare team is there to support you in thinking about your decision to become a parent, maintaining your health throughout pregnancy and once your baby is born, and thinking about how to manage difficult conversations with your family about your condition.

Some teams in the hospital have a psychologist as a member of the team, who can speak to you and your partner if you need support thinking through your decision as to whether to have a child or not, or if you want to discuss any particular worries you have. Ask a member of your healthcare team who knows you well, if they can make a referral on your behalf.

## Links to appropriate resources

- 1. The Cystic Fibrosis Foundation Trust** has lots of information on planning for parenthood which could be helpful to those with other chronic or life-limiting conditions. <https://www.cff.org/Life-With-CF/Transitions/Family-Planning-and-Parenting-With-CF/>
- 2. The Cleveland Clinic** have a resource on Planning for Parenthood after a Cancer Diagnosis <https://my.clevelandclinic.org/ccf/media/Files/Cancer/CNR-938-cancer-fertility.pdf>.



These toolkits have been written by NHS clinical psychologists and neuropsychologists working for University Hospitals Bristol. They have been co-designed with service users and healthcare staff. These toolkits are only intended to provide general advice and information. Please discuss your individual needs with your doctor or specialist nurse. If you would like more information about psychology services please go to:

<http://www.uhbristol.nhs.uk/patients-and-visitors/support-for-patients/psychological-health-services/>

We would like to thank patients and other healthcare staff for their contributions to this toolkit.

For access to other patient toolkits please go to the following address:

<http://www.uhbristol.nhs.uk/patients-and-visitors/support-for-patients/psychological-health-services/resources/>

For this leaflet in large print or PDF format, please email [patientleaflets@uhbristol.nhs.uk](mailto:patientleaflets@uhbristol.nhs.uk)

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