



4. Should we have a baby?

A guide to help women with cystic fibrosis make informed choices

Should we have a baby?

What you and your partner need to think about before going any further

Moral dilemmas

Many people have a very strong urge to become parents. It is often thought that one of the primary reasons for living at all is to have children and pass on our genes and characteristics to future generations.

However, the decision to have a baby has to take account of other factors, especially when one of the parents has health problems. Of course no one can guarantee to live to see their children grow up and become adults. At any time anyone could develop a disease or have an accident that could cause incapacity or death. However, for people with CF the risks of this are far higher, despite current research and all the advances in treatment.

So what are the moral dilemmas that need considering before embarking on pregnancy and parenthood? Perhaps these are some of the questions that might arise for you:

- *Why do I/we want to have a child?*
- *Whose needs will come first – mine, my partner's or my child's?*
- *How well am I? How well can I hope to be after going through pregnancy and child birth?*
- *How will I feel if I become ill and find it hard to care for my child?*
- *What other sources of care and support do we have? How permanent are they?*
- *Will our child be an only child?*
- *What will it be like for our child to grow up knowing that I am unwell and will not get better? How will we cope with explaining about CF to him/her?*
- *Am I likely to live to see our child grow up?*



*Whose needs come first
– mine, my partner's
or my child's?*

Obviously these are difficult questions and some of them may seem as though they don't have to be faced at present – particularly if you are well and have needed very little treatment up until now. It may also seem very unfair that you even have to think about any of these things – after all most couples drift into parenthood without having to consider the future, trusting that they will cope with whatever life throws at them along the way.

However for anyone who is to take on the enormous responsibility of bringing a new life into the world, it is always wise to recognise that responsibility, to discuss and plan for it with your partner and to remember especially the needs that your child will have for the next eighteen years and beyond.

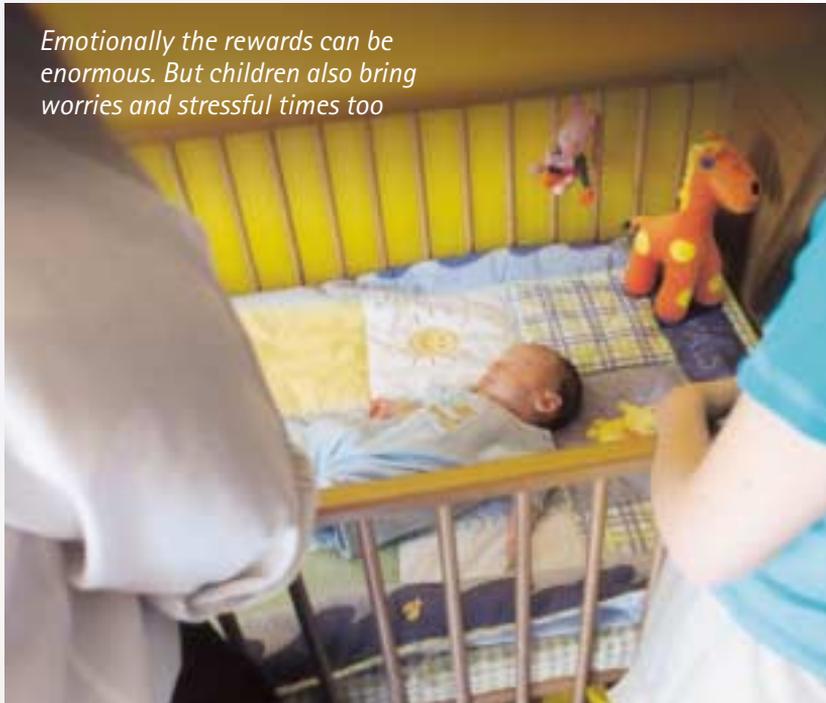
What are the implications of being a parent?

Everyone who becomes a parent will experience joys and frustrations. The joys come from the amazing fact that you have created another human being, with whom you will have a lasting and unique relationship.

But having a child also has its difficult times and this is true for everyone – sleepless nights, the constant demand for your attention, the need for endless energy, and the inevitable concern about whether you are doing enough to meet all of your child's needs. Things always become a lot more difficult if either you or your child is ill.

You will need to consider how your daily treatment programme will fit in with the demands of parenthood. It is important to consider whether you have the physical stamina, and the organisational skills, to look after a child as well as yourself.

The dilemma over whether to become a parent can be complicated by the knowledge that you have CF. This adds to the factors that any prospective parent needs to think about – such as whether or not they can afford to have a child and whether they are ready to accept the ties and responsibilities of parenthood.



Emotionally the rewards can be enormous. But children also bring worries and stressful times too



Do you have the physical stamina and the organisational skills to look after a child as well as yourself?

Will you need any extra help?

The physical side of parenting can be quite tiring when the baby or child is small, and dependent on you to do everything. Although this becomes easier as the child becomes more independent, there is still a need to be constantly 'on the go' and energetic. 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 need for physiotherapy and drug preparation, and medical appointments. You may need to organise childcare if you require hospitalisation for any length of time.

Emotionally the rewards can be enormous. But children also bring

worries and stressful times too. However this is no different for you or for any other person who becomes a parent.

Financially, children cost money. You may need to take into account the costs of extra food, clothing, heating, equipment, toys, and the possible loss of earnings, especially if you already have considerable expense in maintaining your own health. Also growing children need lots of space to play – so might a house move be necessary in future? How far do you live from the school your child will attend? Might you need a car at some stage? These are some of the practical considerations that you may need to take into account in your planning.

The difficult decision – should we remain childless?

Only you and your partner can answer this question, taking into account many different factors, but especially how well you are. Would you have concerns about increasing the number of people who carry the CF gene? Will you be healthy enough to be an involved parent? Will you be able to carry a pregnancy without major ill effects? What if your health is deteriorating? Is it acceptable to become a parent when you may be too unwell too often?

What if you should die? The effect on a child of having a sick parent who subsequently dies before the child reaches maturity may be very far reaching. Would you want to put your child through this?

Have you considered the implications for your partner of losing the person he loves, and then bringing up your child by himself?

All these issues need to be talked about in depth, so that you both know and understand each other's thinking and feelings.

For a personal account from a patient

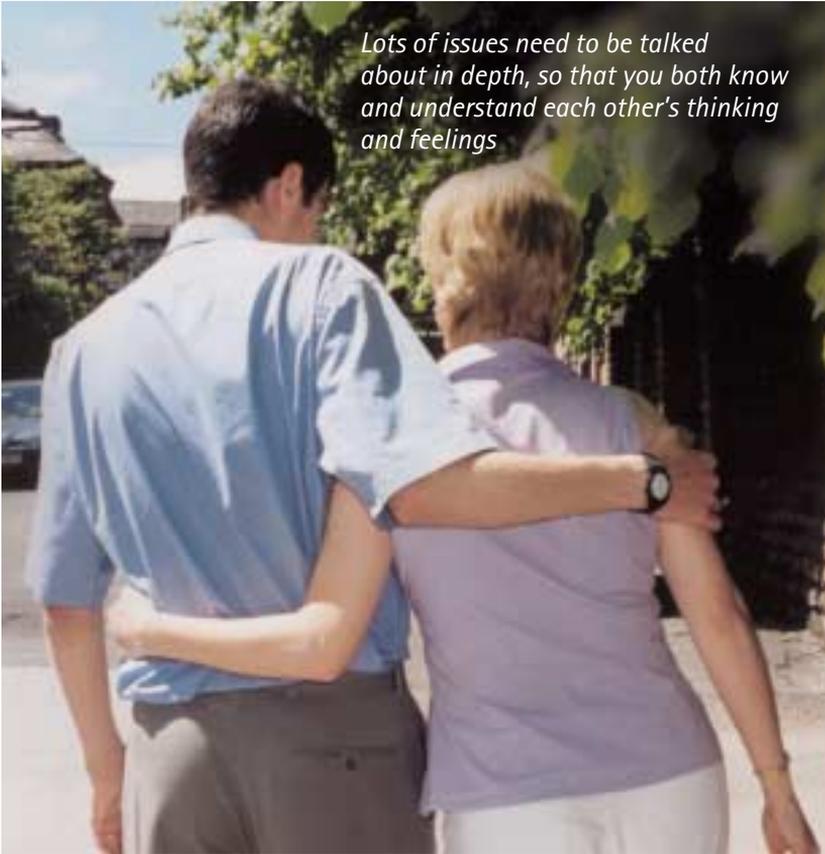


who has made this difficult decision please see the article entitled Parenthood – Difficult decisions by Sarah Pearson in the Adult CF Association Magazine Input (Issue 20 – winter 1998/1999, available from the CF Trust, Tel 020 8464 7211).

Alternative life goals and positive alternatives to parenthood

Whatever you decide about whether or not you wish to have a child, it is important to have other goals in your life as well. If after much discussion and advice seeking you decide that parenthood is not the choice for you, you may feel quite sad. On the other hand you may feel a sense of relief that you no longer need to struggle with this important decision. Deciding to be childless can be a very positive step.

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



Lots of issues need to be talked about in depth, so that you both know and understand each other's thinking and feelings

experiences as your health and resources allow. Sometimes it takes a while to achieve a pregnancy for a variety 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 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 – especially if exercise is involved! There should be a lot more to life than a single interest. You probably have a lot of work to do to maintain your health and you should try to get the most out of your relationships and opportunities. It is important to recognise this and to enjoy the best quality of life for as long as possible.



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Leaflet 2: How can I have sex safely?

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treatment? – A patient's perspective

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