6. How could we become parents?

A guide to help women with cystic fibrosis make informed choices

How could we become parents?

This leaflet provides information about many different ways in which you may be able to become parents, whether or not you are well enough to go through a pregnancy.

The first section is for those of you who have decided to try to get pregnant but are finding this difficult. It deals with the possible causes of and the many different treatments for fertility problems – for both you and your partner. It also looks at the potential costs (financial and emotional) of fertility treatment and where you may be able to get help if you need it.

If you are unable or unwilling to risk pregnancy or if fertility treatment is not successful, there are other possible ways to become parents. The second part of this leaflet (from page 21) looks at these alternatives, including surrogacy, fostering and adoption. Some of you may become parents by caring for your partner's children from a previous relationship, and step parenting is also considered.

Fertility treatments

If we have fertility problems what help is available to give us the chance to have a child and what is involved?

If you and your partner are wanting and trying to have a baby there may be many reasons why this could prove difficult and it should not be assumed that it is because you have CF. Until you have had tests to find out what the problems are (or are not) it will not be possible to decide what treatment is possible for either of you.

This section will explain many of the possible causes of infertility and the different treatments that can be used to try to overcome them. Some treatments may be available to you free of charge, on the NHS, and others are very expensive as they are only

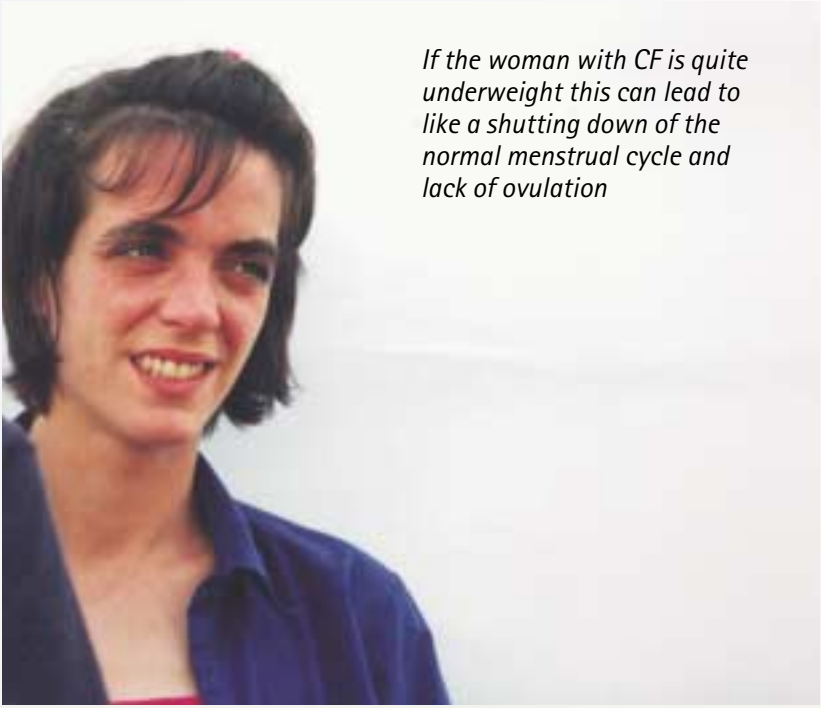
available at present if paid for privately. Adding money into the decision making process can cause many more dilemmas but is a very real factor for most couples. So for each treatment there is a rough guide to how much it might cost, as well as the likelihood of its success in helping you to achieve a pregnancy.

The cost of treatment will vary according to where you live and whether or not your Health Authority is prepared to fund none, part or all of the treatment you need. At present the service to infertile couples varies considerably across the country, although there is a commitment to stop these inequalities. If you ask your GP he/she will be able to advise you about your local situation. Some GP's may take your CF into consideration in making decisions about referrals and recommendations for treatment. Always consult your CF team too.

Costs of privately funded treatment will vary from clinic to clinic. It is best to do some investigating before you make any commitment to treatment, and it would be sensible to ask several clinics to send you their price lists. Some clinics have patient information evenings where you can join a group of other potential patients, and find out quite a lot of information, which might be useful for you.

Possible causes of infertility in women who have CF

Fertility problems may arise in two very different ways. Firstly, the woman with CF may have developed problems, totally unrelated to CF, that lead to infertility. Examples of this might include sexually transmitted diseases or endometriosis (which can lead to blockage of the fallopian tubes) or disorders of the ovary which interfere with the production and release of eggs (ovulation). Secondly, the fertility problems may be more directly linked to cystic fibrosis. For example if the woman with CF is quite underweight this can lead to a shutting down of the normal menstrual cycle and lack of ovulation. There is also some suggestion that the cervical mucus (through which sperm have to swim to get to the eggs) may be thicker and therefore more difficult for the sperm to penetrate. Women with CF may therefore require treatments which either boost ovulation or which help the sperm to get more easily at the eggs (through treatments such as intrauterine insemination or IVF).



If the woman with CF is quite underweight this can lead to like a shutting down of the normal menstrual cycle and lack of ovulation

Treatments that increase fertility

Drug treatments

Women who do not ovulate may respond to quite simple drug treatment such as Clomiphene. This is given as a tablet, usually for five days only early in a woman's menstrual cycle. Treatment is quite simple and usually requires very little in the way of monitoring (scans and blood tests may help to confirm that ovulation is occurring). Where treatment with Clomiphene is unsuccessful more powerful ovulation induction treatment, using injections (gonadotrophins) may be advised. The risks however of multiple pregnancy (twins or triplets) are higher with gonadotrophin treatment and more intensive monitoring is therefore required. Treatment is however relatively successful with pregnancy rates of between 10% and 20% per cycle.

Costs of this treatment: The cost of drugs would depend on the individual's requirements. For instance a woman requiring little stimulation to ovulate may spend around £400. A woman requiring more powerful stimulation would expect to pay around £1000.

Intrauterine Insemination (IUI)

Intrauterine Insemination (IUI) is the name of the process that is used to inject sperm through the cervix and high up into the womb.

IUI is used as a general means to boost fertility or more specifically where it is believed that the cervical mucus is contributing to fertility difficulties by interfering with the ability of the sperm to get through. Although treatment can be performed without any stimulation of the ovaries, the results are much better when used in association with ovarian stimulation (either with Clomiphene or gonadotrophin injections). Monitoring (scans +/- blood tests) are used to identify the most fertile time of the cycle. The woman's partner is then asked to produce a sperm sample and one or two inseminations are then carried out very close to the time of ovulation. The insemination is very similar to a smear test but a fine catheter is passed through the cervix to deposit the sperm high in the uterus.

Pregnancy rates of 10% to 15% per cycle are to be expected and many couples would have three to six cycles prior to considering moving on to more aggressive treatments such as IVF. IUI can only be used where the fallopian tubes are healthy.

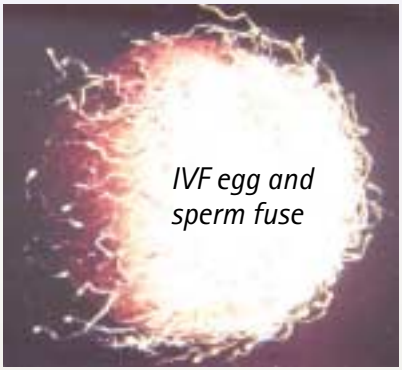
Costs of this treatment: The cost of Intrauterine Insemination is around £400 (or £450 if donor sperm is used.)

In vitro Fertilisation (IVF) treatment explained

IVF treatment (sometimes known as 'test tube babies') would only be considered for a woman with cystic fibrosis if intrauterine insemination had failed or if you had a fertility problem (unrelated to CF) which necessitated IVF (eg. tubal damage secondary to a sexually transmitted disease or burst appendix). It may also be needed if your partner has fertility problems (eg. low sperm count).

Basic IVF treatment is very similar for women with and without cystic fibrosis. Usually the ovaries are quietened down using injected or sniffed drugs (usually Buserelin) – this is called down regulation – before the treatment cycle itself is started.

The ovaries are then stimulated with gonadotrophins (see page 4) usually for ten to twelve days. A triggering injection of Profasi (or HCG) is then given which brings about the final maturing of the egg within the ovaries and the eggs are then collected 36 hours later. This is a minor surgical procedure, usually performed either under sedation or a general anaesthetic. The eggs are collected by passing a very fine needle, under ultrasound guidance, through the wall of the vagina and into the ovary.



IVF egg and sperm fuse

Your partner is then asked to produce a sperm sample and after preparation the sperm are added to the individual eggs. Twenty four hours later the eggs are checked for signs of fertilisation. Two days after the egg collection, fertilised eggs, which continue dividing, are replaced into the cavity of the womb (the process is very similar to that described for IUI on page 4). As the rate of multiple pregnancy (twins or triplets) is linked to the number of embryos replaced, serious consideration must be given to this very important aspect. Although the legal maximum permitted in the UK is three embryos, you may prefer to put back only one or two to reduce the risk of a multiple pregnancy (though this does reduce the pregnancy rate overall). Other 'good' embryos can be frozen to be transferred at a later stage.

The success rates from IVF average 15.5% per cycle nationally (HFEA Annual Report 1998) but pregnancy rates do vary widely between clinics and also depend on a number of factors including the woman's age. Women with CF generally attempt pregnancy at a rather younger average age than many IVF patients and so an improved chance of pregnancy can be expected.

Costs of IVF treatment: The initial cost of IVF would be approximately £1800. Each subsequent transfer of embryos costs around £650.

Added risks of a multiple pregnancy if you need IVF treatment

All couples having IVF treatment need to consider the risks and possible complications of a multiple pregnancy (ie. twin or triplets), and this is even more important if you have CF.
A single pregnancy would place enormous demands on your body and if you were pregnant with twins or triplets these physical demands would at least double. Not only will there be an increased risk to your health, but there is the added risk of a premature birth, with the possible complications that this can cause to the babies.

After the birth it is important for most mothers with CF to work hard to improve their lung function again – by clearing the infection which is likely to have collected in the bases of the lungs that have been squashed during the pregnancy. This extra treatment is hard enough to fit in if you only have one small baby to care for. The added pressure of caring for twins is a challenge to most healthy parents, but if you have CF too, it could make it almost impossible to look after yourself as you should. To neglect your care would be positively dangerous, both to yourself and to the welfare of the children. Certainly your clinician will talk seriously to you about this issue before you embark on IVF.

A useful source of help and advice is:

TAMBA – Twins and Multiple Births Association, Harnott House, 309 Chester Road, Little Sutton, South Wirral L66 1QQ, Tel 0151 348 0020

Selective reduction

Having struggled to conceive a pregnancy, it is one of the most profoundly difficult actions to purposefully end the potential development of one or more embryos if you feel unable to cope with more than one baby and you are expecting twins or triplets. Not only is there a risk to the whole pregnancy and its possible loss, but there may be feelings of personal distress and guilt.

However, there is a process called selective reduction which uses an injection to cause the death of one embryo if you are expecting twins (or 2 embryos if you are carrying triplets). This would only be undertaken after the implications were clearly understood through medical and psychological counselling. You would need to be referred to a specialist pregnancy unit for this to be done by an expert team, who could offer you proper care in a supportive environment.

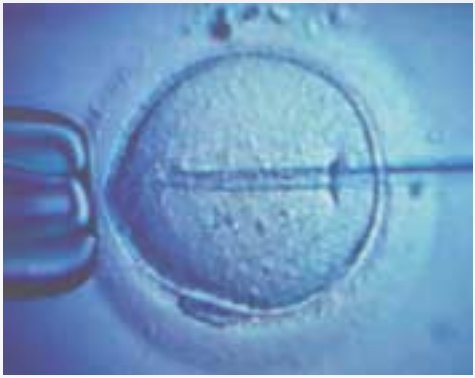
Extra treatments needed if your partner has fertility problems

If your partner also has a fertility problem, provided sperm can be obtained intrauterine insemination or IVF may be appropriate. Where the sperm count is very low the recommended technique is now ICSI (Intracytoplasmic Sperm Injection). With this technique the eggs are collected from the woman as in a


Blastocyst hatched

standard IVF cycle but individual sperm can then be injected directly into the eggs. The resulting embryos are transferred as in IVF. If the embryos successfully develop and hatch, the blastocyst (shown above) will hopefully implant in the lining of the womb and the pregnancy will start. Sixteen days after the transfer of the embryo, the clinic will be able to test whether or not you are pregnant. Home testing kits are not very accurate at this early stage. Success rates now with ICSI are as good, if
not better, than standard IVF. The key is of course whether sperm can be obtained. The technique is also suitable where sperm have to be surgically recovered from the man because of an obstruction (eg. because he has had a vasectomy or a failed vasectomy reversal).

Costs of this treatment: In addition to IVF, ICSI would cost in the region of £700. A surgical sperm recovery would cost approximately £800.



Where the sperm count is very low the recommended technique is now ICSI, during which eggs are collected from the woman as in a standard IVF cycle but individual sperm is then injected directly into the eggs

Pre-Implantation genetic diagnosis (PGD)

If your partner is a carrier of CF, any embryos produced by IVF can be tested to find out if they contain two faulty CF genes. It is then possible to choose the embryos which carry only one faulty gene for transfer to your womb. This process is called Pre-Implantation Genetic Diagnosis. It is explained more fully in leaflet 3.

Costs of this treatment: In addition to IVF, PGD adds approximately £1000 per IVF cycle.

How many tries can I have?

In the same way that couples might try for many months to achieve a pregnancy, many couples will need to try a number of cycles of IVF before having a successful result. In addition couples will need to be aware that conditions such as miscarriages, congenital abnormalities and ectopic pregnancies can all still occur with fertility treatment. An ectopic pregnancy is one where the embryo implants and grows in the fallopian tube. Unfortunately this is a serious condition in which the woman may experience severe pain and prolonged bleeding. As a life saving procedure, the growing pregnancy and the fallopian tube, and possibly the ovary, must be removed surgically. Sadly, this will leave the woman with an even greater infertility problem.

Although occasionally doctors can identify couples where the prospects of success are very poor and the couples are therefore advised not to proceed with any further treatment, these cases are the exception. More often than not the number of treatment cycles is determined by patient choice and resources. Many Health Authorities limit the number of cycles of any given treatment that couples can access on the NHS. Those couples funding their own treatment may also set financial limits on the amount that they are prepared to spend or are able to spend on treatment.

Donor Insemination

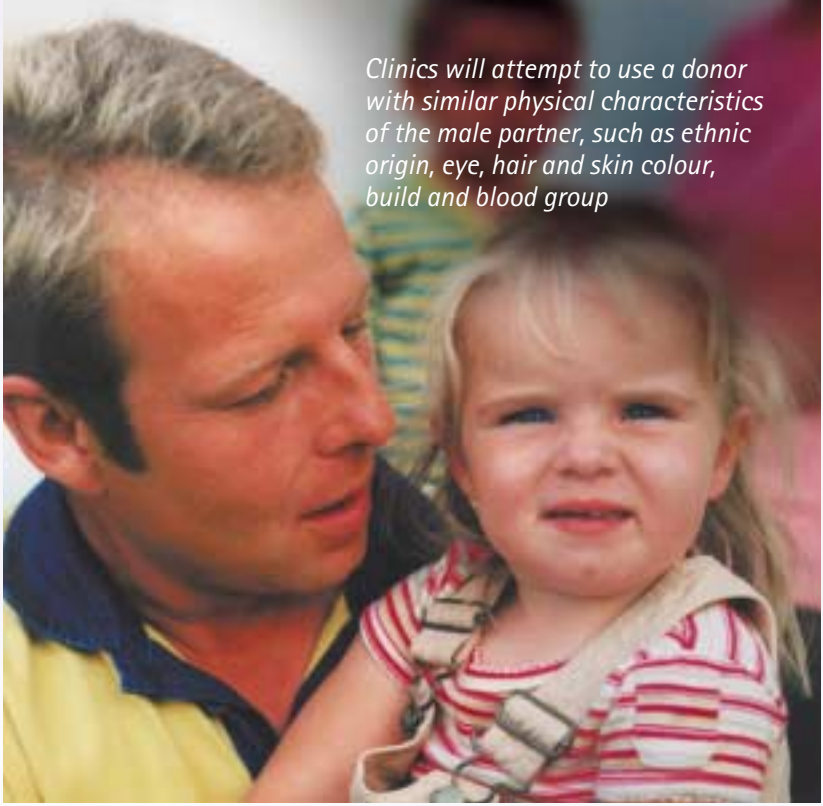
Donor Insemination (DI) means using the sperm from an anonymous donor to try to achieve a pregnancy. This may be an appropriate treatment for you if your partner has no sperm or if he has been found to be a carrier for cystic fibrosis (in these circumstances the risk of having a child with cystic fibrosis is 50%), or some other serious genetic disorder.

Donor Insemination is carried out in clinics licensed by the Human Fertilisation and Embryology Authority (HFEA). Donor Insemination is available in some clinics on the NHS. This will depend on your local Health Authority. You will need to check this with your GP or at the clinic. It is also available in private fertility clinics. Information about clinics that offer DI is available from the Human Fertility and Embryology Authority (HFEA) Tel 020 7377 5077.

Sperm donors undertake health screening checks and a full medical history is taken. More recently donors have also been specifically screened for cystic fibrosis carrier status. They are also screened for HIV, which involves sperm being frozen and quarantined for at least six months until the donor has been definitely cleared of having HIV.

The clinic will take the physical characteristics of your partner, such as ethnic origin, eye, hair and skin colour, build and blood group, and will attempt to use a donor with similar characteristics. However, at times this may be difficult. In which case the clinic will discuss this with you before treatment to enable them to find the most appropriate match. The donor's identity is confidential and you will not be able to know his identity nor the donor your identity. However you may be able to have some non-identifiable information about the donor. You will need to ask the clinic about this.

Licensed clinics are required to inform the HFEA about you and your partner,



Clinics will attempt to use a donor with similar physical characteristics of the male partner, such as ethnic origin, eye, hair and skin colour, build and blood group

the treatment you have had, the donor who provided the sperm and whether any child was born as the result of treatment. This information is entered on the HFEA confidential register. The register is kept so that any person over the age of 18 (or 16 if they are planning marriage) can find out if they were born by assisted conception (DI or IVF treatments). This enables the person to find out whether they are related to someone with whom they wish to have a child. Your child will not, however, be able to find out the identity of the donor, but non-identifiable information may be available.

It is a legal requirement that HFEA licensed clinics must take account of the welfare of any child born as the result of treatment, or any child who will be affected by the birth of a child. The clinic, therefore, may contact your GP or other agencies concerning the welfare of the potential child. In certain circumstances the clinic may ask for a detailed assessment of your health and/or social circumstances. The clinic then may refer your case to the clinic's ethics committee for consideration, before a decision is made whether to proceed with treatment. In some cases the clinics and/or the ethics committee may decide that it is not appropriate to offer treatment. If this is the case the clinic will discuss this fully with you.

Any child born to a married couple will be legally the child of the husband. However, for unmarried couples the male partner will not have automatic parental responsibility of that child

Before starting treatment both of you will be asked to sign a consent form agreeing to the treatment. As with Intrauterine Insemination, donor insemination relies on identification of the fertile time of the cycle. DI may be performed in the woman's natural cycle, but it is more common now to use some form of ovarian stimulation and very often intrauterine insemination is carried out. Once again pregnancy rates of the order of 10% to 15% can be expected.

Any child born to a married couple will be legally the child of the husband. However, for unmarried couples the male partner will not have automatic parental responsibility of that child. Unmarried couples concerned about how parental responsibility affects their legal responsibilities should seek legal advice. The donor is not the legal father, and has no legal responsibilities for the child.

Before deciding whether to have DI treatment, there are several issues you and your partner may need to consider:

- *The implications of the treatment for yourselves, your family, any children you have and any child born as the result of DI*
- *Who you intend to tell about your decision to have treatment and their possible reactions*
- *Your feelings about the reasons for having DI, the treatment itself, the donor and the fact that the child will not be your partner's genetic child*

In deciding to go ahead with treatment you will also need to consider whether you will tell the child about his/her origins by donor insemination. This is a matter for you as a couple to decide and you may find it helpful to explore the following issues:

- *The possibility of telling the child. Do you both see this in the same way?*
- *Who else knows about you having DI. Will this affect your decision about telling?*
- *The consequences of telling or not telling*
- *At what stage you would consider telling the child*
- *Your feelings about telling the child*
- *The child's right to consult the HFEA register at 18 (or 16 if he/she is getting married)*

A counsellor is usually available in the clinic for you to talk to about the implications of the treatment, and your thoughts and feelings about DI. Many clinics may suggest that you see the counsellor to talk through the consequences of having a child by DI.

Costs of this treatment: If donor sperm is used with Intrauterine Insemination the cost is around £450. If donor sperm is used with IVF treatment it adds approximately £50 to the costs.

You may also find it helpful to contact: ***DI Network****, PO Box 265, Sheffield S3 7YX, Helpline: 020 8245 4369. A self-help group for those contemplating DI or parents of children born as the result of DI.*

There are several books that are available concerning DI:

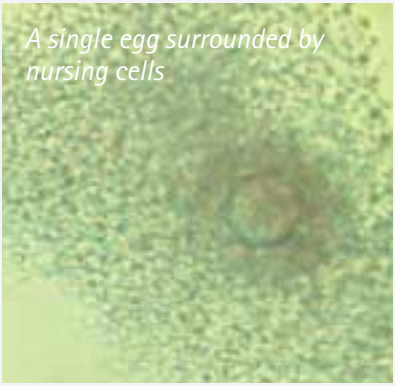
The Gift of a Child – by Robert and Elizabeth Snowden, University of Exeter Press, 1993, ISBN 0 85989 407 X

My Story: A book for children about DI – Infertility Research Trust 1991 ISBN 0 901100-29-3

Let the Offspring Speak. Discussions on Donor Conception – The Donor Conception Support Group of Australia, 1997, ISBN 0 646 32494 2

Egg donation

If you are unable to use your own eggs either because you have no eggs, or you do not want to use your own eggs, you may wish to consider using eggs from an egg donor. In your case you may wish to avoid the risk of creating a child who has cystic fibrosis because your partner has been found to be a carrier of the CF gene. By using the eggs of a non-CF carrier woman the risk of cystic fibrosis would be almost nil (see leaflet 3 – Could our baby have cystic fibrosis?). The knowledge that the child may be a carrier of the gene may not be a major issue for you as you probably know that CF carriers are usually healthy individuals.



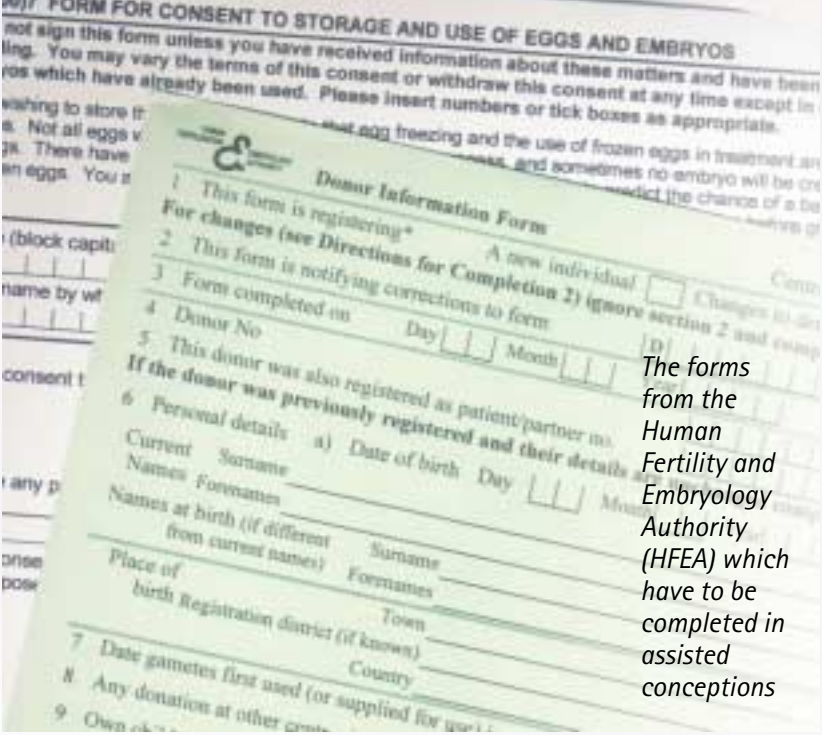
A single egg surrounded by nursing cells

The woman who will be your donor will have offered her healthy eggs in order to help someone less fortunate than herself. She usually has proven fertility, ie. has her own children, is under 35 and has been thoroughly screened and checked medically. She will have given a careful genetic history to the clinic, been screened for HIV, Hepatitis B & C, Rubella, sexually transmitted diseases, and also consented to be screened for CF carrier status. Following full counselling about her motivation and her understanding of what she is agreeing to do by the clinic, she will be accepted as an egg donor.

Unless you bring a friend or relative as a donor, the donor will be anonymous. However the clinic may have encouraged her to leave written, non-identifying information about herself which you are entitled to receive if you want it. Otherwise the information will be sent to the Central Register in London and kept on file in case it is requested by the offspring of the donor-assisted conception when they reach 18 years (or 16 if they are planning to marry).

The treatment involves the donor being stimulated with hormonal drugs in order to produce several eggs in each ovary. The eggs are collected and fertilised in the laboratory with your partner's sperm. Two days later you will have up to 3 embryos transferred to your womb in the hope that a pregnancy will be established.

The clinician will be very careful in advising you about the number of embryos to be transferred and most people would decide on one, at the most two. This would lower the chance of a multiple pregnancy (twins or triplets).



The forms from the Human Fertility and Embryology Authority (HFEA) which have to be completed in assisted conceptions

It is important for you, as the recipient, and your partner to consider your true feelings about accepting another woman's eggs, and whether you will tell the child of its genetic origins. The same principles apply as in sperm donation (see page 12). For couples where there is a genetic illness in the family it can be a way round the genetic problem. It also makes it more likely that you would want to explain to your child that they have a very low risk of being affected by CF. Your partner's CF status would need to be confirmed of course.

There are two other ways of receiving donor eggs. You can bring a known donor with you. This could be relative or a friend. Secondly, you could consider egg-sharing with another woman who has healthy eggs, but who needs IVF treatment for a non-egg related condition eg because her partner has fertility problems (See page 15).

Costs of egg donation: The costs of this treatment is around £3200 per cycle of egg donation. The cost of transferring further embryos to your womb (which were frozen as part of that cycle of donation) is £650.

Egg sharing

As explained above you could benefit by receiving eggs from another woman who is also needing treatment. Egg sharing is a relatively new way of offering IVF treatment, and can be one way of accessing treatment, which would otherwise be too costly for the woman sharing her eggs. You will need to read the HFEA's Patients guide to clinics and DI centres to find out which licensed clinics can offer this treatment (Tel 020 7377 5077). Basically it involves two couples, both of whom need IVF treatment, but who are anonymous to each other, receiving treatment at the same time. One woman is the egg provider, or donor, and the other is the egg receiver or recipient. As you have CF you could only be considered as an egg recipient. Both couples share the cost of the IVF treatment cycle, with the recipient (ie. you) paying the larger share. The egg provider is stimulated by drugs to produce eggs, hopefully more than 8, and the eggs are checked for quality and then randomly allocated 50% to each couple. The sperm of the male partners is then used to create the embryos, which are carefully labelled and left to develop in the incubator. Two days later up to 3 embryos (probably fewer) are transferred to the womb of the correct woman in the hope that a pregnancy will begin.

You might want to consider this option, or donor insemination, if your partner is a carrier for CF. Both of these options mean that only one of you will be the genetic parent of the child.

Before treatment starts you will have the opportunity to discuss all the issues which arise with the counsellor at the assisted conception unit. This will help you to make a good decision and to feel at ease with the implications of using donated genetic material. You will also have an in depth discussion with the infertility clinical specialist to make sure that you understand all the additional medical implications of the treatment because you have CF.

Every couple will be treated as an individual couple and your wishes will be taken into serious consideration before treatment begins.

Costs of egg sharing: The cost of egg sharing to the recipient (ie. you) is approximately £2800 per cycle of egg donation. There would extra costs of £1500 if your partner needs surgical sperm removal and the eggs are fertilised by ICSI.

Other useful sources of information and advice are:

National Egg and Embryo Donation Society
St Mary's Hospital, Whitworth Park, Manchester M13 0JH. Tel 0161 276 6000

ACEBABES – Assisted Conception Babies
Support for families following successful fertility treatment. Contact Doriver Lilley on 01332 832558

Daisy Network
PO Box 392, High Wycombe, Bucks HP15 7SH.Support for women suffering an early menopause

When egg sharing both couples share the cost of the IVF treatment cycle, with the recipient paying the larger share

Accessing fertility treatment

General advice about fertility may be obtained through your General Practitioner. With increasing specialisation however most fertility assessment and treatment is carried out through specialist fertility clinics run by gynaecologists with an interest in fertility work, backed by a specialist team of nurses, counsellors, scientists and support staff. Most couples seeking fertility treatment will therefore be referred for assessment directly to a fertility clinic. Although 'basic' fertility assessment is available on the NHS in most areas, the range of treatments available and the length of waiting lists may vary widely. Because of the particular time constraints on CF patients many may choose to access self-funded, private treatment. Particularly in the assisted conception field the majority of treatment is provided in the private sector in the UK at present, but the situation may change in the future.

Moral and ethical decisions in infertility treatment

The role of Human Fertility & Embryology Authority – HFEA

For anyone who is to be assisted to become pregnant the responsibility to consider the needs and welfare of the child or children that may be born as a result of the treatment is shared between the couple and the medical team. The HFEA also lays down guidelines which have to be followed before fertility clinics are licenced to carry out their work.

Welfare of the child

The HFEA have made it clear that the welfare of any child born through assisted conception, or the welfare of any existing child of the family must be of prime importance. So what do they mean by 'the welfare of the child'?

Initially it means that, as a third party, the clinical team needs to ask questions in order to be reassured that the potential parents are not, or have not been, involved in child abuse or violence nor have they lived a lifestyle which could endanger a child. The HFEA also asks clinics to consider the need of the child for a father (or mother). Therefore the issues around a child being brought up in a family where there is chronic ill health will have to be discussed quite openly. This means looking at the family support systems, both emotional and practical, and the roles of the people involved.

The child may lose a parent before he or she reaches young adulthood. Therefore it is wise to consider how the child can be supported emotionally through a parent's death, and who would be willing to take on the parenting role in the future.

Practical aspects need to be thought through carefully as well. For instance setting aside money for the future, organising access to child care, naming a guardian, writing a will, having some kind of insurance policy against future needs.

Some clinics may refer your request for treatment to their Ethics Committee who will ask for an assessment report to be written. Using this report they will consider and decide whether there are enough safeguards in place to allow treatment to proceed.

This assessment process may seem intrusive and unfair because most people are able to make their own decisions about having a family. Also many other children live with ill health in a parent, other children lose parents through war and accidents, and many

other children are raised in single parent families possibly not knowing the identity of their parent.

Therefore with all this in mind it is important for you to look seriously at why you want a child, to consider the strength of your relationship with your partner, and to build a good support network of family members and friends around you before you begin treatment.

If you are able to discuss and plan for your child's future and demonstrate that you have considered all the above questions seriously, then it may be a lot easier for your medical team to support your request for treatment.

Sources of help: The Counselling Service

If you are being treated through the NHS you may find there is a counsellor attached to the clinic, with whom you can discuss any issues which are important for you. In particular, if you are having donor insemination or egg donation, the counsellor will help you look at the implications of using donated genetic material to conceive your child.

By law all licensed clinics should offer you the opportunity of counselling, and it may be helpful to use the counsellor as a support while you are coping with the emotions aroused by treatment. It is likely that you will be asked by the clinician to take part in a counselling session to discuss the implications, both ethical and practical, of having treatment. This does not mean that the counsellor will have special knowledge about CF, but that he/she can understand the many feelings you may be experiencing at this sometimes stressful time.

Many counsellors have been trained in a first profession eg. teaching, nursing, social work, before retraining as counsellors. Most will have a diploma in general counselling and a thorough understanding of the process and psychological effects of assisted conception. The counselling service is usually free, confidential and easily accessible.

You can meet with the counsellor before, during and after treatment. Some people may find one session is sufficient, but others may have many appointments over a long period of time. Perhaps it is worth asking your CF nurse if you can meet with a counsellor, before you make a final decision about asking for a clinical consultation at the infertility clinic.

A useful source of information is:

BICA – British Infertility Counsellors Association
69 Division Street, Sheffield,
South Yorkshire.
Tel 01342 843880

BACP – British Association of Counselling and Psychotherapy
1 Regent Place, Rugby,
Warwickshire CU21 2PJ.
Tel 01788 550 899

What financial help is available to help with infertility treatment?

If you need very costly infertility treatment it is unlikely that there will be any charitable help towards this. Some private clinics can offer a form of credit card to help you spread the costs over a period of months.

So where else can large sums of money be obtained from?

- ***Bank loans***

Usually only available to people who are in paid employment.
Interest rates are usually quite high.

It is important to clarify repayment terms and to be sure not to be over committed financially. Remember if pregnancy does occur then you may need time off and getting ready for a new baby is also very expensive! Also remember to add to the calculation the extras (like holidays) that you may no longer be able to afford.

Maximise your benefits

Make sure that you are claiming all the Disability Living Allowance (DLA) and other benefits to which you are entitled.

If you have not already done so, check your benefits with a Welfare Rights expert. Even a small increase in your weekly income can help towards off-setting repayments of loans.

It may also be worth asking at the same time what benefits would be available to you as a family if the worst scenario happened and you and your partner could no longer work because of the demands of your care and the needs of your baby. If your income was reduced in this way could you afford to repay any loans you have?

Relatives and friends

The disadvantage of having to ask relatives and friends is that it means your need for treatment cannot be kept to yourselves. This can add to the pressure if enquiries about the success of each treatment follows. Obviously everyone's situation is different and sometimes families would love to help, but are simply not able. Others may view your treatment as an investment in their family's future too.

Self help groups

Make use of advice from voluntary organisations:

CHILD – the national self help network for those trying to have a family.
Charter House, 43 St Leonards Road,
Bexhill on Sea, East Sussex TN40 1JA.
Tel 01424 732361

ISSUE – to improve the quality and delivery of infertility treatment.
114 Lichfield Street, Walsall WS1 1SZ.
Tel 01922 722888

How else could we become parents?

If you have decided not to risk a pregnancy, or if you have tried fertility treatment without success then there are other options which may still be open to you as a couple.

If your fertility treatment has not been successful

Sadly for some couples fertility treatment may not give them the baby they want so much. It is not always understood why embryos which may look perfect do not implant and grow. Humans are very poor at reproducing themselves, and this holds true whether you have CF or not.

Your clinician may decide to end treatment for medical reasons. This decision may be affected by your declining health or because the fertility treatment has repeatedly failed. However many couples come to a point at which they realise that treatment should end. This could be for physical, emotional or financial reasons and may be accompanied by a whole host of emotions or for some a sense of relief.

Living as a childless couple is not the end of the world and nor is it inevitable. The important thing to remember is that you have both tried to become parents, and therefore there may be fewer regrets at not succeeding. As a couple you may need to review your life together and try to develop interests and times of enjoyment, which will be meaningful to you in the future.

It may be worth considering other options like surrogacy (if you could possibly still afford it) and adoption or fostering. But whatever happens your partner will have feelings too about this next stage in your lives together. It would seem to be a time to talk and plan ahead whatever challenges you may meet in the future.

Surrogacy

Surrogacy is the process by which one woman has a pregnancy and gives birth to a child for another woman who finds it impossible to go through a pregnancy and childbirth. There are various reasons why you might want to consider surrogacy.

Firstly, because you have cystic fibrosis it may be too dangerous for you to become pregnant or to give birth. However there are other reasons which would make surrogacy a possible solution and the British Medical Association (BMA) has agreed that the following criteria would justify offering surrogacy as a treatment option:

- *Chronic ill-health may make pregnancy or childbirth too risky for the mother or the child*

- *A woman who has been born without a uterus, or who has had a hysterectomy, may still have working ovaries but would need a surrogate to be the carrier of her child*

- *A history of many miscarriages or several stillbirths may be a strong reason for surrogacy*

- *When IVF treatments have consistently failed over many attempts it may be an option for some women who have the emotional stamina to follow another route to parenthood*

- *There may be other medical reasons why a woman has been advised not to become pregnant*

There are two kinds of surrogacy, and it is important to consider carefully which option is the correct one for you.

The first is straight surrogacy in which the surrogate mother is inseminated with the sperm of your partner. The child conceived in this way is therefore the genetic child of the surrogate mother and your partner.

Secondly there is host surrogacy in which the genetic embryos of you and your partner are created in the laboratory and then transferred to the uterus of the surrogate mother. Some people may need to use donor eggs, or donor sperm, to create the embryos but this will all be discussed at the time of your consultation at the Infertility clinic.

Many clinics do not offer straight surrogacy because of the increased risk that the surrogate mother may refuse to part with the child because she is his/her genetic mother.

The most successful surrogate arrangements can occur when a close relative of the woman eg. a mother or sister, offers to be the surrogate. In this case the motives and emotional links with the commissioning parents are quite clear and many of the complications of using an 'unknown' surrogate just do not occur.

Licensed clinics will only treat you if you have already met and made a relationship with your surrogate. It is illegal for anyone to coerce or advertise or receive money for finding and offering a surrogate to a couple

and therefore most people will approach a charitable group such as COTS (Childlessness Overcome Through Surrogacy) Tel 01549 402401, who can help and advise you in your search. Surrogacy is not illegal in this country. COTS usually has a long waiting list of couples hoping to meet a surrogate. They will require you to be assessed before acceptance on to the waiting list. Some people search on the internet for a surrogate, but this can be risky for many reasons, and the information is usually US based and therefore not so appropriate for people who live in the UK.

The clinic will also refer you and your surrogate to the clinic Ethics Committee who will look carefully at the reasons for the surrogacy, the suitability of the surrogate and the welfare of any child born through the arrangement. Should they be satisfied that all parties are fully aware of the implications and possible outcomes then treatment can proceed.

You will need to take into account the requirement to freeze and store your embryos, or the frozen sperm of your partner, for 6 months to ensure that the possibility of infection from HIV is absolutely minimal. You can begin this process before you have all the other details in place.

After the birth of the child there is still a legal process to establish you and your partner as the legal parents of the child. To protect the interests of the child some conditions are laid down by the court and must be fulfiled before any treatment can begin.

These conditions are as follows:

- *You and your partner must be married*
- *You must both be over 18*
- *You must both be resident in the UK*
- *There must be no suspicion that the surrogate was coerced into the arrangement and all financial arrangements must be accounted for and legally acceptable*
- *The child must be the genetic child of your partner and yourself, or be genetically related to one partner, or be created from donor gametes in a licensed infertility clinic*

The Court will appoint a 'Guardian Ad Litem,' ie. a Social Worker with experience of assessing the legal situation and whose main concern will be protection of the interests of the child born through the surrogacy arrangement. She or he will visit both the surrogate and the commissioning parents, ie. yourselves after the birth and will report back to the Court. If everything is in order a Parental Order will be given which allows the commissioning parents to be declared the legal parents of the child.

However, if the child has been created from both donor eggs and donor sperm (ie. a donated embryo) then as the commissioning parents, you will have to apply to adopt the child. For more information see section on page 25.

Information about all children born through surrogacy is recorded by the HFEA on the Central Register. Any person over 18 (or 16 if they are planning marriage) can have access to this information.

It is very unusual for commissioning parents to remain secretive about the origins of their child and many parents and surrogates remain in contact long after the birth. Although surrogacy can be a difficult and emotionally draining method of creating a family, it can bring great happiness to couples whose hopes of parenthood were non-existent.

Costs of surrogacy: Legitimate costs to the surrogate are very variable, are negotiated privately and should be added to the treatment costs. Treatment charge for surrogacy starts at around £4000 for an individual cycle and is reduced to £3200 for each subsequent cycle. This includes the cost of creating the embryos, and having them transferred, plus all the counselling and assessment time within the clinic.

To find out which clinics offer surrogacy read through the HFEA's *Patient guide to clinics and DI centres,* HFEA, 30 Artilliery Lane, London E1 7LS.
Tel 020 7377 5077

Fostering and adoption

If you have reached the decision that it would be unwise, impossible or too costly to have the treatment required to enable you to have a child of your own, then you may want to consider the possibility of fostering or adopting a child.

So what's involved?

Every prospective foster parent and adoptive parent has to be carefully assessed by specialist workers from Social Services or the fostering or adoption agency. This is because the most important consideration in placing a child with a foster family or adoptive family is always the welfare of the child. Inevitably part of the assessment process is to consider the health of the applicants and whether they are likely to be able to provide the child with a stable and loving home for as long as this is needed. Any child who is 'looked after' by the local authority (formerly known as being in care) will already have experienced separation from his /her birth parents for some reason and so security and continuity of care will be very important for that child. The possibility of him/her 'losing' another parent will have to be weighed up, as this could cause the child further harm.

The adoption or fostering agency panel, who make the final recommendation following the assessment process, will want to be sure that any new family has the potential to care for a child into independence. For this reason the panel may limit the age group for which you are approved or may not feel able to recommend you at all. It is sometimes helpful to ask for the adoption agency's panel to consider the facts about your CF and your current state of health before beginning the lengthy assessment process. It is especially important that the panel has up to date information about cystic fibrosis and also a medical report explaining how you are affected as an individual.

You are probably aware that these days there are very few small babies available for adoption and families are often asked to consider whether they could care for older or disabled children. Each family's strengths and weaknesses will be carefully matched with the needs of each individual child. The experience that you and your partner have in coping with the extra demands caused by your CF and all your treatment, may well be viewed very positively. Short-term, short-break (respite) or crisis fostering may be recommended for you rather than longer term fostering or adoptive placements. However shorter term placements may be more difficult emotionally for you, when the time comes for the child to move on.

It is important to remember that most children who are placed in a foster home do have a birth family who for one reason or another are unable to care for them for the time being. Unless the child is at risk of abuse it will usually be considered to be in their best interests to keep their contact with and eventually return to their birth parents if at all possible. Even when a child has been adopted into a new family there is the possibility that they will maintain some contact with their birth family.

The disruption in their lives that most children who are 'looked after' have experienced makes it very likely that they will have some difficulty in settling into a new home, especially if they are old enough to realise what is happening. Inevitably, therefore, fostering and adoption can be very hard work and most prospective foster parents and adoptive parents are offered training before they are approved. This training may be essential in helping them cope with

the difficult behaviour or emotional reaction that the child may display.

This description of the process of being approved as foster or adoptive parents and then of the task of caring for a child who needs a loving home may appear more daunting than you might have expected. However many people make excellent foster or adoptive parents and enjoy a good relationship with the children they care for and make a great deal of difference to their lives. In order to be realistic about what is involved it is important to remember that the needs of the child will always be put first and fostering and adoption is no easy task!

If you decide that you would like to find out more information about adoption or fostering then it may help you to get started if you contact one of the following organisations:

Your local Social Services department – the address and telephone number will be listed under your local council in the telephone book.

British Agencies for Adoption and Fostering – Tel 020 7593 2000

National Foster Care Association – Tel 020 7620 6400

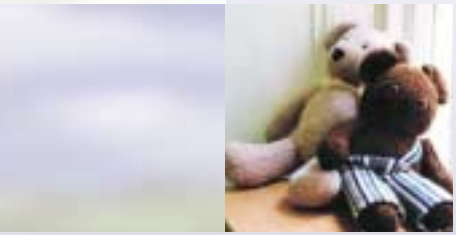
Step parenting

If your partner already has a child or children from a previous relationship, then you will become their step parent when you marry your partner. This may mean that you look after your step family either full or part time – depending on the residence and access arrangements for the children.

Step parenting can be rewarding and also hard work. It can be particularly difficult if your partner and the children's mother do not easily agree about matters that affect the children. There is a lot of potential for the children to 'divide and rule', especially if they resent the break up of their parents' relationship or if they have unresolved grief if their mother has died.

It is especially important to work together with your partner in agreeing about matters such as discipline, financial arrangements and responsibility for day to day care of the children. A ready made family can bring lots of joy and fulfilment too. Step parenting is becoming increasingly common in Britain and there are publications and courses available to help prepare for becoming a step parent available from:

Parentline Plus (formerly the National Stepfamilies Association), Central Office, 520 Highgate Studios, 53-79 Highgate Road, Kentish Town, London NW5 1TL. Tel 020 7209 2460.



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Leaflets in the series:

Leaflet 1: Can I have a baby?

Leaflet 2: How can I have sex safely?

Leaflet 3: Could our baby have CF?

Leaflet 4: Should we have a baby?

Leaflet 5: How can I plan for a safe pregnancy and birth?

Leaflet 6: How could we become parents?

Leaflet 7: How does it feel to go through infertility treatment? – A patient's perspective

Leaflet 8: What is it like to be a parent?

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