

FREE

The HFEA guide to

infertility

2006/07

Your treatment
choices explained

Where to find
the best support

Questions to ask
your doctor

HUMAN
FERTILISATION
&
EMBRYOLOGY
AUTHORITY

Welcome



You've been trying for a baby for some time now. You didn't think it was going to be this difficult to get pregnant. Is there a problem and, if so, what can you do about it? Who can you go to for reliable, independent information about such a very personal subject? And if you do need medical help, where should you go?

These are just some of the questions we at the Human Fertilisation and Embryology Authority (HFEA) often hear from people considering fertility treatment. One of our roles, as the UK regulator of fertility treatments such as IVF, is to provide independent information so that you can understand all the different options, helping you to choose the treatment that is right for you, as well as being safe.

Hundreds of people have shared their experiences with us and told us the things they would like to have known before they started

treatment. Based on this we have put together this Guide for you, your partner, family and friends. Of course everyone's circumstances are different and this Guide cannot replace personal medical advice from your GP and clinic staff. But we hope it will help you to get the most out of discussions with your GP and clinic staff, as well as feeling that you are making informed choices throughout your treatment.

To help you decide where to go for treatment, we have also introduced an online, interactive Find a Clinic function on our website: www.hfea.gov.uk. Here you can enter details about your needs and circumstances, such as where you live, your age and the type of clinic services you are looking for.

The site will provide a list of the clinics that meet your criteria, and give you essential information about their performance: for example, how many people in your age group they

have treated and how many babies have been born. You can also see our latest inspection report for each clinic, which will help you to understand more about what it's like to be a patient there.

Infertility is a fast-moving and complex area of medicine. New issues arise all the time, which is why we are constantly updating our website with information for patients. I'd encourage you to visit it regularly for the most up to the minute information, as well as to find out more about how we inspect and regulate clinics and the vital role that patients play in helping us to set and enforce standards.

We are always looking at ways in which performance can be improved and welcome your views. If you would like to tell us about your own experience at a clinic, there is a questionnaire on our website which you can fill in and return to us - whatever you say will be kept confidential.

If you would like to help the HFEA to keep patients' views at the forefront of regulation, you may wish to join our online patients' panel, Fertility Views, by visiting www.hfea.gov.uk/fertilityviews. Anything that you tell us helps us to make sure that we focus on the issues that matter to you.

And, of course, we are always looking for ways to develop this Guide, so do let me know what you found helpful and where you think it could be improved by emailing admin@hfea.gov.uk.

May I wish you the best of luck with your treatment.

Suzi Leather

Dame Suzi Leather
Chair, HFEA

Contents

SECTION ONE: BEFORE TREATMENT BEGINS

- 4 **Fertility matters**
What it means, how it works and how babies are created
- 6 **Is there a problem?**
What could be stopping you starting a family
- 8 **Finding the right help**
Who to turn to and what to expect
- 10 **Counting the cost**
When is NHS funding available and what are the costs of private treatment?
- 12 **Call the clinic**
Finding the right one for you
- 14 **Talking it over**
How counselling and support groups can help you at every stage

SECTION TWO: YOUR TREATMENT OPTIONS

- 16 **At the clinic**
- 18 **Drugs and surgery**
- 20 **IUI: Intrauterine Insemination**
- 22 **IVF: In Vitro Fertilisation**
- 26 **ICSI: Intra-Cytoplasmic Sperm Injection**
- 28 **GIFT: Gamete Intra-Fallopian Transfer**
- 29 **Using donated sperm, eggs or embryos**
- 34 **Surrogacy**
- 36 **Freezing and storing embryos**
- 38 **If you become pregnant**
Making the transition from fertility patient to parent-to-be
- 40 **Moving on**
Considering your options if treatment has not worked

SECTION THREE: FURTHER INFORMATION

- 42 **Clinics licensed by the HFEA**
- 44 **Useful contacts**
Groups and organisations that can provide information and support
- 46 **Ask the clinic**
Questions you can ask at your consultation

Disclaimer

Every effort has been made to ensure that information provided in the HFEA Guide to Infertility is accurate as at April 2006, but this cannot be guaranteed absolutely. The information in this Guide does not constitute legal or other professional advice, and is intended to provide general information only. The HFEA cannot vouch for the information supplied by other organisations mentioned in this Guide. Nor does the inclusion of such organisations' details in the Guide imply any endorsement by the HFEA. Photographs in the Guide are posed by models except for patients' own stories and those on pages 2, 22, 25, 26 and 39.

Fertility matters

IT TAKES JUST ONE SPERM AND ONE EGG TO CREATE A NEW LIFE, BUT THERE'S MORE TO FERTILITY THAN THAT. WE LOOK AT THE MIRACLE OF MAKING BABIES

Before we start to look at infertility, it helps if you know something about fertility - what it means, how it works and how babies are created. The exact moment of fertilisation is when a woman's egg and a man's sperm fuse to form a single cell. But for this to happen successfully, certain things must be in place.

Your hormones, which are your body's chemical messengers, must be balanced and the bodily systems that produce eggs and sperm must be working at optimum levels. In addition, intercourse must take place around the time of ovulation when an egg has been released from the ovary.



Eggs and sperm

FOR WOMEN



We are all born with a certain number of eggs, but you have to wait until puberty before the hormones that kick-start your menstrual cycle and ovulation come into play.

- Successful egg production depends on the interaction of several different hormones. Part of the brain known as the hypothalamus starts off the process by producing gonadotrophin-releasing hormone (GnRH) which stimulates the small gland at the base of your brain, the pituitary, to release follicle-stimulating hormone (FSH). This in turn triggers the follicles, or egg sacs, to start developing in the ovaries.
- These follicles produce oestrogen which stimulates the pituitary gland to produce another hormone called luteinising hormone (LH), the magic body chemical that triggers ovulation once a month until you reach the menopause. The exact time of the month for ovulation depends on your own individual cycle, which in an average 28-day cycle will be around days 12-15, day one being the first day of your period.
- At ovulation, the ripest egg sac bursts to release an egg, which starts to

travel down the fallopian tube where it may meet a sperm depending on whether you have had intercourse within the last four days. Eggs live and can be fertilised for 12-24 hours after being released and sperm can stay alive and active in your body for 12-48 hours, so you don't have to have intercourse at the exact moment of ovulation to get pregnant.

- After ovulation, the remains of the egg sac form a small yellow body called the corpus luteum, which then starts producing the hormone progesterone whose job is to increase the blood supply to the lining of your womb, making it the perfect environment for a fertilised egg. It takes around five days for the fertilised egg to reach the womb and by the time it embeds itself in the womb lining, it will be made up of around 150 cells.
- If the egg isn't fertilised, or is fertilised but doesn't attach itself to the lining of the womb, it starts to break down, the corpus luteum shrinks and progesterone levels plummet. As a result, the blood vessels in the womb lining break up, the walls of the womb contract and you have a period, which is in fact the lining of your womb (known as the endometrium) being shed.

FOR MEN



As you reach puberty, the same hormones that control ovulation in women stimulate the release of testosterone, which is responsible for producing sperm.

- Gonadotrophin-releasing hormone, or GnRH, produced by the hypothalamus in the brain, triggers the release of follicle-stimulating hormone (FSH) and luteinising hormone (LH) from the pituitary gland. FSH stimulates sperm production in the testicles while LH stimulates the testicles to produce testosterone.
- From the testicles, sperm travel to the epididymis, a 40ft coiled tube, where they mature, which takes between nine and ten weeks. They then travel down another tube, the vas deferens, to the penis ready for their next journey.
- At the point of ejaculation during intercourse, your penis releases as many as 300 million sperm into your partner's vagina but only a few survive the hazardous journey through the neck of the womb (cervix), uterus and fallopian tubes. And ultimately only one will burrow its way into an egg.

Boost your fertility

Here's what you both can do to increase your chances of getting pregnant as well as lowering the risk of complications during pregnancy.

EAT WELL - A balanced diet will help ensure a woman's body is healthy enough to conceive and nourish a developing baby. A healthy diet can also help to keep sperm production at optimum levels.

WATCH YOUR WEIGHT - Being overweight or underweight can disturb the menstrual cycle.

TAKING SUPPLEMENTS - The government recommends that all women trying for a baby should take 400mcg of folic acid a day to help protect against conditions such as spina bifida.

DRINK WISELY - Alcohol may affect fertility and increase the risk of miscarriage as well as affecting sperm quality. Government guidelines advise no more than one to two units once or twice a week for women and two to three for men.

QUIT SMOKING - Smoking has been linked to infertility and early menopause in women and sperm problems in men, as well as being a factor in a premature or low birth-weight baby.

BEWARE DRUGS - Some prescription drugs can lessen your chances of conceiving, so if you are taking regular medication and want to try for a baby, talk to your GP about alternatives. Street drugs such as marijuana and cocaine should obviously be avoided.

BE ACTIVE - Regular, moderate exercise of around 30 minutes a day helps maximise your fitness and keeps your weight in check (see above). It also boosts levels of endorphins, the body's own happy hormones which may help to get you both through this stressful time.

KEEP IT COOL - For maximum sperm production the testes should be a couple of degrees cooler than the rest of your body. So it may help men to wear loose-fitting underwear and trousers and to avoid activities that boost the temperature of the testes such as saunas and hot showers.



Did you know?

Making love less often won't increase your chances of conception. You are much more likely to get pregnant if you make love every couple of days.

All in a cycle

FOR WOMEN



The average monthly cycle - the time between periods - is 28 days, day one being the first day of your period. The most fertile time depends on the length of your cycle, which can vary (see below).

But as a general rule:

- Days 1-5: You have your period.
- Days 6-14: The womb lining starts to build up and, as levels rise,

becomes thicker, ready for the possible arrival of a fertilised egg. Oestrogen also stimulates the mucus produced by your cervix (neck of the womb) which thins it down, making it easier for a sperm to swim through.

- Days 15-28: Rising levels of progesterone prepare the womb environment still further for a fertilised egg. If fertilisation has not taken place the hormonal balance changes accordingly and your cycle starts all over again.

Ovulation

At puberty, a girl's body starts to make the hormones that will cause her eggs to mature. Until the menopause, she will release an egg (ovulate) each month, around about day 14 of her monthly cycle (day one is the first day of a period). The average monthly cycle - the time taken between periods - is 28 days, although this differs from woman to woman. Your most fertile time depends on the length of your cycle.

Cycle length	Fertile days
23 days	5-8
25 days	9-12
28 days	12-15
31 days	15-18
33 days	17-21
35 days	19-22

Talk to a doctor if your cycle is longer or shorter than shown.

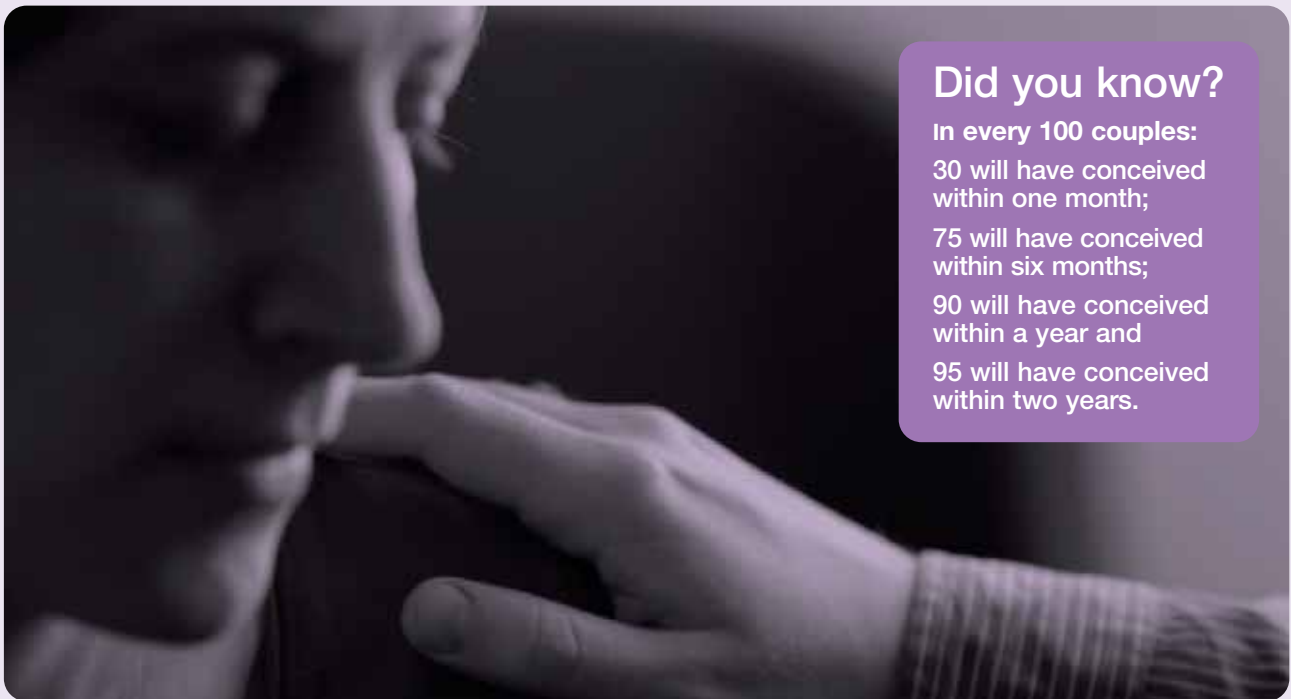
Is there a problem?

STARTING A FAMILY IS NOT ALWAYS AS SIMPLE AS YOU THINK. READ ON TO FIND OUT WHAT COULD BE STOPPING YOU

Getting pregnant can be harder than you think. If you are having intercourse regularly without using contraception you should conceive within two years, but in any one month your chances of conception are only around 20 to 30 per cent.

But first some reassurance – if you are having problems conceiving, there is plenty of help available to you, to identify possible causes and how to treat them. You are not alone; around one in seven couples has difficulty.

Infertility is often thought of as a female concern, but in fact in nearly a third of cases (32 per cent) it is because of male problems, such as a low sperm count. Conditions affecting the woman's fertility can include damage to the fallopian tubes (16.7 per cent of cases), ovulatory problems (4.9 per cent), endometriosis (3 per cent) and conditions affecting the uterus (0.3 per cent). Sometimes it can be a combination of factors that account for infertility (17 per cent of cases) and sometimes there is simply no identifiable reason (18.7 per cent).



Did you know?

In every 100 couples:

30 will have conceived within one month;

75 will have conceived within six months;

90 will have conceived within a year and

95 will have conceived within two years.

What can go wrong?

FOR MEN



- Sometimes a man does not produce enough sperm (known as a low sperm count), or the sperm are not of a sufficiently high quality to fertilise the egg. It is also possible that there are problems with the tubes that carry sperm. If a man finds it difficult to get an erection, or has trouble ejaculating, sperm may not reach his partner's vagina.

FOR WOMEN



- Sometimes a woman's ovaries do not release eggs, or the fallopian tubes can be blocked or damaged, which means that eggs are not carried from the ovaries to the womb. This can also prevent a fertilised egg from reaching the womb, or prevent sperm from reaching and fertilising one of the eggs.
- There can also be problems with the womb lining, which mean that a fertilised egg is prevented from implanting successfully. There may not be enough lubricating mucus from the neck of the womb, the consistency of the mucus could be too thick or it could affect the ability of the sperm to swim towards an egg.

YOU ASK...

I am really stressed at work. Could this be why I am not getting pregnant?

The jury is still out on this one but some experts think stress could be a factor in infertility and numerous research projects are being carried out in this area. There is no doubt that female hormones are affected by anxiety and tension. Stress is also thought to lower sperm production in some men.

I am 37 and my partner is 40. Are we too old to have a baby?

Fertility wanes in men and women with age, but the decline is steeper in women. Figures suggest that 94 per cent of women aged 35 years and 77 per cent of women aged 38 years will conceive after three years of trying. Male fertility is also thought to take a downturn with age, although to what extent is less clear.

I have never had trouble getting pregnant before so why is it taking so long this time?

Regardless of whether you have had a baby or babies with your current or previous partner, you may still find it difficult to conceive. Have there been any major changes in your lifestyle? For example, have you had any gynaecological or medical problems? Are you having sex as frequently as you did when you were last trying for a baby? You may also not be as fertile as you were, especially if it is a few years since your last baby.

All about BMI

The body mass index (BMI) is a measure of your weight in relation to your height. If your BMI is between 25 and 30, you are classed as overweight, and if it is above 30, you are classed as obese. In both these cases, you may find it harder to conceive. Some clinics may take your BMI into account when deciding if you are eligible for treatment. Use this chart as a guide to your BMI range by finding the point where your weight (going across) meets your height (going up).

Beyond the obvious

There may also be underlying factors which are hindering your chances of conceiving.

FOR WOMEN

- Previous surgery, for example for appendicitis, cancer or an ovarian cyst, may have caused scar tissue, which is blocking your fallopian tubes. Infections such as chlamydia or gonorrhoea can scar the fallopian tubes and prevent sperm from reaching an egg. You may be suffering from polycystic ovary syndrome, which is caused by hormonal imbalances, making ovulation erratic: symptoms include heavy, irregular or absent periods, weight gain, acne and excess body hair. Endometriosis, where tissue

similar to the womb lining grows elsewhere leading to inflammation, pain and scarring, can also damage the fallopian tubes and ovaries.

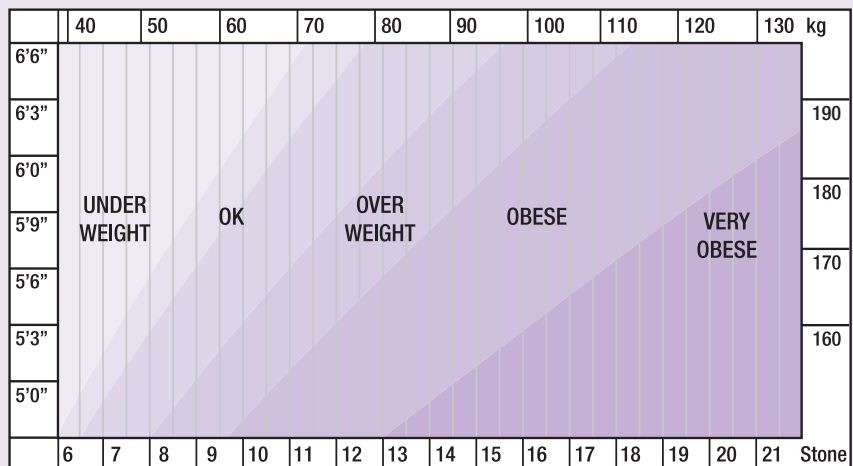
- Other conditions that can have an impact on your fertility include diabetes, epilepsy, thyroid and bowel diseases, as well as gynaecological problems such as a previous ectopic pregnancy or more than one miscarriage. Being overweight or underweight can also affect how easily you conceive. If you have a body mass index (BMI) of over 29 or under 19, for example, you may find it more difficult to get pregnant (see 'All about BMI' below).

FOR MEN

- If you have ever had inflamed testes, usually caused by a virus such as mumps, or drug treatment or radiotherapy, your sperm production may have been affected. Genetic problems are another possible reason for sperm abnormalities. A previous bacterial infection can cause scarring and blockage of the tubes, while surgery, for example to correct

a hernia, undescended testes or twisted testicles, can damage the tubes or impair blood flow to the testes. Diabetes, medication or surgery on the urinary tract can cause retrograde ejaculation, when sperm travels backwards. Being overweight can also affect the quality and quantity of sperm. A job that brings you into contact with chemicals or radiation is another factor to consider.

Body Mass Index Graph (courtesy of Cancer Research UK)
© Cancer Research UK www.cancerresearchuk.co.uk



Finding the right help

IF THE MONTHS GO BY AND YOU STILL HAVEN'T CONCEIVED, IT COULD BE TIME FOR A CHAT WITH YOUR GP

If you are both young and healthy and have been trying for a baby for 18 months to two years without success, a visit to your doctor could help to highlight potential problems earlier rather than later. But if you

are over 35, it is a good idea to make an appointment with your GP after six months, as fertility tests can take time to complete and your age may affect the treatments available to you.



In the surgery

Your GP will listen to your concerns, make a note of your medical history and give you a physical examination. This is usually followed by a few basic tests, which can include:

FOR WOMEN



- Cervical smear test if you haven't had one recently.
- Urine test for chlamydia, which can block your fallopian tubes, preventing you becoming pregnant.
- Blood test to see if you are ovulating. This is done seven days before your period is due.
- Blood test to check for German measles (rubella) which, if contracted during the first three months of pregnancy, can harm your unborn baby.
- Blood test during your period to check for hormone imbalances.

FOR MEN



- Sperm test to check for abnormalities,
- Urine test for chlamydia.

Ask your GP

- Why am I being offered the test?
- Are there any alternatives?
- What will the test show?
- How long will the test take?
- When can I expect the results?

Going forward

If your test results are normal and you have been trying for a baby for less than 18 months your GP may suggest you make a few lifestyle changes (see page 5) and go on trying for a bit longer. If, however, the tests reveal a possible fertility issue, especially if you are in your thirties or older, they may make an appointment for you to see a specialist at your local hospital or fertility unit. Some fertility treatments are available on the NHS and your GP should be able to tell you what these are. The private sector also provides a full range of services.

Your GP should refer you for further tests without delay if:**FOR WOMEN** 

- Your monthly cycle is less than 21 days or longer than 35 days.
- You're not ovulating.
- You have had previous gynaecological conditions such as endometriosis, an ectopic pregnancy or a pelvic infection.
- You are in your thirties and have been trying for a baby for over 18 months.

FOR MEN 

- Your sperm test shows abnormalities.

FOR MEN & FOR WOMEN 


- You have abnormally shaped pelvic organs.
- You have been trying for a baby for three years or more.

Ask your GP

- What clinics and treatments are available locally?
- Do you refer patients to a particular clinic or specialist and if so why?
- What kind of a clinic is it and what treatments does it offer?
- How long will we have to wait for an appointment and is there anything we can do to speed things up?
- If we need fertility drugs and tests can we get them on the NHS or will we have to pay?

At the clinic

Further tests at your local hospital or fertility clinic may include:**FOR WOMEN** 

- Blood tests to find out if you are ovulating.
- Ultrasound scan to look at your womb and ovaries.
- Follicle tracking – a series of ultrasound scans follow the development of a follicle to see if an egg is developing.
- Hysterosalpingogram – an x-ray to check your fallopian tubes.
- Laparoscopy – an operation in which a dye is injected through your cervix

and a flexible tube with a tiny camera attached is used to check for tubal blockage.

- Hysteroscopy – a telescope with camera attached is used to view your uterus to check for conditions such as fibroids or polyps.
- Hysterosalpingo-contrast sonography (HyCoSy) – a vaginal ultrasound probe is used to check the fallopian tubes for blockages.
- Occasionally, tissue sample may be taken from your womb lining to be analysed.

FOR MEN 

- Semen analysis to check sperm numbers and quality.
- Sperm antibody test to check for protein molecules that may prevent sperm fertilising an egg.
- Sperm invasion test to see if sperm are swimming through the cervical mucus and are still active.

Talking it over

It can be difficult to appreciate just how stressful infertility can be unless you have been through it yourself and you may find your family and friends are not as understanding as you would like them to be. To help you through what many couples describe as 'this emotional rollercoaster' you may find it helpful to join a support group where you can meet other couples who are

going through the same experience. Ask your GP for details of any local groups or see page 44.

You will also find a lot of internet support sites run by people who have similar experiences. You may also find it helpful to talk to a counsellor who specialises in helping those with fertility problems (see page 14).

Busting the jargon

INFERTILITY - means you are unable to conceive.

SUBFERTILITY - which is more common, means you have problems that make conception difficult if not highly unlikely without medical help. This term is also used if you can get pregnant but keep having miscarriages.

PRIMARY INFERTILITY - is the term used for couples who can't conceive.

SECONDARY INFERTILITY - refers to couples who, after having had one or more babies, can't conceive or who have had one or more miscarriages or stillborn babies. Secondary infertility is more common than primary infertility.

Counting the cost

WHEN ALL YOU WANT IS A BABY NO PRICE CAN SEEM TOO HIGH, BUT BEFORE STARTING TREATMENT YOU DO NEED TO THINK ABOUT THE FINANCIAL SIDE

You can either have NHS-funded treatment or go privately. The treatment won't necessarily be any better in the private sector, but you can probably start treatment more quickly, although there may still be waiting lists for treatments such as egg donation.

NHS-funded treatment

Provision of NHS-funded treatment can still vary across the UK but the NHS aims to offer women between the ages of 23 and 39 at least one free cycle of IVF, assuming you meet the eligibility criteria. Some criteria are set out in the National Institute for Clinical Excellence (NICE) fertility guideline (see www.nice.org.uk) and others are determined locally, such



as the treatment of couples where one partner already has a child. The NICE guideline applies to England and Wales only - Scotland and Northern Ireland have different criteria. For the most up to date information, talk to your GP.

NHS treatment may be available at your local hospital or a private clinic if your Primary Care Trust or Health Board has a contract with them. Waiting lists vary. Unless you are exempt, you will have to pay prescription charges for drugs.

Possible restrictions

- If initial tests show up no identifiable cause for your infertility you may be offered tests and other treatments, such as fertility drugs and intrauterine insemination, before being offered IVF.
- Women must be under 40 and, after clinical assessment, be thought to have a good chance of responding positively to treatment. For example, they should not be coming up to the menopause.

- There may be criteria relating to existing children.
- The Choice of Referral scheme, which came into effect from 1 January 2006, gives most patients some choice of where they are seen when they are first referred by their GP for an outpatient appointment. This will include couples who are being referred to a specialist for tests to determine the cause of infertility. However, patients' right to choose under the scheme does not extend beyond the first outpatient referral.

Are you eligible?

To find out if you are eligible for NHS funding, the first person to speak to is your GP, as you will usually need a referral from them.

Alternatively, you can contact your Primary Care Trust (England), Local Health Board (Wales), Health Board (Scotland) or Health and Social Services Board (Northern Ireland) direct, and ask for details about their funding policy, and who is eligible.

Going private

In theory, anyone with the means can have private treatment, but individual clinics still have rules about whom they will and won't treat. We recommend you ask the clinic about their eligibility criteria early on.

So what's involved if you go privately? You pay for your drugs and treatment at a private unit of your choice and you get to choose your consultant. Treatment prices can vary widely from clinic to clinic depending on what tests and treatment you are offered. A single attempt at donor insemination, for example, can cost as little as £100 and usually no more than £500. A cycle of IVF, however, can cost anywhere between £800 and

£3,000, depending on where you live and the clinic you choose. Drugs and consultations will be extra.

That said, private clinics are in competition with each other and prices tend to be fairly similar. The drugs used for IVF are expensive, so check if they are included in the overall price. If they aren't, it's worth comparing prices from different sources such as your clinic's dispensary and local pharmacies, as prices can vary. Sometimes they may be available direct from the pharmaceutical company.

Some fertility clinics offer egg-sharing schemes in which women can donate eggs collected from a cycle of IVF to another woman in return for a reduced price IVF treatment. They will still have to pay for any extra treatment needed.

Both NHS and private clinics pay a fee towards the costs of being regulated by the HFEA. Regulation is needed to ensure the clinics comply with the law and that practice is safe and appropriate. The fee paid by clinics to the HFEA is based on the number of IVF and donor insemination treatments they carry out.

We charge the clinic directly and some include this in their overall fee to patients, as they do for the other costs of running a clinic. Some clinics, however, may pass this cost directly on to you as an additional cost: £104.50 for each IVF cycle or £52 for each donor insemination cycle. Do check with your clinic what their practice is.

For more information visit www.hfea.gov.uk/ForPatients

How it adds up

Costs typically cover:

- First and follow-up consultation appointments for a couple.
- Simple tests such as hormone tests, ultrasound scans and sperm tests.
- Special tests such as hysterosalpingogram (fallopian tubes x-ray), ultrasound tracking of egg development, trial embryo transfer and genetic tests.
- Assisted conception treatments, including intrauterine insemination, donor insemination, IVF, ICSI, egg or sperm donation or frozen embryo donation.
- Freezing and storage of sperm and embryos.

Our story: We were treated on the NHS



Sara, 34, a civilian in the police force, has polycystic ovary syndrome (PCOS) and her husband Kevin, 40, a police officer, has a variable sperm count. After treatment the couple, who live in the Midlands, are expecting their first baby. Sara tells their story:

Treatment time

'We were treated on the NHS and only had to pay an extra £270 to have our embryos frozen. We had no problems

getting NHS treatment as I'm under 38 and have no children. We couldn't have had treatment if we had not been eligible because we were not prepared to bankrupt ourselves for a baby. I took fertility drugs and was offered several other treatments before being offered IVF. Our first two attempts failed but on the third attempt we used ICSI as well and I conceived.'

Feelings

'We've been open right from the start and friends and family have been very supportive. Several couples at work have approached us for help and advice. You feel different but we have joined a support group which has helped.'

Our relationship

'On the whole it hasn't affected our relationship. As we have been so open

with everyone else we don't feel we have to talk about it with each other all the time and so far we have been alright.'

Our tips

- Find out what you can about your options. We knew little when we started and sometimes I feel we don't know very much as there are always new things coming out. I have tried to look up things but until you are lying there you don't know what's going to happen or how it will affect you.
- Keep a sense of perspective. At the end of the day it's not the end of the world if it doesn't work.
- Get support. There's nothing to be ashamed of. Just because you can't conceive you are not a freak.

Our story: There are long waiting lists in our area



Helena, 34, a business management consultant, and her husband Ian, 34, a surveyor, had private fertility treatment. They live in London and now have a daughter, Sienna, who is a year old. Helena tells their story:

Treatment time

'There are long waiting lists for fertility treatment in our area and we didn't meet the criteria so we chose a private clinic. After monitoring three cycles, which cost

£1,200, we were offered IVF. While we were waiting I conceived naturally but miscarried. We then tried again, which cost £3,000, but our eggs and sperm did not fertilise. Then we tried IVF with ICSI twice costing £9,000. On the second attempt I conceived.'

Feelings

'I felt incredibly optimistic, although the worst time was after the miscarriage. The clinic gave me a huge amount of confidence and each time we started a new treatment cycle we felt good because we were doing something. Friends and family were really supportive but devastated when it didn't work.'

Our relationship

'Working through the many different treatments together and all the ups and downs that came with them brought us closer as a couple.'

Our tips

- Choose your clinic carefully. It's vital that the 'fit' between you and your clinic feels right. We looked at a couple before settling on the one we went to.
- Take care of yourself. I decided I would try some anti-stress therapies including acupuncture.
- A positive pregnancy test doesn't mean you will have a baby. Because of my miscarriage I felt really stressed out for the first 12 weeks of my pregnancy half expecting it to be snatched away again.
- It's okay to have a bad day. Your baby is no different to any other so don't feel guilty if you feel tired and exasperated with your crying baby.

Call the clinic

WITH SO MANY ASSISTED CONCEPTION CLINICS, YOU MAY HAVE TO SHOP AROUND BEFORE FINDING THE RIGHT ONE FOR YOU

There are about 80 HFEA-licensed clinics in the UK so it's not surprising you may find the choice overwhelming. It's worth spending some time exploring all your options so that when you do make your final decision you feel comfortable with it.

A good starting place is to find out if you are eligible for NHS treatment, or whether you will have to go privately (see page 10), as this may affect your choice of clinic – around a quarter of clinics take private patients only. If you are having NHS-funded treatment, find out if you can have a say in the choice of clinic (some private clinics take NHS patients if there is a suitable contract with the relevant health authority). If not, ask your GP why you

have been referred to a certain clinic and also if there will be any costs to you (see page 10 for more about costs and page 42 for a list of clinics).

You can use the HFEA website's interactive clinic search facility (see HFEA clinic search, opposite) to draw up a shortlist of possible clinics who you can then contact. This will help you to compare what each one offers, including prices if you are going privately. You might then want to arrange to visit a few so you can get a feel for the place.

Making a final decision can be exhausting and confusing, so here are a few pointers to help you on your way.

Location, location, location

The first thing to consider is where the clinic is. Getting up in the middle of the night and trekking half way across the country to have eggs collected or to give a sperm sample can be stressful, which is exactly what you don't want at this already anxious time. Taking time off from work for consultations and treatment may also be tricky. So it may be worth choosing a clinic that's within easy travelling distance.

If you do opt for a clinic that is further away you may be able to have certain treatments carried out at a local hospital (referred to as a satellite or transport centre).

Think about

- How far away is the clinic from home or work?
- How easy is it to get to?
- Is there public transport or a car park?
- Are there any treatment arrangements with a more local hospital?

First appearances

Do your homework and find out as much as you can about the clinic. Some may have special interests and expertise in specific treatments.

You may feel drawn to older establishments with a tried and tested reputation, but don't dismiss new clinics, which may offer equally high standards of treatment.

When making initial enquiries take into account the attitude of the person at the other end of the phone. For example, are they sympathetic to your questions? It is very important that you are made to feel involved in the decision making rather than just feeling as if you are on a conveyor belt.

Of course you may have doubts as to whether you are making the right choice. One of the best ways to allay them is by talking to other patients. No one can possibly say that such and such a clinic is the best one for you but they can share their personal experiences (see page 44).

Think about

- Will you see the same doctor or nurse every time?
- Can you choose between a male and a female doctor and nurse?
- What provisions are there for the protection of your privacy and dignity in the clinic?
- Do the staff sound welcoming and proud of their work?
- Can the clinic put you in touch with other patients?

Support lines

Rest assured, all clinics offering IVF and other treatments will give you the chance to talk over your treatment and any worries you may have with a counsellor. There are usually several different types of counselling available (see page 14).

Think about

- What types of counselling or support groups does the clinic offer?
- Are these services free or will we have to pay extra?
- Does the clinic offer patient support groups?

Rules and regulations

Does the clinic have any selection criteria for patients? For example, do they only take couples under a certain age, and are single women and same sex couples welcome? And maybe it has a cancellation policy if too many or too few eggs are produced as a result of taking fertility drugs as well as time restrictions on different treatments.

Think about

- The length of the waiting time.
- Any restrictions such as age or sexual orientation.
- How many cycles of treatment are allowed before trying another or stopping treatment all together.

Success rate

There's not a clinic in the world that can promise you will go home with a baby but it is important not to choose a clinic just because its success rate looks good on paper. Success rates, or live birth rates as they are called, are incredibly difficult to interpret. For example, a clinic that accepts only younger couples with straightforward infertility issues will usually have better success rates than a clinic that takes older couples or couples who need more complicated treatment. It's

also worth looking at the clinic's multiple birth rate. A high multiple birth rate may account for a clinic's high live birth rate - but multiple births carry a greater risk to both mother and babies. See the HFEA clinic search, below, to help you evaluate the success rate of a clinic.

Think about

- The live birth rate for the type of treatment you are having.
- The life birth rate for your particular age group.

Embryo transfer policy

Clinics can replace two embryos at each IVF attempt, or three if you are aged 40 or over (and using your own eggs). Replacing more would increase your chance of having a multiple pregnancy, with its associated health risks. Some doctors prefer to replace one embryo to reduce this risk, and freeze any remaining embryos to be used in the future, if the treatment is unsuccessful.

Think about

- What is the rate of multiple births for the clinic, and how do you feel about this?
- What are the clinic's criteria for freezing embryos?

YOU ASK...

What kind of questions will the clinic ask about my circumstances?

By law, before you start treatment, your clinic must consider both your potential baby's welfare (including "the need for a father" specifically mentioned in the 1990 Human Fertilisation and Embryology Act) and how the birth may affect any other children you may have. The assessment is designed to foresee any circumstances in which your potential baby might experience serious harm. The clinic will ask you some questions about your medical and social history, for example, whether you have had any contact with social services over the care of any children you may already have. Cases in which serious harm is likely are very rare, so most people can start treatment without delay. Occasionally, with your consent, a clinic may want to make further enquiries to relevant individuals or agencies such as a GP or social services. Policies about treating single women, same sex couples and older women vary from clinic to clinic. Clinics will often apply an upper age limit for the women they will treat, although none is set by the HFEA or the law. The HFEA has recently revised its guidelines to clinics on this issue. For more information, see www.hfea.gov.uk/ForPatients

HFEA clinic search

A good way to find a list of licensed clinics in your area with details of their services and success rates is to use the interactive find a clinic function on the HFEA website (www.hfea.gov.uk).

Here's how it works:

- 1 Start by entering your postcode or region, your age band, type of treatment you are considering (if you know it) and whether you are an NHS or private patient. If you don't know yet, you can enter both.
- 2 The locator will bring up a list of clinics that meet your criteria, so you can see how many people in

your age group have received that treatment and for how many it has been successful. The number of treatments carried out can be a good indicator of the level of experience of the clinic.

- 3 To find out more about the clinic, click on the most recent HFEA inspection report. Inspections are carried out at regular intervals and the reports will give you the most up to date information.



Talking it over

THE GOING CAN BE TOUGH, BUT THERE IS SOMEONE AT EVERY STAGE TO HELP

We all have times when we need someone to talk to who will really listen. You and your partner may be finding it hard to deal with your diagnosis of infertility, feeling unsure about what all the language and jargon mean, or wondering how you will ever cope with all the tests and treatment. This is where a counsellor can help.

Friends and family may be supportive, but it is often useful to talk about your feelings with someone who doesn't know you and who will not judge what you say or are feeling from a subjective point of view. Counselling can help you explore your feelings, become clearer about your situation and find new ways of coping.



Considering the implications

All HFEA-licensed clinics have to offer access to **implications counselling** before you consent to treatment. This involves a counsellor talking to you about the treatment you are having or plan to have, so that you understand exactly what it involves and how it might affect you and those close to you - now and in the future.

This is especially important if you are considering treatment with donated sperm, eggs or embryos or surrogacy arrangements - all of which involve complicated issues. You will need time to explore how you feel, to adjust to this different way of planning a family, to consider the legal implications and decide if this is going to be the right decision for you. Spending time with a counsellor can help with this and enable you to feel better prepared for parenthood through donation or surrogacy.

Facing up to feelings

If you need emotional support before, during or after fertility treatment, **support counselling** is available at many clinics. You can ask for written information and if you need additional support, your clinic will have information about other services in your area.

This form of counselling is especially useful in helping you to work through the emotions you may experience at specific times during treatment, such as when you first find out you have fertility problems, when you are waiting for results, if you are faced with a negative outcome, or if you are both having to come to terms with the fact that there is no further suitable treatment for you to try.

Dealing with the past

Infertility can throw up all sorts of issues. For example, it can sometimes trigger painful memories from your past or the treatment may be making you depressed or anxious. **Therapeutic counselling** shows you how to work through some of these difficult issues to great effect. It can really help you to deal with the impact that infertility may be having on your life and your relationships with other people. Ask the doctor or specialist fertility nurse for information. If it is not available at your clinic, they can refer you to an independent counsellor elsewhere.

Making contact

Your clinic should provide you with the contact details of a counsellor. Different clinics have different costing policies, so check whether you have to pay extra for counselling. You may choose to have just one or two sessions or more, as and when you feel you need them.

They usually last for an hour and you can expect to see the same counsellor each session.

If for any reason you don't feel happy or comfortable with your counsellor, talk to them about what's worrying you. If you feel you still can't communicate, ask to be referred to another counsellor.

WHAT COUNSELLING CAN GIVE YOU...

- 1 The opportunity to talk freely and openly without being judged.
- 2 The chance to explore feelings and sensitive issues that are troubling you.
- 3 Help in understanding the factors that may be contributing to your difficulties.
- 4 Support in finding your own solutions and new ways of coping.
- 5 The knowledge that what you share with your counsellor will be treated as confidential unless there are exceptional circumstances.

For information on counselling organisations and other forms of patient support, see page 44.

YOU ASK...

Since we started trying for a baby, sex has become much less fun. What can we do?

Couples with fertility issues often find their love life suffers. Intercourse becomes much more about making a baby rather than about fun and showing your feelings for each other. If you feel this is affecting your relationship a skilled counsellor can help you to explore the difficulties as well as working with you to resolve them.

My friend has just had a baby and I can't bring myself to tell her that we are finding it hard to start a family. What can I say?

Deciding whether and what to tell family and friends can be hard. You need to think about who you are going to tell and what you are going to say. If you do decide to confide in someone it may help to explain to them exactly how they can support you. You may want to talk this through with your counsellor to consider all the possible issues.

The expert says...

'We're based in the IVF Unit and see over 300 people a year for counselling. Some come for just one or two sessions while others need many more. They may want to come on their own or as a couple.'

'Some of our work involves helping people to talk about their experiences and to understand the underlying issues which makes it easier for them to find ways to cope or sort out problems.'

'It's not surprising that infertility affects the rest of people's lives. It's pretty hard to face friends with children, or to deal with talk at work about families or with someone going on maternity leave. Within a relationship, too, infertility can cause a huge amount of stress.'

'We offer people a safe space where they can focus on their problems and be supported in finding their own solutions. Often, just sharing feelings with someone outside their circle of friends and relations brings a sense of relief.'

'There are certain key times which can be particularly difficult. At the start of a first treatment cycle, people are often anxious and uncertain about what to expect.'

'During treatment they often say it is an emotional rollercoaster as they wait and see if they produce enough eggs, if they fertilise, and how many embryos are created. If people have had any problems with any of these issues in a previous treatment it will be especially stressful.'

'Then, after the embryos are transferred there is the long, anxious wait for results. The day of the pregnancy test is usually very tense.'

'Many of our patients see counselling as a useful way of preparing for treatment – as an extra source of support and stress management during it. It can be especially important for those faced with a negative pregnancy test or if there are problems with the pregnancy itself.'

'A skilled counsellor can play a vital role in enabling couples to deal with the emotional challenges of these difficult experiences.'

Jennifer Hunt

Senior Infertility Counsellor
Hammersmith Hospital

Our story: Ask about support or counselling options



Caroline, 35, and her husband Andrew, 36, a farmer, live near Sevenoaks, and have unexplained infertility. Their daughter, Adelaide, who is now four, was born after IVF. Caroline tells their story:

Treatment time

'I was on Clomid for six months and then had three attempts at IUI, none of which was successful. We then went

onto IVF on the recommendation of our consultant and on the fourth attempt I conceived Adelaide.'

Feelings

'To start with we felt a bit unsure and the idea of having to have IVF took getting used to. We were hit quite hard emotionally. I thought it was going to work first time so it was a shock when it didn't. Those friends and family we did tell were extremely supportive. However we didn't tell a lot of people because we felt it was quite private.'

Our relationship

'When you are trying for a baby it takes all the spontaneity out of sex so it is quite a strain. We would get quite excited when having the embryos replaced and then feel utterly despondent when it didn't work. But we

worked through it giving each other support. In many ways it brought us closer together.'

Our tips

- Ask at your clinic about support or counselling options. Support is absolutely vital because infertility treatment can be such a solitary experience. No one in the waiting room ever talks to each other.
- Set up a group if there isn't one. The consultant set up a first meeting of a support group and invited us along. After that a group of us carried on organising monthly meetings. It was invaluable to get together and chat with like-minded people who were going through the same thing. We made some very good friends through it who we still have today.