Gene Testing

Firstly your partner must have a gene test to check whether they are a carrier for CF. This is a small blood test that your partner's GP or your own CF nurse can carry out. Please make an appointment with your GP or CF nurse .If your CF nurse takes the blood sample, you will be invited in together. The CF nurse will give you information about the test and possible results.

There are 3 possible out comes for your partner as a result of this gene test. Your partner may unexpectedly have 2 CF genes in which case they will be diagnosed with CF, this is extremely rare but possible. Secondly your partner may have 1 CF gene and 1 normal gene or finally they may not have any CF genes.

There are thousands of CF genes. This test will only screen for the most common genes which is about 29. Due to this, the test can never be 100% certain that your partner does not have any of the CF genes; therefore you will never be given a 100% negative result.

The blood sample will be sent to the Liverpool Women's Hospital and your CF nurse will arrange to see you and your partner when the results are available.

We recommend that anyone considering antenatal screening should be seen by a genetic counsellor, this provides an opportunity to explore and discuss the options available to you as a couple.

Related Factsheets available from I N UK:
ICSI (Intra-Cytoplasmic Sperm Injection)

For further information visit:

www.lhch.nhs.uk

If you require a copy of this leaflet in any other format or language please contact us quoting the leaflet code and the language or format you require.

إذا لديك الرغبة في الحصول على نسخة من هذه المعلومات بأيّ لغة أخرى أو بشكل آخر (على سبيل المثال بخطوط كبيرة) ، الرجاءالاتصال علينا على الرقم 0151 600 1257 موضحاً الشكل او اللغة التي ترغب فيها.
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W celu uzyskania niniejszej informacji w innym języku lub formacie (np. dużym drukiem), prosimy o kontakt z nami pod numerem 0151 600 1257 podając wymagany format lub język.
Haddii aad u baahan tahay koobiga wargelintan oo luqad ama qaab kale (sida far waaweyn) fadlan nagala soo xiriir 0151 600 1257 adiga oo noo sheegaya luqadda ama qaabka aad wax ku rabtid.

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Liverpool Heart and Chest Hospital NHS
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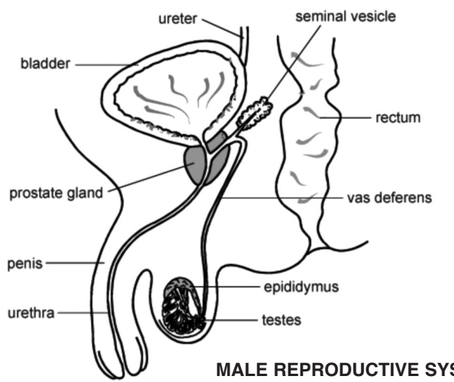
Infertility in Male Patients with Cystic Fibrosis

Excellent, Compassionate and Safe care for every patient, every day

This leaflet is to be used as an aid to discussion with the Cystic Fibrosis team regarding infertility in males.
This provides information about infertility in male patients with Cystic Fibrosis (CF). We hope it answers some of the questions or concerns you may have. It is not intended to replace talking with medical or nursing staff and is to be used in conjunction with a discussion with the Cystic Fibrosis Nurse Specialists.

Does Cystic Fibrosis alter fertility?

98-99% of males with Cystic Fibrosis are infertile. For reasons we do not understand, the presence of one or more CF genetic mutations can lead to the lack of development of the vas deferens, a tube that connects the testicle to the urethra (urine tube). Other parts of the normal anatomy of this region may also be missing such as the epididymus (a coiled tube draining sperm and fluid from the upper area of the testis), seminal vesicle and ejaculatory ducts. Sperm mature in the epididymus and the seminal vesicles produce much of the fluid ejaculated. The ejaculatory ducts pass the sperm and the ejaculate fluid into the urethra during ejaculation.



MALE REPRODUCTIVE SYSTEM

As you can see from the diagram above the vas deferens are present. However in male CF patients they are absent.

In 98%-99% of male CF patients the vas deferens (see above diagram) is blocked or absent. This means only 1-2 males out of 100 will be able to father a child naturally. Sperm which is stored in the testis cannot reach the seminal vesicle to be released in the semen and ejaculated as the transportation tube the vas deferens is absent or blocked. The actual act of having sex is normal in CF males, however the fluid that is ejaculated probably does not have sperm in it.

How will I know I am infertile?

If you are thinking of having children then you can ask your CF doctor or specialist nurse to check for Congenital Bilateral Absence of Vas Deferens by arranging a sperm count test. Your CF nurse will fill in a referral form with you and then she will fax it over to the Liverpool Women's' Hospital at Crown Street.

You will then receive an information pack with instructions of what to do.

After this procedure your CF nurse will invite you back to discuss your results.
Finding out that you are infertile can affect you emotionally and you may want to discuss any anxiety around the issue with your CF Nurse Specialist.

If you are sexually active you need to act responsibly and protect yourself from sexually transmitted diseases, even if you have been informed that you are infertile e.g., wear a condom.

Can I have children?

There is a way that you can become the biological father of a child but it requires the expertise of a specialist team and commitment from you and your partner. Unfortunately however, there are no guarantees that these procedures will be successful. Most commonly in CF a procedure called Surgical Sperm Retrieval is used. There are three different types, each requiring a local or general anaesthetic. They are listed overleaf.

Percutaneous Epididymal Aspiration (PESA). A fine needle is inserted into the epididymus, and sperm are obtained by gentle suction.

Testicular Sperm Aspiration (TESA). A fine needle is inserted into the testis and samples of tissue are obtained by gentle suction.

Testicular Sperm Extraction (TESE). A small incision is made in the testis and a tissue sample is obtained (sperm are removed from this). Two or three stitches are then used to close the wound – these dissolve in about 10 days.

The procedures PESA and TESE are the most common methods used for men with CF.

If I have a surgical retrieval procedure what will happen?

There will be a little bruising and tenderness of the scrotum for 24-48 hours after the procedure. When a skin opening is necessary, there will be a few stitches that will dissolve in 10 -14 days – the doctors and nurses will give you careful instructions at the time. All surgical procedures carry a small risk of bleeding or infection, but in practice, most men are back to full activity within 3-7 days.

Once the sperm is retrieved what happens next?

The sperm is analysed to check sperm count, sperm motility (ability to swim), and sperm morphology (shape). The sperm may also be checked for its fertilising potential. When the results of the sperm tests are available then a decision is made on what treatment option is the most appropriate for the couple. In men with CF the most common treatment option is Intra-Cytoplasmic Sperm Injection **(ICSI)**.

ICSI is the direct injection of sperm into the middle of an egg and bypasses all the natural barriers that sperm have to encounter. This takes place in the laboratory as part of the IVF procedure (see below).