



**Cystinosis sexual health and
fertility**

Cystinosis: sexual health and fertility

Fertility in men

Puberty in male patients can be delayed by 2-3 years. The accumulation of cystine in the testes causes a decrease in the amount of testosterone produced by the testes. Male patients with nephropathic cystinosis reach puberty at approximately 16-17 years of age.

The ability to have an erection and engage in a sexual relationship is unaffected.

Infertility is very common amongst males with nephropathic cystinosis and there have been no reported cases of a male with nephropathic cystinosis fathering a child. Research has shown that patients with nephropathic cystinosis, even with early cysteamine treatment, produce no, or very little, sperm. Although it has been suggested that in vitro fertilisation may be possible for some patients.

Fertility in women

Female patients with cystinosis are generally believed to reach puberty at approximately 14-15 years of age. Ovulatory cycle development and sexual development are relatively normal in female patients.

Female patients have a good chance of giving birth to a child. There have been several reported cases of women with cystinosis giving birth to a healthy baby, providing renal/transplant function is satisfactory.

However no one is sure what affect cysteamine has on the developing foetus. It is therefore very important that if you are planning to start a family, or conceive unexpectedly, you discuss this with your consultant.

Contraception

Using contraception is the use of hormones, devices, or surgery to prevent a woman from becoming pregnant. It is important to know that most types of contraception do not protect against sexually transmitted infections. The male condom is the only form of contraception that protects against STIs as well as pregnancy.

Find out about all the different types of contraception at www.nhs.uk/conditions/contraception. Contraception is available through your GP, community contraceptive clinics, sexual health clinics and some young people's services.

If you have had a transplant it is important that you discuss contraception with your transplant team as some types of contraception may not be suitable.

Glossary

Azoospermia: A condition in which the male has no measurable level of sperm in the semen.

Foetus: An unborn baby more than 8 weeks after conception.

In Vitro Fertilisation: The process whereby an egg is fertilised with sperm outside of the body and the resulting embryo is transplanted into the women's uterus.

Ovulatory: In relation to ovulation; the release of the ovum (the egg) from the ovary.

Sperm: The male reproductive cell.

Semen: The male reproductive fluid, containing sperm.

Testosterone: A hormone produced mainly by the testes that stimulates male secondary sexual characteristics.

Useful article:

Besouw, M. et al: Fertility Status in Male Cystinosis Patients Treated with Cysteamine.