

Information for families about genetics

SUMMARY OF GENDER AND FAMILY ISSUES:

- ***Some diseases are inherited, which means they are passed on from parent to child. If you are concerned about this because there is a disease in your family, your doctor may be able to offer you a test to find out who is or might be affected.***
- ***Men and women sometimes have different attitudes to disease, and often men are more reluctant to seek medical treatment. Remember that, whether you are a man or a woman, your doctor is there to help you with any concerns you have.***
- ***If you are concerned about you or a family member being affected by a disease, you can contact your national genetics society about what tests and help are available, using the EuroGenGuide links page.***

Gender and family issues in genetic testing and research

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Your role in the family



Men and Women often have different responsibilities within their families, and the particular concerns that you have may differ, depending on whether you are a Man or a Woman.

There might be a lot of questions that you wish to ask your doctors about your options, if you are considering treatment or taking a genetic test.

Inheritance

You share genetic information, i.e. DNA, with your parents, children and siblings, and this is how you are biologically related to them.

- Sometimes there are mistakes in parts of DNA, these are known as 'mutations', and some of these mutations can cause diseases.
- When two people have a child, half of the genetic information from each parent is transmitted to the child. Therefore the mutation that causes a disease is sometimes passed by the parent to the child or children.
- Whether or not this happens depends on many factors, for instance which half of each parent's DNA goes to form the child, the exact nature of the particular mutation, and which genes have been affected.

- Similarly, some people's genetic make-up may make them susceptible to developing a certain condition through exposure to environmental factors. For example some people are more at risk of developing lung cancer from exposure to cigarette smoke than others.
- If there is a genetic disease in your family, its nature, severity and whether or not it will be transmitted to the next generation, are complex matters. It is important to obtain informed advice about genetic testing and inherited conditions.

Remember!

"just because one of your parents has a genetic condition does not necessarily mean that you will develop it too, and your children will not necessarily develop any condition that you or your partner have."

- However, you may wish to find out whether your children will be affected. Talking with a genetic counsellor is often a good idea, as they can talk you through the various issues, and this can be very reassuring.
- If you want to find out whether there are genetic counselling services in your country, you can contact your country's genetics network (if there is one) via the the website for the European Society of Human Genetics: <https://www.eshg.org/>

Men, Women and Disease

There are differences in the prevalence and severity of a broad range of conditions between the sexes.

- Many general differences in the basic biology of males and females can affect health. Apart from purely anatomical differences (e.g. prostate cancer occurring only in men), better knowledge of sex differences in diseases is needed for better diagnosis, prevention and treatment. *Therefore relevant information for men may differ from information for women.*
- Some conditions affect one sex but not the other. For example, only men are affected by some forms of muscular dystrophy. Equally, only a woman will be faced with making reproductive decisions about her own body.

- The information that is relevant to you may differ depending on whether you are a man or a woman, and you may have different concerns when considering your treatment options

Understanding complex medical information

Medical information can be technical and complex, and difficult to understand. It can be confusing being presented with complicated information like this.

Also, some countries may not have a dedicated genetics networks, or genetics may not be recognised as a distinct medical specialty. There may not be a dedicated genetics network where you live.

- If any of this applies to you, you should ask your doctor in the first instance. You can also contact the European Society of Human Genetics to find out about genetics services in your country: <https://www.eshg.org/>
- The EuroGenTest network has produced a wide range of information leaflets about different aspects of possible treatment in genetics, and in particular about genetic testing, translated into 17 different languages. These can be found by following the following link: <http://www.eurogentest.org/patient/>

Your rights as a patient

- You have a right to seek the best treatment available to you, whatever your circumstances.
- You are entitled to ask your doctor if a genetic test exists for a particular disease that you are concerned about, and to ask for advice and support about any condition that you think may run in your family.
- Even if genetic services are not widespread where you live, your doctor can help you to find out where you can access a genetic test and advice, if they are not immediately provided where you are.

Improving services and information about genetics

- Genetic research and genetic counseling services have the potential to bring about widespread benefits by treating or reducing the impact of the effects of genetic diseases on families and individuals.
- This means that, by being willing to take a genetic test, or prepared to participate in research, you would be contributing in the long term to helping an increasing number of people who are affected by genetic disorders in the future.

Taking advantage of new technologies

Europe is becoming increasingly closely integrated in many different respects.

- Web-based communication in particular makes it easier than ever to make contact with other people throughout the continent who are affected by genetic diseases
- If you suffer from a disease that is very rare, neither you nor your doctor may know anybody else who is also affected. This might make it difficult for you to get the help and support that you need.

Reproductive choices

Whether you are a man or a woman, decisions about whether to have your own children will be some of the most significant you will make throughout your lifetime.

One of the most difficult challenges you will face will be if you discover that a pregnancy will be affected by a genetic disorder.

In a situation like this you will want to think carefully about all the options you have and what will be the best decision for you, or you and your partner, to make.

- Your doctor can present you with information about all your options in order to help you to decide freely for yourself what the right decision will be.
- If you are not considering starting a family right now, however, you might feel that you do not need to pursue any further information about any genetic condition that you or your partner may have.

You may want to bear the following in mind when making decisions about your reproductive choices:

Choice and Information

So you can make the right decision for you and your pregnancy, you will need relevant information concerning the baby's condition.

- It is your right to decide what happens with your own pregnancy and nobody else's.
- When your doctor is giving you good advice, he or she should not try to persuade you to take one course of action over another. Instead, at what might be a very confusing time, he or she should provide the impartial information you need to make the right choice.
- If you don't know about all your options, then you may not be able to make the right choice for you and your family. Information and advice about the kinds of decisions you might face during pregnancy can be found at the website for Ante-Natal Results and Choices: <http://www.arc-uk.org/>

Big decisions!

Opportunities for continuing consultation during your pregnancy are important if you are trying to make difficult decisions about your pregnancy.

- You, or your partner, may be considering whether or not to continue with a pregnancy that will result in your child having a genetic condition.
- Decisions like this are difficult, and you may change your mind over the course of days or weeks following a test result for a disorder.

- You are more likely to reach a clear-minded decision, and one that is the best for both you and your pregnancy, if you have taken time to consider all aspects of your situation thoroughly.
- If you are considering a termination, don't rush into making a decision while you are considering all your options, but remember that there will be a time limit by which you will have to make your decision. Your doctor can advise you how much time you have to make your decision.

Your medical care

If you discover that your baby will be affected by a genetic condition and you continue with the pregnancy, you will probably want to know as much as possible about the condition.

This is likely to include the implications of living with it, and what help there is available for you and your family.

- Your doctor will be able to direct you to resources where such information is available, if he or she is unable to provide it themselves.
- Telling your doctor about your wishes and feelings will help you to receive the right treatment for your child.
- Remember that the decision is yours. By providing you with all the information you need, your doctor should help you to come to the choice that is right for you.

Termination

If you discover that your baby has or will develop a genetic disorder, you and your partner may decide not to continue with the pregnancy.

- A decision like this may be one of the most significant of your life, and may be very distressing.

- The right choice will be whichever you make freely and in full possession of the relevant facts.
- Your doctors have to respect your right to make decisions about your own body and should offer you the relevant information (in some cases this may include genetic screening of the unborn child to determine whether or not it has inherited a genetic condition).

Information for Men



Studies show that men often delay seeking medical advice until later than women, and therefore can delay diagnosis and treatment of medical conditions.

This means that diseases such as cancer in men can be more advanced by the time a diagnosis is made.

If you are a man and you are concerned that you may be affected by a disease, it is important that you do not delay in seeing your doctor.

You are not responsible for the genes you inherit, so you cannot be blamed if you are genetically susceptible to a disease.

In some diseases (some types of cancer, for example), your genetic make-up may make you more likely to develop the disease if you also live an unhealthy lifestyle or are exposed to certain types of environments.

It is important to bear these risk factors in mind when making decisions about the way you live. A bad diet, or being exposed to cigarette smoke, are examples of such risk factors.

- The longer a medical condition is left undiagnosed, there may be less that can be done to manage or improve it. Any children you have are also at risk if they are unaware that you have a condition that involves genes and which could be passed on to them.
- You may have a family to support and be concerned about the effect upon them on discovering that you are affected by a genetic disorder.
- Some diseases, for example prostate cancer, kill large numbers of men every year. There may even be a history of it in your family, and if this is the case it is important for your own health that you consider seeking advice to determine how likely it will be that you will develop it, and whether your children might inherit it.
- Some bodily problems are more difficult to discuss than others, and you might be embarrassed to reveal them. However, remember that your doctor is a professional who carries out examinations of many people on a daily basis.
- It's very important that you put your own health first and seek out treatment if you think you might need it.

- Although it is understandable that you might have worries about seeing a doctor, do not delay seeking treatment, in many cases - cancer in particular - the more advanced a condition is, the less chance there is of treating it effectively.
- The impact on your family is likely to be far worse if a condition that you have is diagnosed late.

Information for Women



Men and women often have different psychological and emotional attitudes towards seeking treatment for an illness or suspected illness.

- Studies show, for example, that women are typically more likely to seek advice and treatment quickly when it is necessary. As a woman you may be reading this for one of the following reasons.
- If you are reading this because you are a carrier of a genetic disorder, or are concerned that you might be, you are doing the right thing in seeking out the information you need for the future and for your own peace of mind.
- Alternatively, it is possible that you are reading this because you are pregnant and you have reason to be concerned that your baby has or will be affected by a genetic disorder.
- You are not responsible for the genes you inherit, so you cannot be blamed if there is an increased likelihood of your developing a particular disorder.

- In some diseases though (such as some types of cancer) your particular genetic make-up may make you more likely to develop the disease if you have an unhealthy lifestyle or are exposed to certain types of environments, and so it is important to bear these risk factors in mind when making decisions about the way you live.
- Bad diets, or being exposed to cigarette smoke, are examples of these risk factors.

If you are not making reproductive decisions but are concerned about another member of your family, the following information may be of use to you:

As a woman you may play a number of roles within your family. As well as being a daughter you may be a wife, mother, sister, aunt, niece, and so on.

The responsibilities you bear towards other members of your family will depend on your particular situation, so there is no one right course of action in every case.

- Women sometimes find themselves being the family members responsible for the health of the family. Traditionally this has often been the responsibility of the mother, though this is changing as family arrangements become more varied.
- You might have a relative with a genetic disease and feel that it falls to you to find and maintain treatment. This might be difficult if knowledge of genetics is limited where you are, but your doctor is there to help you and even if they cannot provide advice, tests or treatment directly, they will be able to find out for you where you can get help and advice.
- Genetic counseling services may be particularly important to you if many of the day-to-day decisions about your family's health fall to you.

- You will want to make the right decisions for your family, and it might be difficult to know what is for the best. In these situations, a genetic counselor who can explain your situation and your options and discuss with you your worries may help a great deal.

If you are affected by a genetic condition:

If you have a genetic condition, you might be concerned how this might affect your life in terms of your opportunities, your relationships, and your existing or future children. If this is the case then it might really help to seek out genetic counseling.

Your doctor will be able to find out where you can access genetic counseling services, and even if they are not available in your country it will be possible to contact them elsewhere in Europe.