



Children's health and parents related by blood



Cousin marriage and genetic risk

We have been talking with community members and they tell us that people want better information and services to support families in understanding the issues around cousin marriage and children's health. This leaflet aims to answer some common questions.

Why is genetics important for me and my family?

Have you ever wondered why members of the same family look similar? This is because blood relatives share a large number of their genes. Genes are the codes that determine your inherited characteristics. For example, your genes influence your eye colour, hair and skin colour, the size of your feet and hands, and much more.



We inherit our genes from our parents. We can also inherit some disorders that are passed on through unusual genes (also referred to as changed genes). These are called genetic disorders. Genetic disorders can cause children to die or to have a life-long disability. There are thousands of different genetic disorders, including cystic fibrosis, tay-sachs disease, sickle cell anaemia and thalassaemia.

Families from all communities can be affected by genetic disorders. However, some genetic disorders– known as ‘recessive’ disorders – are more common in families where partners are blood relatives (consanguineous), for example, cousins.

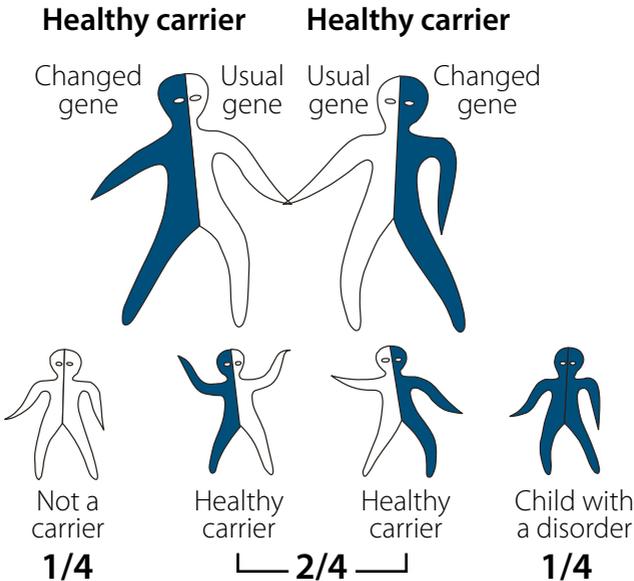
Most children born to parents who are cousins are healthy, but a recessive disorder can occur when there is an unusual (changed) gene in a particular family and both parents happen to have this changed gene.

How are recessive disorders inherited?

Everyone has two genes for every inherited characteristic, one received from each parent. The picture shows a healthy couple. Each partner carries one changed gene for the same recessive disorder. They do not have the disorder themselves because their other gene works normally. They are called 'healthy carriers'

Each of their children inherits one gene from each parent. So there are three possibilities for every child.

1. There is a one in four chance that the child would inherit a usual gene from both parents; **the child would not have, or carry, the disorder.**
2. There is a two in four chance that the child would inherit a usual gene from one parent and a **changed** gene from the other parent; the child would, like its parents, be a healthy carrier of the disorder and could pass the gene on to the next generation.
3. There is a one in four chance that the child would inherit a **changed** gene from both parents; the child would have the disorder.

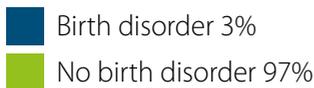
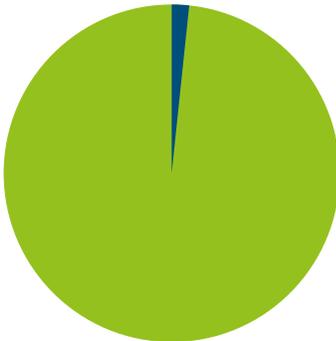


The chance of having an affected child is the same each time the couple has a baby. Their next child could have the disorder, be a healthy carrier (like its parents) or be completely free of the disorder. The chances are the same each time the mother becomes pregnant.

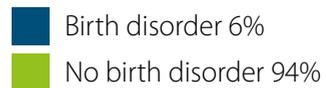
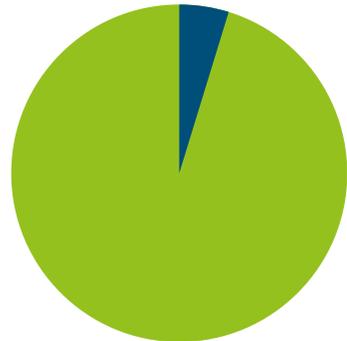
More about genetics and cousin marriage

Because genes get passed on in families, if a couple are blood relatives, there is a greater chance that both will carry a changed gene for the same recessive disorder, and will be a 'carrier couple'. Research shows that for every 100 babies born to unrelated couples, fewer than three have a birth disorder, whereas for every 100 babies born to closely related couples, five to six have a birth disorder*. This extra risk is mainly because of 'recessive' disorders, which are one type of birth disorder.

Unrelated couples



First cousin couples



*A birth disorder is a health problem that a baby has from birth.

Some common questions

I hear a lot about this issue in the Pakistani community. Does this affect other communities as well?

Genetic disorders are found in every community. However, communities where cousin marriage is common have more children with recessive disorders. In the UK, the Pakistani origin community has the highest level of cousin marriage, so a higher proportion of children in this community have recessive disorders.

I know people who are married to cousins and have healthy kids. Is it really true that marrying a cousin results in disabled children?

Being married to a cousin is not the reason that a child is born with a disability. Most babies born to cousin couples are healthy. A problem only arises when there is a changed gene for a recessive disorder in the family and both parents happen to carry this changed gene. For such a couple, there is a $\frac{1}{4}$ chance in every pregnancy that the child may inherit the disorder. This happens because the child inherits the changed gene from both the father and the mother (see diagram on page 2).

When a cousin couple has a healthy child, this may be because the parents do not carry the same changed gene or because the child did not inherit two changed genes that the parents share.

I don't see why this issue is relevant to me. I am already married to my cousin. Is there any point in learning more about this?

Whatever the stage of your life, genetic information may be valuable to you and your family. People who are well informed are in a better position to make the right choices for themselves. Genetic services can be useful for anyone who may have a genetic disorder in their family or for people who are concerned about such conditions.

I am interested to know more about this important issue but I want to understand the religious and moral aspects, not just the scientific evidence.

Thinking about marriage and childbearing raises religious and moral questions in many people's minds and you may want to discuss the information in this leaflet with family, friends and other people who you trust.

My husband and I are not cousins. In fact we are not even related, but my child has a genetic disorder. If genetic disorders are linked to cousin marriage, then why is my child affected?

Genetic disorders can affect anyone. Every couple, including those not related, has a small chance of having a baby with a genetic disorder. For most genetic disorders, the risk of having an affected baby is the same whether or not the parents are related to each other. Only recessive genetic disorders are more common when parents are related.

I am married to my cousin and my older son has a serious genetic disorder. However, my younger son is completely healthy. If cousin marriage is related to genetic disorders then why is one son OK while the other is not?

Being married to a cousin is not the reason that a child is born with a genetic disorder. The problem arises when there is a changed gene for a recessive disorder in the family and both parents happen to have this changed gene (see diagram on page 2). In this case, the older son must have inherited a gene for the disorder from both his mother and his father. There are two possibilities for the younger son, who is healthy. Firstly, he may be a healthy carrier of the condition like his parents, having inherited one usual and one changed gene. Secondly, he may have inherited a usual gene from each parent and therefore is neither affected nor a carrier.

Where can I find out more information?

If you want to know more – for example if your partner is a blood relative, or you are thinking of having a partner who is a blood relative, and you are concerned about possible effects for your children, or you are concerned about a genetic disorder or disability within your extended family, please speak to your GP. Take this leaflet with you. He or she may refer you to your local regional Genetics Service where they offer specialist counselling and advice. They may also be able to offer tests to identify some recessive conditions, and new tests are rapidly becoming available.

Other resources:

UK Genetic Alliance www.geneticalliance.org.uk

UK Thalassaemia Society www.ukts.org

UK Sickle cell society www.sicklecellsociety.org

UK Jewish Genetic Disorders www.jewishgeneticdisordersuk.org

UK Tay Sachs www.guysandstthomas.nhs.uk/our-services/genetics/clinics/tay-sachs/patients.aspx

Please share this information with family and friends who may find it useful.

To get in touch with the Redbridge LSCB Child Death Overview Panel (CDOP) team, Please contact Monica Clarke, Redbridge CDOP Co-ordinator at:

Email: nem-tr.CDOP@nhs.net **Tel:** 020 8708 5961/3103.

We wish to acknowledge the contributions of Bernadette Modell, Emeritus professor of community genetics, University College London, Director, WHO Collaborating Centre for Community Control of Hereditary Disorders.

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