

Cousin marriage and genetic conditions

We have developed this leaflet after talking with community members. They tell us families want better information around the issues of cousin marriage and genetic risk. This leaflet aims to answer some common questions based on the facts in Bradford.

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Common questions: Are there other reasons for inherited conditions?

Chromosomal, genetic and congenital anomalies can affect any family, whatever their background or ethnicity. Being an older mother or being married to your cousin significantly increases the risk of congenital anomalies (birth defects), as outlined in The Lancet in July 2013.

The majority of babies born to couples who are blood relatives are healthy. Whilst cousin marriage increases the risk of birth defect from 3% to 6%, the absolute risk is still small. Cousin marriage only accounts for a third of birth defects.

I hear a lot about this issue in the Pakistani community. Is this relevant to other communities?

Inherited conditions are found in every community around the world. Communities that practice cousin marriage have higher numbers of children with inherited conditions. In the UK, the Pakistani origin community has the highest level of cousin marriage and a higher proportion of children with inherited conditions.

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

Most babies born to cousin couples are healthy; however, there may be a higher risk of their baby having an inherited condition. The problem arises when there is an unusual gene in the family and both parents have this unusual gene. With such a couple, there is a chance a child may inherit the condition for every pregnancy they have. This happens if the child inherits the unusual gene from both the father and the mother. When a cousin couple has a healthy child this may be because they do not have the unusual gene, or because that child did not inherit the unusual gene from both parents.

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 your stage in 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. Genetics services can be useful for anyone who has an inherited condition in their family or people who are concerned about such conditions.

My husband and I are not cousins. In fact we are not even related, but my child has a genetic condition. Why is my child affected?

Genetic conditions can affect anyone. Every couple, including those who are not related, has a chance of having a baby with an inherited condition. Children of unrelated parents have a two to three per cent chance of being born with a genetic condition.

I am married to my cousin. My eldest son has a serious genetic condition but my younger child is healthy. If cousin marriage is related to genetic conditions, why is one of my kids not affected?

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. The problem arises when there is an unusual gene in the family and both parents have this unusual gene. With such a couple, there is a chance a child may inherit the condition for every pregnancy they have. This happens if the child inherits the unusual gene from both the father and the mother. When a cousin couple has a healthy child this may be because they do not have the unusual gene, or because that child did not inherit the unusual gene from both parents. In this case, the older son must have inherited an unusual gene from both his parents. The younger may be a carrier of the condition, having inherited one usual and one unusual gene. Alternatively he may have inherited two usual genes, one from each parent.

I am interested to know more about the religious and moral aspects, not just the scientific evidence.

Thinking about marriage and childbearing raises religious and moral questions for many people. You may want to discuss this information with family, friends and other people you trust.

Contact information for Muslim scholars willing to discuss these issues:

Mohammed Arshad (Head of Chaplaincy)

Shaheen Kauser (Female Muslim Chaplain)

Bradford Teaching Hospitals NHS Foundation Trust

Tel: 01274 365819

Email: Mohammed.arshad@bthft.nhs.uk

Shaheen.Kauser@bthft.nhs.uk

Where can I find out more?

If you are concerned about an inherited condition or disability within your extended family and how it might affect you, please speak to your GP. Take this leaflet with you. You may be referred to your local Regional Genetics Service who offer specialist counselling and advice. They can offer tests to identify some inherited conditions.

The wording in this publication can be made available in other formats such as large print and Braille. Please call 01274 432020

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 code that controls the body. For example you genes control your eye colour, the size of your feet and hands and much more.



We inherit many things from our parents. In the same way, we can inherit some diseases and disabilities from our parents through unusual genes. These are called inherited conditions.

Families from all communities can be affected by inherited conditions. Some are more common among families where couples are blood relatives, for example cousins. Most children born to cousins are healthy, but there can be problems when there is an unusual gene in a particular family and both parents happen to have this unusual gene.



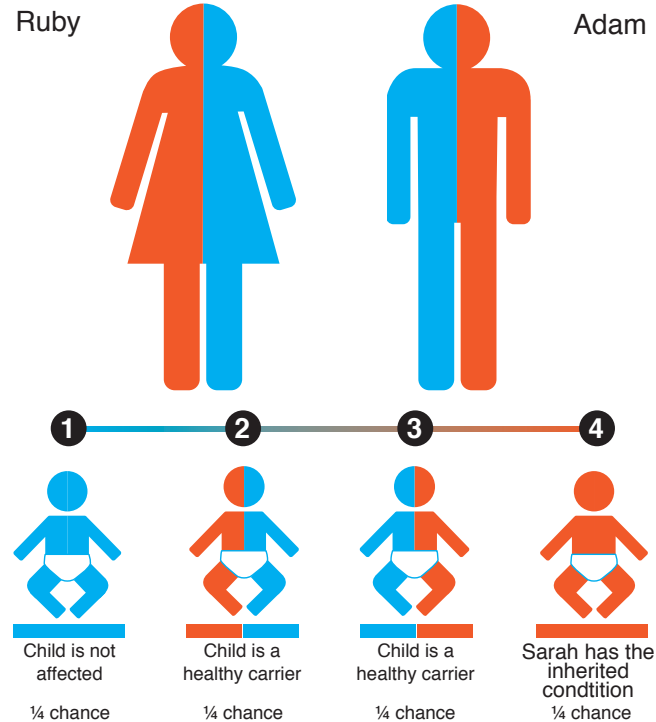
How do children get inherited conditions?

Using Ruby and Adam as an example; they are a healthy couple who both have an unusual gene for the same inherited condition. Ruby and Adam are called "healthy carriers" because, even though they have one unusual gene, they do not have the disorder themselves. They have both passed on this unusual gene to baby Sarah who has the inherited condition.

In each pregnancy, their child inherits one gene from Ruby and one from Adam. So in every pregnancy the child has a chance of inheriting an unusual gene or a usual gene. There are four possibilities every time Ruby becomes pregnant:



Changed gene Usual gene Usual gene Changed gene



1. If the child receives a usual gene from both Ruby and Adam, then the child will not have the inherited condition
2. If the child receives an unusual gene from Ruby but a usual gene from Adam, then the child will be a healthy carrier and could pass the unusual gene on to the next generation
3. If the child receives a usual gene from Ruby but an unusual gene from Adam, then the child will be a healthy carrier and could pass the changed gene on to the next generation
4. If the child receives the unusual gene from both Ruby and Adam, then the child will be affected by the inherited condition.

The chance of an affected child is the same each time Ruby and Adam have a baby. Their next child could have an inherited condition like Sarah or be a healthy carrier or be completely free of the condition. The same one in four chances are there each time Ruby is pregnant.

How do inherited conditions affect different communities?

Genetic conditions affect all communities and can cause children to die or have lifelong disability. There are thousands of different inherited conditions.

Communities that marry cousins, like Adam and Ruby, have a higher number of one particular group of inherited conditions. These are called recessive disorders which cause a range of serious diseases and disabilities. Examples include Primary Ciliary Dykinesia (PCD), thalassaemia and Tay-Sachs disease. Because genes get passed on in families and inherited conditions are rare, if a person marries a blood relative there is a greater chance that both will have a gene for the same recessive condition and be a 'carrier couple'. This means that there are more carrier couples, and therefore more children with inherited conditions, in communities that practice cousin or other close blood relative marriage. In Bradford, cousin marriage is common within the South Asian community, especially with people of Pakistan origin.¹ Of the UK communities that have cousin couples, the Pakistani origin community is the largest with the highest level of cousin marriage.

Research in Bradford shows that for every 100 babies born to unrelated couples fewer than three have a birth condition whereas for every 100 babies born to closely related couple five to six have a genetic condition.² This extra risk is mainly because recessive inherited conditions are more common among blood related couples.

In Bradford, there are more parents who share unusual genes and this is why Bradford children are more likely to experience serious genetic disease than children in some other cities.³

The Bradford District Child Death Overview Panel report shows a significantly higher percentage of children who died did so because of genetic, chromosomal and congenital anomalies than compared nationally. Genetic conditions occur in all communities. The increased risk with local related couples is due to recessive inherited conditions.⁴

1. European Journal of Public Health: consanguineous marriage: results from the Born in Bradford study <http://eurpub.oxfordjournals.org/content/24/5/862>
2. Sheridan E. et al The Lancet Risk factors for congenital anomalies in a multiethnic population 2013 [http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(13\)61132-0.pdf](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(13)61132-0.pdf)
3. Bradford JSNA 2014 http://www.observatory.bradford.nhs.uk/Documents/4_5_2_Child_Mortality.pdf
4. Child Death Overview Panel Report 2014/15; www.bradford-scb.org.uk