Involving Fathers in Ante-natal Screening for Sickle Cell Disorders: Improving Informed Decision Making

Recommendations from the Project for Mothers, Fathers and Families

- Sickle cell is the most common genetic disorder in the United Kingdom. Yet many health care professionals may not be aware of the condition. Ensure you get the access to the best services that you feel that you need.

- Sickle cell can affect anybody but is more common in people of African, African-Caribbean, Indian, Arab and Southern Mediterranean origin. In order to find out if you may be affected, try and gain an awareness of your family history and health.

- Young people need role models to understand how to talk about these issues that affect them. This includes their families, friends and health care professionals.

- Information on sickle cell disorders and carrier status may not always be given in school or may focus purely on the medical or genetic consequences. Young people also need to gain an understanding of what it means to live with sickle cell.

- Testing for sickle cell can occur at any time and is your choice to make. You do not have to be in a relationship or thinking about children to have a test.

- If you are a carrier or have sickle cell, do become aware of your reproductive choices regardless of whom you fall in love with. It is important to be aware of all the options available to you.

- Generally, a woman will be invited to have a test for sickle cell during ante-natal care to find out if she is a carrier. If she is a carrier, her partner will be invited for a test during ante-natal care. These tests are not routine but offer choices with pros and cons.

- If you have been tested elsewhere or outside of the United Kingdom, you may be invited to repeat that test despite knowing your carrier status. Discuss this choice and why it is being offered to you.

- If you and your partner are both found to be carriers, there is a one in four chance that your child might be affected. You will be offered counselling. Discuss what questions you want to ask beforehand. Consider gaining follow-up information with a voluntary sector organisation.

- You can have a test during pregnancy to find out if your child has a sickle cell disorder. There is a small risk associated with miscarriage. No one can tell you how severely affected a child will be. Treatments are, however, available. Your choice is to continue with the pregnancy or terminate it. This is not an easy decision to make and a decision that is right for one person might not be right for you. People, for example, agree to a test for different reasons; some use it to make a decision about termination, others to prepare themselves for the birth of a child who has the condition. It is your and your partner's choice about what to do.

- Your child will also be tested after it is born. If it has a sickle cell disorder, the child will be given appropriate treatment. Discuss when and why you need to find out and if prenatal testing is an option for you.

- If you have a child with sickle cell, it is sometimes useful to get in touch with voluntary sector organisations, medical specialists and local services to ensure that you have all support you need.

- Sickle cell is a variable condition and affects everyone differently but can be very serious. There is at present no cure. Bone marrow transplants are sometimes used, but are not accessible for everyone. Transplants also carry serious health risks.

- Mothers, fathers and siblings need support but are often overlooked in services. This is a long standing problem. It is, therefore, important for families to understand what is available to them and support each other. Discuss if you want to be tested too and what that means for you as a family.

A copy of the final report and resources can be found at:
http://www.york.ac.uk/media/healthsciences/documents/research/public-health/23116_A4_report%20v3.pdf

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