



Anwar's Story

These notes are to accompany the Sibs Talk Lite Primary School worksheets

My name is Anwar. I live with my mum and my sister. My sister is called Fatima. She has a heart condition. She was born with this. Because her heart doesn't work as well as mine does, Fatima can get tired very easily. I have fun playing with Fatima but she can feel very cold and get out of breath when she plays outside with me. Fatima has lots of hospital appointments and check ups to see if her heart is working properly. Sometimes I go with her and sometimes I don't. My mum says that Fatima might need an operation on her heart when she gets older.

Questions

1. What does Anwar think about his sister's heart condition?
2. How does Anwar feel when he wants to play with his sister?
3. What might Anwar think about the hospital appointments?
4. What might Anwar think about Fatima's operation?
5. Who can Anwar ask for help with his feelings?

Information about issues raised (pre- reading)

Growing up with a brother or sister who is disabled or who has special educational needs, or a serious long-term condition, has much in common with all sibling relationships – rivalry, loyalty, fairness issues, and having fun together. When one sibling is disabled these feelings may be more intense. Siblings want to have ordinary lives and to have positive relationships with their disabled brothers and sisters. They also want their disabled brothers and sisters to get the support they need so that they can have ordinary lives too.

Not understanding the condition

Many siblings don't receive accurate and age-appropriate information about their brother or sister's condition. This can lead to young siblings developing their own theories about it, which may be misleading and cause distress to the sibling, for example, thinking that they caused it to happen or that it can be caught like a cold. Siblings are often asked by others at school about their brother or sister's condition and they need to be able to explain it simply and with confidence. Siblings can feel left out of family discussions about disability or illness, and only find things out when they overhear them from other children at school. Siblings may feel it is a taboo topic at home and avoid asking questions in case they upset their parents. Siblings may take certain aspects of a condition personally, for example, thinking that their brother or sister with autism doesn't like them when he/she doesn't like being hugged due to sensory problems.

Coping with Mixed feelings

At times siblings will have strong feelings of love, protection, pride and joy in their relationships with their disabled brothers and sisters. At other times they may feel anger, resentment, embarrassment, guilt, and sadness in the sibling relationship. For example, a sibling may feel affection towards their brother or sister and want to care for them and at the same time feel resentful if this means they are not able to play with a friend. It can be very hard for siblings to cope with the negative feelings they have if they don't have permission to talk about these. Siblings who experience challenging situations at home, such as frequent medical emergencies, doing a lot of care, aggressive behaviour, disrupted sleep, parental depression, or bereavement may have more worry and have low mood. If not dealt with at an early stage these can lead to anxiety and depression in siblings. During the teenage years many siblings start thinking about the future and

may worry about how their brother or sister will be supported if their parents can no longer do this.

About Sibs

Sibs is the only UK charity representing the needs of siblings of disabled people. There are over half a million young siblings and at least 1.7 million adult siblings in the UK, who have grown up with a disabled brother or sister. Sibs aims to enhance the lives of siblings by providing them with information and support, and by influencing service provision throughout the UK.

Thank you for supporting siblings of disabled children in your school.

Email info@sibs.org.uk

Tel 01535 645453

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Sibs relies on donations and grants to support siblings. If this information has helped you in your work, please consider making a small donation at www.sibs.org.uk/donate