## **"THE MOST IMPORTANT THING IS THAT THE CHILD FEELS ACCEPTED"**

There is also a series on TV which you can watch, called 'Bikkels', in which children with a sick or disabled family member are being followed (https://www.npostart.nl/bikkels/25-01-2015/VPWON\_1229824).

Support from family, teachers and doctors is very necessary. Parents should talk to their children, so they know what's difficult for them and what is bothering them. They should be open to their child about their sick sibling's disorder: tell them what it is and what changes or difficulties are to be expected. If you don't do this, the children will (sometimes wrongly) interpret everything themselves. The children should be encouraged to ask questions. They should be stimulated to have their own life, hobbies and friends, and make their own choices. Ask family and friends to also give attention to the siblings, not only to the sick child.

Make sure the healthy children also receive a gift from time to time, and not only the sick child. Talk to your child about the different reactions people have towards the disease and how they can deal with those. Ask them what they are worried about and discuss it. Have fun together. In short: spend quality time with your children.

### **NEED MORE INFORMATION?**

Read this text in full and find more information about doctors and more on our website:

Website: www.cmtc.nl

Email: president@cmtc.nl

Children's website: jezz.cmtc.nl



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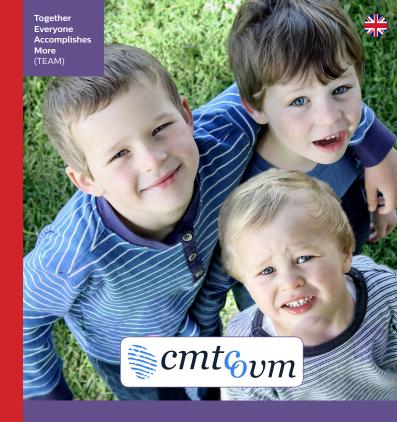
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### When your brother or sister is ill

A sick child impacts the whole family, which sometimes leads to the siblings being overlooked. In a family with a sick child, most attention often goes to the sick child. Because of that, the healthy siblings sometimes don't get enough attention. They often completely adjust themselves, so they don't trouble the rest of the family. Later, this might cause problems. We are talking about children between 0 and 23 years old who grow up with a sick family member. That means they have a brother/sister/father/mother with a physical and/or mental illness. About 10 to 25% of children grow up with a sick family member.

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### WHEN YOUR BROTHER OR SISTER IS ILL



# Positive and negative sides of being a caregiver

Through having been a caregiver from a young age, those children have developed some skills/characteristics. They are often very independent, have a sense of responsibility, agcuire social and caring skills, and they are proud to be able to take care of others. Apart from those positive sides, there are some negative ones. The young caregivers often experience more stress and their mental health might suffer under it. especially in the case of a parent with mental problems. School results might also get worse. As regards social problems: they often think they are alone with their problem and feel less at ease when they are with children who don't have this problem. Because they often have to help more at home, they have less free time. As long as they are caregivers, they know what to do, but as soon as they are not, they don't know who they are and they don't know what to do anymore. They somewhat lose their identity. Young caregivers also haven't learnt to indicate their own boundaries and therefore find it difficult to say no.

#### Development

One of the biggest fears of children when they are very young is to be separated from their parents. Children may feel like this for example when a parent is absent because he/she is at the hospital with a sick child. If they are one or two years old, they can interpret this absence as a punishment for something they did wrong. They might also be afraid of mutilation; that they would get the same illness as the sick family member, especially if it is a physical disorder. When they are a little older (preschool age), they might believe they have caused the illness in some way. It is important to talk to the child about this, so he/she knows he/she is not to blame. If children of school age notice their parents are stressed out or very busy, they will not ask for attention even if they need it. They efface themselves because the sick child/parent comes first. They don't want to be extra trouble. When having reached puberty, children sometimes become afraid the disease is genetically transmittable, for example in the case of a skin disease: that it is infectious. Again: it is important to discuss this.

### THE SHORT- AND LONG-TERM IMPACT OF A SICK CHILD ON ITS FAMILY IS OFTEN A LOT BIGGER THAN PEOPLE THINK.

Explain that it is not infectious and tell other children as well.

The children also don't really dare to leave the family so they can live on their own. They think the family still needs them. Being adults, they find it difficult to express that they want to live their own life and feel guilty if they do.

### Pitfalls

Most conversations are about the sick child and the disease. The sibling protects the sick family member and vice versa, and because of that, it is not discussed. The young caregivers are especially good at socially desired behaviour. They know how to handle fear and how to behave in a way that doesn't show their anxiety to the outside world. Because of that, most people who associate with them, think they are doing well. The children also don't dare to express everything, like when they don't like something about their sick brother or sister. Family members as well as teachers and doctors don't notice this and don't realise this might have consequences.

#### What can help?

It helps when it is recognised/appreciated that you are a caregiver. Also useful is to have access to information about what it's like to have a sick sibling. This information was very scarce not so long ago, as Anjet van Dijken (1976), who grew up with a visually impaired and slightly disabled brother, also noticed. After her parents passed, she was on her own at a very young age and became her brother's guardian and mentor. In 2013, she wrote a book about it, together with other people who have a sick/disabled sibling. In her book 'Brussenboek' (http://brussenboek.nl/boek/), 36 children and adults (between 6 and 69 years old) show what it's like to live with a disabled or mentally or physically ill sibling. In the meantime, Anjet published a second 'Brussenboek'.