KINDERKREBS SCHWEIZ CANCER DE L'ENFANT EN SUISSE CANCRO INFANTILE IN SVIZZERA CHILDHOOD CANCER SWITZERLAND

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Siblings in the shadows – the new awareness campaign from Childhood Cancer Switzerland

When a child is diagnosed as having cancer, it turns the lives of those affected upside down from one day to the next. In this extreme situation, the majority of parents have little time and energy left for their other children who are thus often in the shadows of their sick brother or sister and suffer along with them – mostly silently and unnoticed. To prevent them from suffering long-term psychological consequences, siblings need an environment aware of their situation to accompany and support them. It is important to bring their needs back into focus and provide them with strategies that will help them cope. In its new awareness campaign, Childhood Cancer Switzerland draws attention to the major challenges faced by those affected and details possible solutions and offers of support. The campaign will be launched on 15 November 2021.

Around 300 children and adolescents are diagnosed with cancer every year. When a child has a life-threatening disease, the emotional and social balance of the whole family is rocked. Siblings experience the fears, worries and insecurity of their parents while, at the same time, being affected by them themselves. They too have to come to terms with this completely new situation and are often left to their own devices. Looking back, those affected say that they suffered from this loss, felt neglected, unloved and lonely. A young woman whose brother was diagnosed with cancer reports: "I was often frightened and sad. Today, I would say that I had to grow up very quickly and that I actually brought myself up in many ways."

How do siblings react to the extreme situation?

Just how much a person suffers depends on a lot of different factors. While some siblings openly show feelings of fear, loneliness, jealousy, envy, anger and even guilt, others are more restrained. The latter tend to hold back their feelings in order to protect their parents. While outwardly they show very little and appear to be bearing up well under the circumstances, inwardly they struggle with their emotions and suffer "in silence". The range of feelings and reactions is thus wide and often contradictory. "Some siblings come out of the illness more mature inside, feeling more independent and empathetic. The trust and strong cohesion within the family are also seen as positive. However, if it is not possible for them to come to terms with the experience, fears, insecurity, feelings of guilt and depression can remain and these sometimes accompany those affected for the rest of their lives," says Prof. Nicolas von der Weid (MD), Head of Oncology / Hematology at the University Children's Hospital Basel (UKBB).

What do siblings need?

Parents can be supportive by actively involving the sibling in what is going on, giving them information about what is happening and generally showing appreciation for their help.

Open and age-appropriate communication about the disease and the therapy, giving them the opportunity to ask questions and talk about their feelings helps, as does appreciating what they do to help and what they are having to do without. Hospital visits are also important because they give siblings the chance to develop a realistic view of what is happening with their brother or sister. Having their own social life with friends, activities and interests – spaces and times that are detached from their sibling's illness – is equally important for their psychological well-being. Parents often feel out of their depth in this balancing act between normality and the exceptional circumstances they are now facing. This is what one mother has to say: The life-threatening illness of a child is in itself an immense challenge. But it becomes all the more difficult when you have another child who is not doing well either." This is why it is all the more important to inform the sibling's social environment, such as school or nursery, about the situation and to get outside support if needed. This may also include psychological support if the emotional burden becomes too great for the sibling.

What kind of support is available for families?

If family resources alone are not sufficient to cope with such a crisis, early professional support is recommended. This can make a decisive contribution to reducing the immense strain for all family members. The psycho-oncological care offered in children's hospitals is therefore aimed at children with cancer, their parents as well as their siblings. There are numerous support services to help families get through the crisis better. These range from short "breathers" for parents through leisure activities for families and holiday camps for children with cancer and their healthy siblings to rehabilitation stays. We are committed to ensuring easier access to a stay in a family-oriented rehabilitation because it is so beneficial for everyone affected. To ensure that parents of children with cancer are also better protected legally, we campaign for them at a political level. For example, the care leave introduced in 2021 ensures that parents have more time to care for a seriously ill child. Ideally, healthy siblings also benefit from this. The aim of these offers and measures is to provide families with targeted support during one of the most difficult phases of their lives and to give them strategies to overcome this crisis as unscathed as possible.

About the "Siblings in the shadows" campaign

The awareness campaign is being launched on 15 November 2021. We would be happy to arrange interviews with affected persons and experts on request.

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Childhood Cancer Switzerland

The umbrella organisation Childhood Cancer Switzerland (CCS) was founded in 2015 by renowned Swiss childhood cancer organisations. The focus of the activities is the joint fight against cancer and its late effects in children and adolescents with the aim of improving the situation of those affected throughout Switzerland. This includes the optimisation of treatment options, the development of new therapies and medicines that are accessible to everyone, better psychosocial support for affected families, and optimal follow-up care and support for childhood cancer survivors. Childhood Cancer Switzerland is involved in all these areas at national level with its own projects, PR and awareness campaigns, political commitment, a national contact point for survivors and the provision of financial resources. More information at www.childhoodcancer.ch