Children in the blind zone

In encounters with someone who has been afflicted by illness, accidents or crises, it is sometimes easy to forget that the patient has a family that will also be affected. In recent years the health services have established good routines to take care of parents as next of kin, whereas children as next of kin have remained quite invisible as a group. It is therefore gratifying to see that the *Norwegian Electronic Manual of Medicine* has recently been updated with the chapter *Children as next of kin*.

Every year, nearly 3,500 children witness one of their parents falling ill with cancer, 6,000–9,000 have a mother or a father in prison, and 70,000 children have parents with alcohol problems that affect their daily functioning (1). Such stressors often entail major and long-lasting changes to the family situation. Society is undergoing constant change, and is developing in a more multicultural direction, with a greater diversity in family patterns than previously. At the same time, the number of divorces is increasing, with a growing number of single parents as a result. To some, this also entails a weakening of networks. Such issues make it difficult to recognise the needs of a family in a situation where the parents are affected by serious health problems. In general, we can assert that children constitute a particularly exposed and vulnerable group and may need extra support in such a situation.

Even though most parents want the best for their children, providing adequate care for them may be difficult when the parents are troubled. Children are sensitive to their parents' state of mind, and may easily assume the role of caregiver. Caregiving tasks appropriate for their age group may help them cope and develop, whereas too great or overwhelming a responsibility may be a harmful burden. Over time, parents needing help may lose their «normal view» of a child's tasks and responsibilities, whereas shame and guilt may cause the parents' illness to remain a well-kept family secret. This may become a heavy burden on the family – and on the children in particular – and may persist in the long term (2).

Adverse childhood experiences

Children who are exposed to adverse childhood experiences such as overwhelming care burdens or negligence are at an increased risk of developing health problems, in the short as well as in the long term (3–5). Recent research has helped establish a far deeper understanding of fundamental correlations between lifetime experiences and health. It is now well known that toxic stress during the foetal stage and early childhood may affect health later in life, for example in the form of illness in adulthood (4, 6, 7).

Certain stages of development are especially critical. For example, our ability to bond with other people is particularly sensitive during the first couple of years of life (8, 9). At the same time, we now know that the brains of small children are far more plastic than has been previously assumed. In other words, if a child has been exposed to harm/negligence, there is great potential for rehabilitation – which also underscores the importance of intervening as early as possible.

Legal provisions about children as next of kin

To improve the follow-up of children as next of kin, the Ministry of Health and Care Services in 2007 established *BarnsBeste* – a national competence network for children as next of kin (11). On 1 January 2010, the Health Personnel Act and the Specialized Health Services Act were amended with provisions aiming to ensure that these children be taken care of and provided with necessary support (12, 13).

«Serious neglect occurs more often than we like to think»

According to the law, health personnel have an obligation to clarify whether the patient has children, undertake an investigation of the children's need for information and follow-up, and to undertake necessary steps. As part of the efforts to systematise and disseminate knowledge on children as next of kin, *BarnsBeste* has collaborated with specialists to prepare a separate chapter on this topic in the *Norwegian Electronic Manual of Medicine* (1). The goal is to reach out to general practitioners. The possibilities should be good, since the majority of the country's general practitioners have access to the *Norwegian Electronic Manual of Medicine*.

Green, yellow and red response

It is crucial to underscore that children whose parents are ill are essentially *healthy* children, and that their behaviour often represents a normal reaction to an abnormal situation. It is essential to assess behavioural change in children in light of the situation in which they find themselves. Children may have strongly varying reactions to a stressful life situation. Some react by withdrawing and making themselves «invisible», others by rage and unruly behaviour.

Children who are exposed to neglect may have symptoms that meet the criteria for diagnoses such as ADHD and behavioural disorders. There is a risk that this «diagnosis» becomes an explanation in light of which all symptoms are interpreted. As a result, traumas and neglect can be overlooked (14).

A general practitioner (GP) is able to follow the family over time, and this provides good opportunities to assess children in their actual situation. The *Norwegian Electronic Manual of Medicine* describes the GPs' various opportunities for responding according to the traffic-light method. If the children are well taken care of and the caregivers cooperate well, there is no reason for further interventions (green response). If children are at risk of harm and the caregivers fail to realise the situation and/or reject offers of help, health personnel have a duty to report the matter to the child welfare services (red response). If there is doubt, further investigations must be undertaken, the children's situation must be assessed and other actors should be consulted as appropriate (yellow response).

A respectful approach

It is far from easy to be a child whose parents are ill – but neither is it easy to be a parent who is ill. A guilty conscience for failing to be a good parent is common even among those who are healthy and fit. Opinions are divided as to how parents should behave and what children need. Herein lies a challenge to health personnel: How can we respectfully draw the attention of suffering parents to the feelings of their children, when the parents themselves are struggling and vulnerable? What reactions should parents and their environment be on guard against?

How can we best take care of and support the entire family – including children and the other, healthy parent? While accepting the painful recognition that serious neglect occurs more often than we like to think, we need to mobilise the energy and the courage to act wherever we have reason

to believe that children are being exposed to such things.

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