

Expert Consensus Statement

on Provision of Healthcare, Social Care, and Education Provision for Children Living with Life-Limiting or Life-Threatening Conditions in the Home Environment

The presented statement outlines the key aspects of care provided to children living with a serious life-limiting or life-threatening condition within their own social environment and highlights the need to provide support to caregiving families. The final statement consists of **13 key aspects** of care which are presented below.

1. Children with a life-threatening or life-limiting condition and their families have access to healthcare, social care, and education at all stages of the illness, regardless of whether a diagnosis has been established.
2. Families are provided with the necessary care and support also during the perinatal period.
3. The care provided also includes psychological and spiritual support, which is available at all stages of the illness and following the death of the child.
4. Families caring for a child with a life-threatening or life-limiting condition have access to healthcare, social, and other services that enable them to receive sufficient and regular respite from caregiving responsibilities.
5. Children with a life-threatening or life-limiting condition and their families have access to the necessary care and services regardless of the region in which they live.
6. Children with a life-threatening or life-limiting condition have equal access to education and educational services, taking into account their individual needs and without discrimination on the grounds of their health condition.
7. Healthcare and social services, including specialised palliative care, are also available at the end of a child's life.
8. Families caring for a child with a life-threatening or life-limiting condition are guaranteed timely and adequate financial support by the state to ensure sustainable care, including adaptations of the home environment and the provision of medical and assistive equipment corresponding to the child's individual needs.
9. Services for families caring for a child with a life-threatening or life-limiting condition are continuous and coordinated. Families have access to professional support that assists them in organising the entire care process and accompanies them through all stages of the child's illness, including transition to adult services and following the possible death of the child.

10. Parents caring for a child with a life-threatening or life-limiting condition are ensured protection of their rights and access to professional social and legal counselling, including advice relating to employment law.
11. Every child with a life-threatening or life-limiting condition and their family are equal and fully valued members of our society and are not subject to social exclusion.
12. Following the death of the child, families have access to bereavement care, psychosocial support, and legal counselling, which they may use according to their needs and even after a period of time has passed. Bereaved caregivers are also entitled to appropriate financial support.
13. Appropriate care and support are also provided to the siblings of the ill child and to other close persons.

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