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Private paediatric hospice – is it such a bad idea?

OPINIONS

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The decision to grant NOK 30 million annually to a private paediatric hospice in southern Norway is not compatible with the kind of ethical reflection that must be made on a daily basis in the public health service.

Paediatric palliative care in Norway is not primarily about dying children, but about the approximately 7500 children and adolescents who are living with serious illness (1). Less than 3 % of these children and young people die during childhood (2).

A hearing was held on 30 September 2020 on Report No. 24 to the Storting (Norwegian Parliament) (Palliative care – We're all going to die one day. But all other days we are alive) (3). In a debate on 22 September, Tuva Moflag (Labour party), the spokesperson for the Standing Committee on Health and Care Services, said that the Committee had received a surprisingly high number of comments on Chapter 7, on paediatric palliative care. Following the announcement in autumn 2019 by the then Minister of the Elderly and Public Health, Sylvi Listhaug, that the user organisation Norwegian Association for Children's Palliative Care would receive NOK 30 million for the establishment of Norway's first private paediatric hospice, more than 30 contributions to the debate have appeared in Norwegian newspapers. such as *Dagens Medisin, Dagsavisen* and *Fædrelandsvennen*. An article on palliative care (The

organisation of palliative care: professionally sound or an undemocratic political game) (4), written by the authors of the Norwegian Official Report *På liv og død* (A matter of life or death) (5), points out that the process is characterised by the inclusion of high-profile names on the payroll of publicly-funded organisations in order to put in place a specific solution. There is unwavering opposition between the Norwegian Association for Children's Palliative Care on the one hand and the unified medical community, the majority of service user organisations and the Norwegian Directorate of Health on the other. Why does this issue evoke such strong feelings?

Norway is lagging behind

Neither palliative care of the seriously ill, nor hospice philosophy, meaning holistic treatment and care, is a new phenomenon. On the contrary: a holistic approach is the very core of the concept of *palliative care,* as defined by the World Health Organization in the last century (6).

> ***«According to the 2020 instructions from the Ministry of Health and Care Services, priority should be given to establishing regional paediatric palliative care teams»***

In other countries, paediatric palliative care has been a medical specialty for decades. In Norway, the first national guidelines were published in 2016, with recommendations for organising palliative care in a way that would ensure equal services for all children and adolescents (7). In 2019, the country's first regional palliative care team for children and adolescents was established at Oslo University Hospital. With a budget of NOK 2.2 million, the team has contributed to the setting up of local paediatric palliative care teams at nine out of ten medicine divisions in the South-Eastern Norway Regional Health Authority. According to the Ministry of Health and Care Services' 2020 instructions to the Norwegian regional health authorities, priority should be given to establishing regional paediatric palliative care teams (8). The Central Norway Regional Health Authority has earmarked NOK 1.2 million for this purpose while the Western Norway Regional Health Authority has started a regional network with similar funding. The Northern Norway Regional Health Authority has not yet taken any action.

Tailormade

Children and adolescents in palliative care present with very complex conditions, for instance pontine glioma, spinal muscular atrophy, leukoencephalopathy caused by perinatal asphyxia, congenital anomalies, hepatic, renal or cardiac failure. Repeated operations may be necessary as well

as advanced examinations under anaesthesia, life-sustaining treatment such as tracheostomy, home mechanical ventilation, gastrostomy, pacemaker or parenteral nutrition over long periods of time.

While the child is on the transplant waiting list, in the paediatric intensive care unit or receiving respite care, the parents must carry on with their lives as best they can. The hospitals try to accommodate their needs. Paediatric and adolescent wards can draw on the services of affiliated child psychologists, social workers, physiotherapists, occupational therapists, music therapists, and hospital clowns, as well as offering pastoral care services, play therapy and hospital school. In some areas, the 'hospital at home' system provides advanced care that entails the specialist health service visiting the child at home. Last, but not least, the paediatric and adolescent wards have well established structures for the important cooperation with the local municipalities. It is within these structures that each child must receive tailormade, holistic health care services ((7); (9), p. 26).

In the child's best interests

Unfortunately, the paediatric and adolescent medicine divisions have not been empowered to offer cohesive organisation of the overall provision of services. Interdisciplinary work is resource-intensive (10). Several professionals must meet on a regular basis to create the cohesiveness that each particular child and family needs.

> ***«Freedom of choice means not having to travel to a paediatric hospice far away, but to be able to choose to stay where you live, surrounded by your loved ones»***

In line with the UN Convention on the Rights of the Child, children and adolescents who are seriously ill have a right to treatment by specialist health services (11). This also applies when a child is dying. Freedom of choice means not having to travel to a paediatric hospice far away, but to be able to choose to stay where you live, surrounded by your loved ones.

Fairness includes equal treatment opportunities and a responsible distribution of resources (12). Palliative care competes for the resources administered by the regional health authorities in the same way as life-prolonging immunotherapy, more MRI machines or new medications to combat cardiovascular diseases. In the revised state budget, the Ministry of Health and Care Services increased the basic grant to the regional health authorities by NOK 600 million with the primary aim of reducing patient queues and reducing the backlog in the wake of the COVID-19 pandemic (13). It was added that the funding should also be used to establish regional paediatric palliative care teams, as previously stated in the 2020 instructions.

We can only hope that the backlog caused by the pandemic will be limited, so there will be some funding left for children and adolescents in need of palliative care.

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