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When children will not grow old

EDITORIAL

ANJA LEE

uxleea@ous-hf.no
Anja Lee, PhD, specialist in paediatrics and senior consultant at the Division of Paediatric and Adolescent Medicine, Oslo University Hospital.
The author has completed the ICMJE form and declares no conflicts of interest.

HENRIK HOLMSTRØM

Henrik Holmstrøm, MD PhD, specialist in paediatrics, senior consultant at the Division of Paediatric and Adolescent Medicine, Oslo University Hospital and professor at the Institute of Clinical Medicine, University of Oslo.
The author has completed the ICMJE form and declares no conflicts of interest.

A holistic approach throughout the course of life-limiting illness – palliative care – provides a better quality of life for sick children and their families.

'One day we shall die. But all the other days we shall be alive.' (1) This quote from Per Olov Enquist is especially relevant for children and young people living with a severe illness. Extreme prematurity, neurodegenerative disease, congenital heart defects and cancer are examples of life-threatening and/or life-limiting conditions (2). There is no systematic overview, but based on figures from other countries, around 3,500 children in Norway are currently living with such conditions. Around 250 children and young people die in Norway every year, mostly due to a life-limiting illness.

The term 'palliative care' is often associated with incurable cancer and care in the final days of life. This misconception poses a challenge for the field, particularly because many doctors also cling to this outdated understanding (3). Paediatric palliative care 'is the active total care of the child's body, mind and spirit' (2). The aim is to facilitate the best possible quality of life for the patient and their family, regardless of whether curative treatment is an option for the child or not. Provided it is in the child's best interest, life-prolonging interventions such as cardiac surgery for congenital heart defects, home ventilator treatment for neuromuscular disease, or a percutaneous gastrostomy for feeding difficulties, can be part of a palliative approach. These examples demonstrate that ethical reflection must be an integral part of paediatric palliative care (2).

The first national guidelines for paediatric palliative care in Norway were introduced in 2016 (4). The guidelines recommend that each health region and each paediatric department establish interdisciplinary paediatric palliative care teams, and that specialist and primary health services form a collaborative hub for optimal organisation of care. We have previously described inadequate follow-up for children with severe chronic illnesses and believe that there is insufficient interdisciplinary care in the health service (5, 6). Given the current framework in specialist health care, it is not realistic to establish structured patient pathways as recommended by the Norwegian Directorate of Health's guidelines. Ensuring the quality of these services requires additional resources (5).

Palliative care should be offered from the time of diagnosis. At hospitals we like to compare ourselves with, such as Rigshospitalet in Copenhagen and Charité in Berlin, patients and their families are offered contact with the hospital's paediatric palliative care team as early in the process as possible. Such a team may consist of two healthcare workers, e.g. a doctor and a nurse, who work closely with the department responsible for the patient. Other professionals (social worker, physiotherapist, psychologist, chaplain, music therapist, teacher, GP, school nurse etc.) are involved as needed. The paediatrician is responsible for communication about the diagnosis and prognosis, and crucially, for symptom relief, which is essential for the patient's and family's quality of life. The term 'palliative care' becomes less intimidating when the family experiences how the palliative care team is there to help, support and facilitate. A course of palliative care could last for a few hours or several decades. The need for follow-up will vary over time, and only an interdisciplinary team will be able to address the various needs of the patient and family.

Much of the work that is internationally defined as 'paediatric palliative care' is carried out daily in specialist as well as primary healthcare services. The challenges of palliative care are well-known in neonatology, paediatric oncology and child habilitation. From personal experience, we know how easy it is to get lost in the nitty-gritty of such situations; the next test, the next day, the next procedure. A paediatric palliative care team will be able to maintain the long-term perspective needed to make the best decisions.

In order to successfully provide paediatric palliative care and ensure universal access to follow-up throughout Norway, a change in attitude among healthcare personnel and reorganisation of the healthcare service are needed (7). Better communication, coordination and continuity in follow-up make life easier for patients and their families. When the child's best interest becomes the primary focus, unnecessary treatment can be avoided. The patient and family gain a greater degree of autonomy and can get involved in the decisions about the course of treatment for the time remaining. They get the opportunity to prioritise and manage their time. The concept of 'anticipatory grief' is acknowledged. Good palliative care can improve the quality of life for the whole family and help shape the memories that parents and siblings will carry with them for the rest of their lives.

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