

BRIEF | PR



One liner. Brief in a tweet

Palliative , Not Terminal: Paediatric palliative care is not just about caring for children in their last days , and when they are dying , it's about helping children and their families live a good life even with a serious illness.

Background

Palliative care for children involves active, total care of the child's body, mind, and spirit and support for the family. It is a comprehensive system of care for children with serious, life-limiting, or life-threatening illnesses and their families, ensuring that they receive the necessary and adequate support at every moment of their difficult life journey.

Palliative care has been a much-discussed topic recently, both in the professional and lay fields. However, when it comes to paediatric patients, the topic is very sensitive, and for many people, it remains a misunderstood and stigmatised area.

At the same time, it appears that although awareness of palliative care is increasing among the broader professional and lay public, the distinction between palliative care for children and adults remains taboo.

Apart from the specificities that arise from the care of the paediatric patient in general, the main difference lies in the spectrum and distribution of diagnoses requiring palliative care. While the adult population is predominantly cancer patients (approximately 75-80%), children account for only 20% of these diseases.

In a broader context, two groups of children require palliative care: those who have a life-limiting disease, i.e. a condition where premature death is common (neuromuscular diseases, degenerative CNS diseases, inherited metabolic disorders, complex inherited defects, consequences of prematurity), and those who have a life-threatening disease, i.e. a condition where there is a high probability of premature death due to severe illness (cancer diagnosis, intensive care after severe trauma, etc.). However, diagnosis is only part of the process; the severity of the disease itself, its course and complications have a major impact on the palliative care needs of the child and his/her family.

The international study "Make Every Child Count" (2020) shows a gradual increase in the prevalence of serious life-limiting and life-threatening diseases in children from 26/10,000 (2001) to 66/10,000 (2020). The study's authors estimate a further increase of 11% in 2030. Experts attribute the increase to improved diagnosis of the diseases in question, but also to improved medical options (curative treatment, intensive care, preventive measures), which leads to longer survival of children with these diseases, and often, they can live into adulthood.

In the Czech Republic, there is still a lack of empirical data on the number of children in need; it is estimated that there could be up to 15,000 children.

Other differences between child and adult care include, for example, the incapacity of paediatric patients to make treatment decisions or the different developmental needs due to the child's age, which places a higher demand on the provision of care and, thus, on quality assurance throughout their lives.

In the last five years, paediatric palliative care has made dynamic progress in the Czech Republic. The number of providers providing care to paediatric patients has increased, but there are significant differences in the availability and level of services for seriously ill children with palliative needs in different regions of the Czech Republic.

Longterm support for caring families based on systemic respite care, key to preventing caregiver burnout, is still unavailable.

Availability and variability of services, enough caring professionals and easy orientation of families in the health and social care system are the main pillars of quality comprehensive care for children with serious life-limiting or life-threatening illnesses and their families so that they receive necessary and adequate support at every moment of their difficult life journey.

Challenge

In Czech society, serious illness and the death of children are taboo subjects, leading families to often experience social isolation.

The challenge is to overcome the taboos surrounding children's palliative care, raise awareness of its complexity, and show that it is not only about the terminal phase of children's lives. As abroad, it focuses primarily on improving the quality of life of children with serious, life-threatening, or life-limiting illnesses and providing their families with the necessary support at every stage of the disease.

Target audience

Our primary target audience is the general public, but we also want to reach journalists and content creators in the health and family field through whom the topic is communicated.

Our target audience is policymakers who can push for systemic change to support the availability and variability of services for caring families.

Finally, we reach all informal caregivers, parents and families of children with serious diagnoses for whom it is important to notice that someone is advocating for their interests.

Insight

People mainly associate palliative care with the end of life. However, palliative care for children and young adults involves much more than the end of life. As defined by the World Health Organization, the care is tailored to the individual needs of the child and appropriate to their age and cultural background. Palliative care must also respond to and be prepared to meet the specific needs of adolescents and young people.

Palliative care for the child and his/her family should begin at the time of diagnosis, continue alongside all curative procedures throughout the illness and continue at the time of death; it includes bereavement care.

The aim of palliative care is to alleviate suffering and improve the quality of both children and their caregivers' life

In most cases, the place of serious diagnosis is the hospital. This is why it is often the place where the child and family with palliative needs are identified. The conciliar team for specialised palliative care, which is part of teaching hospitals and hospitals with the status of a highly specialised care centre, usually consists of a doctor, a nurse, a social worker, a psychologist and a clergyman. This team identifies the child, ensures that his or her needs and those of his or her family are met, and helps with the transfer to the region.

Long-term inpatient care is an important part of the care system for patients who cannot be discharged from an acute bed directly to home care. This care should consider the individual needs of the child and his/her family, helping to further stabilise the health condition and stabilise the family. It should also include the provision of the necessary education, aids, and follow-up to home care.

According to available research, the needs of children with life-limiting or life-threatening illnesses are the same across Europe. Research shows that children often prefer to stay at home, and families usually want to keep their children at home throughout the course of their illness and dying. [The Charter of Rights of the Child with a Life-limiting and Life-threatening Illness](#) also states that the home should be the centre of care. Caring for children with a serious diagnosis is challenging, and the care system should ensure that there is enough support for carers to cope.

However, practice shows that the availability of home-based services usually depends on where the child lives and the type of illness. Often, these services do not reflect the real needs of the child and family, nor the trajectory of the child's illness. The health, social and education services system is complicated, disconnected from surrounding

services and opaque. Necessary respite residential services are still inadequate. There is a lack of outreach workers, and paediatricians are not systematically trained in general palliative care.

Strategy

Our goal is to create a strong and understandable PR campaign that will reach the target groups in terms of information and hint the possibilities of system solutions.

In the campaign, we work with real-life examples through the personal stories of families and the expert insight of palliative care professionals.

In developing content and arguments, we will make maximum use of the existing [Concept of Care for Children and Adolescents with Serious Life-Limiting and Life-Threatening Diagnosis and their Families](#) and related professional texts and publications.

Campaign Objective

Prepare a comprehensive PR campaign for the next 3 to 6 months with the following two goals:

1. Increase public understanding of palliative care for children, focusing especially on improving the quality of **life of children and their families**.
2. Highlight the specifics of paediatric palliative care and the necessity of accessibility and variability of care across regions in the Czech Republic.

Key message

Several childhood diseases have prognoses that can last many years and are very difficult to predict. In the future, the number of children with serious, life-threatening, or life-limiting illnesses will increase. Survival is also likely to increase; a not insignificant percentage of children will live to adulthood.

Palliative care for children means tailoring it to the child's individual needs and being appropriate to the child's age, the family's cultural background, and the disease's current state. Effective palliative care requires a broad multi-professional approach.

The needs of these children and their families are the same across Europe. In practice, we must ensure the quality, variability and accessibility of children's palliative care across the country.

One of the priorities is to provide comprehensive care, preferably in the child's natural environment, even in the terminal state of the disease. This requires long-term systemic support for families and carers.

Brand Personality/Tone of voice

Our communication about children's palliative care is always warm, empathetic, and supportive but firm and professional on a professional level. We strive to capture the attention of our readers and encourage them to seek further additional information. We inspire an approach that is respectful. We avoid the passive voice.

Timeline & Budget

The estimated available budget is between 200,000 and 500,000 CZK. We plan to fund this through grants, but if the concept is exceptional, we will try to seek additional funding.

Campaign Do's and Don'ts

Do:

- When publishing real stories, we respect the ethical principles of communication as much as possible (it is not enough for us to rely only on the consent of the family; we want the family to be well-informed and educated about the possible negative effects of communication).
- We always speak with respect for the emotions of families.
- We work with validated data sources only.
- Use comparisons with foreign countries, relying on already published scientific studies and available research.

Don't:

- Do not use manipulative or sentimental content.

- Don't abuse emotions in your communication; children's palliative care is not primarily about sadness and tears; it is about the importance of every moment in a child's life.
- Honour the rules of truthful and fair communication. Do not simplify the topic, nor twist or embellish our arguments.

Other useful info

In the campaign, we highly recommend involving experts from organisations under the umbrella of the Concept of Care for Children and Adolescents with Serious Life-Limiting or Life-Threatening Diseases and their Families (konceptce.info).

Web & Social media channels

Website - <https://www.paliativnimedicina.cz> , <https://pallium.cz>

Instagram - <https://www.instagram.com/institutpallium/>

Facebook - <https://www.facebook.com/paliativnimedicina>, <https://www.facebook.com/institutpallium>

LinkedIn - <https://www.linkedin.com/company/institut-pallium/>

YouTube - <https://www.youtube.com/@ceskaspolecnostpaliativnim7579>, <https://www.youtube.com/@institutpallium>

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