

# Pediatric Palliative Care – building bridges between hospital and community care for child and family

**Simone Keller**, Pflegeexpertin Pädiatrische Palliative Care, Inselspital, Universitätsspital Bern, [simone.keller@insel.ch](mailto:simone.keller@insel.ch)

**Brigitte Griffiths**, Pflegefachfrau und Teamleitung Kinderspitem Bern, Spitem Bern, [brigitte.griffiths@spitem-bern.ch](mailto:brigitte.griffiths@spitem-bern.ch)

## Background

Pediatric palliative care focuses on providing relief symptoms and stress for the patient and it's family in a life-limiting healthcare situation. The goal is to improve quality of life for all - the child and the surrounding family. Pediatric palliative care can take place prenatal, if a child is diagnosed with a life limiting illness before birth, and last throughout the lifespan up to young adults. Most of the children in pediatric palliative care, are diagnosed with a rare disease and therefor face an unknown live expectancy and disease management.

## Methods & Objectives

A pragmatic case series practice development project shows examples of successful partnerships in a pediatric palliative care setting. The approach of integrated care within health care professionals in different settings, as well as patients and families, serves as best practice to enhance partnerships for care in pediatric palliative care. The goal of this pragmatic cases series practice development project is to demonstrate, how successful pediatric palliative care with a family integrated focus can be performed, when health care staff in the hospital and community setting are collaborating in a partnership for care.



### Lielle's story of a short life

Lielle is born as a baby sister to her brothers and welcomed by her parents Mirjam and Marcel. But Lielle's start into life is already prepared to say goodbye to her, whenever she is no longer able to face the symptoms of her complex congenital heart defect, diagnosed early and confirmed at 32nd week of pregnancy. Mirjam and Marcel are confronted with a challenging decision making process. To ensure empowerment in taking "there" decision, several discussions with specialists take place.

The parents decide against highly invasive therapies for her unborn. Options for the course and care are discussed with the pediatric palliative care Team (PPC) and a perinatal care plan is drawn up in partnership with the parents, setting out the family's wishes: "We want to cherish and enjoy the time we get to spend with our Baby. It is very important to us, that the siblings can welcome their sister as soon as possible after birth, if she is still alive. If she dies before, we decide spontaneously where and how we take that. If circumstances allow, my main wish (Mirjam) is to go home as soon as possible! If possible, I would like to hold her myself at birth or Marcel. We want to do as much as possible ourselves, e.g. putting on diapers and clothes after the birth...".

The setting to give birth to Lielle is prepared within round table discussion in the nearby regional hospital, together with the parents, obstetrics and the PPC team of the tertiary hospital. The parents' concerns and the hospital's options are discussed, responsibilities are defined and a basis of trust is established.

Weeks later Lielle is born gently in the water, is full of life and is allowed home with her parents a few hours after birth, where she is lovingly welcomed and cared for by her brothers and family, closely accompanied by a midwife. A few days later, Lielle's condition deteriorates and the parents contact the PPC team. Symptom control measures are implemented as previously discussed with the support of the midwife. A doctor and nurse from the PPC team arrive a short time later, where symptom control is assessed and adjusted. Lielle passes away peacefully some hours later imbedded, loved and cared in the arms of her parents, surrounded by her family. Accompanied by an undertaker, specialized on child burial, the family and friends are allowed to say goodbye to Lielle at home for several days.

## Results

Integrated care in pediatric palliative care demonstrates different paradigms and enables to set up health care settings for successful pediatric palliative care in partnership with families and different health care settings and professionals. Key factors to support a comprehensive continuum of care, include enabling patients and families, based on their individual needs, and are guiding the care pathway in individual care situations.

## Conclusion:

Integrated pediatric palliative care takes place long before end of life care and has the power to build bridges between different health care settings. Pediatric Advance Care Planning includes:

- Symptom management
- Cooperation and communication between stakeholders
- Clarify on-call availability between stakeholders
- Preparing the place of death & end of life settings and procedures
- Being flexible for changes



## References:

Zimmermann K, Simon M, Scheinmann K, Tinner Oehler EM, Widler M, Keller S, Fink G, Mitterer S, Gerber AK, von Felten S, Bergstraesser E. Specialised Paediatric Palliative Care: Assessing family, healthcare professionals and health system outcomes in a multi-site context of various care settings: SPHERA study protocol. BMC Palliat Care. 2022 Nov 2;21(1):188. doi: 10.1186/s12904-022-01089-x. Erratum in: BMC Palliat Care. 2023 Feb 22;22(1):13. doi: 10.1186/s12904-023-01136-1. PMID: 36324132; PMCID: PMC9628037.

Mitterer, Stefan; Zimmermann, Karin; Fink, Günther; Simon, Michael; Gerber, Anne-Kathrin; Bergsträsser, Eva (2023). *The funding of specialised paediatric palliative care in Switzerland: a conceptualisation and modified Delphi study on obstacles and priorities*. Swiss Medical Weekly, 153(12):3498.

Akyempon AN, Aladangady N. Neonatal and perinatal palliative care pathway: a tertiary neonatal unit approach. BMJ Paediatrics Open 2021;5:e000820. doi:10.1136/bmjpo-2020-000820

Photo: Annick Ramp, [republik.ch/2024/01/27/solange-das-herz-schlaegt](https://republik.ch/2024/01/27/solange-das-herz-schlaegt)