STANDARD CLINICAL PRACTICE RECOMMENDATIONS FOR PALLIATIVE CARE

How to uphold quality of life of all children with an oncological disease and ensure a dignified death for the minority of children and adolescents, who cannot be healed, in modern paediatric oncology.

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INTRODUCTORY PAGES

- Standard Clinical Practice Recommendations for Palliative Care in paediatric Oncology
- Palliative Care
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2. BACKGROUND AND RATIONALE

In the last decades paediatric oncology in Europe has progressed from healing only a minority of children and adolescents to ensuring survival in the great majority of affected patients. Even oncological diagnoses that were a certain death sentence only a few years ago can now be treated, prolonging life and, in some cases, turning a rapidly progressing disease into a chronic condition.

These feats have been achieved through the refinement of structured treatment protocols, the introduction of a myriad of modern medications—allowing individualised treatment—technical progress in surgery and radiotherapy, and, very importantly, by improving supportive care during the intense phases of oncological treatment, especially by preventing sudden death from serious infectious complications.

The World Health Organization (WHO) states that Palliative Care for children is the active total care of the child's body, mind, and spirit, and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease(1).

However, Palliative Care is viewed as the discipline caring for patients whose life expectancy is clearly limited, helping to create an environment that allows a dignified and, as far as possible, symptom-free death, and accompanying the grieving process of the bereaved family. Despite the increasing awareness that these goals can only be reached by early introduction of Palliative Care — since we cannot predict the future of the individual patient — there is a significant hurdle, because the term "Palliative Care" continues to be associated with treatment failure, loss of hope and death. Therefore, it is often introduced only at a late stage of the patient's pathway through their illness, when the autonomy of the affected child or adolescent is already impaired and hope is lost on the treating oncologist's side.

One of the main achievements of Palliative Care is focusing on the individual needs and wishes of the patient and their loved ones, allowing them to make choices that improve their quality of life and give them the freedom to have meaningful experiences. To achieve this, open communication and building a relationship with the child or adolescent and their parents is essential. Empowering them to make informed choices and decide how they want to live their life means that Advance Care Planning, including anticipation of worsening symptoms and preparation for their relief if they occur, plays a key role.

Supportive care should be tailored to match these choices. Most clinics, for example, have strict rules about fever in neutropenia, requiring the febrile patient to be hospitalized for at least 48 hours and treated intravenously with broad-spectrum antibiotics. There is data(2,3) that, in most cases, oral antibiotics taken at home would also be safe. When curing the disease becomes less likely, spending time at home and going to school or on vacation could be more valuable to the family than being as safe as possible, and the option of taking this small risk should be discussed. These processes take time, optimally a multiprofessional supportive team, and, to be appropriate, they need to be reevaluated throughout the course of the illness. It is also less difficult for affected families to talk about severe symptoms and death when these risks are still theoretical and not imminent.

One way to reduce the hurdle to introducing Palliative Care early is to be transparent about the patient's prognosis. The Bow Tie Model of Palliative Care(4), for example, allows this. It defines the role of Palliative Care as supportive care during acute treatment, shifting to rehabilitation and survivorship care, or hospice and bereavement care during the course of the illness.

Palliative Care is an essential part of high-quality paediatric oncology and should be offered in all European paediatric oncology centres.

3. PATIENT GROUP

Palliative Care should be available to all patients with life-threatening or life-limiting oncological diseases.

Early and integrated paediatric palliative care

Paediatric palliative care (PPC) should be introduced early during a life-limiting or life-threatening disease and provided alongside disease-directed treatment. Early integration acknowledges that acceptance of prognosis and shifting goals of care are dynamic processes that require time, continuity, and repeated sensitive conversations with children and families.

PPC aims to address physical symptoms, psychosocial distress, existential concerns, and family needs proactively, rather than being limited to the terminal phase. Early involvement of palliative care teams has been associated with improved symptom control, better communication, and enhanced support for families and healthcare professionals.

Models of PPC delivery vary across Europe and may include hospital-based teams, outpatient services, home-based care, or specialised PPC networks. Regardless of the model, timely access to PPC expertise should be ensured whenever significant symptom burden, psychosocial distress, complex decision-making, or uncertainty about goals of care arise.

3.1. Diagnostic Criteria

“Green lights” to consider for the referral to specialized PPC for children with cancer.(5)

At diagnosis
• Life-threatening illness (e.g., extended brain glioma) or advanced-stage cancer (e.g., stage IV neuroblastoma; solid metastatic tumor)
• Diagnosis of a tumor with an event-free survival rate estimation <40% with current therapies.
During illness
• Progressive metastatic disease
• Recurrent or resistant diseases, also after organ failure
• Major toxicity during treatment
• In case of prolonged hospitalization (>3 weeks) or prolonged admission to intensive care unit (>1 week) without signs of improvement
• In case of three or more unplanned hospitalizations for serious medical issues within a 6-month period
Related to complex needs
• Difficulties in symptoms management, in particular of pain
• Major psychosocial stress or limited social support
• Introduction of new devices (gastrostomy or tracheostomy) requiring complex care during the transition from hospital to home
• Difficulties in decision-making or communication processes

Table adapted from Benini et al., 2022 and used with permission

PPC provision across Europe is heterogeneous regarding availability, timing of integration, and organisational models. While international recommendations emphasise early and integrated palliative care from diagnosis onwards, access to specialised PPCservices - defined as services providing 24/7 coverage by a specialised physician and a multidisciplinary team - varies considerably between countries and regions(6).

In some European healthcare systems, specialised PPC is structurally embedded and available across care settings, including outpatient and home-based care. For example, in Germany, specialised outpatient PPC services support children with life-limiting conditions and their families

through multiprofessional teams working alongside primary treating services. Such models facilitate early palliative involvement, continuity of care, and coordination between inpatient and outpatient settings.

Other countries rely primarily on hospital-based or consultative models, and in some settings access to specialised PPC remains limited. This variability underscores the importance of adaptable recommendations that can be implemented within different healthcare systems while adhering to shared principles of early integration, multiprofessional collaboration, and patient- and family-centred care.

Current landscape in Europe

EPIDEMIOLOGY OF CANCER AND PALLIATIVE CARE PROVISION

Cancer remains a significant public health challenge, listed among the top ten leading causes of death globally for children, and the second leading cause of death in high-income countries(7). In the WHO-European Region the annual incidence of childhood cancer is estimated at around 150 per million in Europe (with regional variation). Currently, approximately 20% of children with cancer in Europe die although favourable trends in mortality have been observed across the European Union (EU). From 1990 to 2015, total childhood cancer mortality rates in the EU declined by 2.8% per year, reaching 2.6 per 100,000 in the latest available calendar years (7). However, significant disparities persist(7). For example, in leukaemia patients, mortality rates decreased from 1.6 to 0.6 per 100,000, achieving an average annual percent change (AAPC) of -4%. Despite the deepest declines in Central-Eastern countries, this region still reported the highest recent rates (0.9 per 100,000), while Southern European countries maintained comparatively high rates (0.8 per 100,000). Regarding the overall mortality, the highest recent mortality rates were observed in Central and Eastern European countries, while Southern European countries had higher rates compared to Northern-Western Europe.

PPC PROVISION IN PAEDIATRIC ONCOLOGY SETTINGS

The availability and integration of PPC services show notable variability across Europe as reported by a recent study(8). Specialized PPC, which is defined within this survey as care delivered by a dedicated paediatric oncology team with expertise in palliative care, complex symptom management and ethical decision-making, was found to be available in more than half (64.6%) of participating paediatric oncology centres across Europe.

However, capacity deficits are reported:

- In over one-third (38.7%) of centres, service capacity was reported to be lower than demand.
- Development of specialized PPC provision is less accentuated in low-to-middle-income countries.

ESTIMATED NUMBERS OF CHILDREN NEEDING PPC

It has been estimated, that 4 million children worldwide with oncological disease need PPC(5). This cancer-related need is a subset of more than 21 million children who require palliative care across all life-limiting conditions, and it reflects children with oncological diseases who would benefit from PPC at some point during their illness, not just at end of life.

Despite reduction in childhood cancer mortality, according to the Cancer Atlas(9) we can estimate more than 6000 paediatric cancer deaths/year in Europe (SIOP-E Countries) but many of the 35’000 new cases/year will experience one or more “Green lights”-criteria thus have a reason for referral to specialized PPC during treatment or follow-up.

General principle:

In a treatment-phase with low probability of success, high quality of life (defined individually) is the most important goal. Oncological treatments should be chosen / adapted to enable the best possible quality of life. Open communication is important to enable children/adolescents and families to make decisions according to their individual needs. Patients in Phase I and II studies should always be offered palliative care in parallel including Advance Care Planning. Accordingly palliative care should not be mentioned as an alternative to inclusion into a Phase I or II study but as an integral part of required supportive care during and after the study participation.

3.1.1 Evaluation of Symptom Burden

3.1.1.1 Possible Tools/Scores

The systematic use of validated outcome measures is central to paediatric palliative oncology practice. Standardized scales improve objectivity in symptom evaluation and management, enable longitudinal monitoring, and strengthen interdisciplinary communication across hospital and community settings(10–12). Their structured implementation supports earlier identification of unmet needs, more precise titration of interventions, and more transparent shared decision-making with families. At a programmatic level, they enable benchmarking between centres, support quality improvement strategies, and facilitate harmonized research.

In paediatrics, outcome assessment such as multidimensional and symptom scales should rely on patient-reported outcomes (**PROMs**) and, when necessary, **proxy reports**(13). Self-report should be prioritized whenever developmentally feasible, as child–parent agreement is only moderate, particularly for subjective domains such as emotional distress or suffering. Proxy input remains necessary in younger children or those with cognitive impairment but should be interpreted cautiously. Although the evidence base for PROMs in PPC is expanding, it remains less robust and more heterogeneous than in adult oncology, highlighting the need for harmonized methods and stronger psychometric validation.

Outcome measurement tools in paediatric palliative oncology can be broadly classified into symptom-specific scales or multidimensional measures. **Symptom-specific tools** focus on a single construct (such as pain, fatigue, nausea, or distress) and are particularly useful for monitoring targeted interventions or titrating treatment. **Multidimensional scales** assess several domains simultaneously (typically combining physical symptoms, emotional well-being, functional status, communication, and sometimes family impact) within a single structured framework. These tools are especially valuable in PPC, where suffering is rarely confined to one symptom and clinical decision-making requires an integrated understanding of the child's overall condition and context.

Any tool in order to be used in a particular clinical environment should be adapted and validated. Cross-cultural adaptation in PPC settings requires particular rigor because constructs such as "quality

of life," "suffering," "well-being," or even "palliative care" are deeply embedded in linguistic nuance, family dynamics, and cultural meaning(14,15). Translation cannot be limited to semantic equivalence; it must ensure conceptual equivalence. Forward–backward translation, expert consensus panels, and cognitive debriefing interviews with children and caregivers are essential to explore how items are interpreted. Psychometric evaluation in the target population must confirm reliability, construct validity, and responsiveness. In paediatric oncology, where proxy reporting is common, particular attention must also be paid to the interaction between child self-report, parent proxy perception, and professional assessment.

Examples of available scales

- **General Symptom Burden / Multidimensional Assessment**: Edmonton Symptom Assessment System (ESAS): Example see appendix; Memorial Symptom Assessment Scale (MSAS; validated paediatric versions); Children's Palliative Outcome Scale (C-POS), SENS scale (paediatric version, which is being used but not scientifically validated see below)
- **Pain Assessment**: Brief Pain Inventory (Long and Short Forms); Wong-Baker FACES Pain Rating Scale; FLACC Scale; Non-communicating children´s pain checklist.
- **Fatigue**: Brief Fatigue Inventory, EORTC QLQ-FA12
- **Psychological Distress / Emotional Symptoms**: NCCN Distress Thermometer; Patient Health Questionnaire-9 (PHQ-9); Patient Health Questionnaire-2 (PHQ-2), KINDL® (Language versions - kindl.org)
- **Performance/ Functional Status**: Palliative Performance Scale; Karnofsky Performance Status; ECOG Performance Status
- **Neonatal and Developmentally Specific Tools**: CRIES Scale; Neonatal Infant Pain Scale (NIPS); Neonatal Pain, Agitation and Sedation Scale (N-PASS)

Many of the existing scales are still not widely validated and therefore should be considered critically when used in a particular cultural and linguistic setting. PROMIS (Search & View Measures) offers a diverse set of measures, which have also been translated in several languages for free.

The SENS (Symptom, Expectations, Network, Support scale) is an example of a multidimensional tool that encompasses not only physical but a holistic evaluation of the patient. It is being used in some Swiss paediatric centres but not yet fully validated.

SYMPTOMS / IMPACT OF THE ILLNESS ON THE PATIENT AND FAMILY

Physical Symptoms – Patient	Assess using an instrument: e.g. modified Edmonton SAS, FLACC-R, KUSS, etc. depending on ability to communicate/age/neurological state/Cognition
Psychological Symptoms – Patient	Signs of distress: withdrawal, anxiety, depression, sleep disturbances, etc.
Social Stressors – Patient	Isolation from peers; hobbies, activities Child/parent interaction, etc.
Spiritual Symptoms – Patient	Despair, feelings of guilt, wanting to protect loved ones from own suffering, questions about meaning ("Why?"), grief, feelings of shame, loss of control,
Physical Symptoms – Family / Siblings	Insomnia, pain, exhaustion, etc.
Psychological Symptoms – Family / Siblings	Anxiety, depression, despair, guilt, rumination, aggression, "shadow children", regression of development in siblings
Social stressors – Family / Siblings	Impact on relationships; family life/partner relationship; care in an institution; sibling care; circle of friends; isolation as a family; blaming; activities; work, finances
Spiritual Burden – Family / Siblings	Questions about meaning ("Why?", "How can I be a good parent/sibling"), grief, feelings of guilt and shame, need to show only hopeful/positive emotions, despair/hope, spiritual pain, religious rituals, cultural aspects

EXPECTATIONS / DECISION-MAKING OF PATIENT AND FAMILY

Expectations – Patient / Expectations – Family	Fear regarding prognosis, unclear diagnosis? General expectations, spiritual aspects and resources, ethical values
Medical and Nursing Expectations and Goals	Medical and Nursing Decisions Knowledge and understanding of the medical situation Needs and wishes regarding current therapy/care Goals regarding future diagnostics/therapy Limitation of therapy, resuscitation status (code status)
Personal History	Parents' professional situation Financial decisions/planning of the family, obligations (siblings/relatives) Values, worldview, religious beliefs/faith
End-of-Life Decisions (usually not part of the first assessment)	"Unfinished business" for patient and family, will, advance directive/advance care plan? Religious rituals, preferred place of death, who may certify death? Who will certify death if at home and preparation (legal forms at hand) Funeral arrangements/planning Repatriation to the home country

NETWORK ORGANIZATION

Private Network	Relatives, friends, volunteers – who can do what? If necessary: create lists.
Professional Network	Lead professional Development of a care plan; involvement of family physician / paediatrician? Home care nurses, school or residential facility, pharmacy, medical equipment provider, physiotherapy, psychological support, social work, pastoral care
Living Circumstances	Living situation (at home, in an institution) Equipment for care/transport within the home Medication storage Administration of medication by caregivers/staff in the facility Transport options/car
Emergency Plan	Detailed specification of who can be reached, how, when, and where – professionals (also depending on place of residence/region information to local rescue services) Detailed specification of who can be reached, how, when, and where – family

SUPPORT FOR THE ENVIRONMENT / FAMILY

Patient Concerns	Current burden and resilience of the environment/family
Family Concerns	Current resources and burden/resilience of family members and the wider family network Grandparents' burden
Support Options	Possibility of respite for family members? Support by volunteers, respite services, household assistance Expansion of home care support (home care nurses) (Hospice stay), current resources
Financial Problems of the Family / Relatives	Possibility of leave from work? Financial support options, social counselling Entitlement to insurance benefits

3.2 Elements of Care

3.2.1 Models of Palliative Care

Palliative care in paediatric oncology can be structured into different models, which may also be regarded as levels of care: **basic/general care**, **specialized paediatric palliative oncology care**, and i**ntegrated care between oncology and palliative teams**.

Each model corresponds to a different level of patient needs and disease complexity but is also dependent on available resources. Regardless of the model, palliative care should be embraced from the time of diagnosis, with parallel planning and holistic attention to physical, psychological, social, and spiritual needs(6). This perspective supports the integration of palliative care into paediatric oncology as a continuum across levels of care, rather than as a late-stage intervention (Figure 1)(16).

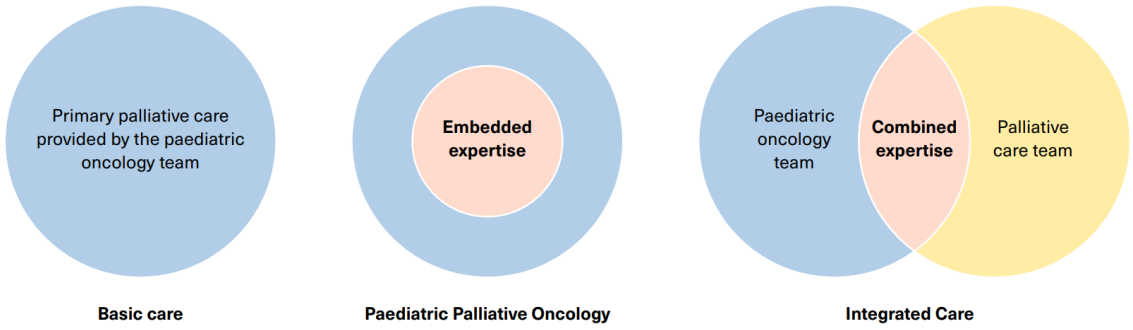


Figure 1: Possible models of PPC delivery in paediatric oncology (used with permission from *Lacerda A, et al., Embracing paediatric palliative care in paediatric oncology from diagnosis onwards. Ped Blood Cancer 2023).*

At the **basic level**, palliative care is provided directly by the paediatric or oncology team and focuses on the management of symptoms that can be addressed with standard supportive measures. This level is appropriate for children whose prognosis may still include cure or long-term survival (>40%), but who nonetheless experience pain, fatigue, or psycho-social distress requiring attention.

The **specialized level** involves the intervention of a dedicated PPC oncology team, with expertise in complex symptom management, ethical decision-making, and psycho-social support. This level is particularly indicated for patients with poor prognosis, such as those with less than a 40% chance of cure, children enrolled in early-phase clinical trials, or those affected by progressive brain tumors and severe neurological sequelae. In these cases, the symptom burden is often high and requires advanced competencies to ensure quality of life.

Finally, the **integrated level** represents a collaborative model in which oncology and palliative care teams jointly manage the patient. This approach is especially relevant when the disease trajectory is uncertain and requires parallel planning, maintaining hope for cure while simultaneously preparing for possible decline. Integrated care ensures continuity across curative, supportive, and end-of-life phases, and provides families with structured communication, shared decision-making, and holistic support(17).

Model of Care	Definition	Examples
Basic / General Palliative Care	Supportive care provided by the primary paediatric/oncology team without specialized expertise.	- Symptoms manageable with standard supportive measures. - Child undergoing curative therapy but experiencing pain, fatigue, or psycho-social distress.
Specialized Paediatric Palliative Oncology Care	Care delivered by a dedicated paediatric oncology team with expertise in palliative care, complex symptom management and ethical decision-making.	- Complex symptom burden (pain, dyspnoea, refractory nausea, existential distress). - Child with prognosis of cure <40%. - Enrollment in Phase I/II clinical trials. - Progressive brain tumors or severe neurological sequelae.
Integrated Care (Oncology + Palliative Team Collaboration)	Joint management by oncology and palliative care teams, ensuring continuity across curative, supportive, and end-of-life phases.	- Disease trajectory uncertain, requiring parallel planning. - Families needing structured communication and shared decision making - Patient/Parents need for home-based PCC

3.2.2 Organisation of a Palliative Care Team

PPC is delivered by a multiprofessional team with competencies in symptom management, psychosocial support, communication, and ethical decision-making. Team structure and service organization vary across Europe according to healthcare systems and available resources. PPC may be provided within basic/general oncology care, through specialized PPC teams, or through integrated oncology–palliative care collaboration (see Section 3.1.0 Models of Care).

Effective PPC requires early integration, clearly defined responsibilities, and structured collaboration with paediatric oncology services.

MINIMUM STANDARD
Centres providing paediatric oncology care must ensure:

- Access to professionals trained in basic palliative care competencies within the oncology team.
- Availability of specialist PPC consultation for complex symptom burden, psychosocial distress, ethical conflicts, or end-of-life care.
- Clearly defined communication pathways between oncology and PPC teams.
- Documented care planning, including emergency plans and Advance Care Planning (ACP).
- Structured handover processes during transitions (hospital–home–hospice–ICU).
- Access to PPC expertise must be possible outside regular working hours, either locally or through regional networks.

RECOMMENDED STANDARD
Centres should aim to provide:

- A dedicated specialised PPC team consisting of trained physicians, specialist nurses, psychosocial professionals, and access to social work and spiritual care.
- Sustainable 24/7 coverage through an adequately staffed rota system to ensure continuity and prevent professional burnout.
- An on-call service led by experienced PPC clinicians able to provide:
  - Telephone consultation for families and professionals

  - Urgent clinical assessment (home or hospital-based where applicable)
  - Coordination with emergency services
  - Rapid review of symptom crises and treatment plans

- Regular interdisciplinary case conferences between oncology and PPC teams.
- Joint family meetings for complex decision-making.
- Structured collaboration with community services, primary care providers, and specialised home-based PPC networks where available.

INTEGRATION WITHIN THE ONCOLOGY PATHWAY

PPC involvement should be guided by patient needs rather than prognosis alone.

Integration may occur:

- At diagnosis in high-risk or advanced disease
- At relapse or disease progression
- At enrolment in Phase I/II trials
- In the presence of complex symptom burden or psychosocial distress

Continuity across care settings is essential.

Transitions between hospital and home must include:

- Clear medication plans
- Updated ACP documentation
- Defined emergency contacts
- Direct communication between responsible professionals

The treatment schedules and flow diagrams presented in this document illustrate principles of timing and parallel planning. These should be adapted to national legal frameworks, institutional structures, and resource availability.

3.2.3 Advance Care Planning and Shared Decision making in Paediatric Oncology

DEFINITION AND AIM

Advance Care Planning (ACP) and shared decision-making are core components of PPC and should be embedded early in the trajectory of paediatric oncology, alongside disease-directed treatment. Early integration acknowledges that prognostic awareness, acceptance, and goal formulation evolve over time and require continuity, trust, and repeated conversations with children and families(6).

In this context, ACP is understood as a structured, ongoing process that supports children, adolescents, and their families in reflecting on what is most important to them and in preparing for future care. It combines medical information with individual values and goals to guide decisions about current and future treatment options (18).

ACP in paediatric oncology is not limited to end-of-life decisions. It helps to formulate values (“What makes a good life for your child?”), define personal goals (“What does a good day look like?”), and anticipate potential scenarios (“What would you want us to do if things change?”). It embraces the dual commitment to hope and realism, helping families to hope for the best while preparing for the worst(6).

TIMING AND PROCESS

ACP should begin once a relationship of trust has been established and prognosis is uncertain or evolving. ACP should be implemented alongside disease-directed treatment and adapted as goals of care evolve, rather than being reserved for the terminal phase(6). It should be revisited regularly, especially at key points such as at progression to high-risk disease, relapse, progression, or major treatment transitions (5, 18).

A complete ACP process typically includes:
– establishing an understanding of the child's illness and likely course;
– exploring values, priorities, and cultural or spiritual needs;
– clarifying the child's and family's preferred level of involvement in decisions;
– translating these discussions into specific, documented care plans.

SHARED DECISION-MAKING

Shared decision-making (SDM) is the collaborative application of ACP principles to specific clinical situations. It combines professional expertise with the family's lived experience, ensuring that decisions are informed, transparent, and aligned with the child's best interests(18).

All professionals share responsibility for maintaining open, consistent, and ethically grounded dialogue throughout the illness trajectory. Clear documentation of decisions and their ethical rationale is essential to ensure continuity and transparency.

Practical communication approaches supporting ACP implementation are outlined in Section 3.2.3. Ethical considerations are further discussed in Section 4.3 (Ethical Challenges and Bioethical Framework).

3.2.4 Communication and Relational Aspects in PPC

Definition and Aim

Effective communication constitutes the ethical and relational foundation of PPC. It operationalises ACP and SDM by fostering mutual understanding, trust, and participation between families and professionals(20,21).

Ethical communication recognises that information sharing and relational engagement are inseparable components of respect for the child's and family's moral agency. This approach is consistent with the child's right to participation according to evolving capacities, as articulated in the United Nations Convention on the Rights of the Child(22) and reflected in contemporary paediatric ethics (23).

Core Principles

Communication should be truthful, compassionate, and developmentally appropriate. It is a longitudinal process rather than a single disclosure event and requires sensitivity to the child's cognitive, emotional, and social maturity (24).

Cultural, spiritual, and linguistic contexts influence how information is received and interpreted. Access to professional interpreters and culturally competent support is therefore essential(25,26).

Structured Communication Approaches

Evidence-informed frameworks can guide clinicians in conducting emotionally complex discussions and in responding to distress while maintaining empathy and clarity:

– SPIKES – a six-step model for delivering serious information with empathy (27)

– NURSE – a mnemonic encouraging acknowledgement and exploration of emotion (21)
– "The 6Cs and 3Ws" – a structured conversational aid developed by the SickKids Paediatric Advanced Care Team(28)

These approaches promote clarity, validation, and shared meaning. Documentation of key discussions enhances continuity across teams.

Children and Adolescents with Diverse Needs

Every child has the right to be involved in decision-making according to evolving capacities (United Nations, 1989(29)). For children with neurocognitive or communication challenges, adaptation of language, visual supports, and predictable routines is recommended(30).

Supporting Parents and Siblings

Families benefit from structured guidance on how to communicate with their child and with one another about illness, uncertainty, and possible deterioration. Early and honest discussions may reduce uncertainty, prevent misunderstandings, and decrease decisional conflict(20).

Siblings should be included in age-appropriate ways to maintain a sense of belonging and to prevent feelings of exclusion or isolation. Opportunities for questions, emotional expression, and participation in meaningful rituals can support adaptive coping.

Parental coping improves when healthcare professionals acknowledge emotions explicitly, provide relational continuity, and model empathic communication (20,21). Consistent professional support may reduce parental anxiety and strengthen trust in the healthcare team throughout the illness trajectory.

Interprofessional and Cultural Aspects

Consistent communication across disciplines is essential to uphold trust. Divergent messages between oncologists, palliative care specialists, and nursing staff can undermine confidence and increase moral distress among professionals (31).

Regular interprofessional case discussions and joint family meetings should therefore be standard practice.

Embedding communication training and reflective practice within institutional education programmes strengthens moral resilience and professional competence (21).

Integration within this ESCP Framework

Embedding structured communication training, emotional literacy, and reflective practice within institutional education programmes strengthens team competence and moral resilience(32). These competencies help ensure that communication remains a core component of high-quality, ethically grounded paediatric palliative oncology across European healthcare systems.

Structured conversation aids may further support clinicians in initiating and guiding developmentally appropriate discussions. Examples include “The 6Cs and 3Ws – Talking to Kids about Serious Illness” (28), developed by the SickKids Paediatric Advanced Care Team, which provides practical prompts for addressing hopes, worries, and contingency planning in a child-sensitive manner.

Integrating such tools within the ESCP framework promotes consistency, transparency, and equity in communication standards across centres while allowing adaptation to national legal and cultural contexts.

3.3 Ethical Challenges and Bioethical Framework

Ethical reflection is a cornerstone of paediatric palliative oncology, where curative and comfort-oriented aims frequently coexist and evolve. Clinical decisions require ongoing moral deliberation in contexts of uncertainty, emotional complexity, and relational interdependence(25, 18). Empirical data from healthcare professionals in PPC further illustrate the ethical complexity surrounding professional responses to death-related expressions, highlighting variability in interpretation and response(33).

Paediatric decision-making occurs within a triadic moral relationship integrating parental responsibility, professional duty of care, and the child’s participation. A relational understanding of autonomy acknowledges that children’s self-determination develops within trusting relationships(23).

The four classical principles of biomedical ethics — autonomy, beneficence, non-maleficence, and justice — remain foundational(34,35). Their application requires contextual sensitivity in paediatrics.

Typical ethical challenges include:
– balancing hope and realism(19),
– assessing proportionality of treatment burden and benefit(26),
– addressing moral distress within teams(31),
– navigating cultural and legal diversity across Europe(32).

Best interests must be understood as dynamic and multidimensional, encompassing physical, emotional, psychosocial, and spiritual well-being(23).

Procedural approaches to ethical deliberation — including structured ethics consultation — enhance transparency and shared responsibility(26)(18).

3.4 Psychosocial care

Multidimensional psychosocial assessment and family-centred care

Psychosocial care is a core component of PPC and should be provided from diagnosis and throughout the disease trajectory(6,36). Key objectives and responsibilities of psychosocial care include a holistic approach to treatment, prevention of avoidable trauma, focus on the family and it should be centered on the individual, the identification of resources, supportive therapy, on adapting to the course of the disease, interdisciplinary cooperation and basic ethical attitudes(37).

Assessment should adopt a family-centred perspective, recognising the systemic impact of serious illness. Multidimensional psychosocial assessment should occur at key transition points such as diagnosis, relapse, or clinical deterioration.

Relevant domains include:

- symptom burden and psychosocial impact,
- understanding of illness and prognosis,
- hopes, fears, and major concerns,
- coping resources and risk factors,
- social and financial challenges (including problems with housing especially if clinic is far from home of family),
- spiritual or existential needs.

Support should be delivered by trained professionals (such as psychologists and social workers) within a multiprofessional team and adapted to developmental stage and cultural context (5).

3.5 Supportive Treatment

3.5.1 Tools:

Care Plan:

The aim of a care plan is to provide a single document that contains all relevant information for both the family and the professional team, enabling them to manage the child's symptoms efficiently and to support the family individually throughout the course of the child's illness. Potential emergencies should be anticipated so that the family never feels helpless and suffering can be prevented as far as possible.

A good care plan must include at least the following elements:

- Date of the plan and most recent revision
- Names of the professionals who prepared the plan
- Identifying information (name, date of birth, gender)
- Weight and height, including date of measurement
- List of relevant diagnoses
- List of allergies
- Brief list of expected or possible emergencies and their management
- List of professional emergency contacts (available 24/7)
- Decisions regarding measures to be taken in life-threatening emergencies according to ACP discussions (e.g. no ICU treatment, no resuscitation), with space for clarifying explanations
- For young adults: reference to existing DNR orders outside the care plan
- Signatures of physician and parents as well as child if old enough

- Address and contact details of the family and other caregivers
- Religious and/or cultural background of the family
- Space to document special wishes of the child and of the family
- List of symptoms, with available escalating management measures (nursing and medical measures) for each symptom that can be implemented by the family and their care team at home or in the hospital
- List of involved professionals (medical professionals, psychologists, social workers, school contacts, therapists, and other key professionals), including phone numbers and email addresses, as well as information on who should receive a copy of the care plan
- List of aids and medical devices required by the child
- Space for additional comments
- Medication plan (regular and as required), either included in or linked to the symptom section, structured by the symptoms treated and including clear escalation instructions

4 PPC SYMPTOM GUIDE

Introduction to communication about symptoms and thinking ahead

Communicating about Death and Palliative Symptoms

Death is an integral part of life. Although some parents attempt to shield their children from this topic, empirical evidence demonstrates that children benefit from open and age-appropriate communication about death. Promoting emotional competence in challenging situations is essential for the development of resilience. Children have the right to be informed and included in decision-making processes; such information should always be conveyed in a manner appropriate to their age and level of understanding. Supporting children in processing and expressing their natural reactions to grief is of central importance.

In cases of severe illness or a terminal prognosis for the child, early and open communication is recommended. Children intuitively perceive changes in their environment and emotional tension. Attempts to protect children from the reality of illness, loss, and death may result in negative consequences:

- Increased worry and anxiety
- Emotional effort to interpret the situation
- Development of their own, often distressing scenarios and feelings of guilt
- Loss of trust in parents
- Receiving information from insecure sources without the opportunity to ask questions
- Withdrawal with fears and questions, as the topic is perceived as taboo

Therefore, early, clear, and honest information about life-threatening illnesses and the possibility death is advisable. Supporting children in their individual coping and decision-making is essential.

Children’s reactions to distressing news are heterogeneous; they range from crying and screaming to refusing to talk. It is important to provide a safe space for expressing feelings, asking questions, and ensuring physical security.

Although such conversations are emotionally challenging, they impart important competencies to children:

- The ability to engage in difficult conversations
- Appreciation as an integral part of the family
- Openness with caregivers even during stressful life phases
- Destigmatization of death as a natural stage of life

There is no ideal time for such conversations; willingness to engage may vary and should be respected. Disclosing the topic can have a relieving effect, and the child's individual needs must be considered.

Open communication also promotes the child's self-determination, particularly in the context of their own dying process. Self-determination is a central element in reducing fear and helplessness.

If the cultural/religious background, or the personal value system of a family makes it difficult for them to speak openly with the child, the medical team should inform the parents about the advantages of open conversation in a way that signals respect for their cultural/personal beliefs, in a well-chosen setting and with professionals they trust. If they still don't want to communicate openly this decision should be accepted by the team, so the therapeutic relationship does not suffer because of this conflict. In time opinions might change, so the topic can be broached again if suffering is apparent.

Knowledge and information counteract fear. After informing the parents about the impending death of their child, the family should also be educated about likely symptoms at the end of life (e.g., anxiety, depression, restlessness, neurological pain, dyspnoea, coughing, sleep disorders, nausea, loss of appetite) as well as the changes during the dying process (e.g., skin color, body temperature, breathing, bodily fluids). Knowledge and information counteract fear. In addition to symptom management, proactively providing necessary aids to avoid waiting times and unnecessary hospital stays is crucial for improving the family's quality of life.

Literature to delve deeper into this topic:

Kempkes, C. (2023). Shaping Farewell. Humboldt.(38)

Schroeter-Rupieper, M. (2020). Does Dying Go Away Again? Answers to Children's Questions About Death and Grief. Gabriel.(39)

Schroeter-Rupieper, M. (2020). Forever Different: The House Book for Families in Times of Death and Farewell. Patmos.(40)

Canadian Virtual Hospice. (2003–2020). KidsGrief.(41)

4.1 Anxiety and Depression

Definition, Causes, Consequences

Anxiety and depression in PPC refer to emotional, cognitive, and behavioural responses to life-limiting illness. Causes include physical suffering, impaired communication, existential fear, disrupted routines, family distress, and medication side effects. Consequences may include impaired coping, reduced participation in care, sleep disturbances, irritability, and decreased quality of life.

Diagnosis

There are no specific diagnostic instruments to measure anxiety or depression validated for children in the palliative phase. Assessment relies on:

- Clinical evaluation by paediatric psychology/psychiatry services.
- Observation of behavioural changes (withdrawal, irritability, sleep disturbances).
- Age-appropriate conversations with the child or adolescent that are orientated towards the developmental stage.
- Input from caregivers, teachers, and nursing staff.
- Self- and proxy report (with greater weighting on the self-report) with additional questionnaires concerning anxiety or depression disorder

Diagnosis should distinguish between normal emotional responses to severe illness and symptoms requiring intervention.

Recommendations

DO

- Discuss influencing factors with child and family.
- Explain how lack of information can lead to fear, fantasies, and suffering in isolation.
- Inform the family about mutual emotional influence between child and caregivers.
- Adjust communication and interventions to the child's developmental stage.
- Co-create a plan of emotional care with the child and family.
- Establish daily/weekly routines, including rituals, emotional activities, and normalizing activities.

CONSIDER

- Exploring the child's developmental understanding of death.
- Differentiating normal responses from existential concerns and psychiatric symptoms.
- Providing about 1–1.5 pages of background explanation to family as needed in an easily understandable language.

Treatment

Non-Pharmacological

- Psychological counselling and play therapy.
- Family therapy.
- Relaxation and mindfulness exercises.
- Structured routines and activity scheduling.
- Spiritual and existential support according to family preference.
- Peer support groups.

Pharmacological

- Treat uncontrolled pain and physical symptoms.
- Review and discontinue medications that may cause or worsen anxiety and depression.
- Consider SSRIs or anxiolytics preferably after consultation with paediatric psychiatry.
- For short relief lorazepam can be titrated to need

DON'T

- Do not ignore early signs of emotional distress.

- Do not provide false reassurance or misleading information.
- Do not rely solely on medication when psychosocial stressors are predominant.

Evaluation

- Monitor effects and side-effects of interventions.
- Reassess the child's or adolescents emotional state regularly.
- Integrate the patient's and caregivers' perspectives into treatment adjustments.

4.2 Pain

Definition, Causes, Consequences

Pain in PPC may be nociceptive, neuropathic, visceral, or more frequently mixed. Psychological, social and spiritual needs influence pain perception. Causes include tumour infiltration, treatment side effects, immobility, and procedures. Consequences include reduced mobility, sleep disturbance, anxiety, and diminished quality of life, which in turn elevate the perception of pain. The combination of these causes can lead to "total pain".

Diagnosis

- Careful history of pain with particular attention to evaluate triggers, timing, and response to prior treatments.
- Developmentally appropriate pain scales (FLACC, Wong-Baker, VAS).
- Caregiver and clinician observation.
- Pain diaries
- Self and proxy report (e.g. Pediatric Pain Disability Index (P-PDI)
- Consider neuropathic features (tingling, burning, allodynia as well as plausible mechanical irritation of nerves according to tumour localisation).

Recommendations

DO

- Treat the underlying source when possible.
- Use multimodal analgesia.
- Provide anticipatory guidance to families.
- Open communication to address psychological and spiritual needs.
- Consider non-pharmacological strategies (heat, massage, distraction).
- Use standardized conversion tables for opioid rotation.

CONSIDER

- Differentiating nociceptive vs. neuropathic pain vs mixed pain.
- Bone pain and visceral pain as special entities.
- Consultation to a specialized pain unit for complex pains.
- Interventional procedures when appropriate.

Treatment

Non-Pharmacological

- Distraction, relaxation, modification of dysfunctional thoughts via cognitive restructuring, play therapy and psychoeducation.
- Physiotherapy, massage, heat/cold based on tolerance.
- Open conversations to address anxiety, loneliness, unmet spiritual needs.

Pharmacological

- Acetaminophen/NSAIDs (NSAIDs especially important in treatment of bone pain).
-
- Opioids for moderate–severe pain:

- avoid the use of weak opioids (codeine, tramadol) as much as possible and start directly with morphine titration, preferably orally
- if at first only break through pain experienced start with immediate release opiate like morphine (morphine starting dose orally 0.1-0.2mg/kg max. 5mg every 4(-6) hours)
- if chronic pain, calculate baseline treatment dose (sum of boluses given over 24 hours and converted to continuously/long-acting drugs - for example fentanyl patches (many centres cut matrix-fentanyl patches diagonally to adjust dose(42) since there are no formulations appropriate for smaller children; morphine 2.5mg orally/day=1mcg/h fentanyl transcutaneously given)
- Always add immediate release bolus for breakthrough pain. When rotating opiates consider reducing the dose by around 20% because of reduced tolerance
- consider the use of advanced pain control techniques (nerve blocks, epidural catheters, in selected cases palliative radiotherapy) in case of pain refractory to conventional therapies, especially in case of bone pain from metastases associated with nerve plexus involvement

- Adjuvant therapy for neuropathic pain (gabapentinoids, amitriptyline, ketamine, clonidine or dexmedethomidine) or use of methadone (combined somatic and neuropathic pain treatment but careful start because of accumulation in fatty tissues and increased release around day 3 or 4 of treatment. Conversion from other opioids difficult and variable/long half-life. Methadone is therefore a specialized pain treatment).

DON'T

- Do not undertreat due to unfounded fear of opioids.
- Do not delay opioid initiation when indicated.

Evaluation

- Regular reassessment of pain intensity and function.
- Monitor side-effects (constipation, sedation).
- Family and patient feedback.

Misbeliefs about Opioids

- Opioids are safe when titrated to pain and do not cause respiratory depression if dose is carefully adjusted to experienced pain/dyspnoea.
- Addiction risk in palliative care is extremely low and since in this situation causes of pain often cannot be treated effectively, need to be given until the end of life.
- Opioids do not hasten death when used properly but might prolong live due to reduced stress.

4.3 Dyspnoea

Definition, Causes, Consequences

Dyspnoea is a subjective sensation of breathlessness. Causes include tumour burden, infection, anaemia, effusions, pulmonary disease, and anxiety. Leads to fear, panic, fatigue, and reduced activity.

Diagnosis

- Clinical assessment; no single diagnostic test.
- Observation of respiratory patterns.
- Pulse oximetry when relevant (often not necessary and can cause anxiety at the end of life).
- Identify reversible causes.

Recommendations

DO

- Explain the symptom to reduce fear.
- Optimize positioning (open chest, leaning forward to optimize diaphragm function and reduce the work of breathing, for example supported sitting at a table with Arms on pillows, resting arms on knees, supported upright in bed, high-side lying with pillows).
- Provide airflow (fan directed at face if well tolerated (handfan), open window).

CONSIDER

- Low-dose opioids (see below).
- Treating anxiety if contributing.
- Managing secretions.

Treatment

Non-Pharmacological

- Calm environment, breathing techniques.
- Airflow therapy (directed at face see above).
- Oxygen supplementation if this enables better participation in meaningful activities (titrated to need for activity and not SpO2 goal): can cause dry mucous membranes and nose bleeds

Pharmacological

- Opioids for air hunger (for example Morphine orally starting dose if no concomitant pain 0.05(-0.1)mg/kg every 4 hours): treatment aim is no subjective feeling of air hunger and relaxed face/posture, no stress because of hypoxemia. Symptoms of hypoxia (tachypnoea, high ventilation breathwork) will persist until last hours of life despite successful treatment of dyspnoea.
- Benzodiazepines for panic or as second line, although with less evidence than opioids.
- Inhaled steroids or bronchodilators if airway inflammation.

DON'T

- rely solely on oxygen without hypoxemia.

Evaluation

- Assess comfort and respiratory effort.
- Family perception of relief.

4.4 Cough

Definition, Causes, Consequences

Cough may be protective or distressing. Causes: infection, secretions, asthma, reflux, airway compression. Consequences include exhaustion, chest pain, vomiting.

Diagnosis

- Identify triggers and quality (dry/wet).
- Clinical chest exam; imaging if appropriate.

Recommendations

DO

- Treat underlying causes.
- Maintain hydration.

CONSIDER

- Humidified air.
- Secretion management.

Treatment

Non-Pharmacological

- Humidification, positioning.

Pharmacological

- Antitussives (if non-productive cough).
- Bronchodilators or inhaled steroids when indicated.
- When combined with dyspnoea opioids (see above)

DON'T

- Avoid strong antitussives when cough is needed for airway clearance.

Evaluation

- Frequency, severity, and functional impact.

4.5 Haematological Signs

Definition, Causes, Consequences

Include anaemia, thrombocytopenia, leukopenia.

Causes: disease progression, treatment effects, bone marrow infiltration.

Consequences: fatigue, bleeding risk, infection.

Diagnostics

- CBC when clinically relevant.
- Assess symptoms rather than relying solely on lab values.

Recommendations

DO

- Use symptom-oriented transfusion decisions.
- Minimize blood draws.
- If sudden severe bleeds are anticipated have dark bedding/towels at hand to minimize trauma for loved ones as well as quick acting benzodiazepine (i.e. buccal midazolam or rectal diazepam).

CONSIDER

- Discuss with families the benefits vs. burdens of transfusions at each stage of the disease.

Treatment

Non-Pharmacological

- Activity pacing.

Pharmacological

- Keep prophylactic platelet transfusions according to CBC values while the patient is stable.
- Transfusions for symptomatic anaemia or bleeding.
- Topical and systemic treatments for bleeds ready: tranexamic acid for topical use (soaked compresses to stop bleeds) and/or oral use
- Prophylactic use of nose cream
- Consider prophylactic dose of antihistamine especially if transfusing in home setting

DON'T

- Avoid routine transfusions without clear benefit.

Evaluation

- Monitor symptom relief.
- Monitor side effects like hyperhydration in last days of life with respiratory problems.

4.6 Skin

Definition, Causes, Consequences

Skin problems include dryness, pruritus, pressure injuries, infection, treatment-related lesions, and tumour infiltration.

Causes: immobility, medication effects, dehydration, poor perfusion.

Consequences include pain, discomfort, infection risk, and emotional distress for child and family.

Diagnosis

- Visual inspection and palpation.
- Identification of pressure points and lesion patterns.
- Review of medications, nutrition, and hydration status.

Recommendations

DO

- Maintain regular skin hygiene.
- Apply moisturizers and barrier creams.
- Relieve pressure regularly.
- Educate caregivers on gentle handling and skin checks.

CONSIDER

- Consulting dermatology for complex wounds.
- Specialized dressings based on wound type (moist, dry, infected).

Treatment

Non-Pharmacological

- Gentle cleansing and hydration.
- Frequent repositioning.
- Use of soft bedding and pressure-relief devices.

Pharmacological

- Cream (oily).
- Topical steroids for inflammation.
- Antihistamines for pruritus.
- If caused by opioids consider opioid rotation and or aprepitant (2mg/kg max 80mg daily for 3-13 days)
- Antibiotics (topical or systemic) if infection present.

DON'T

- Avoid harsh soaps or excessive friction.

Evaluation

- Monitor healing, comfort, and caregiver understanding.

4.7 Nausea and Vomiting

Definition, Causes, Consequences

Nausea and vomiting are common and multifactorial: medication effects, intracranial pressure, obstruction, metabolic imbalance, anxiety.

Consequences: dehydration, malnutrition, fear, and decreased quality of life.

Diagnosis

- Identify triggers (movement, smells, meals).
- Review medications.
- Assess for constipation or obstruction.

Recommendations

DO

- Treat underlying causes.
- Offer small, frequent meals.
- Avoid and treat contributing factors: bad smells, high temperatures…

CONSIDER

- Multifactorial origin requiring combination therapy.

Treatment

Non-Pharmacological

- Acupressure, relaxation, distraction.
- Fresh air and avoidance of strong odours.

Pharmacological

- Antiemetics (ondansetron/palonosetron, metoclopramide, antihistamines, aprepitant, levomepromazine, lorazepam): often combined continuous treatment (especially when elevated intracranial pressure as cause of nausea) and a plan for break through nausea necessary
- Steroids (only for short duration and be aware of mood changes) or proton pump inhibitors when indicated.

DON'T

- Don't assume nausea is psychological.

Evaluation

- Frequency of episodes, hydration status, patient comfort.

4.8 Constipation

Definition, Causes, Consequences

Constipation is infrequent or difficult stool passage.

Causes: opioids, decreased mobility, dehydration, low fiber intake, neurologic impairment.

Consequences: abdominal pain, nausea, agitation, urinary retention, and reduced appetite.

Diagnosis

- Stool history and abdominal assessment.
- Review of medications.
- Consider obstruction if sudden, severe, or accompanied by vomiting.

Recommendations

DO

- Encourage hydration and mobility when possible.
- Initiate prophylactic laxatives with opioid therapy.

CONSIDER

- Differentiating between functional constipation and potential obstruction.

Treatment

Non-Pharmacological

- Scheduled toileting routines.
- Encouraging movement if feasible.

Pharmacological

- Osmotic and stimulant laxatives.
- Methylnaltrexone or low dose oral naloxone (3-5mcg/kg/dose 4/day, increase up to 12mcg/kg/dose, orally or via nasogastric tube) in patients with suspected opioid-related constipation and no response to laxatives(43–46).
- Rectal suppositories (glycerol or - especially if neurological defecation problems - Sodium acid phosphate with sodium bicarbonate) or enemas with normal saline or commercial enemas if refractory.

DON'T

- Do not rely solely on stool softeners.

Evaluation

- Monitor stool patterns, abdominal discomfort, and caregiver feedback.

4.9 Neurological Symptoms

Neurological symptoms in PPC may include seizures, dysphagia, urinary retention, neuropathic pain, altered tone, neurologic deficits (common with growing CNS-lesions) and impaired consciousness. These symptoms may arise from primary neurological disease, treatment effects, metabolic abnormalities, or progressive disease.

Diagnosis

- Clinical assessment remains central due to limited validated tools in paediatric palliative settings.
- History of onset, progression, triggers, and relieving factors.
- Review medications that may contribute (e.g., opioids, anticholinergics, benzodiazepines withdrawal).
- Invasive testing should be avoided unless it changes management.

Recommendations

DO

- Identify reversible causes when consistent with goals of care.
- Ensure safety during seizures: protect from injury, maintain airway.
- Organize neuro-orthopaedic aids, wheelchair, motorized bed, incontinence products, ptosis crutches/props and other devices as needed.
- Manage contributing factors: fever, electrolyte disturbances, medication toxicity.
- If intracerebral pressure is elevated bed with 30% elevation of upper body.
- Support feeding and swallowing with texture modification always respecting choices of affected child (for example if eating is important for quality-of-life swallowing should be encouraged even if difficulties are noted: quality of life is more important than safety in palliative situation); consider alternative routes like nasogastric tube if aligned with goals.

- Monitor for urinary retention/incontinence; consider intermittent catheterization or if this is not well tolerated urinal condom (in teenage boys) or indwelling catheter when needed.

CONSIDER

- Distinguish between disease-related symptoms and treatment side effects.
- Evaluate whether interventions align with quality-of-life priorities.

Treatment

Non- Pharmacological

- Positioning and physiotherapy to manage tone and comfort. In dystonia slow movements/physical touch.
- Behavioural and sensory strategies for irritability.
- Caregiver education on seizure first aid.

Pharmacological

- **Seizures:** rescue benzodiazepines (buccal/intranasal (nasal causes burning sensation due to acidic PH so use nose cream before use if possible) midazolam, rectal diazepam); maintenance therapy as appropriate.
- **Neuropathic pain:** gabapentinoids, tricyclic antidepressants, ketamine i.v./s.c, clonidine, methadone see below.
- **Dysautonomia:** clonidine, dexmedetodine.
- **Spasticity/Dystonia:** baclofen, benzodiazepines, clonidine, gabapentin high dose, analgesia.
- **Urinary retention:** anticholinergic dose review; alpha-blockers if appropriate.
- **Hypersalivation:** glycopyrrolate, glycopyrronium-bromide, scopolamine, topical botulinum toxin injections

Evaluation

- Frequency and severity of symptoms.
- Side effects of antiepileptics or other medication.
- Impact on comfort and family perception.

4.10 Delirium

Delirium is an acute, fluctuating disturbance in attention, awareness, and cognition. In children, signs may include agitation, hallucinations, withdrawal, sleep-wake reversal, or sudden mood changes.

Diagnosis

- Clinical diagnosis is based on behavioural changes and mental status assessment.
- Identify and treat reversible causes when aligned with goals: infection, metabolic disturbance, medications (slow down withdrawal if this is cause of delirium), hypoxia, dehydration.
- Few paediatric tools exist; rely on clinical expertise and caregiver observations.

Recommendations

DO

- Reduce environmental overstimulation; maintain a calm, familiar setting.
- Ensure hydration, oxygenation, and comfort.
- Review medications potentially contributing to delirium (e.g., opioids, anticholinergics, steroids).

- Provide reassurance to child and caregivers.

CONSIDER

- Differentiating delirium from anxiety, depression, or existential distress.

Treatment

Non-medicinal

- Regular orientation cues.
- Soft lighting, presence of family and familiar objects.
- Especially if awareness is disturbed: explanation of sounds and sensations when caring for the patient
- Sleep hygiene support.

Medicinal

- **First-line:** low-dose antipsychotics (e.g., haloperidol) if severe and distressing.
- **Alternatives:** atypical antipsychotics (e.g., quetiapine) when sedation is undesirable.
- **Avoid:** benzodiazepines unless treating withdrawal or seizure-related delirium.

Evaluation

- Improvement in awareness, agitation, sleep.
- Side effects: extrapyramidal symptoms, sedation.
- Family report of distress.

4.11 Mouth Care

Mouth care is essential to maintain comfort, prevent infection, and support communication and nutrition(5,36).

Assessment should be gentle and regular. Management includes hydration of oral mucosa, avoidance of irritants, treatment of candidiasis or mucositis, and adaptation to the child's comfort and developmental level.

Diagnosis

- Clinical inspection of the oral cavity: mucosa hydration, lesions, coating, erythema.
- Review symptoms: pain, difficulty swallowing, altered taste.
- No specialized diagnostic tools required; assessment should be gentle and adapted to the child's comfort.

Recommendations

DO

- Assess the oral cavity regularly and gently.
- Maintain frequent mouth hydration using water, or approved moisturizing agents. Towards the end of life, the child's favourite drink should be used to avoid distress.
- Encourage soft brushing or swabbing according to developmental ability.
- Treat underlying causes (e.g., candidiasis, mucositis).

- Educate caregivers on simple daily routines.
- Use non-irritating lip moisturizers.

CONSIDER

- Adjusting feeding methods and textures.
- Reviewing medications that may worsen dryness.
- Evaluating for pain contributing to reduced oral intake.

TREATMENT

Non-medicinal

- Regular mouth rinsing with saline or water.
- Soft toothbrush or foam swab for gentle cleaning.
- Use of artificial saliva or moisturizing gels.
- Humidification of the child's environment.
- Application of barrier ointments for lips.

Medicinal

- **Candidiasis:** topical antifungals (nystatin) or systemic agents if severe.
- **Mucositis:** topical analgesics or coating agents.
- **Pain:** systemic analgesia adjusted to severity.

Evaluation

- Improvement in comfort, ability to eat/drink, and sleep.
- Reduction of dryness, coating, or ulceration.
- Family observations regarding comfort and ease of care.

4.12 Hydration and nutrition at the end of life

Definition and Ethical Framework

Clinically assisted hydration and nutrition (CAHN) are medical interventions and must be evaluated according to proportionality and best-interest standards (18,5).

In advanced illness, artificial hydration or feeding may increase symptom burden, including dyspnoea, peripheral oedema, ascites, increased respiratory secretions, or discomfort related to invasive devices. Decisions to initiate, withhold, or discontinue CAHN should occur within structured shared decision-making with parents and, where appropriate, the child.

Reduced oral intake is typically part of the natural dying process and is not usually associated with suffering when meticulous comfort measures are provided (36). Prioritising comfort and avoiding burdensome interventions does not constitute neglect but reflects a shift in goals of care toward quality of life and dignity.

Diagnosis

- Assess swallowing safety and risk of aspiration.
- Evaluate whether hydration or feeding contributes to symptom burden (e.g., dyspnoea, oedema, vomiting, increased secretions).
- Clarify documented goals of care and Advance Care Planning (ACP).
- Review proportionality of transfusions in the context of fluid overload or respiratory compromise.

- Explore parental understanding and emotional concerns regarding nutrition and hydration.

Communication with families

Families may experience significant emotional distress when fluids or feeding are reduced, often because nourishment is strongly associated with care, nurturing, and hope. PPC standards emphasise the importance of compassionate, clear explanations of the physiological changes that occur at the end of life, reassurance that lack of hunger or thirst is common, and visible attention to comfort-focused care(5). Involving nursing staff in these discussions can help translate medical decisions into concrete, reassuring bedside care and support parental confidence.

Recommendations

DO

- Explain the physiological decrease in appetite and thirst at the end of life.
- Prioritise meticulous oral care as the primary intervention for perceived thirst.
- Individualise decisions based on comfort and overall goals of care.
- Adjust volumes of food and hydration (oral or parenteral) to avoid distress.
- Reassess regularly as clinical conditions evolve.
- Provide visible comfort-focused bedside care to reassure families.

CONSIDER

- Cultural, spiritual, and familial meanings connected to food and fluids.
- Emotional distress linked to the symbolic role of nourishment.
- The balance between potential benefit and treatment burden.

DON'T

- Do not continue artificial hydration solely for symbolic reasons if it increases symptom burden.
- Do not equate reduced intake with suffering without careful clinical assessment.
- Do not withdraw hydration without clear communication and shared decision-making.

Treatment

Non-Pharmacological

- Frequent mouth care (every 1–2 hours as needed).
- Use of soft swabs moistened with water or saline.
- Lip moisturisation with non-irritating products.
- Ice chips or small sips if safe.
- Humidified room environment.
- Small sensory "tastes" using drops or sprays of preferred beverages applied to oral mucosa when swallowing is unsafe.

Pharmacological

- Management of nausea, dyspnoea, or discomfort related to overhydration.
- Adjustment of medications contributing to dryness where appropriate.

Evaluation

- Ongoing assessment of the child's comfort.
- Monitoring for signs of fluid overload or aspiration.
- Regular review of family understanding and emotional response.
- Documentation of decisions and their ethical rationale.

4.13 Terminal Secretions / "Noisy Breathing"

Terminal secretions occur as swallowing reflex decreases and secretions accumulate in the oropharynx. They are typically more distressing to caregivers than to the child.

Diagnosis

- Audible gurgling or rattling breathing.
- Do not require invasive investigations.

Recommendations

DO

- Reassure family that the symptom is usually not painful.
- Reposition child (lateral positioning) to facilitate drainage.
- Review and reduce fluids if excessive secretions are present.

CONSIDER

- Discuss goals of care before initiating medications.

Treatment

Non-medicinal

- Gentle repositioning; avoid forceful suction.

Medicinal

- Anticholinergics (e.g., glycopyrrolate, scopolamine, hyoscyamine) to reduce secretion production.
- Note: effects may be modest and onset may be delayed.

Evaluation

- Family comfort and understanding.
- Reduction in noise intensity.
- Side effects such as dry mouth, urinary retention, agitation.

4.14 Fatigue

Fatigue is common in advanced illness due to disease burden, sleep disturbance, medications, anemia, malnutrition, or psychological stress.

Diagnosis

- Primarily clinical; consider reversible causes consistent with goals of care.
- Assess sleep patterns, anemia, medication effects, pain, emotional distress.

Recommendations

DO

- Prioritize energy-conserving activities.
- Create a balanced daily routine.
- Treat contributing symptoms: pain, anxiety, sleep issues.

CONSIDER

- Discuss expectations with family; differentiate fatigue from depression.

Treatment

Non-Pharmacological

- Scheduled rest periods.
- Activity pacing; encourage participation in meaningful activities.
- Increase caloric intake if compatible with good quality of life

Pharmacological

- Corticosteroids (e.g., dexamethasone) may provide temporary improvement but can affect mood negatively.
- Psychostimulants (low dose methylphenidate) may be considered cautiously in select cases.
- If anemic and aligned with goals of care blood cell transfusion.

Evaluation

- Family perception of energy and comfort.
- Activity level.
- Medication side effects.

4.15 Refractory Symptoms

Refractory symptoms are those that cannot be adequately controlled and produce intense suffering despite appropriate, optimised and tolerable interventions after evaluation by an expert team.

Diagnosis

- Multidisciplinary review to confirm refractoriness to interventions.
- Consider emotional and spiritual needs (e.g. unresolved conflicts, unspoken fears)
- Clarify goals of care and expected outcomes.

Recommendations

DO

- Explore all reasonable therapeutic options.
- Ensure clear communication with family about prognosis and expectations (including discussing a DNR order)
- Consider integration of palliative sedation when appropriate.

CONSIDER

- Whether treatment burden outweighs benefit.

Treatment

Non-pharmacological

- Environmental adjustments.
- Psychosocial support.

Pharmacological

- Intensified symptom-targeted therapy (including consulting with specialized pain and/or palliative care team).
- Transition to palliative sedation (see below) where indicated.

Evaluation

- Continuous assessment of comfort.
- Review with caregivers and team.

4.16 Palliative Sedation

Palliative sedation is the monitored use of medications to reduce consciousness to relieve intolerable suffering due to refractory symptoms at end of life(47).

Diagnosis

- Confirm symptoms are refractory (as above).
- Interdisciplinary agreement and informed consent from guardians.

Recommendations

DO

- Clearly explain goals, process, and expected outcomes to family and patient, if appropriate.
- Discuss goal of consciousness-level under palliative sedation (awake and comfortable to sleeping deeply).
- Use proportional sedation - lowest depth and circadian duration needed for relief (for instance, it may only be needed at nighttime).
- Maintain and adjust symptomatic treatments used previously, including opioids (which should not be used as sedatives).
- Monitor regularly for comfort, not physiologic normalization.

CONSIDER

- Ethical principles and local regulations.

Treatment

Pharmacological

- **First-line:**
- **Midazolam** is considered the first option. Doses in paediatric palliative sedation are not standardized. Usually after a loading dose (0.03-0.1mg/kg max 5mg as a bolus), guidelines recommend continuous iv/sc perfusions with 0.05-0.1 mg/kg/h of initial dose
- **Levomepromazine/chlorpromazine or haloperidol** should be considered in the presence of delirium, although they are considered mild sedatives.
- **Dexmedetomidine** could be indicated, especially in the presence of complex pain patterns or dysautonomia.
- **Alternatives:** barbiturates or propofol in specialized settings.

Evaluation

- Ongoing comfort assessment.
- Family understanding and support.
- Use a validated sedation scale as the Ramsay or Richmond Agitation-Sedation scale.

Ramsay Scale

Score	Term
1	Patient anxious and agitated or restless or both
2	Patient cooperative, oriented, and tranquil
3	Patient responds to commands only
4	Patient asleep, shows brisk response to light glabellar tap or loud auditory stimulus
5	Patient asleep, shows sluggish response to light glabellar tap or loud auditory stimulus
6	Patient asleep, shows no response to light glabellar tap or loud auditory stimulus

Ramsay MA, Savege TM, Simpson BR, et al. Controlled sedation with alphaxatone-alphadolone. Br Med J 1974; 2: 656-659. doi: 10.1136/bmj. 2.5920.656.

Richmond Agitation-Sedation Scale

Score	Term	Description
+4	Combative	Overtly combative or violent and an immediate danger to staff
+3	Very agitated	Pulls on or removes tube(s) or catheter(s) or has aggressive behavior toward staff
+2	Agitated	Frequent non-purposeful movement or patient ventilator dyssynchrony
+1	Restless	Anxious or apprehensive but movements not aggressive or vigorous
0	Alert and calm	
–1	Drowsy	Not fully alert but has sustained (> 10 seconds) awakenings, with eye contact, to voice
–2	Light sedation	Briefly (< 10 seconds) awakens with eye contact to voice
–3	Moderate sedation	Any movement (but no eye contact) to voice
–4	Deep sedation	No response to voice, but any movement to physical stimuli
–5	Unarousable	No response to voice or physical stimulation

Sessler CN, Gosnell MS, Grap MJ, et al. The Richmond Agitation Sedation Scale: validity and reliability in adult intensive care unit patients. Am J Respir Crit Care Med 2002; 166: 1338-1344. doi: 10.1164/ rccm.2107138.

5 GRIEF AND BEREAVEMENT

The death of a child represents one of the most profound and destabilising life events for families and is associated with increased risks of prolonged grief disorder, depression, anxiety, and adverse physical health outcomes(48–50).

Bereavement care is an integral component of PPC and extends beyond the moment of death(36). The death of a child represents one of the most profound and destabilising life events for families and is associated with increased risks of prolonged grief disorder, depression, anxiety, and adverse physical health outcomes(48–50).

Structured bereavement support is considered a standard of high-quality PPC(19,32). Families should be offered time and space for farewell, according to their cultural, spiritual, and religious values. Support may include memory-making practices, anticipatory guidance, and the developmentally appropriate involvement of siblings (44)(51).

Grief reactions vary widely and are influenced by relational dynamics, cultural context, coping style, and the circumstances of death. Professionals should provide structured follow-up opportunities and facilitate access to psychological, social, or spiritual care where needed(26,48). Continuity of care may include condolence communication, follow-up meetings with the care team, and referral pathways for families at increased risk of complicated grief, which is an intense, debilitating grief that lasts for a year or more and significantly impairs daily life.

Bereavement Care After the Death of a Child

Postmortem Priorities and Creating Space for Farewell

Following the death of a child, the clinical focus shifts from curative or symptom-directed treatment to relational presence and family support. Healthcare professionals should convey calmness, clarity, and respect, and provide families with sufficient time and privacy to shape their farewell according to their needs. Dedicated farewell rooms or protected spaces within hospitals may support this process.

Sensitive communication immediately after death is associated with improved long-term parental adjustment(51, 44). Clear explanations of what has occurred, reassurance that the child was kept comfortable, and validation of parental efforts are essential components of compassionate postmortem care.

Care of the Deceased Child

After death has been confirmed, medical devices are removed respectfully, visible bleeding is controlled, and the child's body is prepared in accordance with institutional and cultural practices. Although washing the deceased is not medically required, it may represent a meaningful ritual for families. Parental participation in postmortem care can support cognitive and emotional integration of the loss.

Families should be offered opportunities for memory-making, such as hand- and/or footprints or -molds, photographs, or keeping a lock of hair. Evidence suggests that memory-making practices are generally experienced as meaningful and may support adaptive grieving, although individual preferences vary(48,51).

Siblings should be supported in developmentally appropriate ways. When they wish, opportunities to say goodbye—through touch, symbolic gestures, or private rituals—may reduce confusion and promote understanding of the reality of death (44). No child should be pressured to participate; autonomy and readiness must be respected.

Family Reactions and Cultural Sensitivity

Reactions to the death of a child vary considerably and may include intense emotional expression, withdrawal, anger, guilt, or apparent emotional numbness. There is no uniform or "correct" way to grieve. Professionals should avoid pathologizing culturally normative expressions of grief while remaining attentive to risk factors for prolonged or complicated grief reactions(48).

Culturally sensitive bereavement care requires openness to diverse mourning practices and spiritual interpretations of death. When requested or indicated, spiritual care providers, psychologists, or social workers should be involved early.

Continuing Support Beyond the Moment of Death

Bereavement support extends beyond the immediate postmortem phase. Recommended practices include condolence communication, optional follow-up meetings with the clinical team, and structured bereavement programmes when available(47, 50).

Follow-up conversations may help families:

- clarify medical events,
- address unresolved questions,
- integrate the experience into their life narrative,
- and maintain a sense of continuity with the care team.

Healthcare professionals may also benefit from opportunities for debriefing and reflective practice following the death of a child, both to support moral resilience and to prevent cumulative moral distress.

Because grief responses differ within families, children and adolescents may require additional support in school or community settings. Enhancing “grief literacy” within the child’s social environment may reduce isolation and misunderstanding.

6 REFERENCE LIST

1. Palliative care for children [Internet]. [cited 2026 Apr 15]. Available from: https://www.who.int/europe/news-room/fact-sheets/item/palliative-care-for-children

2. Vidal L, Ben Dor I, Paul M, Eliakim-Raz N, Pokroy E, Soares-Weiser K, et al. Oral versus intravenous antibiotic treatment for febrile neutropenia in cancer patients. Cochrane Database Syst Rev. 2013 Oct 9;2013(10):CD003992. doi:10.1002/14651858.CD003992.pub3 PubMed PMID: 24105485; PubMed Central PMCID: PMC6457615.

3. Morgan JE, Cleminson J, Atkin K, Stewart LA, Phillips RS. Systematic review of reduced therapy regimens for children with low risk febrile neutropenia. Support Care Cancer Off J Multinatl Assoc Support Care Cancer. 2016 Jun;24(6):2651–60. doi:10.1007/s00520-016-3074-9 PubMed PMID: 26757936.

4. Hawley PH. The bow tie model of 21st century palliative care. J Pain Symptom Manage. 2014 Jan;47(1):e2-5. doi:10.1016/j.jpainsymman.2013.10.009 PubMed PMID: 24321509.

5. Benini F, Avagnina I, Giacomelli L, Papa S, Mercante A, Perilongo G. Pediatric Palliative Care in Oncology: Basic Principles. Cancers. 2022 Apr 13;14(8):1972. doi:10.3390/cancers14081972 PubMed PMID: 35454879; PubMed Central PMCID: PMC9031296.

6. Lacerda A, Martínez MA, Dumont B, Leiss U, Kokkinou G, Scheinemann K, et al. Embracing paediatric palliative care in paediatric oncology from diagnosis onwards. Pediatr Blood Cancer. 2023;70(10):e30561. doi:10.1002/pbc.30561

7. Bertuccio P, Alicandro G, Malvezzi M, Carioli G, Boffetta P, Levi F, et al. Childhood cancer mortality trends in Europe, 1990-2017, with focus on geographic differences. Cancer Epidemiol. 2020 Aug;67:101768. doi:10.1016/j.canep.2020.101768 PubMed PMID: 32593162.

8. Pedraza EC, Raguindin PF, Hendriks MJ, Vokinger AK, De Clercq E, Rüesch K, et al. Palliative care services in paediatric oncology centres across Europe: A cross-sectional survey. EJC Paediatr Oncol. 2023 Dec;2:100125. doi:10.1016/j.ejcped.2023.100125 PubMed PMID: 38223237; PubMed Central PMCID: PMC10785771.

9. Cancer Atlas [Internet]. [cited 2026 May 5]. Available from: https://canceratlas.cancer.org/burden-of-cancer/cancer-in-europe/

10. Dupuis LL, Vettese E, Grimes AC, Beauchemin MP, Klesges LM, Baggott C, et al. Symptom Screening Linked to Care Pathways for Pediatric Patients With Cancer: A Randomized Clinical Trial. JAMA. 2024 Dec 17;332(23):1981–91. doi:10.1001/jama.2024.19585 PubMed PMID: 39535768; PubMed Central PMCID: PMC11561721.

11. Feudtner C, Nye RT, Boyden JY, Schwartz KE, Korn ER, Dewitt AG, et al. Association Between Children With Life-Threatening Conditions and Their Parents' and Siblings' Mental and Physical Health. JAMA Netw Open. 2021 Dec 20;4(12):e2137250. doi:10.1001/jamanetworkopen.2021.37250

12. Dussel V, Orellana L, Requena ML, Avery M, Becker D, Ullrich CK, et al. Integrating Electronic Patient-Reported Outcomes and Palliative Care in Pediatric Advanced Cancer: The PediQUEST Response Multisite Randomized Controlled Trial. J Clin Oncol. 2026 Mar 10;44(8):685–97. doi:10.1200/JCO-25-01036

13. Leahy AB, Steineck A. Patient-Reported Outcomes in Pediatric Oncology: The Patient Voice as a Gold Standard. JAMA Pediatr. 2020 Nov 1;174(11):e202868. doi:10.1001/jamapediatrics.2020.2868 PubMed PMID: 32832974; PubMed Central PMCID: PMC8103813.

14. Rosenberg AR, Bona K, Coker T, Feudtner C, Houston K, Ibrahim A, et al. Pediatric Palliative Care in the Multicultural Context: Findings From a Workshop Conference. J Pain Symptom

Manage. 2019 Apr;57(4):846-855.e2. doi:10.1016/j.jpainsymman.2019.01.005 PubMed PMID: 30685496.

15. Cain CL, Surbone A, Elk R, Kagawa-Singer M. Culture and Palliative Care: Preferences, Communication, Meaning, and Mutual Decision Making. J Pain Symptom Manage. 2018 May;55(5):1408–19. doi:10.1016/j.jpainsymman.2018.01.007 PubMed PMID: 29366913.

16. Pellegatta et al. La definizione della eleggibilità alle cure palliative pediatriche. Medico E Bambino. (9/2016):573–8.

17. Integrating palliative care and symptom relief into paediatrics [Internet]. [cited 2026 Apr 15]. Available from: https://www.who.int/publications/i/item/integrating-palliative-care-and-symptom-relief-into-paediatrics

18. Society CP. Goals of care conversations and advance care planning for paediatric patients living with serious illness | Canadian Paediatric Society [Internet]. [cited 2026 Apr 15]. Available from: https://cps.ca/en/documents/position/advance-care-planning

19. Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J, Royal College of Paediatrics and Child Health. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. Arch Dis Child. 2015 May;100 Suppl 2:s3-23. doi:10.1136/archdischild-2014-306666 PubMed PMID: 25802250.

20. Wolfe J, Grier HE, Klar N, Levin SB, Ellenbogen JM, Salem-Schatz S, et al. Symptoms and suffering at the end of life in children with cancer. N Engl J Med. 2000 Feb 3;342(5):326–33. doi:10.1056/NEJM200002033420506 PubMed PMID: 10655532.

21. Back AL, Bauer-Wu SM, Rushton CH, Halifax J. Compassionate silence in the patient-clinician encounter: a contemplative approach. J Palliat Med. 2009 Dec;12(12):1113–7. doi:10.1089/jpm.2009.0175 PubMed PMID: 19698026; PubMed Central PMCID: PMC2939848.

22. OHCHR [Internet]. [cited 2026 Apr 18]. Convention on the Rights of the Child. Available from: https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child

23. Streuli JC, Michel M, Vayena E. Children's rights in pediatrics. Eur J Pediatr. 2011 Jan;170(1):9–14. doi:10.1007/s00431-010-1205-8 PubMed PMID: 20461530.

24. Sisk BA, Friedrich A, Blazin LJ, Baker JN, Mack JW, DuBois J. Communication in Pediatric Oncology: A Qualitative Study. Pediatrics. 2020 Sep;146(3):e20201193. doi:10.1542/peds.2020-1193 PubMed PMID: 32820068; PubMed Central PMCID: PMC7461134.

25. Barrett M. Competencies for democratic culture: living together as equals in culturally diverse democratic societies. Strasbourg: Council of Europe; 2016. 75 p.

26. Human Rights and Biomedicine [Internet]. [cited 2026 Apr 22]. Guide on the decision-making process regarding medical treatment in end-of-life situations - Human Rights and Biomedicine - www.coe.int. Available from: https://www.coe.int/en/web/human-rights-and-biomedicine/guide-on-the-decision-making-process-regarding-medical-treatment-in-end-of-life-situations

27. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. The Oncologist. 2000;5(4):302–11. doi:10.1634/theoncologist.5-4-302 PubMed PMID: 10964998.

28. How to talk to children about serious illness? Connected Care [Internet]. 2025 Mar 3 [cited 2026 Apr 18]. Available from: https://connectedcare.sickkids.ca/how-to-talk-to-children-about-serious-illness/

29. UN. General Assembly (14th sess. : 1959), editor. Declaration of the Rights of the Child [Internet]. 1959 [cited 2026 May 6]. Available from: https://digitallibrary.un.org/record/195831

30. Coyne I, O'Mathúna DP, Gibson F, Shields L, Leclercq E, Sheaf G. Interventions for promoting participation in shared decision-making for children with cancer. Cochrane Database Syst Rev. 2016 Nov 29;11(11):CD008970. doi:10.1002/14651858.CD008970.pub3 PubMed PMID: 27898175; PubMed Central PMCID: PMC6734120.

31. Ventovaara P, af Sandeberg M, Blomgren K, Pergert P. Moral distress and ethical climate in pediatric oncology care impact healthcare professionals' intentions to leave. Psychooncology. 2023;32(7):1067–75. doi:10.1002/pon.6148

32. Radbruch SMS Eduardo Garralda,Birgit Jaspers,Holger Brunsch,Maaike Rijpstra,Jeroen Hasselaar,Michaël Van der Elst,Johan Menten,Ágnes Csikós,Sebastiano Mercadante,Daniela Mosoiu,Sheila Payne,Carlos Centeno,Lukas. Review of European Guidelines on Palliative Sedation: A Foundation for the Updating of the European Association for Palliative Care Framework - Séverine M. Surges, Eduardo Garralda, Birgit Jaspers, Holger Brunsch, Maaike Rijpstra, Jeroen Hasselaar, Michaël Van der Elst, Johan Menten, Ágnes Csikós, Sebastiano Mercadante, Daniela Mosoiu, Sheila Payne, Carlos Centeno, Lukas Radbruch, 2022. J Palliat Med [Internet]. 2022 Oct 27 [cited 2026 Apr 19]. Available from: https://journals.sagepub.com/doi/10.1089/jpm.2021.0646?url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&rfr_dat=cr_pub++0pubmed

33. Alt F, Neu MA, Frühwein H, Bozzaro C, Faber J, Paul NW. Death wishes and death thoughts in paediatric palliative care: a survey of German healthcare professionals. BMC Palliat Care. 2025 Dec 12;25(1):23. doi:10.1186/s12904-025-01973-2

34. Beauchamp T, Childress J. Principles of Biomedical Ethics: Marking Its Fortieth Anniversary. Am J Bioeth AJOB. 2019 Nov;19(11):9–12. doi:10.1080/15265161.2019.1665402 PubMed PMID: 31647760.

35. Gillon R. Medical ethics: four principles plus attention to scope. BMJ. 1994 Jul 16;309(6948):184–8. doi:10.1136/bmj.309.6948.184 PubMed PMID: 8044100; PubMed Central PMCID: PMC2540719.

36. 10 Facts on palliative care [Internet]. [cited 2026 Apr 21]. Available from: https://www.who.int/news-room/facts-in-pictures/detail/palliative-care

37. Schroeder D, Chatfield K, Singh M, Chennells R, Herissone-Kelly P. Ethics Dumping and the Need for a Global Code of Conduct. In: Schroeder D, Chatfield K, Singh M, Chennells R, Herissone-Kelly P, editors. Equitable Research Partnerships: A Global Code of Conduct to Counter Ethics Dumping [Internet]. Cham: Springer International Publishing; 2019 [cited 2026 Apr 21]. p. 1–4. Available from: https://doi.org/10.1007/978-3-030-15745-6_1 doi:10.1007/978-3-030-15745-6_1

38. Abschied gestalten | humboldt Verlag [Internet]. [cited 2026 Apr 21]. Available from: https://www.humboldt.de/product/9783842642539/abschied-gestalten

39. Geht Sterben wieder vorbei? von Mechthild Schroeter-Rupieper | Thienemann-Esslinger Verlag [Internet]. [cited 2026 Apr 21]. Available from: https://www.thienemann.de/produkt/geht-sterben-wieder-vorbei-isbn-978-3-522-30564-8

40. Für immer anders [Internet]. [cited 2026 Apr 21]. Available from: https://shop.verlagsgruppe-patmos.de/fuer-immer-anders-011267.html

41. KidsGrief.ca [Internet]. [cited 2026 Apr 21]. Available from: https://kidsgrief.ca/

42. Hawley PTMC Philippa. Experiences with Cutting Matrix Fentanyl Patches as a Method of Dose Titration in Cancer Patients - Phoebe Tsz Man Cheng, Philippa Hawley, 2017. J Palliat Med [Internet]. 2017 Dec 1 [cited 2026 Apr 7]. Available from: https://journals.sagepub.com/doi/epub/10.1089/jpm.2017.0368

43. Tofil NM, Benner KW, Faro SJ, Winkler MK. The use of enteral naloxone to treat opioid-induced constipation in a pediatric intensive care unit. Pediatr Crit Care Med J Soc Crit Care Med

World Fed Pediatr Intensive Crit Care Soc. 2006 May;7(3):252–4. doi:10.1097/01.PCC.0000216421.72002.09 PubMed PMID: 16575353.

44. Maxwell LG, Kaufmann SC, Bitzer S, Jackson EV, McGready J, Kost-Byerly S, et al. The effects of a small-dose naloxone infusion on opioid-induced side effects and analgesia in children and adolescents treated with intravenous patient-controlled analgesia: a double-blind, prospective, randomized, controlled study. Anesth Analg. 2005 Apr;100(4):953–8. doi:10.1213/01.ANE.0000148618.17736.3C PubMed PMID: 15781505.

45. Luthra P, Burr NE, Brenner DM, Ford AC. Efficacy of pharmacological therapies for the treatment of opioid-induced constipation: systematic review and network meta-analysis. Gut. 2019 Mar;68(3):434–44. doi:10.1136/gutjnl-2018-316001 PubMed PMID: 29730600.

46. Akkawi R, Eksborg S, Andersson A, Lundeberg S, Bartocci M. Effect of oral naloxone hydrochloride on gastrointestinal transit in premature infants treated with morphine. Acta Paediatr. 2009 Mar;98(3):442–7. doi:10.1111/j.1651-2227.2008.01128.x PubMed PMID: 19046344.

47. Physicians' opinions on and practical experiences with palliative sedation therapy in children: an international survey in five European countries - PubMed [Internet]. [cited 2026 May 7]. Available from: https://pubmed.ncbi.nlm.nih.gov/41102707/

48. Lichtenthal WG, Corner GW, Sweeney CR, Wiener L, Roberts KE, Baser RE, et al. Mental Health Services for Parents Who Lost a Child to Cancer: If We Build Them, Will They Come? J Clin Oncol Off J Am Soc Clin Oncol. 2015 Jul 10;33(20):2246–53. doi:10.1200/JCO.2014.59.0406 PubMed PMID: 26033819; PubMed Central PMCID: PMC4486343.

49. Rando TA. Loss and Anticipatory Grief. Lexington Books; 1986. 280 p.

50. Kreicbergs U, Valdimarsdóttir U, Onelöv E, Henter JI, Steineck G. Talking about death with children who have severe malignant disease. N Engl J Med. 2004 Sep 16;351(12):1175–86. doi:10.1056/NEJMoa040366 PubMed PMID: 15371575.

51. Rosenberg AR, Postier A, Osenga K, Kreicbergs U, Neville B, Dussel V, et al. Long-term psychosocial outcomes among bereaved siblings of children with cancer. J Pain Symptom Manage. 2015 Jan;49(1):55–65. doi:10.1016/j.jpainsymman.2014.05.006 PubMed PMID: 24880001; PubMed Central PMCID: PMC4280260.

52. Meert KL, Thurston CS, Briller SH. The spiritual needs of parents at the time of their child's death in the pediatric intensive care unit and during bereavement: a qualitative study. Pediatr Crit Care Med J Soc Crit Care Med World Fed Pediatr Intensive Crit Care Soc. 2005 Jul;6(4):420–7. doi:10.1097/01.PCC.0000163679.87749.CA PubMed PMID: 15982428.

7 APPENDIX 1 – FURTHER EDUCATION / USEFUL ADDITIONAL RESSOURCES

Association for Paediatric Palliative Medicine Formulary 2024 (6th edition):
Formulary Download

Basic Symptom Control in Paediatric Palliative Care (Source Together for Short Lives):
https://www.togetherforshortlives.org.uk/app/uploads/2017/12/SCM-formulary-10th-edition-with-APPM-6th-edition.pdf

Revidierter Fragebogen für KINDer und Jugendliche zur Erfassung der gesundheitsbezogenen Lebensqualität - Revised questionnaire for children (KINDer in German) and adolescents to assess health-related quality of life *(Ravens-Sieberer & Bullinger, 1998):*
Language versions - kindl.org

Why we need Palliative Care in Paediatric Oncology

SIOPE PALLIATIVE CARE Working Group

May, 2023

Palliative Care is about adding support, not decreasing hope.

Paediatric Palliative Care is for children, adolescents, young adults (CAYA) and their families, offering a wider scope of specialist support beyond the immediate caring team. Time has come to dissociate Palliative Care from death and make it available to paediatric cancer patients early in their journey.

Palliative Care focuses on improving quality of life, throughout treatment and beyond.

Palliative care offers holistic, proactive and user-centred care, focusing on improving quality of life for CAYA and their families throughout their cancer journey.
It facilitates improved pain and symptom management, supports the entire family system, fosters communication between healthcare professionals and families, and promotes advance care planning.
Recognising that needs and priorities may be different and change throughout the illness, Palliative Care provides each family with personalised care in line with their wishes and preferences.

Is it ever early to introduce Palliative Care in Paediatric Oncology?

It's never too early to introduce Palliative Care. Whatever the prognosis, CAYA with cancer and their families go through a similar journey of change and uncertainty. Some may need more support than others to adjust to the new reality, but they will share a mix of concerns and anxieties. Furthermore, there may be unexpected turns, with periods of deteriorating health and life-threatening complications, even death. Through early Palliative Care involvement, families will already have the tools and support they will need.
Early Palliative Care allows for more time to plan and to provide the best possible support for the entire family along the cancer journey, whatever the outcome.

Check our page and apply to become a member of the group

Early Palliative Care allows for more time to plan and to provide the best possible support for the entire family, along the cancer journey, whatever the outcome.

RESSOURCES:

Example Edmonton Assessment Scale:

Symptom and Burden Assessment

(based on the Edmonton Assessment Scale (ESAS), 1991)

Date: _____

Signature: Nurse: Physician:

0 Self-assessment 0 External assessment (if applicable, use two colours to distinguish child/parents)

Bitte Please circle the level of burden currently experienced for each symptom.
0 = Does not burden you / your child, no impairment of quality of life
10 = Severely burdens you / your child and/or restricts you/your child in daily life / quality of life

Pain:	0 1 2 3 4 5 6 7 8 9 10
Specific assessment using an age-appropriate pain assessment tool	
Breathing:	0 1 2 3 4 5 6 7 8 9 10
Nausea/Vomiting: (Reflux, gastric tube)	0 1 2 3 4 5 6 7 8 9 10
Nutritional problems: (Special diet, appetite)	0 1 2 3 4 5 6 7 8 9 10
Urinary retention/Incontinence:	0 1 2 3 4 5 6 7 8 9 10
Constipation/Diarrhoea:	0 1 2 3 4 5 6 7 8 9 10
Specific assessment using the Bristol Stool Form Scale	
Sweating/Fever:	0 1 2 3 4 5 6 7 8 9 10
Ascites/Oedema:	0 1 2 3 4 5 6 7 8 9 10
Tiredness/Fatigue:	0 1 2 3 4 5 6 7 8 9 10
Sleep disturbance/Sleep rhythm:	0 1 2 3 4 5 6 7 8 9 10
Mouth/Mucosa:	0 1 2 3 4 5 6 7 8 9 10
Specific assessment using: Oral Assessment Guide for Children	
Skin/Itching:	0 1 2 3 4 5 6 7 8 9 10
Delirium/Anxiety:	0 1 2 3 4 5 6 7 8 9 10
Sadness:	0 1 2 3 4 5 6 7 8 9 10
Dystonia/Spasticity:	0 1 2 3 4 5 6 7 8 9 10
Seizures:	0 1 2 3 4 5 6 7 8 9 10
Activities of daily living:	0 1 2 3 4 5 6 7 8 9 10

→ More than 5 points → detailed assessment of the problem with → Nursing diagnosis
→ Less than 5 points → repeated assessments during the course of the illness

Assessment of Quality of Life:

Quality of life assessment (different colours for different family members)

Lowest QoL 0 1 2 3 4 5 6 7 8 9 10 **Highest QoL**

Assessment of Family Burden

Assessment of Family Burden (different colours for different family members)

Not burdened at all 0 1 2 3 4 5 6 7 8 9 10 **Extremely burdened**

Example of Care Plan:

PPCN
Paediatric Palliative Care Network CH

Palliative Care Plan

Personal information	**plan number :** ☐♂ ☐♀ ☐⚥	
Surname: First name (s):	Date of birth:	Care plan established, date: In lieu of/date : Completed by:
Diagnosis		**Weight:** date: **Height:** date:
Allergies/Intolerances		☐ **No known allergies**
Emergency Management		
Symptoms to expect a. b. c. d.		Stepwise treatment plan a. b. c. d.
Emergency contacts (name/priority/relationship/phone number) 1. 2. 3.		
Resuscitation status **Resuscitation** yes ☐ with limitations ☐ no ☐ Discussed with:		**Further details, if required** (important if limitations/resuscitation status do not resuscitate)
Therapy options Diagnostics yes ☐ with limitations ☐ no ☐ Supplemental oxygen yes ☐ no ☐ Antibiotics yes ☐ no ☐ Airway suctioning yes ☐ no ☐ Bag/mask ventilation yes ☐ no ☐ Admission to intensive care unit yes ☐ no ☐ Non-invasive ventilation yes ☐ no ☐ Intubation/mechanical ventilation yes ☐ no ☐ Inotropic drugs yes ☐ no ☐		**Further details**
Additional advance care plan yes ☐ no ☐ Medical treatment agreement yes ☐ no ☐		**Supplementary notes**

PPCN

1/6

This document was discussed with: Signature (if required): doctor/ parents/guardian Date:

Address	**Mother** name: phone number: E-Mail address:
	Father name: phone number: E-Mail address:
	Further phone numbers:
Religion:	

Special wishes

Child
Family

Treatment plan yes ☐, separate treatment plan (no signature required) no ☐, signature required, doctors name: date: signature:	
General management of symptoms/problems **Including non-pharmacological and pharmacological management, stepwise action plan**	
pain	
dyspnoea / excessive secretions	
nutrition/hydration	
constipation/diarrhoea	
nausea / vomiting	
neurological disorders (epilepsy, increased intracranial pressure, dystonia, spasticity)	
agitation / anxiety / depression	
infectious disease/fever	
hemorrhage	
micturition	

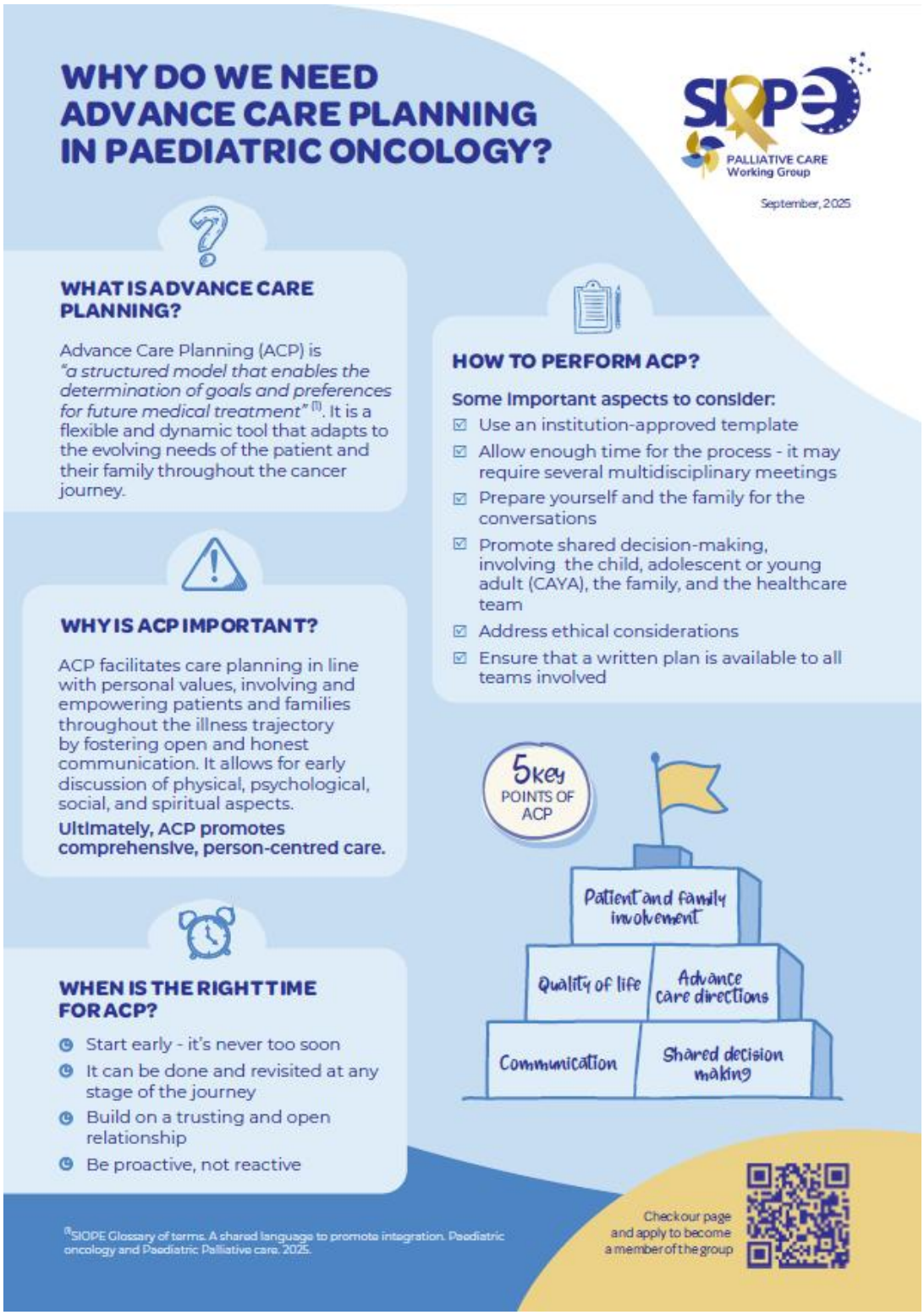
General management of symptoms/problems Including non-pharmacological and pharmacological management, stepwise action plan	
disorders of sleep/ wakefulness	
skin disorders	
itchiness	

Key professionals involved	Competence	Availability	Phone number E-mail-address	Info in case of an emergency admission to hospital	Copies of this personal plan are held by
Lead:				☐	☐
Pediatrician / general practicioner:				☐	☐
Medical specialist:				☐	☐
Specialist Palliative Care: medically: custodial:				☐ ☐	☐ ☐
Nurse practitioner:				☐	☐
„Kinderspitex" – community nursing , lead:				☐	☐
Kinderspitex, nurse practitioner:				☐	☐
Social worker:				☐	☐
Psychologist:				☐	☐
Nutritionist/lactation consultant:				☐	☐
Physical therapist:				☐	☐
Other therapist:				☐	☐
School /institution:				☐	☐
Spiritual guidance:				☐	☐
Pharmacy/Homecare:				☐	☐
Volunteer:				☐	☐
:				☐	☐
:				☐	☐

List of devices/aids: Notes:

Attachments:

Advance Care for children and adolescents:



Name:		

ACP – Advanced Care Plan for minors

FOR EMERGENCY MANAGEMENT SEE FINAL PAGES

Name:	
Parents/Legal guardians:	1. 2.
Address:	
Diagnosis:	

ALLERGIES:

-

To contact in

IN AN EMERGENCY :	
Other situations :	

Siehe auch Notfallkontakte auf der letzten Seite

This document is a tool to support discussions about care preferences and the communication of wishes. It aims to enable clinicians and families to make good decisions together. Not every page or section needs to be completed
Es muss nicht jede Seite/jeder Abschnitt ausgefüllt werden.

DATE OF PLAN / LAST REVIEW	

Regardless of the date of the plan, it should be reviewed regularly and updated when circumstances change.

Name:		

DECISION-MAKING

Primary language		Interpreter required:	Yes ☐ No ☐
Information to support communication or assess decision-making capacity:			
Details für decisio-making: for example, details about those involved if the child is in care; other important family members/carers involved; how would the child/family like to be involved in the decision-making process?			
Important information about legal capacity and where to find further information. Further guidance will be available on the CYPACP website. See also last page.			

Contacts

Name/role/department/organisation and contact details:					
		Name und Kontaktangaben			Name und Kontaktangaben
☐	Primary care provider		☐	Short-term care service	
☐	Emergency doctor		☐	Psychosocial team	
☐	Medical examiner		☐		
☐	Palliative care team*		☐		
☐	Hospice*		☐		
☐	GP		☐		
☐	Paediatrician		☐		
☐	Nursing service		☐		
☐	Hospital (ward & outpatient clinic)		☐		
☐	Emergency room		☐		

It is advisable to always keep a copy of the care plan with the infant/child/young person.

Name:		

MEDICAL HISTORY

Summary diagnosis/diagnoses:
Current situation:
Medical history, key moments along the way; previous pregnancy losses/neonatal/infant deaths (especially in prenatal planning)

Personal aspects

Personality/quality of life before the illness: (Can help others recognise deterioration, set goals for recovery. You may also want to document your concerns about your child's health now and in the future.)
Recommendations on how to make the child/young person/yourself feel more comfortable: (e.g. communication methods, special preferences, music, stories, games, etc. Please note where you can find more detailed, separate care plans, if relevant)
Social/psychological/spiritual/educational support: (if found helpful)
Family details: Please provide details of siblings, attach a family tree if helpful; other significant family members/friends/carers

Name:		

Priorities/Goals/Values

Needs of the baby/relative/child/young person: (Consider support for achieving quality of life in everyday life and specific goals, e.g. place of care; spiritual needs; desired outcomes; what I value most/would like to avoid; legacy and remembrance work during my lifetime)
Family wishes (including siblings): (Consider how you would like to be supported as a family in order to achieve everyday quality of life, and what specific goals you have, e.g. where you would like to live as a family; who you would like to involve; support and needs of siblings (e.g. medical, spiritual or cultural background); legacy and memory preservation during your lifetime; what you value most/what you would like to avoid)
The wishes of others: extended family, school friends, carers

Name:		

End-of-life wishes

If your child/young person is approaching the end of their life, is there anything we should know to ensure they receive the best possible care?

Priorities for care, including preferred location of care at the end of life and after death: Please indicate whether the preferred location of care at the end of life differs from the location of care after death.
Spirituelle und kulturelle Wünsche im Zusammenhang mit Tod und Sterben: (dazu gehören Glaube, Überzeugungen und persönliche Wünsche wie Musik, Familientraditionen und Rituale)
Wishes for remembrance and inheritance (with family/siblings/friends, if applicable) Consider how you/your child would like to be remembered. This may also include wishes for and/or (digital) legacies.
Preparation/communication of the procedure for administration after death: (e.g. 1. Required documents (who will take on this role?) 2. Handling of connected devices and removal)
Funeral wishes and bereavement support, as well as other wishes of the family: e.g. preferred time for removal of equipment from the house. If necessary, obtain detailed information or further advice.
Organ and tissue donation:

Name:		

Dealing with expected complications/deterioration in health

Reference to separate documents (and where to find them), e.g. symptom management plan, special care plan(s). Please weigh up the risk (version control risk) of duplicating information that is already listed in separate management plans, while recognising that this section can be very helpful for quick access in emergencies.
NOTE: For antenatal care plans, this section can be deferred (if desired) until the postnatal assessment. General Management.

Current course of medical treatment: e.g. disease-oriented therapy, clinical trials, etc.
Comments on probable deterioration (if known and relevant): Consider the probable cause(s) of deterioration, including signs, symptoms and warning signs.
Management of progressive deterioration (if different from the general deterioration described below): It may be useful to refer to other sections, such as priorities of care, when the end of life is recognised.

Management in cases of acute deterioration

Airways: Tracheostomy (also note whether the upper airways are clear) and airway aids
Breathing: oxygen, pressure and ventilation support

Name:		

Circulation/heart: access; diuretics; blood pressure support; implants – what the patient has, when and how to change or switch them off
Neurology: Indicate whether a VP shunt or reservoir is present and what measures should be taken in the event of a blockage; role of pulsed steroids in neurological deterioration; treatment of acute seizures
Treatment of infections: Including central venous catheters and specified temperatures for the individual child
Nutrition and hydration: Including presence or discussion of nutrition tools
Blood tests: Check frequency, indication and specific tests or adjust routine tests
Blood products: Consider type, frequency and indication, e.g. blood test or clinical symptoms
IV/SC access: Portacath; Hickman; Midline; others; and discussions about subcutaneous access
Condition-specific interventions/general: not mentioned previously, may include when to call 122, transfer to hospital
Other patient plans/where to find them: plans for symptom management, special care plans (e.g. for ventilation), etc.

Name:		

Management of acute significant deterioration/emergency

For review with 'Management of expected complications'
Further documents: 'End-of-life wishes'

Note any deviations from the plan described below if the parents/guardians are not present. If no parent is present, it is assumed that the plan described below will be followed, even if the parents/guardians are absent.

In the event of a life-threatening incident, the following measures must be taken: Add patient-specific details below				
				Comments (patient-specific decisions, e.g. duration)
Basic Life Support	Yes ☐	No ☐	Airway clearance	
	Yes ☐	No ☐	Airway aids	
	Yes ☐	No ☐	Bag and mask/mouth-to-mouth resuscitation/tracheostomy	
	Yes ☐	No ☐	CPR	
	Yes ☐	No ☐	Defibrillation	
Airway	Yes ☐	No ☐	Suctioning of mucus	
	Yes ☐	No ☐	Intubation	
Breathing	Yes ☐	No ☐	Oxygen supply	
	Yes ☐	No ☐	High-flow therapy	
	Yes ☐	No ☐	Non-invasive ventilation	
Circulation	Yes ☐	No ☐	Intravenous access	
	Yes ☐	No ☐	Intraosseous access	
	Yes ☐	No ☐	Cardiac medication/resuscitation medication (usually in conjunction with chest compressions)	
Other	Yes ☐	No ☐	Emergency transfer to hospital	
	Yes ☐	No ☐	Consider admission to intensive care unit	

Additional comments on the above decision or other relevant decisions

Please record details of implantable devices, e.g. VNS/pacemaker/defibrillator, and how to manage these devices at the end of life; long-term IV access; respiratory support (further details may be included in separate care plans or on the "Anticipated Complications" page (e.g. specific information may be included if a life-threatening emergency occurs at school). Consider revoking the ACP for planned operations, etc. Indicate preferences for transfer, e.g. to a local hospital or to a specialist centre if more appropriate (note: depending on the situation and local guidelines, preferences may not be possible). Consider how interventions for emergency medical personnel should be carried out and draw up plans for ongoing management.

Name:		

Summary version of the ACP Advanced Care Plan

1	Name:		Date:	

Summary of information relevant to this plan, including diagnosis and relevant personal circumstances:

Details of other relevant documents and where they can be found (e.g. ACP; advance decision to refuse treatment or advance directive (DNR); emergency plan for the carer):

I have legal power of attorney (e.g. registered health care proxy; person with parental responsibility). If 'yes', provide details in section 8 Yes ☐ No ☐

3 What is important to me when making decisions about my treatment and care in emergencies::

4

Priority for the preservation of life, even at the expense of some comfort		Priority for comfort, even at the expense of life support
Priority for extending life	OR	Prioritising comfort
CPR desired		CPR not desired
Signed: _____		

Name:		

5	Capacity to consent and/or represented by?		
Is the person capable of participating in the development of recommendations for this plan?	☐Yes ☐No	If 'no', to what extent is the person incapable of consenting? In this case, a discussion should be held with the family and/or legal guardian Document capacity to consent in patient file	
Einwilligungsfähigkeit in Pat.akte dokumentieren			

6	Involvement in the preparation of this plan		
The clinician(s) signing this plan confirm(s) that: (Select A, B or C, OR complete section D below):			
A	☐	This person is mentally capable of participating in the preparation of these recommendations. They were fully involved in the creation of this plan.	
B	☐	The person concerned is unable to participate in the creation of these recommendations, even with support. Values and wishes were taken into account, as far as they could be determined. The plan was created in consultation with the parents/legal representatives, where applicable.	
C	☐	This person is under 18 years of age and (please select 1 or 2 and, if applicable, 3, or explain in section D):	
	☐	1	Has the necessary maturity and understanding to participate in the preparation of this plan.
	☐	2	Does not have the necessary maturity and understanding to participate in this plan. Values and wishes have been taken into account, where known.
	☐	3	Parents/guardians were fully involved in the discussion and preparation of this plan..
D	If no other option was chosen, valid reasons must be given here. (Document full explanation in medical records):		
Date, names and roles of persons involved in decision-making:			

7	Signatures of treating physicians			
Profession	Name			Date/Time
Name of emergency contact (main contact person in purple)	Role/relationship	Available 24 hours a dayTick if Yes	Emergency number	
Patient/family:		☐		
Patient/family:		☐		
Professional:		☐		
Professional:		☐		
Professional:		☐		

9	Das Formular wird überprüft (z. B. bei einem Wechsel der Pflegeeinrichtung) und bleibt relevant		
Review date	Designation (grade/specialty)	Clinician name	Signature

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