

Palliative Care and Grief Counseling in Perinatology and Neonatology



Recommendations for professional caregivers in the field of prenatal diagnostics, pregnancy crisis counseling, obstetrics, neonatology, pediatrics and aftercare



Palliativ- und Trauerbegleitung in der Neonatologie

Impressum

Publisher

Bundesverband „Das frühgeborene Kind“ e.V.
Darmstädter Landstraße 213
60598 Frankfurt am Main
Germany

All rights reserved.

Copying permitted only with the prior consent of the publisher.

Text & Editing

PaluTiN panel of experts

Layout

Bundesverband „Das frühgeborene Kind“ e.V.

Typesetting & Print

Volkhardt Caruna Medien GmbH & Co. KG

Images

www.dein-sternenkind.org

with the generous consent of the initiator Kai Gebel

Printing: 1st Edition May 2018

Bibliography and related publications

www.fruehgeborene.de/fuer-fachleute/palliativversorgung-und-trauerbegleitung



*Initiative for the implementation of the Charter for the Care of the Severely Ill and Dying in Germany, and its recommendation for treatment.

Content

Greetings	4
Preface	5
Introduction	6
Recommendation 1 Focus on needs and hope	9
Recommendation 2 Empowering Parenthood	11
Recommendation 3 Communication – professional, honest, attentive and transparent	13
Recommendation 4 Evaluating therapeutic goals and treatment choices together: Stepwise, sound and sustainable	15
Recommendation 5 Advance care planning	18
Recommendation 6 Comfort Care towards the end of life	21
Recommendation 7 Grief counseling	24
Recommendation 8 Spirituality, religion and pastoral guidance	27
Recommendation 9 Support systems: networks & interfaces	29
Recommendation 10 The team duality: care and self-care	30
Epilogue* The central significance of composure	32

* A removable copy of the epilogue is located at the center of this brochure and can be kept as a reference.

Greetings



Dear reader,

The goal of the Charter for the Care of the Severely Ill and Dying is to avail every human being the right to die with dignity. What meaning does this hold for the parents, however, when they are told „Your child will die immediately after birth“? What does it mean to lose a newborn or unborn child? How should one deal with this loss in a dignified and humane manner?

Feeling sympathy is hardly sufficient to enable a person to comprehend the suffering of those impacted, much less to find helpful words. The time from diagnosis to death, but also the period after death, is an incredibly difficult time. The pain and grief remain in the heart and accompany the affected families into the future. That is why it is important to provide professional and caring help—help that expresses closeness and compassion, but also leaves time for grief and solidarity.

The focus of the “PaluTiN” handbook is to provide guidance to parents and families; to give doctors, caregivers and professional counselors practical tools for dealing with this exceptional situation and to help prepare for the difficult time before, during and after the death of a child. I am thankful to all those involved in this field. The death or imminent death of a child also creates a strained social environment. For all affected, help and better times seem so far away. Nevertheless, what the helpers provide is highly valuable. They make the situations somewhat better for the affected families. And every bit of help makes a great difference.

The recommendations in this handbook provide valuable guidance to strengthen the relationships between professional caregivers and families, as well as to enhance the caregivers' skills and decision-making abilities. When a child dies, when parents go through this, a dignified death is a prerequisite to be able to grieve and say goodbye. My heartfelt thanks go out to the authors of this handbook for their valuable contributions.

Kind regards,

A handwritten signature in blue ink that reads "Dr. Franziska Giffey". The signature is fluid and cursive.

Dr. Franziska Giffey
Federal Minister for Family Affairs, Seniors, Women and Youth

Preface

Whenever parents lose their child, it is an enormously emotionally stressful situation for the family, regardless of whether the child is a stillborn or dies later in life. The earlier this painful loss occurs, the more precious every opportunity becomes that the family has to spend with the child, providing care as well as saying goodbye. In many cases, premature birth or a congenital life-limiting disorder is the cause of early death in the perinatal period. In Germany, a total of 2405 children died in 2015* before reaching the first year of life, the majority within the first seven days after birth and most likely while being cared for in the neonatal unit of a pediatric hospital. Understandably, this poses a tremendous challenge for the unit's team members.

The recommendations being presented are intended as a practical orientation for treatment teams and counselors who assist (expectant) parents in these exceptional situations. They have emerged from the expertise and experience of respected members of all the relevant specialties involved in this area, as well as from the experiences of the parents. The PaluTiN project group (palliative care and grief counseling in peri- and neonatology) came together under the umbrella of our association in order to develop a useful guidebook for contemporary palliative care and grief counseling in the perinatal and neonatal phase based on clinical studies and scientific literature, taking into account as many relevant aspects as possible. There is, however, little to no scientific evidence available in this field. I would therefore like to take this opportunity to especially thank the members of the project group, who are presented in more detail from p. 32 onwards, for the vigorous discussion and debate on this sensitive topic, that ultimately resulted in the carefully compiled content contained within this handbook.

The recommendations herein refer to situations which may run a similar course, deliberately leaving room for individual adaptation, accommodating the varying needs of the affected parents. It is paramount to be sensitive to these needs and to consider an individualized approach in each case. These recommendations can promote confidence and professionalism in caring for a dying child and its family, which is in a very vulnerable state due to the exceptionally emotional situation. In order to cope adequately with what they have experienced, they are dependent on competent, empathetic support.

We are grateful for the generous support of this project by the KKH Kaufmännische Krankenkasse and the Bahn BKK as part of the self-help promotion program. I would like to thank you for your interest and readiness to make use of these recommendations in order to provide valuable support for affected families.

Sincerely



Barbara Mitschdörfer

Chairwoman
BV „Das frühgeborene Kind“ e.V.

*Source :www.destatis.de/DE/ZahlenFakten/GesellschaftStaat/Bevoelkerung/Geburten/Tabellen/Saeuglingssterblichkeit.html



Introduction

“Seriously ill and dying newborns, as well as their parents and loved ones, have a right to comprehensive medical, nursing, psychosocial and spiritual care and support that takes their individual life situation into account.”

(In the spirit of the Charter for the Severely Ill and Dying in Germany)

Why is special consideration of the palliative care of newborns necessary?

Among all deaths recorded in Germany for children and adolescents, newborns comprise the largest single cohort of nearly 40%. The following points illustrate reasons why newborns demand special consideration in the context of palliative care:

- Cases where the diagnosis of a life-limiting disease is established prenatally require palliative care and accompanying family grief counseling to commence before the patient is even born. For parents, this means that they must begin to make crucial decisions on behalf of their child and exercise their parental responsibility even though they may not yet feel like parents.
- Cases where the diagnosis of a life-limiting disease is established immediately after the birth of the child fall into a particularly sensitive period of parent-child bonding. Specifically, bonding and relationship building need to take place simultaneously with the beginning of the mourning process
- Due to the dynamic of the clinical situation, neonatal palliative care primarily takes place within the inpatient setting of perinatal centers. The children, therefore, rarely live together with their families at home.
- As a result of all these factors the newborn child often fails to secure a firm place in its individual family structure and history. Parents can neither look back upon common experiences nor plan a common future. For the family and society the child usually remains unreal - as if it had never existed. Since other family members were often unable to get to know the newborn, they do not know the person for whom the parents are grieving. As a result, orphaned parents are left alone with their grief and increasingly feel socially and emotionally isolated. For parents the enduring impact of the life and death of their unborn or newborn child remains to this day scarcely acknowledged.



Principles

The pediatric group IMPaCCT (International Meeting for Palliative Care in Children, Trento) of the European Association for Palliative Care (EAPC) established a definition for pediatric palliative care in 2007. This was based on a general WHO definition of palliative medicine (WHO Definition Palliative Care) and is applicable to all life threatening and life limiting childhood illnesses. It forms the basis for the following recommendations:

(Craig et al. 2008):

- Pediatric palliative care is the active and comprehensive care of children and youth suffering from life-threatening or life-limiting illness. This takes equally into account the body, mind and spirit of the child and ensures the support for the entire impacted family.
- It begins when the illness is diagnosed, regardless whether or not the goal of the treatment is directed at curing the disease.
- It is the task of professional care givers to assess and minimize the extent of the child's physical, psychological and social stress.
- Effective pediatric palliative care is only possible with a broad based multidisciplinary approach, which includes the family and the use of available community resources.
- Pediatric palliative care can also be successfully implemented in cases of limited resources. It can be provided in hospitals with the highest levels of care, in the community or at the patient's home.

Objective of these Recommendations

Consistent with the principles of palliative care, the emphasis for newborns, even with incurable, early life limiting diseases, is not on extending the lifetime of the child at all costs, but upon ensuring the best possible quality of life for the child and supporting the family. The points described above clearly illustrate why palliative care of newborns differs significantly from other pediatric palliative care situations. Nevertheless, professional caregivers in German-speaking countries can currently neither draw upon evidence nor consensus-based national recommendations for this unique care situation.

It is therefore the purpose of these recommendations to provide practical guidance and standardization in the support and care of newborns in palliative care and their families. The prenatal period, the birth, as well as the time after the death of the child are explicitly included.

Given that palliative care is practiced in a multi-disciplinary approach, these recommendations have been compiled by representatives of the various professions and specialist disciplines, as well as by parents. Their genesis was motivated by the desire to align the personal experiences of the families with professional and scientific competencies. They should be made available to all caregivers. The present recommendations do not claim to be able to answer all questions. They should rather serve as an orientation and encourage discussion and continuous development.

Notes

- In this text, the term parents includes expectant parents as well as couples and partnerships where one of the partners is not a biological parent, but assumes this role for that child.
- When the recommendations refer to newborns, they always include both premature and mature babies
- For the sake of textual simplicity all gender identifications have been referenced with masculine pronouns.

Recommendation 1

FOCUS ON NEEDS AND HOPE

The diagnosis of a life-limiting illness before or surrounding the birth process plunges unprepared parents and families into a life crisis. All parties involved should recognize that parents bring ambivalent feelings, individual needs, hopes and desires into this situation. Parents should be supported and, as far as possible, enabled to recognise their needs and be encouraged to express them. Hope can remain a central theme and a source of strength. The affirmation and appreciation of the child as a human being – even before birth – is very important for many parents.

1

Implementation

- The diagnosis of a life-limiting illness for their child elicits conflicting feelings such as disappointment, anger, shame and guilt as well as anxieties, worries, insecurity and grief from the parents.
- In many cases parents initially feel great hopelessness and loneliness. Lost is their unbroken hope for a healthy child and for a life together as a family.
- And yet parents describe that hope remains and that specific requests and desires evolve, such as:
 - ✗ getting to know their child and to accompany him on his journey,
 - ✗ having time together as a family,
 - ✗ ensuring their child does not suffer and
 - ✗ providing a proper resting place for the child after his death.
- Parents sometimes also hope that, contrary to the prognosis, the child's situation will improve beyond what they themselves and the team expect.
- Parents should have the chance to hold on to their hopes until the end, as hope often serves as a source of strength and helps to endure the painful process. Acknowledging hope is independent of treatment decisions.
- Providing information and support can help parents to find their footing and deal with the current situation. This requires the readiness of the team to give the parents time and space to recognize their feelings and needs. Parents should be encouraged to express their desires and values.
- The individual needs, hopes and desires of the parents may differ from those of the team.

- The individuality of each child and each family is respected. Their desires and needs are met in a respectful, open and active manner. The family's psychosocial development processes are supported with sensitivity.
- The family is supported and encouraged to maintain a regular everyday routine as far as possible despite the extreme situation.
- Ideas offered by the multi-professional team serve as prompts for the parents to enhance and explore their own active and creative possibilities. Opportunities may arise which have not yet been previously considered or articulated. This applies to pregnancy and childbirth, the child's care and comfort, as well as possible spiritual practices.
- Support in organizational matters (e.g. care of siblings, letter of excuse, domestic help) can provide families additional latitude.



EMPOWERING PARENTHOOD

When birth and death coincide, parents have little time to grow into their role as parents, get to know their child and give it a place within their family. Therefore the child's care team should support, actively promote and protect the parent-child relationship. This process begins before birth and continues beyond the death of the child.

2

Implementation

- Parents should be supported in getting to know their child and giving him a place within their family. All parental instincts and efforts to care for their child should be valued and actively encouraged
- In this limited time, parents need as many opportunities as possible to be with their child, get to know him and grow into their parental role. This requires people at their side and recurring opportunities to articulate their fears and struggles. Together individual paths and solutions can be found in helping parents to engage with their child.
- Even if a prenatal diagnosis of a life-limiting disease has been made, it is important to encourage the bonding process. Indeed, the pregnancy can become a significant family life event and an important time to remember.
- To ease the development of relationships and roles, it is necessary for parents, siblings and family members to be perceived, acknowledged, encouraged and valued by all parties.
- Parents who fear the bonding process need to realize that evading the pain of bereavement only appears to make parting easier, and may lead to future health problems. Parents should be encouraged to commit emotionally to the child in order to allow them to take their first steps in dealing with the loss through a consciously designed parting. They need the support and skill of staff in dealing with pain and avoidance reactions. Access to the experience of other affected parents and personal dialogue among each other can also be helpful.
- The staff's natural and caring approach to the dying or deceased child can serve as a role model for parents. It can make it easier for them to approach their dying or deceased child and deepen their bond.
- Parents need to be encouraged to involve siblings and other important people from their family and social circle and to offer them the opportunity to get to know the child.

- Parents should be encouraged to use the ir retrievable time until the funeral to spend as much time as possible with their child and to admire, understand and mourn him together with his siblings and other significant persons. Here, too, the parents may initially require greater professional guidance to offer support, orientation and suggestions, which may recede gradually as the parents assume individualized ownership of the process.
- By providing the child a place within the family and circle of friends, the family members come to know for whom it is that the parents are grieving. They are thus better able to support the mourning family with understanding and long-term support. For the grieving parents, this reduces the risk of social and emotional isolation, as well as the great worry that their child will be forgotten.
- The family should be encouraged to create a firm place in the family history for their deceased child. Through their own individual attachment to their child and the inclusion of siblings and people from their personal environment, it can become easier for parents who have been orphaned so early to integrate what has happened into their lives and to face the challenges of the future.



COMMUNICATION - PROFESSIONAL, HONEST, ATTENTIVE AND TRANSPARENT

The relationship between family and treatment team is rooted in partnership and professionalism. The communication should be professional, ongoing, honest, empathetic and transparent. Parents should be confident that they are being listened to carefully and that no information is being withheld from them. Especially in critical or dynamic situations, discussions should be timely and not delayed.

Implementation

- In addition to speaking, communication includes non-verbal expression of thoughts by means of posture, gestures, facial expressions and behavior. Therefore, the fundamental demeanor is characterized by acceptance, respect, esteem, empathy, attentiveness and authenticity. This can be felt by the family in everyday contact and in all conversations.
- The following discussions are particularly challenging for professionals and parents:
 - ✗ Presenting the diagnosis of a life-limiting illness, especially if marked by prognostic uncertainty,
 - ✗ Discussions to clarify therapeutic goals, to plan the birth and (anticipated) treatment
 - ✗ Discussions concerning the child's dying, his death and the time thereafter
- For the parents, these conversations will leave a powerful imprint on the rest of their lives
- Professionals too may at times be especially challenged by these discussions and react with a degree of uncertainty, hesitancy or even avoidance. That is why they require both individual and team skills, special abilities and attitudes, as well as continuous reflection and training.
- Within the team staff should be encouraged to identify insecurities as they can affect anyone. Professionals and teams need support and the opportunity to acquire, reflect upon and develop these skills.
- Discussions with parents should take place with the awareness that parents are themselves experts and have the essential capacity to make sustainable decisions for their child and themselves.
- The ability of individuals to recall and concentrate under conditions of extraordinary stress is diminished. This is why stressed parents often need several conversations on the same subject, in which the questions are sometimes repeated several times, but also new aspects are discussed.

- Crisis talks and other encounters need a protected, appropriate setting. They need to take place in a calm environment, if possible free of time pressure and disturbances.
- Particularly important conversations should be scheduled as dependably as possible in order to give both parents the opportunity to participate and to prepare themselves. Particularly in critical or changing situations, conversations should be timely and not delayed.
- Parents should be confident that no information is being withheld from them and that their contact persons are dependable. At the same time, the possible desire of parents not to know should be respected.
- In addition, parents should be able to trust that they can tell and ask the professionals anything without having to fear negative consequences for themselves and their child. It is important that they are accepted in their attitude and that their ambivalence be respected.
- Parents are less likely to raise critical, very personal or emotional issues with medical staff members, and rather address them to specialists such as parent counselors, grief counselors, psychologists, social pedagogues and pastors. Here too they may also raise topics that are not directly related to the treatment of the child.
- During these discussions, suggestions on identifying and utilizing personal resources can be made, as well as to expand the scope for the parents to enhance and explore their own active and creative possibilities.
- Parents need attentive communication and support to help them find their own individual path, which should remain calm and sustainable even years in the future.

Recommendation 4

EVALUATING THERAPEUTIC GOALS AND TREATMENT CHOICES TOGETHER: STEPWISE, SOUND AND SUSTAINABLE

A continuous, open and honest exchange of information, values, goals and treatment options between the expectant mother or the parents and the treatment team is the foundation for sustainable decisions. The active process of shared decision-making should enable the parents and the specialists involved to understand the situation in all of its dimensions. Parents should be supported in making clear long-term decisions that are in the best interest of their child.

4

Implementation

- The diagnosis or the symptoms of a severe, life-limiting illness present complex challenges for treatment decisions and interventions.
- Especially important consideration should be given to:
 - ✗ various ethical, legal and emotional aspects prior to and after birth,
 - ✗ the responsibility toward the expecting mother, the child and family,
 - ✗ a potentially unclear prognosis,
 - ✗ the necessity to make decisions without delay in acute stress situations.
- Parents have the right and, in the majority of cases, the desire to take an active part in the decisions concerning their child. For the treatment team this means continually sharing ideas with the parents, listening to them, getting to know their values and, if desired by the parents, shaping the decision making process together with them as equals (shared decision-making).
- In decisions taken during pregnancy, the mother's right to self-determination is the legal priority. At the time of birth the parents are entitled to the representation of the child in health matters as their natural legal custodial right. It is therefore their task to decide which steps are to be taken in the best interest of the child.
- Parents should be offered regular opportunities to actively participate in the decision-making process. They are continually encouraged to determine for themselves the degree of their involvement.
- The decision-making process unfolds gradually and requires sufficient time. Nevertheless, decision making should not be unnecessarily delayed.
- The basic prerequisites for the decision-making process are open, understandable, empathetic communication and a comprehensive exchange of information with the parents.

- The support provided by the treatment team consists of a careful, stepwise examination of all options together with the pregnant mother/parents.
- Parents should be asked in what manner, how extensively and with how much detail they would like information to be provided..
- Medical information should be communicated in a clear and comprehensible manner. Local, national and international studies on prognosis and treatment options should be taken into account as far as possible, for example in the form of evidence-based decision-making aids.
- The medical indication for treatment can be established after the therapeutic goal has been clarified. A treatment is only indicated, however, if the desired therapeutic goal can be realistically achieved. The medical assessment is carried out by the treatment team.
- It is essential to include, in addition to the medical point of view, the expertise of midwives, nurses, therapists (physiotherapists, music therapists, etc.) and specialists in psychosocial and spiritual issues. This offers the opportunity for a holistic perspective for all participants, making it easier for parents to assess the impacts of their decision on the future life of their child and family. Outside input may provide opportunities for parents to increase their treatment and intervention options.
- As a next step, i.e. after sharing and exchanging all information, including the possible involvement of other experts as needed, all existing options for the specific situation, including their opportunities and risks, are discussed with the parents.
- It is also imperative to discuss with parents whether and when life-prolonging measures should be limited, terminated or not initiated. This is necessary if the therapeutic goal cannot be achieved through already initiated or planned measures or if the harm is more likely to outweigh the benefit..
- Parents have the option to delegate either partially or completely the consideration of the therapeutic options to the treatment team. This can be revoked at any time.
- The discussion of recommendations should continue between parents and team regardless of any delegation of decision making. Parents often perceive the recommendations for treatment and actions specific to their individual child as a support for their parental responsibility.
- The central point in the decision-making process is to become aware of the aims and desires for the child and its family. It is important to remember that the assessment and therapy goals of those involved may differ. It is helpful to clearly identify these differences and to continually share views.
- The freedom to offer input with regard to the possible alterations in the therapeutic plan is allowed to both the parents, as well as each member of the treatment plan. These suggestions should be considered with sensitivity by the team leader. The consensus developed within the team and with the parents should be implemented and supported in a timely manner. In cases where uncertain-

ty, doubt or dissent exist, a formal ethical decision-making mechanism should be pursued. The utilization of a case discussion, if needed with external moderation and consultation (clinical ethics consultation, ethics committee), can be helpful. This consultation can take place with or without parents, but should always be explained transparently and discussed in detail with the parents.

- Should the parents wish to seek additional advice, this should be supported. This is not dependent upon whom the parents consider to be helpful. Calling for a „second opinion“ should not be interpreted as a sign of distrust or an expression of a developing conflict between parents and the treatment team. Most parents want a second opinion in order to have a sound foundation upon which to consider essential decision, e.g. a change in the therapeutic plan..
- Once medically, ethically and legally sound parental decisions have been made they must be respected by all concerned, even if the treatment team would prefer a different treatment option. In very rare cases, if a viable decision is not reached, the ethical concept of causing no harm can become the guiding principle for treatment.
- It is important and helpful for each step in formulating a transparent therapeutic plan for all participants. Formal documentation of the process and decisions facilitates the interdisciplinary exchange of information and can prevent loss of information.
- It is important and helpful for each step in formulating a transparent therapeutic plan for all participants. Formal documentation of the process and decisions facilitates the interdisciplinary exchange of information and can prevent loss of information.

Recommendation 5

ADVANCE CARE PLANNING:

5

Advance care planning provides the foundation for discussing and planning future treatment decisions and interventions for the child in a joint discussion process with the parents. Medical and non-medical issues are considered for different stages of the illness. This also means that decisions are summarised in writing in a transparent and easily understandable manner. The advance care plan should then be communicated to all affected and involved. Notwithstanding any ambivalence among parents and specialists, this stepwise process offers greater reassurance to all involved that the desires and objectives for the child will be implemented.

Implementation

- Palliative care begins with the indication or diagnosis of a life-limiting progressive disease.
- Outside of curability, situations will inevitably arise during the clinical course in which alternative therapeutic goals and treatment options will suggest individual courses of action. Supplementing the current treatment plan, advance care planning is utilized together with the parents to define the measures to be taken in the event of future developments.
- In the case of a prenatal diagnosis of a life-limiting illness, advance treatment planning should also include the medical and psychosocial care of the expectant mother up until birth, as well as during birth itself.
- The discussion regarding the development of an advance care plan should be initiated especially if, from a medical point of view, the deterioration of the child's state of health or death is likely or possible.
- The advance care plan encompasses the discussion of medical and non-medical issues that already play a role or may become important in the course of treatment. It builds upon the physical, social, psychological and spiritual needs of the child and its family. These needs should be carefully identified in the discussion and considered by the multi-professional team. Parents should be encouraged to formulate their wishes and goals.
- The initiative for using advanced care planning can come from any member of the treatment team or from the parents.
- The parents should be advised of all the options in an expert and empathetic manner considerate of the individual situation. As described in Recommendation 4, the process of prioritizing treatment options should be developed together. Within the framework of the advance care plan, especially for future crisis situations and in the event of clinical deterioration, treatment options should be considered and implemented individually.

- Discussions of treatment options, especially in advance, tend to elicit ambivalent feelings among parents and specialists. Reservations and obstacles that arise require an empathetic, open discussion process. By providing clarity and information this process can give the parents and treatment team more confidence when dealing with critical situations. In addition, this process usually aligns with the parents' desire to contribute actively to their child, themselves and their family.
- For parents, the discussions are often more important than the written documentation. For this reason, the primary emphasis in advance care planning should be the multi-step discussion process over the written plan, whose principle importance is to the specialists.
- The advance care plan addresses the following stages in the course of the illness:
 1. Disease progression, i.e. when the child's condition slowly deteriorates,
 2. Acute life-threatening crises
 3. Altered baseline status following an acute crisis.
- Outside of supporting parents in emergency and crisis situations, it is the goal to identify their wishes and decisions for future interventions. It should be sought to document the outcome of the advance care discussion in writing. The documentation should include specific details of the discussion process, the therapeutic goals and methods. Both medical and non-medical aspects should be considered. This would include, for example, the integration of and the care for the siblings.
- Detailed documentation improves the chance that the parent's wishes will be faithfully implemented by different treatment teams in crises and emergency situations.
- Especially for an acute emergency situation, it is important to specify in detail whether life-prolonging measures should be initiated, and if so, which ones and to what extent. It is also wise to include a „medical emergency care directive“ in the written document. This should be signed by the treating physicians and, if possible, by the parents. This makes it possible to provide the first responders and specialists involved in an emergency with clear instructions.
- For palliative treatment in the home environment it is particularly important that the treatment plan anticipates measures for symptom control for foreseeable crises. For example, medication required under certain circumstances should be provided and its administration ensured.
- Even when an advanced care plan exists, the immediate situation must be continually reevaluated, and decisions adapted to the current circumstances.
- Early discussions can benefit both parents and the treatment team by reducing the concern that decisions will need to be made under time pressure.
- Parents should be free to refuse the offer of advance care planning and its documentation.

- Dealing with any remaining uncertainties in an open and honest way avoids conflicts and usually enhances parental trust in the treatment team.
- All involved disciplines and professions should have a role in preparing and implementing the advance care plan, which should be clearly documented and distributed to all relevant parties.
- Effective interfaces among interdisciplinary care team members and other disciplines are particularly important to ensure the sharing of information and implementation of the treatment plan. Coordination and formal documentation help to prevent the loss of information. The cooperation of all parties involved and avoiding the loss of information are important prerequisites for the confidence and trust of families.
- A thorough reevaluation is necessary involving discussions between the parents and the various disciplines in order to adapt goals and therapy to changing needs and situations.

COMFORT CARE TOWARDS THE END OF LIFE

The process of dying is recognized as an important part of life. In caring for newborns and their parents as the process of dying sets in, the focus is upon avoiding suffering and on providing personal attention. The dignity and well-being of the child must be respected at all times. The treatment team provides comprehensive medicinal and non-medicinal treatment for the best possible control of symptoms and interacts empathetically with the parents and family in multi-professional cooperation. The child and the family are supported in an attentive and sensitive manner according to their individual needs.



Implementation

- The essence of palliative care for newborns with life-limiting illnesses is not upon life prolongation at any cost, but rather upon providing the best quality of life, emphasizing the well-being of the child and his family.
- In any medical decision, the best interests of the child should have the highest priority. This means that no treatment may be carried out that burdens the child without providing him with a tangible benefit. All diagnostic and therapeutic procedures should be critically examined in this respect. This would also include such life-supporting measures as respiratory assistance, supplemental oxygen, infusion therapy, partial or complete parenteral feeding or feeding via nasal gastric/duodenal tubes.
- During end of life care – at the very latest - any stressful diagnostics should be avoided, whether invasive (e.g. blood drawing), or non-invasive (e.g. weighing, blood pressure or temperature measurements, ultrasound). Even monitoring should be carefully reconsidered. A monitor often draws the attention of parents and staff to the device and can thereby distract from the child.
- The dying child should be carefully and systematically examined for evidence of pain and other signs of suffering such as shortness of breath, restlessness and anxiety. The parents' assessment of the child's condition should be taken into account. Developing symptoms must be recognized, promptly evaluated and effectively treated.
- The reduction of painful, stressful procedures and nursing measures is at present the most effective strategy to reduce pain and discomfort in a severely ill newborn baby.
- Every child has the right to appropriate pain treatment and symptom control through non-medicinal and medicinal measures. These should be available at any time during the dying process and at any location (in the birthing room, in the neonatal ICU, in the children's hospice, or at home).

- There should also be a general reduction in external environmental stressors (e.g. light, noise, cold, commotion). A suitable design of the child's immediate surroundings and a sensitive work style are helpful.
- The administration of drugs such as opiates and benzodiazepines with the primary therapeutic aim of alleviating suffering and symptoms should proceed despite possible respiratory or circulatory depressing side effects. Here it is essential to maintain full transparency with the parents regarding the medical treatment.
- Symptom-relieving medication can be administered via existing superficial, central or indwelling intravenous catheters, as well as orally, nasally, rectally or transdermally. Intramuscular injections as well as single dose venous or subcutaneous injections should be avoided.
- The immediate care of the child is exclusively based upon its individual needs ('optimal care'). The focus should be to support the child's well-being, prevent symptoms or alleviate them, e.g. closeness and skin contact, hearing familiar voices or melodies, positioning to ease breathing, or avoiding hunger and thirst.
- It should be noted that parents are the most important care givers for the child. They are acknowledged along with all their needs, wishes, worries and fears. They are supported in exercising their parental autonomy and caring. For many parents it is important to be able to do something actively for their child during this stage of life. This parental need should be met with information and guidance. With their experience, the treatment team provides the parents with reassurance and calmness while escorting their child through this final step of life.
- Even during this highly emotional time, the creation of lasting memories can be important. This should be supported and offered individually, attentively and sensitively, without disturbing intimacy.
- Human closeness remains the highest priority while the newborn is dying. In virtually every case, the supportive presence of the parents should be made possible. If the parents cannot be reached or for personal reasons are not able to be present, the necessary closeness and human attention should be provided by another family member, friend or someone from the team.
- Especially during dying, every family's right to privacy should be taken into account. The parents can decide whether to remain alone with their child or would prefer that a team member be present for support. Family members requested by the parents should be given expeditious access to the child, if not already present. This applies especially to siblings.
- Once the final stages of the dying process have begun it is the team's primary task to be in attendance without being intrusive. The goal is to enable the child to die in comfort and with dignity.

- Parents should be braced for possible symptoms, reflexes and behavior patterns of the dying child in order to avoid confusion and fear. Individual variability in the duration of the dying process should also be pointed out.
- Parents should be reassured that they will not be left alone at any time unless they request it.
- Parents report that they find an attentive accompaniment as helpful and experience the time they spend with their child as valuable and meaningful.



Recommendation 7

GRIEF COUNSELING

7

"Grief is the normal reaction to a significant loss."¹

For affected parents, grief at the beginning of life often means having to say goodbye to their child before they have welcomed him into the world and into their family. Supportive grief counseling fosters the parent-child relationship as well as and the bonding process within the entire family. It carefully seeks out paths and taps resources for a healthy continuation of an emotionally, psychologically, socially, spiritually and physically stable life.

¹ see K. Lammer, „Trauer verstehen“ (Understanding Grief); the bibliography and further publications regarding this specific topic can be found at: www.fruehgeborene.de/fuer-fachleute/palliativversorgung-und-trauerbegleitung.

Implementation

- The parents' mourning process often begins with the diagnosis, and requires a personalized, reliable and on-going support system from the onset.
- Grief counseling does not only support the family emotionally. It also offers help towards self-help, for practical organizational needs, for the development of necessary support systems and the transition back into the home environment.
- The long-term goal of grief counseling is to enable grieving families to integrate the loss of the child into their lives and family history.
- At the beginning of their bereavement journey, parents need a proactive, accessible contact. At all times they are free to accept or reject individual offers of support. Offers of grief counseling should be repeated, periodically, as the parents' mental state, needs and situation may often have changed with time.
- Grieving parents and their families need reliable and readily available contact persons. These should encourage them to express their thoughts, fears and challenges and to ask questions at any time.
- The time spent with the child is so brief, that every opportunity to create and deepen attachment counts. Every experience during the life and the death of the child is invaluable, since these memories serve to preserve the entirety of a family's history. .
- Fears of deepening attachment to the dying or deceased child can be counterbalanced by positive narratives from other parents in the same situation. Hearing that grief is not worsened by repeated encounters can encourage parents to make use of the time while their child can still be experienced. Parents maintain the choice at any time to not see their child.

- Many parents require individual orientation and explanation as to the extent to which it is possible for them to be present with their child. Personnel, staffing, environmental and organizational practices should be designed to enable families to spend time with their child up until the burial. As part of grief counseling, parents are offered the opportunity to create shared experiences and to give the child a place within the family. This includes not only parental activities with the child, such as washing, cleaning and breastfeeding, but also the gathering of memories. This also includes the opportunity to invite siblings and important family members to get to know the sick, dying or deceased child and thereby better understand whom it is that the parents grieve.
- Many parents consider it a great relief when grandparents or other close relatives are also offered counseling because they do not feel themselves to be in a position to comfort their relatives. Often they also need encouragement to express their needs to their relatives. Written information has proved helpful in providing support to grieving parents.
- From the moment of diagnosis the parents exist in an exceptional situation. As a result, it may be necessary during grief counseling to raise topics that the parents themselves will seldom initiate. This includes for example:
 - ✗ Inclusion of siblings and addressing their grief,
 - ✗ Individual differences in expressing grief and coping with the potential for conflict in the relationship,
 - ✗ Ambivalent feelings in cases where not all the babies from a multiple birth survive,
 - ✗ Dealing with feelings of insecurity and social isolation,
 - ✗ Preparatory steps for reentry into daily life,
 - ✗ Midwife support and services,
 - ✗ Finances (e.g. funeral costs, loss of income).
- In order to ensure that outpatient grief counseling may continue, it is necessary to identify potential resources with the parents, allowing them access to a support network. In addition to current information about available regional grief counseling and psychosocial services (e.g. midwives, grief support groups, social counseling, therapists, outpatient children's hospice services, community and church services), the degree of readily accessible support from family and social circles should also be discussed. Information regarding midwife care covered by health insurance is often appreciated.

• During professional grief counseling it is important to identify situations that threaten to exacerbate grief. The following risk factors may overwhelm available resources, increasing the likelihood that grieving might be intensified by:

- ✗ Denial, avoidance and postponement of grieving,
- ✗ Traumatic circumstances surrounding the death,
- ✗ Life circumstances that impede grieving,
- ✗ An ambivalent relationship to the deceased child,,
- ✗ Lack of a supportive social environment,
- ✗ Lack of access to support systems,
- ✗ Lack of personal resources,
- ✗ Additional unresolved losses or crises.

In situations where the grief is intensifying, the mourner should be offered a referral for appropriate and specialized assistance.



SPIRITUALITY, RELIGION AND PASTORAL GUIDANCE

When birth and death occur so closely together, it creates an existential crisis. Life plans are destroyed. Assumptions about life, its meaning, its values and its spiritual-religious grounding are suddenly called into question. It is the task of the team to continually offer spiritual and religious support to the involved families. This may include a variety of very different types of support, and applies to all participants, regardless of their spiritual or religious orientation. Pastoral care likewise takes into consideration the needs of other parents and of unit staff.



Implementation

- People enquire into the mystery of life and seek its meaning. This is a characteristic trait of human existence, which we call spirituality. Religiousness denotes the integration of this basic spiritual need into the framework of a religion.
- At the junction between life and death, spiritual and religious questions acquire special significance. This junction becomes painfully and unexpectedly apparent when a child falls into mortal danger before, during, or soon after birth, or when death coincides with birth or follows soon thereafter. Herein lies the emotional instability and vulnerability of those involved.
- Pastoral care is attentive to the spiritual and religious needs of parents. Many in these situations hold onto their faith as a source of strength, its encouragement through pastoral care offering an additional resource for coping. If one's own faith is not (or is no longer) perceived as supportive and comforting, however, parents may consider pastoral care as an additional burden. The question of guilt, even if it is not expressed outright, can nevertheless be an important issue, and one to which the treatment team and especially the pastoral care giver should be attuned.
- Pastoral care is offered with an utmost respect for the diverse values of a multicultural society. At the same time, there are also individuals who expect and request spiritual direction.
- In their approach and manner the pastoral care workers convey to their clients that they stand by them and they are searching for answers together. They are sensitive to the spiritual and religious needs of their clients, and do not offer ready-made answers. Their spirituality is recognizable and truthful; they wish never to promote their own ideas, much less to impose them.

- Regardless of their religious orientation, pastoral workers offer a protected space based on the confidentiality of pastoral care. Parents thereby have the opportunity to reflect on their situation with a counterpart who has experience in the field of obstetrics and neonatology but is not part of the treatment team.
- It is necessary to distinguish between the broader spiritual-pastoral and the narrower religious-pastoral services. Baptism, blessing, prayer, as well as greeting and farewell rituals place the child in his uniqueness at the center of the parents and treatment team, regardless of his state of health. At the same time, they remind us of the lack of control over life despite all the technological possibilities. Rituals are an expression of love and appreciation. They open up another dimension of familial experience in the midst of all the medical treatments. They demonstrate appreciation for the child, connect him to the community and thereby give him a permanent place there, even if he dies. Rituals can connect the parents and the team with each other.
- Pastoral workers also support parents who have witnessed or learned of the death of another child.
- The pastoral worker's contact with parents can also continue beyond their inpatient stay. Because pastoral workers are not tied to the routine of the unit, this may provide some relief for the team.
- Many parents fear that death is near as soon as a team member refers them to a pastoral worker. For this reason, it is important that there be ongoing consultation between the treatment team and the pastoral care givers, striving to involve them as early and as regularly as possible. In this way pastoral care can be perceived as a natural part of the support system. Nevertheless, pastoral workers remain dependent on the advice of the team members as to when and where their assistance is needed.
- Pastoral workers can additionally play a helpful role for the treatment team in coping with their own work stress, and with their own spiritual and religious questions and needs. In these cases, talking, as well as rituals may provide relief and support.
- Support on spiritual and religious issues can also be provided by others: by members of the treating or psychosocial team, or by a pastor from the parents' own community. It is part of the autonomy of patients and family to choose their own spiritual guide.
- It is of great importance for all those involved to develop and strengthen a basic confidence that coping can succeed.

SUPPORT SYSTEMS: NETWORKS & INTERFACES

Palliative care of newborns, as well as counseling and grief support for affected parents is an interdisciplinary process. An important prerequisite for high-quality, individualized and adequate support for the whole family is collegial and transparent cooperation among the respective network partners inside and outside the clinic. The early determination of a responsible primary contact person who co-ordinates efforts should help to ensure cross-communication and care.



Implementation

- Palliative care of newborns begins with the diagnosis, which is sometimes already established prenatally; grief support for parents extends beyond the death of their child. For this reason, an interdisciplinary, cross-sectoral network is needed from the outset, consisting of outpatient and inpatient care providers.
- External and internal interfaces are of particular importance. For this reason, clear lines of communication and responsibility should be defined, and ideally, shared documentation should be assured. At the same time, the principles of data privacy must always be observed, particularly with regard to the consent of the persons involved.
- Families and network partners require that responsibilities be clear, transparent and well defined in order to ensure optimum care. This also includes the designation of a coordinator whose responsibilities include being aware of possible gaps in care or communication and who can propose solutions.
- There is no universal standard for the structure of a well-functioning network of support systems. Regional solutions are therefore required based upon available facilities and human resources.
- Only close and reliable multi-professional cooperation ensures the reduction of communication problems and helps to effectively enable available support systems. For this it is necessary to be informed and up to date about regional network partners in order to be able to advise parents comprehensively, as well as to include them in the planning of a support network.
- The evaluation of networking performance should be defined individually as well as structurally, and should fundamentally be inclusive of all parties

THE TEAM DUALITY: CARE AND SELF-CARE

10

Perinatal-palliative care is particularly challenging both personally and existentially. It therefore requires both appreciative respect and special support. Optimal support for the patients and relatives will only be possible if the resources of the team members are effectively strengthened and their resilience is fostered.

Implementation

- The team works daily in the stressful, demanding realm between life and death.
- In order to take good care of the patients and families entrusted to them it is necessary to recognize one's own needs and to take them seriously. Only those who take good care of themselves can continue to take good care of others.
- High quality palliative care and grief counseling also require professional objectivity in order to assess the needs of the child and family and to be able to take appropriate action. Palliative support personnel should establish sufficient closeness to allow trust, but nevertheless maintain adequate perspective and a sense of boundary in order to recognize their own limitations.
- The team members' demeanor towards each other is characterized by solidarity, mutual regard, trust and critical self-examination.
- The team members should be involved in the development and planning of therapeutic options. A shared understanding of the different points of view lessens the moral stress. This equally suggests that every team member has the right to initiate a discussion about therapeutic goals.
- Regularly held discussion forums within the institution help give every team member the opportunity to address things that have occurred in a constructive, respectful and empathetic manner. Within the team, attention should be given to monitoring that each member remains able to cope with the strain of caring for dead and dying children, as well as for their families. Whenever this tolerance is exceeded the responsibility should be assumed by another team member.
- Rituals and the development of a "Abschiedskultur" (farewell culture) offer support and orientation to employees dealing with stressful and extreme situations.
- Both professional and personal interaction, as well as continued education and supervision contribute to professional self-care.

- Selected members of the team should hold special qualifications, as well as have reflected upon their own attitudes towards death, dying, separation and grief in order to support inexperienced or overwhelmed colleagues. These special support persons are available on site and easily approached, offering accessible help and early intervention.
- Each team member has the obligation not only to take care of himself, but also to look out for other team members. This includes an active rest break culture as well as opportunities to recuperate after palliative care or grief counseling.
- The institution and the facility have an obligation to provide the necessary personnel, space and organizational resources to allow these requirements to be implemented.



EPILOGUE - THE CENTRAL SIGNIFICANCE OF COMPOSURE

- Appropriate behavior within a palliative setting is grounded in specific views about life, which, in their entirety, we refer to as „composure“.
- ✗ Composure is based upon values and experience which every human being possesses and which are not necessarily associated with academic qualifications.
- ✗ Composure evolves throughout one's life.
- ✗ Composure is an inner compass that provides orientation.
- ✗ Composure is a question of inner clarity, especially in dealing with suffering.
- ✗ The examination of one's own composure and that of others is fundamental to good cooperability.
- For our work in palliative situations this means:
 - ✗ The reference point of our actions are the needs of the ailing children and their families.
 - ✗ We don't give the parents preformed answers, but alternative options for action in such a way, that they can make their own choices.
 - ✗ We strive to provide care and support for the children and their families, which comprehensively enables their autonomy, especially their self-determination.
 - ✗ We are aware of the central importance of relationships in the familial structure.
 - ✗ We recognize and respect the values, needs, wishes, hopes and rights of all family members involved.
 - ✗ We value the skills and experience of parents in caring for and accompanying their ailing children and involve them in this process. In doing so we identify the personal resources of the families.
 - ✗ We trust in our expertise and competence, while maintaining an open, questioning attitude. It is an attitude that reveals a great deal of knowledge about the nature of that which is being experienced, yet little about the history, the circumstances, the surroundings or the life perspectives of those undergoing the experiences.
 - ✗ We distinguish between compassion and commiseration.

- ✗ We listen attentively.
- ✗ We communicate at eye level.
- ✗ We speak in simple, understandable language, carefully and in appropriate detail.
- ✗ We recognize our own limitations and communicate them within the team.
- ✗ We are aware of our values, and we self-examine them and our actions critically.
- ✗ We respectfully acknowledge that it is the parents who will live with the impact of their decisions and not us.

Useful information about the PaluTiN project



The intention to develop recommendations for palliative care and grief counseling in perinatology and neonatology under the auspices of our organization emerged, as so often happens, during an annual conference of the German Society of Neonatology and pediatric intensive-care medicine (GNPI).

Having set this goal, representatives of the professions involved in this subject, as well as involved parents, were persuaded to participate, thereby founding the PaluTiN working group. The term „PaluTiN“ is a German acronym for palliative care and grief counseling in perinatology and neonatology.

The cooperation of the panel of experts was based on mutual esteem, constructive cooperation and high level of motivation. The result is now available to you and we are proud to be able to say that it contains the expertise, the experience and the high expectations for clearly formulated recommendations from all of the group participants, which can hopefully be of value to you.

The bibliography and further publications concerning this specific field can be found at www.fruehgeborene.de/fuer-fachleute/palliativversorgung-und-trauerbegleitung .

We are looking forward to your feedback!

Your national association Bundesverband „Das frühgeborene Kind“ e.V.

Contributors to the PaluTiN working group



Dr. med. Lars Garten

Neonatologist, palliative care physician, senior Physician at the Clinic for Neonatology and Head of the Palliative Neonatology Team at the Charité University Hospital, Berlin



Marcel Globisch, M.A.

Sociologist, Department Head for Content and Development at the German Children's Hospice Association, Head of the Division for Hospice Work and Palliative Care for Children of the German Hospice and Palliative Care Association



Kerstin von der Hude

Psychosocial parent counselor in neonatology and member of the neonatology palliative team at the Charité University Hospital, Berlin. Systemic couple and family counselor (DGSG), ethics counselor in health care (AEM), grief counselor.



Karin Jäkel

Orphaned mother of an extremely premature twin child, senior lecturer for protestant religious education, founding member and board member of the regional association „Früh- und Risikogeborene Kinder Rheinland-Pfalz“ e.V. (Premature and At-Risk Born Children Rhineland-Palatinate)



Dr. med. Kathrin Knochel

Palliative care physician and ethics consultant at the Children's Palliative Center Munich, Dr. von Haunersches Children's Hospital, University Hospital of Munich



Prof. Dr. med. Dipl. Soz. Tanja Krones

Head Physician for Clinical Ethics at the University of Zurich Hospital/University of Zurich, President of the International Society for Advance Care Planning, Member of the Board of the Central Ethics Commission of the German Medical Association



Tatjana Nicin

Midwife, Representative of the German Midwifery Association, Dipl. Educator for Special Needs, IBCLC Breastfeeding and Lactation Consultant, Nursing Department of Obstetrics in the Hanau Clinic



Dr. Franziska Offermann

1st Chairwoman of the Federal Association of Orphaned Parents and Mourning Siblings in Germany (VEID), grief counselor (BVT), trauma consultant (DeGPT/BAG-TP), yoga teacher, coach



Monika Schindler

Specialist pediatric nurse, M.Sc. (Palliative Care), nursing director neonatology and pediatric intensive care unit, University Hospital of Mannheim



Prof. Dr. med. Uwe Schneider,

Specialist in gynecology and obstetrics, perinatal physician, Professor of Prenatal Diagnostics and Fetal Physiology and Senior Physician of the Clinic for Obstetrics at the University Hospital of Jena



Beatrix Schubert

Theologian (catholic theology), since 2004 pastoral assistant in the clinic pastoral care station at the University Hospital of Tübingen, responsible for the Women's Hospital and the Department of Neonatology of the Children's Hospital



Dr. med. Thomas Strahleck

Neonatologist, palliative care physician, clinical ethics consultant, crisis resources management instructor, senior physician in Pediatrics 4 at the Stuttgart Olga Hospital

Contact Information

Bundesverband
„Das frühgeborene Kind“ e.V.
Frühgeborenen Informations Zentrum
Darmstädter Landstraße 213
60598 Frankfurt am Main

Germany

Tel: +49 (0)69-587 009 90

Fax: +49 (0)69-587 009 99

Mail: info@fruehgeborene.de

Internet: www.fruehgeborene.de

Hotline for Germany

nationwide toll-free service number

0800 - 875 877 0

Monday, Tuesday, Thursday and Friday

from 9.00 AM to 12.00 AM

Wednesday

from 4.00 PM to 7.00 PM

With friendly support*:



*We thank the health insurance KKH for the financial support to develop and print the PaluTiN-Recommendations in German language and the health insurance BAHN-BKK for the financial support to translate and print the PaluTiN-Recommendations in English language.