Paediatric palliative care

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Inhoudsopgave

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summary

In November 2022, the revised version of the Dutch evidence-based guideline for paediatric palliative care was published. In this guideline, recommendations are provided on different topics related to paediatric palliative care, including symptom treatment, advance care planning and shared decision-making, organization of care, psychosocial care, and preloss and bereavement care. An overview of the complete guideline methodology and included topics is provided in 'Palliative care for children: methodology for the development of a national clinical practice guideline' [van Teunenbroek 2023].

Recommendations on symptoms

Here, we provide all translated recommendations on the diagnosis, (non-)pharmacological treatment, and evaluation of the following symptoms: anxiety & depression, delirium, dyspnoea, haematological symptoms, coughing, skin complaints, nausea & vomiting, neurological symptoms, pain, death rattle and fatigue. Furthermore, we provide recommendations on paediatric palliative sedation, and forgoing hydration & nutrition including communication, preparation, execution, and evaluation.

The recommendations are based upon evidence (if available), clinical expertise, and patient and family values. The strength of each recommendation is graded according to published evidence-based methods and categorised as strong to do (green), moderate to do (yellow) or strong not to do (red).

For (non-)pharmacological treatment of symptoms, the evidence-based recommendations have been published in the paper entitled 'A Dutch Paediatric palliative care guideline: a systematic review and evidence-based recommendations for symptom treatment' [van Teunenbroek 2024]. This paper provides an overview of the identified evidence, key considerations and recommendations for symptom treatment.

Recommendations on advance care planning, shared decision-making, and psychosocial care including preloss and bereavement care

The translated recommendations on Advance Care planning, shared decision-making, psychosocial care, and preloss and bereavement care will be published here as soon as possible.

Referenties

van Teunenbroek KC, Kremer LCM, Verhagen AAE, Verheijden JMA, Rippen H, Borggreve BCM, et al. Palliative care for children: methodology for the development of a national clinical practice guideline. BMC Palliative Care. 2023;22(1):193.

van Teunenbroek KC, Mulder RL, Ahout IML, Bindels-de Heus K, Delsman-van Gelder CM, Galimont-Collen AFS, et al. A Dutch paediatric palliative care guideline: a systematic review and evidence-based recommendations for symptom treatment. BMC Palliat Care. 2024;23(1):72.

General recommendations

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Beyond the specific recommendations given in this guideline under the relevant topics, there are general recommendations that are important in any palliative course, and at any stage of the child's illness. Therefore, they are repeated separately here.

General

DO	• Always use an individualised care plan, provided the child and parents have consented to the plan. • Should questions arise, consult colleagues with expertise in palliative care.

Communication

DO	• Provide clear information at the right time throughout the palliative process.
	• Actively listen to the child and parents/family, consult and decide together if possible.
	• Take into account:
	  ◦ Needs and wishes of child and family
	  ◦ Siblings
	  ◦ Physical, psychological, social, and spiritual impact
	  ◦ Cultural background
	• Keep in mind that how (bad) news is communicated to child and family often determines the course of communication and shared decision-making in the palliative process.
	• Offer ACP conversations as a standard part of care for all children with a palliative diagnosis and their families.

Consider	• The use of sound and video recordings for all important discussions so the child and family can listen back to the conversation.

Treatment

DO	• Always keep in mind that involving additional caregivers in the home or in the hospital may be perceived as burdensome by the child and family. • Evaluate the effect and side effects of each treatment at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Advance Care Planning & Shared Decision-making

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Advance Care Planning

DO	• Offer ACP conversations as a standard part of care for all children with a palliative diagnosis and their families. In doing so, consider the specific situation and burden bearing capacity of child and family. • Integrate ACP as a continuous and dynamic process in the care of child and family from diagnosis through the end of life by holding regular conversations. • Start ACP conversations early in the disease process to encourage acceptance and allow space to prepare for the future. • Hold timely discussions with the child and family when the need to prepare for specific scenarios increases, as the child's condition deteriorates or when the child approaches end of life. • Provide explanations and written information to child and family to prepare for an ACP conversation and provide opportunities to include others they may wish to have present during the conversations. • Include the content of ACP conversations and any treatment arrangements in the medical record. • Have a health care provider trusted by the child and family lead the ACP conversations. This may be the primary caregiver, or another trusted caregiver, such as a case manager, or a caregiver outside the treatment team trained in ACP conversations. • When preparing and conducting ACP conversations, use a conversation guide to provide structure and to ensure relevant topics are covered. • Structure the ACP process through preparation, interviewing and reporting. • Discover, discuss and note in the ACP process what the child and family's values, goals and preferences are for future care and treatment medically, psychologically, spiritually and socially. • With the consent of parents and child, share specific treatment agreements with all health care providers involved.

Shared Decision-making

DO	• Think ahead of time what treatment decision(s) must be made in the short and longer term and how you will explain the need for these decisions to child and/or parents. • Consider in advance what (treatment) options are available and how you will explain them in a way that the child and/or parents can understand. • Consider in advance how many conversations you think you will need to come to a decision and within what time frame you would prefer to have these conversations. Explain this to the child and parents. • Start the conversation with an agenda and ask the child and/or his parents what they want to discuss. • During the conversation, strike a good balance between the information you give and the information you want to receive from the child and/or his parents. • Explain the advantages and disadvantages of the treatment options clearly and concretely. This includes the option to “wait and see” and the option to forgo further curative or life-sustaining treatments and focus entirely on comfort care. • Give the child and/or his parents the opportunity to ask questions about the various treatment options and to share their views and experiences. • Consult with the child and/or parents as to their preference and, if asked, explain your preference as well. • Come to a decision that all involved are comfortable with and summarise it. Prevent the child and/or his parents from feeling too burdened by the responsibility of this decision. • Involve the child even if he or she is under 12. Do this in a way that is developmentally appropriate. This also applies to the words you choose.

Roles of child, family and caregivers in ACP and shared decision-making

DO	• Involve child and family in framing ACP and shared decision-making in terms of form, content, preferred place, time and stakeholders and tailor this process to their needs. • Involve the (perspective of the) child in ACP conversations and shared decision-making in accordance with the child's developmental age. • In the ACP process and in shared decision-making, recognize the child and family as experts in living with illness and in assessing their quality of life. Ensure your actions reflect due consideration for the knowledge and experiences of child and family.

Communication skills during ACP and shared decision-making

DO	• Regularly provide child and family with clear and honest information about diagnosis, prognosis, treatment and uncertainties surrounding the child's situation throughout the disease process. Match this information to their (language) abilities and needs. • Use specific communication skills such as exploratory listening, acknowledging emotions, using concrete, appropriate and clear language, and formulating value-based goals during ACP conversations and shared decision-making. • During ACP conversations and shared decision-making, consider the communication preferences and cultural, religious and philosophical beliefs of child and family (see also: cultural, spiritual and religious support). • Be aware in your preparation and during ACP conversations and shared decision-making that these discussions can be perceived as very difficult by the child and family. Do this by exploring child and family attitudes toward ACP and responding empathetically to their emotions without making the emotions the focus.

Psychosocial care

Vastgesteld: 23-05-2025 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

This chapter is subdivided into subchapters and/or sections. To view the content, click on the subchapter and/or section title in the left-hand column.

Psychological interventions

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Psychological interventions

DO	• The primary health care provider is responsible for initiating psychosocial care, but other caregivers can also identify and draw attention to the need for psychosocial care. The interpretation of psychosocial care takes place in consultation with the child, family and multidisciplinary team.
	• Provide clear information to child and family (including siblings) about the emotional consequences that may be appropriate for the syndrome.
	• Be alert that child and family (including siblings) may have problems in the areas of:
	  ◦ Social emotional development.
	  ◦ Cognitive development.
	  ◦ Mental health.
	• Be aware that it is important for a child to have the space and opportunities in activities and conversations to be able to express himself/herself appropriate to his/her developmental stage about the experience of his/her illness and impending death. Note that there may be developmental differences in emotional responses, experiences and understanding of death.
	• If emotional burden persists, refer child and family to expert psychosocial care services to help with the processing of profound experiences and stress, and assist with coping and building resilience. Consider a medical pedagogical employee, medical social worker or a psychologist. To provide support for religious and spiritual suffering and answer questions on meaning, a spiritual caregiver may be consulted.
	• Actively monitor the well-being of siblings and provide appropriate support including practical and social support, educational, psychological or cultural, spiritual and religious support.
	• Keep in mind that other family members (e.g. grandparents) and loved ones (e.g. friends, boyfriends or girlfriends) who are important to the child and family may need support including practical and social support, educational, psychological or cultural, spiritual and religious support. Be aware that emotions of other family members and loved ones may also have a significant effect on child and family.
	• Respond promptly to rapid changes in the child's condition, who may need rapid access to psychosocial support including practical and social support, educational, psychological or cultural, spiritual and religious support.

Social and practical support

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Social and practical support

DO	• The primary health care provider is responsible for initiating psychosocial care, but other caregivers can also identify and draw attention to the need for psychosocial care. The interpretation of psychosocial care is made in consultation with the child, family and multidisciplinary team.
	• Strive for as much continuity in care providers as possible. Keep in mind that this is important for confidence in the care and provides peace of mind for children and their parents or health care proivders.
	• When having conversations with child and parents, such as when changes in the course of illness occur, it is important to:
	  ◦ Allow time and space for emotions.
	  ◦ Provide honest and open information appropriate for the child and family. Also provide space for those who do not want to know.
	  ◦ Establish what the parents and child already know.
	• With changes in the course of illness, give parents the opportunity and space to reflect with caregivers on how they will communicate with the child and siblings. Help parents by creating this space.
	• Inform parents about potentially confrontational questions that child, siblings may ask. Explain that parents do not have to have ready answers and can use the questions to find out more about what is on the child, sibling's mind. Explain that parents do not have to hide their emotions from their child(ren). Children are usually perceptive to the feelings of their loved ones so hiding emotions can be confusing for a child. Explain to parents that they can explain to their children that they are grieving and can remain available to them.
	• Be alert that children and parents have different needs regarding social and practical support and that these needs may change during the course of the illness. This may include the following:
	  ◦ Social support including attention to parenting, relationship with spouse or partner or sibling support. If necessary, involve a (medical) social worker, a medical pedagogical employee, psychologist or spiritual counsellor. Also refer to peer to peer contact groups if necessary.
	  ◦ Material support including housing, home modifications, aids for medication administration or mobility and transportation.
	  ◦ Practical support such as access to respite care, attention to the work situation of parents or attention to the wishes of the child, family and loved ones. If necessary, engage wish foundations such as Make a Wish, Make a Memory, Living Memories Foundation.
	  ◦ Educational support including attention to educational facilities at home and in the hospital.
	  ◦ Financial support including attention to financial and organizational issues.
	• Be alert that caregivers may also need social and practical support and spiritual support.
	• Discuss necessary practical arrangements with parents or caregivers after their child's death and provide them with written information. Emphasise that things may feel different after death and that arrangements can always be adjusted. These may include arrangements regarding:
	  ◦ Care of the body.
	  ◦ Funeral preparations.
	  ◦ Postmortem examination.
	  ◦ Relevant legal considerations, including:
	  ▪ The involvement of a 'child death overview panel'.
	  ▪ Mandatory notification of the coroner after death.
	  ▪ Determination of the death.

Cultural, spiritual and religious support

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Cultural, spiritual and religious support

DO	• In discussions with children and their parents, investigate whether there are aspects of their religious or philosophical beliefs that should be taken into account in care, especially in decision-making about treatment options. • Ask about the uniqueness and specialness of the child and the specific meaning-making of parents, especially with regard to their child's quality of life and his or her place in the family. • Explore whether children and their parents would like to talk to someone about their beliefs and values (e.g., religious, spiritual or cultural). Refer to a spiritual counsellor for this purpose, if necessary. • Take into account and enquire about what rituals are performed and what needs the children and parents may have, especially in the terminal phase. • Be open to spiritual experiences that may play a role in children and families without being linked to religion or a philosophical framework. Ask what is meaningful, and important to them at this time. • Be alert to the influence of culture and, if parents wish, include their family or other people in their network in communication around decision making, as they may otherwise exert an unseen influence on the decision-making process. • Be open to the fact that parents have the right to "consciously not want to know'. Also provide space when parents want to know more. • Be aware that certain terminology can create misunderstandings. For example, "We are going to discontinue treatment" suggests that treatment is available, but is being withheld from this child. • Be aware that in many cultures the child's spiritual well-being takes precedence over the importance of hearing the truth and that for religious reasons it may be difficult for parents to agree to discontinue treatment. • Keep in mind that if parents hold out hope for a good outcome until the end it does not mean that they have not heard or understood the bad news. • Engage a spiritual counsellor when uncertain about the appropriate approach to people of a different culture or religion or for information about performing rituals.

Preloss and bereavement care

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Preloss and bereavement care for parents

DO	• The primary care provider is responsible for initiating bereavement care conversations. In consultation with child, family and multidisciplinary team including primary care providers, it is ensured that the desired bereavement care conversations take place. • Loss is what parents experience as loss; this can vary from person to person. Be alert to loss experiences from the time the child is suspected of a serious condition until well after the child's death. • Be alert to parents' experiences of loss, even some professional interventions may feel like a step backwards to parents and thus a loss. Provide support if parents need it. • During the end of life of their child and in crisis situations, parents usually try to remain strong to support their child and to cope with the situation. During this period, parents may deeply suppress their own emotions. Assist and support parents to cope at this time. • Explain to parents what normal grief reactions to expect from themselves and other people. Grief reactions are normal reactions in an abnormal situation. • Offer parents emotional peace of mind during the palliative phase. Designate one or two caregivers who will talk with parents about their feelings of loss and grief if the parents have the capacity to do so. Be sensitive to what the parents need, for example, is their coping more loss-oriented or recovery-oriented. Other caregivers can keep the atmosphere lighter and less serious unless parents initiate a deeper conversation. • Be quick to recognise signals from parents, such as questions or comments, that parents want to talk about loss or deeper concerns. • Whenever possible, discuss parents' wishes, the child's prognosis, and loss at arranged times. This ensures that parents know when to prepare emotionally for such a conversation and when parents should not expect it. • Make parents feel safe and secure in their child's palliative journey by: seeing and acknowledging the child, approaching parents as equal partners, not making decisions apart from parents, and keeping parents fully informed. • Actively offer initiatives or information to parents about possible support in terms of choices that can be made, making memories, loss and grief, and support options for parent and family. • Discuss how parents want to say goodbye to their child. Consider cultural differences. Discuss whether there are religious aspects that are important in dealing with loss and mourning and what caregivers can do/contribute in that regard. • Prepare parents for winding down and stopping support from regular caregivers and transferring care. Ensure that parents continue to feel supported immediately after the death and the ensuing bereavement period, and that parents know how they can access additional support. • Provide space for parents to have multiple bereavement conversations with caregivers who were involved in their child's care before, during and after death. Because children receive care and treatment in different settings, this may require multiple conversations with different caregivers. Ensure the presence of familiar caregivers who can reflect on the child's life and identity, answer questions, and go through the illness and death process and the process of decision-making.

Preloss and bereavement care for children

DO	• Explore with parents whether or not and how they want to talk to their children about the approaching end of life and death. • Explain to children in developmentally appropriate ways what is going on and what will happen. • Give the child the opportunity to talk about their emotions and feelings to a trusted adult outside the family. • Involve siblings at the time of death by giving them a meaningful task appropriate to their developmental age and level of responsibility. • Help children regulate and normalise emotions by assigning words to behavioural expressions of emotions. • Help siblings find a way to adequately express their emotions. • Children grieve intermittently. At times they experience the loss and at other times the loss does not exist for a while. Support children in this and also accept that children quickly turn their attention to other activities. • Children's conceptualisation of death changes and develops as they mature. As a result, after several months or years, a child may have to process new aspects of their grief and new questions may arise.

Symptoms

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Anxiety and depression

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Diagnostics of anxiety and depression

DO	• Rule out physical causes and delirium and treat these whenever possible. In doing so, be especially the possibility of pain. • In case of acutely severe and/or persistent concerns around anxiety and/or mood, involve registered psychosocial care provider with experience in palliative care.
Consider	• Consider consulting experts with knowledge and experience in palliative care.

General treatment of anxiety and depression

DO	• Discuss with child and family all factors that may influence anxiety and depression in the child (including siblings). • Inform child and family about (counter-)transmission and reinforcement of emotions among themselves. • Discuss the management of emotions for all members of the family. • Fill in gaps in knowledge with child and family, while guarding against providing too much information. • Connect in contact and conversations to the developmental level (cognitive and emotional) of the child and be alert to the existence of discrepancies in development. • Draw up a (psychosocial) care plan together with the child and family, using Advance Care Planning. Support parents in prioritising care. • Organise a day/week structure with attention to rituals, emotion-oriented activities and activities that are "as normal as possible" (recovery-oriented).
Consider	• Consider exploring their understanding of the child's death. • Consider distinguishing between existential themes, normal appropriate reactions (requiring help) and the possible existence of psychiatric disorders.

Treatment of cause of anxiety and depression

DO	• Treat physical causes whenever possible:
	  ◦ Treat pain that is inadequately controlled.
	  ◦ Discontinue or modify medications that cause or worsen anxiety and/or depression.

Non-pharmacological treatment of anxiety and depression

DO	• Provide psychoeducation about the symptoms. • Organise a day/week structure with attention to rituals, emotion-focused activities and activities that are "as normal as possible" (recovery-oriented). • Involve a registered psychosocial counsellor with experience in palliative care when deploying counselling or treatment.
Consider	• For anxiety, consider engaging experts in self-management in the form of mindfulness, relaxation, self-hypnosis or guided fantasy.

Pharmacological treatment of anxiety and depression

Pharmacological treatment of anxiety

DO	• Discuss the use and initiation of medication with a child psychiatrist experienced in palliative care or a paediatrician. • When initiating medication, consider whether supporting psychotherapy is appropriate and feasible.
Consider	• For anxiety reduction in dying children, consider intranasal midazolam. • For acute anxiety, consider intranasal midazolam or oral lorazepam. • For acute anxiety in paediatric delirium or psychotic dysregulation, consider antipsychotics (risperidone, haloperidol).

Pharmacological treatment of depression

Consider	• Use of medication in consultation with a child psychiatrist experienced in palliative care or a paediatrician. • When using medication, consider whether supportive psychological therapy is appropriate and feasible. • For moderate to severe depression in children 8 years and older, consider fluoxetine. • Consider SSRIs especially for children with cancer. • Consider methylphenidate.
DO NOT	• Administer TCAs because of the potential for serious adverse effects and the need for determinations of blood levels.

Evaluation of anxiety and depression

DO	• Evaluate the effect and side effects of treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Coughing

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Diagnostics of coughing

DO	• Take a history and perform careful physical examination.
Consider	• Consider additional investigations aimed at your differential diagnosis, keeping in mind therapeutic implications and burden on the child. • Consider sputum culture if infection is suspected. • Consider imaging studies if they have therapeutic implications. • Consider speech therapy assessment for safety and effectiveness of swallowing.

Treatment of cause of cough

DO	• Treat underlying asthma with airway dilators and/or inhaled steroids.
Consider	• In case of (suspected) bacterial infection, consider antibiotics. • For interstitial lung disease, consider corticosteroids. • For support in gastroesophageal reflux, consider raising the head of the bed. • For clinical signs of gastroesophageal reflux, consider acid inhibition or (trial treatment with a) prokinetic. • In cases of swallowing disorders, consider thickening nutrition or starting tube feeding. • In children with tube feeding, consider reducing portions, increasing feeding time or setting feeding time to continuous. • In pleural fluid, consider pleural puncture and (temporary) drainage. • In localised lesions, consider radiotherapy or chemotherapy. • In case of central lower airway obstruction, consider stent placement. • In case of side effects (hypersalivation), consider change of medication. • In heart failure, consider diuretics. • In case of posterior drooling, consider consultation with specialist on drug and possible surgical treatment options including pros and cons for the child.

Treatment of rib fractures caused by coughing

Consider	• Consider the advice of a physical therapist or bandage therapist for rib fractures caused by coughing and if analgesia is ineffective.

Non-pharmacological treatment of coughing

Postural advice

Consider	• If coughing is productive, consider placing the child in a sitting or standing position.

Physical therapy techniques for sputum mobilisation

Consider	• Apply physical therapy techniques for sputum mobilization such as breathing exercises, air stacking, compression, cough machine "cough assist," postural drainage, PEP, and huffing. • Discuss with child and parents that physical therapy techniques should be discontinued if the child continues to weaken, and treatment becomes too burdensome.

Pharmacological treatment of cough

Non-opioids

Consider	• If coughing is nocturnal, consider administering honey or dextromethorphan.

Opioids

DO	• Start opioids orally or parenteral if coughing causes discomfort. Here, morphine is the first choice.
Consider	• Consider noscapine or codeine. Effect has not been demonstrated in cough.

Nebulisation with saline or cold steam

Consider	• Consider nebulisation with physiological or hypertonic saline or cold steam.

Evaluation of coughing

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Death rattle

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Diagnostics of death rattle

Consider	• Consider establishing death rattle based on observations. • If in doubt, consider performing physical examination for further causes such as airway compression, corpus alienum, pulmonary oedema or pneumonia. • If in doubt, consider confirming mucous stasis by having the child cough or huff. Only if the child is still able to do so and this is not too burdensome.

General treatment of death rattle

DO	• Discuss before the terminal phase what death rattle is and explain to those involved that it is not uncomfortable for the child. Repeat this information at the time that the death rattle occurs. • Explain that the death rattle is a normal symptom in the dying process. • Repeat this information at the time the death rattle occurs.

Non-pharmacological treatment of death rattle

Suctioning

DO NOT	• Avoid suctioning in the case of death rattle in the terminal phase given the additional discomfort.

Body position

Consider	• Consider lateral position and adjusting head positions when feasible.

Reduce fluid intake

No recommendation possible	• Recommendations to adjust the amount of fluid administered to prevent death rattle or facilitate coughing cannot be given due to lack of evidence. There appears to be no reason to include death rattle as a factor in determining terminal fluid management.

Pharmacological treatment of death rattle

Anticholinergic agents

Consider	• Standard medication does not seem appropriate. Should relatives wish to do so, anticholinergic agents ((butyl)scopolamine, glycopyrronium, and atropine) may be considered.

Evaluation of death rattle

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Delirium

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Diagnostics of delirium

DO	• Engage parents and involved caregivers to diagnose delirium, especially in the home setting. An important question is: Does the child show the behaviours recognisable to the child?
Consider	• Consider consultation with a child and adolescent psychiatrist before making the diagnosis. • In the home situation, consider low threshold use of observation lists CAP-D, SOS-PD and PAED. • With signs of apathy, consider diagnosis of hypoactive delirium.

Treatment of cause of delirium

DO	• Screen critically ill children daily for modifiable risk factors and treat them.

Non-pharmacological treatment of delirium

DO	• Deploy, whenever possible, non-medical interventions focused on prevention, orientation, communication, matching stimuli, and safety to treat paediatric delirium. • Involve parents in the child's care as much as possible. • Delirium is an intense experience for all involved. Provide adequate (after) care for the child and family, environment, and caregivers (in the form of training).

Pharmacological treatment of delirium

Drug treatment for prevention of paediatric delirium

No recommendation possible	• Opinions on the use of drug treatment for prevention of paediatric delirium, for example with antipsychotics, cannot be substantiated due to lack of evidence.

Antipsychotics (haloperidol, risperidone, and quetiapine)

Consider	• In children with delirium, consider treatment with medication if non-drug interventions do not have a sufficiently rapid effect. • Depending on the adverse effects profile, drug interactions and available routes of administration, a choice may be made between risperidone or haloperidol. • In case of non-response or adverse reaction to first administered drug (haloperidol or risperidone), consider switching drugs or administering quetiapine. • When starting antipsychotics, be alert to side effects including extrapyramidal symptoms and prolongation of QT interval. • For severe acute dystonia as a side effect of medication requiring treatment, consider biperidene.

Benzodiazepines

Consider	• In children in the terminal phase with refractory delirium, consider palliative sedation.

Evaluation of delirium

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Dyspnoea

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Diagnostics of dyspnoea

DO	• In children between 6 and 18 years of age, use a VAS or NRS scale to estimate the degree of dyspnoea or evaluate interventions. • In children under 6 years of age or those with (severe) intellectual disabilities, ask representatives (parents and caregivers) to use a VAS or NRS scale to estimate the degree of dyspnoea or evaluate interventions.

Consider	• The following additional testing if it has therapeutic implications:
	  ◦ Measurement of respiratory rate, oxygen saturation using pulse oximeter or the number of words that can be said on one breath.
	  ◦ Laboratory examination (haemoglobin, blood gas).
	  ◦ Additional X-ray examination, pulmonary function tests, bronchoscopy.

Treatment of cause of dyspnoea

Consider	• In case of dyspnoea due to growth of primary tumour, pleural fluid or metastases, consider radiotherapy or chemotherapy. • In cases of local airway obstruction, consider tracheotomy, stent placement, or in specific cases, intraluminal treatment (laser, cauterisation). • Consider treatment of infection or other comorbidities such as asthma, arrhythmias, reflux, drainage of fluid collections in pleura, pericardium or peritoneum, pneumothorax. • In case of anaemia, consider blood transfusion at Hb < 5 mmol/l (see: erythrocyte transfusion - hematologic manifestations).

Non-pharmacological treatment of dyspnoea

High-intensity training

No recommendation possible	• High-intensity training appears to have no effect on dyspnoea compared with low-intensity training. The application of high-intensity training cannot be substantiated. Therefore, giving a recommendation is not possible.

Physical therapy techniques

DO	• Provide information and advice on breathing exercises and other physical therapy techniques (see also: Coughing - physical therapy techniques for sputum mobilisation).
Consider	• Consider employing a physical therapist to apply physical therapy techniques, such as breathing exercises and alternating positions (see also: Coughing - physical therapy techniques for sputum mobilisation).

Non-invasive ventilation

Consider	• In cases of dyspnoea due to Cystic Fibrosis, consider non-invasive ventilation.

Use of a ventilator

Consider	• Consider the use of a 'hand-held' fan to cool the face.

Oxygen

Consider	• Consider administering oxygen as a trial treatment. Stop administering oxygen if it does not work.

Relaxation and distraction techniques

DO	• Create a calm environment.
Consider	• Consider bringing in experts for self-hypnosis. • Consider relaxation and distraction techniques and the use of comfort talk.

Pharmacological treatment of dyspnoea

Opioids and benzodiazepines

DO	• Give fentanyl nasal spray intranasally for rapid treatment and anxiety reduction. • Start morphine orally, intravenously, or subcutaneously if the shortness of breath causes discomfort.
Consider	• Consider lorazepam or midazolam (in combination with morphine) to reduce perceived discomfort, especially if anxiety is also present.

Corticosteroids, dilators and mucolytics

Consider	• In cases of dyspnoea arising from airway swelling, atelectasis or broncho-obstruction, consider dexamethasone, other steroids, pulmonary dilators or mucolytics.

Treatment of refractory dyspnoea

Consider	• In terminally ill children with refractory dyspnoea, consider palliative sedation (see: palliative sedation).

Evaluation of dyspnoea

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Fatigue

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

Diagnostics of fatigue

Anamnesis, physical examination, additional investigations

DO	• Perform a complete history including sleep anamnesis and physical examination for quality of life and treatable causes of fatigue. Use the bio psychosocial model as a starting point.
Consider	• Consider performing diagnostics for treatable causes of fatigue. • Consider using an instrument to gain insight into what is important to the child and contributes to the child's quality of life. • For further diagnostics related to sleep, consider referral to a specialised sleep centre if there are clinical reasons for this.

Measurement tools for assessing the degree and dimensions of fatigue

DO	• Use the PedsQL Multidimensional Fatigue Scale to assess the dimensions and degree of fatigue in children between 2 and 18 years of age. • Use a Visual Analogue scale to readily monitor fatigue in children during the period of stable disease.
Consider	• Consider using a Visual Analogue scale with faces to map fatigue for children with intellectual disabilities.
DO NOT	• Use of the PEDS FACIT-F is not recommended.

General treatment of fatigue

DO	• Provide education about the consequences of reported/measured fatigue, the factors that may affect its severity, and the possibilities and impossibilities for alleviating or reducing fatigue. • Repeat this conversation as needed. • If possible, support the education with written advice and instruction. • When choosing treatment, connect to modifiable triggering and/or maintaining factors that play a role in fatigue and fit the parents' and child's request for help and expectations. • Establish treatment according to the principle of "the right care in the right place". That is, provide treatment and support close to home where possible, supplemented by remote expertise where needed.
Consider	• Consider using a discussion tool (e.g. child and adolescent tool My Positive Health) as a tool for choice of treatment to gain insight into what child and parents find important.

Treatment of cause of fatigue

DO	• Treat electrolyte disorders, metabolic disturbances, dehydration, malnutrition. • Treat comorbidities, such as asthma and/or bacterial infections, pain and itching. • With underlying depression, discuss therapeutic support. With underlying depression, discuss therapeutic support. • For sleep disorders, promote strategies for regular sleep/wake rhythms. • Avoid stimulants, such as caffeinated beverages. • Recommend relaxation and distraction activities.

Consider	• With weight loss, consider treating the underlying cause. • If Hb < 5, consider blood transfusion. • In sleep disorders, consider short-term treatment with short-acting benzodiazepines. • Consider remediating potentially fatigue-inducing medications such as psychopharmaceuticals, antihistamines and beta-blockers.

Non-pharmacological treatment of fatigue

Psychoeducation

DO	• Provide psycho education focused on fatigue and strategies for coping with fatigue to the child and parents.
Consider	• Consider referral to a health care provider or psychologist with expertise in treating fatigue.

Lifestyle counselling focused on fatigue

DO	• Offer lifestyle advice aimed at fatigue in the areas of diet, exercise, and sleep. • Emphasise the importance of balancing physical, mental activities, relaxation, and rest in a day.
Consider	• In case of physical fatigue, cognitive fatigue, or functional limitations, consider referral to an occupational therapist for an intervention aimed at optimising the balance between load and load capacity.

Movement

DO	• Advise the child to move daily (out of bed) according to individual (physical) capabilities (including bedridden children). • If desired and physically possible, offer the child an exercise/training program supervised by the (paediatric) physical therapist.
Consider	• Consider consultation or referral to a rehabilitation physician for an integrated (multidisciplinary) approach to fatigue and functional (physical) limitations.

Nutrition

DO	• Recommend nutrition with adequate calories, protein and other nutrients to support energy needs during (exercise) intervention.
Consider	• Consider diagnosis and treatment of nutritional deficiencies because they may contribute to fatigue. • Consider referral to a dietitian.

Sleep and sleep hygiene

DO	• Offer advice on sleep hygiene to create optimal conditions for good sleep.
Consider	• Consider offering the child and parents, e-health interventions focused on fatigue.

Pharmacological treatment of fatigue

DO	• Keep in mind that there is no scientific evidence for pharmacological treatment of fatigue. If there is any effect at all, the effect often wears off quickly.

Consider	• In children with a limited life expectancy with fatigue, if treatment options are ineffective or if the aforementioned measures are not feasible, consider treatment with methylphenidate. Keep in mind possible side effects.

Evaluation of fatigue

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Forgoing hydration and nutrition

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

Effect of abstinence from (artificial) fluids and/or nutrition

DO	• Include decision-making about not starting or discontinuing (artificial) fluids and/or nutrition in Advance Care Planning conversations. • In preparation for the last phase of life, communicate with parents on the topic of (artificial) fluid and/or nutrition abstinence. • Clarify with child (if possible) and parents that not starting, reducing or discontinuing (artificial) fluids and/or nutrition at the end of life is part of the natural process. • With refractory symptoms, weigh the pros and cons of not starting or discontinuing (artificial) fluids and/or nutrition. • Reduce or discontinue (artificial) fluids and/or nutrition if the child experiences discomfort as a result. • Continue to confirm that not starting or discontinuing (artificial) fluids and/or nutrition is in the child's best interest and that the child is not suffering extra. • Discuss the joint assessment of signs of discomfort, whether based on a specific scale or not, and agree how to deal with it. • In case of discomfort due to thirst/hunger, discuss to initiate additional sedation. • Continue to give the child good lip and mouth care. • Prepare parents for the changing appearance of the child. • Document the policy around (artificial) fluids and/or feeding in the medical record and individual care plan.
Consider	• Consider comfort feeding if (artificial) fluids and/or nutrition are not started or discontinued. • Consider organising training for caregivers on the responsibility and communication around not starting or discontinuing (artificial) fluids and/or nutrition in the terminal phase.

Key discussion points (artificial) fluid and/or nutrition abstinence (not starting or discontinuing) with parents/child

Topic	Explanation
Comfort	Comfort arising from feeding or from stopping feeding. Comfort of the child comes first.
Change in the child's appearance	Dehydration causes the child's face and body to change.
Duration of the process	Impossible to predict well/precisely. Prediction can possibly be supplemented by indication, for example, if anuria occurs, the kidneys have stopped functioning and it rarely lasts more than a few days.
Care during the process	Although the children often do not show signs of discomfort, it may still be good to continue to perform certain relieving actions: wetting lips, putting drops in eyes if necessary, repositioning the child, etc.
Rethinking	Sometimes during the process the parents feel the need to revisit the considerations that led to the decision about stopping fluids and feeding. Take the time to do so.

Haematological symptoms

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

Diagnostics of haematological symptoms

DO NOT	• Do diagnostics unless it has important therapeutic implications without undue burden on the child.

General treatment of haematological symptoms

DO	• Provide information on causes, symptoms, treatment options and disease course of anaemia, increased bleeding tendency and thrombosis.
	• In children in the palliative phase, always weigh the benefits of treating haematological conditions against the disadvantages and risks.
	• At risk of life-threatening bleeding:
	  ◦ Discuss the possible impact of a life-threatening (pulmonary) haemorrhage with parent(s) and/or child.
	  ◦ Discuss what to do in case of acute severe life-threatening bleeding.
	  ◦ Provide dark towels in the home.
	  ◦ Have an emergency kit at home for acute life-threatening bleeding with instructions on how to act and what medication to administer.

Consider	• In case of wish activities/fulfilment consider active intervention, which is temporarily effective, such as erythrocyte transfusion, platelet transfusion or Fresh Frozen Plasma (FFP) transfusion to reduce the risk of severe bleeding.

Treatment of anaemia

Erythropoietin

DO NOT	• Give erythropoietin in chemotherapy-associated anaemia.

Vitamins & iron

DO NOT	• Give vitamins and nutritional supplements in anaemia if life expectancy is short.

Erythrocyte transfusions

DO	• In children with long-term anaemia with bone marrow failure (e.g., MDS) in the palliative phase, adopt an individual transfusion policy based on perceived quality of life. • In hematologic children with anaemia based on bone marrow failure, give erythrocyte transfusion on an individual basis at an Hb between 4.3-5.0 mmol/L or with symptoms of anaemia.

Treatment of thrombocytopenia

Thrombocyte transfusions

DO	• Adhere to the platelet limits from the national transfusion guideline in palliative procedures (such as placement of an epidural catheter).

Consider	• In children with thrombocytopenia due to production disorder, consider adhering to the transfusion limits from your national transfusion guideline. • Before a particular physical activity with risk of bleeding, consider a platelet transfusion.

Treatment of bleeding

DO	• Treat nasal bleeding with local adrenaline, xylometazoline, spongostan or possibly local coagulation by ENT physician. • Consult with a paediatric surgeon when local bleeding cannot be easily stopped.
Consider	• In bleeding due to thrombocytopathy, consider desmopressin (DDAVP). • For persistent or severe bleeding tendency due to coagulation factor deficiency, consider vitamin K, FFP and/or recombinant factor VII. • In thrombocytopenia and mucosal bleeding (nasal, gum bleeding, menorrhagia) anti-fibrinolytic medication to reduce bleeding tendency. Do not give fibrinolytic drugs in haematuria. • If bleeding occurs, consider platelet transfusion: see section on platelet transfusion.

Treatment of thrombosis

Consider	• Consider giving a DOAC for symptomatic thrombosis.

Evaluation of hematologic symptoms

Consider	• Evaluate the effect and side effects of the instituted treatment at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Nausea and vomiting

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

Diagnostics of nausea and vomiting

DO	• Look for possible causes and treat them. • Weigh up how much a diagnosis is appropriate depending on the child's situation.

General treatment of nausea and vomiting

DO	• Create a calm environment. • Provide information about the possible cause, influencing factors and expected duration of the nausea and vomiting if it is intercurrent. When doing so, also point out the symptoms, consequences and risks of possible dehydration. • Provide information on the purpose, action, possible side effects and proper intake of antiemetics. • Indicate when the effect of treatment can be expected and the reason for adjusting treatment. • Check for anxiety, tension or other psychogenic factors. • Discuss with child and/or parents the role of nutrition in relation to life expectancy and its possible change.

Consider	• In children with severe multiple disabilities, check for obstipation, urinary tract infection or nutrition-related discomfort, and consider causal treatment in combination with:
	  ◦ Gastrointestinal venting,
	  ◦ A lower intake rate and/or lower osmolality of tube feeding,
	  ◦ Feeding via duodenum tube or a jejunostomy,
	  ◦ Reducing total fluid and caloric intake, and/or
	  ◦ Starting prokinetics.
	• In children with severe multiple disabilities, assess for autonomic dysfunction, visceral hyperalgesia and/or central neuropathy and consider drug treatment options such as gabapentin, pregabalin, Tricyclic Antidepressants and clonidine.

Treatment of the cause of nausea and vomiting

DO	• Treat the cause of nausea and vomiting whenever possible.

Non-pharmacological treatment of nausea and vomiting

DO	• Discuss with child and/or parents the role of nutrition and its possible change in relation to life expectancy.
	• Educate about various options when fluids and nutrition are not well tolerated:
	  ◦ Administering smaller portions of oral fluids.
	  ◦ Reduce total amount of nutrition.
	  ◦ Possibly administer tube feeding or parenteral fluids.
	• Provide relaxation and distraction, especially in situations involving anxiety.

Consider	• Consider providing nutritional counselling. Involve a dietitian, if necessary. • If the smell of food leads to symptoms, consider offering cold meals. • Consider having the child suck on ice cubes, crushed ice, or frozen piece of fruit. • In case of decreased gastric motility in children receiving tube feeding, consider, in consultation with an attending physician, a switch to semi-elemental nutrition or blended diet under the guidance of a dietitian. • Consider self-hypnosis for nausea and vomiting in children with cancer.

Pharmacological treatment of nausea and vomiting

Nausea and vomiting with identifiable cause

Consider	• The use of medication for nausea and vomiting requires a rational approach. Base the choice of medication on the main (probable) cause and the pharmacological properties of the medication.

Nausea and vomiting with no apparent cause

Consider	• For nausea and vomiting without identifiable cause or with insufficient effect of causative treatment, consider administration of antiemetics according to the step-by-step plan below (and deviate from the order if necessary): • **Step 1** Consider starting with: 1. A serotonin (5-HT3) antagonist, such as ondansetron; and/or 2. A dopamine (D2)-antagonist, such as domperidone or metoclopramide; and/or 3. An antihistamine such as cyclizine. • **Step 2** Consider adding or substituting agents from the first step with: 1. Dexamethasone. 2. Granisetron (instead of ondansetron). 3. Haloperidol (instead of domperidone or metoclopramide). 4. Chlorpromazine or levomepromazine (instead of cyclizine) • **Step 3** Consider adding: 1. Aprepitant. 2. A cannabis preparation containing dronabinol in consultation with an expert.

Evaluation of nausea and vomiting

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Neurological symptoms

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

This module is divided into sub-modules and/or sections. To view the contents, click on the sub-module and/or section title in the left column.

Epilepsy

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

Diagnostics of epilepsy

DO	• Strive for classification of seizure type and epilepsy syndrome in all children. Involve a (paediatric) neurologist in this effort.
Consider	• As an additional means of diagnosing seizures, consider the use of film recordings by parents or caregivers. • Consider performing an EEG. Keep in mind the child's condition and comfort. • Consider performing blood tests for a possible cause of epilepsy such as hypoglycaemia or electrolyte disturbance. • In children with intellectual disabilities, consider a multidisciplinary approach with a physician experienced in treating children with multiple disabilities, paediatric neurologist and/or behavioural health professional.

Treatment of cause of epilepsy

DO	• Evaluate and if possible, treat triggering factors of seizures, such as electrolyte disturbance.

Non-pharmacological treatment of epilepsy

Ketogenic diet

Consider	• In children with difficult-to-treat epilepsy, consider a ketogenic diet.

Psychological interventions

Consider	• In children with epilepsy, consider psychological interventions such as relaxation or cognitive behavioural therapy.

Pharmacological treatment of epilepsy

Seizure treatment

DO	• In children known to have epilepsy, establish a seizure treatment plan and include any treatment restrictions. • In children with first seizures: most seizures stop spontaneously within 2-3 minutes. After 3 minutes, give seizure treatment according to the step-by-step plan. • Evaluate the effect after each step. • If epilepsy cannot be controlled, consult with a paediatric neurologist.

Maintenance treatment

DO	• Initiate maintenance treatment with antiepileptic drugs if there are multiple seizures or if a seizure is highly likely to recur. Always do this in consultation with a paediatric neurologist.
DO NOT	• Do not start preventive maintenance treatment with antiepileptic drugs in children with neurological disorders of the brain who do not have epileptic seizures.

Treatment of refractory epilepsy

Consider	• In the case of a refractory form of epilepsy from which the child suffers, consider administration of intravenous anaesthetics (see: palliative sedation).

Evaluation of epilepsy

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Movement disorders

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

Diagnostics of movement disorders

DO	• Discuss the possibility of filming movement disorders with parents to support diagnosis. • Consult with a (paediatric) neurologist readily to make the diagnosis.
Consider	• Consider additional diagnostics (including MRI) depending on the situation and condition of the child.

General treatment of movement disorders

DO	• Explain movement disorders to child and/or parents. • Consult with a paediatric neurologist readily about possible treatment options.

Treatment of cause of movement disorders

DO	• Rule out medication as a possible cause of movement disorders.

Non-pharmacological treatment of movement disorders

Treatment aimed at reducing impairments due to movement disorders

Consider	• Check for movement disorder luxating factors such as physical discomfort, constipation, bladder retention, inadequate rest, pain and anxiety. • Consider low-level consultation with a (paediatric) physical therapist, occupational therapist or paediatric rehabilitation physician. • Consider using assistive devices to help the child sit, stand or lie down as optimally as possible.

Pharmacological treatment of movement disorders

Consider	• In acute status dystonicus, consider biperiden. For other acute movement disorders, consult readily with a paediatric neurologist with expertise in movement disorders. • In dystonia, consider treatment with baclofen (see also: spasticity), clonazepam, trihexyphenidyl or gabapentin. • In focal dystonia, consider botulinum toxin A injections in consultation with a paediatric rehabilitation physician (see also: spasticity). • In persistent status dystonia, consider a deep-brain stimulator (surgical).

Evaluation of movement disorders

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Spasticity

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

Diagnostics of spasticity

Consider	• Consider additional diagnostics (MRI cerebrum or myeloma) depending on the situation and condition of the child.

Treatment of cause of spasticity

DO	• Investigate whether there is a cause for increase in spasticity. Treat and (re)assess (after 24 hours) any infection, bladder retention, constipation or non-optimal sitting/lying position.

Non-pharmacological treatment of spasticity

Physical therapy and/or occupational therapy

DO	• Advise the child on optimal supported posture (in standing, sitting and lying down) to promote the child's movement and performance of daily activities and prevent complications of spasticity.
Consider	• Consider using assistive devices and orthoses/ splints to prevent complications due to spasticity and to support movement. • Consider referral to a physical therapist, occupational therapist or rehabilitation physician for treatment and advice focused on (coping with the limitations due to) spasticity.

Pharmacological treatment of spasticity

Baclofen (oral/intrathecal)

DO	• Consult with a paediatric neurologist or paediatric rehabilitation physician for drug options for treatment of spasticity.
Consider	• Consider treatment with baclofen (oral) or in combination with Tizanidine. • Consider an intrathecal baclofen pump.

Benzodiazepines

DO	• Consult with paediatric neurologist or paediatric rehabilitation physician for medication options for treatment of spasticity.
Consider	• For acute painful muscle spasms, consider diazepam. • Consider midazolam when there is a need for sedation or treatment of epilepsy.

Botulinum toxin type A injections

Consider	• In cases of localized spasticity, consider botulinum toxin type A injection in consultation with the rehabilitation physician.

Evaluation of spasticity

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Increased intracranial pressure

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

Diagnostics of increased intracranial pressure

Consider	• Consider additional diagnostics (MRI cerebrum) depending on the situation and condition of the child.

General management of increased intracranial pressure

Consider	• If intracranial pressure is elevated, consider dexamethasone. • Consider relieving lumbar puncture to reduce symptoms, and referral to neurosurgeon if elevated intracranial pressure persists.

Evaluation of elevated intracranial pressure

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Neurological deficits

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

Diagnostics of neurological deficits

Consider	• Consider additional diagnostics (including MRI cerebrum or myeloma) depending on the situation and condition of the child.

Non-pharmacological and pharmacological treatment of neurological deficits

Obstructive double vision

DO	• Pay attention to the child's approach.
Consider	• Consider an eye patch or taping a lens.

Incomplete closing of the eyes

DO	• Use methyl cellulose eye drops during the day. • For sleeping, use oculentum simplex ointment and a watch glass plaster.
Consider	• If redness of the eye occurs, consider more frequent drops and/or ointments, both with or without antibiotics.

Visual hallucinations

DO	• Advise children to close their eyes briefly and then open them again. • Provide good room lighting; this may reduce the likelihood of visual hallucinations developing.
Consider	• Consider referral to a vision expertise centre to get targeted advice for how to deal with the visual problems.

Hearing problems

DO	• Make it known that you are present by touching or looking at the child. • Talk quietly and clearly. • Avoid excessive ambient noise. • Use visual support through text, pictures or gestures.
Consider	• Consider hearing aids or solo aids depending on the child's condition. • Consider referral to an expertise centre on hearing problems to obtain practical advice on managing the hearing problems.

Swallowing difficulties

DO	• Provide optimal nutrition in terms of consistency; consider thickening beverages. • Offer drinking with a straw or from an appropriate drinking cup. • Provide breaks between sips to prevent choking. • Monitor administration of medication and adjust the form of administration as needed.
Consider	• Consider involving a speech therapist or occupational therapist for swallowing advice. • To prevent aspiration or for adequate intake, consider a feeding tube.

Problems with talking

DO	• Be alert to changes in communication abilities. • Make best use of support in communication.
Consider	• Consider guidance from a speech therapist (possibly along with an occupational therapist) for advice on supportive communication devices appropriate to the child's abilities.

Loss of strength

Consider	• Consider guidance from a (paediatric) physical therapist, occupational therapist, paediatric neurologist and/or paediatric rehabilitation physician.

Urinary retention

DO	• Be alert for spinal cord injury or other neurological symptoms in cases of urinary retention.
Consider	• Consider placement of an indwelling catheter or intermittent catheterization.

Evaluation of neurological deficits

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Pain

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

Diagnostics of pain

DO	• Use an age-appropriate measurement tool to measure pain severity. • In children who are unable (or no longer able) to communicate verbally, use an observational scale such as the comfort scale or the FLACC.
Consider	• In nonresponsive children, consider using modified assessment such as NCS-R. • In children who are unable (or no longer able) to communicate verbally, consider assessing the child's facial expression and other expressions of pain. Include parents' assessment in this assessment. • Consider additional testing if it has therapeutic implications for the child.

General management of pain

DO	• Create a calm environment. • Provide information about causes of pain, treatment options and disease progression. • Discuss with child and parents what factors influence pain. • Promote child and parents' autonomy by providing advice on measures they can implement themselves, e.g., posture modification, relaxation exercises, self-medication, etc. • Involve child and parents as much as possible in the treatment of pain and agree on how care can be given (preferably through the pain passport). • Discuss what can be done in acute pain and how to continue medication according to schedule. • Ensure that adequate (dosage) advice and medication are present and think ahead several steps. • Engage a paediatric palliative care team or pain team on a low-threshold basis.
Consider	• Consider involving an occupational therapist or (paediatric) physical therapist to provide advice to child and parents on postural changes, relaxation options and possible assistive devices.

Treatment of cause of pain

DO	• Treat any causes that trigger or exacerbate pain if possible.
Consider	• Consider chemotherapy in susceptible malignancies. • Consider local radiotherapy, for localized pain due to primary tumour or (bone) metastases. • Consider nuclear therapy, in case of multiple painful bone metastases or if local radiotherapy on the bone metastases is not possible. • Consider surgery, in pathologic fractures of vertebrae or long pipe bones, ileus or localized pain due to tumour growth.

Non-pharmacological treatment of pain

Complementary and alternative therapies

Consider	• Consider the use of complementary therapies.

Psychological interventions for children

Consider	• Consider the use of psychological therapies for children.

Psychological interventions for parents

Consider	• Consider cognitive behavioural therapy for parents.

Pharmacological treatment of pain

Stepwise pain management

DO	• Treat pain according to a set (time) schedule, through the most appropriate route and adapted to the child. • Follow a stepwise approach to pain management, such as the WHO ladder. • For complex pain problems, involve a paediatric palliative care team and/or a pain team.
DO NOT	• Use codeine in children.

Step 1 - Non-opioid

DO	• Administer in mild to moderate pain, paracetamol, ibuprofen or a combination of paracetamol and ibuprofen.

Step 2 - Opioids for severe pain

DO	• Administer morphine as first choice in case of severe pain.
Consider	• In severe pain, consider administering opioids in consultation with a paediatric palliative care team and/or pain team, for example fentanyl, hydromorphone, oxycodone, or methadone.

Step 3 - Adjuvant analgesics

Consider	• For specific conditions e.g. inflammation or oedema, consider corticosteroids. • Consider administration of clonidine or ketamine. Consult with a paediatric palliative care team and/or pain team first.

Neuropathic pain

DO	• If neuropathic pain is suspected and standard analgesia is not efficient enough, involve a specialist from a paediatric palliative care team and/or pain team.
Consider	• In case of neuropathic pain, consider tricyclic antidepressants such as amitriptyline. • In case of neuropathic pain, consider anticonvulsants such as gabapentin.

Adjuvant analgesia

Consider	• In children with spastic palsy, consider implanting a baclofen pump. • In children with osteogenesis imperfecta, consider administering bisphosphonates. • If classical pain management is ineffective or pain is located at a specific site, consult early with an experienced pain team about the possibilities of an invasive pain management technique.

Evaluation of pain

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Palliative sedation

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

Education and communication about palliative sedation

DO	• Introduce palliative sedation early during Advance Care Planning conversations in preparation for the last stage of life and at the child's dying stage. • Check with the multidisciplinary team that all conditions for palliative sedation are met. • Consult experts and/or paediatric palliative care teams about communication about palliative sedation and the implementation of palliative sedation. • When palliative sedation has been decided upon, discuss the process of palliative sedation with the child, parents and/or loved ones. Pay attention to purpose of palliative sedation, course of the dying process, implementation of palliative sedation, and agreements between child, parents and caregivers.

Implementation of continuous palliative sedation

DO	• Use the step-by-step plan for the recommended agents and corresponding dosage schedule in continuous palliative sedation. • If symptom-oriented medication (e.g., morphine) is given continuously parenterally, continue the symptom-oriented medication and the medication for the purpose of continuous palliative sedation via a separate pump to prevent unwanted increase in symptom-oriented medication when the dosage of sedatives is increased. • In children with alcohol abuse, drug use and/or higher doses of psychopharmaceuticals (including chronic use of benzodiazepines with the indication of antiepileptic drugs), consult with paediatric palliative care team prior to palliative sedation. • If in doubt or questions about necessary dosages, consult with a paediatric palliative care team.
Consider	• In case of no or little effect of subcutaneous administration of midazolam and/or levomepromazine, consider switching to intravenous administration. • When administering medication intravenously, consider administering boluses slowly over several minutes because of the risk of apnoea with some agents.

Implementation of acute palliative sedation

DO	• Deploy acute palliative sedation when all of the following criteria are present:
	  ◦ An acute life-threatening complication that cannot be treated causally or symptomatically;
	  ◦ The complication leads to unbearable suffering;
	  ◦ The child is expected to die within minutes/hours due to the complication.
	• Anticipate if acute complications are expected during the palliative phase by:
	  ◦ Discussing the possibility in advance with child, parents and/or loved ones;
	  ◦ Creating a plan (available to all involved) for acute sedation if needed.

Evaluation of palliative sedation

DO	• Evaluate the effect of palliative sedation after 30 minutes using comfort score and/or FLACC score and also pain score if pain is among the refractory symptoms. If in doubt whether the effect is sufficient, consider increasing the dose. • If in doubt about medication/doses used, consult readily with a paediatric palliative care team.

Consider	• In case of no or little effect of subcutaneous administration of midazolam and/or levomepromazine, consider switching to intravenous administration.

Skin complaints

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

General skin care

DO	• Actively look for skin abnormalities by examining the entire skin.
	• Give children without skin abnormalities usual skin care without restrictions of washing and bathing.
	• Use ointments applicable to the condition of the skin.
	• When choosing between a cream or oily ointment, consider conditions such as hot/cold weather.
	• Use products with as few additives as possible.
	• Prevent skin irritation by:
	  ◦ Ensuring that the child's, parents' and caregivers' nails are short. If necessary, have the child wear cotton gloves while sleeping to avoid the effects of scratching.
	  ◦ Ensuring a cool ambient temperature and preventing children from being dressed too warmly.
	  ◦ Advise against prolonged washing, bathing and showering, using lukewarm water and preferably no soap. After washing, dab skin dry and do not rub with a towel.

Treatment of dry skin

DO	• Give child and parents understandable information about prevention and treatment of dry skin and factors that adversely affect dry skin.

Consider	• To prevent dry skin, consider:
	  ◦ Using a soap-free wash emulsion with neutral pH and/or bath or shower oil and without dyes and fragrances.
	  ◦ Do not use soap and/or bath products with high pH.
	• For dry skin, consider:
	  ◦ A bath/shower frequency of 2/3 times per week.
	  ◦ A bath/shower water no warmer than 37 degrees Celsius.
	  ◦ Rubbing the skin regularly with an ointment or cream.
	  ◦ Using bath/shower oil.

Treatment of diaper dermatitis and intertrigo

Treatment for prevention of diaper dermatitis and intertrigo

DO	• Give the following advice to prevent diaper dermatitis in children:
	  ◦ Make use of disposable diapers.
	  ◦ Change diapers regularly (every 2 hours if necessary, except at night).
	  ◦ Gently cleanse the skin after each urine/faeces discharge with soap-free and alcohol-free wipes or with a cotton washcloth and lukewarm water (possibly with a soap-free wash gel or oil).
	  ◦ Use zinc ointment FNA to protect the skin.

Zinc oxide

DO	• Use zinc oxide ointments in children with diaper dermatitis/intertrigo.

Miconazole

DO	• In children with (persistent) diaper dermatitis or intertrigo, treat fungal infection with miconazole 2% cream or ointment 2 times daily for 2 to 3 weeks.

Udder ointment, cornstarch

DO NOT	• Corn-starch and powder are strongly discouraged due to the undesirable ingredients.

Pressure ulcers

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

Diagnostics of pressure ulcers

DO	• Take a history and perform careful physical examination of the entire skin. • Grade pressure ulcers based on the NPIAP/EPUAP pressure ulcer classification system.

Diagnostics of pressure ulcers

Stages of pressure ulcers according to the NPIAP/EPUAP pressure ulcer classification system
Category I Non-expressible redness in intact skin Intact skin with non-obscured redness in a localised area at the level of a bony protrusion. Dark skin may not show visible discoloration and is therefore more difficult to assess. The area may be painful, stiff, tender, warmer or colder compared to adjacent tissue.
Category II Loss of part of the skin layer or blister A shiny or dry superficial wound with a pink wound base, without wound impaction or bruising. Part of the dermis (dermis) has disappeared. The wound may look like an intact, an open or a ruptured blister. A blister filled with fluid (plasma) and/or blood also belongs to category II.
Category III Loss of an entire layer of skin (fat visible) A layer of skin has fallen away, leaving subcutaneous fat visible. Bone, tendons and muscle are not exposed. Wound attachment, undermining or tunnelling may be present. The depth of Category III decubitus varies by body location. The bridge of the nose, the ear, the back of the head and the ankle have no subcutaneous (fat) tissue, so the wound is superficial. In areas with a large amount of fat, extremely deep wounds can develop. Bone and tendons are not visible or immediately palpable.
Category IV Loss of a complete tissue layer (muscle/bone visible) Loss of a complete tissue layer with exposed bone, tendons or muscle. A fluidized wound deposit or necrotic scab may be present. There is usually undermining or tunnelling. The depth of the wound varies by body location. Decubitus can spread into the muscles and/or supporting structures (e.g., fascia, tendon or joint capsule) easily causing osteomyelitis or osteitis. Exposed bone or muscle tissue is visible and immediately palpable.

General treatment

DO	• Provide the child and family with understandable information about prevention, risks and treatment of pressure ulcers. • Agree with child, parents and caregivers on roles and decide together on responsibilities related to pressure ulcer prevention/treatment including pain management, nutritional counselling, occupational therapy and physical therapy. • In children at risk for pressure ulcers, inspect the entire skin daily with extra attention to high-risk sites (bone) and other pressure points. • Prevent pressure ulcers by regularly applying alternating positions. • Use pressure-reducing mattresses. • Protect the skin from humidity. • Ensure good nutritional status. Enlist the help of a dietician for this, if necessary.

Non-pharmacological treatment

DO	• Determine whether wound healing or symptom relief is the goal of treatment.
	• Assess the wound for infection, pain, fragility, oedema, colour, odour, and deterioration.
	• Clean the wound (especially for yellow or black wounds and/or odour issues) by flushing with tapwater once daily.
	• Choose a wound dressing appropriate to the wound. Use the classification model in the WCS Wound Book (also available as an app) for this purpose, if necessary.
	• Choose dressing materials that meet a wide range of requirements if more symptoms occur, such as odour, extreme exudate formation and bleeding tendency.
	• Indicate rapidly occurring changes in the skin and respond to them promptly.
	• If necessary, involve a (paediatric) physical therapist, occupational therapist, or medical device manufacturer in using assistive devices or making adjustments so that skin lesions are less stressed.
	• Limit the smell of the wound by using:
	  ◦ Antiseptic agents
	  ◦ Topical metronidazole gel
	  ◦ Antimicrobial dressings
	  ◦ Charcoal dressings
	  ◦ Use odour neutralizers such as cat litter or activated charcoal

Pharmacological treatment

Consider	• Consider treatment of pain due to wounds. • Consider surgical debridement of necrotic tissue to promote wound healing and prevent/heal infections.

Evaluation

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Fungating wounds

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

Diagnostics of fungating wounds

DO	• Grade the wound according to the staging system of fungating wounds.

Diagnostics of fungating wounds

Staging of fungating wounds
Grade I Intact epidermis with imminent skin deterioration due to underlying tumour tissue.
Grade II Incipient encroachment of the subcutis.
Grade III[1] Deep penetration with encroachment of the subcutis.
Grade IV[1] Dry and/or confluent necrosis up to 30% of the wound surface.
Grade V[1] Dry and/or confluent necrosis on more than 30% of the wound surface.
[1]For grades II through V, exudate, bleeding tendency, pain and itching may be present.

Non-pharmacological and pharmacological treatment

DO	• Provide clear information to child and family about fungating wounds. Explain that priority is given to the child's comfort and pay attention to the psychosocial consequences of the cancerous ulcer. Provide psychosocial and/or spiritual support if necessary. • If possible, treat the underlying malignancy. • Clean the wound and care for it using wound dressings and locally or systemically administered medications. • Treat factors that adversely affect the fungating wound, such as poor nutrition/hydration status, pressure spots, oedema formation.

Evaluation

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Radiodermatitis

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

Diagnostics of radiodermatitis

DO	• Apply preventive measures to prevent radiodermatitis. • Grade the skin abnormalities using the NCI/CTCAE table.

Diagnostics of radiodermatitis

Grading of radiodermatitis (NCI/CTCAE)
Grade 0 -
Grade 1 Mild erythema or dry desquamation.
Grade 2 Moderate to fiery erythema, patches of wetting desquamation, mainly confined to skin folds, moderate oedema.
Grade 3 Wetting desquamation not limited to skin folds, bleeding from minimal trauma and abrasion.
Grade 4 Life-threatening consequences; Skin necrosis or ulceration of dermis; spontaneous bleeding of involved skin, skin graft indicated.

General treatment

DO	• Grade the degree of severity of radiodermatitis using the NCI/CTCAE table and tailor treatment accordingly.

Evaluation

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Blisters and blister-related conditions

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

Treatment

DO	• Determine the reason for blistering (exogenous or endogenous or a combination). • Provide understandable information to child and family about the risks of fragile skin with blisters or skin that has a tendency to blister. • Prevent expansion of blistering by recognising and avoiding external factors as much as possible. • Inspect the entire skin at least daily and record where blistering is and where it is about to occur (often red or grey skin abnormalities). • Make arrangements with any cooperating (multidisciplinary) healthcare providers regarding care for the prevention/treatment of blistering and consult or refer to a dermatologist/specialists in the field of blisters.

Evaluation

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.

Itching

Vastgesteld: 16-07-2024 Regiehouder: Nederlandse Vereniging van Kindergeneeskunde (NVK)

Diagnostics of itching

DO	• Take a history of itching and perform careful physical examination.
Consider	• In cases of itching, consider additional laboratory tests if indicated. • In cases of itching, consider a consultation with a dermatologist.

Treatment of cause

Consider	• Consider as treatment of the underlying cause (if possible) of itching:
	  ◦ Adjustment of medication.
	  ◦ Treatment of infection.
	  ◦ Treatment of iron deficiency anaemia.
	  ◦ Treatment of underlying endocrinological conditions such as diabetes.
	  ◦ Removal of bile duct obstruction, by placing a stent (if life expectancy is longer than a few weeks) or nasobiliary drainage.
	  ◦ Chemotherapy (e.g., in malignant lymphoma).
	  ◦ Radiotherapy (e.g., in Hodgkin's disease).

Non-pharmacological treatment

DO	• Take good care of the skin. • Prevent skin irritation. • Pay attention to mental well-being.
Consider	• In children with itching, consider using ointments based on skin condition. • In children with itching, consider complementary therapy, such as hypnosis.

Pharmacological treatment

Local treatment

DO	• Treat dry skin (see dry skin module).
	• In children with itching due to eczematous skin abnormalities, alternate cream with corticosteroids with a neutral cream. Preferably let cream with corticosteroids soak in for 30 min before applying oily ointment over it.
	• In children with itching due to fungal infections, use topical antimycotics such as miconazole cream (2dd) or terbinafine cream (1dd).
	• Use in children with itching due to bacterial infections:
	  ◦ Antibacterial agents such as chlorhexidine 0.5% in 70% alcohol with 1% glycerine 85% (chlorhexidine spirit FNA).
	  ◦ Disinfectants such as disinfecting soaps or betadine scrub (dissolved and not applied directly to the skin, supplemented if necessary, with fusidic acid ointment 2%).
	  ◦ Hygienic measures (own towel).

Systemic treatment

Consider	• Consider pharmacological treatment of itching depending on the cause, in accordance with the paediatric formulary. • For itching due to cholestasis, consider stent placement for (bile) flow obstruction, naloxone (provided the child is not on opioids), colestyramine or ondansetron (be cautious in use). • For itching due to other causes or itching non-responsive to other agents, consider a sedative antihistamine.

Evaluation

DO	• Evaluate the effect and side effects of the treatment instituted at the appropriate time, and adjust treatment as needed. Involve child and family in this process.