We welcome the opportunity to submit evidence to this consultation. Together for Short Lives is the UK charity for children and young people who are expected to have short lives – and their families. This submission highlights the importance of open, honest conversations with families when considering clinically assisted hydration and nutrition. We make three recommendations – to healthcare educators, the government and the CQC – that will support healthcare professionals to make sure families are well-informed and involved in decisions about their child’s end of life care.

About us

1. Together for Short Lives is the UK charity that, together with our members, speaks out for children and young people who are expected to have short lives. We are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can’t change the diagnosis, but we can help children and families make the most of their time together.

2. We are a membership organisation and represent professionals and organisations spanning the statutory, voluntary and private sector who provide end of life care to babies, children and young people. Our response, below, sets out what those working in children’s palliative care have told us about malnutrition in end of life care.

What we would like the APPG to recommend

3. This response sets out the principles of how healthcare staff, including dietetics services, should approach the conversation and decision around forgoing assisted nutrition and/or hydration with children and young people at the end of their lives and their families. **We would like these principles to be reflected in education and training programmes which clinicians and nursing staff undergo and call on the Royal Colleges and the Council of Deans of Health to make sure that this is the case.**

4. **We would like NHS England and NHS clinical commissioning groups to make sure that they plan and fund end of life care pathways for children and young people which adhere to these principles of good practice.** Commissioners should specify that good practice in nutrition and hydration is included in commissioning specifications.

5. **We would like the Care Quality Commission (CQC) to make sure that they assess the way in which services provide nutrition and hydration to children and young people at the end of their lives. CQC should assess all services which could potentially provide end of life care to children, including hospitals, children’s hospices and community-based services.**

Children’s palliative care

6. Children’s palliative care is an active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, death and beyond. It embraces
physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of symptoms, provision of short breaks and care through death and bereavement.

Malnutrition in children in end of life care

7. Most children who receive end of life care do not suffer from malnutrition and, in the experiences of our members, most children continue to take food and fluids as they wish until very late in the disease process. However, a combination of reduced appetite and metabolic demands of advanced disease may mean that they are in a negative calorie balance for a period of time before death and hence lose weight. In general, feeding and administration of fluids ceases very close to the time of death due to unconsciousness and/or the loss of gut function, which makes enteral feeding impossible.

Interventions

8. Nutrition and hydration provided by tube or drip are regarded in law as medical treatment, and should be treated in the same way as other medical interventions¹. Clinically assisted hydration and nutrition can be ethically and legally withdrawn if it is considered in the best interests of the child. However, in these circumstances a second opinion, from a physician not previously involved in the care of the child or young person must be sought².

9. If there is a consensus that clinically assisted nutrition or hydration would not be of overall benefit to the child and treatment is withdrawn, the patient must be kept comfortable and any distressing symptoms must be addressed. Their condition should be monitored and the benefits, burdens and risks of providing clinically assisted nutrition or hydration must be reassessed in light of any changes in their condition³.

10. To inform this evidence, we spoke to a medical director at a children’s hospice who emphasised that they would ‘never deny fluids to a child who was very clearly thirsty’. They told us that in most cases they would administer small volumes (sips) or good mouth care to keep a child comfortable if they are unable to consume larger volumes of fluid.

11. Children who are very close to death and are unable to eat or drink due to unconsciousness and/or the loss of gut function rarely show any sign of suffering at this stage of their illness and if they do, this can be managed through non-medical


support of the child and the family, together with the careful use of sedative agents as needed.

Conversations and Choice

12. Feeding is a particularly emotive area for patients and staff and the role of assisted feeding for an infant or child (by nasogastric tube or gastrostomy) should be considered very carefully and discussed fully with the family\(^4\). A 2013 study of parents who decided to forgo artificial nutrition and hydration (FANH) found that all of the parents they interviewed believed the decision should rest with them. However, in making this decision, they ‘desired the input and support of the health care team’\(^5\).

13. It is especially important that healthcare professionals, including dietitians, consider the views of the child and of those close to them (including their cultural and religious views) and explain the issues to be considered, including the benefits, burdens and risks of clinically assisted nutrition or hydration\(^6\).

14. It is also important for young adults to be able to choose if, when, or in what circumstances they would wish for nutrition and/or hydration to be withdrawn if they reach their end of life phase. This should be assessed by those competent to assess young adult’s ability to make decisions.

15. Rapport et al. found that the setting for discussing FANH was unimportant to parents; what mattered was the timing of the discussion and who introduced it and, crucially, whether they were ‘ready’ for the discussion to take place. The researchers found that parents felt ‘ready’ to discuss FANH when they perceived their child to have a poor quality of life\(^7\). They also found that parents found it helpful if the healthcare professionals acknowledged the child’s perceived poor quality of life and feeding difficulties and explained why FANH was a reasonable option. They also appreciated the options being discussed in a sensitive, non-judgemental and supportive way, and being given enough time to reach their decision. Parents found it difficult when professionals expressed divergent opinions, which led to them feeling negatively judged.

For more information, please contact:

Shaun Walsh
External Director of External Affairs
07506 211 765
shaun.walsh@togetherforshortlives.org.uk

Patrick McKenna
Public Affairs and Policy Officer
0117 989 7820
07964 470 879
patrick.mckenna@togetherforshortlives.org.uk

---


