

Supporting emotionally a parent or carer. (Respondent 010)

Meeting the families for the first time knowing that their child is dying. Having to gain their trust and confidence in your ability to provide care that will allow their child to die with dignity. (Respondent 020)

To ensure that the terminal stage is discussed by all involved. (Respondent 023)

Timing of discussion and opportunity to discuss. (Respondent 068)

My concern is that young people are being supported by health professionals that care for paediatrics and there is any obvious GAP when they become young adults. (Respondent 076)

Denial, non acceptance, insufficiently informed relating to the severity of the child's condition or the young person themselves may be in denial, non-acceptance, especially around feeding and swallowing. Communication, not having up to date information, insufficient, multi-disciplinary meetings. (Respondent 081)

Future wishes - advanced care planning. Transition. (Respondent 082)

Opening the discussion about planning when parents seem reluctant. Maintaining an optimistic yet realistic view in planning the emotional rather than the medical aspects of care. Discussing what families want when sometimes knowing that resources aren't in place to provide this. (Respondent 089)

Uncertainties about available services. Transitional issues. (Respondent 102)

Communicating with children/family about death. (Respondent 114)

When families and children/young people have opposite view points. When severely disabled children are unable to make informed choices. Advocacy services often do not have the skills in this area (if required). (Respondent 154)

In the nature of my work load the majority of children have multiple complex disability and truly taking their views/preferences into account can be very complex. Establishing the optional balance to support within the home and giving parents a complete break by admitting the child to hospital or hospice can be complex. There is the danger of professionals deciding 'the correct' solution based on their training and prejudice and the parents feeling under pressure to do the right thing. (Respondent 162)

All of it really. Boundaries, what's appropriate for one family is not appropriate for another. For some families palliative care has never been discussed as we know it will be too upsetting but should we be discussing it regardless. (Respondent 168)

Some families will talk more openly about wishes, death and dying - easier to plan for wishes. It is upsetting sometimes for families when we try to bring up this subject. Consultants do not always do this without prompting. Often difficulties with consultant support in the community setting. Consultants from the Trust do not provide home visiting. GPs have never come across a child requiring terminal care at home at home in all of my situations, but are always willing to help. (Respondent 169)

The decision that curative treatment is no longer appropriate. (Respondent 195)

Involving the child and extended families. (Respondent 196)

Conflicting ideas. Attitudes of parents and staff. (Respondent 222)

Discussing and managing end of life care. Time to be with children and families to plan properly often provide a reactive service not a proactive because of this. (Respondent 104)

Meeting the clinical needs and balancing that with individual needs of the family and their wishes. Finding resources to meet the wishes of the family and meet needs of the child. Being responsive enough to meet needs with limited resources. (Respondent 103)

A large number of our children had learning disabilities and some have very little communication skills which can make it difficult in establishing their wishes rather than these parents wishes. It can also be difficult because of the parents wishes about how much the child should know about their illness. Without being negative about a child's illness but also being realistic about the condition and the future. (Respondent 105)

Probably the initial acceptance that their child is not going to recover and that we need to change the approach and risks of treatment. (Respondent 186)

As a voluntary organisation we not have a lot of input into the planning of services. We do however serve the needs of parents and children who do access palliative care services, or the use of the facilities for respite care. Most of our families value the input of all services they access including ours as part of a package of support. As voluntary organisations it is often hard for us to be accepted as 'as good'/valuable as a 'hospice' or hospital. (Respondent 225)