

Title	Palliative Care (Paediatrics)
Version	2

1	Introduction
2	Definitions and Principles
3	Advanced Care Planning
4	Referral

1.0 Introduction

Even with the optimum medical care available, CF remains a life-limiting condition. The terminal phase is usually marked with increased frequency and severity of respiratory exacerbations, oxygen dependence and poor lung function. Due to the variable nature of CF there is no accurate way to predict when this phase will be reached and how long it will last. The majority of deaths occur in patients on the active transplant list due to a lack of donor organs.

2.0 Definitions and Principles

2.1 Definitions

The World Health Organisation (WHO) defines Palliative Care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” (WHO, 2016). Palliative care for children and young people with life-limiting or life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition throughout the child’s life and death. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement (Together For Short Lives, 2018).

2.2 Principles

Palliative Care should:

- enhance quality of life and care for every child/young person with a life-limiting condition and their family
- affirm life, and regard dying as a normal process
- neither hasten nor postpone death
- provide relief from pain and other distressing symptoms
- integrate the psychological and spiritual aspects of patient care
- offer choice. Choice is key to a palliative care approach; choice of place of care, choice of place of death; and choice of emotional and bereavement support
- give the child and family an active role in discussions about their care and take into account their age and level of understanding
- offer a support system to help patients live as actively as possible until death
- offer a support system to help families cope during the patient’s illness, and in their own bereavement
- use a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- use parallel planning to take account of possible unpredictability in the course of the condition.

NICE Guidance (2016)

3.0 Advance Care Planning

The Cystic Fibrosis Trust has developed an Advanced Care Plan document for people with CF. The most up to date document can be found on the CF Trust website and is designed for the individual to be able to complete on their own, with family, or with members of the team as the individual prefers. Advance care planning is completely optional. It should be explained and offered to patients but never pushed or forced upon individuals

Introducing discussions about palliative care and advanced care planning will vary across all patients. Triggers to start advance care planning include discussions with the consultants around prognosis, transplant or transplant referral. Patients may also be keen to start advance care planning earlier, for example those with unpredictable disease (history of haemoptysis or pneumothorax).

For the advance care plan to be completed it must be reviewed and signed by a member of the CF team. The team member can be of any profession but should have a good, already established therapeutic relationship with the patient. Ideally they will also have completed specific training on how to complete advance care planning. Further guidance is provided on the Cystic Fibrosis Trust website.

This document is not set in stone, and the individual is encouraged to update it or make changes whenever they wish. It is recommended that the ACP document be reviewed every 6 months and it is the responsibility of the Cystic Fibrosis Multi-Disciplinary Team to remind the individual when it is due to be reviewed.

4.0 Referral

4.1 Stoke-on-Trent children: access to the Children's Palliative Care team is via Treetops, a local hospice for children and young people funded by the Donna Louise Trust. Contact on: 01782 654440

4.2 Shropshire children: access to the Children's Palliative Care Team is via the Community Nursing Team who work in palliative care in the community, and the Hope House Hospice. Contact on: 01743 450855

5.0 References

Cystic Fibrosis Trust (2017) Advance care planning for people with cystic fibrosis – guideline for healthcare professionals <https://www.cysticfibrosis.org.uk/sites/default/files/2020-12/Advance%20Care%20Plan%20guideline%20for%20healthcare%20professionals%20v2.pdf> [accessed on 29th June 2022]

Cystic Fibrosis Trust (2017) Planning for end of life <https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/planning-for-end-of-life> [accessed on 29th June 2022]

NICE (2016) End of life care for infants, children and young people with life-limiting conditions: planning and management. www.nice.org.uk/guidance/ng61 [accessed on 29th June 2022]

Together for shortlives (2018) A Guide to Children's Palliative Care Supporting babies, children and young people with life-limiting and life-threatening conditions and their families <https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/> [accessed on 29th June 2022]

World Health Organization (2016) Planning and implementing palliative care service: a guide for programme managers <https://www.who.int/publications/i/item/planning-and-implementing-palliative-care-services-a-guide-for-programme-managers> [accessed on 29th June 2022]