

<b>Title</b>	Palliative Care (Adults)
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## 1. Introduction

Cystic Fibrosis (CF) can be an unpredictable condition and knowing when someone with CF is in the terminal phase of illness isn't always straightforward. Sometimes people with CF appear to be very unwell and clinical teams feel that they are approaching end of life, and then they make a good recovery. Unfortunately, this unpredictability can happen the other way around too and people with CF (pwCF) can deteriorate rapidly. Palliative care focuses on improving a patient's quality of life as well as managing end-of-life care.

End-of-life care for pwCF is managed differently to most other conditions. Active treatment is continued for people being considered for lung transplantation, and many therapies e.g. intravenous antibiotics usually continue alongside palliative care for the purpose of symptom relief.

## 2. Definition

National Institute for Health and Care Excellence (NICE), 2021, defines palliative care as "the active holistic care of people with advanced, progressive illness".

## 3. Principles of Palliative Care for Adults (NICE 2021, Cystic Fibrosis Trust 2017)

- Professionals providing palliative care should aim to meet the needs of the patient and their family or carers within the limits of their knowledge and competence, and seek specialist advice from palliative care professionals when necessary. Resources and information packs to support CF inpatients at UHNM in their last days of life can be ordered via UHNM palliative care team
- Referral to palliative care team does not mean that death is imminent – palliative care teams have very specific expertise/ knowledge in dealing with symptom management e.g. pain, insomnia, anxiety
- Preferred care setting should be discussed with patients and their families/ carers
- Anticipatory prescribing should be considered
- Common physical symptoms should be managed e.g. nausea, vomiting, breathlessness
- Psychological needs should be assessed and met

- Social needs should be assessed and met such as help/ support with shopping, personal care, and housework
- Needs of family and carers should be determined/ supported
- Attempts should be made to estimate the patients’ prognosis to facilitate planning and reduce anxiety for patient and family/ carers
- A multi-disciplinary team approach to palliative care is often required due to complexity of conditions
- Patients should be given opportunities to discuss topics important to them such as advance care planning and estimated prognosis

#### 4. Advance Care Planning

The Cystic Fibrosis Trust (End-of-life planning, 2017) has done a lot of work in recent years regarding end-of-life planning. The creation of an advance care plan (ACP) can assist patients to “hope for the best, but plan for the worst”. The ACP form should be completed with the patient and signed by a member of the CF team. It is important that this team member is someone who has a good, already established relationship with the patient. The team member leading the advanced care planning is responsible for agreeing that everything documented is appropriate and realistic for patient care. There are online documents and templates to support CF teams who are completing ACP forms with patients

(<https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/planning-for-end-of-life>).

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 and/or as part of annual review. Patients may also be keen to start advance care planning earlier, for example those with unpredictable disease (e.g. history of haemoptysis or pneumothorax).

Advanced care planning is an entirely optional, flexible process which should be regularly reviewed once commenced (at least every 6 months). It is the responsibility of the CF Multidisciplinary Team to alert patients when the ACP is due to be reviewed, and patients are encouraged to make changes whenever they wish.

#### 5. Organ Donation

Organ donation is often discussed in CF care, but usually in terms of patients being the recipient of donor organs. It is possible for people with CF to donate organs (apart from lungs) after their death. It is important for healthcare professionals providing palliative care to CF patients to have conversations about organ donation with patients and their families/ carers, as having such conversations ensures that patient wishes are upheld.

#### 6. Referral

- Services are specific to the location that patients live in
- Referral forms are available on request from the local CF Team

Location	Services	Contact Info
Dudley	Dudley Community Macmillan Team	<a href="mailto:dgft.dmscah@nhs.net">dgft.dmscah@nhs.net</a> Monday to Friday contact via 01384 321523 (9am-5pm) Weekends/bank holidays contact via 01384 321600 option 1 (9am-5pm) Referral proforma required

<b>Sandwell</b>	Sandwell Community Palliative Care Service	<a href="mailto:swb-tr.SWBH-GM-Connected-PC-Hub@nhs.net">swb-tr.SWBH-GM-Connected-PC-Hub@nhs.net</a> Referral proforma required
<b>Stoke</b>	UHNM Palliative Care Team	01782 674029 <a href="https://www.uhnm.nhs.uk">Palliative Care   University Hospitals of North Midlands NHS Trust (uhnm.nhs.uk)</a>
	Douglas Macmillan Hospice	01782 344300 <a href="#">Home - Dougie Mac</a> Referral proforma required
<b>Stafford</b>	Katharine House Hospice	01785 254 645 <a href="https://www.khhospice.org.uk">Katharine House Hospice - Free Care for Local People (khhospice.org.uk)</a> Referral proforma required
<b>Shropshire</b>	Severn Hospice (Shropshire) Community Palliative Care Team	Severn Hospice, Bicton Heath, Shrewsbury, STY3 8HS 01743 236565 <a href="#">Home - Severn Hospice</a>
	Palliative Care Team (Royal Shrewsbury Hospital)	01743 261649 <a href="https://www.sath.nhs.uk">Palliative Care at Shrewsbury and Telford Hospital NHS Trust (sath.nhs.uk)</a>
<b>Telford &amp; Wrekin</b>	Telford Hospice	Apley Castle, Telford, TF1 6RH. 01952 221350 <a href="#">Severn Hospice - Telford - Severn Hospice</a>
	Palliative Care Team Princess Royal Hospital	01952 641222 EXT 4565 <a href="https://www.sath.nhs.uk">Palliative Care at Shrewsbury and Telford Hospital NHS Trust (sath.nhs.uk)</a>
<b>Walsall</b>	St Giles Hospice (Lichfield)	<a href="tel:01543432031">01543 432031</a> <a href="#">Home   St Giles Hospice</a> Referral proforma required
	Walsall Community Team	Telephone number (01922) 602622
<b>Wolverhampton</b>	Compton Care Hospice	0300 323 0250 <a href="#">Compton Care   Palliative Care   Charity   Wolverhampton</a>
<b>Wyre Forest</b>	Wyre Forest Community Palliative Care Team	01562 751562
<b>UK</b>	Hospice UK	<a href="https://www.hospiceuk.org">https://www.hospiceuk.org</a> 020 7520 8200