



# demelza

extraordinary care for extraordinary children

## The positive impact of the children's hospice nurse inreach role within the acute hospital setting

### A seamless approach to palliative care

**Michelle Wickens**, Lead Nurse Clinical Governance and Quality – Demelza  
**Jackie Tyler**, Head of Nursing for paediatrics – Maidstone and Tunbridge Wells NHS Trust (MTW)

#### Background

Demelza delivers extraordinary care to extraordinary children who are facing serious or life-limiting conditions. Supporting them and their families at every step – from first diagnosis and for as long as they are needed. Acute hospitals often have minimal understanding of the breadth of holistic and palliative care services available to children, their families, and the wider professional network.

#### Aims

To identify children who meet Demelza's criteria for referral when they access acute services and support existing service users throughout acute admissions.

To educate and support staff on the care of children with complex health needs to develop confidence and skills to improve the patient experience – both within the acute healthcare setting and Demelza teams.

To ensure that all staff are aware of the facilities and support available within the hospice service.

#### Methods

- Placement of a nurse within the acute paediatric ward at Tunbridge Wells Hospital one day a week, with an honorary contract and access to clinical databases and all services.
- Presence at core meetings including those for specialist teams – including oncology and epilepsy, and to understand the needs of the acute staff and services.
- Deliver bespoke training to the acute team.
- Educate on referral criteria and services available to children and families.
- Provide respite for the caregivers during a child's admission.
- Promote the full range of hospice services on the wards.
- Introduce the concept of hospice services at the beginning of their journey, addressing myths and anxieties and work towards being recognised as a member of the multidisciplinary team.
- Regular meetings with the senior management team to continually review the service.
- Reciprocated education: nurse to have opportunities to update acute clinical competencies.



*Having someone to lean on when one of your kids is in hospital (let alone two or even all three of them) makes such a huge difference. We can't be everywhere at once and it can be a massive strain to worry about what's going on at home, or in another hospital room. Getting that on-the-spot respite from Beth, who can sit with Oscar or Sofia while I grab a coffee and recharge for 20 minutes is fantastic. Demelza bring their services to life in a way that's different than anywhere else we've ever been. We would never want to be without them now."*

Jay, Dad to Sofia, Oscar and Luca:

### Impacts of the children's hospice nurse inreach role in the acute setting

#### Child and young person

Friendly face of Demelza.

Take activities from home into hospital.

One-to-one fun care on the ward.

Improved experience and journey.

Safe, familiar person.

Time to care.

A listening ear.

Fully focused on the child.

In-depth knowledge of the child – what they like to do, what works for them.



#### Families

Addressing myths around palliative care.

Holistic care and continuity of service from home, in hospital and at Demelza.

Availability of support which can be implemented early.

Respite available on the ward with a trusted known person so that parents can have personal space and time away from their child.

An advocate for families – a listening ear with access to all services.



Access to expert, clinical and emotional support from diagnosis and throughout their journey. Improved knowledge within the acute trust and Demelza of child and young person's palliative care needs to support effective nursing and care delivery.

#### Demelza

Increased appropriate referrals.

Improved signposting to other services both at Demelza and within acute settings.

Clear lines of communication to support service delivery.

Insight into processes and restrictions for families within acute care setting.

Promotion of Demelza services and enhancement of reputation.

Improved engagement with families whose child requires palliative care.

Updating of Demelza nurses with focused acute skills that will benefit care within the hospice.



#### Maidstone and Tunbridge Wells NHS Trust paediatric department

Breaking down myths and barriers about hospice care.

Improved knowledge of services provided and processes to support families.

Improved training for staff on palliative care.

Improved quality of care provision.

Improved discharge planning resulting in reduced length of stay.

Knowledgeable learning disability nurse on the workforce to support care improvements – passports, communication aids and training.



Improved staff engagement and knowledge of care delivery across acute, community and Demelza services. Additional skills available within the joint workforce. Collaborative seamless working pathways. Shared learning.

#### Conclusions

Hospice care has become embedded within the acute hospitals multidisciplinary team with a change in perception of what Demelza can offer to a child and family. There has been an increase in appropriate referrals and signposting to Demelza from the acute hospital with children and families being identified and referred earlier, improving their experience and journey.

Collaborative working provides seamless, holistic care, breaking down barriers and addressing myths surrounding the word hospice. The development of training programmes and knowledge of services available actively encourages and supports staff from all services to provide quality of care for the children, young people and their families.

Strong links have been established between the acute hospital and Demelza and this model is being developed for implementation within other NHS Trusts.

# demelza.org.uk

Registered Charity No. 1039651

Demelza's Guide to Services

