

A Virtual MDT in Adolescent Palliative Care

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An email based "virtual MDT" allowed multiple professionals to support a patient and her family in the final months of her life. This is an example of a model that works well in the coordination of the highly personalised packages of care that are needed to deliver palliative care to children and adolescents.

BACKGROUND

A 17 year old girl had been diagnosed 8 years previously with a brain ependymoma. She developed 3 mid to lower spinal relapses, and no further curative treatment was possible. The palliative care team generated a symptom management plan, and she went home, with local services contacted.

A meeting was arranged in her local hospital. The principles were based on the model of care outlined in the Choices Review.¹ The team focussed on 2 key aspects:

"I want involvement in and control over decisions about my care"

"I want the people who are important to me to be supported and involved in my care"

The approach taken was to meet and listen to her and her parents, and start trying to build relationships. It was imperative to understand their experiences, as well as their wish to consider 'natural' treatments.

Over the following 6 weeks, her disease progressed causing paraplegia, irregular bowel and bladder function. She lived with her parents, and was now having regular contact with the community children's nurses and her local young people's hospice. This was supported by the wider team, but key individuals were emerging.

Introducing palliative and hospice services can be challenging due to preconceived ideas of these services and a fear of losing the support of the local services that have been involved since diagnosis up until this point.² Although nearly all work was done in the home, the hospice provided an environment to work in partnership with the community therapists – her physiotherapist assessed her in the hydro-pool and liaised with a private therapy facility. The occupational therapist saw her for assessment of hoist and sling equipment. This enabled the family to be introduced to the hospice environment, with the possibility of access to emergency care within the hospice, if required.

The family were extremely proactive in making their own arrangements where there were issues with equipment etc..., and the team established good ways of working with this.

The provision of individualised care requires integrated working between all professionals involved to ensure care is received when and where it is needed. The number of professionals involved and the risk that care could become increasingly fragmented and disjointed was a concern for the team. During this time the family also went abroad for complementary therapy, adding a further dimension to her care package.

LISTEN • TRUST • BUILD RELATIONSHIPS

THE SOLUTION

We started an email thread including 16 of the key professionals. It was recognised that the time course of her deterioration had potential to be both lengthy and complex and this approach was felt to give the best opportunity to provide sustainable support.

Individual nhs.net email (or alternative secure email addresses) were used to facilitate communication, valuing individual contributions whilst avoiding professionals from becoming over protective of their roles. Consent for this method of communication was obtained and documented at the start of the thread, with a protocol for communication.

Over the next 3 months, a total of 75 emails were sent on this thread. They included updates on discussions, care plans, visits, practical issues, questions for general consideration, highlighting potential issues or worries, or issues flagged up by the family. Replying to subsets of the group was discouraged, but forwarding updates to local teams strongly encouraged. Symptom plans, prescriptions and her Advance Care plan were included.

The breakdown of who sent "cc all" messages is as follows.

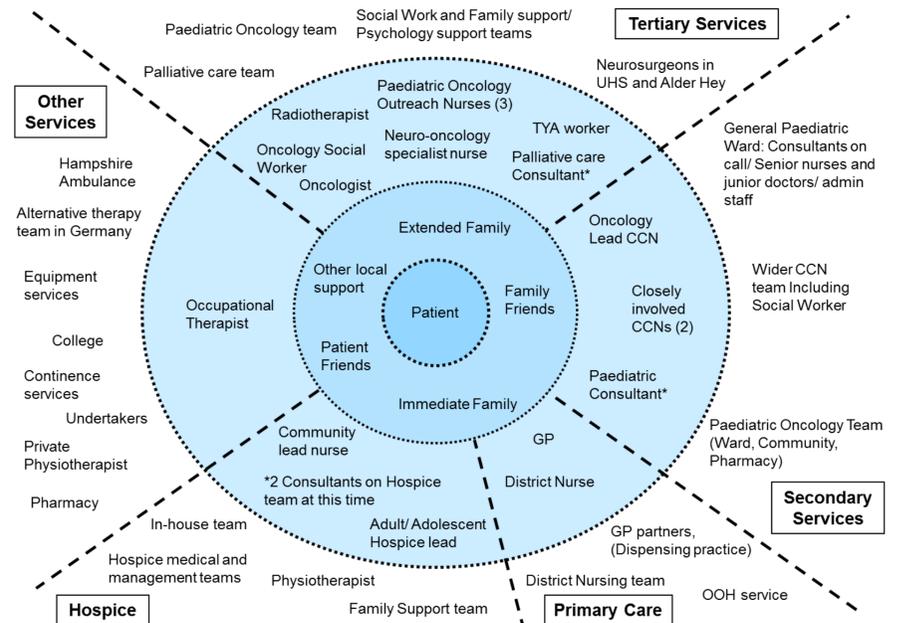
Individual	Number of emails
Lead Paediatrician	27
2 Paediatric outreach oncology nurses	12 (All from locality lead nurse)
Hospice nurses	13 (11 from inpatient lead, 2 from community lead)
3 Community nurses	13 (9 from lead nurse)
Occupational Therapy	2
Neuro-oncology nurse	2
Palliative care consultant	2
Social Worker	1
Radiotherapist	1
GP, TYA link, Oncologist	0
Total	75 (7 post mortem)

During this time, practical issues relating to mobility, transport, sourcing equipment and adaptation in the house were addressed. Day support and swimming facilities were provided in the hospice. Pain, nausea, raised intracranial pressure, pressure ulcers, constipation, urinary retention, incontinence and urinary tract infections were managed. Relationships with the wider teams were established and nurtured.

Her symptoms remained reasonably controlled until the day of her death when she was admitted with escalating raised ICP and urosepsis. She died peacefully 7 hours after admission to hospital. She was transferred to the hospice, enabling the family to receive immediate emotional and bereavement support from both care-staff and family support team through sensitive communication as outlined by NICE.³

SUSTAINING HIGH LEVELS OF SUPPORT

THE MDT



SHARED RESPONSIBILITY

THE MODEL

The difficulties in the paediatric palliative care include:

- Teams often come together around the family, not necessarily having worked together, and often not knowing each other. This can be even more problematic when symptoms escalate, and the need for practical support around the clock becomes more pressing.
- The issues of funding, working within professional boundaries, delayed referral and service fragmentation, and the potential for error, confusion and sustainability.⁴

The importance of involving the specialist palliative care services early, good relationships and close links between services established in advance, and effective communication is known to be essential to help build relationships with patients and alleviate any fear.⁵

We developed a model in which:

- Individuals were able to develop some form of relationship with the family, making individual contributions.
- The burden upon each professional was never too great, because it was shared across the group, and we were all able to work within our own area of expertise.
- We could do so confident in the knowledge of what had already been said and done, and ensure that our colleagues were able to follow up on any intervention knowing what had happened previously, and how.
- We were also confident that decisions and plans had been shared and discussed with the wider team, reducing the likelihood of error or missed opportunities.
- The family were able to work in a way that they were most comfortable with. They preferred to have a plan, adapting it themselves as they went along. They did not seek the help of professionals unless they felt they really needed it but when needed they called the place they felt would most likely help and respond quickly. This model of working could potentially have been hard to support and sustain, though in reality it wasn't.

Key elements were:

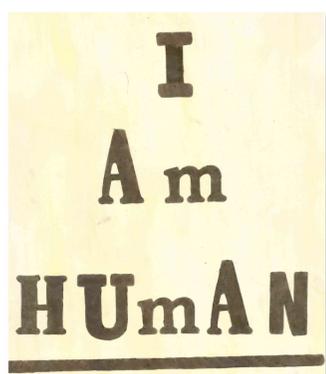
- Committed, as a team, to the provision of seamless support throughout the illness
- Commitment from all team members to patient and family centred care - understanding what they needed and making it happen.
- Providing points of contact for the family and a back up at all times.
- Respecting professional boundaries and skills, whilst sharing responsibility

This model of care provides a way for geographically and professionally separate team members to work collaboratively in supporting families.

Email will never replace need for face to face and verbal contact. Rather it provides the support structure for these critical contacts to be timely, expert and patient focussed.

The family expressed their satisfaction with this way of working, particularly saying that they had felt that all the professionals were really listening to them and communicating with them and each other, something that was unusual in their experience.

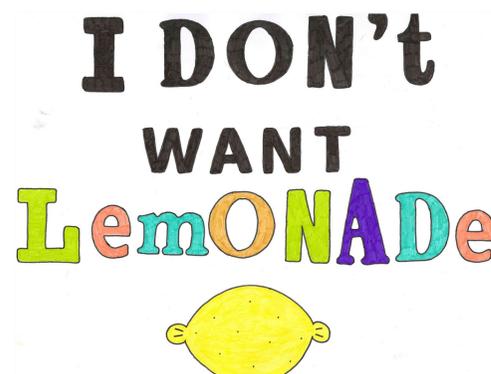
COMMITMENT • COMMUNICATION • RESPECT



A response to being a patient in the system



A response to being told there was no further treatment available



If life gives you lemons, make lemonade, but...



Her final drawing

References:
1. DOH. 2015. *What's important to me. A Review of Choice in End of Life Care.* The Choice in End of Life Care Programme Board. London.
2. Golman A, Bearesmore S, & Hunt J. 1990. *Palliative Care for Children with Cancer – Home, Hospital or Hospice?* Archives of Disease in Childhood, 65, p641-643
3. NICE. 2012. *Patient Experience in Adult NHS Services: Improving the experience of care for people using adult NHS services.* NICE: London.
4. Love A, & Liversage L. 2014. *Barriers to accessing palliative care: A review of the literature.* Progress in Palliative Care. 22(1), p 9-19.
5. Grinyer, A. 2012. *Palliative and End of Life Care for Children and Young People. Home, Hospice and Hospital.* John Wiley and Sons Ltd: Oxford.