A Virtual MDT in Adolescent Palliative Care
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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. Her palliative care team generated a symptom management plan and they were discharged, 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 focused on 3 key aspects:

1. “I want involvement in and control over decisions about my care”
2. “I want the people who are important to me to be supported and involved in my care”
3. “I want the people who are important to me to be supported and involved in my care”

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.

Over the next 3 months, a total of 75 emails were sent on this thread. They included updates on discussions, becoming over protective of their roles. Consent for this method of communication was generated a symptom management plan, and she went home, with local services contacted.

THE SOLUTION

We started an email thread including 16 of the key professionals. It was recognised that the geography of the hospital was such that the potential for both lengthy and complex and this approach was felt to be the greatest opportunity to provide support to the family.

Individual nhs.net email (or alternative secure email addresses) were used to facilitate communication, reducing 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, developing relationships with patients and alleviating any fear. 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 model of working could potentially have been hard to support and sustain, though in reality it wasn’t.

Key elements were:

- Patient Experience in Adult NHS Services: Improving the experience of care for people using adult NHS services. NICE. London.
- Progress in Palliative Care. 22(1), p 9
- A Virtual MDT in Adolescent Palliative Care
- Patient Experience in Adult NHS Services: Improving the experience of care for people using adult NHS services. NICE. London.

LITERATURE REVIEW

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 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 families.


COMMITMENT • COMMUNICATION • RESPECT

SHAREd RESPONSIBILITY

SUSTAINING HIGH LEVELS OF SUPPORT

A response to being a patient in the system
A response to being told there was no further treatment available

If I like you, I want you to be someone, but... Her first drawing