ACT Information

ACT
Valuing short lives

Using telehealth to support care at home in children's palliative care

ACT recognises the challenge of reaching out to children, young people and families – especially those living in remote and rural environments, who are trying to maintain a normal, day to day life in their own home, but need regular contact with health professionals. Telehealth is a technology which can support professionals and services in providing care closer to home.

This information briefing aims to set out goals for professionals working with telehealth, or for those who are interested in using it in the future.

What is telehealth?

Telehealth is a term that is being used more frequently, and refers to the use of advanced communication technologies in health and social care environments.

The term telehealth describes a process where technology is employed to monitor, diagnose, manage or treat patients at a distance. The purpose of this is to mitigate the effect of distance and sometimes even time in the provision of effective and efficient healthcare.

There is not yet much concrete evidence regarding the use of telehealth in support of children's palliative care in the UK, however learning from pilot studies and developments is beginning to be shared.

There is published literature from Australia, Canada and the USA (where remote access to services is a common problem) that suggests such innovation is gaining widespread acceptance, and that children, families and healthcare professionals find it both usable and acceptable.

When should telehealth be used?

There is a good case for telehealth being used to complement existing children's palliative care services for families that live remotely or at a distance from specialist services. Telehealth can enable them to have more choice in how and where they receive their care. If telehealth can be accessed from home it could be an effective mechanism to enhance optimal care to most, if not all, life-limited babies, children and young people, as well as their families – regardless of where they live.

How will it improve services to children and families?

Telehealth has the potential to:

- Provide services closer to families' homes.
- Provide access to much wider range of expertise in remote and rural areas.
- Reduce the time and costs associated with travelling to and from big urban centres.
- Enhance communication and sharing of good practice.

How does it work?

The dynamic nature of symptoms related to children's palliative care means that children and families need to report symptoms as they are happening, rather than waiting until a health professional visits. Despite the fact that many families wish their child to remain at home and in their own community, they are often unsure of who to contact and how, when they need support.

Telehealth empowers individuals experiencing life-limiting illnesses, as well as their families and carers, through the provision of clear lines of real time communication. It predominantly involves healthcare interventions delivered by specialist staff, often in hospitals, to remote locations including families' homes. It is mainly focused on using video conferencing equipment to send and receive sound and images, on a secured network. As such, telehealth acts as a bridge between the patient and the specialist centre, and is set to enhance rather than undermine local care and support.

For professionals, being able to see as well as talk to patients and their families is often preferable to using the phone. Capturing non verbal communications and using the camera as a diagnostic tool can make a significant difference to clinical outcomes and the quality of care offered to children.

John's story – a telehealth case study

John and his family were known to the oncology team for a number of years, since before diagnosis at the age of four. His lively character and the hardship experienced by the family made a big impact on the entire clinical team. The periods where he was admitted for prolonged treatments were characterised by all as 'memorable' and the challenges in co-ordinating care across various environments were significant. Yet, despite much support and excellent care, John's prognosis was poor and after two and a half years of battling with cancer, the focus of treatment turned from curative to palliative care. The main effort was on enhancing John's quality of his life during the precious few months he had left with his family.

The parents knew that they wanted to spend as much time together at home where John could be with the people who loved him most. The clinical team were adamant that everything must be done to enable this family to exercise real choice in the place of death for their child.

It was the clinical team who first thought of telehealth, as a mechanism to link the home environment to the specialist services offered by the hospital based team.

After gaining the consent of the parents to use telehealth at home and with total support from John, a laptop unit was installed in the home and training was given to all users. Getting used to remote interaction via a small computer screen was the next hurdle to be conquered. John adjusted very quickly to talking to his nurse on the screen. The clinical team found this to be a very effective tool for the delivery of remote services when and where they were needed.

John died at home in the arms of his mother a few hours after the team visited him for the last time. The house call was prompted following a scheduled telehealth session where it was clear that John was near his end of life. It was this call that made such a big difference and enabled John to experience a good quality of death – something that would have been more difficult without being able to establish the telehealth link. Returning the unit shortly after John's death, his mother wanted to stress that it was the effective link through telehealth, which made her feel safe at home.

ACT key standard for telehealth

Telehealth should be considered as a viable mechanism to support access to 24 hour care and support for children with complex health conditions, particularly when they are at their end of life. Embedding new communication technologies and associated practices may enhance the provision of children's palliative care, and supports continuous symptom assessment, review and control. It may also support better access to specialist advice.

Goals to help achieve the standard

- Telehealth should be considered as an enabling element to complement or enhance a prescribed care package, and to deliver appropriate services wherever a child and family live.
- Telehealth should be recognised as an important supportive tool for generalist and specialist children's palliative care.
- Telehealth should be used as a way of offering more choice on how and where life-limited children and their families receive care and support - particularly at end of life.
- All those who are expected to work with telehealth applications should receive training. This training should enable users to acquire the skills to operate as competent and safe users.
- Technical support should be made available for all telehealth users (both service users and providers) at all times to ensure a robust and reliable service is being delivered.
- Key issues relating to information governance such as information sharing and confidentiality as well as other ethical issues concerning telehealth practice should be embedded in on-going clinical and professional education.

Resources, links and further reading

Scottish Centre for Telehealth & Telecare: http://www.sctt.scot.nhs.uk

Telehealth digital stories: http://www.patientvoices.org.uk/telehealth.htm

A systematic review of economic analyses of telehealth services using real time video communication: http://www.biomedcentral.com/1472-6963/10/233

Kings' Funds Telehealth reading list:
http://www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/22836/Telemedicine,_telehealth_and_telecare_2010%5b1%5d.pdf

RCN Telehealth resource: http://www.rcn.org.uk/development/practice/e-health/telehealth_and_telecare

Kidd, L., S. Cayless, Wengstrom, Y. Johnston, B. (2010). Telehealth in palliative care in the UK: a review of the evidence. Journal of Telemedicine and Telecare. 16(7): 394-402.

About ACT

ACT is the only organisation working across the UK to achieve a better quality of life and care for every life-limited or life-threatened child or young person and their family. To achieve this we:

- Campaign for the development of children's palliative care services.
- Work with professionals to develop best practice.
- Empower and support families.

ACT supports a membership of families and children's palliative care professionals across the UK and provides a national helpline and information service. ACT produces a range of publications and resources, including care pathways for life-limited or life-threatened children and young people, and publishes the International Journal of Paediatric Palliative Care.

ACT takes a lead on lobbying and campaigning for sustainable children's palliative care services and plays a key role in ensuring that the needs of all affected children and their families are heard.

What is children's and young people's palliative care?

Palliative care for children and young people is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

There are estimated to be 23,500 life-threatened or life-limited children in the UK – and half of these children will have substantial palliative care needs at some point.

It is estimated that around 80,000 to 100,000 family members and carers provide 24 hour care and support for a child – many of whom have very complex health care needs and disabilities.

Our vision

Our aim for children's palliative care is one of well Co-ordinated services that enable, support and inform families so that they can exercise real choice relating to:

- Choice of place of care.
- Choice of social opportunities.
- Choice of place of death.
- Choice of emotional, psychological and bereavement support.

Every child or young person in UK with a life-limiting or life threatening condition, regardless of race, religion, age or where they live, should have access to the sustainable, holistic, family-centred and high quality palliative care and support they need.

To find out more about ACT or for further details about using telehealth to support care at home in children's palliative care, visit our website www.act.org.uk, call us on 0117 916 6422 or email info@act.org.uk.

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