

P104 DEVELOPING A PARENT-LED BEFRIENDING SERVICE IN A CHILDREN'S HOSPICE

¹Dorothy Gillespie; ¹Donna Louise Children's Hospice, Stoke-on-Trent, UK

10.1136/bmjspcare-2013-000591.126

In autumn 2010 funding was secured to pilot a bespoke Parent and carer befriending model designed around the specific needs of parents and carers who use the hospice.

Befriending is recognised as a successful model for providing emotional, psychological and practical support. Befriending models are used nationally and internationally to help and support a wide variety of people, children, teenagers, parents.

Aims of Befriending

- Improve the social well-being and psychological health of parents and their families.
- Reduce parental isolation
- Ensure that parents who discover their child has a life shortening illness are supported, through befriending to understand their child's special needs and their own feelings about them.
- Parents become empowered and better able to manage their family's new situation
- Parents are able to communicate better with professionals

Approach Used Five parents were recruited and trained to become Parent and Carer befrienders.

This is a volunteer role and is designed to be flexible to respond to the ever changing needs of the befrienders own unique family situation.

All the recruits undertook a 40 hour training programme to provide them with the knowledge and skills necessary to be a professional parent befriender.

Parents or staff can refer to the service; information is in the family information packs, around the hospice and on the hospice website.

Outcomes Between Jan 2011 and Jan 2012, 11 parents/ carers were befriended.

An average of 40 hours per month of support is being offered to families.

All parents who have used the befriending service reported benefitting from the service and would recommend it to another parent.

Parents rated the befriending service on a scale of 1-10 the average score was 9.3.

Application to Hospice Practice This service user led/ volunteer based model is transferable across all hospice settings.

- It is a low cost, high return service development in terms of value added for befrienders and the befriended.

P105 EVALUATION OF THE ROLE PLAYED BY PARENT REPRESENTATIVES WITHIN OUR LOCAL PAEDIATRIC PALLIATIVE CARE NETWORK

Emily Harrop, Bridget Taylor. *Helen & Douglas House Hospices, Oxford, Oxford, UK, Oxford Brookes University, Faculty of Health and Life Sciences, Marston, Oxford, OX3 0FL*

10.1136/bmjspcare-2013-000591.127

Background Regional children's palliative care networks play a role in planning and delivering equitable and high standards of

care, support and services to children with life-limiting and life-threatening conditions, and their families¹. Our local network has had a parent representative since 2010, and is one of only three to do so.

Aim To evaluate the success of the role

Methods We retrospectively reviewed the agenda and minutes of every meeting held between 2010 and 2013.

Results 15 meetings were held during the study period, and a parent representative was present at 14. Input made by parent representative included contributions to the work plan; engagement in discussions; offering information; and making specific requests.

Evidence was found that all the questions and requests made by the representatives were addressed. There were also clear signs that the representatives had had a wide influence, on shaping their role within our network, they have also influenced the education delivered by our group and made significant contributions to the ongoing work plan.

Conclusions

1. **Do we have regular parental representation?** 93% of meetings had a representative present
2. **Do Parent Representatives feel able to speak in the meetings?** Only one meeting attended by a representative didn't have a clear contribution. The parent representatives requested a regular dedicated agenda item, since then all meetings show a clear input.
3. **Are they heard?** 7/7 requests were accommodated and 8/8 questions were addressed either within the meeting or by follow up
4. **Do they make a significant contribution?** Parent representative lead to a clear development of the parent representative role, as well as a meaningful contribution to virtually every topic addressed by the group.

Applications This study demonstrates an example of good practice that may guide other networks in seeking user engagement. It highlights the impact and value of appropriate parental representation within paediatric palliative care networks. We have shared our experiences with others through Together for Short Lives network summit.

P106 EMPOWERING CHILDREN AND GUARDIANS IN MALAWI

¹Kate North, ²Joan Marston, ³Jean Tazue, ³Lameck Thambo. ²International Children's Palliative Care Network, ²Help the Hospices, London, UK, ³Palliative Care Association of Malawi

10.1136/bmjspcare-2013-000591.128

Introduction The project aims to support the development of children's palliative care services across Malawi. The project aims to integrate children's palliative care into existing service provision in 3 central hospitals.

Aims In this piece of work within the project, the project team aim to empower children and their guardians to be involved in, and inform, decisions that are made about the provision of paediatric palliative care, at local and national level.

Methods Regular empowerment workshops and focus group meetings are held with project beneficiaries (children and their guardians).

An advocacy meeting was between child beneficiaries and the Minister for Health for Malawi.

Learning and Results