

Hope House Children's Hospices

PARENT PARTICIPATION FORUM EVENTS – October 2013

Introduction

Hope House Children's Hospices believes strongly that service development must be needs led and that the direction of travel must be guided by the views of the people who use our services. The Parent Participation Forum was therefore established to facilitate meaningful discussions with parents and to enable their views to be fed back to the Board of Trustees. This feedback can then be used by the Board as they take strategic decisions and plan for the future.

All parents whose child accesses hospice services were invited to participate in the forum as well as parents who had been bereaved in the previous 3 years. The response from parents was very positive and the first Forum meetings were held at Hope House and Tÿ Gobaith on the 10th and 11th October 2013 respectively. On the day of the event several parents found they were unable to attend for a variety of reasons and ultimately 4 parents attended at each hospice. The meetings were also attended by the Vice Chair of the Board of Trustees and were facilitated by the Chief Executive and Director of Care. The Director of Fundraising also attended and supported the Hope House event.

Format of the day

The day commenced at 11am with coffee, brief introductions and an explanation of the programme. The CEO then gave a presentation on the strategic direction the organisation had taken over the last few years, key highlights and the current financial situation. Parents were then asked to comment on what had prompted them to come to the meeting and then to jot down issues/ideas/wishes that were important to them on post-it notes. They were asked to make these comments assuming we lived "in an ideal world" without the need for practical or financial limitations restricting their contributions. Parents could use as many post-its as they liked and the individual notes were then stuck onto posters on the wall. Each suggestion was then read out and the author had the opportunity to explain their thinking where necessary so that there was clear understanding amongst everyone present. This process led onto very interesting discussions about many diverse issues and the willingness of parents to share such insightful, personal and objective contributions was fantastic.

During a buffet lunch, whilst more informal chat continued, the CEO arranged the post-it notes into themes. Parents were then given 5 sticky stars each and were asked to score the theme (or individual idea where appropriate) according to how much of a priority the issue was for them. They could place all 5 stars against 1 theme if they chose, or they could place 1 star each against 5 different issues. Once the scoring had taken place, it was evident

which themes parents felt should take priority and this was backed up by a final discussion of the findings. After agreeing to reconvene the Forum in the spring of next year, the meeting closed at 2pm.

Key findings

The 4 themes which scored the highest overall and will need to be discussed by the Board of Trustees alongside the organisational development strategy were:

- **Transition and support for young adults**
- **In-house respite provision**
- **Outreach services**
- **Sibling support**

Details of individual comments within these themes can be found in Appendix 1 (attached). The table in Appendix 1 also shows the additional themes identified which, although were not scored as priorities were still clearly important to parents.

Next steps

In the current economic climate it is very unlikely that Hope House Children's Hospices can make significant investment into care services in the short term. That said it is extremely important that the organisation has a clear focus on future development and the priorities identified by the Parent Participation Forum will greatly assist the Board of Trustees and Senior Management Team to develop strategy in line with what people who use our services want and need.

All the themes and individual comments will be explored by staff at various levels within the organisation and any steps which can be taken in the immediate future to address issues or improve services within current resources will be collated into an action plan and fed back to parents, children and young people.

We are greatly indebted to the parents who supported us in this exercise and look forward to continuing this dialogue next year.

Kath Jones
Director of Care
November 2013

Appendix 1

Table of Themes and Individual Comments

Theme	Scoring	Individual comments	Current situation
Transition and support for young adults	9 stars	<ul style="list-style-type: none"> • Hospice for young adults 18 – 25 years (3 comments) • General support in transition • Lobbying Government for some sort of change in transition services 	In addition to the newly appointed Transition Nurse we are working with children’s hospices nationally as part of a Transition Taskforce looking to improve services and lobby Government for legislative changes. We are also collaborating in research looking at the needs of young people as they approach transition.
Respite (in-house)	7 stars	<ul style="list-style-type: none"> • More stays at hospice (4 comments) • No reduction in allocated nights • Organise stays with friend groups • Step down facility from hospital to home works very well and is important • Some in-house stays planned in advance, some nearer the time 	Families are currently allocated a set number of nights (based on clinical need and individual circumstances) respite booked up to 12 months in advance. Families can request additional emergency stays and when vacancies arise the Co-ordinators will contact families who have expressed an interest for additional short notice stays.

Theme	Scoring	Individual comments	Current situation
Expand outreach	6 stars	<ul style="list-style-type: none"> • Outreach support in hospital – very important (2 comments) • Support on discharge from hospital • Outreach support for whole family – i.e. outreach nurse for hospice child and sibling support for brothers and sisters simultaneously • More outreach availability (3 comments) • Overnight outreach 	<p>Outreach nursing is a priority led service. Support for end of life care is always considered the priority. Support for sick children in hospital and support during times of crisis is provided as often as possible. Respite from the outreach nursing team can only be offered if the team is not fully occupied with the previously mentioned situations. Overnight respite is not provided due to the impact this has on availability for other families (except in end of life care).</p>
Expand sibling support	6 stars	<ul style="list-style-type: none"> • Sibling support in-house when families are staying (3 comments) • Transport from home for siblings to attend sibling events • More sibling support at home (2 comments) • More sibling days out 	<p>There is currently a vacancy in the sibling support team which has impacted on the hours available. However the sibling support service has recently been moved into the outreach team which has increased flexibility. Sibling support is provided for families in crisis as a priority and support for others is offered as resources allow.</p>
Hydrotherapy pool	3 stars	At Tŷ Gobaith	<p>A feasibility study was undertaken into the possibility of a hydrotherapy pool at Tŷ Gobaith 2 years ago. Unfortunately the costs would be prohibitive and cannot be justified. Trips out for resident children to a local hydrotherapy pool are arranged weekly.</p>

Theme	Scoring	Individual comments	Current situation
Bereavement support and counselling	2 stars	<ul style="list-style-type: none"> • Snowflake Days are extremely important (2 comments) • Continue bereavement support (2 comments) • Tribute funds are important 	<p>Snowflake Day is recognised as an extremely important event for bereaved families and will be continued at both hospices. Bereavement support and counselling is a high priority for the organisation and there is no plan to reduce this service. Tribute funds remain an active initiative managed by the Fundraising Team.</p>
In-house systems and service provision	2 stars	<ul style="list-style-type: none"> • Shorter checking in process • More long shifts for staff so child can be cared for by same person in the morning and at bed time (Hope House) • No uniforms! • More trips out • More physiotherapy using child's own equipment and hydrotherapy • More music therapy 	<p>Although it is recognised that the admission process can feel quite long, the safety of the children is paramount and we feel it would be a mistake to try and cut corners. Long days (double shifts) are being reduced to ensure better staffing of the hospice and fair working patterns for all staff. A non-uniform policy will be maintained at the hospices. The physiotherapists target their support where it is felt to be most needed; we would ask families to let the care team know if a particular physiotherapy intervention would benefit the child during his/her stay. Trips out are arranged as often as possible, however the health of the children and staff numbers may limit availability for trips at times. Music therapy is available 1 day per week at Hope House and 4 hours per week at Tŷ Gobaith.</p>

Theme	Scoring	Individual comments	Current situation
Equipment and technology	2 stars	<ul style="list-style-type: none"> • Voice activation or other ways of controlling environment/TV independently (2 comments) • I Gaze • Equipment library for loaning to families • Having equipment to meet families' individual needs – e.g. standing frames 	<p>We have no voice activation devices. The young adult lounge has an automatic door opener and profiling beds can be controlled by young people who are able to use their hands. Occasionally we have been able to pass on donated equipment to a family who needs it. Limited storage space prevents us from being able to keep items for use by individual children.</p>
Ethos of care/relationships	1 star	<ul style="list-style-type: none"> • Really important that team know individual families • Important that fundraisers know who you are • Team really knowing the child is important • Staff mixing in the dining room is very positive 	<p>Individualised care, tailored to a family's needs is central to our philosophy. The social interaction of staff and families in the dining room is valued by the organisation.</p>

Theme	Scoring	Individual comments	Current situation
Help and advocacy for parents	1 star	<ul style="list-style-type: none"> • Advocacy and social work is very important • Need someone to talk you through services that are available – public and charity – a comprehensive guide • A “this is what we can do for you” guide for parents • Key workers • Training support for parents and other agencies – recognised qualification/certification • Library of help available – e.g. colleges of further education, alternative respite facilities (especially as Social Services no longer have an Information Officer post) • Social work support after death of child very important 	<p>The Social Work Team comprises 2 full time social workers at Hope House and 1 at Tŷ Gobaith with 1 full time Team Manager. Leaflets about the services the organisation provides are given to families as they start to use the hospice. We are involved in a Key Worker pilot study in Shropshire and Telford and Wrekin which has been very positive, however this comes to an end early in 2014. The Transition Team is currently compiling a resource about alternative services available in specific areas.</p>
Miscellaneous comments/ideas		<ul style="list-style-type: none"> • Holiday lodge with support for families (1 star) • Satellite respite/day facilities – especially in remote areas • Fun days for families 	<p>Tŷ Gobaith hosts fun days for families, now every other year. A fun day for Hope House families was arranged in 2012 at a venue close to the hospice, led by the Fundraising Team.</p>