

HOPE HOUSE CHILDREN'S HOSPICES

Family Satisfaction Survey 2013

Between March and June 2013 families were given a simple questionnaire to complete on discharge from the hospices. These questionnaires contained 3 questions which were designed to measure the quality of care a child had received, to highlight any improvements which could be made and to invite any other additional feedback families wished to offer.

The surveys could be anonymous if the parents chose, or names could be provided if a personal response was required. Any completed surveys could be posted in the hospice suggestion box or returned to the Director of Care in a reply paid envelope.

A total of 24 questionnaires were returned at Hope House and 9 at Tŷ Gobaith. The response rate was far lower than we had hoped for but there could be a variety of reasons for this. Many parents prefer to provide feedback verbally on discharge and would not then feel the need to comment in writing. At Tŷ Gobaith regular follow up phone calls are made to a family following discharge and feedback is often given at this point. Despite the low number of respondents it was felt to be a worthwhile exercise as it provided some families with a feedback mechanism which they were comfortable with. As well as the overall findings of the responses, the survey enabled individual concerns of families to be addressed in a timely manner.

Summary of Responses

<i>How would you rate the care you/your child received at Hope House/Tŷ Gobaith</i>					
Rating	Excellent	Good	Satisfactory	Fairly poor	Very poor
Hope House	79%	17%		4%	
Tŷ Gobaith	89%	11%			

The majority of families rated the care received as being excellent or good. One family rated the care at Hope House as being fairly poor. This respondent explained that normally they were happy with the care provided but that on this occasion the child's care plan had not been followed accurately resulting in discomfort for the child. A full investigation was undertaken and a breakdown in communication was identified. The child's care plan was subsequently updated and a senior nurse at the hospice discussed the situation in detail with relevant staff.

Suggestions of how things can be improved

Two respondents (1 from Hope House and 1 from Tŷ Gobaith) suggested that more walks outside and trips out would be nice.

Response: Outside activities are arranged as frequently as possibly but are reliant on a variety of factors such as staffing numbers, minibus drivers, health of resident children and weather. Staff do recognise how important different experiences are to the children and young adults and will do all they can to promote these opportunities.

One respondent from each hospice also felt that it would be better if the admission process could be shortened. Suggestions included being able to go through the care plan before coming in and if nothing had changed, not having to go through it on admission. One parent wondered if the medication could be written up in advance (following the reconciliation phone call), so that it could then just be checked off on admission, rather than having to write it all up from scratch.

Response: If there are major changes to a child's care plan, an outreach nurse may come to the home to review this prior to an admission, however this very much depends on other demands on the outreach nursing team at the time. It is not considered safe practice to write up medicines in advance as the nurse does require an accurate confirmation prior to transcribing any medication. There are sometimes last minute changes to medicines made between the reconciliation phone call and the admission. Also if the nurse undertaking the reconciliation phone call transcribed the medication at that time, she would need to be the nurse completing the reconciliation documentation on admission which would be very difficult to guarantee. That said we do recognise that the length of the admission process can be daunting and in 2014 we will be conducting a couple of small pilots looking at how we may reduce the length of time involved, without compromising safety and quality of care.

Respondents from **Hope House** also suggested the following:

A set structure to the day's activities for the child.

Response: Currently we do not have a set structure to the day within the Hospice other than lunch & tea times, this is predominantly due to the fact that each child/young person has an individualised care-plan and their day would predominantly follow that. Some children therefore have a very set and structured day to meet their needs and others have a more flexible day depending on what activities are available for them to participate in and best meets their needs. However, this will be discussed further at the team meetings to establish if there is anything we could do to support a more structured approach that would still provide some flexibility for those that need it.

Increased access to the hydrotherapy pool (2 respondents)

Response: We had prolonged technical difficulties with the hydrotherapy pool at Hope House which did mean the pool had to be closed for several weeks. This issue has now been resolved and the pool is fully operational. We hope this means that children can now enjoy this facility on a more frequent basis.

More consistent completion of hospice to home diary to gain a more complete picture of child's stay.

Response: The completion and use of the hospice to home diaries/activity sheets will be a particular objective for the care teams in 2014. Work will be undertaken to help us understand what information families want and to raise this awareness amongst care staff.

Provision for families to cook their own food in the parents lounge upstairs so they can feed very selective family members without feeling awkward about having to ask for different foods.

Response: Unfortunately the small kitchenette concerned will not accommodate the storage of necessary cooking items and equipment. We also have a health and safety responsibility to all children, families and staff and separate cooking facilities could be challenging to monitor. We cannot stress enough however that we are more than happy to cater for different requirements, likes and dislikes, just let the kitchen know (with a bit of notice) and they will do their best to meet your needs.

Three families made suggestions relating to the care of individual children/young people which staff were able to respond to immediately. These included issues around tactile play, use of Skype and use of video to increase staff's knowledge and understanding of a child's seizure patterns.

Response: We are delighted that families found the questionnaire a useful tool to give feedback and enhance their child's care. A supply of feedback forms will continue to be available in the foyers of both hospices and we welcome suggestions/comments from any family member. These forms can be used anonymously (if preferred) and can be returned in the reply paid envelopes kept with the feedback forms or can be placed in the red suggestion box in the foyer.

Further comments

Respondents from both hospices took the opportunity to tell us how they feel about the service provided and we are very grateful for their kind words. A small selection of these comments is shown here:

- *Tŷ Gobaith is a wonderful place with wonderful staff. We think you are all amazing.*

- *You all do an amazing job and I'm incredibly grateful to all staff for your level of care and being wonderful.*
- *Everything was exactly as expected from Hope House – excellent doesn't come near the care provided – it's beyond excellent.*
- *He loves coming and we enjoy the break knowing he's so well looked after.*

We are sincerely grateful to all who took the time to let us know how they felt and most importantly, how we can endeavour to improve.

Kath Jones
Director of Care
December 2013