



Re- Evaluation for Investing in Children membership:

Butterwick House Children's Hospice

Butterwick House Children's Hospice is a purpose built "home from home" providing care for children and young people with long term medical needs. Butterwick House offers a friendly and relaxing environment for babies, children and teenagers and their families, allowing them to feel safe, to have the opportunity to play, have fun, and to be listened to and supported.

The staff team at Butterwick House encompasses nurses, nursery nurses, health care assistants, specialist social workers, family support worker, chaplain, aromatherapist and doctors. Butterwick House also has a number of trained volunteers who contribute to the running of the hospice.

There are four bedrooms, a very large lounge with a kitchen area and a computer area. There is a newly developed messy room, multi-sensory room, hydrotherapy pool and a sensory garden. There is accommodation for families who wish to stay at the hospice with their children, and Butterwick House also has an adapted minibus for children and teenagers to use for outings.

For this re-evaluation I had the pleasure of meeting with Daniel and Andy, two young people who visit Butterwick House on a regular basis, and also Gail and Alison who work at Butterwick.

Evidence of Dialogue and Change

Equality Audit Tool

Gail and Alison explained that Butterwick Children's Hospice take part in an Equality Audit which is from the Association of Children's Hospices. It is a constant cycle which is led by two members of the team, not the managers. Feedback is given in the care team meeting and then planned into working practice.

The process of gathering information for the audit is very much based on speaking to children and young people and their families and using their input to develop the service. Gail feels that this makes sure that staff are constantly reminded that they need to be flexible and responding to the needs of their current client group. They are always challenged to think about children and young people. See attached evidence gathered.

Activities

Butterwick have taken a more flexible approach to activities, with access to the pool and other facilities in Butterwick available to children and young people and their families by making a phone call to make an appointment, subject to availability. On the day that I visited Daniel and Andy, they were part way through a four day stay at Butterwick during half term week. On that particular day Daniel had had a pyjama day. He hadn't felt like getting dressed and just wanted to have a day in his pyjamas, then later on he wanted to go in

the pool and so this is what he did. He told me, **“We take each day as it comes. You can just relax, it’s all okay.”**

Daniel said, **“There’s lots of activities to do, and electronic equipment.”**

Andy went on, **“You can bring your own games.”** And Daniel added, **“You can bring DVD’s and stuff.”**

Andy told me about a time when he and Daniel and another friend, who often visits at the same time as they do, enjoyed a DVD night. All three young people got out of their wheelchairs and got into their beds, then their beds were brought into the lounge so they could watch Big Momma’s House 2.

Andy said, **“When we can be bothered we play hide and seek. Once we played dodgeball.”**

Andy enjoys watching the television while Daniel is keen on playing on the Playstation. They are both glad that the lounge is so big and allows them all to do different activities in the same room. Andy said, **“I like to watch the soaps, it’s a good job there’s the other TV for the games. I stayed up until two once, just watching DVD’s.”**

Bookings Diary

Children and young people have requested stays with friends, and this is arranged accommodating school and college. Andy and Daniel enjoy spending time together at Butterwick as they are the same age, and they are in the same class at school. Andy told me, **“Someone else from our school comes as well sometimes.”**

Budget

Due to budget constraints there is now a set petty cash budget for weekend activities and the young people have been told how much money there is and they decide as a group what they will spend the money on. Daniel said they talk about **“where we feel like going.”** If everyone doesn’t want to go out that’s fine, **“you can stay here if you want,”** Andy told me, he also said they had to work together sometimes, **“If all three of us wanted something different it’s too hard, we have to agree.”**

Outings Policy and Procedure

This is currently being developed and should be ready in very soon. There has been a lot of work for the procedure part of the work - with a great deal of reference to including children and young people in planning all aspects of outings. This is a development from last year’s work on the policy.

Feedback

Generally feedback is on a one-to-one basis with young people and their family having 2 key workers to talk to. It is a very individual process, and staff at Butterwick involve families as much as possible. An example of this was when a health visitor informed Butterwick that a family of a 2 year old child wanted to use Butterwick once a week; however, when Butterwick contacted the family they felt that their child wasn’t ready for that yet, and neither were they so the staff at Butterwick have made different arrangements for that child.

Disability Helper Dog

Daniel has a disability helper dog and he requested that his dog came to Butterwick which was agreed, however it has meant that his choices in trips have been limited as it was not suitable to take the dog on the bus for big trips out. He said, **“Sometimes the dog has a rest when I come here, he works really hard. Sometimes he comes though. When I went to Kielder he was left behind.”**

Families

Andy talked to me about a time recently when he'd had a stay in hospital. During his time in hospital he and his family were asked if there was anywhere he could go to continue his care other than hospital. Andy was keen to get out of hospital as he was bored, so he suggested Butterwick House and they agreed to continue his care there and also his family were able to stay there too. **“I got treatment here so it wasn't boring, and my family were here to stay. It was about two weeks, they got all their meals.”**

Daniel and Andy both said that their families like Butterwick House. Daniel said, **“My sister always wants to stay.”** Andy added, **“My brother and sister do too. It's a long drive to get here but it's worth the drive though.”**

Their families stay for a cup of tea or coffee before setting off again.

Andy told me, **“My mam and family can ring me when they want or I can ring them on that phone when I want.”**

Food

Daniel told me, **“Sometimes we go out for meals and stuff.”** Both Daniel and Andy agreed that they could ask for just about anything to eat. They thought that staff prepared for their stay as there was always food in that they like to eat. Andy said, **“If there's nothing you like they look in the freezer.”** Daniel added, **“Or they go next door to have a look. They get ready for us.”** There are always snacks to have and everyone at Butterwick House is able to make Daniel's favourite eggy bread!

Other Opportunities for Development

Care Team Meeting Day

Every other month a care team meeting day is held, which pulls together the whole team, including the unit social worker, counsellor, and medical adviser. During this meeting day there is a 2 hour slot during which approx 8 children and young people are discussed in detail as an annual review. It is held in this way so that all staff can contribute to the discussion as often due to shift patterns and the booking in of young people some staff do not always have as much contact with some young people. Staff work 13 hour shifts to provide the most consistent care package.

Each child or young person has a key worker and co-key worker assigned to them and their families.

Communication Courses

Staff have requested training on communicating with children and young people who do not communicate verbally. Staff recognise that the young people have difficult issues to be brought out, and staff want them to be comfortable with them.

Contact with Children & Young People and their Families

There is an expectation that key workers will ring families if they haven't seen them recently for their input into the review. Requests from families are heard at the review and it is useful as the bookings team are also at the meeting and staff can discuss how often children stay and the needs of the children and their families.

Family Day

Butterwick held a Family Day in the summer and put on lots of the activities that the young people who visit Butterwick experience for their families to try out too.

During the day families were asked to fill in a questionnaire, and there was particular reference to siblings and what activities and trips they would like to take part in. There are plans to develop a sibling group using ideas from that day, and outdoor activities were requested.

Discussions

Teenagers have said that they want to talk more, have more opportunities for discussion, this does happen already but young people have said that they want more.

There is clearly a great deal of opportunities for children and young people at Butterwick House to have their say in how they spend their time whilst staying there. Andy said, **“Everybody’s friendly, it’s a lovely atmosphere, it’s the people.”**

Daniel added, **“I don’t think you can describe it, it’s just a happy atmosphere. You can just relax its all okay, you feel safe.”**

It is clear from Andy and Daniel just how much they enjoy their time at Butterwick House, and they both felt very strongly that another year of membership should be given.

Sadly, since this evaluation was written, Andy has passed away, however, both his and Daniel’s contribution to the report show that Butterwick House very much deserve their Investing in Children membership.

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