

Hospice Needs Assessment Report

2011 - 2012

Background

The assessor is a BA Hons second year Social Work student on placement from Anglia Ruskin University. She has been asked to ascertain from as many J's clients and families as possible their requirements from a young adult hospice building. Initially, the findings were to be delivered by way of presentation to The Land, Property and Planning Board Committee at the end of January 2012. This was extended to week commencing 25 February 2012 with a written report submitted week commencing 13 February 2012. Due to the limited time frame between commencing client and family engagement to the delivery of findings, it was decided to approach this project as a 'needs assessment' activity as oppose to a piece of social research. This is because of the lengthy time frame involved in obtaining advance ethical approval. The needs assessment was conducted between the period of 1 December 2011 to 8 February 2012.

Needs Assessment

The sample of young adults (here on in referred to as 'clients') and family's thereof assessed were a purposive sample, purposely selected to allow the assessor to explore the assessing area in greater detail and depth. The sample assessed were biased in that they were chosen to take part in the assessment because of a pre-existing relationship between them and the assessor; however this was not exclusive. The assessment took the form of an interview, with semi-structured, open questions. At times it was necessary for probing questions to be asked in an attempt to extract deeper and broader thoughts and answers. The assessment was conducted in this manner because it was believed this would allow for a broader conversation around client and family requirements of a young adult hospice building. In all instances the needs assessment took place face-to-face, however in the case of two primary carers, the assessment occurred over the telephone. The needs assessment questionnaire is attached at annex 1 (NA1).

Client Profile

Two client groups were assessed, verbally and non-verbally communicative. Of the verbally communicative clients, nine were assessed. Of the non-verbally communicative clients, none were assessed; though engagement was had with their primary cares (parent(s)). Every attempt was made to engage creatively with the non-verbally communicative clients however their parents(s) deemed this an unattainable task due to their children providing inconsistent choices. In addition the parent(s) believed their child to have limited cognitive ability. With this in mind, the assessor asked the parent(s) to put themselves in their child's shoes and to respond to the assessment from their child's perspective. For ease of reading, these responses will be communicated in this report as if this client group were directly engaged with.

Verbally communicative

Eight clients were assessed, seven male and one female. Five of which are wheelchair users, one is a non-wheelchair user and two occasional wheelchair users. All clients live at home with their parent(s). Of the eight clients assessed, engagement was had with five extended families. The age range of these clients was from 18 to 42 years, with the average age being 29.75 years. All anonymised assessment responses are attached to annex 2 **(NA2)**.

Non-verbally communicative

Nine clients were assessed, three male and six female. All nine clients are wheelchair users. Of the nine clients, four are in education, two have full time carers, one attends a day centre and two have carers and engage in education. All nine clients live with their parent(s). The age range of these clients was from 18 to 27 years, with the average age being 20 years. All anonymised assessment responses are attached to annex 3 **(NA3)**.

Common Themes – wishes from the clients

Verbally communicative

There were distinct commonalities between the needs of those assessed. These materialised by way facilities which should be offered. All eight clients assessed said they would attend and engage with a Young Adult in-house hospice facility. My interpretation of the information provided during the assessment, indicates a need for social engagement and inclusion in activities which are predominantly in-house, though a desire for external social engagement was occasionally expressed. My interpretation of the feedback was that these young adults wanted to engage in social activities with each other, as oppose to engage with external, unknown peers. I formed the impression that clients viewed The J's Hospice as an organisation to link them with new peers with similar needs to their own. No reference was made towards the organisation being somewhere to attend for medical reasons; however one client made reference to it being a facility to accommodate end of life. The majority of clients expressed their want for the hospice building to be a warm, welcoming and homely environment. One described it as a building which felt like a holiday – so he would want to go back.

All clients highlighted the importance of choice of services for them to engage (or not) in. All clients wanted a social room where they could meet up and engage in computer games, have discos, take part in themed events, trivia and quizzes, watch a movie through a home cinema system and have internet access and sky TV. They all spoke of it as an area to catch up with friends and a chance to have a drink (though none expressed a desire for an alcoholic bar).

The majority of clients assessed expressed a need for different spaces in the hospice building – a social room which was the hub, a lounge, dining area and quiet room. My interpretation of the lounge was a space which was not as 'active' as the social room, and the quiet room was a space to be private and alone with ones thoughts, books or magazines but a room which was not the bedroom they were staying in if visiting overnight.

All clients assessed express the desire for external garden space, with two making additional requests for an indoor garden area. They all saw the garden as an area for them to become involved with vegetable patches, gardening and having the option of planting and tending to flowers. Most saw this as achievable through raised garden beds. The majority of clients also made reference to the garden being a sensory experience with fragrant flowers and herbs. A majority expressed an interest for a water feature in the garden, hard landscape, a BBQ terrace area to enjoy during the winter or summer and for there to be shelter. The two clients who spoke of an internal garden space saw this as being able to bring all of the above outdoor facilities into a smaller indoor courtyard with a glass roof so the sky could be seen and bring natural light indoors. I believe an indoor garden area was sought so that garden space was accessible during colder winter months.

All clients assessed expressed their want for singular bedrooms. They saw these as being neutral in colour, with appropriate adaptations and equipment for their conditions. For example the positive impact of having raised plug sockets (and plenty of them for equipment) demonstrates an inclusive environment in a world which is predominantly exclusive to their lifestyle. The majority of clients wanted items such as armchairs and shelving in the bedrooms. All clients expressed the need for ensembles with appropriate aids such as hoists and tracking systems. Many asked for profile beds and spoke of a need for double beds so that partners and friends could stay over.

During the assessment many extrapolated views and needs were expressed. As these are not commonalities, they will not be mentioned in this report. This information can be found in the individual responses annexed at **NA2**.

Non-verbally communicative

Again, there were distinct commonalities between the needs of those assessed. These related to facilities and social engagement. All nine said they would use a Young Adult hospice facility building, predominantly for overnight respite, however there were a couple who expressed a preference for day facilities. My interpretation of the information provided in the assessment indicated towards a need for social engagement and inclusion through group activities which were predominantly in-house, though a desire for external social engagement was occasionally expressed. Art therapy (or classes), music therapy, themed events (such as puppet shows, discos and fancy dress) and home cinema experiences were common preferences. There was also a strong expression for complimentary therapy, physiotherapy, a hydrotherapy pool and sensory rooms – the benefits of such forms of therapy were expressed, and these were deemed paramount for a young adult hospice. There was a general consensus that a lot of fun had to be incorporated into the social activities. The majority expressed a want for the hospice building to be a warm, welcoming and homely environment which was family friendly. Again, there was an expressed need not to make clients feel like medical patients.

All clients expressed a desire for external garden space. They all made reference to the garden being sensory and interactive with water features and a wheelchair accessible playground. They also believed the garden should facilitate sporting facilities such as wheelchair football. Some expressed the enjoyment they experience from outdoor animals and wildlife, such as hens, ducks and wild birds attracted by bird feeders. All clients assessed who wanted vegetable patches and a small holding

expressed their excitement and the benefits of being able to use produce from the grounds in hospice cooking.

The majority of clients asked for a social room where they could engage in themed events and watch movies through a home cinema system. The majority of clients expressed a desire for different spaces in the hospice building – a social room which was the hub of the hospice, a dining area and a quiet room. My interpretation of the quiet room was one which was less engaging and interactive so as to have a more calming influence on them and reduce excitement – one does not always want to be in an energy charged environment.

All but two clients expressed a desire for singular bedrooms (they were related). Clients saw the bedrooms as being gender appropriate in colour and decoration. Bedrooms should also be adapted to the physical conditions and mentality of clients; for example the bedrooms would have visual and auditory stimulation. Ensuites were not deemed necessary.

In relation to mealtimes, all but one client expressed a desire to be engaged with food, even those who do not eat verbally. Choice was highlighted as an important factor in food engagement. Many clients expressed a wish that meal times took place in a multi-functioning room which they could be in, even if they chose not to sit at the table. Many spoke of the importance of the social interaction had at dinner time and the importance of having the option to engage in this atmosphere regardless of their oral eating abilities.

During the assessment many extrapolated views and needs were expressed. As these are not commonalities, they will not be mentioned in this report. This information can be found in the individual responses annexed at **NA3**.

Wishes from the Family.

There were distinct differences and commonalities between the family members of the two client groups. All family members expressed the wish that their child is well looked after in a well-equipped facility which was as non-clinical as possible. Most expressed the importance of choice being offered to their child in terms of whether they wanted to engage in facilities and activities. It was important that there was not expectancy in participation. Most parents did not see it necessary for there to be constant activities available to their children, as this is not how life usually is.

Verbally communicative

A limited number of parents were assessed in this group in comparison to the other group. This was primarily due to appointments being made at a time when their parent(s) were out of the family home. However, five family carers were assessed. Of these five families, two sets were husband and wife and three were maternal primary carers. Parental views were generally very similar to one another. These primarily concerned The J's Hospice providing a varied social environment for their child to engage and participate if they desired. Most of the parents expressed they would not want to stay during their child's visit, though some would like to be able to come in for a drink. A homely environment was also sought with little reference to their child's clinical care due to the numerous hospital and medical appointments their child has been engaged with over the years.

Non-verbally communicative

The majority of parents expressed they would like family living quarters which they could stay in during the first few bookings so as to be on hand if staff required their assistance with any basic or medical care. I sensed the first few overnight stays was viewed as facilitating introductions for both the parents and their children until such time as confidence had been built in The J's Hospice. Once trust was built, this would allow parents to stay away safe in the knowledge that their child was being fully and appropriately cared for. During their stay, parents expressed the importance of having the choice to engage in meal times and the general goings-on at the Hospice. Many of the parents expressed their previous experiences in children's hospices as ones where choice was not an available option. Many of the parents expressed that they would view their stay as a break and a time to relax, doing as little as possible (other than if they needed to assist with care for the child).

Parents also expressed the helpfulness of being able to seek advice from different professional staff. These included:

- 1) A GP (or an adult equivalent of a paediatrician). Parents expressed that this would be useful in instances where, for example, a new symptom was being demonstrated by their child and they sought advice; one parent expressed how they felt that now their child was part of adult services no one professional saw them more than twice – they are unknown to professionals and there is no, or little relationship had with medical professions.
- 2) A Counsellor. Some of the parents expressed a desire to 'unofficially offload'. They felt the association with counselling was too formal and they viewed themselves as carers who have managed their child's illness for many years and the need for official counselling was not required. However 'unburdening' unofficially would be a nice.
- 3) Social Worker. Some of the parents expressed a wish to be able to speak with someone in know of the British benefits system and who could advise on available financial support through the form of benefits. One family referred to the British benefit's system as a 'minefield'. Human Rights was also an area of knowledge sought by one particular family.

Other facilities

- 4) Sibling Groups. This was viewed as beneficial, and in some instances crucial, for siblings of those who lived in a household with illness and disability.
- 5) End of life care was a topic of conversation the assessor initially had not thought to engaged in, however it was raised openly by three carers from the non-verbally communicative clients and by one verbally communicative client. These people saw The J's Hospice as an organisation which facilitated end of life care either at the hospice building or in family homes.

Conclusion

The evidence collated thus far demonstrates a need for a Young Adult Hospice building and that this facility will be used in many ways. Most clients were users of Little Havens Childrens Hospice and all spoke very highly of that service and their facilities, however now that they have reached 'adult' age they felt adult hospices were not entirely appropriate for their still youthful spirit. The assessor took on the message of "these young adults still had so much life left to live" and now they were thrust into

mainstream society, with limited support from appropriate agencies, it were these new mainstream encounters which made them not always feel socially included due to their differing physical and mental needs and abilities. Therefore their lives were becoming increasingly insular and isolated. As such they saw the Young Adult Hospice as being a facility to keep their social engagement alive. On the other hand, some of the clients began developing their life threatening or life limiting illness in adulthood, and were free from their condition as a child. As such they had no previous experience of who to approach for services that could support their increased care and social needs. It is this group that the assessor believes would benefit the greatest from a young adult hospice facility as it creates the opportunity for them to view their change in medical condition as something which can be accommodated and offer a network of similar individuals who can aid and assist in this transition from an old to new life style. The J's hospice has a real opportunity to create an inclusive environment which is equipped for varying needs that mainstream society omits from its structure.

Those assessed saw the building as being a multi-functional unit, available to wider society, both socially and in business with the view of generating revenue for the charity. During some discussions, clients and their families thought it a real possibility that The J's could create employment for its clients. This was seen as being offered by way of upkeep of the facility/building, the staffing of kitchens and general housekeeping. Further one client spoke of how they believed The J's would be sensitive and accommodating towards disability and illness which other businesses did not empathise with, and therefore things such as regular breaks or hospital appointments would not be seen as an obstacle that interfered with the delivery of work.

This assessment highlights a number of ethical dilemmas whilst also demonstrating structural, societal and cultural discrimination towards a marginalised societal group. On the one hand, clients and their family's speak of a need for social engagement which they feel they are not receiving from 'mainstream' society whilst on the other hand The J's could arguably run the risk of institutionalising and further isolating an already marginalised societal group from society should engagement always be within the parameters of the Hospice building. However attention to detail and multi-disciplinary collaboration would undoubtedly eradicate any such occurrences.

All participating clients have been informed that they are free to request a copy of this report and that there is a note on their file that they participated in this needs assessment. They were all given the opportunity to disengage from future focus groups, however none (at the time of writing) asked to be removed from further participation.

Lastly, as a recommendation, the assessor believes that to be truly inclusive of all The J's clients, every attempt should be made to creatively engage with non-verbally communicative clients. This can be made through smaller tasks (i.e. this assessment was too large scaled, and therefore excluded participation) such as seeking preference to colour swatches for bedrooms, asking closed questions with yes and no answers and gaining these through repetition. Another method of engagement could be by utilising family members they communicate with or teachers at their schools who may have specialist equipment which can be used.

ANNEXES

NA1

COMMUNITY NEEDS ASSESSMENT
FOR YOUNG ADULTS AWAY FROM HOME RESPITE CARE

PATIENT WISH LIST FOR THE J'S HOSPICE BUILDING

QUESTIONS ASKED TO THE CLIENTS:

- 1) If The J's built a hospice building, would you use it?
- 2) How often do you think you would use the hospice facilities?
 - a. Day care facilities?
 - b. Respite overnight care?
 - c. Both?
- 3) What do you see there being in the building?
- 4) What sort of facilities do you think the hospice should offer?
 - a. Counselling?
 - b. Therapy?
 - c. Physio?
- 5) Do you want a social room?
 - a. What do you see the social room offering?
- 6) How do you envisage/see the facilities being offered?
- 7) Are there any other rooms that you would like in the building?
- 8) Do you think that the hospice should offer a cafe service or formal dinner arrangements?
- 9) Would you like there to be animals in the building?
- 10) Would you like a garden?
- 11) What do you want in the bedrooms?
- 12) Is there anything you would like to add?

QUESTIONS ASKED TO THE FAMILY:

- 1) What service would you like The J's Hospice to offer your daughter/son?

- 2) Would you come and spend time at the hospice in your own right, or would you spend time there to support your daughter/son?
- 3) If you would spend time there in your own right, how would you like to do this?
- 4) Do you think there should be family living quarters?
- 5) Would you like a cooked hot meal or a cold finger meal if you were there at lunch or dinner time?
- 6) Is there anything you would like to add?

NA2

COMMUNITY NEEDS ASSESSMENT
FOR YOUNG ADULTS AWAY FROM HOME RESPITE CARE

PATIENT WISH LIST FOR A J'S HOSPICE BUILDING

QUESTIONS ASKED TO PARTICIPANT 1

- 1) If The J's built a hospice building, would you use it?
 - Yes.

- 2) How often do you think you would use the hospice facilities?
 - I would stay over 4/5 times a year and use it for day time activities.

- 3) What do you see there being in the building?
 - 3 rooms/areas designed in a way so that they are all together but distinctly different area.

- 4) What sort of facilities do you think the hospice should offer?
 - Crafts
 - Arts
 - Physio Room
 - Relaxing rooms
 - Sensory rooms
 - Swimming pool
 - Social room
 - Cinema experience.
 - Music therapy
 - Counselling
 - Baking classes

- 5) Do you want a social room?
 - Yes

- 6) What do you see the social room offering?
 - Nails
 - Computers (for social networking)
 - Acupuncture/Reiki/Reflexology (these were offered by my practice educator, however SJ said she would engage in these as she hadn't experienced them before).
 - Wii
 - The room must be multi-functioning.

- 7) How do you envisage/see the facilities being offered?
 - Booking system

- 8) Are there any other rooms that you would like in the building?
- Lounge and chill out room.
- 9) Do you think that the hospice should offer a cafe service or formal dinner arrangements?
- Hot meals should be made available at lunch and dinner times (set times)
 - There should be a choice of food.
 - There should also be the option to take food/drinks away
- 10) Would you like there to be animals in the building?
- Cats and dogs are therapeutic
 - Fish in a tank would be nice.
- 11) Would you like a garden?
- Yes
 - Strong smells
 - A grow your own patch – vegetables and flowers
 - Daffodils
 - Hard landscape, not soft flooring
 - Internal courtyard area
 - Terrace.
- 12) What do you want in the bedrooms?
- Neutral colours
 - Soft furnishings
 - Bathroom/en suite
 - TV/radio
 - Armchair/sofa
 - Important to be able to escape from the communal area
 - Shelving/reading lights/ambient lighting
 - Chest of drawers
 - Plug near the bed so I can listen to audio books/book rest
- 13) Is there anything you would like to add?
- It would be nice to go on day trips.

QUESTIONS ASKED TO THE FAMILY

- 1) What service would you like The J's Hospice to offer your daughter/son?
- Social activities – see point 6 below for additional information.
- 2) Would you come and spend time at the hospice in your own right, or would you spend time there to support your daughter/son?

- No. Though we would be willing to volunteer there. Also we would like to pop in (if and when the need arose) for a Saturday night dinner if our daughter was staying plus a couple of hours.
- 3) If you would spend time there in your own right, how would you like to do this?
N/A
- 4) Do you think there should be family living quarters?
N/A
- 5) Would you like a cooked hot meal or a cold finger meal if you were there at lunch or dinner time?
N/A
- 6) Is there anything you would like to add?
- We would like the environment to have soft colourings.
 - Rooms to open up into a garden/outdoor space.
 - Outdoor seating space and outdoor awareness.
 - Sky domes to allow natural light into the building.
 - Religious/sanctuary/meditation/spiritual room.
 - Movie experiences/Saturday night movie night.
 - Entertainment – dances and discos
 - Themed events.
 - For our daughter to not be forced to take part in events – she be allowed to come and go as she pleased.
 - Ample of parking facilities.

END

COMMUNITY NEEDS ASSESSMENT
FOR YOUNG ADULTS AWAY FROM HOME RESPITE CARE

PATIENT WISH LIST FOR A J'S HOSPICE BUILDING

QUESTIONS ASKED TO PARTICIPANT 2:

- 1) If The J's built a hospice building, would you use it?
 - Yes when home from university.

- 2) How often do you think you would use the hospice facilities?
 - Both overnight and day time visits – provisionally 4 times a year over night stays.

- 3) What do you see there being in the building?
 - Computer/internet/games consoles (x-box).
 - Educational courses – history and IT app programming and designing.
 - Neutral coloured rooms.

- 4) What sort of facilities do you think the hospice should offer?
 - Complimentary therapy.
 - Hydrotherapy pools – though I cannot use these myself, others should have this facility.
 - Clos-o-mat toilet – allows for washing and drying with dignity.

- 5) Do you want a social room?
 - Yes, with a home cinema system that a lot of people can enjoy together.

- 6) How do you envisage/see the facilities being offered?
 - Art classes/therapy – I cannot do this because of my condition but would try it if offered in a way accessible to me.
 - Day trips – cinema, history/museum/military museum etc.

- 7) Are there any other rooms that you would like in the building?
 - I need a quieter room where I can sit and have a conversation as I have got a quiet voice and cannot always be heard – a lounge type room.

- 8) Do you think that the hospice should offer a cafe service or formal dinner arrangements?
 - No preference as I do not eat food. I enjoy being part of meal times though.

- 9) Would you like there to be animals in the building?
 - Outdoor animals only.

- 10) Would you like a garden?
 - Yes, dependant on weather and temperature.

- The garden should be sensory and user friendly – at Little Havens there are paths going round the garden which is smooth pathing with no cobbles or gravel.
 - It would be good to have raised flower beds.
- 11) What do you want in the bedrooms?
- Fairly large room to get around in wheelchair.
 - Hoists,
 - Profile bed,
 - TV,
 - Computer consoles,
 - A lot of plug sockets as I use a lot of sockets for all my equipment,
 - Access to outdoor space from bedroom,
 - Ensuite wet rooms which are a decent size to position things, and
 - Clos-o-mat toilet.
- 12) Is there anything you would like to add?
- I would take on appropriate employment if offered at the hospice.
 - It would be nice to have people come into the hospice to talk about employment options of getting into the work place.
 - It is important for the designing of the building and the interior to be as non-clinical as possible as hospital environments hold negative connections.

QUESTIONS ASKED TO THE FAMILY:

- 1) What service would you like The J's Hospice to offer your daughter/son?
- Complimentary therapy
 - Trips out
 - Arts and music do not interest my son
 - Employment opportunities – this would make my son feel secure as they would be aware of his needs and accepting of these.
 - Counselling.
 - Outside space is very important.
 - Raised flower beds so plants can be touched.
 - Water features.
 - Benches with space – a social area to spend time outside, such as BBQs on a Saturday night.
- 2) Would you come and spend time at the hospice in your own right, or would you spend time there to support your daughter/son?
- Would depend on my son's feelings about us staying – we are guided by his choices.
 - Would like to give our son his own space.
- 3) If you would spend time there in your own right, how would you like to do this?

- N/A
- 4) Do you think there should be family living quarters?
- 5) Would you like a cooked hot meal or a cold finger meal if you were there at lunch or dinner time?
- He is sociable and will sit with others to eat food as it's a social element.
- 6) Is there anything you would like to add?
- The building should be nice and big where our son can spend time doing different things, e.g. social rooms with TVs and computers.
 - The accommodation should be nice for overnight visits with a homely feel to it as he already has a lot of hospital appointments.
 - We would be happy knowing he was safe, secure and being looked after.

END

COMMUNITY NEEDS ASSESSMENT
FOR YOUNG ADULTS AWAY FROM HOME RESPITE CARE

PATIENT WISH LIST FOR A J'S HOSPICE BUILDING

QUESTIONS ASKED TO PARTICIPANT 3:

- 1) If The J's built a hospice building, would you use it?
 - Yes.

- 2) How often do you think you would use the hospice facilities?
 - Predominantly social day care. I am not ruling out respite, however I would have to feel confident in the carers.

- 3) What do you see there being in the building?

- 4) What sort of facilities do you think the hospice should offer?
 - Not for me personally, but for others:
 - Swimming pool
 - Hydrotherapy pool
 - Computers,
 - Games, both board and computer
 - Social area/bar area (though not necessarily with alcoholic drinks)
 - Trips to places to go out would be really nice,
 - Cinema area with normal chairs and space for wheelchairs and beds
 - St. Thomas' have a small theatre area and that would be nice at this hospice.
 - Would be nice to feel like I was going away for a weekend – a holiday, and although there will be medical staff, it is important for the atmosphere to feel holiday-like.
 - Treatment room where you can get your hair done and other treatments such as manicures.
 - Massage
 - Physio
 - Counselling
 - Spiritual room/multi faith room/somewhere to think – a place where everyone feels comfortable.

- 5) Do you want a social room?
 - Games room
 - Bar area
 - Somewhere to sit and chat and relax with friends and carers.
 - Could just have a coffee
 - Play board games/computer games
 - Disco
 - TV

- 6) How do you envisage/see the facilities being offered?
- 7) Are there any other rooms that you would like in the building?
- Chill out room,
 - Conservatory area,
 - Somewhere to sit and relax as some days it's not warm enough to go out,
 - The games room should be off the social room.
- 8) Do you think that the hospice should offer a cafe service or formal dinner arrangements?
- There should be choice of whether to eat at the dining table or not.
 - Meals should be offered over a couple of hours and a coffee shop facility for those who haven't got up in time.
- 9) Would you like there to be animals in the building?
- Some people may be allergic, a bit dodgy.
 - Outside animals are okay – rabbits, guinea pigs and birds.
- 10) Would you like a garden?
- Fish pond
 - Seating/BBQ area
 - Garden area can be seen from conservatory.
 - Always looking pretty and smells nice.
 - There should be a water feature,
 - Raised flower beds so patients can do gardening.
 - Sensory
 - Different surfaces – not just for wheel chairs
 - Sensory flooring for those who cannot see
 - Different sounds – need a garden that is available to everyone who are missing senses.
- 11) What do you want in the bedrooms?
- Somewhere for clothes
 - TV/DVD
 - Ensuite
 - Computer
 - Sky
 - Tilting bracket so that you can watch TV when lying in bed most hospitals have them
 - Comfy chairs for family and friends - No plastic chairs.
- 12) Is there anything you would like to add?
- End of life care in the hospice.
 - Homely and calm environment – not like a hospital, somewhere where you feel comfortable.

QUESTIONS ASKED TO THE FAMILY:

- 1) What service would you like The J's Hospice to offer your daughter/son?
- 2) Would you come and spend time at the hospice in your own right, or would you spend time there to support your daughter/son?
 - No.
- 3) If you would spend time there in your own right, how would you like to do this?
- 7) Do you think there should be family living quarters?
 - Yes. Dependant on my son's sickness is dependent on whether we would come and stay.
- 4) Would you like a cooked hot meal or a cold finger meal if you were there at lunch or dinner time?
- 5) Is there anything you would like to add?

END

COMMUNITY NEEDS ASSESSMENT
FOR YOUNG ADULTS AWAY FROM HOME RESPITE CARE

PATIENT WISH LIST FOR A J'S HOSPICE BUILDING

QUESTIONS ASKED TO PARTICIPANT 4:

- 1) If The J's built a hospice building, would you use it?
 - Yes.

- 2) How often do you think you would use the hospice facilities?
 - I would stay as often as possible – would visit once per week, and stay over for 2/3 weeks per year.

- 3) What do you see there being in the building?

- 4) What sort of facilities do you think the hospice should offer?
 - Lounge for relaxing in.
 - Library with comfy chairs – somewhere to curl up and read a book/magazine
 - Wii, skalectics, coffee/tea facilities.
 - Music therapy rooms
 - Massage therapy – I would try other forms of therapy if available.
 - Wouldn't want to make jewellery or take part in acupuncture (needle aversion)
 - Themed events such as cinema nights/days, Italian themed days (fancy dress, trivia, dressing up), Quiz nights and day trips.

- 5) Do you want a social room?
 - Yes.

- 6) How do you envisage/see the facilities being offered?

- 7) Are there any other rooms that you would like in the building?

- 8) Do you think that the hospice should offer a cafe service or formal dinner arrangements?

- 9) Would you like there to be animals in the building?

- 10) Would you like a garden?
 - Yes if it's a nice day we could have a BBQ in the summer or even the winter on fireworks night.
 - Sensory garden with scented flowers/herbs

- Shaded area
 - Water feature “trickle sound” and to be able to watch it. No need for a pond with the health and safety dangers (Alnick Gardens in Northumberland have a good water feature).
 - Must be wheelchair friendly.
 - No cobbles or pebbles
- 11) What do you want in the bedrooms?
- Yes
 - Cupboards/TV/curtains and carpet
- 12) Is there anything you would like to add?
- No

QUESTIONS ASKED TO THE FAMILY:

- 1) What service would you like The J’s Hospice to offer your daughter/son?
- A place where I am confident that the staff understands my son’s requirements and that he was safe when left there in The J’s care.
 - Would feel comfortable knowing that my son wanted to attend off his own accord, and that he was not being forced to go – there is a difference between knowing each other needs a break and the person wanting to go off their own accord.
 - To offer end of life care – this is an important provision to offer.
- 2) Would you come and spend time at the hospice in your own right, or would you spend time there to support your daughter/son?
- Yes, would come to spend time with RY.
 - Wouldn’t come and spend time there on my own.
- 3) If you would spend time there in your own right, how would you like to do this?
- 4) Do you think there should be family living quarters?
- 5) Would you like a cooked hot meal or a cold finger meal if you were there at lunch or dinner time?
- 6) Is there anything you would like to add?

END

COMMUNITY NEEDS ASSESSMENT
FOR YOUNG ADULTS AWAY FROM HOME RESPITE CARE

PATIENT WISH LIST FOR A J'S HOSPICE BUILDING

QUESTIONS ASKED TO PARTICIPANT 5:

- 1) If The J's built a hospice building, would you use it?
 - Yes.

- 2) How often do you think you would use the hospice facilities?
 - Twice a week during the day – I would not stay over.

- 3) What do you see there being in the building?

- 4) What sort of facilities do you think the hospice should offer?
 - Outdoor wizard tournament:
 - He wants a room to practice in
 - He would like to do this on his own
 - Sleigh dragons
 - Held twice a year
 - Prize is a wizard's cup.
 - Music therapy
 - Sensory – where I can experience the touch of different textures, i.e. feathers and bubble wrap. I would also like to experience the sensation of a waterbed. I don't want to experience any light sensor as it triggers headaches.
 - Hydrotherapy.

- 5) Do you want a social room?
 - Yes

- 6) How do you envisage/see the facilities being offered?
 - Doctors surgery
 - Education

- 7) Are there any other rooms that you would like in the building?
 - Chill out room where a bunch of people can watch a movie or have stories read tot hem
 - Games room – Nintendo Wii

- 8) Do you think that the hospice should offer a cafe service or formal dinner arrangements?

- 9) Would you like there to be animals in the building?

- I like animals, in particular cats and owls
- 10) Would you like a garden?
 - Yes.
 - 11) What do you want in the bedrooms?
 - No
 - 12) Is there anything you would like to add?
 - No

QUESTIONS ASKED TO THE FAMILY:

- 1) What service would you like The J's Hospice to offer your daughter/son?
 - Support for my grandson
- 2) Would you come and spend time at the hospice in your own right, or would you spend time there to support your daughter/son?
 - To support my grandson.
- 3) If you would spend time there in your own right, how would you like to do this?
 - In an art room – not art classes, but a room where I could go in and pick up some art materials if I felt like it (this answer was forcefully extracted from 'nan').
- 4) Do you think there should be family living quarters?
- 5) Would you like a cooked hot meal or a cold finger meal if you were there at lunch or dinner time?
 - Cooked.
- 6) Is there anything you would like to add?
 - No.

END

COMMUNITY NEEDS ASSESSMENT
FOR YOUNG ADULTS AWAY FROM HOME RESPITE CARE

PATIENT WISH LIST FOR A J'S HOSPICE BUILDING

QUESTIONS ASKED TO PARTICIPANT 6:

- 1) If The J's built a hospice building, would you use it?
 - Yes.

- 2) How often do you think you would use the hospice facilities?
 - I would stay the night six times a month.

- 3) What do you see there being in the building?

- 4) What sort of facilities do you think the hospice should offer?
 - Sensory room with soft padding, bean bags and waterbed.
 - Physiotherapy.
 - Complimentary therapy.
 - Comfy girls corner for mum to read magazines.
 - Discos and events like Britain's Got Talent nights.
 - Horse racing night for my dad in the social room.
 - Swimming pool
 - Jacuzzi

- 5) Do you want a social room?
 - Yes

- 6) How do you envisage/see the facilities being offered?
 - Doctors surgery

- 7) Are there any other rooms that you would like in the building?

- 8) Do you think that the hospice should offer a cafe service or formal dinner arrangements?

- 9) Would you like there to be animals in the building?

- 10) Would you like a garden?
 - Yes, with a playground.

- 11) What do you want in the bedrooms?
- I would like mine to be green.
 - With an electric double bed
 - Bedside table
 - Over the bed table
 - Sofa/armchair
 - HD TV & DVD player
 - PS 3
 - PC
 - Desk for PC to go on.
 - Curtains
 - Laminate floor
 - Eminem and Michael Jackson posters on the wall.
 - Posters of naked girls on the walls.
- 12) Is there anything you would like to add?
- I don't want my family to stay over.
 - Can the hospice be designed like a house with bedrooms upstairs.
 - Day trips would also be nice to car races.
 - Cooked dinners would also be nice.

QUESTIONS ASKED TO THE FAMILY – FAMILY NOT ASKED:

- 1) What service would you like The J's Hospice to offer your daughter/son?
-
- 2) Would you come and spend time at the hospice in your own right, or would you spend time there to support your daughter/son?
-
- 3) If you would spend time there in your own right, how would you like to do this?
-
- 4) Do you think there should be family living quarters?
- 5) Would you like a cooked hot meal or a cold finger meal if you were there at lunch or dinner time?
-
- 6) Is there anything you would like to add?
-

END

COMMUNITY NEEDS ASSESSMENT
FOR YOUNG ADULTS AWAY FROM HOME RESPITE CARE

PATIENT WISH LIST FOR A J'S HOSPICE BUILDING

QUESTIONS ASKED TO PARTICIPANT 7:

- 1) If The J's built a hospice building, would you use it?
 - Yes.

- 2) How often do you think you would use the hospice facilities?
 - For day care facilities and overnight respite care.
 - I would not use it during the day. It depends what is going on.
 - I would stay over if mum and dad were going away for a weekend.

- 3) What do you see there being in the building?

- 4) What sort of facilities do you think the hospice should offer?
 - Massage therapy - I would not come down especially for therapy but would book to have it if I was coming down anyway.
 - A home cinema system so we could watch movies/have a home cinema experience.
 - PC's
 - Tuck box
 - Sky TV in the main room, not the social room, but if it was in all rooms, that'd be great.
 - Art room would be good and art sessions offered which made art work an achievable thing to do, i.e. putting a paintbrush in my mouth.

- 5) Do you want a social room?
 - Yes

- 6) How do you envisage/see the facilities being offered?
 -

- 7) Are there any other rooms that you would like in the building?
 -

- 8) Do you think that the hospice should offer a cafe service or formal dinner arrangements?
 - Cafe style catering, as not everyone wants to eat at specific times.

- 9) Would you like there to be animals in the building?
 - Fish tank – would be nice to watch fish swimming about and it is relaxing to listen to the sound of water.

- 10) Would you like a garden?
- I would like an indoor garden area with a fountain, somewhere I can sit and listen to the water. A space which is indoors but feels like your outdoors. A space I can use in the winter. There should be herbs, smelling plants (similar to Old Riffhams, Little Baddow).
- 11) What do you want in the bedrooms?
- I am not worried about how it is decorated.
 - Would like patio doors to go outside in the summer so I can go outside when i wake up before seeing everyone else.
 - Bedroom would need storage facilities, an ensuite bathroom, double beds (so that partners can stay over together, TV and DVD player, chair/sofa for carers to visit, sky TV that plays differently to other rooms (streaming), under floor heating (rooms have to be of a warm temperature).
 - The bedroom has to feel like home – no florescent light bulbs. Spot lights would be nice – two different lights so that the room doesn't have to be bright.
- 12) Is there anything you would like to add?
- Not to have carpet in all the rooms as it's silly with wheelchairs.

QUESTIONS ASKED TO THE FAMILY – FAMILY NOT ASKED:

- 1) What service would you like The J's Hospice to offer your daughter/son?
-
- 2) Would you come and spend time at the hospice in your own right, or would you spend time there to support your daughter/son?
-
- 3) If you would spend time there in your own right, how would you like to do this?
-
- 4) Do you think there should be family living quarters?
- 5) Would you like a cooked hot meal or a cold finger meal if you were there at lunch or dinner time?
-
- 6) Is there anything you would like to add?
-

END

NA3

COMMUNITY NEEDS ASSESSMENT
FOR YOUNG ADULTS AWAY FROM HOME RESPITE CARE

PATIENT WISH LIST FOR A J'S HOSPICE BUILDING

QUESTIONS ASKED TO THE PARTICIPANT 8:

- 1) If The J's built a hospice building, would you use it?
 - Yes.

- 2) How often do you think you would use the hospice facilities?
 - Overnight respite during weekends, once a month.

- 3) What do you see there being in the building?

- 4) What sort of facilities do you think the hospice should offer?
 - Music therapy
 - Sensory room
 - Aromatherapy (though must be aware of scents which affect epilepsy).
 - Hydrotherapy
 - Bowling ally
 - Movie watching
 - Audio stories

- 5) Do you want a social room?
 - Yes

- 6) How do you envisage/see the facilities being offered?

- 7) Are there any other rooms that you would like in the building?

- 8) Do you think that the hospice should offer a cafe service or formal dinner arrangements?

- 9) Would you like there to be animals in the building?
 - Yes, ones which are small enough to sit on my lap.

- 10) Would you like a garden?
 - Yes.
 - Sensory garden would be nice.
 - Shaded garden facilities where there are enclosed spaces.

- 11) What do you want in the bedrooms?
 - Yes. It must be homely and cosy with dimmer switch lighting

- Gender appropriate
 - Profile bed and airflow mattress
 - In the room can there be a music system
- 12) Is there anything you would like to add?
- The hospice must create an atmosphere which is sociable and interactive with lots of people around.
 - It would also be nice for there to be weekend groups where themed acting or musical activities take place.

QUESTIONS ASKED TO THE FAMILY:

- 1) What service would you like The J's Hospice to offer your daughter/son?
 - Well staffed where the approach is fluid and flexible over plans which may change.
 - Staff who know my child.
 - Staff who are competent and know my child's file, medication, likes, dislikes and her care plan.
 - We do not want to feel like we are leaving your child in the care of people who are not competent and confident in their care.
- 2) Would you come and spend time at the hospice in your own right, or would you spend time there to support your daughter/son?
- 3) If you would spend time there in your own right, how would you like to do this?
- 4) Do you think there should be family living quarters?
- 5) Would you like a cooked hot meal or a cold finger meal if you were there at lunch or dinner time?
- 6) Is there anything you would like to add?
 - Doctor's surgery providing a similar service to paediatricians. It would be nice if someone could look at the medication my child is on and either recommend any changes/alternatives, or keep it the same.

END

COMMUNITY NEEDS ASSESSMENT
FOR YOUNG ADULTS AWAY FROM HOME RESPITE CARE

PATIENT WISH LIST FOR A J'S HOSPICE BUILDING

QUESTIONS ASKED TO PARTICIPANT 9:

- 1) If The J's built a hospice building, would you use it?
 - Yes. Our first children likes to be out and about if the facilities are correct for him.
 - For our second, it depends on them feeling comfortable in the environment. He likes to stay at home and is not as 'outdoorsy' as the other. This child likes his bedroom, there is everything he needs in it and is happy to stay at home.

- 2) How often do you think you would use the hospice facilities?
 - Predominantly day care facilities, though would stay overnight if felt comfortable enough.

- 3) What do you see there being in the building?
 - Wifi for internet access.

- 4) What sort of facilities do you think the hospice should offer?
 - Games room
 - Chill out room
 - Piano
 - Themed days
 - Hydro pool
 - Film watching
 - Dressing up
 - Wheelchair swings
 - Quizzes – AS has ethnic minority carers and is often asking them questions and is interested in their home countries.
 - Massage
 - Physio
 - Music therapy
 - Art therapy/classes
 - Trivia
 - Wheelchair football
 - Education and training

- 5) Do you want a social room?
 - Yes, with big screen TV
 - Games console
 - Music systems
 - Pool table for the more able bodied

- Bar area (non-alcoholic drinks)
 - In warmer weather, the social room should be outside
- 6) How do you envisage/see the facilities being offered?
- Booking in advance having seen a timetable of what events are happening and when.
- 7) Are there any other rooms that you would like in the building?
- 8) Do you think that the hospice should offer a cafe service or formal dinner arrangements?
- No preference.
 - Our first son does like to lick food to taste it – this should be offered at dinnertime, but should also have the choice of whether to engage or not.
- 9) Would you like there to be animals in the building?
- Nice, but some can be allergic and some can carry bacteria.
 - Fish would be ok – large tanks.
- 10) Would you like a garden?
- Yes.
 - Giant snakes and ladders so the patients can be the game pieces.
 - Giant skittles where a ramp can be used to release the ball.
 - Giant chequers – carers can move patients around the board.
 - Can be creative with local services – get local fire services etc involved.
 - Raised flower beds
 - Water feature
 - Bird feeders so people can see the birds
 - Railway tracks round the grounds/gardens where the patients can be transported around (wheelchair accessible)
 - Noises and statues
- 11) What do you want in the bedrooms?
- French doors that open out into the grounds.
 - Would like adjoining rooms with double doors which open up into each other – they like to keep an eye on each other. Forcing them apart would be like splitting up best friends.
 - Not necessary for an ensuite.
 - It would be nice if bedrooms could be personalised for the eldest – for him to have things in the room that the staff know he likes – to make it personal.
- 12) Is there anything you would like to add?
- Views from the two clients (with parental input)
 - *The hospice should have bedrooms, garden, computer room/games console*
 - *Music making facilities and DJ'ing*
 - *Karaoke*

- *Radio controlled cars/helicopters/scalectrics*
- *Balloons blown up and wheelchairs to run over them*
- *Screamer balloons*
- *DVD quizzes*
- *Giant Jenga where the boys can drive through it to knock it down.*
- *Spoken to in other languages*
- *Read to.*
- *Games which encourage groups – team games.*

QUESTIONS ASKED TO THE FAMILY:

- 1) What service would you like The J's Hospice to offer your daughter/son?
 - The same level of care that they offer their sons.
 - Right environment with fully capable staff
 - Feel that they are cared for and are safe and secure

- 2) Would you come and spend time at the hospice in your own right, or would you spend time there to support your daughter/son?
 - We would like a break – we don't get it anymore
 - Would be nice to stay over to facilitate the introductions and make the stay easy for them (saying "good morning" and "good night").

- 3) If you would spend time there in your own right, how would you like to do this?

- 4) Do you think there should be family living quarters?
 - Yes.

- 5) Would you like a cooked hot meal or a cold finger meal if you were there at lunch or dinner time?

- 6) Is there anything you would like to add?
 - It would be nice to have drop in facilities where we can ask nurses/doctors questions about anything that crops up.
 - Social workers that know about rights and benefits and to point them in the right direction for assistance.
 - It is a minefield out there.

END

COMMUNITY NEEDS ASSESSMENT
FOR YOUNG ADULTS AWAY FROM HOME RESPITE CARE

PATIENT WISH LIST FOR A J'S HOSPICE BUILDING

QUESTIONS ASKED TO PARTICIPANT 10:

- 1) If The J's built a hospice building, would you use it?
 - Yes.

- 2) How often do you think you would use the hospice facilities?
 - Respite away from the home 3 or 4 weekends per year

- 3) What do you see there being in the building?

- 4) What sort of facilities do you think the hospice should offer?
 - Sensory room with a water fountain/feature
 - Music therapy where musicians come in and engage
 - Hydrotherapy pool
 - Art room (work with hands)
 - Hot tub/Jacuzzi (though not a Jacuzzi bath, it has to be a flat based Jacuzzi).

- 5) Do you want a social room?
 - Yes

- 6) How do you envisage/see the facilities being offered?

- 7) Are there any other rooms that you would like in the building?

- 8) Do you think that the hospice should offer a cafe service or formal dinner arrangements?

- 9) Would you like there to be animals in the building?
 - Yes, fish can provide a peaceful and calming atmosphere.

- 10) Would you like a garden?
 - No outdoor space is important, but if there is one, it would be nice for swings for AC to go on.

- 11) What do you want in the bedrooms?
 - Yes.
 - With an ensuite (possible to have ensuite as adjoining room to two bedrooms)
 - Ceiling track hoists bedrooms with a bath/shower tray.

- TV/music/mobile sensory units
- Safe-side beds
- Laminate flooring
- Curtains.

12) Is there anything you would like to add?

QUESTIONS ASKED TO THE FAMILY:

- 1) What service would you like The J's Hospice to offer your daughter/son?
- 2) Would you come and spend time at the hospice in your own right, or would you spend time there to support your daughter/son?
 - No.
- 3) If you would spend time there in your own right, how would you like to do this?
- 4) Do you think there should be family living quarters?
- 5) Would you like a cooked hot meal or a cold finger meal if you were there at lunch or dinner time?
- 6) Is there anything you would like to add?
 - Sibling groups
 - Doctor to be on call, as do not think a doctor will give up its time to be at the building continuously.
 - The environment mustn't be boring.
 - Would like this building to be built sooner rather than later.
 - Am losing faith in the building being built.
 - Should be designed like a bungalow.

END

COMMUNITY NEEDS ASSESSMENT
FOR YOUNG ADULTS AWAY FROM HOME RESPITE CARE

PATIENT WISH LIST FOR A J'S HOSPICE BUILDING

QUESTIONS ASKED TO PARTICIPANT 11:

- 1) If The J's built a hospice building, would you use it?
 - Yes

- 2) How often do you think you would use the hospice facilities?
 - Once a week for overnight and day time care.

- 3) What do you see there being in the building?
 - Equipment to enable position changes so that I can take part in activities.
 - Swimming pool/hydrotherapy pool/large spa (has to be hot enough for bad circulation).
 - Sensory rooms
 - Outdoor activities
 - Wheelchair accessible swings
 - Things that you don't get at home
 - Cooking facilities – I enjoy being in the kitchen when others are cooking (it's a creative activity stimulating senses – noise and smells). Usually in hospices kitchens are out of bounds places, but if this could be worked around, it would be great for me to be involved in cooking through my carer.
 - I really love being in a social environment

- 4) What sort of facilities do you think the hospice should offer?
 - Music therapy – I love instruments
 - Trampolining
 - Physio should be incorporate into other things
 - I find art quite boring.
 - Adult education, e.g. cooking classes. It doesn't matter that I can't eat what my carer cooks, it is the experiences I have during the cooking processes – I love being in the kitchen.

- 5) Do you want a social room?
 - Yes.
 - I enjoy other peoples company; I like the noise, activity and social engagement.
 - I enjoy the chat and gossip, the hub of activities.
 - Another social element that would be good, are themed nights and events such as cooking/movie experiences and any sort of music engagement.

- 6) How do you envisage/see the facilities being offered?

- Booking system – though not great for parents as in the past my experiences are that there is not flexibility over booking. Flexibility would be good, for example to not have to book so far in advance as we are not the sort of family to book advance holidays.
- 7) Are there any other rooms that you would like in the building?
- 8) Do you think that the hospice should offer a cafe service or formal dinner arrangements?
- Both – choice is nice.
 - Although I can't eat, it is nice to be part of meal times as she enjoys the social engagement
- 9) Would you like there to be animals in the building?
- All animals should be kept outside.
 - The only animals which should be indoors are fish, not four legged ones.
 - Chickens are a great idea, as not only are they friendly and productive but the hospice could use their eggs in their food – would be nice to obtain ex-battery hens. I find chickens very funny and entertaining.
 - It would be nice to have ponies, rabbits and guinea pig – the more able kids could help look after them.
- 10) Would you like a garden?
- I like outdoor garden spaces but with things going on in it – such as a duck pond.
 - If a garden is made to be a sensory one then it needs to be interactive.
 - Gardens are my favourite thing.
- 11) What do you want in the bedrooms?
- Bedrooms should be gender appropriate – we have to pack enough for visits and overnight stays without bringing own belongs to make the room girly.
 - The bedrooms should have lots of sensory lights.
 - I have the radio on all night whilst asleep.
- 12) Is there anything you would like to add?
- No.

QUESTIONS ASKED TO THE FAMILY:

- 1) What service would you like The J's Hospice to offer your daughter/son?
- Something similar to Little Havens – we really liked their set up.
 - We didn't like how the nurses were – very clinical. I think it is important for the approach to care to be treated as 'normal'
 - There needs to be an element not always 'having to be entertained', they should be allowed to just stay in their bedroom if they like – this is what normal 20 year olds do.
 - An accessible environment who understands disability.

- My child should be in a setting appropriate to her needs.
 - My child picks up on carers being relaxed.
- 2) Would you come and spend time at the hospice in your own right, or would you spend time there to support your daughter/son?
- We would stay there initially so that we can be called upon to help out – it's not respite if we can't help if help is needed for her to be comfortable as we will worry about it.
 - This is also in her best interest.
 - In time when we are more comfortable with the set up, there wouldn't be a nice for us to stay and then we can spend time with our other children and maybe think about going away whilst she is at respite.
- 3) If you would spend time there in your own right, how would you like to do this?
- When we do stay, it would be nice to spend our time as lazily as possible.
 - Little pressure
 - Good wholesome meals without feeling guilty that someone has cooked it for us.
- 4) Do you think there should be family living quarters?
- Yes.
- 5) Would you like a cooked hot meal or a cold finger meal if you were there at lunch or dinner time?
- Both – options and choice are nice.
- 6) Is there anything you would like to add?
- For us to know and feel confident that those looking after our daughter can do it well, but if something arose where difficulties were being had, that members of staff would pick the phone up and call us to assist.
 - Our other children would be interested in sibling groups/trips. I think this is more important now as teenagers than when they were younger as they are more able to talk about their feelings as teenagers and to also experience that they are not the only ones having and living the experiences of having a sick sibling.

END

COMMUNITY NEEDS ASSESSMENT
FOR YOUNG ADULTS AWAY FROM HOME RESPITE CARE

PATIENT WISH LIST FOR A J'S HOSPICE BUILDING

QUESTIONS ASKED TO PARTICIPANT 12:

- 1) If The J's built a hospice building, would you use it?
 - Yes.

- 2) How often do you think you would use the hospice facilities?
 - I would use it for respite overnight care as I already have day care facilities which I use.
 - I don't want to say how often, but more than 2 weeks a year.

- 3) What do you see there being in the building?

- 4) What sort of facilities do you think the hospice should offer?
 - Sensory room
 - Music rooms
 - Massage
 - Dancing
 - Things have to be made fun.
 - Themed days, which should be made fun – pirate days doing treasure hunts, 60s/70s events, cowboys, Halloween, Easter egg hunts.
 - Home cinema experiences.
 - Amateur dramatics

- 5) Do you want a social room?
 - Yes.

- 6) How do you envisage/see the facilities being offered?

- 7) Are there any other rooms that you would like in the building?

- 8) Do you think that the hospice should offer a cafe service or formal dinner arrangements?
 - Dining room and lounge all in one so that non-eaters can still be in the same room – a sense of inclusion.

- 9) Would you like there to be animals in the building?
 - Fur makes me wheezy as I have a tracheotomy, though farm trips are ok.

- 10) Would you like a garden?
 - Yes, a sensory.

- 11) What do you want in the bedrooms?
- A sensory bedroom which is gender appropriate (colours and furnishings etc).
- 12) Is there anything you would like to add?
- No.

QUESTIONS ASKED TO THE FAMILY:

- 1) What service would you like The J's Hospice to offer your daughter/son?
- A personal one where my daughter is not made to feel like a client.
 - She is currently at Douglas House which does not feel family friendly
 - There should be a family atmosphere.
 - She is happier in a family environment/atmosphere.
 - The building should be built like a family home with relaxing and living rooms.
 - It would be great if we could use the J's respite services in an emergency situation, e.g. if a sibling is ill (there is a big age gap between siblings so the younger one could fall ill/have an accident).
- 2) Would you come and spend time at the hospice in your own right, or would you spend time there to support your daughter/son?
- No, we would use the opportunity to spend time together as a family.
 - However if we were there at a meal time, it would be nice to have the opportunity to have a meal if it was late.
 - It would also be nice to be able to talk to others about problems – maybe the nurses.
 - An in-house doctor (maybe a local GP) to come in and help as I do not always get to see the same person twice. To have an experience where I do not have to repeat myself and SB's story twice would be nice.
- 3) If you would spend time there in your own right, how would you like to do this?
- 4) Do you think there should be family living quarters?
- Yes, in a separate upstairs area to where the care and bedrooms are.
- 5) Would you like a cooked hot meal or a cold finger meal if you were there at lunch or dinner time?
- 6) Is there anything you would like to add?
- I have found children's hospices better than adults. Although some young adults do not always need to be treated like children.
 - Familiar staff to build relationships, friendships and to be build a trusting relationship.
 - My daughter is happier when everything runs smoothly.
 - I would be interested in engaging my other daughter in something – like a sibling group.

- It would also be nice to have the option of being able to unofficially offload, nothing formal with a counsellor, but I am used to everything with my daughter now.
- I think The J's Hospice should offer end of life care in separate quarters and for families to be able to attend and stay/visit. Personally, I would not want to intrude on other guests and put them in an awkward situation (they know why I'm there).
- I think the building should be built on one level.

COMMUNITY NEEDS ASSESSMENT
FOR YOUNG ADULTS AWAY FROM HOME RESPITE CARE

PATIENT WISH LIST FOR A J'S HOSPICE BUILDING

QUESTIONS ASKED TO PARTICIPANT 13:

- 1) If The J's built a hospice building, would you use it?
 - Yes.

- 2) How often do you think you would use the hospice facilities?
 - I am still at school so the need for day care is not that great as if I were at home.
 - I would use it when mum and dad had occasions/events where it would be unfair to put me through the event, e.g. an all day family wedding, V Festival, anything where we were having a late night.
 - I would book in advance, every 6 weeks for 2/3 nights as this is what has been recommended to mum and dad.
 - I prefer this to be on weekends because if it was during the week, then it would eat into my time at school (school get annoyed when she has time off).

- 3) What do you see there being in the building?
 - Lounge area available for visitors to come and visit – bedrooms are not always ideal as they can become full with visitors.

- 4) What sort of facilities do you think the hospice should offer?
 - Sensory room: Relaxing area with visual stimulation, noises, mirrors, music, smells, touch (space blankets), fiberoptic lights, bubble tubes, pressing buttons for noises.
 - Art – with a lot of help, finger painting
 - Water and sand play
 - Themed days
 - Puppet show
 - Dress up in character suits, bunny, telly tubby
 - Clowns that make animals from balloons
 - Panto
 - Disco with bubble machines and a child atmosphere.

- 5) Do you want a social room?
 - I don't understand what a social room is for.

- 6) How do you envisage/see the facilities being offered?

- 7) Are there any other rooms that you would like in the building?
- 8) Do you think that the hospice should offer a cafe service or formal dinner arrangements?
 - At mealtimes there should always be an alternative available for those who cannot eat such as watching the TV, but still in the same room as those eating so they are included in conversations.
- 9) Would you like there to be animals in the building?
 - I like animals, love dogs, cats, horses and donkeys, but she needs a wipe down as she can be allergic.
- 10) Would you like a garden?
 - Yes – sensory garden which is tarmac (always better for wheelchairs).
- 11) What do you want in the bedrooms?
 - Gender appropriate colours.
 - Fully adjustable bed (height and head)
 - Cot-sides on bed/bumpers
 - Air flow mattress
 - TV/DVD player, visual stimulations (image projector), CD player
 - Will provide own DVDs and CDs – positives of this are that I will always watch something I like, negatives are that I don't get to try anything new.
- 12) Is there anything you would like to add?

QUESTIONS ASKED TO THE FAMILY:

- 1) What service would you like The J's Hospice to offer your daughter/son?
 - A continuation of what they have experienced from children's hospice – fits with my daughter's needs.
- 2) Would you come and spend time at the hospice in your own right, or would you spend time there to support your daughter/son?
 - If my daughter stayed overnight, then it would be nice to spend time at the hospice in family quarters (self-contained) so that we were not far away if anything happened to her. But we wouldn't get involved with her care too much unless we needed to.
 - We would like the room to have its own tea and coffee facilities. A kitchen area would be nice where we could prepare breakfast.

- 3) If you would spend time there in your own right, how would you like to do this?
 - Yes, just as a break with my husband.

- 4) Do you think there should be family living quarters?
 - Yes.

- 5) Would you like a cooked hot meal or a cold finger meal if you were there at lunch or dinner time?
 - Cooked dinners - It would be nice to have the option of having either a cooked dinner with others or by ourselves if we did not want to socialise.

- 6) Is there anything you would like to add?
 - It would be nice to have the option and availability of staff members that if the need arose I could unburden myself to them. If complimentary therapies were available whilst I was staying, I would book myself in to have one or two.
 - It would be nice to be able to seek the advice from nurses about issues which may arise – they are always such a good source of advice. It would also be nice to phone to seek advice if we were not booked in.
 - Our son would not be keen on using the facilities of the hospice.

COMMUNITY NEEDS ASSESSMENT
FOR YOUNG ADULTS AWAY FROM HOME RESPITE CARE

PATIENT WISH LIST FOR A J'S HOSPICE BUILDING

QUESTIONS ASKED TO PARTICIPANT 14:

- 1) If The J's built a hospice building, would you use it?
 - Yes.
- 2) How often do you think you would use the hospice facilities?
 - Overnight stays and daytime visits.
- 3) What do you see there being in the building?
- 4) What sort of facilities do you think the hospice should offer?
 - Hoists
 - Showers
 - Baths
 - Profile beds
 - Space for care
 - Massage
 - Physio (within reason)
 - Pampering – nails
 - Art therapy and classes –did these at little havens
 - Music – I like classical & Pop – I like singing along (there is a large musical/interactive mouse which she allows those using it to sing along with – a bit like karaoke).
- 5) Do you want a social room?
 - Yes – large and homely with a TV/DVD player
 - Social activities would be good too like themed nights – cinema experiences.
 - I engage with puppet shows and clowns – animation. I was recently bought the Take That concert video as it is very animated with large caterpillars and elephants.
- 6) How do you envisage/see the facilities being offered?
- 7) Are there any other rooms that you would like in the building?
 - Rooms which offer space for quiet time, somewhere I can go when I get tired.
- 8) Do you think that the hospice should offer a cafe service or formal dinner arrangements?
 - Both cafe and dinner.

- I engage in this at school and at home – I enjoy the hustle and bustle of meal times. I sometimes get fed up though and it would be good if there is an alternative for her to be engaged with if this happens.
- 9) Would you like there to be animals in the building?
- Not sure on animals.
- 10) Would you like a garden?
- I enjoy both indoor and outdoor garden spaces.
- 11) What do you want in the bedrooms?
- Warmth as I can get very cold.
 - Profile beds with mattress which helps with pressure sores
 - TV/DVD player
 - Books so that she can be read to – and audio books.
 - The room should be colourful rather than plain.
- 12) Is there anything you would like to add?
- No need for an education element to her respite time.

QUESTIONS ASKED TO THE FAMILY:

- 1) What service would you like The J's Hospice to offer your daughter/son?
- Short respite stay past 19 years of age as can't go to Little Havens or seaside cottages.
 - It should be geared up to be fun and not a miserable place.
 - Both midweek and weekend respite should be offered
 - Need to offer end of life care – with options available for it to be at the hospice or at home.
- 2) Would you come and spend time at the hospice in your own right, or would you spend time there to support your daughter/son?
- We have other children (boys) and as they grew older, they became noisier so we began to not stay at the hospices when she was in for respite, and now they are older they want to be at home.
 - It would be nice to stay at the end of life time.
- 3) If you would spend time there in your own right, how would you like to do this?
- 4) Do you think there should be family living quarters?
- Yes – with bedrooms upstairs with own kitchen and lounge – self contained.
- 5) Would you like a cooked hot meal or a cold finger meal if you were there at lunch or dinner time?
- It should be optional if we want to come and engage in meal times or not.

6) Is there anything you would like to add?

- Not interested in sibling groups as the boys are now older.
- There should be services available to see a nurse/doctor in a separate room, and whilst we wouldn't need benefit advice, I can image there are people who would.
- A chapel would be a beneficial and essential part of the hospice.

END