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Unlocking the door to children's hospices

REIMAGINING THE ROLE OF DISNEY IN THE HOSPICE JOURNEY

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“Once we got over the threshold we never looked back.”

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Background and context

The number of children with life-limiting (LLC) and life-threatening conditions (LTC) in the UK is rising. Children's hospices are key providers of children's palliative care, offering a range of services from short breaks, therapy services, care at home, sibling support, emotional and spiritual support through to end of life and bereavement care. Children's hospices provide comfort, optimism, and joy to families and inspire hope, at the most challenging of times. Despite the growth of children's hospice services and the advantages that they offer in care it appears that only small numbers of children with life-limiting conditions are admitted to hospices across the UK; it is estimated that only approximately 10% of the 99,000 children in the UK with a life-limiting or life-threatening condition currently access hospices (TfSL, 2019).

In August 2020 Together for Short Lives held a focus group with four Leaders of Care from children's hospices across the Thames Valley, to describe the pathway that children and families experience when using hospice services. Certain points along the pathway were identified as particularly stressful for families (Figure 1), the most stressful time being initial referral to the hospice when the decision is taken by families to cross / or not cross the hospice threshold and access their services. This finding is also supported in the literature. Evidence reports that for people unfamiliar with a children's hospice, the terms 'hospice' and 'palliative care' are negatively associated with illness and dying (Price et al., 2018). Research also shows that first impressions count, and the physical environment of a hospice plays a role in whether it is perceived positively as attractive and non-threatening or the reverse (Downing et al., 2014).

Entering a hospice often symbolises separation for parents; a time where parents make a decision to leave home, cross the threshold and enter an unfamiliar world in which they initially experience a sense of 'outsideness'

(Relph, 1976). The hospice is an unusual environment, described by Gola et al. (2016) as a *"hybrid between the complexity of a technological hospital and the presence of psychosocial factors and variables similar to home environments"*. There are many other reasons that families choose not to access hospice services, e.g., the family may not have fully accepted or come to terms with their child's prognosis, the timing may not be right for them, or they may not fully understand what the hospice can provide for their child, for siblings, for the parents and for their wider family. The idea of letting go of the control of their child, the guilt associated with what parents see as not fulfilling their parental responsibility and then eventual separation from their child by leaving them at the hospice and allowing someone else to care for them are huge challenges for many families.

Described as the *"humanisation of spaces of care"* (Gola et al., 2016), the psychological benefits of a feeling of attachment to a place has been shown to reveal positive effects on memory, emotional support, escape from stressors of life and creation of a feeling of safety, security, and belongingness (Scannell and Gifford, 2017). Gola et al. (2016) talk of children's hospices needing to be *"prosthetic environments"*, that is, environments that are purposefully planned to enhance and meet the needs of children, families, and staff. Generating a home-like atmosphere, in terms of both the welcome and the feel and the fabric of the hospice, is potentially critical to helping to create a sense of attachment. When a place provides the characteristics required to meet individual needs, it is evaluated positively and attachment to place has a role in how people interpret and react to change (Anton and Lawrence, 2016).

Since their conception, hospices have aimed to offer safe care in an environment that is home-like (Hain, 2019). Therefore, it is likely that parents will quickly decide whether the

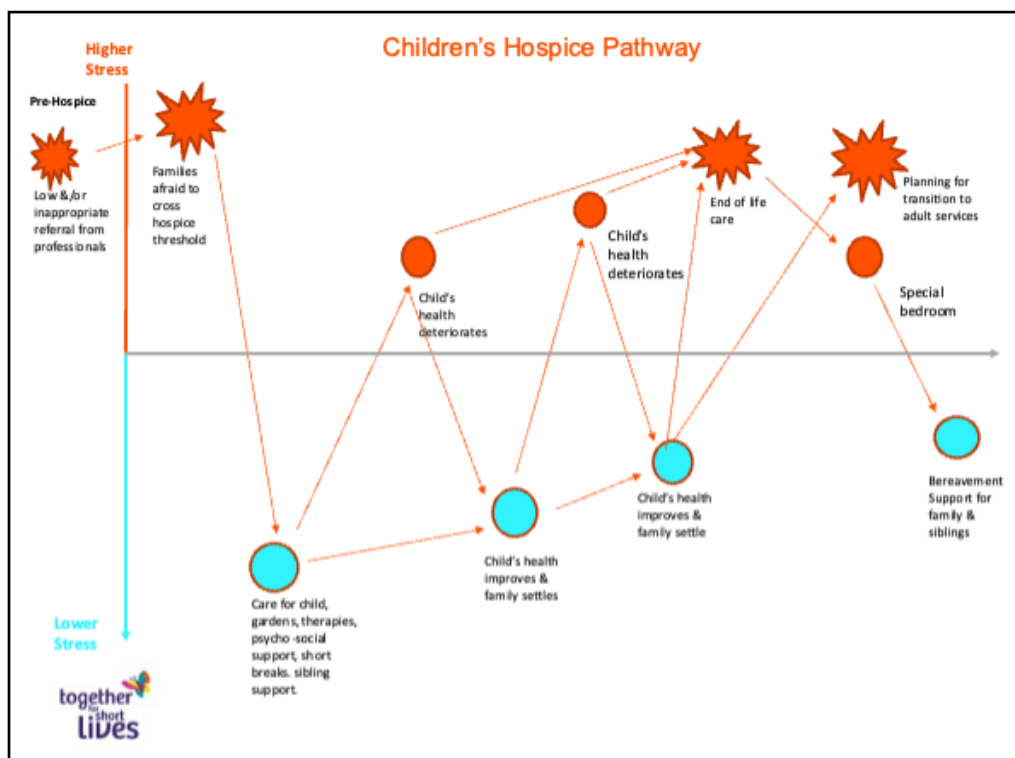


Fig 1 Families' journey through the hospice

hospice could be an environment that will offer a sense of security and safety for their child. Recent work by Dunbar et al (2020, 2021) suggests that parents' views of the identity associated with a hospice can change if there are certain complimentary characteristics that work together. Parents need to know that their child will be cared for safely by staff who have appropriate expertise, knowledge and skills, and who could tailor care to their child's individual and unique needs. Evidence also suggests that meeting with other parents helps create a feeling that the hospice is somewhere where they belonged. Enabling parents to perceive and understand the therapeutic nature of accessing the hospice, viewing it as a less threatening environment and more of a place of shelter may mean that access can be improved and the decision to cross the threshold is less daunting.

Since Walt Disney first brought animators and characters to visit hospitalized children in the 1930s, Disney stories have inspired a world of hope for seriously ill children. Disney is renowned for creating immersive experiences and personal moments that deliver comfort and joy to children facing serious illness,

easing the anxiety associated with needing medical care.

Building on Disney's experience of providing comfort & inspiration to seriously ill children for more than 80 years, Together for Short Lives developed and implemented a project in partnership with children's hospices, funded by The Walt Disney Company, with two aims:

1. To understand the reasons why sometimes families find it difficult to take up referrals to children's hospice services, what the barriers have been for them and what the solutions might be to break down these barriers and unlock the doors to children's hospice care for other families in similar situations.
2. To understand what / where / whether The Walt Disney Company has a role to play in the hospice journey that will help increase children's emotional resilience through:

- Reducing fear and anxiety
- Increasing confidence
- Increasing sense of belonging and feeling valued in the hospice environment

Methods

Throughout the summer (July to August 2022), fun days were held at 10 children's hospices across the UK. Hospices were awarded a grant to identify and invite families to a fun, activity-filled discovery session led by hospice staff and volunteers, with a team from Together for Short Lives present at each session to capture the learning from families.

Hospices were encouraged to invite any families that were on their caseloads, including families who may have been referred to the hospice and had never accessed the service. Alongside play and creative activities with children, parents were encouraged to meet other parents and to share their thoughts and ideas about coming to the children's hospice with the team from Together for Short Lives. Learning was captured in a variety of ways:

1. DISCOVERY TIME

During the activity session parents were invited to join a member of staff from Together for Short Lives to explore how they felt when they were first told about the children's hospice services, what their thoughts were about their first visit, whether / how their feelings changed once they had visited

/ met staff / received a service. Families were also asked their opinion and suggestions on what / where / whether The Walt Disney Company has a role to play in the hospice journey.

Appendix 1 details the prompt sheet that was used by staff from Together for Short Lives who facilitated the discovery phase of the events.

2. SUGGESTION WALL AND DISNEY MURAL ARTWORK

A suggestion wall was also used to capture parents' ideas about a potential role for Disney in the hospice journey. In addition, examples of Disney mural artwork were displayed and families were asked to comment on what they liked / disliked, and whether something like the murals would be useful in hospices.

3. DISNEY RESOURCE

Disney also developed a Beauty and the Beast story time resource, which families and staff were asked to review, sharing what they liked / disliked, what was missing, what would have made it better.



Findings and discussion

Table 1 identifies the hospices who took part in the activity fun days and the numbers of families who attended each event. Across the ten hospices, 79 conversations with parents (mothers as well as fathers) were recorded, transcribed verbatim, and independently analysed. Of the 516 attendees at the events, a very small minority were from backgrounds other than white British. The length of time families had accessed the hospice varied considerably, ranging from families using services for years right through to some visiting the service for the very first time.

Hospice and location	Number of adults attended	Number of children including siblings attended	Total number attended
St Oswald's (Newcastle)	15	22	37
Ty Hafan (Wales)	37	49	86
Hope House (Wales)	4	9	13
CHAS Rachel House (Scotland)	16	20	36
Rainbows (East Midlands)	29	35	64
Andy's (Grimsby)	10	11	21
Claire House (Liverpool)	29	44	73
EACH the Nook (Norfolk)	30	38	68
Noah's Ark (London)	22	38	60
Helen and Douglas House (Oxford)	27	31	58
Total	219	297	516

From the thematic analysis of the conversations with parents, four themes were identified which capture the reasons why families find it difficult to take up referrals to children's hospice services, what the barriers have been for them, potential solutions to break down these barriers and Disney's role in unlocking the doors to children's hospice care. All quotes are anonymized to protect the identity of the families; they have however been attributed to the hospice where the family is receiving care and support.

Theme 1

The psychological barriers to accessing children's hospice services

Consistent with previous research, for many of the parents that we spoke to across all hospice sites, perhaps the single most salient 'barrier' to families accessing children's hospice care was the fears evoked by the notion of palliative hospice care for children. Moreover, the word 'hospice' itself, when first proposed to parents, induced stark concerns of their children dying quite soon:

"The word 'hospice' freaked us out [...] As soon as they said the word 'hospice' and 'memory work', I just completely shut it down. I was, like, 'No, I'm not doing that. My baby is not going to die". (EACH)

"Unfortunately, 'hospice', people assume it's somewhere you die. It's the last entry into a place and you exit out the back. That's a description of hospice really, isn't it"? (Ty Hafan)

"So yes, it is very contrasting, I mean, people hear the word 'hospice' and it's the negative side of life". (CHAS)

For some parents, their previous experience of adult hospices compounded their fears that their child would die if they entered the hospice.

"It's difficult because my dad, he had terminal cancer. So, he spent a bit of time in a hospice. So, straight away hospice for me was where someone goes to die, basically. I didn't realise it was where children could come, have a good time and where parents could get respite. It just seemed to me like it was a medical thing rather than respite. That was the first thing that I thought. Hospice just didn't seem like a good thing, but I think that was obviously because of my dad". (St Oswald's).

The extracts above illustrate and reflect the significant concern felt by many parents who immediately felt overcome by the negative thoughts and feelings that they had previously associated with hospices; viewing them

simply as a sad place associated with death. Research suggests that the language used in palliative care clearly has an influence on how it is perceived by patients, their families and health professionals. It is recognised that the term "palliative care" presents some negative connotations as it is often used synonymously with end of life, as a term describing the terminal phase of a disease.

"It's really hard because I think you associate hospice with dying. And so I felt very much like, if we had hospice support then that meant my child is going to die. And we'd already come so far, and I was trying to get my head around the fact that she was alive and that she hadn't died, so to then be faced with and acknowledge, 'Oh actually, yes she is still really ill'". (EACH).

"It was a bit overwhelming because, obviously, we assume hospices, you know, end of life and a place to die. We didn't know what it was, so it put us off for quite a while. [...] we thought it would be, like, hospital and drab". (Helen and Douglas House).

Furthermore, a child's illness exerts incredible emotional pressures on parents. For parents, the concept of accepting palliative care at the hospice is often identified as giving up hope for their child. Many parents were therefore reluctant at first to accept hospice support for their child partly because – upon reflection – they struggled to accept the life limiting consequences of their child's condition.

"I think it's taking that first step over the [...] You've got the decision. I almost feel like I get how people feel. Are you accepting that that's how things are going to be because you're stepping over the threshold and you're now in a hospice, so that's how your life is"? (Claire House).

For several parents, the fear of hospices as a place of dying and difficulty accepting the life-limiting nature of their child's condition, resulted

in them declining hospice support – sometimes for a period of years. This is illustrated below by parents who recalled feeling unable to cross the threshold and receive hospice care because of the fears they associated with it:

“Before we needed the hospice, I didn’t really know very much about it. I assumed it was all old people or children who were coming here essentially to die was what my impression of it was. I didn’t know anything about respite [...] I knew several children who had passed away and had come to the hospice, so that obviously coloured my views of it and who had been very poorly when needing the hospice. So, because of that, it took me about two years before I decided that I actually did need some support” (Andy’s).

“I didn’t think it was anything like this. When it got recommended to me, I was like, ‘No, I’m not going there, I don’t need to go there yet.’ When I heard ‘hospice,’ I was just scared”. (Claire House).

In addition to these psychological fears and reservations, various parents further described what they saw as a broader social stigma and public perception regarding children’s hospice care which can complicate conversations parents have with family members and friends, and further risk reinforcing negative parental attitudes and refusal to accept hospice support for their child:

“I think when people initially get put over to the hospice or when we’ve been talking about palliative care and end of life care, and what we want and our aspirations and everything else, [...] And we’re just starting all that now, but you just feel that it’s all the stigma around it. And I think usually you associate hospices with older people, maybe not with children”. (EACH).

“My husband’s side of the family, they haven’t had a lot of death and dying in their family at all. They haven’t had any exposure to or experience of hospice, palliative care, at all. So, obviously, their mind is just like, ‘It’s going to be a place where there’s just beds with dying children in,’ and clearly that’s not really a very nice thought”. (Hope House).

“The perception around hospice, isn’t there? And I suppose that was why, for so long, that we didn’t [attend] because there’s a difference between having limited and complex medical conditions than end of life and I think the perception of that is just generally not understood”. (Claire House).

There is a larger psychosocial barrier to children’s hospice care that many parents try to navigate, as they struggle to overcome the fears of death and dying which they clearly associate with the ‘hospice’ setting, and their acceptance of the life-limiting nature of their child’s condition.



This perceived stigma around hospice care for children, culminating in a host of negative psychological and social views, deterred many parents from accepting hospice support when it was first offered. For some parents the idea of using a hospice for respite “hadn’t even crossed my mind but I rang our local council to see if there was any respite that I could get, and they were the ones that referred us to the hospice”.

In contrast to adult hospice settings where care delivery is primarily focused on people’s experiences of dying and bereavement, it is vital that children’s hospices are identified as a place that caters for the child’s whole disease trajectory, offering short breaks, therapeutic support, whole family support, symptom management and when needed end of life care.

“Changing the narrative” is part of a wider project by On Road Media funded by the True Colours Trust to help understand how people think when they hear the term children’s palliative care and help shift public perceptions by changing the way children’s palliative care is reported. At a societal level, unhelpful narratives and attitudes can hinder the provision of the right care and comprehensive support for children and families. Inaccurate perceptions compound the challenges families experience, creating additional suffering and isolation. They can also hinder referrals to, and families’ uptake of, hospice services. Some parents even voiced an initial mistrust of the healthcare staff who suggested referring the child and family to further hospice care support:

“Hospice, I always thought it might be they take your child, ask you to take them there forever. [...] The first time, I was, ‘No, I’m not going to give my son to them’” (Rainbows).

“I think, in general, just the word hospice. It was a case of, well, the consultants, do they know something that we don’t? Is there something they’re not telling us. You just automatically think end of life care” (CHAS).

It was clear from our conversations that the psychological and social misgivings parents felt when first introduced to the idea of hospice care for their children; they felt overcome with fear, found it difficult to accept, were conscious of social stigma and even felt mistrust, all of which acted as a stark barrier to their entering into and accepting palliative care at the hospice for their children.

However, the reality is that for many parents who eventually cross the threshold and uptake services at the hospice the experience is very different: “When we actually came, we came and had a look around and it was just the complete opposite of what I was expecting”; “they are so welcoming”. For many parents the reality is summed up in this quote: “You have an in-built thing of what a hospice does and ... is nothing like that. This hospice is nothing like that. It was a fun place, it was bright, it was focusing on the positives” and “just having a look around. If you have a look around, your mind is just instantly changed”.

The next three themes concentrate on addressing the question as to what / where / whether The Walt Disney Company has a role to play in the hospice journey that will help increase children’s emotional resilience through:

- Reducing fear and anxiety
- Increasing confidence
- Increasing sense of belonging and feeling valued in the hospice environment

Figure 2 depicts the responses we received when asking parents and children what words they associated with Disney. Clearly fun, princess, magic, Mickey and family were among the most popular words used.

The first theme described as “‘A place for living’: Creating the feeling of magic at the hospice” was one way parents imagined fear and anxiety to be reduced.



Figure 2 Words that parents and children associated with Disney

Theme 2

‘A place for living’: creating the feeling of magic at the hospice

When asked about Disney and its possible role in children’s hospices, across the UK, parents were overwhelmingly positive in their feedback at the prospect and voiced various ideas for how they felt Disney could best support hospices. The focus of many of their ideas was the inclusion of Disney imagery to help decorate and “brighten up” the hospice environment. Many parents, particularly those of younger children, described the positive benefits of bright décor and creating a “dream sort of feeling”, using colour to change the

narrative from the idea that a hospice is “black and dull and sad to it’s a place for living”. One parent even suggested, “If it was down to me, I’d make the whole building Disney”.

The view that Disney imagery was well-suited to be included within a children’s hospice was shared by many parents, not only to add aesthetic colour and vibrancy but also as a way to help evoke a sense of magic and familiarity. When asked specifically about the Disney mural artwork, parents particularly

commented on the importance of colour, light and darkness. They liked the murals (in particular Islands) where the colour palette was described as “warm, bright and vibrant” and less “gloomy”. Parents associated brighter colours with a sense of “hope”.

However, for some parents and young people some of the murals were too “busy” and even described as “chaotic”. Instead, they wanted something to look at that was generally “more peaceful and calming”. Water murals and galaxies were viewed as much more “relaxing”. For older young people, the murals were viewed as “childish”. However overall, most parents agreed there may be a role for murals to make the hospice a brighter space, with some commenting that they could be used as a welcome distraction for children and families on their first visit to the hospice. Some suggested they could be used as puzzles, treasure hunts – find Moana, count the number of fish etc. Practically, parents suggested that a wrap would be a better idea than a permanent mural and would enable the hospice to change the look more regularly.

It was also evident that many parents associated Disney with creating a feeling of comfort and familiarity, many using the term “magical”. This idea was shared by many parents who felt that Disney occupied a unique position for both children and their families, as a prominent source of positive escape and fantasy that could be translated into the hospice space through its visual iconography. There were many ideas:

“I don’t know how it would do sensory wise. I suppose you could have the characters all different textures or whatever, or a theme for each of the kids’ bedrooms, [...] so you would be in the ‘Mickey Mouse’ room tonight, instead of ‘Room 1’. [...] You could be in the princess castle up the stairs”. (CHAS).

“For this place, maybe have the rooms a bit like that. I know you’ve got older children as well, so even a selective room. Maybe they wouldn’t stay there every time - because there are only 8 rooms. Maybe take in turns, every so often, they get the Encanto room, or the Lion King room, or whatever”. (St Oswald’s).

One dad suggested that this sense of familiarity was so strong that not only did it make their child “feel comfortable”, it also created a sense of wanting to return to the hospice, “I want to come back, I don’t want to leave”. These extracts provide detail of the ways in which various parents envisaged Disney decoration being included within the hospice space, whether as a Disney mural or as room decoration. Moreover, they restate the sense of familiarity and comfort that parents felt would be imparted via the inclusion of Disney imagery; in effect, introducing Disney imagery into the hospice space to help create a feeling of magic within the hospice that is both comfortable and familiar for children and their families.

“I think that if Disney were involved with the hospice, then it would make it much more accessible for families because Disney are all happy and it’s all light and wonderful. So, if you know as a family that you’re going to be entering into something that could potentially be a horrible time, then having Disney there makes it better. It lessens the doom and gloom of everything” (Andy’s).

In addition to colour and imagery there was also a strong consensus that anything developed should have an interactive and sensory nature to it. For example, parents suggested that Galaxy could be painted on a ceiling with bright LED stars and moon features. Others suggested balloons that moved, the inclusion of sounds like the water falling, a lion roaring etc. Others wanted texture and touch points.



[Murals] “Yes, they’re lovely, they are lovely, and all kids relate to Disney, don’t they? Everybody knows it” (EACH).

“I think the sensory part of Disney, I think that is a key to do all that, to open that to children who have sensory issues, sensory processing disorders, or have visual impairments. There’s more than one sensory aspect, right? So, if they might not be able to visually see something, they might be able to see lights or the sound, the music. It gets them excited. They might not be able to physically partake in that but the whole visual side and the music still enhance their experience” (Noah’s Ark Hospice).

For some parents the idea of an immersive experience was very exciting. One parent described the positive effect this would have on a child:

“Online, somebody’s done a Disney room and it’s a bedroom that’s built into a castle, the magic castle and it has projections onto the ceiling of the fireworks. It’s like being inside Disney, inside the bedroom. [...] The way it’s done, the projections go onto all the walls so it’s multi-centric, the fireworks are on the walls. So, when a kid’s in bed they’re in the firework display. Amazing” (Claire House).

In summary there was no doubt that association with Disney, their characters and films engendered positive feelings for families, a sense of magic and familiarity which encouraged positive thinking and feelings. However, whilst creating a pleasant environment offers a sense of enrichment ultimately it was the relationships, the staff, the care that parents and their children experienced which enabled families to feel comfortable, assured of using hospice services and changing their perception of the hospice identity.

“I would comfortably leave her here. If you said, ‘Right, go to the shop now,’ I would happily leave her here because I know everyone’s got the best interests in heart. The medical side is always important, and I understand that, everyone’s medically trained but it’s not that, it’s the actual trust I have in the place itself and that I know they’re going to play with her. I know she’s not going to sit in a room, like a hospital, and look to the ceiling until I get back. It’s just that, it’s that actually they’re to give her the best time in the world, and that’s just lovely” (Rainbows).

The next theme builds on the association of Disney in capturing and creating memories for families.

Theme 3

Time to be family: creating memories

For parents with a child with palliative care needs, the trajectory of their child's condition is unpredictable and uncertain. For some parents, despite acknowledging the anticipated length of life for their child would be shorter than normal, the progression, path and timing of this creates anxiety and fears about the future, "you don't know what is around the corner". Therefore, taking every opportunity to create memories and experiences as a family is vitally important. Alongside the expected requests for a specific Disney holiday experience or a Disney UK complex, parents had some ideas about Disney's role in creating and capturing memories with their child.

Disney music and soundtracks were something that parents felt had a very positive influence for their children and family. Children's hospices strive to create experiences that enhance a child's quality of life, normalising the high input of care necessary and making it as accessible and attractive as possible. The value of music therapy in children's palliative care is recognised in the literature; it has a strong focus on enhancing quality of life, is used to improve emotional wellbeing, to alleviate feelings of fear, pain, loss, and to facilitate self-expression. Children who are non-verbal often readily respond to opportunities to communicate through music.

"Music, for me, in my experience, has been one of the best therapies [...] it makes their minds work more. My child's had a stroke and when they're small, neuropathways are still developing and there's a window. If you don't access that window, they might not be able to reach their full potential they could've. So, things like music, things like visual simulation, sensory play, all this kind of stuff might actually improve their life. So, yes, those things are really important and I think that that's a huge door that could be accessed" (Noah's Ark Hospice).

The power of Disney music was captured by one parent who described how every time she heard Disney music she experienced a sense of family:

"It's all about family and being together. And every time I hear it, I always think, 'Family.' And I feel like when you play songs and things and do things like that in places like this, you'll automatically think of that memory and how it holds that memory and it just sticks there forever" (Claire House).

Others just wanted to experience singing alongside their child and siblings, to witness the stimulation and excitement that music created in their child. Capturing activities at the hospice was important for parents, especially those who were not resident with their child during their stay. Parents described the importance of capturing experiences such as art activities, face painting, hydrotherapy pool, playing outside. One mother described how she was so preoccupied with caring for her daughter 24/7 that she rarely got the opportunity to take photos with her, "to get someone to capture that moment that we probably wouldn't capture, it's just lovely". Many of the hospices had the ability on the activity days to produce instant photos and this was clearly very well received by families and children alike. One parent asked:

"Is there a way of capturing those moments in a file, a CD type thing, a DVD that can then be shared with parents? Is there a way of them, when they draw and do creative art activities, of capturing that and turning that into a story about that child and capturing the inspiration that these children are to their families" (Andy's).

Siblings of children with life-limiting conditions, due to the complexity of their life circumstances are also more vulnerable than the average child to poor mental health, learning, social and economic difficulties. They get less of their parent's attention and time. Routines in the family

house often centre around meeting the needs of the child with a life-limiting condition. It's easy for parents to be pre-occupied and focused on always caring for the other child. There is little time left to help with everyday needs of other siblings, such as homework, hobbies, social activities, and childhood experiences. Many siblings take on the role of young carer for their brother or sister, often meaning that they lose out on playdates, sleepovers, trips out and fun with their own friends. Like their parents, they too live with the uncertainty of when and how their sibling will die in childhood. The place they describe as and want to be home is overtaken by supplies, equipment, professional visits, carers. There is often little privacy to be a family or have friends to their home.

"Another thing we've noticed is that it's the siblings that also miss out as well. For us, there's so much time spent with...., with getting him changed, she misses out on stuff. [...] I think that's massively underestimated, of how much the other siblings miss out on stuff" (CHAS).

Evidence suggests happier families leads to better outcomes for the LLC child, parents / carers, and siblings (Larsson et al., 2018). Parents described how accessing the hospice also created opportunities for them to spend quality time with their other children, for siblings to just be siblings, for memories and experiences to be created with other children.

The challenges faced by parents of a child with a life-limiting condition are well documented: financial pressures – often one or both parents have to stop working, shortage of services and trained workforce meaning that many are caring for their child 24/7, practical issues, coping with unexpected change and uncertainty, fighting for services and advocating for their child.

It is vital therefore that services available via hospices are accessed and parents are encouraged to uptake that provision. The next theme explores how the hospice story can be reimagined through Disney.



Theme 4

‘Showing the door’: reimagining the story of children’s hospice care through Disney

As discussed earlier, many parents feel that there is a social stigma regarding children’s hospice care. Several parents attributed this to a broader lack of awareness and knowledge about children’s hospice care in society, and felt that addressing this could help children and families to better understand and access children’s palliative support in the future:

“It is that stigma, it is that association of, ‘My child’s under hospice care, therefore they’re going to die.’ And I think somehow trying to remove that stigma would remove the fact that we’re supporting our hospice and that being a bad thing and a sad thing and a negative thing, to somehow embracing that, it’s just a different journey. I don’t know how that is facilitated, I really don’t. I don’t know” (EACH).

Consequently, many parents felt that Disney would be well-placed to help raise awareness of children’s hospices, as a well-known and reputable brand that is synonymous with storytelling, childhood and the magic of family time. Parents felt that Disney could use its high profile to help raise awareness of, and even help to alleviate the negative stigma surrounding children’s hospices and children’s palliative care:

“I think that [Disney] supporting with things like outreach services would be amazing. If they were the ones that were introducing the thought of hospice into people’s minds, then that would massively impact the way that people look at the hospice” (Andy’s).

Parents also commented that increased awareness could potentially lead to children accessing hospice services earlier.

“That awareness of what hospices offer, is just not out in the community, healthcare professionals aren’t aware of it and, therefore, they don’t tell the families, and so there’s a role for Disney in promoting hospice services in a very different way, a bit like an estate agent, so that they understand what’s there” (St Oswald’s).

Some parents also described how increased awareness would enable parents to talk more freely with their families and friends, and feel less isolated or “different” about accepting care and support from a hospice. In addition to this, parents felt there was a role for Disney in telling the story of being a parent:

‘It would be helpful if Disney could do adverts or just advertise in any way their work with hospices and link it to Disney so that kids are excited to go’ (CHAS).

“We found the initial conversations with family and friends really difficult and if anything could be made simpler for other families going through that journey that maybe just having a high profile partner [...] like Disney just educating, promoting, talking about hospice care and palliative care and changing the way the people, the public’s perception of this industry would be massive for the families that come to hospices and make those conversations easier when talking to their friends and family” (Ty Hafan).

“We would love to see Disney represent our population and capture stories and present them to the general public, so that there’s much more awareness of the work parents do, the learning that they have as families” (Andy’s).

If Disney was to help raise the public profile of children’s hospices, in whatever form, it was further envisaged and hoped by some parents that this may help to reimagine the story of children’s hospices, in moving away from hospices as a sad place of dying toward a place of care, respite, joy and love:

“I think it would also help for other people to understand that these aren’t sad places to come into, that they’re really, really happy. Each child or each young adult likes or wants to do and know all of them, you know, what everybody likes. That’s what makes such a massive difference. They don’t just have to go with the flow, that they get to choose individually what they want to do, and it’s a lot of thought that goes into it” (St Oswald’s).

Moreover, by helping to reimagine the story of children’s hospices and lessen the stigma around them, Disney could act as a vital conduit for children and families – helping them to access essential palliative care when it is most needed. Indeed, almost all parents voiced significant praise for the hospice care their children had received once the parents themselves made the decision to embrace such support, despite the psychosocial barriers: “it felt like an amazing...it just felt like being wrapped up really in a big hug that day”.

Aside from the impact that hospice care has on the ‘ill’ child, the positive benefits to parents’ health and wellbeing are clear. Caring for a child with a life-limiting condition brings many challenges. The impact is enormous – rather than having the time to concentrate on just being a ‘family’, parents face huge challenges: fighting for access to services; negotiating budgets and resources; juggling

caring responsibilities for other children or family members; isolation; emotional and psychological strain. The risk of premature death for mothers of a child with a life-limiting condition is more than 50% higher than mothers of children with no long-term health condition. And mothers caring for a seriously ill child have a significantly higher incidence of depression, anxiety and serious mental illness, and physical conditions such as cardiovascular disease, type 2 diabetes, hypertension, and obesity (Fraser, 2021). Parents described how at the hospice they had time to get some sleep, to spend time with their other children, enjoyed peer support from meeting parents like themselves, had time to do ‘normal’ things and experienced an overall reduction in anxiety.

“Once we got over the threshold, we never looked back. ... was here last week for three nights symptomatic stay... we’ve actually had sleep” (Helen and Douglas House).

“It was just completely beyond my expectations. I came with a friend actually because I was a bit nervous, a bit, you know, so overwhelming. We’ve just got the diagnosis and it was just a bit too much. So, I had a friend who came to support, and we both, when we left, were like, ‘This is actually quite a nice place’” (Helen and Douglas House).

“With ..., she loves it, absolutely, well, they all love it when they come here. You say, ‘We’re going to Hope House.’ And her siblings are all excited and everything” (Hope House).

Many children with life-limiting conditions have profound physical, cognitive, and sensory disabilities. Further to creating a feeling of magic within the hospice using Disney imagery or music to create a sense of comfort and familiarity, a number of parents also felt that it would be especially beneficial for Disney to reimagine how they could use their current resources and outputs to provide a more sensory-based set of equipment that could be incorporated alongside artworks or murals,

as a way to help stimulate and be inclusive of children with sensory and / or cognitive impairments. The extracts below stress the therapeutic and inclusive aspects that such resources may provide, whether via the stimulation of visual, sound, touch, or smell – so that children of all sensory and cognitive abilities can more fully engage with, and benefit from, the care that a children’s hospice provides.

“Disney, perhaps, could have a role in making some of their resources, books into sensory equipment or make it more sensory focused for children with disabilities” (Andy’s).

When invited to take part in the project, nine out of the 10 hospices agreed to receiving a specially created Disney Beauty and the Beast storybook with storytelling paddles. Of those nine hospices, one hospice did not receive the resource in time for the event; and we are only aware of two hospices that used the resource during their day. The feedback received from hospices who decided not to use the resource demonstrates the need to ensure resources are suitable for this population of children and young people, and also consider the impact we expect to see from interventions. Feedback received showed that the resource was not a good fit for the mood for the day:

“It wasn’t suitable to use at an activity day that had lots of other exciting and engaging things going on for children (treasure hunts, face painting, singing, and dancing).”

“We couldn’t use the paddles as the only children who could hold them were well children.”

“It is a nice idea for a bedtime story or quiet time activity but wasn’t something we could make work during an interactive activity day.”

“The resource didn’t include any sensory interaction, which is incredibly important for our children.”

“There were so many exciting and engaging things going on for the children, this didn’t particularly grab their attention.”

However, the hospices who received the resource were delighted to include it in their libraries to use with children in the future. We understand this might be disappointing; the power of Disney, and the positive impact it has on children and hospices, was apparent throughout every single one of the activity days. However, it appears that this resource was not quite the right fit for the cohort of children, or the interactive, activity focused days we were running.

Some parents discussed the need for storytelling to not only include sensory details but also be inclusive of the needs of this group of children, to consider their cognitive and / or physical disabilities. In addition to being mindful of equality, diversity and inclusion principles, one parent suggested that story telling resources had images of children using wheelchairs. One parent summed up the power she saw in Disney as:

“Disney have got the money, they could maybe think about training people all over the country to actually be able to provide physical sensory storytelling experiences.”

Recommendations

Our discovery sessions have demonstrated that there are a range of ways Disney can help more seriously ill children and their families to experience the comfort and joy provided by children's hospices. There are a range of interventions we could continue to explore with Disney for the next stage of this important project, which would deliver different levels of impact for care providers as well as seriously ill children.

1. At a systemic level: The shared vocabulary of Disney's stories and characters could be used to shift the general population's perceptions of children's hospices – what they do, when children can access them, and how they can help families. For example, public facing campaign to destigmatise and demystify children's hospices; shorts available on Disney+ or in movie theatres.

2. At a community level: We could explore using Disney storytelling to reframe children's hospices for families who receive or are eligible for a referral to a service; film or online resource that's shared with families at the point of referral to bring to life the full range of care and support that can be accessed at a hospice. Building on Disney's experience of providing customized training to equip hospital staff with engagement tools and personalized knowledge to enhance patients' and families' experiences, develop a training resource for health care practitioners

to inform them about the breadth of services available at a children's hospice and when families can access them.

3. At an organisation & individual level: Bring comfort and joy into children's hospices by transforming existing Disney resources into interactive, sensory equipment especially (collaboratively) designed for hospices; transforming hospice spaces using colour, storytelling, interactive murals, or digital displays; provide inspiration and hope by creating moments for families to capture special memories and experiences with their seriously ill child.

We would like to work in collaboration with Disney and children's hospices to ascertain which of these interventions would have the greatest impact in the first instance, and as such, should be prioritised for development in the next stage of this project. Once this has been agreed, we will work with the Disney team, parents and children's hospices to create prototypes for development that we can test and begin to understand how they will impact the number of families choosing to take up a referral to a children's hospice.

We hope this is useful for the team – for us, it really emphasises the importance of co-creating resources and understanding the specific needs of this unique group of children.



Conclusion

We are enormously grateful to the children's hospices for organising the fun days for families, so that we can better understand how families feel about being supported by their local children's hospice. We know that first impressions are so important, which is why we hope that these amazing activity days will shine a light on all the incredible support that children's hospices have to offer. Together for Short Lives would be very keen to organise further events in partnership with children's hospices. Each event was attended by at least three members of staff and overall their evaluation was very positive. The days created excellent opportunities to interact and engage with families and children, to meet hospice staff and direct them to other support offered by Together for Short Lives. Lessons were clearly learnt to ensure consistency of offer and communication and expectations for staff and families for any future event planning. Going forward for any future events it is particularly important that we consider and agree representation of brand. Hospices were disappointed that they could not dress up in Disney costumes and found this restrictive in advertising the day to their families.

We owe special thanks to all the families (parents, children, grandparents, carers) who were willing to talk and share their experiences with the Together for Short Lives team. The value of the events was demonstrable to the families and hospice staff involved. One dad who had visited the hospice previously and reported he didn't like it, came back for the fun day and gave us this feedback.

"As soon as we walked through the doors today, the atmosphere of the event and the hospice just felt so different. We were blown away and relieved by the event today and seeing all the families together. Seeing so many different members of staff, being able to meet other parents and other children and just getting to be together. We don't have much experience of talking to other families in our situation so yes, we were really thrilled with the day. I feel so much better, the hospice feels a lot warmer, just more comfortable, and less sterile."





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CHAS, Rachel House Children's Hospice, Avenue Road, Kinross, KY13 8FX

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Appendix 1

Prompt sheet for questions

Those already supported by a hospice

History of referral and how parents came to use hospice services

This is because Disney are interested in understanding whether when/where/how/what information is given has an impact on whether families feel able to engage or not. This plays into the crossing the threshold piece

1. When did you first hear about the hospice, what information did you receive and from whom?
2. What words did you associate with hospice then?
3. How did you feel when you were first told about the children's hospice services?
4. What did you think when you saw the building/environment for first time, how welcoming was it?

Change over time

5. How have your feelings towards the hospice changed at all in the time you've been supported by them?
6. What has helped with that transition in thought? Are there any new words that you would now use/associate with hospice, or care your child receives from the hospice?

Introduction to hospices

Try to find out generically what families' thoughts are before we introduce Disney

7. How do you think families could be better introduced to the idea of being cared for by a hospice service?
8. Is there anything that would want to make their child / family spend more time in a hospice? Services, activities etc?

Disney

9. What words do you associate with Disney?
10. As a family what are your experiences of Disney? e.g., TV, characters, stories, films
11. Do you think Disney could have a role in supporting families to use hospice, either before, during or after a visit?

Prompts – decorating rooms, using the mural artwork, having Disney storytime, having Disney books, having a Disney film library, having mini 'premieres' when new films come out, anything else?

12. I want to show you some Disney mural artwork.

What do you think, do you like it, dislike it, why, why not, could something like this be useful in hospices, what would your children/siblings think of this?

Those not supported by a hospice

History journey to hospice

1. Have you ever been offered support from a children's hospice?
2. (If yes – why did you not take up the offer?)
3. Do you understand how a children's hospice may be able to support your family?
4. How did you feel as you arrived here today? Probe here re: the environment, how it could be improved etc, what would make them want to spend more time here?
5. Are the areas of concern that have affected your decision to use hospice or not e.g., Is it the idea of what hospice stands for, or feelings it instills in parents? Is it what you think happens in the building? Is it the reality that it brings? Is it the geography of the building, or anything else?

Introduction to hospices

Try to find out generically what families' thoughts are before we introduce Disney

1. How do you think families could be better introduced to the idea of being cared for by a hospice service?
2. Is there anything that would want to make their child / family spend more time in a hospice – services, activities etc?

Disney

3. What words do you associate with Disney?
4. As a family what are your experiences of Disney? e.g., TV, characters, stories, films
5. Do you think Disney could have a role in supporting families to use hospice, either before, during or after a visit?
Prompts – decorating rooms, using the mural artwork, having Disney story time, having Disney books, having a Disney film library, having mini 'premieres' when new films come out, anything else?
6. I want to show you some Disney mural artwork. What do you think, do you like it, dislike it, why, why not, could something like this be useful in hospices, what would your children/siblings think of this?
7. Are there any incentives which would help you to come to the hospice?

There will also be a suggestion wall for parents to write down some ideas to address Disney's questions.