

**What this paper adds:** The paper recommends the availability of planned short breaks and appropriate emergency respite care for all young people with life-limiting conditions to prevent carer burnout, deterioration in health and wellbeing, and inappropriate hospital admission. This paper highlights the lack of appropriate short break and emergency respite care provision when children's hospice provision is not available for children's hospice users, and those making the transition from them. This is despite a clear need for this care provision being expressed by families, health and social care professionals and hospice staff.

**Implications for theory, practice or policy:** Policy makers and funding bodies should review access to appropriate short break and emergency care provision from a range of services for young people with life-limiting conditions. Particular attention is needed for the increasing numbers of young people with life-limiting illnesses who are reaching the upper age limit of children's hospice service provision and requiring transition into adult services.

## **Short break and emergency respite care: what options for young people with life-limiting conditions?**

### **Background**

The Worldwide Palliative Care Alliance (WPCA) (2014: 19) estimate that approximately 1.2 million children globally are 'in need of palliative care at the end-of-life'. This is an estimated figure as currently there are no databases available (Hill and Coyne, 2012; Noyes *et al.*, 2013). Within the United Kingdom (UK), around 49,000 children and young people have palliative care needs resulting from an

incurable, irreversible or progressive illness, or a curable condition where treatment can fail (Together for Short Lives (TfSL), 2013; TfSL, 2015a). Although a relatively small population, there are over 300 different conditions for which children and young people with life-limiting conditions (LLCs) require specialist palliative care, therefore their needs can be diverse, complex and expensive (Marie Curie, 2012; WPCA, 2014).

Furthermore, with technological and medical advancements, the number of young people with LLCs surviving into adulthood, and requiring transition into adult services, is rising, resulting in palliative care involvement which may last decades (TfSL, 2013; Care Quality Commission (CQC), 2014). Indeed, over the past decade the number of 16-19 year olds with palliative care needs in England rose by almost 45% (Fraser *et al.*, 2012). Just under a quarter of children and young people being supported by children's hospices are now over 16 years old (Devanney *et al.*, 2012; Marie Curie, 2012). Between 2009/10, the number of 18-25 year olds in England who had LLCs, or life-threatening conditions (LTCs), stood at 12,827 (TfSL, 2015b). Although the upper age threshold of the 53 children's hospices in the UK varies from 18-35 years of age, most do not provide support once the young adult reaches 19 (Devanney *et al.*, 2012; TfSL, 2015c).

Only a limited number of care providers can meet the individual and complex needs of this growing and ageing population, resulting in young people with LLCs and their families having difficulty in obtaining services (Ling, 2012; Thomas and Price, 2012; Noyes *et al.*, 2013). Difficulties in providing appropriate palliative care services arise because the condition may be rare, specific to childhood, or distinctly different to

those of older adults (Rogers *et al.*, 2011; Ling, 2012). Additionally, the illness may follow a different trajectory to adult conditions (Smith *et al.*, 2014). These young people may require many episodes of critical illness management over a prolonged period of time before requiring end-of-life care, whereas adult patients typically have more predictable palliative care needs, often requiring only one episode of end-of-life care (Ling, 2012; Hill and Coyne, 2012).

Understanding the changing trends of palliative care needs for young people with LLCs is vital for palliative care and statutory service planning (Hain *et al.*, 2011; Marie Curie, 2012; Knapp *et al.*, 2012). Commissioners and service providers in the UK have new responsibilities to ensure the delivery of appropriate, equitable and sustainable quality care which meet the specific needs of this increasing population (Marie Curie, 2012).

## **Aim**

The study aimed to explore the impact, and benefit, of planned short breaks and emergency respite care provided by a children's hospice in the North West of England on young people with LLCs, families and stakeholders. This paper will focus upon one key finding, with two key issues, which is the lack of alternative respite care options when children's hospice care is not available for young people with LLCs eligible to receive children's hospice care and those approaching the transition from them.

## **Methods**

### Design and sample

An evaluation approach was selected to assess the impact of a children’s hospice planned respite care (also known as short breaks) and emergency (unplanned) respite care (Robson, 2010; Lambert, 2012). Emergency care refers to unplanned care being needed for the young person, for example, as a result of family needs (e.g. family illness or bereavement) or a breakdown of care, rather than a medical emergency for the young person. It may also include symptom management and step-down care between hospital and home. The voices of children’s hospice users are seldom heard in palliative care research so a qualitative methodology was implemented to give participants, including young people from 11 years of age, the opportunity to discuss their experiences (Grix, 2010; McLaughlin, 2012). A two phase data collection process was adopted with data collected between December 2013 and June 2014. The participant inclusion criteria is shown in Table 1.

**Table 1. Participant Inclusion Criteria**

<b>FAMILIES</b>
i. <i>‘current users’</i> who had used the children’s hospice service for at least two years
ii. <i>‘bereaved families’</i> who were more than 3 months post-bereavement
iii. parent/carers aged 18 years or over
iv. sibling(s) of current hospice service users aged 11 years or older
<b>YOUNG PERSON FORUM</b>
i. current users of hospice services aged 11 years or older
ii. sibling(s) of current service users aged 11 years or older
<b>HEALTH AND SOCIAL CARE PROFESSIONALS</b>
i. Professionals with an ongoing relationship with the hospice and families

who use the service
<b>HOSPICE STAFF</b>
i. All members of the Senior Management Team and Heads of Service

### **Ethical considerations**

University Faculty ethics approval was obtained and permissions granted by relevant NHS Trusts and Directors of Social Care. All standard processes including recruitment, consent, confidentiality, and storage of data were adhered to (Department of Health (DH), 2005).

### **Data Collection**

#### Phase 1 – qualitative data

Phase 1 comprised semi-structured individual or family interviews with young people, parents/carers and siblings, professionals and hospice staff, young person forum and three multi-disciplinary professional meetings. A purposive sample was identified in consultation with hospice staff, who distributed invitation packs including an information sheet, consent form and contact details on behalf of the research team. Interviews took place at a time and location convenient for the participants.

Separate consent or assent processes were followed for all participants, including young people, with written or verbal consent obtained before data collection commenced. Parents gave consent for the young person to participate, whilst assent provided a formal means for young people who wanted to participate to do so (Gibson and Twycross, 2007).

## Phase 2 – Survey

The key findings from Phase 1 were developed into separate online surveys for families, professionals and hospice staff using SurveyMonkey® to engage with a larger sample of hospice users and stakeholders. The mixed method surveys, containing open and closed questions about the children's hospice core services, were piloted by families, professionals and hospice staff representatives to assess their face validity, resulting in minor changes.

Participants were recruited via email or letter sent out by hospice staff on the research team's behalf; a link to the survey was added to the hospice social media webpage; paper copies were made available as required. Implied consent was assumed on return of completed surveys.

## Phase 2 data analysis

Open and closed responses were collected in phase 2; only open text responses, which were subject to the same thematic approach as the phase 1 interviews, are reported here (Miles and Huberman, 1994).

## **Results**

### **Hospice Provision**

The children' hospice in the study is a ten-bedded hospice, providing free planned short breaks, emergency respite care and end-of-life care to young people who have LLCs or LTCs and their families. The term young person/people throughout this paper refers to the children, young people and young adults with LLCs who use the

hospice services from birth until the age of 23, which is the upper age threshold of the hospice in this study. At the time of the study the hospice provided care to approximately 170 families. Between July 2012 and July 2014 the hospice provided 794 planned short break episodes in hospice and 123 in the family home via their hospice at home service. The hospice also provided 106 emergency respite episodes in hospice and 458 in the family home.

A total of 135 participants were recruited to the study across two phases, as shown in Table 2.

**Table 2. Study Participants**

<b>PHASE 1 - INTERVIEWS/FOCUS GROUP</b>	<b>Number of Participants</b>
Parents/Carers (including 1 sibling)	8
Health and Social Care Professionals	7
Hospice Staff	7
Young Person Forum	6
Three Multi-Professional Meetings	25
<b>Phase 1 Total</b>	<b>N=53</b>
<b>PHASE 2 - SURVEYS</b>	
Families	33
Professionals	24
Hospice Staff	25
<b>Phase 2 Total</b>	<b>N=82</b>
<b>Total Number of Participants</b>	<b>N=135</b>

We asked all participants: *“If [hospice] emergency care was not available to you on any occasion, what did you do instead?”* We found that the young person’s complexity of need and the requirement for competent carers were directly related to the lack of appropriate short break or emergency respite care provision when children’s hospice care is not available. We also identified high levels of anxiety experienced by young people with LLCs and their families about losing access to children’s hospice provision as transition to adult services approached, or through no longer meeting the eligibility criteria. The themed findings are presented with anonymised quotations, identifier numbers allocated by the research team (aside from the young person forum to protect participant anonymity) and the source of the data.

### **Complexity of need**

Young people with LLCs who access the children’s hospice have complex and profound palliative care needs. Meeting the young person’s needs can negatively affect parental relationships and those with the young person’s siblings and the wider family. The young people with LLCs worried about the impact of their condition upon their family. One young person gave an example of how her family use planned short breaks to compensate:

*“It’s all me, you know, ‘cause I’ve got a lot of appointments ... and [sibling] misses out on a lot, so they [parents] try and give him a bit of time as well while they have the time to do it”* (Young person forum).

Participants reported that the complexity of the young person's needs can result in children's hospice users having little or no choice of alternative care provision from informal or formal carers when children's hospice care is not available. Barriers to accessing alternative respite care increase as the young person grows physically larger or requires bulky equipment that cannot easily be accommodated in other locations. These issues can make it difficult, if not impossible, to visit or stay with informal carers, such as extended family members, or to be cared for in other care settings, including the homes of foster carers. Opportunities for typical family outings can be limited, leading to the young person and family feeling isolated and struggling to maintain social relationships. One family explained the difficulties encountered in going out:

*"It is a work of art when we take him out because of all the equipment we've got to take, all the machines we've got to take, he's [young person] on oxygen and he has all his medicines and feeds... he developed the need for suction, physio... oxygen, gastrostomy-fed, in a wheelchair"* (Family interview 1).

This point was also highlighted by one young person who reported they cannot stay overnight, even at the children's hospice, for more than a couple of days due to requiring a specialised mattress that cannot be moved easily:

*"I really have trouble with ... mattresses and beds really, 'cause I've got a lot of sores all over my body and my skin's only — in places one layer thick, it breaks down very easily — so I have to be careful on what I sleep on"* (Young person forum).

## **Carer competency**

Families need to know that formal and informal carers have the high level of skills, training and confidence required to deal with various medical or technological issues such as oxygen and feeding administration, ventilators, syringe drivers, bulky equipment and manual handling. As such, families rejected the possibility of using informal carers such as family, friends and neighbours, even in an emergency, due to them lacking the level of skill, experience, physical strength or confidence to provide high quality care for the young person.

*“Now the children are big ... I can't ... leave them ... My mum's very capable but she's seventy... Changing a nappy of a ... [teenager] who's big and heavy... It's hard work physically as well... it's not just about the medical needs of the children even. It's the physical aspects of looking after them... It's heavy work” (Family interview 2).*

Participants felt that ongoing relationships, continuity of care and good communication skills between carers and the young person and family were important for building trust. These were also key to carers maintaining the expertise required to meet the young person's complexity of need. Recruiting and training suitable carers can be a lengthy process for families. Furthermore, families are unable to use standard carers due to them being untrained and lacking the expertise required, as highlighted by a hospice staff member:

*“For emergency care, usually there are no other providers/family members who are trained to provide the level of care required for the child. In these cases usually the family have no one else to help them”* (Hospice staff survey 19).

### **No other choice**

Participants emphasised that alternative formal emergency respite care suggestions, such as use of the young person’s existing community carers or direct payment workers, continuing healthcare staff and children’s community nursing teams were also typically not appropriate. Alternative service providers may have inflexible schedules/rotas or an inability to provide responsive 24/7 care. A member of staff explained:

*“There’s no other services that I know of that can actually put care in. Say a family phones today, no one would be able to put care in tomorrow ... They don’t seem to have that flexibility, so it is a case of, if we can’t help, there is no other help available really”* (Hospice staff interview 4).

Hospital was dismissed as an option by families, professionals and hospice staff, who said that hospital staff cannot meet the holistic needs of the young person and their family, especially when the young person is non-verbal. Families feel unable to leave the young person alone in hospital as hospital staff do not know the young person and are unable to spend one-to-one time with them, further increasing their stress. One family illustrated their concerns:

*“Although it sounds like easy, ‘Oh well ... at least you have got the hospital’, [hospital staff would] have even less of an idea of what the children’s needs are... [Hospice staff] have got some knowledge of [children] because of their previous stays but the hospital staff wouldn’t have a clue where to begin”*  
(Family interview 2).

As with hospital provision, participants were concerned that staff from other children’s hospices or respite care providers would not know the young person and not provide continuity of care. Not all families access other hospices or respite options as a result of differing eligibility criteria, age restrictions and the young person’s complex medical needs. A family explained:

*“[We] tried using a respite centre in [place name]....that takes ... the more autistic, challenging behaviour type children, but they weren’t geared up for more profoundly disabled... It wasn’t right, on quite a number of levels really”*  
(Family interview 2).

Importantly, adult hospice provision or nursing homes were viewed by families, professionals and hospice staff as being completely unsuitable for young people with LLCs, due to them generally being targeted towards older adults. Furthermore, it was regarded unlikely that staff would have the skills and expertise to meet the young peoples’ diverse and complex needs:

*“It's not appropriate for [young person] to go into a nursing home. Her anxiety - it would be detrimental to her health... and ours, 'cause there'd be none of that continuity of care, they wouldn't know her” (Family interview 3).*

### **The impact of having few or no alternative care options**

It was evident that the lack of alternative emergency care options caused anxiety for the children's hospice users, potentially impacting upon their health and wellbeing. The lasting implications of having to neglect their own needs and those of the rest of the family due to having no suitable alternative emergency care options were apparent:

*“Say if you weren't feeling well, and this is what happened to me really, I kept putting it off. I had ... problems and I kept going ‘It's all right, it's all right... I don't need to go to the GP, I don't need to go to the hospital’. I put it off till I was an emergency, rushed in [to hospital, and now have lifelong problems]” (Family interview 3).*

Families are prevented from participating in important appointments or events taken for granted by the general public, such as weddings. A mother explained the consequences of having no alternative care provision when she was hospitalised:

*“It meant I had to go into theatre for emergency surgery by myself and had a week in hospital without my husband being able to see me as he had to stay home with our children. We have no family at all” (Family survey 20).*

Families discussed the valuable assurance and importance of hospice emergency respite care provision:

*“The emergency stuff, if it’s a real emergency, how can you do without that? What would you do? ... I think it’s more valuable, if you actually weighed it up, the planned stuff is lovely don’t get me wrong, and it’s something to look forward to ... and it does sort of get you through, you know, ... but if I was given the choice ... I think that actually ... [emergency respite care] is more valuable”* (Family interview 2).

### **Transition from the Children’s Hospice**

Some participants discussed the lack of appropriate provision for young people upon leaving children’s hospice provision. Sibling support also stops once the young person has been discharged. Young people, families, professionals and hospice staff spoke of this leading to high levels of anxiety and concern about the future.

*“It is a growing number and is of major concern, certainly to me and all of the members of my team that people from the [hospice discharge] age... fall off the shelf. I’ve had discussions with quite a number of individuals who are deeply worried about it”* (Professional interview 14).

This point was also highlighted during the young person forum:

*“Unfortunately 'cause I'm coming to the age where I have to leave ... [children's hospice] support is going to stop, so ... [sibling] won't intermingle with many other kids and other siblings that understand what you've been through” (Young person forum).*

Reaching the upper age limit of the children's hospice was viewed as having a double impact upon families, as a consequence of the psychological effects and the subsequent lack of continuity of care following transition. This was explained by one participant:

*“Many of the children that are now reaching 18, they were told all of their childhood that they're unlikely to reach adulthood, so there are issues with 'Does this mean... that the end is very near?' ... Families ... worry that they're losing all of their care staff... that they might have had... for most of their lives” (Professional interview 8).*

After many years of having the support and security of children's hospice emergency care, families spoke of feeling alone and fearful of what will happen in the future without that support:

*“We have no other options which will be VERY scary from this year when [hospice] facilities won't be an option for us anymore” (Family survey 32).*

## **Discussion**

Young people with LLCs can have complex and profound needs, often with many co-morbidities. Caring for these young people can be challenging, and physically and emotionally exhausting. It can result in stress and isolation, negatively impacting upon the health, education, social wellbeing, family functioning, financial stability and quality of life of the whole family, including siblings and grandparents. These findings are congruent with previous research which adds that the effects can be lifelong (Thomas and Price, 2012; Remedios *et al.*, 2015).

Palliative care for children includes the provision of respite care and short breaks (World Health Organisation (WHO), 2015), whereas palliative care for adults typically focusses more upon predictable palliative care needs, one episode of end-of-life care and symptom management (TfSL, 2015d; Ling, 2012; Hill and Coyne, 2012). We identified that the individualised, practical, emotional and psycho-social support delivered by the children's hospice via planned short breaks made a huge difference to families. These findings support the literature which states that planned short breaks increase family resilience and reduce the stress and isolation experienced (Carter *et al.*, 2013; Remedios *et al.*, 2015).

For quality short breaks and emergency respite care, young people with LLCs and their families require effective communication, coordinated support and carers with a high level of skill, training and confidence to meet the young person's fluctuating needs; staff from the children's hospice met these requirements. Families in this study reported difficulty in accessing, recruiting and retaining competent staff or training family members, corroborating findings elsewhere (Eaton 2008).

When talking about emergency respite care delivered by the children's hospice, families reported feeling reassured by the potential to access it, and stated that it is holistic, responsive and can accommodate the young person's complex care requirements. However, two key issues were highlighted: The lack of provision when children's hospice care was not available for (i) those still eligible to receive children's hospice services and (ii) those leaving the service as a result of reaching transition age or through no longer meeting the children's hospice eligibility criteria. Alternative care options to children's hospice care mentioned by some participants were viewed as inappropriate, resulting in families who access children's hospice services having limited, or no, choice of appropriate alternative services for emergency respite care if the children's hospice is not available. Although hospitals were frequently suggested as an alternative emergency respite care option, participants claimed that hospital staff do not have the time, experience and resources to provide continuity of care. Furthermore, other providers in the community such as direct payment workers were reported as being unable to provide responsive 24/7 care and lacking the necessary skills. These findings support previous studies which suggest that alternative care providers are unable to meet the unique palliative care and multiple complex healthcare needs of these young people (Ling, 2012; Thomas and Price, 2012; Carter et al., 2013; House of Commons Health Committee (HoCHC), 2015a).

Although McNamara (2013) states that young people with LLCs, their families and professionals should have confidence in the transition to adult services, some families and stakeholders in this study reported a high level of anxiety about leaving children's hospice care. The lack of provision for short breaks and emergency respite

care following transition was a concern. The young people were scared for themselves, their siblings and family, whilst parents spoke of feeling alone and fearful of what will happen in the future, especially in an emergency. Participants viewed adult care provision as being unsuitable for young adults with LLC's, whose needs are distinctly different to those of older adults, corroborating the findings of Rogers *et al.* (2011), Ling, (2012) and Kirk and Fraser (2014). It was suggested that some of the young people may be developmentally inappropriate for adult hospices or services, despite being viewed as an adult chronologically (Doug et al., 2011; CQC, 2014). Furthermore, some participants said that adult settings have a different culture and ethos to children's hospice provision, being targeted towards older people and end-of-life care, rather than rare, complex and fluctuating health conditions, often extending over many years. Moreover, participants were concerned that adult sector staff, including palliative and district nursing teams, can be unfamiliar with, and inexperienced in dealing with, the young peoples' rare and complex paediatric diseases. Additionally, there is unfamiliarity with the technology required due to infrequent contact with this client group, resulting in a lack of confidence, knowledge and skills to meet the age-specific needs of this population (Lidstone, 2013; CQC, 2014; TfSL, 2015b). These findings replicate studies reporting families feeling abandoned, trapped and isolated when appropriate adult services are not in place (CQC, 2014; Kirk and Fraser, 2014; Noyes et al., 2014; TfSL, 2015a).

We found that transition from children's hospices occurs when the young person and their family are requiring increased support. Participants mentioned the increased challenge of caring for the young person when they are physically larger and

heavier. They also mentioned deterioration in the young person's health and having awareness of the young person's mortality, especially when they were not expected to live beyond childhood, which support the findings of previous studies (Marie Curie, 2012; Kirk and Fraser, 2014).

Professionals and hospice staff reported concerns about the impact of discharge upon young people and their families. A key concern was the removal of planned short breaks and access to emergency respite care which the families had previously experienced, with no similar suitable service provision being offered, a concern also reported in the literature (CQC, 2014; Noyes *et al.*, 2014).

It is important to note that, at the time the study was conducted, dedicated respite care services were not available for young people with LLCs in the geographical location of the study. The authors note that some children's and adult hospices in other parts of England, at this time, were providing or developing dedicated services.

There is limited research about the access to appropriate services and outcomes for young people with LLCs and their families following children's hospice discharge (Kirk and Fraser, 2014). Yet there is evidence to suggest that poor continuity of care following transition into adult services can result in young people and their family having unmet emotional support needs (Kirk and Fraser, 2014); adversely affected social, educational, vocational and spiritual outcomes (Marsh *et al.*, 2011; Marie Curie, 2012:5); inadequate management of complex co-morbidities, deterioration in the young people's physical and mental health and inappropriate, costly hospital admissions (Campbell *et al.*, 2012; CQC, 2014). Most disturbingly, it is suggested

that earlier death can result from poor transition (Marsh *et al.*, 2011; Marie Curie, 2012:5).

### **Conclusions and recommendations**

Literature supports our twofold findings to recommend that children's hospice users and their families *and* the increasing population of young people with LLCs surviving into adulthood, thus reaching the children's hospice upper age threshold and requiring transition into adult services, should have regular short breaks and emergency respite support. Short breaks and emergency respite support are essential to increase resilience and decrease the risk of deterioration in health and wellbeing, carer breakdown or abuse (Carter *et al.*, 2013; Remedios *et al.*, 2015); preventing social care intervention, inappropriate hospital admission or costly out of home placement (Ling, 2012; Robertson *et al.*, 2011). Having few, or no, appropriate alternative short break and emergency respite care options when children's hospice provision is not available, can have negative and far reaching consequences for young people with LLCs, their family and society.

Literature highlights the importance of implementing preventative services that could reduce, or prevent, the need for intensive health and social care support, especially in current times of limited resources (King and Jackson, 2015). Therefore, we suggest that appropriate provision for planned short breaks and emergency respite care provision should continue following discharge or transition from children's hospices, as recommended in the Noyes *et al.* (2014) composite palliative care model. Furthermore, this reflects the young people's and their families' right to safe,

user friendly and integrated services that promote wellbeing and quality of life (Care Act, 2014; Department for Education and Department of Health, 2015).

Although transition into adult palliative care may require the input of joint paediatric and adult palliative care teams, adult sector staff would gain the knowledge and competency required to care for the young person; allowing the opportunity to build trusting relationships with families and potentially saving costs in the long term. Children's hospice staff understand how complex the lives of young people with LLCs and their families can be and, as such, are well placed to support transition and development of appropriate services for them.

The lack of literature identifying the numbers of young people who do not subsequently receive planned short breaks or emergency respite care when discharged from children's hospice provision is of concern, and clearly requiring exploration. Research is also undoubtedly required to explore the impact and outcomes of transition from children's hospices upon those with LLCs and their wider family. Finally, awareness of the increasing numbers of young people with LLCs who require dedicated and age appropriate short breaks and emergency respite care in adulthood needs to be raised internationally.

### **Limitations**

This study has a number of limitations. Firstly, the conclusions are limited by the study being conducted on one site and small sample size limits representativeness and generalisability. Secondly, reliance upon hospice staff to recruit participants can result in practitioner gatekeeping and selection bias, affecting research quality

(Crocker *et al.*, 2015). Thirdly, some participants were still using the children's hospice services and the lack of negative comments about the services provided by the children's hospice may reflect family bias. Fourthly, all family interview participants were of White British ethnicity, reflecting a lack of diversity in ethnic or cultural backgrounds. However, results are congruent with other research findings adding weight to this study.

### **Acknowledgements**

Sincere thanks to the young people, families (including siblings), health and social care professionals and children's hospice staff for participating in this study. Special thanks to the hospice staff for their continued communication and support, our Public and Patient Involvement volunteers, and the families who piloted the survey. Claire House Children's Hospice funded the evaluation.

### **Key words**

Young People, Life-Limiting, Palliative Care, Short Breaks, Respite Care, Transition.

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