

# Meeting the needs of young adults with life-limiting conditions: A UK survey of current provision and future challenges for hospices

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## Abstract

**Aim:** The aim of this study was to seek views of UK children's and adult hospices on the availability and challenges of providing services for young adults with life-limiting conditions.

**Background:** Internationally, there are a growing number of young adults with life-limiting conditions and/or complex needs which are degenerative, progressive and diverse and involve complex life-long symptom, medication management as well as palliative care. There are 55,721 young adults, aged 18–40 in England, which continues to increase. The hospice sector is experiencing demands to extend services for this population despite concerns about the appropriateness of adult hospices and their nursing staff to provide care for the complex and unfamiliar conditions of this patient group. Evidence is needed of hospices' views and the main challenges faced providing services for young adults.

**Design:** Descriptive cross-sectional survey.

**Methods:** xChildren and adult hospices completed an online survey exploring service provision and their views of respite care for young adults with life-limiting conditions from 18 years old and onward. Data were collected between October 2015 - February 2016.

**Findings:** Respondents ( $N = 76$  hospices) reported that children's hospices predominantly provided short breaks and end-of-life care; adult hospices provided mainly symptom management, end-of-life care and day services. Main challenges were lack of existing adult respite services; lack of funding and capacity; lack of a skilled workforce in adult hospices; and the need for better integrated service provision.

**Conclusion:** Examples of good collaborative working were reported. With an increasing population of young adults and pressure on families, it is vital that services work together to find sustainable solutions to the challenges.

## KEYWORDS

family carers, hospice, life-limiting conditions, nursing, palliative care, parents, transition, young adults

## 1 | INTRODUCTION

Life-limiting conditions (LLC) is a term used to describe degenerative and progressive illnesses with no reasonable hope of cure that will ultimately be fatal (Fraser, Miller, Aldridge, McKinney, & Parslow, 2013; Together for Short Lives [TfSL], 2015a). The needs of young adults with LLCs are diverse and involve complex life-long symptom, medication management and palliative care (Noyes et al., 2014). It is estimated that 21 million children and young people between 0–19 years of age could benefit from accessing palliative care worldwide (Connor, Downing, & Marston, 2017). Due to medical advances, the number of 16–19-year olds with palliative care needs in the UK has increased by 45% over the past decade leading to an increasing number surviving into adulthood (Marie Curie, 2012). The most recent reported data (2009/10) for young adults indicate that there were 55,721 young adults, aged 18–40, with complex needs and LLCs living in England and this number continues to increase (Care Quality Commission (CQC), 2014; Fraser et al., 2013). It is difficult to gain a clear picture of young adults living with LLC due to a lack of empirical data, or data referring to different age groups, conditions and definitions of LLCs (Savage, 2011).

Young adults with LLCs often have multiple comorbidities in addition to their primary diagnosis, requiring care which is ongoing, complex and unpredictable. Daily care is typically provided by family members with support from paid carers and health- and social-care professionals. This level of care is associated with increasing costs that, in tandem with the rising population, is placing increasing demands on adult services, commissioners and service providers to meet the needs of young adults who transition to their services (CQC, 2014; Marie Curie, 2012). Transition is defined as the purposeful, planned movement from paediatric to adult medicine on entering adulthood (Blum et al., 1993, 2002). Evidence of transitional care from paediatric to adult healthcare for young people with complex or chronic conditions gathered in the UK and Europe has highlighted the need for young people to be prepared early for their transition to strengthen their developing independence (van Staa, Jedeloo, van Meeteren, & Latour, 2011). Early planning provides the opportunity to explore young people's needs across a range of medical, psychosocial and vocational issues and encourages a multi-agency approach with good parallel planning for the young person's ongoing care as well as end-of-life care (TfSL, 2015a). Issues highlighted as important to address with young people as a part of transition planning include disease knowledge, social and peer support, contraception, education, employment, housing, accessing resources, developing personal goals and appropriate social care (Bomba, Hermann-Garitz, Schmidt, Schmidt, & Thyen, 2017; TfSL 2015b). As part of their transition planning and move into adult services, these young adults require access to age and developmentally appropriate respite care (Together for Short Lives, 2015b). However, due to the differences in how respite care is conceptualized, funded and provided between child and adult services (NHS Choices, 2015), this aspect of transition planning can be challenging.

### Why is this research needed?

- There are a growing number of young adults with life-limiting conditions or complex needs which require complex life-long symptom and medication management and palliative care.
- There is a reported lack of appropriate short breaks or respite care provision for young adults leading to the hospice sector facing demands to meet the needs of this population.
- Despite the expertise of hospices, there are reported concerns about the appropriateness of adult hospices and their nursing staff skills to provide care for this patient group, which have complex and unfamiliar conditions. Evidence is needed of their views on the availability and challenges of providing care for young adults.

### What are the key findings?

- There was a clear indication that some adult hospices do not see a role for their services with the young adult population unless it fits clearly with their current provision.
- Main challenges identified were a lack of existing age/developmentally appropriate adult respite services; lack of funding and capacity; lack of a skilled workforce in adult hospices; and the need for better integrated service provision.
- Examples of good collaborative working or expansion of services were reported by both children and adult hospices in some areas of the UK which is encouraging, but suggests that there may be disparity in accessing appropriate services across regions.

### How should the findings be used to influence policy/practice/research/education?

- These findings highlight the need for children and adult hospices, who wish to provide services or work together, to look at the key issues raised relating to the lack of alignment between transition categories, referral processes and eligibility criteria.
- The sustainability of services and collaborative partnerships is a key and requires services and commissioners to look at how best to use existing resources to meet the demands in their region. Additionally, young adults with personal budgets with the ability to purchase care from their chosen providers will need support to identify and negotiate the best care possible.
- The perceived lack of a confident and skilled nursing workforce in adult hospices persists, despite educational interventions in recent years. Further development and spread of shared learning opportunities, joint transition planning and upskilling interventions will ensure that adult hospice staff have the knowledge and confidence to support practice.

**TABLE 1** Together for Short Lives definitions of short break care and specialist short break care (TfSL, 2013)

Short Break Care	Specialist Short Break Care
<p>Three main functions:</p> <ul style="list-style-type: none"> <li>To provide the child or young person with an opportunity to enjoy social interaction and leisure facilities.</li> <li>To support the family in the care of their child in the home or an alternative community environment such as a children's hospice.</li> <li>To provide opportunities for siblings to have fun and receive support in their own right.</li> </ul> <p>Short breaks may offer the whole family an opportunity to be together and to be supported in the care of their child or it may offer care solely for the child or young person.</p>	<p>Specialist short break care refers to a setting of care, a programme of care or a service that provides additional care for highly complex or technology-dependent children who may otherwise be excluded from short breaks provided by social care.</p> <p>It may take place in the child's home or in a setting outside of the home such as a hospital, long-term care facility or hospice.</p> <p>Specialist short break care provides the support required to meet the child's holistic care needs and enables children and families to access short break services.</p>

## 2 | BACKGROUND

There are not only similarities but also differences in the service provision of children's and adult hospices due to the different underpinning focus of care and eligibility criteria. Children's palliative care begins from the point of diagnosis or recognition of condition through to death and bereavement. Therefore, hospice care may last many years with regular planned respite care at home, or short breaks at the hospice for the child, with or without the rest of the family. Many children's hospices also provide emergency respite care, tailored sibling support and postdeath care in cool rooms (TfSL, 2015c). Adult hospices typically care for the older adult population in the last year of life, with more of focus on end-of-life care and symptom management as their condition progresses rather than planned short breaks. Both services provide symptom management, end-of-life and bereavement care, along with a range of individualized services such as counselling and support for family members (Hospice UK 2016; Together for Short Lives, 2015c). Moreover, adult hospice staff have reported not feeling competent in dealing with complex diseases which originate in childhood or of supporting young adults with complex needs (Care Quality Commission, 2014; DH 2008; Doug et al., 2011; Noyes et al., 2014; Potts, 2009).

Typically the term "short breaks" or "specialist short breaks" (for highly complex or technology dependent children) is used in children's services to define the functions of respite care (World Health Organization (WHO), 2015). Together for Short Lives, the leading UK charity provides clear definitions of short break care (see Table 1). The focus in adult social care tends to be more on giving the carer a break and is typically referred to as "replacement" or "respite" care (NHS Choices, 2015).

Evidence on the use and impact of respite services/short breaks for children and young people with LLCs demonstrates that respite care is essential for increasing family carer resilience (Mitchell, Knighting, O'Brien, & Jack, 2016; Whiting, 2014), reducing the risk of carer breakdown (Carter, Edwards, & Hunt, 2013; Mitchell et al., 2016; Remedios et al., 2015) and avoiding unplanned hospital admissions or social care intervention (Ling, 2012; Robertson et al., 2011). These benefits are linked to parents and carers having a break from intensive care provision, reduced fatigue, improved quality of life (Remedios et al., 2015), increased trust and confidence in the care being provided to their child, improved emotional and social support

(Ling, 2012; Mitchell et al., 2016; Whiting, 2014) and more time to spend with each other and their other children (Robertson et al., 2011). During times of crisis such as family illness, some providers offer emergency respite in hospice or at home which is highly valued by families (Knighting, Mitchell, O'Brien, & Jack, 2014).

Once a young person has transitioned from child-centred services to adult services or they reach the maximum age limit of a children's hospice, if using one, they are unable to access these services, resulting in challenges identifying and accessing appropriate adult services for many with complex needs (Kirk & Fraser, 2014; Knighting et al., 2014; Noyes et al., 2014) There is increasing evidence that poor continuity of care after transition, including lack of respite provision, is associated with a range of unmet needs for young adults and their families. In addition to the strains on the family mentioned above, young adults can experience poor social, educational, physical, mental, vocational and spiritual outcomes and inadequate management of complex comorbidities (Doug et al., 2011; Marsh et al., 2011; National Collaboration for Integrated Care and Support, 2013). Most disturbingly, poor transition to adult services and the additional loss of services may result in the earlier death of young adults with LLCs (Marsh et al., 2011).

Whilst transition can be well planned with appropriate respite/short break care for some families, other parents have described the transition process as "like falling off a cliff" when support from children's services ends and appropriate adult services are not available (TfSL, 2015d). For those who have used a children's hospice, transition can also result in young adults and their families feeling abandoned by having to leave a familiar and supportive environment as well as being detached from relationships they have built up over several years (Mitchell et al., 2016). Despite increasing research on young people's transition into adult health services, there is little evidence about the quality, accessibility or availability of respite/short break care or broader hospice services for young adults with LLCs and the impact has on their health and well-being and that of their family (Remedios et al., 2015).

## 3 | THE STUDY

### 3.1 | Aim

The aim of the study was to answer the question: What are views of staff working in children's and adult hospices in the United

Kingdom (UK), on the availability and challenges of providing services for young adults with LLCs aged 18 years or over? As the study was a preliminary exploration into this area of service provision, with a focus on respite care, no upper age limit was applied. We use the term “services” in the rest of the paper to be inclusive of all types of respite/short break/other services available via hospices.

### 3.2 | Design

The design was an online anonymous, descriptive, cross-sectional survey. Patient and public involvement (PPI) was integral to the research. A PPI advisory group of three young adults with LLCs and six parents whose children have LLCs and 12 professionals/providers, including hospice sector staff, general practitioners and service commissioners, collaborated on the development of the study aims, participant materials and survey.

### 3.3 | Participant recruitment

A convenience sample was recruited via an email invitation, which was sent to all 221 hospice leads in the UK by Together for Short Lives ([www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)) and Hospice UK ([www.hospiceuk.org](http://www.hospiceuk.org)), both leading national palliative care charities. The invitation explained the study, provided a link to the survey on SurveyMonkey© and asked that only one person from each hospice complete the survey to avoid duplication of any information submitted as no identifying details were requested. A reminder email was sent out 2 weeks later.

### 3.4 | Data collection

Data were collected between October 2015 - February 2016. The survey containing five closed questions to gather service location, respondent's role; upper age limit or length of time been providing services; the current services offered to young adults with LLCs; and any intention to develop future services if none were currently provided. Six open questions gathered information on: challenges around transition planning/discharge from or to hospice; details of any collaborative working between children and adult hospices; awareness of appropriate services; plans for future provision; views on how to meet the respite care needs of young adults with LLCs in the future; and any other comments.

### 3.5 | Validity and reliability

The surveys were reviewed by young adults, academics and hospice staff ( $N = 10$ ) to confirm face and content validity before dissemination. A rigorous process of developing and refining themes was followed with a nominated team member to facilitate any disagreements (BJ) to ensure that there was consensus in the team and reduced risk of bias during the analysis (Miles & Huberman,

1994; Green & Thorogood, 2004; Saks & Allsop, 2007; Noble and Smith, 2015).

### 3.6 | Ethical considerations

Ethical approval was granted by the University Faculty Research Ethics Committee (Ref: SC 18).

## 4 | DATA ANALYSIS

Data were imported into SPSS (Statistical Package for Social Sciences v22). Descriptive statistics were used to analyse and report the quantitative data. Open-text responses were analysed using a content analysis approach following several key sequential steps to systematically organize, reduce, refine and analyse the data (Clarke & Braun, 2013). TM and AK conducted initial analysis to identify emergent themes and topics, in the anonymized verbatim quotes, which were validated by the team. Further analysis to refine themes was conducted by KK and MP. All team members reviewed the final themes allowing for consensus to be reached in the thematic mapping of the data, enhancing rigour and trustworthiness of the analysis (Miles & Huberman, 1994; Noble and Smith, 2015).

## 5 | RESULTS

Staff from 76 different hospices were participated (34% of the 221 hospices in the UK), comprising 13 of 51 children's hospices (25%) and 63 of 170 adult hospices (37%). Respondents were from all the regions across England, with adult hospices also taking part from Wales, Scotland and Northern Ireland. The 63 respondents who provided details of their role were from three types of roles: Chief Executive/Clinical Director ( $N = 23$ ), Manager/Consultant/Head of services ( $N = 29$ ) or Transition Team Lead/Co-ordinator ( $N = 11$ ).

### 5.1 | Current and planned service provision for young adults

Respondents were asked to identify from a predetermined list the services they currently provide to young adults with LLCs, (i.e. those aged over 18 years or having reached the maximum age for children's hospices in their region) and the length of time they have provided these services. Of the 57 who reported their current provision, four children's hospices and 17 adult hospices ( $N = 21$ ) reported that they do not currently provide any services to this population. The services reported by the hospices are presented in Figure 1.

Six children's hospices provided a variety of the listed services, with the exception of day services and a predominance of providing short breaks and end-of-life care (30%,  $N = 3$  each). 'Other' services delivered by 4 (40%) children's hospices included: support with transition such as counselling, provision of social opportunities,

development of independent living skills; day care and an on-call service for symptom management and end-of-life care. Thirty adult hospices reported providing all services with a predominance of symptom management (47%,  $N = 22$ ), end-of-life care (47%,  $N = 22$ ) and day services (36%,  $N = 17$ ). "Other" was selected by those who had previously provided services to individual young adults or were currently working with local partners where needed (40%,  $N = 19$ ), for example, to support transition, equipment loans, supporting advance care planning or family support including pre- and post-bereavement. As service provision to young adults is a relatively new area for adult hospices, respondents were asked how long they had been providing care to this patient group. Not all adult hospices reported how long they have been providing care to young adults; but 10 had started to do so in the last 2 years and 13 had been done so for "more than 5 years."

Five children's hospices reported additional services they would like to offer in the future or were developing, including skills to support young adults' transition to adulthood (social support and independent living, education and employment opportunities), along with support and training for parents around advance care planning. Twenty-one adult hospices reported service developments including integrated service provision with other services; engaging with national initiatives such as UK Transition Regional Action Groups; local scoping studies to explore potential numbers of young adults who may need services; supporting independence post-transition; and the building of units/facilities. Nineteen adult hospices reported that they were not planning to develop any services for young adults in the future, due to a range of issues which are outlined in the challenges section below.

## 5.2 | Current and perceived challenges to service provision

Many of the hospices described the challenges they face in developing or providing services to young adults with LLCs or

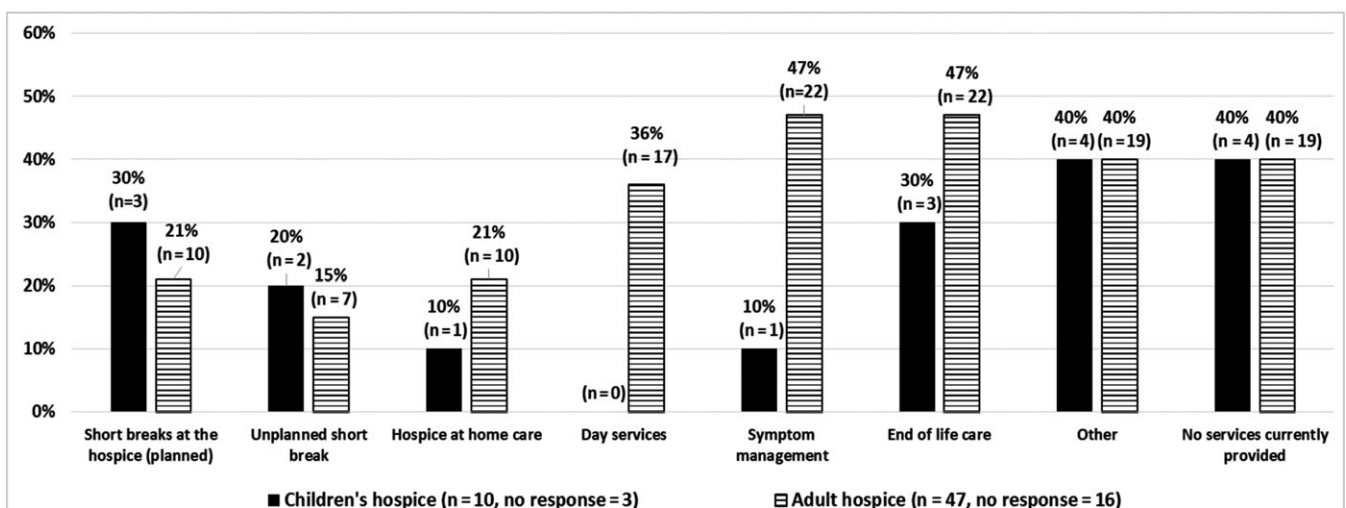
supporting transition from a children's hospice to adult hospice. Information from children's and adult hospices are presented together here, as both services provide care for young adults of 18 years and above. Four of the children's hospices provided care for young adults up to 26 years of age if they had been using the hospice since childhood. The findings are presented in the following themes: lack of existing adult respite services; lack of funding and capacity; lack of a skilled and confident workforce in adult hospices; and the need for better integrated service provision between children and adult hospices, along with other providers, to develop and improve access to appropriate services. Exemplars of data from the open responses are presented as anonymized verbatim quotations with respondent identifiers for adult hospices (AH) and children's hospices (CH). A numerical identifier was allocated as the surveys were completed.

### 5.2.1 | Lack of existing adult respite services

The lack of age and developmentally appropriate services for young adults was a key challenge identified by both children and adult hospice staff. Respondents identified a mismatch between the expectations of families and the services which adult hospice services primarily provide (end-of-life care, symptom management). One adult hospice respondent stated:

*Children's hospices are much more geared up to providing regular respite than we are in adult hospices - and that respite can even be their main focus of care. Meeting the expectations of the young person and their family/carers as they leave children's hospices is difficult as the equivalent service doesn't really exist in the adult world (AH13).*

The use of different eligibility criteria and purpose of provision highlight the challenge of trying to fit young adults with LLCs into



**FIGURE 1** Children's and adult hospices providing services to young adults with LLCs ( $N = 57$ , no response = 19) [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

the adult hospice end-of-life care focus, leaving families feeling deserted as a result:

*Families feeling abandoned when no longer able to access our hospice at home services and the young person does not meet eligibility criteria for adult hospice at home teams (CH2).*

Eight children's hospices and 13 adult hospices described the inappropriateness of providing care for young adults in an environment predominantly occupied by older adults, suggesting adult hospices may not be suitable to meet the needs of young adults with LLCs and their families. Some respondents recommended that specific environments should be provided and that they need to be local to families:

*Our families and young people say - they want a service - but they are often put off by the older persons accessing this type of care - they are wanting a bespoke service - often with children's [hospices] extending their remit. They want local - not travelling miles - to access care (CH10).*

## 5.2.2 | Lack of funding and capacity

Funding and capacity issues were reported by three children's hospices and 23 adult hospices as the biggest challenges for adult hospices to provide or develop age/developmentally appropriate respite services for young adults. This included reference to an unwillingness of budget holders to contribute towards the costs:

*Lack of provision. Lack of consistency in terms of service availability in different areas. Lack of understanding/awareness from commissioners (funders). Unwillingness of budget holders to pay the actual costs, or even half the actual costs of a short break (CH3).*

Adult hospices argued that funding must be provided to be able to meet the increased demand for respite services and care for this growing population of young adults:

*Finance is the biggest challenge. Most young adults are 100% health funded and commissioners do not have enough young people with complex life limiting conditions in their area for this to be a priority before, or unless, there is a crisis (AH23).*

Whilst some adult hospices were keen to work towards providing respite care for young adults, others were not. Three children's hospices and three adult hospices suggested that adult hospices are resistant to provide care for this group of young adults as they do not feel that it fits their service provision or capabilities:

*We believe adult hospices have a very limited part to play in meeting the supportive and palliative care needs of this group. Adult hospices have very different skill set and environments to children's hospices and are not equipped to meet many of the wider transitional care needs. (AH1).*

## 5.2.3 | Lack of a skilled workforce

Another challenge identified was the perception that adult hospice staff may not have the necessary expertise or confidence to meet the complex and profound needs of this population. This was identified by respondents from both hospice sectors. Adult hospices referred to the lack of necessary knowledge, skills and awareness of complex conditions which arise in childhood to care for young adults with LLCs:

*Young adults are transferring from children's services with conditions that adult services have no knowledge of, therefore lack understanding about what this means for their day to day care and support (AH23).*

Children's hospices identified particular skills and knowledge that need to be in place in the adult hospice workforce such as an understanding of young adults giving consent and the mental capacity act. Two children's hospices and nine adult hospices specifically highlighted the need for additional training for adult hospice staff who care for young adults with LLCs. One adult hospice commented:

*Ensuring an appropriately trained and skilled workforce ... there is a need for upskilling of their staff to ensure they can meet the needs of these young people who can present with a range of medical complexities (AH22).*

Whilst an adult hospice emphasized that adult nurses have many transferable skills, others suggested that it was a matter of building confidence in adult hospice staff to provide care for young adults:

*I believe that there are a great deal of transferrable skills that adult health care professionals have that can be used when caring for a young adult with a life limiting condition (AH13).*

*The main challenge in the adult hospice is the difficulty in getting adult hospice carers engaged. It is purely based on a fear of unknown and the complex needs of the clients. (AH36).*

## 5.2.4 | Integrated service provision to enhance development and access to services

An important challenge to provide care for young adults with LLCs was the need for better integration and collaborative working

between all services to explore new ways of working. Staff from eight children's hospices and 15 adult hospices described how collaborative relationships between hospices and commissioners of services (Clinical Commissioning Groups [CCG]) should lead to a better understanding of and management of continuing health-care (CHC) packages, which provide funding for care:

*CCG's and CHC [commissioners] having transition on the agenda, looking at commissioning intentions and improved joined up communication - adults and children's services [currently] work in silos and this leaves everyone thinking it is the other persons responsibility (CH9).*

A significant challenge to planning transition and greater collaborative working between children's and adult hospices is the underlying difference in their referral processes and eligibility criteria. Three children's hospices and 13 adult hospices reported this as a challenge:

*Current transition care categories are not aligned with our adult hospice referral criteria, so whilst adult patients with life-limiting illnesses who have active specialist palliative care needs may be referred and accepted for hospice care, there are a large cohort of patients under the care of children's hospices who will not meet the criteria for referral to adult hospices as the referral criteria differ (AH11).*

Adult hospices reported that as they did not accept self-referrals, families were reliant on professionals, who may not be fully aware of adult hospice services, to make referrals. Eleven adult hospices reported that they had received few, or no, referrals for young adults possibly due to this issue:

*We take referrals based on need rather than a specific end-of-life time scale so any young adult who had need / felt they would benefit from our services could be referred. I think the key here is who refers and why as I wonder what circumstances would prevail to get a GP/consultant to consider asking for our help (AH4).*

It was also highlighted that new ways of working are required for young adults who are able to use personal budgets (allocated from health- and social-care services for their care and support needs) to purchase care from their preferred providers:

*This is an area [adult] hospices have to face up to; it is likely we'll meet empowered young people who have control of their budgets and needs that will need addressing in a way not done before. . . . they may bring paid carers [agency carer or nurse] with them creating a*

*potential difficulty over responsibility for care delivery (AH8).*

Although challenges were identified about collaborative working, there were reports of existing collaboration. Nine children's hospices described work including ad hoc support to adult providers; staff training in adult hospices; supporting access to independent living schemes; establishing groups to review ongoing processes; developing early triage systems to identify those who would need the support; and a jointly-run youth group for young people taking place in an adult hospice. One children's hospice did not currently provide services but was developing training packages that would facilitate adult hospices to support young adults once they had transitioned out of the children's hospices.

Ultimately, cultivating integrated service provision in local regions, not just hospices, was seen by many as the way to improve choice, access and available services for young people with LLCs in the future:

*Conjoined working and delivery needs to improve, especially with regards to joint budgets . . . and strategic planning - there is a need for partners in 3rd (charity) and private sector to respond to the growing numbers of young people with LLCs living in their local areas and requiring support whether it be hands on care, advice and advocacy, or respite breaks. (AH22)*

## 5.2.5 | Meeting the future needs of young adults with LLCs

Respondents from both hospice sectors emphasized the importance for young adults with LLCs to have opportunities to socialize and develop peer support:

*Provision of social opportunities. . . opportunities to socialise with their peer group whilst trying different activities and having fun. Opportunities will include fun days, short breaks and social events (CH4).*

Emotional and informational supports, along with preparing young adults for end-of-life care, were also reported as important:

*We aim to help young people deal with the emotional impact of living with a life-limiting or life-threatening condition and if appropriate, ensure they receive support to prepare for end-of-life. We also aim to provide information and/or training that will enable parents to support the advance care planning process (CH4).*

Several staff from adult hospices suggested that services should be provided in a variety of locations, by different providers to give young adults greater choice. One respondent spoke of more care

being offered at home and suggested that adult nursing homes may provide a service:

*May need to look at more support within the home to allow carers to go have a break. More nursing home facilities with the appropriate skills to meet the complex needs would help with the increasing demands (AH2).*

Providing choice through a range of services and opportunities to meet the varied and sometimes complex, needs of young adults were seen as keys to developing individually tailored care:

*Based on our experience, there is a need to have a range of opportunities available to meet the needs of this growing cohort of young people. Short breaks, brokered breaks, specialist tourism services, building-based respite and adult hospice provision all need to be developed to provide a spectrum of available respite resources for these young people and their carers/families (AH22).*

One respondent highlighted that building a unit attached to a children hospices may just move the transition age rather than resolve the issue and that community-based care may be a more sustainable option as the population grows:

*If children's hospices all opened young adult units then the transition age would just be moved along. It may be more beneficial to have community independent living centres with staff support as required for the individual needs of the young people (AH20).*

## 6 | DISCUSSION

Findings from this study describe a mixed picture of UK hospice service provision for the growing number of young adults with LLCs. The children's and adult hospices who are providing care for young adults with LLCs over the age of 18 have reported not only some similar but also different provision. This seems to reflect the standard provision in each hospice sector in the UK (Hospice UK 2016; Together for Short Lives, 2015c) and variable upper age limit across the children's hospices. Parents have highlighted an urgent need for purpose-planned short break provision for their children once they have transitioned out of children's services (Swallow, Forrester, & Macfadyen, 2012). Yet, the variance of upper age limit for discharge from children's hospices and limited adult services available to meet young adults' needs pose significant challenges to children's hospices when supporting young adults approaching transition. The adult hospice sector faces an increasing demand for a range of services it has not typically provided, such as planned short break care, along with limited experience of young adults with LLCs. However, some children's hospices and adult hospices across the UK are responding to

the identified need and developing services, despite these changes taking place in a fragile economic climate (Hospice UK, 2015).

Many of the recent UK guidance documents and reviews which have addressed the issue of transition (e.g. Independent Review of Children's Palliative Care Services in England, Craft & Killen, 2007; Better Care, Better Lives, Department of Health, 2008; National Institute for Clinical Excellence, 2014) have highlighted that hospices have an important role to play in the process, but they have not specifically identified who should take responsibility to develop or deliver the services (McDonald, 2016). The differences between the eligibility criteria and types of services that children's hospices and adult hospices offer are challenging when planning for the transition of young adults with LLCs. Hospices in this study reported engaging with national initiatives such as the Together for Short Lives Transition Taskforce and regional action groups to share resources and skills and develop services and training packages. Both children's hospices and adult hospices provided the examples of extending their services, sometimes with the addition of new buildings or refurbishment to provide separate or additional spaces that were age/developmentally appropriate, or by developing their teams to provide support in the community and at home. Conversely, some adult hospices have reported that too many challenges exist to develop their services for young adults with LLCs. These challenges include a lack of resources or funding, lack of a skilled and confident workforce to support the complexity of care required and the challenge of providing a service to a small population in their region.

Staff in both hospice sectors highlighted the need to re-examine transition categories and eligibility criteria as whilst young adults with LLCs who have active palliative care needs may be referred and accepted for adult hospice care, there are a large cohort under the care of children's hospices who would not meet the criteria for referral to adult hospices and therefore will experience a loss of support and services. There is also a need to explore the commissioning of appropriate services. Young adults with LLCs have some distinctive psychosocial and physical needs compared with the adult population using adult hospice services, including sexuality, decision-making and consent, a reliance on parents rather than self-advocacy and limited peer support (Fraser et al., 2014; Pritchard et al., 2011). The planning of services for young adults with LLCs needs to acknowledge that they are not a homogenous group and their needs will vary depending on their comorbidities, age of diagnosis, severity of complex needs, life experiences, knowledge of their condition, personal goals and expectations of services (Bomba et al., 2017; Lidstone, 2013; Together for Short Lives, 2015b).

Whilst it is important to acknowledge that staff in adult hospices may have little experience of complex diseases which originate in childhood, or supporting young adults with complex needs, (Care Quality Commission, 2014; Doug et al., 2011; Noyes et al., 2014; Potts, 2009), many are skilled nurses and the issue, where it exists, is not an insurmountable challenge. Adult nurses have considerable transferrable skills appropriate to caring for young adults with LLCs. This topic has received attention in recent years including a Delphi study to identify the core priorities for training (Sivell, Lidstone,



Taubert, Thompson, & Nelson, 2015) and development of an education package for multidisciplinary adult specialist palliative care teams successfully delivered to prepare adult staff to care for young adults with LLCs (Sivell et al. 2013). Subsequently, it has been reported that a range of shared learning and collaborative activities such as shadowing, sharing of staff from children's hospices to adult hospices and joint transition planning meetings have been used to increase adult hospice staff knowledge and confidence in providing care to this population. (Lidstone, 2013). However, the need for additional training for the workforce is not without cost implications and may be a contributing factor to the resistance of adult hospices when considering the service provision.

This study highlights that meeting the needs of young adults with LLCs can offer not only challenges but also opportunities to rethink how care is provided. Whilst the data from this exploratory study do not represent all provision across the country, no firm patterns of provision can be stated; there were examples of excellent work in some areas of the UK, such as jointly-run groups for young adults and supporting access to independent living schemes. However, children's hospices in other areas reported that young adults currently do not have access to services or face challenges accessing the limited range of services available, evidencing a disparity of access and provision. Respondents demonstrated a clear need for good integration and collaborative working between services who can support each other and use existing resources and skills to provide individually tailored provision to meet the needs of these young adults.

Internationally, there are different approaches to hospice care which are driven by funding models for palliative care (Groeneveld et al., 2017) and the context where they are delivered (Bruera & Sweeney, 2004). The findings of this study provide preliminary evidence on areas for future service development and research to evaluate models of transition and provision of hospice care for young adults that will be relevant elsewhere in the world, for example, USA where there is also a rise in this patient population and hospice care is provided (Lindley, Mark, & Lee, 2009).

## 6.1 | Limitations

When interpreting the findings of this study, it is important to recognize that approximately a third of UK hospices participated (the sample was dominated by respondents from adult hospices), so the findings may not be representative of the broader hospice sector, although there was consistency in the views reported. The development of services will also have continued since the survey closed. The survey was developed for this exploratory study as no validated surveys existed. The open responses to the survey provide an indication of the views and main challenges faced, but it is acknowledged that they do not provide the same depth of detail as qualitative interviews which would be recommended for future research exploring this area of service provision. Despite these limitations, there are key messages to share about the transition of young adults from children to adult hospices and provision of services for those who

have not previously used a hospice service but need appropriate services as they move into adulthood.

## 7 | CONCLUSION

A mixed picture of hospice provision for young adults with LLCs was reported by the children's and adult hospice in this study. Examples of collaborative working between hospices, along with the extension of existing services to include broader age limits or building of facilities, were reported. However, clear challenges affecting transition planning and development of services were also reported including a lack of existing, appropriate adult services; a lack of alignment between referral processes and eligibility criteria between hospice sectors; lack of funding and capacity; and a lack of skilled staff in adult hospices for this patient population. With an increasing population of young adults with complex health and palliative care needs and pressure on families, it is vital that hospices and other services work together to find sustainable solutions to appropriately meet the needs of young adults.

There is a lack of published evidence on the views and experiences of young adults and their families of respite/short break provision after transition to adult services as the majority of literature has been gathered from the children's hospice population. Similar research is needed with young adults with LLCs and their families in the UK to explore their experience of adult provision and so their preferences can inform the development and delivery of services (Smith, Graham, & Herbet, 2017). Research is also needed to establish population data, review and summarize the available evidence and to evaluate collaborative working between hospices and other sectors to provide short break/respite care and broader services for young adults and their families in regions to explore what works, for whom and in what contexts.

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## CONFLICT OF INTEREST

No conflict of interest.

## AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE [<http://www.icmje.org/recommendations/>]):

- substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;

- drafting the article or revising it critically for important intellectual content.

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