



**‘It's brilliant! It's working! It's needed!’**

## **A Hospice Short break Innovation for Young Adults**

### **Service Evaluation Report**

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# Background

## Young adult palliative care

Due to medical advances an increasing number of young adults with life limiting conditions and complex health needs are now surviving into adulthood (Doug et al, 2011, p78, Mitchell et al, 2016, p58). The most recent prevalence study found the number of 14–25 year olds living with a life limiting condition in the UK has increased by 40% in the past 8 years, and that prevalence was highest within young adults with congenital and neurological conditions (Gibson–Smith et al, 2021, p9.).

The needs of young adults with life limiting conditions are described as diverse and complex, involving life–long symptom control, medication management and palliative care (Noyes et al., 2014 cited by Knighting et al, 2018). There is a growing complex population requiring transition from children’s services to adult palliative care. Following transition from children’s hospice care, families experience reduced support often at a time of great need due to deterioration and disease progression (Kirk and Fraser, 2014, p345).

Adolescence and young adulthood is recognised as a distinct developmental phase of life, requiring age appropriate settings and models of care (Smith et al 2011, p34; CQC, 2014; Together for Short Lives, 2015). However the evidence relating to young adult palliative care needs and service models is sparse (Clarke and Fasciano, 2015). The lack of a universal definition of young adult palliative care is also hindering progress (Doug et al, 2011).

In the UK, access to adult palliative care services is inequitable for young adults with life limiting conditions, with multiple barriers to a successful transition from children’s hospice care. Young adults often find they do not meet the eligibility criteria of adult hospices, due to their conditions differing significantly from older adults with rare, complex and unpredictable conditions (Mitchell et al, 2016, p358). Adult hospices report concerns about their relative lack of competence and confidence in being able to meet young adults’ unique needs (Knighting et al, 2018, pp1–9). There is mutual anxiety about adult hospices being equipped to provide care, with research highlighting that parent carers struggle to trust services providing care for their child (Eaton, 2008, p3200, Ling et al 2015, p58).

## Short breaks

Short breaks and respite care are considered an essential component of palliative care provision for young adults with life limiting conditions (Knighting et al, 2021, pxxi). Short breaks, including residential care, are a key element of children’s hospice

provision, often seen as a ‘life–line’ for parents (Kirk and Pritchard (2011), providing them with a much–needed break from caring. However, respite is not a service traditionally offered by adult hospices, with the respective hospice models evolving from different philosophies (Cook et al, 2013, p2).

Nationally there is a lack of suitable respite provision for young adults with palliative care needs, with very limited options for onward referral once too old to receive children’s hospice support (King and Barclay, 2007, p201, Cook et al, 2013, p2, Knighting et al, 2018). Anticipating losing the short break provision can be a source of significant anxiety for young people and their families at the time of transition (Murphy and Mackay, 2015). Some have described it as being like “falling off a cliff edge” (Together for Short Lives, 2015).

The adverse impact on families of caring for a child with complex needs is well evidenced in research (Remedios et al, 2015). As children with complex care needs reach young adulthood parents’ need of respite and acceptance of respite increases (Macdonald and Callery, 2007) and siblings experience a lack of parental attention (Robertson et al, 2011). The lack of suitable respite availability in adult services presents significant challenges to these families.

A recent systematic review carried out by Knighting et al (2021) reported the negative consequences of the lack of respite and short break provision in young adults with palliative care needs, including reduced quality of life, as well as a detrimental physical and emotional impact on aging parent carers and the whole family.

There are a small number of residential hospice short break services for young adults with life limiting conditions within the UK but, to date, these have all been based in children’s hospice settings (Kirk and Fraser, 2014; Young et al, 2013) including Martin House Hospice, St Oswald’s Children’s Hospice, Naomi House and Jack’s Place, often when services have been extended due to the lack of provision in adult care. Knighting et al (2021) cite the lack of evidence of respite provision for young adults, and highlight the need for service evaluation and research to inform the planning and commissioning of appropriate services.

### The Zest service at St Elizabeth Hospice

An innovative short break service has been set up in the East of England as part of Zest, one of the St Elizabeth Hospice family of initiatives. Zest provides developmentally appropriate palliative care for young adults aged 14 years upwards. Co-produced with local stakeholders, including families and statutory services, Zest

offers social groups for young adults and families, proactive clinical reviews as well as access to the wider hospice multi-disciplinary team, and specialist palliative care as required. It includes transition support for young adults leaving children's services with complex palliative care needs.

Zest found that most families had no had access to an age appropriate residential short break provision that could meet their complex medical needs, after discharge from the children's hospice. The loss of respite for families had a continual significant impact on quality of life and well-being for the whole family. As Zest continued to co-produce its model of care with service users, there were consistent requests for the hospice to consider providing residential short breaks for young adults to address this unmet need.

### Short break pilot

In 2018 Zest was awarded a grant from Together for Short Lives as part of the 'Improving transition fund'. This funding enabled the employment of a young adult care nurse specialist in a new transition coordination role for young adults 14–19 years, and provided the opportunity to pilot a residential short break provision for young adults 18 years upwards.

The hospice agreed to fund a pilot with an associated service evaluation to assess demand, benefits to families, operational modelling and cost of delivery, in order to determine whether the adult hospice is an appropriate setting for a young adult short break service. The pilot service was co-designed with young adult patients and their families. Activity provision was a core part of the short break model of care. The aim was to provide weekend short breaks for two young adults at a time, in the hospice day unit which was not being utilised at weekends. The plan was to provide three weekends per month, enabling a caseload of up to 18 young adults to receive four short breaks each during the year of the pilot.

St Elizabeth Hospice needed to enhance the staffing capacity, competence and confidence in order to be able to meet the complex care needs. The process to recruit new care team members was co-produced with families, including co-hosting a recruitment open day, and some young adults involved in the interview process.

Ten registered nurses and 10 care assistants were recruited (many of whom had training in paediatrics and care for people with learning disabilities), joining a small number of the existing adult hospice staff. Most joined the short break care team as a second job with the desire to be part of the pilot service and contribute to resolving a local unmet need. Unlike the usual staffing ratios in the adult hospice the short break

care model was closer to that of a children's hospice, with a registered nurse on each shift, along with two additional health care assistants during waking hours and one health care assistant during the night.

### Purpose of the service evaluation

Detailed evaluation of this new service was built into the delivery of the pilot, with the aim of facilitating future service optimization. The evaluation had the following objectives:

- To identify the outcomes and benefits of the service for young adults and their families.
- To capture feedback to enable learning and evaluation of the new provision.
- To explore the experiences of staff, including skill mix, training and support needs.
- To scope the financial and service delivery implications to determine the future of the service.

## **Methods**

An evaluation process was iterative, with patients, their families and hospice staff continually providing feedback, to enable improvements to the delivery model during the pilot period, as well as afterwards. A number of different methods and approaches were included to allow all objectives to be met.

### Service user feedback

All patients, their parents/carers and siblings were invited to participate in the evaluation. Service users were encouraged to be open and honest about their experiences to enable learning from the pilot.

Semi structured questions were designed, with adapted versions specific for the patients, their parents/guardians and siblings. Everyone was offered the option of participating via face to face or telephone interview or by completing a questionnaire version which was posted, emailed and provided by Survey monkey. The options regarding potential benefits and outcomes in the questions were generated by existing evidence in literature on short breaks in children hospice settings or similar. The

questions were tested out with a young adult patient and a parent/carer to check they were comprehensive, relevant and inclusive. Amendments were made accordingly.

The majority of the young adults did not have the capacity to participate in the evaluation themselves. Therefore questions were included that enabled their parents to represent them and report their views of the perceived benefit of the service for their young adult. Service user feedback was gathered from siblings during the pilot. Feedback from parents and young adult patients was gathered at the end of the pilot.

All of the young adults and their families were asked to set goals as part of the short break pilot. These could be long or short term. These were requested on admission as well as an open question in the questionnaires/interviews.

Ethics approval was not sought as this was a service evaluation. All service users were provided with written information explaining the purpose of the pilot and the service evaluation, with an invitation to provide written informed consent.

## Staff feedback

All short break care team members were invited to participate confidentially in the service evaluation with involvement facilitated by a project volunteer.

Two focus groups with staff occurred during the pilot, and staff were asked to consider the questions:

1. How are you feeling about working as part of the short break team?
2. Do you feel adequately trained and equipped to support short breaks?
3. Can you tell us about any learning needs or training that you feel you have?
4. How would you rate your confidence in supporting young people and their families in short breaks?
5. What is going well?
6. What are the areas for improvement?
7. What difference do you think this service will make/is making to young people and their families?

After the end of the service pilot, all staff members were again invited to provide feedback either via questionnaires or semi-structured telephone interviews with the project volunteer, using the same questions.

## Financial and practical evaluation

The set up and running practicalities and costs of the pilot service were recorded and collated. Overheads for the service were calculated, including the staffing costs incurred in the provision of short breaks. These costs were analysed to enable the calculation of the average cost of each short break per young adult (see Appendix 1 for more details).

## **Results**

### Process data

The short break pilot was carried out between 10<sup>th</sup> May 2019 and 15<sup>th</sup> March 2020. The service stopped two months earlier than planned due to the onset of the Covid19 pandemic.

In total 18 young adults and their families accessed the pilot service. Three families chose to access only daytime short breaks and did not contribute to the evaluation. Out of the 15 families who accessed residential short breaks, 10 families consented to participate in the service evaluation.

The ages of service participants ranged from 18–28 years old and there were 9 males and 6 females.

The table below illustrates the types of conditions across the caseload, using the Together for Short Lives four categories of life-limiting and life-threatening conditions in children. The majority of the young adults were in category 4; 10/15 had a profound learning disability and used non-verbal communication.

Definitions (Together for Short Lives, 2018)	Number of young adults in pilot
<p><b>Category 1: Life threatening conditions for which curative treatment can be feasible, but may fail.</b></p> <p><i>Examples: cancers, organ failures of heart, liver, kidney, transplant and children on long term ventilation.</i></p>	1
<p><b>Category 2: Conditions where premature death is inevitable.</b></p> <p><i>Examples: cystic fibrosis, Duchenne muscular dystrophy and SMA type 1.</i></p>	3
<p><b>Category 3: Progressive conditions without curative treatment options</b></p> <p><i>Examples: Batten disease, mucopolysaccharidosis, and other severe metabolic conditions.</i></p>	1
<p><b>Category 4: Irreversible but non–progressive conditions causing severe disability and susceptibility to health complications and premature death.</b></p> <p><i>Examples: Severe cerebral palsy, complex disabilities such as following brain or spinal injury.</i></p>	10

Seven young adults were in receipt of NHS Continuing Care funding, with the remaining 8 young adults receiving their care and support funding from the local authority.



## Number and length of short break stays

In total 54 short breaks were provided. The number of short breaks accessed by families during the pilot was:

- 6 families accessed 3 short breaks
- 4 of families accessed 5 short breaks
- 3 families accessed 4 short breaks
- 2 of families accessed 2 short breaks

The reasons for the variation in the number of short breaks included families starting to participate at different times, cancellations and the premature cessation of the pilot service due to the Covid19 pandemic. Every young adult and their family remained engaged in the pilot throughout the 10 month period, with only one withdrawal as a result of a participant's death (expected).

Most families received a 2 night short break. Length of stay varied for reasons including young adult or family choice, deterioration and staffing:

- 80% two night stays
- 10% three night stays
- 10% one night stay

## Service evaluation participants

From the ten families participating in the evaluation, there were ten parents/guardians, six siblings and three young adults.

From the four young adult patients who would have been cognitively able to participate, three patients participated in the evaluation, respectively completing one face to face interview, one telephone interview and one questionnaire. The three young adults were aged between 18 and 27. One young adult accessed five short breaks and the other two accessed three short breaks each. All three respondents had not accessed short breaks in adult care before. They were dependent on their parents for all their needs, had minimal experience of having an external carer and had very rarely stayed outside of the family home.

Two focus groups were held at the beginning of the pilot, with a total of 11 staff with approximate equal split of nurses and healthcare assistants participating. The second focus group was held four months into the pilot with 1 nurse and 3 healthcare

assistants participating. Further focus groups were not possible due to the Covid19 pandemic.

At the end of the pilot, staff feedback was gathered from 2 nurses and 6 care assistants through questionnaires and semi-structured telephone interviews (four of each). Due to staff anonymised participation it was not possible to know the total number of different staff members who participated in the feedback opportunities.

## Service User Evaluation

### Young adults

All three young adult participants rated their experiences of short breaks as 'good' or 'excellent'. Two said they now felt 'very confident' about taking part in short breaks' one felt 'fairly confident'. The situations and needs of the three young adult participants varied greatly, as did their responses about their experience during the pilot and their views on the benefit of short breaks.

One young adult wanted to continue to use the hospice short breaks in the future, one 'maybe' would continue but preferred short breaks in their own home, and the other young adult did not require future short breaks as they were hoping to move to university.

### *Perceived benefits*

All three considered the service had provided each of the following benefits: a break from being at home, a break away from parents, time with friends and social opportunities with other young adults. They all also considered that the service had enabled them give their parents a break and to build confidence away from home/parents.

Two participants viewed the service as enabling them to develop independent living skills and was facilitating future living outside the family home, for example by empowering them to make meals or bake.

*What I got out of it was what I wanted– to build up my independence and confidence, and a bit of fun as well!*

Other examples of goals achieved related to their perceived increased autonomy, with the ability to choose what activities they did:

*To stay up late and go to bed at chosen time*

*To be able to do more activities in the community – went bowling and to the pub*

#### *Suggested improvements*

Suggestions for improvement reflected the short break pilot was being accommodated in the hospice day unit which was not fully equipped for residential care. Comments highlighted the need for the environment to be further adapted for short breaks and aesthetically more appropriate for younger patients:

*Quite basic, not as good as could be... [bedroom] doesn't feel like a bedroom, it feels like it's still a meeting place like it's usually used for, it's a bit samey... this hospice is made for old people.*

One young adult described the impact of being allocated the bedroom that did not have an overhead hoist in situ:

*One of the other times I had to sleep in a room without an overhead hoist so had to use a manual hoist... It really impacts as positioning is essential when I am hoisted out into my chair.*

It was also suggested that the short break facilities could be improved by having height adjustable tables in the living area to promote independence.

The feedback on the experience of care identified the challenges of high dependency care needs and how, despite having three staff supporting two young adults, this did

not always feel enough for the young adults. Two of the young adults recalled episodes where they felt more care staff were needed:

*I would prefer it if there were more staff that I wouldn't have to wait for help while they were helping the other young adult.*

*One or two times when the other young adult needed 2-3 carers help, which left me on my own sitting on the Xbox, I was fine with it but if there had been anything....*

*vast difference in our needs as I rarely needed much attention.*

One young adult also shared recognition that they were receiving care from a new staff team including those unfamiliar with their care needs:

*It's really hard when the staff haven't done this type of care before, they have to get used to us.*

One young adult shared the negative consequences of when their short break care experience compromised comfort and sleep:

*I went home feeling shattered because I was unable to get enough sleep.*

Although planned activities were enjoyed, participants did not want them to occur early in the day:

*Activities later on the day not as early, as get too tired getting up early as morning routine takes time so can't sleep in. If we go out too early I get tired and I fall asleep, I fell asleep at bowling, then there's no point! It's meant to be respite, not getting up early, being on time for the taxi is a mad rush.*

Feedback on the length of stay varied. The short breaks were originally intended to be for three nights (Friday–Monday) but this was reduced to two nights. When short breaks continued into Mondays it was clear overlapping with the adult day unit activities was not appropriate:

*I woke up one Monday and day care was full and I was walking around in my pjamas– that was a bit awkward!*

Two young adults said they found the two night stay length just right, whereas one person felt it was too short for practical reasons:

*If I've brought all my stuff then have to pack it all up again 2 days later it's a short time, it takes ages to get all my stuff together...Ideally the 3 nights we had before is what I liked.*

## Siblings

Six siblings participated in the evaluation, representing five families. All respondents opted to complete the questionnaire. Ages ranged from 12 years old to early 20's.

### *Perceived benefits*

The highest rated benefit of the short breaks chosen was the ability do something not usually possible when the family are caring for their brother/sister. Three participants chose the ability to try a new experience and to be able to spend more time with their parents/other siblings as the next highest rated benefit:

*He had a great time and we went on a little holiday.*

Two siblings identified other benefits including the opportunity to have more quality time with their parents and having respite from caring for their sibling:

*It's quiet, and I get to have a bit of a rest.*

*There is more peace and quiet in the house.*

The sibling participants also perceived benefits the short breaks provided for their brother or sister. The highest rated perceived benefits chosen by four of the siblings were their brother or sister being able to fun, being able to on outings, meet new people, have time with their friends, and a break from being at home:

*It's a great opportunity for social interaction, being able to spend time with and meet new people outside of her regular environment, visit new and exciting places and gives her a much needed sense of enjoyment.*

*A very much needed break away for her, away from the usual busy household.*

Three siblings felt it was beneficial for their brother or sister to try new things and go to new places:

*He can chill and have fun when he wants and he can try new experiences.*

The opportunity to build independence was recognised by one participant:

*My Brother gets the opportunity to build trust with other people with his personal care. He will become more confident around people other than his family.*

Sibling participants also shared their observations of their brother/sister enjoying their short break stay:

*Really good, he had a lovely weekend and was very excited about his next stay.*

*She always has a positive and happy reaction when spoken to about it and the carers always give good feedback too.*

### *Suggested areas for improvement*

There were no concerns identified by siblings about their brother or sister accessing the short break service. There were also no needs or suggestions about how the service could help the siblings feel more relaxed about their brother or sister's short breaks.

### *Parents/Guardians*

Ten parent/guardians (five male and five female) provided feedback from six face to face interviews conducted, two telephone interviews and two questionnaires. Eight out of 10 parents/guardians rated their experience of short breaks as 'excellent' with every parent/guardian wanting to continue to access the service and considering St Elizabeth Hospice their future preferred provider of short breaks. Every participant would recommend the hospice short break service to families with similar needs.

### *Perceived benefits of the service*

Overall parent/guardians praised the standard of care received. They expressed a sense of trust in the hospice care team. For some this was particularly important, having transitioned into the adult hospice after receiving short breaks at the children's hospice for many years, where they had built up trust over time:

*Reassurance, reassured that we are in good care, good respite because of the number of years at [children's hospice] then coming somewhere different is a big upheaval.*

*[Name of children's hospice] do a great job but he's grown out of that now he's ready for an over 18's world in a comfortable environment where he is comfortable with the people he is with, St Elizabeth Hospice are more than capable of doing that.*

All parents/guardians said they were 'confident' or 'very confident' about the care provided. One parent described feeling 'on call' during short breaks and unable to fully relax. However, although confidence levels varied between families, there was evident trust in the care provision:

*Peace of mind that he is in a safe and secure environment with people we all trust.*

Overall parent/guardians spoke positively about their experiences of accessing the short break pilot and their hope for the service to continue.

*It's brilliant! it's working! It's needed!*

The parents/guardians selected a wide range of the potential benefits presented in the questions. The highest rated benefit identified by every participant was the impact of short breaks in allowing parents/guardians to spend time with other children and family members;

*Go to [location] and give our younger son his time.*

Other benefits that were identified by all parents/guardians was the respite from the demands of their usual care giving routine:

*To get up when I want, go to bed when I want. To be able to breathe and relax.*

Participants valued the ability to engage in a leisure activity. The benefit of physical rest, enhanced well-being, and the reduction of possible need for out of home placement. These benefits suggest short breaks increased the sustainability of care in the family home. As one parent stated:

*You've got to re-charge your batteries and be in the right frame of mind, look after ourselves so we can give [name of young person] our best care.*



Benefits of the short breaks identified by parents (multiple choices allowed)

Benefit identified by parents	Number of responses out of 10
Spend time with other children and family members	10
Break from the routine and time constraints of care	10
Re-charge batteries	10
Engage in a leisure activity	10
Physical rest	9
Time out for mental well-being	9
To enable opportunity for separation to reduce dependence on parent carers	9
To reduce the need for out of home placement	9
Spend time with friends	9
Spend time with partner	8
Time to reflect	8
Sleep	8
Break from the responsibility of care	8
Enable sense of renewal	8
To do something you wouldn't normally be able to do as a family	8
Increase ability to cope	8
To give more attention to other children	8
To enable preparation for change of care arrangements in the future IE reduction of parental involvement in care	8
Preservation of self-identity outside of care role	7
Spend time away from home	7
To carry out tasks usually difficult to achieve EG DIY	6
Break from having carers in the home	5

Parents/guardians were asked to identify their 'top two' benefits. Spending time with other children was most commonly chosen (by four parents/guardians) followed by physical rest (by three parents/guardians). However, there was wide variation with 14/22 benefits identified by at least one person as being in their 'top two'.

Although the intention had been to work with families to identify their goals from the short break service, only a limited number of goals were recorded during the pilot. Staff suggested this was due to both families not being certain of their goals, as well as staff lacking the time or skills to ascertain the goals.

Short breaks enabled families to go out for a meal with greater ease and without having to think about the needs of their young adult:

*We can go out for a family meal, as we feel guilty as [name of young person] can't eat. He's come and behaved really well but nice to go out without him.*

*Go out for a meal is easier. When you're booking somewhere it's hard needing a large space re wheelchair.*

A number of families expressed the goal of wanting to have 'time out' either to relax or to go on a short holiday with other family members. Being able to select the dates of short breaks enabled families to plan how to optimise their respite. Several families went away for a short break themselves, an activity not usually possible when caring for their young adult:

*Went away to Christmas markets which wouldn't have been possible with [name of young person].*

*Enabled us to have a weekend break away, change of scenery for us.*

As well as planning events during short breaks, families also benefitted from being able to be spontaneous, with spontaneity usually limited when caring for their young adult with complex needs:

*Short breaks have allowed us to be spontaneous...like getting up and just thinking let's do this today or let's go away for the weekend. We cannot do things without planning for every eventuality otherwise.*

*Just pack the car and go away for a night.*

*To be able just to go out like 'normal' adults.*

Other outcomes included parent/guardians achieving both leisure and domestic tasks not possible when caring for their young adults including cycling and walking on the beach. A member of staff recorded the DIY task achieved that was shared by a parent that would otherwise not have been possible:

*Changing the radiators, too cold for [name of young person] to do this when they are at home.*

Parent/guardians also perceived considerable benefits for the young adult themselves:

<b>Benefit to the young adult</b>	<b>Number of responses out of 10</b>
Access to different activities and outings	10
A break away from parents	10
Time with friends	9
Social opportunities with other young adults	9
A break from being at home	8
To build confidence away from home/parents	8
To build up independent living skills within own capabilities	7
To help consideration of living outside the family home	5

As well as gaining respite themselves, parents/guardians recognised that the short breaks also gave young adults respite from home and parental care:

*Enable [name of young person] to have a holiday in the same way we would have a break from our parents.*

*A break, not the same four walls and same faces, it's just different and something nice from here!*

Parents/guardians recognised the benefit of short breaks affording the young adult opportunities for time and attention outside the family home:

*[name of young person] enjoys having the time of staff to help her achieve stuff she can't do at home, or bother me with– social opportunities.*

*Other people to think of what to do, access to more equipment, I run out of ideas. Can't offer activities all day.*

Parents recognised short breaks provided opportunities to develop socially:

*I think it has opened him up to a new world, there is other people out there that are the same as [name of young person] and same age.*

*More sociable. Getting a different group of friends, broadening his friendship group, both other young adults and adult staff. Broadened his horizons, there is a world outside of [children's hospice] care environment.*

Opportunities to develop independence away from parental care was also acknowledged:

*Positive thing that [name of young person] has had to communicate with other nurses, helped communicate needs and direct care.*

*Being able to be away from home, staying for 3 nights was a big thing.*

The parents/guardians also the benefit to the young adults of being part of the co-production of the service. One parent recalls the positive achievement and empowering opportunity this enabled:

*Helping to interview for new short break staff. He likes to help to be part of ...he likes being asked by you, it gives him a sense of being part of the team, he feels important, he's stuck in his chair but he feels useful, he is contributing to decisions.*

### *Suggested areas for improvements*

Many parents/guardians had participated in the co-design of the service and shared ongoing suggestions for improvement throughout the service pilot. Feedback was given on the environment and facilities, the experience of service provision and the length of stay.

Comments on the facilities echoed feedback from the young adults both in terms of the environment being too clinical and needing to be adapted to be more age appropriate:

*Maybe decorating, something a little bit more, posters, pictures, themed bedroom, difficult to cater for all tastes. The rooms they sleep in are a bit clinical.*

The temporary facility was not yet fully equipped with all the equipment the young adults needed, meaning that parents/guardians had to bring items from home:

*We understand but if we had own building longer would be better, we have to pack up all that stuff from home and then two nights and then they're back again. It's strenuous on the parents to do that but it's definitely a welcome break.*

Equipment, such as ceiling track hoists in all bedrooms, were requested, although it was recognized that specific items from home would at times be need to meet young people's needs:

*Getting a sore back, as a result of using mattress at hospice. Difficult to match same mattress and comfort at home (same issue at home). During short breaks- tried different types, air flow causes movement that affects comfort, then tried a third type which was a bit better.*

The need to replicate the home environment, equipment set up, care techniques and routine were prioritised by parents. Although one parent suggested short breaks in their own home could remedy this, the majority of parents/guardians wished for short breaks to continue in the adult hospice setting.

A few parents/guardians did not consider the admission and discharge processes, checking in and out of medications, personal belongings and equipment, to be efficient.

*Despite writing the list of what is brought in still things went missing, and didn't come home, which is frustrating.*

*Not coming home with clothes or coming home wearing someone else's clothes! It's difficult as we need to put a lot of changes in due to needs as it might help to keep clothes to minimum but this is difficult.*

Again echoing comments from a young adult, one parent commented on the lack of flexibility in the timings of outings, with them being too early in the day.

Parent/guardians discussed the length of short break stay. Half (five) of the parents/guardians felt the length of stay (two nights) was too short. Four felt it was just right, and one said 'it depends'. Overall a 3 night short break model was preferred by parents, as had been originally intended.

## **Staff evaluation**

Collated feedback across the pilot is presented including staff experience, perceived benefits of the service and suggested areas for improvement.

### *Staff experiences*

Staff shared their initial apprehensions, mixed with excitement about being involved in the new service:

*Feel a bit daunted, but not thrown in the deep end ....we have all chosen to jump in*

Staff reported the value of spending time with the young adults before they came in for a short break, for example through shadow shifts either at the hospice, other care settings, or the young adult's home. This provided staff the opportunity to get to know the young adults and learn about their care needs from those who knew them well, enabling staff to feel prepared for providing short break care.

At the beginning of the pilot the staff group were highly motivated and expressed feeling well supported in their roles. Throughout the pilot, enthusiasm and motivation within the staff participants remained high. Staff's job satisfaction appeared closely linked to perceived benefits of the service they were part of making happen. Staff commented on the positivity in the team, with everyone wanting to be a part of the service. The feedback suggests intrinsic motivators contributed to positive staff morale:

*Leaving every shift knowing I have made a positive difference to the young person's life.*

*The job is fun! No better job than putting a smile on a young person's face.*

Being part of the new service from the beginning was also linked to job satisfaction, through involvement in the service development:

*Being involved from start and it being a pilot has meant we have all learnt together.*

*We have shown that it is completely possible to make it happen and build it from the ground upwards, families are desperate for this to become a permanent fixture and repeat bookings have shown that this has been a success.*

The team identified the benefits they observed for the young adults and their families. This included enabling parents to spend time with their other children, physical rest and opportunity to do things not usually possible. They reported developmental benefits for the young adults through having a break from parental care, enabling them to make choices EG bedtime, meals, activities and observed increased confidence and autonomy they observed in the young adults:

*For the young adults it is an opportunity to have fun, they thrive on having more independence and an opportunity to break the rules and be a normal teenager! They get to truly be themselves and have fun!*

Staff also shared their observation of the social benefits and peer support between the young adults staying together, the friendships made and shared experiences:

*Watching young adults develop friendships and support each other, 2 lads on play station one with more physical ability supporting another.*

*The growing bond in relationships between the young people has been priceless to watch.*

*Getting young people in and having them able to share a room – sleepover giggling and being silly with a friend.*

It was clearly acknowledged that whilst the service provided families with respite benefits, the focus on provision was the experience and opportunity offered to the young adults during their stays:

*This is not a respite service it is breaks for young adults*

Staff cited acknowledged a key success was achieving the families' trust in the care they were providing:

*We are able to provide much needed respite and a facility where parents can leave a young adult and know they are in safe hands.*

*The young adults and their families getting to know our team and to feel comfortable and safe when staying with us.*



*Getting such positive feedback from the parents – they put their trust in us to look after their children and to know that we have created this service for them is wonderful.*

Staff acknowledged the importance of having a registered nurse on each shift, and the need for a one to one staff to patient ratio. Staff reported the benefit of the blend of experience and skill mix within the care team. Employing paediatric nurses enabled staff to appreciate the importance of family-centered care, an approach less familiar to staff who had always worked in an adult setting. Support for each other's growth and development was also evident:

*The confidence and competence in individual staff has been lovely to see grow too and the way in which we support each other.*

Experiential learning over time with associated confidence growth was evident, with staff also gaining affirmation when families wanted to continue to access short breaks.

Staff were eager to learn and develop skills not commonly practiced in the adult hospice setting. Care assistants requested to also be trained in non-invasive ventilation alongside the nurses. Staff identified varied training needs, including generic refreshers, caring for patients who use non-verbal communication, and assessing mental capacity. Maintaining confidence and competence in complex care remained a priority for staff throughout their feedback.

#### *Suggested areas of improvement*

Staff identified the vital importance of having in depth understanding of the complex needs of the young adults. They recommended longer handover times between shifts, more detailed person-centred care plans and ideally a staff member on shift who has in depth knowledge of each young adult. The need for detailed care planning to be effectively communicated and the difference this makes to providing good care was discussed:

*Need to have systems that allow us to capture and relay on to others what is important to the young person/family – the little details over and above the care plan/ nothing to do with their abilities. E.g. lights on at night or not – just as we would if one of our family were going somewhere to stay.*

Staff reported challenges with finding activities compatible for both young adults and the pre-planned activities and outings being appropriate on the day. The lack of hospice wheelchair accessible transport, and the reliance on advance taxis bookings for outings, limited ability to respond to health needs and choice of the young adults on the day. Staff expressed a desire to improve flexibility of activities to better meet the interests and care needs of the young adults.

The challenges of temporary facilities in the hospice day unit was highlighted. This included care staff having the additional tasks of setting up and packing up of the rooms, in readiness for the adult day unit to be operational after the weekend. Staff felt this also limited the options for activities and freedom to use the space when being mindful of the time constraints of having to pack everything away again. However there were not specific concerns expressed about the environment falling short of being a suitable space to meet the care needs of the young adults. It was viewed that dedicated purpose built facilities was an aspiration for the future and a key enabler for service improvement.

## **Discussion**

This short break service evaluation has been highly positive. Young people and their parents/guardians consistently expressed a wish for the service to be ongoing, and there were no withdrawals. The staff care team described high levels of motivation, job satisfaction and commitment to supporting the new service.

### **Main benefits**

Many themes emerged through the evaluation, with consistent findings across young adults, siblings, parent/guardians and staff.

The short break pilot provided social and developmental benefits for the young adults and respite benefits for families. The range in choices of top two benefits highlighted

the fact that needs were varied and individual. However, the overall highest rated benefit was the opportunity short breaks provided families to spend quality time together, whilst not care giving. The interdependence between young adult and family benefits was evident, with positive experiences for the young adult then allowing families to value their respite.

The experience of the healthcare professionals was highly positive. The evaluation demonstrated that the adult hospice staff had benefitted from the opportunity to gain competence and confidence in providing complex care for young adults. The resulting trust of families in the care provided was a key indicator of success.

The value of using a co-production approach with both service users and staff throughout the pilot emerged as a strong theme. The involvement of young people and their family carers in the service co-design, in staff recruitment, and in evaluating and refining the service, all contributed to a sense of empowerment and ownership. This was arguably a key contribution to the trust achieved and the success of the pilot.

### Areas for improvement

The challenges of the temporary nature of the short break pilot facilities were evident in the feedback. Practical and aesthetic improvements in the environment would be needed for a permanent service. Provision of wheelchair accessible transport would be of value to optimise the short break experience.

Use of detailed care plans and handovers, to convey the complex care needs, would also be beneficial. Parent-produced short videos could improve communication and allow the small details to be shared, that could have a significant impact on high quality individualised care provision.

### Contextualisation within existing literature

To our knowledge there is no existing published evidence on the provision of residential short breaks for young adults palliative care needs in an adult hospice setting. The evaluation evidenced that the Zest short break service is able to successfully address this respite need.

The evaluation highlighted that social opportunities and activities within the short breaks were highly valued. Young adulthood is a time of profound social development, challenging for those with palliative care needs and reliance on parental care (Clark and Fasciano, 2015). The evaluation suggested that activities during short breaks did enable opportunities for choice, spontaneity and social development. This aligned with existing research of young adult short breaks in children's hospice settings, where a personalised approach enabling individual preferences to be accommodated was also found to be valued by the young adults (Kirk and Fraser, 2014, p349).

Knighting et al (2021) found that for parents to trust services, relinquish care and accept respite they need to be confident the short break is enjoyable for their young adult. A high ratio of the pilot caseload had a profound learning disability and used non-verbal communication. Research has found that gaining the trust of parents in this circumstance to be imperative to enabling short break care (Kirk and Fraser, 2014). Feedback from families evidenced that trust in both the care provision and short break experience during the pilot was achieved, and could be considered the most significant indicator of success.

Adult hospices have previously reported apprehension in their ability to meet the complex care needs of young adults (Knighting et al, 2018, p6). The positive staff feedback in this evaluation suggests that these concerns were not realised in practice. Findings suggest recruiting new staff with existing paediatric or complex care experience, and high levels of intrinsic motivation in the team enabled this adult hospice to overcome such challenges.

Intrinsic motivation is recognised as a key factor for staffing resilience and retention (West et al, 2020), as well as directly leading to better quality care (Largarde et al, 2019). During the evaluation staff described their motivation was strengthened by their belief in the benefits of the service, and the opportunity to be part of the development from the beginning.

The value and benefit of co-production of health services is well recognised (Conquer, 2021), including enabling short break services for young adults to be flexible, individualised and fit for purpose (Knighting et al, 2021, pxxiv). Co-producing the short break pilot with service users and staff arguably increased the potential for this new service to succeed.

## Strengths and limitations of the evaluation

The consistency of findings between patients, family members and healthcare staff increases the validity of this evaluation. Service users and staff were well represented, but the narrative voice of young adults – particularly those without the capacity to communicate – was limited. Although parent/carer feedback on perceived benefits and improvements needed was collected, it is recognised in literature that parents are not always able to fully represent their young people's views and feelings (Welch et al, (2014).

Due to the COVID pandemic the pilot had to be terminated early, and longer-term findings could not be assessed. This reduced the opportunity to engage participants in the end of pilot evaluation. As this is a service evaluation the results are not generalisable.

## Implications for service providers

This evaluation provides a persuasive rationale for the provision of short breaks for young adults in an adult hospice setting. There is evidence that adult hospices are capable of meeting the complex care needs of young adults. It is possible to overcome the challenges to staff competence and confidence through training, support and the coproduction of a service delivery model.

The findings evidence the importance that short breaks are enjoyable and beneficial for the young adult, to enable families to then gain from the respite it provides.

Service design and models of care should therefore focus on the short break experience for the young adult first and foremost, which in turn will enable services to successfully provide respite for families as a secondary outcome. The term 'short breaks' is widely used within children's services, adult providers could embrace this terminology to improve young patient and family understanding and facilitate development of services that hold fast to the essential ethos of paediatric hospice short breaks.

Recommendations for adult hospice services aspiring to set up a young adult short break service include the following:

- Co-produce the operational model with service users and staff to enable learning, access to expert resource and equal investment in the success of the service.

- Provision of time for care planning and to enable staff to learn individual complex care needs before providing care, including staff being able to shadow parents/carers to build mutual competence and confidence.
- Use of person-centred care tools to enable detailed knowledge of individualised care needs, including preferences, usual routines and what is important for the young adult, particularly for those who are non-verbal and unable to easily direct their care and make choices.
- Use of photographs and videos to aid understanding and replication of usual care practices EG positioning in bed, feeding techniques, etc.
- Provision of adequate handover time between shifts to ensure quality information sharing
- Multiple occupancy of short breaks to enable maximum social benefit for the young adults. Where possible enable social matching.
- High staff ratios (1:1 normal).
- Flexible activity provision (where possible planned in advance with those staying) with access to wheelchair accessible transport to support outings.
- Agree threshold of communication with parent carers during short breaks EG regular updates or what parents would like consulting on during the short break stay.
- Complex care training for staff including seizure management, gastrostomy care, suctioning, long term ventilation, recognising deterioration and managing medical emergencies EG choking, collapse etc.

It is recommended that services are fully resourced to ensure high standards of care and individualised short breaks. This is a high cost provision for adult hospices to undertake in addition to their core business. Accessing additional statutory funding streams for short breaks as part of the young adults care and support plans that CCGs and local authorities have a duty to provide is recommended to enable a sustainable funding model. Engaging commissioners in the development of personalised short breaks provision where there is unmet need is recommended to enable families to access crucial respite support (Rochira, 2018 cited by Seddon et al, 2021, p10).

### Future research

This is a local service evaluation, therefore qualitative research that provides more rigorous and generalisable findings would be valuable. Future research should strive

to enable inclusive participation for young adults with learning disabilities. The experiences specific to siblings, as well as parent carers of young adults with complex palliative care needs would benefit from exploration, including their unique position of often simultaneously caring for their aging parents.

Identification of an appropriate outcome measure tool to capture short and long term impact of short breaks on young adults with complex palliative care needs and their families, would be beneficial. This confers with a recent paper by Seddon et al (2021), scoping the future short break research agenda, particularly a need to understand the medium and long term benefits for carers of short breaks. Qualitative examination of the long term impact of short break support on sustainability of preferred place of care and bereavement outcomes for families would be of particular relevance to palliative care.

Further research into the factors that enable adult hospice staff to be competent and confident to deliver complex care for your young adults would be beneficial to support wider service provision.

## **Conclusion**

This short break service appears to be of value to families and possible to be successfully provided by an adult hospice. Future research is recommended to strengthen the evidence for service design and development, to support a growing population of young adults with complex palliative care needs and their families.

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## Appendix 1 – Financial analysis

The set up costs of the pilot were collated. These included staff recruitment and training, the time required to complete initial care plans and shadow shifts for staff with the caseload of young adults accessing the short break pilot. Other set up costs included refurbishment EG decorating rooms, bedroom furniture and installation of overhead hoist. Refurbishment costs were met by a grant obtained for this purpose.

The running costs of the short break service were collated analysing the staffing establishment, catering and activities (including outings and transport) throughout the pilot. An average cost per young adult per short break was then calculated. A grant was obtained to cover the costs of the activities and outings throughout the pilot, enabling choice and exploration of options based on a weekend activity budget that the young adults could be allocated. Due to needing to use wheelchair taxis as significant amount of the activities costs were spent on transport to enable access to activities in the community.

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