



**University
of Suffolk**

**A review of the implementation of the
Zest programme:**

**A young adult palliative care and transition
service in East Suffolk**



Part of the St Elizabeth Hospice family

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Foreword

Amazing advances in medicine mean young adults with life limiting conditions are living longer and needing to transition from children's to adult's services. Together for Short Lives launched the UK wide Transition Taskforce in 2014, with St Elizabeth Hospice engaging in this national effort. The vision was and remains that all young people with life limiting conditions will make the transition to adult services and live their lives as independently as possible, according to their wishes, while receiving the care and support they and their families need. This report highlights the importance of an excellent transition service and the difference it can make to young adults, carers and professionals.

This report documents the journey of St Elizabeth Hospice as they seek to meet the needs of over forty young adults and their families. Their outstanding efforts over many years have at last found the recognition they deserve.

Over the years many organisations and institutions have sought to provide the necessary care and support that was needed for young adults with life limiting conditions. Few were so well coordinated, nor so comprehensive in their approach to transition as St Elizabeth Hospice. The Zest service adopted a coordinated programme with other organisations, aspiring to become a regional provider of young adult care across East Anglia. This highly readable report evaluates their progress and outcomes to date.

The Report was commissioned by St Elizabeth Hospice and funded by Together for Short Lives. The report provides a great deal of valuable insight from young adults, families and professionals. It is comprehensive in its approach and detailed in its coverage of the still unresolved issue of transition. Zest demonstrates how important it is to listen to families especially parents who often feel excluded in the transition process.

Without doubt the key requirement identified is the transition coordinator, both to coordinate and upskill staff, particularly in adult services, and to ensure that service users and their families are cared for and supported. With military precision, this role occupies the middle ground between children's hospices and adult services. The report also evidences that respite care is still seen to be vital. Zest are providing an age-appropriate short break respite service in the hospice setting; this allows young people to have social and development opportunities. Skilling up the adult workforce gives young adults and families' confidence to utilise the respite provided.

Through wide-ranging quantitative and qualitative analyses this report then focuses on four principal themes, engagement, the implications of living longer, the value of ongoing respite care and support, and future possibilities. A unique element of the report is the wealth of first-hand experiences. From the four themes, important deductions are made concerning the vital need for co-production with families.

The Zest Service demonstrates how an adult service is helping to make transition smoother and more manageable. Zest has developed into an excellent model that could be replicated in other parts of the UK. This report has a great deal of valuable learning to offer other services that are vitally needed to support this growing population of young adults and their families.



James King



B. Barclay

Contents

Foreword	2
Executive Summary	4
Introduction	4
Figure 1. Zest Model Services	6
Methodology	6
Number and Pattern of Referrals	7
Figure 2. Characterisation of the length of patient engagement with the Zest Service	7
Transition Coordinator Service	7
Ongoing Pathway of Care and Support	8
Table 1. All patient contacts recorded during evaluation period.	8
Short Break Weekend Stays	8
Figure 3. Proportion of short break weekend stays, and day care provided by the Zest service.	9
Exploring Zest Service Usage by Primary Diagnosis	9
Figure 4. Categories of life-limiting and life-threatening conditions (TfSL, 2018)	10
Figure 5. Classification of patients using the Zest service based on primary diagnosis	11
Figure 6. Average length of engagement with service for patients in each classification	11
Face to Face Contacts by Category	11
Telephone Contacts by Category	12
Table 3. Telephone contacts for patients categorised by primary diagnosis.	12
Figure 7. Number of short break weekend stays, and day care recorded for patients in each classification	13
Qualitative Interviews	13
Theme 1: Engagement and the importance of the Service	15
1.1 Early engagement	15
1.2 Developing relationships	16
1.3 Environment	16
Theme 2: Transition	17
2.1 Living Longer	18
2.2 Role of the transition coordinator	19
3.1 Respite Care/short breaks	21
3.2 Empowerment	26
3.3 Parent/Carer/Family Support	28
3.4 Key Elements That Make Zest Work	30
References	42

Executive Summary

The needs of young adults with lifelong conditions (LLCs) are diverse and involve life-long palliative care. Due to medical advances, a growing number of young people with LLCs are surviving into adulthood and therefore undergo transition from children to adult services. There are many challenges faced by young adults and their families during this period and there is a need for specific transitional services to support them. This service evaluation was completed to understand the needs and services provided by a local provider (Zest) to support this client group over a two-year period. It included a mixed methods approach using both qualitative interviews with service providers and users, and quantitative analysis of existing data sets. Analysis of the quantitative data suggests that the service is predominantly used by patients with a primary diagnosis of irreversible but non-progressive conditions. During the period of evaluation, 1394 contacts were recorded and almost half the patients utilised a short weekend break/day care. Analysis of the qualitative data suggests that the needs of young adults with LLCs are diverse and complex. Participants identified large gaps in the provision of transitional care support which the Zest service went some way to address. Participants suggested that their key elements that made the service work included, good communication, co-production and the Zest Transition Nurse Coordinator. Short breaks were also consistently emphasised as being important for respite, support and autonomy. The results suggest that services such as Zest are vital to both patients and their carers and may aid the transition from childhood to adult services.

Introduction

This report presents the key findings from the review of the 'Zest service - a young adult palliative care and transition service in East Suffolk', conducted between August 2021 & February 2022. It was commissioned by St Elizabeth Hospice (funded by Together for Short Lives) to get a greater understanding of the need, referral patterns, and the various elements offered by the service as well as its impact on service users.

The opportunities to develop and support innovative services within health and social care to meet the needs of individuals is becoming increasingly necessary (DH, 2019). The experience of life-limiting conditions (LLCs) is a term used to describe degenerative and progressive illnesses with no reasonable hope of cure that will ultimately be fatal (Fraser et al 2014; Together for Short Lives, 2015a). 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).

The needs of young adults with LLCs are diverse and involve complex life-long symptom, medication management and palliative care (Noyes *et al.*, 2014). 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). 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 can vary considerably depending on where their treatment is and what staff are available to support them (Savage, 2011).

A recent report completed by [Gibson-Smith *et al.* \(2020\)](#) suggests the number of young people with a LLC in England rose from 27,316 in 2009/10 to 38,261 in 2017/18. The numbers of young people with a LLC were diagnosed while still in childhood and therefore eligible for transition and support services. There are many challenges faced by young adults and their families during this transition period. Transition from children to adult services is defined as the “purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents/young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems” (Blum *et al.* 1993).

Private, voluntary and independent organisations are constantly trying to improve the pathway for young adults with LLCs by developing innovative services to support them In East Suffolk. The Zest service model has been in development at St Elizabeth Hospice for several years, co-produced with local families and a Suffolk network of health and social care stakeholders. In 2017 they made a successful application for a grant from ‘[Together for Short Lives](#)’ to further develop and enhance the model. The funding from this grant enabled the employment of the first paediatric trained Zest Nurse whose role included new transition coordinator. The funding objectives also included the upskilling of the adult hospice team to meet the needs of young adults in the preparation for transition with LLC as well as to further the ambition of the Zest service.

Key stakeholder partners in the pilot of the transition coordinator role included EACH, Ipswich Hospital, Suffolk County Council Disabled Children and Young People’s Team, the adult CHC services at the local CCG, the neuromuscular advisory service, and the local community paediatric team. Based at the hospice, the main aims of the transition coordinator role included supporting patients aged 14-19 years, their families and carers in transition by:

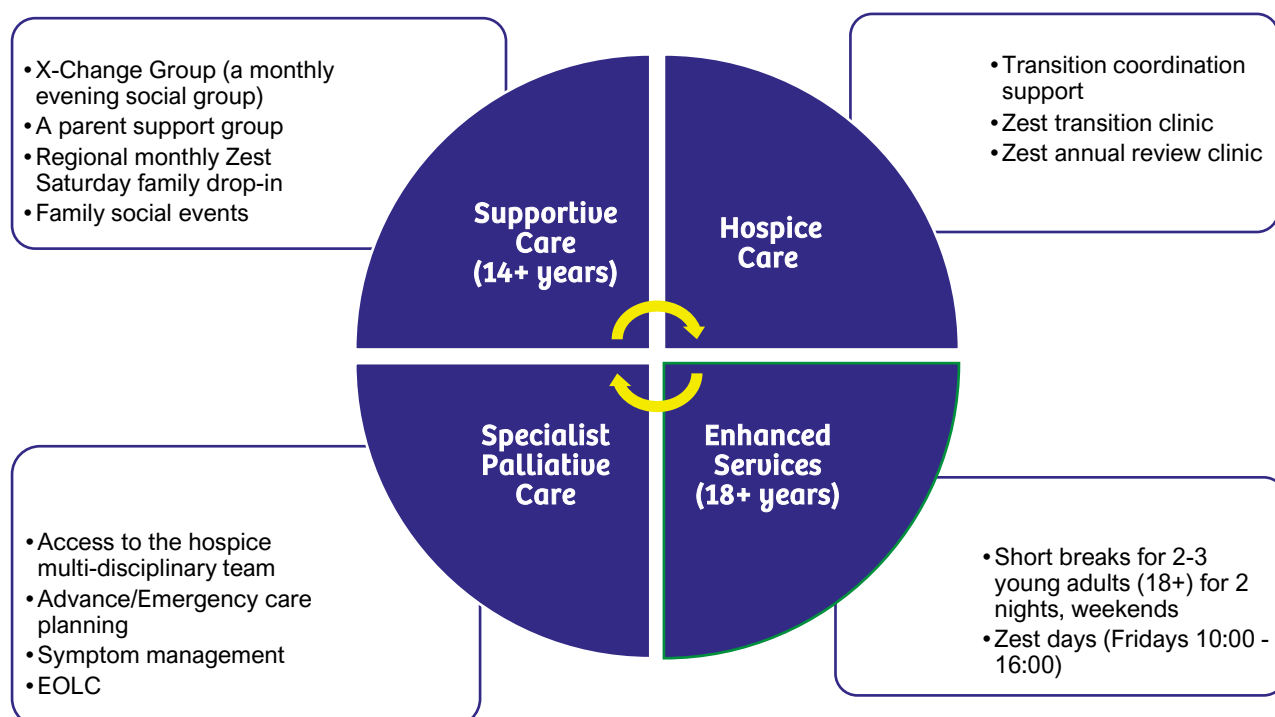
- Providing a one point of contact
- Providing expert advice and guidance to navigate transition to adult services
- To support the well-being of families during transition
- Providing practical information and support about their needs
- Explaining the financial support available, and how they can access it
- Exploring what is important to their physical and emotional wellbeing
- Signposting or referring them to local activities and resources

The transition coordinator role also aimed to reduce duplication of efforts between organisations and bring services together to address unmet needs. The enhanced service was implemented and developed over a thirty-month period and this service review is exploring how the service has been used over the past two years.

Young adults with LLCs and their carers can self-refer to this service by calling or emailing the team themselves or, alternatively, a health professional can make a referral on behalf of the individual with a LLC to the team. Support is available from the time of referral through to their treatment and beyond.

Figure 1 below outlines the services provided within the Zest model.

Figure 1. Zest Model Services



Objectives for this service evaluation were to:

- Develop a greater understanding of the numbers, referral patterns and reasons for referral to the Zest service
- Explore the individual experiences of the team members in supporting young adults with LLCs through their pathway over the past 2 years and develop a comprehensive understanding of the role and functions
- Obtain a greater understanding of the role and function of this service in the wider community from local stakeholders and service users

Methodology

A mixed method of qualitative and quantitative approaches (*Bryman, 2015*) was used to collect the data, this included analysing existing data sets which were used to collect demographics and referral patterns about the service over a two-year period. Interviews provide in-depth information pertaining to participants experiences and viewpoints of a particular topic (*Bryman, 2015*). Therefore, semi-structured interviews were conducted with various members providing the service, stakeholders, and service users.

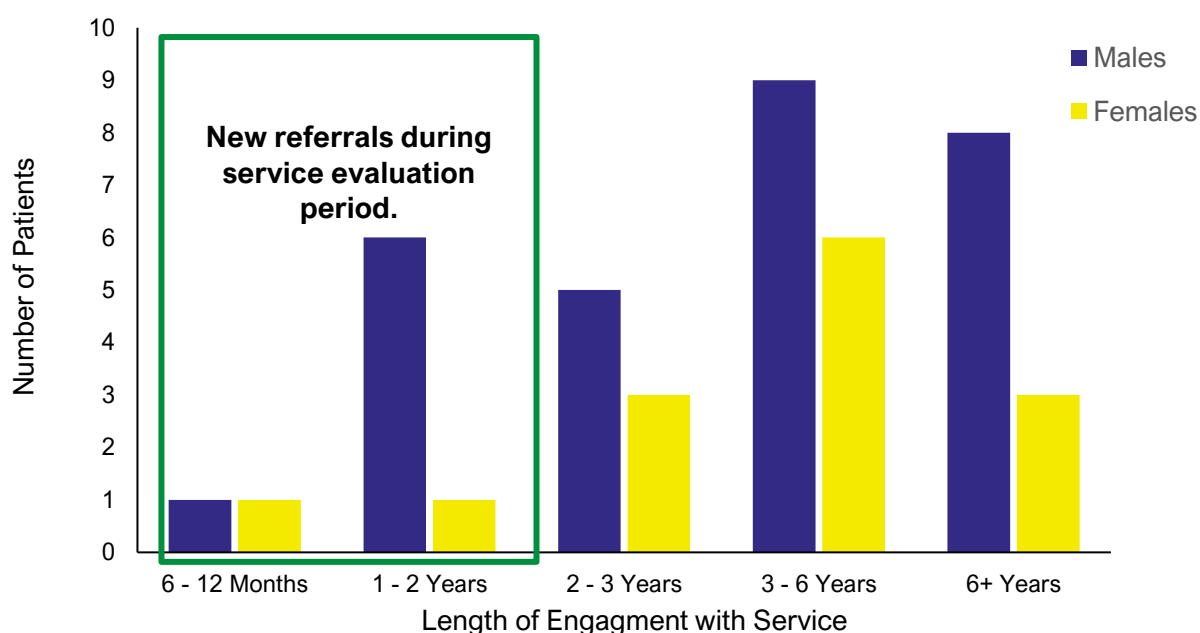
Twenty-three semi-structured interviews in total were completed, this included ten from the partnership organisations who were all involved in the care and support of the transition caseload, and a schedule of seventeen questions (see Appendix i) were used as prompts. Six interviews were conducted with local and national stakeholders who provided support

either locally or nationally. Seven interviews were conducted with service users these included two young adults and five parents or carers and a schedule of ten questions was used as prompts for these interviews (See Appendix ii).

Number and Pattern of Referrals

As illustrated in Figure 2, there have been 9 new referrals over the past two years, which accounts for 20% of the total number of patients currently engaged with the service (43 patients). Seven of the new referrals are male; a trend which is also reflected in the total number of patients where 67% of the patients using the Zest service are male, compared to 33% female. However, despite the differences in referral patterns there are no differences in the way that males and females engage with the service. The average age of the patients using the service is 23 years, although patients range from 15 to 42 years. Specifically, 21% of the patients using the service are aged between 15-18 years and the remaining 70% of patients are 19 years plus.

Figure 2. Characterisation of the length of patient engagement with the Zest Service



Transition Coordinator Service

During the period being evaluated, the Transition Coordinator Service recorded 253 contacts with 12 patients. Predominantly, contacts were made by telephone (227 contacts; 90%), rather than face-to-face (26 contacts; 10%). The number of face-to-face contacts was reduced in this period due to the impact of the COVID-19 pandemic and the redeployment of the Zest Nurse.

Ongoing Pathway of Care and Support

During the period being evaluated, 1394 contacts were made with the patients currently using the Zest service. Of these, 31% (438) were face-to-face contacts and 69% (956) were made by telephone or video. On average, patients received 10 face-to-face contacts and 22 telephone/video contacts within the two-year period. While there was no difference in the average number of contacts between male and female patients, there was considerable variability between patients depending on their individual needs; the number of face-to-face contacts ranged from 0 to 38, and the number of telephone/video contacts ranged from 1 to 96. [Table 1](#) presents a detailed illustration of all contacts recorded during the evaluation period. By far the most prominent was contacts with a registered nurse, which accounted for 65.4% of all the contacts recorded within this period.

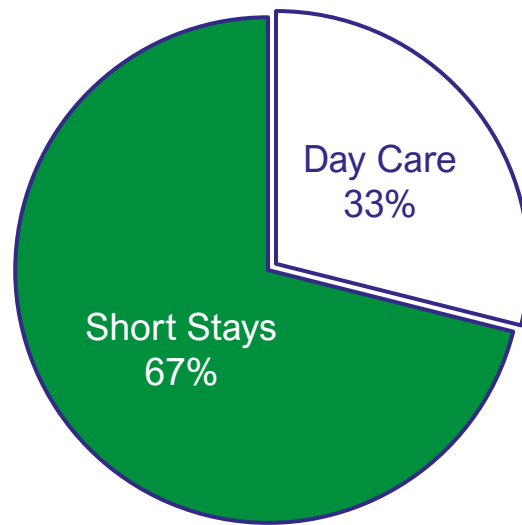
Table 1. All patient contacts recorded during evaluation period.

Contact	Number of Face-to-Face Contacts		Number of Telephone/Video Contacts		Percentage of Total Contacts
	14-18 Yrs	19+ Yrs	14-18 Yrs	19+ Yrs	
Administration	1	1	0	51	3.8%
Community CNS	0	34	0	34	4.9%
Emotional Wellbeing	0	32	0	12	3.2%
Healthcare Assistant	7	68	0	26	7.2%
Medical	1	44	0	73	8.5%
Occupational Therapist	0	6	0	35	2.9%
Physiotherapist	0	24	0	85	7.8%
Therapy Assistant	0	8	0	9	1.2%
Zest Nursing Team	31	181	72	559	60.5%
TOTAL	40	398	72	884	100%

Short Break Weekend Stays

The Zest service also provides specialist nurse-led short break care for young adults aged 18 years and over at weekends. The Zest Short Break Unit allows for young adult patients to take some time out from their daily routine to have fun and socialise, whilst providing vital respite for their families. This can be in the form of day care, or a short break weekend stay. In the past two years, a total of 89 short stays have been provided for patients using the Zest service. In total, almost half of the patients engaged with the Zest service (47%) have had at least one short stay, although some have had up to seven short breaks during this time. During short break weekend stays or day care, 388 contacts were also recorded. [Figure 3](#) illustrates the uptake in the types of short break care offered by the Zest service.

Figure 3. Proportion of short break weekend stays, and day care provided by the Zest service.



Exploring Zest Service Usage by Primary Diagnosis

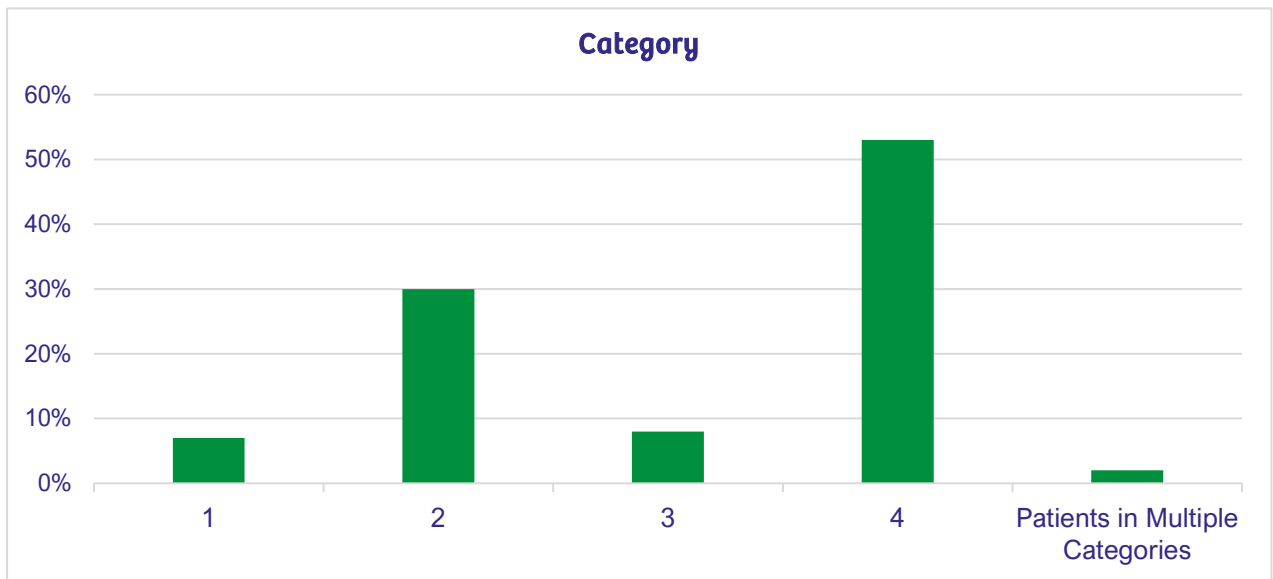
Primary diagnosis for the patients using the Zest service varies significantly with no fewer than 25 separate conditions. Subsequently, patients' primary diagnoses were categorised into one of four broad groups (Figure 4), each incorporating a range of conditions likely to benefit from a palliative care approach and/or support from children's palliative care services (*Together for Short Lives, 2018*).

Figure 4. Categories of life-limiting and life-threatening conditions (TfSL, 2018)

Category 1	<p>Life-threatening conditions for which curative treatment may be feasible, but can fail, where access to palliative care services may be necessary when treatment fails, irrespective of the duration of that threat to life. Or reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.</p> <p><i>Examples: cancer, organ failures of heart, liver, kidney, transplant and children on long-term ventilation.</i></p>
Category 2	<p>Conditions where premature death is inevitable, these may involve long periods of intensive disease-directed treatment aimed at prolonging life and allowing participation in normal activities. Children and young people in this category may be significantly disabled but have long periods of relatively good health.</p> <p><i>Examples: cystic fibrosis, Duchenne muscular dystrophy and SMA Type 1.</i></p>
Category 3	<p>Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>Examples: Batten disease, mucopolysaccharidoses and other severe metabolic conditions.</i></p>
Category 4	<p>Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care.</p> <p><i>Examples: sever cerebral palsy, complex disabilities such as following brain or spinal cord injury.</i></p>

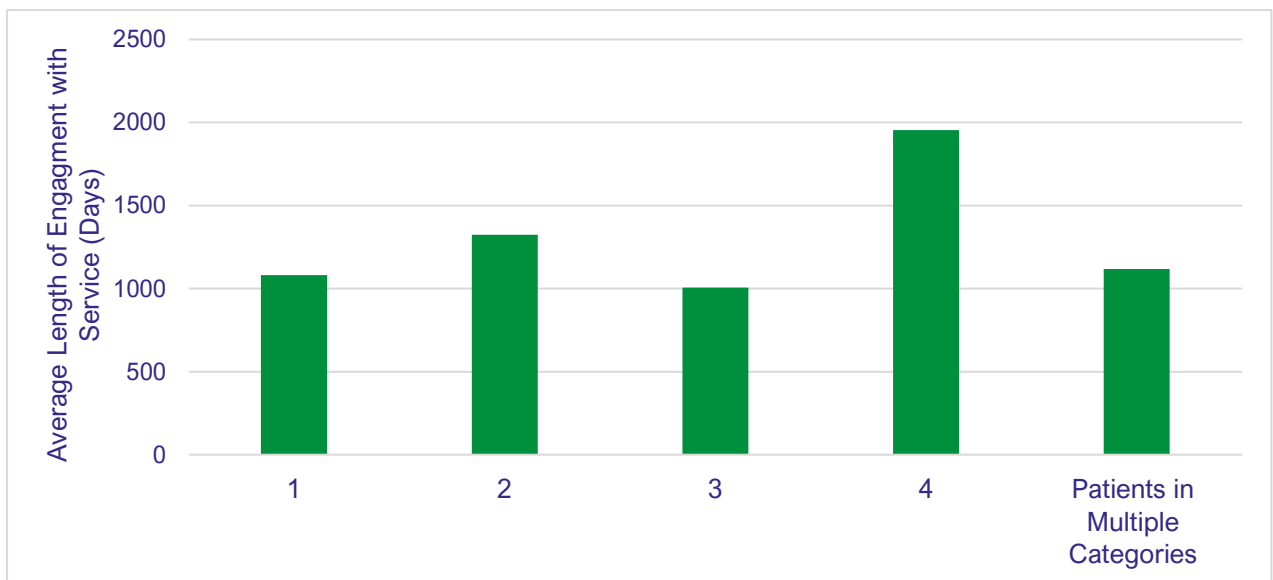
The categories identified above are not discrete; patients can be classified into more than one category at a time. [Figure 5](#) illustrates the current classification of the patients using the Zest service based on the categories presented above.

Figure 5. Classification of patients using the Zest service based on primary diagnosis



Classification of the patients in this way enables us to explore how the service might be used by patients with differing needs. Figure 6 illustrates the average duration of engagement with the service, by patients in each category.

Figure 6. Average length of engagement with service for patients in each classification



Face to Face Contacts by Category

Patients with a primary diagnosis consistent with category four demonstrated the highest number of face-to-face contacts. Table 2 below, illustrates the distribution of face-to-face contacts for patients within each category.

Table 2. Face-to-face contacts for patients categorised by primary diagnosis

Face-to-Face Contacts	Category				Patients in Multiple Categories
	1	2	3	4	
Administration	0	0	1	1	0
Emotional Wellbeing	0	14	9	9	0
Healthcare Assistant	6	30	7	32	0
Medical	1	11	5	28	0
Occupational Therapist	0	4	0	2	0
Physiotherapist	0	15	8	1	0
Zest Nursing Team	22	86	7	129	2
Therapy Assistant	0	3	5	0	0
TOTAL	29	163	42	202	2

Telephone Contacts by Category

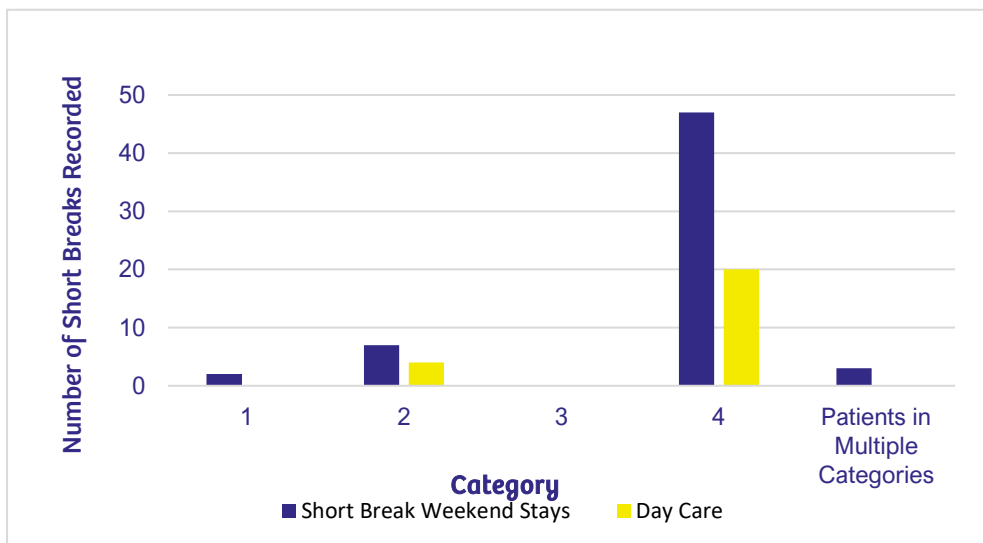
A similar process was used to investigate how patients in each of the categories are utilising telephone contacts. These data are illustrated in Table 3. As with face-to-face contacts, the highest number of telephone contacts were recorded for patients with a primary diagnosis in category four. The highest number of contacts for patients with primary diagnoses in categories one, two and four was with the registered nurse, whereas patients classified as having progressive conditions without curative treatment options (Category 3) utilise telephone contacts differently to other patients; focussed on medical needs.

Table 3. Telephone contacts for patients categorised by primary diagnosis.

Telephone Contacts	Category				Patients in Multiple Categories
	1	2	3	4	
Administration	1	19	6	25	0
Emotional Wellbeing	0	4	1	7	0
Healthcare Assistant	1	10	2	13	0
Medical	2	15	9	47	0
Occupational Therapist	0	11	0	24	0
Physiotherapist	0	64	1	20	0
Registered Nurse	72	259	6	327	1
Therapy Assistant	0	5	0	4	0
TOTAL	76	387	25	467	1

Figure 7 illustrates how the specialist nurse led short break weekend care provide by the Zest service is utilised by patients with primary diagnoses in each of the categories. Patients with a primary diagnosis in category four utilised both the short break weekend stays, and day care the most, accounting for 80% and 83% of the total number of short break stays recorded, respectively.

Figure 7. Number of short break weekend stays, and day care recorded for patients in each classification



Qualitative Interviews

Twenty-three semi-structured interviews were completed, this included: ten of the service team who either provided daily support, short breaks or coordinating services; six interviews were conducted with local and national stakeholders who provided financial support either locally or nationally; seven interviews were conducted with service users, these included two young adults and five parents or carers.

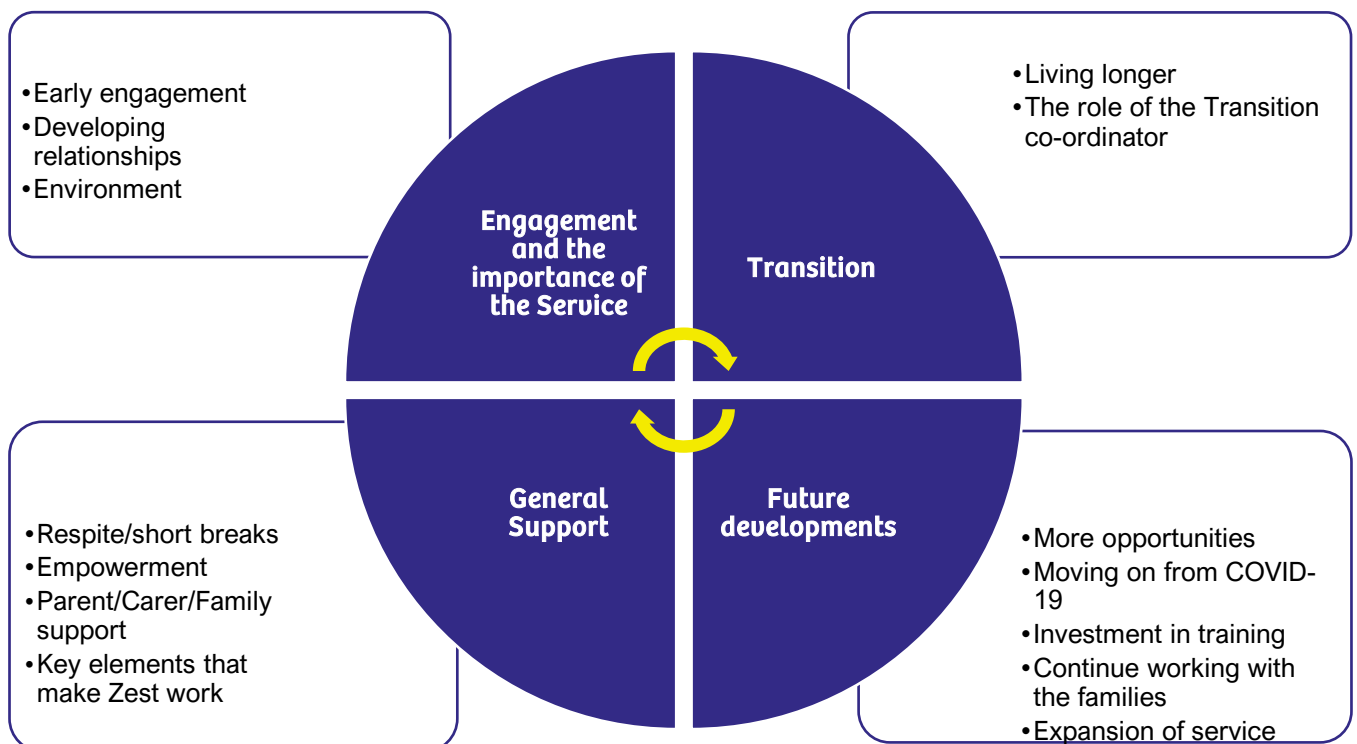
These interviews were conducted by the review team lead via a virtual platform or face to face; consent was received to record each interview and once completed they were transcribed by members of the research team. The schedule of questions used in the interviews were based on the objectives of the review.

A thematic analysis was used to define themes from the transcriptions, this analysis was conducted using the framework developed by the National Centre for Social Research (*Richie et al. 2002*), designed specifically for qualitative, applied research projects. All the interviews were transcribed and to reduce bias and allow for member checking, all transcriptions were returned to the participants to ensure they were a true record of the interviews. Minor revisions of the transcripts were made as requested.

A thematic framework was established by revisiting the aims of the review whilst looking at the emergent issues and identifying any emerging themes. The interview transcripts were annotated manually by each of the researchers independently. Prominent and unifying themes were identified. In addition, we systematically examined differences between the proposed themes. From this, a range of experiences for each theme were considered and differences in coding were resolved by consensus.

The following overall themes emerged from this process:

- Engagement and the importance of the Zest service
- Transition
- General Support
- Future developments



Theme 1: Engagement and the importance of the Service

This theme encompasses the thoughts of the service users, service providers, and stakeholders about the need to engage and the importance of the service. It will be discussed under the following sub-themes:

- Early engagement
- Developing relationships
- Environment

1.1 Early engagement

Amongst the stakeholders, service providers, and service users the need for early engagement and the need for the service was consistently emphasised. Most of the participants stated that the Zest service is needed to fill a void from a lack of other similar services.

“I mean historically there was a huge gap for children, not just for Hospice care, but when they become adults, transferring from children services to adult services, its vital to have this service and that early engagement happens” (SPC).

“There’s nothing else. There’s nothing else out there at all. For us zest is the only thing really, we feel comfortable, and [name of young adult] feels comfortable, in accessing it because we’re just very limited around here” (SUP1).

“There’s always been people talking about the need for this for years, probably 20 years” (SPEH.)

“I think the need for Zest service was to bridge between paediatrics and adult services to try and get young people to engage with the Hospice even though their conditions might be relatively slowly progressive by the Hospice criteria. But to get them to engage with it, not just parents” (SPS).

“There is no service for the young adults in our neck of the woods. And it has just been an absolute joy to get this up and running” (SPJ).

“I mean I think, probably the early engagement with these young people helps make it work” (SHJ).

“When young people reached the age of 16-18, there is a lack of services for transition generally, as well as for respite, it’s important to have service commissioned and that people needing it engage early” (SPE).

“I got involved because way before Zest was set up, there was nothing for teenagers. They used to leave the children’s hospice, and they had all these services to help them their families and siblings and when they left us at 18- they used to literally leave and there was nothing for them no support, and I remember listening to one dad talking about his son (he is now at Zest) and he said I hope he will end his days at the children’s hospice because there

is nothing else out there to support him. I didn't know what to say because I knew there was nowhere to guide him too" (SPS).

1.2 Developing relationships

Participants stated that one of the most important elements of the Zest service was the co-production with the families which helped develop their relationships. Participants reported that Zest works well as the families feel that they are listened to and understood and that the young adults are at the centre of the service.

"Knowing the young adults is the most important bit, being able to support them, look after them, meet their medical and psychosocial needs on a day-to-day basis, we try to get to know them as soon as possible and this means sometimes doing home visits" (SPK).

"So, there was so much to unpick and work with really and it took a lot of time for these relationships to develop, what actually really mattered was developing the relationships particularly with the young people, but definitely with their parents as well so that they trusted you" (SPM).

"I think it's a really joined up way of working, I think the control isn't taken from young adults and their families. I think it's pushed by us/them, and so I think Zest is always listening, and looking at ways that they can be better, and making sure the young adults voices are heard, but not forgetting us the families" (SUP2).

"I think they really understand the needs of the young people, and the young people are really at the centre of what they are trying to do. I think they really engage with the service users, learn from them, and develop their service based on the needs of the young people. And so, I think that's probably the core value of the service, it is that young people are at the heart of it" (SPC).

"It works because it is tailored to their needs it is individualised and it responds to need, and we have done research in terms of what else is out there and tried to meet the need that perhaps is not being offered" (SPG).

"I think it's just the whole approach, the inclusiveness, the idea that they've created it out of local needs, that they've created it because this is what families and young people have said they wanted, and they work really closely with them" (SHA).

"The young adults come forward 1st, and then you got the staff that shadow and carers are there as well" (SUP3).

1.3 Environment

The participants highlighted the importance of having the Zest service separate from the adult hospice care and said the differences between paediatric and adult are notable. They suggested that the environment that the Zest service provides is needed to act as a suitable transitional middle ground for the young adults moving from paediatric to adult care.

"You know that the model is slightly different in children, to adult's palliative care. It's much more kind of short breaks, focus less on end of life. And I think that's what Zest is all about, they're trying to bring in that quality-of-life element for the young people" (SHJ).

“Children received really high levels of intervention from children’s hospices and for respite etc. Then for them going into an adult service was quite a big shock because it was a very different offering in the adult services but the Zest service bridges the gap” (SPV).

“You know, we’ve done lots of research around this issue, we were involved in the Care Quality Commission. They did a report called ‘From the pond into the sea’, they just found the gaps were huge, and adult services don’t know what to do with these young people, they’re not used to supporting them” (SHL)

“You’ve still got to be able to find somebody with the level of training and skills you need to meet the need, but I think generally the Zest has just filled a gap that there just wasn’t a service for a very specialist cohort of young people. The numbers aren’t huge, but the impact and the benefits to that group of people is huge having that service” (SHM).

“When young people reached the age of 16-18, there is a lack of services for transition generally, as well as for respite; those families that have been supported really well throughout childhood, perhaps through the children’s hospice, then go into adult services and there isn’t necessarily always the clinical expertise to be able to look after that young person but Zest provides it” (SPE).

“The transition from child Hospice services to adult Hospice services, it’s not an easy one, and so when I got in contact with the Hospice before Zest was a thing, I was like this is gonna be really weird because I’ve had experience with the children’s Hospice, I haven’t had any experience with the adults Hospice, I don’t know what the differences are, so, when Zest started becoming a thing I thought it was sort of really good. It’s helps get the patients accustomed to a more adult service and helps get the parents transitioning as well, which I know from my parents, it is quite a thing for them as well” (SUP4).

“Those families that have been supported really well throughout childhood, perhaps through the children’s hospice, then go into adult services and there isn’t necessarily always the clinical expertise to be able to look after that young person. And there are some services out there that can meet some needs, but especially given the level of complexity that a lot of our continuing healthcare patients have, they don’t always meet those level of needs, that’s why the Zest service is important” (SPE).

Theme 2: Transition

This theme includes the thoughts of the service users, service providers, and stakeholders about the importance of supporting the transition to adult services. It will be discussed under the following sub-themes:

- Living longer
- Role of the transition co-ordinator

2.1 Living Longer

Participants said there is a growing need for the Zest service given that medical advancements mean that young people with LLCs are living longer. Therefore, the need of continued collaborative support past the age of 18 is necessary as previously they would not have expected to live beyond the paediatric care stage.

“It wasn't there before, several organisations are working together and I think the fact that the numbers just keep going up, the referrals keep going in from all types of other agencies. It's just showing how much medicine has advanced, and there needs to be a place with joined up care for these young adults. When we used to hear about young adults being on inpatient wards in hospices it was really tough. So, the Zest service feels like it is what they deserve, their place, it's just got a really good feel” (SPH).

“The need is going to grow because the group of people we are supporting here would not have lived much more into adolescence and wonderfully that they are now with the medical input but we now have to keep catching up with this as medicine progresses, we have to catch up with the repercussion of that, which are good but they are the consequences we have to put up with” (SPV).

“Well, I guess as we're in an era where medical science can help people a lot and stay alive for long enough to need these services, the transition is scary moving from child or young teenagerhood to adult hood” (SUP4).

“So, I saw the need for young people who were outgrowing children services, living longer and not having that same service, but also not really having much service at all in adult services, or not knowing who was their point of contact in adult services” (SPC).

“I mean my understanding would be that, you know, there's been a huge cliff edge on transition like forever, and we know that the numbers of young people living longer with those conditions are growing, and so less children are dying in childhood, and more leading to transition, and their needs are ever more complex” (SHJ).

Other participants stated that the Zest service is needed to meet the complex needs of the young people with complex LLCs who may not need to stay at the hospice but still need support. Furthermore, the participants suggested that it is more age and stage appropriate than a full adult hospice.

“We were so disconnected with the services and the support. So, we were a bit isolated in terms of the fact that everyone else was established both through being in the children's hospice and being in the area. [Name of young adult] had never accessed a hospice, he hadn't needed too, and then obviously he deteriorated, the services prior to Zest would not have been suitable for the likes of [name of young adult] so the services offered by Zest, has enabled him to access a service which he does need, and support that we all need, but in an appropriate manner” (SUP5).

“Compared to the rest of the hospice service that sees hundreds of patients, our patient base is quite low in comparison, but the needs of the young people and their families is different. So, I think there is definitely a need for the Zest service” (SPC).

“It was what we were looking for from our point of view, it was somewhere that could handle the complex care, because in the normal care services there was a brick wall. They weren't offering choice, so he was a bit stuck. And we spent a long time looking at these other centres, but it turns out that the staff weren't going to be appropriate for the level of care that [name of young adult] needs. So, I'm thankful for when the Zest opportunity come up, because it has that level of nursing, that you can tell when you go to Zest, the confidence is there, they're not fazed by anything from the suctioning, oxygen, their feeds, and it just put you at ease. They felt like “oh, they know what they're doing”. And that was that's what we wanted” (SUP4).

“The transitional care for example some learning disabilities may not always fit in with the hospice and like all of our patients there will always be a number of people who are frightened of a hospice setting because hospice means death and dying to some people. Particularly with this group of people it's about living with an illness for a very long time which could mean for many years” (SPV).

2.2 Role of the transition coordinator

This theme highlights the thoughts of the service users, service providers, and stakeholders about the specific benefits of the transition coordinator role. Most participants said that the transition coordinator role was incredibly impactful. They reported that she is a point of contact, supportive, reliable, a source knowledge, and a common thread/link between different services. Consequently, most participants suggest that she is a key person, not only vital to the service users, but also to the service providers, as a go to person for questions and advice.

“I think she's been a real source of support to those families. I think a lot of the families that we've had contact with have said that having the transition co-ordinator is a positive. They say the feel supported that there's somebody there, sort of almost advocating for them and fighting their corner if you will” (SPE).

“It gives a person a name and a contact, health care and social care is quite bewildering even for those of us who work in it. It can be really difficult to navigate the system and I know this from personal experience, and I am in the business. For families to have someone who is a named person who can help you to navigate the complexities of health and social care is brilliant-it must be a plus and I think we all need this in everything to be honest-a go to person” (SPG).

“Yeah, I think the co-ordinator is the go-to for the families and for other professionals. I think it helps coordinate everything and brings everything together; not only that it prevents the parents having to coordinate” (SPH).

“I should imagine it's a blessing for the families to have somebody, one person that they can actually rely on, and who is the constant, who is linking everything together for them” (CPC).

“The co-ordinator is the most amazing support to the families and to the young adults” (SPJ).

“Oh my God massive, the co-ordinator has made such a difference, I have just had two of my family transition over to Zest and they just could not praise this person enough, they talked

about all she had done for them the information she has about services and again if she doesn't know it, she will find out. I email her with questions, and she gets back to me straight away, sometimes I panic wondering if I have done something right and I refer to her for confirmation that it is right" (SPS).

"She's a bit of a linchpin between all of us. She's quite often the common thread that runs through from social care through into adult care, so that's quite nice, and I think that must be really quite reassuring for those families" (SPE).

"The co-ordinator has been absolutely amazing, from day 1 she's been brilliant. She's not just a coordinator she gets everything for him, and she deals with it and she's very kind and caring person. So, for me, from day 1 she's been our support" (SUP1).

"I don't know what we'd do without the co-ordinator, because we don't have a social worker, our son is under continuing care, we don't get any support from them, she has been our person to deal with everything, she's worth her weight in gold. I don't know what we'd have done without her" (SUP1).

"The co-ordinator does represent a life line for me personally and professionally in terms of the fact that she is a named person, who is essentially invaluable and I know she's going to come back to me and I know that she'll sign post me in the right direction, and I implicitly trust her professional judgment on just about everything and I categorically know that she's got the young people's interest, and their families, at heart and she always strives to want to do the next thing or follow the next avenue she's not just sitting complacently, entirely comfortable with the service that's set up now she's always looking to expand it evolve it, whatever, redirect it" (SUP5).

"It's very much a point of contact. I feel like it was the point of contact for any other referrals that may need to be made, any issues or just comments, or anything and helping the patient, and the parents actually, feel sort of safe and calm in this new environment. So yeah, it's a very good role and very important one" (SUD).

"Oh hugely! One, because she understands, she's obviously worked in this field for a long while, and you get the same feeling from all the staff. I mean when I went there, it's one to one for quite a period of time, they will come and sit with you over a cup of tea, and they really talk through the details, and want to know the ins and outs of [name of young adult], but also the family as well. So, it's not just clinical, it's more personal. You feel like you're making friends, which is a big part of it" (SUL).

"She's that link between the EACH Hospice and our Hospice, and she reiterates everything to us. She is amazing" (SPJ).

Service providers also state that the transition coordinator role has increased the communication, co-working, understanding, and coordination of staff, both at the Hospice and other local services.

"I just think it's doing this role is doing a really good job. I think just kind of seeing the service that wasn't there before to now. Yeah, it makes a really big impact to these families and young adults, and I'd like it to just happen more" (SPH).

“The problem really from EACH’s point of view, was that when children were leaving our services, they had nowhere to go. We had nowhere to transfer them to, and they’re often left feeling kind of lonely and suddenly cut off and had nowhere to go. Having the coordinator role filled a very definite big need and big gap” (SPC).

“I was at the time, working with the United Kingdom Transition Task Force. Something that we set up deliberately was the coordinator role when it was quite clear there was going to be no early government intervention in the transition from children services to adult services for young people with these kinds of conditions. We felt that that was awful” (SHD).

Theme 3: General Support

This theme demonstrates the thoughts of the service users, service providers, and stakeholders about the support mechanisms provided by the Zest service. Participants suggested how providing respite care in a safe and social environment provided support whilst empowered the young adults to have ownership of their care as well as giving their carers a rest. It will be discussed under the following sub-themes:

- Respite Care/short breaks
- Empowerment
- Parent/Carer/Family support
- Key elements that make Zest work

3.1 Respite Care/short breaks

Many participants said that the short breaks are important for the young adult’s socialisation. Specifically, participants said the short breaks are important for the young adults to develop social skills, meet young adults with similar conditions or needs, and to have time away from their parents/families to experience typical teenage activities.

“I think probably their initial expectation is that respite, a short break, or even just a little bit of day care for their young adult, just to know that they can still socialize with their peers a bit really. And as a parent, perhaps have a bit of time to do those things that are really tricky to do when the young adult has many health needs” (SPK).

“I think it’s just the whole focus on the patient having a normal life. Sort of being able to do things that they might be, being supported, to do things that they might be limited doing otherwise. like sort of going back to the weekend break things or being able to go out to the cinema or go bowling or things like that which they might not get to do otherwise. It sort of gives them the support they need” (SUP7).

“I thought respite was great. It’s really nice, very friendly. You know these people, you make friends with these people and you just see it as an opportunity to meet with people of a similar age, who are maybe not going through the same thing as you because there’s such a range of different conditions and what have you, but who are going through something that can be related to on some level” (SUP6).

“It's an opportunity to get together. It's difficult for them because I've heard other people say actually having the thing that bonds you together is that you've got a life limiting illness is a bit weird. But often these young people, if they get to know each other, they do become very good friends and support each other” (SHJ).

“I know some of the young adults want to get away from their parents as teenagers do, so it's just about getting that happy medium, and the most brilliant thing is that the families now really trust our service, which is wonderful” (SPJ).

“Freedom away from parents, that's what it's about. We all need time away from family, a break. that's how it is” (SUP4).

“That's what we've seen, the respite and the social bit, as far as the young adults are concerned, they get an awful lot out of it, in different levels” (SUP7).

“He needs to socialize. He needs to mix with other people. You don't just want to be stuck at home indoors all the time. I mean, I can take him out for a day trip to the beach along the front, but he doesn't need just my company, he needs to be socializing with other people with similar illnesses. So, I mean even the first day we went to Zest, we immediately got that feeling that we found somewhere where A. was going to continue the social side which he got at school. There were similar people there, the carers all know the staff are brilliant, and we felt like we had a day out; mixing with people that know what they're doing, made us comfortable, I could come away and feel confident that they were looking after him and he was having a good day. So that was the main point for us, and we certainly felt like we found somewhere that's it's going to be a good thing for him” (SUT).

“Yeah, I think it is that respite, to be able to have a bit of a break; because I think for a lot of these families, they can meet other young people” (SPE).

“I think it gives them a chance to be away from the family, and the family to be away from the young person, because normally young people are not always with their parents, and they need that break and to be with other people that have similar issue to them as well can be very rewarding” (SPV).

“We have one young man who said I love Zest for my socialising for being with my friends-he has got that to look forward too, and they have sleep overs there we are quite a big part of Zest” (SPS).

Participants also suggested that the short breaks and group days are important as they enable the young adults to have fun through engagement in fun activities that they would otherwise not be able to take part in. They said the activities provided through the service get the young people out of the house, provide a needed distraction and something to look forward to.

“Our young lad, he doesn't get a great deal out of anything, because of his situation, whereas other ones do get enjoyment out of it, so there is that element” (SUP4).

“We felt like we had a family fun pack day, and it was a full day as well, from 10 till about four. It was good, the atmosphere was brilliant, it was good” (SUP6).

“The well-being for the young person first, it’s important, giving them time to rest and enjoy and have fun, it’s helpful as well. It makes you forget about your pain at the hospice, I’m distracted, I am excited to be there, seeing staff who haven’t seen me for a while” (SUP7).

“These young people have life limiting conditions, their lives are short, and we can make it the best possible for them. And this isn’t about meds, all they want is to go out, they want to go to the cinema and they want to go bowling and they want to do those things like other young people their age do” (SPM).

“So, it’s lovely, relaxed, friendly, just sort of a good place for young adults to be really and giving them a little bit of independence while still making sure that they have the care they need and the attention they need” (SUP3).

“The options for my week were staying at home, watching TV, and playing video games, not having much of a social life. So, every week, having the opportunity to have a break from it all, go off for a couple of hours at the Hospice with my friends and doing like fun activities and things, yeah, it’s good” (SUP5).

“It was just such a nice place. I looked forward to it every week when I didn’t have much else to look forward to when I was not feeling well at all, and it was something to look forward to and a lovely bunch of people” (SUP3).

“I helped pilot short breaks, weekend breaks thing where a couple of patients at a time would spend a couple of nights at the Hospice and do fun activities: go to the cinema, play video games, play other games. Just do fun things with the time, to give the patients a bit of time away from their parents, bit of time to just relax and do fun stuff whilst knowing that they have the care they need” (SUP2).

“There is loads of need for the service, for the children they need the social aspect of it, they can play games and there is nowhere else that these children can socialise in the community where they are safe” (SPS).

“I think young people want opportunities to do things, to get out of the house and have some fun with each other. And I think things like music therapy and having days out and doing art stuff help” (SHJ).

“They want something that the young people are going to enjoy. You know it’s really important for them, for the young person, to be happy and enjoy what they’re accessing; and you know, feedback we have is that the young people really enjoy the service as well” (SHM).

In addition to being vital to the young adults, participants suggest that the respite, group days and short breaks are equally as important for the families and carers of the young adults as it offers them psychological, emotional, and technical support. Others said the service allows them to form connections with other families going through similar experiences and this allows the open sharing of information and the formation of a support network. The short breaks also offer the families a chance for respite and a chance to unwind and engage in events such as therapy and pampering sessions. Some other participants suggested that the

respite is important for families with other children, as they have time to give additional attention to them.

“It's difficult, especially if you're in a household, and not necessarily always respite for the parents, but for other siblings, so that they can have some extra time with their other children” (SPE).

“Well respite for one thing although I do appreciate, they've got their hands tied, or limited rather, with the number of people that can use the service. We're only one person and obviously they've got the staff, they've got to have the financial backing as well to be able to run the system, so but when [name of young adult] has been there it's given us respite, because we don't get much respite, we used to get respite at the hospice, when that ceased, we didn't get much” (SUP2).

“It's the getting together, I think that's the big thing, the getting together and meeting other people and cause we've all got questions and we've all got the answers, well we haven't all got the answers, I might not have the answer to someone else's problem, but collectively” (SUP5).

“The chats that we have, the young people go off and do their own thing, play and things like that, and the parents go sit in the room and have a discussion. It could start off with someone asking a question “well I've got an issue about this” and someone will say “well go on this website” or “ask this person” or. And then the conversation then develops for the next hour and half, 2 hours. Sometimes they have therapy and things like that, pampering sessions for the ladies. It's not my thing, my wife does. I did have head massage here one evening that was quite interesting” (SUG)

“We weren't sure what to expect, but I think once you come, you realise how comfortable, the help, and it's not just [name of young adult] who accesses it, it's the whole family that gets involved. But I think when you first come, you think it's just going to involve that one person but it's actually the whole family that gets involved and then you meet people, we've got great friends that come here” (SUP1).

“The parents often say it gives them an opportunity to just have time with other families, to help build resilience, and build up some kind of support, rather than being dependent on the Hospice service” (SPC).

“I came as my first group carer thing the last time and I know with lockdown everybody probably felt isolated, but I'd never used the services id always been on the professional side of it and I just went away, and I thought I'm not alone. I shouldn't take comfort in other people's misery but I'm not alone” (SUP5).

“I feel myself coming back to it because they're the families and parents that understand that you just can't live your life, you can't just go out spontaneously with people, your life just doesn't operate like that, so now I've gone full circle and realised that those parents are having the same struggles as I am and I've reconnected with them almost because everyone else's life is moving on and I don't mean it in my life has stopped I just mean it that my life has moved in a different direction” (SUP6).

“I think all families need a break and it's not just the mum or dad, it's both of them, especially during this time, and I always get emotional for this, because I just feel like during this time of COVID, and always brings tears to my eyes, because they've been there 24/7. They haven't had any help. It hit everybody hard, but for them to have someone with such complex needs, that they need this. They both need that time away from each other to do different things. I think that it's potentially on the surface social contact, actually and then some support with coordinating care and then it possibly will over time then begins to drift more into emotional support around progressive conditions” (SPA).

“The respite is helpful and the other therapies, a place for the parents to meet up with families who are going through the same thing as us” (SUP5).

Many participants also noted that during the short breaks the families and carers feel reassured and safe as they know the young adults are cared for by competent, confident, and trained key workers who are able to meet the young people's complex needs which is not always the case with other support services.

“I think the physical space and I think the confidence that the people, the clinical teams know what they're doing” (SPS).

“They basically go with what they think will keep the young person alive. If you want me to be honest” (SPA).

“They would like respite; they also want time to talk to other families for themselves as well as for the young person. They want to feel safe, and they want us to listen to them” (SPV).

“And for the young person to be looked after in a safe manner by people who know what they're doing, and to be stimulated and engaged in activities” (SPH).

“And like I say the parents say that they feel their young adults can stay there and they know they're safe. They know they're not going to get a phone call to say “your son/daughter has had a seizure. You need to come and collect them” and that's something that would happen in some of the adult overnight respite services. And we've got families that now feel they can actually book something to do as a family without their young person. They know they're going to be safe and enjoy themselves, they know that they're not going to get a last minute “Well, actually, we're having to cancel your stay” (SHM).

“They want a reliable service, one that has staff that are trained to meet the needs of their young person, or to have the skills to be able to be trained up to meet the needs of the young person” (SHP).

“Because these families, they hang on to threads of hope, and this is what Zest is, it's that opportunity to know that you're going to get that quality break where your young person is going to be safe and well cared for, and it's just knowing that that's a guaranteed opportunity, and the only reason that wouldn't go ahead was really if a family member then felt unwell, “actually little Johnny isn't as well as I'd like him to be, so perhaps I won't accept this break”, but they're trained to meet the needs, so with regards to safety and meeting needs, the families can be assured that the young person is going to be safe” (SHM).

“I know everyone says it, its somewhere that’s safe. Because we have used direct payments for years for [name of young adult], but when we’ve taken on carers for direct payments, he didn’t have issues, so people working with him haven’t got the same skill set. It’s been quite worrying, until they’re trained up about episodes occurring, like fainting or dropping or going blue, whereas I know categorically that when he comes here, I don’t have to worry about whether they’re trained up or they are competent in this. At the end of the day, when you’ve got someone who’s changing and you don’t know what’s coming next, but there is a service that can meet that next bit it’s something that you don’t have to start fighting for or get people trained up, its already there” (SUP5).

“Parents say it all the time, but the hospice is a little safe heaven. I’m now on the receiving end, I’m on the flip side of what it’s like, and it is a little cocoon that keeps you safe from the big bad world and sometimes you just need to take a breath” (SUP4).

“Obviously for me it’s just respite, and [name of young adult] absolutely loves his time here, he feels comfortable, I feel comfortable leaving him, I know he’s cared for” (SUP6).

3.2 Empowerment

Most of the participants suggested that having a safe place for the young adults to socialise away from their parents empowered them and allows them to achieve independence and autonomy.

“Independence away from their families and gives some opportunity to spend time with other young people and gives them a break from their parents. Parents want a break from the young people, but young people probably want a break from their parents, and the activities Zest provides certainly give them an opportunity to participate in things that perhaps they hadn’t had the opportunity to do before” (SPC).

“From a social aspect, young adults really want to be around their peers, and also from a parent point of view, having that peer support, actually having some of that time, and also the support of the professional team really helps” (SPH).

“It was allowing a little bit of growing up that they needed in a very safe way, both for themselves, but very much for their parents as well” (SPM).

“It’s just about getting that sort of happy medium of home life, and a bit of Zest, and just having a bit of normality, because at the end of the day, they are just teenagers, and they want to do teenagerly things, and we can provide that for them, which is wonderful” (SPJ).

“I think a lot of it is, they want their young adults to be as normal as possible and being able to go out and socialise and do teenage things” (SPJ).

“Enabling young people to have the best life they can. I know they have provided some end-of-life care for some of these young people, which is important too. Uh, yeah, I think it’s about maximising quality of life” (SHJ).

“They don’t get a break. And even for the young adults, they’re not socializing. To see to see them thrive when they come to us, and they come in happy and they’re excited to be here” (SPC).

“And it’s sort of also helping them to have a bit more self-agency really? Building them up to be a bit more self-reliant, it’s part of growing up, isn’t it?” (SHJ).

“Helping young people to have as much autonomy as possible, and parents to be able to be helped to let go as much as possible” (SHA).

“They have a normal teenage day-a sleep over, this is probably the only opportunity they will have to have a sleep over with mates. Being able to have these sleepovers is just priceless” (SPS).

Some participants also noted that the short breaks, groups and days out offer a routine which helps develop confidence in the young adults.

“It's nice to give them the stability, the continuity. Some of them might not be verbal, but they know what's going on it builds their confidence, and a good routine for them is good” (SPC).

“He comes to zest on a Friday, every Friday, and he absolutely loves that, that's part of his routine, this is his life, zest. The X-change night as well, which is on a Tuesday, and we access the family day as well, Saturday, which is every once a month I think it is, on a Saturday, when the family comes, so there is nothing like Zest really” (SUP1).

Furthermore, participants noted that the short breaks allow the young adults to get familiarised with the hospice. This is important as the young adults may not need the hospice services initially but may do in the future and thus the familiarisation with the hospice via the short breaks allows for a smooth transition.

“And of course, if they're not well, they have got health care needs, and so it's also an opportunity for them to get to know St Elizabeth's in case they become end of life, and they want support from St Elizabeth's Hospice for end-of-life symptom management etc” (SPC).

“This is a very slow introduction for the children to an adult hospice, an adult hospice is very different, it is very clinical, we are not clinical we only have clinical room where we keep our medications, so it's a big step for them coming to an adult hospice. The children get to know the Zest staff slowly and it really is a perfect transition” (SPS).

3.3 Parent/Carer/Family Support

Most participants suggested the need for support both physically and psychological for parents/carers and families around the transitional period and said that the Zest service provided this essential support.

“We have a parent support element in a separate room, for usually about an hour, but like recently we had a pamper event for the whole evening. And hearing some of the parents afterwards, having said how they didn't really realize they necessarily needed it, but it was really good to come to something like that, and more so because they got to talk more with a group, and realize quite how similar what they're going through can be sometimes. Because obviously COVID had a massive impact, and the shielding and the isolation for some of these families, it must just have made them feel quite lonely and quite under pressure a lot of the time” (SPK).

“Psychological support for parents around transitions and around complex needs as moving into adult services is very scary. Obviously support around equipment, support around obviously consent issues and capacity and how these change when the child turns 16” (SPG).

“I just became aware of how much support the parents needed, and I think you know everyone thinks about transition for the young person, in terms of being brave enough to let the young person go a little bit, trusting a whole new bunch of people. There is sort of a parent support group but having more support that parents could have access to such as counselling or practical stuff I think is really important” (SPM).

“I think for some of them it is about having a connection with other families that are going through the same, to have that support network. It's difficult, especially if you're in a household, and not necessarily always respite for the parents, but for other siblings, so that they can have some extra time with their other children” (SPE).

“And there's also once a month Zest family drop-in group, where families go in, and we provide staff for that; so, these families can see familiar faces when they first go over there, and also the short break care” (SPC).

“I think also for the families, say, if you've got other siblings, they can do things with them, and sometimes a lot of our families say “we're not doing anything” and you expect them to do things, but they're not; because they just want a night just to sleep, it's just little things like that, which I think some people take for granted, but for them, that's like heaven” (SPJ).

“So, I think the social aspect, and like I said, the groups as a family, and short break care. So, for families to really have that break. It's a two-way thing, it's good for parents, and the rest of the family, to have some time, and to do things that they might not be able to do when the young adult is around; but also, for the young adult, to become a bit more independent, and to get to know some different young adults as well, so that social aspect. I think it's all really well needed” (SPH).

“I think it's about the family having respite as well, especially if they've got siblings, which most of them have got brothers and sisters, that are in mainstream school, wanting to do mainstream things” (SPJ).

“A connection with other families that are going through the same, to have that support network. And for the young person to be looked after in a safe manner by people who know what they're doing, and to be stimulated and engaged in activities. It's difficult, especially if you're in a household, and not necessarily always respite for the parents, but for other siblings, so that they can have some extra time with their other children” (SPE).

“The families have an understanding that we can say to a family “Actually, I don't know the answer, but I know somebody that might”. And that's really helpful, for us as well, because I don't have all the answers, and I don't think anybody else does either. But actually, I know somebody that might know a bit more than I do about the situation” (SPE).

“I just think support, so support them emotionally as well, that peer support, and just someone to go to if you've got a question. I think going into adult services can feel quite overwhelming for young adults and parents. So, I think having someone to ask a question and having a bit of support is really important” (SPH).

“The families have a parent group and on the Tuesday's, they have a take away and they just sit around and chat and when I speak to the parents afterwards they just seem so happy. The parents do not have that community support, they say to me that their friend group gets very small and then they have none and they are often very lonely. Because of the Zest evenings they build up these relationships with other parents in similar situations to themselves” (SPS).

“I think for some of them it is about having a connection with other families that are going through the same, to have that support network” (SPE).

3.4 Key Elements That Make Zest Work

Participants reported several key elements that make Zest work. This included teamwork and good communication between the Zest staff as well as with other services.

“Teamwork, communication. We have a good team, especially now” (SPJ).

“I think it's just part of ensuring our communication is clear. That's really important because I think the young adults and their families need to know that we're together, we're not going to fall apart if there's a problem” (SPC).

“I think organisations have worked really hard at their partnerships and links in the area. So, I think that helps as well, because I think other services can then, talk to families and young people about what's on offer. Because they understand what it is they need, and I think that helps to give a better service for the young adults” (SHJ).

Other participants stated that the staff and the people behind the Zest programme are what enable the programme to work well.

“I think it works, because the people that are behind it, like Helen and Cath, fundamentally believe in what they're doing, and I think that shows” (SPE).

“Teamwork and the staff, the hard work of the staff, it wouldn't be possible without them, and the volunteers” (SUP1).

“The staff for one thing and the facilities they've got here at the moment also make it work. Staff is the big one really” (SUP5).

“I think it's giving the families confidence that someone is there that knows what they're doing. I'm not saying that some care places don't, but it's just that extra level of care. And they've got a very good way with it, with the people there. So, I think that they're happy, we're happy, [name of young adult]. is having a good day, and that that can't be bad, can it?” (SUP7).

“The presence of people who have the skills to sort of to give you the care you need at the same time, but not like hanging around you with needles and tubes waiting for you to need them” (SUP3).

Theme 4: Future developments

This theme encompasses the thoughts of the service users, service providers, and stakeholders about the future developments of the service and potential improvements to the service to enable the service to continue to grow.

Most participants reported that they wanted the service to continue to grow by including more staff and a creating a bigger service. They suggest that in order to have more staff additional training is needed.

"I think more staff is always key, so that we're a bit more solid, and we can cover for those sicknesses" (SPK).

"It's a hard one, and I think staffing at the moment it's tough, and across the board, you know is hard" (SPC).

"Our only problem at the moment is staffing, and it's everywhere. It's not just the Hospice, it would be lovely if we could have more staff on, it would be lovely if we can have two trained members of staff on each shift rather than just one" (SPJ).

"I guess some really just more people doing it. I think it is being quite stretched. They were talking to me about how they've tried to embed it across the hospice, so it's not just relying on the two people leading it, so it's more of a business type model, which I think is a really good one. I can't think of anything" (SHJ).

"Extension of what they've got already. My personal thing is a lot of the staff here obviously they might be working full time on other jobs, but wouldn't it be great if some staff here could also work as personal assistants with the families" (SUH).

"I don't really know, apart from expanding it, being able to have more staff therefore you could possibly offer more respite, that sort of improvements really, I can't think of anything else" (SUP6).

"I think it's just going to get bigger and bigger. I think when we look at numbers, and the amount of young adults that are coming through, it just keeps getting bigger, the referrals keep coming in. I think that speaks volumes about how well it's being received, and how it is changing and impacting on families' lives. So, in the future I'd like to see it grow and the transition coordinator has done amazing things, but I think it could do even more" (SPH).

"I just hope that Zest continues and gets bigger and stronger. I really don't know what we'd do without Zest" (SUP).

"The parents, and the families, and the young adults are just an amazing bunch of people, and I think the service is so needed, and if we can expand it and get more people involved" (SPJ).

"I think they need to invest in training for the HCA's because this would make a big difference to their staffing levels as a HCA we should be able to look after gastrostomy tubes etc, there is an awful lot more HCA's could do to help the nurses" (SPS).

Participants also stated that with the growth of the service they would like the service to be spread out and shared across the country and offered to more people.

"I think the whole service can be expanded and also opened up to people maybe in the East of England area, there's no service equivalent in other areas" (SPG)

"I think just more for it to be extended across, like I said, it's a post code lottery, if you live in Ipswich or the Zest catchment, you've got a winner, you're absolutely winning at transition, that changes if you don't; so, it would be lovely to see the model shared, and other young adults having their opportunity for a good transition" (SPH)

“I think of all the projects we've funded; I think this is the one that we think probably has the most legs. It's a model that because they've got the business case developed, and they've managed to secure CCG funding. It kind of demonstrates that it can be done. (SHJ)

“I think it's very much seen as a gold standard model within the East of England, but I've been sitting on the Norfolk and Waveney children's and young people's transition group, and the Cambridge and Peterborough Transitions Group, and everybody keeps saying “what is St Elizabeth 's doing? What are Helen and team doing?” They're very much perceived as streets ahead in what they're doing, and a lot of people turn and ask them” (SHA)

“In an ideal world you would want services on your doorstep but from this group of people a relatively small number we want to be more of a regional service which means sometimes people may have to travel a bit more and the expertise we are gaining we can share a bit more also to the wider group of professionals. It would be nice to offer more Zest services to Great Yarmouth & Waveney because it had been a bit East Suffolk however, we are saying that people can come here for the service outside of East Suffolk and I think that is the right model to develop. We can also do remote support and it may be that we can help other professionals to develop remote services where they are based. It's about spreading the word and it is a model that works, H has spoken at many different conferences and we always get very similar responses that this is a good model and Together for Short Lives we are getting very good feedback about the services” (SPV)

“Well, I would certainly like to see it evolve. I mean if they could even offer because they only do Fridays, and then they offer four weekends a year to us or [name of young adult] for respite. But it would be so wonderful if it could spread out near this way to Bury St. Edmunds, and I'm sure there's going to be a need for it in other areas as well” (SUP7)

Participants also suggested that the Zest service would benefit from having its own building or space to cater for the specific demands of the young adults in transition.

“Have its own place in the future, somewhere it's part of the hospice but its own place where we can do a lot more stuff” (SUP2)

“I think the demand, and the young adults coming in, is going to just increase in numbers, which will hopefully mean other things come hand in hand with it, like the staffing and hopefully a little bit more area perhaps for us, because we've a shared building that sometimes has its own difficulties of being used for different things at different times, and having to re set up a lot of the time in a short turnaround time scale” (SPK)

“I think it would be lovely to have our own building, which was just for our lot, but still have a big involvement with the Hospice, but for them it would be lovely just to have it, so rather than our Community care unit and we have to turn it into sort of like a little holiday camp for the young adults at the weekend, and then put it back to the Community care unit. It would be really nice to have our own building, and our own base, so it is young adult orientated 24/7, not just at the weekends” (SPJ)

“I do think the environment side of things could be improved, I mean like how it is set up, it's not really set up for Zest it is set up for a different area of the hospice. The bedrooms are right down the other end the doors slam and that disturbs them. You have to pack up at a

certain time so the other service can come in. I am not criticising it because it is amazing but in an ideal world it would be great if it was its own service” (SPS)

“I don't know longer term whether they would want to have a separate young adults' unit. Or whether that's a possibility financially where there's enough funding for that. I don't know, that would be ideal I guess, if we could have a young person's service, separate even from St Elizabeth's maybe” (CPC).

“I just hope that Zest can continue and get funded, even get a bigger place, and grass. I think there's plenty of people that want to access it, it's just not having the right place and funds and everything to make that happen” (SUP1)

“For me, I think we need our own building or an area that is just for Zest. because obviously it's shared. Our young adults just need their bit of space on their own. I think we need that so we can have respite and different things cause were limited to where we can have things and what we can do because people are using rooms and renting rooms. It's just that we'd love to have our own little unit or space and funds so that we can continue to make Zest bigger” (SUP4)

In relation to growing the service, participants reported that the Zest service could be improved by offering additional days or an at home service.

“They need to have like a week. Yes, they're having the weekends, but I think it could be great to have, I don't know if we have it as a Hospice long-term goal, but it would be lovely to have our own place and to have seven days that they could come in” (SPC)

“That would be amazing, and people could come in during the week. So, if it was an all-week service. But that is a dream, I think that's what we would all like” (SPJ)

“Yeah, even if they had a week respite, or weekend, or a day, or days, or a drop in, just a bigger service” (SPCJ)

“Because at the moment it's only weekends, it's quite limited. I personally would like to see it perhaps being a bit more” (SPE)

“Yeah, so for us the only thing that I would like to see more is respite. Obviously, they're very good, they do what they can, but [name of young adult] gets one weekend a month and he's only had one stay this year because of Covid and not having the staff and having to find staff again. So, for me, respite is a big thing, but I'm hoping that, obviously we want Zest to continue as long as possible, but funding and for them to get the weekend more often and be able to have respite would be fantastic for all of us. We're all in the same position but we really do need our respite” (SUP1)

“I mean, if it was on a Monday, Wednesday, Friday, I mean superb, [name of young adult]. would be getting so much more social care, it would be brilliant” (SUP4)

“It would be great if they could offer it in more places and more days a week, it would be fantastic” (SUP7)

“Selfishly for me I would like someone to come at home for night-time and have five days a week provision somewhere that is geared up to the medical needs, complexity needs, having

everything on site, making it a bespoke package, wouldn't it be great if there was more provision than one day. But it's great because that one day is secured" (SUP3)

Participants reported that in future developments of the service it is paramount that the Zest service continues to work closely with the families to ensure that the service is delivering and tailored to meet the needs of the family and young person.

"I think we need to continue working with families and making sure that what we're delivering is what the families want and need" (SPM)

"For a lot of families, they'd want their young individuals to not be there overnight so it's a very personal thing, it would be nice to have a choice like "do you want a night here at your place and we come to you or do you want them to come to the hospice?" (SUP6)

In addition to more days, participants also reported that more resources and more opportunities such as additional trips and activities will be of benefit to the Zest service.

"Eventually, once things calm down a bit, we can start taking them out on sort of little visits, and going out and about, whether it's the zoo or the beach or whatever (SPS)

"Just more, just more opportunities for young adults and their families" (SPH)

"More resource obviously, so that they could offer more short breaks. But I could say the same for EACH really, if we had more resources, we could offer more" (SPC)

"I mean they could have more busy days with activities. They could even do cooking. I mean [name of young adult]. doesn't eat, but he could still get the pleasure out of the cooking and the smell. I think it's so important to be socializing and mixing well with people" (SUP5)

"Those opportunities for the young people to actually live and develop in the time they had, and to give their parents a break were so important those short breaks and if that could be expanded more" (SPM)

Participants expressed concerns about funding in influencing the future of the Zest service.

"But obviously funding is always a worry, because being the service that we are relying on outside sources" (SPK)

"And not just only open, because obviously some of it is funding, and they're limited for that funding to have that disease day or the weekend" (SPC)

"And then another thing is the fund-raising to try and get our own minibus, so that we don't have to borrow it from the Hospice" (SPJ)

"I would hope that it could carry on doing what it does do and possibly even, it comes to down finance doesn't it, if the finance is there to maybe even expand it. That's the big question with whatever subject you're talking about in this day and age, is finance" (SUP2)

Finally, participants stated that in order to grow the Zest service further it is important to continue to raise the awareness and public profile of the service through having a community impact, advertisement, and networking.

“I think having the media support, and Ed Sheeran, and some of the top names, and a really good charity shop in the centre of town, well, close to the central town locally. I think that's given a quite a nice profile and got the word out as well” (SPK)

“Probably, raising a greater awareness, especially about death and dying as we have been trying to do this for many years and I think it is working better now. If people understand other people's conditions or challenges, then we are more likely as a society to be able to support that and that means your local community like the compassionate communities theory and your local neighbourhood. By raising the profile of a group and we advertise the service and make videos etc and I think that gives them a bit of a voice that perhaps they did not have before” (SPV)

“I don't think Zest is out there enough” (SPC)

“I think the community in Suffolk are really getting to know Zest now because they have just opened up a shop and it is advertised a lot now, so people are getting to know about it” (SPS)

“It's just getting the word out, by making it more accessible. Because I'm sure, there must be, I found myself a lot over the last 18 months saying to myself “well surely [name of young adult] can't be the only disabled person in a wheelchair in this world”. Because wherever you go down the benefit route, the care route, and you feel like you're the only ones. You could think “it can't be”. But then, all of a sudden, there was this little light at the end of the tunnel. And now [name of young adult].’s got this social care place where we can go and have a good day out and come back, and I'm hoping he's going to have a weekend there soon” (SUP1)

Discussion

Due to medical advancements, there has been a growth in the number of young people with LLCs in the UK surviving to adult hood (Connor, Downing, & Marston, 2017). This has led to a demand in 15-19-year-olds requiring specialist palliative care in the UK. Whilst adult hospices are available, there is a lack of hospices which are able to cater for the complex needs of young adults with LLCs. There is also a discrepancy between the children's and adult hospices and a lack of transition from child to adult services. The quality of life of these young adults can vary considerably depending on where their treatment is and what staff are available to support them. Hence there is a demand for services like Zest to meet the needs of individuals with LLCs and offer a suitable transition from childhood to adult services. St Elizabeth hospice in collaboration with local and national partners developed the Zest service which provides palliative care support, transition coordination, short break respite, day services and groups for young adults and their families transitioning from children to adult services. This service review reports on the activity of the team over a two-year period.

There are currently a total of 43 young adults engaging with the Zest service. On average, these patients have spent 1617 days (approximately 4 years and 5 months) involved with the

service; ranging from 210 days (approximately 6 -7 months) to 4019 days (>11 years). The average age of the patients using the service is 23 years, although patients range from 15 to 42 years of age, there are currently a greater number of males using the Zest service (67%) compared to females (33%), but there is no difference in the way that males and females engage with the service. There was a spread of patients within all categories classified within the **Categories of life-limiting and life-threatening conditions (TfSL, 2018)**, although category four was the most prominent. The highest overall percentage of face-to-face contacts was with the Zest nursing team.

One of the most striking comments which emerged from the qualitative interviews was that the service was needed because there is nothing else available for young adults transitioning from children to adult services. Thus, the Zest programme fills a void and allows the young adults to experience early engagement with the adult services, allowing for a smoother transition from the children's services. The participants also stated that this gap in services has been historical and a problem for many years, which is now somewhat addressed by the Zest service.

Leading on from this, participants stated that they felt there was a noticeable gap between the children's and adult's services, which the Zest programme went some way to address. The evidence suggests that transition interventions should aim to bridge the potential gap between child and adult services (*Kerr et al. 2020*) and that transition planning should involve evidence-based interventions which lead to improved patient centred outcomes such as the adolescent/young adult increasingly taking responsibility for engaging with services providers, adhering to treatment strategies and contributing to their disease management plan (*Aldiss et al. 2015*). Participants stated that one of the most important elements of the Zest service was the co-production with the families which helped develop their relationships, made them feel that they were listened too, their needs understood and most importantly that the young adults were encouraged where applicable to proactively engage in their management plan.

In addition, another problem identified was that the experience for young adults transitioning to adult services can vary considerably depending on where they are geographically located which often depends on the local investment by commissioners to this service. The evidence suggests there are huge challenges of providing care for young adults relating to physical, psychological, practical and/or social factors (*Kerr et al. 2020*). This was evident in a number of participants emphasising that the care available is a 'post code lottery'. The evidence further suggests that while the Zest service offers local support, this is not general to the UK, and consequently participants wish the Zest service to be extended to other areas, using the lessons learnt from this model to develop future services.

Furthermore, the evidence suggests that staff in the adult hospices had very little experience of complex diseases which originate in childhood (*Care Quality Commission, 2014; Doug et al., 2011*). The Zest service operates a shared care model, running groups and short breaks in collaboration with staff from the children's hospice, enabling learning and upskilling of the adult hospice team. Consequently, participants reported that they felt well supported and acknowledged the many skilled nurses and the issue, when recognised, was not an insurmountable challenge (*Knighting et al. 2017*). Most of the participants who delivered the

service suggested they had considerable transferrable skills appropriate to caring for young adults with LLCs and described 'how they wanted the service to continue to grow by including more staff'. However, to enable this to happen all participants suggested there needed to be more investment and additional staff training required.

Moreover, Individuals with a LLC commonly experience a range of physical, emotional and social concerns and furthermore, a diagnosis with an LLC not only impacts the person who is diagnosed but those close to them too (*Knighting et al., 2017*). Recognition of the need to identify concerns and provide personalised support for both the young adult and the carers and families is a real challenge. Organisations and cancer charities are constantly trying to improve the cancer pathway by developing innovative services to support patients. 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 (*Bomba et al. 2017*). Although adult hospices provide excellent specialised services, there lacks the appropriate universal support and skills amongst professionals to provide care for this patient group as they often have complex and unfamiliar conditions. The need for hospices to be central to the development of transitional care services for young adults have been highlighted in many reviews and reports but they have not specifically identified who should take responsibility to develop or deliver them (*McDonald, 2016*).

Regarding the essential aspects of the service, the importance of the transition co-ordinator role was highlighted by many participants, with some describing it as a 'lifeline and the link pulling all the services together' and a key point of contact for all those involved in the service. During the period of evaluation, the Zest transition nurse made a total of 253 contacts with the patients. Predominantly, contacts were made by telephone (227 contacts: 90%), rather than face-to-face (26 contacts; 10%). The number and type of contact varied significantly depending on the preferences of each patient. This evidence supports the evidence which suggests that a transition coordinator is the key worker to specifically support the young adult with a life-limiting condition to transition to adult services (*Kerr, & O'Halloran 2017*).

The arrival of the first phase of the COVID-19 pandemic brought about an incredible scale and pace of transformation (*DoH, 2020*), in the way services were delivered. It really impacted on the Zest service where all social activities for the young adults were cancelled. Most of the services users described how 'challenging it was for everybody not having any respite from the twenty-four-hour care'. This was further compounded by the 'lock downs' that were introduced by the government and enshrined in law with the hope of protecting the NHS and reducing the spread of the virus (*Brown & Kirk-Wad 2021*). The impact of the Covid-19 pandemic should be considered both in terms of limiting the provision of the coordinator role (due to periods of redeployment) and reduced face to face contacts. However, despite the disruption the Zest nursing team/Transition Coordinator maintained contact with the young adults and their carers to ensure their essential needs were met in line with what was permitted during various 'lockdowns'. Participants described their disappointment with the lack of services during this time but stated they were equally 'frightened of getting the virus which would have had devastating effects on them and their families, most suggested they were grateful for the help they received from the Zest service

during this difficult time. However, they suggested the contact provided by the team was very reassuring and enabled them to 'offload some of their concerns'.

Another essential aspect for the success of the Zest service was suggested to be effective communication between healthcare professionals and the adolescent/young adult and their parents/carers as identified by Kerr *et al.* 2020. Service users suggested that this enabled the development of the adolescent/young adults' autonomy and enhanced their confidence in the service whilst being at the centre of decision-making relating to their care.

Additionally, the service provides a specialist nurse led 'short break' for young adults aged 18 years and upwards, this can be in the form of day care, or a short stay break. In the past two years, almost half of the patients engaged with the service (47%) and have had at least one short stay, with some having up to seven short stays during this time. This allows young adult patients to take some time out from their daily routine to have fun and socialise, whilst providing vital respite for their families.

Many participants recognised the importance and the need to develop the adolescent/young adults' autonomy and suggested the short breaks provided were an important aspect of the service which allowed them 'to develop social skills, meet young adults with similar conditions or needs'. Others stated that having time away from their parents/families enabled the adolescent/young adult to achieve independence and experience typical teenage activities whilst gaining confidence in relationships with service providers and in decision-making.

In addition to the short breaks being suggested to be beneficial for the young adults, the benefits of the short break for the families of the young people were also highlighted. 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 (Kerr *et al.*, 2020, 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). This was echoed by the participants interviewed as part of this review who suggested 'the short breaks are vitally important both for the young person and their families'. The short breaks were suggested to be vital as they provided the families emotional, physical and social support.

Recommendations

The interviews with the participants highlighted several recommendations for future improvements. Firstly, although the development of the young persons' independence was embraced by most parents/carers some described how 'difficult it was having to step back and allow the young adult to make independent decisions about their care'. Perhaps this is an element of the transition which needs further consideration as participants described their feelings of disempowerment and loss in their involvement with their child's care decisions when they reached the age of eighteen. Secondly, it was suggested that adult hospices lack specialist staff who are trained in the needs of individuals with LLCs and that adult hospices are not well adapted to meet the needs of young people with LLCs but more so suited for

people at the end of life. Consequently, more training to develop additional specialist staff and adaptations to hospices, such as those utilised in the Zest programme, may be beneficial. Leading on from this, many participants noted that they would like their own facility which would allow for more specialist support and opportunities for more respite and activities for the young person. Several participants were concerned about issues around funding impacting on these recommendations. Furthermore, participants noted that the amount of transitional care support they received was highly dependent on their postcodes. Participants consistently reported how much the service is valued and suggest that there is the potential to develop this service further and use it as a model for the development of similar services throughout the country. Finally, participants recommended that to extend the service, there needs to be an increase in awareness of the Zest programmes and the complex issues surrounding LLCs.

Conclusions

This mixed method study has given important insights into the Zest service over the past two years. Using the experiences of service providers, service users, and stakeholders has increased the understanding of the need, referral patterns, and the various elements offered by the service as well as its impact on service users.

Analysis of the quantitative data revealed that the service provides palliative care for patients who are classified into each of the four broad groups identified as likely to benefit from a palliative care approach and/or support from children's palliative care services (*Together for Short Lives, 2018*). Predominantly, the Zest service is being used by patients with a primary diagnosis consistent with category four; irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. During the period of evaluation 1394 contacts were recorded and almost half the patients had utilised a short weekend break stay or day care.

Analysis of the qualitative data revealed that the needs of young adults with LLCs are diverse and complex and they require specialist palliative care (*Noyes et al., 2014*). Participants identified large gaps in the provision of transitional care support which the Zest service went some way to address, this included: differences between adult and children's services, a growing number of young people with LLCs living into adulthood, a lack of transition services and stage/age-appropriate services, and the availability of services being highly influenced by geographical location, thus emphasising the need for the Zest service. Participants suggested that the key elements that made the service work were good communication and the staff behind the service. In particular, the Zest nurse/Transition Coordinator was vital in developing strong relationships through working with the families and young people. The Transition Coordinator was identified as a key worker. The short breaks were also consistently emphasised as being important for respite, carer/family support and for the autonomy of the young persons.

Appendix 1: Zest questionnaire for Staff

- What is your role or connection to the Zest service?
- What is your understanding of the need for this service?
- What services do you think families want or need when they accept a referral or self-refer to the Zest service?
- What benefits do you think the Zest service provides to young people and their families?
- What do you see as the key elements of the Zest service? (IE what makes it work)
- How could the Zest service be improved?
- What has been your involvement in the transition project funded by Together for short lives? (Cue: Transition coordination role)
- What type of support do you provide to the young adults who are in transition from Children's to adult's services?
- How confident did you feel to support the young people transitioning from children's to adult's services?
- Are you able to tell us on average how long you (or other staff) spend each month supporting each young person in transition to adult's services?
- What type of staff are mainly carrying out the above contacts?
- Have you noticed a change in the amount of time you spend in these tasks since the Transition Co-ordinator role has been in place? If yes, please describe what difference you have noticed.
- Are there any areas of duplication of effort with other services which are no longer duplicated since the Transition Co-ordinator role has been in place? If yes, please describe.
- What impact do you think the Zest service and the transition coordinator role has on the wider community and other services?
- From your experience, what impact has the transition coordinator role made to your workload?
- What impact do you think the transition coordinator role has had on the wellbeing of families in transition?
- What are your thoughts about the future of the Zest service, including the transitional care model developed during the project?
- Any further comments

Appendix 2: Zest questionnaire for service users

- How did you hear about the Zest service?
- What has been your experience of using the service?
- What is your understanding for the need for this service?
- What services do you think families want or need when they accept a referral or self-refer to the Zest service?
- What benefits do you think the Zest service provides to young people and their families?
- What do you see as the key elements of the Zest service? (i.e. what makes it work)
- How do you think the Zest service be improved?
- What are your thoughts about the future of the Zest service, including the transitional care model?
- Any further comments

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