Alex’s journey to respite

“it’s been six years since their last respite…”

A report on the innovative pilot trialling the provision of a new specialist short break stay service for young adults with life-limiting conditions, including the sharing of the pilot evaluation, learnings, and recommendations for the future.

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Young adults and their families/carers were asked,

"What is respite? What is a short break stay?"

"Give you a break being away from home"

"Gives my mum a break!"

"An opportunity to meet new friends…"

"A few days away"

"To get away from Mum and Dad"

"To do different things – art, music…"

"Meet other people to talk to…"

" (A) different environment"

Alex’s Journey to Respite

We will follow the journey of Alex, Leslie and Mackenzie as they access the young adult services at The Prince and Princess of Wales Hospice, from referral to their short break stay.

Alex

A fictional young adult – a persona (for further information see Appendix 2) - based on the characters and experiences of all the young adults who accessed the SBS Pilot. Alex represents many more young adults waiting in the wings with unmet needs. Alex lives with his parents Leslie and Mackenzie and is a full-time wheelchair user. They have a complex disability and multiple co-morbidities. He is medically stable but always at risk of a sudden deterioration in his health.

Alex, what does a good day look like for you ?

“When I’m happy, out with friends, playing football. I like a good meal too and a trip to the cinema. When I’m healthy…”

What does a hard day look like for you?

“When I’m in pain, lonely, not sleeping. When my equipment’s not working. When my carers cancel and my parents are just done in…”

Leslie & Mackenzie

Alex’s parents - a fictional partnership and two further personas - based on the characters and experiences of the families accessing the SBS pilot, representing others providing around the clock care for their young adults. Leslie works full time. Mackenzie is Alex’s unpaid carer - a position they never imagined being in. They have another child, Jamie, who lives away from home at university. Both have elderly parents who they worry about.

Alex was referred to PPWH during the COVID pandemic:

“Since children’s services ended, we as a family have not accessed adult respite”

Alex has some hours of care each day and some “floating hours of respite” for their parents. At the point of referral, it was explained to Leslie and Mackenzie that PPWH would not be able to provide respite at that time but would hopefully do so in the future. They were happy to receive updates on the service.

A few months later, a phone call was made to Alex’s family.

Mackenzie talks openly, “*I want to care for him at home but think that I’d need back up… I’m not sure that I am brave enough to care for him (at the end of his life)… but hope that I can focus on being his parent and be with him…*”

Leslie shares, *“we feel unsupported since leaving paediatric services… I feel that people have given up on Alex… I feel that I can’t go out and leave them, I’m worried… we’re so alone…”*

1: Introduction

Children with life-limiting conditions, such as complex neurodisability and neuromuscular conditions, are living longer[1,2] due to targeted intervention, new medical treatment options, and improved standards of care. However, a dichotomy exists. Living into adulthood will likely result in: increasing frailty, disability and dependence, and the stark reality of the need for twenty-four hour, seven days a week care. At this time, we are aware that social care is inadequate across Scotland and the majority, if not all, care of the young adult (YA) falls on family, who will often have long periods without a break or respite.

Across Scotland there is a lack of age-appropriate and accessible services for these young adults (YA), resulting in them having unmet needs. These unmet needs can be associated with poor physical and psychosocial outcomes for the YA and their families alike.

Since moving to the new hospice in 2018, the Prince & Princess of Wales Hospice (PPWH) has been able to offer care to young adults, setting up the first dedicated Young Adult Service (YAS) in Scotland to address the inequity of access to adult specialist palliative care and to meet the unmet needs of these young adults.

Speaking to the young adults and their families who were already known to PPWH they shared the reality of their day to day lives: it became unambiguously apparent that age-appropriate bespoke short break stays (SBS) were urgently needed for this community.

A short break or respite allows those caring for the YA to have a break from their caring responsibilities as well as offering the YA new experiences.

This report looks at the innovative pilot trialling the provision of a new specialist short break stay service for young adults with life-limiting conditions at PPWH and follows previous briefing papers and presentation of informal results.

2: Background

2.1: An increasing need

The number of YAs, aged 14-25, living with life-limiting conditions in the UK has increased by 40% in recent years, the majority of whom live with congenital and complex neurological conditions.[3] In Scotland the ChiSP Report 3 also demonstrates that children with life-limiting conditions will now survive into adulthood with increasingly complex needs. The data demonstrates that the complete prevalence in the 16-20 year age group was 53.8 per 10,000 in 2009/10, increasing to 73.3 per 10,000 in 2013/14.[4]

Surviving into adulthood means living with diverse physical, psychological and socioeconomic needs.[5] Outliving an original shorter prognosis also means that there is a need to transition from child to adult health and social care services. This period of transition is a time of uncertainty, and it is recognised that adolescents and young adults require developmentally appropriate settings and models of care.[6] However, across the UK – and more so in Scotland - there is a lack of such care resulting in inequitable access for those in need.[5,7]

2.2: Who should care?

It is unclear where this emerging "forgotten" population should receive holistic support. Locally the YAs may be known to Children's Hospices Across Scotland (CHAS), the Children with Exceptional Health Care Needs (CEN) NHS Managed Network, the Scottish Muscle Network (SMN), or PAMIS (Promoting a More Inclusive Society). It is understood by these organisations, and reported by the YAs and their families, that there is no equivalent care to that received in child services when moving to adult services. In fact, barriers exist including a failure to recognise this group of individuals as having palliative care needs.

> **"Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual."**
>
> World Health Organisation, 2020

It is clear that this population do have palliative care needs as defined by the World Health Organisation, but real and perceived barriers to accessing adult hospice care exist:

- The conditions the YAs live with differ considerably to those seen regularly in adult palliative care.[8]
- Staff share concerns that they lack competence and confidence in managing the complex needs of the YAs.[5]
- The admission criteria to hospices for supportive care is not met.

2.3: Short break stays

When considering transition, it is important to see the process as a total model of care with five aspects. Social care is seen as an integral part of child transition from child to adult services and sits alongside healthcare[9]:

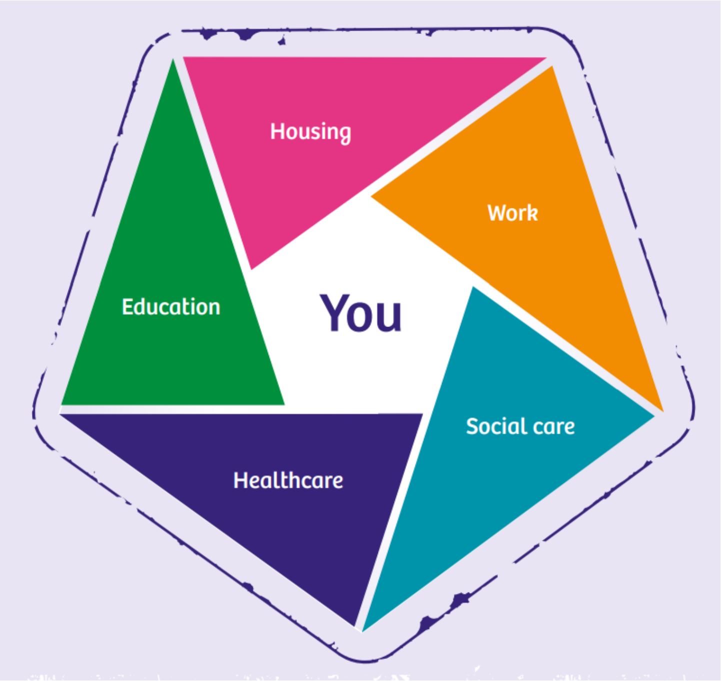


Figure 1: the 5 aspects of transition

Keeping this in mind, short break stays and respite are an important part of the transition process for the young adults, helping them to feel empowered, be as independent as they can be, and help their families and carers experience a life beyond caring. A short break or respite allows those caring for the YA to have a break from their caring responsibilities as well as offering the YA new experiences.[9]

Child and adult hospice services differ significantly in that the provision of short break stays and respite are seen as an important part of the role children's palliative care. Such respite is offered and delivered to children and their families living with life limiting conditions; the burden of care on the family being recognised. In contrast, respite in adult palliative care is not traditionally recognised as a criterion for admission. Without the opportunity of short break stays or respite in an adult service after transition – a period when it is recognised that the YA's needs become more complex and that there is an increased need for such a service – YAs experience a deteriorating quality of life and there is a detrimental effect on the wellbeing of families.[7,10,11]

2.4: The role of PPWH

A number of children's hospices across the UK offer hospice based short break stays for YAs, for example, Martin House Hospice, St Oswald's Children's Hospice, Naomi House and Jack's Place. CHAS pre pandemic were able to offer respite for YAs on their case load but post pandemic, with a reduction in bed numbers, they are unable to guarantee respite stays and may cancel to prioritise end of life care.

A recent systematic review demonstrated a lack of evidence of respite provision for YAs and highlighted the need for service evaluation and research.[12] PPWH has recognised for some time that they had a role to play in the provision of short break stays within the safe, inclusive, and welcoming environment of the hospice and could add to the existing small evidence base. Their development of a short break service was underway when The Zest Service at St Elizabeth's hospice, who deliver a developmentally appropriate palliative care service for YAs aged 14 years up, opened their doors.

3: Aim & Objectives

The Aim:

To trial the provision of a new specialist short break stay service for young adults with life-limiting conditions, who were considered to have specialist palliative care needs, and currently known to the YAS at PPWH.

The Objectives in 2019:

- To explore the validity of flexible short break stay provisions for young people living with a life limiting condition within the hospice environment: is the hospice environment appropriate for the delivery of flexible short breaks stays for young people with life limiting conditions in the West of Scotland?
- To explore the provision of care: what staffing models would need to be in place to support this. What skill mix of staff is needed to support the young people?
- To scope the resources needed to offer everyday living experiences to all young people who attend the short break stay service including providing the young people with the opportunity to be with their peers and have fun through activities appropriate to their likes and choices.
- To scope our capacity and capabilities to be able to provide emergency respite.
- To address the perception that adult hospices have nothing to offer young people with life limiting illness and their families.

While the above objectives remained relevant for the pilot and are relevant for reporting purposes as they add much to the understanding of short break stays, they were streamlined for going live.

The Objectives in 2021:

- To co-produce with young adults and their families/carers a short break service which would meet their needs.
- To provide respite for 12 weeks while accommodating two young adults per week in the YA beds within the in-patient unit.
- To evaluate the experiences and benefits of the SBS to the YAs and their families.
- To test an operational model for SBS and establish the cost of delivering such a model.
- To move safely from a proof-of-concept to a chargeable core service that YAs can access through their own Self-Directed Support or respite budget.

4: Consultation & Discussion

Understanding what was needed in terms of respite or SBS was paramount to the development of the pilot; however, what was of greater importance, was involving the YAs and their families in the co-production of this SBS, taking them on a journey from concept to reality.

Focus groups were held virtually and below is a list of what was explored and discussed:

- Their understanding of what the terms "respite" and "short break stay" mean
- When their last short break stay was and how often they accessed them
- Their good and less positive previous experiences of short break stays
- The barriers encountered that stopped them accessing short break stays
- Whether they had an existing budget for a short break stay
- If an emergency respite care budget was in place
- What would be important to them should PPWH create a short break stay service?
- Was there anything that would make them hesitant about accessing such a service
- How often they would consider coming for a short break stay
- And finally, whether they would like to have a short break stay with another young adult

The full responses can be found in Appendix 3.

Alex:

"I went for a break a long time ago… maybe a couple of times a year… if there was a bed. They'd put me to bed too early… there wouldn't be enough staff, or they wouldn't know what they were doing with my machines… I didn't do much, just stay in my room or go shopping… there wasn't many young people about… But don't get me wrong… sometimes it was great! We'd go to the cinema and museums, watch football… It was real break for my parents…

I had to stop going though… I was anxious about how they cared for me and it wasn't like it was for me… at my age…

I want to come to you cause it's close – to my parents and the hospital… I've built up trust with you. I want to make sure you can meet my needs though – that ok? I'm worried about you doing my care, moving me and settling me at night… And you need to make sure that the equipment's right… I have lots of equipment… at home it's set up perfect – there's no point if the equipment doesn't work…"

Reviewing the discussions, we were able to identify four pillars of delivering a safe and successful SBS:

trust & confidence

personalised skilled care

appropriate environment

safety

The focus group with the carers raised concerns regarding the wellbeing of some of the participants. It was apparent to us during the focus group that Alex's parent was at breaking point. They appeared overwhelmed and tearful through the video call. A family member had been diagnosed with a life-shortening condition.

5: Getting it right

From our initial discussions with YAs and their families/carers we were aware that the level of medical complexity and need that the YAs had meant that many existing respite models were not deemed suitable. They were perhaps not fully accessible, the environment was not developmentally appropriate, the equipment was not such that it allowed the same level of independence at home suitable, the YAs were not staying with peers that they could socialise with, and the skill level and mix of nursing staff was not adequate to instil trust and confidence.

5.1: Trust & Confidence

Trust and confidence are key components of the health care professional – YA – parent relationship. These components take time to establish and develop but are important in terms of:

- Communication
- Improved wellbeing outcomes and higher quality of life
- A better YA/parent experience

For the YAs and their families this meant "getting to know them" in a holistic, person-centred process, starting at the Young Adult Clinic and moving through to the Living Well Hub to meet the extended multi-disciplinary team.

Alex on their first visit to the LWH,

"(I'm) *just so delighted to be coming in and just happy for a blether".*

They met the artists and a picture of who Alex is began:

After a session with Alex, the artist documented,

"He enjoyed the music based on bird song with the addition of little sounds made with percussive instruments… wafting air with large paper fans… he engaged throughout and smiled, laughed in response to particular sounds".

Trust and confidence will grow where competency, consistency, integrity, and compassion are demonstrated. These are attributes the teams involved in delivering care to the YAs display. The YAs and families felt safe and able to come in for SBS knowing the team working with them. An added benefit was the ability of the families to stay in a bedroom close to the YAs in case they were needed to answer questions about the YA's care, further instilling confidence while allowing some degree of respite for them.

5.2: Personalised skilled care

As stated, competency is required to ensure that a therapeutic relationship based on trust is established between the health care professional – YA – family. The YAs and their families using the SBS would be in control of or delivering all cares. They would be competent within their own environments.

For the SBS team to reach such competency, enough for trust and confidence to be instilled and personalised skilled care to be delivered, education and training, with the focus being on the care interventions commonly managed by the YAs and families at home, was seen as a priority.

Education on the following key areas was delivered in collaboration with CHAS, Quarriers:

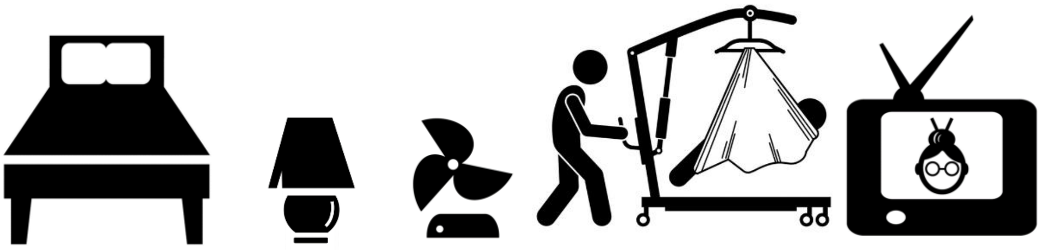
- The YA's medical diagnosis and complexity of need
- A refresher in Basic Life Support (BLS), including cardiopulmonary resuscitation and choking for those in a wheelchair
- Percutaneous endoscopic gastrostomy (PEG) feeding
- The administration of medications
- An update on the management of complex seizures
- The use of non-invasive ventilation (NIV)

5.3: An Appropriate Environment

At home YAs create useable and safe environments around them, achieving more independent living[3,4]. The were very clear about their environmental and equipment priorities for the SBS; a lack of such an environment within the hospice may be a barrier to using the services on offer.

The YAs identified in conversation that access to the following items in the IPU were essential to ensure wellbeing during their stay:

- Equipment: e.g., profiling bed, mattress, tracking hoist
- Technology: e.g., gaming, computer, phones, WIFI.
- Environmental controls: e.g., lighting, heating, call system, monitoring



Getting the environment right demonstrated PPWH's commitment to listening to the YA voice while ensuring that the YAs felt respected and appreciated. The YAs drove the changes to the hospice environment to benefit all the inpatient population.

PPWH was keen to initially pilot new equipment and get feedback from the YAs. There was a considerable cost attached to hiring equipment, but it allowed the right equipment – to enable and benefit many of the YAs accessing the SBS - to be purchased for the second part of the pilot. (The costs can be reviewed in Appendix)

5.4: Safety

Patient safety is a key domain in hospice care and therefore paramount in the delivery of the SBS. Background work was completed ahead of the pilot to reduce risk and ensure the safety of the YA.

This included:

- Consultation with:
    - YAs and their families about their concerns
    - St Elizabeth's Hospice – having already set up a successful SBS
    - Multidisciplinary team responsible for delivering care
    - Lead professionals regarding medical support for in-hours care
    - Local GP surgery regarding out-of-hours (OOH) care
    - Scottish Ambulance Services concerning support in the event of acute deterioration

- Development of documentation:
    - Standard Operating Procedure (SOP), including pathway from offering a SBS to point of leaving and collating evaluation
    - Soft signs and acute deterioration guideline and SBAR
    - Medical handover information sheet for OOH
    - Checklist for admission
    - Bedside paperwork

- Completion of essential documentation:
    - Medicines reconciliation and Kardex
    - Resuscitation status and ceilings of treatment
    - Emergency care plans, e.g., seizure management, cardiac management
    - "This is Me" document or Health Passport

6: Proof of Concept

With the consultation process completed and steps started to "get it- the SBS - right", a presentation was given to the Hospice Board of Directors: funding was agreed to support the YAS access a proof-of-concept pilot for the creation of a SBS Service.

This was on the basis that two unfunded beds within the specialist palliative care IPU would be utilised for a total of 12 weeks, bringing in two YAs at a time for respite. Although delivered in the IPU, the SBS was to be built around a social and wellbeing model of care and not around an elective palliative care admission.

6.1: The stay

All YAs on the YAs caseload were offered a SBS, at no financial cost to them, from Monday to Thursday to help us shape the service. We had considered offering stays from Friday to Monday, but it was felt that the risk of them being in the hospice with less staff over the weekend was not acceptable during the pilot.

The YAs arrived at lunchtime on Monday and were welcomed by the team at reception, the porters helping to deliver their equipment to their room. They had full access to the hospice building during their stay, including the BarGaCree Café, Art Room, YA Lounge (with all important gaming equipment!), Changing Place and dedicated outdoor gardens. They were also able to access a range of services provided by the hospice including the Living Well Service, Art Service, Family Support Service, and Complementary Therapies.

The YAs left late morning on the Thursday, some enjoying lunch, a session with the artists, or a massage before leaving.

6.2: The model of care

The main provision of care, with the YAs having one to one care, was in the 6 bedded ward within the inpatient unit and provided by the SBS team consisting of:

2 Band 5 staff nurses – seconded from IPU.

2 Band 4 Advanced Health Care Assistants

The team worked with the oversight of Ann Bradley, IPU Charge Nurse, Fiona Wylie, Lead for Strategy and Implementation, and Sheonad Laidlaw, Specialty Doctor.

The staff attended training to ensure they had the knowledge and skills to care for the YAs.

6.3: The YAs

At the time of planning the pilot our caseload sat at 21 YAs who had a mix of complex neurodisability and neuromuscular conditions:

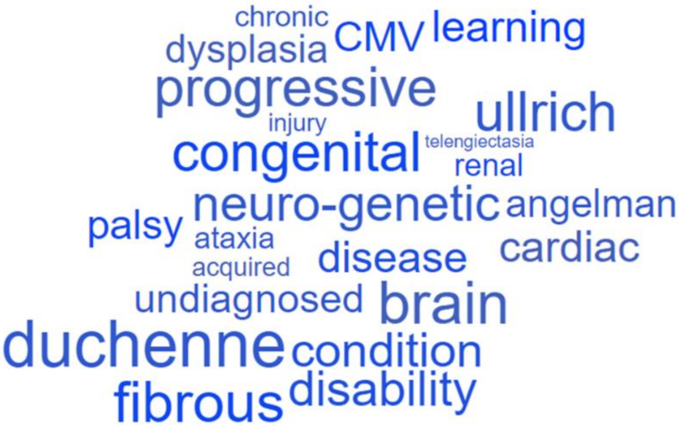
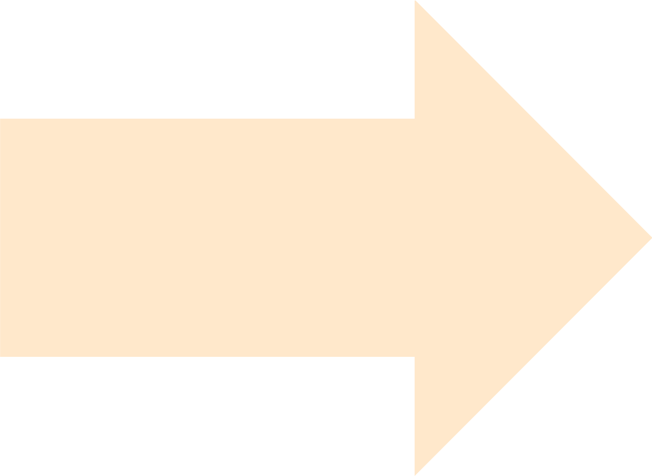


Figure 2: Word Cloud of YA diagnoses

The caseload was reviewed to determine which YAs were medically stable, with infrequent acute hospital admissions – this was following feedback from another provider of SBS who had difficulties bringing in those who were unstable and because of concerns from the medical team at PPWH.



5 declined the offer of a SBS due to "being too busy", "not feeling (they) need it", or feeling their care was too complex and that their needs were already being met by their families (this was despite the YA team knowing that the families were under considerable pressure due to the burden of care).

Figure 3: Flow of participants

Table 1: Categorisation of YAs conditions accessing the SBS

Definitions (Together for Short Lives, 2018)	Number of young adults in pilot
Category 1: Life threatening conditions for which curative treatment can be feasible but may fail. *Examples: cancers, organ failures of heart, liver, kidney, transplant and children on long term ventilation.*	0
Category 2: Conditions where premature death is inevitable. *Examples: cystic fibrosis, Duchenne muscular dystrophy and SMA type 1.*	6
Category 3: Progressive conditions without curative treatment options *Examples: Batten disease, mucopolysaccharidosis, and other severe metabolic conditions.*	1
Category 4: Irreversible but non-progressive conditions causing severe disability and susceptibility to health complications and premature death. *Examples: Severe cerebral palsy, complex disabilities such as following brain or spinal injury.*	5

50% of the YAs had a profound and multiple learning disability and used non-verbal communication.

Alex arrives for their first short break stay.

Their smile says it all!

They are comfortable and relaxed in the environment.

Mackenzie is anxious, hovering, fussing, and talkative,

“it’s been six years since their last respite…”

7: Evaluating for the Future

7.1: Who Benefited?

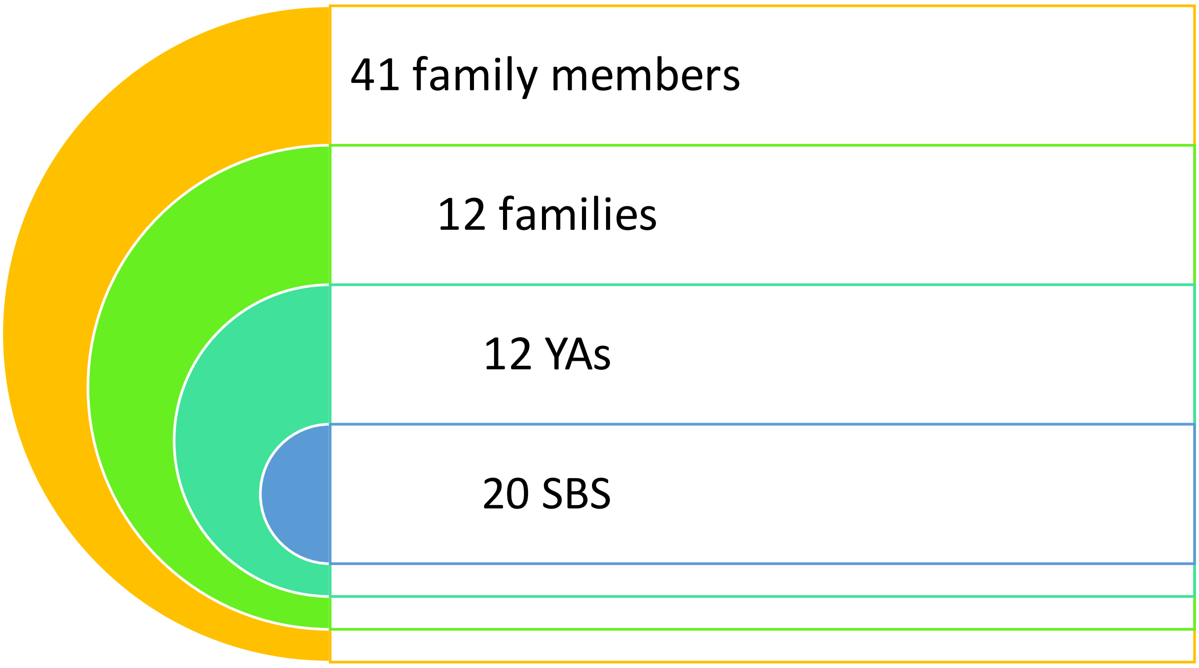


Figure 4: the size of the benefit
NB that the grandparents included were receiving direct care from the YA's parents and the 2-night stay was due to the YA attending college.

Figure 5: finer demographics of the beneficiaries

Figure 6 below gives an overview of numbers attending the SBS over 11 weeks between May and November 2022. More infographic details of the SBS Pilot Part 1 and 2 can be found in Appendix 5.

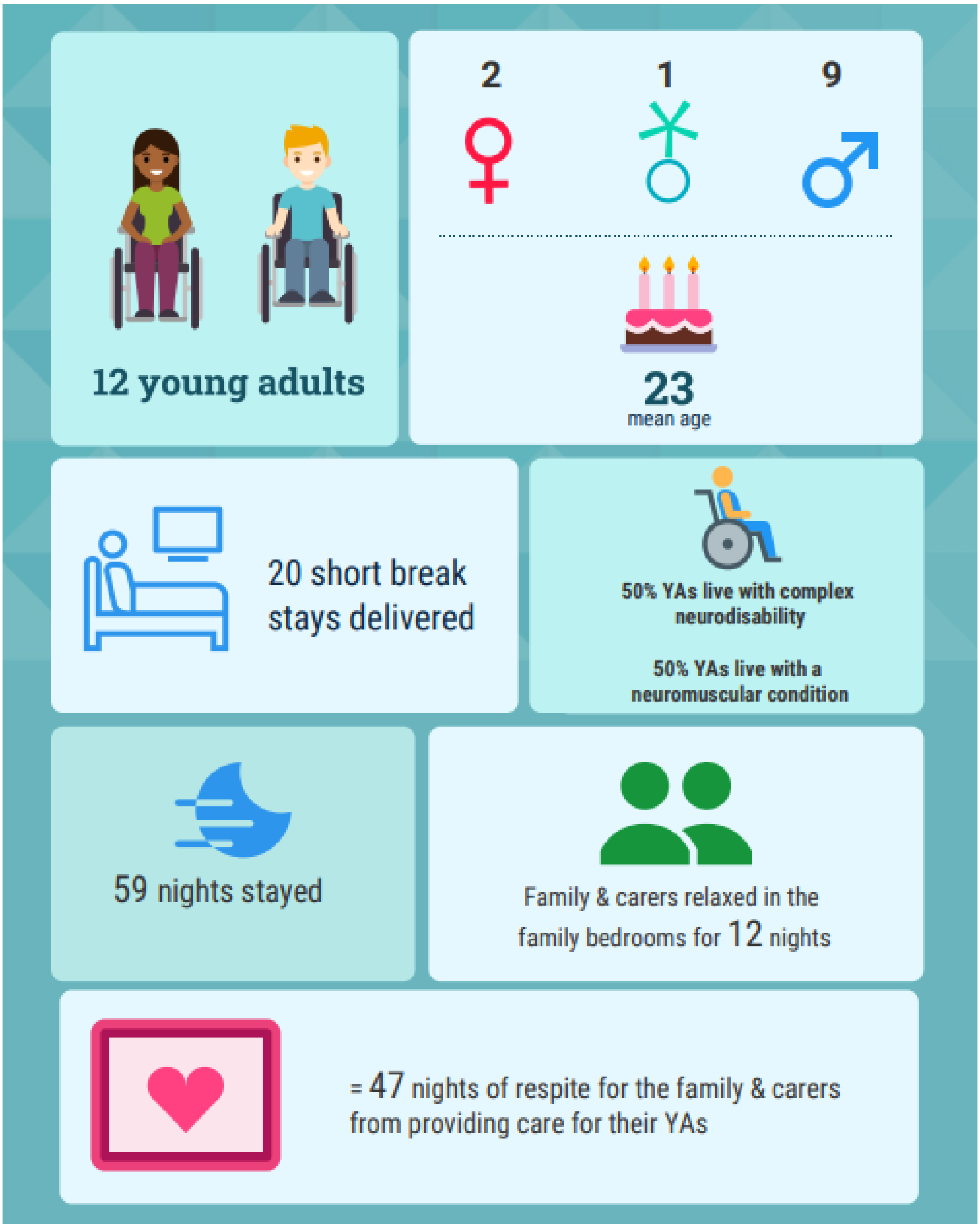


Figure 5: the demographics and numbers explained further

7.2: The evaluation process

Each YA, or their family, were offered the opportunity to participate in the evaluation of the SBS pilot. This was done in a couple of ways:

- A simple conversation using the Wellbeing Outcome Measures (SHANARRI) as a template at the time of discharge.
- One to one evaluation with the completion of a questionnaires later.

83% of the carers completed an evaluation questionnaire.

75% of the YAs completed questionnaires, 33% of these were completed by their family on their behalf. Full results can be seen in Appendix 6.

Below shows how YAs (figure 7) and their carers (figure 8) felt the experience of SBS was:

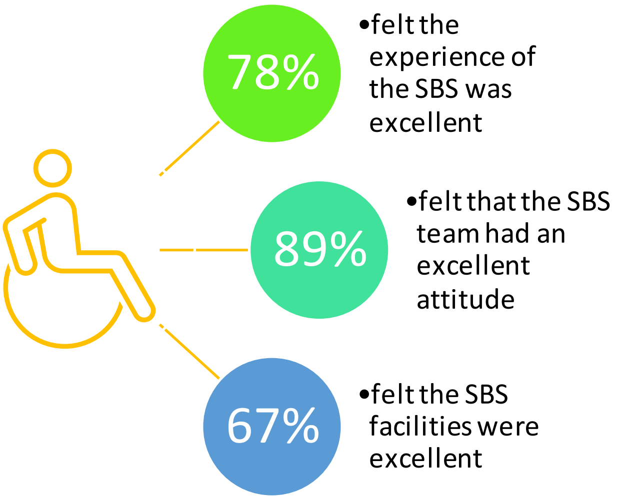


Figure 7: overall feedback from YAs

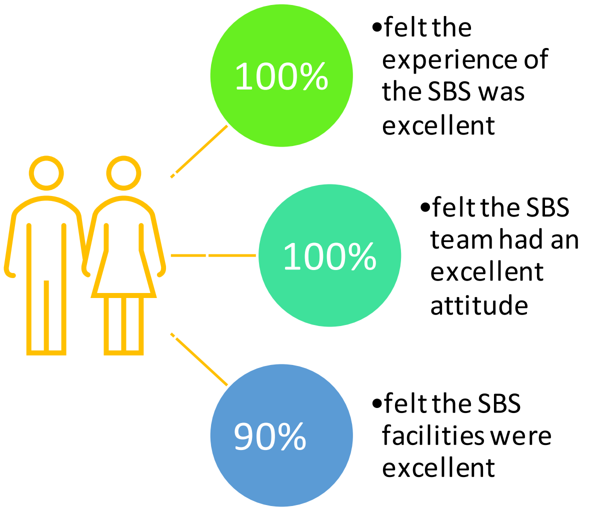


Figure 8: overall feedback from families/carers

7.3: Supporting YAs - their responses

The questionnaire focused on the benefits of the SBS for them.

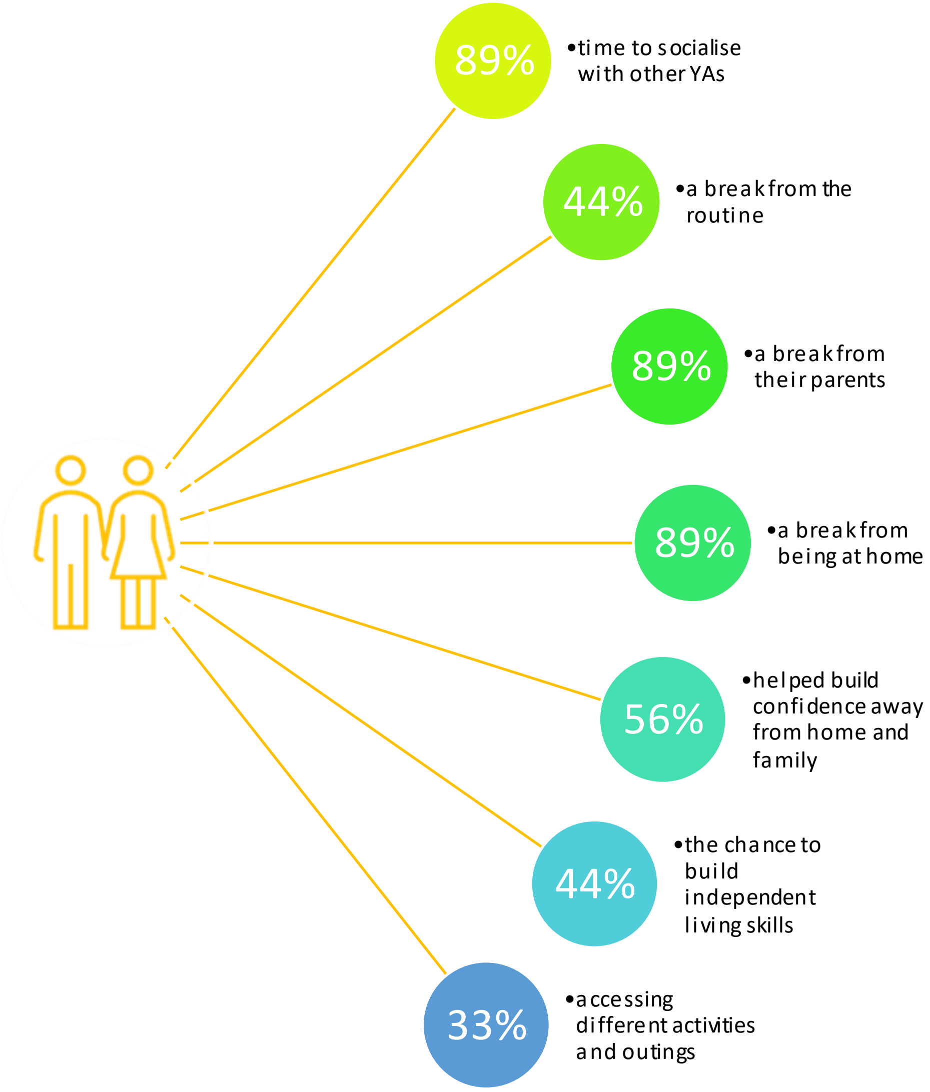


Figure 9: Perceived benefits for the YA

> Alex *"I'd like to stay longer… 5 nights maybe? This gave me time to reflect and time out for my mental health. I got some rest and some sleep and also time away from the everyday routine… I got used to other people helping me and doing my exercises…it was like being on holiday, relaxing and hanging out with others. Being able to chat to people in a similar position to me what great – aspirations, hopes and ideas for the future…"*
>
> When asked if there had been any challenges that they had had during their stay:
>
> Alex *"The automatic doors to the YA lounge weren't working and I had some difficulty in using some of the equipment… for showering and bathing… and the POSSUM… I wanted to get out more… maybe go for a drink or see a film…"*

None of the YAs felt that there had been any detrimental effect on them in accessing the SBS and 78% felt extremely confident (22% somewhat confident or neutral) about accessing SBS in the hospice.

In the future 89% would prefer to have a SBS at home/hospice if the service was offered in the future, 67% thought the stay was "too short" and 33% said it was "just right".

78% would recommend the SBS to friends or others who need similar care. In conclusion however 100% said that they would continue to access the service in the future.

Feedback on the environment

As was to be expected, given the attention to detail regarding environment during the scoping , there was feedback by the YAs about the environment:

The YA bedrooms were thought to contain too much furniture to allow access for wheelchairs: furniture was removed to allow easy turning in the room.

The POSSUM environmental controls were not in place for the first part of the pilot and had only just been installed for the second part. Staff were unfamiliar with using them and there was an issue with one system that a parent needed to fix. Staff were also unfamiliar with the technology in the room, for example casting from device to tv.

Only one shower chair was available, although a shower trolley is also in the ward for the use of the YAs:

"The shower chair was a bit uncomfortable; it gave me pins and needles in my legs. The power cable for the possum was in the wrong outlet, but my Dad came and fixed it. One day I was up earlier than usual and needed to use the shower chair, but it was already being used. It was awkward. So there was a delay in attending to my person care."

The automatic doors to the Young Adult Lounge were not working and made moving between areas difficult for the YAs (and staff).

7.4: Enabling families/carers – their responses

> "People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and wellbeing"
>
> National Carers Strategy December 2022. ISBN: 9781805253020

The questionnaires specifically looked at how the carers were enabled to support their own wellbeing. Some highlights are shown in Figures 10 and 11.

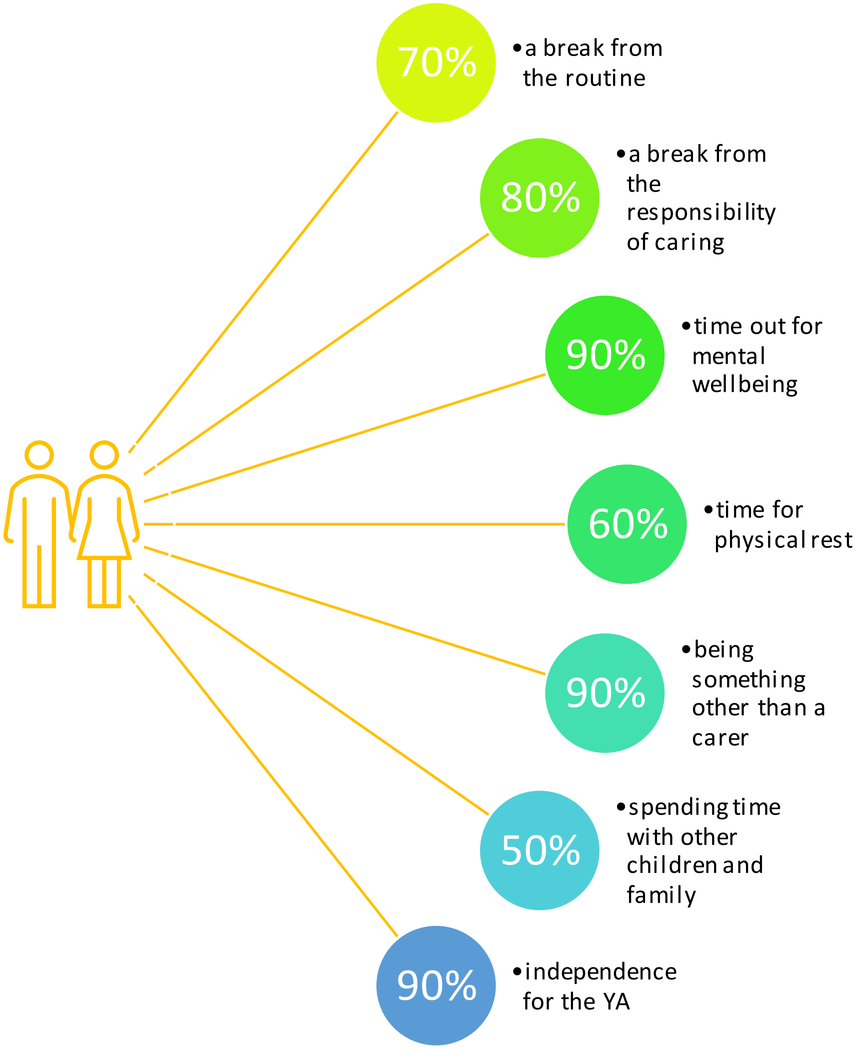


Figure 10: Perceived benefits for the carer

Leslie, *"My experience of the SBS was excellent, the staff had really good attitudes, and the facilities offered were mostly great. We'd perhaps like some flexibility to come at the weekend and for longer too."*

Mackenzie *"I feel that I can cope better after the break, my batteries are recharged. We've been able to spend more time with Alex's sibling, going out for a meal – we enjoyed that! Leslie and I have seen our pals but also had a break away together – that's unheard of!"*

Leslie *"A break (SBS) to be myself. I had a real sense of calm and peace... it was great to get lost in time for myself...I got a full night of sleep – uninterrupted! Allowing Alex the opportunity to be without me is very important..."*

The families were asked how they thought the SBS benefits their YAs:

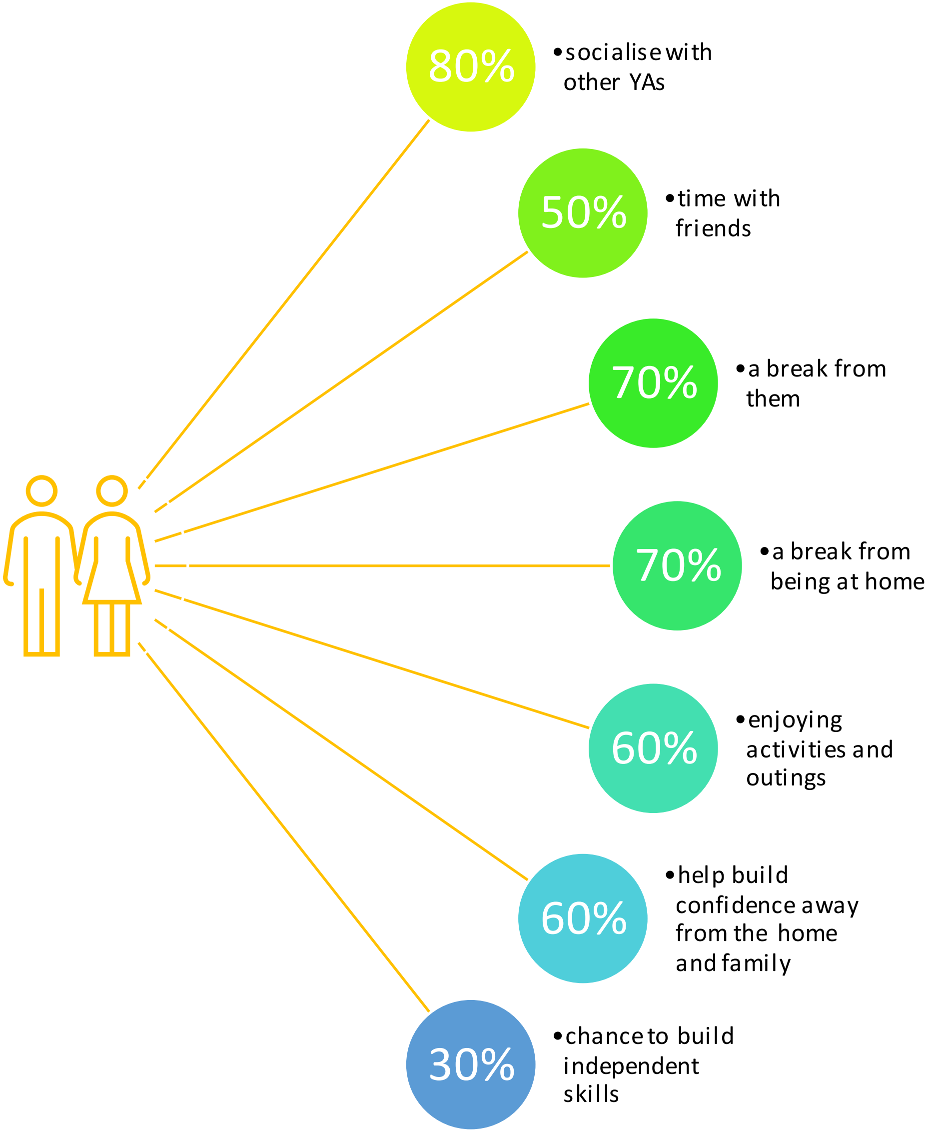


Figure 11: Carer perceived benefits for the YAs

Mackenzie *"It's such a welcome environment, from the moment you step in the door you know that someone cares. They know the staff and the building...that's increased Alex's confidence... it's made them feel better in themselves... that they could go out elsewhere and not depend on me".*

When the families were asked about any potential detrimental effects of the SBS, only one replied that there was: the potential of seeing the "possible future" of their YA's condition caused them anxiety. They also stated however that this may be a positive – the YA being able to spend time with peers and ask questions of them that they might not feel comfortable asking their parents.

100% of the carers felt extremely confident in accessing SBS in the hospice and would like to access the SBS in the future, within the hospice rather than home.

50% felt that the length of stay was “just right”, the rest felt it was “too short”.

Overall, the families would be “very likely” to recommend the SBS to friends and other people who need similar care.

> Leslie *“At a time when respite is in short supply, this has been a lifeline for us. We found it reassuring that we could stay over the first night and we left feeling that the staff knew how to work with Alex… it’s good for Alex to know that their care can be picked up by other people…*
>
> *The facilities for parents are great… parking is a bit stressful though. We couldn't find a space that allowed us to get YA in and out easily. Our vehicles need wider spaces. It's frustrating. Perhaps we could have reserved spaces when we're coming in to drop off.”*

7.5: Staff Feedback

Fulfilling fun enriching

Inspiring uplifting

Full feedback can be found in Appendix 7.

The staff feedback was overall very positive with a real sense of joy and renewal in the work that they undertook to support the YAs and their families/carers:

- “It’s been a very positive experience.”
- “It’s been a gratifying experience. It’s also been a welcome break from being surrounded by death and a tonic after the pandemic.”

They became aware of the positive impact of the respite on the family/carers:

- “One parent told me “It might not be what (they) want, but it’s what we need.””
- “Parents have told us about the importance of getting a good night’s sleep and it’s allowed parents to get away for the first time in years. And it’s been nice to give people that opportunity.”

And saw first-hand the positive effect it had on the YAs:

- “It’s been great to see the difference between the Monday person and family versus them on a Thursday. They’re more relaxed because they’re becoming to trust us.”
- “Seeing friendships forming has been very rewarding.”

Staff realised that they had created a safe environment to meet the needs of the YAs and their families/carers:

- “The confidence that parents trust us has been revealing. At first, they are determined to stay, but once they see their young person is in good hands, they feel confident to leave and take some time for themselves.“

There was a real shift in how they perceived the day to day lives of those benefiting from the SBS, the reality of caring for an individual with complex health care needs being experienced first-hand:

- “Learning about how society treats disabled people and their carers and how little support is out there for them… They are almost forgotten…hidden…”
- “The lack of community support for families has been a real eye-opener.”
- “What families face on a day-to-day basis.”

Th pilot was not without challenges and the staff identified key areas:

- Adapting from a medical to a social care model
- Administration of medications
- Appropriate environment – noisy, buzzers, inaccessible areas for wheelchairs
- Communication of information resulting in near misses for the YAs

The challenges raised promoted further discussion about ongoing training needs, the environment of the IPU, and improved communication, all with the goal of delivering a safe SBS for the YAs.

8: Discussion

8.1: The benefits

The SBS evaluation was open and honest, and highly positive. Hopefully the infographics shared in section 7: Evaluating for the future demonstrate the benefits for all involved.

Highlighting the most beneficial aspects of providing a SBS:

For the YAs, they were able to have a break from their parents and socialise with other YAs while helping build confidence away from their home and family.

For the families and carers, they were able to experience a break from the responsibility of caring, to be something other than a carer, spend more time with their families, and focus on their physical and mental wellbeing. While doing so they perceived that their YAs were having a break from them, building confidence away from home, and socialising with peers.

For the staff an opportunity to work with a different cohort of individuals was exciting and encouraged learning, development, and career progression. Caring for YAs and putting life into their days was for some a welcome change to the symptom management of those admitted for end-of-life care.

8.2: Challenges

Equity of Access

Initially questions were raised about the suitability of an adult hospice and palliative care service providing respite for YAs life-limiting conditions and the inequity in not providing a respite service for those, in particular, with progressive neurological conditions. Those with such conditions diagnosed into adulthood can have similar symptoms and may be considered suitable for respite. It was recognised that the illness trajectory of the cohorts was significantly different, with the burden of care falling on families of YAs over decades rather than months to year, leading to the deteriorating health of the unpaid carers.

Trust and confidence

Building relationships with the YAs and their families/carers took time and this was underestimated by all involved. Despite the YAs being well known to the individuals delivering the YA clinic, they were not known to the SBS team who would be delivering the care. In fact, the team only met them on a couple of occasions on an informal basis prior to them arriving for the first stay. The trust and confidence needed for the YA to feel comfortable in PPWH was built through direct care during the stay, with the families/carers staying close by in the family rooms. The difference in those attending was visible between arriving and departure, everyone appearing more relaxed as they left to go home. The trust and confidence that ensued was testimony to the enthusiasm, motivation, and professionalism of the SBS team and to the high-quality nursing care delivered.

Mackenzie, *"Best night's sleep ever for the 3 nights YA was in respite. Trusting someone else to look after their needs is huge for me… the PPWH know them so well that I was able to turn off."*

Environment & Equipment

We know that the PPWH is purpose-built with extensive open spaces both internally and externally, and that it is a safe, inclusive, and welcoming environment but is the environment right to deliver a permanent SBS from?

YAs and their families/carers did not feedback in the evaluation process that they had concerns about the YA bedrooms being part of the in-patient unit (IPU) but this was often raised during their initial visits and tours. The staff also wonder whether the IPU is the right environment as it can be noisy and too bright for the YAs, but also that the YAs can be noisy and disruptive for those in the ward for end-of-life care.

> *"Young People want to use the middle social area, they don't want to spend all their time in their bedrooms or in the young people's longue but are potentially being exposed to the dying and the grieving there, if sharing on the ward, and that's not appropriate."*

Staff shared that the YAs wanted to use the communal spaces beyond their rooms and did while in the 6 bedded ward, but on the occasions they stayed within the 10 bedded bay this was not possible. The YA lounge was used but access was difficult due to the automatic doors not working.

The equipment was hired or purchased having been identified by the YAs as being required for a SBS and overall received positive feedback. The challenge is that the equipment is specific to the individual, one piece does not necessarily meet the needs of all. It might also be the case that more than is required at a time – although the limiting factor here may be staffing numbers and not the availability of equipment.

It is not financially viable to have many different pieces of equipment to meet the needs of all individuals; families are asked to consider bringing in their own equipment for the comfort of the YAs.

Activities: on home ground

Following the initial period of consultation, our YAs indicated that, whilst accessing the hospice services for social support, they would like opportunities such as trips to the cinema, museums, music festivals away from the hospice. In the interests of safety, for the purpose of the pilot, most activities were delivered on site to minimise risk and ensure staff were available should they be needed e.g., in the event of a YA having a seizure. Those who did venture out with the grounds were not at risk of seizure activity and quite used to being independent: however, this meant transport was necessary and this proved to be problematic with a lack of wheelchair accessible taxis being available.

Activities while in the hospice included attending the Living Well Hub and spending time in the sensory room and with the artists. Staff feel that more activities are needed and more resources to deliver the activities:

> *"Needs to be more activities. The sensory room is very childlike, and these are adults we're dealing with"*
>
> *"Need to find out what's available out in the community, but this presents its own challenges."*
>
> *"Need Netflix account, although need to be wary that not all young people want to just watch the TV – some want to go out the pub."*

Evaluation from the YAs after the SBS told us that they would like to access activities out with the hospice grounds. We need to explore the use of goal setting for the YAs ahead of future SBS to allow us to plan for activities and trips, and look at better solutions for wheelchair accessible transport while the YAs are staying with us.

Safe and personal care

The YAs and families/carers wanted a level of skilled and safe personal care which instilled confidence not offered by other models of respite and PPWH wanted to deliver a model of care that was safe.

The risks of caring for this population were highlighted at the start of the pilot:

- unknown conditions of paediatric medicine and a team unfamiliar with caring for those with such diagnoses
- different complex health care needs including epilepsy
- unfamiliar medications
- risk of sudden and rapid deterioration
- frailty and resuscitation

These were addressed through upskilling and teaching of the team, particularly around the current caseload, Basic life support, (BLS), the management of epilepsy, non-invasive ventilation (NIV), and Percutaneous endoscopic gastrostomy (PEG) administration of feeds and medication, and the development of protocols to minimise risk for the YAs.

There were two near misses which required a "hot debrief".

The first involved a YA becoming pyrexial with a high temperature following a presumed aspiration of food. The on-call doctor was called, the mum of the YA called in, rescue antibiotics were given, and the

YA came to no harm. It was recognised that also staff knew they took some oral diet – as well as being PEG fed – mealtime had not previously been witnessed by them. Mum was happy to come in the day after to feed the YA and a clearer understanding was gathered - Oral diet meant small "tastings" of food. The staff had acted appropriately, and the mum was glad that they had phoned her to come in.

The second near miss was due to a lack of an updated health passport for the YA – it had been completed seven years previously – and miscommunication between staff at handover. The YA had been positioned in bed on their wrong side, putting their breathing at risk. This only came to light when a parent called in to check on how the YA was. The incident was dealt with quickly and no harm came to the YA. This resulted in additional training being sourced for the SBS team in postural care management.

The anxieties and concerns of the nursing team eased as the pilot progressed and they gained knowledge of the YAs, confidence in the cares they were providing, and a renewed sense of job satisfaction and achievement.

Staffing levels

Dedicated one to one, if not two to one, care delivered by trained staff competent in caring for those with medical complexities was deemed an essential requirement for delivering safe and personal care. To do so PPWH needed to enhance staffing capacity, competence, and confidence. It was hoped to recruit staff with previous experience in paediatrics or care for YAs with learning disabilities. Recruitment proved to be problematic, and the decision was made to second staff from the IPU. This needed careful consideration to not leave the IPU short-staffed in the delivery of specialist palliative care. Two registered nurses were seconded to the pilot and 2 health care workers were upskilled to deliver more elements of care.

One registered nurse and one advanced health care worker were assigned to each shift. This worked well in the main except for when personal cares were required which needed two staff members to one YA. The moving and handling process to ensure safe care often requires two people due to postural management and moving and handling, and can take a considerable amount of time, e.g. for one YA who is fully ventilated, personal cares took up to three hours.

Although the SBS was delivered in the IPU where medical cover is available, it was necessary to inform the YAs and their families/carers from the start that the SBS was not a medical model of care and that there would be no routine access to medical care. Care would be akin to that received at home ("home from home") with the YA (with capacity) or legally responsible person (if the YA lacked capacity) - deciding, if appropriate, the next steps in their own or their YAs care should their health change.

8.3: Strengths and Limitations

The eagerness to participate in evaluation, the findings, and consistency of the findings between YA and families/carers led to rich data demonstrating the validity of the evaluation and the importance of the SBS to those who participated.

Staffing levels and the inability to deliver the pilot over 12 weeks was initially seen as a limitation but on reflection was a strength. The gap between part 1 and part 2 allowed quality improvement to be undertaken – “they said, we did” – with the result being that part 2 was perceived to be more relaxed.

9: The future of SBS at PPWH

Following the successful pilot and having demonstrated the need for specialised short stay breaks for young adults with life limiting conditions we are now focusing on rolling out a core service.

We know that the number of YAs living into adulthood is increasing, that these individuals are isolated and have inequitable access to medical care and if appropriate, adult hospice and palliative services, that the burden of care is falling to their families resulting in physical and mental unwellness: the YAs and their families/carers are in desperate need of this service .

We know we have the environment, the equipment, and the skilled staff to safely run a developmentally appropriate SBS on a small scale with known benefit to those enjoying and benefiting from a stay. The question is whether we can scale up to a larger, potentially seven days a week, all year-round service?

Cost

We have known from the inception of the service that it would need to "pay its own way" as the two young adult beds have no funding from the Health and Social Care Partnership (HSCP). We have always been upfront with the YAs and their families/carers about this; to have not been would have jeopardised our relationship with them.

The pilot allowed us to determine necessary staffing levels and create a sustainable service model around this based on experience and need. Although the pilot ran with a band 5 registered nurse and an AHCW per shift, it is thought that going forward a registered nurse would only be required overnight. This means that one night of a SBS will cost £596 (or £24.83 per hour which is comparable to other care providers); we need to ensure that the price set is not prohibitive and that equitable access to respite is possible. It should be stressed that the aim is to run this service at cost neutral, with the cost covered by the YAs own respite budgets.

With this price being set, we have shared information about booking future SBS with our current caseload, encouraging them to consider their care budgets and or self-directed support, and to have conversations with their social workers about their need for respite. There are, however, several issues relating to budgets and the inequity of their allocation which should be mentioned here as they threaten the potential for the future service to be successful:

- The level of budget each YA receives can differ greatly, with the days of respite ranging from none to forty-six per year.
- Budgets can be held in different ways – by social work, by the YA and their family, or by both – and therefore controlled in different ways.
- Budget reviews have not happened over recent years due to the COVID-19 pandemic and can suffer from a lack of prioritisation by local authorities.
- Unspent budgets are being clawed back by cash strapped local authorities, adding unnecessary pressure on to the YAs and their families/carers.
- Many of the carers, despite the Carer's (Scotland) Act 2016, have not had carer's assessments, the results of which would feed into the total budget allocated.

Social workers are uncertain as to why PPWH is the place to deliver respite care –"right place, right care" - for YAs with complex health care needs over existing – and cheaper – respite models. It will be necessary to share the results of this pilot to make them aware why the service at PPWH is exactly what the YAs and their families/carers need to feel confident and safe. By informing the social workers, information will pass on to health commissioners, and local authorities will gain knowledge of the importance and benefit of PPWH's respite model.

Staffing

The YAS and their families/carers are keen to be able to access SBS over seven days a week throughout the year. To do so we need to ensure skilled staff, working at the appropriate YA to staff ratio, are employed to cover a minimum of nine short stays a month (nine short break stays or twenty-seven nights a month will allow the service to break even and make a small profit). We know that recruitment and retention of staff is problematic post pandemic and are currently working hard to recruit to a bank of staff willing to work with YAs. These staff will require appropriate training and upskilling to ensure that the YA trust and have confidence in them to deliver safe care.

Without appropriate staffing we will not be able to deliver a sustainable SBS and there is a risk that booked SBS would have to be cancelled in the event of insufficient staff levels or staff sickness. This has the potential to mean families losing much needed respite and paid for holidays, while there would be a reputational risk to PPWH in not being able to provide a service.

Respite Models

With the experience gained during the SBS, and the knowledge that families are looking for day respite, staff feel that a day respite model could be developed within the Living Well Hub. This is being considered for future development, again with a daily cost attached. To offer this we would need to consider the timing of the sessions, the activities offered, and the potential for trips out with the hospice. In addition, access to appropriate wheelchair accessible – reliable - transport is difficult and without transport YAs will not be able to enjoy an afternoon or a night out.

Conclusion

Much is still to be done until the SBS service is up and running as a core service, but we are constantly gaining knowledge and developing the model of care. The first chargeable SBS will be delivered for YA and their family in July-August, enabling the family to go on holiday. It truly is an exciting time to be offering YA services in Scotland. PPWH is the only hospice in Scotland to be doing such ground-breaking work with this often-forgotten cohort of individuals and their families. We have the opportunity to make a difference to their day to day lives, while adding to the evidence regarding SBS and YAs attending adult hospice services and leading the way for other adult hospices in Scotland.

10: Appendices

Appendix 1: References

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Appendix 2: Alex and their Persona

Definition:

A persona – one person, one voice, the perfect YA or family member

There are benefits to using a persona.

It gives the reader better insight into the individuals accessing the service; a persona allows the reader to better know these individuals. Painting a picture of an individual allows others to realise and visualise who you are talking about, keeping them focused on their needs, and allowing them to relate to a life never imagined.

A persona allows the stages and paths of the individual's journey to be plotted, documenting their unique reflections, needs and concerns at each stage.

Having this persona allows better communication about the individual and creates an easily relatable and sharable story with the wider community, within PPWH and beyond, and develops investment in the individual and the services they are accessing.

Finally, a persona can allow the creation of a better service for all who may benefit, reduce inequalities, drive innovation and strategy, and allow the sharing of a story.

Please note, non-binary names have been chosen randomly.

Appendix 3: Focus Groups for development of the Short Break Stay Service

Online Focus groups for YAs and their families, held separately to allow open dialogue.

Q1. What is your understanding of the terms used?

- Short break stay
- Respite

No one really mentioned there being differences between the two apart from respite being more about different carers

- Give you a break being away from home
- Gives my mum a break!
- Gives me an opportunity to meet new friends
- Respite means the same to me
- A few days away
- Go to the cinema
- To get away from Mum and Dad
- To do different things – art, music therapy
- Meet other people to talk to
- Different environment

Q2 When was the last time you accessed a short break stay? If more than 1 venue, please list them. Different

• July/August 2018 – Mallard Springburn – 4 beds • June 2018 – attacked by one of the children – I was the oldest there – autistic kids.	• Robin House – a long time ago • 2-3 years ago (mum went to visit Iceland for 6 nights, nothing since then) •	• Rachael House 4 years ago for 4 days	• CHAS – 4 years ago

Q3 **If applicable** in the past how often would you use this facility?

- Once a month (every 5 weeks)
- Infrequent
- Couple of times a year – depending on availability, however it was often cancelled due to bed being needed for someone who was at end of life
- Infrequently

Q4 **If applicable** what was your experience of the short break stay – good and less positive

Less Positive:

- Every time I went there was an issue and I came home early
- Nothing positive – difficult to meet my needs
- boring foods)
- Put me to bed about 7.30 pm – only one person on nightshift and they didn't start until 10.pm – only went three times
- I got sent home due to bed bugs and then another time a gas leak
- Some staff were nice, but we didn't do much while I was there visited Braehead and the park. They had their own transport but it was horrendous
- Some Planned activities or just sit in your room and watch movie.
- There was a communal area you could use but most of the time no one else about
- The centre I went to most autistic kids couldn't have a conversation with you and also I didn't feel safe with the kids always touching my equipment
- Never got offered any other places
- I need to be local in case something happened for my Mum to come and get me
- I don't think staff knew what they were doing and I didn't need bipap machine then but I do now!
- They didn't have the right shower chair
- I was calling out but no one heard the baby monitor in the room

Consequences of a change to service model:

- Didn't enjoy it – general feeling was you were now a certain age –therefore you don't go
- I felt I wasn't really welcome as things were changing.
- Staff appeared afraid to talk about what was happening in the hospice
- Getting up later in the day – no one was up!

Good times:

- Watch TV, go to the cinema, used to meet everyone
- Familiar territory
- Just a break!
- Liked the distance – felt like a holiday
- Parents/family stayed – benefit for them
- Really enjoyed being out and about doing activities like hockey, museums places like that, but at the end it was just the cinema or nothing due to not having enough staff

Q5 If applicable what has stopped, you accessing flexible short break stays. Please select all that apply

Funding	✓ ✓ (CHAS provided this free of charge)
Previous experience	✓
Anxiety about health needs being met	✓ ✓ Sometimes they were short-staffed/busy
Find age-appropriate environment/facility	✓ ✓ (not at the end – but couldn't find anywhere else to move to)

Q6 Do you currently have a budget for flexible short break stays?

Yes	✓
No	√ no budget
Unsure	√

Q7 **If applicable** when was this last reviewed?

- Don't know – care agency for respite.
- The last time care staff stayed in the house
- Not sure can ask Social Worker
- No carers at the moment

Q8 Do you have an emergency respite fund included in your budget?

Yes	
No	√ - never heard of this Plan– family would have to help
Not sure	√√

Q9 If PPWH were to create this new service What would be important to you about the development of this service?

- Hospice on our door step and it's not too far from hospital
- Also close to my mum if something happened
- Try first to see if it would meet my needs
- Having environmental control – unique home environment for you.
- That the staff can take care of all my needs
- Nothing for me I have met a lot of people in the Hospice just event to sit outside
- I know everyone in the Hospice. Built up trust, even though its been a year since I have been in the Hospice. Just to go for a walk in the park, or maybe go to Silverburn
- To go out for dinner
- Hospice – therapies, massage/ relaxation
- Loving LWH – chill out
-
-

Q10 would there be anything that would make you hesitant about accessing it?

- Access to my Computer – Minecraft
- Having Flexibility
- Maybe 2+ dates to start with
- Panicky about care and settling in at nights
- Taking time to be very patient – induction needed?
- Panicky about movements and the amount of time it takes to settle me at night
- I need my own mattress and equipment is that possible to have this brought here
- I have a lot of equipment (Chair, own cups, cutlery, plates etc) can I bring it? how would I get it here

Q11 IF you could access this service how often would you want to access it?

- No preference of weekends or week nights
- 2-3 nights preferred
- If offered 5 nights how would you feel? I would feel fine.
- In and ideal world 5 days every 6 weeks
- Weekends/week days – not bothered (several times a year)

Q12 Would you be keen for us to organise your stay when another young adult is staying for support and company?

- If you came and had a relationship – got used to them I would like to return with them
- Share ideas with other people etc
- Less lonely maybe
- it would help me get away from the house
- Not bothered good for some I know but equally happy to meet new people
- Peers- I didn’t really bother about this, good to have experience of this

Q13 Any other comments that have not been covered by the above questions?

- I want to be the first to try it. However before this I need to get serious medical things sorted out
- Air mattresses
- Coming in would help build up relationships
- Carers/parent team learning from staff and vice versa
- If I wasn’t feeling great I probably wouldn’t come. I would need to assess on the day if my chest was not great
- Sick of family/carers
- To have other people near me
- Maybe activity – could lift J’s mood
- To have something to look forward to
- I have a special mattress they have stopped making them
- Taking mattress with them
- Explore getting right for every one as we are all different with different needs
- Have Inductions
- I would want to stay overnight for the first time with family/carer until I get used to it
- I might not come in if I was under the weather it would depend on what you mean by this
- You would need to assess needs/equipment over the ‘phone a week before

- I would be worried for Sean, day to day can be different.
  Once S got to trust them (the staff) there would no looking back. Rachael House was far away Jim (dad) can be there in 10 minutes
- Lots of equipment if the stay is too short
- Postural positioning can be hard but S can tell staff what I need. Plus, Jenny is good at giving you tips
- Not concerned about staff caring for any other needs. Toileting etc. I was when I was younger, maybe it would have bothered me then but not now
- View positively away from family – peace and quiet
- Prepare for future admission by having short break stay
- Phone a week before to check meds

Appendix 4: Environmental Costs

Purchased two environmental controls (POSSUM) £8,097

Hired two artic beds for trial £3,800

Purchased two ultracore plus mattresses £420

Purchased Invacare tilt and recline shower chair £1,241

Other (Smart Plugs, Chromecast etc) £287

Total: £13,845

Appendix 5: Infographics from Part 1 and Part 2 of the SBS Pilot

Young Adult Short Break Stays

Part 1: May - June 2022

9 young adults

27 nights of respite

3 ♀ 1 ⚲ 5 ♂

55% live with a neuromuscular condition

45% with a complex neurodisability

23

mean age

13

interactions with the artists

The Living Well Hub

6 visits to the LWH

1 hair cut styled

Relaxing complementary therapies enjoyed

1 jacuzzi bath splashed in

1 cinema night watching Top Gun

1 x F-14 Bobcat model plane built

The Prince & Princess of Wales Hospice

Glam up! with make up and manicures

1 Dungeons & Dragons game night

"Let it Go!" sung too many times to remember

1 taxi journey

1 walk around Bellahouston Park

1 trip to the Burrell Collection

Numerous toasties, curry, fajitas & pot noodles devoured

Lots of episodes of Friends, Better Call Saul, Stranger Things, & Arcane League of Legends watched

1 call to OOH Dr

2 additional medicines prescribed

1 "rescue" antibiotic required

1 phone call to an allied health care professional (AHP)

1 interaction with family support

27 nights away from home for the YAs

Family & carers relaxed in the family bedrooms for 11 nights

= 16 nights of respite from providing care for their YAs

"I am confident in the team, and feel confident to be left alone... I loved playing games and cards and going to the park and the gardens of House for an Art Lover" YA 2

"...I would definitely use (this service) as it helps me be independent - without my mum and dad... be my own person" YA 1

"There had been no issues with food... it was great to meet the chef beforehand... it was perfect for the YA's needs" Parent 3

"The Food Is Absolutely Fantastic It's Better That Some Five Star Hotels In My Opinion!" YA 5

"The staff were lovely and overall it was a huge success!" Parent 4

"If this becomes a regular thing, my husband and I will be able to take some time off together, perhaps go away for a couple of days together..." Parent 1

"they (were) looking forward to getting their hair done and make up done... and watching a Harry Potter Film " Parent 6

"For me it was good not to have to be there all the time. Although I did feel like a helicopter parent sometimes. But again, it's all about building confidence for the future..." Parent 3

Young Adult Short Break Stays

Part 2: October - November 2022

11 young adults

32 nights of respite

2	1	8
♀	⚲	♂

55% live with complex neurodisability

45% with a neuromuscular condition

25

mean age

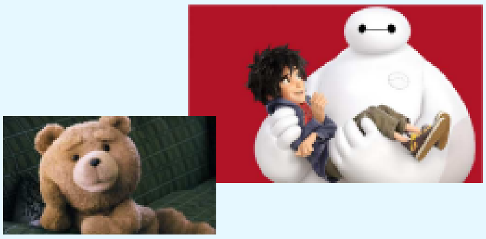
Too many hours to count spent gaming... and Trivial Pursuits too!

Take away curry & a wee dram enjoyed

Hair braiding - a new skill learned by staff!

Learning continues: 4 days of college attended

Film nights: Big Hero 6 and TED!



The Prince & Princess of Wales Hospice

A dance party,

a staff birthday celebration,

and smiles to the Emmerdale theme tune

"(a positive) ... being able to have a good chat to people in a similar situation, about aspirations, hopes and ideas for the future or just in general."

Young Adult

"A break to be myself. I had a real sense of calm and peace. Broke the monotony of the day. Great to get lost in time for myself..."

Parent

Carers able to enjoy a gig - and fish & chips

Ultimate relaxation requested - light changing bulbs & aromatherapy

Creating memories with family away from home

32 nights away from home for the YAs

Family & carers relaxed in the family bedrooms for 1 night

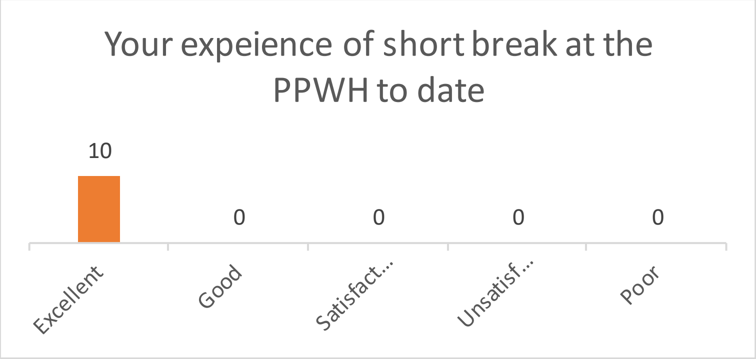
= 31 nights of respite from providing care for their YAs

Appendix 6: Short Break Stay End of Pilot Evaluation Questionnaire

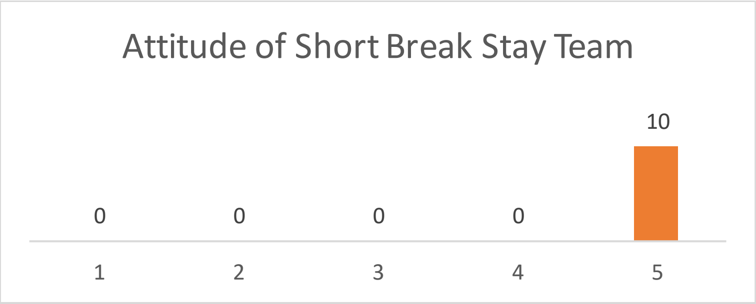
Caregivers Responses

About your Young Persons Stay

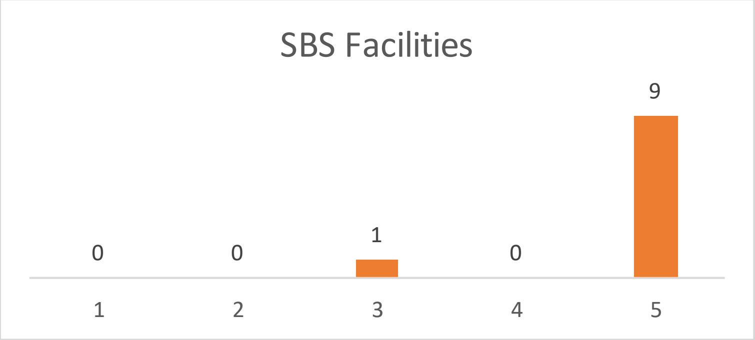
How would you rate your experience of short breaks at the PPWH to date



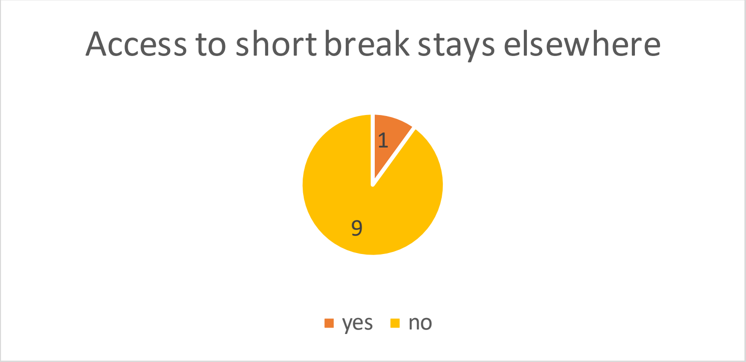
Overall, how you describe the attitude of the short break care team (1= poor; 5= excellent)



How would you describe the short break facilities (1 = poor; 5 = excellent)

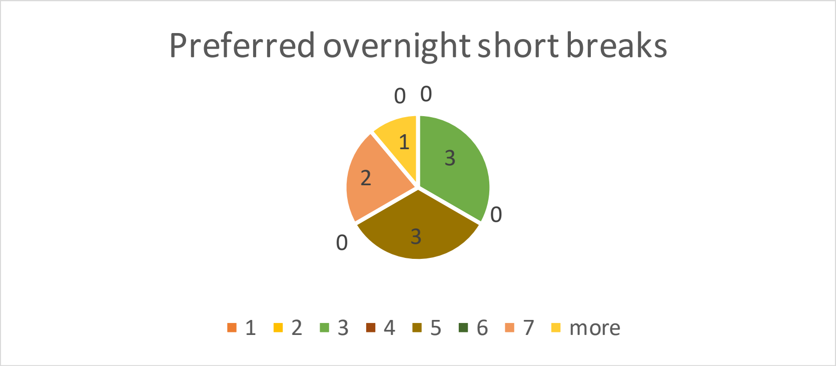


Do you currently access short breaks elsewhere?



Comment:
Planned respite with Michael Tracey project - Lodge Lochgoilhead, 27 - 30 December. Negotiated by Social Worker. Funding (SDS) needs to be sorted to ensure YA still can get access.

How many nights would your preferred overnight short break be?



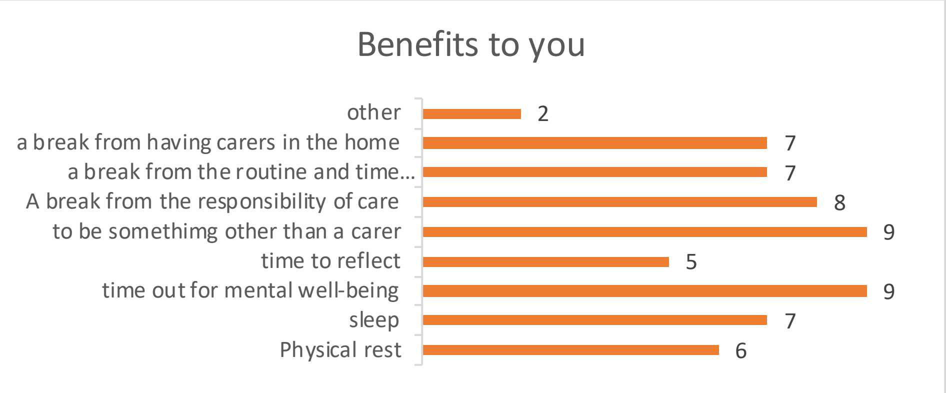
Comments

Weekends would be preferred.

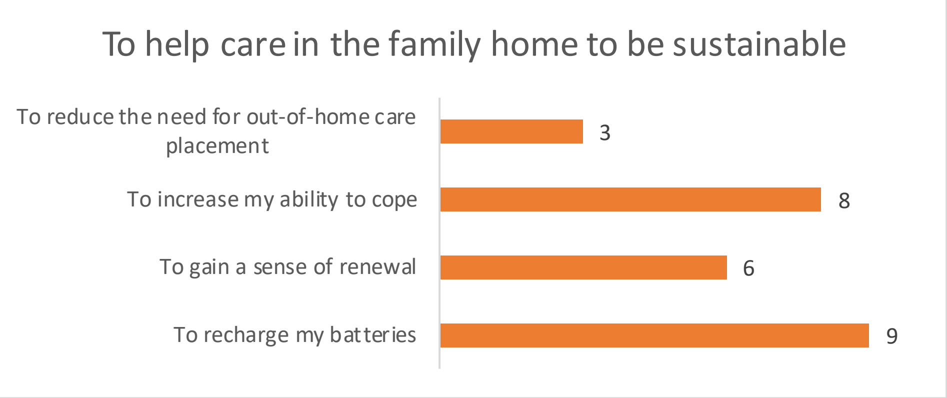
Hope there would some flexibility. Have used SB for 6 nights before. It would be great if it could be extended, if you need it. To let parents get away for a couple of nights. Especially over the weekend - that would be good for working families.

Benefits of the Short Break provision

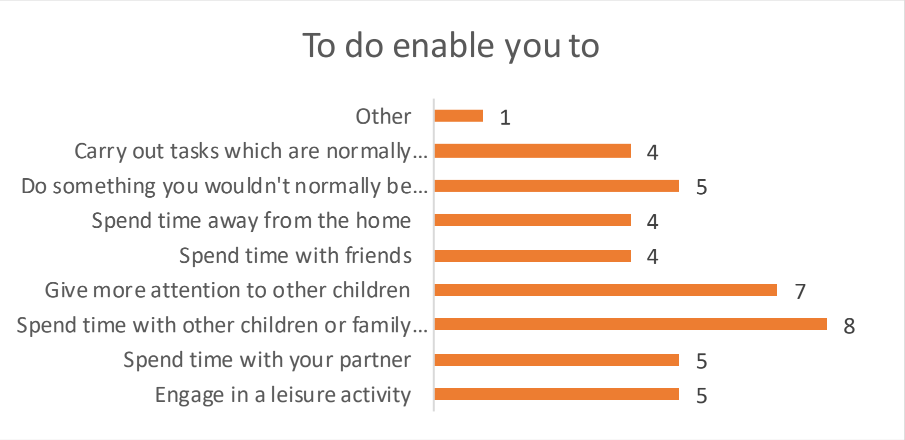
To provide a break from caring to enable



To help care in the family home to be sustainable



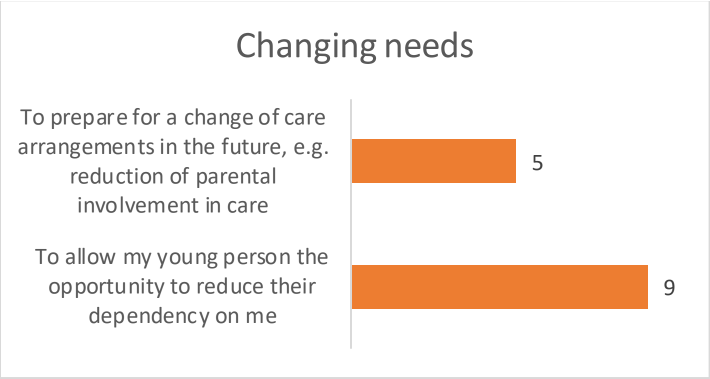
To enable you to



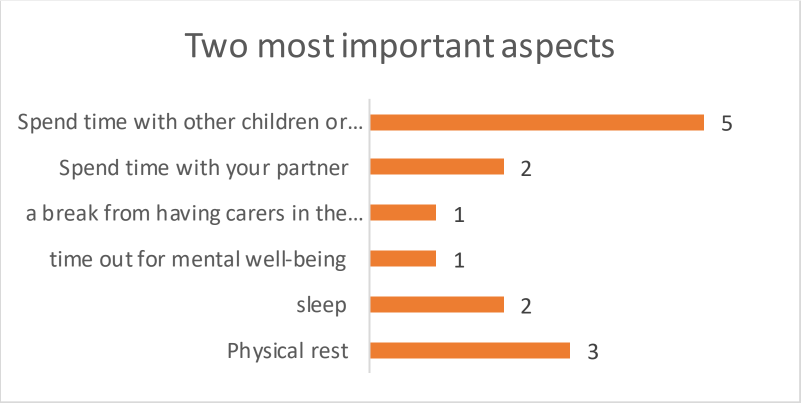
If you did something that you wouldn't normally do as a family, what did you do?

Be able to go away on a break
Just spending time with our other children, giving them our full attention and not having to do things for YA.
Went for lunch with my girls
Going for dinner with daughter
We went for a meal and to concert.
We actually came in to visit YA a lot. But after seeing the care he was provided I would be very happy for him to be at the hospice and maybe have a break go see my best friend down south next time.
I still went to my work as I am nurse so I don't have much time to do leisure activities and if I do, it's with YA.
Went out for dinner

Changing Needs



Out of all of the above, please tell us which two are the most important to you

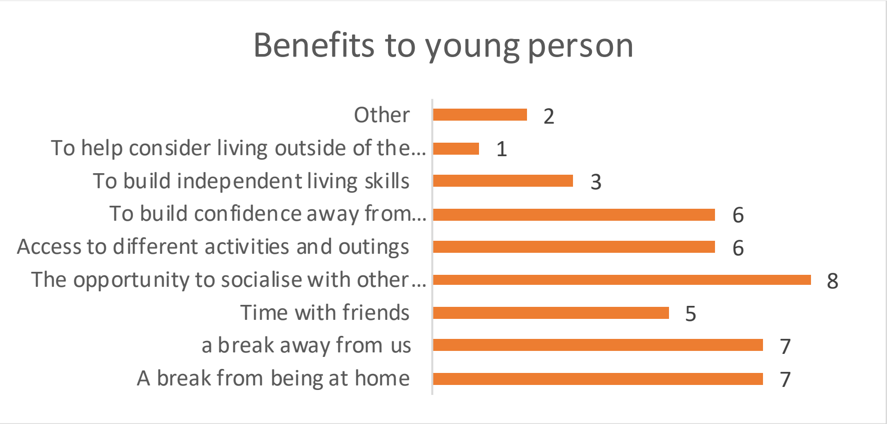


Comments

For me, the simplicity of being able to go to bed when i wanted to rather than when everything else has been sorted from the drug routine to the feeding tube and 1 ear constantly alert for sounds. Best nights

sleep ever for the 3 nights YA was in respite. Trusting someone else to look after her needs is huge for me, but the PPWH know her so well that i was able to turn off
A break to be myself. I had a real sense of calm and peace. Broke the monotony of the day. Great to get lost in time for myself. The thought that someone has thought about this group of boys and their carers is great. it's all the support you get around it from the hospice that makes all the difference. That we've been noticed and that someone cares. that doesn't happen often.
Spending time with my children and grandchildren and of course my partner
Don't know. Rest is a big part of it. Getting a lie in and can spend time with the rest of the family.
Allowing YA the opportunity to function without me is very important
Spending time with my wife and family. Getting a full nights sleep (uninterrupted).

What do you see as the benefits for your young person who has accessed the short break service.



Please tell us about any other impact of achievement you believe your young person has accomplished during the short break pilot.

Being in a different environment as YA does not get into any other places meaning family homes friends homes etc
it's such a welcome environment, from the moment you step inside the door, you know that someone cares. And that's increased YA's confidence.
YA loves coming to the hospice especially the hub on a Tuesday afternoon for music and spending time with physiotherapist and OT
So relaxed away from home. He is really clingy to me. He knows the staff and the building - it's made a difference. He got to know the staff before his SBS experience.
I'm surprised he went for the second time, knowing what YA wants to do, that he was willing to take responsibility - he sucked it up and did it for the greater good.
I feel YA benefited so much from the experience it actually really helped bring him out of depression. It has made him feel better in himself that he could go elsewhere and not depend on me.
It was good for YA to get out away from the house and have a chance to spend time with other people.
Meeting new people. Different surroundings. Lots of activities.
YA's break was a very positive experience as she seemed genuinely pleased to see me on her return.
She enjoys the respite and the staff and enjoys the company of the other young adults.

Has there been any detrimental effects on you or your young person in accessing short breaks at the Hospice?

None - Great Service

No we are happy with it.

Yes YA was used to going fir breaks to Rachel house hospice which stopped a few years ago that to me was YA's break from everyone me the carers etc and he looked forward in going to these breaks different people to chat with etc he in other words had something to look forward too and I feel that especially now he no longer has his dad around he would benefit even more also for me

YA1 shared one stay with YA2, who is a little further on in his (conditions) journey and I have some anxiety exposing YA to his 'possible future'. Although this might be a good thing, he might be able to ask YA questions he wouldn't ask me, so that peer support is good, but I do worry about it.

No

No

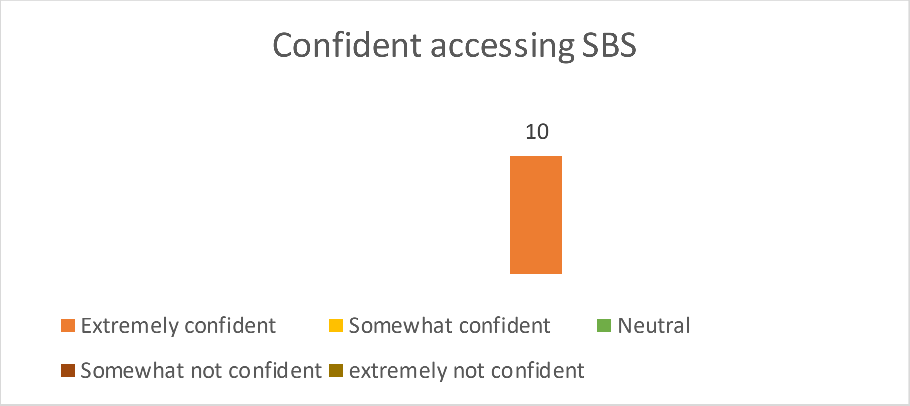
No - YA moaned about it, and we were given a blow-by-blow account of everything that happened - he's a bit of a pessimist.

None what so ever.

No

No

How confident do you feel now about accessing short breaks at the Hospice?



Has there been any challenges or concerns you can tell us about?

No

It's good to have the (condition) boys together, if possible. It allows conversations that they might not be able to have with family members.
I wouldn't want the group to get any bigger - two/three people who got on well together.

None you are all amazing

SDS is changing. Unsure how this will work in the future.

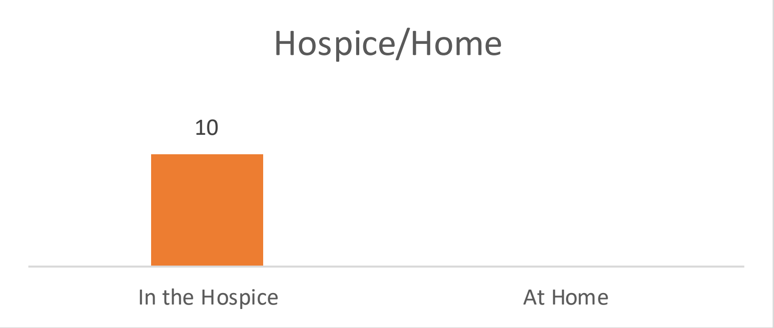
Sharing the shower chair was a problem. YA woke up earlier than normal one day and needed to use the chair, which was, unfortunately in use.

No

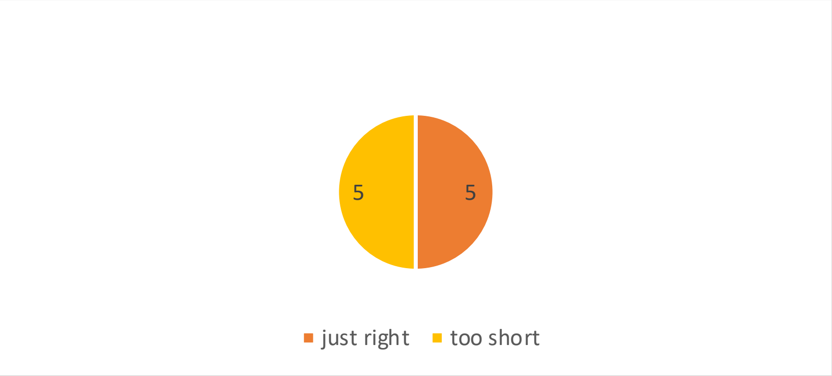
Nothing of any concern or challenging in any way.

The challenge for us was YA having a seizure while in for a short break stay. The way it was handled by staff was excellent and very reassuring for us.

If we could offer short breaks in your home or in the Hospice, which would you prefer?



Did you find the length of short breaks



Do you have any other feedback or suggestions on the short break service to help us improve?

Is there anything else about the Short Break Service at the Hospice that you'd like to tell us?
Fantastic service and a life line for some families
At a time where respite is in short supply, this has been a lifeline for us.
No just think if it was fir a week people could consider gong away on holiday etc
The staff are all amazing
No
I found it reassuring that I could stay over for the first visit. It was great that AHCW knew what YA was about. The food was right - just the way he required it. I left feeling secure that the team know how to work with YA. Other than the problem with the Possum, but that was only teething problems. The facilities for parents are great - and it's great that you have them. Parking is a bit stressful though. We couldn't find a space that allowed us to get YA in and out easily. Our vehicles need wider spaces. It's frustrating. Perhaps we could have reserved spaces when we're coming in to drop off. Changing needs: I was very happy that YA was able to tell other people what he needs. For me to know that YA's care can be picked up by other people. And it's good for YA to know that he can rely on other people if he needs it.

Only suggestion I have is maybe too much furniture on a wheelchair accessible room.
Maybe weekend breaks would be great as it would give us a chance to do something as a couple.
Install a hydrotherapy pool which would be beneficial to the young adults.
It’s been great to give myself and husband time to do something outside our routine.
Very happy with the time spent there and the excellent care YA received.

Would you like to continue to access the short break service at the Hospice?

Yes	10
No	0

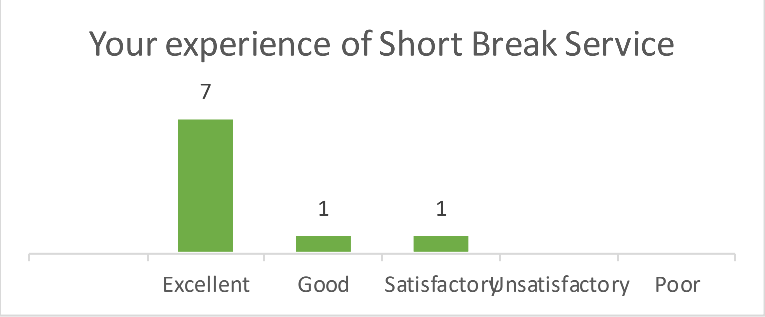
How likely are you recommend the short break service at the Hospice to friends or others who need similar care?

Very likely	10
Somewhat likely	0
Neither likely nor unlikely	0
Somewhat unlikely	0
Very unlikely	0

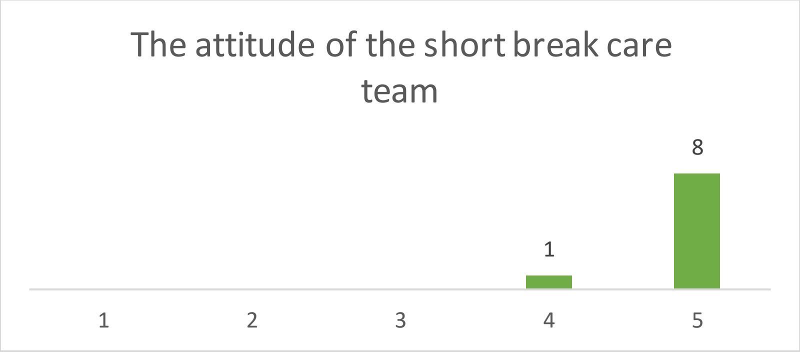
Young People's Response

About your stay

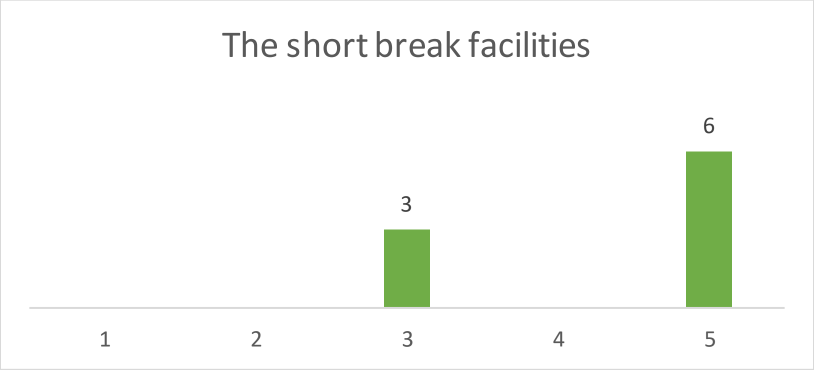
How would you rate your experience of the short break at the PPWH to date



Overall, how would you describe the attitude of the short break care team? (1 = poor; 5 = excellent)



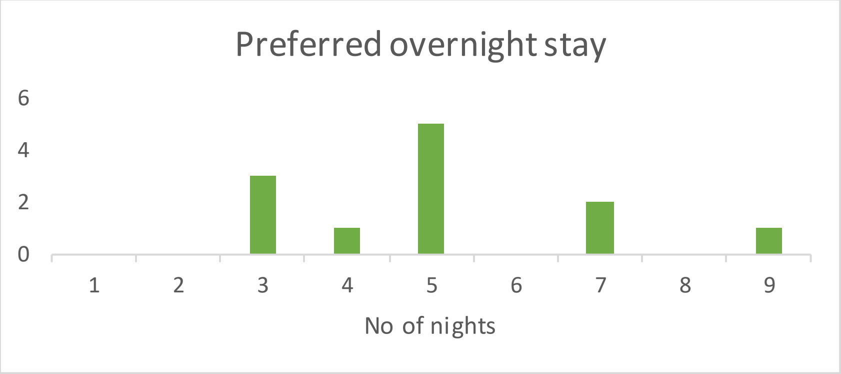
How would you describe the short break stay facilities (1 = poor; 5 = excellent)



Do you currently access short breaks elsewhere?

Yes	0
No	9

How many nights would your preferred overnight short break be?

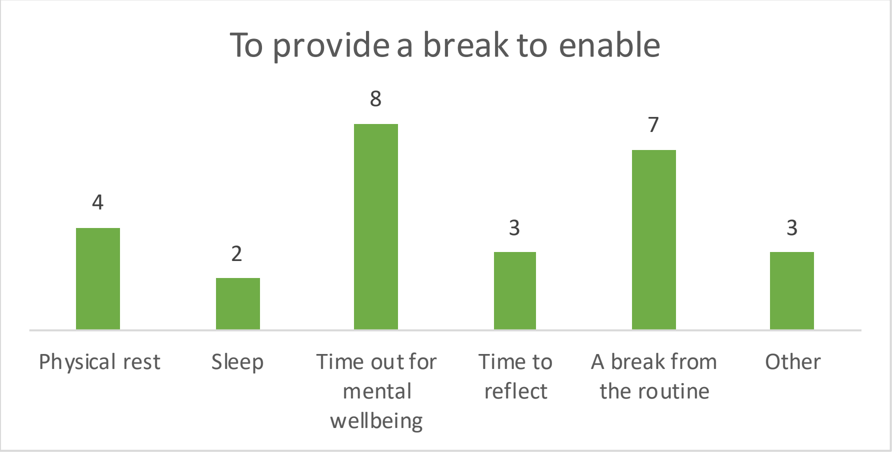


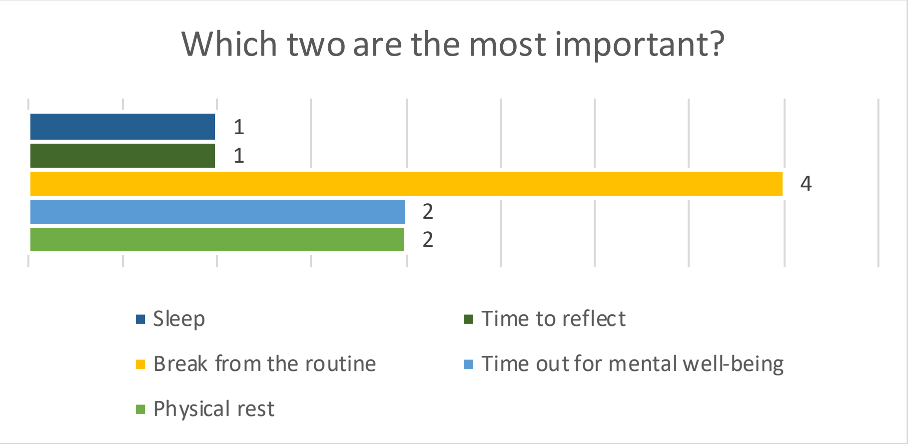
Comments

7 nights
5 Or 7 Nights
9
7
3
5
3
3 nights just about right.
4 days to a week

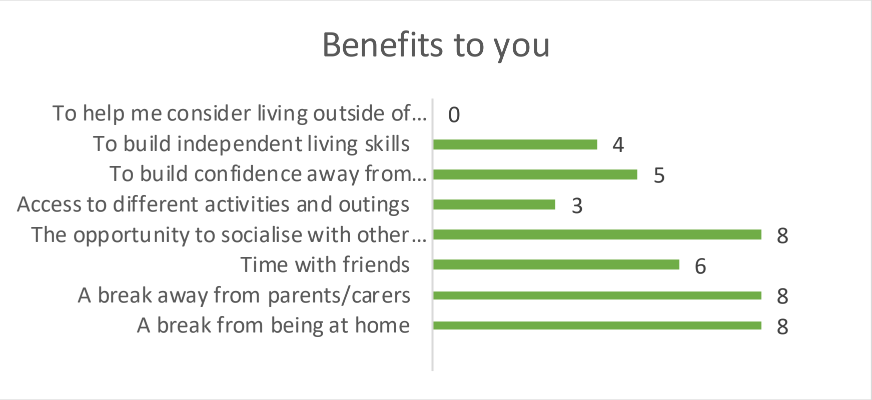
Benefits of the Short Break Provision

To provide a break to enable





What were the benefits to you in accessing the short break service.



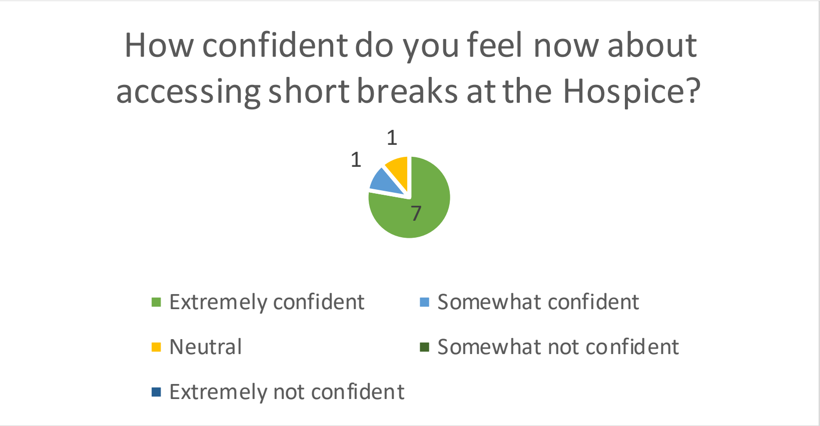
Please tell us about any other impact or achievements you have gained during the short break pilot.

I Have Started To Get Used To Other People Helping Me From My Day To Day Routine For Example Getting Assistant From The Staff To Get Me Dressed - Showered - Personal Care - Assistant When It Time To Eat And Drink - Doing My Respiratory Exercises Using My Cough Assist Machine / Nebuliser And Let My Mum Step Back From Providing My Care It's Easy Said Than Done I Get Really Nervous And Anxious But I'm Starting To Over Come It All And Trusting Knowing Everything Will Be Fine The Staff Are Really Friendly It's Like Being On Holiday Resort Relaxing And Hanging Out With Others Getting To Know Other People And Staff Around The Hospice And Just Wandering Around
Being able to have a good chat to people in a similar situation, about aspirations, hopes and ideas for the future or just in general. It's also been quite interesting trying out new things I didn't know I would enjoy: Dungeon's and Dragons was a standout example.
Gained some independence. Spending time with friends. Break from parents.
I'm already a beautiful specimen - I've got all the confidence!
I had a great time everyone is so nice and helpful was nice to get away myself without family.

Has there been any detrimental effect on you in accessing short breaks at the Hospice?

No It Hasn’t Caused Any Detrimental Effect On Me What So Ever Accessing The Short Breaks At The Hospice As I’ve Said Before The Staff Are Really Friendly It’s Like Being On Holiday Resort
No
No
Smaller scope of meeting up with more than one other person.
Nothing
Nothing damaging at all.
No only positive.

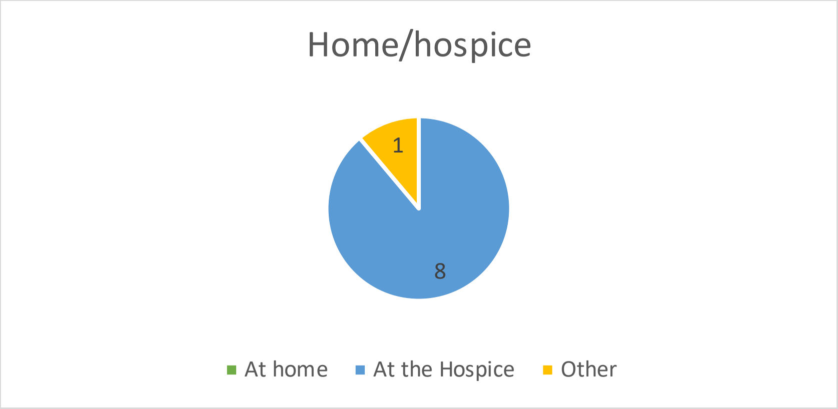
How confident do you feel now about accessing short breaks at the Hospice?



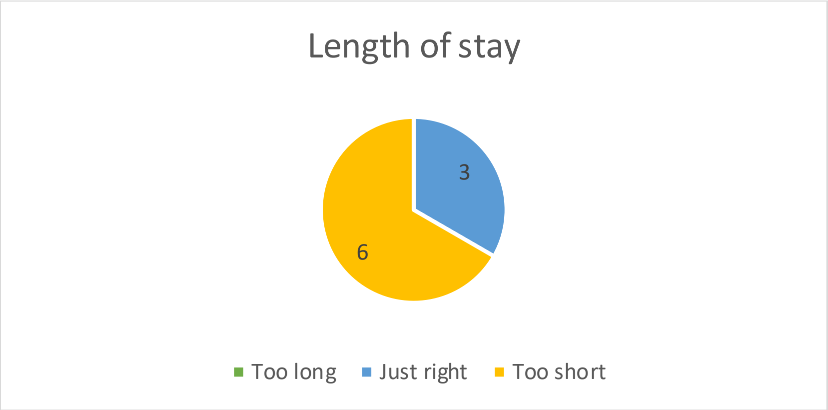
Have there been any challenges or concerns you can tell us about?

As Of Right Now I Don’t See And Concerns And Challenges It’s Nothing Negative What So Ever But I Would Rather Like To Discuss This Question In Person Or Over Zoom If That Would Be Okay With You And It’ll Be Easy For Me Because I Struggle To Type And It’ll Be Easy For Me To Speak And Talk About It
None
The doors to the Young Person's lounge not working on both visits - had to prop them open. Need more trips/excursions - wanted to get out, maybe go to the pub or the cinema Size of the group was okay, wouldn't have more than 3 people here at the time. Prefer a small group to a large one.
Difficulty using some of the equipment such as the shower chair and unsure if I would consider taking a bath because of the hard board you lay on?
None at all.
I felt the same between visits. The shower chair was a bit uncomfortable; it gave me pins and needles in my legs. The power cable for the possum was in the wrong outlet, but my Dad came and fixed it. One day I was up earlier than usual and needed to use the shower chair, but it was already being used. It was a awkward. So there was a delay in attending to my person care. There was an annoying light in the ceiling at night. I prefer complete darkness.
It couldn't have been better.

If we could offer short breaks in your home or in the Hospice, which would you prefer?



Did you find the length of short breaks



How likely are you to recommend the short break service at the Hospice to friends or others who need similar care?

Would you like to continue to access short break service at the Hospice?

Yes	9
No	0

Appendix 7: Staff feedback

Young People's Short Break Stay Pilot Evaluation

Staff Focus Group, 21 November 2022

Present: AHCW1, AHCW2, RN1, RN2, CN, FW and note

It was outline what PPWH Fiona W outlined what feedback would be used to evaluate the SBS pilot, this will include need to demonstrate and make visible the value and impact of the pilot, especially to Local Authorities who may be funding the service in the future.

What has gone well during the pilot?

- It's been a very positive experience. I have enjoyed it immensely. "I can't believe I get paid for this!"
- It's been great to see the difference between the Monday person and family versus them on a Thursday. They're more relaxed because they're becoming to trust us.
- Need to be mindful of the implications on all in-patient staff on the move from a medical model to a social model of care.
- I feel I should be doing 'more medical stuff', but then I remember it's more about giving everybody a break.
- Seeing friendships forming has been very rewarding.
- But again, need to be mindful that not everyone wants to make friends – it can't be forced, and it may need careful consideration when putting young people together. Some take time to warm up.
- One parent told me "It might not be what ___ wants, but it's what we need."
- Parents have told us about the importance of getting a good night's sleep and it's allowed parents to get away for the first time in years. And it's been nice to give people that opportunity.
- Parents have been reassured that we remember how to care for their young person. We're getting to know their routines.
- Monday is all about settling in, and by Thursday, we're getting to know the young people and it's time to go.
- The documentation for each person has been good, but we may need to think about doing it differently. Again, with the shift to a social model of care, we probably don't need to document as much medical information. Do we need the active care chat?
- The shift arrangements seem to work pretty well, although there can be a lot of waiting around on the first day.
- Needs to be more flexibility around weekends.
- Note that Young People would prefer a 7-day visit – a proper holiday – some see this as a break in their 'holiday home'.
- Seizure management has been a learning experience.

What has proven more difficult

- It's a different way to look after people.
- I've learn to adapt my outlook from a non-medical viewpoint – getting to know the Young People.

- Learning to back off to empower the Healthcare Support Workers.
- Updating care plans.
- (HCSW) dealing with medications. It's all about confidence with the meds.
- Nothing complicated with their medication, and all the HCSW are competent and well trained.
- (HCSW) I feel confident enough, just making sure the correct medications are in the lockers.
- Overall, it's been a positive experience.

What has surprised you about it

- Surprised how well it's gone. Very smooth
- Learning about how society treats disabled people and their carers and how little support is out there for them. And yet, they keep smiling and are grateful for what little they get. They are almost forgotten/hidden.
- Even how the PPWH building has been laid out can be difficult for those in wheelchairs, some areas are not very accessible.
- The lack of community support for families has been a real eye-opener.
- What families face on a day-to-day basis.
- The confidence that parents trust us has been revealing. At first, they are determined to stay, but once they see their young person is in good hands, they feel confident to leave and take some time for themselves. That's been a real boost.
- The second pilot was different from the first – there was no apprehension about leaving their young person. They were more relaxed and had a greater level of trust.

What needs to be in place for the service (moving forward)

- Need to consider whether the 10-bed area is the best place for the service. The Young People have particular needs in terms of light (most prefer dark spaces) and the level of noise, especially from buzzers from the other area.
- It would be better if it were possible to move bedrooms to the Living Well Hub space.
- Is the ward the best place for this social model of care?
- Young People want to use the middle social area, they don't want to spend all their time in their bedrooms or in the young people's longue but are potentially being exposed to the dying and the grieving there, if sharing on the ward, and that's not appropriate.
- The challenge with the 10-bed area is noise from buzzers and the light.
- Non-verbal young people can be very noisy in their own way and that doesn't work for palliative patients.
- Providing a 7-day service would be good.
- No need for a staff nurse. Band 4 Healthcare Support Workers can manage the day-to-day aspects of the service. Don't think it needs 'advanced' HCSW, want to get away from the medical model. Although you may need someone to coordinate the service.
- There might be staff who would want to join a bank to pick up extra shifts working with young people.
- Transport – it would be great to able to get out and about. We could factor transportation into the costings.
- Asking beforehand what the young people want to do during their visit.

- Needs to be more activities. The sensory room is very childlike, and these are adults we're dealing with.
- Need to find out what's available out in the community, but this presents its own challenges.
- Need Netflix account, although need to be wary that not all young people want to just watch the TV – some want to go out the pub.
- We need to find a balance. The Living Well Hub space could be utilised more – we could watch films on the projector or offer complementary services. Opening at the weekend would be good.
- If we offered day respite at the weekend, families could do weekend things with other children.
- Day respite would be a good way to get to know the young people before they come for a short break stay. We're not going to offer a SBS 52 weeks a year, so how can we engage and offer services to young people out with that time.
- For those new to the service, respite during the day could build confidence as there would be a lot more staff around.

What further training and development has the pilot identified for you?

Fiona reported that staff will get training in peritoneal dialysis from the renal team in February 2022, as well as scheduled training from Elaine Cowan. The PAMIS team has offered postural care training also.

It's been a gratifying experience. It's also been a welcome break from being surrounded by death and a tonic after the pandemic.

Describe your time on the SBS pilot

Out of all the above, please tell us which two are the most important to you.