



ANNUAL ACTIVITY REPORT
AND OUTCOME PROGRESS
REPORT 2016 – 2017



Children's Hospices Across Scotland

CHILDREN'S HOSPICES ACROSS SCOTLAND ANNUAL ACTIVITY REPORT AND OUTCOME PROGRESS REPORT YEAR ENDED 31 MARCH 2017

ANNUAL ACTIVITY REPORT

INTRODUCTION

In 2016-17, Children's Hospices Across Scotland (CHAS) received £680,000 from Scotland's 32 local authorities. This funding contributes towards providing specialist palliative care, which responds to the needs of babies, children, young people and their families, to offer care and support wherever the family chooses. We provide families and health and social care professionals with access to a range of specialist support across disciplines including nursing, medicine, social work and allied healthcare.

We support the whole family, as and when they need it, throughout their journey in CHAS from referral to bereavement, during their transition to adult services or through discharge should they no longer need our support. The services we offer can be in one of our purpose built hospices (Rachel House, Kinross and Robin House, Balloch), in the family home or in a hospital setting on a planned or emergency basis. Each of our children's hospices can accommodate up to eight babies, children and young people and their families. Our CHAS at Home service also covers the whole of Scotland offering nursing care and support in the family home to give families a break from caring for their child.

Children and young people with palliative care needs and their families are offered the opportunity to be cared for, respected and nurtured as individuals in an environment which offers rest and recuperation from the demands of caring. We support their choice of life-enriching opportunities, helping the child and his or her siblings to live life to the full, creating shared experiences and treasured memories.

We also make connections between families, health and social care professionals, the media, supporters and influencers to raise awareness of our work and promote joined up service provision for families.

Knowing that your child may die before you do, is the unthinkable reality that thousands of families across Scotland have to cope with every day. Each week, three children die in Scotland from an incurable condition. We are committed to making sure that no matter how short their time together may be, it is a time filled with happiness and fun.

This monitoring report covers the year from 1 April 2016 to 31 March 2017.

CHILDREN'S HOSPICES ACROSS SCOTLAND ANNUAL ACTIVITY REPORT AND OUTCOME PROGRESS REPORT YEAR ENDED 31 MARCH 2017

ACTIVITY INFORMATION

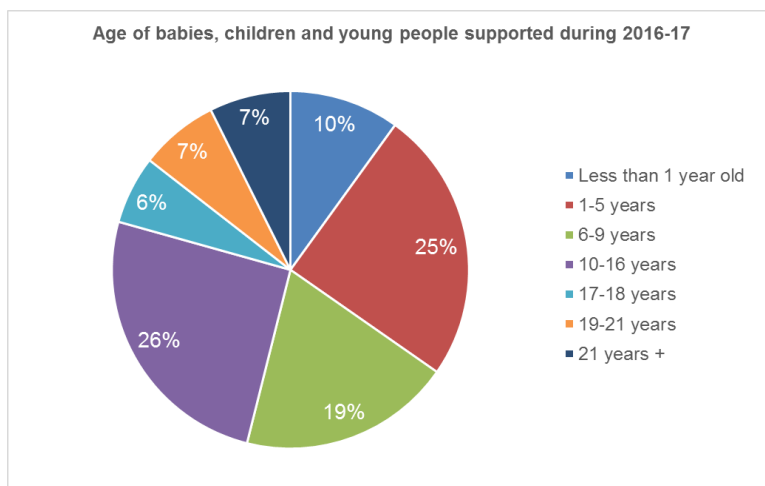
Number of babies, children and young people supported

During 2016-17, a total of 421 babies, children and young people were supported by CHAS services. This number includes the children who have died and also the number of children discharged during this period.

Age profile

Shown opposite is the age profile of the babies, children and young people supported by CHAS during 2016 - 17. The gender breakdown for these children and young people is 175 females and 246 males.

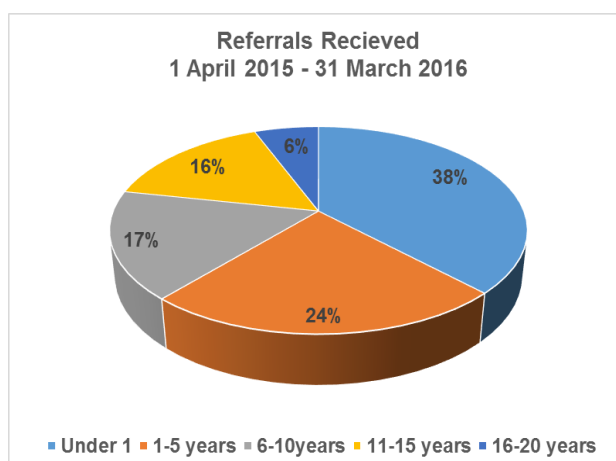
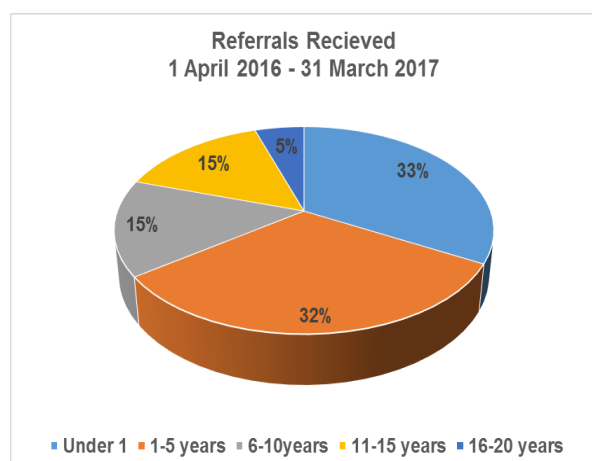
We work in partnership with other organisations to develop innovative ways to respond to the unique and specific needs of young adults.



Referral activity

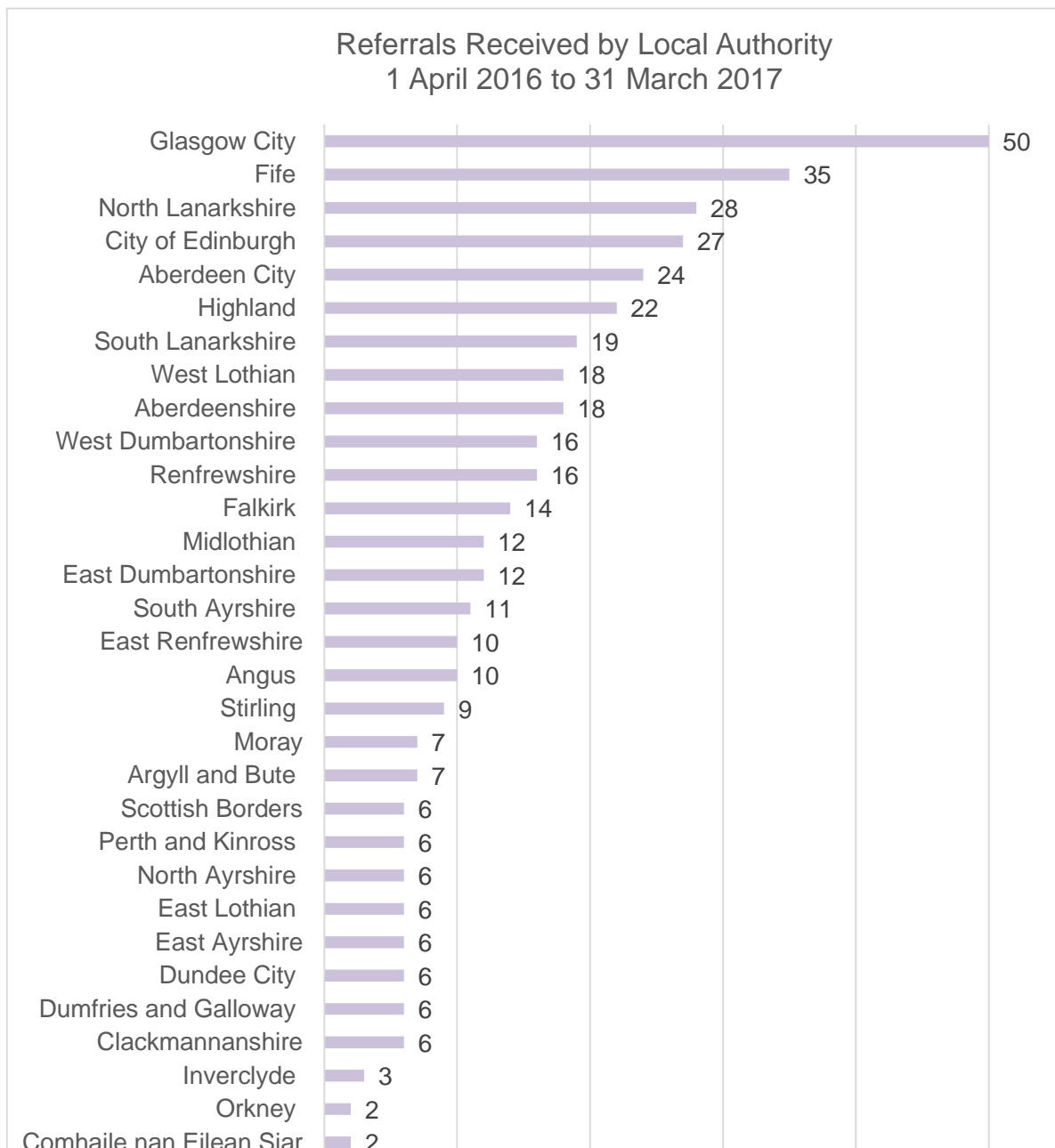
Across our services, 152 new referrals were received during 2016-17 of which 129 babies, children and young people were accepted. Of these referrals, 63 children were referred to CHAS as a direct result of working with the Diana Children's nursing team. 26 of these children and their families went on to receive additional support from CHAS.

The charts below show the age profile of referrals received between 1 April 2016 and 31 March 2017 and for the previous financial year as a comparison.



**CHILDREN'S HOSPICES ACROSS SCOTLAND
ANNUAL ACTIVITY REPORT AND OUTCOME PROGRESS REPORT
YEAR ENDED 31 MARCH 2017**

Table 1: Referrals Received by Local Authority



Bed nights

During 2016-17 Rachel House and Robin House received over 1,000 admissions of babies, children and young people and provided almost 11,000 bed nights.

- 4,214 bed nights used by babies/children/young people on planned short breaks and emergency admissions
- 6,640 bed nights used by families (4,409 for parents and 2,231 for siblings)

CHILDREN'S HOSPICES ACROSS SCOTLAND ANNUAL ACTIVITY REPORT AND OUTCOME PROGRESS REPORT YEAR ENDED 31 MARCH 2017

Day visits

Day care support at the hospices also takes place to suit the needs of individual families. These occasions are still relatively low in relation to overall activity. Robin House provided 210 day visits and Rachel House provided 146 day visits.

CHAS at Home

Over 1,029 home care visits were provided during the reporting year. Home care is provided to families by the CHAS at Home team who are based at both hospices and also in Aberdeen and Inverness. On average, 131 families were supported in their own homes each month.

The Care Inspectorate undertook its annual announced inspection of our CHAS at Home service in March 2017. The report gives 'excellent' and 'very good' scores for the two specific areas assessed (quality of care and support and quality of management and leadership) and states that the "key themes expressed by parents were the knowledge, sensitivity and care provided by the staff, their flexible approach and how this contributed hugely to allowing parents to have a break or spend time with their other children. Parents were happy to leave their child with CHAS staff, confident that they would be cared for and have fun".

A copy of the inspection report is available on the CHAS website www.chas.org.uk

Family Support

Family support is provided for babies, children, young people and families during their visits to the hospices. However the Family support Team also provide support outwith the hospices through home visits, attending hospital visits, meetings or by telephone. During the year, this outreach service by the Family Support Team supported an average of 144 individuals, making 452 visits along with over 1,985 telephone calls highlighting the extent of support provided to families beyond the hospices.

Deaths

78 babies, children or young people died during the year. Of these 14 died at home, 47 died in hospital, 17 died in Rachel House or Robin House. A total of 33 children/young people used the Rainbow Room (our bereavement suite) at either Rachel House or Robin House, which equated to 182 nights when one or more of the rooms were in use.

Bereavement support

Eight bereavement group meetings which supported seven adults and siblings were held in addition to one-to-one person-centred bereavement support when it was assessed to be more appropriate than group support. A total of 440 face to face bereavement support meetings and 507 bereavement telephone contacts were provided during this period.

CHILDREN'S HOSPICES ACROSS SCOTLAND ANNUAL ACTIVITY REPORT AND OUTCOME PROGRESS REPORT YEAR ENDED 31 MARCH 2017

Remembering Days for families were held in Rachel House in May 2016, attended by 60 families (176 people) and in Robin House in August 2016 which 56 families (253 people) attended. These annual events are an important element of our bereavement support of families as they are highly valued by all those who attend.

Transition

Our Transition Team, funded by the Big Lottery Fund is now fully operational and is delivering on its objectives and project plan. The team is enabling young people aged 21 and over to transition from CHAS services to age appropriate care within an adult environment over a three-year period. The transition team worked with a total of 74 young people during the reporting year. During the year, 17 young people have been discharged from the service and nine young people aged 21 or over have died.

Discharges

14 babies or children were discharged for reasons other than transition. This is a lower number than in the previous year. These children were more stable and are expected to live into adulthood, when at the time of acceptance this did not seem likely. In most of those who have been discharged their families had reduced their use of CHAS services as their child's condition stabilised.

CONCLUSION

This Annual Activity Report highlights the various aspects of the services provided to babies, children, and young people with life-shortening conditions and their families. The services offered by CHAS continue to provide an integrated and unique support service to families, with increasing choices for families in terms of preferred place of care and/or death for their child, whether this be at home, hospice or hospital.

Should you require any further information please do not hesitate to contact Gillian Anderson, Executive Support Manager, at gilliananderson@chas.org.uk or by calling 0131 444 4011. Details of our publications can be accessed by visiting http://www.chas.org.uk/about_chas/our_publications

CHILDREN'S HOSPICES ACROSS SCOTLAND ANNUAL ACTIVITY REPORT AND OUTCOME PROGRESS REPORT YEAR ENDED 31 MARCH 2017

OUTCOME PROGRESS REPORT

INTRODUCTION

In consultation with local government, CHAS agreed the following outcomes as part of the National Funding Agreement 2015-18:

- Children, young people and their families have access to relevant information to enable them to make informed choices
- Parents and siblings are offered appropriate support and opportunities to be included
- Children and young people are supported by the provision of holistic care, offering the opportunity to live life to the full

This section of the annual activity report provides an update on the progress made to meet the above outcomes. In addition to providing an update on the agreed outcomes of the current National Funding Agreement, it is the intention of this report to demonstrate how CHAS contributes to the following National Performance Outcomes.

- Our young people are successful learners, confident individuals, effective communicators and responsible citizens
- We have improved the life chances for children, young people and families at risk
- Our children have the best possible start in life and are ready to succeed.
- We have strong, resilient and supportive communities where people take responsibility for their own actions and how they affect others.

OUTCOME 1: CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES HAVE ACCESS TO RELEVANT INFORMATION TO ENABLE THEM TO MAKE INFORMED CHOICES

For a growing number of children and young people, medical advances mean they may now live longer than was expected than when they were first diagnosed with a life-shortening condition. For these young people, moving from children's to adult services is an important and yet sometimes difficult period. Our Transition Team offers specific services to young people and their families facing this previously unexpected development. We invite them focus on their aspirations and ideas for future adult life, and work with them to reach these goals.

By March 2017, 17 young people were transitioned from CHAS services into an environment of their choice. At the end of the reporting period, the team continued to support 43 young people in their transition process. All of the young people who are reaching their 18th birthday and are due to transition from CHAS by their 21st birthday have been given the opportunity to consider their choices in order to make an informed decision about their transition to adult life.

The Transition Team worked with a 19 year old man who has been using CHAS services for around 10 years and is in the process of his transition. During the past

CHILDREN'S HOSPICES ACROSS SCOTLAND ANNUAL ACTIVITY REPORT AND OUTCOME PROGRESS REPORT YEAR ENDED 31 MARCH 2017

year the Transition Team and the young person worked together to create links with his local palliative care team. He now trusts them with his care and treatment.

The Transition Team work actively with parents to ensure their needs are met and they feel supported to cope with the move away from CHAS services. Some of this work is enabling families to make positive memories of the time they do have together and breaks/activities they share, given the health of the young adult can be precarious. A significant amount of time is spent securing grants for young people and carers to enable them to have special days out, breaks away from home, and chances to make positive memories.

For example, we supported one young man who always had a desire to travel, but could not go abroad due to his illness, to have a short break in Scotland with his mum. The grants secured by the team enabled the young man and his mum to pay for travel, meals out and special activities. CHAS loaned a digital camera for them to capture their precious moments. Both mother and son reported having a fantastic break. Sadly his condition deteriorated and he died a few months later.

Other key highlights from our Transition Team work include:

- Initiating a 'Try Before you Fly' event at Edinburgh Airport, attended by 145 people with wheelchairs who were able to work with the airport staff to assess how it may be possible for them to travel abroad. Seven families using CHAS services attended this event.
- We have developed relationships with all the adult hospices through referring young people to them, and when requested by them to help with their ongoing development – for example, our Transition Manager presented a lecture to St Andrews hospice in 2016 as part of their education programme looking at needs of young people with life shortening conditions. We have ongoing links with many of the hospices including St Columba's (Edinburgh), Marie Curie (Glasgow and Edinburgh), Highland Hospice (Inverness), Strathcarron, and Prince and Princess of Wales Hospice (Glasgow).
- Tested a variety of models of informal respite solutions for example with Leuchie House
- Presented case studies at the International Short Break Association Conference in Edinburgh

Our Family Support Team undertake a significant element of preventative work in early years such as parenting skills, practical support such as advocacy and benefit support, sibling support, anticipatory care planning, preventing reception into care as well as formal child protection work and looked after children. Each child or young person and their family who are accepted for CHAS services has a CHAS GIRFEC assessment completed as soon as it is possible. This allows us to establish their needs and identify who we can work in partnership with to meet those needs.

Through the work of the Family Support Team, CHAS understands that around two thirds of the families using CHAS services do not have an allocated local authority social worker therefore we frequently perform that function. As an example, we regularly identify welfare or child concerns that are not deemed formal child protection concerns by the local authority. However we start the conversation and

CHILDREN'S HOSPICES ACROSS SCOTLAND ANNUAL ACTIVITY REPORT AND OUTCOME PROGRESS REPORT YEAR ENDED 31 MARCH 2017

get people around the table and raise our concerns. Many local authority social work teams can only act in a crisis, whilst we can intervene at an early stage and prevent escalation.

For example - a young person's Mum said her daughter had been quiet of late and her mum wondered if she was worried about her older brother (with life-shortening conditions) she asked us to undertake a piece of work with her daughter. Our activities worker spoke to the daughter and discovered that her parents had been shouting and swearing at each other a great deal and she had been smacked by her father a few times and she got scared. We passed this information on to social work and in the meantime our social worker and activities worker spoke with the parents about their daughter's worries.

Both Mum and Dad agreed that things were really hard in the house and they were barely managing. They had relationship difficulties, they both discussed anticipatory grief and financial issues and the couple were on the verge of separating. The work that we did was to firstly ensure the young person was safe. The dad did admit to smacking his daughter. We then undertook direct work with the parents separately and then together and then linked them into their community for further couple support. We undertook more sessions with the young person around safety planning and reengaging with her parents.

The work of our teams ensure that the children, young people and their families using CHAS services have the time, space and support to allow them to make informed choices about their care, their support and their future allowing them to be confident and effective individuals, communicators and responsible citizens.

OUTCOME 2: PARENTS AND SIBLINGS ARE OFFERED APPROPRIATE SUPPORT AND OPPORTUNITIES TO BE INCLUDED

We actively encourage children, young people and their families supported by CHAS to let us know what we can do to help, care and support them better in their journey with us. By inviting them to give feedback about our services, we can make sure that what we offer truly reflects a child focused service and allowing us to get it right for every child.

Below are some examples where CHAS has offered parents and siblings support and opportunities to be included:

- The CHAS at Home team attended a planned home visit but when they arrived they discovered the mum was in the process of being admitted to hospital, leaving a worried grandparent to care for the child. The team supported the grandparent to care for the child, administer medication and the child's feed. The team organised with Rachel House for the child and grandparent to be admitted as an unplanned stay, which lasted for five days.
- The Robin House Team responded to an emergency referral of a neonate being discharged home from hospital to die at home. The parents do not speak English, so an interpreter was used for all communication. They did not wish to use Robin

CHILDREN'S HOSPICES ACROSS SCOTLAND ANNUAL ACTIVITY REPORT AND OUTCOME PROGRESS REPORT YEAR ENDED 31 MARCH 2017

House due to the distance from home, so CHAS at Home visited weekly to support mum in her care of her 'angel'. Through an interpreter, they have had discussions about end of life care planning and the team are planning to do some memory making with mum at next home visit. They are in contact with the local children's community nursing team and co-ordinate their visits to cover either end of the week so it is not too long between contacts with the family. They have involved CHAS medical staff, hospital professionals and the family GP to share wishes of the parents around place of death, certification and after care.

- A homecare staff member organised and facilitated a trip from hospital to home for a young person who has been a hospital inpatient since last November following a heart transplant. This enabled the young person to spend her birthday at home with her siblings, family and friends which she really enjoyed. Mum expressed her gratitude and said that she did not think the trip home would have happened without homecare support.
- Two nursing team members, collected a young person from a Care Home and brought him back to the hospice for a bath. He was temporarily having to stay in the Care Home until a care package could be set up to allow him to be at home. The service had limited bathing facilities. Staff members went out again and spent time with him.
- A child who was in foster care was brought to Robin House to enable his biological family to spend Christmas with him. His mum was able to spend time with him, which was really important for them both.
- The Aberdeen team are supporting a new family where the mum with no family around her, speaks little English and is extremely isolated. The dad speaks English but works night duty. The staff have worked hard with the community staff, and an NHS interpreter, sourcing innovative ways to communicate with mum, including printing out general phrases in Bangladeshi, for when dad isn't available. By ensuring that the mum was able to communicate with the teams, her sense of isolation is reduced and she has the opportunity to be involved in her child's care.
- A family at the hospice was filmed talking about their positive experience of anticipatory care planning for their baby. This film was commissioned by Healthcare Improvement Scotland, Living Well in Communities Team who are co-ordinating a two year national programme to raise the profile of anticipatory care planning to support a more consistent, mainstreamed and person-centred approach. The Diana Children's Nurse for the North completed the Anticipatory Care Plan with the family. This incredible film has been a key part of the Scottish implementation programme and it can be seen using the link:
<https://www.youtube.com/watch?v=CckvdiwZ3Q>

Other developments and evaluations, which have been recorded through our user participation process, which involved families included:

CHILDREN'S HOSPICES ACROSS SCOTLAND ANNUAL ACTIVITY REPORT AND OUTCOME PROGRESS REPORT YEAR ENDED 31 MARCH 2017

Feedback about our service

There are several ways for children and families to give their feedback on the environment, or the care and support they receive when staying in Rachel House, Robin House or receiving care from CHAS at Home. 77 compliments and 33 comments/suggestions were received during the period that related to the quality of care or the environment.

The outcomes from the suggestions and compliments are displayed on the wall in our 'You Said We Did' flower garden. The opportunities to give feedback include:

- a. The Improvement Tree
- b. After Your Visit Questionnaires
- c. Comment Cards and Post Box
- d. Feedback on periods of care from CHAS at Home
- e. What Matters to Me Day. This photograph is an example of the lovely creative work that children are helped to do, and shows the things that matter to one little girl.
- f. One-off evaluation: Vote for your favourite space creation area in Robin House. In this example a voting chart was placed into the lounge for children, young people, parents and siblings to vote for their favourite space creation area and to leave comments. There were 44 votes in total and The Play Room receiving 18 votes and was the "Winner"



The feedback is often anonymous and complimentary. Compliments have been received regarding holistic care, the kindness of the staff, the welcoming and relaxed atmosphere in the hospices, the clean and tidy environment and the fantastic food.

The following quotes are an example of feedback received:

“Relaxing atmosphere, staff lovely as always, lots of activities”

“Staff are attentive, reacted to a change in her wellbeing and engaged with me to decide on new way forward with care plan”

“my son was cared for at the very highest standard, staff were extremely caring”

Of the 33 suggestions received during the reporting period, below are some examples of where the feedback has been used to improve our services:

- A juicer was bought for the family kitchen

CHILDREN'S HOSPICES ACROSS SCOTLAND ANNUAL ACTIVITY REPORT AND OUTCOME PROGRESS REPORT YEAR ENDED 31 MARCH 2017

- A wheelchair swing was installed in the Rachel House garden
- Side tables were purchased to be used next to the sofas in the children's rooms
- Packed lunches are now available for day trips, if requested by the children and families
- Lighter lunches are now available and dinner is served at 5pm instead of the two meals

User participation

There have been a number of opportunities for children and families to participate in changes or developments to the services.

There was a consultation around changing the venue for the annual Remembering Days for bereaved families who used Rachel House. Although 156 families were asked to give their opinion on a possible change of venue there were only two replies. Both of these people participated in a telephone interview, they also came to one steering group meeting and a debrief meeting following the event.

The outcome of this consultation has been that the Remembering Days were changed to a venue out with the hospice. One of the bereaved parents who attended the steering group meeting also took an active part in the service and is hoping to write an article for the next edition of the bereaved families' newsletter.

Feedback was gathered following the day and some examples are shown here:

- A few parents said that they were unsure about how it would be but were reassured by the beautiful venue, and that the service and all other aspects had stayed the same.
- Some found the venue a bit difficult to find but thought it was perfect for the service.

Children, young people and families were involved in the development of the 2017 - 2020 strategic plan. Families and young people were offered the opportunity to take part in the planning process. A total of 32 family members and children participated in a number of ways including telephone interviews, workshops and individual meetings. Both hospices hosted 'CHAS Plan weeks' which engaged children in activities that described what they wanted CHAS to look like in 2020. The photo opposite shows one child's response.



Our Family Support pathway outlines that early intervention is key to reducing risk and stress for families who live with babies, children and young people who have life-shortening conditions.

CHILDREN'S HOSPICES ACROSS SCOTLAND ANNUAL ACTIVITY REPORT AND OUTCOME PROGRESS REPORT YEAR ENDED 31 MARCH 2017

The Family Support Team can fill a local authority social work gap if a child or young person is at end of life. We can visit at home, bring the child or young person into hospice or support them in hospital.

As an example of where we included a parent in their child's care, we recently worked very closely with a young mum who was only able to with her son whilst he received respite with CHAS. The mum was able to stay with her child with our support. We worked with the mum on her parenting and we were able to feedback to social work our findings. In doing so, we supported the mum to make informed choices and decision about her child's future.

OUTCOME 3: CHILDREN AND YOUNG PEOPLE ARE SUPPORTED BY THE PROVISION OF HOLISTIC CARE, OFFERING THE OPPORTUNITY TO LIVE LIFE TO THE FULL

Over the past year we have helped many families to create and capture priceless memories. For some families this starts even before their baby has been born. Supporting families through memory making can bring a sense of happiness in their darkest hour. No baby is too small, or time too short, to create memories with their family – from hand and foot prints, or locks of hair, to clay moulds of their feet. They are truly precious keepsakes.

Our specialist teams develop and deliver a busy programme of in-house musical and creative arts activities, visits from partner charities, and trips to fun attractions and shows. Our Family Support Team respond to the individual abilities of the babies, children and young people, making the most of their communication, emotional and physical abilities.

All of the 421 babies, children and young people we supported during the year were able to take part some form of memory making experience or activity designed to increase self-esteem, develop resilience and build relationships with their siblings, parents and other family members.

CHAS works creatively with existing and new partners with a view to further enriching the experience of children, young people and their families and engage them through a variety of activities. These include:

- The Clown Doctors (drama practitioners) who respond to the individual abilities of the children, making the most of their communication, emotional and physical abilities
- Music Therapy - Music making is part and parcel of the way that all children learn about the world around them and develop new skills. It is a safe way of taking risks and developing independence. It is playful and intrinsically interactive. Above all it enables parents and carers to see the possibilities for their child at a time when they can otherwise be overwhelmed by the challenges ahead.
- Cool Creatures and Zoolab who bring animals into the hospice to allow children to experience and learn about exotic creatures

CHILDREN'S HOSPICES ACROSS SCOTLAND ANNUAL ACTIVITY REPORT AND OUTCOME PROGRESS REPORT YEAR ENDED 31 MARCH 2017

- Artistic opportunities for children and young people to express their creative abilities

Support offered to siblings included helping them with their school work and enabling them to stay connected with their school community while they were staying in the hospice. Special group events were held to enable siblings to share experiences with others in a similar family situation. Bereaved siblings took part in memory making activities as well as contributing to the funeral service of their brother or sister, acknowledging the significance of that bond and helping them to express their grief.

CHAS supports all siblings to participate in some form of personal development activity. An example of this was our Family Support Team accompanied 12 siblings on a week-long residential leadership academy with Columba 1400 on the Isle of Skye. The siblings who attended came from a mix of current and bereaved families.

It was a hugely positive experience for both the young people and staff who participated, and we believe that without exception every participant came away with deep and positive personal development. One young person created an art piece called "Twists and Turns" and used it to describe the impact of her sibling's ill health on her life. Some quotes from the siblings who attended the event are shown below:

"It made me see I was a worthwhile person – that I had the potential I could achieve anything I wanted to."

"I'd never been listened to before and it's a great feeling, when people actually care what you've got to say."

"I used to be really shy I didn't speak to anybody but after I went to Columba I've found I'm able to speak for myself and others."

These activities have demonstrated where CHAS can add real value to the lives of the siblings and parents of a child/ren with a life-shortening condition and offer them the best possible start in their life and an increased opportunity to succeed into adulthood.

Should you require any further information please do not hesitate to contact Gillian Anderson, Executive Support Manager, at gilliananderson@chas.org.uk or by calling 0131 444 4011. Details of our publications can be accessed by visiting http://www.chas.org.uk/about_chas/our_publications