

Submission to APPG for Children Who Need Palliative Care inquiry into

'the extent to which the government is meeting its end of life care choice commitment for babies, children and young people in England'

About Rainbow Trust Children's Charity

Rainbow Trust Children's Charity provides emotional and practical support to families where a child has a life threatening or terminal condition. Through nine teams of Family Support Workers we provided support to more than 2,300 families last year in England.

We enable families to make the most of their time together, providing expert practical and emotional support, where they need it, for as long as it is needed.

Rainbow Trust pairs each family with a dedicated expert Family Support Worker to help them face and make the most of each new day. Family Support Workers support the whole family in the place of the family's choice, providing a bespoke service according to the family's needs, from diagnosis, through treatment, and for some, through bereavement. This support often involves working in the family home and forming close working relationships with family members.

Rainbow Trust Family Support Workers fill in the gaps between the hospital and hospice, and help link services together. Alongside paid staff, volunteers are providing additional capacity to teams which is proving a valuable way to expand the provision of practical support to families.

Contents:

Part 1 of this submission sets out the importance of emotional and practical support for families where a child has palliative care needs, and how Rainbow Trust's service aligns with the End of Life Choice Commitment. In our experience, a lack of understanding of the benefits of this type of support are a key barrier to sufficient funding being available for all families in England to access it, should this be their choice.

Part 2 of this submission looks more widely at the experiences of parents and Family Support Workers as to the choices that families currently feel able to exercise, the choices they would like to have, and the obstacles that they encounter at present.

Our concluding comments provide a summary of our main arguments, and an appendix includes family stories to provide greater insight into the sort of emotional and practical support that families may choose to access, subject to where they live.

Part 1:

1. How the Rainbow Trust service aligns with the End of Life Choice Commitment

The 2016 publication of the Government End of Life Choice Commitment, in response to the independent review of choice in end of life care, recognised that care for children differs in some ways from adults, and must encompass the whole family.

The subsequent publication of the 2016 NICE Guideline on *Care for the Dying Infant, Child or Young Person*, the *One Year On* progress report by the Department for Health and Social Care, and the development of a new national bereavement care pathway, have further contributed to focusing attention on the particular needs of terminally ill children and their families.

Rainbow Trust strongly welcomes this activity. Choice is at the heart of the government's strategy, and is central to the support that Rainbow Trust provides to families.

The majority of our referrals come from hospitals, community nursing teams or other health professionals, but families can also self-refer. At their initial assessment, a Family Support Worker discusses with a family what area of support might make the most difference to the family's ability to cope. This discussion informs the creation of a personalised care plan for the family before support commences.

Support can include:

- helping families at home
- providing transport to and from hospital appointments
- attending important appointments with doctors or consultants
- playing with the sick child
- looking after siblings
- taking children to and from school
- talking to brothers and sisters who struggle to understand what is happening
- helping a family make memories
- supporting families to plan for end of life and funerals
- bereavement support.

The voice of the child is something that Rainbow Trust seeks to place centrestage. For instance, a separate framework is used with children when carrying out initial assessments and self-assessed outcomes, and the service is in the process of developing a children's consent form. Children's input is also obtained during an annual Snapshot Audit when service users and referrers are asked for their views on the service.

In light of the wide range of types of support that families can choose to receive, Rainbow Trust feels that it is a good example of the community based services which are mentioned in the 2016 End of Life Choice report:

Community-based services and forms of support for children and their families can provide the kind of flexibility, responsiveness, continuity of care and care coordination that support children to have independence and choice.

The End of Life Choice Commitment also highlights the need for continuity and coordination of care for children and young people, which can be enhanced when Rainbow Trust Family Support Workers attend meetings with families and are present during conversations with clinical staff.

The Rainbow Trust service includes bereavement support which is a current area of focus for NHS England. This bereavement support is often cited as of particular value to families who find that previous contact with health professionals who had cared for their child, sometimes over many years, is abruptly halted when their child dies. In contrast, support from a family's existing Family Support Worker can continue and this continuity is often found of great benefit when other services fall away.

2. The choice to seek emotional and practical support as part of palliative care

Children's palliative care is often considered through a clinical lens, despite the most common definition recognising the holistic nature of children's palliative care.¹

Before addressing the particular questions asked by the Inquiry, it is important to consider what children and families actually need to manage at a time of great stress and anxiety. At present, all children will receive some sort of clinical palliative care as available through universal access to the NHS.

However, not all children and families can access emotional and practical support, and we would argue this is in fact essential for many families to cope effectively. Whatever medical treatment is available for a child, a family will struggle if they are unable to attend an appointment at the same time as they need to drop siblings at school, or if they cannot manage the transport of a child's bulky equipment to attend an appointment by public transport, for instance. Another example would be if one parent's employment becomes at risk because of repeatedly needing to take time off at short notice to respond to their child's medical crises.

Fiona Smith, Royal College of Nursing Professional Lead for Children and Young People's Nursing, speaking in March 2017, explained:

"When a child is seriously ill it is about so much more than physical health care – the whole family needs emotional help and support. Nursing staff do all they can to care for children and their parents during these difficult times, but in the current health care climate there's only so much they can do."

"The kind of support Rainbow Trust provides is invaluable to families and saves millions of pounds. However, the Government needs to recognise the importance of social palliative care for children and families and ensure that it is accessible for all those who need it."

A parent who responded to our request for views for this submission described a variety of areas in which she felt she had or had not experienced choice, but also added:

"It goes without saying that Rainbow Trust has by far been the one area of practical support we could not have coped without."

Another parent says:

"Practical support is really important to me. I don't need help every day or every week but it makes a huge difference when someone else can make a phone call for me or sort something out so I can be with my son and don't need to sit down at a computer to sort something out."

¹ See Together for Short Lives website page on Definitions accessed 11th January 2018: http://www.togetherforshortlives.org.uk/professionals/childrens_palliative_care_essentials/definitions

Rainbow Trust is confident that this type of support brings significant benefits to children and their families. To measure the impact of a Rainbow Trust Family Support Worker in a family's life, each family is asked to score themselves in outcome areas at the point of referral and again at six months. This process is also followed with families who have been supported by Rainbow Trust for more than six months.

The following figures show the percentage of families reporting an improvement in their ability to cope in these outcome areas in 2017:

- 80% quality of life - being able to plan family activities at home, or to have time outside the home together
- 66% quality time - enjoying time together as a family, and communicating well together
- 82% stability and confidence - not feeling overwhelmed by conversations with medical professionals, or by practical demands such as daily chores
- 81% managing stress - frequently feeling highly emotional because of the situation
- 66% economic wellbeing - the ability to pay bills, and cope with the costs incurred in travelling to appointments.²

4. Obstacles for children and their families who wish to access emotional and practical support as part of their palliative care

The main obstacle to families being able to choose to receive emotional and practical support is a lack of funding. Rainbow Trust operates in nine parts of England³ and aspires to operate across the UK. There are very few other services offering the type of support that the charity provides. This indicates that in some regions of the UK, families may be receiving very little emotional and practical support from the voluntary or statutory sector.

While not all families will wish to receive this support, some families will benefit from accessing support which is more than can be provided by their own resources and networks. It is likely that the need is significantly greater than the 2,300 families who were able to access Rainbow Trust support in 2016-17.

The number of children with a life threatening or life limiting condition in England in 2009-10 was estimated at 40,000 in the most recent academic study⁴. The figure is likely to have grown considerably since then as more recent research in Scotland suggests⁵ in light of improvements in medical technology enabling more babies to survive birth and more children to live longer with their complex needs.

In the areas where Rainbow Trust does have teams, there are occasions when the charity has had to open a waiting list for its services, while always prioritising families where a child is at end of life. For example, our Essex team (covering Essex, parts of north east London, and parts of Suffolk) has a waiting list of 18 families at time of writing in January 2018.

² For more information, see <http://rainbowtrust.org.uk/our-impact>

³ For more information, see <https://rainbowtrust.org.uk/about/where-we-support>

⁴ *Life-limiting and life threatening conditions in children and young people in the United Kingdom; national and regional prevalence in relation to socioeconomic status and ethnicity*, University of Leeds/ Together for Short Lives, 2011. The estimated number of children across the whole of the UK was put at 49,000. http://www.togetherforshortlives.org.uk/assets/0000/1100/Leeds_University_Children_s_Hospices_UK_-_Ethnicity_Report.pdf

⁵ *Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study)*, University of York, 2015. This states: 'The absolute numbers of children and young people with a life-limiting condition in the complete estimates have risen from 12,039 (2009/10) to 15,404 (2013/14)'. See <https://www.chas.org.uk/news-articles/children-in-scotland-requiring-palliative-care-chisp-report>

Two factors require consideration. Firstly, there is low awareness of the essential nature of non-clinical palliative care provided in the community, alongside clinical palliative care, and, secondly, related to this, there are fewer statutory funding sources for non-clinical palliative care.

a) Low awareness of the essential nature of non-clinical palliative care provided in the community:

- Children's hospices across England rightly deserve their worldwide reputation as being at the forefront of best practice in child palliative care. Hospices can provide state of the art facilities which give both children and their families, a much-needed place to go for a break, or for additional nursing/ medical support.

The role of hospices will continue to be crucial as the number of children with terminal and life threatening illnesses grows, with medical technology enabling more children to live longer than ever before with their diagnoses or conditions. However, hospices are only one part of the picture. Children and their families have needs every day, throughout the year, and they need support when they leave the hospital or hospice

- In comparison, community palliative care is often invisible and of lower profile, despite being cost effective and often available to families on a more regular basis. Building understanding of the existence and essential nature of this support is vital for families to be able to self-refer to such services, for professionals to refer families, and for local authorities to commission these non-clinical services.

b) Lack of statutory funding sources for non-clinical palliative care:

Paradoxically, while the diverse ways in which a service like Rainbow Trust can support families will act to enhance their choice around the care and support that they receive, the same diversity makes it harder for the charity to meet the narrowly defined criteria for statutory funding or contracts.

- There are currently few incentives for local commissioners to fund our services, financial or otherwise, despite the benefits that such support can bring to children, families and wider society. As Rainbow Trust set out in our *Hidden Savings* report in 2017, the savings that our service enables for the health and social care system are conservatively estimated at £2 million each year.⁶
- These include freeing up hospital beds when families feel better able to manage their child's condition at home, and reducing the number of missed appointments when Family Support Workers assist in helping a family to cope with the large number of appointments their child may have and by providing transport.
- Such support both saves money and enhances choice for the whole family, including siblings whose needs are often not met through currently available services. Support can also benefit other close relatives, help parents to stay together despite raised stress levels and enable all family members to manage their feelings better and potentially avoid long term mental health problems which can be difficult and costly to address.

⁶ *Hidden Savings: How Rainbow Trust Children's Charity saves money for the health and social care system*, Rainbow Trust Children's Charity, 2017. www.rainbowtrust.org.uk/hidden-savings

- A key challenge is the lack of sustainable and predictable Local Authority funding, and the fact that funding for Short Breaks services are under great pressure. As shown in recent research by Together for Short Lives, many local authorities are failing to commission short breaks for children who need palliative care, despite being legally obliged to do so.
- This research found that more than one in five (21 per cent) local authorities are failing to meet their legal duty to commission short breaks for disabled children with life-limiting and life-threatening conditions. This figure has worsened in the past year; one in seven (14 per cent) local authorities were failing to commission short breaks for these children in 2016.⁷
- Rainbow Trust receives less than three per cent of its income from statutory sources. What the charity does receive comes from a decreasing number of local authorities as part of their funding for Short Breaks, and a grant from the Big Lottery Fund which ends in February 2018. One piece of feedback from the Big Lottery Fund regarding a bid to expand neonatal support said that funding was not appropriate because such support ought to be provided by the state . and yet the purpose of the Rainbow Trust bid was to provide support which is not currently provided by the state.
- Some Local Authorities state that to be eligible for Short Breaks Funding, a child or young person must have an Education, Health and Care Plan (EHCP) which the majority of the children that receive Rainbow Trust support do not have. Some Local Authorities state that Short Breaks services must be open to children with all types of disability and not just children with palliative care needs.
- Local Authorities increasingly stipulate that referrals must come through their Children with Disabilities Teams. However, Rainbow Trust referrals rarely come to the charity via a Local Authority, with the majority coming from hospitals, community nursing teams or other health professionals. In contrast, referrals from Local Authorities often do not meet the criteria for Rainbow Trust support.
- Increasingly, where Rainbow Trust does work with a Local Authority, this is through a Framework Agreement with a number of Short Breaks providers. This is a contract by which a provider can become a preferred supplier+of a Local Authority for Short Breaks. Rainbow Trust is part of several Short Breaks Frameworks and they each happen in a slightly different way. When a Local Authority receives a referral, they then offer it to their providers, who may have to compete to provide support.
- A further challenge with a Framework agreement is that Rainbow Trust does not know how many referrals may come in, and therefore how much funding may ultimately come to the charity, which creates challenges in planning the allocation of staff.
- Sometimes a commissioning strategy is good and Rainbow Trust is successful in its bid, but the process is laborious. Sometimes there is a requirement for the charity to provide extremely detailed information which is time-consuming for Rainbow Trust to provide, and out of proportion to the sum being sought (e.g. requests for calculation of carbon emissions by our service).

⁷ *Commissioning Children's Palliative Care in England*, Together for Short Lives, 2017.
http://www.togetherforshortlives.org.uk/assets/0002/2232/Commissioning_children_s_palliative_care_in_England_-_2017_edition.pdf

- In terms of clinical funding streams, there is an unhelpful split of clinical and non-clinical funding. This means a service providing emotional and practical support without nursing care does not qualify for the NHS England Children's Hospice Grant Programme, and is not funded by any Clinical Commissioning Groups (CCGs) despite the savings being made for the health system through its interventions.⁸
- In addition, the strategic drive towards personal budgets, while on the surface appearing to support choice, is problematic for a service like Rainbow Trust. The concept of being in charge of buying and organizing your child's care is, in our experience, not appealing to the majority of the families that we work with. For many, it would be an additional burden when time is precious, and for some it is simply out of the question, if, for instance, English is not their first language.
- Furthermore, families where a child's condition fluctuates and has periods of being well, such as cancer, or a condition that rapidly deteriorates, are unlikely to have the time or interest to apply for a personal budget, which again reduces the number of families likely to take these up.
- Personal budgets are also problematic in that Rainbow Trust offers a free service, and prioritises families by need, rather than their ability to pay. There would be no incentive for a family to use a personal budget to buy the charity's services when other families are not paying for the same support.
- Despite the prioritisation of bereavement care by NHS England, including the development of a new bereavement care pathway, none of the charity's bereavement support is funded through statutory funds.

In light of these challenges, we believe that children and their families are not able to exercise an important choice in terms of palliative care, which is to receive tailored, expert emotional and practical support to complement their essential health care.

Part 2: Exercising Choice: The Experience of Children, Parents and Family Support Workers

This section considers more broadly the overall experience of choice across diverse aspects of palliative care, and the barriers that families report to exercising choice.

Inquiry question 1

What choices can children and young people in England with life-limiting and life-threatening conditions - and their families - reasonably expect to make?

Do these vary in relation to different conditions?

Inquiry question 2

Can children and young people in England with life-limiting and life-threatening conditions make these choices?

⁸ *Hidden Savings* report, *ibid.*

To what extent is this the case? Is this being measured - and, if not, can it be?

Do these vary in relation to different conditions?

Answers to these two question areas are presented together in light of the amount of overlap.

One point which underpins Rainbow Trust's response to these two question areas is that, while the promotion and availability of choice sounds positive, no choice is real unless it is actually feasible for those offering the choice to deliver it.

Another issue to bear in mind is that many children with complex conditions may vary between stable and less stable episodes, and experience repeated relapses and recovery. Parents may for some time struggle to identify a child with complex needs as being in need of palliative care and potentially requiring plans for end of life care. This can itself be a barrier to exercising choice as to treatment and care.

Rainbow Trust would also highlight the ethical question of whose choice it is when a child is under 18 and there are decisions to be made around treatment options. There are challenges in promoting choice when a child and their parents may not share the same views. Clarifying the legal status of a young person's ability to decline treatment would be helpful.

Parents and Family Support Workers listed the following areas as aspects of palliative care in which families do experience choice, although with some caveats:

- **Nursing care at home:** The availability of 24 hour nursing support and out-of-hours medical advice is dependent on where a child lives, as shown in recent research from Together for Short Lives.⁹ In our experience, covering gaps in care can be reliant on the goodwill of hard working staff.
- **The choice of whether or not to use a personal budget to pay for care:** Parents value this choice although they highlight that the burden of managing a budget is something that not all families wish to take on.
- **Access to a local hospice:** Access to a hospice is much valued by families for both overnight stays and for family support and outreach services, depending on where a family lives. However this choice is limited by whether or not there is a bed available on the date that a family would like to use the hospice. Some families also mentioned that because they had to travel some distance to make use of a hospice, it was of

⁹ *Commissioning Children's Palliative Care in England*, Together for Short Lives, 2017, *ibid.*

less value to them as a break than they would have wished because of the return travel time.

- **Access to complementary therapies:** Therapies such as massage, music, art, and sensory activities are among those available and chosen by families.
- **Medical consent:** An important area of choice for families is the right to stop treatment and the fact they can provide or decline consent for invasive procedures.
- **Pre-bereavement counselling:** Families appreciate having access to such counselling when available.
- **Choice as to the place of death for a child or young person:** Families and staff report that they do feel there is a choice as to whether their child or young person can die at home, in a hospice or in a hospital. However, as highlighted below, families do not always realise they may have other choices, such as to bring their child's body home before a funeral if the child did not die at home.

Stephanie Nimmo's family received support from Rainbow Trust. She recently wrote about how she valued having a choice when her daughter Daisy was dying in January 2017:

'The most important thing for me now was to give Daisy dignity in death. I had hoped that we could transfer her to home or hospice for a compassionate extubation but she was too unstable. The last thing I wanted was for her to die in an ambulance in the middle of London.

I was offered the chance to move her to a private room for her final moments, but I did not want her disturbed any more. We pulled the curtains around, had the lights dimmed and played music. Patients were moved temporarily so we had no strangers around us.¹⁰

- **The ability to follow religious and cultural beliefs:** This is an important area of choice for some families which they highly value. At times, cultural and/ or religious beliefs can raise ethical issues with hospital care staff, such as consent to receive blood products or to allow a post mortem.

¹⁰ 'Letting my daughter go', BMJ 2018; 360 doi: <https://doi.org/10.1136/bmj.j5771> (Published 03 January 2018) Cite this as: BMJ 2018;360:j5771

How Choice can vary according to a child's condition:

- **Inequality in support available for cancer and non-cancer diagnoses:** Rainbow Trust Family Support Workers are acutely aware of the differing levels of support available to families where a child has a cancer diagnosis. For instance, children with cancer receive extra support from Paediatric Oncology Outreach Nurse Specialists (POON nurses). However, the degree of support is still dependent on where they live, with POON nurses in Bristol currently unable to provide end of life support at home owing to staffing constraints, meaning that parental choice may be compromised.
- **Inequality in support for children with undiagnosed or extremely rare conditions:** Seriously ill children with undiagnosed genetic conditions, also known as syndromes without a name (SWAN), will often experience less choice in their care and treatment. Around 6,000 children are born in the UK each year with a genetic condition so rare that it may often be impossible to obtain a diagnosis. Some of these will subsequently require palliative care.
- In 2016, 8 per cent of the children and families supported by Rainbow Trust had an undiagnosed condition, and this figure has been rising owing to advances in medical care and technology.
- Without a diagnosis it can be difficult to access information and support. A child may not have a standard treatment plan, and nursing care at home can be harder to access. Parents may struggle to find information relevant to their child's condition, as well as having no idea of what the future might hold. Parents often take on the task of researching their child's condition and treatment options in light of there being little or no experience among the professionals that they encounter.
- A 2016 report by Rare Disease UK included survey data showing that 73 per cent of respondents without a diagnosis felt it had been a barrier to accessing treatment. Four out of five respondents felt that being undiagnosed had been a barrier to receiving appropriate coordinated care.¹¹
- Without a diagnosis, there may be no obvious support group to join, and parents can feel a much greater degree of social isolation as a result. Some report that accessing hospice care is difficult, and completing forms with a field to name their child's condition can be difficult.

¹¹ *The Rare Reality – an insight into the patient and family experience of rare disease*, Rare Disease UK, 2016; <https://www.raredisease.org.uk/media/2361/patient-experiences-2015.pdf>

How Choice can vary according to a child's location:

- **The amount of health and care support being commissioned will vary according to each CCG and Local Authority:** The ability to access out of hours care, community nursing, Short Breaks, or equipment, for instance, is highly dependent on the individual commissioning choices made by a CCG and Local Authority, as demonstrated by recent research.¹²
- **Geographic isolation:** Rural areas, and being based on an island such as the Isle of Wight, inevitably compounds the reduction in choice that some children and their families have in terms of their care.

Choices that families report that they do not feel able to make:

- **Access to promptly organised and well-coordinated care:** Families report that they would like to see care and equipment put in place more quickly, and for there to be one lead person to coordinate their package of care, which can involve a large number of people. This could to some extent be met by the role of a named medical specialist as recommended in the NICE Guideline for *End of Life Care for the Dying Infant, Child or Young Person*.
- However the guideline is yet to be implemented by many CCGs, and the role is described in a purely medical context. Families would like to be able to access the support they want without having to make phone calls or appointments to chase what they are entitled to. Many report the wish to have an advocate to assist them when they receive new information as they often feel unable to take on board all that they are told in the first instance.
- As bereaved parent Stephanie Nimmo wrote recently for the BMJ: *'For children living with unpredictable complex conditions there has to be a good and early relationship with palliative care services to make plans and be able to change plans'*.¹³
- **Support to manage personal budgets:** Families who have a personal budget (a small minority of those supported by Rainbow Trust) would value more support in administering their budget so that they can exercise choice with a lower burden on their time.
- **The choice to receive sibling support:** Support for the siblings of a child with a terminal condition is reported as of great importance to parents. Those supported by Rainbow Trust can access this through individual or group time with a Family Support Worker, but statutory support is often limited to Young Carers groups which a child may not qualify for.

Many families feel a huge sense of guilt that a child's siblings are not receiving the attention that they need. As one parent explained, *'I will always have that guilt that [the sibling] could not have a normal life in those early years.'*

¹² *Commissioning Children's Palliative Care in England*, Together for Short Lives, 2017, *ibid*.

¹³ *'Letting my daughter go'*, *ibid*.

Another parent said, *“There’s only one of you and I found it was one of the hardest things to juggle, I felt a lot of guilt towards the other siblings, I felt they were very much missing out, whether it was due to hospital stays or the strict routine I had at home”*

- **The ability for a child to follow a blended diet:** A specific concern from some families is that they may not be supported to provide a blended diet for a child fed through a tube depending on the particular policy of their local hospital trust. This is a source of much anguish for some parents who wish to provide as normal a diet as possible for their child, and who believe this is of greater nutritional value. When not supported to administer such a diet, a child’s ability to attend childcare or school can be curtailed as the parent must attend to provide the food at meal times.
- **Choice around their child’s death:** While families do usually feel able to make choices around where their child may die, some have felt less able to exercise choice in the time immediately after the death. Families wish to spend as much time as they wish with their child’s body, but access to a cold room, or cold cot or mattress so that a body can be brought home, can depend on availability and on proximity to services.
- **Choices in bereavement:** Family Support Workers report that access to ongoing counselling, in addition to any pre-bereavement support they have received, can be difficult.
- Families can also struggle in bereavement as they experience high emotions but also face immediate practical changes. For instance, families are often unclear about how their benefits will change as a result of the end of Disability Living Allowance and Carers Allowance, and they may have to adjust to the sudden removal of a wheelchair adjusted vehicle. It is not unusual for a child’s specialist bed to be removed from the family home within 24 hours of their death.

The measurement of the above choices will rely upon the ability of each service to capture the relevant information in a meaningful way.

Inquiry question 3:

What are the barriers preventing children and young people from making these choices? Do these vary in relation to different conditions?

Are there barriers which are preventing services from offering choices?

- **Parents report not having enough information to make the most of the choices they have:** This was a recurring theme in drawing together this submission. The ability to exercise choice is highly dependent on knowing what choices are in fact open to you, and can rely on a family’s particular capacities and ability to be proactive at a very challenging time as their child moves towards end of life. As mentioned above, access to information can be particularly difficult for families where a child has an undiagnosed condition.

Example: Choice in early stages of bereavement

Rainbow Trust supported a family with a terminally ill son. At end of life, his parents chose for their son to die in a hospice. However this was not so much a positive choice but owing to the fact they did not have confidence that the health professionals who had been involved in his care were able to manage his pain correctly at home, and the family did not want him to die in hospital.

The child's body was then sent to a chapel of rest near the family home so the parents could visit him regularly as there was a long period of time before the cremation. The parents had always wanted him to be at home. However if a Rainbow Trust member of staff had not mentioned bringing his body home for his final night the parents would not have known this was an option, since it had not been discussed with them at any point by other professionals. This took place, and the parents felt that this was the greatest gift of all in the circumstances: that their son came home one final time.

- **Lack of medical information or contradictory information:** Limited access to professional guidance is cited by some as a barrier to being able to make informed choices about care and any further treatment. Another issue on which parents would appreciate information is around options for medical donations for research or transplant.
- One parent explained that the support of an independent professional while her child is an in-patient or attending appointments was beneficial, which in her family's case came from a Rainbow Trust Family Support Worker: *'It is really helpful to have support which is independent of the hospital, and isn't directly linked to the hospital, but from someone who knows the hospital.'*
- **Too little signposting to non-medical information:** Families frequently report that they hear about relevant services and benefits (such as Blue Badges for cars) much later than they were eligible to take them up. As one manager explained, *'People are not aware of what can be available for them.'*
- Many parents struggle to ask for help, with one parent commenting: *"It's a big step for families to acknowledge they need help. There is a lot of pride."*

Another said, *'Initially our priority was treating [our daughter's] cancer – we had a "we can cope, thanks" mentality so it never crossed my mind.'*

A third said, *'It took me a lot to admit I needed help, because I felt like I was admitting I couldn't cope.'*

- Better signposting of available support and quicker input from local authority social services are often mentioned as particular areas for improvement which would benefit parents. One parent said:

“I think more should be done to help parents identify what they are entitled to (regardless of income) and help them go about it. The last thing you want when your child is lying in hospital fighting for their life is to have to wade through those dreadful forms. You need someone who can help you fill them in and just say “sign here”.”

Likewise a bereaved parent commented, *“In my experience I learnt more from other carers than from the professional”*. She explained that she found it fairly easy to talk to people but she understood that many parents may not be as forthcoming. For that reason she felt, *“There should definitely be a professional person that can visit new carers to inform them with the appropriate information.”*

Families would also like more information on funeral packages and other practicalities after a child’s death.

- **Communication barriers:** Poor communications between parents and professionals may limit the ability of parents to exercise the choices that they wish. Sometimes poor communication relates to language barriers when English is not a first language. At other times families report challenges in terms of the ego of professionals interfering in decision-making, or a lack of empathy among professionals in their attitude towards families. Additionally, some families report difficulty in understanding information with legal implications.
- **Unreliable support as a result of workforce constraints:** A direct barrier to the exercise of choice is the availability of nursing and care staff. Rainbow Trust teams report that families often say they are let down by private carers booked in to provide care in the home, and appointments are frequently cancelled. As an example, some support is only provided by pairs of nurses once a child reaches a particular weight. If one nurse or carer is off sick or on holiday then a visit will be cancelled.

Are there barriers which are preventing services from offering choices?

- An important way to improve choice for children and families would be to encourage more partnership work between children’s hospices and community palliative providers to provide new forms of support in more parts of the UK. The main barrier to this is the competition between services in applying for funds which is unavoidable

in the current funding environment. In our view the best outcomes occur when it does not matter which service will be taking the credit.

Inquiry Question 4:

What are the opportunities for improving the extent to which children and families can make these choices?

What policies do the government, NHS England and others have in place to improve choice for children?

Are there examples of where children and families have been offered choices that others can learn from, including from Northern Ireland, Scotland and Wales?

- The NICE *Guideline for Care of the Dying Infant, Child or Young Person* has set out clearly what good looks like especially in a clinical context. At the same time, work on a national bereavement pathway will provide valuable guidance on what good bereavement care and support entails, and the *Ambitions* framework offers a detailed view of what local action is required.
- Attention should therefore now be focused on how to turn each of these into a reality for all families at a time of resource and workforce constraints, and competing priorities within the health and social care system.
- Underpinning any improvement in choice has to be ensuring that the health and social care system has the necessary staff, skills and resources to deliver the care that children and their families wish to receive. At the same time ensuring the most cost effective use of existing resources is vital.
- An important step forward in Scotland has been the decision to have parity in statutory funding for children and adults hospices. This is a welcome step forward and should be accompanied by ensuring parity in funding of clinical and non-clinical palliative care services.

Inquiry Question 5:

What actions can be taken to improve the extent to which children and families can make these choices, and by whom?

The Department for Health and Social Care should:

- **Address the shortfalls in the NHS England national, specialised and CCG budgets** as a necessary prerequisite for all CCGs and Local Authorities to make the Choice commitments a reality and to implement the NICE Guideline on End of Life Care for the Dying Infant, Child or Young Person.

- **Address the known workforce challenges** at a national level in order to ensure sufficient trained staff are available to provide the amount and level of care that families wish their child to receive.¹⁴

The Department for Health and Social Care and NHS England together should:

- **Establish more equitable access to existing funding for child palliative care for non-clinical services:** Existing children's palliative care funding streams should be opened up to non-clinical palliative care services.
- **Communicate commissioning responsibilities more clearly:** The Department for Health and Social Care and NHS England should make it a priority to write to CCGs and local authorities to make clear which parts of the health and care system in England are responsible for commissioning palliative care for children and young people aged 0 - 25.
- **Develop a mechanism to ensure there is accountability for children's palliative care:** The Department for Health and Social Care and NHS England should develop a system to monitor how CCGs and local authorities are supporting children's palliative care in accordance with their legal duties.

It is vital that palliative care is recognised as about the whole family, and is not seen as a purely medical process. As explored in Section 1, a family's ability to access emotional and practical support can be an important factor in enabling it to cope better with a child's condition. However, this access is dependent on where families live, and a lack of funding to enable services like Rainbow Trust to reach more families in more parts of England. One way to address this would be to establish more equitable access to existing funding for child palliative care.

The charitable palliative care sector should:

- **Renew its focus on partnership working:** An important way to improve choice for children and families would be to encourage more partnership work between children's hospices and community palliative providers to provide new forms of support in more parts of the UK.

Section 3: Concluding comments

Access to both clinical and non-clinical palliative care will continue to vary according to where a child lives until there is greater clarity about who is responsible for delivering on the commitments, and until there is a mechanism to ensure accountability once this is clarified.

This submission has argued that despite the positive progress being made, an artificial divide between health and social care continues, and this restricts choice for children and their families.

The emotional and practical support provided by organisations such as Rainbow Trust remains undervalued and little understood. Just as well-resourced adult social care can

¹⁴ *The state of the UK children's hospice nursing workforce A report on the demand and supply of nurses to children's hospices*, Together for Short Lives, 2017: http://www.togetherforshortlives.org.uk/assets/0001/9508/Together_for_Short_Lives_-_The_state_of_children_s_palliative_care_nursing_in_2017.pdf

facilitate the timely discharge of patients from hospital and potentially prevent readmission, charitable non-clinical palliative care services can reduce the burden on the health system by meeting the essential needs of children with a life threatening or terminal condition and their families.

It is a paradox that while the diverse ways in which a service like Rainbow Trust can support children and their families will act to enhance their choice around the support that they wish to receive, and is saving money for the health and social care system, the same diversity and tailoring of support makes it harder for the charity to meet the narrowly defined criteria for statutory funding or contracts.

We urge the All Party Parliamentary Group to take note of the cost effective nature of such services, and to press the Department for Health and Social Care to open up existing funding streams to cost effective services providing emotional and practical support which are enhancing the ability of children and their families to exercise choice at the end of life.

For more information please contact:

Anne Harris, Director of Care
anne.harris@rainbowtrust.org.uk

Sophie Dodgeon, Policy & Campaigns Manager
sophie.dodgeon@rainbowtrust.org.uk

Appendix

Family stories demonstrating the value of tailored, flexible support to support choice in palliative care

1. Charlie Prunty (mother) and Emma Smart (her daughter who died in 2013)

Emma Smart had started school in September 2010 and it seemed that every day she would come home with a different bug. But Emma's mum Charlie put this down to the start of school as there were a lot of bugs around. Charlie would keep taking Emma to the doctors and they would keep giving her medicine, antibiotics etc., but she just kept getting ill.

Along with the illnesses, Charlie noticed that Emma just had no energy: 'You would pick her up from school and she would be asleep in the car minutes later'. Charlie explains, 'She also started to lose control of her bladder in the night so at the beginning of December we went to an emergency doctor'.

Emma was diagnosed with a urine infection and so was given antibiotics, but at this stage she had lost a lot of weight, was jaundice and Charlie just knew something else wasn't right: 'Two days before Christmas that year, I called the doctor out'. Charlie recalls 'She just wasn't right and I really thought she should be in hospital, but of course you don't want to push for these things at first. However, I knew she really wasn't well when on Christmas Day she didn't want to open presents which is very unusual for a three year old. We gave Emma and her older sister and brother (Amy-Louise and Sam) Christmas day and decided if she was not better by Boxing Day, we'd go to hospital'.

Emma wasn't better on Boxing Day so the family went in to hospital and luckily saw the same doctor that they had seen right at the beginning who immediately saw how much weight Emma had lost in just three weeks and sent Emma straight to A&E. In A&E they tried to take Emma's blood and it was then that they realised just how serious it was as Charlie explains: 'Her blood looked more like a weak blackcurrant drink as there were so few blood cells in it. It turns out her heart wasn't pumping the blood around her body, it was basically pumping cancer'.

She was diagnosed with Leukaemia and was taken straight to the Marsden hospital (a specialist hospital in Surrey) where they were told Emma had Acute Myeloid Leukaemia (AML) which is the worst one to have. Charlie remembers: 'We were given lots of information about it, but I hardly understood any of it and I was determined not to go and look it up on the internet as we were told that is the worst thing you can do'.

On New Years Eve 2010, just five days after originally going into hospital, Emma's cancer was confirmed and it dawned on Charlie that she hadn't slept for those last five days.

*"I just remember sitting in the Marsden and thinking, where the hell am I?
How did it get to this? I was thrown into a world that I had no knowledge of"*

Emma was to start intensive chemotherapy, which Charlie found hard to comprehend: 'They're basically going to poison her to treat her. Chemo is a poison that they wanted to put it into her body, and you have to sign a form to say you consent. It's times like those that you just have to trust the doctors. So I sat back and watched them get my child better'.

Charlie noticed that morale on Emma's ward was very low: 'Basically all the kids with AML eventually die, I was very aware of this so I hosted cheese and wine nights on the ward. At first, only a few people turned up, but after a while lots of people would come and it would give us all some relief'.

After her chemotherapy Emma had five months out of hospital whilst she was in remission. Charlie remembers: %was looking forward to sending Emma back to school and we were having a trip to the Tower of London when Emma's temperature suddenly spiked. We went straight to hospital and this time I was much pushier, I asked for blood tests to be taken and we had the results the next day+.

This was in September 2011, around the time of Emma's 4th birthday which the family celebrated in hospital. But Charlie found it hard to celebrate as doctors had given her some bad news: %They had told us that Emma's chance of survival was now only 25-30 per cent which I remember thinking wasn't a great chance at all+.

But Emma made it back to remission and her chances of survival went up to 50 per cent.

Emma needed a bone marrow transplant and as she was already on the list, they already had 10 matches. She went straight in to have the transplant and then was in lockdown for three weeks after that, where only Charlie and her partner Kevin were able to see her.

Then, on Christmas Eve Emma's family had the best Christmas present ever - Emma had started to form her own blood cells. The doctors decided to open the doors to her ward, and although Emma wasn't allowed out, she was allowed other visitors in.

Emma was eventually allowed out in February, but by March she was getting poorly again. At this stage Charlie was very exhausted: %was doing a lot of the nurse things at home and looking after her constantly+.

This is where the Smart family first met Rainbow Trust. Charlie was assigned Family Support Worker Steve from Rainbow Trust's Southampton team. Steve also had a Family Support Volunteer Worker Annabel who supported the Smart family alongside him. Charlie explains just how hard things had got before Rainbow Trust: %Before Rainbow Trust it was really hard, I never got a break and had just no time out plus my other children weren't getting the attention they needed. It's hard to give your sole attention to children when so much of it is focused on your sick child+.

Annabel and Steve would take Emma's elder sister Amy . Louise and brother Sam out for the day and would also provide emotional support to Charlie, however their support was to be even more invaluable.

Emma was constantly in and out of hospital and when Emma was in hospital, Annabel would visit the family and spend time with her there.

Around the beginning of April 2012 Emma went back into hospital, but this time she wouldn't come out. Charlie remembers: %Emma had a few dips but would always bounce back quickly, but near the end of that year she didn't+.

%One evening the doctors came and told us it was back. They asked me to come out of Emma's room while someone would sit with Emma. I was told that Sceptic shock had brought it on and then the doctors told me that there was nothing else they could offer her. We just fell to pieces, I cried and just couldn't speak+.

As the news was sinking into Charlie, she found it really hard to tell others. In the end Charlie decided to share the news on Facebook and so posted a big picture of Emma with the message: *"It is with a heavy heart that we're telling you Emma has relapsed. She's going to Frimley Park hospital if anyone wants to see her for her last few days"*.

Emma chose to spend her last days at Frimley Park (their local hospital) and was taken there on Christmas Eve. Charlie remembers: %She had 100 visitors that night, including Annabel. But it was only Annabel that Emma allowed to stay in the room. This helped me massively as it showed how much she trusted her and allowed me out to speak to the visitors+

Emma was christened by the hospital Vicar on Christmas Day. %All we wanted is for her to last past Christmas day+Charlie recalls %We wanted to give Emma a Christmas and to give Amy-Louise and Sam a Christmas and we didn't want Christmas day to be the anniversary of Emma's death+

Emma did survive Christmas day and even saw in the new year of 2013. But Charlie was preparing herself for the inevitable:

%I think from the moment you're told your child has cancer you prepare for them to die. You hope they don't, but deep down you are preparing yourself for them to die. So when you're told, you just kind of accept it. All through Emma's time on the wards you would watch other children die and as you got to know families better you would go to their funerals+

On New Year's Day 2013, something in Emma changed. %We had washed her hair and she had been playing but suddenly her breathing changed+Charlie remembers. %Doctors had told us that that would be a sign. That's when we had to prepare her to die+

Frimley Park hospital had a cabin below the wards and Charlie and Kevin took Emma there as she was on a ward of children and they didn't want them to see her die.

%When we went to the cabin I sent Kevin out so I could prepare her, I knew he wasn't ready for her to die and would find it hard to accept it, but I just had to make Emma comfortable. It was hard but I just had to keep strong. She shouted her last words and they were typical of Emma - STOP CRYING! she said. Then, I lightly put a blanket over her and said what would be the hardest words I would ever have to say:

It's ok baby, you can go now+ And she did+

Emma died on the first of January 2013. Rainbow Trust has continued to support Charlie, Amy-Louise and Sam after Emma's death.

%We had to organise her funeral, but we had no money. We'd had time to ask Emma what she wanted but didn't know how to pay for it+

Friends set up a campaign on Facebook and raised £2000 which paid for a horse and carriage, which eventually was police escorted.

Steve and Annabel helped Sam and Amy-Louise read at the funeral, standing by them as they did it and Steve also read Charlie's words for her as she was too emotional to do it on the day.

The day finished with a big balloon release: %We got everyone to write a message for Emma and tie it to the balloon and then we sent them up to her+, Charlie remembers.

After the funeral, Rainbow Trust continued to support the family as Charlie describes: %I was able to open up with Steve and Annabel, it took me a while but they stuck at it. That's the biggest thing, sometimes I just vent, but you can really talk to them. It's hard to talk to family because they're grieving too+

Since Emma's death, Charlie has found it hard to leave the house and often has panic attacks if she does. Charlie says "It's mostly because for 2 years I didn't have any time for myself, I just needed to stop and pick myself up and I decided to just stay indoors to do this. Everyone knows us in this area because Emma was in the paper so will ask about Emma if I go out."

However, Rainbow Trust has helped maintain a sense of normality in the house. During the summer holidays Steve has taken the kids out for breaks and taken them swimming and Annabel will come and spend time with Charlie and talk to her and Charlie will leave the house if Annabel is with her.

Charlie describes how important this support has been: "You have no idea how important their bereavement support is. You've had no life bar the hospital for 2 years and then when Emma died, bang! It stopped. I had no idea what to do; looking after Emma was my life. I just felt empty and lost when it all happened. All of a sudden your child dies and you feel like you've been put on the scrap heap, you've been going to hospital every day for years and now there's no reason for you to go there. In a way, the hospital is your safety net and it's taken away from you. But having Rainbow Trust's support continue is so important, because you are still getting support. I had no support bar Rainbow Trust. Rainbow Trust's support isn't taken away like everybody else's. Even if sometimes it's just a phone call, it's just good having that person there."

"Annabel will take me out of the house, we'll go shopping or to the pub for lunch. We just sit, chill and chat. I will go out on my own, but prefer an adult to be with me."

"They haven't just helped life have some normality; they are a life-saver. That time after the death, life goes on, friends disappear, go back to work, but Rainbow Trust are still there, keeping some sort of normality."

Rainbow Trust has also helped Amy-Louise and Sam cope with Emma's death as Charlie explains: "The kids have no idea what to do with the aggression that they have from grieving, they have a psychologist who comes but Steve and Annabel will take them off separately when they need it or together if that is best."

Charlie could not be more grateful to Steve and Annabel: "Annabel is an amazing lady, she deserves so much credit for coming and visiting us to spend time with me and the kids. She's amazing to give up her time to do that. Both of them were there at the drop of a hat when Emma was ill and you can't choose when that would happen. That hospital safety net is now Rainbow Trust, they have become our safety net. I know I have someone there if I were to go into a crisis. For me the support was really important at the funeral and leading up to when Emma died. On that Christmas Eve before Emma died, when Annabel showed up and then Steve was there the next day, was just so precious to me. I'll never forget that. That is support; that is what I'm talking about."

"They support me sometimes without actually supporting me. Just knowing they're always there is good to know."

2. Vicky, Rick (parents) and Samuel, Essex

Samuel from Essex was born with a severe heart condition and needed monitoring 24 hours a day. His heart could stop with any kind of stress. Vicky and Rick, his parents, could never leave him alone so, as well as looking after their other two children, the couple was left struggling to have any semblance of normal life. Family Support Worker, Sarah, supports the family. From transport to hospital appointments, support in hospital during Samuel's open-heart surgery, playing with Daisy and Betsy at home or taking them out for the day and giving respite for Mum when things have just got too much, Sarah is there for them.

%Without Sarah, I'd have no kind of break. We take life one day at a time but having her support means we can have days out or I can do chores knowing Sarah is looking after Samuel as well as I would.+ Vicky, mum to Samuel.

3. Dawn (mother) and Zia (baby)

Zia was born 10 weeks prematurely and weighed just 2.3lbs. Dawn, her mum, was overjoyed but felt overwhelmed with Zia's major health issues. She found it difficult to bond with Zia and didn't feel confident taking care of her as Zia was so ill. Dawn self-referred to Rainbow Trust as she knew she needed help. Her Family Support Worker spent time with Zia in the neonatal unit and supported Dawn emotionally. Dawn was able to talk about her fears and helped her find the confidence to look after her precious baby girl

%I found it so hard, I wanted to put Zia into care as I didn't think I could cope. Having Marlene, our Family Support Worker, there for emotional support made all the difference. I can't put into words how much she has helped me.+ Dawn, mum to Zia.

4. Carol and Dean (parents) and Kia (daughter)

Kia was seven when she was diagnosed with a rare genetic disorder. Carol and Dean, her parents, struggled to manage caring for her and Brayden, her older brother. Carol had to give up her job and eventually their home, as they could not keep up with the payments after spending more than £90 a week travelling to Newcastle for hospital visits. Carol, their Family Support Worker, started supporting the family and took mum and Kia to the hospital, saving them train fares, which meant they could afford to keep their rented home warm in the winter. This reduced the huge financial strain on the family and they could focus on taking care of their children. Carol also spent time with the family in the home, giving mum a break and Brayden some fun.

%Carol signposted me to benefits that we were entitled to which helped us manage our bills. We didn't have to spend it all on travel and that meant we were under so much less financial strain.+ Carol, mum to Kia.