

# Hidden Savings: How Rainbow Trust Children’s Charity saves money for the health and social care system

These appendices are to be read in conjunction with the report *Hidden Savings*, available at [rainbowtrust.org.uk/hidden-savings](http://rainbowtrust.org.uk/hidden-savings)

## APPENDIX 1

### Information on data sources to support calculations of the potential money saved to public services as a result of Rainbow Trust interventions

Challenges faced by families whose child has a life threatening or terminal illness	Rainbow Trust interventions	Estimated costs to public services in absence of Rainbow Trust interventions
<p><b>Parents experience high levels of stress and anxiety, and often have no time for themselves after attending to their child’s practical and emotional needs.</b></p>		
<p>Parents can be physically worn out by the demands of caring. They may experience broken sleep and may need to physically move their child or bulky medical equipment with direct repercussions for their own health.</p> <p>The impact of caring on parents is well documented. For instance: <i>‘A survey of parents of disabled children by the charity Scope found that nearly half (47 per cent) had been to see their GP because of stress and worry, and the vast majority said they felt frustrated (80 per cent), stressed (78 per cent) or exhausted (70 per cent) as a result of the struggle to access local services for their children.’</i></p> <p>Source: <i>Life to the Full: Care and Support in the UK for Children with Life-limiting and Life Threatening Conditions</i>, a report by Demos commissioned by the True Colours Trust, 2015.  <a href="http://www.truecolourstrust.org.uk/wp-content/uploads/2015/11/Life-to-the-full-Main-Report.pdf">www.truecolourstrust.org.uk/wp-content/uploads/2015/11/Life-to-the-full-Main-Report.pdf</a></p> <p>Research by Contact a Family found similar levels of stress, with almost half of parents surveyed saying they have felt so unwell that they asked their GP for medication or to see a counsellor.</p>	<p>Rainbow Trust interventions can reduce stress and anxiety within the family.</p> <p>The regular presence of a Family Support Worker can enable parents to look after their own physical and mental health needs by giving them a break from caring, whether at home or in hospital.</p> <p>As a result, parents feel able to cope more effectively with the demands of the situation.</p>	<p>£44-65 for cost of GP consultation/ visit</p> <p>£46 prescription costs per consultation</p> <p>Mental health care clusters (initial assessment) £284</p> <p>Improving Access to Psychological Therapies (IAPT) £105 per patient contact</p> <p>£125 per week for one to one support from mental health social worker.</p>

Source: *Forgotten Families: The impact of isolation on families with disabled children across the UK*, Contact a Family, 2011.  
[www.cafamily.org.uk/media/381636/forgotten\\_isolation\\_report.pdf](http://www.cafamily.org.uk/media/381636/forgotten_isolation_report.pdf)  
Of carers (of both adults and children) surveyed by Carers UK, '54% of carers have suffered depression because of their caring role; carers also felt more anxious (77%) and more stressed (83%) because of their caring role.'

Source: *State of Caring 2015*, Carers UK [www.carersuk.org/for-professionals/policy/policy-library/facts-about-carers-2015](http://www.carersuk.org/for-professionals/policy/policy-library/facts-about-carers-2015)

Accessing local authority support can be challenging. Under the 2015 Care Act, parents of a disabled child are entitled to a Carer's Assessment which can help a family access local authority support. However, assessments can take months and parents frequently complain that they do not have the energy to pursue services for their entitlements.

According to Carers UK, those caring for a disabled child under 18 were more likely to have asked for their assessment (22%) than have been offered one (13%). 48% of those caring for a disabled child under 18 have waited more than 6 months for a carer's assessment when the requested one. 28% of carers of a disabled child who were proactively offered an assessment have waited or been waiting for more than 6 months.

In terms of the experience of receiving an assessment, 74% of those surveyed whose main caring role is for someone with disabilities or serious illness who is under 18, felt that the support they need to provide care for others was not sufficiently considered in the assessment process.

Source: *State of Caring 2016*, Carers UK.

The toll is not only emotional. Carers (of both adults and children) providing round the clock care are more than twice as likely to be in bad health than non-carers, according to Carers UK, using data in the 2011 Census. The 2015 GP Patient Survey highlighted that 70% of carers caring for 50 or more hours a week had a long-standing health condition, compared to 51% of non-carers. The survey revealed higher levels of arthritis, high blood pressure, long-term back problems,

Source: *Unit Costs of Health & Social Care 2015*, PRSSU (Personal Social Services Research Unit of University of Kent), page 134.  
[www.pssru.ac.uk/project-pages/unit-costs/2015/](http://www.pssru.ac.uk/project-pages/unit-costs/2015/)

<p>diabetes, and mobility problems amongst carers, as well as anxiety and depression.</p> <p>A particular problem can be sleep deprivation. A survey in 2012 found that of parents with disabled children, over 93% are up in the night with their children, and 49% felt that they have health issues due to the lack of sleep.</p> <p>Source: <i>'Tired all the Time'</i>, The Family Fund, 2013.  <a href="http://www.familyfund.org.uk/tired-all-the-time">www.familyfund.org.uk/tired-all-the-time</a></p>		
<p><b>Anxiety about their child and other siblings, money worries, physical exhaustion and a lack of time to spend with their partner can put great strain on relationships.</b></p>		
<p>The heightened stress can in the worst cases contribute to family breakdown. This is well recognised, with some Local Authorities citing this as a factor in the provision of Short Breaks, as well as being documented in academic research:</p> <p><i>'Where families are caring for a child with a life-limiting or life threatening condition and providing around the clock care, relationships often suffer, with 36% experiencing a breakdown of the family.'</i></p> <p>Quoted in <i>'Welfare Reform and Work Bill House of Lords Committee Stage: A briefing from Together for Short Lives'</i>, December 2015.  <a href="http://www.togetherforshortlives.org.uk/assets/0001/3202/Welfare_Reform_and_Work_Bill_-_a_briefing_for_Peers_from_Together_for_Short_Lives.pdf">www.togetherforshortlives.org.uk/assets/0001/3202/Welfare_Reform_and_Work_Bill_-_a_briefing_for_Peers_from_Together_for_Short_Lives.pdf</a></p> <p>The full reference is <i>Trajectory of certain death at an unknown time: children with neurodegenerative LTC illnesses</i>, Steele R, in <i>Cancer Journal of Nursing Research</i> 32, 49-67, published 2000.</p>	<p>Rainbow Trust emotional and practical support may help to reduce the likelihood of family breakdown at times of extreme stress.</p> <p>Although not a direct cost saving for public services, where parents have already separated before the death of a child, there are examples of when a Family Support Worker has been able to assist parents to agree on a funeral plan despite their differences.</p>	<p>£1,820 annual cost of family breakdown for every taxpayer (£48 billion total cost)</p> <p>Source: <i>Counting the Cost of Family Failure</i>, Relationship Foundation, 2016  <a href="http://www.relationshipsfoundation.org/counting-the-cost-of-family-failure-2016-update/">www.relationshipsfoundation.org/counting-the-cost-of-family-failure-2016-update/</a></p> <p>See also:  <i>Fractured Families: Why stability matters</i>, Centre for Social Justice, 2013 – page 52. The costs to the public purse include lone parent benefits, tax credits, housing benefits, health and social care, education and civil and criminal justice.  <a href="http://www.centreforsocialjustice.org.uk/library/fractured-families-stability-matters">www.centreforsocialjustice.org.uk/library/fractured-families-stability-matters</a></p>

		<p><i>Fully Committed? How government could reverse family breakdown</i>, Centre for Social Justice, 2014.  <a href="http://www.centreforsocialjustice.org.uk/library/fully-committed-government-reverse-family-breakdown">www.centreforsocialjustice.org.uk/library/fully-committed-government-reverse-family-breakdown</a></p>
<p><b>In the experience of Rainbow Trust, one parent, usually the mother, will often give up any paid employment they have to focus on caring for their child and to manage the high number of appointments.</b></p>		
<p>Rainbow Trust is not aware of detailed research into the employment of parents of children with a life threatening or terminal illness, but research does exist into the experiences of parents of disabled children more broadly. For instance, a survey of 900 parents of disabled children by Working Families found that combining work and caring responsibilities is often not felt to be feasible: <i>'Of the parents who are currently not in work 79% felt that they had no choice but to give up work at or very soon after the diagnosis of their child.'</i></p> <p>Source: <i>Off Balance: parents of disabled children and paid work</i>, Working Families, 2015. <a href="http://www.workingfamilies.org.uk/publications/off-balance-parents-of-disabled-children-and-paid-work/">www.workingfamilies.org.uk/publications/off-balance-parents-of-disabled-children-and-paid-work/</a></p> <p>In the longer term, a return to the labour market can be difficult because of the gap in work history, lost or outdated skills, and lowered confidence.</p> <p>Although not focused on the small group of parents whose children have a life threatening or terminal illness, surveys do suggest that working while caring for a disabled child is a serious challenge. According to Contact a Family, only 16 per cent of mothers with disabled children work, compared to 61 per cent of other mothers.</p> <p>Source: Contact a Family, Facts and figures, accessed December 2016. <a href="http://www.cafamily.org.uk/media-enquiries/">www.cafamily.org.uk/media-enquiries/</a></p>	<p>Rainbow Trust family support can potentially help to prevent a parent from giving up work to help with attending frequent hospital appointments, visiting a child who is a long stay in-patient, or taking siblings to school while the other parent acts as primary carer.</p> <p>Conserving a stable income is especially important when many families whose child is seriously ill find that their expenditure rises - see below.</p>	<p>An average UK salary in 2016-17 is £27,500, according to the Office for National Statistics Annual Average Salary Survey.</p> <p>A full-time job at this wage would contribute approximately £5,633 in income tax and National Insurance to national Exchequer.</p> <p>A 0.5 post at this average salary would contribute £1,233 in tax and National Insurance.</p> <p>This does not include employers' tax contributions or employee pension contributions.</p>

**Parents often report to Rainbow Trust that the cost of petrol and car parking to attend frequent hospital appointments is a challenge.**

Many organisations have conducted research onto the costs faced by families with seriously ill babies or children. Such additional spending can include the cost of petrol, car parking and food that is bought from hospital shops during long and stressful days in hospital.

Research from CLIC Sargent suggests that parents with a child undergoing active cancer treatment spend on average £600 per month extra. Their research also found that 1 in 6 parents of children undergoing cancer treatment had built up debts of over £5,000.

Source: *Cancer Costs*, CLIC Sargent, 2016.  
[www.clicsargent.org.uk/content/cancer-costs](http://www.clicsargent.org.uk/content/cancer-costs)

Research by Bliss notes that hospital parking can cost as much as £72 a day, despite government guidance that free or reduced parking should be available to anyone visiting critically ill or long-stay patients. Bliss also note that more than 40 per cent of neonatal units lack the basic kitchen facilities that allow parents to stay with their babies without having to leave the ward to eat. More than a third of hospitals whom they surveyed offer parents no support with meal costs.

Source: *Families kept apart: Barriers to parents' involvement in their baby's hospital care*, Bliss, 2016 [www.bliss.org.uk/families-kept-apart](http://www.bliss.org.uk/families-kept-apart)

A 2013 survey of parents with a baby in a neonatal unit by found that parents spent an average of £75 each week on travel, either by car or public transport, to be with their baby, and £32 on car parking.

Source: *It's not a game: the very real costs of having a premature or sick baby report*, Bliss, 2013. [www.bliss.org.uk/campaigns-and-policy-reports](http://www.bliss.org.uk/campaigns-and-policy-reports)

In a 2014 survey of more than 3,500 families with a disabled child, 31 per cent of families said they sometimes go without food, and 33 per cent said they sometimes go without heating. 51 per cent had been threatened with court action for non-payment of bills.

Rainbow Trust support can sometimes contribute to families better managing the extra costs which can result from having a seriously ill child.

Examples include saved spending on petrol for hospital appointments when Rainbow Trust vehicles are used, saved spending on car parking if a family does not have a Blue Badge (e.g. is waiting to receive one), and if their hospital does not have, or has not alerted them to, free or discounted parking schemes.

Family Support Worker assistance can also help a family to avoid added childcare costs for siblings when a parent is accompanying a sick child to appointments or visiting their child as an in-patient.

Costs are borne by the NHS when families access the NHS Low Income Scheme. This enables patients (or parents of child patients) who are on low incomes or receiving specific benefits or allowances to be reimbursed in part or in full for travelling costs when hospital appointments or treatment are required.

Source: NHSE England, [www.nhs.uk/NHSEngland/Healthcosts/Pages/Travelcosts.aspx](http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Travelcosts.aspx)

Parents can also request the use of the Patient Transport Service if their child has a medical need for transport. This service was priced at £31 for outpatients and £39 for admitted patients in the 2009-10 NHS Reference Costs.

Source: *Appendix NSRC04*: [www.gov.uk/government/publications/nhs-reference-costs-2009-2010](http://www.gov.uk/government/publications/nhs-reference-costs-2009-2010)

Other costs incurred by families are less visible to the public purse but it is reasonable to assume a

<p>The top three extra costs for raising a disabled child are listed as: Higher heating and utility bills, additional transport and childcare costs, and more frequent washing and replacing household goods, clothes and toys.</p> <p>Source: <i>Counting the Costs</i>, Contact a Family, 2014  <a href="http://www.cafamily.org.uk/media/805120/counting_the_costs_2014_uk_report.pdf">www.cafamily.org.uk/media/805120/counting_the_costs_2014_uk_report.pdf</a></p>		<p>public benefit in families avoiding debt and not needing to claim housing benefit or income support, or to access crisis services.</p>
<p><b>A high number of appointments can result in some families missing appointments because the parents are struggling to cope with the practical demands of their situation.</b></p>		
<p>In the experience of Rainbow Trust Family Support Workers, the high number of appointments which a child may have can result in some appointments being missed because the parents are struggling to cope with the logistics of travel to hospitals, which can be many miles away, and the practical demands of their situation such as the care of siblings and the need for a parent to remain in employment.</p>	<p>Rainbow Trust support can sometimes prevent families from missing hospital appointments.</p> <p>In some instances, Rainbow Trust teams have made arrangements with families and their hospitals to receive appointment letters so that a Family Support Worker can support families to attend appointments, and help families plan their logistics when appointments are at risk of being missed.</p> <p>This has avoided intervention by local authority Social Services who were known to have concerns around potential neglect of a child.</p>	<p>Cost of missed appointment incurred by CCG: £208 for a paediatric consultant-led outpatient attendance or £96-£153 unit cost for outpatient palliative care depending on degree of specialist care required.</p> <p>Source: <i>Unit Costs of Health &amp; Social Care 2015</i>, PRSSU (Personal Social Services Research Unit of University of Kent), pages 83 and 107.</p>

**A hospital which notices that a child's parents do not frequently visit their child as an in-patient may in the most extreme scenario trigger a safeguarding case.**

<p>Barriers to parents visiting their child as experienced in our neonatal work include:</p> <ul style="list-style-type: none"> <li>• Complicating factors such as twins receiving treatment in different hospitals, and the parents needing to visit each child</li> <li>• Parents who have poor natural support networks</li> <li>• Parents who cannot drive</li> <li>• Parents who cannot bring older siblings with them if a unit has 'winter visiting hours' - such restrictions can mean that siblings are not allowed on a ward and parents who lack childcare can then find it hard to visit their child.</li> </ul>	<p>Rainbow Trust transport support can sometimes enable parents to visit their baby or child more often than would otherwise be possible.</p> <p>For example, neonatal units can be miles away from the family home. In one example, Rainbow Trust services enabled a mother to visit her baby in a level three neonatal unit when the alternative was a three-hour journey each way on public transport which would not be possible around school pick-ups for her older children.</p> <p>Similarly, specialist treatment centres, such as for children's cancer, can be many miles away.</p> <p>In some instances, Rainbow Trust teams have made arrangements with families and their hospitals to receive appointment letters so that a Family Support Worker can support families to attend appointments, and help families plan their logistics when appointments are at risk of being missed. This has avoided intervention by local authority Social Services who</p>	<p>The cost of a child safeguarding meeting when professionals are concerned that a child is at risk runs into many hundreds of pounds in light of the range of professionals whose time is required for casework and meetings.</p> <p>Potential cost savings to Local Authority: £40-55 per hour of client-related work by a Child Social Worker.</p> <p>Source: <i>Unit Costs of Health &amp; Social Care 2015</i>, PRSSU (Personal Social Services Research Unit of University of Kent), page 189.</p> <p>Average overall cost of child protection core assessment: £1,151, plus £1,626 for average total cost of case management processes for a 'Child in Need' over a six-month period.</p> <p>Source: <i>Unit Cost Database</i>, New Economy Manchester, March 2015.  <a href="http://www.neweconomymanchester.com/our-work/research-evaluation-cost-benefit-">www.neweconomymanchester.com/our-work/research-evaluation-cost-benefit-</a></p>
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	<p>were known to have concerns around potential neglect of a child.</p>	<p><a href="#">analysis/cost-benefit-analysis/unit-cost-database</a></p> <p>In a more serious scenario, the cost saving to both health and social care services could be in the range of £5,924 to support a Family in Crisis over a 6-month period, including weekly visits by a Mental Health Support Worker, a Mental Health Social Worker, and weekly 1 to 1 family support provided by social services.</p> <p>Note this is a conservative estimate given that the case study is for a child without additional needs.</p> <p>Source: Case study in <i>Unit Costs of Health &amp; Social Care 2015</i>, PRSSU (Personal Social Services Research Unit of University of Kent), page 134.</p>
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**Children may feel isolated during long periods as an in-patient. Parents may feel overwhelmed with information during meetings with hospital staff. Both of these can result in additional demands on nursing staff.**

<p>Children may feel isolated during long periods as an in-patient, and may seek the attention of nursing staff. Anecdotal reports indicate that, unsurprisingly, on busy wards it is extremely difficult for nursing staff to spend time with a child doing non-essential activities.</p> <p>Parents often report that they feel overwhelmed with information during meetings with hospital staff and as a result they might seek assistance from nurses in checking what they have been told.</p> <p>A parent who input to Rainbow Trust’s submission to the Department of Health consultation on a new Carers Strategy in 2016, explained, <i>‘Sometimes they’d forget to inform me of what was happening next, they didn’t always find time to come and sit down and go through what they helped with... it makes you panic.’</i></p> <p>Another parent who input to Rainbow Trust’s submission explained her desire for the support of an independent professional while her child is an in-patient or attending appointments: <i>‘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.’</i></p>	<p>Rainbow Trust support may sometimes contribute to reducing demands on nursing staff.</p> <p>For instance, a Family Support Worker can sit with a child and provide craft activities or company during periods as an in-patient, or they may attend medical meetings with parents and help them to digest information that they are told, reducing the need for parents to check information with staff.</p>	<p>It cannot be assumed that, in the absence of Rainbow Trust ward support, a nurse would necessarily have the capacity to sit with a child.</p> <p>However, the cost saving to CCG may be in the region of £11.50 to £31.50 for half hour of nursing staff time, depending on a nurse’s grade.</p> <p>Source: <i>Unit Costs of Health &amp; Social Care 2015</i>, PRSSU (Personal Social Services Research Unit of University of Kent), page 227.</p>
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**In the absence of a parent having easy access to a vehicle, a child can be an in-patient for slightly longer than necessary.**

Feedback from Rainbow Trust Family Support Managers is that this is an issue which is commonly experienced. Further research might indicate how frequently this occurs.

For instance, some families have relied on Rainbow Trust for transport home between treatment dates when the child would otherwise stay as an in-patient until the next treatment.

Rainbow Trust transport support can sometimes enable a child to be discharged earlier because a vehicle is available to transfer them to home

A non-emergency ambulance to transfer a child to their home: estimated £99 average cost to CCG.

Source: *Unit Costs of Health & Social Care 2015*, PRSSU (Personal Social Services Research Unit of University of Kent), page 107.

Potential savings to CCG per bed day vary according to the degree of care required. Specialist paediatric inpatient care is costed at £388 per bed day for a child, and at £424 for a neonate requiring the lowest levels of 'inpatient' or 'normal' care.

Source: *End of life care for infants, children and young people, Full Guideline*, National Institute for Health and Care Excellence, 2016, page 240.  
[www.nice.org.uk/guidance/ng61](http://www.nice.org.uk/guidance/ng61)

**A lack of confidence among medical staff that parents can manage at home, and/ or lack of confidence among parents that they can manage can sometimes result in a child being an in-patient for longer than necessary.**

<p>Feedback from Rainbow Trust Family Support Managers is that this is an issue which is sometimes experienced by their teams. Further research with professionals could indicate how frequently this occurs.</p> <p>Families can feel overwhelmed when discharge is discussed when they have become used to medical support at the bedside. In addition, when nursing staff are stretched on a neonatal or paediatric ward there can be limited time for staff to hand over care to parents and to build their confidence as to how they might manage their infant or child's condition at home. For example, a particular source of worry can be when a child has a Hickman line (a central venous catheter) which a parent can be concerned about keeping in place correctly.</p> <p>Academic research on delayed discharge among children includes <i>Retrospective, cross-sectional review of delayed discharge after paediatric tracheostomy</i>, by Rafferty A.; Knight L.; Knight D.; Bew S, in <i>Journal of Laryngology and Otology</i>; Dec 2012; vol. 126 (no. 12); p. 1247-1253. This study of 101 children concluded that where there was prolonged hospitalisation after a tracheostomy, it was often influenced by social factors.</p> <p>Another consideration for discharge is also the amount of space in a family's home. For instance, if a child who is being discharged will need 'Total parental nutrition' (intravenous feeding) then it is important the child is not sharing a room so that any overnight nursing support will not disrupt other members of the family. Assistance from a voluntary sector provider such as Rainbow Trust can help a family to organise their home to be ready for this overnight support or even to find new accommodation.</p>	<p>Rainbow Trust support can sometimes facilitate early discharge from hospital by providing doctors and parents with the confidence that the family can cope at home.</p> <p>Staff confidence can also relate to a family's housing. In one example, Rainbow Trust worked closely with a family whose child needed a bone marrow transplant. The consultant had concerns for the child's safety on discharge from hospital after the transplant because of overcrowding in the family's existing flat provided by social housing.</p> <p>Rainbow Trust staff supported the family in applying for improved social housing and, after some persistence from the family, the authorities accepted their need to move. The family moved to more appropriate accommodation two days before the son was discharged. Rainbow Trust hired a van to assist the family, and medical staff felt more confident that discharge could be carried out.</p>	<p>Potential savings to CCG per bed day vary according to the degree of care required.</p> <p>Specialist neonatal inpatient care per cot day is costed at £464 for a neonate requiring normal' care, rising to £533 for neonatal critical care without an external carer.</p> <p>Specialist paediatric inpatient care per bed day is costed at £388 for a child rising to £849 -£1,297 for 'intermediate critical care'.</p> <p>Source: <i>End of life care for infants, children and young people, Full Guideline</i>, National Institute for Health and Care Excellence, 2016, page 240.</p> <p>Preventing the cost of a home visit: unit cost of £44 per hour for a community nurse.</p> <p>Source: <i>Unit Costs of Health &amp; Social Care 2015</i>, PRSSU (Personal Social Services Research Unit of University of Kent), page 169.</p>
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**Without additional support a child may be re-admitted to hospital more quickly because parents feel isolated by their situation.**

Parents who feel isolated by their situation and by the needs of their seriously ill child, as well as any siblings, could seek their child's readmission to hospital more quickly. In contrast, parents who feel supported to cope in their homes may feel better able to judge when medical interventions are needed. Further research might indicate how frequently this occurs.

An academic study on discharge concludes that a multi-professional out of hours' telephone service for families of children with life limiting conditions may help reduce admissions.

Source: *What delays discharge in children with life limiting conditions? A qualitative study of the perceptions of parents and medical professionals* by C Wensley, in Archives of Disease in Childhood: Education and Practice Edition; Jun 2013; vol. 98, 2013.

Rainbow Trust support can sometimes prevent readmission to hospital by enabling parents to feel more confident in managing their child's symptoms and treatment.

A Family Support Worker will work in conjunction with community nursing teams to support families to remain in the family home where appropriate by providing social care.

This support is often focussed on siblings while the community nursing team support the sick child. As a result, parents can feel better able to cope.

£231 average cost to CCG for an ambulance to see, treat and convey a patient.

Source: *Unit Costs of Health & Social Care 2015*, PRSSU (Personal Social Services Research Unit of University of Kent), page 107.

Potential savings to CCG per bed day vary according to the degree of care required.

Specialist paediatric inpatient care per bed day is costed at £388 for a child, and at £424 for a neonate requiring the lowest levels of 'inpatient' or 'normal' care.

Source: *End of life care for infants, children and young people, Full Guideline*, National Institute for Health and Care Excellence, 2016, page 240.

**When siblings are not supported to manage their complex feelings during their sibling's illness and when bereaved, the impact can be significant.**

<p>Worry about their sick brother or sister, feeling isolated from their friends, having no time for hobbies, feeling jealous about the attention their sick sibling is receiving, or feeling angry at the lack of attention parents can give them are all common responses to their situation. These can all make a sibling vulnerable to developing mental health or behavioural problems.</p> <p>Unfortunately, the siblings of disabled children are known to be at an increased risk of being teased or bullied for being different.</p> <p>Source: 'Do Siblings Matter Too?' Family Fund/ University of Portsmouth, 2015. <a href="http://www.familyfund.org.uk/do-siblings-matter-too">www.familyfund.org.uk/do-siblings-matter-too</a></p> <p>Over the longer term, some siblings report a long-term impact on their mental health. For instance, some siblings find the original bereavement of their brother or sister is intensified or relived following subsequent deaths of friends, relatives or pets. Becoming a parent themselves can lead to anxiety when their child reaches the same age as their sibling was when he or she died.</p> <p>Source: SIBS UK webpage. <a href="http://www.sibs.org.uk/support-for-adult-siblings/adult-sibling-bereavement/">www.sibs.org.uk/support-for-adult-siblings/adult-sibling-bereavement/</a></p> <p>At the same time parents often report that they feel guilty that their other child or children are not living a 'normal' life. Parental anxiety levels are raised.</p>	<p>Rainbow Trust Sibling Support Workers can contribute to reducing the risk of a sibling developing mental health or behavioural problems.</p> <p>In the most extreme cases this could require input from child and adolescent psychiatry services in the short term, as well as having long term repercussions for mental health.</p> <p>One parent told Rainbow Trust that sibling support for her healthy daughter meant the sister got '<i>some normal time, like going to the park to feed animals...I will always have that guilt that she could not have a normal life in those early years.</i>'</p>	<p>It is reasonable to assume that the potential cost savings to public services of early intervention to assist siblings in managing their emotions and grief could be significant.</p> <p>£44-65 cost to CCG of GP consultation to make referral</p> <p>£811 cost to CCG for 6 months of CAMHS weekly sessions</p> <p>Source: <i>Unit Costs of Health &amp; Social Care 2015</i>, PRSSU (Personal Social Services Research Unit of University of Kent), page 135.</p>
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**Keeping a sibling's routines going can be difficult alongside frequent hospital appointments or a period when a child is an in-patient, with consequences for the siblings' attendance at school and education attainment.**

<p>Families often tell Rainbow Trust that their lives are 'turned upside down' when their child is diagnosed with a life threatening or terminal condition.</p> <p>As documented by SIBS UK, an organisation specialising in the needs of adult or child siblings of disabled people, a young sibling may have their sleep disturbed by noise made by their sick brother or sister, or by sharing a room with them. They may lack concentration in lessons, and have too little time for homework alongside helping at home, which can result in a negative impact on their school attainment. In addition, any feelings of isolation or experience of bullying may also have a detrimental impact on their learning.</p> <p>Source: SIBS UK website. <a href="http://www.sibs.org.uk/supporting-young-siblings/siblings-schools-project/sibling-wellbeing-attainment-school/">www.sibs.org.uk/supporting-young-siblings/siblings-schools-project/sibling-wellbeing-attainment-school/</a></p>	<p>From 2012-2016, Rainbow Trust Children's Charity has assisted 356 siblings through transport to and from school, and support with homework.</p> <p>12 children in Central London increased their school attendance between March and August 2016 as a result of their Support Worker's interventions.</p> <p>For example, a girl supported by the Central London team went through an intensive 6 weeks in hospital to undergo a bone marrow transplant. Her mother had no way of getting her younger brother to school and the only option was for him to spend his days at the hospital with them. The Sibling Support Worker provided transport to and from school to ensure he could attend school daily.</p> <p>Source: <i>Rainbow Trust 'Me Too!' Year 4 Interim Report for Big Lottery Fund</i></p> <p>Families can face both practical and logistical problems. For instance, a single mother whose seven-year-old daughter was</p>	<p>Cost savings to Local Authority in reduced demand on educational support services.</p>
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undergoing a bone marrow transport was concerned about what she would do with her 20-month son while she was visiting his sister in hospital because the hospital transport refused to let the toddler travel with his mother and the seven-year-old.

A Family Support Worker was able both to provide transport and to advocate for the toddler to get a place in nursery near the home when the sister was discharged. As a result, the mother could drop the son at nursery, then get transport to the hospital with her daughter and then collect her son on the way home.

## APPENDIX 2

### How Rainbow Trust monitors changes in families' ability to cope

Rainbow Trust has designed a process to monitor changes in a family's situation during the course of Rainbow Trust support. Six areas in a family's life are measured to assess changes over the course of receiving support. These areas were identified by families that Rainbow Trust worked with in a 2013 consultation into what they valued the most about the services.

Many factors will play a part in a family's ability to cope with their child being diagnosed with a terminal or life threatening condition. The extent to which Rainbow Trust's interventions contribute to desired outcomes cannot be precisely determined. However, by capturing information during the course of a family being supported and by taking into account the lack of alternative sources of support, it is possible to be confident that a positive contribution is being made.

### Methodology of outcome monitoring

The Family Support Worker engages the main carer of the family in conversation about the family situation, and explores the six areas of focus on the flower below.

The emphasis is on ensuring that there can be an open discussion of areas of need between the Family Support Worker and the carer. It also assists the development of appropriate support plans with the family. Regular reviews are planned with the family and capture changes within their situation, alongside the impact of Rainbow Trust support. This process does not capture the child's voice. However, Rainbow Trust uses age appropriate resources to gather feedback from children on our service, and this provided input to a 2016 snapshot audit. In future, it is intended that external verification for this approach will be obtained.

The benefits of using this approach are that the family have the space and time to talk as deeply as they wish about their current family situation and to express what support they would most value. At the same time, Family Support Workers can obtain an overall picture of family life and determine where the support from our services is most needed.

The process may also highlight opportunities to direct the family to other sources of support, such as Carer's Allowance, Disability Living Allowance, or equipment or grants from other voluntary organisations.

