

New
Philanthropy
Capital

Valuing short lives

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Iona Joy

Children with terminal conditions

A guide for donors and funders



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Executive summary

Need

No one knows exactly how many children and young people in the UK are enduring life-limiting conditions. However, it is estimated that there are up to 25,000 people under the age of 19 suffering at any one time. The effect of these conditions on children is profound, especially if the condition is neurological. The lives of their families also become extremely stressful and complicated. Over half of mothers with a life-limited child have significant mental health problems. There is the additional burden of grief.

The journey for a patient starts when the problem is identified during childhood. The shock of diagnosis of a life-limiting condition is then followed by prolonged or sudden decline. Eventually the person will die, while still a child or a young adult. Care and support for children and young people, such as hospice and palliative care, should be provided as soon as a diagnosis is made, regardless of age. Care should include short breaks for the patient and support for the entire family, and continue if the young person survives beyond 18. Finally the need for care intensifies towards the end of life.

Delivery of care by government

Historically the state has delivered care that is less than ideal and it has fallen to the charitable sector to meet demand where possible. NPC believes that there are significant areas of unmet need. In general, services are poorly co-ordinated and under-resourced. There are geographical areas of poor provision; there are not enough services for adolescents and young adults in most places; black and minority ethnic communities may also be (unintentionally) excluded.

There are grounds for cautious optimism, however. The development of community health services for life-limited children, supported by the New Opportunities Fund, may improve the situation, but it is too early to say. Local NHS bodies must also commit to funding these new services after 2006. The introduction of Children's Trusts to co-ordinate services and pool resources around children's needs, rather than service provider's convenience, may benefit families in future.

Contribution by charities

Without the charitable sector, the lives of families with children suffering from life-limiting conditions would be intolerable. Since the early 1980s, the charitable sector has developed important services, such as hospices, which previously did not exist. Even now, 94% of funding for hospices comes from charitable donations. Charities continue to provide these and other vital services that the government is not providing.

Charities are constantly advocating for the rights of these families to reasonable service provision. They do this at the family level — helping families to access services; at the local level — liaising with local government agencies to develop services and bid for funding; and at the national level — trying to influence government policy.

Contribution by private donors

The sector needs private support for strategic efforts. The main priority is to provide the representative umbrella body, ACT, with enough financial resources to realise its full potential in influencing policy, co-ordinating activities in the sector, and representing end users.

A mapping exercise would help to establish who is doing what, where and for whom, so that services could be planned effectively. Funding for research would help answer numerous questions. There is need for education and training of both specialist palliative care professionals and also generalists, so that those who come into contact with life-limited children are able to respond.

There are also opportunities to support direct service delivery, including practical respite, bereavement support and family accommodation at hospitals. Hospices are a crucial component of care. Those that are appropriately planned, managed and integrated with statutory services would benefit from support. ACH, the body representing hospices, can manage grants to organisations that tackle particular issues, e.g. access to services by black and ethnic minority families. Donors can encourage initiatives that address problems concerning the transition of patients from childhood to adulthood, another pressing issue.

The lives of children with life-limiting conditions and their families can be intolerable. State support does not cover day to day needs so charities fill the gap.



Photograph supplied by Leslie McIntyre

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Introduction

In April 2004, NPC published a report: *Caring about dying: palliative care and support for the terminally ill, a guide for donors and grant-makers*. In this report, children were mentioned, but while NPC was undertaking the research it became clear that palliative care for children was a large topic meriting a report in its own right.

In July 2004, The True Colours Trust agreed to support two research projects by NPC:

Ordinary lives: disabled children and their families, a guide for donors and funders, and

Valuing short lives: children with terminal conditions, a guide for donors and funders.

These research projects have been running in tandem, and in many areas have overlapped. Consequently, the two reports cross-reference each other frequently, instead of covering the same ground. *Ordinary lives* is the longer of the two reports, and covers *all* disabled children and their families. It looks at the issues from several perspectives: children, families, professionals and policy-makers, and society. It covers leisure, equipment, education, short breaks, housing, and emotional and financial support. It discusses service provision by the government and charts key legislation and government initiatives.

This report on children and palliative care also assumes some familiarity with palliative care generally. A summary of *Caring about dying* is available if required.

The purpose of this report

This report is a guide for donors interested in funding palliative care for children. It provides the detailed information and analysis required to understand the extent and nature of the need that exists, the types of activities being undertaken to address the need, and the effects of such activities. The report also recommends which charities donors should fund. There is a separate, short recommendation report available to donors for each charity chosen. Organisations and individuals are constantly developing new projects and updating existing ones, so recommendations may vary over time. NPC can help with grant-making for projects.

This report addresses all types of donor. While it aims to help all in this spectrum, it should be recognised that parts of the report have been written for the benefit of newcomers to the subject. When the report refers to 'donors', it includes grant-makers, private individuals, companies or anyone else wishing to donate funds or provide grants.

Methodology

The work behind this study consisted of the following stages: desk-based research, discussions with experts, and visits to projects in the field. NPC has reviewed reports and papers, including various government, policy and regulatory documents, as well as academic papers and research undertaken by some of the larger charities.

In order to increase understanding of the issues, NPC conducted interviews with a range of individuals from key charities, umbrella bodies, clinical experts within the NHS and academia, and also talked to the Department of Health. In total over 40 people were consulted and they are listed in the acknowledgements.

The purpose of these interviews was two-fold:

- understanding the problem: defining the key areas of need and if, and how, these are being addressed
- understanding the role of the charitable sector: describing the current role of the sector, the gaps, and where the priorities lie, and to discover charities of interest.

Given the large number of charities operating in this sector (there are 36 children's hospices alone), NPC was unable to interview all of them and was only able to sample some. NPC reviewed the annual accounts and reports of each charity visited or interviewed and followed up where necessary to clarify information.

Charities are a major source of information on their activities and interest groups. However, if they did not supply information requested, NPC could not include their activities in the report.

Scope

Because of differing legal and political frameworks in the various countries of the UK and time limitations, this report mainly focuses on England. However, most of the findings are applicable across the UK and a number of the charities cited provide UK-wide services.

This report is flexible on the upper age limit of young people covered. The issue of transition from childhood to adulthood among many people with life-limiting conditions is an important one, and is included within the report.

Opinions expressed in the report are the author's own.

Structure

The report is divided into three broad sections. Section 1 describes the overall picture of the needs of children with life-limiting conditions and their families in the UK. Section 2 discusses the delivery of care and support to children with life-limiting conditions, and compares what is ideally required to what is actually happening; at the same time it explains the effects of such care and support. The section then outlines funding flows and explains what the statutory sector provides and what the charitable sector provides. It also highlights some strategic initiatives. Section 3 describes the activities and contribution of the charitable sector in more detail. Section 4 provides a number of funding recommendations, and explores the impact of funding such recommendations. Section 5 draws together the report's conclusions.

The need

No one knows exactly how many children and young people in the UK are enduring life-limiting conditions. However, it is estimated that there are up to 25,000 people under the age of 19 suffering at any one time. The effect of these conditions on children is profound, especially if the condition is neurological. The lives of their families are stressful and complicated. Over half of mothers of life-limited children have significant mental health problems. There is the additional burden of grief.

The journey for the patient starts when a problem is identified during childhood. The shock of diagnosis of a life-limiting condition is followed by prolonged or sudden decline. Eventually the person will die while still a child or young adult.

Care and support for children and young people, such as hospice and palliative care, should be provided as soon as a diagnosis is made, regardless of age. Care should include short breaks for the patient and support for the entire family, and continue if the young person survives beyond 18. The need for care at all levels intensifies towards the end of life. However, health and social services often lack resources to provide such services to children. The absence of clear national data on numbers of children, their conditions, and services provided, shows that these children are not a priority.

This section examines the numbers of families needing care and support for children and young people with life-limiting conditions. It explores the following areas:

- children's experience of terminal illness and the effect it has on families
- the types of service needed by children and families, and which agencies or 'service providers' (government or charitable) would ideally provide them
- definition of palliative care and support in the context of children and young people
- how family preferences for care and support are not being met, highlighting particular deficiencies.

Background

What does life-limiting mean?

The title of the report refers to children with terminal conditions. However the 'term life-limiting' is less restrictive than 'terminal' and better describes the conditions faced by the children concerned. The report will use this term.

Life-limiting conditions are those that have no reasonable hope of cure and from which people will die. Many of these conditions, for example muscular dystrophy or rare metabolic disorders, cause progressive deterioration rendering the children and young people increasingly dependent on parents and carers.¹ Other conditions result in high dependency upon carers from early on in life, but are non-progressive, such as severe cerebral palsy. These are likely to increase susceptibility to premature death and, as such, are life-limiting.

Conditions such as cystic fibrosis are progressive over a long period of time, but for many years, with good medical support, the children and young people can take part in normal activities. There are also life-threatening conditions where medical intervention may prove successful, although there is a substantial possibility of premature death.¹ Curative treatment may fail, in which case the condition becomes life-limiting. Cancer and irreversible organ failure are examples. In many of these cases children remain able-bodied for most of their lives.

Having a life-limiting condition brings with it medical and emotional complications that add to the burden of disability and ill health. Many people with life-limiting conditions are disabled, and face similar issues to those explored in NPC's concurrent report on disabled children and their families, *Ordinary lives*. This subset has more complicated needs, which is why a separate report is necessary. As a practical example, some of the social care services (theoretically) available to disabled people are not available to life-limited people because of the medical component of the care required. Also there are some with life-limiting conditions who would not regard themselves as disabled, and would fall outside the scope of *Ordinary lives*, but who nevertheless have needs.

Age range of this report

A person who is diagnosed during childhood may die when still a child, or survive into young adulthood before succumbing to the condition. Of the young people who die under the age of 25 from natural causes (generally life-limiting conditions), 39% are over 15 years old. Many more die between the ages of 25 and 34.²

This means that the age range of this report is necessarily untidy. The group considered are children and young people who are diagnosed with a life-limiting condition before 18 even though they may survive until their twenties or even early thirties.

Care and support for children and young people should be provided from diagnosis and should continue until the end of life regardless of age, beyond 18 if required.

History of services for life-limited children

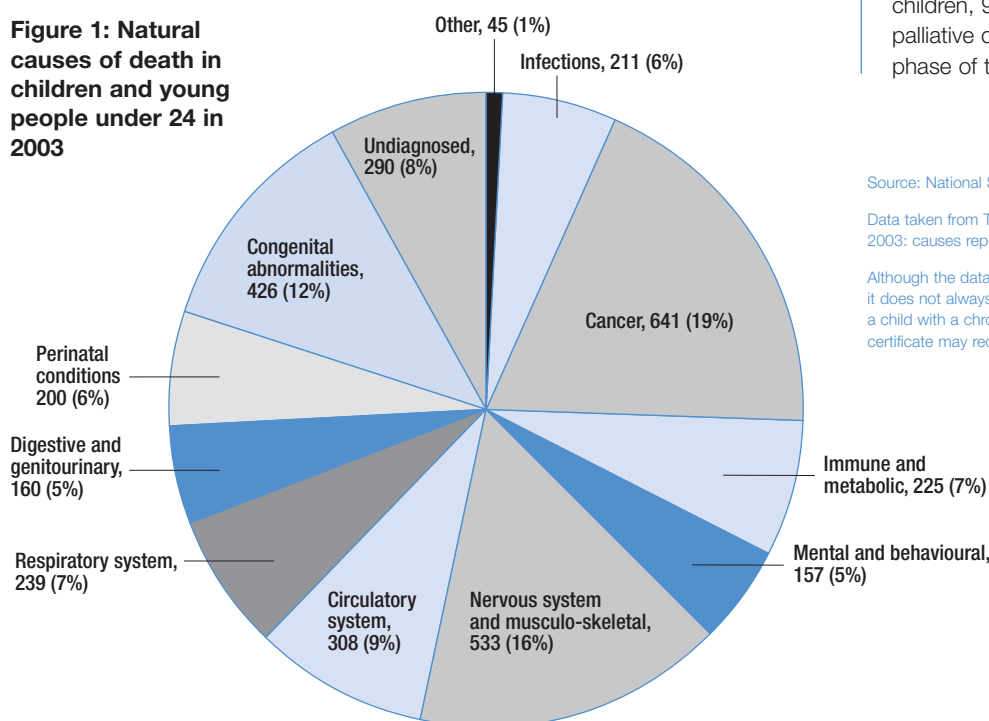
The history of services dedicated to life-limited children is short. The first children's hospice opened in 1982 despite scepticism among many paediatricians that such a service was required. It opened a floodgate of families needing the support offered by the hospice. Over the next two decades, recognition of the needs of these children grew exponentially. The NHS has also contributed to the development of services. However, both the charitable sector and the NHS are still developing to meet existing need. Caseloads have increased, both in terms of numbers and longevity. Knowledge about this subject is still developing.

Causes of death in children and young people

In England and Wales 5,535 children and young people under age 24 die each year. Over 60% (3,435) of them die from 'natural' causes,* most of which are life-limiting or life-threatening.²

Figure 1 shows how the natural causes of death are fragmented. The biggest 'killers' (with each accounting for less than 25%) are cancer, perinatal conditions, congenital abnormalities, disorders of the nervous and musculo-skeletal systems, and organ failure. Figure 1 also shows how small the numbers are each year, when divided between conditions.

Figure 1: Natural causes of death in children and young people under 24 in 2003



Although the number of deaths per annum is small, the number of cases needing care at any one time is much higher, because the children's needs extend over many years.

How many children and young people live with life-limiting conditions?

There are an estimated 25,000 children and young people under the age of 19 with life-limiting conditions in the UK.³ Some will survive into early adulthood, but the data on this group is not clear. Appendix 1 gives a full explanation of the data and calculations.

Available data is generally poor, which reflects the way government service providers have overlooked children with these conditions. The figures for the conditions have been extrapolated from a few localised studies, rather than systematically from national registers of people with each particular condition. There are separate numbers available for a few conditions, but these are confusing, because the method of calculation is inconsistent across conditions.[†] The information is particularly unclear about those with health conditions that are not progressive, but nevertheless reduce life expectancy, e.g. severe cerebral palsy.

Appendix 1 describes the numbers of children affected and the distribution between conditions. To summarise, most of the 25,000 children will have 'some' palliative care needs. Of these children, 9,000–12,500 will have 'substantial' palliative care needs, not only in the terminal phase of their life but also as they grow up in the

Source: National Statistics website www.statistics.gov.uk

Data taken from Table 2 of deaths registrations in England and Wales, 2003: causes report of Health Statistics Quarterly 22.

Although the data is informative, it must be treated with caution because it does not always reflect the underlying cause of death. For instance, if a child with a chronic metabolic condition dies of heart failure, the death certificate may record heart failure.

* Excludes injuries.

[†] There are a number of epidemiological categories that can confuse comparisons unless the reader knows which is which. Prevalence, which represents the number of cases at any one time, can be one measure of need in terms of numbers of people affected. Incidence rates generally refer to number of new cases in any period (usually each year) and can also indicate need in terms of how frequently the condition appears. Mortality rates indicate how many people die of a condition in one year. The risk of a child experiencing a life-limiting condition is another form of helpful measurement, but is only measured with respect to a few conditions.

shadow of their condition. An overlapping group is adolescents and young adults aged 13–24 who need quite complex care. Between 6,000 to 10,000 young people are estimated to fall into this category.⁴

Many of the conditions are very specific, and although the aggregate absolute numbers are significant, at a local level these numbers are small. This has, to a certain extent, deprived these people of good treatment. There are 304 Primary Care Trusts (PCTs)* in England and Wales; there may be only about 70–75 life-limited cases in any one PCT, with half needing full palliative care at any one time. This compares with about 3,000 adult cancer patients using a PCT at any one time; it is unsurprising that health services have recently been paying significant attention to cancer patients.

Although the numbers may be small, impact on families is enormous. If one assumes that the average family consists of four people including the patient, then there are nearly 300 people significantly affected in each PCT: 90,000 in England and Wales alone. The economic cost to families and communities is high, in part because caring for sick children reduces parents' ability to earn income.

Main groups of life-limiting and life-threatening conditions

Cancer

One in 650 children will contract cancer before the age of 15. The incidence of cancer in children is increasing at about 1% per annum.⁵ However, survival rates are improving and now stand at 70%, ten years after diagnosis. Over a quarter of childhood cancer cases are leukaemia, which is increasingly viewed as a treatable disease. Now that more children are cured of cancer, it is increasingly important to investigate the late effects of treatment, and the long-term effects of the disease. There is also more attention on the quality of life and psychosocial issues for survivors and patients undergoing treatment.

The number of new cases (1,500 per annum) exceeds death rates (640 per annum under age 24). ACT estimates that about **11,500** children under age 14 have cancer at any given time,³ but many more (unquantified) are diagnosed in late adolescence.



Photograph supplied by Acorns Hospice

Cystic fibrosis

Cystic fibrosis affects **7,500** people in the UK, 70% of them under 20.⁶ Each year there are 260 new cases and 156 people die. People with cystic fibrosis have an average life expectancy of 31,⁶ and survivors over age 20 are included in this report. The nature of the disease means that palliative care is generally required only towards the end of life.

Muscular dystrophy

Duchenne muscular dystrophy affects one in 3,500 males in the UK; there are 1,500 known cases today. Life expectancy increased to age 25 in 2002 (from 14–15 in the 1960s) thanks to improvements in care (such as ventilation).⁷ There are other types of muscular dystrophy and spinal atrophy, which are rarer but can be devastating.

Cerebral palsy

Cerebral palsy, in severe forms, significantly reduces life expectancy. A recent study tracked 1,942 children born between 1966 and 1986 as they developed, until 2000. It found that mortality rates for those under age 20 average 13%, and that over half of those with severe motor disabilities resulting from cerebral palsy are likely to die before the age of 30.⁸ Non-progressive conditions (such as cerebral palsy) are not always recognised as life-limiting, which sometimes leads to the exclusion of these children and young people from services.

The relatively small number of affected children has disenfranchised this group.

* Primary care trusts are the bodies responsible for delivering most NHS services. They include general hospitals and community health teams.

“Many families we work with who care for a child with a degenerative condition often live with the minimum of help and very little access to long-term planned support.”

Social worker¹⁰

Cardiac and other organ failures

Cardiac failure is another common life-threatening condition for children. Each year 5,000 babies are born with a heart defect.⁹ Many defects are treatable by surgery or drugs and not all are fatal. Actual deaths each year from conditions of the circulatory system (with the heart a substantial component) amount to only 308 in England and Wales, less than 10% of children diagnosed with heart conditions. Failure of other organs, less common than heart failure, can also result in premature death.

Metabolic and neurodegenerative disorders and other rare conditions

There are also many unusual metabolic* and neurodegenerative disorders; each condition affects only a small number of patients. Even Batten's disease, one of the better known disorders, only accounts for 300 known cases. Appendix 1 includes a snapshot of the multiplicity of non-malignant cases. In an area around Bath, 45 conditions are recorded from 92 cases, so each obscure condition may only affect one or two children.

Are these children and young people getting the services they need?

A detailed description of the services required and actually supplied is explored later in the report. However, it is important to highlight the scale of the gap in service provision at the start.

Despite the number of children requiring palliative care and other support, there has been little systematic mapping of the children, families and the existing provision of children's services. In some areas provision may be quite good; in other areas it is unclear who is providing what, if anything. It is generally felt that the needs of many children and their families are unmet, but to what extent is difficult to determine, given the absence of reliable data.³ Adult services have been mapped,[†] which has proved helpful to both the government and the charitable sector. If a similar exercise were undertaken for children and young adults, then many of the questions posed by this report would be answered more satisfactorily.

In 2003, the Association for Children with Life-Threatening and Terminal Conditions and their Families (ACT) sent a survey to the parents of life-limited children. Nearly half the parents questioned identified services they needed that were difficult or impossible to obtain. Over half of the parents experienced barriers to accessing services frequently or all the time. Less than half recorded using nursing services, and just over half used hospice services — even though most families might want to use them. Families also wanted more information about how to access services. There were pleas for quicker responses to housing adaptation and equipment needs, and to better co-ordination of services.

ACT sent the same survey to the professionals involved in the children's care. A large proportion had similar concerns to the parents: professionals felt that 30% of respite and nursing services were inadequate. Availability of services did not equate to adequacy: where encouraging figures were recorded for availability, the adequacy of these same services was often reported as very low (never more than 40%) by the same professionals. Only 24% of psychological support was useable.

The data in this survey could mean either of the following:

- over half of families are not getting services that they require
- most families are getting less than half of the services they require.

Neither situation is acceptable.

Although some local data is available, UK-wide data is not; NPC can only speculate about the lack of provision. Absence of data may itself be an indicator of meagre service provision. More positively, the development of services after 2004, using funding from the New Opportunities Fund (described in more detail later), may go some way in addressing these deficits, although it is too soon to determine impact.

Children with cancer seem to receive good services¹¹ compared to those with some non-malignant conditions. The availability, or otherwise, of residential short breaks (also referred to as respite)** and palliative care (such as that offered by hospices) indicates gaps in provision for children with non-malignant conditions. This includes hospice at home and community support. Roughly 4,000 children use hospices,¹² yet 9,000–12,500 children have palliative care

* Metabolic diseases are a group of 1,300 identified life-threatening disorders (usually genetic) in which errors of metabolism occur. This defect results in vital chemicals not being processed properly, so deficiencies essential to normal bodily functions arise on the one hand, and surpluses (often to toxic levels) accumulate on the other. The consequences are often fatal, leading to progressive physical and mental handicap.

† The National Council for Palliative Care reviews and maps service provision from time to time. Its report in 1999 influenced the government's decision to provide an extra £50 million to the sector.

** Respite and short breaks: although historically the palliative care movement talks about respite when referring to the provision of care that allows the carer to take a break from direct caring, increasingly the term 'short breaks' is being used in preference. NPC has used the term 'short breaks' in *Ordinary lives: Disabled children and their families*. To be consistent, this report will use the same terminology.

needs.³ This either means that families are choosing not to use hospices, or families are not getting access to hospices when they need them.* The government only contributes 6% to the cost of hospices. This report shall consider in more detail later whether more hospices or other forms of support are required. However, this data suggests that there is a general shortfall in palliative care services and short breaks.

How are children and their families affected?

How conditions affect the child

The journey of a life-limiting or life-threatening condition from diagnosis to death is often a complex one. The patient and family will encounter a number of different health, education and social care professionals, volunteers and others in various locations. The degree of care and support on this journey will change as the disease progresses and will vary enormously depending on the medical condition.¹³

Different conditions result in different experiences. The child may experience different types of physical, mental and emotional pain. Children's understanding and attitude to their illness and to death often change as they develop physically and emotionally. They can become depressed or frustrated during a long period of sickness; distressed if they feel they are being misled; or rebellious against obvious over-protectiveness. Ill-health also causes children to feel isolated from friends.

Cancer

In the case of cancer, children often remain able-bodied, with full cognitive functions until close to the end of their lives. (The exception is where the cancer affects the brain). The child will still

need medical care, and the physical pain and unpleasantness of symptoms towards the end of life can be intense and require careful management. The emotional pain and fear for both the child and immediate family are also intense and require psychosocial support. The experience of good health which is then cut short by illness has similarities with bereavement. Even if a child survives cancer, the treatment or disease may have damaged long-term health (fertility is a particular issue here) and the brush with mortality will have been traumatic.

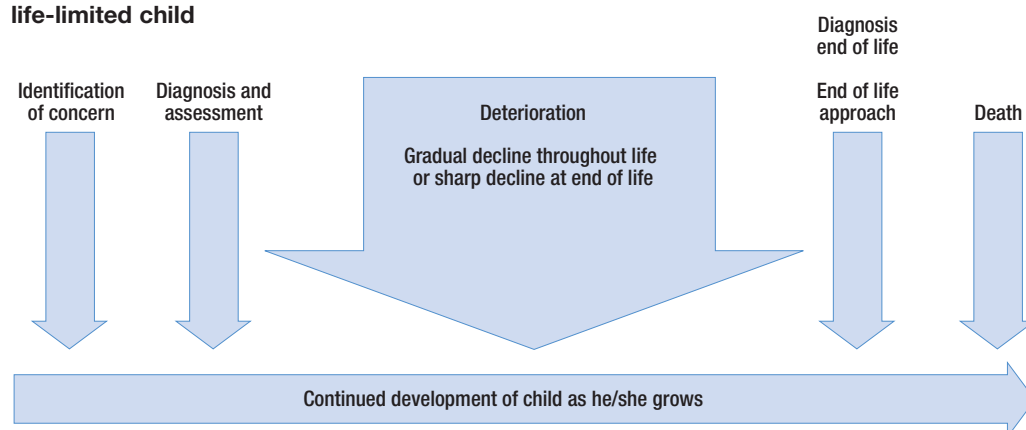
Cystic fibrosis

Cystic fibrosis is a frightening disease. It needs intense medical management and involves frequent trips to hospital. Mechanical respiratory support, physiotherapy to help loosen mucous in the lungs, and diet (children need extra calories and protein because of poor metabolic function) all complicate the child's life. Mobility and cognitive functions are not usually damaged until the end of life, when mobility may be limited because of shortness of breath. The disease trajectory[†] of cystic fibrosis means that palliative care is not often demanded by those affected until near the end of life, at which point intensive care and support is required.

Muscular dystrophy and other neurodegenerative conditions

Muscular dystrophy and other neuromuscular and neurodegenerative disorders are cruel conditions that do not immediately manifest themselves. The child begins life reasonably mobile and healthy, but deteriorates with age. The deterioration is particularly acute during adolescence, just when the person is seeking independence and worries about his relationship with his peer group. It mainly affects boys, and

Figure 2: Journey of a life-limited child



* Hospices not only care for children who are actually dying. The services they offer is described in more detail later, but include services to children who are in the early stages of terminal illness.

[†] The word trajectory is often used to describe the development and progression of a disease.

generally does not affect cognitive abilities (although learning disability sometimes accompanies muscular dystrophy). However, the physical effects are very demanding — the young person becomes weaker across all neuro-muscular functions. As the disease progresses, even the lifting of a light object, such as a cup, or parts of their own bodies, becomes impossible. So the young person becomes highly dependent physically, even though intellectually he may be independent. In addition, by late adolescence the boy will have grown and gained weight, with implications for lifting and moving.

Conditions resulting in complex needs from early life

Many life-limited children die of other **rare conditions** (e.g. metabolic disorders, chromosomal abnormalities). The pathology of such conditions is clinically complex. They may have severe **cerebral palsy**, which leaves them vulnerable to health complications. This can lead to impairment in mobility and cognitive development. Children suffering from these conditions will have particular emotional and behavioural needs and may require specialist help. They may also be 'technology dependent', i.e. requiring equipment in order to move around, communicate, feed or even to breathe. The time span of these illnesses may extend over many years. Advances in medicine are enabling children to live much longer than has historically been the case, some reaching early adulthood.

Frequent hospital visits can be distressing. Some treatments, at home or in hospital, are invasive. The flushing of nasal feeding tubes, or the fixing of syringe drivers, are painful procedures, which can be traumatic. Intelligent children will want to be warned about what is involved. A child with impaired cognitive ability feels pain and discomfort like any other child and will require comforting.

Children's understanding of their illness depends on their level of development and how adults present the illness. This understanding will affect children emotionally.

How conditions affect the family

The stress on families with life-limited children is acute. Although it is difficult to describe the life of such a family, the logistical challenges presented by a typical day are described below.

When the family wakes up in the morning, the parents may not have had much sleep because their child may have been distressed or had a fit in the night. Parents frequently suffer continual sleep deprivation.

The first challenge is to get any well children dressed, fed and to taken to school if the ill child needs 100% supervision. It may take a long time to feed, wash and dress the ill child, making it difficult to organise the other children. There is probably medication to administer (e.g. drugs, ventilation, special feeding tubes). The ill child might also go to school, so has to be ready too.

Laundry is a big task for any family, but the quantity of laundry increases for children with special needs. Parents frequently mention laundry as a major burden.

A child with limited mobility will need lifting throughout the day, when moved or taken to the toilet. The amount of lifting will depend on whether the child is able to use a wheelchair and how the house is physically arranged. Home adaptations are a big issue for such families.

Many children require regular, complex medication, and parents have to know how to administer it. Others are dependent upon technology and cannot be left unattended. Feeding a sick child can be time consuming; there may be worries about their medical condition if it changes. Entertaining a child with communication difficulties and other sensory problems is also challenging and time consuming.

Leaving home to go shopping, or take other children to school and activities, is usually not an option for the parent looking after the child, unless a short breaks service is available. Taking the child to the shops is difficult; if the parent has no one to leave the child with then shopping is a dilemma. An ordinary child-minder would not be qualified to look after a severely ill child, given the need for expert monitoring and

“Lack of sleep and constant fighting for help put a huge strain on us as a couple and a family. Our son is hyperactive and has some behaviour problems, which are difficult to cope with on no sleep. The struggle to find a doctor to take responsibility for J makes us feel very alone and, at times, helpless.”

Parent¹⁰

medication. An experienced family member may be prepared to undertake the task, if the family is fortunate enough to have one.

An appointment with a specialist, e.g. paediatrician or physiotherapist, may involve travelling to a hospital or specialist unit. If the family has a suitable car, it will be time consuming, but possible. If the family does not own a car, the logistics of getting to hospital can be a nightmare and there is the problem of picking other children up from school. Sometimes health care professionals may come to the house, but if this happens frequently, families can find themselves invaded by outsiders and their time together as a family is reduced.

Then there is the evening: caring for the ill child does not stop, but the other children have to be fed, helped with their homework and put to bed. Of course, the ill child also has to be fed, medicated and put to bed.

The logistics are just about possible if there are two parents, particularly if the one who is working has understanding employers. Should there be more than one ill child (it is not uncommon for a condition to affect more than one sibling, particularly if it is genetic), or if there is only one parent, then the logistics become unmanageable.

Children with less complex needs may have different and less logistically onerous routines, but there will still be stresses and strains. There are heavy emotional demands. For the rest of the family, knowing that the ill child will die is painful. Family members can lose their identity, with individuals increasingly thinking of themselves as secondary to the ill child. Siblings have their own particular needs, which are increasingly recognised. Parents rarely have time to themselves and this puts stress on relationships.

Families of children who suffer from a rare or undiagnosed condition can feel particularly isolated. The available medical research and information may be limited or even non-existent; it can be especially frightening if there are few people 'in the same boat'. Those who are affected feel abandoned.

There are often financial implications. A study by the Centre for Research in Social Policy found that it cost an average of £8,300* a year to bring up a child with a severe disability. The minimum essential budget from birth to age 17 is therefore about £143,000[†], with the largest proportion spent on transport. This is at least three times

“Trying to cope with taking your child for dialysis three times a week, looking after two other children, spending most of your time in hospitals, [doing] house chores, giving medication and injections on time...”

Parent¹⁰

more than the amount required to raise a child without a disability.¹⁴ The additional expenditure includes trips to the hospital, heating, housing, clothing, bedding, laundry, equipment and housing adaptations. Most children's parents are the primary caregivers and have to take time away from work, which means that family income is lower, adding to the extra expense. It is hard to imagine how difficult family life must be when there is not enough support. The concerns are not only humane. There are also many hidden health and social costs: poor health of carers and problems among siblings. In Bath, the Lifetime Service (described later) found that 54% of mothers and 30% of fathers had significant mental health problems. There were emotional and behavioural problems in 24% of siblings.¹⁵ Better planned services that avert medical crises could reduce the use of acute hospital services.

NPC's report *Ordinary lives: disabled children and their families* covers many of the practical, social and financial issues confronted by families and children with complex needs in greater detail. These issues apply equally to children with life-limiting conditions (often a similar group). Readers may want to read *Ordinary lives* in conjunction with this report.

“We are totally stressed; my wife and I live on a knife's-edge, the children fit constantly. We have not been away together for many years, and are also financially stretched. We had to find £40,000 for adaptations plus £20,000 for the vehicle.”

Parent¹⁰

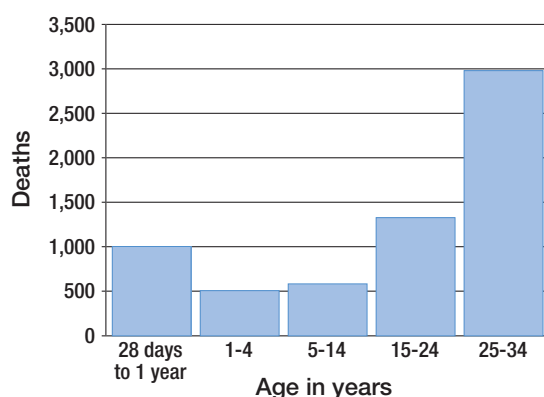
* This has been calculated by adjusting the 1997 figure of £7,355 by the consumers' expenditure deflator to arrive at the 2004 figure of £8,333.

[†] This has been calculated by adjusting the 1997 figure of £125,000 by the consumers' expenditure deflator to arrive at the 2004 figure of £143,000.

Adolescents and young adults

Many children with life-limiting conditions survive into adolescence and adulthood. It is estimated that there are 6,000–10,000 people with complex needs in the 13–24 age range. There are others with less complex needs, but these are not quantified. There are also young adults over 24 who suffer from conditions incurred in childhood, but again there is no data for how many. Figure 3 demonstrates this by showing deaths from natural causes (excluding accidents and injuries) by age. Survival rates to early adulthood are improving and there are three groups of conditions where this is particularly noticeable: cystic fibrosis, muscular dystrophy and cancer.

Figure 3: Numbers of deaths from natural causes by age in 2003



Source: National Statistics website www.statistics.gov.uk

Data taken from Table 2 of deaths registrations in England and Wales, 2003: causes report of Health Statistics Quarterly 22.

Adolescents have different needs from both children and adults.⁴ Teenagers continue to develop physically, emotionally and socially, and do not want care in an environment geared to children. Like their peers, terminally ill adolescents seek greater independence, but this occurs at the time when their deteriorating health makes them more, not less, dependent on parents and other carers. This leads to isolation and depression is a frequent problem.

When they approach adulthood, young people and their families face uncertainty because they are forced to switch to different adult services. They fear leaving an established medical and care team and having to develop new relationships with professionals who may be unfamiliar with both the condition and the young person. The young person may also worry that adulthood brings them closer to death.¹⁶

The transition from adolescence to adulthood is not well understood or correctly addressed. Only scattered information exists on how this group should receive services, and no one has analysed what services they actually receive. Indeed, suitable adult services may not exist to cater for conditions incurred in childhood. Practitioners repeatedly state concerns that when people reach 18 and cease to qualify for paediatric care, they have enormous difficulty accessing appropriate specialist care for their condition.

What care and support is necessary?

Care needs often differ from the care that is provided. Here the report describes ideal scenarios, which put the activities of service providers into context. The activities of service providers are described in more detail in Section 2.

Every child and family requires different types of care. Which type, will depend on the following issues:

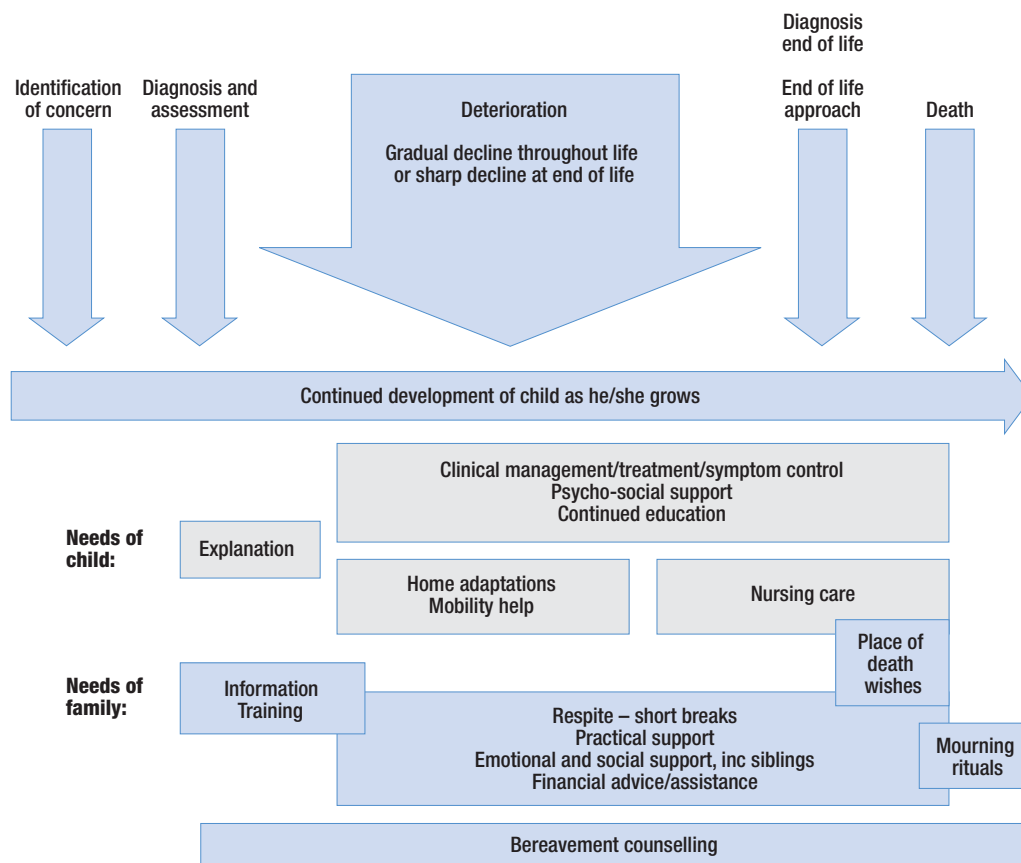
- condition of the child
- age of the child
- circumstances of the family
- geography
- cultural background.

Children with impaired cognitive abilities have different needs from those with normal cognitive abilities, but impaired mobility. An adolescent is different from a toddler. Numerous characteristics affect the family's needs: the presence of siblings and their ages; whether the family has one parent or two; the health of the parents; whether there is support from an extended family or social network; and financial circumstances. The family's own tastes and personality are also important. Families in urban centres, where they may be close to services, have different challenges from more isolated rural families. Cultural and religious issues also play an important part in what care and support is provided and how.

The Kennedy report into high mortality rates from heart operations in Bristol emphasises the need for children to be cared for in a child-centred environment. In order to respond sensitively to children's emotional needs, professionals must understand how children may react to their condition.

“I need approximately 10–20 hours a week to have someone to care for, mainly to cuddle, my son so I can provide a normal family life for the rest of my family: shopping, cooking meals, caring for my other child. This support was provided by a charity until recently, when their non-lifting policy prevented any physical contact with my son.”

Mother¹⁰

Figure 4: Journey of a life-limited child with complex needs and the support required

Care and support for families covers a wide range of activities, but many of these can be integrated:

Support and information. This must initially be given to the parents, and include: information on the condition; advice on how best to care for their child; and where to get help. It can be extended to the children themselves and their siblings as they grow up. Advice on obtaining benefits may be important if the principal earner has to give up work to care for the child.

Advocacy. Parents need advocacy to help them get support from health, education and social services. Children with complex conditions need equipment and home modifications that can be expensive. Relevant authorities frequently delay or avoid payment for such items.

Short breaks. These can be delivered at home or in residential units. Parents are usually the primary care givers at home and the pressure on them is extreme. Many parents are unable to access routine assistance with care, so short breaks are a lifeline. Short breaks come in many different guises: they could be for a couple of hours, so that the parent can go shopping with another child, or they could last a week, so that the rest of the family can go on holiday while the sick child has a holiday of his or her own. Short breaks should be routinely provided, rather than sought out when the carer is exhausted.

Support for the child. Children will benefit from psychosocial, emotional and spiritual support when coming to terms with their current physical condition and future death. Bringing young people together for treatment or recreation is helpful. Some people benefit from online support services.¹¹

Support for the entire family. The child's illness and care disrupts family life. Siblings may lack the attention normally given to children and may otherwise suffer because of the situation. They may have no one with whom to discuss their fears and emotions. They may also grieve for the sick child even before death. All family members may feel isolated due to the rarity of a child's condition. Regular hospital attendance creates geographic and logistical problems for families torn between staying with the child being treated and spending time with healthy siblings. Help to alleviate such problems is welcome. Bringing families together in support groups to share experiences is also popular.¹¹ Families value access to a wide range of services, rating help with care in the home and short breaks care as equally important components.¹⁷

Members of the family also need to come to terms with the expected death of the child. Psychological, emotional and spiritual support, including bereavement support, should start at diagnosis and will be required before and after the death of the child.

“And she's lying there ill and you are thinking: 'How many times do I have to answer these questions?'”

Parent¹⁸

Clinical care, therapy, symptom management

Medical treatment and care for the specific condition is necessary. Strategies for pain and symptom management will vary with the clinical condition. Many types of therapy are desirable, including occupational therapy, arts therapy and physiotherapy. As the health of the child deteriorates, the need to control distressing symptoms (including pain) will be essential to well-being.

Care during the terminal stages. Care at all levels will intensify during this period.

Comprehensive care, palliative or otherwise, involves more than one discipline, and a multi-disciplinary approach is desirable. Team members may come from more than one service provider, which presents challenges in terms of liaison. Carers express frustration at endlessly having to repeat information to many service providers. Strain on families is enormously reduced by efficient liaison between services and shared documentation.

Parents value choice and information to help make choices and timely interventions.

What is palliative care in the context of children?

Palliative care affirms life and aims to help patients live as fully and actively as possible until their death. The approach tries to alleviate the 'total pain' of the dying person, concentrating not only on relief of physical symptoms, but also on the need for social, psychological and spiritual support. It provides a support system for family and friends as they adapt to their loved one's deteriorating condition and eventual death. Support should begin at diagnosis or even before diagnosis, because waiting for test results can be stressful.

There are several definitions of palliative care:

'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychosocial* and spiritual.'

World Health Organisation, 2002²⁰

“Support group meetings for parents — they're brilliant. You get to learn a lot and you get to realise you are not on your own — there are other people going through the same stuff.”

Parent¹⁸

'Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancements of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement.'

ACT and Royal College of Paediatrics and Child Health – Guide 2003³

The Sheffield Model of care takes this a step further in describing how patient treatment and care can be divided into three areas:

- disease-directed therapy to cure the disease, prolong life or maintain life
- patient-directed therapy, which would include the full range of palliative care activities, support and information
- family-directed therapy providing support and information.

The Sheffield model stresses how integration improves the outcomes of the three strands of care and how they must be available from the identification of the problem, i.e. before diagnosis.

Children's palliative care is distinct from care for dying adults in a number of ways. Children have emotional, developmental and educational needs during the various stages of their development in the same way as healthy children. They often have complex impairments to physical or intellectual achievement. Care is often needed over a long period because the conditions may be present from early in life. As life draws to a close, the importance of appropriate care cannot be understated. A 'good' death not only benefits the ill child or young person, but also their loved ones and carers.

'As a society, we fight shy of pondering on death, yet inherent in each of us is a deep desire, both for oneself and for those we love, for a 'good' death. It would be absurd to try to describe that concept more fully beyond saying that everyone in this case knows what it means: not under anaesthetic, not in the course of painful and futile treatment, but peacefully in the arms of those who love [her] most.'

Mr Justice Hedley[†]

Not all children with life-threatening conditions require palliative care. But it is NPC's contention that children with life-limiting and life-threatening conditions should have access if it would benefit them and if they choose to have it.

*Psychosocial support means care that may use formal psychological methods and enhances well-being, confidence and social functioning. Such an approach would be focused on the individual's needs about the situation they are encountering and would emphasise both affirming the individual's feelings and discussing ways to cope.

[†] High Court Ruling 7 October 2004 on the Charlotte Wyatt case

Where should care be provided?

There is no absolute requirement that services should be provided in the family home or in a different setting. Some services are better suited to a specific place (e.g. hospital) but this is not always the case. Ideally, families should be allowed to choose. In reality however, for cost and logistical reasons, families may not have such choice.

There are a few important principles, regardless of location, that are desirable when providing care and support. Parents and family members are central to the care of sick children and separation (except when short breaks are actively sought by tired family members) should be avoided. Parental experience is invaluable but often overlooked, and parents and family members frequently crave the respect that they feel they deserve for the care they are giving the child.¹⁸

It is important to recognise that children should feel at ease wherever they are being cared for, and should not feel restricted from acting as they normally would at home. Space to play and freedom to move around are important. Education must be provided. It may be necessary to employ teachers when care is provided in an in-patient setting and the child is unable to attend his or her usual place of education. Parents and family members should have access to facilities in order to stay with the child when they wish.

Death of a child

The majority of children want to die at home in familiar surroundings.²² Hospitals can be noisy and frightening, and some families may not have access to a hospice, or choose not to use one. However, as with adults, the death of a child can require intense clinical and nursing input in order to keep the child as comfortable as possible. It can be terrifying to deal with the death of a child at home unless there is professional support. Unfortunately 24/7 nursing cover for children who are dying is not always available outside hospitals or hospices, and so parents are forced to take their children to hospital, or face the prospect of being alone when the child dies.

Given the numbers of deaths involved (about 3,000 each year, 10 per PCT), it does not seem much to ask that the availability of 24/7 care is arranged, if required, when the end is imminent.



Photograph supplied by Leslie McIntyre

Bereavement

Parental grief is recognised as the most intense and overwhelming of all types of grief.²³ The process of bereavement starts before the loved one dies and in the case of children may begin at diagnosis, when parents experience the loss of a normal child. The quality of life and death will frequently affect the experience of bereavement. 'Poor' deaths have a worse effect on the bereaved than 'good' deaths.²⁴

“No parent should be expected to face their child's death alone and unsupported.”

Parent²¹

NPC is concerned that not all service providers recognize that hard-to-reach groups need attention.

Acorns children's hospice in Birmingham was set up in 1986 because several families at a specialist school did not cope well after their child's death, with some family members committing suicide. At the time, social workers reported that one in seven mothers with life-limited children may attempt suicide at some stage. Acorns hopes that its work helps to prevent such tragedies taking place. The ability of parents to cope is thought to be crucial for the remaining children.²⁵ Supporting siblings, either in the normal course of hospices' work or through dedicated programmes, can alleviate their sense of being left out or ignored. It also reduces their fear of being the sibling of a child with a rare and fatal illness.

In a hospital, carers often feel stranded once their loved one dies. Most report a lack of emotional support from health professionals and little guidance about obtaining death certificates and organising funerals. Grief is sometimes described as having three stages: it starts with an initial stage of shock, disbelief and denial; this is followed by a mourning period; the last stage sees a shift of attention to the outside world and re-engagement in enjoyable activities.²⁶ These stages may overlap. Some find it hard to get through a particular stage; psychological support is valuable in such cases.

Children's experience of bereavement is influenced by their stage of development. The ability of parents to manage and communicate their own grief is thought to be critical for the emotional health of the children in the family.²⁵ Communication prior to the death is also crucial; many children are not told that their sibling will die. Some may think their own bad behaviour has led to the death.²⁷ Open communication within families can reduce anxiety.²⁸

Difficult to reach groups, such as black and ethnic minorities

NPC's research found that there was uncertainty about who needed services where. Many service providers voiced concerns that there are groups who are difficult to reach; for example, black and ethnic minorities. The numbers of children in this group are potentially significant: approximately one fifth of the hospital population under the age of 19 in England and Wales is made up of children and young people from black and ethnic minority backgrounds.²⁹

There are various obstacles to some minorities accessing services, such as language and culture. Translation services are not always easily accessible.³⁰ It is a frightening prospect for your child to be cared for by people with whom communication is difficult. In some cultures

women are not permitted to leave the house without their husband, which inhibits them from using services. Families may be worried that their child's dietary or religious requirements may not be met in a residential unit. Some cultures may hold little concept of respite, as they may view seeking help as failure. The need for honour and dignity inhibits them from seeking help beyond the family.

It is important not to generalise and assume that all minority ethnic groups 'care for their own' and do not need support. Community teams that have managed to reach such groups have found that they do need support. However, ethnic minority communities seem to lack knowledge about palliative care services. Where communities do know about services, they sometimes lack confidence that the care provided will be sensitive to their culture and beliefs.

Once services are accessed, it could be important to a black or minority ethnic family that special dietary needs are understood and catered for. Fasting is of profound religious significance in some faiths. It may also be important that the child dies while conscious, for religious reasons (so certain types of pain relief would be inappropriate). Extended family and friends would require space for prayer or ritual when death occurs. Sensitivities around handling the body properly after death need to be understood.

There are service providers, such as Acorns, that have developed a 'client base' reflecting the cultural mix of their community. However, NPC is concerned that not all service providers recognise that hard-to-reach groups need attention. The Association of Children's Hospices (ACH) recognises the need to influence practice within the children's hospice sector with respect to black and minority ethnic communities, and has begun to address this.

NPC's research also found that people in deprived areas are not using services, and that people with some diseases (such as severe cerebral palsy) are not referred to services because their condition is not always recognised as life-limiting.

Development of practice

There is now a body of guidance documentation that articulates what services children and families should receive. The government, in theory, endorses this. ACT has been particularly active in preparing this documentation, in conjunction with the Department of Health. ACT's most recent publication, *A framework for the development of integrated multi-agency care pathways for children with life-threatening and*

life-limiting conditions (December 2004), identifies the range of services needed.* The National Service Framework for Children philosophically supports the ideas promoted by ACT. Standards 6-9 stress the importance of multi-agency working and child-centred services for children who are ill, disabled, with complex needs and long term conditions.³¹ The National Service Framework exhorts local authorities and health services to work together on a number of fronts to provide the necessary services.

Section 2 will explore the implementation of these guidelines.

The children's palliative care sector started in the 1980s, and is still developing. There are new initiatives that are changing the landscape but have not yet been evaluated. One unanswered question is: How do the needs of families change when services are provided? For example, if an excellent range of social, practical and financial help were available to families who are at breaking point, would their need for residential short breaks diminish? How would families rank preferences, if a full range of services were available? How would parents spend resources to improve lives? Service providers are starting to ask these questions, and the ACT research 'Voices for Change' provides some initial pointers, but so far the evidence is inconclusive.

Summary

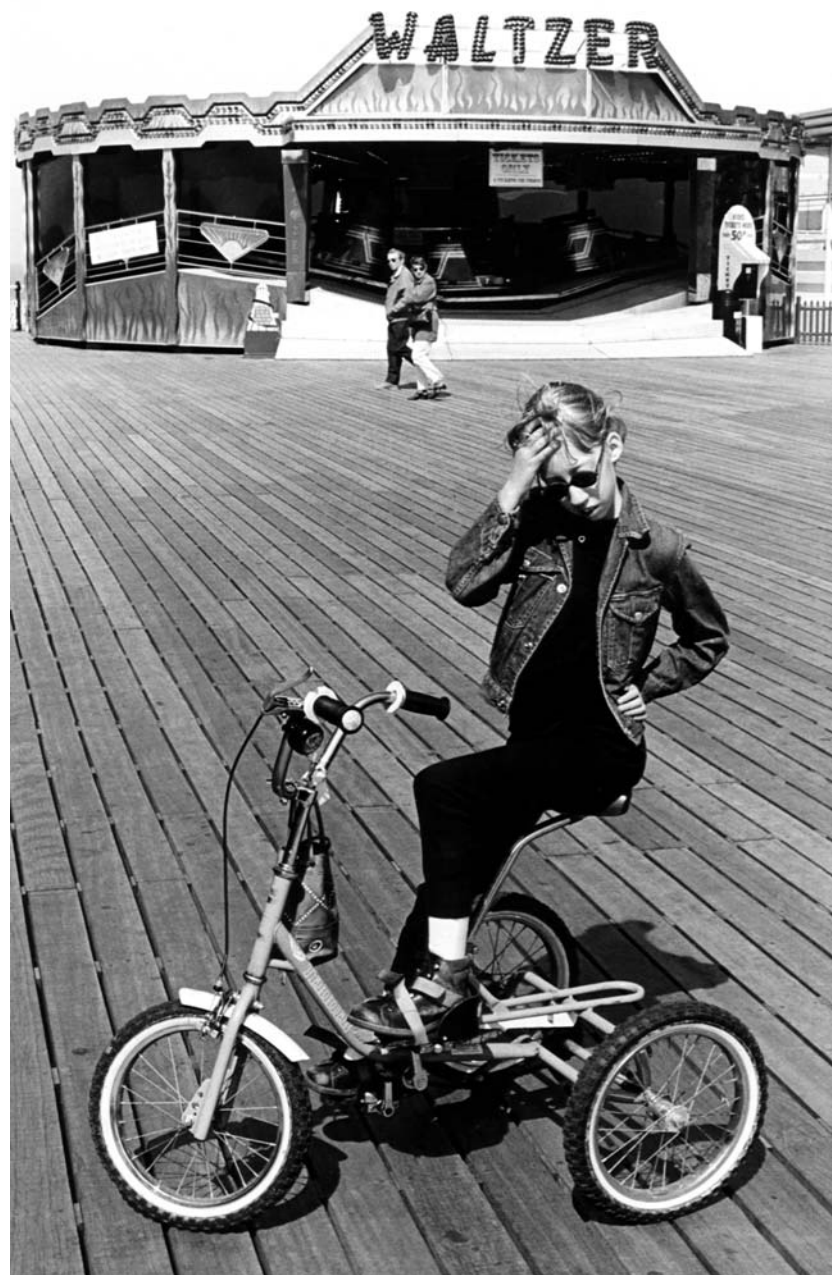
It is difficult to quantify the number of people who are facing the challenges of having a life-limited child in the family. NPC estimates there are 25,000 families in the UK coping with the mortality of child, adolescent or young adult. At any one time, there are 80,000–100,000 family members who will lose a child, and each year 2,000 family members are bereaved. Families should receive a choice of services.

There are important unanswered questions about specific needs for families:

- what gaps remain, two years after the publication of ACT's 'Voices for Change'? How serious are these gaps?
- which services are missing and where?
- which services would families prioritise, ones they receive at present or ones they would like to receive?

These unanswered questions make it difficult to know what the resource priorities are and, therefore, to recommend what extra funding is required.

There are many unanswered questions. Constant evaluation of needs and progress is vital if resources are to be targeted effectively.



Photograph supplied by Leslie McIntyre

* The word *pathway* is often used to describe the interaction between the child or family and the various agencies providing services. The connotations are apt: if the path is not clearly marked, the users easily get lost.

In the past, state-run services have been poorly co-ordinated and under-resourced. The current structure of health and social services militates against the delivery of good services and the charitable sector has had to close gaps.

NPC believes that there are significant areas of unmet need. Some geographical areas have poor provision; there are not enough services for adolescents and young adults in many areas; it is difficult for black and minority ethnic groups to access services; and the quantity and quality of care varies depending on the patient's clinical condition.

However, the situation might improve now that the government is developing community health services for life-limited children, supported by the New Opportunities Fund. At the time of writing, these services were being evaluated. After 2006, local NHS bodies must commit to funding them. The introduction of Children's Trusts to co-ordinate services and pool resources around children's needs, instead of the convenience of service providers, may benefit families and improve efficiency. There are signs that the state is recognising the wisdom of collaboration. However, such practices are slow to spread and in the meantime many families are struggling.

This section examines the provision of care in detail. It considers families' experiences of care, the role of the government and recent strategic responses to the problems. It also analyses the funding of the sector.

How is care delivered?

Public bodies and the charitable sector both provide services. The question of 'who does what' varies depending on the local health services, local charities, the condition of the patient, and where the patient is being cared for. In Section 1, the report explained that the numbers of families affected were not well recorded. The same applies to services, which have never been mapped. The National Council for Palliative Care identified areas of acute need for adult palliative care services and changed government policy after a detailed mapping exercise in 1999. It is possible to map children's services (and caseload), and was done successfully in a small area of south Wales. There is at present a mapping exercise with emphasis on adolescents and transition to adulthood being undertaken in southeast England.

Services provided by the health service and hospices

Hospitals/paediatric units

Children frequently attend hospital for medical care, and the level of service depends upon the nature of their condition. Some hospitals have condition-specific units, e.g. cancer or cystic fibrosis. Some therapies are delivered in the child's home by a member of the hospital paediatric team. There are five main hospital centres of paediatric palliative medicine: Great Ormond Street Hospital in London, Alder Hey Hospital in Liverpool, Birmingham Children's Hospital, St James's University Hospital in Leeds (in conjunction with the local hospice), and the University of Wales Hospital in Cardiff (a new children's hospital is being built). Other paediatric hospitals (such as the Bristol Royal Hospital for Children) also have to cope with life-limited children.

Children's community nursing teams

Some PCTs provide children's community nursing teams. These offer health care services to a range of children, from those who are not life-limited but need care (e.g. diabetics), to those with life-threatening conditions. Their scope varies enormously: a few PCTs have fully functioning teams available 24/7; others have a skeleton service during weekday office hours; some PCTs have no team at all. Specialist paediatric palliative care teams operating across several PCTs (described below) are increasingly supplementing these nursing teams. Sometimes nurses will develop specialist skills: one concentrating on acute cases, another on chronic ones, for instance. Their activities are varied — in one visit they may act as 'key worker' helping to access social services, in another they may train a parent to use ventilation equipment.

Paediatric multi-disciplinary palliative care teams

Coverage of the UK is not yet comprehensive. The first eight 'Diana Teams' (as these are called) in England and Wales were set up in 1999. Originally pure nursing teams, they covered eight out of 126 health districts (as they were then demarcated). They are regarded as a good model of care.³² Some have evolved into multi-disciplinary teams.

From 2003, the NHS and the charitable sector have jointly started developing teams along similar lines, in about 71 other districts. **The New Opportunities Fund (NOF)** pays for them. These multi-disciplinary teams (often referred to as **'NOF' teams**) provide services in the family home, ranging from short breaks (e.g., a morning a week by a care worker) to specific symptom control by a specialist nurse. They also provide bereavement services and benefits advice. The configuration and services of each team vary.

The teams cover a wider area than the children's community nursing teams, though they support them with training and expertise. The impact of these teams has yet to be evaluated, since most of the research relating to care needs and experiences occurred before the teams were developed.

Paediatric oncology outreach nursing services ('POONS') group

Most paediatric oncology units offer a nursing outreach service to children with cancer; 108 of these nurses have formed a group (POONS) to develop and disseminate best practice. The nurses are involved from diagnosis and liaise with community services.

Hospices

These are an important component, providing both short breaks care and terminal care for the child, and many other therapeutic and psychosocial services. Whether a hospice provides such services at the child's home, or during day or in-patient care, will vary from hospice to hospice. These are described in more detail later.

Non-medical service providers

Life-limited children require many of the same services as disabled children. Social services may be involved in aspects of care, and the education sector plays a role. There are also services such as holidays and home equipment. These are covered in NPC's report *Ordinary lives*. Charitable services are described in more detail later.

Lifetime Service in Bath: example of a home team⁶³

In Bath, the eight local Primary Care Trusts have supported the development of a home care service, the Lifetime Service, for children with non-malignant life-threatening and life-limiting conditions. Not all the PCTs have the same referral criteria and offer the same financial commitment, so the service is not consistent across all eight PCTs.

The Lifetime Service's professionals consist mainly of nurses and psychologists. It is not officially 24/7, although in practice the nurses are 'flexible' about delivering care in an emergency. Lifetime doesn't generally deliver short breaks care, but instead liaises with local charities that do. In addition to the clinical and nursing care offered, Bath also trains other service providers in the area (social services, parents, teachers, other care professionals) in some of the techniques required (e.g. using ventilation equipment) to look after ill children. Bath also helps parents navigate the system to obtain the social care required. Psychologists form part of the team helping families cope with some of the psychological pressures.

Bath is generally regarded as one of the leading teams in the country in the development of care for children with complex needs. There are 16 professionals looking after 275 children, with the intensity of care varying. Complex cases may cost £100,000 per annum to look after, but cases that are less demanding bring down the average cost to about £4,000.

Social services

Local authorities should provide some of the social care (including home adaptations), but this does not always happen in a timely manner, if at all. Social workers and occupational therapists work hard to help children, but there are too few of them.

Short breaks units other than hospices

There are short breaks units that do not meet the precise criteria of children's hospices; they provide practical respite or short breaks that do not require specialist expertise.

Wish granting

Helping families with an ill child to go on trips, e.g. to Disneyland, or for a life-limited child to meet a favourite celebrity, is an important part of morale boosting for children and families whose lives can be bleak. The memory of such events is comforting after the child's death.

“We have never been offered help from a social worker, even though we have asked several times. It feels like I am fighting a battle all by myself, without any training or preparation for this. I sometimes feel like screaming, but no one would listen anyway. So why bother.”

Parent¹⁰

“No one seems to understand the physical and emotional strain looking after a terminally ill child has on a carer, and strain on the family. Constant obstacles are placed to prevent children getting rights.”

Parent¹⁰

Bereavement services

These help families to come to terms with the loss of a child. The charitable or public sector provides these services, depending on the area.

General support, information and advocacy

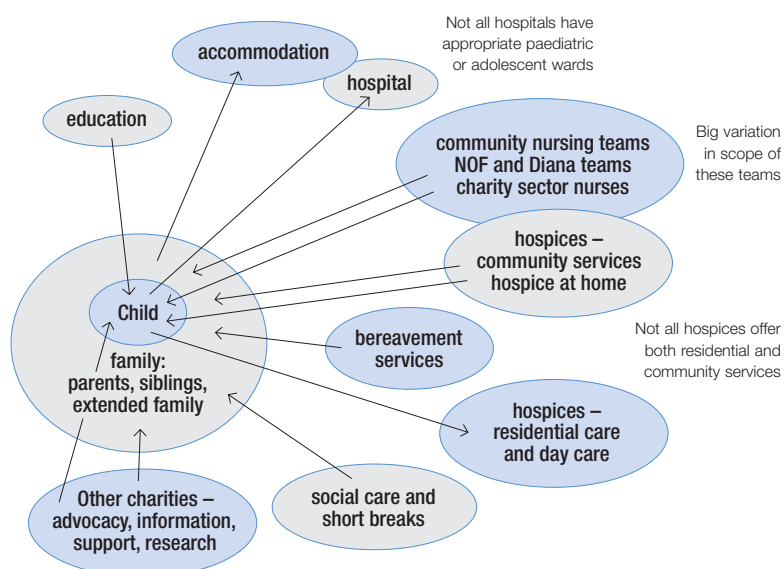
Some support and information comes from the hospital, hospice and nursing services, but other help is available from condition-specific organisations. Advocacy is needed on several levels: for families to obtain the services they are due, and at regional and national levels.

Home from home accommodation

Support during hospital stays, particularly home from home accommodation for families, is not restricted to life-limited children. However, for such families it can be a lifeline, given the amount of time sick children spend in hospital. A few hospitals provide such accommodation, but more often charities develop this accommodation even if the statutory sector may on occasion maintain the service once it is up and running.

Figure 5 summarises the services involved in the provision of care and support. Different conditions have developed different emphases on how care and support is delivered. For instance, children with cystic fibrosis will receive most of their support from specialist units in hospitals, and use community services less than children with neurological conditions.

Figure 5: Services providing care and support to life-limited children



Experiences of care....

Many families have experienced poor care from the state. Nursing care for children may not be available when needed and out-of-hours care is particularly inconsistent. Although 70% of the country has 'access' to a children's community nurse, the reality is that there may be one person covering a large area, with no 24/7 service available.³³ The service might not include specialist paediatric palliative care expertise.

Nursing care is needed to help with specific medical tasks. Parents are not qualified to check on equipment, administer complex medications, treat various ailments, understand symptoms and know whether the child needs to be admitted to hospital. If there is no nurse, the family will have to go to hospital (even if the problem is straightforward) or they may remain stranded and uncertain, worried that the child is distressed or in medical danger.

Short breaks care is not always available either at home or elsewhere. In the home, short breaks care is needed so that the parent/carer can go shopping or take a sibling out. Children with complex needs can be left only with a qualified or experienced care professional. In complex cases, this might have to be a nurse. Less complex cases simply require a sitting service for a few hours.

As mentioned earlier, hospices are used for palliative care and short breaks care away from home and in the home. The service can run throughout the child's life, not just at the end of it, unlike adult hospices. However, out of the 9,000–12,500 children identified as needing palliative care, only 4,000 use children's hospices. Children with complex needs (mainly related to the rare metabolic disorders, cerebral palsy, muscular dystrophy and other genetic abnormalities) are the largest users of hospices; these groups account for up to 8,000 children.* This shows that many children are unable to access the short breaks care and other care they urgently need. Professional and public misconceptions about hospice care (often perceived, wrongly, as only terminal) inhibits referrals of children soon after diagnosis. Children with cancer and cystic fibrosis tend not to use hospices extensively, because their disease trajectories are not as suited to the care provided by hospices. Short breaks care may not be required as much.

Some social care requirements are not met in a timely manner. Local and education authorities do not always take the needs of children seriously.

* See appendix 1

'My son has behavioural problems relating to his condition. All we've asked for is a behavioural specialist to come and advise us on how to handle him so that he can remain at his nice school, which is finding his behaviour increasingly disruptive. We've been asking for this for 18 months but nothing has happened. He was 'statemented', but they couldn't get that right either. He is visually impaired, but they missed this off his assessment. We just go round in circles' Parent²¹

The services themselves are often fragmented. A few areas are developing 'one-stop shops' such as Child Development Centres,* but in many areas people have to go to different places to access services. Families experience obstacles in accessing services and report distrust between the different agencies. Navigating the system is difficult for families even if services are available.

Professionals may be eager to provide good services, but are repeatedly hampered by structural and institutional divisions between central government, local authorities and local health services. The internal strife that occurs over who actually pays and delivers is not helpful to the delivery of good care. Budget constraints and difficulties in recruitment and retention of staff exacerbate these problems. This experience is not just confined to children who are life-limited, but that is of little consolation.

Even with reasonable support from central government, it is difficult to overcome local divisions because of the way local bodies are funded and governed. Policy changes are not felt on the ground. A near bankrupt PCT may be unable to carry out the demands of central government. Services are unevenly distributed across the country.

There are deficiencies in the provision of care addressing life-limited children's disabilities. NPC's report *Ordinary lives* explores the lack of care and support for all disabled children, including those with complex needs.

These comments paint a bleak picture, though occasionally there are signs of improvement, for example, in the joint working practices in areas such as Lancashire and Cumbria. These are described in more detail later.

Staffing and recruitment

In general, paediatric palliative care is not well developed as a clinical area; at present only six paediatric consultants in the UK are appointed as specialists in palliative care. There are a number of general paediatricians involved (about 80 with varying levels of palliative care expertise),

Comments on services from parents and professionals to ACT¹⁰

'Parents have to be very persistent to get appropriate services, some just give up, others go on crusades. Family life suffers, marriages break up, other children in the family suffer.'

Health professional

'It took more than a year to have home adaptations made. This meant we were lifting and carrying our daughter up and down stairs, caring for her toilet needs in a cramped space. We have spent considerable sums of money on a chiropractor with our bad backs as a result of lifting and handling. The younger siblings were sometimes required to aid in our daughter's care. Both parents were needed for most care, which meant the other children had to fend for themselves.'

'...health and education authorities each say the other is responsible for providing services. [We] have to travel to different hospitals for different equipment — one for shoes, one for seating, one for wheelchair etc.'

'Bureaucracy is rife and only serves to place more obstacles rather than help. It also creates frustration and mistrust among service users. We have used a single agency system while we were overseas and it was much simpler to access services.'

'Information about service providers is very fragmented. There is no one agency to oversee all our needs. We do our own research and chasing-up to get anywhere. The whole situation is a quagmire and would easily deter and demoralise the not-so-determined amongst us. Indeed this has affected us just so in the past.'

'All the health authority tells us is that "there is only so much money in the pot, you know". "It costs too much to train carers for decent respite". "It is a mother's job to look after their children, not the health service". "Try not to get so upset". These are all comments I have heard from our health authority.'

'I seem to be constantly reminded about people's budgets. While I appreciate there is always a shortage, I know families around the country in similar situations receiving much better services than my son.'

Parents

and a few adult palliative care doctors also take an interest in children and adolescents.³⁴ Part of the problem is the small number of cases: a GP who is not connected to a palliative care team would probably come across only two to three cases of a child dying at home in the whole of his or her career.³⁵ However, children's hospice doctors, when they are local GPs by background, can be helpful bridges between charity and statutory service providers and also help develop medical practice.

It is estimated that the number of nurses specifically qualified in paediatric palliative care is less than 100.³⁶ However, many more nurses have some palliative care qualifications or experience. It is difficult to recruit and retain of nursing staff across both the statutory and the charitable sectors. This prevents the development of services in a number of cases (some funded posts are not actually filled). A broader strategy is now needed to address the lack of paediatric palliative care nurses. ACH has

* New initiative putting children's services into one unit, delivering a 'one-stop-shop' service

Neuromuscular disorders in Wales³⁷

NPC estimates that there are about 125 people with muscular dystrophy in Wales.* A network has been set up to try to address the problem of young adults with neuromuscular disorders, including muscular dystrophy. The co-ordinator (a specialist in medical genetics) is worried about the lack of funding for services for young adults; at age 18 they can no longer access paediatric services.

An example is the need for physiotherapy to keep a person in reasonable physical shape, given the problems of their condition. At 18, the person with muscular dystrophy stops receiving physiotherapy through the paediatric route and has to go on a waiting list for an adult neurologist to see him. The neurologist might then refer him to an adult physiotherapist (who may not have experience of the condition) and who also has a waiting list. There are cases where the person has gone without physiotherapy for 18 months, and as a result, their condition deteriorated unnecessarily. The person is then seen as a 'crisis' case when the 'crisis' could have been avoided by careful management.

This example is symptomatic of a system that does not allow for transition between childhood and adulthood.

identified this as an area of concern within the children's hospice movement and intends to tackle the problem. Both the Royal College of Paediatrics and the Royal College of Nursing have also established Special Interest Groups in Paediatric Palliative Care to develop the specialisation. There are universities and charities collaborating to develop courses. The technical demands on nurses are growing because the technology to assist life-limited children (ventilators, home dialysis, feeding tubes, hoists, chairs etc.) is becoming more sophisticated.

Transition from childhood to adulthood

Services for adolescents and young adults are not well mapped, but where mapping has taken place, it is clear that the services this group receives are generally either inadequate or inappropriate.

The health system has particular quirks. For example, the Royal College of Nursing (RCN) views all patients over 18 as adults, so if a young person with a prolonged condition turns 18, they have to move to an adult ward in hospital, often a geriatric ward. Parents will no longer be able to stay with them on the ward.

Worse still, expertise in a particular condition may be contained within the paediatric specialist area, with adult physicians knowing little about essentially childhood conditions, so patients lose access to vital medical expertise. This can have devastating consequences for a family that is forced to change services. The process of gaining access to 'adult' services (where they exist) may take months. Sensible planning should avoid waiting lists, but resources for planning young adult services are few and far between.

Hospices may also have a cut-off age (usually 18). Patients diagnosed after this age are not eligible for services and instead have to go to an adult hospice. There are cases where children diagnosed before 16 are refused access after they are 19, even though they die shortly after (in unfamiliar surroundings). A few hospices do not accept children diagnosed before 16 if the trajectory of the disease means they are unlikely to die before their nineteenth birthday. Yet adult hospices are rarely geared towards the needs of young adults.

Education services are also withdrawn at the age of 18/19, which is often when more, rather than less, support is needed. Social isolation becomes a problem and, in any case, the people concerned may not be ready to cease education.

This is even more traumatic for adolescents with learning disabilities who are suddenly expected to use adult services the moment they turn 18, even though their developmental age may be much lower. Many children with complex needs have learning disabilities.

Strategic and local responses from government

There are several significant recent responses from the government to the issue of children and palliative care:

- NOF funding of £48 million for three years in 2003
- Government Response to the House of Commons Health Committee Report on Palliative Care issued in September 2004
- National Service Framework for Children, Young People and Maternity Services (NSF) issued in October 2004 by the Department of Health (DH) and Department for Education and Schools (DfES)
- Endorsement of the Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions by ACT published in December 2004
- Every Child Matters and Children's Trusts.

NOF

The Big Lottery Fund, the new body that has arisen from the merger of the **New Opportunities Fund (NOF)**[†] and the **Community Fund**, is making a substantial contribution to the area in the short term. In October 2000, the government announced additional funding of £48 million to support palliative care services for children, and used NOF to cover this. Although this is not

* 2.9 million people living in Wales, 59.2 million people living in UK in 2002 implies that 5% of population live in Wales. 5% of the 2,500 people with muscular dystrophy implies 125 are living in Wales.³⁸

[†] NOF was set up in 1998 to distribute Lottery money to health, education and environment projects. NOF funds new projects rather than existing work and grants tend to last for three years. This report shall continue to refer to NOF rather than the Big Lottery Fund because the sector refers to NOF.

government money, it is regarded as a government initiative. The funding has been allocated to 71 home-based care teams (the 'NOF' teams described earlier), 25 hospices developing new services, and 39 bereavement services. The funding is spread over 2003–2006. There are concerns about sustainability because it is unclear if PCTs will have the funds to continue services after 2006 when the funding runs out.

In order to qualify for NOF funding, 'NOF' teams had to put in 'bids' with the support of PCTs and SHAs. The idea was that the NHS would pick up the funding after NOF monies expire in 2006. Inevitably, this process favoured those parts of the country where there was interest and expertise in children's palliative care. Consequently, there are areas where no NOF bids were submitted, or bids were rejected because local PCTs would not support them. So areas where there have been no successful NOF bids (unless they already have a Diana Team in place) are likely to lack essential services.

The NOF initiative has had benefits that are not only financial. It has encouraged service providers to collaborate (charities, PCTs and other services) in order to produce convincing bids. Working relationships have improved as a result. These strategic bodies have sometimes continued to exist in order to continue their work in planning services.

National Service Framework (NSF) and Commons Select Committee

The Government Response to the Commons Health Committee refers to the NSF and highlights areas of concern that the NSF is to address, notably the importance of the family as carers, and transitional care for young people approaching adulthood. It appears to rely on the NSF to deliver change where needed, but also states that:

'To help PCTs in their strategic development of these services, the DH [Department of Health] plans to undertake further work on the range of options and service models for children's palliative care. The DH is also awaiting the publication of guidance on children and adolescents with cancer by NICE'. The National Institute of Clinical Excellence (NICE) guidance is due for publication in June 2005 and includes a section on children's palliative care.

The NSF includes 11 Standards in total, relating to many aspects of children's health and well-being. It highlights the importance of multi-agency working and issues around transition

Are services better provided regionally?

The number of life-limited children and young people in any particular area is small, and not all services need to be available in all local areas. Offering a full multi-disciplinary specialist service to just 70–75 life-limited children (not all of them actively needing palliative care) in one PCT would be resource intensive. A tiered approach may be more realistic. A team covering about 800 life-limited children at the Strategic Health Authority (SHA) level makes more sense. In Cambridgeshire the SHA undertakes the key co-ordinating role. Other services could be delivered at this level, for example equipment libraries where children could use wheelchairs that older children have grown out of. Basic home services shared with other users (e.g. children who are ill in the short term) should be available locally and consistently, but often are not.*

from childhood to adulthood. One of the Standards states:

'Local Authorities, PCTs and NHS Trusts [are to] ensure that:

'24-hour access to expertise in paediatric and family care (often provided by local community children and young people's services to enable continuity of care) is available.....24-hour expertise in paediatric palliative care (provided by those with specialist palliative care training) is available.'

A full transcript of the section in the NSF on palliative care is provided in Appendix 2.

Although the NSF will help professionals to argue for more resources and attention in this area, this document was issued with no budget attached. Responsibilities are, generally, rather than specifically, allocated. Because the document tells local authorities and health services to provide various services and standards between them without allocating clear responsibility for delivery, the responses are all too often 'who is paying for this?' and 'it's not my problem'.

In most areas of the UK, access to 24 hour care and expertise as suggested by the NSF seems a long way off. Frontline service providers would like joint budgeting between service commissioners so that such squabbles are overcome. As noted earlier, in a few isolated areas there are attempts at budgetary collaboration, with some success, but such coherence is rare. Children's Trusts may help here.

Central government can publish documents exhorting local service providers to provide particular services, but the gap between rhetoric and reality is daunting.

* There are 28 SHAs in England and Wales and they oversee the activities of the PCTs.

It was good to have everybody in the room because then you're not telling your story over and over again... Everybody gets to be aware of the difficulties...

Parent¹⁸

Children's Trusts and joint working

Government policy in relation to children has evolved in the wake of the Victoria Climbié case, resulting in the Children's Act 2004 and the Every Child Matters initiative. The government is at present piloting Children's Trusts. These aim to reform the way services are delivered. Children's Trusts encourage joint working and the pooling of resources between health, social services and education. They have powers to hold joint budgets. If successful, this could improve the lives of children considerably. However, there is concern that without additional resources it will be difficult to achieve the objectives of Children's Trusts. There are also cultural obstacles to overcome in introducing shared resources.³⁹ However, in Brighton, which is one of the pathfinder Children's Trusts, there is optimism that services will improve because of better co-ordination.⁴⁰ The work of a local charity, aMAZE, in co-ordinating the views of families and gathering data is helping the development of the Children's Trust's work.

Government response to the charitable sector

Shortly after the National Service Framework was issued, ACT published its more detailed description of how the NSF should be deployed for life-limited children. The Royal College of Paediatric and Child Health and the DH (who paid for it) endorsed this work. Dr Stephen Ladyman, MP, the former Parliamentary Under-Secretary of State for Health, said:

'The ACT Care Pathway guidance, funded by the DH, has been written to complement the NSF. It highlights how the requirements of the NSF, in relation to children's palliative care, can be most effectively met. I am pleased to offer my endorsement and expect service commissioners to use the points identified within the Pathway to facilitate discussion with providers of children's palliative care services, from both the statutory and voluntary sectors, and across all agencies and disciplines involved.'

There was no mention of who pays for this.

The recommendations of the ACT work on care pathways reflect earlier work identifying the wide range of needs of whole families in coping with a life-limited child. It is helpful because it identifies what needs to happen at different stages during a patient's journey. It sets out five simple standards to be followed:

- Every family should receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided both for the child and the family in language that they can understand.
- Every child and family diagnosed in the hospital setting should have an agreed transfer plan involving hospital, community services and the family, and should be provided with the resources they require before leaving hospital.
- Every family should receive a multi-agency assessment of their needs as soon as possible after diagnosis or recognition and should have their needs reviewed at appropriate intervals.
- Every child and family should have a multi-agency care plan agreed with them for the delivery of co-ordinated care and support to meet their individual needs. A key worker to assist with this should be identified and agreed with the family.
- Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this as closely as possible.



Photograph supplied by Leslie McKintyre

In Lancashire and Cumbria, professionals report a positive experience of joint working. Good co-ordination of services is also reported in the Newcastle area. This is partly because the local hospice found and funded a multi-agency service co-ordinator.

'Regular meetings give you opportunities to talk to people about how things are in their bit of the organisation, whether there's anything we can do to make it easier, and whether we should be doing things differently. I think that those meetings have definitely enhanced our work with families.'

Professional¹⁸

As noted earlier, in reality there are glaring problems. Requirements for specialist equipment and home alterations (before leaving hospital) are rarely handled promptly or appropriately. There are frequent incidents of children dying before equipment is supplied. Another problem is that an 'assessment' of need does not equate to a right to service or statutory obligation. The notion that every child and family can achieve an end of life plan in accordance with their wishes is highly dependent on charitable sector service provision, especially hospices.

Department of Health (DH)

The DH is expected to publish further guidance for commissioners to complement the NSF. However, at the time of writing, the content and its expected publication date were unknown, despite pressure from ACT and ACH to publish guidance they had worked hard to influence.

Another concern for providers of palliative care services is the lack of resources within the DH to look after the interests of children needing palliative care. There is no central co-ordinating body or senior dedicated 'champion' of children's palliative care. Cancer has a full time cancer 'Czar' who is committed to a wide range of adult palliative care issues, and has the power to make changes. Cancer survival rates have improved as a result. There is no equivalent for children with life-limiting conditions. The responsibility for these children is split between the Minister for Children, Minister for Disabilities, Minister for Health and Minister for Education (Special Education). Their attentions are not focused on this small group of children.

Research and education

The principal academic centres for children's palliative care research and/or education are in Cardiff/Swansea, Bristol and London (Great Ormond Street Hospital). The funding of these centres is generally a mix of the local university and NHS. Occasionally a grant-making trust may pay for a particular programme. Education and research frequently overlap in centres. Dr Hain in Cardiff observes that there are few people doing research and it is quite difficult to access funding because health, education and social services all have separate budgets for research. A table of academic centres contacted during NPC's research and their activities is included in Appendix 3.

The main preoccupations of the academic centres are:

- developing a range of courses for professionals and non-professionals to improve expertise in children's palliative care across the board

- solving pain management problems for children and young people with conditions that may not respond to mainstream pain management techniques
- developing a better understanding of the trajectories of the different conditions, and the consequences for the transition from childhood to adulthood
- more research into the effects on families, e.g. mental health of parents and siblings.

Who pays for what?

In the same way that service delivery varies with location, so too does funding. The NHS is a large contributor in terms of medical facilities and services. The New Opportunities Fund also provides significant funding. Local authorities contribute some resources. However, charitable donations pay for most of the other services (short breaks, information and support, and help with day to day living).

NHS

NHS funding for palliative care is channelled mainly through PCTs, with the occasional funding via SHAs. There is no central funding for children's palliative care in England. Funding from PCTs and SHAs covers:

- hospital expenditure (but not all, some paediatric units developed by charitable appeals)
- GPs
- children's community nursing teams
- paediatric multi-disciplinary teams (partial)
- paediatric oncology outreach nursing services (POONS) (partial)
- children's hospices (up to 6%).

The NHS meets only part of the cost of specialist paediatric multi-disciplinary teams. The rest is provided by NOF until 2006, in the expectation that PCTs will then take over. The Diana Teams, which formed earlier (at a cost of £4 million),⁴¹ are now mostly covered by the NHS, although some are still in the process of securing funding.

The contribution of the NHS to the cost of paediatric oncology outreach nursing services depends on location and the contribution of CLIC Sargent or Macmillan Cancer Relief to the service.

In England, the NHS contributes on average 6% of children's hospice expenditure through 'service level agreements'.^{*} There is little consistency across the UK; and there are substantial funding inequalities. Calculations in

^{*} NPC's calculations using latest available data from Caritas and financial statements submitted by charities

service level agreements do not take into account the fluctuating nature of need for palliative care services. This can be a disadvantage for hospices, because they have to meet staff costs, whether or not all beds are occupied. Hospices often cover multiple PCTs – the average is nine to ten, but Naomi House in Winchester counted 40 PCTs within its range – and this makes the negotiation of funding arrangements highly complex. Some hospices decide that the effort required to manage the contracts exceeds the financial benefit. Funding of hospices by the NHS would work better at SHA level, but SHAs have tiny budgets. Because hospices provide short breaks care, local authorities should contribute to this cost, but in reality this rarely, if ever, occurs.

Local authorities

Local authorities provide some funding for multi-disciplinary teams when the budget is not fully covered by NOF and when the teams include the elements of psychosocial support that would normally be provided by local authorities.

Combined funding in Scotland

In Scotland, the Executive committed the state to funding 25% of the costs of Children's Hospice Association Scotland (CHAS), which is the main palliative care provider. The Health Boards are to fund 12.5% and the local authorities 12.5%, totalling £1.4 million. Not all of this funding has been received so far, more like 21%.

Health Boards are also responsible for providing community nursing services.

NOF and Diana teams, value for money?⁴²

Costs of NOF and Diana teams vary but can be in the region of £400,000–450,000 per annum, not all of which is provided by NOF. An example would be the Coventry and Warwickshire Diana team that covers four PCTs. It has a budget of £350,000. This includes a substantial component for training and support to the local community nursing team.

This multi-disciplinary team consists of a skill mix of carers, nurses (nine senior and junior), psychologist, social worker and administrators. It provides the family with specialist support, supplementing other local services. The team works closely with other services to deliver seamless care. Together they support 200 children, half of whom need palliative care at any one time.

The Diana team focuses upon support in the home, support to brothers and sisters, and is able to prioritise resources in the terminal care stages, round the clock if necessary.

The team spends roughly £3,500 per family to provide quite intensive services. This is good value, given the benefits to the families concerned.

New Opportunities Fund

The NOF funding of £48 million spread over 2003–2006 is divided between the following strands:

- £15.3 million to 25 children's hospices to develop services and pay for capital expenditure.
- £30 million to the 71 home care teams (described earlier) providing specialist paediatric multi-disciplinary palliative care in the children's own homes.
- £2.8 million (approx) to 39 bereavement services (about £75,000 each).

The home care teams are known generally as 'NOF' teams. PCTs are supposed to take over funding in 2006.

Charitable sector

The charitable sector provides substantial resources to the field of children's palliative care. Charities often have a greater chance of getting statutory funding if they can make a case that funding would result in a total cost saving. This is harder to make in the case of many children's services, such as hospices. The emphasis on short breaks care provides no obvious savings for the NHS, although in reality, short breaks improve the health of the carers. It may also help to avoid emergency hospital admissions. Charities fund the following services:

- children's hospices, including hospice at home (94%)
- hospitals' charitable appeals
- nursing services
- general support, information and advocacy
- financial support
- home from home accommodation capital costs
- bereavement services
- wish-making.

The charitable sector provides the lion's share of funding for hospices; NPC estimates 94% in total. It entirely funds the high capital costs of developing children's hospices. Other short breaks services, such as the Jessie May Trust, are also frequently paid for by voluntary donations.

Charitable fundraising initiatives, to build extra wards or develop extra services, frequently supplement hospital budgets. This is especially the case with paediatric units, which regularly fundraise from the public. Quantifying how much of this fundraising applies to services for children with life-limiting conditions is impossible.

Table 1: Funding of services — £ million per annum

Organisations delivering services	Statutory funding	NOF funding	Charitable funding	Total funding
Diana Teams*	1.3	n/a	n/a	1.3
NOF teams†	18.0	10.0	minimal	28.0
Children's hospices (income)**	4.4	5.1	64.8	74.3
Other short breaks, nursing and home from home	minimal	0	10.0	10.0
Other annual NOF funding	n/a	0.9	n/a	0.9
Condition specific charities††	nil	minimal	40.0	40.0
Total funding	23.7	16.0	114.8	154.5

Total charitable funding exceeds £115 million per annum.

Specialist disease groups, such as cancer, muscular dystrophy and cystic fibrosis, rely on voluntary donations for services that statutory funders might normally be expected to pay for: CLIC Sargent and Macmillan Cancer Relief often contribute to oncology nursing services, and several charities provide hardship grants for equipment and home modifications.

Although the charitable sector usually pays for home from home accommodation, occasionally the local PCT finances the running costs.

Payment for bereavement services varies enormously, but some organisations have substantial voluntary donations.

Analysis of the figures

Total charitable support for children with life-limiting conditions amounts to at least £115 million.[‡] At its crudest, this equates to about £3,800 per life-threatened child, including those with cancer who survive.[§] Much of the income of condition-specific charities is spent on research: £11 million in total.

Children with **cancer** are well supported at roughly £6,000 per annum per child with cancer.[¥] Income for the children's cancer charities, including nursing services and home from home accommodation, amounts to £27 million. Some large cancer charities not

specialising in children also fund research into children's cancer, but their expenditure is not included here.

The incomes of the other main condition-specific charities (cystic fibrosis, muscular dystrophy and metabolic disorders) amount to £15.4 million. The group affected by cystic fibrosis receives £1,150 per child, although additional support for this group comes from specialist units within the NHS and cannot be quantified. The group affected by muscular dystrophy receives about £2,200 per annum per person. People with metabolic disorders receive even less: about £1,000.[°] Cerebral palsy is excluded from Table 1 because there is no data on expenditure for children with severe cerebral palsy. SCOPE covers life-limited and non life-limited children with cerebral palsy; but it does not offer specific services to those who are life-limited. Children with complex needs have requirements that are expensive and cost more than able-bodied children with cancer or cystic fibrosis. Children with complex needs, including muscular dystrophy, cerebral palsy and rare metabolic conditions, are substantial beneficiaries of children's hospices.^{††} And this income generated by the hospice sector is about £18,500 per child. Hospices provide some of the services that, if the child were to have cancer or cystic fibrosis, they would get from the specialist charities.^{‡‡}

* When originally set up, the eight Diana teams cost £4 million over three years.

† NOF funding runs from 2004 and is taken from public details of programmes funded by NOF. The total funding of NOF teams is an estimate by NPC based on roughly 70 teams, each costing on average £400,000 per annum. Statutory funding is deduced from this.

** The funding figures for statutory and charitable funding are taken from charity accounts (if submitted to NPC) and Caritas. Not all charities submit accounts to Caritas, however, and the data was incomplete. The dates of the accounts available vary from 2002 to 2004.

†† Excludes nursing and home from home already included, but includes £11 million of research.

‡ NPC has not comprehensively reviewed the accounts of every charity that may be contributing to efforts, only the main ones.

§ 25,000 life-limited children, add back about 5,000 cancer patients who are not life-limited (difference between 11,500 and 6,900, see Appendix 1), so divide £114 million by 30,000.

¥ Dividing total income of cancer charities (£27.3 million) by CLIC Sargent's figure of 4,600 for children with cancer.

° NPC calculations 2005 (internal spreadsheet).

†† N.B. Hospices offer an important service to children with cancer who may be neurologically impaired or come from a difficult social environment.

Relative contributions from government and charities

Children's hospices get roughly 6% of their income from statutory funders at present. With the introduction of NOF funding this increases to 13%. None of the condition-specific organisations receive statutory funding.

Although the government provides considerable resources for clinical care (in the form of inpatient hospital care, some of the local nursing services, GPs, drugs and equipment) it provides little for day to day living. It funds 26% of help and care, if NOF is included. Charities have to provide many of the services identified here because government services are chaotic or non-existent. The public also often helps to pay for hospital infrastructure. In conclusion, 26% is a poor proportion of contribution. Resources from both the government and charities are insufficient.

Summary

Many families have frustrating experiences of care because services are unavailable or badly organised. NPC is concerned that many services are driven by criteria, rather than by the needs of the child and family — it seems all too easy to be 'disqualified' for a service because of age or medical condition, even though the need is self-evident. This 'rationing' of services is a false economy.

There are services, however, which are developing: community palliative care teams supported by NOF funding could make a big impact, but it is too early to say how great, and there are concerns about sustainability. Hopefully PCTs and SHAs will value these services and not reduce funding after 2006. These services are likely to be helping large numbers of families at a reasonable average cost. For the families concerned, the benefits will be extremely valuable. NPC suspects that such teams may actually save money for the government by improving the well-being of families and averting crises.

Does this matter to a private donor? Yes, because any charitable activity that supports these efforts, either through advocacy or sharing of expertise and resource, will benefit the children, families and society in general.

The next section will consider what charities are doing to contribute to these efforts.

Some of the services provided and paid for by charities should be the responsibility of government.



Photograph supplied by Association of Children's Hospices

Contribution by charities

3

Without charities, the lives of families with children affected by life-limiting conditions would be intolerable. Charities have developed vital services, such as hospices, which previously did not exist, and continue to provide them in the absence of government responsibility. They are constantly advocating for families' rights to reasonable service provision — at the family level (helping families to access services), at the local level (liaising with local government agencies to develop services and bid for funding), and at the national level (trying to influence government policy).

This section looks at various activities that charities provide or fund. It will cover hospices, which are the most visible component of charitable service provision, as well as charities offering other forms of support, practical help, information and advocacy. There are also a number of charities described in *Ordinary lives* that also help children with life-limiting conditions who are disabled.

In the previous section, NPC raised its concerns that services try to 'box' affected individuals (who may be an inconvenient age, for instance). Some charities have to exclude groups (e.g. children in late adolescence moving into adulthood) because they have to ration resources and focus. This is understandable but also frustrating. It results in some people who, by not fitting with anyone's criteria, being more disadvantaged. Some of the services offered to life-limited children could be extended to disabled children (for instance technology-dependent children) whose quality of life and stress on families is equally distressing.

Hospices

Background

Children's hospices are the main charitable sector providers of care for children with life-limiting conditions. At present there are 36 fully operational members of the Association of Children's Hospices (ACH) serving nearly 4,000 children each year. Six of these hospices do not offer residential facilities, but concentrate on hospice-at-home services or day care. The others all have residential beds – 219 in total. A further seven hospices in development are members of ACH.⁴³ There are also a handful of other organisations that are close to complying with the definition of a children's hospice.

When the first children's hospice was set up in 1982, it opened a flood-gate of demand and rapid growth. Hospices have played a key role in helping to develop paediatric palliative care methods and protocols, including clinical protocols, and also many psychosocial services. Medical care is still evolving, and the relationship between hospices and local GPs is part of this evolution.⁴⁴

Individual hospices offer widely varying services. They may include:

- residential short breaks care, end-of-life care and emergency care during 'episodes' when symptoms require stabilisation.
- short breaks care and end-of-life nursing care for children in their own homes, sometimes referred to as community care or hospice-at-home
- psychosocial care for families at home, also sometimes referred to as community care, which does not include nursing
- day care, including a wide range of therapies and stimulation (multi-sensory rooms, hydrotherapy pools)
- social events for both children and families as well, to promote support networks
- telephone advice, liaison, contact and key worker services in helping families navigate available services
- bereavement and pre-bereavement support, often continuing for as long as it is required after a child's death, and starting as early as possible after diagnosis.

“Local authority social workers seem to be non-existent; therefore families rely on the charity social worker to sort things out. Respite care and holidays are sorted out by charity based social workers.”

Parent¹⁰

The impact of care in a children's hospice

'Acorns turned it into something graceful, something dignified — and not just his death, his life too.'

Parent of a child who died at Acorns Children's Hospice⁴⁵

'Charlie is now eight and has an undiagnosed neurological disorder. He is blind, severely epileptic, has profound physical and learning difficulties. This is extremely demanding both physically and mentally because Charlie is completely dependent on us 24 hours a day. All our friends tell us that we need a break but in order to take that break we must be able to leave Charlie with people who are able to meet all his needs. Helen House is the only place I have felt confident leaving Charlie. Medically he is very complex, but they take it all in their stride. It is also the only place where I don't feel Charlie's happiness is compromised by our needing a break — he has a ball! When I go to collect him I am reminded of how I felt at about his age when my mum used to come and pick me up from friends' birthday parties.'

Parent of a child making use of Helen House, Oxford⁴⁶

Parents often refer to short breaks as a lifeline. This suggests that those who do not get short breaks are left at breaking point. Families receiving support in the community or through a hospice are relieved of the constant strain of having to

battle for appropriate support. Families say they value the sense of support, and the welcoming environment. Hospice care makes them feel less alone and helps them to address the issue of the child's death openly.⁴⁷ As with adults, if loved ones are able to look back on a peaceful death and good experiences leading up to it, they are less likely to encounter problems in bereavement.

Differences between hospices

Not all hospices offer all of the services above. While hospices have to comply with relevant legislation, such as the Care Standards Act, individual services vary, depending on:

- the provision of services elsewhere in the area by the NHS, local authorities and other charitable service providers
- location (urban or rural, wealthy or deprived)
- inclination of the hospice's founder and subsequent trustees
- availability of resources.

The criteria for full membership of the Association of Children's Hospices (ACH) are:

- care and support for children with a short life expectancy and their families in whichever way most suits their needs, in separate and specially designed accommodation, or in their own home
- terminal and emergency care are available, when and where appropriate, 24 hours a day, 365 days a year, regardless of funding
- bereavement support.

These criteria are demanding, and depending on local circumstances, hospices tackle them in different ways. Some do not fully meet the criteria. ACH (at its discretion) also offers associate membership to organisations who meet some but not all criteria. It also offers project membership to hospices in development.

Table 2 depicts some of the differences between hospice services and priorities.

All the hospices NPC visited exhibit high standards of care. Some children's hospices are open and collaborative, and there are examples of successful regional joint working. Regional mergers (being contemplated by some) could increase efficiency and efficacy. Groupings of hospices on a regional basis are likely to make their voice much stronger when dealing with their counterparts in health and social services. It could also improve recruitment success, and result in better procurement prices. This has been Acorns' experience. However, some hospices are nervous about loss of autonomy and so do not actively pursue close collaboration with other hospices and service providers.



Photograph supplied by Acorns Hospice

Table 2: Examples of hospice priorities

Hospice example	Definition
CHASE, Surrey	<p>Regards its community/hospice-at-home service as a flagship service, notwithstanding a very well-appointed residential unit providing a colourful hub for community activities. Chief Executive argues cogently for community services because most care of children takes place at home, yet statutory services in the area are inadequate in meeting the depth of service required.</p> <p>An NHS nurse is available 9-5 on weekdays but only able to spare half an hour on his/her visit and this is not enough: CHASE wants to provide 24-hour coverage for all eventualities at home, and its professionals want to have the flexibility to spend several hours in the home if that was what is required. During weekdays CHASE does not fill all its beds, although weekends were generally over-flowing.</p>
Demelza House, Kent	<p>Shares many of the concerns of CHASE, but is also keen to emphasise the importance of providing individualised care packages for families. If a family (for social reasons) needs regular short breaks, and Demelza is able to resource this, then this should be provided. Demelza operates a system where if a bed is unexpectedly available, it will offer it to families as a 'bonus night' on a rota system.</p>
Martin House, Yorkshire	<p>Perceives a great demand for its residential unit and therefore expansion to provide facilities for adolescents is a high priority. It is supporting the local PCT in developing its community nursing services (which are quite good) rather than supplanting them. As the paediatric palliative care consultant in Leeds straddles the PCT and the hospice, Martin House is in a good position to do this.</p>
Acorns, Birmingham	<p>Does not provide hospice-at-home nursing services, but does provide an intensive community service which helps to advocate for services for its cases. Acorns is reluctant to commit to funding a home nursing service which it worries would be unsustainable, and instead perceives great need for residential short breaks, and so has opened a new unit in an area without provision. It is also developing its adolescent services.</p>
St Oswalds, Newcastle	<p>Strenuous efforts to work with the statutory services to ensure they (LAs and PCTs) meet statutory obligations and to improve a full range of services. To this end St Oswalds supplies a multi-agency services co-ordinator to guide referrals through the statutory system, monitor cases, improve collaboration. St Oswald's say this has been an excellent investment. Funding from six local PCTs is currently around 25%.</p>
Naomi House, Winchester	<p>It has 40 PCTs to contend with, so has long since abandoned any idea of obtaining statutory funding given the paltry sums and hassle involved. Instead it focuses on perfecting its residential care.</p>

Hospices provide an excellent standard of care. But there is scope for increased financial efficiency by following the example of hospices who have successfully reduced costs and reserves.

Most hospices agree that families should have choice. However, in some cases, what was understood by choice seemed limited in scope. The criteria for membership of ACH highlight interesting priorities: all members must aspire to provide emergency *care at any time*. Not all residential units, given their resources, are able to guarantee this. Management face some difficult dilemmas.

Given regional differences, varieties of service models, and varying resources, it is inevitable that individual service providers have different priorities. There is no 'one size fits all' or 'perfect model' of care delivery. As long as service providers engage with the needs of local communities and families in the most intelligent and professional manner possible, then they are in a strong position to determine the best services for the families involved.

Expenditure on hospices

Running children's residential hospices is expensive, because of the intensive care needs of children. The crude cost of providing such

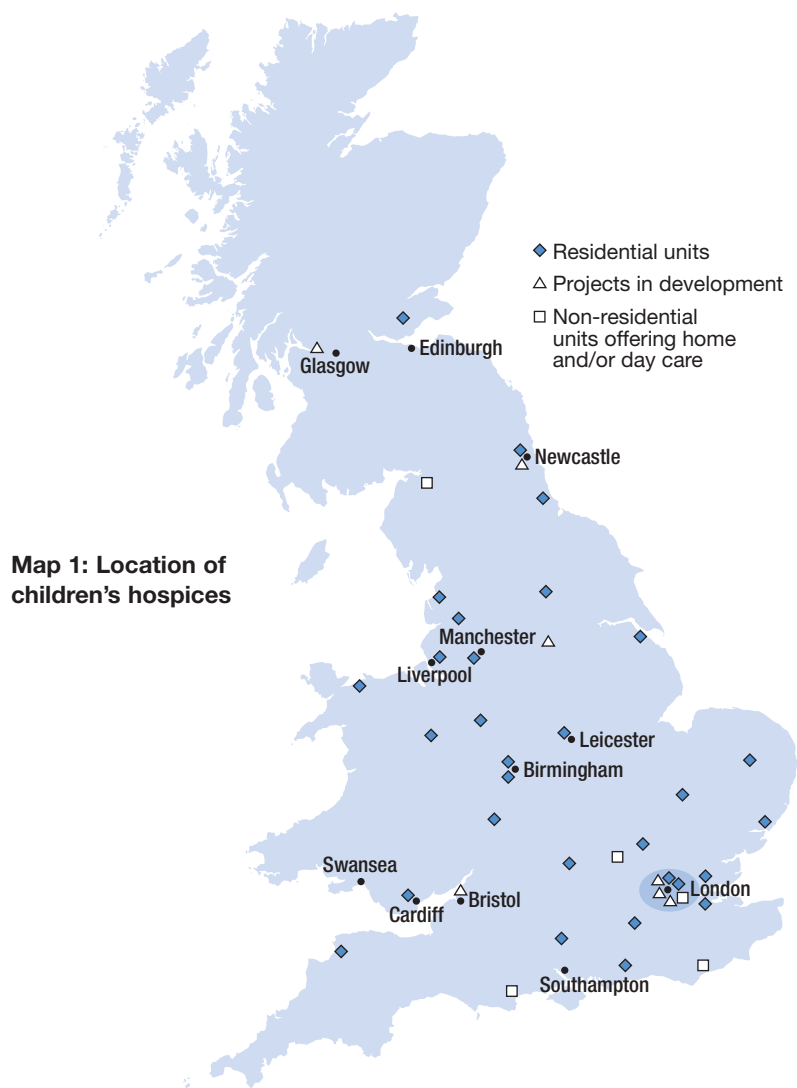
care is £450–£700 per bed-night, depending on facilities, economies of scale, staffing ratios, and age and condition of the children. This is considerably more than an adult hospice, because of the requirement for high staff to patient ratios for children. A fortnight's short break for a child will therefore cost up to £10,000. The capital cost of building children's hospices is about £400,000–£500,000 per bed. This may seem expensive, but if one includes the parents and siblings as beneficiaries of such services, then the real cost per beneficiary is much lower.

For most children, the centre of care is their home. Although parents see short breaks away from the home as important, they would like more continuing support in the home.¹⁷ It is interesting to compare the costs of such home care or community services with residential services. One hospice offered an approximation of the cost allocation between its residential and community services. The numbers implied that the residential services cost three times as much (per child) as the community services.*

Children's hospices generate income of £74 million each year.[†] Expenditure is £52 million per annum, i.e. £13,000 per child. In the last period of recorded financial results, the sector generated a surplus of £22 million, bringing total reserves to an average 18 months' expenditure. Some hospices have three years' expenditure in reserves, reflecting the conservatism of trustee boards. NPC would like to see a portion of the value in the reserves unlocked and invested in income generation (e.g. fundraisers and shops). This would bring a higher profit than investment and deposit rates. The money could also be used to develop additional services, such as facilities for adolescents, which would require some one-off capital outlay. Reserve levels can be reasonably held at under 12 months, given the loyalty of donors to children's hospices. Some hospices succeed in running their services with six months of reserves.

Utilisation of hospices and gaps in supply

The demand for services often exceeds supply. Well located hospices record utilisation of roughly 80-90% (some beds are deliberately left available for emergency admissions). However, there can be periods of lower demand, e.g. during the week when children are at school and short breaks are difficult to arrange. When other excellent services are available, demand for hospice services is lower. Some hospices use their facilities imaginatively during low periods of demand, e.g. having a rota of children to invite at short notice.



* CHASE figures: community care for 175–190 children costs £386,000 => £2,000–2,200 per child. In-patient care for 221–242 children costs £6,900–7,650.⁴⁸

[†] NPC analysis using latest available data from Caritas and financial statements submitted by charities.

Most hospices find they would like to offer more care for the families using their services, and are also concerned that some families outside their geographical area are not able to access their services. The figures bear this out: as mentioned earlier, 4,000 children are at present using hospices, yet many more have needs. Map 1 shows how hospices are not evenly distributed, and do not reflect local demography.

As can be seen, coverage is patchy (no hospice in Cornwall), which creates long journey times. When Ty Gobaith opened in north Wales it reduced the journey distance by 100 miles for children who formerly attended Hope House in Oswestry. In other places, hospices are clustered close together, which is appropriate where populations are dense, but not if the area (e.g. the southeast) is already well served by residential units.

Fundraising for children's hospices, as with adult hospices, is very much a local affair. How much can a hospice squeeze out of the local population on a sustainable basis? Acorns achieves £1 per head of population, a sum similar to the average across the sector. A large constituency is needed in order to achieve economies of scale. Is this enough, however, to meet all the needs of the community? In the area where Acorns operates, there may be 1,200 children needing palliative care, but on £6 million a year it only accommodates the needs of 640 children.* This implies a shortfall, which begs various questions: Do all 1,200 children want hospice services? Are there ways of obtaining more funding? Or could a complementary lower cost service relieve pressure and allow the hospice funding to go further?

Adolescents and young adults

There are only a few hospices with facilities dedicated to adolescents and young adults:

Douglas House, a sister unit to Helen House in Oxford (the first children's hospice), **Martin House** in Yorkshire and **Acorns** in the Midlands. However, some hospices run activities, such as special weekends, dedicated to this age group. Four hospices in the southeast have commissioned a mapping exercise that will look closely at provision for adolescents and young adults. They will use the results to determine what to do about this group.

Ellenor Foundation, a hospice at home service, is piloting the development of services to help the transition from childhood to adulthood. In particular, it is examining whether some groups of young adults (particularly those with full

cognitive abilities) fare better in special units attached to adult hospices. Ellenor has encouraged adult hospices (which often reject patients who they consider 'too young') to develop appropriate services for young adults. It has also piloted a pathway for adolescents and young adults since October 2004. Ellenor is persuading professionals in adult services to develop relationships with the young people who will come into their care, from the age of 16, two years before transfer at 18. It will evaluate the current pilot project in 2006.

Development of new hospices

The development of new children's hospices is a major issue. Because anyone can start a children's hospice from scratch (generally a response to bereavement), they are often started in locations that are not ideal. Consequently, there are clusters in some places. The implications of poor planning are serious:

- **Local fundraising capacity.** Developing an additional hospice too close to an existing hospice will cannibalise the existing hospice's ability to fundraise from the local area. It also compromises the new hospice's own fundraising efforts when the excitement of the capital appeal has died down. This has happened more than once in the past.
- **Waste.** Building an expensive unit in the wrong place seems wasteful when the money could be better spent on a hospice further away or on developing badly needed services from existing hubs. In addition, hospice groups benefit from economies of scale: Acorns is aiming to reduce its costs to the bottom of the cost range through such efficiencies.
- **Recruitment.** The wrong services in the wrong place drain valuable human resources away from the NHS and existing service providers. Local PCTs take a dim view of such developments.
- **Gaps.** There are plenty of gaps in service provision. The development of physical sites for children, and increasingly for adolescents, is still required, but not always in locations conveniently close to the founder. They are more likely to be in locations where large capital sums for such projects are harder to find.
- **Expertise.** Existing hospices generally offer better expertise in developing new facilities, because they have done it before. Experienced hospices are less likely to repeat flaws in new buildings.

More provision of services (at home and residential) are required. But careful planning is essential. Existing hospices are well placed to expand.

* 6 million people live in Acorns' area. Acorns estimates 1,200 children need palliative care.

Short breaks
and practical
support are vital
for families.

Other providers of palliative care, support and other services

Charities specialising in home and family support

Not all children and families want to use hospices, but they may welcome other services. For most children the centre of care is the home; parents would like more continuing support there.[†] A number of charitable sector and health service nursing teams provide such care, although at present they only reach a small proportion of affected families. Some children's hospices are also active in community based care.

The **Jessie May Trust** (Jessie May) is a nursing service based in Bristol. It provides short breaks and support (including sibling support) to families with terminally ill children in the home, and symptom control or terminal care for the child itself. Jessie May actively looks after over 51 families, and provides bereavement support for 13 more families. It does this on a turnover of £300,000–£350,000 per annum. Demand exceeds supply, so each family is assessed, to determine which family needs what most urgently. Jessie May's nurses have the level of nursing required for children with complex needs, but are also able to support the whole family. A mother can take a break with a sibling, knowing that her sick child is in competent hands. Jessie May also has a bereavement support worker and a cultural development officer is developing links with BME communities. It also holds family events (parties, days out) so that families can meet with other families in similar circumstances.

The service offered is different from the service offered by an NOF team (which is more medical in nature and does not offer short breaks). Jessie May liaises closely with other service providers in the region, e.g. Bath Lifetime, the statutory service provider. Together they develop a care package for each patient. When Children's Hospice South West, now in development, is ready, residential short breaks will also be available for families in the area.

It costs Jessie May £4,700 per annum to support an affected family where the child has complex medical needs, but the return in terms of maintaining the family's sanity is enormous. Nursing support also shortens hospital stays. It costs much less than residential hospice care. However, Jessie May Trust receives no statutory funding because the health services view it as 'social care', and the social services view it as 'health care'. Neither will purchase services in the 'wrong' category. Yet the referral process requires both parent and medical practitioner to sign off on a referral, and the consultant community paediatrician in Bristol warmly

endorses its service. Jessie May is receiving £50,000 per annum for three years from NOF, but is worried the local PCT will not continue funding it.

Jessie May Trust⁴⁹

'Jessie May visits are my lifeline, without them I could not leave the house.' Mother

'Without the Jessie May Trust nurses, many children would spend far longer in hospital, away from their brothers, sisters, parents and friends, or in a hospice away from usual family life. . families can truly 'live their lives' in the place most of them would prefer to be – at home.'

Consultant Community Paediatrician, Bristol

Support and short breaks that are practical, rather than medical, are also extremely valuable for families. **Rainbow Trust** is such an example: it supports 700 families in the southeast and northeast, offering short breaks at its two homes for families with sick children to visit, and seven outreach teams of four to six workers.*

The homes are equipped for people with disabilities (including hydrotherapy pools). However, each feels like a normal home with a garden and climbing frame for able-bodied children to use. Each home can accommodate two to three families at a time, or 300–400 families a year. The family might stay for a weekend or part of a week. The homes are not equipped with complex medical equipment (a hospice would be a more appropriate environment if the medical needs are acute). Rainbow Trust wants to create a happy environment for the family so that there are good memories. The staff stay in touch with families after bereavement because the relationships built up over the years can be quite strong.

The Rainbow Trust focuses on the entire family. Its services are flexible and practical. The outreach staff can home-sit while parents are with a sick child in hospital, or help a mother at the end of her tether with washing, or picking up siblings from school. Because the services are non-medical, there are limits on how many children with complex medical needs it can handle. Roughly half of the children helped have cancer, the rest tend to have organ, metabolic or immune disorders. Rainbow Trust's turnover is roughly £2.1 million, which translates to a cost of £3,000 to support a family whose child is ill. For the family concerned this support is invaluable at a time of crisis. Often the logistical difficulties of having a sick child are overlooked by statutory and other services, and it is not necessary to have an expensive, fully qualified children's nurse baby-sitting the siblings of a sick child. The Rainbow Trust fills an important practical gap in service provision.

* Rainbow estimate that it reaches 1,000 families each year, by adding families using its short breaks homes to families using the outreach. NPC has re-estimated the number assuming significant overlap between these two groups.

Rainbow Trust⁵⁰

'Priceless time with my family — it's hard to express — you can't measure a rainbow with a ruler.' Father

'We go to Rainbow House on a regular basis. We went there recently to celebrate what would have been Luke's birthday. We had only good times there. The memories associated with it are all happy ones.' Mother

'We decided to bring [Amy] home and one of the Rainbow Trust family support workers came to our house and spent time with her and was with us the night she died.' Parents

Crossroads schemes in some areas offer similar short breaks to families.

Contact a Family, described in more detail in *Ordinary lives*, provides a wide range of services, support, information and advocacy to families where there are disabled children. Many of these services are helpful to families with life-limited children too.

Siblings

NPC found that many hospices and other charities are incorporating siblings into their work plans, which is encouraging. **SIBS** is a relatively new charity set up as an umbrella body for services to siblings of disabled children. It offers an advice and support line for siblings and professionals, and also provides help and training on setting up sibling groups. It has produced a set of fact sheets in many languages aimed at both siblings and professionals. It is not specifically geared towards siblings of life-limited children (NPC did not find organisations that had been specifically formed to look after this group). It seems that they are not ignored; rather their needs are increasingly recognised by other providers.

Hospital accommodation

When a child is in hospital, the availability of local accommodation can make a great deal of difference to a family, allowing it to remain together during treatment. Such accommodation can also improve recovery and rehabilitation times. **The Sick Children's Trust** has seven houses and provides accommodation for 81 families at any one time. The concept is simple: The Sick Children's Trust raises funds to build or adapt premises close to hospitals treating children. It then employs house mothers to look after the premises (also available to families for informal support). Where possible, The Sick Children's Trust negotiates with the local PCT to pay for maintenance and cleaning, but this is not always achieved. The service is not limited to

children with life-limiting or threatening conditions, but this group of children benefit greatly from regular use of these facilities.

The cost to build or acquire premises varies depending on location, but the extension of one of its houses by six bedrooms costs £650,000 (£110,000 per room). The book cost of its property portfolio is £5.4 million. It costs about £55,000 per annum to run each house (which generally has 8–12 bedrooms). The cost per night per family (including depreciation and fundraising costs) is roughly £22.* The length of stay varies, so the cost of an 'episode of care' cannot be calculated, but the benefits are wide-ranging: families and marriages kept together, siblings separated from parents less frequently, savings on transport costs, peace of mind, and early discharges because children can remain close to hospital.



Photograph supplied by The Sick Children's Trust

CLIC Sargent Cancer Care also offers accommodation, and liaises with local PCTs and other charitable accommodation providers to ensure no overlap of service. CLIC Sargent's homes are only open to families whose children have cancer. It is developing a new home at the Middlesex Hospital in central London (where real estate is expensive) for £5 million. This will service a new paediatric oncology centre which will treat 160 patients a year. It will have 15 bedrooms and will be able to accommodate 12 families. The cost per night per family is roughly £22.†

Home from home accommodation is very helpful for families when children attend hospital.

* The 2004 The Sick Children's Trust annual report shows c£670,000 total expenditure and reports 29,565 bedroom nights filled = £22.

† The 2003 CLIC annual report shows £443,000 expenditure on homes from homes. CLIC can offer 20,440 bedroom nights per annum = £22.

Adolescents

The Golden Freeway is an initiative to help adolescent boys with muscular dystrophy access information technology, in particular the web. The project reduces social isolation and improves self-esteem by allowing the boys to undertake tasks independently using specially adapted equipment.⁵¹

Condition specific charities

Cancer

With 70% survival rates, not all of the services offered to young cancer patients relate to life-limited children, although arguably nearly 100% of cancer cases are 'life-threatening'.

A group of paediatricians set up the **UK Children's Cancer Study Group (UKCCSG)** in 1977. It is a national professional body responsible for the organisation of the treatment and management of children with cancer in the UK. Based in Leicester, it has 22 regional centres, and is funded mainly by Cancer Research UK and other childhood cancer organisations.

UKCCSG's main remit is the co-ordination of national and international clinical trials, including biological studies. Its stated objective is to improve welfare and services for children and young people with cancer. Its activities include national cancer registration. It also provides information for patients and families. It works with other children's cancer charities, such as CLIC Sargent Cancer Care, to achieve its objectives.

Cancer and Leukaemia in Children (CLIC)

merged with **Sargent Cancer Care** in November 2004 to form **CLIC Sargent Cancer Care**. The two organisations' activities are complementary, so the merger will result in a comprehensive national service with little duplication. The combined organisation offers everything except for clinical care that is covered by the NHS. Its main activity is providing nurses (a CLIC activity) and social workers (a Sargent activity) to support families at home. There are 140 social work and nursing posts in total.

Sargent's includes sibling support. CLIC also provides seven 'homes from home' near oncology units. The combined organisation also provides holidays and hardship grants to families. There is a small budget for research. It intends to develop an advocacy role in the field of children's cancers, e.g. to encourage medical vigilance of how mobile

phone use may result in increased brain tumours in children. The combined annual income of the two charities is about £14 million.* CLIC supports 2,000 children, which it estimates is 50% of children who have cancer.[†] CLIC's coverage is roughly £4,000 spent per child. Sargent's coverage is wider, because it has professionals based at 20 out of the 21 UKCCSG centres. The combined charity would like to provide comprehensive coverage, not only geographically but also to meet all services demanded. It has commissioned York University to make a survey to determine the needs of families and will develop a strategic plan later this year.

A large proportion of childhood cancer cases begin in adolescence, and the **Teenage Cancer Trust** focuses on the needs of adolescents in hospital. It has helped to develop eight wards attached to oncology centres. There are a further 20 in the pipeline. It also helps with education and advocacy, and holds weekend events for teenagers with cancer. It has funded a professorship at the Christie Hospital in Manchester. It estimates that it assists 2,000 teenagers each year on an income of £3.4 million.

Children with Leukaemia has an income of £9.7 million, nearly half of which goes towards research. It provides homes from home at two hospitals, and helps with holidays.

The NHS benefits from the work of cancer charities. CLIC Sargent Cancer Care and Macmillan Cancer Relief pump prime nursing posts, contributing to the cost of 250 children's community nurses with specialism in cancer.** Children's cancer charities also contribute to hospital funding^{††}

Muscular dystrophy and spinal atrophy

There are 21 different types of congenital muscular dystrophy, the most common being Duchenne. There are also other neuromuscular conditions. With Duchenne, although signs of the condition are detectable when children are less than five years old, deterioration is not marked until the child is about eight. Most patients only become wheelchair-bound during teenage years. Duchenne occasionally causes learning disabilities, but most children have normal intelligence and enjoy a standard education until school facilities can no longer cope with the logistics demanded by their deteriorating physical condition. Muscular

* NPC has treated the income from shops as net rather than gross.

[†] CLIC estimates that 4,600 children under 21 are actively experiencing cancer. This is different to the number of children NPC uses which includes a large cadre of children who have experienced cancer.

** The CEO of CLIC Sargent claims that 70–80% of these nursing costs are covered between CLIC Sargent and Macmillan. However, it is difficult to quantify as Macmillan just pump-primes posts, so older posts are now picked up by PCTs. CLIC Sargent has continued the funding of posts they have developed on a longer term basis, but their policy is changing towards the Macmillan model.

^{††} Between them, CLIC and Children with Leukaemia have contributed over £1m to the Bristol Children's Hospital appeal.



conditions such as Duchenne are specialised. Professionals must understand the details of its manifestation in order to plan current and future care. The problem is that most professionals are unfamiliar with the trajectory and characteristics of the disease.

Muscular dystrophy patients use hospices extensively. The **Muscular Dystrophy Campaign** (income £6 million) supports children and their families with information and advice. Together with the NHS, it co-funds 13 MDC Family Care Advisors, who are based in clinics around the country. These advisors help to negotiate home adaptations and better facilities for children. The MDC also helps to educate professionals.

The MDC's top campaigning issues are grants and benefits to people with muscular dystrophy, wheelchairs and access, and research funding. It believes the statutory grants available to people with disabilities are too low: only £20,000 is available for home adaptations that frequently cost £40,000. Lifting heavy patients using inadequate equipment causes injury to carers. There are cases of local authorities taking children into care rather than providing home adaptations. The Joseph Patrick Trust, which is part of the Muscular Dystrophy Campaign, provides part funding towards the cost of equipment (home modifications, hoists, special wheelchairs).

Jennifer Trust provides support and information for people with spinal atrophy, a condition with similarities to muscular dystrophy. It also funds

research into the condition. It has developed networks of families affected in six UK regions. It also loans equipment.

Cystic fibrosis

The trajectory of a cystic fibrosis patient differs from that of other life-limiting diseases. Although the disease demands extensive medical intervention and management, patients remain able-bodied for most of their lives; it is only towards the end that they become incapacitated. This generally happens when they are young adults, although deterioration may start from late teens. Patients spend reasonable amounts of time in hospital throughout their life (forming strong relationships with their medical care teams), but when out of hospital, apart from needing regular physiotherapy, lead fairly normal lives.

Cystic fibrosis sufferers tend not to use children's hospices much, and do not require many short breaks until the end. However the disease is frightening and unpleasant, and although hope for a heart-lung transplant may be offered for much of a young patient's life, the shadow of early mortality hangs heavily over the family. The condition may also extend to more than one sibling. Watching the deterioration of an older sibling can profoundly affect a younger child with the same condition. Cystic fibrosis does not bring learning disabilities (although a child with a learning disability may have cystic fibrosis); indeed patients are observed to have normal to above average intelligence.

The Cystic Fibrosis Trust is the main charity supporting those with cystic fibrosis. Nearly half of its £8.4 million annual expenditure goes on research. In the past, this research has improved therapy, for example, enzyme tablets for digestion. At present the organisation is focusing on gene therapy, which it does not expect will provide a cure in the short term but would help to treat and manage the disease. In 2004, it spent £1.7 million on clinical care, support and education. It has helped to set up 41 specialist treatment centres in the UK. In many of these centres the Trust is developing wards that are appropriate for young adults. Once the wards are developed, the PCT then runs them. The Trust is also involved in the training of doctors and nurses in specialist cystic fibrosis care. It runs a helpline, provides hardship grants and fields 12 advocates around the country to help support those affected.

It is difficult for the families affected by a disparate group of rare conditions or severe cerebral palsy to raise large amounts of funding, except via hospices.

Metabolic diseases and other rare conditions

This is a grouping of a wide range of specialist conditions that affect the metabolism and are highly destructive. Some of this group are disabled both physically and cognitively from an early age and their needs are often complex.

Children Living with Inherited Metabolic Diseases (CLIMB) is a small charity (£400,000 spending per annum)* which aims to 'ensure the best possible quality of life for children, young people and families affected by metabolic disease and alleviate their suffering with the ultimate aim of prevention and cure'. It funds research, provides information on **730** different conditions, supports families and professionals, and can help families with equipment and other costs. It also educates professionals and others about this unusual group of conditions.

The Society for Mucopolysaccharide Diseases raises just over £1 million per annum. It provides an advocacy service, information and support, and raises funds for research. It estimates that 1,000 children and adults are affected by these diseases, and since 1980 has been maintaining a database of cases.

Bereavement support

Most children's hospices provide bereavement support to families, many of whom they will know well. NOF teams may also have bereavement services included as part of their service — £2.8 million of NOF funding was provided to 39 projects. Generally, a single post was funded for three years.

Other voluntary organisations specialising in a wide range of bereavement issues may provide bereavement support, for instance **Cruse Bereavement Care**. About 4% of Cruse's enquiries are from parents who have lost children.

The effect of bereavement on children can be quite profound. Many factors will influence the response to the death of a sibling, such as age, closeness in age, age of the child who has died, and other family circumstances. The death of a child may make the surviving sibling feel a wide range of emotions including loneliness, anxiety for the safety of the rest of the family, guilt, lack of motivation, over-developed sense of responsibility, isolation and resentment. Problems with low self-esteem are common. Many people are not sure how to deal with a bereaved child and tend to avoid the issue in order to protect the child, which adds to a child's confusion. Parents, schools and others

coming into contact with children often need guidance on how to help children come to terms with the loss of a loved one. Statistics on children experiencing bereavement indicate health behavioural problems: they attend GPs' surgeries more frequently; 'delinquent' behaviour is more common; and they are often bullied.⁵³

A clinical psychologist with a special interest in palliative care founded **Winston's Wish**. It is one of the first organisations formed to focus on children who are bereaved in a variety of circumstances. It provides support to whole families, including parents helping children cope with bereavement. Although more often the cases involve parental death, Winston's Wish sometimes deals with cases of sibling bereavement. Most of its activities include one-to-one therapy and work with memory boxes;[†] a helpline; social events (sometimes involving therapy); and regular weekend camps for family groups. Children value meeting others who have had similar experiences because it can reduce their sense of isolation.

Although mainly limited to Gloucestershire where it is based, Winston's Wish offers training for other service providers and it has a helpline open to all schools that need advice on how to handle bereavement of a pupil. It would like all service providers who come into contact with children to have much greater understanding of issues around bereavement. It even wants schools to include loss in the PSE curriculum.

The benefits of such support are hard to articulate, but Winston's Wish has identified indicators that can gauge the self-esteem and other emotional responses of a bereaved child. It has started tracking the children, and it is receiving positive feedback, even many years after the support was originally received.

The Child Bereavement Trust (CBT) was started in 1994 and provides support to families through the provision of information on-line, including a weblog for bereaved families. With the support of the DH and private funders, it has developed 13 bereavement support posts in NHS trusts. It also provides support and training to professionals (including education, NHS, police and social services) who come into contact with bereaved families. This includes courses, information and a helpline for professionals.

The **Childhood Bereavement Network** was set up to improve access to high-quality local and national information about bereavement. It guides and supports bereaved children, young people, their families, and other caregivers.

* Calculated from reserves number on website £100,000 for three months = £400,000 ⁵².

[†] Memory boxes are decorated boxes filled with photographs, poems or other memorabilia to help a child remember their loved one.

It provides a directory of services, and co-ordinates a number of service providers in this field via its consultative panel of 16 organisations.

The Compassionate Friends offers local contacts to support bereaved families directly. It has chapters across the UK.

The **Child Death Helpline** is based at Great Ormond Street and Alder Hey Hospital in Liverpool. It is a helpline open part-time and manned by volunteers who are bereaved parents themselves. They are supervised by a professional team to provide the necessary support. It means that bereaved parents and other family members can talk to someone who has been through a similar experience. Any parent of any dead child can telephone regardless of the age of the child when they died or how long ago the death occurred.

Umbrella bodies

There are two voluntary sector umbrella bodies for children's services:

They are Association for Children with Life-threatening or Terminal Conditions and their Families (ACT) and the Association of Children's Hospices (ACH). Both are based in Bristol, and work together on a number of fronts. Each has observer status on the other's boards. For the moment the organisations remain separate, representing two slightly differing interest groups.

ACT represents affected children and their families and professionals, and also accepts membership from relevant organisations working in the field. It is broader based than ACH, having 330 members including children's hospices, community teams, and other organisations, as well as the parents and children. ACH represents only children's hospices and is therefore at one remove from the end user group. Nevertheless, ACH endeavours to serve the interests of the children and families and puts this at the centre of its work.

Both organisations have been instrumental in influencing government policy.⁵⁴

Association for Children with Life-threatening or Terminal Conditions and their Families (ACT)

ACT was founded in 1992 by the late Professor David Baum, Professor of Child Health at the Institute of Child Health in Bristol and President of the Royal College of Paediatrics and Child Health. At that time, little was understood about the needs of children with life-limiting conditions. ACT's work over the past 12 years has had a

significant impact on the understanding of needs, and on the improvement of care.

'ACT's vision is to achieve the best possible quality of life and care for children and young people with life-threatening or life-limiting conditions and their families. ACT aims to influence, co-ordinate and promote excellence in the provision of care and support for children and young people with life-limiting conditions and their families.'

ACT website

In order to achieve this, ACT has the following objectives:

- To transform and inform the attitudes of government and service commissioners about palliative care for children and young people. ACT campaigns for the provision of co-ordinated services for children, including better short breaks provision and improved services in the community.
- To lead the development and continued improvement of services for children (including adolescents) through research, the promotion of good models of care and effective communication. Sharing of knowledge and increasing the evidence base of research are important components of this.
- To enhance the knowledge and skills of professional carers by providing specialist literature and education opportunities. Training in palliative care for non-doctors and nurses, e.g. the creation of an NVQ in children's palliative care for care assistants and volunteers would help in this regard.
- To support families with a national information service (including a helpline and 'signposting' service) and give them a national campaigning voice. There is evidence that families have difficulty in accessing services because of a lack of information; increasing information directed appropriately at the children (including adolescents) would improve this situation.

Since 2001, ACT has published a number of papers (listed at the end of this report) on what care children should ideally receive, versus care they actually receive. Practitioners rely on these papers a lot when considering which services to develop. The papers help to explain some of the issues confronting families with life-limited children. Nearly every expert and practitioner interviewed by NPC stressed the vital role that ACT plays in producing these reports and campaigning within and without the DH and other government departments for a better deal for young people. They also saw ACT's wider

ACT represents all children, families and service providers, and so has a balanced overview. Its role influencing policy is benefiting many families who are consequently experiencing better services.

ACH is well positioned to add its weight to ACT's efforts. Its role as grantmaker could help pilot services to underserved groups

co-ordinating role between the hospices and the rest of the palliative care sector as very important.

However, in terms of income and resources, ACT is small and vulnerable, with only £150,000-£200,000 annual income, little of which comes from steady independent sources.

Association of Children's Hospices (ACH)

ACH is a membership organisation which grew out of meetings in the 1990s between the heads of care of some of the early children's hospices. It was registered as a charity in 1998. It now has 43 members.

'ACH is the national voice representing children's hospice services in the UK, and through them the life-limited children and their families who use them. The charity works together with other organisations to support the development of best practice and provision of children's hospice services across the UK. All ACH's activities are shaped by a philosophy which keeps the life-limited children and their families at the heart of their work.'

ACH website

ACH's objectives are to raise public and professional awareness, promote and support the work of children's hospices, and facilitate education, training, research and further service development. Recently its work has tried to improve corporate fundraising for charities, also to improve communication and liaison between members, supporters and patients. Care standards and quality assurance are integral to ACH's work.

In 2003, ACH established a Corporate Fundraising Scheme. ACH delivers and manages the scheme, which enables hospices to generate income through corporate adoptions on a national basis. So far, partnerships with the Foresters and the Co-operative Retail Society have raised £1.5 million for the sector. A scheme with Somerfield (supermarket groups) is commencing in July 2005 and may raise a similar amount. Under this scheme ACH retains some funds for its own costs.

ACH is also active in influencing government policy.

The major issues that confront ACH are not dissimilar to those that ACT has to grapple with, but it particularly wants to address the following areas:

- raising the profile and understanding of children's hospice services
- statutory funding of children's hospices
- recruitment and availability of paediatric palliative care specialists, either clinical, nursing or doctors

- collaboration between children's hospices to develop best practice in the sector
- development of new services in the most effective manner
- absence of coherent, up-to-date mapping of children's services
- adolescents and young adults who are poorly served.

ACH is concerned that new hospices should be developed on the basis of assessments of needs and in collaboration with existing services. It is considering developing a charter mark for new hospice proposals so that hospices that have undertaken needs assessments are identified for funders. At present it is difficult, except through the anecdotal experience of people on the ground, to determine which areas are worst served.

ACH's fundraising success in 2004 increased its annual turnover to £1.6 million, although roughly £900,000 of this was passed to member hospices. Its membership subscriptions are a strand of steady, independent income contributing to a financial base that is stronger than ACT. The challenge for ACH is the disparity of its member hospices discussed earlier, many of which hold strongly varying views on what best serves the beneficiaries. ACH has to tread a fine line between encouraging good governance and practice, without inhibiting local variations developed in response to the most urgent needs on the ground.

ACH has the capacity to act as a grant-maker, in a similar way to Help the Hospices. It is currently administering a grant to develop services to black and minority ethnic groups.

Help the Hospices

Help the Hospices is the umbrella body for adult hospices, but many of its programmes are available to children's hospices too. It administers grants on behalf of grant-makers and children's hospices can access some of these, for instance programmes involving training and education. Issues to do with adult palliative care can also affect palliative care for children, and Help the Hospices' policy work can help in this regard.

Research and education

Universities and the NHS fund a number of academic and clinical centres (described earlier) which may also be accessing grants from the private sector, e.g. Bristol. Research and education is important in developing the sector. Researchers should, where possible, engage with the children and young people themselves, so that they can describe their experiences and guide the research.⁵⁵

Charities also undertake research and education. **Acorns** hospice, in collaboration with **ACT**, is developing a research project (designed to benefit from Acorns' 20 years of experience) during 2005. It will evaluate its own services and compare them to different types of service, and also examine what is being done in other parts of the country.

Acorns also offers courses to professionals and other service providers. ACT is aiming to help develop an NVQ in paediatric palliative care to benefit non-medical personnel, including parents.

The **Teenage Cancer Trust** is developing a specific oncology nursing qualification with the Royal College of Nursing.

Medical research

This report does not cover clinical research although this is an interesting, important and difficult area. Arguably, if through medical intervention it is possible to prevent, cure or effectively treat life-limiting conditions then all attendant human, social, educational and medical problems evaporate. The dramatic improvements in children's cancer survival rates are testament to this.

Medical research is heavily reliant on charitable funding. The larger disease groups (cancer and cystic fibrosis) have had some success obtaining funds for research, but obtaining funds for rare diseases is much more difficult. Families affected are often forced to set up new charities in order to get the condition onto the scientific agenda, which then have to compete with much larger charities for funds. An example would be the Lowe Foundation, set up in 2000 to fund medical research into the rare Lowe syndrome. It has managed to raise £250,000 since it started, has set up a scientific advisory board, is funding four research projects, and has organised an international scientific symposium to pool findings on the condition. However, it has been unsuccessful in obtaining funding from government.

The SPARKS Foundation funds medical research into neonatal issues, premature birth, spina bifida, cerebral palsy, and treatment for early year conditions, in an effort to prevent disabilities and life-limiting conditions. It has funded pain research at the Lifetime service in Bath.

Action Medical Research is at present funding 68 medical research projects totalling £7 million; the projects cover a broad spectrum of medical issues. Only some of its projects relate to children with life-limiting conditions, although recent work includes research into pain, Hurler syndrome, cerebral palsy and Guillaume Barre syndrome.

Jeans for Genes is a successful fundraising initiative that collaborates with other charities, such as the Society for Mucopolysaccharide Diseases, in order to pioneer new therapies.

Summary

Charities are very active in this sector and their work is vital. Many people's lives would be intolerable without charitable support. Charities have been responsible for developing vital services, and have had to work hard to lobby for improvements in public services. It is particularly difficult to gain leverage from activities when the government has not made children with life-limiting conditions a high priority. As a result, charities are sometimes plugging gaps, which one would expect to be the responsibility of government.

In terms of organisation, the sector is immature, as demonstrated by the need to plan services more coherently. Some charities recognise this and are trying to introduce better networking. Many activities are still in their early days of development, but others are ready to learn from experience and undertake serious evaluations of their services. Given the lack of resources for this area, an analysis of resource allocation would be beneficial.

Charities are vital and must strive to maximise effectiveness through planning and collaboration.



Photograph supplied by Leslie McKintyre

Funding recommendations

There is unmet need in the delivery of services to children and young people with life-limiting conditions. Crudely estimated, the sum of £154 million directly spent on these children (or £6,200 per child) seems quite large. However, how can one price the quality of life and death of a very ill child and the sanity of his or her family? Some children have intensive needs, which even if expensive, are required for humane reasons. Other families just need a little extra, inexpensive help to make life bearable.

The sector needs private support at a strategic level. The priority is to provide the representative umbrella body, ACT, with enough financial resources to realise its potential in influencing policy, co-ordinating activities in the sector, and representing end users. A mapping exercise would help to establish what is happening (or not) where, by whom and to which users. This could be used to effectively plan services. Funding for research would help answer numerous questions. There is need for education and training of both specialist palliative care professionals and generalists so that those who come into contact with life-limited children are able to respond.

There are also opportunities to support the delivery of direct services, including practical respite, bereavement support and family accommodation at hospitals. Hospices are a crucial component of care; those that are appropriately planned, managed and integrated with statutory services would benefit from support. ACH, the body representing hospices, can manage grants programmes to organisations tackling particular issues, e.g. access to services for black and minority ethnic families. Donors can encourage initiatives to address problems around the transition from childhood to adulthood, another pressing issue.

This section explains how different activities can improve the situation of families. These activities include strategic initiatives that impact the whole sector.

Funding opportunities exist at strategic level and also for donors wanting to support direct service delivery.

Why fund care and support for children with life-limiting conditions?

The current government funding of care and support for life-limited children is inadequate. But why should a private donor step into the breach?

The needs of life-limited children are not a priority for statutory service providers. There are too few of these children, and other demands on budgets are more pressing. Critics of the charitable sector blame charities, notably hospices, for allowing the government to shun its responsibilities by conveniently filling the gap, and then not driving a hard bargain to obtain appropriate funding. They claim that the strong history of charitable funding for children's hospices has acted as a disincentive for the government to invest more resources in children's palliative care.

Charities respond, justifiably, by saying that if they did not exist, there would be no provision at all. The interest group is too small to be politically noticeable and the realities of health budgets are harsh, with many PCTs already running deficits. If PCTs allocated funding to palliative care for children, they would be removing resources from larger interest groups, such as cancer patients. Whether voters would support increased taxation to fund the expansion of health services to cover all patient groups is not a subject for this report. However, there is another view that services could grow without substantial increases in statutory resources if they were better configured. The charitable sector should support the statutory sector in achieving this.

NPC's recommendations reflect this reality, despite the discomfort some donors feel in funding services that arguably the NHS should provide. Some of the charities recommended are seeking to improve government policy and attempting to leverage government funding. Other charities, such as those operating in areas where no government funding is available, are also recommended. Some options involve channelling funds to unfashionable or risky areas. Funding programmes tackling weaknesses in the sector, which could increase the impact and efficiency of future donations, is another attractive option. Umbrella bodies are useful here: they can co-ordinate new programmes, stimulate strategic research, and influence government bodies to adopt best practice developed by charities.

Urgent funding needs

Association for Children with Life-threatening or Terminal Conditions and their Families (ACT).

Within the sector, ACT is admired for its work in co-ordinating and articulating the needs of the sector in order to influence policy. As a body that does not represent a particular interest group, it has great potential to tackle a number of the sector-wide problems that worry practitioners. The absence of a senior dedicated 'champion' of children's palliative care within the DH reinforces the need for strong sector representation.

ACT's recent financial history has been difficult, which has inhibited its development. The acting chief executive has had to spend time fundraising at the expense of addressing sector issues. The organisation urgently needs funds. Once a core is securely in place, ACT will be in a position to plan and execute its future contribution to the sector. It could undertake particular projects to solve problems, some of which, in common with many organisations, could be funded by grant-makers with particular interests. However, it cannot rely upon pure project funding to develop effectively.

ACT has already made a real difference because it views the sector as a whole. If it sees good ways of working in one place, it can spread the word by explaining the benefits to commissioners at a strategic level. ACT is also in a position to develop greater participation of children and families in the development of strategy. It could also oversee specific sector projects, either alone or in conjunction with ACH. Initiatives that experts and practitioners would like to explore could best be undertaken with the involvement of ACT. However, if ACT is not itself strengthened, then the value of its involvement would diminish.

Mapping of needs versus existing services

A full picture of the need for services, and how and where those services are provided (or not) would help service providers to develop activities and allocate resources. In 1999, the National Council for Palliative Care published a comprehensive analysis of needs and services for adults. This has been invaluable for the government and the charitable sector in developing services to fill gaps identified in the report. It resulted in the government committing extra resources to reduce inequalities. However, an equivalent mapping exercise has never been undertaken for children and young people affected by life-limiting or life-threatening conditions, except in South Glamorgan in Wales, published in 1995. This study demonstrated that paediatricians had under-estimated the numbers of children affected in the area, and helped put the case for developing hospice services in Wales.

Practitioners bemoan the lack of information on who is delivering what and where. They say this information would help practical implementation. Ideal service delivery models exist, but who takes responsibility in practice will take some time to resolve. The information the sector requires not only relates to children but also to **adolescents and young adults**. It also needs to know what services are required to help people with the transition from childhood to young adulthood.

Demand for palliative care services:

- what are the numbers of children or young people affected by each condition?
- which conditions are affecting them and what is the trajectory of each condition?
- where are these families?
- how might the picture change over time?

Existing services:

- what is provided by **government** (health, local authority, education) in each area?
- what is the coverage of the **NOF** and **Diana teams** — geographical and service level?
- What services are being provided by **charities** in each area?
- how well co-ordinated are these services?
- how are they funded and is the funding sustainable?
- are there areas that are working really well, and if so, how?

Future services:

- what gaps need to be plugged and how?
- how might demand change over time?

Assessment of training needs:

- are there enough professionals available in each area with the right qualifications to meet the demand for services?
- where could they obtain the necessary training in order to do the work?
- what additional courses/means of education are needed to improve availability of manpower?

In the southeast of England, four hospices have clubbed together to undertake some preliminary mapping at a cost of £25,000. The terms of reference cover most of the areas above (not training) and place particular emphasis on adolescence and transition to adulthood.

NPC would like to see this project expanded in scope to include assessment of training needs, and in the whole of the UK. ACT could co-ordinate this mapping exercise with assistance from ACH. The exercise would determine the scale of the problem and services, and would help the government and the charitable sector to

Charities supported should exhibit characteristics of well-run organisations.

plan and develop services. It would provide coherent evidence of inequalities, and also point to solutions.

Alternatively, the author of the earlier study is planning a mapping project to cover the whole of Wales. This would be a start and could be replicated.

Grants programmes to support service development

In adult palliative care, Help the Hospices has developed several grants programmes to care providers to develop services targeting particular issues. ACH is starting to emulate this with a small grants programme to develop services to black and ethnic minority groups. Such a grants programme could also provide material for research: services developed could be evaluated to establish whether they met the requirements of affected families. The following areas could be targeted:

- adolescents and young adults, and transition services
- hard to reach groups, such as black and ethnic minorities
- activities that support statutory services and NOF teams*.

A programme targeting transition to adulthood could capitalise on the experience of hospice services such as Douglas House, Martin House and Ellenor Foundation.

Research

Research and evaluation of new approaches is crucial. Demonstrating efficacy is important in order to get other practitioners to consider implementing new strategies or setting up new programmes. It will also convince funders, including government, of the value of a new initiative.

Dissemination of results will enhance the impact of a piloted service. Funding a network of hospices or national research body where there are existing information-sharing networks and educational programmes, will help dissemination.

The **Bristol Child and Adolescent Health Unit** estimates that a one year research project costs £50,000. For this, it could, for instance, conduct a thorough assessment of the work of community teams, or research some of the issues surrounding the transition from adolescence to adulthood. Those trying to address transition from adolescence and adulthood have been fumbling in the dark, and bemoan the lack of research that would inform service development. This research would have a significant impact on the efficacy of service development.

The children's palliative care team in **Liverpool** would like to employ a nurse research fellow and develop a full research programme, in conjunction with its existing activities.

There are few readily available examples of comparative evaluations of services. **Acorns** hospice and **ACT** are addressing this by developing an evaluation of Acorns' own services, together with a comparison with other services (some local, some further afield). This evaluation will check that it really is offering what families prefer. It will cost £50,000 and provide invaluable comparative insight, which might open up some of the debates within the sector about how best to allocate resources.

Education

General education, particularly professional qualifications, is the state's responsibility. However, the charitable sector can have a role in developing new training courses where there is a shortage. For example, there is a shortage of trained nurses in paediatric palliative care. A number of charities, including **ACT**, would like to develop more courses in conjunction with existing providers. This would raise the profile of the discipline and could lead to better standards of care for dying children in hospitals, hospices and in the community. If ACT were funded, it would be free to pursue such an objective, with the possibility of recovering some of the development costs from fees charged by institutions offering the courses at a later date.

Medical research

This report does not cover medical research into particular conditions. However, it is an important area of interest to donors, and NPC is likely to examine this in future.

Service delivery outside the hospice sector

Not all of NPC's funding recommendations are strategic. There are some charities providing useful services where the impact of support is rewarding.

With the **Sick Children's Trust**, or **CLIC Sargent**, once a home from home has been purchased and adapted, it is a simple matter to manage the property. The benefits to families are enormous. The **Rainbow Trust's** practical services to families are also good value, but the organisation only covers the southeast and the northeast; other areas could benefit from the development of similar services. Rainbow Trust wants to expand, and it is in a position to help other organisations develop similar services. **Winston's Wish** has developed a good model

* A 'multi-agency co-ordinator' supplied by St Oswald's Hospice in Newcastle has helped to integrate the services being offered in the region so that the demand for some services has reduced.

of bereavement service in Gloucestershire, and more resources would enable it to help other areas develop and benefit from its experience.

Should donors fund children's hospices?

There are not enough short breaks facilities for families in many parts of the UK. Hospices provide short breaks and therefore deserve support. However, they should be viewed not purely as buildings, but as service centres supporting families. The debate as to where resources should be allocated: for services at home, or short breaks services within a hospice, will continue and needs to be monitored.

Families would like choice when offered services. They need a great deal of support in the home, but many would also like to be able to entrust a life-limited child to a place outside the home where he or she will be fully cared for. The need for short breaks remains, but depending upon the level of support available for care within the home, the need for short breaks outside the home may well diminish. Whether there is a need for the charitable sector to provide home care, or not, is often a question of what statutory services are providing in the area concerned, and no two areas will be the same.

NPC was able to visit only a handful of hospices and there may be others that warrant and need support. NPC can however make various suggestions to donors wishing to investigate the funding of hospices of their choice.

The following are characteristics of sound organisations. They would apply to any charity wanting to maximise effectiveness:

- willingness to collaborate
- culture of learning and knowledge sharing
- flexibility and responsiveness to changing circumstances
- consultation with user groups
- trustee boards with an appropriate skills mix.

Private donors should consider whether a hospice has these characteristics. They should also check that the hospice meets the needs of the local area. Visiting other hospices nearby (if they exist) would be informative. Specific questions relating to hospices would help the process of appraisal:

- does the management convincingly articulate the needs of families?
- have the needs of children in the area been clearly articulated in the context of other services being provided by the statutory sectors and other charitable organisations? For example, if there is no home support in the area, has the hospice considered developing it?

- how does the hospice relate to other service providers, both local and regional? Does it talk to the hospices nearest to it?
- how does management involve service users in determining what services are delivered and how? How flexibly does it respond to need?
- is the hospice able to provide evidence that it is meeting legislative requirements?
- what is the composition of the hospice trustee board? Is there a useful mix of skills?
- is it possible to get references from users and/or other service providers, e.g. the local PCT?

A donor may want to consider donating to a hospice under development. In this case, these are key questions:

- who is developing the hospice and why? (Development by an experienced service provider, e.g. Acorns developing a new unit in the next door county to its current unit, is generally preferable to someone inexperienced starting from scratch)
- has a full needs assessment been undertaken to demonstrate the need for the hospice?
- how are other service providers, most importantly the local PCTs, reacting?
- what does ACH think about the location? Is it aware of other hospices or hospice developments that might cannibalise this one?



Photograph supplied by Acorns Hospice

Acorns has undertaken the development of its unit in Worcester in a disciplined and responsible manner. Although the unit, costing £6.5 million in total, will be opening at the same time as publication of this report, Acorns has had to dip into reserves - £250,000 - to complete the project, and is looking for contributions to the capital appeal in order to repay reserves. Unlike many other hospices, Acorns operates a tight reserves policy.

Table 3: Costings associated with outputs and consequent results

Activity	Cost per unit	£100,000 buys	Beneficiaries
Residential care	500-700 per 24 hours	167 bed nights – equivalent to half a years' full time care for one child	12 families – fortnight's break
Full home care support for child with intensive complex needs eg Bath Lifetime	£100,000-£150,000 pa	Support for 1 child	1 family – nearly full time help
Place at Children's Trust, Tadworth (see Ordinary Lives)	£100,000 pa	Support for 1 child	1 family – nearly year round accommodation
Home short breaks, involving care of sick child*	£6,000 pa to support family (nursing qualified) £105 per hour nursing care for child with complex needs	2 nurses	12 families – each would get a morning off twice a month
Practical short breaks – mixed bag of services, not necessarily nursing eg Rainbow Trust	£20 per hour, ie £60 for a morning or to pick up children from school	3 family support workers, each with a caseload of 20 families	60 families - each would get a morning off twice a month
Home from home – eg CLIC, Sick Children's Trust	£22 per night per family	Most of the cost of one room in new extension (SCT)	113 families over five years if each family stays eight days (SCT)

Comparison of costs of activities and possible results

Table 3 provides indicative costings for the activities reviewed. This gives a potential funder an idea of how many lives will be changed by a donation of £100,000, and in what way. These can be scaled up or down as appropriate. Table 3 shows the variation in intensity of activity depending on the level of the child's needs. At one end of the spectrum a year's residential care in a hospice might cost £200,000. Although most children use hospices for much shorter periods (Acorns provides on average 15 days of respite per annum, spread over several visits), it still gives an indication of the effort involved to look after children with such complex needs. At the other end of the spectrum, £100,000 could cover the practical support (such as regular availability of someone to collect children from school) of 60 families. It is unhelpful to make

judgements as to whether one activity is more cost effective than another just because it is cheaper. What price can one place on the comfort and dignity of an extremely sick child? However, it does demonstrate that for some families, a little can go a long way to help.

General points on funding

Depending on circumstances, NPC favours unrestricted funding for charities. Exceptions to this would be a collaborative programme (e.g. ACT/ACH grants programme or the mapping exercise). Designated funding would be appropriate in this case.

NPC would encourage programmes, particularly new initiatives or roll-out of initiatives piloted earlier, to include a component for evaluation purposes (and research if appropriate) in order to contribute to the developing knowledge base.

* These figures are fully costed. Assuming £105 per hour, each visit of 3+ hours costs around £340 including travel, i.e. 294 visits per annum if £100,000 available. If each family receives two visits per month, 294 visits can cover 12 families.

Activity	Cost per unit	£100,000 buys	Beneficiaries
Bereavement support – eg Winston's Wish	£1m pa to run the service supporting 300 families + training and support other organisations	Support to 30 families Five weekend camps	30 families helped with healing process or 150 children and adults attending camps
Bereavement support – eg Child Death Helpline	£100,000 pa to support 36 volunteers	3,000 calls pa – average 18 minutes	900 parents calling in crisis for the first time, many other parents repeatedly using the service
Research – eg Bristol Child and Adolescent Health Unit	£50,000 to support a research fellow for a year	Two research fellows, two pieces of research e.g. pain management, or parental mental health	Children affected by pain, parents whose mental health needs are poorly recognised
Research e.g. children's services mapping	£250,000 to map England	Map a big chunk of England	Needs of 8,000 children mapped
Umbrella bodies e.g. ACT	£200,000 pa at least needed for ACT	£50,000 to do a piece of research, £50,000 to campaign to government and service commissioners on the results	Area (e.g. Warwickshire) adopting improvements affecting 550–780 children ⁴²
Umbrella bodies e.g. ACH	£100,000 pa needed for Care Development Project	Would strengthen relationships between hospices and PCTs and develop palliative care forum	4,000 children use hospice services – improvements identified would benefit children incrementally

Charities benefit from stable funding which allows them to plan effectively rather than firefight.

Summary

The sector needs private support at a strategic level and NPC's recommendations reflect this. NPC believes the priority is to provide ACT with enough financial resources to realise its full potential in influencing policy, co-ordinating activities in the sector, and representing end users. A mapping exercise is also vital to establish what is happening (or not) where, by whom and for which users. Funding for research would help answer many questions.

However, there are also good opportunities to support direct service delivery, including practical short breaks, bereavement support and family accommodation at hospitals. Hospices are another area requiring support, if developed by an experienced management team in response to genuine local need. Hospices can also be supported via ACH programmes that administer grants.

NPC estimates that at any one time there are around 25,000 children and young people under 19 with life-limiting conditions. There are many more young adults whose conditions were diagnosed in childhood. Families are also affected: NPC estimates that there are 80,000-100,000 family members coping with a child with a life-limiting condition, and around 3,400 bereavements each year. However, accurate numbers of people affected, and information about their current and future needs, are only available in some areas. There has been no nation-wide assessment of services received by the families. Relative to the wider population, the numbers are small, and so this somewhat fragmented group finds itself disenfranchised.

Experiences of care are frustrating for many families: either services are not available, or they are not well organised. The quality of services is variable. In general, there are substantial areas of unmet need in terms of:

- geography
- adolescents and young adults
- communities that are hard to reach
- complex conditions.

Some geographic areas lack services that are available in other locations. The age range of young people dying of natural causes (most of them life-threatening or life-limiting conditions) clearly demonstrates that most die during adolescence or early adulthood, yet this group is frequently excluded from services or receives inappropriate services. Many services are driven by criteria instead of the needs of the child and family — it seems all too easy to be 'disqualified' for a service because of age or condition, even though the need is self-evident. This 'rationing' of services seems, to NPC, to be a false economy. Some conditions need more resources than others, but get an insufficient amount relative to 'easier' conditions.

The sector as a whole has only emerged in recent decades; it barely existed before the 1980s. Consequently, there is a great deal of work to do, to catch up with rising demand from children who survive neonatal and early childhood medical crises to grow into adolescents and young adults. The recent development of services and reform of government structures may improve the

depressing picture painted by ACT's 'Voices for Change' survey undertaken in 2003. Community palliative care teams supported by NOF funding could make a significant impact, although evaluation of their implementation is still in progress. The services that community palliative care ('NOF') teams provide are likely to be helping large numbers of families at reasonable average cost, with considerable benefits for the families concerned. NPC suspects that such teams may actually save money for the government by improving the well-being of families and averting crises. However, there are concerns about their sustainability after NOF funding expires in 2006. Will PCTs and SHAs honour commitments to fund NOF teams after this time? The development of Children's Trusts — which will pool resources and co-ordinate services — may also help to improve service delivery for little extra cost, but again it is too early to determine their success.

Ideally families should receive a choice of services. However, there remain unanswered questions about families' specific needs and priorities:

- To what extent are gaps subsisting two years after the publication of ACT's 'Voices for Change in 2003'? How serious are the deficits?
- Which services are missing and where?
- Which services would families prioritise, if they had to allocate resources? The ones they currently receive, or ones they would prefer to receive if they had to choose?

If these questions were answered, it would help service providers to prioritise action and allocate resources. A mapping exercise to determine what is happening (or not) where, by whom and for which users, coupled with research into particular needs, issues and best practice, would help answer the questions repeatedly posed by this report.

The provision of appropriate care and support to children and families relies heavily on the charitable sector. Many people's lives would be intolerable without charitable support. Charities have been responsible for developing vital services, and have worked hard to lobby for improvement in public services. However, it is difficult to gain leverage from activities when the

government has not made children with life-limiting conditions a high priority. Charities sometimes seem to be plugging gaps that one would expect to be the responsibility of government.

Children's hospices collectively represent the biggest providers of care and support to children with life-limiting conditions. They receive just over half (£65 million per annum in income) of the total charitable funding (£115 million) identified by NPC for this sector. Yet despite the importance of the services they provide (a 'lifeline' for many families), hospices only receive 6% of their funding from government. The children's hospice movement (dating from the early 1980s) is still young, but is starting to mature. The movement could consolidate service provision at a regional level and achieve efficiencies and economies of scale similar to Acorns' three units. Hospices also harbour experience, which needs to be disseminated among newer hospices and shared with the outside world. However, future expansion into under-provided areas needs to be undertaken carefully and rationally, because in the past development of new hospices has not always been in the best location. Hospices are also in a good position to tackle specific problems, such as the transition from childhood to adulthood, and the access to services by black and minority ethnic groups. The best way to achieve this would be via grants programmes administered by ACH, the umbrella body for hospices.

Other charities complement the hospice movement by providing services such as practical short breaks and help at home, bereavement support and family accommodation at hospitals. Some condition specific charities provide specialist advocacy services and support with information tailored to the particular needs of the condition, as well as lobbying for improved government services. Childhood cancer is particularly well supported (£27 million per annum). However not all conditions are well represented by condition specific charities. Whilst groups affected by cancer, cystic fibrosis, muscular dystrophy and mucopolysaccharide disease have active charities sponsoring their cause, children with rarer conditions and severe cerebral palsy have no such representation except via ACT or the hospice movement.

The most urgent need for private support is at a strategic level and NPC's recommendations reflect this. The charitable sector's relationship with the government at national, as well as local, level provides opportunities and challenges. The impact of guiding government towards optimal service delivery is far reaching. The sector's main umbrella body, ACT, needs additional resources in order to realise its full potential to influence policy, co-ordinate activities in the sector, and represent end users. ACT can also help to address deficits in training at all levels of the sector.

On average, the charitable sector generates income of around £4,600 per life-limited child. Put another way, the UK population is donating just a little over £1 per head towards this group. Given the level of statutory services, this is not enough to meet the often complex needs of such children and their families. More resources are required, not only to provide more services, but also to improve the effectiveness of spending by the government and the charitable sector on this under-represented part of the population.



Photograph supplied by Leslie McKintyre

Appendix 1

Malignant and non-malignant diseases – numbers of cases

In calculations involving children, NPC assumes that there are 14.75 million children under 19 in the UK and 13 million in England and Wales in 2002.³⁸

Cause of death

Statistics for cause of death by age only available for England and Wales: 5,535 people under 24 die each year, 3,435 of natural causes.²

Table 4: Causes of death

Deaths under 24, England and Wales 2003	
Infections	211
Cancer (all neoplasms)	641
Immune and metabolic disorders	225
Mental and behavioural disorders	157
Nervous system and musculo-skeletal	533
Circulatory system	308
Respiratory system	239
Digestive and genitourinary	160
Congenital abnormalities	426
Perinatal conditions	200
Undiagnosed	290
Other	45
Total natural deaths	3,435
Accidents etc	2,136
Total deaths under 24	5,571

How does the sector group the conditions?

There are four broad groups of life-limiting conditions. These are often used by practitioners to help identify children's particular needs (using definitions jointly provided by Association for Children with Life-Threatening and Terminal Conditions and their Families (ACT) and the Royal College of Paediatrics and Child Health in 1997):

Group 1: Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary when treatment fails. Children in long term remission or following successful curative treatment would not be included. Examples are cancer and irreversible organ failures of heart, liver and kidney.

Group 2: Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. An example is cystic fibrosis.

Group 3: Progressive conditions without curative treatment options (i.e. cannot be cured), where treatment is exclusively palliative and may commonly extend over many years. Examples are muscular dystrophy, Batten disease, and mucopolysaccharide diseases.

Group 4: Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death. Examples include severe cerebral palsy, and multiple disabilities following brain or spinal cord injuries.

How many cases are there at any one time?

Using district-based data from Northern Ireland and Scotland, ACT found that there are 1.72 life-limited children under age 18 per 1,000 children. Using the same prevalence for children under age 19 (for which numbers of children are readily available) this implies 25,370 under age 19 across the UK (22,360 in England and Wales). This assumption is a liberty because some children may have died, but numbers on children under age 19 are more readily available than numbers under age 18, and in any case represents the group better. This excludes young adults.

The more condition-specific numbers of life-limiting cases simply don't add up — not least because no one uses the same measurements, age ranges etc. Table 5 shows this indicating various sources, with *some of the explanations of origins of figures in footnotes in the text*.

The numbers for **cancer** are unclear, despite the National Registry of Tumours in Childhood. The UKCCSG estimates that one in 650 children under 15 will contract cancer.⁵⁷ If 11 million children (2002) in the UK are aged 0–14, then 16,923 will have had cancer. But 30% of these may have died in the process, leaving 11,846 behind. Others may have been cured. The trend for cancer as depicted by Figure 6 is that incidence of cancer is rising but that mortality is dropping.

ACT uses a figure of about 11,500 children under 14 having cancer 'at any one time',^{3*} so assuming survival rates of 70% at ten years, 3,450 are life-limiting. However, we also know that roughly half the deaths of cancer under 24 occur between the ages of 15 and 24, which would imply that there are many more children in this age range with potentially fatal cancer — doubling the number gets you 6,900. The incidence of cancer in children is increasing at about 1% per annum.⁵ Survival rates are good: on the one hand roughly 1,500 new cases of cancer occur each year,⁵⁸ on the other 641 young people under 24 actually die each year² Leukaemia accounts for 25% of cancer cases.

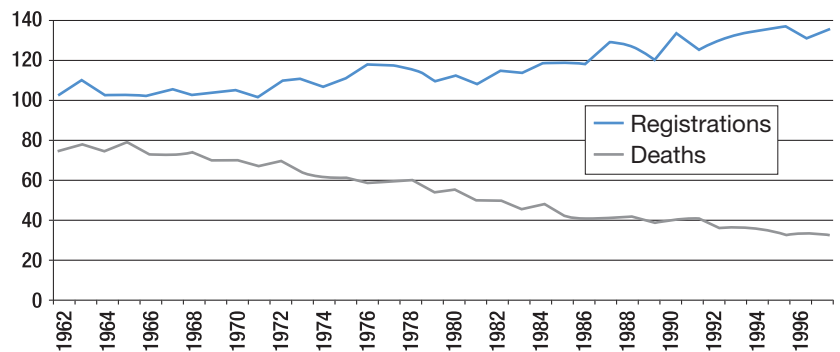
Further confusion arises from the numbers supplied by CLIC: 4,600 between 0–21 at any time. Are these the children in active treatment perhaps?

Cystic fibrosis affects 7,500 people in the UK, 70% of them under the age of 20⁶ Each year 156 people die of it. People with cystic fibrosis have an average life expectancy of 31, so survivors beyond the age of 20 are included in the 7,500. (For information, ACT puts a figure of 4,500 for those under 18).[†]

Cardiac conditions affect 5,000 babies each year in the UK.⁹ However, only 308 people in England and Wales under age 24 die each year, suggesting that less than 10% of cases are fatal. Because the life expectancy of children with fatal heart conditions is unknown, it is difficult to determine how many children could be defined as life-limited at any one time.

The number of deaths from **metabolic and other rare disorders** is confused by the data quoted by CLIMB (1,500 deaths per annum)^{52**}

Figure 6: Incidence of cancer versus deaths per annum between 1962 and 1996.



which does not relate to the data provided by national statistics, but this may be because of classification. NPC uses national statistics. This group of diseases includes Battens disease (16 new cases per annum and 300 known cases in the UK) and mucopolysaccharide disease (around 1,000 estimated cases among children and adults). The rest of the diseases are fragmented. The estimate of 1,600 is based on 300 Battens + 300 mucopolysaccharide children together with 1,000 others. This figure could be much higher. CLIMB has identified 700 different diseases, presumably each has at least a case.⁵²

Since 1980 the Society for Mucopolysaccharide Diseases has maintained a research database to identify the incidence of mucopolysaccharide ('MPS') and related conditions in the UK. Between 1974 and 1991 the Society calculated a mean annual birth rate of 737,823. In the same period a minimum incidence of 511 diagnoses of MPS diseases were recorded, representing a mean annual birth rate of 28.4. This represents the average minimum incidence of MPS and related diseases of 1:26,000.

Duchenne **muscular dystrophy** affects one in 3,500 males in the UK. There are 1,500 known cases.⁵⁹ Life expectancy has increased to 25 in 2002 (from 14–15 in the 1960s)⁷ and there are also other types of muscular dystrophy.

Cerebral palsy – a recent study tracking 1,942 children from 1966–1986 until 2000 found that mortality rates for those under 20 averaged 13%, and that over half of those with severe motor disabilities arising from cerebral palsy are likely to die under the age of 30.⁸

* Data used by ACT is quoted from a study by Stiller in 1995 which may be out of date.

† using 1995 UK Cystic Fibrosis Survey, the figure for under 18's was 4,500.

** 16,000 families apparently affected—not clear what percentage is life-limited.

Table 5: Main groups of life-limiting and life-threatening conditions: summary of information available

Condition	Cases at any one time	new cases per annum	Risk per child	deaths per annum	Group
Cancer* ⁶⁰	500-700 per 24 hours	11,500 of which 3,450 likely to die	2 in 1,000	640	Group 1
Cystic fibrosis [†]	7,500	260	5 in 1,000	150-160	Group 2
Muscular dystrophy**	2,500	260	1 in 3,500 males	60?	Group 3
Metabolic/immune disorders	1,600??	??		225	Group 3
Cerebral palsy ^{††}	37,000 of which 4,800 likely to die <20	1,800 of which 234 might die <20		n/a	Group 4
Cardiac	n/a	5,000 but not all are fatal		308	Group 1
Others Total (min)	19,550	n/a		n/a	

Palliative care needs

The numbers of 'severely ill children with life-limiting conditions in need of palliative care' are estimated to be 60–85 children under 19 per district of 50,000 children. (This equates to 12 per 10,000).³ There are 295 districts, so 17,700–25,000 have 'some' need. This ties in with ACT's summary. ACT continues to say that half of these children will have 'substantial' needs, i.e. 9,000–12,500. Some of these will have cystic fibrosis or cancer and therefore are less likely to use hospices. NPC estimates 8,000 children might benefit from hospice support.

* figures for cases relate to children under 15, deaths are for children and young people under 24. If there were data available for under 19s, this figure would be much higher because half of cancer deaths under 24 occur over the age of 15. Also this only relates to England and Wales.

[†] 52,000 births per annum in UK38 = 1,000 births per week. 5 babies born with CF per week⁶ i.e. 5 babies per 1,000 births.

** This group includes children <18 with a wide variety of muscular disorders, and some will survive beyond 18.

^{††} The figures relating to CP have been calculated as follows:

1 in 400 children have CP.⁶¹

These figures imply around 37,000 CP cases (14.75m children ÷ 400).

Mortality rates under 20 estimated by NPC to be 13% (out of 1942 cohort, and using survival rates, 247 children die <20 = 13%)8 = 4,810 life limited cases at least.

Table 6: Bath Lifetime's sample of conditions

Organ Category	%	Diagnoses
Respiratory	22.00	Cystic Fibrosis • Atypical TB • BPD
CNS abnormality	8.1	Cerebral palsy • Microcephaly • Birth asphyxia • Spina bifida • Arachnoid cyst (inoperable) • Von Hippel-Lindau • Hydrocephalus
CNS degeneration	20.3	San Filippo • Hurler Scheie • Nieman Pick • Unknown degenerative • Multiple sclerosis
Cardiovascular	14.6	Complex congenital heart disease • Cardiomyopathy
Syndromes	6.5	Unknown syndrome • Retts syndrome • Nagers syndrome • Cockaynes syndrome • Chromosome deletion • Cornelia de Lange • Edwards syndrome
Renal failure	4.1	Bilateral ureterocoeles • Multiple abnormalities • Neuropathic bladder • Post urethral valves • Post transplant
Neuro-muscular Degeneration	12.2	Duchenne dystrophy • Spinal muscular atrophy • Other muscular dystrophy • Progressive neuropathy
Metabolic	4.1	Atherosclerosis • 3MGA • Mitochondrial disorder • Tyrosinaemia type 2 • Metabolic — unknown
Other	3.3	Gastroschisis/shortgut • severe osteogenesis imperfecta • Epidermolysis bullosa
Liver	4.9	Biliary atresia • Alpha 1 antitrypsin • Deficiency • Other liver disease
Total	100	

Bath sample of non-malignant cases — fragmentation

This data is taken from the Bath Lifetime Service's *Development of an NOF proposal for palliative care for children* 2003 and the commentary is taken from the same source. The principal author is Simon Lenton. It shows how fragmented the conditions are. It says:

'There are still few population-based studies to estimate either the prevalence, range of conditions or morbidity associated with life-threatening illness. Figures from the most recent study in Bath are included to emphasise the wide range of conditions. The authors acknowledge that children with severe disabilities — mainly severe learning difficulties associated with cerebral palsy, are probably underestimated, as clinicians rarely perceive them as life-threatening during early childhood, although this becomes more obvious in late adolescence.

The data shows the wide range of diagnoses, and consequently it can be assumed that a wide range of clinicians and tertiary centres will be involved, at least initially in making the diagnosis, if not on a day-to-day basis in providing care. Despite this wide range of diagnoses the associated morbidity is remarkably similar.'

Appendix 2

National Services Framework commitments to palliative care

Quoted from the NSF published by the DH and DfES in October 2004:

Palliative Care

5.14 Palliative care is an essential part of care for many disabled children who have complex health needs. For some children and young people, palliative care is needed only for a short time; for others, it will be the only focus of care from the time a life-threatening or life limiting condition has been diagnosed. Palliative care services can include short-term breaks, counselling, family support services, pain management and symptom control. When services are provided, it is particularly important that these are easily accessible, timely and in the setting of the family's choice.

5.15 High quality palliative care services should be available for all children and young people who need them. Palliative care services are provided by a network of agencies, including the NHS, children's hospices, the voluntary sector and social care and education services. Co-ordination and close liaison between agencies is therefore essential. It is important to recognise the changing needs of young people receiving palliative care as they move from children's services. The *Health Select Committee report on Palliative Care* has identified the importance of transition from children's to adult services.

See *Standards 4, 6 and 10*

Local Authorities, Primary Care Trusts and NHS Trusts ensure that:

- Palliative care services provide high quality, sensitive support that takes account of the physical, emotional and practical needs of the child or young person and their family, including siblings. Services are sensitive to the cultural and spiritual needs of the child, young person and family;
- Services maximise choice, independence and creativity (access to preferred interests or activities) to promote quality of life;
- Services are delivered where the child and family want, for example in the home, hospital, hospice or other setting;
- Services include the prompt availability of equipment to support care, access to appropriate translation services, and workers skilled in using communication aids;
- Palliative and terminal care services are regularly reviewed with parents or carers, children and young people, and gaps in provision identified and addressed;
- Short term breaks, palliative and community health and social care services for children and young people with life-limiting conditions and/or complex health needs is planned in partnership with voluntary sector providers and children

and young people's hospices in localities where these exist;

- Provision of services includes, where appropriate:
 - a) 24-hour access to expertise in paediatric and family care (often provided by local community children and young people's services to enable continuity of care) is available;
 - b) 24-hour expertise in paediatric palliative care (provided by those with specialist palliative care training) is available;
 - c) Pain and symptom control;
 - d) Psychological and social support;
 - e) Spiritual support which takes account of the needs of the whole family;
 - f) Where required, formal counselling or therapy;
 - g) Arrangements to avoid unnecessary emergency admission to hospital are in place;
 - h) Protocols for immediate access to hospital, if needed, are in place, and
 - i) A process for keeping the general practitioner informed.
- The care of children and young people with life-threatening diseases is informed by evidence of best practice.

Death of a Child

5.16 Death in childhood may be sudden and unexpected, for example, because of a road accident, or may occur at the end of a long-term illness. Whatever their circumstances, it is important that families receive care which is sensitive, and appropriate to their individual needs.

5.17 Parents should be supported in making their own decisions about what happens to their child. They will also need support to deal with the host of practical considerations surrounding a death, which can be extremely difficult for grieving relatives to manage.

5.18 Information and support may also be important in helping the family make sense of why a death has occurred, and in understanding the differing grief reactions of family members. See *Standard 11*

Local Authorities, Primary Care Trusts, NHS Trusts ensure that:

- Following a bereavement, parents and families are given the time, space and information to make practical arrangements and decisions, and receive continuing support to cope with their loss, and
- When a child dies unexpectedly, appropriate investigations are undertaken according to best professional practice.'

Appendix 3

Centres of research and education

Where and who	What
Wales University of Swansea Dr Ruth Davies Dr Zac Maunders	<p>Dr Davies and Dr Zac Maunders have recently developed a multidisciplinary diploma in paediatric palliative care. A second diploma in loss and bereavement is being developed. Both diplomas will be available as distance learning courses in future.</p> <p>Dr Davies is developing an All Wales Mapping Study (to follow an earlier important study in South Glamorgan).</p>
Institute of Child Health (University of Wales) Cardiff Dr Richard Hain	<p>Dr Hain is keen to model the trajectories of the key diseases in each of the four groups of life-threatening conditions so that there is no excuse for failure to plan for these children by the statutory bodies. Pain, particularly in adolescents, is another area of interest for him, and also the effect of opioids on children. The Institute has a clinical training post.</p> <p>Dr Hain runs a distance learning diploma/MSc in paediatric palliative medicine for doctors.</p>
Dr Davies and Dr Hain are currently conducting an All Wales Scoping Study of Research Priorities for Paediatric Palliative Care to develop research and education.	
England Centre for Child and Adolescent Health (University of Bristol), Bristol Dr Alan Emond Dr Nicola Eaton Mary Lewis, Dr Simon Lenton and Dr Fiona Finlay hold honorary academic appointments here.	<p>The Centre is multi-disciplinary and offers courses, particularly to community nursing teams, on how to run services and evaluate them. Participants on these courses contribute to the unit's research agenda. The Centre has developed data sheets for services. These collect data on the experience of the care of children with life-limiting illnesses, including days spent in hospital (or saved from being in hospital because of a particular service), days off work, and siblings' days off school. Such data will be useful in illustrating potential resource allocation arguments for improving, say, community care.</p> <p>The priorities for the Centre's future research revolve around transition to adulthood (including sexuality), parental mental health, siblings, staff absenteeism, symptom control, and the evaluation of community teams.</p> <p>The Centre is conveniently close to the two umbrella bodies of the voluntary sector, ACT and ACH, and also experienced service providers, such as Bath Lifetime.</p>
Great Ormond Street Hospital, (GOSH) London Dr Ann Goldman Dr Fenella Craig Jean Simons	<p>Dr Goldman has been the frontline pioneer of children's palliative care for the past twenty years. GOSH holds a clinical training post.</p> <p>GOSH is interested in research into pain and symptom management and the ethics of decision making.</p> <p>Jean Simons is a social worker and member of the GOSH palliative care team, in particular helping with the Child Death Helpline.</p>
Alder Hey Hospital, Liverpool Dr Lynda Brook	<p>Developing the Liverpool Care Pathway for the Dying Child, following on from earlier work undertaken by the Royal Liverpool University Hospital and Marie Curie Cancer Care for adults. Alder Hey also offers educational meetings and includes palliative care as part of its general teaching. From September 2005 it will offer a BSc in paediatric palliative care. Professionals there are also researching pain (teenagers as well as children), and the experience of GPs.</p>

Where and who	What
UK Children's Cancer Study Group, Leicester	UKCCSG is has 22 regional centres, which co-ordinate research around children's cancers. UKCCSG has developed treatment protocols and helped to start the paediatric oncology outreach nursing service. The main centre is in Leicester.
Oxford Brookes, Oxford Helen Bennet	Offers accredited short courses on children's palliative care, which form modules towards graduate and post-graduate qualifications in various professional disciplines, including nursing and social work. Roughly 20 people take these courses each year; demand has increased because of the development of NOF teams. Oxford Brookes would like to see even wider dissemination of palliative care knowledge and increasing transfer of skills and experience between oncology nurses and nurses looking after other specialist conditions. There are plans to develop an NVQ in collaboration with ACT.
Courses are also available at South Bank University and Brighton.	
Royal College of Nursing Institute, Radcliffe Infirmary, Oxford	College has a post for a paediatric palliative care research fellow.
Royal College of Paediatrics and Child Health	The College has a special interest group in palliative care.
Department of Nursing, University of Lancaster, Lancaster Dr Anne Hunt Dr Bernie Carter	Dr Hunt has a special interest in pain management. Dr Carter has done research into the benefits of multi-agency services.
Midlands Paediatric Palliative Care Networks Dr Angela Thompson Dr William Whitehouse	Two groups in the Midlands and East Midlands, consisting of paediatricians, nurses and other professionals, are developing common approaches and standards of care, and acting as education resources for professionals involved with life-limited children
Other activity	There is some community based research in Leicester and there is also research activity, as part of the School of Health and Social Care, in Reading. There are clinical training posts in two children's hospices in Oxford and Leicester.
Contribution of charities	Hospices also take part in training and research. Acorns and ACT are developing a research project (designed to benefit from Acorns' 20 years of experience) during 2005. It will evaluate Acorns' own services and compare them to different types of service, and also examine what is being done in other parts of the country. It will ask why services differ. There are clinical training posts in two children's hospices in Oxford and Leicester. Acorns also offers courses to professionals and other service providers. ACT is hoping to develop an NVQ for non-professionals. The Teenage Cancer Trust is developing a specific oncology nursing qualification with the Royal College of Nursing.
Scotland	
Little academic research and education is taking place in Scotland: Scotland has no resident consultant in paediatric palliative care. ⁶²	

Appendix 4: Charitable sector delivery

While researching this report, NPC visited over ten organisations and also had conversations with and obtained information from many others (15). The following lists some of the organisations in this field. However this list is not comprehensive and inclusion or exclusion in the text below does not necessarily mean a recommendation or rejection. NPC analysts did not visit all the projects below. Expenditure figures in the table are 2003 annual figures unless otherwise stated.

Children's hospices

There are 30 children's hospices in the UK offering residential and other services, and six hospices offering no residential services, but providing day care or hospice at home. A further seven are at project stage. NPC visited three and spoke to a further four in detail* for sampling purposes. Those visited are not listed here because it would be inappropriate to single them out. Hospices offering specialist services have been mentioned in the text.

Umbrella bodies

Organisation	Description	Expenditure (latest figures, £k)
Association for Children with life-threatening or Terminal conditions and their families (ACT)	Umbrella body with children's hospices, community nursing teams and condition-specific groups as members. Publishes guidance on children's palliative care and campaigns for professionals. Voices the views/needs of children with life-limiting conditions and their families on what service provision should be. Runs and provides a helpline for affected families.	160
Association of Children's Hospices	Umbrella body for the children's hospices. Key concerns are the planning of future children's hospices, lack of appropriate trained staff and training and lack of knowledge about all services available to life-limited children. Fundraises on behalf of the sector generally.	1,600

General Support

Organisation	Description of work	Expenditure (latest figures, £k)
Rainbow Trust	Residential short breaks and practical respite in the home.	2,400
Sick Children's Trust	Home from home accommodation for families.	600
Jessie May Trust	Short breaks at home, nursing.	300
Winston's Wish	Bereavement support for families in Gloucestershire, including weekends. Advice to other service providers.	1,000
Childhood Bereavement Network	Network of bereavement support services for children who are bereaved.	2,700
Child Death Helpline	Helpline for parents who have been bereaved.	100
Child Bereavement Trust	Body developing bereavement services.	n/k
Starlight Foundation	Wish making.	n/k

* Visited: Acorns Selly Oak, Naomi House, Christophers at CHASE. Contacted and spoken to: CHAS (Scotland), Martin House, Demelza House, St Oswald's, Ellenor Foundation.

Condition specific children's charities

Organisation	Description	Expenditure (latest figures, £k)
CLIC Sargent Cancer Care for Children (CLIC stands for Cancer and Leukaemia in Childhood)	CLIC and Sargent Cancer Care merged in late 2004, realising that the two organisations were highly complementary. Support and information for children with cancer and their families, home from home accommodation, adolescent activities, care, social/financial support for short breaks, research.	15,000 estimated for combined group
Teenage Cancer Trust	Builds and refurbishes hospital wards treating teenage cancer patients. Raising awareness around teenage cancers.	2,200
Children with Leukaemia	Funds research (medical). Also supports homes from home and provides holidays.	9,700
Cystic Fibrosis Trust	Advocates and campaigns for care and support in all aspects of their lives (five advocates around the country). Advice and information — regional networks.	8,400
Muscular Dystrophy Campaign	Funds research (medical). Practical, medical and emotional support: 11 MDC care advisers and telephone/email advice and information. Grants for equipment.	6,100
CLIMB (Children Living with Inherited Metabolic Diseases)	Funds research (medical). Facilitates medical treatment. Provides information, advice and support for families and professionals including grants to help meet equipment and other costs. Educates professionals and others about this group of diseases.	370
Society for Mucopolysaccharide Diseases	Provides advocacy service. Provides information, advice and support for families and professionals, including grants to help meet equipment and other costs. Funds medical research.	1,200
Action Medical Research	More general medical research fundraising body.	n/k
Sparks (Sports Aiding medical Research for Kids)	Funds medical research into neonatal issues, premature birth, spina bifida, cerebral palsy, and treatment for early year conditions.	1,200

Glossary

24/7: Round the clock, seven days a week, all year round

ACH: Association of Children's Hospices

ACT: Association for Children with Life-Threatening or Terminal Conditions and their Families

BME: Black and minority ethnic

DH: Department of Health

GP: General Practitioner

LCP: Liverpool Care Pathway for the Dying Patient, now being extended to children

NICE: National Institute for Clinical Excellence

NHS: National Health Services

Non-malignant diseases: Non-cancerous conditions

NOF: New Opportunities Fund, a lottery body, now merged with Big Lottery Fund

POONS: Paediatric Oncology Outreach Nursing Services

PCT: Primary Care Trust

Psychosocial care: Care that may use formal psychological methodology and enhances well-being, confidence and social functioning. Such an approach would be focused on the individual's needs about the situation they are encountering and would emphasise both affirming the individual's feelings and discussing ways to cope.

Respite: Care provided for children on a short term basis to allow families to have a break from caring and to allow children to have a break from their parents.

Short breaks: This refers to respite care above. Increasingly the term 'short breaks' is used in preference to respite care.

Specialist palliative care: Care delivered by a multi-disciplinary team, including consultants in palliative care.

SHA: Strategic Health Authority

Umbrella Body: A not-for-profit organisation that co-ordinates a sub-group of voluntary sector organisations. Activities might include co-ordinating education, commissioning research and running national charitable activities, such as a helpline.

Further reading

ACT's publications as follows:

Guidelines for palliative care for young people aged 13-24 (2001)

Voices for change, current perception of services for children with palliative care needs and their families (2003): this opened up the debate and provided some shocking insights into the struggles faced by families.

The Guide to the development of children's palliative care services was updated in 2003, which, together with a *Guide to the assessment of children with life-limiting conditions* and *Voices for change* helped to inform the distribution of the NOF funding in 2003.

In 2004, *A framework for the development of integrated multi-agency care pathways for children with life-threatening and life-limiting conditions* has been released, and in 2005 the DH's complementary publication on commissioning services will come out after heavy input from ACT.

ACT also publishes a regular journal, *PaedPalLit*.

ACH offers publications for hospices and hospice users including the *ACH pack* for families, *ACH Quality Assurance Package* for hospices and professionals, and *ACH Guidelines for Good Practice in a Children's Hospice*.

Other books:

Leslie McIntyre, *The time of her life* (2004)

Julie Stokes, *Then, now and always, supporting children as they journey through grief: a guide for practitioners* (2004)

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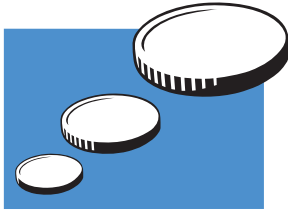
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