

Family & Parenthood
Policy & Practice

**Financial
implications
for parents of
the death of a
child**

Anne Corden, Roy Sainsbury and
Patricia Sloper

**Family
Policy
Studies
Centre**

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The Social Policy Research Unit (SPRU) is an autonomous research unit at the University of York. SPRU's work is concerned with the development of policies and the delivery of services to support people made vulnerable by poverty, ageing, disability or chronic illness. Most of the Unit's work is within the related fields of social security, social care and health care.

More information about SPRU is available on <http://www.york.ac.uk/inst/spru/>

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1

Introduction

Background

Much is now known about the financial implications for parents and families of caring for a chronically sick or disabled child, 98 per cent of whom are cared for mainly at home (Bone and Meltzer, 1989). Parents caring for a disabled child, especially mothers, are less likely to be in paid employment than other parents and may face financial hardship associated with lack of opportunity to work (Bennett and Abrahams, 1994). At the same time, there are likely to be increased expenses for the family (Baldwin, 1985; Beresford, 1995; Dobson and Middleton, 1998).

The social security system acknowledges such financial implications for families through a number of different benefits and allowances both for the disabled child, and their parents or carers. There is evidence, however, that the benefits currently available do not always meet the additional costs (Dobson and Middleton, 1998). Provision by local authorities of equipment or home adaptations under the Chronically Sick and Disabled Person's Act (1970), and in some cases grants from housing authorities for structural alterations to family homes, may also ease some of the financial pressures of caring for a very ill or disabled child. The Family Fund Trust provides grants to some families for items related to the cost of the child and a number of specific national and local charities make funds available.

This structural network of financial assistance and additional support falls away quickly if the child dies. By 1999 evidence was emerging from children's hospices that, for some parents, the period immediately following the death of their child is one in which they face significant financial problems, with serious implications for the healing and adjustment process on which the surviving family must embark. Staff at Martin House, a children's hospice which by 1999 had had experience of offering ongoing support to 400 bereaved families, expressed concern about financial aspects associated with the death of a child. They identified a number of issues which affected many of the families who continued to receive support from the hospice after the death of their child. These included the cessation of some benefits; the impact of low parental income, often associated with problems in resuming or starting paid work; the impact of spending patterns acquired during

the final months of a child's life, which take time for readjustment to changed circumstances; the cost of funeral arrangements, and, for some, the legacy of debt accumulated during the period of care.

Hospice staff found it hard to know how to approach these aspects in the support service they offered, and how much attention should be paid to such financial issues in staff training and preparation. Their experience led them to believe that the financial problems could be widespread, and sometimes acute, among bereaved families. The aim of the research reported here is to throw light on the issues which contribute to financial difficulty in the period following bereavement. Greater understanding of the effects of financial circumstances on the families' lives at this stage will, it is hoped, provide pointers to ways in which families might be helped to overcome or even avoid some of the problems. Findings may be used to help to improve the services and support offered by hospices; other health and social care, and bereavement services; advice agencies; voluntary organisations providing services to parents, and a number of government departments and agencies.

What is already known

There is little literature or research about financial aspects associated with the death of children, but it is useful to review what is known about some of the issues identified by hospice staff.

The cost of funeral arrangements

The Manchester Unity Friendly Society has surveyed the costs of funerals regularly over the last 20 years. Their latest survey (Oddfellows, 2000) found the average cost of a funeral in Great Britain in 2000 to be £2,048 and a cremation, £1,215. Costs have increased by more than the rate of inflation over the last 10 years. The costs of burial appear to have risen by 25 per cent in the last two years, largely reflecting the increased charges for funeral plots, many of which are owned by local authorities who now charge market prices.

A funeral is now a major expense for families. Currently, the British funeral industry is undergoing

considerable change, with rapid trends towards monopolisation and commercialisation (Drakeford, 1998). Drakeford describes some of the recent developments in marketing practices which increase the overall cost of a funeral, and concludes that 'many of these developments are intrinsically inimical to the interests of poorest consumers' (p512). The final bill for the funeral is often substantially more than the original quotation (Oddfellows, 2000) which is likely to increase budgeting problems for low-income families.

The Manchester Unity Friendly Society survey is concerned with the costs of adult burials and cremations. It is hard to get specific information about funeral costs for children. Some firms of funeral directors conduct children's burials at cost, and some offer a basic service without charge (Hindmarch, 2000), but practice is variable and there is little information available.

Some parents claiming an income-related benefit may be entitled to a Social Fund funeral payment. This covers the essential cost of the burial or cremation, and, by discretion, up to £600 for components such as funeral director's fees, flowers and cars for relatives. The cost of a headstone is not covered in the regulated part of the Social Fund. In 2000, a typical headstone cost £450–£500 (Oddfellows, 2000) but can be much more expensive, depending on choice.

Impact of low parental income

Parents of disabled and chronically sick children are less likely than other parents to have paid employment, especially mothers. A number of factors contribute to this (Kagan *et al.*, 1998). Parents may leave work, or never join the labour market, preferring to care for their child. Employers may not be sympathetic to the need for parents to have time off work to keep medical appointments or deal with periods of acute illness, and education services may also be inflexible, making it hard for parents to combine their own work with the necessary support of their child.

Those parents who would like to work meet additional barriers in the lack of appropriate child care for an ill or disabled child. Many children who die as a result of impairment or chronic illness have complex support needs. The 'rolling out' of care from hospital to the community has led to home care for the majority of such children. This may place considerable demands upon parents' time and expertise, and often requires their periodic involvement in care and nursing tasks throughout the day and/or night. Some children at home need 24-hour care. Families report problems in securing suitable packages of care in these situations, and their ability to maintain employment may be limited by the lack of appropriate substitute care (While *et al.*, 1996; Kirk, 1999a, 1999b). During the period leading up to a child's death, both parents may therefore be depending on out-of-work income.

If a parent does maintain employment, earnings may be depressed if family circumstances have made it hard to seek promotion or better-paid work.

A disabled or very ill child may be entitled to Disability Living Allowance care and/or mobility components to meet the extra costs of disability, and older children may have some entitlement to earnings replacement benefits in their own right, through Severe Disablement Allowance. In addition to the Child Benefit available for all children, some parents who care for disabled or very ill children claim Invalid Care Allowance, and some are entitled to additional premiums in Income Support and Housing Benefit. It is known that some parents have problems getting information about the benefits available (While *et al.*, 1996).

When the child dies, there is currently no further entitlement to Child Benefit, Disability Living Allowance or Invalid Care Allowance.¹ Depending on the payments methods which the parents have been using, it is possible for some parents to have been paid in advance monies to which they subsequently were not entitled because the child died before the end of the payment period. Recovery of such 'overpayments' may be sought. This is more likely to happen with Disability Living Allowance, where amounts of entitlement can be high (DSS, 1999).

The parents' own benefit status may also change, with the loss of entitlement to Invalid Care Allowance and carers' premiums. There is some acknowledgement of the need for a period of adjustment after care-giving has ended, in that the carer's premium in Income Support for parents in receipt of Income Support and Invalid Care Allowance (worth £13.95 for one parent in 1999) continues to be paid for another eight weeks. At the end of this period, some parents may find that they are required to start seeking work in order to maintain entitlement to out-of-work benefits.

Some research has addressed the long-term income and employment effects of caring for an ill or disabled family member, after the period of care has ended (Lewis and Meredith, 1988; McLaughlin and Ritchie, 1994) but this work did not focus in depth on the situation of parents whose child had died.

Impact of previous spending patterns

The spending patterns of a family caring for a disabled or chronically ill child reflect needs and priorities which are often different from those in other families (Dobson and Middleton, 1998).

Families may need to spend extra on heating the home, as a result of using more rooms for longer parts of the day and maintaining constant warmth. If less time is available for running the household there are fewer opportunities for economising in food purchase and cooking. Special diets or the need to tempt an ill child to eat may result in increased spending on food, and more costly eating patterns for the whole family. Some

families may invest in large or adapted vehicles, which are more expensive to run. Domestic equipment bought to make caring easier (for example, industrial washing machines and tumble driers) is expensive to run. There may be considerable expenses associated with hospital appointments and in-patient spells, including costs of transport, and subsistence costs for parents (Sloper, 1996; Callery, 1997).

Families caring for a child with a life-threatening illness may want to spend extra on the child's siblings, as a form of compensation or respite from stressful situations, or to provide ways of occupying or entertaining the other children. Outings and holidays for the whole family may become specially important as a child nears the end of life.

Some of these spending patterns may be hard to change, to accommodate to new financial situations after the death of a child.

The legacy of debt

We know that some parents caring for severely disabled or very ill children borrow money or put off paying bills in order to be able to have what they need (Beresford, 1995). Some families thus already have a 'legacy of debt' which follows them into bereavement, and to which they may add in order to pay the additional expenses of funerals. Staff at Martin House reported that it was not unusual for bereaved families with whom they were in touch to talk about the large sums of money owed to a variety of creditors, including fuel boards, banks, commercial credit companies, building societies, retail outlets, garages, travel and holiday firms, relatives and friends. Some bereaved families were believed to be in danger of repossession of their home as a result of mortgage arrears.

The scope of the research

Parents of children who have received hospice support represent a special group, among all those parents who experience the death of a child. In 1998, there were just under 3,000 deaths of children and young people aged 1–19 years in England and Wales (ONS, 1998). The main underlying cause of death in childhood is injury and poisoning, and the second underlying cause is cancer/leukaemia. The children's hospices are less likely to be in touch with parents whose children die unexpectedly, and quickly. The families they serve are more likely to be those in which a child has cancer, congenital anomalies, respiratory diseases or diseases of the circulatory or nervous system. Many such families have been caring for a child with substantial medical and social support needs over a long period of time.

In early 1999 Martin House was in touch with 240 families who were caring for their child and 100 bereaved families. By 2000 there were 20 other children's

hospices in Great Britain, but of course only a minority of families whose child dies receive hospice support.

The fact that bereaved parents in touch with a children's hospice are such a small and 'special' group is not, however, a constraint on the usefulness of the research reported. Hospice staff are in a unique situation of long-term contact with bereaved parents, most of whom stay in touch with staff for at least two years. Staff get to know the families well, and learn what is important in their lives. Hospice staff are also of key importance in the development of appropriate, quality services for families, and their professional knowledge and experience is influential and respected in the fields of medicine and social work. Their experience is that there is a lack of systematic knowledge available to them about the financial aspects associated with a child's death, and no body of knowledge and expertise about how to deal with the problems that arise. This currently limits the usefulness of the help they can offer families. Staff in other organisations in touch with bereaved parents, including hospitals and bereavement services, confirm the need to know more about the financial implications associated with the death of a child.

Preliminary, exploratory research conducted from a hospice setting thus provides a valuable first step in opening up this area, and putting financial aspects onto the agenda for debate and discussion, and professional scrutiny. Findings are of immediate, practical value for policy and practice in the children's hospice setting, and for other support services in touch with parents of children with life limiting conditions. Findings will inform policy and practice of government agencies, including the Benefits Agency and Child Support Agency; the Employment Service; local authority departments, and developments in the New Deal programme. The report is also relevant for financial and regulatory organisations, including banks and building societies, and there are implications for funeral companies and employers' organisations.

The approach adopted

This was a small-scale, exploratory study in areas of great sensitivity, and the researchers worked closely with staff at Martin House in designing the research. Members of the project advisory group, who included staff from other children's hospices and parents' support services, and bereaved parents, also informed the early stages of the research.

The work was conducted in three parts:

- interviews with parents in 17 families, who had been in touch with Martin House;
- group discussions and interviews with key staff in health and social services, and in Martin House;
- a postal survey of all children's hospices, and a number of bereavement services and support groups for parents.

Interviews with parents

Parents from 16 families who had experienced the death of their child within the last two years, and one couple who believed that their child had a short time to live, agreed to take part in the study, and talked in detail about financial aspects of their lives before and after their child's death. The group was selected to include both lone parents and two-parent families; families with different sources and levels of income; and families living in different parts of the area served by Martin House, including urban and rural locations, and different local authority areas. There was a full age range among the children who had died, from one to 17 years. Most of the children who had died had been ill for at least one year, and some for much longer.

All the bereaved families were still in touch with Martin House – those whose child had died more recently were receiving support from the bereavement team, and others maintained contact by attending remembrance days or keeping in touch with individual staff. Most of the families who took part had received help from Martin House while caring for their sick child. The group also included two families where the facilities and services offered by Martin House had not been taken up until after the child's death.

Interviews with parents took place in late 1999/early 2000. Details of the selection and recruitment of parents, response to invitations, the conduct of the interviews, and the analysis of the material are appended.

Interviews with key professional staff

It was important to obtain perspectives from key professionals in touch with bereaved families in the area served by Martin House. A series of interviews and group discussions was held, to gather staff perceptions about the financial circumstances and labour market participation, generally, among families they worked with; ways in which advice and assistance about financial matters is currently made available; problems that arise, and what service or policy developments might be helpful.

People taking part included:

- senior staff at Martin House;
- members of the care team, bereavement team and social work staff at Martin House;
- local authority social workers;
- consultants, nursing staff, health visitors and social workers in local oncology services and child development centres.

Discussions with staff took place in parallel with interviews with parents.

Postal survey

In order to put the experiences of parents, hospice and other professional staff into a wider context, a postal survey of all the children's hospices in the United Kingdom was undertaken in early 2000. Twenty-one questionnaires were distributed of which 18 were completed by a key member of the hospice staff. In many cases, the respondent had consulted with other colleagues before completing the questions.

Topics covered in the questionnaire included:

- information about the hospice, and what support is provided for bereaved parents;
- the extent to which bereaved parents talk about financial issues with hospice staff, and what kind of problems are reported;
- views on the factors which contribute to parents' financial problems;
- how financial issues are dealt with by the hospice;
- suggestions as to how financial problems for bereaved parents might be lessened, or avoided in the future.

The questionnaire was also sent to a number of organisations which provide other forms of advice, support and services to bereaved parents. Four such organisations returned completed questionnaires.

Research team support

The three members of the research team were senior members of the research unit, and experienced in researching sensitive and difficult topics. Talking to recently bereaved parents made particular demands, however, and the research funders agreed that it would be helpful if the researchers had access to some professional support. At the beginning of the project the team met, as a group, with a professional counsellor, to talk through the topics under study and to consider what personal impact and effect there might be. This helped the team prepare positively. A further group meeting with the counsellor took place, at the end of the research, to talk about experiences associated with doing this work, in order to move on. The counsellor was available to individual researchers during the project. This way of working, to support research staff engaged in demanding work which might be risky to emotional health, is still relatively novel but proved helpful. It is fully reported and discussed elsewhere (pending).

Structure of report

In what follows, the focus is on emerging issues and themes, and the structure of the report reflects this approach. We set evidence from the 17 families who took

part alongside the views and perspectives of key professional staff in the same local area. The parents in the study group were not selected to be representative of all families using children's hospices, in a statistical sense, but there is no reason to believe that they are unusual. They comprise more than one-third of all the bereaved parents with whom Martin House was in touch in 1999 whose child had died in the previous two years.

We use evidence from 18 other children's hospices across the United Kingdom (out of the total of 21), and four other organisations which support bereaved parents to show how far the findings reflect experiences in other parts of the country, and in other types of settings, and what the general patterns are.

We do not use blocks of the parents' own words in this report, and we do not present vignettes or case studies. That approach would mean further involvement for bereaved parents, in discussing manuscripts and considering how their personal circumstances were being presented for publication. We felt this was beyond the scope of this exploratory research, at this stage. The occasional words and phrases in italics are, however, those which parents said. We hope that what we have written reflects the parents' wishes to throw light on financial issues in a way that can be used to help other families.

The report is organised as follows. Chapter Two looks first at the financial costs of caring for a chronically sick or disabled child, in the months preceding the child's death. Chapter Three describes the immediate financial impact for parents when their child died, and Chapter Four explains some of the long-term financial implications. The final chapter discusses suggestions for changes which might be helpful, within the current policy environment.

Note to Chapter 1

- 1 The Secretary of State for Social Security announced on 3 October 2000 the Government's intention to extend the period of receipt of Invalid Care Allowance for up to eight weeks after the death of the person being cared for (DSS, 2000). It is likely that this will come into effect in 2002.

2

The costs of care

There have been several previous studies of the costs of caring for a disabled or seriously ill child (Baldwin, 1985; Smyth and Robus, 1989; Dobson and Middleton, 1998) and Kagan *et al.* (1998) have documented the difficulties parents face in combining paid employment with caring for a disabled child. We know that parents who look after very sick children at home are likely to experience reduced earnings, or leave paid work altogether. In particular, long periods of illness have been shown to result in increased expenditure and financial difficulty for families with disabled children (Dobson and Middleton, 1998), and the considerable costs to parents of involvement in their children's hospitalisation have also been highlighted (Callery, 1997). The high expenses incurred are rarely met by the benefits available for themselves and the child concerned. Knowing that a child's life is likely to be limited, however, brings a further perspective to bear on decisions that may have to be made about employment, using household resources or seeking additional financial support.

This chapter explores these issues further. The first part explains how some of the families interviewed had already experienced considerable reduction or interruption in earnings during the period of their child's illness. At the same time, they needed to spend more money in order to care for the child, as discussed in the second part of the chapter. The last part looks at families' budgeting strategies during the final months of the child's life. How far their income and resources matched what they wanted to spend during this period had considerable influence on their financial situation at the time of their child's death.

Interruptions in employment

The parents' situation with regard to employment in the period preceding their child's death has to be understood in the context of the general family circumstances during the caring period and the pattern of development of the child's illness or condition. Parents were of different ages, and at different stages in their family life. Some had other children, whereas for some parents the child who had died was their only child, or the last to be still at home. Some of the children

born with a congenital condition had always been ill or developmentally delayed, whereas others had experienced the onset of illness at a later stage in their childhood. There were thus a number of influences on parents' decisions about working during their child's life.

In most families, at least one parent had been employed outside the home immediately preceding the onset of the child's illness, either before the child's birth or before the child became ill. The period of disruption of family life which followed, often involving intensive investigations and medical appointments, hospital stays, operations or treatment, usually meant some interruption of employment for parents. Parents dealt with this in different ways, for example by extending maternity leave, explaining situations to employers and asking for time away from work, or by taking sick leave.

For some children, such as oncology patients, after initial treatment and establishment of maintenance regimes there was hope of eventual recovery, and parents tried to return to previous routines. In such cases, parents who had taken time off work to manage the period of disruption found it natural to return as soon as possible, especially if the child felt better and was able to go back to school. Others who carried on working included parents of children whose progressive life-limiting illness would nevertheless probably allow the child to have several relatively unproblematic years following diagnosis.

Parents took different courses according to their individual circumstances and expectations, and the employment opportunities available. Advantages perceived in trying to continue paid work included financial security and being able to maintain living standards. Keeping normal routines of family life, including going to work, could be specially important if there were other children in the family. Keeping in touch with supportive colleagues and friends at work was also valued. People who had invested many years of their lives in their paid work, building up skills and experiences, developing careers, or watching family businesses grow felt they had much to lose if they left work. For some parents who were able to think ahead to a period without their child, continuing with their work offered some possibility of continuity and structure in the life that lay ahead of them.

Deciding not to do paid work

Not all parents wanted to continue to try to work. Some thought it important to be at home with their child all the time after being told that their child's life might be limited.

Mothers who had expected to return to work after maternity leave sometimes felt differently after the birth of a baby with a congenital condition. They wanted to spend all possible time with their child. Those who still would have liked to have been able to go back to work or educational courses sometimes found this had not been possible, because of the appointments, medical investigations and procedures for their baby, and operations or stays in hospital.

As children's illnesses developed, and children became older, it could become harder for parents to continue doing paid work. Towards the end of their lives many of the children needed intensive support at home, and in some cases 24-hour care and supervision was required. Even when some care was provided by professional care staff, other relatives or friends, parents had most of the day-to-day responsibility. The frequency and intensity of the various caring tasks and procedures could be physically and emotionally demanding, and not all employers were sympathetic to the amount of time parents needed to be away from their jobs, and the uncertainties of the situation.

None of the parents who had been caring for their sick child for several years without a domestic partner had thought seriously about working outside the home during that time. Times when it had previously been possible for them to do some paid work were when they had been living with the child's father, or when the child was very young and the nature of the condition had not yet made particular demands for extra care.

Balancing paid work and care

Two-parent families sometimes had more opportunities than lone parents for working while their child was ill, and keeping a job to return to after the child died. One option was for parents to continue or adopt separate roles, as main breadwinner and main carer. Both men and women main earners had sometimes maintained this role throughout their child's illness. Parents who had remained in full-time work during many years of a child's illness had generally remained at fairly low earnings levels, as they forfeited opportunities for promotion or overtime.

Another option for parents was to work in a different way, if an employer would agree to change shifts, reduce hours or move the employee to less demanding kinds of work. If one parent moved to a better-paid job, this was some compensation for the income lost when the other parent gave up work to care for the child. One arrangement tried was for both partners to work part-

time, sharing the child's care, but this did not always allow enough flexibility to match the demands of the child's care, and such arrangements had been fairly short-term, usually in the final year of the child's life. Engaging a professional nanny for a sick baby was an option for higher-earning parents but it proved hard to recruit somebody with appropriate skills and experience, and this arrangement was also relatively short-lived. When parents tried to make plans in advance about ways of combining work and care, problems could arise when children lived much longer than original prognoses.

Fathers who had initially been the main full-time breadwinner explained how stressful it had been to continue in this role, knowing that their child's life was limited, especially if they had demanding jobs or worked long hours. They could feel marginalised and excluded from what was happening at home, and the interactions between their partner and the doctors and professionals. Men who had to learn from their partners how to use increasingly complex medical technology or manage drug regimes felt less confident in their ability to help their child. As children got older some became heavy, and hard for mothers to lift or move on their own, and some teenage boys preferred their fathers to help them with aspects of intimate care.

In order to cope with such caring demands working fathers asked for paid or unpaid leave, or sent in sickness certificates from sympathetic family doctors. Having to take time off work could be a further source of stress, however, if an employer was unsympathetic, or it meant letting down colleagues. In such circumstances, some fathers had decided to give up work or take early retirement. This had not been an easy decision for the men involved. It could be hard to look ahead to the implications for the time after the child died; and one way of dealing with current emotional pain and stress was to *'take it a day at a time'*. Parents who had talked at length to community nurses about the future implications of giving up work completely thought, in retrospect, that such discussions had been valuable. Not all men had the opportunity to make their own decisions about whether to leave work because employers who were unable to manage long or unpredictable employee absences ended contracts.

Those parents who had been helped at the workplace to keep their jobs while their child was so ill had much appreciated this. Workplaces which allowed parents to take occasional compassionate leave with full pay included large manufacturing companies and public sector employers. The same employers had allowed periods of absence of up to eight weeks, formally registered as 'sick leave' with certification from GPs, but generally understood by supervisory staff to enable parents (men and women) to care for children. Another arrangement which enabled a mother to keep a part-time job with a national company over several years was an agreement that she would come into work whenever

possible, and be paid just for days worked. Self-employment as a sole trader was another way of doing small amounts of work and keeping in touch with potential customers while caring for a child.

Interruptions to or ending employment meant, for many of the families concerned, significant reductions in income. Taking time off work could also mean loss of pay, or transference to sickness benefits. Fathers who had taken early retirement or moved from a full-time post to part-time work had seen a drop in earnings of more than a half. Fathers who had previously worked significant amounts of overtime saw earnings plummet as their priorities changed and they chose to work shorter hours. Mothers who had been second breadwinners had sometimes been contributing more than a third of earned income, which was lost to the family. Families in which neither parent did paid work mostly relied on Income Support.

It was not unusual for a family to have experienced several separate reductions in earnings during the caring period, with moves from full-time to part-time work, loss of earnings from a second breadwinner, loss of earnings during periods of unpaid leave or time off work 'sick', and then moves out of employment altogether and on to Income Support. The picture also included, for some families, other significant reductions in income during the caring period, due to parental separation or widowhood, periods of unemployment or parental ill-health, or having to give up activities which brought in income, such as taking paid lodgers.

The picture gained from parents was confirmed in interviews with staff. It was their experience that in most cases at least one parent, and in many families both parents, eventually gave up employment to care for the child. They pointed out the lack of alternative carers to allow parents to carry on working and also that parents want to be there with their children in the last part of their lives. In our survey of children's hospices in the UK, respondents from 15 of the 18 hospices returning a questionnaire reported that giving up work to care for a child was a very important contributor to families' financial problems following their eventual death.

The need to spend extra

There is a considerable body of evidence about the extra expenses incurred by families with a severely disabled or chronically sick child (Baldwin, 1985; Dobson and Middleton, 1998). This study confirms those findings, and adds additional perspectives about items and services which families needed to spend money on, when their child approached the end of life.

Most of the parents interviewed thought that household spending on gas/electricity, telephone and transport had increased in order to meet their child's needs. Adaptations and equipment, house extensions or removals were an additional major expense for some

families, as was clothing and bedding for the child, and laundry. Some families spent extra on food, both for the child concerned, and for other members of the family, and depending on individual circumstances, some families spent heavily on toys, games and activities, outings and holidays.

This section continues by looking briefly at each of these kinds of expense.

Gas and electricity

It is expensive to maintain the levels of even warmth required by some very ill children, and most parents interviewed described high fuel bills all the year round.

There were often heavy demands on electricity. Lights could be on in the house throughout the night, for supervision and care purposes. The need to heat food quickly, and disrupted mealtimes could mean that ovens and microwaves were in frequent use. There was heavy use of powerful washing machines and tumble driers.

Continual technological support from ventilators, suction pumps, feeding pumps, or monitors/alarms made further demands for power. Power-controlled wheelchairs owned by teenagers needed recharging. Older children who slept little sometimes kept on televisions, videos, or tapes for much of the day and night, and some parents had bought specialist 'soothing' or 'stimulating' light/sound items which needed to be plugged-in to the electricity supply.

Parents saw no scope for reducing their fuel bills while caring for their child. The need to spend more on fuel often resulted in arrears being owed to the utility companies. Fifteen of the 18 hospices responding to the postal survey reported some experience of bereaved families telling them about financial problems caused by fuel debt which had to be dealt with following the death of their child.

Telephone

Having at least one telephone was seen as essential by the parents interviewed. Looking after such ill children required being able to contact medical and nursing services quickly. Parents used their telephones to talk to social services personnel, staff in voluntary agencies and organisations, and the children's hospice. Parents whose children needed a number of visits during the day from paediatric/caring staff spoke of their role in '*co-ordinating the professionals*', mainly by phone, meaning that they helped staff to organise visiting schedules efficiently. There were advantages to the parents of helping to control things in this way, but there were also financial costs, especially if the professionals were using mobile phones.

Much day-to-day business might be conducted by phone from the home. Parents valued the speed and ease of communication, but financial costs could be high. Some parents also relied on telephones for social

contacts with relatives and friends, and to keep in touch with key family members whose support they valued. One observation was that towards the end of their child's life, friends phoned the house themselves less frequently, less confident about what to say in such circumstances. Parents found themselves initiating the calls and paying for them more frequently than before, when costs were shared more equally.

Having a second, mobile phone was important to some parents who needed to keep in touch with home while at work, or out of the house.

Heavy use of the telephone could also extend beyond the life of a child and some families could find themselves with large amounts owing to telephone companies. Fifteen of the 18 hospices in the postal survey reported that they had experience of dealing with families with financial problems caused by telephone bill arrears after the death of their child.

Transport

The study provided further evidence of the additional costs related to transport for parents caring for a child with a life-limiting condition (Dobson and Middleton, 1998; Roberts and Lawton, 1999). Most of the parents felt that having a private vehicle was essential. Having access to a reliable family vehicle in case of medical crisis meant that some families spent much more on their vehicles, in terms of outlay and servicing, than they would otherwise have chosen.

Large or adapted vehicles could be essential, in order to keep the child comfortable, take along all the equipment needed, and accommodate other children. This increased outlay and running costs. Using the vehicle to go to hospital could mean heavy expenditure on fuel and maintenance. Families who lived some distance from regional medical or specialist services faced particular problems.

When a child spent time in hospital, this sometimes meant mothers and fathers both driving separately to the hospital most days, to fit in with other family and work commitments.

It was not unusual for families to run two vehicles, one for using when the child was a passenger and the other for parents to get to work, or for quick local trips such as fetching other children from school. The only family without any vehicle lived at a relatively short distance from the services they used. They felt very constrained, but with no earnings or savings could not afford to buy their first car.

Clothing and bedding

Parents often spent extra on clothes and bedding for their child, because they needed larger stocks to accommodate the need for continuous changes, and the frequent washing wore clothes out more quickly. Some

parents had to buy incontinence pads, because their child needed more than were supplied free.

Clothing was a particular expense for children whose weight fluctuated considerably, for example children receiving steroid treatment. There could be little choice of less expensive items when looking for suitable clothes to dress children with rigid limbs or painful bodies. Children with allergies or skin conditions were also expensive to dress, and appropriate bedding could be costly. Again there was often no choice of fabric or item, and no cheaper options.

Older children had their own preferences about clothing, in the same way as young people who are not disabled or ill. It could be hard not to respond to a child's request for particular items of clothing for parents who knew that there would be few further opportunities for their child to enjoy choosing clothes. Keeping children looking nice, in bright or pretty clothes, became specially important to some mothers. It was both a demonstration of their care, and a reinforcement of positive images of their child.

Food

Most parents found food an expensive item during periods when their child was in hospital, and they had to buy meals for themselves, and sometimes the whole family, in cafes or hospital canteens. Similarly, ready-cooked meals or takeaways were needed when sick children had needed particular attention at home and parents were tired or needed to spend time with other children. For some families, periods when they had time to shop properly, plan and cook their own food at home came relatively infrequently.

Needing to tempt a sick child to eat could also be expensive, especially if there were other children who did not expect to be excluded from treats. Parents remembered times when family meals had meant constant trips to McDonalds, or always having expensive ice-cream desserts.

Equipment and house adaptations/ removals

Much of the special equipment and nursing aids needed for home care had been provided or loaned by health trusts, social services and sometimes, Martin House. Some parents wanted items which could not be provided in this way, and several families had bought their own equipment to make life easier for themselves and their child. Items needed could be very expensive. A stair lift (not provided by social services for children) had cost £2,000. An all-terrain buggy with carrier for equipment, bought so that the whole family could enjoy country walks, had cost £350. Electric wheelchairs used by older children, reclining chairs and automatically-adjusting beds were very expensive items.

Families who bought standard items such as prams and car seats sometimes quickly discovered that they were not suitable for their child, and replacements were needed at further expense. Families who would normally have 'economised' in equipping a new baby by using second-hand prams, buggies or cots had found this was not possible. Their babies were not comfortable in standard equipment, were allergic to the fabrics or at extra risk of infection, and expensive new items had been necessary.

One reason that families bought their own equipment was their experience of the 'wrangles' that went on between health and social services departments as to which department had financial responsibility. Experiences of delays and broken promises had led some families to go out and buy what was needed themselves – physiotherapy equipment, suction machine, nebuliser, electric bed, support wedges and cushions. Parents found it very hurtful when caring authorities tried to avoid financial responsibility for their child. This study provided further evidence of the lack of clarity over funding responsibilities for equipment needed by children at home described by Kirk (1999a).

Parents who had not been able to find equipment they needed had sometimes designed and made their own. This could be expensive, however. Making an extra-warm rainproof cover for a buggy meant that the family could go out together more often, but fabric and fastenings had cost the father £300.

Not all families who had adapted their houses, with additional living space or bathrooms, had been eligible for financial help. Even when the local authority paid for most of the basic building work, families usually had to meet some of the costs of redecoration, carpeting and curtains, and the additional furniture needed.

The need for accommodation suited to their child's needs (Oldman and Beresford, 1998) led some families to move house during the period of their child's illness, with removal expenses and start-up costs for a new home. Other families had experienced a house move when the breadwinner's job was relocated. Again, costs of moving were heavy, but the continuity of employment had seemed very important to the families concerned.

Toys, activities and holidays

Keeping a sick child entertained during lengthy hospital visits or in-patient stays was not easy, and new toys, books or activity sets had become part of the routine for several families. Toys at home often received hard use and were often spoilt, needing to be replaced.

Older children with limited mobility were sometimes specially expensive to make provision for. Television was helpful, but families could also find themselves spending heavily on videos, computer games and music CDs. Parents who had used catalogues to buy specialist toys and activity equipment which is marketed towards parents of disabled children, for example sensory

stimulants or soothers, had found this very expensive.

Parents who had more than one child were aware of the effects on their other children of extra toys or activities for their sick brother or sister, and parents had to spend more money in order to seem fair to everybody. During periods when the sick child needed most of their parents' attention, one way of managing home life was to provide new toys or activities as distraction for other children.

Outings or trips were often highly valued. Going out together as a family helped parents and children to enjoy time together, and to be more 'ordinary' and less constrained. Depending on the child's age and condition, however, even simple outings could be expensive. The extra costs of making a buggy warm and waterproof enough for country walks are described above. Accommodating bulky equipment for a child sometimes meant that even getting as far as the local park required two car trips or taxi rides for a family. If their child got cold, families often had to spend more time than usual in cafes or indoor amusements, and spending was increased.

Holidays often seemed very important. When the sick child and the rest of the family enjoyed a holiday parents valued this highly, and some took all possible opportunities for going on holiday, knowing that there might not be many more chances. Many of the families in this group had received help with paying for holidays, as we see in the next part of the chapter. For those who did not receive help, holidays seemed a big expense.

Paying for professional help

Local authorities who help families care are increasingly making charges for services and some parents paid for domestic help provided.

Employing a professional nanny for a child was expensive, involving fees of up to £600 per month, but it did enable both parents to continue some paid work outside the home. In another family nursery fees for the child's sibling cost around £400 per month. Again, this was thought to be quite expensive, but provided some normality and security for the other child during the disruptive period of diagnosis and intensive treatment of the sick child. Paying for six hours a week for 'baby-sitting' enabled a mother to pursue a personal interest to which she was committed.

This part of the chapter has summarised what families told us about their additional costs while caring for their child. Findings here provide further illustrations of what is known already about the expenses of caring for a disabled child. The issues discussed by families were all familiar to staff who were interviewed for the study. They pointed out that there was always considerable extra expense associated with the needs of children with life-threatening illness, and that, in their experience, this level of expense was greater than is currently covered by the available benefits.

The families studied here all knew that their child's life was likely to be limited. This influenced decisions about how to manage their household budgets and how much money to spend. As one member of staff pointed out, the families know that their child is going to die, but they do not know when. They have to make decisions based on the child's life at the time: this may be for one year or many years, in most cases they don't know how long the child will live. The next part of this chapter describes how families attempted to balance their resources and expenses, the decisions they made about spending, and the influences on their financial situations in the months preceding their child's death.

Managing household budgets

Household incomes included a number of benefits and allowances which went some way to compensating for interruptions or reductions in income, and the extra costs of care. There are also various charitable and trust funds available to parents of severely ill or disabled children. Not all parents experienced major problems in balancing resources with needs during the period of care, but some families found this very hard, and by the time their child died, were in considerable financial difficulty. This part of the chapter explores the way parents managed household budgets, and prioritised their spending while caring for their child.

Benefits and allowances

Most parents taking part in this study received Child Benefit, Disability Living Allowance and Invalid Care Allowance in the months leading up to their child's death.

Child Benefit is universally available to parents of all children under 16 years, and when the interviews were conducted weekly rates of payment of Child Benefit were £17.10 (eldest or only child of a lone parent), £14.40 (eldest or only child in a two-parent family) and £9.60 (other children).

Disability Living Allowance (DLA) is a non-contributory, non-means-tested benefit designed to help meet the extra costs of disabled people. The care component is paid at three rates according to the severity of disability and need for care, and there is no lower age limit. The mobility component of Disability Living Allowance is paid at two rates according to the severity of problems in getting around, and at the time of the study was available to children aged five years and over.

Invalid Care Allowance is a non-contributory, non-means-tested benefit, available to a person not in paid employment, who provides regular and substantial care for somebody receiving higher rates of Disability Living Allowance. In a two-parent family, only one parent may receive Invalid Care Allowance.

The only parents who had not been receiving Child Benefit for their child who had died were those whose child was over 16 years and was receiving Severe Disablement Allowance in their own right (around £54 weekly).

All the children concerned had been receiving the care component of Disability Living Allowance mostly at the highest rate, £52.95 per week. Most of those aged over five years had also been receiving the mobility component at higher rate, £37.00 per week, which was sometimes paid directly to Motability, in respect of leasing or purchasing arrangements of vehicles for the family.

In most families in this study, one parent was claiming Invalid Care Allowance at the time their child died. Invalid Care Allowance was currently paid at £39.95 per week, and some parents were entitled to additional amounts for adult or child dependants.

Claiming benefits

Parents' experience of applying for Disability Living Allowance had been variable. Some parents of children who had been diagnosed with a congenital condition soon after birth had started receiving Disability Living Allowance (and Invalid Care Allowance) from the time their child was three months old. Others applied later in the child's life, when illnesses developed or disabling conditions became worse. Most had learned about this benefit from health or social care professionals with whom they were in touch.

Those parents who, looking back, knew that they could have applied earlier and had '*messed out*' on monies to which they had been entitled expressed mixed views. In retrospect, a couple who had felt they could not justifiably say that their three-month baby needed '*extra care*' although they knew she was technically entitled, did not regret their decision to delay their application. In contrast, a lone mother who initially decided that her son was '*not disabled enough*' to qualify for Disability Living Allowance wished she had received better advice, and applied earlier.

There were also some examples of parents who did not claim the mobility component due to lack of knowledge of its existence, or not realising that it was possible to appeal against an initial refusal by the Benefits Agency. The parents concerned had heavy transport costs and the extra allowance would have been helpful. In retrospect they were critical of the information and advice offered by hospital staff about the mobility component.

Staff interviewed pointed to a number of problems in ensuring that parents claimed the benefits to which they were entitled. The complexity of the application forms for Disability Living Allowance was seen to be a problem. A successful claim could depend on 'how well you fill the form in', and this process was emotionally

draining for parents. There are special rules to enable speedy access to Disability Living Allowance in the case of life-threatening illness, but, of course, this requires families to come to terms with the diagnosis. Parents who are not emotionally ready to make an application on this basis may miss out on some of their entitlement for a while.

Health and social services staff offered practical help in telling parents what financial help was available and in completing application forms, but pointed to the lack of systems for inter-agency coordination to ensure that all parents were able to receive such support. They pointed out that financial issues were not covered in their training; and, for health staff, this was not part of their job remit. Staff said that if families appeared to need specialised advice they would refer them to other agencies. Even if it was not part of their formal remit, however, they would provide help with benefit claims, because referring on would often mean more delays.

Using benefits and allowances

Once established, Disability Living Allowance was seen as regular and reliable, in the same way as Child Benefit. Some children had been receiving higher rates of both components of Disability Living Allowance for eight or nine years when they died, and this benefit was firmly established as part of the household budget.

The pattern of receipt of Invalid Care Allowance by a parent could mirror the child's receipt of Disability Living Allowance. Several parents had uninterrupted receipt of Invalid Care Allowance since their child's first award of Disability Living Allowance. In such families, Invalid Care Allowance had also come to be characterised as a regular, reliable and long-term source of income. This was not a general pattern, however. Parents who had left work to care for the child during their final months had only been receiving Invalid Care Allowance for a short period. Some parents had made a number of separate claims interspersed with short spells of work, or temporary contracts, when the child's condition allowed this. This arrangement did not always go smoothly, and some parents felt they had lost entitlements. For example it had proved hard to provide to the Benefits Agency in the way required on the application form information about casual earnings from work obtained through an agency.

In two-parent families, 'switching' the claim for Invalid Care Allowance between parents seemed sensible if both were trying to take opportunities for paid work. Lack of understanding about the Invalid Care Allowance rules had led to some unexpected disappointments. For example, a parent who had taken just one day's work found this led to loss of that whole week's allowance, and the requirement to make another application the following week. There is further discussion in Chapter Four about the implications for

National Insurance contributions protection for parents who claimed Invalid Care Allowance.

Those parents whose main source of income came from out-of-work benefits received allowances and premiums, or child additions for the child concerned (in Income Support, Housing Benefit, and widowed mother's allowance) and carer premiums in Income Support and Housing Benefit.

Other financial entitlements included adoption allowance, and child maintenance from fathers who lived apart. None of the mothers entitled to child maintenance actually benefited financially, however, because the maintenance due either was not paid, or was deducted pound for pound from Income Support entitlements.

Most of what parents had to say about their use of the benefits claimed in respect of the child or their own caring role centred around the 'package' of Child Benefit, Disability Living Allowance and Invalid Care Allowance. As explained already, most parents were receiving this package in the months leading up to their child's death.

The pattern was to use this package of benefits as a general contribution to regular household expenditure, to go into the kitty for day-to-day family expenses and paying bills. The benefits were seen as generally compensating for reduced earnings, or helping to meet the need to spend more. Systematic 'earmarking' of disability or caring benefits, in the way that we know some mothers use Child Benefit (Bradshaw and Stimson, 1997), was unusual, and found to be a good way of budgeting only by mothers able to meet general household expenditure from their partner's earnings, or additional sources of income. Thus, use of Disability Living Allowance and Invalid Care Allowance to pay nursery fees for a second child fitted one mother's conceptualisation of these benefits as her personal income. On the other hand, use of Disability Living Allowance specifically to pay for equipment and nursing aids for the sick child fitted another mother's conceptualisation of this benefit as belonging specifically to the child. In the latter approach, the mother made an early decision that it was important not to incorporate the disability benefits into general household resources, because they would not be available when the child was no longer there. Her approach was based on considerable previous experience of caring for severely disabled children.

Conceptualisation of Disability Living Allowance as a benefit to be spent specifically on the child can lead to problems, however, in families which find it hard to pay regular household bills. Parents who were glad that they were able to use Disability Living Allowance to 'spoil' their child with clothes, sports gear, music and toys were, at the same time, worried about the mounting rent arrears, and unpaid electricity and phone bills. Their mixed feelings included some guilt about the amount of benefit received, alongside an urge to spend as much as possible on items that might turn out to be the child's last opportunity.

Balancing needs and resources

There was a wide range of experience in balancing needs and resources during the period of care. At one end of the spectrum were parents who said that they had no particular financial anxieties during this period. At the other end were parents who said that by the end of the caring period they were in serious financial difficulty with a number of debts. Most, however, although experiencing constraints and problems, had avoided major debts accumulating. In two-parent families, it was helpful if both parents had similar attitudes towards spending priorities.

The previous part of the chapter explained how benefits and allowances went some way to enable the extra spending necessary, and helped to compensate for reductions or interruption in earnings. Managing the budget usually also involved drawing on other resources: charitable or trust funds, the social security Social Fund, savings or equity release, money gifts or long-term loans from family or friends, or commercial borrowing. These options had different implications for the family's financial situation after their child died, as explained in the following chapters.

Trusts and charities

There was widespread use of funds available from trusts and charities. Among lower-income families, the Family Fund had paid for washing machines, tumble driers, room heaters, furniture and items for house extensions, extra clothing and bedding, family holidays, and driving lessons for parents. It was not unusual for families to have made a number of applications to the Family Fund, and to rely on the Fund for regular annual holidays.

Some parents had access to charities which focus on children with particular conditions or illnesses. National and local children's cancer charities paid towards the travel expenses of hospital visits, helped to meet problematic phone and electricity bills, rent payments, and paid for family holidays. National and local charities which focus on children with mobility problems had paid for items such as a mobile phone, portable oxygen equipment, and given substantial grants towards the costs of adapted computer equipment for an older child, and large adapted vehicles. Parents' trades unions made welfare grants. Individual families had received grants from the Lions, a local police charity, and national charities which focus on 'terminally ill' children.

All the parents taking part knew about the Family Fund, although not all had applied. Not all parents had realised that there were a number of charities to which they might have applied. Parents had different views about using charitable funds. Not everybody was comfortable with the idea, using words such as '*pride*' and '*begging*'. Parents who felt comfortable about approaching charities could be systematic in their

approach, keeping lists, or scanning directories, and making regular applications. Getting personally involved in local fund-raising for children and young people with similar conditions could also provide a social activity and focus of interest for the whole family.

The Social Fund

Families claiming Income Support knew about the Social Fund, and this had been used for grants and loans towards furnishing and equipping a new home, chairs for caring staff who stayed overnight, and travel expenses. Again, some parents who might have applied to the Social Fund chose not to, because they were not comfortable about it. There were also parents who did not know, until too late, that they might have applied for help with travel expenses from the Social Fund.

Despite the availability of a number of sources of additional financial support, staff who tried to access such funds for families found that it was difficult to obtain any help for more routine expenses. Most charities had strict criteria about eligibility and the type of assistance available, and it was particularly difficult to obtain funds for expenses such as rent arrears or fuel bills.

Other ways of managing

Most families who had savings found themselves making substantial inroads into these in the period leading up to the child's death. Moving from having two full-time jobs to Income Support over a period of one year meant that one couple needed to draw at least £500 each month from savings to meet their expenses. Parents who had previously saved regularly, towards a new house or retirement, saw capital diminishing quickly, and worried about the consequences for the future. Other forms of resource mobilisation included early release of children's own money from family trusts, and selling a family car and taking out a lease.

Financial support from relatives could be an important source of help. Children's grandparents made contributions by paying towards or maintaining a family vehicle, paying for an annual holiday, and could sometimes be relied on for help with large household bills. Grandparents had made interest-free loans available at various stages in the caring period. Other relatives, such as cousins and aunts, sometimes made generous money gifts, or informal 'loans' that might turn into gifts. Some parents had also received regular small money gifts from personal friends, as demonstrations of compassion and concern.

Another way in which families could pay for items and services that they saw as necessary or desirable was to defer or default on payments to utility companies, telephone companies, landlords or mortgage lenders. We have already noted that utility and telephone arrears were recognised by most hospices as problems for

parents. In addition, 12 of the 18 hospices reported in the postal survey that at least a quarter of the families who told hospice staff about financial problems after their child had died mentioned rent or mortgage arrears as a source of difficulty.

Overdrafts on bank accounts, and occasional overspending on credit cards were a familiar part of general financial management for some families. Most tried to avoid other kinds of commercial loans, although this had not always proved possible. Commercial loans had been taken out to purchase caravans, vehicles, and house extensions. Hire purchase arrangements were the only form of credit accessible to a family on Income Support, who wanted to buy a large, adapted vehicle. Paying interest on these forms of commercial borrowing was a drain on resources for all families involved.

Concluding discussion

This chapter has discussed parents' financial circumstances during the period when they were caring for their child. There was a general need to spend extra, often at the same time as reduction or interruption of earnings. Benefits and allowances made an important contribution, and individual families drew on a variety of other resources. Some parents felt that money was not a pressing problem while they cared for their child. Others had lived through several years of financial constraint and anxiety; some got into serious debt and felt that financial matters were out of control.

Parents had different aptitudes for managing their resources, and made different decisions and choices. Financial circumstances were also subject to influences which had nothing to do with their child's condition; for example, previous employment histories and opportunities, inheritance, or major events before the child became ill, such as divorce or separation, sale or purchase of homes.

The view of key professional staff interviewed was that the financial impact of life-limiting illness was usually greatest for families who had the lowest incomes, both those who depended on benefits for their total income and those who were just above the Income Support level. However, detailed discussions with parents suggested that the level of family income was only one of a number of factors involved, which interacted in complex ways.

Putting together what parents said about the influences on their financial circumstances, findings suggest that across all income levels the following factors were often helpful in enabling parents to avoid financial problems during the caring period:

- stability of family income
- sympathetic treatment by employers/work colleagues
- readiness of GPs to issue sickness certification to enable time off work

- full take-up of social security entitlements
- stability of accommodation arrangements
- suitability of accommodation
- use of the Family Fund
- financial support from relatives and friends
- timely and efficient delivery of aids and equipment from care services
- accessing charitable and trust monies
- aptitude for careful budgeting/home-management
- shared views about financial issues, between parents in two-parent families
- experience of a previous caring period for a different child/relative with ill-health or impairment
- relatively good health of parents and other children
- active avoidance of debt.

Factors that were often felt to contribute to severe financial constraint, and sometimes major problems, were:

- changes in source or level of parental income, especially reduction or interruption in earnings
- lack of sympathetic treatment by employers
- delayed and partial take-up of social security entitlement
- major expenses attached to moving house
- unsuitable accommodation (inefficient heating, dampness)
- high travel costs (distance from and frequency of visits to medical services)
- delays in delivery of aids and adaptations from care services
- health problems among other family members
- losing aptitude for careful budgeting at time of stress
- problems in relationships between parents, affecting financial decisions
- wanting to 'spoil' a child, and give as many toys, games, clothes as possible
- wanting to spend extra on other children, or parents themselves
- accumulation of unpaid bills, and debts.

The next chapter looks at some of the 'new' financial issues that arose when the child died – including paying for a funeral and experiencing a reduction in social security income.

3

The immediate financial impact

From our work with families and hospice staff it is clear that not all bereaved families experience financial problems. However, the findings from our survey of children's hospices suggest that problems are relatively common. Ten of the 18 hospices responding to the postal survey reported that, in their estimation, most of the bereaved families (that is, over 50 per cent) with whom they have contact tell a member of the hospice staff about financial problems. Of the other eight hospices, seven reported that between one-quarter and one-half of bereaved parents report financial problems.

This chapter is concerned with the immediate financial issues faced by all the parents in our study following their child's death: reduction in income due to withdrawal of benefits and allowances, and arrangements for paying for their child's funeral. The following chapter discusses more long-term financial issues.

Reduction in benefit income

All the parents interviewed said there had been considerable impact, in the weeks following the child's death, from the loss of or reduction in social security. Key contributory factors were:

- the proportion of family income lost;
- how long the benefits had been part of family income;
- how the benefits had previously been spent;
- the family's general financial situation, in the period leading up to the child's death;
- how far the loss of income had been considered in advance;
- parents' perceptions of the links between the monies and their child or their own role in relation to their child;
- the experience of administrative procedures, in withdrawal of benefits.

None of these factors are separate influences in the lives of families, but are closely linked in complex ways. For purposes of discussion, however, the chapter continues by looking in turn at each.

The proportion of family income lost

The previous chapter explained the main benefits and allowances which the families had been receiving and the amounts of money involved. Entitlement to Child Benefit, Disability Living Allowance and Invalid Care Allowance ends when the child dies. Returning order books to the Benefits Agency was often seen as one of the tasks that had to be done quickly among the practical responsibilities of dealing with death, as much as a desire to avoid having money without entitlement. However, some parents were certainly anxious to avoid the possibility of receiving any benefits to which they were no longer entitled and feared possible repercussions.

Depending on previous payment methods (by order books or monthly direct debit arrangements) the timing of the full impact of withdrawal varied slightly. Parents who returned order books for Child Benefit, higher rates of Disability Living Allowance, and Invalid Care Allowance could experience an immediate reduction in income equivalent to at least £144.30 per week.

One perspective on the amounts involved is to consider what proportion they formed of the previous household income. Among the families taking part, those with the highest disposable incomes at the time their child died were, as we would expect, those in which at least one parent had still been receiving earnings. For the highest earning family in the group, income from Child Benefit and Disability Living Allowance for their child, and Invalid Care Allowance claimed by the child's mother represented around 14 per cent of monthly net income. In a two-parent family with a father earning £18–19,000 gross a year the Child Benefit, Disability Living Allowance, and Invalid Care Allowance received in respect of a child of nearly two years old was around 25 per cent of net monthly family income. Parents who earned less lost an even higher proportion of family income.

Measuring the proportion of household income lost is more complicated for parents with unearned income, who were claiming Income Support when their child died. Such parents lost the value of Child Benefit and Disability Living Allowance in the same way as

parents whose main income came from earnings. They also immediately lost the child's own personal allowance in the Income Support calculation (£20.20 for a child up to 11 years and £25.90 for a child over 11 and up to 16 years, in 1999), and the disabled child premium (£21.90 per week). Some experienced reduction in Housing Benefit through loss of the premiums. Invalid Care Allowance had always been taken fully into account in the Income Support calculation, so withdrawal had no separate impact. However, the parent's Income Support carer's premium, £13.95 per week, was linked with receipt of Invalid Care Allowance. So the carer's premium was also withdrawn, but only eight weeks after the child's death, in effect providing a 'phased' reduction in the parents' Income Support entitlement.

For parents claiming Income Support the proportion of overall benefit income lost also depended on other personal and family circumstances, in particular whether the parent had a domestic partner, the number and age of any other children in the family, and the family's housing circumstances. In financial terms, the proportional reduction in income was greatest for parents whose only child had died. As an example, a lone parent who was caring for her child in 1999 had a weekly benefit income of around £236.00, made up of Invalid Care Allowance, Income Support, Child Benefit, and Disability Living Allowance care and mobility components at higher rates. She also received payment for part of the mortgage interest. When her child died, part payment of the mortgage interest continued, but her weekly Income Support reduced to around £65.00, with a further reduction to £51.40 after eight weeks when the carer's premium was withdrawn. She had experienced an immediate reduction of 72 per cent in the money available to her for household spending. After eight weeks, she received 22 per cent of the amount she received each week while caring for her child.

Such a big drop in income felt like an added blow for low-income parents. It meant a need for rapid readjustments in the period immediately following their child's death. For some parents claiming Income Support, expiry of the carer's premium meant a change in administrative definition, from 'carer' to 'jobseeker'. This meant that they would now be expected to look for work in order to qualify for Jobseeker's Allowance. It could be a great shock to discover that they were required to seek work at this stage. This is discussed further in the next chapter.

The findings from the postal survey confirmed that the loss of benefit income was a problem commonly experienced by bereaved families. Eleven of the 18 hospices responding to the survey reported that a lack of income was a problem for most bereaved families who told them about financial difficulties. All 18 hospices said that the loss of Disability Living Allowance was a very important contributing factor to financial problems. The

loss or reduction of Severe Disablement Allowance, Income Support or Invalid Care Allowance was also considered a very important contributor to financial difficulties by over half of the hospices.

How long the benefits had been part of family income

The interviews suggested that there might be less financial impact from the loss of children's disability benefits if these had been paid for a relatively shorter time. Such money could still seem 'extra', and had not yet been incorporated fully into the regular family budget as reliable basic income.

In contrast to the situation described above, parents whose benefit receipt had been stable for several years had become used to relying on all their benefits and allowances in their regular budgeting decisions and the way they managed their household spending. Expenditure patterns were closely linked to receipt of benefit, both in terms of the amounts of money received and in the periodicity of receipt. Families who had been accustomed to using benefits in this way for a long period faced a major disruption in their money management when the benefits were withdrawn.

How the benefits had previously been spent

Closely linked to the effect of length of receipt of benefits was the way in which they had been used. It was only parents who had kept the child's disability benefits for their specific and sole use (medical equipment and nursing aids) who experienced no financial impact when Disability Living Allowance stopped.

Having previously 'ear-marked' the disability benefits for a specific item which continued to be required after the death of the child meant complete re-allocation of resources. We saw in the previous chapter however, that it was unusual for parents to ear-mark their disability/caring benefits. Most parents dispersed disability benefits within general household spending, or used them for items which affected the whole family, such as the family vehicle. Withdrawal of the benefits could then also have a major impact.

For example, high gas and electricity bills covering the final months of the child's life started to arrive in the weeks following the death. Parents who would usually have used their benefits to pay the bills could find they now had insufficient resources, and debts mounted. Some mortgages went into arrears. General anxiety about adjusting to lower household income led some parents to try to 'cut down' immediately, focusing on items such as telephone use, or spending on the child's siblings. Trying not to use the telephone at such a difficult time could reduce the support that might have

been available from friends or family. Trying to change quickly what parents had previously spent on other children could bring additional tensions into the family.

A particular example was use of a vehicle leased through Motability. The terms on which a Motability vehicle is leased require that parents stop using the vehicle when their child dies. This could lead to serious constraints and inconveniences for parents and other children, and sometimes had implications for getting back to work after the funeral.

Hospice staff also noted that the way in which benefits had previously been used affected the impact of their withdrawal. They understood how outstanding bills covering the period when the child was alive, for example heating and telephone bills, were still coming in when benefits had stopped and income was reduced. They also spoke of the difficulties faced by families when vehicles leased under the Motability scheme had to be returned soon after the child died. They felt that this left families isolated and without transport at a time when they needed access to a vehicle to get out. They also pointed to an issue that had not been raised by the small group of families in this study: that of problems encountered by families living in specially adapted housing owned by local councils or housing associations. It was quite often the case that these families would have to move to other accommodation as, after the child died, they were no longer seen as needing such adapted accommodation. This caused both financial and emotional problems in the already difficult time after the child's death.

General financial circumstances in the period preceding the child's death

As we might expect, for parents who were already in considerable financial difficulty at the time their child died, reduction in benefit income brought additional troubles. The possibility of paying accumulated bills seemed even harder, and parents saw financial control slipping away.

It was not the case, however, that parents who felt they had been managing fairly well, financially, while they cared for their child, were always at an advantage in dealing with the reduction in income. Patterns of careful, frugal management of household income which had kept parents out of debt and feeling generally in control of their financial situation, sometimes over several years on low income, could be disrupted completely by benefit withdrawal.

Anticipation of benefit loss/reduction

Parents had known, in a general sense, that benefits would end or be reduced when their child died. We have already seen that there was little delay in sending back order books, or notifying DSS. However, few had thought

in detail, before their child died, about the full amount of money they would lose or how they would adjust their budgeting. It could be a shock to discover what it meant to have no access to a vehicle or to have insufficient cash for day-to-day spending.

Parents claiming Income Support had generally not expected such a big reduction in their income. They had not remembered, if they had ever fully understood, the actual amounts of the various allowances and premiums to which they would lose entitlement.

Few parents had planned in advance what they would actually do about the big reduction in income. While caring for their child, some parents wanted or felt able to cope only with current circumstances. Staff noted that such planning in advance was difficult because few families knew how long the child would live. Prognoses were sometimes inaccurate and families who tried to pace themselves financially, based on the expectation that the child would live to a certain age, could face problems when the child lived much longer, sometimes for a number of years more than originally expected.

All staff acknowledged that whilst families knew intellectually that benefits will stop when the child dies, the practicalities of this were not the most important issue for them during the child's life. At this time they had to make decisions, for example about buying expensive equipment that would improve the child's quality of life, that were valid in the current circumstances, even though these might cause financial problems later.

The staff view was that it was difficult to help families to look at the financial issues that might arise when their child died whilst they were still caring for the child. Many families were not ready to think about this and would block any approach. Health, social services and hospice staff all defined their own roles as primarily to support families in the decisions they made about caring for the child. Some mentioned that they may refer a family on to another agency, such as the Citizens' Advice Bureau, if necessary for more specialised advice, but that a lot of families did not have the time or energy to take this up.

Parents' perceptions of links between monies and their child or their role

The full impact of withdrawal of benefits included, for several parents, the psychological and emotional impact of the loss of what the benefits represented. The immediate end of entitlement to Child Benefit and disability benefit could seem like society's formal acknowledgement that their child's life was over. Parents told us about the shock and pain of such feelings. Similarly, the end of their Invalid Care Allowance could seem to some parents like a formal mark that their 'caring' or parenting role was over, underlining the void in their lives.

Parents of teenagers who had started to receive Severe Disablement Allowance in their own right also spoke of the psychological impact when the benefit stopped. Getting a personal income, making choices about spending, and starting to make contributions themselves to family budgets were what 'ordinary' young people did. Parents were pleased that their very ill children had been able to share such normal life experiences. The young people had discussed with their parents their potential use of their own income, for example, for additional holidays or outings. Withdrawal of the Severe Disablement Allowance then underlined once more the interruption of transition of their child to adulthood, and the young person's own plans that were unfulfilled.

In some families, vehicles obtained or run using Disability Living Allowance had particular significance. It was not unusual for such vehicles to come to be seen as belonging to the child, an extension of the family home which the child inhabited, or even part of the child. Sudden loss of use of a vehicle accessed through Motability carried specific pain of separation from the child. Parents who felt like this expressed anger and bitter feelings when those vehicles were not collected quickly. The car or van which remained parked by their house for several weeks, but which they were not permitted to use, was a source of continuous additional pain.

Administrative procedures

The way in which parents were dealt with by the Benefits Agency or Child Support Agency immediately after their child died was considered important and could have a major impact. What was helpful, in a letter acknowledging the return of an order book or when staff spoke on the telephone, was an initial expression of sympathy for the parents, the use of the child's first name, the use of the word 'died' rather than 'deceased', and an expression of thanks for getting in touch. Parents who had experiences like this felt they had been dealt with appropriately, and some had been relieved, as they had heard about other parents' bad experiences.

For parents with other children who dreaded the return to them of their Child Benefit book with a missing name, it would also have been helpful to have been offered some choice about how this matter should be dealt with.

What was unhelpful, and described in retrospect as '*cruel*' and '*so unkind*', was receiving a standardised letter which did not express sympathy or mention the child who had died, and the inability of staff to talk sympathetically, on the phone or in local offices. Use of the word 'deceased' seemed cold and could be hurtful. Rudeness or unexpected reactions from staff left parents shocked, and compounded their pain. For example, parents who had phoned for advice about their Income

Support had felt that their continuing entitlement had been abruptly challenged. Seeking advice about Disability Living Allowance and being immediately and strongly urged not to cash any more orders left a parent feeling that staff believed she might try to draw money to which she was not entitled.

Having to queue in a local office for advice about Income Support and then not being invited to a private office to discuss the circumstances, in the week of the child's funeral, had been a bad experience.

Being asked to pay back an overpayment of Disability Living Allowance (as a result of having received benefit in advance) had been '*very disappointing*' and considered wrong. Letters which told parents that they might be asked for overpayments shocked those who had not realised this might happen, and left feelings of anger even when money was not subsequently requested.

Parents claiming Income Support who heard for the first time, a few days after their child died, that they would be required to register for work when their carer's premium expired, described this as a great shock. They had been upset and worried about the implications, and were critical of the lack of skill and understanding in the way staff handled this. They felt strongly that ways should be sought to prevent this situation arising for other parents in the future.

Staff had knowledge of a number of difficulties experienced by families in their dealings with financial agencies after a child's death: having to stand in the same queue as everyone else at the Benefits Agency; being treated as if they were fraudulently claiming and having to explain why they had not been 'working' when caring for the child, so feeling that their care of the child was not counted as 'work'.

This part of the chapter has begun to unravel the various strands in parents' experience of the immediate impact of reduction in benefits. Looking back, some felt that they had contained a difficult situation and made necessary adjustments in the months after the death. For others, the reduction in income led to serious financial problems and hardship which they were still experiencing at the time of the interview. Longer-term financial effects are discussed in the next chapter.

Meeting funeral expenses

As we would expect, parents made different choices about the kind of funeral arrangements they wanted for their child. Older children had sometimes made known to parents their own feelings about a funeral. The wishes of members of the wider family could also be influential, and some relatives wanted to make a financial contribution.

The wide range of funeral arrangements meant that there were wide variations in the amounts parents had to pay. Part of the variation in expenses was due to the

different approaches taken to charges for children's funerals within the funeral profession. Funeral directors who were personal family friends sometimes made no charge for their services, and several other parents understood that they had been charged 'at cost' for part or all of the services provided. Among the parents in this small group, the bills received ranged from £150 to nearly £3,000.

The general view among parents was that they had been dealt with kindly and generously by funeral directors. Those who had wanted fairly simple arrangements, or had been worried about possible expense, felt that funeral directors had been helpful, offering appropriate information and dealing well with the financial discussions necessary. Parents who had wanted simple funerals, or hoped that expenses would not be high had not felt pressured towards more expensive or elaborate choices. Parents who decided to apply for Social Fund funeral grants had appreciated the efficiency of funeral directors who dealt with their applications.

It was not always possible to keep costs low, however. Long distances between homes, crematoria or burial grounds, and arrangements that spanned more than one day unavoidably increased expenses. Some parents wanted elaborate arrangements, and knew that their funeral would be costly. Once they had seen, in specialist order books, particular children's coffins or flower displays that they wanted to have for their child, it was hard for such parents to decide that items were '*too expensive*'. At the time, the priority was to have what seemed right for their child and family.

Funeral grants

Not everybody entitled to a funeral grant from the Social Fund applied for help in paying for their funeral, for example when grandparents offered to meet the cost. Those parents who had received Social Fund grants had not had problems with applications: as explained above, funeral directors had been effective in smoothing the process of application. Not everybody who applied for a funeral grant had felt comfortable about this, but parents generally preferred a funeral grant to a commercial loan. Parents who had been surprised when they discovered what income and assets had been taken into account in calculating their entitlement wished they had received a clear and sympathetic letter to explain this. For example, one parent believed that some of the Severe Disablement Allowance paid into her son's bank account and not drawn during his last weeks of life had been taken into account. A polite and sympathetic letter explaining this approach, in advance of receipt of the grant, would have been helpful.

Among parents who were not entitled to funeral grants, those who were able to pay the funeral bill outright included people who still had some savings and

some of the higher earners. Other parents borrowed from relatives or personal friends, and approached various charities and trusts. Although some of the major trusts and charities which support parents do not give grants for funeral costs, parents did receive awards which were formally for other purposes, which were then used to help pay for the funeral. Discovering that she was not entitled to a Social Fund grant, although claiming incapacity benefit had been a shock to one parent. She wished she had understood this earlier: trying to keep a job open by sending in sickness certificates after her child died had seemed sensible at the time, but she would have considered giving up that job in order to be eligible for a funeral grant.

There had been some planning in advance for funerals. Parents currently claiming Income Support who had bought burial plots or opened deposit accounts for the funeral some years ago when they had more money, were helped emotionally as well as financially by having made these plans for their child. Some parents discovered that hospital savings plans, taken out primarily to provide cover for parents' health, covered the costs of burial of the child.

Headstones

Parents who wanted headstones or memorials had an additional bill to pay. Again, some grandparents, relatives or friends offered to help pay, but for some parents buying a headstone involved further borrowing or applying to charities. Paying for a headstone could seem a good way of using the child's own personal savings.

Staff noted the importance of the funeral to families, with some children being involved in planning their own funerals. In their experience, the families who found the most difficulties in paying for funerals were generally those whose income was just above Income Support levels, as they were not eligible for a grant from the Social Fund. They also pointed out that there is little knowledge about expenses attached to minority ethnic funeral traditions and that these may have additional financial implications.

In the postal survey, eight of the eighteen hospices responding said that funeral costs were a problem for most parents with some form of financial difficulty following the death of their child. A further eight hospices reported that between one quarter and one half of families experienced such problems. This was the second most common cause of financial difficulties, loss of income being the most common. Ten hospices also reported that the cost of a funeral and/or a headstone was the source of the largest debts incurred by bereaved families.

This section has explained how parents met funeral expenses, and how some of their choices were related to their financial opportunities and constraints.

For parents who wanted to pay from their own private money for their child's funeral and/or the headstone they wanted, not being able to do this could be a keenly felt disappointment. We see in Chapter Five that these feelings remained for a long time afterwards as a focus for pain and regret.

Concluding discussion

All parents in this study faced an immediate financial impact from the death of their child, in that social security benefits were reduced, and there was a funeral bill to meet. For parents in this study, disability and caring benefits previously received represented a significant proportion of household income, even among those families who had maintained earnings at medium or high levels. For lower income parents, sudden loss of a large proportion of the income usually available for household spending required major readjustment and planning, for which they were not well equipped emotionally, at the time. Parents who faced immediate financial distress and anxiety had a further burden to add to the intense grief and pain of the loss of a child.

At the time of the research interviews all the parents whose child had died were moving forwards, towards new patterns of living. Different ways of household budgeting and management were emerging, according to individual circumstances, and the period of time that had passed since their child died. Parents also had different employment opportunities and expectations. There were some long-term financial implications for all the parents, however, as described in the following chapter.

4 The longer-term financial impact

After the initial financial impact of reduction of benefits and meeting funeral expenses it was easier for some parents than others to establish regular, adequate income and make adjustments to household budgets in the changed family circumstances. This chapter explains, first, some of the decisions taken about paid work, and parents' experiences of maintaining or trying to achieve earned income. The parents taking part were at different chronological distances from their child's death, so some had longer experience than others of the changed circumstances, and had reached different stages of financial adjustment.

In the second part of the chapter we look at some of the longer-term implications of budgeting strategies and financial management within the changed circumstances. What we learn from parents, at these different stages, is what helped them make the adjustments they aimed towards and what made it more difficult. This material helps to fill in the picture of the longer-term financial implications for parents, in moving on from a child's death.

Going back to or starting paid work

Not all parents expected to do paid work again after their child died. Older parents approaching retirement age had few expectations of doing paid work in the future. Parents whose own health was poor thought it would be hard to start working again, for example women who now had musculo-skeletal problems after years of lifting and turning a heavy child. Some parents whose partners had gone back to work expected to be at home caring for their other children, and some women were committed or planned to extend their families by having another child or through fostering or adoption. In most of the families, however, at least one parent expected to do some paid work again, eventually.

Returning to a job

In this group of parents, all those who were formally employed at the time their child died went back to their jobs after their funeral.

Men and women who had been the main or only

family breadwinner throughout their child's illness generally had a period of paid leave or sick leave after their child died, and then went back to work. They had always expected to return to work. It could be hard to do this at a time of such profound family grief, but keeping jobs and securing income seemed a priority for such parents, who believed this would help them in the long run. The normalcy of the workplace, the companionship of colleagues, and having to think about things not connected with home could also be a source of more immediate help and support. Going back to work could be made easier by the intervention of occupational health personnel from the workplace, visiting the parent at home shortly after the funeral, to discuss a possible timescale for return to work.

In retrospect, most of those parents who had maintained a strong 'breadwinner' role in full-time work during the child's final illness and gone back to their job shortly after their funeral, felt that they had taken the right decisions. Their current financial situation was, they believed, easier than it would have been had they not continued working, and their paid work had generally been a help as they learned to live without their child.

Women who had been working part-time, as second earners, during their child's illness also went back to those jobs, after variable periods of sick leave. Financial pressures as a result of loss of benefit income, funeral expenses, and accumulation of bills left the women feeling they had little choice but to go back to work quickly. A further trigger to return to work was a reduction in occupational sick pay entitlement which typically fell by a half after six months.

Parents whose return to work had been driven mainly by current financial pressures (rather than a strong commitment to the breadwinner role or the job *per se*) all felt, in retrospect, that they had gone back to work too soon. At the time, the need to re-establish a secure earned income had over-ridden other feelings and needs, not all of which they recognised at the time. Their return to work was stressful, and they did not get on well, even in work they had previously liked or been strongly committed to.

Self-employment could provide more opportunity to phase in work at an appropriate pace. It was an

advantage, in building up trade again, to have kept in touch with the customer base by undertaking small amounts of work while caring for a child.

One parent noted that being able to take 'voluntary redundancy' for the last months of a child's life, with the employer's offer of probable re-employment afterwards, had seemed a helpful and easy course of action at the time. In retrospect, he wished he had properly understood the implications of the initial decision. He had not felt able to return to work for several months, but having left work 'voluntarily' meant that it was hard to establish entitlement to out-of-work benefits.

Moving off long-term benefit income

Parents who had been claiming Income Support in the last months of their child's life had no jobs to go back to. Thinking about getting work, making applications, finding and keeping a job could all be hard at this stage. Even highly motivated men, who registered for work soon after the funeral, and expected to be the family breadwinner again, did not get work quickly. Years spent providing intensive care for their child turned into gaps in their CVs, and some employers were doubtful that men who had taken a lot of time away from work for family reasons would be committed or reliable as full-time employees. It could be specially hard for young men who had not built up a work record before they started caring, or had not completed qualifications or training. Some men thought in retrospect that they had probably not been emotionally ready to start work, either, and they may not have performed well in interviews. They had not understood this fully at the time.

Women who had started looking for part-time work again soon after the funeral had not had as many problems as the men in finding a job. Prospective employers had accepted their reasons for long periods away from work to care for a child. Some employers had shown understanding of their current difficult situation, and allowed paid leave at subsequent important times, such as remembrance days.

For some parents, even thinking about their future in terms of the world of work was stressful and depressing, and at the time they spoke to the researcher, some saw no way forward from their benefit income. As we saw in the previous chapter, parents claiming Income Support while caring for the only child in their household had not always realised that after eight weeks they were expected to register for work to continue receiving Jobseeker's Allowance.

For parents who had not done paid work for many years, this could be a great shock. Parents who had spent several years at home with their child sometimes felt quite unable to start to look for a job, or even to start thinking about what kind of work they might do. Lone parents had no partner to share responsibility for maintaining income, and at the same time, reduction in

household income had been considerable, as we saw in the previous chapter. The situation was, for some parents, very worrying. Their distress led some to their GP, where they learned that certification of sickness meant that they might continue receiving long-term benefits on the grounds of incapacity for work. Some parents were encouraged down this route by their GP, who felt they were unready for work.

Benefit traps

Gaining incapacity benefits did not always go smoothly. Medical certificates which described parents' incapacity for work to be due to 'bereavement' were not accepted by the Benefits Agency staff who decided benefit claims. Parents had to ask doctors to issue new certificates which described their condition in terms of depression or anxiety as a result of bereavement. The process was distressing, and some parents were uneasy that they were being attributed with medical conditions which did not properly describe their situation. Profound grief did not equate to depression.

Some parents who took the path to long-term incapacity benefits, with labels of depression or extreme anxiety, said they ended up in a 'trap'. They were not expected to look for work any more, and received no formal help in doing so. On the other hand, leaving the security of incapacity benefit in order to try work was risky, and they had now been attributed medical conditions which might need explanation to prospective employers. Even when parents had felt that being called 'depressed' had been inappropriate at the time, months of inactivity and financial stress had sometimes led to the development of depressive illness. There could seem to be no way out.

Parents who felt that they would now need considerable help to move towards work did not know where such help might be found. It appeared a more complex issue than they might discuss with social workers or bereavement counsellors with whom they were in touch. Some parents were living in areas served by a New Deal for Disabled People pilot project, designed to help people on incapacity benefits who would be interested in help with moving towards work, but they had not heard about this.

For parents who did move off long-term benefit fairly quickly, taking a low-paid job at this stage could increase financial problems rather than help to solve them. People who had not had an earned income for many years, and were in the middle of adjusting to new household budgeting patterns could quickly get into financial difficulty if they took jobs which did not generate sufficient earnings to match their outgoings. Mortgages had gone into arrears, and parents had built up overdrafts and debts while they looked for a higher-paid job. One way of trying to deal with such financial problems was to work long hours, for overtime

payments. When interviewed, one person was currently working over 70 hours weekly in order to reduce the debts incurred at the time of moving off Income Support. The person felt that there had never been enough personal time to deal with the child's death at the emotional and psychological level, due to frantic working, and wished there had been an opportunity to discuss financial and employment issues, possibly before the child died.

In the experience of staff, there was great variability in the way employers recognised the needs of bereaved parents. Some were understanding and generous, others were unhelpful. Staff felt that both for parents who had been in employment up to the time of the child's death and for those who had then tried to find work, the need to return to work in order to deal with financial issues meant that many parents were expected to go back to work too soon, with detrimental emotional effects in the longer term. In addition, long periods away from the labour market in order to care for their child disadvantaged parents in returning to work, and it was felt that this was not recognised in the benefit system.

A change of direction

It was not unusual for parents to find that the kind of work they returned to after their child died did not now suit them. For example, it was upsetting to discover that despite a successful previous driving career, a child's illness and death had led to a major loss of confidence on the road. Other men found they had lost the motivation to do work that involved commercial competition, or long hours. Some women who had returned to nursing or teaching found they had now lost interest in this kind of work or found it too stressful.

On the other hand, some parents were considering a change in direction in their work such that they **could** build on the skills and competencies gained during their care-giving. The first step for some was enrolling for further education courses, doing some unpaid work for a voluntary organisation, or spending time helping staff in local schools. Being a full-time foster parent for disabled children was also being considered, or already undertaken.

National Insurance records

Some parents experienced difficult and unexpected effects of gaps in their National Insurance record as a result of their previous breaks in employment. Under current social security legislation only one parent is entitled to claim Invalid Care Allowance. This entitlement includes a Class 1 National Insurance credit, which helps towards the contributions conditions for contributory benefits including contributory Jobseeker's Allowance, incapacity benefit and retirement pension. The other parent, if receiving Child Benefit or Income Support, may

receive Home Responsibilities Protection, which helps to protect retirement pension rights. Decisions as to which parent formally claimed Invalid Care Allowance or Income Support subsequently had long-term effects, when parents tried to claim benefits after the child's death. Some parents who returned to work found they were not covered for contributory benefits when they subsequently became sick or unemployed.

Parents who made this discovery were angry and disappointed, and spoke of feeling '*punished*' for having spent time caring. They wished that they had received clear explanations of the difference between credits and Home Responsibilities Protection, and had a proper opportunity to discuss the long-term implications, taking into consideration possible time-scales for return to work and the parents' own health situation. The fact that Home Responsibilities Protection itself does not provide a full Class 1 credit was a disappointing surprise for some women, who said it seemed as if years of heavy caring and financial sacrifice was apparently unacknowledged within the social security system, and thus of no value to society. Parents who found that periods of ill-health or unemployment in the years following their child's death meant returning immediately to Income Support said that their financial problems were prolonged and increased.

Longer-term implications of budgeting strategies and financial management

As emphasised in the introduction to this chapter, parents were at different chronological distance from their child's death. Some were interviewed only four to five months after their child died, whereas others had lived through a period of adjustment of around two years. Care is needed, therefore, in using this material to discuss 'longer term implications' – parents were looking back over different periods of time. What is possible is to discuss generally what helped parents to make the financial adjustments they were aiming towards, and what made this more difficult.

What was helpful, for longer term financial adjustment?

The following influences were considered helpful, in achieving longer-term financial adjustment:

- general skills and competencies in careful household management;
- being able to respond quickly to change in income sources/levels;
- maintaining some earned income;
- agreement between partners about financial priorities;

- understanding relatives/friends who had lent money;
- understanding bank managers;
- parents' good health;
- having a 'purpose' or 'goal' for which financial adjustment was important;
- lifetime events that eased the financial transitions.

Some explanation and illustration of these factors is useful.

People have different levels of competence in making their money go round, at all income levels, and this was true of the parents in this study. As we might expect, parents who said they were generally careful managers of household monies, and did not expect budgets to get out of control found it easier to make the long-term adjustments needed than parents who said they had always found it hard to manage their money, no matter what the circumstances.

Being able to respond quickly to changes in income levels or sources could require considerable personal discipline and constraint, at a time of great emotional distress. Firmly cutting down on heating, transport, outings, or entertainment was hard, and affected everybody in the family. Some parents found it easier than others to be positive about adopting new spending patterns to fit changed circumstances.

Maintaining at least some earned income during the period of care was considered important for long-term financial stability by those parents who had been able to and wanted to do this. Such parents sometimes acknowledged that they may have missed out on the time they might have spent with their child by continuing to go to work. However, most felt they had made decisions that seemed right at the time, and, in retrospect, had helped them in the long term. It is important to say also that parents who had given up work in order to care did not regret this. They too felt they had made decisions that were right for them.

It was helpful, in establishing financial stability and security, if both partners shared similar financial priorities. The period after the child's death could be a time of considerable strain in relationships between partners. It was easier for parents to make financial adjustments and plans if they generally had the same outlook and expectations about financial resources and expenses.

Parents found it helpful if the relatives and friends who had previously lent them money continued to be generous and understanding about receiving repayments, and realised that it might take several years for large loans to be repaid. Continued generosity of the wider family in contributing towards holidays, or running the family vehicle also helped families gradually achieve financial stability. Similarly, bank managers who were understanding about the continued need for overdrafts helped parents adjust at an appropriate pace. There was

also appreciation of help from building society managers who understood the reason for mortgage arrears.

Parents who maintained good health after their child died generally found it easier to adjust financially, for example being able to work regularly or increase hours of work depended on being in reasonable health. Maintaining mental health was helpful in finding emotional resources to make financial plans and adjustments.

Financial adjustment could be easier for parents who continued to see clear roles and purpose for themselves after their child died. Having other young children or expecting a new baby, for example, made it important to maintain standards of living and rebuild savings. Having another very ill child could be a strong motivating factor in maintaining financial organisation – such families knew what lay ahead. Wanting to be able to pay for older children to go to university or pursue a particular interest meant regaining or maintaining financial control. Parents who themselves now wanted to retrain or pursue further education had a new purpose to save towards.

Finally, some parents thought that they had been 'lucky' in some respects, in that lifetime experiences had happened in ways that eased their financial adjustments. Inheritances, payouts from insurance companies, favourable sales of property had come 'at the right time'.

The focus of this study is on financial circumstances. It is important to emphasise that financial adjustment is only one part of the adjustments families have to make after the death of a child. Staff emphasised that parents' efforts to deal with financial problems at this time could result in delaying the grieving process. In their experience, some parents focused all their energies on dealing with their financial and material circumstances – whether they would lose their vehicle, move house, be able to get a job – all in the period when they needed to have time and space to grieve properly for their child. 'Successful' financial adjustment did not necessarily reflect better general adjustment.

What made long-term financial adjustment hard?

The following influences had made it harder for some parents to adjust, in the long-term:

- not being good at financial management of household expenses;
- finding it difficult to adapt household expenditure to changed circumstances;
- spending money to deal with grief;
- irregular, or prolonged low income;

- long-term effects of non-take-up of benefits during the caring period;
- disagreement between partners about money;
- lack of understanding by commercial organisations;
- change of 'status' within formal systems;
- parents' disability or health problems;
- loss of life purpose or personal goal;
- life events that meant additional financial strain.

Some of these unhelpful influences represent the negative side of the same issues that were seen as helpful, when they had a positive component.

People who had always found it hard to keep their spending within the limits of their resources and manage their money without problem debts, as we might expect, continued to find this a difficult area of life. A parent who currently had severe financial problems said that she and her partner had never managed to match expenditure to income, even before their child became ill.

Some parents took a fairly long time to adjust to changed levels and sources of income. Family vehicles sometimes represented particular difficulty, with long-term effects. As explained, vehicles often had special associations with the child concerned, and some families had been reluctant to change their vehicle although they knew that realistically they could not afford to continue to run it. Fuel and servicing could be a major drain on stretched resources. On the other hand, parents who did decide to sell a large adapted vehicle found a poor second-hand market, and it was not unusual to lose several thousand pounds investment. A different situation faced parents who had leased vehicles or had been buying them on hire purchase through Motability. Their continued access to a vehicle could now require substantial new outlay. Most parents wanted to keep a vehicle of some kind, which usually seemed essential for the family's arrangements, or getting a job.

Trying to find ways of filling long, empty hours, or taking the edge off grief had led some parents to spend heavily in the months following their child's death. Going to the shops, the cinema, or having a meal out provided ways of avoiding the perceived emptiness of their home. Some parents thought an ambitious holiday might help bring some joy back into the family. Trying to engage in positive activity such as redecorating or redoing the garden involved expense. Refocusing on the other children in the family could also involve extra spending – trying new activities which needed new equipment. Parents' stocks of clothes had worn down during long periods at home caring, and new clothes were needed for going back to work or spending more time outside the home. In retrospect, some parents felt that they had spent more than was sensible in this way, but at the time it had seemed a way of helping themselves.

Periods of prolonged irregular income made it hard to achieve financial stability, as we might expect, and parents whose periods at low income level lasted longer than expected also found it harder to make the adjustments required.

The financial effects of non-take-up of benefits during the caring period lasted a long way into the period after the child died, for example the large debts that were hard to reduce, and the need now to replace major household items that parents had felt unable to afford when they were living on incomes below their level of entitlement.

Relationships between parents could become strained and difficult while they cared for a child with a life-limiting condition. Financial problems sometimes became a focus for tension and disagreement. Among the parents interviewed were some whose relationship had deteriorated or broken down since their child died, and financial disagreements and problems were felt to have made a major contribution. A breakdown of relationship between parents after the child's death meant further financial disruption for both partners.

Commercial organisations had not always been helpful or understanding about renegotiating conditions of loans. A couple who owed money to a number of credit card companies for expenses incurred around the period of the child's death was surprised at the lack of understanding, and the lack of staff skills in dealing with their situation, during discussions about repayments.

We have already seen how some parents acquired a different 'status' within the social security system when their child died. Some parents had further similar experiences in other formal systems which led to increased expense or had other long-term financial implications. For example, car insurance sometimes becomes more expensive for a man who does not have children. Discovery of a clause in a divorce agreement that could mean a woman lost her entitlement to residence in the matrimonial home when the child died was a great anxiety, and might mean having to move.

Parents who themselves were disabled or had health problems continued to have interrupted earnings or long periods on incapacity benefits. As explained previously, some parents now had musculo-skeletal problems linked to turning and lifting their heavy child. It was also not unusual for parents to develop a pattern of ill-health in the year following their child's death, which they sometimes associated with depressed immunity resulting from their experience. Poor health or disability of parents meant new patterns of increased expenditure and new budget constraints. The onset of depressive illness, or psychiatric symptoms such as agoraphobia or panic attacks delayed adjustment to changed circumstances.

It took longer for some parents than others to regain purpose in their lives after their child died, and it could be harder to find emotional energy for financial

adjustment. Parents who had invested years of life in being at home caring intensively for their only or youngest child sometimes felt little motivation to look ahead or make plans for themselves. Loss of the focus of their lives; the feeling that they had few marketable skills for engaging with the workplace, and for some, poor health, meant that the process of adjustment, in all aspects of life, was likely to take a long time.

Finally, while this study focused on the child's death, some parents experienced other, unrelated, life events in the year following their child's death which imposed major financial demands or constraints, further delaying financial adjustment. Houses required urgent repairs, arrangements had to be made to care for elderly or sick relatives, breadwinners were made redundant.

Concluding discussion

This chapter has considered the longer-term financial implications for parents, looking at the way in which resources continued to come into the household, and the adjustments made in household budgeting and management in response to the changed circumstances.

All aspects of life are difficult for parents experiencing the profound grief and loss of a child. Adjustments take place over different time-scales, according to individual circumstances and characteristics. Parents in the study group were all at different stages on this journey. Some were now confident about their financial situation, and felt that most of the money problems and financial issues that had troubled them had been dealt with. Some were currently feeling tightly constrained but believed their financial situation was under control, and hoped it would improve in future years. Others were still in considerable financial distress, and found it hard to see a way forward.

All parents, looking back, could make suggestions about how things might have been dealt with or done differently, which would have lessened the negative financial impact, at least, of the death of their child. The last chapter, which follows, discusses the suggestions that parents made, in the context of current policy thinking about bereavement and social security benefits. The chapter also summarises the suggestions from hospice and other staff interviewed in the course of this research and draws on the contributions of other hospices from the postal survey.

5 Suggestions for policy and practice

Most parents interviewed made suggestions for changes in policy and/or practice which might have helped them, or other parents they knew, deal with the financial implications of the death of a child. All key professional staff interviewed, from the hospice, medical and support services, also had suggestions which they felt would help parents. Every hospice responding to the postal survey also provided ideas that might contribute to the development of policy and practice.

The prioritisation of issues was different among parents, and some made several suggestions. In the main, the suggestions made by the staff who were interviewed and those who completed questionnaires concurred with those of parents. This chapter discusses parents' and staff suggestions and possible policy responses. For purposes of presentation in this chapter, we look first at suggestions about issues arising during the period of care. The next part is concerned with funeral costs. In the last part we consider other issues arising after the child's death.

Issues arising during the period of care

It was clear that some of the financial issues that arose in the period following a child's death were rooted in the period of care

Take-up of disability and carers' benefits

Parents stressed the importance of timely and accurate advice about Disability Living Allowance and Invalid Care Allowance, and informed help with making applications, so that they did not miss out on benefit entitlements during their period of care. The previous chapter explained how the effects of delayed or partial take-up of disability and caring benefits had long-term effects, stretching far into the period after the child's death.

There were mixed views about the most appropriate channels for such help, according to individual experiences. Some parents spoke of receiving appropriate advice and help from hospital social workers, nursing staff, health visitors, community paediatric staff, and at Martin House, whereas other parents criticised the same agencies for not making such

advice available, or having insufficient training and expertise to deal with such matters.

Staff recognised that there was a lack of clarity about whose responsibility it should be to provide advice to parents about benefits and to help in making applications. They acknowledged that in many areas there is still a lack of co-ordination between the different agencies who have contact with these families, and this means that families can fall through the net and not receive appropriate advice.

Both parents and staff referred to the difficulties experienced in completing Disability Living Allowance forms, which appeared to have been designed to refer to adults. Staff recommended that the forms should be improved so that the questions were more appropriate to children and recognised the child's needs as intertwined with those of the family, rather than concentrating solely on the child's problems.

The general finding is that full take-up of disability and caring benefits during the caring period can contribute substantially to easing parents' long-term financial situation. Investment in staff training about these benefits would seem to be worthwhile, across all the caring agencies, but there also need to be systems in place to ensure that all families receive timely and appropriate advice. Many staff recommended that there should be a key worker system so that one person has an overview of what is happening and can make sure that information about benefits is given, and discussion of finances and other concerns takes place. Such a recommendation has been made in a number of other research studies (Chamba *et al.*, 1999; Beresford, 1995; Sloper and Turner, 1992) and also in policy (DHSS, 1976; Warnock, 1978; Children Act 1989), yet research continues to show that less than one-third of families with severely disabled children have a key worker (Chamba *et al.*, 1999; Beresford, 1995).

Ensuring that families receive information about all services has long been recognised as problematic and is addressed within the recent *Quality Protects* programme for children's services (DH, 1999). Sub-objective 6.2 is: 'to ensure that parents and disabled children are provided with information about services from the statutory and voluntary sector on an inter-agency basis'. Successful implementation of this objective would do

much to alleviate the problems experienced by some families in this study. However, responses of parents and staff indicate that provision of information will need to be mediated through an identified person who can provide appropriate support and advice. This recommendation is confirmed in a recent study of good practice in information provision to families with disabled children (Mitchell and Sloper, 2000).

Disability Living Allowance mobility component

Parents of children under five years who were not entitled to the mobility component of Disability Living Allowance said that the long-term impact of transport expenses during the caring period stretched far into the period after the child's death, but would have been less if they had had previous access to the mobility component.

Parents were pleased to hear that, from April 2001, children will be able to qualify for the higher rate from the age of three onwards. However, some parents said that they had increased transport costs from the time their baby was born, and argued for extension to children of all ages.

This was also recognised by staff and is confirmed by Roberts and Lawton's (1999) analysis of the transport needs of 37,000 families with severely disabled children. They found that families of children who had frequent medical crises, were dependent on medical equipment and/or had life-limiting conditions were least well served by the financial support available through the mobility component. They recommended that in these instances children of all ages, including infants, should be awarded the mobility component. The children in the present study would all have come within those categories identified by Roberts and Lawton.

Better information about options available for taking time away from work, and the long-term implications

The previous chapter explained some of the long-term implications of decisions about work and benefits which parents had made during the period when they were caring for their child, in particular, issues around National Insurance credits and the protection of future rights to benefits. This was a particular issue for couples where both parents were eventually involved in full-time care of their child. In retrospect, parents who had experienced such effects wished they had received better information about options available to them, and understood the long-term implications in terms of future entitlements to social security.

Most of those who wished that they had understood the implications of decisions made about work and claiming during caring said that they would

probably have taken the same course of action, if they had had full information. What would have been gained was prior understanding of situations which could arise; the possibility of making some plans at an earlier stage, or at least, thinking about possibilities. What they might have avoided were unexpected unhelpful outcomes which led to financial penalty, increased their emotional distress, and left them less equipped to make sensible decisions.

Parents did not find it easy to identify an appropriate agency or organisation for provision of such information and advice. Helping parents think ahead to a period after their child died required considerable skill and judgement. Benefits Agency staff who had been found understanding and helpful in establishing benefit income for couples when both partners wanted to care were thought, in retrospect, probably not equipped to discuss the full implications for the future. On the other hand, caring nurses, social workers or hospice staff who were thought able to talk to parents about a future without their child, were not expected to have full understanding of all the technical issues and options around benefits and work. Although it was hard to suggest which agency might take responsibility for this level of discussion, parents hoped that there might be further discussion and interest at policy level.

Employers' role

Staff noted that the decisions parents made about giving up work to care for their child had far reaching financial implications. These decisions were affected by employers' attitudes and there was wide variability in the way in which employers treated the needs of parents in this situation. Employers' lack of understanding of the need of parents to take time off work, for instance in medical crises, could be a factor influencing their decision to give up work. One staff member suggested that a right to prolonged carer's leave, comparable to maternity leave, to support a very ill child would help, and would recognise the fact that there would be far greater costs to society if parents did not provide the intensive care that these children need.

There were suggestions from some parents that tax breaks for employers might help support employers in allowing paid leave to employees who needed to care for very ill children.

The Employment Relations Act 1999 grants rights to take short periods of time off work to deal with an emergency involving a dependant, so may help parents to take time off for medical crises. It also gives rights to parental leave of up to 13 weeks for each child. For parents of disabled children the right to take this leave is extended up to the child's eighteenth birthday. These provisions could improve the situation for parents of children with life-limiting conditions, but two factors will limit their effects. First, the right to time off does not

include a right to pay, so some parents would find it difficult to take advantage of their entitlement. Secondly, rights to parental leave are only available in relation to children born after 15 December 1999, so will not help parents of children with life-limiting conditions born before that date. A number of suggestions in the Government's green paper on *'Work and Parents'* (DTI, 2000) would be helpful for this group of parents. These are: increasing the amount of parental leave available to parents of disabled children, introducing paid parental leave, and expanding the list of circumstances where employees have a right to take unpaid time off to deal with emergencies related to dependants to include routine hospital appointments.

Support for the caring role

Both staff and parents pointed to difficulties experienced when services were not well co-ordinated, there were delays in provision of appropriate help or equipment, or lack of support to enable parents to continue in employment or to have a break from the caring role. These problems had financial implications – increased private expenditure to avoid delays, and loss of employment opportunities, in addition to increased levels of stress.

As noted above, staff pointed to the need for a key worker system to improve co-ordination and ensure that families received appropriate help. In addition, they suggested payments direct to carers would enable them to purchase support in the home. This facility has now been made available to parents with disabled children under the Carers and Disabled Children Act, 2000. However, the Act does not allow the purchase of 'intimate care' for the cared-for child which means that for many of the children in this group, who need a high level of personal care at all times, the facility might be hard to use.

Help to think about financial issues that might arise if a child died

As described, parents knew how hard it was, during the period when they were caring for the child, to have constructive and helpful discussions about a future without their child. For some parents, thinking towards that time was just too sad. For others, *'taking a day at a time'* was a way of dealing positively with their circumstances.

However, parents who had not anticipated the major financial impact of withdrawal of carer and disability benefits said it would have been helpful to have thought about this a bit more before their child died. Some discussion of the timing of the withdrawal, and what it would mean in practical terms would have meant they were better prepared emotionally to deal with the financial impact. Again, although it was unlikely

that they would have wanted to, or felt able to, make specific advance plans about adjusting their budgets, what subsequently happened would not have been so upsetting and they might have felt more in control of some aspects of their lives.

Parents claiming Income Support who had not realised in advance that they would be required to register as available for work when their Income Support carer's premium was withdrawn eight weeks after Invalid Care Allowance ended, all wished they had understood this properly in advance. They wished they had had an opportunity to talk through what this meant in terms of income, and options available.

Again, parents acknowledged that this kind of discussion required staff with special skills and there were mixed views about which organisation was best suited to undertake such discussion. Nursing, care and hospice staff had often been helpful in talking about the future in terms of possible emotional and psychological response, but were not expected to have full technical knowledge that might be important in individual situations.

Staff also acknowledged the difficulties of preparing parents for financial aspects of the death of their child. They felt that some families would find this very helpful, but it would not be acceptable to others. Many staff did not have training to do this. One suggestion was for families to have access to a nominated financial adviser, possibly from the Citizens' Advice Bureau or social services, both before and after the child's death.

In the responses to the postal survey, many hospice staff referred to the difficulty in raising financial issues with parents who are caring for children in the final months or weeks of their lives. Some parents were thought to be unwilling or unable to think about money at such a time. However, there was also a recognition that financial advice should be made available to any parents requesting it. It was felt that some financial problems, particularly those caused by the accumulation of debts and the sudden loss of income when the child dies, could be prevented by early discussion of financial issues with parents. Two hospices suggested that early help and advice were essential in staving off problems later and that workers involved with the parents should possibly adopt a more direct attitude with them and question them about their financial situation.

There was little consensus in the responses to the postal survey about which organisations or professionals were best placed to supply the sort of financial advice that families needed. Instead, the responses reflected the diversity of people's circumstances and the types of contact they and their child had with statutory and other services. The organisations cited most often included the DSS, social services staff, hospital staff, Citizens Advice Bureaux, charitable trusts and organisations and hospice staff themselves.

Our survey showed that 10 of the 18 hospices which responded arranged some form of training for staff on financial issues facing parents. Various internal and external sources were used for this training including the Benefits Agency, local authorities, and social workers attached to the hospice. The general picture was that when financial issues were raised by parents, staff would try to respond. In 11 of the 18 hospices staff expected to raise issues about money with all parents.

However, there was also a recognition that for many professionals involved in a specialist capacity with parents, such as social workers, and hospice and hospital workers, raising sensitive financial issues about which they were not expert could threaten or undermine their professional role and relationships. One suggestion in response to this tension was the establishment of a new agency with the explicit function of helping families with the whole range of possible financial issues that they might face. From the summer of 2001, a new Working Age Agency will be established by merging the Employment Service with elements of the Benefits Agency. This would seem to be an opportunity for providing parents with information and support across a range of financial issues.

Another suggestion made by parents and staff was that the Benefits Agency might design a short leaflet or 'flier' about 'What happens if your period of caring comes to an end'. Wording would be important, in order to catch parents' attention and enable them to identify themselves among those to whom the information might apply one day. Addresses or help-line numbers could be offered, for more detailed discussion with trained staff. The flier might be sent out regularly, perhaps with letters which announced annual increases in benefit rates, or automatically at six-monthly intervals. This might help parents gradually become familiar with important aspects that they would eventually have to deal with.

Other ways of preventing financial problems

We have already described above how encouraging parents to discuss financial issues before their child dies was thought by some hospice workers to be one means of identifying potential problems before they became acute or serious. Some parents had found informal discussions with others in similar situations, at the hospice or support group they attended, to be one source of information about financial issues. Not all parents felt it was appropriate to have this kind of discussion with other parents, however, and some believed that wrong or inadequate information could easily circulate in this way.

Another suggestion that arose from the postal survey was that the levels of social security benefit paid

to parents and in respect of children themselves should be increased in order to prevent debts accumulating. The point being made was the simple one that for many families levels of income derived from the benefit system were inadequate to meet the needs of the sick child and the rest of the family. Although faced with inadequate income, some families chose to continue spending beyond their immediate means in order to maintain the standard of living they wanted for their child before their death.

There were also suggestions that mortgage lenders, rental agencies and insurance companies should be encouraged to be more understanding of the situations of families with a child with a life-limiting condition, and perhaps develop financial products (in particular insurance policies) that could help families when their child eventually dies.

Issues arising about funeral costs

We saw in Chapter Three that there were several examples of good practice and high-quality service from funeral directors. There was one suggestion for improvement in practice. Those parents who, in retrospect, thought that it would have been helpful to have spent less money on their funeral arrangements, thought that they should not have been shown folios of floral arrangements or children's special coffins that did not also have the costs clearly marked on each item. It could be hard to enquire about prices when expressing interest in items to a funeral director, and hard to be seen to reject options on grounds of price alone. It would have been better to have been able to make a mental note of cost when choosing.

Having enough money to pay for a funeral

Some parents wished that there had been more help available with funeral expenses. One suggestion was to make Social Fund funeral expenses grants more widely available, for example to parents taking sick leave at the time of the death of their child. Another suggestion was that the Family Fund might make help available. At present, the Family Fund Trust is not able to help with funeral expenses under the current definition of the objects of the Trust which are 'to help relieve the stress on families of caring for a severely disabled child', and thus do not extend to help after the death of a child.

Having to make an application for financial assistance with funeral expenses was not the kind of help some parents wanted, however. Preference was to have enough money available (or know that it was forthcoming) to deal with the matter personally, without having to ask for help. Although parents who had

received help from charities or trusts, or the Social Fund had appreciated this at the time, receipt of such assistance could prove to be unhelpful in the longer term. Having been unable to pay for their child's funeral from their own resources could remain a matter for deep regret and pain in future years. A headstone, paid for by a charity, could prove a permanent reminder to parents that they had been unable to bury their child without asking for help. For some parents, financial 'help' received for funerals and headstones brought future emotional problems which were hard to resolve.

A suggestion from hospice staff replying to the postal survey referred to the practice of some funeral directors in their area of providing free funerals for children. If this was standard practice, they suggested, it might help prevent parents creating financial problems for themselves through their desire to provide what they saw as a fitting funeral for their child. The interviews with parents showed, however, that they wanted to choose the arrangements and to be able to pay for these from their own private money.

To enable all parents to meet funeral costs from their own resources without having to ask for help, one suggestion from parents was the automatic payment of one additional year's Child Benefit, as a lump-sum following the child's death. This would involve minimum administration, without a requirement for means-testing. The amount involved would cover the cost of a simple funeral, in most cases. For some parents, such a payment would also represent societal 'valuing' of the parents' caring role, and societal acknowledgement of the importance of an appropriate funeral for the member who had been lost. Immediate cessation of Child Benefit had left some parents with feelings they regretted – that their child's death represented a major 'saving' to the Treasury.

If parents received a bereavement allowance in respect of the death of their child, this might also be used to pay for the funeral. The following section has more to say about the possibility of a bereavement allowance for parents.

Cost of headstones

Headstones or memorial plaques were important to many parents. There was disappointment and surprise that these seemed such expensive items. They had little emotional energy to 'shop around' for a headstone, and this could feel inappropriate anyway. Some parents wanted to know why headstones cost so much money, and what was driving costs (materials, labour, skills or market cartels). They had not found any information to help them understand why a headstone was so expensive. This area might be a future focus of enquiry for consumers' associations.

Issues arising after the child's death

There were a number of suggestions for changes in policy and practice in respect of financial issues arising in the period after death.

Extending benefit payments beyond the death of a child

There was strong support among parents and staff, and from the hospices and other organisations responding to the postal survey, for the idea that the disability and caring benefits which families had been receiving while they cared for their child should be extended in some way after the child's death. An extension or more gradual reduction would help parents avoid some of the major financial problems that could arise in the weeks around the child's death. There would be some buffer between previous household budgeting strategies and adjustments that were now necessary. Expecting parents to be able to deal with the financial impact of loss of a major component of regular income immediately their child died was considered unrealistic, and in some circumstances 'inhumane'.

Extending either Invalid Care Allowance or Disability Living Allowance, or both, beyond the death of the child was suggested. The length of the extension period suggested varied widely. Parents who had found financial adjustment particularly hard argued for longer extension periods, of perhaps six months to one year. Other parents would have welcomed extensions of benefit payments for such a period, but felt that these would be unlikely to gain government or public support. One suggestion was for Invalid Care Allowance to run on for at least the same period as the carer premium in Income Support (eight weeks). As explained in Chapter One, soon after the completion of this research, the Government announced its intention to extend the period of receipt of Invalid Care Allowance for up to eight weeks after the death of the person being cared for. This will require legislative change, and is unlikely to come into effect until 2002, but will certainly ease the financial situation of some parents whose child dies.

Phasing out benefits

Phasing out either benefit or both, was another suggestion, and some parents saw opportunities for parents to choose the way of phasing out benefit that was most helpful to them. For example, if the equivalent of three months previous benefit entitlement was to be made available, some parents might choose to go on receiving proportions of full entitlement, over a longer time, some might choose a lump-sum, while some parents might prefer to have none at all. Different

options could accommodate different kinds of financial and emotional needs; parents could be enabled to feel more in control of this part of their life.

We saw in the previous section that some parents thought first in terms of Child Benefit when they discussed extensions of benefits after the child had died, rather than disability or caring benefits.

From a policy perspective, there are a number of issues to consider when discussing options for extending or phasing-out benefits. These include how well the proposed modification fits the general aims and design of the benefit, the amounts of money that would be made available, how monies would be delivered, and issues of equity and targeting.

In terms of building on existing components of benefits, there would seem to be possibilities in both Child Benefit and Disability Living Allowance. For Child Benefit purposes, the absence of a child from a household where s/he normally lives can be ignored for up to 12 weeks if the child goes into hospital or some kinds of residential accommodation. A sum equivalent to 12 weeks Child Benefit, payable when the child dies, might therefore have some logic in the way Child Benefit already works. (There might be complications if the caring parent was not the same person as the Child Benefit recipient, but this would apply to very few parents.)

Turning to Disability Living Allowance, a three month 'roll-out' after the child dies might be seen as balancing the three month waiting period required at the beginning of the claim, for children not diagnosed as terminally ill at that stage.

A new bereavement allowance/ payment

Rather than extending or phasing out their existing benefits, some parents, and hospices replying to the postal survey, suggested some form of new '*bereavement allowance or one-off payment*' for parents who have lost a child. This was especially the case among parents who had recently experienced the death of an older relative, and felt that their own financial need after the death of their child had been greater than that of a surviving elderly relative who had received widow's payment and pension. It was suggested that such a bereavement allowance might be paid for up to six months after the child's death.

Under current social security legislation, survivors' benefits are associated with the death of a breadwinner. Entitlement is based on National Insurance contributions and the cause of death. A new bereavement payment or allowance for parents might not be easy to fit into this scheme. However, one particular advantage of a general bereavement allowance or payment (and, indeed, any extension of Child Benefit) would be that these could be applicable to **all** parents who lost a child. One

disadvantage of extending or phasing-out disability and caring benefits is that this fails to address the financial problems of parents whose child dies suddenly or unexpectedly, without a previous history of disability or caring benefits. Another disadvantage is non-take-up among families entitled to Disability Living Allowance.

It could therefore be argued that addressing post-death financial problems through run-ons of disability and caring benefits would introduce new forms of inequity. While this is true, the expenditure incurred by parents caring for a very sick or disabled child, and findings from this study of the long-term financial implications of the period of care, do provide an argument for treating these parents differently.

Bereavement benefits for widows and widowers have recently been changed by the Welfare Reform and Pensions Act 1999. The stated long-term aim of the Government is to achieve a system of support for bereaved people that concentrates support on immediate needs and on children and families. While children have traditionally been cast as 'survivors' within policy for financial support following bereavement, there would now seem to be room for consideration of the financial needs of parents whose child has died.

Protection of National Insurance credits

Parents argued for better protection of future benefit entitlement, to cover the period after their child died. One approach might be to extend Class 1 National Insurance credits, currently awarded to parents in receipt of Invalid Care Allowance, to other caring parents, such as those on Income Support who currently can only obtain the more limited Home Responsibilities Protection. Introducing new rules to allow for 'splitting' Invalid Care Allowance or awarding two payments where both parents care for the same child may also be worth considering. (There may be some sort of precedent in the income-based Jobseeker's Allowance 'joint claim' for certain couples, due to be implemented from March 2001.)

For parents who had spent many years caring for a disabled child, what they had done could seem like a job of work, and they felt it was wrong that their contributions record did not entitle them to the same level of protection as people who were employed. Some parents argued that their years of care had saved the State thousands of pounds and felt that they had earned a right to financial protection through the responsibilities they had taken on. Another argument was that recently bereaved parents faced particular risks in trying to do paid work again, for example vulnerability in health and emotional adjustment, and restricted choice of work. Different ways of reducing risk and maintaining financial security were needed, and one way of doing this could be by strengthening National Insurance records.

Service from the Benefits Agency

Parents were disappointed, and sometimes surprised, to learn that when their child died it was considered appropriate for the Benefits Agency to ask for repayment of monies that were technically 'overpaid' due to the delivery arrangements of Disability Living Allowance. They suggested that this policy should be reconsidered, taking into consideration the distress caused to parents who had to send a cheque or post office order which in effect was money for their dead child. They perceived the amounts of money involved as relatively small, in terms of revenue which would be foregone. (There are also related issues in respect of pursuit of arrears of child maintenance by the Child Support Agency but this study did not include experiences of parents living apart from their children and liable for child maintenance.)

We saw in Chapter Three how important it was for parents to receive appropriate service from the Benefits Agency after their child died, in written and telephone communication about their benefits. It was important that the person sending the letter or talking on the telephone said first that they were sorry to learn that their child had died. Parents wanted their child to be named, and to have 'died' rather than to be 'deceased'. Letters or phone calls that thanked parents for getting in touch at such a hard time were appreciated. Curt requests, abrupt or unfeeling remarks were deeply hurtful at this time.

Parents who had to visit local offices in the week or fortnight following their child's death found it intolerable to discuss their business in the public area, or to have to queue alongside other claimants. Finding ways of arranging timed appointments in private rooms for bereaved parents was urged. Another suggestion was for each local office to have members of staff with particular expertise in dealing with recently bereaved people (not only bereaved parents). Parents and health and social care staff felt that training was needed to equip Benefits Agency staff for this role.

Access to support/information about options for future employment

Parents who had spent a period of time out of the labour market in order to care for their child experienced difficulties in returning to work. On the one hand, they felt that they were disadvantaged in the labour market by their period of unemployment, but on the other hand some felt they had learnt new skills which should be recognised as valuable to employment. There was considerable interest in the development of some form of specialist service providing information, advice and support for parents about options for future employment.

Parents who were finding it hard to go back to work wanted to talk about ways in which this might be

made easier. GPs were often understanding about their feelings, but did not have sufficient relevant knowledge about different jobs and ways of working, and financial support. Extensions of sickness certification, and eventual routing to incapacity benefits might seem to help maintain some financial security, but, in the longer term, could make it harder to think about the possibility of going back to, or starting, work. Parents who had never worked, especially those who no longer had dependants and had to register for work to obtain Jobseeker's Allowance, needed quick and easy access to somebody who could advise and support them.

Parents in this study who had gone to government agencies for this kind of advice and support had not received a helpful service. JobCentre staff spoken to had not properly understood the obstacles faced by a newly bereaved parent in re-engaging with paid work. An adviser in the prototype ONE agency was described as '*completely out of her depth*' and unable to deal with the parent's situation. Parents who had not actively sought advice or support sometimes could not think where such help might be available. Lone parents claiming incapacity benefits in North Yorkshire knew little about the pilot Personal Adviser Service in their area, which might have supported them, within the New Deal for Disabled People (see Millar, 2000), and it had not occurred to them to get in touch. We also saw in Chapter Four that some parents who had taken the route to incapacity benefits regretted the categorisation of 'disabled' which now attached to them.

The *National Strategy for Carers* published in February 1999 acknowledges the problems of carers whose period of care has ended, and who need to return to work, and includes a commitment to considering how best to help such people.

Former carers who are over 50 years old are also within the target group for the New Deal 50 Plus programme, launched in nine 'pathfinder' areas in November 1999, and now being extended throughout the UK. This may provide a nucleus of skills and expertise in advising and supporting older ex-carers, some of whom will be recently bereaved. In our study, however, few parents were over 50 years old, and most would not fall within this target group. It also seems likely that the employment and financial issues facing younger bereaved people, some of whom have other dependent children, or hope to build up their family again, will be different from the issues important to older ex-carers.

The planned new Agency for People of Working Age, announced in March 2000 and due to come into operation in July 2001, will bring together services currently offered by the Benefits Agency and the Employment Service, and some support through specialist advisers and job-brokers. The new Agency therefore provides a new opportunity for responding to the needs of bereaved parents. Findings from this study will be important in the planning of the new agency, and

there are implications for the recruitment and training of staff, the promotion and marketing of the agency's services, and evaluation of the service.

Issues for employers

Some parents had remained in work throughout the child's illness, and for most the need to take leave to cope with bereavement was recognised and supported by employers. However, where the need to return to work very soon after the child's death was driven by financial pressures, problems often arose. There are implications here for how employers deal with arrangements for paid or unpaid leave for bereavement and how employees can be supported in making realistic decisions about their return to work.

Concluding discussion

This was a small exploratory study focusing on bereaved parents (couples and lone mothers) who have been in touch with a children's hospice. We do not claim that our findings can be generalised to the wider population of bereaved parents. However, we do believe that the research reported is important and that the findings are relevant in a number of different policy environments.

First, and importantly, we believe that we have shown that it is feasible for social researchers to discuss in detail sensitive financial issues with recently bereaved parents. Just over half of those parents approached agreed to take part, and those who participated said that they wanted to contribute their views and suggestions for change in the hope that other families might be helped in the future. From the researchers' perspective, the practical and ethical aspects of conducting such discussions were comparable to those taken into account in other research on other sensitive topics. It was possible to focus on financial issues when talking to parents about the death of their child. What was discussed was often very sad, of course.

The findings from the research are rich and informative. It is inappropriate to make detailed policy recommendations on the basis of a small exploratory study. We believe that further work is now required, to include the views and experiences of other groups of parents, such as lone fathers, parents who had been living apart from the child and the other parent, and people from minority ethnic groups.

There is also scope for widening the research to include parents whose children have died in other circumstances which have not involved hospice support, in particular parents whose child died suddenly. The financial implications are likely to be rather different from those discussed in this study, but are also likely to have significant immediate and longer-term financial effects.

The general findings from this study are clear. The costs of caring for a very sick or disabled child have long-term financial implications for some parents, and problems caused may extend far into the period after the child has died. All bereaved parents studied felt an immediate financial impact from the reduction of social security benefits, and funeral expenses. This could create new kinds of financial constraint and stress, which could exacerbate and prolong existing financial problems. Some parents who hoped that paid work would eventually provide financial support and stability faced particular problems in continuing or finding work. For some parents, financial and employment problems experienced following the death of their child can delay and obstruct the emotional and psychological processes which must take place for healing and moving forwards. Ways of helping families deal with problematic financial issues, or ways of helping to prevent such problems arising, will contribute to the long-term well-being of families who face a child's death.

Although detailed practical recommendations are inappropriate, findings point firmly to the need for policy consideration, debate and discussion in the following areas:

- continued effort to enable full take-up of Disability Living Allowance and other benefits among families caring for a sick or disabled child;
- consideration of further lowering of the age criteria for the mobility component of Disability Living Allowance, to include all children with a life-limiting condition;
- finding ways of protecting the National Insurance record of all parents caring for a very sick or disabled child, both in recognition of the work done on behalf of society, and to reduce the risks involved in returning to or starting work after a child has died;
- providing opportunities for parents to have appropriate information about long-term implications of working/claiming/spending decisions made while caring for their child; and to be able to talk and think about these issues with a person with appropriate technical knowledge and counselling and support skills;
- finding ways of enabling all parents of children who die to pay privately for a funeral/cremation, and memorial stone/plaque without a test of means or the need to apply to a charity;
- finding ways to 'soften' the impact of immediate cessation of Child Benefit, Disability Living Allowance and Invalid Care Allowance, including consideration of extensions or phased reductions;
- consideration of a new bereavement allowance or payment for bereaved parents of children;

- reconsideration of current Department of Social Security policy to require parents to repay, after a child's death, benefits which have been technically 'overpaid' as a result of payment arrangements;
- consideration of policy within the Child Support Agency regarding the treatment of payments/arrears of child maintenance, when a child dies;
- attention to service issues within the Benefits Agency, Child Support Agency (and similar government departments and agencies), in respect of correspondence, telephone discussions, and local office interactions with parents whose child has died;
- consideration by the Benefits Agency and Child Support Agency of training and support needs of staff who conduct business with parents whose child has died; and consideration about ways of increasing skills and expertise in dealing, generally, with bereaved people;
- providing opportunities for parents whose child has died to have easy and timely access to appropriate information and support in respect of options for employment;
- considering the relationship between support and help with financial/employment matters and the kind of emotional and psychological support provided within bereavement counselling, and looking for a fit between or integration of different forms of support;
- consideration of the roles and responsibilities of the different agencies who provide services for families who have children with life-limiting conditions, to clarify how agencies should take responsibility for providing information and support to families on financial issues.

We believe that the current policy environment of increasing emphasis on care of very ill children by parents rather than in hospital, rapid developments in the children's hospice movement, a new government strategy for carers, commitment to modernisation of bereavement benefits and a range of new initiatives for supporting people who want to do paid work, provide a real opportunity for full debate and discussion of these issues, and further research and enquiry around financial implications of dying and death.

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The first stage of the study was to obtain approval from the relevant Local Research Ethics Committee.

1. Interviews with parents

Building the study group

The aim was to achieve a study group of around 15 families who had experienced the death of their child within the previous two years. Three main selection criteria were used, to include parents with different financial opportunities and constraints:

- type of family;
- source and level of income;
- location of family home.

Type of family

The aim was to include:

- lone parents and two parent families;
- parents whose only child died, and parents with other children;
- parents who lost children of different ages;
- parents who spent different lengths of time as carers.

Source and level of income

The aim was to include:

- parents currently not doing paid work;
- parents working part-time;
- parents doing full-time paid work;
- self-employed parents;
- parents with experience of a range of social security benefits.

Location of family home

The aim was to include families living in different parts of the area served by Martin House, including urban and rural locations, and different local authority areas.

Other criteria

It was important to include some families who were known to have experienced financial problems associated with the death of their child, and some

parents for whom 'money matters' did not seem to be such an outstanding difficulty.

Although Martin House offers support to minority ethnic families, none of the few such families whose child had died in recent years had chosen to stay in touch with the hospice. This study therefore does not include minority ethnic families. Findings will inform how similar research might be taken forward within different communities.

Lastly, but importantly, the aim was to avoid contacting families around the anniversary of the child's birthday or death. It is known that for some families this would be unhelpful.

Selecting the families

It was important to maintain families' confidentiality and avoid bias. Using the above criteria, senior hospice staff selected 20 families from 47 whose child (aged up to 18 years) had died during the past two years, using administrative records and their knowledge about family circumstances.

Martin House sent an information sheet and a letter of invitation to the first 15 on this list in September 1999. People who would like to take part were invited to contact the researchers, to arrange an appointment, and a stamped envelope was included for their convenience.

Eight of the 15 sets of parents, and another parent who had heard about the work and wanted to take part, contacted the researchers during the following month, and interviews were arranged.

A follow-up letter from Martin House resulted in no further interviews. At the end of October Martin House sent letters of invitation to the five remaining parents among the 20 originally selected. There were two expressions of interest in response to the letter, but no further interviews were achieved. It was decided not to try to arrange further interviews until the new year, as the Christmas period is a hard time for some bereaved parents.

In January 2000, Martin House made a further selection, and wrote to ten families. This time, staff followed up the letters with personal telephone calls, to discuss the research, and address any concerns. There was considerable interest, resulting in a further eight interviews.

The final study group comprised 17 sets of parents: 16 of the 30 bereaved families approached who agreed to be interviewed, and one family who was still caring for their child and wished to take part.

The ages of children when they died ranged from one to seventeen years. They had a wide range of conditions, including metabolic diseases, chromosomal abnormalities, progressive neuromuscular disorders, and childhood cancers. Many parents had been providing high levels of care for their children for many years before they died, and one family had more than one child with the same condition.

Conducting the interviews

Most interviews took place in the parents' homes; one was conducted at Martin House. In most interviews with two-parent families, both parents took part together; two mothers chose to talk to the researcher without their partner.

The researcher used a topic guide to steer discussion, and all parents gave permission for the interview to be tape-recorded. Most of the discussions took around one and a half hours. What was talked about was very sad, but it proved feasible to discuss financial matters with recently bereaved parents, and the discussions generated rich and useful material.

The tape-recordings were transcribed for analysis.

Analysis

A detailed content analysis of the data was undertaken, based on the tape-recordings and the verbatim transcripts. A first reading of the material identified the principal themes and sub-themes emerging from the data. This provided a structure for a thematic matrix for organisation of the data. This method of analysis enables emergence of overall patterns and comparisons, as well as within-case analysis.

A summary of key findings from the research was made available to those parents who wished to see this, in advance of publication of the report.

2. Interviews with key professional staff

Selection of staff

The aim was to select a range of key staff in Martin House and the main statutory agencies who had contact with this group of families, both before and after the death of the child. In discussions with senior staff at Martin House, we identified such staff as:

- the bereavement team at Martin House;
- the part-time social worker at Martin House;

- social workers in local authority social services departments;
- staff at the Regional Child Development Centre;
- staff at the regional Paediatric Oncology Unit.

Telephone contact was made with the staff identified and they were sent information sheets about the study. In the case of the Regional Child Development Centre (RCDC) and the Paediatric Oncology Unit, contact was made with the specialist health visitors in each unit to discuss which members of the teams would be most appropriate to interview. For the RCDC, the health visitor felt that she herself had most dealings with this group of families around the issue of finances. For the Paediatric Oncology Unit, it was agreed that a number of different staff within the unit had useful perspectives on this issue, and a group discussion following one of the regular team meetings was arranged. Contact was also made with a social worker in the Children's Disability Team of a Social Services Department serving one of the areas in the study. All staff contacted agreed to take part in interviews.

One to one interviews were held with three staff: the social worker at Martin House, a social worker in a Social Services Department, and a health visitor in RCDC. A group discussion was held with the bereavement team at Martin House. The group discussion in the Paediatric Oncology Unit included staff with a range of experience and responsibilities, including consultants, social workers, health visitors and nurses.

Conducting the interviews

Both group and individual interviews followed the same topic guide, which was designed to investigate professionals' perceptions of the issues raised by families. This covered the respondents' roles with families of children with life-limiting conditions; their perceptions of the significance of issues concerning money among this group of parents; their own roles in meeting parents' needs in respect of financial issues and any difficulties they experienced in these; their ideas for improving services and avoiding or limiting financial problems for bereaved parents.

All interviews except the paediatric oncology group meeting were tape recorded and transcribed for analysis. The group meeting was a large meeting with a certain amount of coming and going as people were called away and it was not practicable to use a tape recorder. The researcher therefore made notes at the meeting and dictated a detailed account immediately after the meeting.

Analysis

A standard qualitative analysis of the material from the staff interviews was conducted, using an approach similar to that described above for the interviews with clients.

3. Postal survey to children's hospices

The postal survey of children's hospices and a number of bereavement services and support groups for parents was carried out in March 2000 after most of the interviews with parents and staff had been completed. The purpose of the postal survey was to see whether the issues raised in the interviews with the parents and staff associated with Martin House were recognised by staff in other children's hospices and organisations in touch with bereaved parents. The intention was that the survey would provide a more general view of the significance of finances for bereaved parents, and help to stimulate suggestions for improvements to services across a number of agencies.

A questionnaire was prepared by the research team and sent to all children's hospices (21) and a small number of other agencies in the United Kingdom. A covering letter set out the purposes and scope of the research and explained the other components of the project design. The respondent was encouraged to consult with colleagues in the hospice/agency when completing the questionnaire in order to capture as much information as possible from people with some experience of dealing with the financial problems of bereaved parents.

The questionnaire covered the following broad areas:

- information about the hospice/agency, and what support is provided for bereaved parents;
- the extent to which bereaved parents talk about financial issues with hospice/agency staff, and what kind of problems are reported;
- views on the factors which contribute to parents' financial problems;
- how financial issues are dealt with by the hospice/agency;
- suggestions as to how financial problems for bereaved parents might be lessened, or avoided, in the future.

Eighteen hospices and four other organisations returned completed questionnaires.

Material was extracted, using tables and lists which showed the range of views and experiences, and emerging patterns.

