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Hospices for Children: A Need in a Sick Society?

Proceedings of a conference organised jointly by
the King's Fund Centre and Helen House Hospice for Children
held at the King's Fund Centre on 2 December 1986

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HELEN HOUSE
a hospice for children

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HOSPICES FOR CHILDREN:
A need in a sick society?

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Introduction

Four years ago Helen House, a hospice for children, opened in Oxford. It was soon seen as a success story, with articles in the press and a television programme highlighting its work helping children with chronic life-threatening diseases and their families. That publicity had consequences which no-one perhaps foresaw; plans for similar schemes are springing up in many parts of the country, prompted by the concern and generosity of all kinds of people.

While there is undoubtedly a need for more support and advice for children and relatives, there is also growing concern that the proliferation of hospices is both haphazard and, in some ways, counterproductive. There is a pressing need to assess requirements coolly and rationally, to evaluate existing services, to plan ahead and to secure appropriate long-term resources. And what about the needs of those not catered for by places like Helen House? What about the belief that hospice is a philosophy rather than a building?

The conference grew out of these concerns, and brought together nearly 100 nurses, doctors, planners, researchers and others with an interest in sick children. They came to compare notes on their activities, to hear more about Helen House, and to discuss their anxieties. The day was a stimulating mixture of talks and discussions in small groups, rounded off by a plenary session which reached a strong consensus - transformed into the recommendations listed later in this report.

A philosophy, not a facility

The origins and work of Helen House were outlined in a talk by Mother Frances Dominica, its founder, illustrated with some vivid and moving slides. A registered children's nurse, she met two-year-old Helen and her parents when the child was recovering in hospital from surgery to remove a brain tumour. After Helen went home, Mother Frances looked after her from time to time to give her parents a break. Helen House grew out of this friendship when Mother Frances saw the parents' needs: the loneliness, the exhaustion and the prolonged grief involved in caring for a dying child.

The idea of Helen House, Mother Frances said, was an extension of that special friendship. It is a philosophy, not a facility, which aims to enable families to care for their sick child at home in specific ways:

- by ensuring that extra community support is mobilised
- by offering respite care
- by phone contact and home visits.

Like a general hospice, it is a place of hospitality for those on a journey from this life to the next. But it also meets other needs; it is not a long-term in-patient home; it offers support and practical care through the chronic phase of the child's illness - which may last for years.

Few children, in fact, go on their initial visit to Helen House already in the final phase of illness. By far the greater need among the referrals is respite care for children with a chronic, progressive, life-threatening disease (see Table 1). The average length of stay is a week, though this has varied between two hours and 13 weeks; 55 of the 132 children visiting since it opened have died, 20 at home and 21 in Helen House. The hospice aims to 'be alongside' the whole family through the terminal phase, at the time of death, and during the long months and years of bereavement.

Mother Frances described the criteria used to assess whether a child would benefit from involvement with Helen House. The child should be under 16, in need of respite or terminal care, referred from anywhere in the UK (supported by a doctor's letter). No fees are charged, and parents and siblings are also welcome to stay. Pets can come too, and the more exotic visitors have included a tarantula! These ground-rules are occasionally broken according to need. At first, she said, they were unsure about who would be referred, but they had decided the priority was 'children with progressive long-term conditions and their families, and the bereavement which begins with diagnosis.'

The referrals began to come in batches from self-help groups. Other parents heard about it from special schools, neighbours and friends. Following a 1980 appeal for funds (it costs £240,000 a year to run) the hospice is financially secure.

The hospice team includes 11 children's nurses (RSCN), an administrator, a secretary, between 10 and 20 volunteers, and 15 others - a physiotherapist, nursery nurses, a teacher, a social worker, GPs and nuns. Everyone shares the domestic work and the approach is non-hierarchical, in keeping with the aim of making the hospice as much like home as possible; no uniforms are worn and first names are used.

'Home is where the children belong ..... They are looking for somewhere to come from time to time which is as much like home as possible,' she said. Helen House provides a loving, supportive environment where parents and children can do things their way, rather than the way the professionals think best. The care is shared, with a mutual exchange of skills. Moreover, it is not attempting to take over from local services, but perhaps act as a gentle reminder of these children's needs.

Experience with symptom relief

Symptom relief is a major preoccupation in caring for the children, and information about the Helen House approach was given by its medical director, Dr Roger Burne, who is also a GP in a practice nearby.

Symptom control for children has, in the past, been based on the assumption that the principles used in adult care should be followed, he said. However, the fact that 83% of the children attended for respite care, with only 12% requiring pain and symptom control and terminal care, suggested that a different approach might be needed, as did the range of diagnoses (see Table 2). Pain in fact was not the dominant symptom - urinary incontinence, seizures and feeding difficulties were more common problems (see Table 3). Many children had multiple symptoms; some required mainly nursing care, while others needed medical input.

Turning to the literature, Dr Burne said guidance was scanty, so they had to think things through for themselves. The use of strong opiates was an example. A study of the distribution of four-hourly doses of morphine sulphate to 21 children who died at Helen House showed no relationship between dose and age. The indications for this group included 14 children in pain, seven with dyspnoea, five with persistent coughs, and four in heart failure. 'Symptom control in the care of dying children is based on assumptions, and much more information is needed', he concluded.

The Helen House studies

What has been learned so far from the four years of Helen House's life? The DHSS is funding an evaluation, now two-thirds completed, and some of the provisional findings were presented by Dr Gillian Forrest, consultant child psychiatrist at Park Hospital for Children, Oxford. The work is still in progress so conclusions at this stage are tentative. In many ways it had been difficult and highly charged emotionally, requiring support from the staff and money from the DHSS but also independence from Helen House, for objectivity. The study had three parts: the families, staff stress, and a national survey of hospice and respite facilities for children.

One major question is whether Helen House fills a gap in NHS services - clearly important in the light of the imminent proliferation of charitable hospice facilities. A national picture of need and service provision was needed, while looking at the hospice's own work in more detail. It has kept records which include some demographic data but few clues as to why families went there, how they had heard about it and what they gained from it; nor had there been any systematic assessment of the effects on its staff.

The study of Helen House itself presented two major difficulties, Dr Forrest said. First, the children were very diverse in age, condition and stage of illness. 'There was no uniform reason for referral, and very varied use of Helen House'. Second, it was hard to evaluate the beneficial effects when the child's health was deteriorating.

Family studies

The first part of this was a retrospective survey of 25 families living within 75 miles, to elicit a descriptive 'consumer' account of the impact of the child's illness and the role played by Helen House. Twenty of the families had an ill child still living and five were bereaved. Mothers participated in semi-structured interviews, often with fathers present, and both parents completed a general health questionnaire, a scale to assess the state of their partnership and a social adjustment scale. The sick child and siblings were rated on behavioural scales completed by the parents. The sicker children were not interviewed as many were suffering intellectual impairment through their disease.

The results were presented by Dr Alan Stein, training fellow in child psychiatry at the Park Hospital for Sick Children. He said that 38% of the families' sick children had neurodegenerative diseases, the largest group. Muscular dystrophy accounted for 23%, cerebral neoplasms were 7.7%, and the rest had a variety of conditions. Surviving children were 10½ years old on average, and had been ill for 7½ years, while the average age of the childen who died was 4½ years, and they had had 2½ years of illness on average.

Looking at symptoms, nearly half the parents named pain as a cause of moderate or great anxiety. This was followed by seizures, swallowing and breathlessness. Threequarters said that they were moderately worried about one symptom, and 10% reported very great anxiety about seizures, and 10% about breathlessness.

The services they had used in the preceding year were also investigated. Very few had weekly contact with any agency. Over the past year 45% saw their GP weekly or monthly, and 55% saw them every few months or not at all. Paediatrician or other medical specialist were seen on average once every few months. 40% could name a social worker, although the contact was not necessarily frequent. 30% had access to some other form of respite care or social service, while 95% had contact with the child education service, usually through special schools.

There was great variation in the amount of contact they had had with Helen House. On average the surviving children spent 3½ weeks per annum there while the children who had died had spent 4½ weeks there during their last year of life. There was regular contact via letters and telephone calls, and occasional home visits by staff which usually continue after the child's death.

Over a third (36%) of the families had referred themselves, a quarter were referred by paediatricians, 20% by social workers, 8% by physiotherapists, 12% by others and none by GPs. Their needs and expectations on arrival fell into 3 broad groups:

* the desire for non-hospital care, with opportunities for talk and support

* a focus on symptom control rather than cure

* the desire for respite care, 'a break'.

So what did families think of Helen House? Overall there was a strong feeling that nothing was too much trouble for the staff and that it was like a big family. Three-quarters felt highly satisfied with the help given, and the rest were moderately satisfied. All said that they were respected as parents; 90% were satisfied with the information they received; 90% felt that they could discuss their worries; 80% felt the amount of discussion was right. The staff were seen as friendly, approachable and helpful rather that efficient or busy. Siblings were seen to be welcome and 74% of them visited often.

The survey revealed some of the stresses the parents endured. Apart from the fear of the child's death, they worried about what would happen if the child passed the age of 16 (and would then generally be too old for Helen House), or outlived the parents. Almost half the families were found to be experiencing 3 or more stressors in addition to their child's illness; these included another affected child, unemployment, money or marital problems, and mental health problems.

Helen House therefore played a major role in supporting the families Dr Stein concluded - they saw it as 'a life-line'. However this part of the study was not designed to evaluate the extent of its general effectiveness. The families that had been seen at Helen House might well turn out to be a self-selected group in that they were suffering especially adverse circumstances and/or had become estranged from local services. Mother Frances added that Helen House families tended to be exceptional, isolated and seeking guidance. She also said that it was likely that parents approaching a hospice implicitly accepted the fatal nature of their child's disease.

A similar methodology is being used in a prospective study of families which is designed to measure the effect of Helen House on the physical, social and mental well-being of the parents. Twenty-five newly referred families are being interviewed, and being compared with 25 families who are not using Helen House facilities, acting as a control group. This work is still in progress.

Staff stress and coping

The second major line of enquiry was staff stress, coping mechanisms and job satisfaction. This was investigated via semi-structured interviews, the General Health Questionnaire, and sickness and turnover rates. The results were outlined by Helen Winterbottom, social worker at the Park hospital. In two months in 1986, 24 of the 28 direct care staff were interviewed for 1-2 hours and completed self-rating health questionnaires. Twelve were nurses and the others were teachers, physiotherapists, social workers, and doctors, or had no formal qualification.

Overall the staff rated their work as engendering moderately high stress and high job satisfaction. There were 3 main sources of stress. Firstly, there were stressors related to children. Sometimes this was connected with the children's suffering, but it could also occur when the expected death did not take place. Uncontrollable pain and perceived mental distress were the chief symptom related causes of stress, though the ability to comfort the children and ease their distress brought high rewards.

There was great variation in the types of illness with which staff found it most difficult to cope. A third were troubled by children with neurodegenerative disorders because of the slow deterioration in their condition, while a fifth found muscular dystrophy difficult, especially in teenagers, where the child became increasingly physically dependant but remained intellectually intact. A fifth had problems with cancer sufferers because it was 'nearer home', and 12% named uncontrollable symptoms or behaviour as a source of stress.

Secondly, there were parent-related stressors. These included the expression of negative feelings by parents towards each other, their children, or the staff, and parents' occasional unrealistic expectations of staff. Staff also felt stressed by some grieving relatives they seemed unable to help.

Thirdly, came staff communication and relationships. A homely atmosphere (including sharing domestic duties) and the emphasis on open discussion appeared to encourage effective coping strategies to deal with this, including informal staff support, on-the-job training and skills development, formal in-service training, and regular meetings at which business was discussed and feelings were aired. Some staff found their own values and religious beliefs an important support.

Another area of stress was diverse personal factors, including feelings of inadequacy at work and the home/work role conflict. Staff sometimes found it hard to set limits and to 'switch off' when they went home, and expressed some conflict between the Good Samaritan and the professional role. There was no evidence of burn-out, however.

The staff reported levels of psychological and psychosomatic symptoms comparable with general population. Those who were showing more symptoms that the norm had experienced more illness and bereavement in their personal lives over the last year. From 1982 to 1986 each member of staff had only 6.2 days off sick a year on average, and the turnover rates were low: 88% had worked at Helen House for at least 2 years, and over half had worked there since it opened.

The main coping mechanism staff identified was informal support - although staff relationships were seen as stressful they were also a source of much comfort and contributed to the high levels of job satisfaction. As Mrs Winterbottom concluded, it is crucial that staff working in hospices should be enabled and encouraged to develop the skills needed to deal with the issues identified in the survey.

The national survey

The third part of the Helen House studies is a survey to ascertain the incidence of children with chronic life-threatening conditions, how many of them die in hospital and how many at home, and the extent of facilities for respite and terminal care. This, it is hoped, will provide a basis for rational, sound planning of future services. All regional medical officers in England and district medical officers in Wales were contacted by post and asked for information - 'clearly a daunting requirement', said Dr Forrest in her presentation of the results. There was no uniform method of collecting or recording these data and some regions and districts simply could not provide the answers.

Data were requested on the number of children with chronic life-threatening diseases, as defined by the ICD9 codes - concentrating on malignant neoplasms (excluding leukaemia here as it has not been a condition for which parents had chosen to use Helen House), inherited metabolic disorders, cerebral degeneration, cystic fibrosis and muscular dystrophy. Ultimately only two regions and two districts failed to provide any information at all, but some could not give separate figures for children; Hospital Activity Analyses did not distinguish between new patients and readmissions; deaths and discharges could not always be separated; some included children not resident within authority boundaries; and the quality of information about the diagnosis on discharge forms varied enormously.

Turning to the place of death, ten regions and two Welsh districts gave figures, usually for 1984, for children aged 14 and under. 'Hospital' was held to include any hospital, NHS or otherwise, or other institution. On average there were 25 deaths yearly in each region, of whom nearly 18 were from malignant solid tumours. The proportion of children dying at home varied greatly, from 70% in South East Thames to 15% in South West Thames; the mean was 40%. In summary, said Dr Forrest, 'in an average sized region of 3.25 million people, we would expect 25 children to die each year of these chronic life-threatening diseases, 10 at home and 15 in hospital.'

The information on respite and terminal care was also patchy and incomplete. Most regions did not know the details and could give no data on social services, special schools and other non-NHS facilities. The preliminary results showed that some home care was provided through community paediatric nursing teams. Only three regions and two districts reported any form of respite care other than acute paediatric wards, such as cottage hospitals, sitting-in and Marie Curie schemes. Some children might have access to respite care for mentally handicapped people.

'The survey will probably tell us more about what is not known,' Dr Forrest concluded. There was no comprehensive picture, but at least another piece of the patchwork was being identified.

Other people's perceived needs: the case for caution

Key questions about the planning of services on a national scale were also raised by Professor David Baum, professor of child health at the University of Bristol. Although Helen House was 'an oasis of tranquility in a world of performance indicators and management efficiency', caution was necessary in considering the national need for similar facilities.

Professor Baum clarified some different approaches by outlining three models of services, using the familiar metaphor of cake to represent health care. Sometimes it was sliced vertically according to specialties, usually based on an organ of the body such as the kidney, but more often in the UK it was sliced horizontally according to age strata. Children had needs which cut across the slices, and the interfaces with different specialist services such as obstetrics or general adult medicine had to be considered. The slice representing childhood specialties ranged from clinical and curative services to convalescence and primary care.

Some children's services were organised on a regional or even supraregional basis, with specialist centres providing expertise and advanced technology. Over time, though, these might change; neonatal intensive care in the last ten years had developed from being a regional specialty to one available to some degree, at least, in each district. At the other end of the spectrum there were services such as childhood diabetes care, 'in your own neck of the woods', which did not require a regional specialist service.

So where did respite care fit in? It all depended how you sliced the cake and whose needs you intended to meet, Professor Baum said. He envisaged a network of interlinking services with the child's home as the focus, and an emphasis on using the full range of local facilities within and outside the statutory services. This pointed to an obvious difficulty with supraregional hospices like Helen House; the child and family could lose out if links were not made and maintained with local services. Continuity and confidence locally were vital, or the family could become demoralised about local provisions.

Equally, local health workers might feel that their skills were being devalued by referral to supraregional services. Professor Baum feared that hospital paediatrics might become a purely acute, hi-tech service, to the detriment of patient care and staff training.

There was a lot to be said for organising hospice-type and respite services on a local basis, Professor Baum concluded, including domiciliary teams and, perhaps, a wing of a local hospital. 'We should look at the magic of Helen House, not to clone it but to see how we can improve the local model'. In discussion, Dr Burne pointed out that Helen House tried to create links with local services and provide gentle reminders of the children's needs. It was not trying to detract from local services.

Group discussions and conclusions

After hearing the main speakers, participants divided into smaller groups for discussion, reporting back to a plenary session chaired by James Smith, assistant director, long term and community care, King's Fund Centre. They looked at three key questions:

1. Do we really need hospices for children?

2. If there is a need for respite care for children, should such provisions be the monopoly of health services?

3. Are the community, health and social services adequate to support children needing long term care at home?

The reports from the groups showed a remarkable degree of consensus and a strong sense of purpose about the way ahead for the care of children with chronic life-threatening diseases.

* Concern about proliferation of hospices

All the groups reported anxiety about the unplanned proliferation of hospices, and questioned whether it was an appropriate response to the needs of children and families. Professor Eric Wilkes summed up the feeling with his comment on rumoured plans to build three hospices within 15 miles of each other - 'a massive irrelevance'. Everyone agreed that there should be no more Helen Houses unless they were carefully planned, well coordinated and strategically placed; Mother Frances perceived a need for no more than three or four in England and Wales.

* Educating the public

Closely linked with the concern about unplanned proliferation was the feeling that the public - and professionals - needed education about the needs of children and families. Doing something to help dying children had a strong emotional appeal and it was hard to say no to people who wanted to found a hospice; instead their enthusiasm and resources should be used more appropriately. 'We need to deromanticise the idea - and to channel their goodwill to buttress existing provision', Professor Baum commented.

* The philosophy of hospice

Speakers supported Mother Frances' view that hospice was a philosophy rather than a facility. The role of hospices and related services needed careful definition to help identify needs and goals, aiming to provide care which could be tailored to meet the individual needs of children and families. In particular the difference between respite care and terminal care should be clearly understood.

* The need for more and better information

All the groups deplored the national and local lack of information needed to help plan services. What happened to the information collected for district reviews? asked Mr Smith. Clearly there was a defect in the system. One group suggested a strategy for collecting information: more information was needed about the numbers of children, with a local understanding of what services were available. A named person or unit could be made responsible for collating local data and sharing it with other districts, perhaps working closely with NHS unit general managers. Professor Baum saw a role here for the hospice movement, with the need for national coordination and an overall plan for the NHS. Another group proposed the establishment of a central, independent body with lay and professional representatives to collect and share information, educate the public and veto inappropriate schemes.

* The need for careful planning

Obtaining the information base was the essential first stage in planning, speakers agreed. The next step was to assess what the true needs were, above all through listening to what children and parents wanted; they were the real experts and professionals should resist the temptation to take over. Although the families coming to Helen House might be a self-selected group who experienced particular problems with local services, there was a clear need for a general improvement in most local facilities and services. What were those parents and children seeking which they could not find locally? A variety of objectives was suggested:

- Respite care for holidays and at night.
- Support and advice, available 24 hours a day as a back-up for families.
- A homely, non-hierarchical, non-institutional approach to care in hospitals.
- Better community services (although some hospice provision would still be needed).
- Choice for children and families, enabling them to die at home if they prefer but letting them make the decisions and respecting their choices.
- Development and coordination of local services across the board.
- Good communication between all the services involved.
- An emphasis on sharing care and expertise through the mutual exchange of skills between children, relatives and professionals.

*   The role of the NHS

Many people were concerned about the role of the NHS in relation to independent facilities like Helen House. Did they absolve the NHS of the need to seek local improvements, or did they enrich the statutory services with new ideas and fresh thinking untrammelled by bureaucracy? It was agreed that hospices should not be seen as equating with NHS provision, nor should they detract or take over from it. However, staff in general hospitals were often unable to provide respite care because of the pressure of acute medicine, while doctors and nurses in hospitals and the community needed more and better education on the needs of dying children and symptom control. There should also be expert teams to back up the primary health care services.

*   Other models for care

Various suggestions were made for different forms of care. Facilities associated with a local hospital were thought to be difficult to organise. There was agreement on the importance of community care, either based in primary health teams or as hospital outreach services, and on the need for continuity, with the general practitioner playing a key role. Fostering children for short periods was another suggestion.

Several comments were made on the appalling shortage of facilities for the young chronic sick. Dr Forrest described the huge variation in the number, type and flexibility of services for the over-16s. Where such facilities existed they were often oversubscribed, leading to distressing solutions - such as respite care for an adolescent in a psychogeriatric ward. Helen House had been asked to help a woman of 22 who was depressed at being cared for in a hospice where most of the patients were elderly. The needs of long-term chronic as well as short-term terminal patients must be given greater attention.

A need in a sick society?

Mother Frances rounded off the day with the sobering thought that hospices were in one sense an indication of a sick society, where people lacked family, friends and neighbours to support them in caring for their ill children. While some families had such support, many others did not, and what Helen House offered above all was 'a preparedness to stay alongside them through the loneliness and isolation'. But as James Smith stressed, enabling a child to have an 'ordinary', 'normal' life and death required much skill. There was plenty of goodwill, emotion and even money, but little established knowledge; now was the time to evaluate the activities and make plans for the future based on a careful, cool and rational assessment of what children and their families really wanted and needed.

Further reading

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Helen House News

A regular newsletter is available about Helen House. For details write to Helen House, 37 Leopold Street, Oxford OX4 1QT. Tel: 0865 728251.

Table 1

Diagnostic Categories of 117 children admitted to Helen House between November 1982 and January 1986

Cerebral tumours	9%
Other malignant disease	9%
Mucopolysaccharidoses	17%
Other metabolic disorders	3%
Neuro-degenerative disorders	23%
Other C N S disorders	13%
Congenital disease	9%
Chromosomal disorders	2%
Multi-system disorders	2%
Auto-immune disease	1%
Neuro-muscular disorders	12%

Table 2

Reasons for admission in 268 admissions in 1985

Pain	2%
Control of other symptoms	8%
Terminal care	2%
Parents unable to cope	5%
Respite care	83%
Other	9%

Table 3

Symtoms most commonly encountered in 268 admissions in 1985

Pain	11%
Urinary incontinence	45%
Faecal incontinence	23%
Seizures	33%
Visual loss	30%
Hearing loss	12%
Excess secretions	10%
Feeding problems	21%
Tube fed	12%
Constipation	23%
Dyspnoea	12%
Cough	8%
Muscle spasm	20%
Muscle weakness	28%
Extrapyramidal symptoms	13%
Oral problems	8%