MEDICAL PRACTICE

Contemporary Themes

Helen House—a hospice for children: analysis of the first year

S R BURNE, FRANCES DOMINICA, J D BAUM

Abstract

Helen House, a hospice for children, opened in Oxford in November 1982. From then until December 1983 care was provided for 52 children with terminal illness, progressive and incurable illness, and very severe handicap. The children came from a wide area of the United Kingdom, and eight died during the year.

The style of care provided in Helen House is based on that of the families in their own homes, with a minimum of rules, regulations, and routines. Terminal care follows the principles developed by hospices experienced in the care of adults. Despite the great sadness and distress associated with every child admitted, Helen House is neither a sombre nor a depressing place.

Introduction

Death in childhood from incurable illness is rare. Nevertheless, several conditions exist that still lead to the death of children despite the best efforts of modern medicine (table I). The terminal care of such patients may be provided in an acute hospital bed or in the child's home. Similarly, children with chronic life threatening diseases may receive occasional respite care in a paediatric ward between spells of care provided at home. Nevertheless, many families find that the stress and dislocation to their lives that result from constantly caring for such children at home are more than they can tolerate, and yet find the provisions of institutional and community care inappropriate or insufficient.

For these reasons it was considered desirable to establish a hospice designed specifically to meet the needs of children with incurable or terminal disease. Detailed accounts of the events leading up to the foundation of Helen House have been reported elsewhere.[1-4] Here we report the work of Helen House from its opening in November 1982 to December 1983.

TABLE I—*Deaths from selected chronic diseases in children aged under 15*

Clinical diagnoses	England and Wales* 1981	Oxford region† 1980
Malignant neoplasms:		
Solid	252	16
Lymphomas and leukaemias	219	19
Spina bifida	321	14
Multiple congenital abnormalities	155	14
Cystic fibrosis	84	3
Cerebral palsy	42	3
Werdnig-Hoffmann disease and spinal muscular atrophy	36	3
Atresia of bile ducts	23	
Central nervous system degenerative disease	15	
Muscular dystrophy	13	1
Mucopolysaccharidoses	11	
Total	1171	73

Sources: *Office of Population Censuses and Surveys. † Oxford Regional Health Authority.

Facilities and staffing

Helen House was purpose built within extensive gardens. It provides accommodation for eight children at a time in single rooms. Two double bedrooms are provided for the use of parents. The whole design is bright, open, and airy and as "home like" as possible. At least one trained children's nurse is on duty at all times. Other staff include two teachers, a social worker, nursery nurses, and a part time physiotherapist.

No staff are employed as cleaners or cooks as all members of staff share these duties in a flexible manner. Medical care is provided by a

Helen House, Oxford OX4 1QT

S R BURNE, MB, MRCGP, medical director

All Saints Convent, Oxford OX4 1RU

MOTHER FRANCES DOMINICA, RSCN, FRCN, mother superior, Society of All Saints

John Radcliffe Hospital, Oxford OX3 9DU

J D BAUM, MD, FRCP, clinical reader in paediatrics

Correspondence to: Dr S R Burne.

general practitioner working part time in Helen House. All staff salaries are paid from an investment fund raised by public appeal.

The parents of one child who died in Helen House wrote an open letter, which described the atmosphere of Helen House in the following words: "As soon as we saw the bright new buildings, the cheerful faces, the beautiful furnishings and tempting toys, we knew that here was a place where Martin would be well cared for, our elder son would have fun, and we would have a rest. It soon felt as if the staff shared our problems and it lightened our burden."

Children: initial contacts

In the 13 months from November 1982 to December 1983 we were contacted about the possibility of admission of 128 children. Some of these had non-life threatening illnesses, moderate handicap, or treatable conditions; these children were not considered to be appropriate for hospice care. A few were seeking long term residential care, which we are not able to provide. Eight children whose admission might have been appropriate died elsewhere before the necessary arrangements could be made. Fifty two children were admitted and form the basis for this report.

The initial inquiries about these children came from a variety of sources. The largest group were parents (19), while general practitioners (five) and consultants (11) together referred just under a third of the children; various other professionals referred the remainder (social worker, five; health visitor, four; other professional agencies, eight). After the initial contact we satisfied ourselves that the family had been properly informed about Helen House and wished to proceed further in seeking hospice care for their child. We also ensured that the child's doctor was in agreement with the referral and was willing to provide the appropriate and essential medical details.

Admissions policy

After the initial contact and with the agreement of the general practitioner we considered the child's suitability for hospice care based on the reports made available to us. In some cases hospice care was thought not to be appropriate and these families were so informed. In other cases the family was invited to visit Helen House, see the facilities, discuss the additional help we were able to offer, and, where appropriate, make plans for the child's first admission. Valuable extra information about some children was obtained by arranging for a member of staff to visit the family in their own home.

Decisions on suitability for admission were taken jointly by the medical director and the head nurse in consultation with other members of the staff. Children in need of terminal care were given first claim on the facilities. Second priority was given to children with severe long term illnesses who were normally looked after at home but whose parents were seeking a period of respite care. Care was offered by agreement at planned intervals or to cover periods of crisis. The 52 children accepted for admission were classified into three categories: (1) those requiring terminal care; (2) those with progressive and invariably fatal conditions; and (3) those with permanent severe handicap requiring substantial nursing care.

Children admitted

Table II lists the clinical diagnoses of children admitted. The largest group consisted of children with central nervous system disorders; of these, 10 had degenerative diseases and 11 non-progressive permanent damage. Children with mucopolysaccharidoses formed the second largest group. Eight children suffered from neoplastic disease, of whom four died during 1983. Thirty two of the children were so severely handicapped or ill as to be totally dependent on others; most of these very disabled children had disorders of the central nervous system (18) or cerebral tumours (four). The children ranged in age from 3 weeks to 18 years. They came from a wide variety of backgrounds: 12 had parents in professional occupations, 13 had parents who were unskilled or unemployed, and 27 had parents who were in skilled or semi-skilled employment. Seventeen children had homes within 10 miles of Oxford while 20 travelled over 50 miles; six of these children had homes over 100 miles away.

TABLE II—*Diagnosis in children admitted to Helen House, November 1982-December 1983*

Central nervous system		*Neoplastic*	
Batten's disease	3	Cerebral tumours	5
Congenital cerebellar ataxia	1	Rhabdomyosarcoma of palate	1
Ataxia telangectasia	1	Neuroblastoma	1
Leigh's necrotising encephalopathy	1	Non-Hodgkin's lymphoma	1
Other degenerative brain diseases	4	*Congenital abnormalities*	
Cerebral palsy	6	Patau's syndrome	1
Congenital hydrocephalus	2	Edward's syndrome	1
Cerebrovascular accident	1	Biliary atresia	1
Postmeningitis brain damage	1	Pulmonary atresia	1
Mental retardation	1	Multiple congenital abnormalities	1
Mucopolysaccharidoses		*Neuromuscular*	
San Fillipo's syndrome	5	Duchenne muscular dystrophy	4
Hurler's syndrome	2	Werdnig-Hoffman disease	2
Hunter's syndrome	1	*Cystic fibrosis*	2
Type VI mucopolysaccharidosis	1	*Fanconi's anaemia*	1

Family health

A questionnaire was completed for 38 children admitted in the first six months. From this it appeared that apart from the problems directly related to the ill child many of the families faced other serious worries. Marital difficulties were described in 10 families, and seven had substantial problems with the physical ill health of one or both parents. Psychological problems were reported in 25 of the mothers and in seven siblings.

The questionnaire also asked for an assessment of the child's previous health care. Half the families considered the previous care they had received in hospital or from their general practitioner to have been good or very good; two families rated previous hospital care as bad or very bad; while six families were dissatisfied with the care given by their general practitioner. A fuller analysis of this questionnaire is being published elsewhere.[5]

Care provided

During the period under consideration there were 220 admissions of 52 children (table III), with an average of 4·2 admissions per child. Fourteen children were admitted once only. Three children had more than 10 admissions, one of whom was admitted on 23 separate occasions. The eight beds in Helen House were open for 404 nights before 31 December 1983. In this time 1417 nights of care were provided out of a possible total of 3232 nights available; this amounts to a bed occupancy of 44%.

TABLE III—*Helen House: admissions November 1982-December 1983*

	No of children	No of admissions	Total nights stayed	Admissions per child	Nights per child
Terminal care	6	17	93	2·8	15·5
Progressive illness	30	126	903	4·2	30·1
Severe handicap	16	77	421	4·8	26·3
Total	52	220	1417	4·2	27·3

One child with Batten's disease had severe problems with prolonged convulsions and dementia requiring frequent and prolonged admissions. She spent a total of 167 nights in Helen House. No other child received over 100 nights' care, the average being 27·3 nights per child.

In addition to care provided for the children during admissions the staff offered regular contact with the families by telephone or letter or through home visits. During the second half of 1983 over 1000 informal contacts were recorded and 33 families were visited at home. At least one member of staff attended the funerals of the eight children who died. Close contact has been maintained with the bereaved families.

One or both parents stayed with their children during the initial admission and during admissions for terminal care. At other times the use made by parents of the accommodation reflected their wishes and the needs of their child. From time to time healthy siblings, grandparents, other relatives, and some pets also stayed at Helen House.

Terminal care

Eight children received terminal care in Helen House (table IV).

TABLE IV—*Details of children receiving terminal care in Helen House, November 1982-December 1983*

Diagnosis	Age (years)	No of admissions	Miles from home
Batten's disease	14	8	170
Medullablastoma	12	5	120
Hurler's syndrome	11	2	20
Rhabdomyosarcoma	7	3	50
Neuroblastoma	5	3	30
Non-Hodgkin's lymphoma	4	1*	80
Hurler's syndrome	2	1†	80
Edward's syndrome	3 months	3	1

*Died in paediatric ward after platelet transfusion.
†Died in hospital after bone marrow transplant.

Four of these had malignancies, three had progressive degenerative conditions, and one had a chromosomal abnormality with associated severe cyanotic heart disease. One child with Hurler's syndrome, who was receiving relief care was offered a bone marrow transplant and died in hospital after this procedure. The child with lymphoma was receiving terminal care; he was transferred to an acute paediatric ward for a platelet transfusion but died before he could return to Helen House.

Our experience of managing the terminal care of children is illustrated by the following two brief case histories.

CASE 1

A boy of 12 with recurrent medulloblastoma was referred to Helen House by his general practitioner for relief care. During his first two admissions in November 1982 and February 1983 he was suffering from increasing ataxia and diplopia but required no regular medication other than dexamethasone. He was also suffering severe and embarrassing flatulence, which was eventually controlled with charcoal biscuits.

During a further admission in April 1983 he started to suffer pains in the head, which were not relieved by full doses of paracetamol or Distalgesic. His dexamethasone was increased and oral morphine sulphate 5 mg every four hours started. This was increased to 10 mg every four hours and gave good relief of his pain.

Apart from one brief visit he remained at home from April to July, when he was readmitted. He was bed bound, paraplegic with gross ataxia, cushingoid, vomiting, and in pain. His regular morphine sulphate was resumed, and again 10 mg every four hours was found to control his pain. Vomiting was controlled with domperidone 10 mg every eight hours. His dexamethasone was stopped. For several days he slept a great deal, but by the eighth day of his admission he was awake, alert, and able to sit out in a chair. This improvement was maintained for four days, during which time he was sociable and appeared to enjoy life. He then lapsed into unconsciousness. All drugs were stopped apart from intramuscular diamorphine and a single dose of hyoscine to relieve excess secretions. He died peacefully on the 14th day of his admission.

CASE 2

A girl aged 13, whose home was 170 miles away, had been diagnosed as suffering from Batten's disease at the age of 7. She was blind and suffering from dementia and epilepsy. The only available relief care locally was a psychogeriatric bed. Her parents contacted Helen House and regular relief care was arranged. During one admission she had several prolonged seizures punctuated by periods of severe dementia. This admission was extended to nine weeks before reasonable control was re-established. Regular relief care was continued for 10 months from the time of her referral. Owing to her progressive deterioration additional admissions to another nursing home were arranged. During the first visit to this home she developed status epilepticus, which failed to respond to high doses of paraldehyde and diazepam. It became apparent that she was terminally ill and she was transferred to Helen House, where she died peacefully.

Relief care

Most children admitted to Helen House came for some form of relief care either on a planned basis or to enable the family to cope with some crisis. The range of conditions and family circumstances are illustrated by the following two case histories.

CASE 1

A girl aged 12 had suffered severe and prolonged convulsions at the age of 2 months. Over the next five years she was extensively investigated and received a wide range of treatments, which were ineffective in controlling her frequent fits. She remained grossly handicapped with severe brain damage and uncontrollable epilepsy. She had severe kyphoscoliosis and recurrent chest infections. She was normally looked after at home by her mother with little outside help. During the year she had nine separate admissions totalling 75 nights.

CASE 2

A boy aged 12 suffering from degenerative brain disease was normally well cared for and supported at home. His mother had long wished to visit her family in America but had been unable to find any form of relief care other than an acute hospital ward to provide the necessary nursing cover. He was able to enjoy a one month holiday in Helen House while his mother visited her relatives.

Discussion

Helen House was founded in response to a pressing need expressed by a few families. Subsequently, in the first year after Helen House was opened, the parents of children admitted were asked for their assessment of the care they had previously received from the general practitioner and hospital services; most did not complain about their previous treatment but were seeking something different, outside the present provisions of the health service. Though we believe that whenever possible a child with an incurable illness should be cared for at home, some families cannot cope and seek admission of their child to a familiar children's ward. Helen House provides an alternative form of care for those who prefer to look after their child at home but are unable to do so continuously and yet find an acute hospital ward inappropriate to their needs.

The care that has been provided for terminally ill children in Helen House has been influenced by the work of hospices caring for adults[6 7] as well as other reports[8-13] and the personal advice of many nursing and medical colleagues. Priority is given to the relief of distress, which must be evaluated in emotional, social, and spiritual terms as well as physically. Any drugs necessary are reviewed frequently with the intention of relieving symptoms while avoiding undesirable side effects. Nevertheless, much still needs to be learnt about the control of symptoms in terminally ill children and we hope that the experience concentrated at Helen House will provide an opportunity to investigate this. In addition to symptomatic treatment of the children Helen House has tried to offer care for the whole family. The house appears to provide a framework within which the healthy brothers and sisters can express some of their thoughts, fears, and fantasies about illness and death. After a child's death continuing support has been offered and accepted by the family in their bereavement.

The bed occupancy of 44% was higher than had been expected in this first year. For the future we estimate that an overall figure of 60% might be optimal for two reasons. Firstly, it is important to retain the capacity to accept children in need of terminal care or in a crisis at very short notice. Secondly, we need to safeguard "time," which is the most valuable commodity of the house, enabling the children and their families and the staff to have unlimited opportunities to talk and listen.

Although Helen House developed outside the National Health Service, we believe that close liaison with both the hospital and the community services is essential. The design and functioning of the house were empirically based, and the full size and scope of the problem both regionally and nationally are to be determined. It would seem prudent to await the results of research into the magnitude of the problem, the range of facilities currently available, and the best ways of dealing with the needs of such children and their families before planning similar developments elsewhere.

We thank the many people at Helen House who have given their time and energy to the work described here.

References

1 Burne SR. Hospice care for children. *Br Med J* 1982;**284**:1400.
2 Farrow G. The soothing touch. *World Medicine* 7 Aug 1982: 39-42.
3 Mother Frances Dominica. Helen House—a hospice for children. *Maternal and Child Health* 1982;7:355-9.
4 Burne SR. A hospice for children in England. *Pediatrics* 1984;**73**:97-8.
5 Dorkins E, *Helen House. Oxford Medical School Gazette* (in press).
6 Saunders CM, ed. *The management of terminal disease.* London: Edward Arnold, 1978.
7 Smith T. Problems of hospices. *Br Med J* 1984;**288**:1178-81.
8 Chapman JA, Goodall J. Helping a child to live whilst dying. *Lancet* 1980;i:753-6.
9 Chapman J, Goodall J. Symptom control in ill and dying children. *Maternal and Child Health* 1980;5:144-54.
10 Cotton M, Cotton G, Goodall J. A brother dies at home. *Maternal and Child Health* 1981;**6**:288-92.
11 Burton L, ed. *Care of the child facing death.* London: Routledge and Keegan Paul, 1974.
12 Bluebond-Langner M. *The private worlds of dying children.* Princeton: Princeton University Press, 1978.
13 Gyulay J. *The dying child.* New York: McGraw Hill, 1978.

(Accepted 26 September 1984)

On the state of the public ill health: premature mortality in the United Kingdom and Europe

JOHN C CATFORD, SHERRY FORD

Abstract

Recently published data on mortality in the European Economic Community and Scandinavia convincingly showed that mortality among men and women aged 45-64 was considerably higher in the United Kingdom than elsewhere. This applied to deaths due to circulatory and respiratory disease, cancer, and all causes. For example, in 1980 in Scotland twice as many, or more, women aged 55-64 per 100 000 died of heart disease than in Belgium, Denmark, France, Greece, West Germany, the Netherlands, Norway, and Sweden. Reductions in mortality from all causes during 1950-80 in the United Kingdom did not match those in other countries, such as Finland and France. Whether the public in the United Kingdom knows about its relatively poor mortality state is doubtful. To secure improved funding of appropriate preventive and treatment services directed at reducing premature mortality, public awareness should be raised urgently so that politicians and political parties will respond quickly in a way that the problem demands.

Introduction

Sir Richard Doll in his Harveian oration concluded that medical knowledge had advanced sufficiently that few people need die of disease before the age of 70.[1] In the United Kingdom it might be thought that such is the case. No particular mention is made in the annual reports of the Chief Medical Officer of the Department of Health that the United Kingdom is experiencing very much worse mortality than its European neighbours.[2] Acute hospital services, which are in the front line for treatment to avoid premature death, were considered by a royal commission in 1979 to be "generally excellent."[3] Furthermore, there appears to be little public concern about premature death related to disease, and what interest there is in mortality seems to focus on deaths from violence, suicide, and unusual types of accidents and deaths in infancy. Of the population over the age of 55, only 3% are seriously worried about having a heart attack (Health Education Council, unpublished observation, Heart Disease Royal Society of Great Britain Omnibus Survey 1981) and 87% are either satisfied or very satisfied with the care available for themselves and their families from the National Health Service.[4] The high degree of satisfaction with the NHS has again been borne out by a recent survey of the Health Education Council and Consumer Association (unpublished observation, 1984), which showed that 83% of people considered themselves to be very or reasonably healthy and 20% could not think of one thing to improve their own health.

We set out to examine how the UK compared with the rest of Europe as judged by the avoidance of death between the ages of 45 and 64. This age group accounts for more than two thirds of all deaths under the age of 65 and is clearly a priority group because its members are usually economically productive and have dependent members of their family, both younger and older, to care for.

Method

The age, sex, and cause specific death rates for 1950 and 1980 were obtained for as many countries as possible in the European Economic Community and Scandinavia. Publications from the World Health Organisation (WHO) giving yearly epidemiological data and vital statistics were studied, and when data were not available approaches were made direct to the WHO or the countries themselves. Suitable data were obtained from the International Classification of Diseases (ICD) chapters for men and women aged 45-54 and 55-64 in 12 countries: Belgium, Denmark, England and Wales, Finland, France, West Germany, Greece, the Netherlands, Northern Ireland, Norway, Sweden, and Scotland. The validity of this type of information from the above countries has not been questioned,[5] and major misclassifications between ICD chapter headings are unlikely. We could not obtain data for 1980 for the Republic of Ireland or Italy. These countries were therefore excluded from this report, as was Luxembourg because its population is less than 400 000. International comparisons were made over time and for groups of diseases. Only the major findings are reproduced here.

Wessex Regional Health Authority, Winchester SO22 5DH

JOHN C CATFORD, MRCP, MFCM, regional specialist in community medicine
SHERRY FORD, MB, DCH, registrar in community medicine

Correspondence to: Professor J C Catford, University of Wales College of Medicine, Heath Park, Cardiff CF4 4XN.