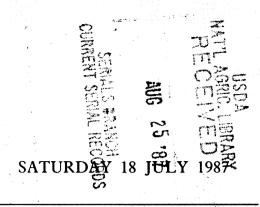
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  receive several on the same subject.

## Hospices for children?

SIR,—As the mother of a terminally ill child with a degenerative brain condition, I should like to add a personal dimension to the debate about hospices for children.

As pointed out by Mr T L Chambers (23 May, p 1309), there are only a few cases of neuro-degenerative diseases a year in a health district, and thus a hospice in every area would be impracticable. If, however, there was a hospice to serve, say, the south, as with Helen House, and one to serve the north, as with Martin House, they would draw from a larger area and therefore increase the likelihood of patients with similar degenerative disorders being brought together. This would eliminate the isolation felt by the families of such children and establish a point for comparing notes on care.

Through Martin House, which will open in August, we are already in contact with two other families with children suffering from metachromatic leukodystrophy—one only 30 miles away. It is a great comfort to find a family who understand your suffering and to be able to compare treatment. As a result of such comparisons, the consultant responsible for one child was persuaded (against his better judgment) to administer diazepam, which had been prescribed successfully for another child. As a result, the child's stressful symptoms resolved, his mother relaxed, and the consultant was surprised and pleased.

The children's hospice differs from an adult one in that it intends to provide only relief and respite care to help families to continue looking after their children, for the most part, at home.

I love my daughter and want to care for her myself at home for as long as possible. She is in the fifth year of her illness. She has not been able to walk or talk for all of that time and has been like a baby for two years, needing constant supervision.

Nursing her becomes more difficult, with erratic sleeping and the constant need to move her to prevent bed sores.

I realise I am luckier than some mothers. My two other children are teenagers and therefore fairly independent. They understand why I become exhausted and they help me. If I had younger, more demanding children the situation would be intolerable without extra support. Furthermore, we have only one affected child, but other families have two or more.

I become angry when people who are fortunate enough not to have such children say what is needed for parents like me and our children. We do not want to shirk our responsibilities but perhaps just to share the care in the loving atmosphere of a hospice, where the child's routine would not be affected, whatever his or her individual timetable, and the parents could have total responsibility for the care of their child if they so wished. Other members of the family are also encouraged to stay, or the child might stay for a short time while the parents refreshed themselves and spent time with other children in the family.

In her closing remarks, Dr Valerie Broadbent (13 June, p 1548) seems to imply that hospices for children are diverting funds from home care. On the contrary, they provide physical and psychological strength for more parents to continue caring for their sick children at home, probably saving the much larger sums that would be needed for full time hospital care. The strain of caring for a totally dependent child for the past four years has been greatly eased by the knowledge that Martin House hospice will soon be available should we need it.

Surely hospitals can cooperate with hospices and not see them as rivals, for all that is really important is to make what little time the child has left as comfortable, happy, and loving as possible and to support the family so that it can continue to this end. The hospice will also be there to support the family after the child's death for as long as is necessary.

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SIR,—As directors of Martin House hospice we share the concern expressed recently by some paediatricians in this journal that the generous public response to financial appeals may result in overprovision and maldistribution of children's hospices in Britain. Unfortunately the term hospice is misleading and we are equally concerned that some doctors and many members of the public have not fully appreciated the role of such units for children.

We envisage Martin House as being the nucleus of a service in the north of England attempting to provide respite care for physically and emotionally drained children and their parents. Such families require medical, nursing, and sometimes spiritual support, which although offered in some oncology units is not so readily available in some district paediatric departments responsible for the care of children suffering from slowly progressive incurable non-neoplastic diseases. Help before and after bereavement does not exclude but often facilitates real terminal care in the home and often encourages families to share their grief with understanding staff by revisiting the hospice after their child has died.

The problem is to strike a balance between hospice and other forms of care, remembering that the two may often be complementary. Martin House will open in mid-August, but our care team has for some months been working with families. These families are eager to make use of our