

## *Personal practice*

# Care by parents of their children in hospital

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**SUMMARY** A care by parent option was introduced into a general paediatric ward without any additional finance or facilities. Most parents coped successfully and were grateful for the opportunity of caring for their children. All believed that their children benefited from their active involvement. The nurses believed that their role was enhanced and their job satisfaction increased. This system offers advantages and could become more generally used in paediatric wards in Britain.

When hospitals were first built they were slow to open their door to sick children. Once the concept of hospital care of children was introduced parents were excluded from seeing their children except at infrequent intervals. This began to change after the late Sir James Spence started the policy of admitting mothers with their children about 1925.<sup>1</sup> This policy became more general in the late 1950s, and by 1959 the Platt report on the welfare of children in hospital recommended that there should be unrestricted visiting of young children, together with accommodation for parents who would wish to stay with them.<sup>2</sup> This practice is now widespread, and whereas the original policy was to encourage the mothers of small babies to be resident, this has now changed, and much older children can have parents resident with them. The National Health Service has been slow to make appropriate accommodation and facilities available for parents who suffer privations gladly to be with their children.

There are, however, many problems encountered by resident parents, which have been well described by Meadow.<sup>3</sup> Sometimes, the parents find it irksome to be with their child in the same cubicle continuously. They may resent nurses caring for their child, they may become bored, and some give the appearance of being lazy, unduly inquisitive, or threatening, especially to junior nurses. The logical solution to these problems is for the parents to be the care givers for their children. This is the natural situation for the sick child within the home. It is the inevitable situation in those parts of the world where health

care is at a premium and has been developed because of its natural appeal in certain parts of the United States. The care by parent system clarifies to the parent his or her role, gives them an active participation and responsibility in the healing process, and conceptually has much to commend it. The child's need of his parent is greatest when he is ill, and the sicker he is the more constantly he requires his parents.

The care by parent scheme frees the nurse to give her greater attention to the sick children with complicated nursing needs. The application of modern technology to medicine can be time consuming, so that each nurse finds that she can only deal with a smaller number of children. The scheme, furthermore, allows the nurse to be free of some of the simpler nursing procedures and enables her to undertake the superior role of advising and counselling mothers and fathers as well as their children. She becomes a health educator.

The care by parent system is claimed to reduce the emotional stress on the child and the family during admission to hospital, reduce the incidence of cross infection, and shorten the period in hospital, consequently minimising behaviour disturbances after admission to hospital.<sup>4-7</sup> The improved communication between the professionals and the parents is helpful to both parties; better health education decreases the likelihood of readmission. The obvious advantages of the care by parent system prompted the staff at the University Hospital of Wales to see whether the system could be intro-

duced into a general paediatric ward, as the prospect of having a special unit built was extremely remote. This paper presents the results of our experience of care by parents, as seen by the medical and nursing professions and the parents themselves.

### Patients and methods

The children are nursed in cubicles, which have folding beds and a small wardrobe or bedside locker for the parents. There is a communal sitting room (and television) for the parents, together with a bathroom, toilet, and kitchen. Smoking is not permitted in the ward. Meals are obtained from the hospital canteen.

After the admission of their child to the hospital, all parents were asked if one of them wished to be resident. Resident parents were informed about the care by parent scheme by the ward sister, if she considered that their child's condition was suitable, and that they would be capable of a satisfactory standard of care. Those who were interested were given literature, which, in addition to giving the usual general information about the hospital, also explained what parents would be able to do if they wished to join the scheme and how they could be helped. If the parents agreed they were given appropriate instruction relating to their own child and support by a specially designated nurse, usually the ward sister or staff nurse.

Parents were expected to be responsible for all the daily routine care of their child, such as feeding, bathing, nappy changing, and supervision of play. In addition, instruction was given by a designated nurse concerning general nursing care. This included measuring and recording vital signs, collecting specimens, giving drugs, charting all information, and accompanying their child for special tests. When specialised nursing procedures were required, such as care of intravenous infusions and nasogastric feeding, parents were asked if they wished to learn the techniques. If they did then they were taught accordingly.

Parents were encouraged to undertake all nursing procedures, but they were only allowed to proceed by themselves if their nurse considered them to be competent. The nurse undertook any procedures that parents could not or would not do, until such time as they were proficient and confident.

The ward sister was responsible for the overall supervision. A nurse on each shift was designated to look after, teach, and supervise the children and their parents. The nurse, patient's cubicle, and records were all made easily identifiable by a colourful, attractive motif by which all the staff were

able to recognise which children were being cared for by their parents.

Medical management continued in the usual way, but the members of the various teams were aware that the observations and records were being performed by the parents, under supervision. For the purposes of the initial study the parents were also seen by a senior registrar (CS/PHR), not normally involved in their care, to discuss the care by parents scheme.

The care was evaluated in three ways. Medical information relating to diagnosis, management, and family structure were recorded. The parents completed a questionnaire in which they recorded what they had done, difficulties they encountered during the admission, and how they felt about their role. The designated nurses also completed, at discharge, a questionnaire concerning the abilities of the parents, difficulties encountered, and how they felt about their role.

### Results

**The patients.** Thirty two families entering the scheme were studied, thirty of whom continued the care until the time of discharge. One mother was withdrawn because of lack of ability, and one mother discharged herself and her child against medical advice.

All the patients were aged under 3 years, and 23 were under 1. Thirty had been admitted as emergencies for observation, investigation, or treatment, and two were electively admitted for investigation. Information on the families is shown in Table 1.

The resident parents consisted of 29 mothers, two fathers, and one grandmother. Eighteen other fathers cared for the children for considerable periods to allow the mothers a break.

Most of the children were subjected to blood tests (24), x ray films (18), urine collection, and swabs from the nose and throat. Stools were collected from six children, and cerebrospinal fluid from three. Other specialised tests included computed axial

Table 1 *Social data of the patients' families*

Marital status:	
Married	27
Single	4
Separated	1
Maternal age	
<17	0
17-21	11
21-30	12
> 30	9
Other children at home	13
Previously resident in hospital	15
Previous nursing experience	6

tomography (two), valvogram (one), electroencephalography (one), echocardiography (one), and cardiac catheterisation (one).

Management was usually simple and consisted of simple nursing care (including oral rehydration therapy), oral medicines, or treatment with nebulisers. In addition to the medical and nursing care, two of these patients received surgery, and together with another child with severe hydrocephalus, required a prolonged stay in hospital. The mean duration of admission to hospital for the other children was 4.4 days. Thirteen were considered to be wholly recovered at the time of discharge, 14 were to complete their recovery at home, and the remaining five had recovered from their acute illness but had other chronic persistent problems.

**The parents.** The views of 31 families were obtained. All expressed approval of the scheme, albeit experiencing anxiety at the beginning. The immediate access to the nurse adviser was critical to the success and deemed necessary by every parent.

Table 2 indicates the skills attempted. The surprising finding that parents encountered difficulty with taking temperatures was due to the facts that the routine was to take the rectal temperature and also that some parents initially found the thermometer difficult to read. Twelve parents were present on the ward with their child during the total admission to hospital, and 20 were only absent for short breaks, mainly for meals in the canteen.

All parents said that they and their children benefited from the scheme. They felt greater confidence about the care and progress of the child and believed that the child was happier and ate and slept better than if they had not been present. All parents stated that they had kept the charts meticulously. They believed that the scheme would reduce the incidence of cross infection between children and were grateful for the privilege of being involved with

their child's care as part of the team, believing that the experience would enable them to cope better with their child's future illnesses. The fact that they were busy with their child helped to eliminate boredom and to promote good relationships with the nurses and doctors. The only negative comments concerned the amenities, such as inadequate kitchen facilities, the excessive distance to the canteen, the small size of the room, and the hospital noise. It did not stop them saying that they would wish to use the scheme on any subsequent occasion.

The 15 parents who had had previous experience of being resident with their child in hospital were emphatic that they found being actively caring and responsible for their child was preferable to just being resident.

**Hospital staff.** The ward sister was responsible for counselling the parents and deciding whether to offer the scheme. Two parents were not given the option because it was deemed that they would not be able to participate for social and emotional reasons. In some instances where the child was very sick on admission the parents were not involved until sufficient improvement had occurred to enable the nursing staff to reduce their professional input.

The nurses considered that the parents performed the tasks satisfactorily in 30 out of the 32 cases. In 15 instances they considered that the standards were in fact better, in two cases worse, and 13 cases of the same standard as would have occurred had the children received the usual ward care. The nurses believed that their relationships with the parents were better than in the traditional method and enjoyed their teaching and supervisory roles in 30 of the 32 cases. They found that it was not difficult to teach the parents the skills required.

## Discussion

Care by parent units have been operating successfully in North America for many years.<sup>8-12</sup> These original units were purpose built, and the parents were required to perform the total nursing care of their child with minimal nursing input. Recently in these units, however, there has been a move towards having a greater nursing presence to help and advise the parents.<sup>13</sup> Although it has been thought to be preferable to have a special unit and staff for the care by parent concept, we have shown for the first time that it is possible to operate the system on a standard paediatric ward with no additional finance or facilities.

In view of the success of the initial trial it was decided to introduce the scheme as part of standard care. This has now been continuing since the

Table 2 *Procedures attempted by the parents in their caring role and their success*

<i>Procedure</i>	<i>Success</i>	<i>Initial difficulty</i>	<i>Failure/refusal</i>
Temperature	27	3	5
Pulse rate	25	4	7
Respiratory rate	24	1	8
Charting (feeding, vomiting, bowel motions)	29	0	3
Collecting urine	10	0	0
Collecting stool	4	0	0
Giving drugs	18	2	3
Nebuliser treatment	5	0	0
Care of intravenous infusion	3	0	1
Topical treatment	1	0	0

summer of 1984 on both the infant (less than 1 year) and general medical children's wards. In practice, the scheme has proved more successful on the infants' ward, where more parents are resident. On this 14 bedded, fully cubicalised unit the number of children being cared for by their parents ranges from none to five at any one time. Sixty per cent of the children would have a resident parent. The main reason that more parents are not involved relates to the often very short duration of the period of admission to hospital, when it is found that by the time the busy nursing staff have spoken to the parents specifically about care by parents, then it is time for that child to be discharged. For longer admissions, however, the scheme has proved more valuable, the parents having sufficient time to learn and use their skills. Ideally, of course, it would be desirable for every parent to be made aware of the scheme at the time of their child's admission, and to become involved in the care within the first day of the child's admission, but in practice this has not happened because of all the demands on the nurses. It is difficult for the nurses to find the time to invest in teaching the parents, when the rewards of this investment are lost to them as the child is discharged. For the system to work effectively it would be desirable for one nurse to be employed, perhaps on a 0900-1700h basis, to have the specific task of 'enrolling' and supervising the parents for the scheme.

Despite these difficulties, the scheme has remained successful, and considerable interest has been shown by the nursing profession. Many parents have shown progressing confidence and skill, having started with the simpler nursing procedures. Nasogastric feeding, in particular, seems to be quickly learnt. One child's parents learned how to cope with total parenteral feeding of their child, who was eventually discharged from hospital, with the parents performing the feeding through a centrally placed catheter. These parents stated that they could never have learned these skills had they not been on the care by parent scheme initially and gradually developed their competence.

Many sick children can be cared for totally by their parents in hospital, with appropriate supervision. Parents who are not actually resident, but who stay for most of the day, can also care for most of their child's needs. This can be done without any special facilities, and indeed it may in fact be preferable for these children to be admitted to a

normal children's ward when they are most unwell and the parents most anxious. The parents then resume responsibility as the child improves and they become more capable. In this manner there seem to be distinct advantages to the children and the parents, who are grateful for the opportunity of caring for their own children, are pleased to be kept occupied, and believe that they are better able to care for their child's sickness in the future. The children benefit from constant care by a few familiar people. The nursing profession is very interested in this concept, and nursing children both with and without the parents in fact enhances their experience. With experience, the system will probably have greater application and become more widely used.

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