

Section 6 Other Paediatric Facilities

Many families are able to take advantage of live-in arrangements and unrestricted visiting offered by hospitals. A family's ability to make use of unrestricted visiting hours will be affected by the family structure (e.g. single parents, siblings), support, resources, childcare, work and financial commitments and access to the hospital (e.g. remote areas) (The ACCH Advocate, 1994).

Maternal deprivation can result from a child's separation from a warm, intimate and continuous relationship with a mother, or mother substitute (Bowlby, 1969). A major source of stress for children is the absence of a trusting personal relationship with at least one caregiver who is frequently and regularly available (Robertson & Robertson, 1989; Wolfer & Visintainer, 1975). Children are particularly vulnerable to the effects of maternal deprivation and loss during periods of high stress, and in unfamiliar situations such as those experienced during hospitalisation (Sheldon, 1997).

If a consistent caregiver is available to a child, and a supportive relationship develops, the stress of separation can be greatly reduced. A consistent caregiver can support the child in a number of ways:

- Assurance, empathy and support before, during and after health care events
- Expression of natural warmth and sensitivity, similar to a parent, which differs from the prescribed roles of hospital staff
- Providing accurate, understandable information in developmentally appropriate ways
- Communicating interest in the child's welfare
- Engaging the child in play activities
- Providing support and more personal, non-medical information to the parents and other family members (Gaynard et al., 1990).

Often another family member or friend can fill in for a parent, but if this is not possible, the hospital may offer alternative arrangements. Robertson (1985) suggests that a 'surrogate' mother should be available to every unaccompanied child, so that contact with one consistent person, taking the mother's role, can be maintained.

Based on this concept, some Australian and overseas hospitals operate highly successful volunteer programs, such as the AWCH Hospital Ward Grandparent Scheme (Dunbar, 1990; Tedeschi, 1988; Lodge, 1988). Carefully selected volunteers work in conjunction with the hospital's social work department, and become the

companion of one child over the duration of his or her hospital stay, or as required. An alternative to this highly committed and organised program is to designate a particular staff member as the special 'guardian', who spends extra time with the unaccompanied child and attempts to build a supportive relationship. Play specialists or diversional therapists are well suited for this task.

Ideally, during times when parents cannot be with their children, such caregiver arrangements should be made prior to admission or as soon as the need arises. The value and importance of a 'parent substitute' may need to be explained to parents. The volunteer should always be introduced to the parents first and then to the child. The final decision should rest with the parents, not the hospital (Lodge, 1988).

Careful consideration is needed in the selection of volunteers. Apart from orientation to the ward environment and the hospital, it has been found that well selected 'grannies' do not require a great deal of training. It is important that the volunteers feel accepted and supported in their role by hospital staff. The social work department may provide structured opportunities for the support and debriefing of such volunteers (Lodge, 1988).

Simple ways of normalising the ward environment can often help children to feel less threatened and more at ease. Modifying the ward to suit various age ranges can assist children in feeling secure and reduce the psychological trauma of the hospital experience (Sheldon, 1997; Audit Commission, 1993). Access to a telephone and being able to receive phone calls reduces feelings of isolation from friends and family members, especially for older children and teens (AWCH, 2005). For older children, contact with school friends and access to facilities they may have at home (e.g. the internet) can also help normalise the hospital experience (Kari et al., 1999).

Being able to dress in their own pyjamas and day clothes can help make a big difference to children of all ages, and avoid any distress upon admission. If hospital clothes must be worn for medical reasons, they should be attractive, age-appropriate and well-fitting. Allowing children to personalise their bed with quilts, a favourite toy, photographs and drawings, can help to make them feel more 'at home' and secure (Tait, 1995). It also provides a focus for interacting with the child (Freda, 1997).

Serving meals in a separate dining area, rather than in bed, can make meal times an enjoyable social occasion. Given the wide variety of cultures residing in Australia, food choice may also be important. Criticisms regarding food variety and choice are common complaints from children

in hospital (Tait, 1995). Presenting food in an appealing manner, both in variety and setting, may make meal times more enjoyable and less of a chore for young patients.

It is helpful to staff to compile personalised information sheets for children upon admission. This is especially helpful in the case of young or disabled children, or for children with limited understanding of English. Information such as food likes and dislikes, sleeping patterns and habits, or special family vocabulary may help to prevent distress when parents are absent (Small, 2002).

Special needs of disabled children

Children with long-term physical and/or intellectual disabilities are particularly vulnerable to the stresses of hospitalisation. Their needs include special physical facilities and resources, and comprehensive staff training to meet individual requirements (e.g. for deaf children, or children with reduced mobility) (The ACCH Advocate, 1994). Families also need support during times of diagnosis and in the ongoing care of a disabled child. The greatest needs during this time are for information, professional support, and information about the availability of social supports, and formal and informal social networks (e.g. support groups) (Rohi et al., 2004).

Comparison table

Other paediatric facilities	1992	2004	Difference	% change
No separate meals area	43.1	60.9	17.8	41.3
Can receive phone calls	89	94.6	5.6	6.29
Can make phone calls	80.6	86.7	6.1	7.57
Choose own food	N/A	89.7	89.7	N/A
Personal information sheets	96	95.1	-0.9	-0.94
Wear own clothes	94.9	99.5	4.6	4.85
Personalise bed unit	95.3	96.2	0.9	0.94
Separate meals area	56.9	39.1	-17.8	-31.28

Survey results

Just over a third (35.1%) of hospitals indicated that they make special arrangements for children whose parents cannot visit them regularly or at all. These arrangements include, in 11.1% of cases, a 'Granny Scheme' and a parent surrogate 18.3% of the time (e.g. a designated nurse, occupational therapist or other staff member).

Listed above are other arrangements that help normalise the hospital environment for children, such as choosing their own food, personalising their own bed, and having separate meals areas.

A separate policy relating to the care of the child with a long-term disability in hospital was developed by AWCH in 1986.

Due to its complexity, this topic was not addressed in detail in either the present or the 1992 survey. However, enquiry was made in general terms about problems experienced in caring for disabled children.

Survey results

Just over a quarter of surveyed hospitals encounter difficulties in caring for children with a disability. Most difficulties related to staffing (71.4%) and facilities (65.3%), such as the availability of appropriate toilets. Many hospitals reported both these factors.

Comparison table

Special needs of disabled children	1992	2004	Difference	% change
Difficulty in caring for disabled children	24.5	26	1.5	6.12
Due to staffing	70.9	71.4	0.5	0.71
Due to facilities	58.1	65.3	7.2	12.39
Both staffing and facilities	37.9	40.8	2.9	7.65

Section 6 Recommendations

- Surrogate carers should be available for hospitalised children without carers e.g. AWCH Hospital Ward Grandparent Volunteer Schemes
- Better support should be provided to hospitalised children with disabilities, through partnerships with key disability organisations who can provide in-services and good practice models to staff
- Increased resources should be allocated for facilities that will enable hospitals to cater better for children and young people with disabilities
- Hospitals should regularly review policies and procedures concerning the management and support of children and young people with disabilities
- Once a child is identified as having special needs, a model or pathway of family support should be developed
- Increased social supports should be made available for children and young people with disabilities and their families through the development of support groups

