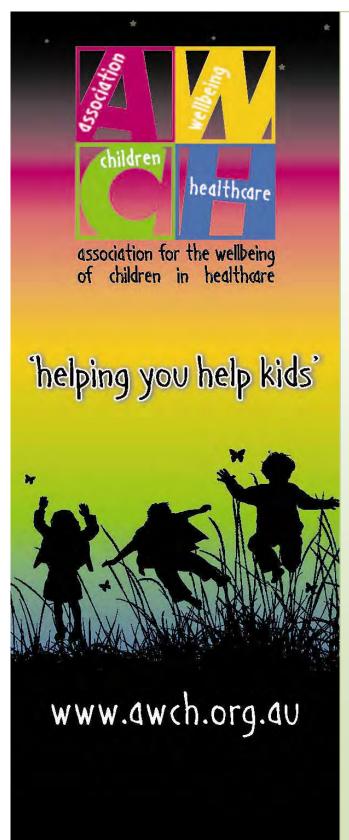


AWCH

Health Care Policy Relating to Children and Their Families

October 1974 Revised July 1999



The Association for the Wellbeing of Children in Healthcare (AWCH) is a national, non-profit organisation of parents, professionals and community members who work together to ensure the emotional and social needs of children, adolescents and their families are recognised and met within hospitals and the health care system in Australia. We believe in:

- access to quality healthcare for all children and young people
- valuing the opinions of children, young people and their families in the delivery of healthcare
- families playing a vital role supporting children and young people receiving healthcare
- fostering partnerships between parents/carers and health care providers
- the provision of culturally sensitive healthcare services
- appropriate information and resources being readily accessible
- challenging the status quo to advance our mission

AWCH tries to ensure a holistic family-oriented approach to the care of children, acknowledging that families are the main support and strength for children and young people when they are sick or have a chronic illness or condition.

PREFACE

It is twenty six years since AWCH first advocated to humanise the treatment of children in hospital.

The initial recommended *Health Care Policy Relating to Children and their Families* formulated by the founders of AWCH remains the benchmark for care of children and adolescents in Australian hospitals and health care system.

This revised policy maintains the philosophy and principles of the original document within the context of today's changing health environment.

Irene Hancock National President

July 1999

INTRODUCTION

The Association for the Wellbeing of Children in Healthcare (AWCH) advocates for a holistic, family oriented approach to child and adolescent health care, and works to ensure that the unique and specific non-medical, psychological, social, and behavioural needs of children and their families in the Australian health care system are recognised and met.

AWCH first released *A Recommended Health Care Policy Relating to Children and their Families* in October 1974. In the preface to the first edition, Sidney Sax, then Hospitals Committee Chairman, commended AWCH for its initiative in developing and publishing a document which soon became a yardstick for evaluating progress in paediatric care in Australia. The Policy attracted considerable praise at a national level, and was declared as the official policy of the Health Commission of New South Wales by the Minister for Health (September, 1975); endorsed by the National Health and Medical Research Council (December, 1978), and, in principle, by Tasmania's Minister for Health Services (October, 1980); adopted as the official policy of the Capital Territory Health Commission (October, 1978); and accepted, in a slightly modified form, by the Minister for Health in Western Australia (1982).

Research and clinical literature concerning the impact of hospitalisation on children's psychosocial health and family functioning provide strong support for the continued implementation of programs and policies espousing family-oriented, and developmentally and psychosocially appropriate, paediatric health care. To this end, this latest version of the *Health Care Policy Relating to Children and their Families* represents a synthesis of the practices and programs shown to be effective for assisting children and families to cope with the hospital experience¹. The recommendations contained herein are aimed at achieving best-practice in the field of paediatric health care.

A Recommended Health Care Policy Relating to Children and their Families (Revised) should be read in conjunction with the AWCH/Australian Council on Health Care Standards (ACHS) Guidelines for Hospital-based Child and Adolescent Health Care (July, 1998), and other guidelines, policies, codes of practice, and statutory requirements pertaining to the provision of child health care services.

For the purpose of this Policy, a 'child' is defined as any person under the age of 15 years, excluding neonates. As this is a somewhat arbitrary distinction, discretion should be exercised in deciding whether the recommendations are appropriate for slightly younger (e.g., 13 years) and slightly older (e.g., 16 years) individuals. The Policy does not address the provision of health care for neonates and adolescents. The special needs of these groups are considered in separate AWCH policy documents.

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¹ A vast array of empirical literature supports the recommendations contained in this Policy document. Information pertaining to any or all of the recommendations can be obtained from the AWCH Library. http://www.awch.org.au/library.htm

POLICY STATEMENTS

- A child should only be admitted to hospital when there are clear and unavoidable indications for this.
- The duration of a hospital stay, particularly for a young child, should be as brief as possible.
- When health care for a child is necessary within a hospital or health care program, a close and continuous relationship between the child and the family/carer should be encouraged and maintained. Facilities and programs to allow for this continuing relationship should be available.
- Parents/carers should be encouraged and assisted to participate in their child's health care at all times.
- Every effort should be made to minimise the physical and emotional distress to children and their families whether inpatients, outpatients, or in other community care.
- Provisions for ensuring that children and parents/carers are prepared adequately for a child's admission to and discharge from a hospital or any other community care facility are essential.
- Professionals delivering care or supervising directly the provision of children's health care should be trained in the unique psychosocial and developmental needs of children and the special needs of families, in health, illness, and disability.
- Hospitals and health care services should demonstrate involvement in community health promotion and health education activities designed to optimise normal child growth, development, and psychosocial health, and support families with children with a chronic illness or disability.
- Ongoing review and evaluation of health care policies, practices, and programs are essential. This should involve health professionals from all levels and disciplines, parents/carers, children (where appropriate), and members of health consumer groups and the general community.

RECOMMENDATIONS

Statement 1

A child should only be admitted to hospital when there are clear and unavoidable indications for this.

- The alternative of community-based or day-stay treatment should be investigated fully prior to admitting a child to hospital.
- Coordinated, community-based services and programs should be available to educate, support, and assist parents/carers in maintaining a child at home, including nursing, medical, respite, and domestic services.
- Ambulatory health care and support services should be available when access to such services is limited, for example, for families residing in rural and/or isolated communities.
- Families should be provided with information about the psychosocial implications of hospitalisation for children.

The duration of a hospital stay, particularly for a young child, should be as brief as possible.

Integrated psychosocial care and a reduced length of hospital stay improve psychological, behavioural, and medical outcomes for children. In light of this:

- All policies, practices, and programs in hospitals admitting children should aim to minimise the length of inpatient stay for a child.
- Coordinated community-based and/or ambulatory services should be available and utilised to support a shorter hospital stay for a child.

When health care for a child is necessary within a hospital setting or other health care service, a close and continuous relationship between the child and the family/carer should be encouraged and maintained. Facilities and programs to allow for this continuing relationship should be available.

- On admission of a child to hospital, arrangements should be made for a parent/carer to accompany the child during the hospital stay.
- Parents/carers should have unrestricted, 24-hour access to their child on the ward/unit (except in situations where child protection issues prevail).
- Significant others, including siblings and relatives, should be provided frequent and flexible visiting opportunities.
- All hospitals admitting children must provide appropriate sleeping accommodation for parents/carers, either at a child's bedside (e.g., reclining chair or folding bed), or in designated parent/carers' accommodation.
- All hospitals routinely admitting children should provide for parents/carers;
 - access to toilet/shower facilities,
 - access to meals,
 - access to laundry facilities,
 - tea and coffee making facilities, and
 - a designated parent/carers' retreat.
- Domestic, economic, and/or personal pressures may prohibit some parents from utilising a hospital's live-in facilities. Parents/carers should not, therefore, be or feel pressured into living with their child in hospital, nor should they feel guilty if they are unable to remain with their child in hospital.
- Provision should be made for parents of an unaccompanied child to access an alternative caregiver to support their child (e.g., the AWCH Hospital Ward Grandparent Scheme).
- If the mother of a hospitalised child is breastfeeding an infant sibling, and wishes to remain with the hospitalised child, provision should be made to admit the breastfeeding infant with her.
- When it is necessary for a breastfeeding mother to be hospitalised, provision should be made to admit the breast-feeding infant with her.

Parents/carers should be encouraged actively to participate in the planning and provision of their child's health care.

- Hospitals should have a written policy stating clearly the rights and responsibilities of parents/carers in relation to their child's hospital care. The policy should emphasise parent/carers' rights to participate in their child's daily health care (including basic nursing care, feeding, and bathing); to be involved in all decision-making affecting their child; and to choose to be present during their child's treatment/procedure, preoperative induction, and recovery. Copies of the policy should be provided to parents/carers, in appropriate community languages.
- Parent/carer involvement in a child's health care should be negotiated between parents/carers, health professionals, and the child, prior to and throughout the period of a child's hospitalisation.
- Education and support should be provided for parents/carers who choose to participate in their child's health care and/or medical procedures. These should be provided by appropriately qualified and/or experienced staff.
- Ward rounds should be flexible enough to allow parent/carer involvement in a child's health care. Providing families with written information about the daily ward routine in advance will allow them to integrate better their activities with that routine.
- Parents/carers should be informed adequately, appropriately, and regularly about their child's medical condition. Medical procedures may only be performed after a child's parents/carers have provided informed consent.
- Communication between parents/carers and health professionals should be in plain, uncomplicated language. Professional health care interpreters should be available to assist children and families from Non-English speaking backgrounds. Child patients and their siblings should not be used as substitute interpreters.
- The special needs of parents/carers of a dying child should be provided for. This should include consideration of the family's cultural, religious and spiritual needs.

Every effort should be made to minimise the physical and emotional distress to children and their families' whether inpatients, outpatients, or in other community care.

- The psychosocial needs of children should remain paramount during the delivery of health care and should not be compromised for reasons of fiscal constraint, and/or staff convenience in performing their tasks, duties, and rounds.
- At all times, hospital staff should treat children with respect and sensitivity. This involves acknowledging appropriately children and their parents/carers on ward rounds, and explaining medical procedures in a manner appropriate for a child's developmental age.
- It is imperative that children feel secure in and familiar with the hospital environment. To achieve this, hospital staff should:
 - inform and encourage families to bring a child's personal items (e.g., favourite toys, pillows, blankets, and so on) into the hospital ward;
 - ensure adequate provision for the display and/or storage of children's personal items (e.g., corkboards for poster display);
 - ♣ encourage children to wear their own clothing during hospitalisation; and
 - if possible, leave technical, invasive, and potentially painful procedures until children are settled and comfortable.
- Children should be accommodated with other similarly aged children, in wards designed specifically for children. Under no circumstances should children be accommodated with adults.
- Children should have access to and be encouraged to participate in developmentally appropriate play and educational activities and programs. The daily hospital routine should be flexible enough to facilitate children's involvement in these activities.
- Developmentally appropriate play and education should be provided by appropriately trained and qualified staff.
- As appropriate, children should be provided the opportunity for involvement in their own treatment, procedures, and/or health care plan.
- Hospitals admitting children should provide for the special dietary requirements of children including those from indigenous and ethnic communities.
- Provision should exist for ensuring adequate psychosocial support for children and families experiencing difficulties coping with and/or adapting to a child's illness, including access to social work and psychological services, and Aboriginal Liaison Officers, as required.

- Appropriate pain relief should be provided for children before, during, and after medical procedures. Methods of pain management should be negotiated between parents/carers, the child, and health professionals. Specific child pain management staff should be available at all times.
- Emergency and Outpatient departments should have a separate waiting area specifically for children and their parents/carers. This area should be furnished with age and developmentally appropriate equipment and facilities to provide recreation and entertainment for child patients and their siblings.

Provisions for ensuring that parents/carers and children are prepared adequately for admission to and discharge from a hospital or any other community care facility are essential.

Recommendations for preparation for admission:

- All hospitals are to make written information available to parents/carers and children to assist with a child's hospital admission. This should inform families of the hospital's lay-out and facilities (including parking, telephones, cafes/kiosks, reception, and parent accommodation) and visiting hours. This information should be available in appropriate community languages.
- Where possible, a pre-admission visit to hospital by parents/carers and children should be arranged. This visit should involve appropriately qualified personnel using child-focussed communication, activities, and audio-visual material to familiarise children with events and equipment they may encounter while in hospital.

Recommendations for discharge planning:

- Parents/carers should be involved actively in the planning of a child's discharge from hospital, including the assessment of a child's ongoing care needs and services required.
- The decision to discharge a child from hospital should be based on consideration of the child's medical and psychosocial needs, and not space and fiscal constraints.
- There should be adequate training and preparatory programs to enable parents/carers to manage their child's health care, including medication and medical equipment, in the home. Where possible, and when necessitated by a child's condition, this should be supplemented by home visits by community nursing staff to review parent/carers' management and the child's health care needs.
- Where appropriate, children should be encouraged and trained to manage their own health care in the home.
- Parents/carers and children, where appropriate, should receive clear advice regarding a child's recommencement of such activities as child care, school, and/or recreational activities.
- On discharge of a child from hospital, a discharge report should be forwarded as early as possible to the child's general practitioner and other relevant medical and community health care staff.
- Specific programs to prepare children and the parents/carers of children transferring to adolescent health care should be in place.
- Early discharge follow-up and pre-admission screening programs for early discharge are desirable.

Professionals delivering care or supervising directly the provision of children's health care should be trained in the unique psychosocial and developmental needs of children and the special needs of families in health, illness, and disability.

- AWCH advocates the mandatory inclusion in all undergraduate health professional programs (including medical, nursing, and allied health programs) of courses focusing on:
 - normal child growth and development;
 - family dynamics;
 - the psychosocial needs of children and their families in health, illness and/or disability;
 - effective communication skills with children, adolescents, and families, especially under stress; and
 - the influence of diverse cultural perspectives on child health issues.
- All education, training and care management should be child- and family-oriented rather than task-oriented.
- Hospitalised children should be cared for by nursing staff with paediatric post-basic qualifications and/or paediatric nursing experience.
- Hospitals routinely admitting children should implement strategies to attract, educate, and retain paediatrically-trained staff. This is especially the case for hospitals in rural and remote areas.
- The health care of children should be multidisciplinary, and involve such individuals as play specialists, music therapists, and others specialising in the unique needs of children. Parents/carers and other family members should form part of the multi-disciplinary team.
- All professional staff have a responsibility to display positive, progressive attitudes and skills in the delivery of health care to children and their families, thereby contributing to the development of a more informed community.
- Provision should be made for paediatric medical and nursing staff to attend professional development courses, seminars, programs, and conferences to further their skills in providing health care services to children and families.

Hospitals and health care services should demonstrate involvement in community health promotion and health education activities designed to optimise normal child growth, development, and psychosocial health, and support families with children with a chronic illness or disability.

- The development and implementation of child-focussed community health and community education programs is essential, and may require coordination of government and non-government services.
- Health promotion strategies for children and families should target accident, injury, poisoning, prevention, and immunisation.
- Preventative strategies should recognise the important role of the family general practitioner in education programs and other interventions targeting preventable disease and disability in children.
- Efforts to promote healthy lifestyles for children and families must recognise and incorporate the vital role played by parents/carers, play groups, child care services, schools, and the media in developing positive, healthy lifestyle habits and behaviours.
- Specific health programs should be developed to address the unique health care needs of Aboriginal children and children from non-English speaking backgrounds.
- The development of specific, integrated support systems for families with chronically ill or disabled children, in the form of genuine respite care programs, community and domiciliary health and allied health services, and subsidies for medical equipment, is essential.
- Strategies should exist for informing community members and health professionals about child protection issues, including reporting mechanisms, legal options, and support and rehabilitation programs for children and their families.
- Procedures for ensuring equity of access to child health services by children and their families should be developed, and must take into account such issues as potential lack of knowledge about services, location, hours of opening, cultural background, physical access, language, literacy, and stigmata attached to specific services and/or illnesses.

Ongoing review and evaluation of health care policies, practices, and programs are essential. This should involve health professionals from all levels and disciplines, parents/carers, children (where appropriate), and members of health consumer groups and the general community.

- Review and evaluation of all policies, practices, and programs relating to children's health care should be continuous.
- The overriding principle of review and evaluation must be improved health care and service delivery for children and their families.
- Formal review and evaluation of policies, practices, and programs relating to children and their families should be undertaken at least every two to five years, using measurable, objective, and proven health care outcomes.
- Appropriate adaptation/modification and policy/protocol formation should be undertaken following the results of any review and/or evaluation.

Contact Information



association for the wellbeing of children in healthcare Association for the Wellbeing of Children in Healthcare (AWCH)

ABN 33 119 036 261

Bldg 7, Gladesville Hospital, Cnr Victoria & Punt

Roads, GLADESVILLE NSW 2111

T: 02 9817 2439

F: 02 9879 4346

Parent Line: 1800 244 396 (outside Sydney)

E: <u>awch@awch.com.au</u>

W: www.awch.org.au