



CHILD & ADOLESCENT

Health Care

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FROM THE PRESIDENT...



Demand for AWCH services and its core business continued steadily throughout the year 2000, with AWCH continuing to play an active role in the health care system as an advocate for children and young people.

AWCH has received an increasing number of enquiries regarding children and adults being regularly accommodated together on hospital wards. An additional area of concern, in light of the proclamation of the 'Children and Young Persons (Care & Protection Act) 1998' in December 2000, is the need to minimise the risk to children in the area of child protection. In NSW AWCH has written letters of concern to the relevant hospitals and the state Minister for Health and is waiting for a response. AWCH will continue to advocate for the separation of children and adults on hospital wards.

With the changes in the delivery of health care and the nature of community volunteering, it was decided that AWCH needed to analyse and discuss its direction and what issues are relevant to the role of AWCH in the future.

In September 2000, the AWCH NSW branch held a planning day. A very productive day was spent discussing the future direction of AWCH and the actions that are needed to be undertaken. The plan was then sent out to all NSW members for comment and feedback and the outcomes discussed with the National Councillors at the annual AGM, held in Canberra in November.

Some of the initiatives in the plan include:

- a parent forum to discuss relevant issues in the health care of children
- a membership drive and kit
- bi-annual 'meet the parent' barbecues
- development of an AWCH poster
- an annual awards ceremony to recognise outstanding contributions to child health
- inservice lunch hours at hospitals talking about AWCH
- further developing of the AWCH website
- developing a sponsorship strategy
- an annual thank-you event for all AWCH volunteers
- updating of AWCH policies.

The Association for the Welfare of Child Health is funded by the NSW Department of Health and supported by the University of Western Sydney.

This newsletter is made possible by the generous donation of equipment from Hewlett-Packard Australia.

RESOURCES

*For your
Diary*

Because of the Olympics it was decided not to hold a conference in 2000. We are planning a much larger conference scheduled for 11 and 12 October 2001- the theme being marginalised groups of children and adolescents: indigenous and non English-speaking background children, homeless young people, children with disabilities, children of prisoners and detainees, and street children.

During the year we were sad to receive the resignation of Lyn Shegog AWCH Tasmanian President and National Councillor – due to ill health. We wish Lyn and her family well. Thank you to Ngia Purton, who has kindly agreed to act in the position.

I would like to acknowledge the ongoing stewardship of the National Office by the members of the ASC: Ron Berney, Penny Kearney, Sue Hawes and Marion Steele as the AWCH Library representative on the ASC, under the able chairmanship of Ron Berney as National Treasurer. A thank you to my fellow directors of Fund AWCH Noel Mills, Ron Berney, Marion Steele and Chair Graham Bench, and an extra thank you to Ron Berney our Honorary Solicitor, who has had some work to do on the AWCH constitution this year for new fund- raising systems.

A thank you to Anne Cutler and Chris Morris at National Office for all their efforts over and

Thank You!

above the call of duty this year and the AWCH Library Staff Marion, Josie and Jenny for their support of AWCH branches and their work for the ideals of AWCH. The AWCH Library has continued to enjoy the support of the University and I would also like to thank Kaye Freemantle for her ongoing support of the philosophy of the AWCH Library and personal support to Marion Steele and her staff.

I wish to acknowledge both the NSW Health Department and the University of Western Sydney for the continued support of the Association.

*Irene Hancock
National President*

shopfront

University of Technology, Sydney

Working with the Community

UTS Shopfront acts as a gateway for community access to the University. It links disadvantaged and under-resourced groups to university skills, resources and expertise to provide both flexible community-based learning for students and to assist these groups to achieve independence and self determination

The Children's Hospital at Westmead

Locked Bag 4001

Parramatta 2145

The Patients' Friend

Betty Radcliffe

02 9845 3535

Pager 6219

The patients' friend acts as a liaison between the patient, the family and the hospital. She is available to provide counsel and information to patients, parents and guardians about hospital processes, procedures, services and facilities.

KIDS HELP LINE

1800 55 1800

kidshelp@squirrel.com.au

www.kidshelp.com.au

THE ESTABLISHMENT OF A PAEDIATRIC DAY UNIT WHERE THE PHILOSOPHY IS BASED UPON NURSES WORKING IN PARTNERSHIP WITH PARENTS

VAL WILSON

**Clinical Nurse Educator (Children's Program)
Lecturer (Centre for Graduate Studies in Clinical Nursing)
Southern Health Care Network & Monash University**

TREND TOWARDS DAY PROCEDURE UNITS

There is a growing number of children who are now treated in hospital as day cases. Research has shown that for these families, the shift in responsibility for care may cause an increase in stress and anxiety. Through involvement with a "Parent - Nurse Partnership Group", it was noted that the needs of these families can be very intense, and if not met can leave the family with unresolved anxiety related to their hospital stay.

The trend towards shorter lengths of stay has seen the emergence of day procedure units around the world. The benefits for both the child and the family have been discussed by several authors. Norris notes that day units are less traumatic for children and their parents, but cautions that this is only true if parents are allowed to participate in their child's care. Recent studies in this area suggest that there may be added pressure on parents and nursing staff when the child is admitted to a general paediatric ward rather than a specific day procedure area. These studies give further credence to the establishment of a separate day procedure unit.

PARENTS INTEGRAL TO THE TEAM

Patients who are admitted to day units may have a greater need for pre-admission services. These services can prepare the parent and the child, hopefully alleviating some of the anxiety associated with hospitalisation. The services should include accurate written and verbal information. This information should be ongoing and reinforced throughout the hospital stay. However, the given information has to be consistent as there is nothing more confusing to the parent than being given different advice from various members of the health care team.

The lack of in-patient time leaves nursing staff with fewer opportunities to meet the needs of the family. Staff have to ascertain early what the needs of the family are, and make

ISSUES Facts Plan

provision for those needs. Involving parents in the care of their child ensures that a personalised approach to care is taken, but it must be remembered that for some parents the level of their involvement may be minimal. Parent participation should be viewed as an integral part of the philosophy of any day unit with health providers and parents working together as a team.

The very fact that the hospital visit is short has added to the stress and anxiety felt by some families. Reasons for this increase in stress and anxiety include:

- parents having a greater responsibility for their child's care (before, during and after hospitalisation)
- being surrounded by children who are very sick (especially when the day area is part of a busy acute-care setting)
- lack of communication between the health care providers
- the family and the type of procedure the child is undergoing.

When a child is admitted for the day, the rate of subsequent unplanned overnight admissions can be quite high. This can be due to the factors such as:

- the families' stress and anxiety
- the ability to care for the child at home
- transport issues
- late theatre times
- post-operative complications
- being admitted to a general paediatric ward rather than a designated day unit.



PARENT SURVEY

Two months after the unit was established a review was undertaken. The premise for this review was to get an understanding from families about their satisfaction with the service provided. This input from families' can help to ensure that standards of care are maintained and that practice can be reviewed and improved. It was decided that the easiest way to get information was through a parent satisfaction survey.

The survey focused on the brochure information, pre-admission information and instruction, care during the hospital stay and coping after discharge. These aspects were then included in the survey because of the issues identified surrounding the needs of the family. The staff were also interested to evaluate how their practice of parent - nurse partnership was viewed by parents.

The number of children admitted overnight (13%) was of concern, however this was mainly due to inappropriate admission of patients due to a shortage of beds in the main ward (they were transferred to the ward within a few hours). The actual figure for day case overnight admission was 5 patients (4%) which compares very favourably with the statistics reported in the literature of approximately 10% in designated day areas.

SURVEY RESULTS

In the literature, coping after discharge was identified as one of the most stressful times for families. It was therefore interesting that the majority of families strongly agreed that they felt confident in caring for their child after discharge. This is hopefully a reflection on the nursing staff's preparation, information and follow-up service. Two parents discussed length of stay, one parent thought the stay was too short for adequate recovery, the other was concerned with the journey home. Whilst these are real issues of concern for some parents, it was pleasing that the majority of parents felt able to cope after discharge.



Parents indicated a few areas of concern, mainly centred around issues of communication. Pre-admission information was unsatisfactory for some parents. The lack of (or incorrect) information meant some families arrived at hospital unsure of how the day was planned. Parents indicated their frustration at being unable to speak to the doctor post-operatively. This is a concern for staff and parents alike and requires further review.

Positive comments are valuable in that they illustrate that current practice is essentially effective. This encourages staff to feel positive about the idea of the day area and parent-nurse partnerships. Staff within the unit at Monash are very proud of the achievement so far. This experience shows us that if we continually open our minds to the relevance of parental input we will surely go a long way to improving the services we provide for families, whether it be short or long term.

The parents in this survey were very positive about the concept of the day procedure area and identified the value it held for their child and themselves. The development of this small team of nurses has ensured parents feel that they are getting a personal service of a very high standard. This is in contrast to the literature that often reveals feelings of inadequacy by the day stay family, in comparison to the "sicker children" on the ward.

BENEFITS

The staff have worked hard at establishing a unit that provides a very high standard of care for day patients and their families. The benefits of having such a unit are highlighted in the responses of the parents surveyed. The positive feedback illustrates a very high level of parent satisfaction with the service provided. Parents strongly indicated that they were made to feel welcome and comfortable during their short stay. They felt confident in the nursing staff and were comfortable asking questions.

Casey's model of partnership has been adapted to suit the environment of the unit. The partnership is illustrated by the involvement of parents in the care of their children before, during and after admission. Parents generally felt able to manage their child's care, including pain management, after discharge. Staff supported parents, even after discharge, by providing adequate information and a call-back service for further information. This positive feedback on the success of partnerships will ensure its continuance in the day unit. Despite the average length of stay on the unit being around four hours the staff were able to deliver quality care, which was not dependent on extended contact with the child.



This survey included a small number of parents and therefore its implications may be limited. However the very positive feedback indicates that for parents the day unit is a success. In order to review and improve the services provided at Monash, parents should be involved in surveys such as this one. This survey, although time consuming, has provided very useful data for future development of services and has highlighted some areas that require improvement.

This is an edited version of 'The Establishment of a Paediatric Day Unit...', reprinted from the National Conference Papers, "Getting Better Together" which are available from National Office - 02 9633 1988

ANNUAL BRANCH REPORTS

AWCH A.C.T

The ACT Branch has continued to function in its quiet, supportive way. We have had a good year.

Play Therapist Visits

Our first major venture was the Play Therapist Visit. For this I would like to warmly thank Professor Graham Reynolds and the Paediatric Unit for their support which made it possible. Sydney Children's Hospital's generosity in paying the play specialist whilst visiting us is also greatly appreciated. Margot Ward was here from Sunday evening 9 April, till Wednesday afternoon 12 April. During that time she made a great impression on many people working with children in the ACT- and I suspect there has been an upsurge in the sale of bubbles.



It is always a thought-provoking experience to spend time with a truly "child- focussed" person. It was a major learning experience for me driving her to her various engagements around Canberra and sitting in on her sessions. I know Margot enjoyed her time here too. She is keen to spend a longer time here in a locum capacity. I hope it is something we can organise in the very near future.

Friends of the Children's Ward Training Program

Thank you to Anthea and Krishna for all their effort in organising another training program for the Friends of the Children's Ward Volunteers. From my involvement it would seem to have been enthusiastically received. Unfortunately there has been a serious "glitch" in the mandatory police checks, which has nothing to do with us; it is a police initiative to reconsider the policy of free police checks. We are still pursuing it and still hoping for resolution before our Open Day in Children's Week.



As most of you know, we had a very successful Open Day in Children's Week last year and we still plan to build on this success this year. Wendy Cummins is our Children's Week Representative. Thank you Wendy.

The AWCH National AGM was held in ACT last year on Saturday 25 November. There was a dinner the night before, which was most enjoyable. Thanks to Moira for organising a wonderful repast.

Thank you all for your outstanding support and loyalty. Each person on the committee is a special person. I thank you all.

*Sue Packer AM
President AWCH ACT (Inc)*

WESTERN AUSTRALIA

I am pleased to report on some of the year's activities and achievements.

We completed the production of the training film *How we do it* featuring the Hospital Familiarisation Programme (HFP). The end result was everything we had hoped for and the film was completed in June 2000. *Dingo Talents* supplied 40 copies of the videos; 26 of these went to each of the children involved in the video and their teacher.

Our HFP figures for the 1999/2000 period amounted to:

- **276 school requests**
- **535 x 2 hour sessions**
- **12,665 children** receiving the programme
- **165 weeks** of medical kit hire.

At the end of 1999 we had to say farewell to three of our presenters, Tracey McKernan, Kelly Kinsella and Kathy Mathews. AWCH has been fortunate to have had these ladies who gave a great deal to the programme. I thank them and wish them every success in their new ventures. We have now welcomed three new presenters, Helen Johnston, Susan Sheppard, and Kathy Musca.

Armadale /Kelmscott Hospital extended an invitation to HFP presenters to visit their hospital. As all presenters were interested in familiarising themselves with their local hospitals, similar invitations were arranged and it was then left to presenters to visit when convenient.

Following an invitation from St Marks School last year, Jane and Kate spoke to 24 teachers from the Independent Pre-School Teachers Association. Jane introduced the HFP programme and Kate spoke on how it was presented.

Hospital Familiarisation Stimulus picture sets, consisting of 10 x A3 laminated pictures, are now available to schools for purchase as a resource, with the cost at \$50 per set.

The new millennium hit us with the realisation of the GST and its implications for AWCH WA. We found the task of deciding what to do quite difficult. However after many months of going through the pros and cons, we are now registered for GST with an ABN number, Income Tax Exempt Charity status, and endorsed as a deductible gift recipient organisation. We now know that was the easy part !!!!!!!

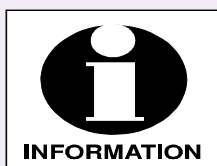
Princess Margaret Hospital have approached AWCH with a view to the possibility of AWCH taking over the tours of the hospital for school children. Although we are quite receptive to the idea, no firm decision has yet been made. These requests from schools are usually for middle to upper primary level and do not conflict with HFP.



In April AWCH was invited to submit a display stand at the International Paediatric Nurses Conference. We welcomed this great opportunity to promote AWCH and Jane Fare put together an excellent display at very short notice. Our committee members and HFP presenters manned the stand during the three days.

Shortly after this event, a meeting to exchange ideas for future projects was planned. Several ideas old and new were discussed, including research. Subsequently it was decided to apply to Edith Cowan University Industry Partnership Research Award Scheme and Alcoa (Peach), to try to raise \$20,000 to research the evaluation of the Hospital Familiarisation Programme. The recent news that both submissions were successful is very exciting for our branch. The project will take twelve months to complete and the results will be valuable to the ongoing development of the programme.

During the past twelve months Dr Dawn Butterworth has been promoting the HFP in the Kimberley region, at the OMEP Conferences in Copenhagen, Singapore, and Jamaica. Earlier this month, Dawn and Lis Mathiasen attended an Early Childhood Conference in Kuala Lumpur. Their presentation of the HFP generated considerable interest resulting in sales of close to \$1,000 for HFP equipment. Congratulations to Dawn and Lis.



We've also had several press articles this year resulting in a number of enquires from parents concerning visits or wanting information regarding hospitalisation. One case in particular will be addressed as an issue with the Health Consumer Council in WA.

My thanks to all who continue to assist in so many different ways - Jane in particular for keeping the HFP running so smoothly and efficiently. A very special thanks also to Isobel Giles, who stepped in as Treasurer amid the turmoil of GST adjustments !!!! and Marjorie's holiday absence.

Ann Taylor
President AWCH WA

AWCH QUEENSLAND

AWCH QLD has met four times during 99-00 and discussed policy issues regarding children, and Queensland's health system and hospitals, including new planning and special schools. It was decided that we really did not have enough people to go out at this time to promote AWCH, but that it would be useful to have my home phone and mobile for information. I have received and forwarded on any queries to AWCH National Office and propose to continue to do so in 2001.

AWCH continues to be a link with the community for families of many children with rare disabilities. As Coordinator of the Australian Tinnitus Association in Queensland, I have brought forward the ideas of linking the tinnitus hearing kit for children and AWCH to promote better hearing health and safety.

The use of the internet to link rural and regional Queensland will be the way of the future once the faster and more reliable networks are running smoothly. A proposal to set up a web site for AWCH to communicate with families and communities in Queensland has been under discussion.

AWCH Queensland has not followed through with an ABN because of the limited actions of the branch at this time. We are advised that we can apply when required.

Helen McAllister
President AWCH Queensland

AWCH NEW SOUTH WALES

AWCH NSW Committee has continued to hold regular bi-monthly meetings using the NSW Nurses Association premises. AWCH would like to thank the Association for their generosity in providing this venue.

Melinda Clarke Secretary, Sue Hawes Treasurer, Ruth Jensen AWCH Hospital Ward Grandparent Scheme Coordinator, Margaret Yates Vice President and Penny Kearney representative on the New Children's Hospital Committee – all deserve a huge thank you for continuing the work of AWCH during 1999-2000.

AWCH NSW has been active lobbying relevant Ministers about the deregulation of the dairy industry, which means children in remote areas will no longer have regular access to fresh milk. AWCH has received responses from the Minister for Agriculture, and the Minister for Health and Aboriginal Affairs, Dr Refshauge, whose office is currently working on the issue and is keeping AWCH informed of any developments.

Another issue of concern was the death of a young child who had been treated at Manly Hospital and transferred to Sydney Children's Hospital. This resulted in an external review of paediatric care across Northern Sydney Health and the closure of the Paediatric Unit at Manly. AWCH had raised its concern with the Minister of Health, Northern Sydney Area Health, the Australian Council of Healthcare Standards, the Health Care Complaints Commission, the Federal Minister for Health and the local MP for the Manly area.



Other activities included assisting with the script for a video made by the Wiggles for Sydney Children's Hospital; attending a media launch of *A Parents and Carers Guide for the Better Use of Television for Children*, and the NCOSS Conference *Connections in the Community*. Ron Berney, Sue Hawes and I attended seminars for charities and NGOs on the new tax system; Melinda Clarke represented AWCH on the *NSW Health Home-Based Support Models Project Advisory Group*; and a number of AWCH NSW members attended the *People's Walk for Reconciliation* across the Harbour Bridge.

Northern Sydney Health is currently reviewing health services across the area. I represent Northern Sydney Health Consumers and AWCH on the Paediatric and Child Health Reference Group and the Child and Family Services Community Health Strategic Plan Steering Committee, respectively.

Melinda Clarke collated responses to the review of the

The Association for the Welfare of Child Health

AWCH Play Policy, which should be ready for redistribution in 2001.

As was highlighted in last year's report, AWCH decided to ensure AWCH activities reflected the changing way health care is delivered today. Following distribution of questionnaires at last year's NSW Branch AGM, we held a meeting in September 1999 and as a result, a Planning Day was held in September 2000. The National Council, in the regular telephone link ups, has indicated the outcome of the NSW Forward Planning Day will assist them in deciding the future directions of the Association.

Irene Hancock
President, AWCH

AWCH VICTORIA



During 99-00, Serge Katin who is the director of a child art institute in the Hermitage Museum in St Petersburg, conducted a seminar supported by music therapist Beth Dun, art therapist Claudia Rossi and social workers Maree O'Toole, Elizabeth Loughlin and Sue Morwood from The Royal Children's Hospital. It was a very successful and informative seminar.

AWCH Victoria has also been involved in the further development of the Play Specialist Course at the University of Western Sydney. An undergraduate stream has commenced and a post-graduate course will be offered in 2001. This is a great leap forward for raising the professional standing of play in hospital in Australia. We must thank the academic staff of UWS, Marion Steele of the AWCH Library and Leanne Hallowell, who through the Australian Hospital Play Specialist Association have put much effort into overseeing the professional aspects of these courses.

As in the past, I must acknowledge the support to AWCH Victoria from the Lady Gowrie Centre in Carlton where we hold our regular meetings. To our sterling Secretary Jenny who diligently keeps the minutes and Leanne's secretary who types these minutes and does the mail - out I must also extend my thanks. I would also like to make a special thank you to Leanne Hallowell, the Treasurer and a great strength behind AWCH Victoria.

Many of the battles of past for the rights of the child in hospital have been fought and won but we must remain ever vigilant to see that these hard - won, commonsense rights are not eroded for economic reasons. I see our future role in mainly promoting the services of the AWCH Library as a parent and professional resource and to keep the rights and welfare of children ever in the public domain.

Bob Greaves
President, AWCH Victoria.

WEBWATCH

www.changingfaces.co.uk

- provides information on facial disfigurement
- deals with the social and emotional consequences

www.nsw.gov.au

- has links to NSW Government departments
- check out Department of School Education for school terms

http://www.ilc.asn.au

- the South Australian Independent Living Centre
- has access to its equipment database

www.nswamh.org

- has information about general mental health especially for Australians living in rural remote areas
- has information about specific mental disorders
- has contact details for service organisations that can help the caller

http://nrccph.latrobe.edu.au

- national resource centre for consumer participation in health
- freecall 1800 625 619
- a clearinghouse for information about methods and models of community and consumer feedback and participation
- links to other organisations

www.hcc-wa.asn.au

- Health Consumers Council of Western Australia
- freecall 1800 620 780
- consumer information, policies, reports
- health links
- news and membership
- action groups

AWCH 8th National Conference

Children on the Margin

Addressing the health needs of marginalised children and young people.

Powerhouse Museum, Sydney

11 and 12 October 2001

This will be a priority conference for everyone concerned with developments in the psychosocial care of marginalised children in the health care system.

Eminent national speakers will present keynotes and join conference delegates to discuss:

- Indigenous children and young people
- Children and young people from a non English - speaking background
- Street children
- Children and young people with a disability
- Children of prisoners and in detention centres

Sessions will cover a range of issues for marginalised children's health care including:

- Children and young people as consumers of services
- Sharing knowledge and showcasing programs
- Highlighting access and equity issues
- Culturally appropriate information-sharing initiatives
- Where are the gaps?

Contact

Conference Action - 02 9956 8333
email: confact@conferenceaction.com.au

NATIONAL OFFICE 99-00 ANNUAL REPORT

ENQUIRIES

During the 1999-2000 period there were 654 enquiries, including :

- Notifications of child abuse; child welfare and parenting issues; child behaviour problems; counselling services for parents and teenagers; overseas vaccinations for infants; access rights of separated parents; immunisation and baby care/health information; carer support post birth of triplets; bed wetting; crisis accommodation for women and children; common childhood illnesses.

- **Advocacy support** – parental presence during anaesthesia induction and in the recovery room; separation of children and adults in hospital wards; the Isolated Persons Travel and Accommodation Scheme; the Carers Allowance, paid by Centrelink; milk subsidy to NSW; the design of new buildings to be child and family friendly; the need for adequately trained and experienced paediatric staff.

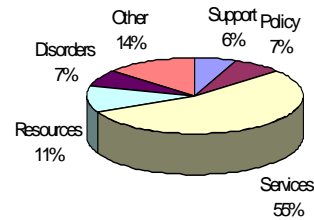
- **Policy/guidelines**—children visiting Intensive Care Units; day surgery; play facilities; the AWCH Ward Grandparent Scheme; rights of the newborn for screening; rights of sick children in hospital; risks and implications for poorly trained and understaffed paediatric wards; well designed children's wards; staff-to-patient ratios; safety issues on the ward; opening a childcare facility; care of hospitalised children outside the ward; mixing children and adolescents in the recovery area; criteria for parental accommodation in hospitals; maternity and disability policies.

- **Support Group information** – Aspergers Syndrome; grief; Lissencephaly; Spinal Muscular Dystrophy; Cerebral Palsy; single mothers; Gastric Reflux; Cohen's; cerebral atrophy; Hereditary Fructose Intolerance; Aspergillosis; Subglottic Haemangioma; Alpha-1-Antitrypsin; Undifferentiated Sex; Osteogenesis Imperfecta; Uveitis; Adam's Oliver; Meningitis; Short Bowel Syndrome; Foetal Alcohol Syndrome; Williams Syndrome; children who have drowned; CMV; Dissociative Disorder; Cri du Chat Syndrome; Hypothyroidism; Tracheo-Oesophageal-Fistula (TOF); Noonan Syndrome; Gardeners Syndrome; Lupus; Pierre-Robin Syndrome; Lujan Fryns; Talipes.

Mixing Adults and Children on Hospital Wards

AWCH has received an increasing number of enquiries regarding children and adults being accommodated together in hospital wards in NSW. This is particularly concerning,

AWCH- ENQUIRY REQUESTED 99/00 (by percentage)



as it appears that this kind of mixing is happening more regularly. There are a number of strategies that can be used to address this issue and AWCH would encourage any hospital having this sort of problem to contact National Office (02 9633 1988) with their concerns.

Parental Presence During Anaesthesia Induction and in the Recovery Room

The parent of a child due to undergo a tonsillectomy was concerned because the hospital they were attending had stated that their policy was to restrict parents during anaesthesia induction and in the recovery ward. After discussion between AWCH and the hospital concerned, it was agreed that the parent could be present both during anaesthesia induction and in recovery. The parent reported a positive outcome and the hospital stated that they had changed their policy to reflect appropriate practice.

New Emergency Wing Built Without Appropriate Facilities for Families

Concerns have been raised that the new emergency unit built at Blacktown Hospital does not address the needs of children and families, ie that there is no separate entrance and waiting area, as well as the absence of a child-friendly waiting area built into the emergency unit. A letter was sent outlining AWCH concerns and AWCH will continue to address this issue.

AWCH Health Care Policy Relating to Children and Their Families

A copy of the AWCH *Health Care Policy Relating to Children and Their Families* has been sent to all Australian hospitals with paediatric beds. This has resulted in a number of requests for more policies and information. Used in

conjunction with *ACHS/AWCH Guidelines for Hospital-based Child and Adolescent Health Care* and the *NSW Health Department Guidelines*, the AWCH policy is proving to be a useful tool to advise health care professionals and parents on the appropriate psychosocial care of children in the health system.

The NSW Isolated Patient's Travel and Accommodation Assistance Scheme (IPTAAS)

The scheme is designed to improve access to specialist medical treatment and oral surgical health care for people living in isolated and remote communities in NSW, through the provision of some financial assistance towards travel and accommodation costs.

Recently, IPTAAS has changed its administration of the scheme which makes it much more complicated for families, who now have to fill out more complex paperwork before they travel to the hospital and also are required to pay two nights accommodation costs up front. This can prove extremely difficult for families in an emergency situation and for those who do not always have available funds.

AWCH would like to hear from any families experiencing difficulties with the IPTAAS Scheme.



Carer's Allowance/Child Disability Allowance

It was brought to the attention of AWCH that the Carer's Allowance entitlement was, in the case of one family, cut off after 63 days of hospitalisation. Centrelink states that there are 63 days allocated for respite care and 63 days allocated for hospital care. Moreover if your child is in hospital for more than 63 days, you can use the respite days up to the total of 126 days before your entitlement is affected.

It is well documented in the literature, that there are additional costs during the hospitalisation of a child and that the financial support of families suffering economic hardship is necessary. If these families are to care for their children during this time, it should not be seen as 'respite' but rather as the carer's contribution to the recovery and well being of their child. It is necessary that the 'family-centred care' approach to the hospitalisation of children be appropriately resourced and funded.

AWCH would like to hear from any families who have had difficulties with the additional costs associated with the hospitalisation of their child.

AWCH is a consumer member of the **Acute Care Implementation Working Group (ACIWG)** which is one of the groups that are undertaking to implement the Government's Plan of Action which outlines strategies to improve the quality and accessibility of public hospital admissions. The ACIWG will oversee the implementation of strategies to improve the management of planned and acute public hospital admissions as outlined in the National Demonstration Hospitals Program (NDHP), including identification of targets for Day - of - Surgery Admissions and Day - Only Admissions. It is heartening to know that pre-admission and discharge planning are on the agenda!

Dorothy Margaret Williams Early Childhood Educator 1920 - 2000

Dorothy Williams, who died suddenly just before Christmas, was a pioneer in early childhood education. Her teaching and lobbying abilities had a wide reaching and abiding influence on the education, health and welfare of young children and their families.

During World War II Dorothy became a supporter and friend to many mothers and children surviving through poverty and hardship. In 1943 she married Dr Alan Williams. Later the extended illness of their eight year old son and their constant vigil in his ward at the Royal Children's Hospital, Melbourne alerted Dorothy and Alan to the needs of children in hospital.

Dorothy lobbied hospital authorities to extend visiting hours, for a safety crossing outside the hospital, and for provision of local accommodation for the parents of sick children. With the support of Alan she was also instrumental in establishing a play program at the Children's Hospital. Following its success, she was asked to set up similar programs at the Austin Hospital and Queen Victoria Hospital. This led to the eventual employment of trained early childhood staff in hospital settings.

In 1996 Dorothy and Alan established the Peter Williams Trust Fund in memory of their son Peter, who died in a hiking accident in 1968, aged 16. The trust focuses on the importance of early childhood experiences and supports those who are working to provide services for disadvantaged children and parents in their role as carers.

Dorothy and Alan were a formidable team in their advocacy for quality care for children and their families. The foundation of the trust was a culmination of their dedication.

AWCH Ward Grandparent Christmas Party 2000



Held in December 2000 at Sydney Children's Hospital, the AWCH Ward Grandparent Scheme Christmas party was a pleasant get-together of ward grandparent volunteers who have worked tirelessly throughout the year to look after hospitalised children.

60 NSW Ward Grandparents visited **308** children in separate visits during 1999-2000, totalling **5835** hours - a fantastic achievement!

AWCH would like to **congratulate and thank** all the ward grandparents for the hard work they do year in year out.

Participating Hospitals include:

- Children's Hospital Westmead
- Sydney Children's Hospital
- Royal North Shore Hospital
- King George V Hospital
- Liverpool Hospital
- Gosford Hospital
- St George Hospital
- John Hunter Hospital, Newcastle
- Port Macquarie Base Hospital

Ruth Jensen - a celebration of her life and a tribute to her community and charitable work 18 May 1927 - 27 February 2001

[Address (edited) given by Irene Hancock at the funeral of Ruth Jensen held on 5 March 2001]

Ruth served the community in two very special ways; firstly as an Association for the Welfare of Child Health (AWCH) Hospital Ward Grandparent and secondly as a member of Ladies of Variety.

In 1986 AWCH commenced a pilot scheme at the Royal Alexandra Hospital for Children at Camperdown, of visiting grandparents to provide support for unaccompanied or unvisited children in hospital and to provide relief for parents. Ruth was the first "Ward Granny" of the scheme.

The importance of the scheme is best described by Ruth in an interview she gave about the scheme. 'For many parents, family commitments, geography, finances or work mean they can't be with their child every waking minute. We look after the children when their parents can't be with them, as if we were their granny. It's letting them know that they have a special visitor, that there is someone there for them and you are not going to give them needles or treatment. They start looking for you;



its a great bonding process. There are three changes of nurses a day; being there makes you feel that you are doing something positive to help that child. You do get very attached, and yes we do cry when they leave but you have to pull yourself together and get on with it because there is another one waiting.' Ruth went on to say 'It's up to the parents whether they keep in touch with their ward grannies and many of them do.'

And keep in touch they did. Ruth was a big part of many families' lives. She managed to bond with everyone in life. She was a most considerate and thoughtful person. If her friends were ill or troubled there would always be a card, a telephone call and an offer of help, not to mention the famous orange cake and fruit slice.

During the early days of the scheme one ward charge sister wrote 'I would like to express my personal appreciation of the care and tenderness shown to K by Mrs Ruth Jensen. Before Ruth established a regular

pattern of visiting and care, K would cry for extended periods of time. The nursing staff were aware of K's needs, but our time was so limited that one-on-one care was impossible. K's contentment grew as he absorbed Ruth's enjoyment of him. The distress of the staff also decreased, and when K died we knew that in his last few weeks of life he had had the extra care and love that should be the birthright of every child'.

Ruth often spoke of the joys she was blessed with. Two of her greatest were to be asked to be Godmother to two of her little "Grand daughters" Valeric from New Caledonia in 1990 and Amelia Louise a little Aboriginal girl from Coonamble in 1992.

She and Gill would often provide accommodation in their home for families of children in hospital. Ruth also took on the role of Grandparent Co-ordinator for AWCH in 1994 and continued until her passing.



As an example one of Ruth's reports at the 1996 AGM, gave statistics of the scheme: 'at 9 NSW Hospitals, 59 Ward Grandparents visited 208 children in 2,415 visits totalling 10,012 hours.

Ruth expanded the scheme by visiting hospitals throughout NSW, giving talks to Service Clubs and organisations. Whenever a hospital required more grandparents, advertisements were placed in the local press of a particular hospital. Ruth would interview every applicant by phone, informing him or her of the commitment required ie. Visit 4-5 days a week, 4-6 hours per day and that they needed both physical and emotional strength.

She travelled to all the facilities by public transport. When the Children's Hospital moved from Camperdown to Westmead, Ruth would catch a bus from her home to Chatswood, train to Central, change for a train to Westmead and walk in her "joggers" to the Hospital and repeat the performance at the end of 5-6 hours, stating that it gave her plenty of time to read. Dr John Yu, when I spoke to him of Ruth's passing, said Ruth would have wanted to die with her boots on. He is so right.

Ruth's service with ladies of Variety was similar in that she arranged and accompanied disadvantaged and disabled children from all over Sydney on outings to the Botanic Gardens picnics and harbour cruises. She held the position of Secretary for a number of years.

Ruth was recognised for her services to children; in the 1994 Queen's Birthday honours when she was awarded the OAM; in 1996 Communicator of the Year and in 1998 received the Variety Club of Australia's Humanitarian Award.

Ruth could not get over the kindness shown to her by family and friends alike when Gill was ill and later when her own health began to fail.

I said to her, 'Ruth you only reap what you sow'.

Irene Hancock
National and NSW Branch President of AWCH

Conferences

2001 General Practice & Primary Health Care

31 May - 1 June 2001

Email: conference@conlog.com.au

Phone: 02 6281 6624

The First Ever Neuromuscular Conference

7-9 November 2001

Sky City, Auckland

Email: Denise@mda.org.nz

Phone: 09 815 - 0247 ex 1

Karitane National Conference

13 - 14 September 2001

Sydney

Email: conorg@ozemail.com.au

Phone: 03 9380 1429

THE LATEST FROM THE LIBRARY

AWCH Library holds information for parents and professionals on child and adolescent health, specialising in psychosocial care. Services are established so that you do not have to visit in person. Anyone from across Australia is welcome to use the library's extensive resources.

Opening Hours: Various

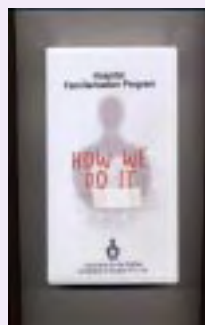
Contact: phone: 02 9685 9318
 fax: 02 9685 9301
 email: awch.av@uws.edu.au
 email: j.laverick.@uws.edu.au

Catalogue Available



The AWCH Library **Audio-visual Catalogue** gives a complete description of all audio-visual items available for loan.

RECENT ACQUISITIONS REVIEW



VIDEO REVIEW

Hospital Familiarisation Programme: HOW WE DO IT

45 mins, colour, 1/2" VHS V/C,
 AWCH W.A., Perth, 2000

The Hospital Familiarisation Programme was introduced by the Association for the Welfare of Children in Hospital (AWCH) in 1983 and is designed to prepare young healthy children for possible hospitalisation or visits to the doctor or dentist. Negative reactions to hospitalisation and medical interventions can have immediate and/or long - lasting psychological effects.

This video shows in detail the different components of the programme including the group session where the children participate in discussions about their own hospital experiences, the showing of various pieces of medical equipment e.g. stethoscope, and the free play time where children are given the opportunity to dress up as doctors, nurses, ambulance drivers etc., while others act being the patients. A video is also viewed in which a young child is admitted to hospital and taken through the usual procedures.

An excellent preparation tool for younger children, from 4 to 8 years, and ideal for showing at preschools.



BOOK REVIEW

PEDIATRIC REHABILITATION NURSING

by Patricia A Edwards, Dalice L Hertzberg, Susanne R Hays, Nancy M Youngblood

Paediatric rehabilitation nursing has evolved over the past 25 years from the separate practices of paediatrics and rehabilitation into a true specialty practice committed to the care of children and adolescents with disabilities and chronic conditions and to their families.

This book provides an important reference for nurses and stresses a continuum of care from hospital to home and community and is presented with emphasis on rehabilitation management to maximise the potential of the child, adolescent and family.

Published by W.B. Saunders. 1999

Magical Christmas Party!



by Debbie Skinner
Child and Adolescent Unit, Hornsby Kuringai Hospital



A Winter Wonderland...



Our Christmas theme this year was a winter wonderland theme. Our simple idea got more and more complex as the months progressed but the result was rather spectacular.

The main ward area was designed and created by the nurses, their families and our wonderful ward clerk, Allison. Everyone contributed whether it be cutting out snow flakes, painting murals, knitting or collecting penguin pictures. We all had our 'homework' which we proudly brought to work!



Three different penguin patterns were used and the rookery just grew and grew. Staff knitted, their mothers knitted and beginner knitters tackled the scarves. We taught an 8 year old boy to knit and he consequently taught one of the nurses (name withheld as he didn't want his dad to know he was knitting sissy stuff!).



We had small penguins on our Christmas tree along with a knitted snowmen and Santas. Below the tree we had an ice display with life size fairy penguins.

Probably the most impressive display was across the ceiling. One of the nurse's fathers made us a chairlift and this seated party penguins - all different and really cheerful. Everyone was amazed by the effect. I think we had close to 100 knitted penguins!

Chairlift Penguins...

The chairlift penguins remain on display and the others are to be sold as a fund-raising venture.

Marion, one of our talented volunteer play ladies, transformed an isolation room into an old-fashioned lounge room complete with fireplace, fake window and all the Christmas trimmings.



The involvement and hard work was a credit to everyone. Our display became well known and we had many visitors. We won first prize in in the hospital decorating contest.

Each year the ward has a Christmas party and invites children who have prolonged and frequent hospital stays. It is wonderful to see them again and I believe the party helps alleviate any fears of further hospital visits.

The party is organised and run entirely by the ward staff. We organise the invitations, the entertainment, the food and fill the ward with balloons - this year white to resemble snow!!



Santa visits and distributes lollies kindly donated by the play ladies. The children get so excited when Santa arrives. This year we had close to 50 children and their families. It is an exhausting day for staff but it is all worthwhile. The children have such fun and the parents appreciate our efforts.





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