

### Session 3

#### **A. Acute Care Experiences: Carer Friendly Practices**

##### **Enhancing Carer Friendly Health Practices**

*Kathy Pride, Sydney West Area Health Service*

In 2006 the Carers Program (SWAHS) initiated the Enhancing Carer Friendly Health Practices (ECFHP) Project. The project's aim is to improve communication between carers and health staff in the acute care setting. An important element of the first phase of the project has been the collection of baseline data to ascertain current work practice. Three pre measures were undertaken: 1. Carer Need Survey- To ascertain what carers expect from acute facilities. 2. Audit of the Patient Assessment on Admission form- To ascertain whether acute facility staff use the existing form to identify carers. 3. Pre Carer Awareness Training staff questionnaire- To gauge carer awareness prior to providing training to identified staff.

Being part of the ECFHP project is an opportunity for participating wards and departments to utilise valuable baseline data to inform what component of enhancing a carers experience they would like to improve.

##### **The Right Information at the Right Time: The results of a carer pilot project**

*Nicola Griffiths, North Sydney Central Coast Area Health Service*

There has been a lot of research on discharge planning practices from hospital to the home setting. This has found that carers received very little (and often unsatisfactory) information concerning care at home. Further, the health and employment status of carers was often not considered in the discharge of patients (Driscoll, 2000; (O'Connell and Baker 2004; Armitage and Kavanagh, 1998; Efraimsson, Sandman and Rasmussen, 2006).

The aim of the Carers Pilot Project was to offer information/resources for carers following hospital discharge of care recipients. Contact was made with the carer soon after discharge, and then followed up. Whilst it is recognised that social workers/discharge planners play a pivotal role in discharge planning, the provision of accurate and appropriate information at the right time for carers is vital in the success/ failure of the caring role. This pilot has shown that the ability to talk through information with a particular worker and ensuring the carer understands this information, eases the caring burden.

#### **B. Developing Resilience**

##### **The Short and Long Term Impacts of Counselling for Carers**

*Eva Soliman, Carers NSW*

This presentation provides an overview of the methods and findings from research on the effectiveness of the NSW National Carer Counselling Program (NCCP). The NCCP is a service that provides short term face to face counselling to all carers in NSW through professionally qualified brokerage counsellors. In 2005, both the long and short term impacts of the counselling program were the subject of research, where these impacts were evaluated for the first time. This research was aligned to the five specific themes of the NCCP standards guideline used by NCCP counsellors to guide and support carers through their caring journey. These themes are: Coping skills and strategies; Carer health and wellbeing; Access to services; Relationships sustained by the carer; Finance and Employment.

The research findings indicated that improvements in the first four areas were significant after counselling. The fifth area of finance and employment indicated little to no change, however, a conclusion can be made that the NSW NCCP enhanced the overall resilience for carers in four key areas. Recommendations from carers and Carers NSW on ways to improve the program will also be presented.

##### **Mind Yourself: A personal and skills development program for carers**

*Marika Kontellis*

The Mind Yourself© Program was the result of innovative thinking and a desire to give Carers an opportunity to apply and participate in a unique personal development journey. Under the guidance of trained and experienced facilitators, participants experienced learning and development opportunities in safe, fun and inclusive environment.

Marika, the Program facilitator will speak about how the program was developed, it's theoretical underpinnings and the results of the independent evaluation. Prudence, program participant will speak of her experience and what the MYS Program meant for her and the other 17 participants. The presenters will argue that the Mind Yourself Program is a benchmark example of Carer/Provider partnerships that can deliver better health and well being outcomes.

## **C. Theory and Practice in Carer Support: The Challenges**

### **How do you Know What Works? Finding theoretical perspectives for effective carer support**

*Barbara Lewis, North Sydney Central Coast Area Health Service*

Do we know what makes effective carer support? Or is what we do *that works*, ad hoc? Are the interventions for carers based on theoretical perspectives that relate to the specific needs of carers or is it just good luck when they work? Why is knowledge of theoretical perspectives important when planning effective carer support programs? These questions are important as competing paradigms of what constitutes an effective carer support program need to be fully responsive, holistic and well targeted to the needs of carers across their life course.

Payne (1997) argues that 'theoretical ideas are an important pillar of mutual understanding and identity' and it allows us 'to specify what we do and why', an important part of theory. We discuss competing theories that can help build up the knowledge base of why certain interventions work and others just don't hit the mark.

### **Health and the Community Sector: Why do we need sustainable collaborative partnerships?**

*Katrina Alexander, Far North Coast Area Health Service, Commonwealth Carer Respite and Carelink Centre*

North Coast Area Health Service (NCAHS) and the Far North Coast Commonwealth Carer Respite/Carelink Centre need to work collaboratively to achieve the best outcome for service delivery to carers.

Some key questions to be addressed include:

- What does collaboration mean for practice?
- What are the benefits of including carers and how do we do this?
- Why is it worth overcoming the challenges and what are the benefits?
- Challenging health and the community partnerships to acknowledge, understand and value the work carers do
- Sharing the vision and sharing of resources – financial and human resources. Building networks.

Incorporating sustainable partnerships through policy development and change are some of the challenges.

## **Session 7**

### **A. Indigenous Carers Moving Forward**

#### **Art as a Process of Healing in Working with Aboriginal Carers: A practical and creative approach**

*Janice Kennedy and Sue Wildman, Aboriginal catholic Ministry Community Centre*

Within Aboriginal communities, there is often little knowledge about the assistance available to carers and the impact caring can have on emotional and physical wellbeing. Indigenous carers are usually supporting more than one family member and often have health problems themselves. Aboriginal health statistics show that diabetes and heart conditions are common amongst Aboriginal communities and these conditions are exacerbated by stress.

A Group work approach that offers the opportunity to gain both practical information and increase personal awareness of the impact of the caring role through creative therapy has been shown to work well with Aboriginal carers. Findings are based on pilot groups conducted at Minto and Penrith. This presentation will look at the workshop process and will include a presentation by one of the carers who now co-facilitates the workshops.

#### **Practical Application in Developing Sustainable Partnerships and Resources in Indigenous Communities.**

*Shelley O'Keefe, Epilepsy Action*

Continuing the model of service delivery trialed two years ago and presented at *Shifting Paradigms* Conference, Epilepsy Action conducted a survey in order to develop resource materials that were culturally and linguistically appropriate for use in Aboriginal communities.

In the process of conducting the survey Aboriginal communities responded with requests for information and education sessions and gave feedback on existing resources, what they need, and why they would read some things and not others.

The survey was designed with assistance from Sheree Freeburn, Aboriginal Development Officer, Carers NSW and was conducted in metropolitan, rural and remote areas in Far North Queensland, NSW, and Victoria with epilepsy educators and local community and health workers.

This paper examines the collaborative work in developing an Indigenous Seizure First Aid poster and to access local communities; The role of Gulaymaldhaany, a Carers NSW initiative, in developing networks with local Aboriginal communities and peak organisations attitudes and beliefs around health and epilepsy in Indigenous communities and the implication in service delivery.

## **B. Making the Connections: Support Culturally and Linguistically Diverse Carers**

### **Making it Work: The theory and practice of partnering with carers from CALD backgrounds**

*Jill O'Connor, Down Syndrome Association and Emily Johnson, Carers NSW*

This paper combines the findings from a literature review of support for CALD carers and an issues paper of partnerships between ethno-specific, multicultural and mainstream organisations with practical lessons learnt from a carer project targeting CALD communities.

It presents the experience of the 'All the Way' project in building/maintaining relationships and consulting with the Arabic, Chinese and Vietnamese communities, delivering education and training to CALD carers as well as translating and distributing printed materials in the three different community languages.

This will provide health professionals, community care workers and policy makers with an insight into some of the issues faced, but more importantly lessons learnt, from creating partnerships with carers in program design and delivery to ensure best possible outcomes for both carers and those they care for.

### **Reaching Out and Connecting to CALD Carers has created a Cambodian Tapestry**

*Patricia Berrutti, Sydney South West Area Health Service*

It is an amazing story of the "Power of One" and how a tapestry can grow within a culturally and linguistically diverse community. How did the Tapestry start? With a Khmer carer reaching out and connecting to carer education programs being offered in Sydney South West by the Carer Information & Support Service. This carer participated in the programs in English and wanted other Khmer carers to be able to access the programs, so the tapestry grew. This one Khmer carer has now made it possible for over 60 Khmer carers, male and female, to participate in the different programs offered. It has further expanded to include a 'Khmer Carer Package' and a written and visual story of the Cambodian experience. That tapestry was shown for Carers Week 2006 and also at the Amnesty International Conference, and may be displayed at Parliament House.

This presentation will also explore how to connect with male and female carers in CALD communities, and how a project can develop many partnerships, and the rippling effects.

## **C. I'm Comfortable at Home: Supporting Carers in Palliative Care**

### **There's no Place Like Home: Challenges in practical support for home based palliative care**

*Britt Granath, The Cancer Council NSW*

Palliative care is any form of treatment that focuses on reducing the severity of the symptoms of a disease and improving the quality of life of patients, rather than providing a cure. Many stakeholders have told The Cancer Council NSW that people providing home-based palliative care for loved ones with a terminal illness need more practical support to undertake their day-to-day caring role.

Preliminary results from stakeholder and community-based consultation have highlighted three overarching issues: Access to medical and allied health services; Assistance with household tasks and physical care; and Information and education for carers.

Taking action on these matters should result in a greater proportion of those with a terminal illness being able to obtain medical treatment in comfort at home, increase their quality of life and reduce the number of hospitalisation, allowing those with end-stage disease to die at home if they so wish.

### **Supporting and Educating Carers in Palliative Care**

*Beth Harvey, Carers NSW*

Carers in the home palliative setting are often overwhelmed with the role they have to undertake during this emotional time. Some are unaware of available services. The Supporting and Educating Carers in Palliative Care Project helped carers to feel better supported, more informed, and confident in their caring role.

Carers NSW partnered with South East Sydney Commonwealth Carer Respite/Carelink Centre to develop and deliver most of the training. South East Sydney Commonwealth Carer Respite/Carelink Centre was also pivotal in recruitment and follow-up, providing transport and respite for attending carers, and talking to carers about respite.

This paper outlines the issues for carers and useful strategies for service providers. The target group was carers in the community.

### **A Community Collaborative Model of Care for People with End Stage Dementia**

*Stephanie Lindsay and Miriam Coyle, South East Sydney Illawarra AHS*

The choice of dying at home as a realistic option for the person with dementia empowers carers and clients. As dementia is a terminal condition, clients and carers benefit from a palliative approach. Palliative care of the person with dementia should encompass the needs of the carer and client in a collaborative partnership with health professionals and community services providers. In this model carers are empowered to make informed decisions through education by the case manager, facilitating a more positive approach during grieving. This presentation explores the opportunities for choice in the palliation of people with dementia illustrated through the use of case studies.

## Session 8

### A. Carers in Acute Care: Carer Inclusion

#### Carer Inclusiveness Acute Service Delivery: Beyond the Rhetoric!

*Pamela Mitchell and Jennifer Lamrock, North Coast Area Health Service*

The Lismore Base Hospital (LBH) Carer Initiatives Working Party commenced in July 2005 in response to feedback from a Carer Forum held as part of the Dementia Volunteer Value Added Veterans Service Project in September 2004. The working party developed 12 strategies to address the issues identified that encompassed changes to care delivery practices, staff education in caring for people with dementia and a formalised process for meeting with carers and documenting needs and patient issues. A Carer Community Consultation Focus group (one of the initiatives from the Working Group) was held in May 2006. Carers were asked five questions relating to the care of children and/or adults who had accessed LBH in the previous 12 months. The evaluation forms completed by the Carers (7) and professionals (2) clearly demonstrated that the Community Carer Consultation was highly successful in being able to express their needs and to discuss outcomes for LBH. This information has been used to inform ongoing and new initiatives. The success of this model for carer consultation and inclusiveness has resulted in a further forum being planned for 2007 in another part of the Area Health Service.

#### Knowing is Understanding: Carers' experiences supporting people with mental disorders dealing with hospitals

*Barrie O'Connor and Toni Cannon, Carers Queensland*

A recent Queensland study explored carer experiences supporting a person with mental health issues through hospital admission, discharge and follow-up processes. Particular concerns included: non-admission of acute mental health cases, sometimes precipitating anti-social and criminal behaviours; patient-doctor confidentiality that excluded carers performing caring and advocacy roles; inadequate discharge planning that ignored patient and carer circumstances (e.g. discharging patients with a cab voucher and no surety of support either to reach home or have adequate follow-up support; Friday discharges to make room for weekend admissions irrespective of patient readiness to leave); poor interagency communication among police, hospitals and family supports; and perceived discriminatory attitudes by hospital staff to those with mental health problems arising from substance abuse. Against a wider literature review, the study recommends steps to: improve interpersonal and interagency communication, give carers an effective and legitimised voice, and ensure families are adequately prepared to support members when they become unwell.

### B. Supporting Parent Carers

#### Building Links: Support and education for parents of newly diagnosed children of autism spectrum disorders

*Emma Pierce and Rebecca Sutherland, Aspect*

Parents report that the period following a diagnosis of autism is one of confusion and stress. Autism Spectrum Australia's *Building Links™* program aims to help parents begin to overcome the isolation of autism by providing education and support in the period following diagnosis. *Building Links™* is an innovative NSW-wide project developed by Aspect's BUILDING BLOCKS® Early Intervention for Autism with funding from NSW Health under the NSW Carers Program. *Building Links™* works in partnership with local service providers to build community capacity & increase skills and knowledge for parents of young children with Autism Spectrum Disorders.

This paper will discuss aims, structure, evaluation process and outcomes of the project in both metropolitan and regional areas of NSW. Results to date have indicated a statistically significant increase in parental reporting of their skills and knowledge, which includes feeling more confident, better able to meet their children's needs and benefiting from the opportunity to make connections with other parents.

#### FamilyCare: A partnership making a difference

*Terrance Ryan, Terry Ryan Consulting and Michelle Frank, Spastic Centre*

This paper describes a successful partnership involving The Spastic Centre of NSW, The Sunnyfield Association, Wesley Mission and parents. This partnership grew out of a desire to provide a resource through which parents could be better equipped to handle the extraordinary demands of full-time caring. The publication "*What about me...? A guide for caring*" was developed from a parent's perspective to support those who are providing such care. This publication led to the rollout of a series of information workshops across NSW, based on a mutual aid model. Mutual aid, where participants are encouraged to support each other, is recognised as an effective approach to supporting families caring for a person with additional needs (Ainbinder et al 1998, Law et al 2001, Solomon et al 2001). The aim of the program is to develop lifelong care strategies that take into account the needs of all family members. Participants in the program have reported the development of greater understanding, knowledge and skills as well as improved family circumstances. The main benefits for the contributing agencies include the development of an innovative service approach, taking steps towards addressing long-term needs and realising the benefits of partnership.

## **C. Carer Support Group**

### **Effective Partnerships in Dementia Care: The findings from the Quality Support Groups Research Project**

*Jo-Ann Brown, Alzheimer's Australia NSW*

Alzheimer's Australia NSW resources a range of dementia carer support groups. Despite their popularity, only anecdotal evidence existed to support the positive impact these groups were having on the lives of carers of people with dementia. Research was initiated to investigate, in a measurable way, how support groups contribute to the health and wellbeing of carers of people with dementia. A range of data was collected from support groups across NSW, and analysed in collaboration with Macquarie University. Evidence from our research indicates that support groups are an effective means of meeting the needs of carers with dementia and that the skills of the group leader are an important factor in that process. We believe this research has the potential to enhance best practice approaches for all carer support groups in the quest for effective partnerships between carers and professionals.

### **Caring Through the Ages – Experiences from the Wellington carers support group**

*Lynne Rich, Wellington Council*

In a partnership between the local Community Health Centre and Wellington Council, the Wellington Carers Group uses a multidisciplinary approach to target those caring for Aboriginal people, the aged, young people and those with a disability. Disciplines involved from both organisations include Child and Family health, Community Nursing, Aboriginal Health, Aged Care and Welfare.

Benefits of this approach include: Linking carers from different ages, backgrounds and caring situations; Utilising the skills, backgrounds, talents and local knowledge of each team member; Allowing for the continuation of the group and decreases the risk of burnout.

Benefits to carers from this approach: Involvement in the decision making of the group; increased confidence of Aboriginal carers; Development of friendships between the group.

The model used is being recognised by other carer's groups, both established and potential, as an effective and innovative way to meet the needs of all carers living in a rural community.

## **Session 9**

### **A. Patient Focused Carer Centred**

#### **Combination Therapy for Chronic Hepatitis C: A family impact study**

*Helen Blacklaws, North Sydney Central Coast Area Health Service*

Chronic hepatitis C affects approximately 250,000 Australians. Hepatitis C can be treated, with the majority of clients achieving a cure. However, treatment is lengthy (6-12 months) and associated with multiple physiological and psychological side-effects. Anecdotal evidence suggests that side-effects have considerable impact not just on the individual receiving treatment, but also on the functioning of the family unit as a whole.

The Central Coast Liver Clinic is conducting a Family Impact Study to examine how the side-effects of combination therapy affect day to day life and relationships within the family entity. The aim of our study is to gain a clearer understanding of family dynamics engendered by the treatment experience.

The aim of the presentation is to describe preliminary data and discuss how support strategies can be developed to maximise families' coping abilities during a prolonged and challenging treatment episode.

#### **Carer Support in Palliative Care – What Do carers want?**

*Julianne Whyte, Regional Social Development Group*

When a patient makes a transition to palliative care their needs can change very quickly as they enter an environment that is generally unknown to most people and surrounded in taboos, new treatment regimes, new ways of caring, and usually a different set of health care professionals making decisions about their care.

Patients and carers report that they want to be listened to and 'heard'. They also report that help is not always about more doctors or nurses, but someone to listen to their fears, explain what the next stage of their journey may look like and respect their 'expert' knowledge of their own life's situation. This paper will focus on a project for palliative care that integrates the psychosocial, spiritual and emotional needs of both the patient and the carer/s into a traditional medical model of care. It was developed in the Riverina with the Division of General Practice, the Area Health Service and the Commonwealth Carer Respite Service.

### **B. Reaching Invisible Carers**

#### **The Hummingbird Project: Young carers, who are the experts?**

*Antonia Ravesi, MISA Lifestyle Support Program*

The Hummingbird Young Carers Project was informed by the "Young Carers Research Project Final Report" 2001 and "The Report from the Young Carers Forum" 2004. The primary aim of the project was to raise awareness of young carers in high school communities and increase their access to support information. The secondary objectives were to reduce the increased risks of young carers leaving school prematurely and respond to the negative feedback from young carers of their experiences of health and support services. The experience of this project has taught us that by using simple strategies we can create a high school culture that supports young carers.

The project also highlighted the importance and benefits of increasing awareness of young carers amongst health professionals, particularly acute health services. This presentation will include practical strategies for health professionals to generate, in particular, better access to information and services for young carers.

### **Working Carers: Australia's ageing army**

*Dona Graham, Working Carers Support Gateway*

Australia's economic wellbeing is dependent on an ageing army of working carers who are buckling at the knees under the weight of their multiple responsibilities.

Industrial relations reform, inflexible workplace practices and an ageing population are all contributing to a ticking time bomb for our economy with demand for those requiring care projected to soar by up to 200 per cent over the next 25 years. The very people who are providing the care will shortly join the ranks of care receivers, leaving a huge hole (well in excess of \$19.3 billion annually) in both the workforce and the economy.

The issues facing working carers deserve immediate recognition and priority. The reality is we will be shortly living in a country where the number of ageing people outnumbers the young. Without action, the financial and social consequences of this scenario on our economy and our society could be catastrophic.

## **C. Unravelling the Maze: Supporting Carers in Mental Health**

### **Partnerships in Action: The development of the Family and Carer Mental Health Program**

*Senior Policy Analyst, Centre for Mental Health*

Since 2002 NSW Health, through the Centre for Mental Health, has undertaken a strategic development process to establish appropriate statewide service planning and delivery for families and carers of people with mental illness.

Through a partnership arrangement with Area Health Services, non-government organisations and carer networks, the Family and Carers Mental Health Program aims to improve resilience and coping skills in families and carers and increase understanding of the impact of mental illness on families and carers in mental health services and the wider community.

The model has two main components. The first is the implementation of the 'family sensitive mental health services' component by all the Area Health Services across NSW. The second is the provision of support services for families and carers, through four non-government organisations selected through an open tendering process, to provide education and training and provide individual support services across NSW.

The presentation will explore the particular characteristics of this partnership model that have been successful and those that have been challenging, and highlight the lessons to be learnt for ongoing partnerships between the government and non government sectors in providing carer support.

### **Hope for Carers: Stronger partnerships for sustainable change in Working with Families in Mental Health**

*Kathleen Hossack and Janice Nair, South East Sydney Illawarra Area Health Services*

In recent years it has become accepted that families should be involved in the management of patients with mental illness. But the reality is that professionals frequently lack skills and confidence in working with families and links between families and professionals have traditionally been weak.

The "Working With Families" (WWF) Project of the Sutherland Division of Mental Health was developed in 1996 to address this situation. Key objectives of the project were to increase the capacity of the service to work more with families and to decrease the distress and burden experienced by families. A key component of the approach has involved the development of sustainable partnerships between professionals themselves and between the health system, families and the community.

This paper will describe the WWF Program at Sutherland and the statewide training that has occurred over the last two years using the WWF model. This training and the systemic framework within which it sits is providing new hope for sustainable change for professionals, carers and consumers.