

## **Carers NSW**

### **25 Years: 1975-2000, a retrospective**

#### **The Beginning**

During International Women's Year 1974, the Council on the Ageing successfully applied for a grant to investigate the extent of care given by family and friends to the frail aged and, as they were then referred to, the handicapped. Clare Grant Stevenson was the Research Officer responsible for reporting on the survey of some 427 people who were caring at home in Sydney.

The title of the report, *Dedication*, described the people of the study. It also characterised Clare's approach to her work and her subsequent activity in the cause of carers. In 1976, she established a subcommittee under The Council on the Ageing with a group of dedicated volunteers working for the recognition of the needs of the people of the study. The first step was to give the study group an identity - she called them 'Carers'

#### **1980s**

The Carers Association of New South Wales became an independent body in 1980 with Clare as Founder President, and with the same band of willing volunteers. In 1981 The Carers Association became a registered charity.

1985 saw the culmination of Clare's many years of lobbying governments when the Carers Pension became available to thousands of people who had devoted their lives to caring for friends and loved ones in their own homes. This was also the year the Federal and State Governments' jointly funded Home and Community Care Program got off the ground.

In recognition of the importance of the work The Carers Association was doing on behalf of carers, money was made available under the Home and Community Care (HACC) Program in 1987, enabling the employment of part-time staff. The staff were still assisted by dedicated volunteers.

The monthly newsletter *Carers News* was launched during this time and this continues to be an important part of our operations.

In 1989 The Carers Association of New South Wales became an incorporated body, and in 1991 Nell Saunders, the Executive Officer welcomed Mrs Shirley Sinclair, wife of the Governor of New South Wales, as Patron.

#### **1990s**

The Carers Association held its first Carers' Conference in 1990 in Sydney. Conferences have been held on most years since then, alternating between Sydney and regional centres of NSW.

In 1991 the Association moved from its one-room office in Surry Hills (made available by the generosity of the Community Health & Anti-Tuberculosis Association) to more spacious accommodation in the Fitzroy Gardens, Kings Cross.

The 1992-1993 Federal Budget made funding available for the Carer Information Kit, which contributed to the expansion of the staff and volunteer base of the Association. This year also saw the inaugural Carers Week celebrations and activities, which have continued annually.

A national peak body was established in March 1993 to represent carers across Australia. Its highest priority is to promote the recognition of the important role of carers in our community, and to lobby the Federal Government about their needs.

1995 saw another increase in funding and a change of premises to York Street, Sydney. During the year the Association sponsored Ngara (To Hear and To Listen) Aboriginal Carer Support Service, a respite options service created to help Aboriginal carers in the Penrith and Blue Mountains areas get respite support. A state Aboriginal Development Officer was employed to support Aboriginal and Torres Strait Islander carer initiatives across NSW.

The Carer Support Kit was made available in 10 community languages and a Non-English Speaking Background (NESB) Access Officer was employed.

Research being a priority for the Association, a twelve month Research Project was commenced to analyse the kit data and survey carers to find out what general practitioners do – or don't do – to support carers. The report on the project was called *Do Doctors Care*.

The Association also received funding to commence a Counselling service. To determine how best we could develop this service, pilot counselling services were implemented and reviewed through 1996 and 1997. The recommendations of the report have guided our work in carer counselling and emotional support.

In 1996 the Nell Saunders room was opened in memory of the first Executive Officer and the Tom Fink Library was established in memory of the husband of the then President, Averil Fink.

1996 was also the year in which the second edition of the 16 Carer Directories was launched.

In 1997 the Association's constitution was revised and the organisation was renamed Carers NSW Inc. In this year Joan Bullock was awarded Life Membership.

In February of this year, Carers NSW held the inaugural Carer Support Worker Conference in Sydney.

A research grant from the Department of Health & Family Services helped Carers NSW understand carers' use and non-use of community services. The report was called *Coping at Home*.

A NESB carer project on the needs of carers in South West Sydney was completed. This has helped to encourage NESB communities to run support groups.

Also in 1997, Carers NSW received funding under the National Respite for Carers program to establish the NSW Carer Resource Centre. This centre continued the work that Carers NSW was previously doing in supporting carers with information, referral and telephone emotional support.

The funding for the Carer Resource Centre was for 3 years, with continuation of funding subject to an evaluation during 1999-2000. The role of the Centre is described in the next section.

Young carers are also a group of carers whose families need support. In 1997 funds from the Department of Health & Family Services helped to provide the following:

- ◆ provision of short term information and support to families
- ◆ an information pack for families
- ◆ a training manual for service providers.

Camps for young carers have been provided through donations and in kind support from the community, the general public and very small government grants. The Young Carer Project Coordinator also distributes a quarterly newsletter.

Carers NSW devised the Carer Checklist in 1998, an information and referral tool piloted with over 100 GPs and health professionals.

The Carer Profile project was funded to research the importance of assessing carers' needs. This year also saw the inaugural Beiersdorf Carer of the Year award, former carers' research – *Picking up the*

*Threads* – and the introduction of the ATSI kit. Carers NSW also received two awards: one for work with carers of people with mental illness; and one for young carers work. Also in this year, Averil Fink was awarded Life Membership.

After five years the Carer Support Kit underwent a review. The recommendations of the review have guided the development of a new package of information for carers.

In 1999 the Carer Resource Centre was receiving an average of 60 calls per day. This year saw an increase in the number of Telegroup Counselling groups to 16 overall.

The third edition of the Carer Directories was completed. We launched, alongside *Picking up the Threads*, the Carer Profile project, which explores the importance of Carer Assessment.

Carers NSW sponsored a delegation to the 1<sup>st</sup> International Carers' Conference held in May in London.

## **2000**

Life Membership was awarded to Patricia Dunn.

The 2<sup>nd</sup> International Carers' Conference was held in April in Brisbane. Carers NSW sponsored a delegation of 40 people and presented many papers on a variety of carer issues.

The major research project in 2000 was a time use survey of carers being done in partnership with the Social Policy Research Centre of the University of NSW.

The Carer Resource Centre is still expanding its support to carers and receiving an average of 80 calls per day. Emotional support to carers is a priority for Carers NSW, and carers are increasingly requesting access to this service.

In 2000 Carers NSW received funding for one year to develop support programs for carers under 18 years of age. A manual about implementing the Telegroup Counselling for Young Carers was funded through a private foundation. This has allowed the association to develop training courses for service providers who have a responsibility for children and adolescents who have family members with illnesses or disabilities. Training on the model of Telegroup Counselling has been completed for mental health providers.

The Strategic Planning process for the next three years has been completed, resulting in a new structure for the organisation.

Carers NSW Inc is now in its strongest position ever to represent NSW carers and to provide them with accurate and appropriate information and support. The community development work, education about carer issues and research and policy work continue to expand. In particular, development work in indigenous and non-English speaking background (NESB) communities remains a high priority for Carers NSW.