



REACHING 'HIDDEN' CARERS

A position paper by the Carers' Coalition

**Developed by Carers NSW
in conjunction with the Carers' Coalition**

July 2001

LIST OF MEMBERS

- ACROD
- ACON – Community Services Network
- ARAFMI
- Alzheimers Association of NSW
- Autism Association of NSW
- Baptist Community Services
- Combined Pensioners and Superannuants Association
- Council on the Ageing
- Epilepsy Association of NSW
- Foresight Foundation
- Home Care Service of NSW
- Interaction Disability
- Jewish Care
- Mental Health Coordinating Council
- Motor Neurone Disease Association of NSW
- Multiple Sclerosis Society of NSW
- NSW Cancer Council
- Northcott Society
- Northern Sydney Home Nursing Service
- People with Disabilities
- Schizophrenia Fellowship of NSW
- SHHH (Self Help for the Hard of Hearing)
- South East Sydney Carer Respite Centre
- South West Sydney Area Health Service
- Stroke Recovery Association of NSW
- The Spastic Centre of NSW
- Transcultural Mental Health Centre
- United Ministry with the Ageing

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This paper has been developed as a result of the work done by Carers' Coalition during 2000-2001.

I. Background

Carers' Coalition believes that supporting carers is important because caring is a normal part of life. Almost everyone will experience it at some stage of their life (either as the carer or person being supported). **Carers always have a relationship with the person they are supporting, either as a partner, family member, friend or other person who cares about them. As a community, if we value these relationships we must also support them.** Caring is part of our 'social capital'; the very fabric of our society.

II. Why Are Carers 'Hidden'?

Carers' Coalition is concerned that many carers are 'hidden' in the community. This means they are not known as carers to any agencies or services and therefore receive no support in their caring role. Some communities are also 'hidden' because they are less well recognised than mainstream communities, or are marginalised. They, too, contain carers. There are many reasons why carers may not know about, or access, the services, that are available to assist them.

Members of Carers' Coalition commented that **many carers do not identify with the term 'carer' and therefore promotional strategies using this word may not be perceived as relevant. What is important is to appeal to the life situation or relationship of the person who is caring.** Members who work with parents of children with a disability said that parent carers identify, first and foremost, as parents rather than carers. Indeed, a paper entitled "Parents Not Carers" was given at the Second International Carers' Conference, held in Brisbane, Australia, in March 2000. Members who work with carers from culturally and linguistically diverse backgrounds (CALDB) and indigenous carers have commented that, for cultural reasons, such groups may also not identify with the term 'carer'.

Another group, which does not relate to the term 'carer' is the **gay and lesbian community**. Even words such as family may not be appropriate. A broader range of terms, such as 'partner' and 'significant other', may need to be used. The attitudes of service providers, and potential discrimination, is another barrier for this group.

Although it is more cumbersome, information may be more easily taken in if a phrase, rather than the single word 'carer', is used.

Using an explanation like “Does someone close to you rely on you for care?” may speak more directly to people’s experience. People may only identify themselves as a carer at a later stage, when their caring responsibilities are very time-consuming. There is also poor general community awareness of the term carer, which is complicated by the use of the term by paid workers, volunteers and by the childcare sector.

Previous research done by **Carers NSW (“Coping at Home”, 1998)** has shown that there are **multiple barriers to getting information and to service use operating for carers**. These included: the carers’ attitudes and values (need for independence, **feel that they are coping, desire for privacy, guilt and so on**), **practical barriers** (had some previous contact with services and found problems with quality or access), **information barriers** (didn’t know who to ask for help or perceived themselves as not eligible), **conflict-based reasons** (person they are supporting or family won’t accept outside help) and other reasons. These **reasons are often complex** and involve many underlying assumptions, and they are also inter-related.

Starting first with carers’ attitudes and values, one reason that many carers may not identify with that term is because of the reasons that they take on the caring role. Australian Bureau of Statistics data (1998) shows that the most commonly cited reason for taking on caring is that it is considered to be a **‘family responsibility’**. Just over half the respondents (57%) gave this as a reason. Other major reasons included that: **‘no other friends or family were available/willing’** (40%) and that caring was an **‘emotional obligation’** (39%). These reasons illustrate that many people see caring simply as an extension of their relationship to the person they are supporting. It is something they are expected to do, or want to do, because they love the person. Often this is then translated into an expectation that they should be able to do it on their own, or that it is not an activity for which the community provides support.

The information barriers that carers have are not as straightforward as they seem. The “Coping at Home” report showed (p37) that a majority of carers did, in fact, know of many community services. They also thought that the services were available in their area. What appeared to be the issue, however, was that **carers did not relate generalised information to their particular circumstances**. They did not understand how services could help *them*. Lack of information delivery by important contact points, such as GPs and other health professionals, did not help.

The “Coping at Home” study surveyed carers who had received a Carer Support Kit from Carers NSW and therefore probably had a greater knowledge of services than carers generally in the community. It is interesting to note how carers found out about the Carer Support Kit

(Table A2 in that report). The second most commonly mentioned source was a mail drop of the Carer Support Kit pamphlet. Australia Post delivered the pamphlets to all homes across New South Wales. This was obviously an important strategy in reaching carers who were housebound, were not known to service agencies or who may previously not have identified with the term carer. Other broad-ranging methods of publicising the Carer Support Kit, such as information on Medicare returns, bus advertisements, Senior Citizens' Centres and so on, also unearthed what would appear to be 'hidden' carers.

It is clear that any strategy to target 'hidden' carers must necessarily target the wider community. We do not know which particular households have caring responsibilities, nor what kind of information they will respond to. **A broad range of strategies, including some which take into account the needs of minority or special needs groups, will be required.** By taking this wider approach, community awareness of carers and caring generally will be raised and information may be passed on by relatives, friends and neighbours of 'hidden' carers.

Another barrier to accessing information and services is that some carers perceive this as 'not coping'. Carers often wait until a crisis occurs to ask for help because they feel that they must manage on their own. **Information about services and supports probably needs to be placed within a context of it helping carers to balance the different responsibilities, that they have, and of being a 'positive management' strategy.** This can be related to the person's stage of life. We must always remember, also, that some people will not want to access services and that no matter how much information is given to them, managing on their own is their choice.

III. Use of the Term ‘Carer’

The Carers’ Coalition, a group of disability, HACC and other community organisations convened by Carers NSW, has developed during 2001 a paper entitled “Reaching Hidden Carers”. This flyer is one section of that larger paper. Carers NSW and the Carers’ Coalition believe that before hidden carers can be reached, definitional issues need to be dealt with. Our thinking on this is outlined below.

One of the main hindrances to targeting carers easily, is confusion over who exactly is a carer. Many organisations within the community sector use the term carer for different groups of people, including paid workers and volunteers. There is no consistency in the use of the term. What this means is that carers as a group are not instantly recognisable.

Carers’ Coalition believes that the term carer needs to be reserved for family members or other people doing care on an informal basis. The term itself recognises the extra responsibilities that a person has because they have a family member, friend, partner or neighbour who has a chronic illness, disability, mental illness or who is frail. (It is important to note that a carer may also be aged under 18). The term carer probably also needs to have accompanying it a statement about the underlying rationale for its use. For example,

A carer is a family member, parent, partner, significant other, friend or neighbour who provides care on an unpaid basis. The person they support may have a chronic illness, disability, mental illness or may be frail.

Caring is a natural part of life and all people will either provide or require care at some stage of their life. Caring may last a short time or it may last many years. Carers have added responsibilities compared to other people at the same stage of life, and thus require support during their period of caring.

It was also agreed by members of the Carers’ Coalition that we would attempt to standardise use of the term carer, and other terms, across the industry, starting with our own organisations. A survey of the term used by member organisations revealed the following terms to be in use:

Informal/family carers

carers
family (carers)
Team
significant others
partners
husbands, wives
Officers
sons, daughters

Volunteers

volunteers
trained volunteers

community awareness
partners
support group coordinators

carers

Paid workers

staff
Family Support

Outreach workers
carers
Care Liaison

RN’s/EN’s

former carers
Coordinators
parents
primary carers

CSN carers
support workers

Stroke Care
Aged Care workers
Attendant Carers
Care Coordinators

What this reveals is that the term 'carer' is currently used for all categories of people involved in the caring situation, hence the confusion over who is a carer. There appears to be most consistency within the informal/family carer group. Here, the term carer is used by *all* organisations. Most organisations also use terms which express the relationship of the carer to the person being supported, for example, wife, daughter, parent, son, significant other and so on. There would appear to be no reason to change this current usage, as both types of terms would be useful at one stage or another.

Recommendation: That organisations continue to use both the term 'carer' and the relevant relationship term to describe informal carers (ie. status quo to remain).

Regarding volunteers, all organisations use this word. Some use it in conjunction with the term carer, while a few groups use specific terms which align the volunteer with either the program they are involved in or the organisation. Given that the term 'volunteer' is so widely used on its own, to reduce confusion it may be best to eliminate use of the word carer within this category.

Recommendation: That organisations use either the term volunteer on its own, or a title indicating the program work that the volunteer is doing. The term 'carer' is not to be used for volunteers.

The category of paid staff was where use of the term carer was most likely to cause confusion. It is suggested that this term is not used for paid workers. Most organisations use job titles, which make it clear what the role of the worker is. This may include use of the term 'care' within that title, for example, 'Care Liaison Officer' or 'Stroke Care Coordinator'. Other positions within organisations presented no problem because the term carer was not used for these positions.

Recommendation: That organisations cease using the word carer for paid staff. It is suggested that more descriptive job titles are used where this is not already happening, eg. Respite Care Worker, Personal Care Assistant, care worker, support worker, etc.

In summary, use of the term carer is to be reserved solely for family or informal carers. Other roles will be delineated by specific terms or job titles, which may include the word 'care'. This should involve minimal change for most organisations.

IV. How Do People Get Information?

In the past, many information initiatives designed to get information to carers have concentrated on using health, medical or disability services. While these are obvious points to target and certainly require more resources, it means that people not in contact with such services do not receive the information.

Carers' Coalition believes that information needs to be targeted much more widely in order to access 'hidden' carers. That is, we recognise that people are not homogenous and that different approaches are needed to inform and raise awareness among different groups. **Therefore, we should aim some initiatives at the types of institutions or services that people in the community generally use.** This might include schools, shopping centres, churches and so on. There are also new or emerging communities, such as virtual or cyber communities, which may be replacing other communities. We need to recognise and work with such communities in order to recognise the changing ways in which people relate to each other.

Combined with the issue mentioned earlier of people not identifying with the term 'carer', Carers' Coalition believes that using the term carer may not be the best way of capturing our intended audience. In conjunction with this, information may need to be produced in a 'subliminal' way, as part of other activities, which are not focussed on health care or caring. This is not to say that information should be generic. It needs to be **timely and relevant** for that community and built from within that community.

This links in with the fact that an important source of information is people's peers. This was certainly borne out by the "Coping at Home" study, in which family and friends was the third most common source of hearing about the Carer Support Kit. Carers may be more likely to take in information, which comes from others in a similar situation, or from people who are known well to them.

It was also thought to be important to **use individuals with credibility in different regions.** Information may be more readily received if it comes from a person with some influence or someone known to that community. Information from within a community may be more readily trusted or accepted.

Carers in rural areas may face other difficulties in accessing information. Certain services or institutions do not exist in some communities and alternatives may have to be found.

Non-English speaking carers may have language or cultural barriers, which prevent them accessing information.

In indigenous communities the concept of family and caring may be different. Past experiences of discrimination may also present a barrier for this group.

It is important that information:

- *is relevant to carers, even if not using the term 'carer';*
- *presents caring as a normal part of life;*
- *comes from a trusted or well-known source;*
- *is available in the places or groups that carers interact with in their everyday lives;*
- *is delivered in the right quantities and at the right times; and*
- *overcomes any specific barriers that a person might have.*

V. Creative Solutions for Getting Information to 'Hidden' Carers and 'Hidden' Communities

In accordance with the principles outlined above, suggestions were as follows:

a. How to get the message across

- using a community development approach;
- use well-known media personalities to deliver messages;
- advertise on Shop-A-Dockets or community notice boards in shopping centres;
- free postcards in coffee shops;
- have a distinct slogan and symbol for carers that is easily recognisable;
- Carers NSW to liaise with the Carers' Association of Australia about continuing to have mail drops of promotional material;
- rather than calling a function a "carers' day", use terms like "information day", "working bee", meetings for people who have been newly diagnosed (where carers might also attend), and so on;
- use either current or former carers within communities;
- use real examples of people in caring situations;
- use information technology;

b. Links with organisations in the community

- target disability and illness specific organisations (where these links do not already exist);
- make links with health insurance companies;
- GPs are a vital link for carers;

- target government departments not used until now, eg. Department of Housing, Department of Education (particularly special education units);
- target employers so that carers get information earlier in their caring cycle;
- target charities;
- target banks and utilities;
- target carers through schools, play groups, childcare centres;
- make links with sporting organisations;
- link in with existing Weeks, such as Cancer Week, Seniors' Week, Mental Health Week, etc;
- various religious groups or institutions (including those that may have a high proportion of people from a culturally or linguistically diverse background);

c. Activities

- hold writing competitions for school students;
- organisations could have stalls at community fairs and functions, market days, etc;
- hold a well-publicised march for carers;
- use the "Positive Speakers Bureau" at activities;

d. Specialist publicity

- target medical specialists through the relevant colleges/professional bodies, journals;
- use niche market publications, such as the ethnic media, gay and lesbian newspapers, community radio, Aboriginal media;

e. Special needs groups

- use land councils and indigenous services like medical centres to target Aboriginal communities;
- educate CALDB access workers to recognise caring issues and make appropriate referrals;
- employ CALDB workers within service organisations to encourage cultural sensitivity; and
- in rural and remote areas use local groups such as the CWA, churches, councils.

VI. Examples of Reaching Hidden Carers and Communities

The following examples of publicity and information distribution initiatives come from organisations that are members of the Carers' Coalition.

(a) Partnership with major government service providers

The Carers' Association of Australia has organised with Centrelink that in each issue of "Disability and Carer Connections" and in some issues of "Age Pension News" the Carer Resource Centre phone number is publicised. Although not all carers receive a Carer Payment or Age Pension, obviously these groups contain all and a substantial proportion of carers (respectively). By forming such an important partnership, large numbers of carers receive regular reminders that Carer Resource Centres are there to provide information, support and referral.

After the mailout of "Disability and Carer Connections", Carers NSW receives a huge increase in calls from carers seeking information. It has been an extremely successful advertising partnership for us.

(b) Using health professionals to distribute information

Carers NSW developed a tear-off pad called the "Carers Checklist" for doctors, pharmacists and other health professionals to give to carers. On one side, the Carer Checklist contains six questions to prompt carers to ring Carers NSW, and on the other side, information about what Carers NSW does. Health professionals are a vital contact point for carers who may receive no other form of assistance. By providing information to carers, health professionals often uncover 'hidden' carers.

In 1999 Carers NSW trialed the Carer Checklist in four areas of New South Wales. About 1000 Checklists were distributed by health professionals during the six month trial period. Carers NSW received a 10% increase in calls due to the distribution of the Checklist. This response rate is in line with responses from other health promotion strategies. Many of the GPs and pharmacists who took part in the trial commented on how having taken part had raised their awareness of carers and caring.

Unfortunately, at the time, Carers NSW did not receive ongoing funding for the Carer Checklist project. However with recent funding being granted for work in the area of mental health, work with health professionals and the Carer Checklist will resume.

(c) Using clients to help distribute information on your service

South East Sydney Carer Respite Centre uses its clients to distribute the Centre's pamphlets and to pass on information to other carers. In lieu of charging a financial contribution, the Carer Respite Centre decided instead to ask users of the service to assist in more practical ways. Carers, who often belong to clubs or groups such as Probus,

Rotary, Senior Citizens' Centres, etc., are asked to take the Respite Centre's brochures along to those groups and give them out. This method of distribution also involves use of 'word of mouth'. Telling others about the Respite Centre requires the carer to have a reasonable knowledge of what the Centre does. The Coordinator of the Centre explained that this allows the carer to integrate the Respite Centre more fully into their knowledge base. Also, the more that carers talk to others, the more people know about the Centre, the more the information spreads throughout the community.

The result of this method of transmission of information has been a substantial increase in the number of carers who ring the South East Sydney Carer Respite Centre for information about respite, to discuss appropriate respite options and for emotional support.

(d) Blanket coverage of everyone in certain communities

Back in 1997, the Carers' Association of Australia organised for Australia Post to deliver its Carer Support Kit brochure to every household in certain communities. This strategy was very successful in uncovering carers who were early in the 'caring cycle' and who were often not receiving any practical assistance.

Carers NSW were, at the time, undertaking the "Coping At Home" study into barriers to service use by carers. Thirteen per cent of the sample found out about Carers NSW via the maildrop mentioned above. This was the second most common source after hospitals/social workers/Aged Care Teams. Many of the carers mentioned how their GP had never told them about the community services, which were available to help.

(e) Strategies involving other groups which may apply to 'hidden' carers

The AIDS Council of NSW's *Community Service Network* (CSN) uses its current volunteers to recruit more volunteers for the program. Current volunteers are asked to tell their friends, family, colleagues and neighbours about their involvement with CSN. They are also given business cards with information about CSN on it and a contact number. Current volunteers distribute these to people who are interested. ACON have found this word of mouth approach to be highly successful.

The business cards are also distributed at community events and in the foyer of their building. The coordinator of CSN feels that this approach is particularly useful where there is an identifiable community.

(f) Using free community service advertisement space in various forms of the media

Many support groups use the community service announcement sections of local newspapers to advertise their activities. In the “Coping At Home” study conducted by Carers NSW (1998), 50% of respondents said that the local paper would be the best place to advertise community services. This is probably because local papers are home delivered and are free. They are an ideal way to reach a housebound population who may not be able to afford to buy other newspapers or magazines.

The Carers’ Association of Australia have also used the free ‘community service announcement’ advertising space on regional TV stations. However the disadvantages of this are, firstly, that the cost of producing ads for screening is still incurred and, secondly, that the ads are often shown at non-peak times, such as the middle of the night. Carers NSW received some response from the ads.

(g) Effective linkages with other services and thus consistent referrals from them

Carers NSW conducts twice-yearly workshops with the network of Carer Respite Centres across NSW. Therefore, a very good link exists between the Respite Centres and the Carer Resource Centre. Reciprocal referrals often occur between the two, as Respite Centres and the Carer Resource Centre have different roles.

(h) Stalls in shopping centres

The Seniors Information Service (SIS) run by Council on the Ageing (COTA) in NSW promotes its service by, among other things, having stalls in shopping centres. In this way, they can tell people about their service face-to-face. Despite shopping centres being a place that people frequent as a part of their everyday life, SIS has modified this strategy by going to smaller rather than larger shopping malls. The Manager of SIS said that “*older people tend not to go to the huge Westfields, etc, because they often can’t find their way around. We’ve had more success going to smaller malls*”. Promoting their service in shopping centres has led to a marked increase in calls from the regions visited.

VII. Recommendations to Progress This Paper

Carers’ Coalition believes that a **multi-layered approach** will be necessary (including a range of organisations) in order that ‘hidden’ carers will identify themselves as carers. The following recommendations are based on that belief:

- 1. That Carers NSW progresses the initiative to see consistency in the use of the term 'carer' by distributing pages 7 and 8 of this paper as a flyer to relevant organisations and government departments;**
- 2. That Carers NSW, in it's dissemination of information to carers, implement the suggestions contained in this paper;**
- 3. That member organisations of the Carers' Coalition, as well as HACC and other community services, also implement these suggestions in their publicity strategies;**
- 4. That government departments at both State and Federal levels take into account the level of funding that may be needed by community service and disability organisations in order to target hidden carers;**
- 5. That government departments, in their own publicity campaigns, disseminate information as widely as possible throughout the community in order that hidden carers may get information which is useful to them;**
- 6. That government departments also be aware that if organisations uncover 'hidden' carers, there may be budgetary implications in meeting any extra demand for services;**
- 7. That Carers NSW and members of the Carers' Coalition who deal with health professionals, educate those professionals about the impact of illness/disability and caring responsibilities on family members or other informal carers. Health professionals are a vital link for carers in obtaining information about the supports available to them. Therefore, it is important that health professionals distribute information to carers;**
- 8. That NSW Health, in it's health promotions and literature, include reference to partners, family members, significant others and other carers and the possible impacts of caring on them. Links to Carers NSW or other organisations that can offer support should also be included;**

9. **That Carers NSW develop links with the NSW Department of Education to ensure that schools disseminate information about support services to parents of children with a disability, chronic illness or mental illness. All children have to attend school, so this makes them an important contact point for parents.**

10. **That Carers NSW continue its work with large employers in order to target carers who are employed. These initiatives can also be extended to unions and may involve education about the recent 'carer responsibilities' amendments to the NSW Anti-Discrimination Act.**

11. **That Carers NSW and other organisations attempt to educate the media about carers (including consistent use of the term) and to use the general media where possible in order to get messages disseminated as widely as possible;**

12. **That Carers NSW load this paper onto its website in order that other organisations can easily access it.**

VIII. Conclusion

The Carers' Coalition believes that, in order to get information to many of the carers in the community who do not identify themselves as such, a wide range of strategies and initiatives must be undertaken. This is because information needs to be disseminated much more widely and to speak to a much broader range of people's experiences than is currently the case. This will involve targeting non carer-specific communities/groups and, often, using words or phrases other than 'carer'. In this way, we are hoping that 'hidden' carers may identify themselves as carers and thus receive the support they need.

Having said that, one of the first steps in being able to identify hidden carers is to clarify who exactly is a carer. Hence the section in this paper on the use of that term. The Carers' Coalition is aware that change generally happens slowly. While we have commenced the work to try and standardise use of the word 'carer', in all likelihood it will take a long time before 'carer' is used consistently across the health, disability and community care sectors. However now that the initiative has begun, we are hoping that there will be a gradual move towards consistency of use and, thereby, an easier identification of informal carers.

Ultimately, once hidden carers are identified, we hope that they will be given adequate and appropriate information, emotional support, education, practical assistance and counselling (where necessary). All of this is aimed at ensuring that carers can continue in their caring role for as long as they choose to do so and that, while caring, their own mental and physical health is not adversely affected and that they are not financially or socially disadvantaged.

IX. References

Alexander, B. and Garner, V. (2000), "Parents of Children with a Disability are Parents, not Carers", paper presented at the Second International Conference on Caring, Brisbane, Australia. Proceedings published by the Carers' Association of Australia, Canberra.

Australian Bureau of Statistics, (1998), "Disability, Ageing and Carers: Summary of Findings", Cat. No. 4430.0.

Carers' Association of Australia (2000), "Warning: Caring is a Health Hazard", Survey of Carers' Health and Well-being, Canberra.

Payne, T. and Ehrlich, F. (1998), "Coping at Home: Carers' Use and Non-use of Community Services", Carers NSW, Sydney.

Payne, T. (1999), "The Carer Checklist Trial", Final Report, Carers NSW, Sydney.

Schofield, H. et. al, (Ed.) (1998), "Family Caregivers: Disability, Illness and Ageing", Allen and Unwin, Australia.