

Finding ways to help stroke survivors and their families

IMPROVING LIFE AFTER STROKE – A NATIONAL PRIORITY

This report contains valuable facts and figures but more than that it gives us an insight into what stroke survivors need and what they are getting.

It is the first time that state stroke associations and the National Stroke Foundation have worked together to ascertain the requirements of stroke survivors and their families.

It is clear that stroke support groups with limited resources are making an important contribution to the well-being and recovery of survivors. But while members of stroke groups are contributing more than 31,000 hours of their time each year as volunteers they can only reach about 4,000 of nearly 347,000 stroke survivors across the country.

This is not how it should be. Time, energy and funding are needed to help stroke support groups equip stroke survivors and their carers with the services, resources, tools and information they need for the stroke recovery journey.

We will be conducting further consultation with stroke survivors and carers this year so that we can develop, implement and gain financial support for strategies that will improve life after stroke for all Australians. This is a national priority for the National Stroke Foundation.



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A REPORT BY THE



National Stroke Foundation



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of Western Australia



Stroke Association of Victoria



Stroke SA



Stroke Association Of ACT Inc.

Stroke Association of the
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INTRODUCTION

At least 346,700 Australians are trying to get on with life after stroke (Senes, 2006). Stroke survivors and their families tell us that they receive little or no information from the health system about their new situation. In 2003, most stroke survivors went home, many with permanent disability. In 2003, it was estimated that only 4,000 stroke survivors and carers were getting to stroke support groups in Australia (National Stroke Foundation, 2003). Stroke survivors say that stroke support groups are one of the most important tools needed to help recover life after stroke.

These figures clearly show a big gap between the number of people living at home with stroke and those being helped by stroke support groups. This gap will keep growing unless an answer is found.

An organised plan for stroke support is needed to help stroke survivors and their families receive the right information and services at the right time on the stroke recovery journey. Over the next 10 years, nearly 500,000 Australians will suffer at least one stroke (Senes, 2006). It is likely that the number of stroke survivors will continue to rise during the decade. This means that there will be many more stroke survivors living at home seeking information and services to help in their recovery journey. Action is required now.

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BACKGROUND

The Clinical Guidelines for Stroke Rehabilitation and Recovery (National Stroke Foundation, 2005) describes peer support as “a process by which stroke survivors may share experiences with others who have undergone a similar experience”.

The guidelines recommend that “stroke survivors should be provided with information about the availability and potential benefits of a local stroke support group and/or other resources of peer support prior to discharge from hospital”.

Peer support can be offered one-on-one or in a group. In Australia, state stroke associations (SSAs) support the stroke support groups operating in their states.

There is little formal research to uphold the argument that stroke support groups improve life after stroke but this does not mean that this work is not effective. Indeed stroke survivors report that peer support is a very important part of the recovery process. The large number of existing groups across many diseases, including stroke, demonstrate that many people find peer support groups helpful.

The importance of peer support is slowly being recognised by the Australian Government in other disease groups. Last year, the government committed more than \$1 million to cancer support groups. As yet, there has not been a similar amount of money committed for stroke.

In 2003, the National Stroke Foundation and a number of state stroke associations started to work together. As a result the Stroke Foundation of Western Australia, the Stroke Association of Victoria, Stroke SA, the Stroke Association of the Australian Capital Territory, the Stroke Association of Queensland and the National Stroke Foundation decided to find ways of helping more stroke survivors and their families at home.

In 2006, the group decided to look at other programs in Australia and overseas to help find more ways to help stroke survivors and their families. This report is the first time that stroke organisations have worked together on such a project.

The report has three parts:

Part 1 Looks at peer support programs in Australia and overseas, examining other disease groups in Australia that have programs that could be used in stroke and overseas stroke programs. A review of the programs is in the result section, together with the international review.

Part 2 The survey of leading stroke support groups in Australia maps current activities, successes and problems. The results of this section may be used to help the work of the state stroke associations and the National Stroke Foundation in the future. See Appendix 1 for a copy of the questionnaire.

Part 3 The survey of health professionals in Australia maps the activities and views of health professionals across the country. The results provided areas that may form the basis of further work. See Appendix 2 for a copy of the questionnaire.

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METHODOLOGY

Part 1

Most of this early work was done using the Google search engine. Members of state stroke associations were asked to suggest organisations and the project officer to follow-up with requests for written materials and more information. This was done by telephone, a small number of site visits and emails for the overseas programs which were in England, Wales and Scotland, the United States of America, New Zealand and Canada.

Part 2

Stroke support group leaders were surveyed using a questionnaire to find out more about the running and needs of their groups. The questionnaire was developed by the state stroke association representatives and the National Stroke Foundation. Firstly, a letter was sent by each association to each leader to tell them about the project. (See Appendix 3) This was followed up with a phone call by the project officer. The questionnaire was sent to all leaders by post.

Part 3

Health professionals were surveyed by questionnaire to find out more about the way that they work and refer to stroke support groups. The questionnaire was emailed to health professionals from the Australasian Stroke Unit Network. It was also sent to people who went to a stroke conference in 2005. Some health professionals then sent the email to friends.

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RESULTS **PART 1** **PEER SUPPORT PROGRAMS IN** **AUSTRALIA AND OVERSEAS**

AUSTRALIAN MODELS OF PEER SUPPORT

The results found many interesting programs in Australia and overseas, each offering food for thought for planning programs and services in the future. Key organisations and services are listed below. A more comprehensive explanation of each program is listed in Appendix 4.

Growing the organisation and public awareness Breast Care Network of Australia is a great example of an organisation that has attained a high level of public respect, mainly through the 'pink lady' campaign. The network has recruited a CEO and Board members with a mix of business skills and an ability to draw attention to the breast cancer cause. The structure ensures that ordinary women with breast cancer are involved, have a say and are properly represented.

Advocacy A number of cancer organisations have training programs to help people who want to influence policy, research and directions.

Telephone support Alzheimer's Australia's National Dementia Helpline uses trained volunteers to provide peer support to people with dementia, their families and carers. The service is backed up by support from health professionals. A person may be referred for face-to-face counselling when difficult issues are identified. Services such as this recognise that for many people – particularly those with disability, who are housebound, or who might want to remain anonymous that the telephone is vital for obtaining information and support.

Growing a network of support groups Organisations such as LungNet assist new support groups by providing high levels of hands-on help through state coordinators. The state coordinators also ensure that support groups have regular contact and supports to keep them in the loop with state and national issues. There is also a tool kit of resources to help new groups including templates, detailed instructions, tips and seed funding.

One-on-one peer support Heart Support Australia has a program of lay counselling using trained peer volunteers. Most of their work takes place in hospitals and rehabilitation centres. The volunteers have won support and access by finding health professional champions. They also have formal agreements with health services.

Funding Most organisations have little or no government funding. They rely on donations, membership subscriptions and corporate sponsorship.

Support groups All of the organisations offer support groups, either directly as one of the key services or through a model of association. This is a reminder that people with all kinds of conditions are drawn to the support and encouragement found in small groups.

This outline has only skimmed the surface of the many kinds of peer support services that are available in for other disease groups Australia.

INTERNATIONAL STROKE SUPPORT PROGRAMS

International stroke support programs and services show the need for different programs or models to meet the needs of the broad consumer base. There is a strong demand for choice in services. Flexibility is needed. Stroke survivors and their families also want to participate in consultation. The information below describes stroke support programs that may be useful in Australia.

United States of America

There are about 3100 stroke support groups in the USA supported by the American Stroke Association and the National Stroke Association. They do not work together. The American Stroke Association programs include the following:

- Information through the website for 1900 stroke support groups
- Consumer literature
- A web-based Family Discussion Group (for questions, tips and mutual support), 'Generation S' (for younger stroke survivors) and online stroke support groups for those who are unable to get to a group in their local area
- Stroke helpline for information and counselling for stroke survivors and their families. Four members of the helpline team have personal experience with stroke (either themselves or through a family member)
- A magazine is provided six times a year with information about stroke treatment and recovery as well as inspirational stories from other survivors. This magazine reaches approximately 10 per cent of the stroke population across the United States.

The National Stroke Association programs include:

- Educational videos
- Stroke survivor and carer materials such as poems and positive thoughts
- Newsletter
- Telephone hot line
- Website for further information
- "Common Threads Pen Pals" – a correspondence program for those who are not computer skilled.

Canada

Stroke recovery groups in Canada run at a number of levels. Stroke Recovery Canada starts its own groups with strong consumer focus and feedback forums. This organisation also offers:

- An affiliation program for stroke groups established by other organisations, or groups that run on their own in the community
- Local 'summits' where stroke survivors and carers come together to discuss their needs and solutions. A stroke recovery group usually starts after this meeting but in some cases different models of support are found such as home visiting
- Regional coordinators to support stroke support groups
- Stroke recovery groups conducted in rehabilitation centres by health professionals and trained stroke survivors who work with those in hospital
- Quarterly magazine to members with up to date information about stroke and stroke recovery, including member stories
- Volunteer conferences across Canada for grass roots operators who support stroke survivors and their carers in the local community.

The United Kingdom

There are about 800 stroke support groups in England and Wales. Half of these are run by the Stroke Association UK with regional coordinators whilst the other half comprises unaffiliated, independent groups. Stroke Association UK programs include:

- Direct service provision to stroke survivors and their families through volunteers and health professionals, including home based services
- Support for 5000 communicatively impaired stroke survivors through communication groups
- Family support service for 12 months after discharge to stroke survivors and families before they are referred to stroke clubs
- Counselling services in the home and by a help line
- Magazine

These services are predominantly funded through Primary Health Trusts.

Scotland

Stroke support in Scotland is provided by Chest, Heart and Stroke Scotland which has just finished a review of community based services. Programs include:

- Direct services to stroke survivors and their carers through a strong volunteer program
- Hosting consumer conferences
- Consumer literature in a range of media including audio, video and other languages
- Support for “Healthy Voices”, a consumer advocacy program
- Patient and carer audit to marry with their stroke clinical services audit
- Newsletter
- Financial support through a welfare grant scheme
- Support for the development and implementation of stroke support groups across Scotland.

New Zealand

The Stroke Foundation of New Zealand programs include:

- Stroke field workers and stroke clubs supporting survivors and their carers. Field workers visit survivors and families in their homes or in hospital providing information about services and life after stroke
- Approximately 70 stroke clubs
- A small number of caregiver groups offered in addition to the stroke clubs
- Telephone support line.

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RESULTS **PART 2** **SURVEY OF STROKE** **SUPPORT GROUP LEADERS**

The survey was mailed to 76 stroke support groups with 66 returned. Results are described in terms of themes explored through the survey.

5A Structure and organisation of stroke support groups

Almost half of the stroke support groups surveyed had an organising group or committee; a smaller number had a mission statement for their stroke support group and/or rules and regulations about how the group was to be run.

The most common pattern for group meetings was to start with a guest speaker or discussion. The groups then finished with time for conversation. Most groups arranged outings to places of interest or for a meal.

A total of 29 of the 66 groups had a health professional involved in some way. These groups tended to be more formal. They had more educational speakers.

Most groups met monthly on a week day but the Young Persons groups met on the weekend. This suggested that there were limited chances for stroke survivors who have regular week day commitments to get to a stroke support group.

The average annual running cost of each group was \$796 although many groups did not answer this question. A number said that direct costs to the group were kept low. Some achieved this with the help of their district health service or community health centre which provided a venue and infrastructure. They also provided supporting staff, covered printing, photocopying and postage. These hidden costs suggested that the real cost of a stroke support group was higher than the figure stated. Administrative savings are also provided by the large volume base.

The costs incurred by stroke support groups include refreshments, transport for members, venue hire, insurance and membership. Other costs that some groups needed to cover included reimbursement for out of pocket expenses. This was usually petrol money to help with transport. Gifts, prizes, outings and subsidised bus trips were also listed. Groups in some states said that they encourage all their attendees to become members of their state association. Some of these organisations provide access to public liability insurance for their groups.

Stroke support groups listed a number of ways in which they are able to generate funds. These included payment of a small, annual membership fee, gold coin donation, fundraising, donations and grants. These grants included Carer's Choice funding and Home and Community Care. One group received a donation from a local council which was spent on hiring a bus for outings.

5B Demographics of stroke support groups

The most common average age group was 61 to 70 years. Whilst only two of the groups specifically met the needs of young people, eight per cent of all groups had people attending who were less than 30 years of age. There were no groups listed in the survey for children or culturally and linguistically diverse sectors.

Most leaders said that once stroke survivors and carers reached a stroke support group, many stayed involved for years. The average number of stroke survivors and carers attending a stroke support group was 19. Almost half of the groups had equal numbers of male and female attendees, most of whom were stroke survivors. Three per cent of attendees were carers alone (after the caring role has ceased).

Leaders said that only 1176 of stroke survivors and carers were regularly getting to stroke support groups (excluding NSW).

5C Links with hospitals

14 of the 66 groups had a hospital visiting program. Existing group members visited new stroke survivors in hospital to offer support and encouragement.

16 groups had their own brochure distributed through local hospitals, community health services and doctors' surgeries.

5 had a poster on the wall at the local hospital to promote their group.

8 received direct referrals from health professionals.

5 sent their newsletter and meeting notices and minutes to hospital staff.

4 had informal, personal links with key staff at the hospital.

Several stroke support groups said that they would like to improve their links with local hospitals. Many leaders were unsure about how to make this happen. They thought that it was important to work with health professionals to make sure that people were given information about their local stroke support group.

5D Forming successful partnerships with health services

A number of stroke support groups were very good at working with their local hospitals and were willing to share their experiences with others. Health professional involvement seemed to be the key strategy with the professional providing contact between the support group and the hospital. This helped in planning for discharge from the hospital. Meetings, telephone calls and newsletters, setting up a hospital visiting program and joining hospital committees also helped. Asking hospitals to mention the support group in hospital newsletters was another way to publicise their existence.

5E Advertising, recruitment and referral for stroke support groups

The most common way of recruiting new members was through word-of-mouth. People who already attended the groups encouraged new stroke survivors and carers to attend. They told people about the benefits of attending stroke support groups. A smaller number of stroke survivors and carers were referred by their state stroke association or by a health professional.

5F Key activities in stroke support groups

Stroke group leaders said that there were four key reasons people attended stroke support groups.

1. Support
2. Understanding
3. Friendship
4. Social activities

Many groups said that education was important but nobody listed this as their most important service.

5G Successes and frustrations for stroke support groups

Stroke support group leaders spoke about what worked well in their group. Some listed special things they were doing and some outlined how the group was structured. Others described the feeling of mutual support and friendship that happened when the group met. The following is a sample of responses:

“Mateship. Social activities - everyone enjoys having good times together. Keeping members active through our physical activities.”

“Caring, being able to talk about anything including any problems they may have.”

“Social lunches – laughter, camaraderie. Friendship and peer support. Our committee structure – sharing the load, wider involvement. A diversity of strengths and interests that members bring to the group.”

“Our most successful meetings have been with guest speakers talking about anything to do with stroke and risk factors, stroke research, stroke prevention and stroke survivors telling their own story.”

The key frustration expressed in the survey was concern in some groups about the lack of new people joining their group. Some groups had very small numbers and were worried that the group would fold unless new people joined. Another frustration was the lack of referrals from hospitals to stroke support groups.

“Numbers aren’t increasing at the rate they should be – we are not attracting new members effectively.”

“Practically all stroke survivors have been hospitalised for some period of time after having a stroke. The lack of referrals from hospitals is very disappointing and frustrating.”

Other groups spoke about the challenge of meeting the needs of people who had been attending the group for a long time while catering for new members – stroke survivors and carers with very different requirements. This caused problems such as how often to repeat topics and guest speakers.

5H Resources for stroke support groups

The list of resources that stroke support group leaders would find useful included:

- Funding assistance
- Awareness raising and promotion of stroke support groups
- Help with transport to get people to stroke support meetings
- Access to quality information about stroke
- Better liaison with and communication from State Stroke Associations.

Other skills and information that the stroke group leaders needed included:

- Quality information about stroke such as videos, DVDs and books for loan
- Ideas about how to work with health professionals
- How to improve referrals from hospitals to stroke support groups
- Ideas about how to set up peer visiting programs in hospitals
- Regular visits from state stroke association representatives
- A chance for stroke support group leaders to meet each other and share ideas
- Training for stroke support group leaders
- Help with sourcing guest speakers.

5I Starting new stroke support groups

Stroke support group leaders said that an information kit would be very helpful when setting up a new stroke support group. It was suggested that the kit contain information on how to set up a group, sample paperwork, notes on how to put together a committee and run a meeting. The resources listed in 5h were also seen as helpful.

5J National Stroke Week

A number of groups ran special activities during National Stroke Week such as information stands and displays at hospitals and in the community. Some groups arranged blood pressure testing, media alerts and radio talk shows. Others held events such as mini golf, afternoon tea, stroke prevention expo, outings and mini Olympics. One group said:

“We give back to the community by engaging in a local activity such as weeding or clean-up projects.”

The state stroke associations and National Stroke Foundation wanted to know how they could help groups with their National Stroke Week activities. The answers were the same:

- Media releases to promote the group
- A hand-out kit containing stroke information
- Funding for National Stroke Week activities
- Regular newsletters to let groups know what is planned for Stroke Week.

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RESULTS **PART 3** **SURVEY OF HEALTH** **PROFESSIONALS**

A total of 188 health professionals replied to the survey. It was difficult to work out a response rate as many completed the survey themselves and then forwarded to colleagues.

6A Demographics

Most worked in a rehabilitation setting or a stroke unit. Almost half the health professionals came from regional and rural settings. Most replies came from nurses (62 per cent) followed by a range of allied health professionals.

6B Health professional involvement in stroke support groups

Most health professionals had a stroke support group running in their area. However 13 per cent did not know if they had a stroke support group in their area.

6C Advertising in hospital

The most common way that health professionals told stroke survivors about the local group was with a brochure (40 per cent). Some simply told people about the group and gave them a phone number (27 per cent). A smaller number displayed a poster (13 per cent). Many health professionals felt that there was not enough information about stroke support groups in their local area (61 per cent).

6D Recruitment and referral from hospital

Health professionals strongly believed that they should tell people about stroke support groups.

“Referral and encouragement need to be a team effort and should be part of discharge planning. Giving a brochure in absence of reinforcement is generally not effective and not followed through.”

Most health professionals did not believe that one person on a team should be responsible for telling people about stroke support groups. However, if they did suggest a member of the team, it was usually the social worker or the nurse.

Half of all health professionals said that they thought that two to six months after the person’s stroke was the best time for them to attend a stroke support group. Almost the same number of health professionals thought that attendance should start within two months of the person’s stroke.

Almost one quarter of all health professionals said that they do not refer their patients to stroke support groups. The reasons can be grouped as follows:

Role in the team

“From the Stroke Unit they tend to go to rehab from which referrals are made if appropriate. Our team has a stroke coordinator who makes any necessary follow-up arrangements.”

Poor understanding of local stroke support group

“I’m not sure of the details of when and where the group meets. I have never been to a meeting or had contact with members, so can’t recommend them. I do refer to SRA NSW [Stroke Recovery Association] and encourage patients to ask about local stroke support groups.”

Letting stroke survivors make choices in their recovery journey

“I inform them that they are available, but tell them that the decision is theirs. I feel they would like to attend this type of group.”

Lack of suitable services

“It depends on the person’s age that is under 55 and/or over 65 years of age. There is very little support at a community level for working with aged or younger stroke survivors.”

Other reasons included lack of transport and perceived lack of benefit for stroke survivors.

Health professionals were asked if they would send more patients to a group if it was run by a health professional. This did not seem to make a difference.

6E Health professional perceptions of stroke support groups

Nearly all health professionals believe groups may help a stroke survivor cope better in the community (97 per cent). They thought that the most important job for a group was support for each other. They believed that stroke support groups had a role in education and provision of information. However, not all health professionals felt that they knew enough about the groups. Very few were worried that groups may cause problems with patient care.

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DISCUSSION

The latest research tells us that at least 346,700 stroke survivors are living in Australia today and that over the next 10 years nearly 500,000 Australians will suffer at least one stroke (Senes, 2006). This means that there will be an even bigger gap between the number of stroke survivors and carers getting to stroke support groups and those who do not. An organised plan for stroke support is needed.

In the past, stroke support groups were started by small groups of committed volunteers with State Stroke Associations providing telephone support and guest speakers. Based on figures cited by the New South Wales Stroke Recovery Association, Stroke Association of Victoria, the Stroke and Migraine Association of Tasmania and the Stroke Association of Queensland, it is estimated that volunteers are currently contributing nearly 18,962 hours every year to running stroke support groups. They are contributing a further 12,314 hours of their time to state stroke association Boards, administration support, education programs, committee representation, media campaigns and peer support. This represents a labour cost saving of \$469,140 per year (Sharkey, 2006).

As a result of this survey, we better understand the needs of stroke support groups.

We know that:

- Only 1176 stroke survivors and carers are going to stroke support groups today (excluding NSW)
- The average membership is 19 stroke survivors and carers per group
- People stay with the same group for a long period of time
- There is a big gap between the number of stroke survivors living at home and the number of stroke survivors getting to a group
- Stroke survivors tell us that stroke support groups form a vital part of their stroke recovery journey
- Groups run on less than \$1000 per year with the support of health organisations and a large volume base.

Stroke group leaders spoke about specific areas where they need help and support, for example:

- A start up kit when setting up a new group
- Advertising their group
- Support with information, guest speakers and resources
- A chance to meet with other leaders to gather new ideas, learn more about running groups and help plan meetings
- Videos, DVDs and books for loan
- Recruitment and referral to their groups to make sure that they continue to run long term.

Some of the opportunities for further work may be found in the results of the survey.

Ways to support recruitment / referral

Health professionals told us that their preferred method of recruitment is with a brochure and/or a poster. As a result of the survey, we now know that less than half of the groups have these items.

A number of health professionals did not have very much information about their local group. They did not know who ran it, where the meetings were held or what happened in a meeting. It could be suggested that this lack of information would prevent many health professionals from referring people to a group. Groups with good links with their hospitals spoke about finding a key person, having regular meetings, sending minutes and having hospital visiting programs as ways of communicating this information.

When to make a referral to a stroke support group

Many health professionals thought that the most suitable time for a stroke survivor to be referred to a group was within the first two months. However the group leaders said that very few stroke survivors get to a group within that first two months. Most stroke survivors and/or carers join a stroke support group somewhere between 2 to 12 months after their stroke.

As a result of the survey, we know that health professionals are telling people about stroke support groups. However, further work is required to understand why or why not people attend stroke support groups and what stroke survivors need when they go home. Stroke survivors and their families need time to come to terms with their stroke and its impact on their lives.

Stroke group leaders have shared many good ideas and suggestions that may be helpful in planning for the future. However, it should be noted that the views of many stroke survivors and carers were not captured. The needs of specific groups such as young stroke survivors, parents of children with stroke, culturally and linguistically diverse groups or those in communication groups were not captured in this report. This leaves many questions that still need to be answered.

Questions such as:

- Do all stroke survivors know that stroke support groups run in their local area?
- Where do stroke survivors go for support if there is not a local group?
- How do we meet the needs of people who do not go to stroke support groups?
- What happens to the rest of the stroke survivor population?

Finding answers to some of these questions will help to better understand the needs of stroke survivors and their carers on the stroke recovery journey.

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CONCLUSION

Many stroke survivors describe returning home after stroke as “a black hole” because they say that there is not enough support in the community. This greatly impacts on how well a person may recover after their stroke. According to the survey, out of 346,700 stroke survivors in four states and the ACT only a few stroke survivors – 1176 – and their carers, are fortunate enough to reach a stroke support group. These people tell us that going to their local stroke support groups is one of the most important tools for recovering life after stroke because they provide a safe place where stroke survivors and their carers can share their personal stroke recovery journeys. The sheer number of these groups that exist across many diseases, including stroke, demonstrate that many people find peer support groups helpful. People vote with their feet.

The small numbers of stroke survivors and carers reaching support groups is not a reflection of lack of commitment or efforts by those people already providing stroke support. It does, however reflect systemic problems and the lack of understanding of the individual stroke recovery journey. Stroke group leaders are delivering amazing results with very few resources. This report outlines a number of opportunities to further develop and support these existing groups. It shows the need for new groups to increase access for all stroke survivors and their carers. It also mentions the work of other organisations in Australia and overseas such as lay counselling and online peer support.

Discussions with overseas stroke organisations show that we all face the same problems. These problems include the voluntary workforce, the lack of long term funding and the capacity of the organisations. This poses a big challenge for each organisation. We need to deal with the predicted growth in the stroke survivor population. We also need to deal with the lack of research. This research helps to guide program development and support applications for long term funding. It will take time, energy and funding to ensure that stroke survivors and their carers have access to the right services, resources, tools and information to make sure that they are equipped for the stroke recovery journey.

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Stroke Support Group Survey

Thank you for participating in this survey about stroke support groups. We are getting in touch with stroke support group organisers from across Australia to try to get a snapshot of how stroke support groups are run. We'd like to understand more about what you do, what works well for your stroke support group and what you'd like to do better. To our knowledge this is the first time that this kind of survey has been undertaken at a national level. The information you provide will increase our understanding of stroke support groups in Australia.

Please answer the questions based on your experience as a stroke support group organiser. This survey should take approximately 10-20 minutes to complete. We greatly appreciate your input and ask that you mail your response, in the reply paid envelope provided marked Attention: Lisa Allwell by 30 April 2006.

QUESTIONS

1 What is the approximate age of the youngest person in your group?

- Under 30 years of age
- 31-40
- 41-50
- 51-60
- 61-70
- 71-80
- Over 80 years of age

2 What is the approximate age of the oldest person in your group?

- Under 30 years of age
- 31-40
- 51-60
- 61-70
- 71-80
- Over 80 years of age

What, do you estimate, is the average age of the people who attend your group?

- Under 30 years of age
- 31-40
- 41-50
- 51-60
- 61-70
- 71-80
- Over 80

3 Approximately how many people regularly attend each meeting?

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Of these, how many are

- A Stroke survivors?
- B Carers or family members?
- C Carer alone – after the caring role has ceased?
- D Health professionals?
- E Other? (Please list)

.....
.....

4 What is the proportion of males to females in your group?

- More females than males
- More males than females
- About equal males and females

5 Can you tell us about the stage at which most people start to attend your group?

- 2 months or less after their stroke
- 2-6 months after their stroke
- 6-12 months after their stroke
- 1-2 years after their stroke
- More than 2 years after their stroke
- It varies

6 On average, how long do people stay involved with your stroke support group?

- Weeks
- Months
- Years

7 How many new members join your stroke support group each year?

- Less than 10 people
- 11-20 people
- 21-30 people
- 31-40 people
- More than 40 people

8 How do people find out about your group (Tick all that apply)

- 1 Through your State Stroke Association
- 2 Referral from the hospital
- 3 Referral from a health professional
- 4 Word of mouth
- 5 Advertising
- 6 Other (please state)

Choosing a number (from the list above) indicate the most common way that people find out about your group.

9 Do people with conditions other than stroke attend your stroke support group?

- Yes
- No

If yes, what conditions do they have?

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10 What services are provided by your stroke support group? (Please tick all that apply)

- 1 Supporting each other
- 2 Educating people
- 3 Friendship
- 4 Provision of information
- 5 Social activities
- 6 Helping people have a better quality of life
- 7 Other (please list)

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Choosing a number (from the list above) indicate the most important service provided by your stroke support group.

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11 What do people tell you is the main reason they attend your group?

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12 What happens at a typical meeting? (For example: social meeting, outings, guest speakers, topics covered, formal or informal, structured or unstructured.)

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13 How often does you group meet?

- Weekly
- Fortnightly
- Monthly
- Other (please state)

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14 When does your group meet?

- Daytime – weekday
- Evening – weekday
- Daytime – weekend
- Evening – weekend

15 Where does your group meet?

- Inner suburbs metropolitan capital city
- Outer suburbs or a metropolitan city
- Regional/rural area

16 Approximately how much does it cost to run your Stroke Support Group?

- Per year (\$)

- or Per meeting (\$)

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17 What costs does your Stroke Support Group incur? (Please tick all that apply)

- Refreshments (tea, coffee, biscuits)
- Transport for members
- Venue hire
- Insurance
- Membership
- Other

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18 How does your Stroke Support Group generate funds? (Please tick all that apply)

- People pay a small membership fee every year
- People pay a small fee each meeting
- Fundraising
- Donations
- Grant
- Other

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19 Do you have any links with your local hospital? (For example, a visiting service to new stroke survivors, referrals from health professionals, posters or brochures telling people about your stroke support group.)
If so please describe:

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20 Have you developed any of your own resources for people who have had a stroke? (Please tick all that apply)

- Newsletter
- Brochures
- Local Services Guide
- Other (please state)

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(Note: If yes, we would be interested in receiving a sample of these written resources with this survey.)

21 Do you have any of the following (Tick any that apply):

- A mission statement
- An organising group/committee
- Rules and regulations
- Fundraising activities

22 Who organises your Stroke Support Group meetings?

- A stroke survivor
- A carer
- A health professional
- Combined peer (stroke survivor or carer) and health professional
- Other (please state)

23 Is your group involved in other activities (For example: Walking groups, art classes, self-management programs.)

- Yes
- No

If yes, please describe them

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24 What works well in you group? (Key successes)

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25 What doesn't work so well? (Key frustrations)

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26 What resources or assistance would help you with the running of your Stroke Support Group?

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27 Is there anything else you would like to tell us about your Stroke Support Group?

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28 Do you run any special activities during National Stroke Week?

- Yes
- No

If yes, please tell us about them

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29 How can we help you to increase the profile of stroke in your local community during Stroke Week?

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Thank you for taking the time to complete this questionnaire.

Please return this survey to the National Stroke Foundation in the reply paid envelope provided marked Attention: Lisa Allwell by 30 April 2006.

Would you like to receive a copy of the survey results?

- No
- Yes

If yes please record your postal address OR email address below:

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Survey of Health Professionals

Survey of Health Professionals Knowledge and Attitudes to Stroke Support Groups

Dear Health Professional

Thank you for participating in this survey about stroke support groups. We are getting in touch with health professionals from across Australia to survey their views and experiences with stroke support groups. We aim to find out what they know about stroke support groups and how and why they refer people to them.

You have been invited to participate because you are working in the stroke arena. We would like you to complete the survey even if you have no knowledge of or contact with stroke support groups.

Stroke support groups vary in the way they are structured but generally they provide support, friendship and information for stroke survivors and carers. Some are facilitated by people with a lived experience of stroke such as stroke survivors, family members and carers, other groups are facilitated by health professionals.

This survey is being done as a partnership project with State Stroke Associations and the National Stroke Foundation. The partners are:

Stroke Association of Victoria
Western Australian Stroke Foundation
Stroke SA Inc
Stroke Association of Queensland
Stroke Association of ACT
National Stroke Foundation.

This survey should take approximately 5-10 minutes to complete.

The information you provide in this survey will be treated as confidential.

We greatly appreciate your input and ask that you email your response to lisa@strokefoundation.com.au. If you have any questions, please call me on (03) 9670 1000.

Thank you

Lisa Allwell
National Liaison Manager
National Stroke Foundation

1 What is your occupation?

- Nurse
- Medical Practitioner
- Occupational Therapist
- Physiotherapist
- Speech Pathologist
- Social Worker
- Dietician
- Other. Please State

.....

2 What is your occupational setting?

- Acute Hospital
- Rehabilitation
- Community Health
- Aged Care Facility
- General Practice
- Other. Please State

.....

3 Where is your occupational setting?

- Inner suburbs metropolitan capital city
- Outer suburbs or a metropolitan city
- Regional/rural area

4 Do you have a Stroke Support Group in your local area?

- Yes
- No (Please go to Question 8)
- Don't know (Please go to Question 8)

5 If you do have a Stroke Support Group in your local area, do you refer your patients to it or encourage them to attend?

- Yes
- No If you ticked No, can you tell us why below then Please go to question 8.

.....

6 If you ticked yes, can you tell us how do your patients find out about their local stroke support group?

- I give them a brochure/flyer
- I tell them about it and give them a contact telephone number
- We have poster on the wall advertising the stroke support group
- We have a stroke peer visiting service
- Other

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7 Who facilitates the Stroke Support Group in you local area?

- A stroke survivor
- A carer
- A health professional
- Combined peer (stroke survivor or carer) and health professional
- I'm not sure
- Other (please state)

.....

8 What, do you believe, is the optimal time for people to start to attend a stroke support group?

- 2 months or less after their stroke
- 2-6 months after their stroke
- 6-12 months after their stroke
- 1-2 years after their stroke
- More than 2 years after their stroke
- None. I don't believe Stroke Support Groups are helpful for stroke survivors and their families.

9 Who do you believe, is best placed in the health care team to refer people to a stroke support group?

.....

10 What do you think, are the services which can be provided by stroke support groups? (Please tick all that apply)

- 1 Supporting stroke survivors and family members
- 2 Educating stroke survivors and family members
- 3 Friendship
- 4 Provision of information
- 5 Social activities
- 6 Helping people have a better quality of life
- 7 Other (please list)

Choosing a number (from the list above) indicate which is the most important service which can be provided by stroke support groups.

.....

11 To follow are a series of statements about stroke support groups. Please indicate the extent of your agreement or disagreement with the statement by circling the number below. You can also circle 'don't know' response for some answers.

A Attending stroke support groups may help stroke survivors to cope better in the community.

1 2 3 4 5
 STRONGLY DISAGREE DISAGREE NEUTRAL AGREE STRONGLY AGREE

B I don't know much about stroke support groups.

1 2 3 4 5
 STRONGLY DISAGREE DISAGREE NEUTRAL AGREE STRONGLY AGREE

C Information about stroke support groups is insufficiently available.

1 2 3 4 5
 STRONGLY DISAGREE DISAGREE NEUTRAL AGREE STRONGLY AGREE

D Health care providers should be responsible for informing people about stroke support groups.

1 2 3 4 5
 STRONGLY DISAGREE DISAGREE NEUTRAL AGREE STRONGLY AGREE

E I worry about stroke support group interference with the management of patient care.

1 2 3 4 5
 STRONGLY DISAGREE DISAGREE NEUTRAL AGREE STRONGLY AGREE

F I am concerned about the quality of information provided at stroke support groups.

1 2 3 4 5
 STRONGLY DISAGREE DISAGREE NEUTRAL AGREE STRONGLY AGREE

G I would be more likely to refer my patients to a stroke support group if it was facilitated by a health professional.

1 2 3 4 5
 STRONGLY DISAGREE DISAGREE NEUTRAL AGREE STRONGLY AGREE

12 Anything else you'd like to tell us about stroke support groups?

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Thank you for completing this survey!

Lisa Allwell
 National Liaison Manager
 National Stroke Foundation
 Tel (03) 9670 1000
lisa@strokefoundation.com.au

Cover letter to Stroke Support Group Organisers

5 April 2006

Name

Street

Suburb

Dear

We would like to invite you to participate in our stroke support group survey. We are getting in touch with stroke support group organisers from across Australia to try to get a snapshot of how stroke support groups are run. We'd like to understand more about what you do, what works well for your stroke support group and what you'd like to do better. To our knowledge this is the first time that this kind of survey has been done at a national level. The aim of the survey is to increase our understanding of stroke peer support in Australia.

You have been chosen to participate because you are the contact person for your local stroke support group and we are very interested in your experience as a support group organiser.

The information you provide will increase our understanding of stroke support groups in Australia. This is a vitally important: as stroke is Australia's third biggest killer and a leading cause of disability in our community. There are currently 350,000 people living in the community with varying levels of disability following their stroke. It is these people and their families and carers who attend groups such as yours.

This survey is being done as a partnership project with State Stroke Associations and the National Stroke Foundation. The partners are:

- Stroke Association of Victoria
- Western Australian Stroke Foundation
- Stroke SA Inc
- Stroke Association of Queensland
- Stroke Association of ACT
- National Stroke Foundation

All of the information you provide in this survey will be treated as confidential.

If you are interested in receiving a copy of the survey report, please tick the box at the end of the survey. For your thoughts and opinions to be included, we would be grateful to receive your completed survey response by 30 April 2006.

If you have any questions, please get in touch with me on (03) 9670 1000.

Thank you so much!

Lisa Allwell,
National Liaison Manager
National Stroke Foundation.

Examples of peer support in Australia

The examples we looked at for this review have some innovative ideas and models both to support and encourage people and to raise awareness. Some of the key learnings from these organisations are summarised below:

Example 1 LUNGNET

LungNet is an initiative of the Australian Lung Foundation (ALF). It is a national network of affiliated patient support groups for people living with a lung condition. ALF or LungNet does not own or control patient support groups but provides support, for both existing and newly formed. The ALF is represented in each state by a committee or secretariat, and a LungNet state coordinator.

WHO IS THE TARGET GROUP?

People with chronic lung conditions: chronic obstructive pulmonary disease is the third leading cause of human and economic burden of disease (following coronary heart disease and stroke).

HOW MANY PEOPLE PARTICIPATE?

LungNet Patient Support Groups provide peer support to over 10,000 people with chronic obstructive pulmonary disease and other lung disorders¹.

¹ LungNet News Special COPD Edition 2005, p 4.

THE LUNGNET MODEL

LungNet services include:

- Helping people find suitable group in their area
- Assisting new groups to form by providing guidance and financial seeding assistance
- National clearinghouse for producing and distributing patient education information
- Communication link between patient support groups.

LungNet Patient Support Groups bring together people with similar life experiences who can offer support, encouragement and companionship. Activities include:

- Regular meetings in a supportive environment
- Speakers with expert information on lung health
- Member to member support (through telephone, hospital and home visits)
- Lung health education information, seminars and patient programs
- Group newsletter and national newsletter
- Social enjoyment and entertainment.

² These Patient Support Groups have some wonderfully creative names. The website, www.lungnet.com.au lists groups with titles such as Chesties Bonding, Puffers and Wheezers, Gas Baggers, Casey Croakers, Chest Nuts, Second Wind, LUST (Lungs under stress and trauma) and LIPS (Lungs in poor shape)

Start-up

People interested in starting a new group, can apply for seed funding (up to \$250 in 2005) from ALF. They are also given a start-up kit and a guest speaker for the inaugural public meeting. The ALF National Secretariat supports new groups during the initial phases.

LungNet has developed guidelines for both support group start-up in a community setting and support group start-up as an extension of a pulmonary rehabilitation program. These guidelines include clear consultation with key health professionals and relevant agencies and include conducting a needs analysis of rehabilitation patients to investigate level of interest and support in establishing a support group. The start-up manual includes a suite of resources and templates.

LungNet has developed protocols for rules and structure, banking and finances, group leadership and group leader responsibilities. All support groups are an entity in their own right and can carry their own name or are promoted as a “local chapter” of LungNet².

Links

There is a clear link between pulmonary rehabilitation programs and patient support groups. LungNet provides patients and health professionals with details of pulmonary rehabilitation programs Australia wide and has developed a Pulmonary Rehabilitation Toolkit to assist health professionals to implement pulmonary rehabilitation programs. People who enrol in a rehabilitation program are encouraged to join a patient support group.

Financial

The support groups become financially self-supporting and are run in a club style, with elected officers. Costs are minimal, being tea, coffee, postage and stationary and perhaps venue hire. Sometimes a simple newsletter is produced. These costs are covered by a gold coin collection at meetings or a small annual subscription. There is no charge for a patient support group or any of its members to be aligned with the LungNet.

Financial support for the LungNet program itself is predominantly from industry (particularly the pharmaceutical industry) rather than government or individual support.

Other peer support services offered by LungNet

If there is no group in a particular area, or if people are living in a rural/remote community, LungNet operates a “foster friends” peer support program using telephone communication. It also operates a toll free information line where people can discuss their needs and they have strong links with health professionals who operate a referral network to local patient support groups.

Example 2 HEART SUPPORT AUSTRALIA

Heart Support - Australia Ltd (HSA) is a national, volunteer, not-for-profit support organisation. It has a small national secretariat (Equivalent Full Time staffing of 1.5) based in Canberra and approximately 60 branches around Australia. Its key service is the provision of lay counselling (encouragement and support) for people with cardiac disease.

WHO IS THE TARGET GROUP?

People with all kinds of cardiac disease: coronary artery disease, heart failure and myocardial infarction, for example.

HOW MANY PEOPLE PARTICIPATE?

HSA does not collect national data on how many people access lay counselling. (This information is retained by individual branches). We spoke with Kerri Buzza, the National Training Coordinator, who trained 204 new lay counsellors in 2005.

THE HSA MODEL

Heart Support Australia's major focus is on the provision of peer support and assistance through a lay counselling service that provides consumers and carers with encouragement, information and support during hospitalisation and rehabilitation.

Lay counsellors are often matched to provide support to people who have similar conditions or who are about to undergo similar surgical procedures (such as coronary artery bypass grafts.) There are also some 'specialist' lay counsellors such as heart transplant recipients who only provide support to other heart transplant patients.

Lay Counsellors

HSA volunteer lay counsellors are either people who have a heart condition or they are family members or carers. They are stable in their condition and have been selected based on their personality, demeanour and commitment to supporting others. Two key criteria in screening are ensuring potential volunteers:

- Are well adjusted to their personal experience of cardiac disease: this includes the stipulation that volunteers must not have had a cardiac event in the previous eight months
- Have an ability to be a positive role model: volunteers must demonstrate that they have made lifestyle changes to reduce their cardiac risk (for example by quitting smoking).

Training

Volunteers can become lay counsellors after undertaking a training course³ designed by HSA and delivered either by a health professional or a Lay Counsellor Manager who is a certified trainer⁴. This two day course is approved by the Commonwealth Department of Health and Aging (DoHA).

The trained lay counsellors then provide direct peer support to people who are in hospital or undergoing rehabilitation or living with a cardiac condition in the community. This program has not been evaluated, but HSA state that, "the experience of over 20 years in delivering such assistance shows that consumers appreciate the services and support from people who have 'been there' and have shared the same experiences."⁵ Volunteer lay counsellors are covered by professional indemnity insurance.

3 Kerri Buzza, the National Training Coordinator of HSA outlined the components of the two day training program. This includes skills development, self-management principles, risk factor management and questions and answers. The training is approved by the Commonwealth Department of Health and Aging.

4 Development of a Volunteer Self-Management Training Program for Heart Support Australia. A Report to DOHA Jan 2004.

5 Development of a Volunteer Self-Management Training Program for Heart Support Australia. A Report to DOHA Jan 2004. p 8

According to www.heartnet.org.au, “much of the work of the volunteer lay counsellor is listening to the client. Verbalising experiences and telling their ‘story’ is something that patients often need to do as part of the healing process. The advantage of the HSA volunteer lay counselling service is that it offers something many health professionals do not have - unlimited time to listen. HSA lay counsellors can offer their support at any time; post diagnosis, before and after surgery and through rehabilitation. They work in a variety of locations including the hospital wards, patient homes, health centres, over the telephone; any appropriate environment that is convenient to the client.”

This was backed up by our interview with HSA who told us of examples where lay counsellors are considered to be such an integral part of the health care team that, “at one Melbourne hospital, the lay counsellor is called before the social worker.”

Boundaries

HSA volunteer lay counsellors do not give medical advice. They do not compare treatment options, health professionals, dietary or exercise advice.

Getting Access to Hospitals

Kerri Buzza explained that HSA has two key strategies in place to facilitate lay counsellor access in hospitals and rehabilitation centres:

- The first is a ‘top-down’ approach: HSA has developed a template Memorandum of Understanding (MOU) which it eventually plans to have in place in all institutions where lay counsellors are operating. The MOU is an agreement which outlines the role and responsibilities of the lay counsellor, HSA and the role and responsibilities of the participating hospital. Negotiating for the MOU and facilitating its signing is done at the hospital administration (not ward/unit) level. All HSA branches have a Lay Counsellor Manager, a senior volunteer who is experienced in lay counselling: It is this person who deals with the MOU negotiations.
- Anecdotally, hospitals want to know that the lay counselling volunteers have been appropriately screened, have participated in an approved training course and do not provide any advice that could be construed as medical information.
- The second strategy is to recruit a ‘champion’ for lay counselling at the ward/unit level. In practice this is usually the cardiac coordinator or the Nurse Unit Manager (NUM). These people work closely with cardiac patients and quickly recognise the difference that talking to a lay counsellor can make especially to allay people’s anxiety. Anecdotally, HSA told us that the organisations where lay counselling is strongest are those with a strongly supportive NUM.

Links

HSA offers services which are designed to complement the medical and allied health professionals, in providing support for heart patients. Lay counsellors work in a variety of locations including hospital wards, patient homes, health centres and over the telephone: they have developed links and arrangements with local health professionals and organisations to facilitate the provision of support.

Example 3 **BREAST CANCER NETWORK AUSTRALIA**

Financial

The national office is funded by DoHA. As noted earlier, its staffing is small: EFT 1.5. The national office does not actively fundraise, but the HSA branches themselves are funded predominantly through membership subscriptions and donations. Heart Support Australia describes itself as, “primarily a service provider and not a fund raising organisation”. However, all branches raise funds as they see necessary for the maintenance of their branch and assistance with their community service activities.

HSA has also had some government project funding (In 2002 DoHA provided project funding for HSA to review its peer support activities and to develop a self-management training program.)

Other peer support services offered by HSA

HSA also provides walking programs, an Internet chat line, and distribution of resources for heart patients and carers.

Breast Cancer Network Australia (BCNA) is a community organisation formed in 1998 by a group of women, all breast cancer survivors. It is an umbrella organisation representing 150 breast cancer groups.

BCNA is based in Melbourne and is represented in all states and territories. Each state has two breast cancer survivor volunteers who keep an ear to the ground for issues across the country and make sure that information is effectively distributed. They are also the local contact for women with specific enquiries or requests.

BCNA describes itself as, “the informed national voice of Australians personally affected by breast cancer. It seeks to empower them and improve their care by advocacy and the provision of information and targeted support ⁶.”

⁶ From the “Reaching out to one another” brochure. BCNA

WHO IS THE TARGET GROUP?

Women diagnosed with breast cancer and their families and carers.

HOW MANY PEOPLE PARTICIPATE?

130 Member Groups (Breast Cancer Support Groups) nationally, and 16,000 individuals.

THE BREAST CANCER NETWORK AUSTRALIA MODEL

Breast Cancer Network Australia provides a variety of programs to raise awareness of breast cancer and provide support to survivors and their families.

These include:

- Field of Women: a travelling exhibition which consists of 14,600 ‘pink lady’ silhouettes which visually represents the number of Australian women now diagnosed with breast cancer annually.
- My Journey Kit is a free comprehensive information kit for women newly diagnosed with breast cancer. The kit was developed over several years following input from hundreds of breast cancer survivors around the country. It is endorsed by relevant Medical Colleges in Australia including the Royal Australasian College of Surgeons. More than 10,000 kits have been distributed in the first year since its launch.

7 Issue 2 Spring 2005 *The Beacon*

8 www.bcna.org.au

- BCNA produces and distributes a free, quarterly national magazine, *The Beacon*, with a circulation of over 20,000.
- *Seat at the Table*: this program recruits, trains and supports breast cancer survivors as consumer representatives on a variety of national and state committees where decisions are made regarding breast cancer. Breast Cancer Network Australia's *Seat at the Table* program is internationally recognised as best practice in the area of consumer involvement in health care.
- Breast Cancer Support Groups – 130 Member Groups nationally, and 16,000 individuals⁷.

Member Groups

BCNA encourages support and advocacy groups to join their network. According to its website, “BCNA is the national voice of Australians affected by breast cancer. The more people and groups we have behind us the more powerful our voice.”⁸

There is no cost for groups to join. Benefits include:

- Quarterly update about breast cancer issues and activities
- Group details included on the BCNA website
- Fundraising assistance – access to pink lady badges for sale
- Access to national and state based activities.

BCNA has both member and associate groups. Member groups are consumer driven, that is they are made up of women with breast cancer and generally led by them. Many are support groups, but others are also advocacy or action groups, e.g. Breast Cancer Action Group.

Associate groups are generally established to help and support women with breast cancer. The Otis Foundation is an example of an associate group. The Foundation consists of a Board of Directors who work (independently from government) to raise funds and properly manage a property which is then used as a retreat by women affected by breast cancer.

Links

BCNA has managed to become an organisation with strong public recognition in only seven years and this appears to be due, in part, to the recruitment of a high profile Board with a broad range of skills to provide leadership and strategic direction. (Well known Board members include Raelene Boyle, Terry Bracks, Patricia Edgar and Jocelyn Newman. The Board is also balanced with people who have management and strategic planning skills, financial and fundraising skills, legal expertise, journalism and public relations and people who understand the not-for-profit sector. Many of them have a personal experience of breast cancer.)

Financial

BCNA is funded by corporate donations. It has a major corporate partner (Bakers Delight) and several supporting partners and sponsors. Its website lists nine companies that provide pro-bono services. BCNA also raises funds through its 'pink lady' brand and licensed products. BCNA has established innovative partnerships: For example Australia Post supplies free mail bags for the postage of “My Journey Kits”.

Example 4 CANCER VOICES NSW

Cancer Voices NSW (CVN) is an independent, peak advocacy organisation providing a unified voice for all people affected by cancer in New South Wales. It was established in 2000 with an aim to be “the voice for people with cancer in New South Wales⁹”. CVN is an umbrella coalition for the members who belong to cancer advocacy and support groups. It also has individual members, carers, and cancer care professionals.

As a network, CVN provides a forum for people affected by cancer to share ideas and experiences. The key role is to advocate and provide consumer representation at forums where decisions are made about cancer.

A key plank of its 2006 advocacy program is to promote survivorship and support¹⁰. This involves a program to:

1. Seek recognition of the important role support groups have in assisting many patients in dealing with psychosocial factors of diagnosis, treatment and recurrence.
2. Work for awareness of and regular referral to, cancer support groups by general practitioners, cancer specialists and centres. This involves the strategic use of consumer representatives on decision-making committees and working parties.

WHO IS THE TARGET GROUP?

People with all kinds of cancer living in New South Wales.

HOW MANY PEOPLE PARTICIPATE?

CVN represents 4000 individuals who are members of cancer support groups.

Membership in June 2004 comprised the following;

112 organisations are represented within the membership

85 organisations have full membership

214 individual associate memberships

THE CVN MODEL

CVN, in conjunction with The Cancer Council NSW, offers training in cancer consumer advocacy. Representatives are graduates of the Consumer Advocacy Training course which is held two or three times a year.

CVN representatives contribute to decision-making by representing the needs and issues of people affected by cancer. It participates in committees and working parties of organisations such as the Cancer Council NSW, NSW Department of Health, Area Cancer Management Groups, DoHA, professional colleges, research organisations, National Health & Medical Research Council and Consumers' Health Forum of Australia. This list demonstrates that CVN is involved in advocacy across a range of national, state and local groups.

Cancer consumer representatives also sit on many working parties for site-specific cancer (e.g. breast, prostate, bowel, lung, etc) for their own member organisations, and at state and national levels. In 2005 they had 30 consumer representatives sitting at 65 decision making tables in New South Wales and nationally.

CVN has an online request form for consumer representation, and a nomination and selection process to best match the consumer representatives with the group making the request. It also publishes a regular newsletter that outlines what is happening at state and national level with the groups where they have representation.

⁹ www.cancervoices.org.au

¹⁰ www.cancervoices.org.au

Links

The CVN website lists four partnership organisations: The Cancer Council NSW, The Cancer Council Australia, Cancer Institute NSW and the NSW Department of Health.

¹¹ CVN Newsletter 21, December 2005.

The CVN model has been recognised as very successful: in 2005 new Cancer Voices organisations were established in other states¹¹ (Western Australia, Victoria, the Australian Capital Territory and New South Wales). CVN approached all State and Territory Cancer Councils to ask that they help cancer consumer groups start up. A new national group has also recently been established called Cancer Voices Australia.

Financial

CVN is entirely funded by donations. There is no fee to join, but it suggests a donation of \$30 for groups and \$10 for individuals.

Example 5 ALZHEIMER'S AUSTRALIA

Alzheimer's Australia is the national peak body for people living with dementia, their families and carers and provides leadership in policy and services. In the early 1980s, state and territory Alzheimer's Associations were established as self help organisations by and for family carers of people with Alzheimer's disease and other dementias. The National Federation was formed in 1989 with membership from all state and territories.¹² State Alzheimer's organisations each provide slightly different services, but generally these include information, support, advocacy and education.

WHO IS THE TARGET GROUP?

People with dementia and their families and carers

THE ALZHEIMER'S AUSTRALIA MODEL

National Dementia Helpline

The National Dementia Helpline is a service staffed by a mix of professional counsellors and trained volunteer advisers. Many of the advisers have personal experience in dementia care. The service provides information, advice and local referrals to 23,000 callers nationally each year¹³.

¹² www.alzheimers.asn.au

¹³ Alzheimer's Australia Annual Report. Page 6

We spoke to Alan Stott, the Coordinator of Telephone and Support Services and Infrastructure at the Victoria office of Alzheimer's Australia. Alan explained that when people telephone the national toll free number, calls are put through to the Alzheimer's Australia branch office in their state. In Victoria one professional dementia counsellor and three volunteers are rostered to take calls.

The service provided by the Dementia Helpline is:

- Understanding and support for people with dementia, their family and carers
- Practical information and advice
- Up to date written material about dementia
- Information about other services
- Details of the full range of services provided by Alzheimer's Australia.

The peer supporter takes the call, and then provides support and advice and written material as required. Peer supporters have access to professional counsellors with whom the caller can speak if they need specialised advice. They can also make an appointment for the caller to meet with a counsellor face-to-face in some situations.

Training: Telephone support volunteers attend a training program of one day a week for eight weeks. This course covers topics such as understanding dementia, services available in the community and communication skills. People then observe other peer supporters and listen in to their conversations with people who phone for support. When they feel comfortable, volunteers handle calls independently. Counsellors are available for debriefing as necessary.

Alzheimer's Australia has been providing a helpline service since 1989. It monitors the quality of its service using a caller evaluation survey.

Links

Alzheimer's Australia works in partnership with other peak consumer bodies and stakeholders, as well as government.

Financial

Alzheimer's Australia is funded by a mix of Australian Government funding and donations. It has attracted the high profile support of Hazel Hawke to create a Research and Care Fund in her name. It has also attracted corporate support, for example the Macquarie Bank Foundation sponsors the national website. It has pharmaceutical support for Dementia Awareness Week and the National Conference and pro bono legal and financial advice from other organisations.

Other Peer support services offered by Alzheimer's Australia

Alzheimer's Support Groups: Support Groups are generally held monthly and are attended by those who care for a person with dementia or are family members or friends of someone with dementia. Groups meet for about two hours at a local venue. A leader, often a health professional, plans with group members an interesting and relevant program for a year and facilitates the meetings.