

SYDNEY SOUTH WEST AREA HEALTH SERVICE

Carers Action Plan 2007 - 2012



Acknowledgement

Thank you to all carers, staff and services who contributed to the consultation process and development of this Plan.

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CHIEF EXECUTIVE'S MESSAGE

Carers provide more care to older and frailer people, those with chronic health conditions, and people with disabilities in our communities, than any other service or group of people. Being a carer involves considerable time, effort, and expense, often over a number of years. Carers are often a critical part in a patient's access to health care and community services. As a result, it is vital that clinicians and other staff consult with carers and involve them in all aspects of care and care planning.

Many of us only become aware of the importance of carers when we have to provide support to someone who is close to us, such as a parent, a spouse, a relative, or a neighbour, with a chronic health problem or disability. It is at this point, that we realise how difficult it sometimes can be to get the level of care and support, to which we believe everyone is entitled. Some carers, such as Aboriginal and Torres Strait Island and those from culturally and linguistically diverse backgrounds have experienced difficulty gaining access to health services. I therefore encourage staff to pay particular attention to these carers, as they will require additional support.

Our health services will become more responsive and effective if we understand clearly the needs of our patients and the people who support them. We can only do this if we continue to consult with carers regarding the delivery and development of our services. Working with carers will become even more important over the next two to three decades as our population ages and grows.

This changing demographic will also impact on our staff as they increasingly combine work and caring responsibilities. We know that a larger proportion of carers are women, and also that women make up a large proportion of the workforce. This will pose particular challenges for SSWAHS in meeting the needs of staff who are also carers.

The Area Executive and Senior Management are committed to ensuring that carers are valued and recognised, and that services and workplaces provide them with better support. I welcome the Sydney South West Area Health Service Carers' Action Plan as it brings carers to the attention of our staff and community. The Plan is a crucial step in providing direction in working with this very important group, and will make a significant contribution to enhancing our work with carers. Health staff will be true partners, to complement the support that carers provide on an ongoing basis.



Mike Wallace
Chief Executive

1. Introduction

1.1 What is Caring?

Caring is a normal part of life and human relationships. Most people expect to provide care to others and receive care during their lives. While caring is a normal part of life and can be a very positive and life enhancing experience, people often must take on a caring role with little notice and it can be a very stressful time, particularly if it occurs over a long and extended period.

Carers provide care and assistance to another person, usually in a regular and sustained manner, to someone with an illness or disability. This can include frail older people, people with disabilities, people with mental health problems, people with alcohol or other drug dependency, people with dementia, people living with HIV/AIDS, and people with a chronic or terminal illness.

Usually a carer is a family member (including parents, spouses, children, grandparents, uncles and aunts, or nieces and nephews). However carers may also be a friend, neighbour or another community member. They often don't see themselves as carers but just as partners, relatives or friends. Carers may be from culturally and linguistically diverse backgrounds, or an Aboriginal person. They may be a colleague within SSWAHS, or someone from another agency.

Carers provide this support and assistance without payment (other than a carer allowance or carer payment). The care can be provided by one person or by a network of people and can change over time.

Some family members or friends take the main responsibilities for caring. These people are usually described as primary carers, and provide the most informal assistance on an ongoing basis to another person who is restricted by one or more core activities in the areas of communication, mobility and self care. A secondary carer provides informal care in a supporting role where either another family member or formal services provide the majority of care (Carers Association of South Australia Inc, 2001).

1.2 Who are Carers?

The *Australian Bureau of Statistics (ABS) 2003 Survey of Disability, Ageing and Carers (SDAC)* profiles carers. In Australia, there are 2.6 million carers, including 474,600 primary carers. Of these, 6.6% were under 18 years and 7.2% 75 years and over.

In NSW, there are 748,000 carers representing approximately 11% of the NSW population, with 20% being primary carers. Although carers are in all age groups, primary carers are most likely to be 45 years of age and over:

- In NSW, 72% of primary carers are women;
- Of all primary carers, 91% were caring for a close family member, 40% care for a partner, 29% care for a child and 31% for other;
- Caring tends to be a long-term commitment, with 33% reporting that they have cared for at least ten years; and over one half of primary carers provide at least 20 hours of care a week;
- 36% of primary carers are employed and 54% of these are employed part time;
- 17% (388,800) of all carers in Australia are under 26 years of age (*Disability, Ageing and Carers: Summary of Findings, Australian Bureau of Statistics, 1998*)

1. Carers

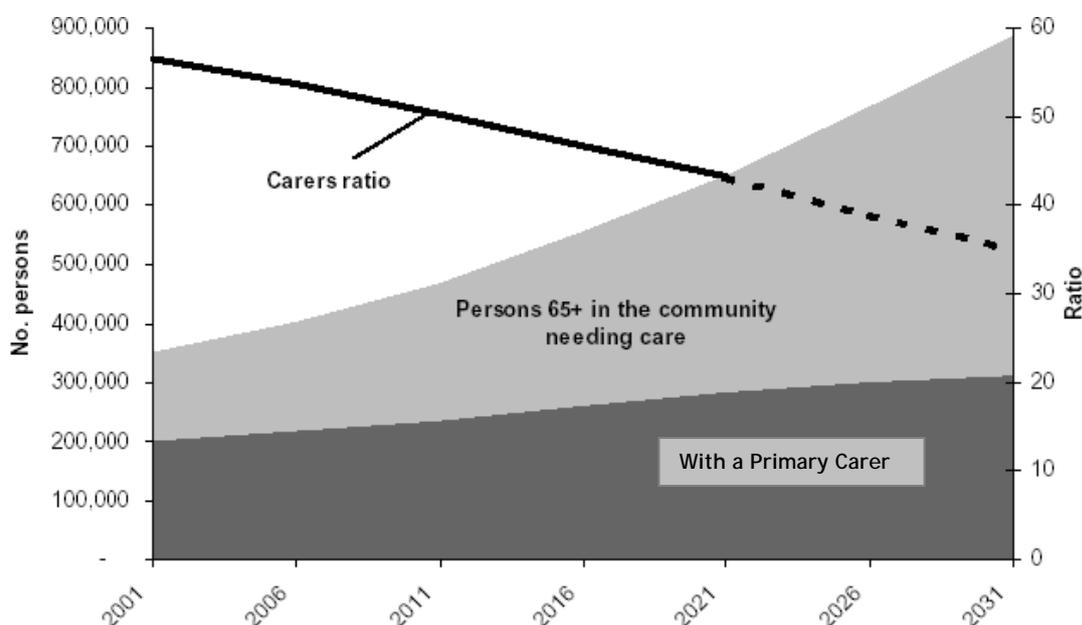
- *Carers provide assistance and care to another person in a regular and sustained way*
- *Caring is usually a long term commitment*
- *11% of the population are carers*
- *Being a carer can affect your financial circumstances, and mental and physical health*
- *The NSW Carers Plan 2007-2012 aims to focus attention on the needs of carers*

- Carers tend to have lower incomes than the rest of the population and more than half rely on government assistance.

Of concern is that as the level of disability increases, so too does the amount of time provided by primary carers. Almost 2/3rds of primary carers of people with a profound disability provide care for more than 40 hours per week.

Predicting the future of caring is complex. The Australian Institute of Health and Welfare (AIHW) and National Centre for Social and Economic Modelling (NATSEM) have considered future demand and supply of informal care. The figure following shows projected demand and supply of carers. It indicates that demand for carers will increase as the population ages and, at the same time, the number of carers is expected to reduce as women increasingly work outside the home. Dependent on future policy, carers are anticipated to combine work and caring.

Figure 1: Projected Demand and Supply of Carers in Australia (Source: NATSEM Simulations 2004)



At the same time, the availability of volunteers to support carers and the people they care for is also changing, with each generation having a different view of how or whether they can volunteer. Services such as Meals on Wheels, and Neighbour Aid which rely on volunteers to provide support to people living in the community will be affected by these changes.

1.3 The Cost of Caring

Caring does not come without cost, impacting on health and welfare. The 2003 SDAC found that only 25.7% of carers were satisfied with their caring role and 29% indicating that their wellbeing was adversely affected by their caring role. Concerns reported by carers were:

- 46.4% frequent interruptions to their sleep;
- 33.7% feeling weary and lack of energy; and
- 29.2% worry or depression (depression has also been shown in clinical studies).

A Carers Australia Survey in 1999 found that injury was an issue, with 33% of carers reporting physical injury in the course of providing care. Half of these injuries occurred in lifting or carrying the person or other objects.

Access Economics (2005) has considered how caring should be valued. It estimates that the opportunity cost of time devoted to caring in Australia is approximately \$4.9 billion (noting that the rates of employment and labour force participation by carers is substantially below that for other Australians) and that the replacement valuation (to replace the work done by informal carers with paid care services) would be \$30.5 billion.

1.4 Support for Carers

At a Commonwealth and State level, there has been an increasing recognition of the importance of carers in supporting people with a range of health and other needs. The Commonwealth and NSW Governments provide this support through a number of mechanisms. This support is described in detail in Section 4.8.

At a legislative and strategic level there have been several initiatives in NSW. In 1999, *the NSW Government Carers Statement* was released to gain public input into funding (and service) decisions to increase supports for carers. The *Review of the 1999 NSW Carers Statement; Background Paper (2007)* identified major changes in support for carers including:

- The *NSW Antidiscrimination Amendment (Carer Responsibilities) Act 2000* which created an obligation on employers to accommodate, where possible, employee's responsibilities as a carer. This makes discrimination or unfair treatment against carers (who are immediate family members) in employment unlawful.
- The establishment of the NSW Carers' Program which provided a variety of supports including support and training for carers, emotional and social support, and building better professional practice. Funding and policy initiatives include:
 - General support through direct funding of Area Health Services and local and state non-government organisations; and funding to Carers NSW to take on peak activities;
 - Support to carers of people with a mental illness through the establishment of the NSW Mental Health Family and Carers' Program which funded area health services and non-government organisations;
 - Support to young carers via the NSW Young Carers Project; and
 - Developing a NSW Cross Agency Action Plan for Carers to improve awareness and responsiveness to carers needs.

In 2007, the *NSW Mental Health Act 2007* was amended to include specific attention to carers. Section 71 of the Act defines the "primary carer" as being: the guardian; a person nominated by the patient as the primary carer; or if none of these, the spouse, a person primarily responsible for providing support or care to the patient, or a close friend or relative of the patient. Section 72 defines who may be nominated (or revoked) as a primary carer.

The Background Paper (noted above) provided guidance in the development of the *NSW Carers Action Plan 2007 - 2012*, which was released January 2007, and outlines the NSW Government's commitment to carers over the next five years. It includes significant new support for those living with mental health and physical disabilities as well as expanding measures to support carers such as the NSW Carers' Program. It also recognizes that support for carers covers a range of areas including community support, health, education, transport, employment and industrial relations. The plan articulates the NSW Government Vision:

The NSW Government will contribute to carers achieving quality of life for themselves and the people they support. In the context of their caring role, carers will be:

- *supported to achieve physical and emotional wellbeing and to participate in work and community life;*
- *valued as key contributors to community wellbeing and as key partners and providers of care; and*
- *considered in the development of public policy in NSW".*

1.5 The Broader Context

The *NSW Carers Action Plan 2007 - 2012* articulates with major NSW Government Plans.

The *NSW State Plan A New Direction for NSW (2006)* - a ten year plan which outlines the goals for the NSW Government: Rights, Respect and Responsibility; Delivering Better Services; Fairness and Opportunity; Growing Prosperity Across NSW; and Environment for Living. The plan priorities include attention to carers: improved access to quality health care (S1); improved survival rates and quality of life for people with potentially fatal or chronic illness through improvements in health care (S2); improved employment and community participation for people with disabilities (F2); improved outcomes in mental health (F3); and reduced avoidable hospital admission (F5).

The *NSW State Health Plan A New Direction for NSW Towards 2010 and Beyond* reflects the health priorities in the NSW Government's State Plan. It contains strategies to be implemented by NSW Health to address these goals with equity in health a fundamental principle. In particular, the plan includes a focus on carers within the key strategic areas of creating better experiences; strengthening primary health, continuing care in the community; and building a sustainable workforce.

Future Directions for Health in NSW - Toward 2025 Fit for the Future outlines seven long-range future directions for the NSW health system over the next twenty years.

New South Wales: A New Direction for Mental Health (2006) is a five year plan to improve care to people with mental health problems. Carers are a key component of the plan. Strategies include a focus on improving advice and support for carers, providing education and training, and involving carers in assessment, care planning and discharge planning.

The NSW Government *Better Together: A New Direction to Make NSW Government Services Work Better for People with a Disability and Their Carers 2007 - 2011* is a whole of government plan which focuses on delivering better services for people with a disability, their families and carers.

The NSW Government *Stronger Together: A new direction for disability services 2006 - 2016* focuses on disability services and emphasizes three major target areas: strengthening families; promoting community inclusion; and improving the system's capacity and accountability. Although this plan focuses primarily on services funded through the Department of Ageing, Disability and Home Care it will have implications for health services which work with DADHC.

2. The Sydney South West Communities

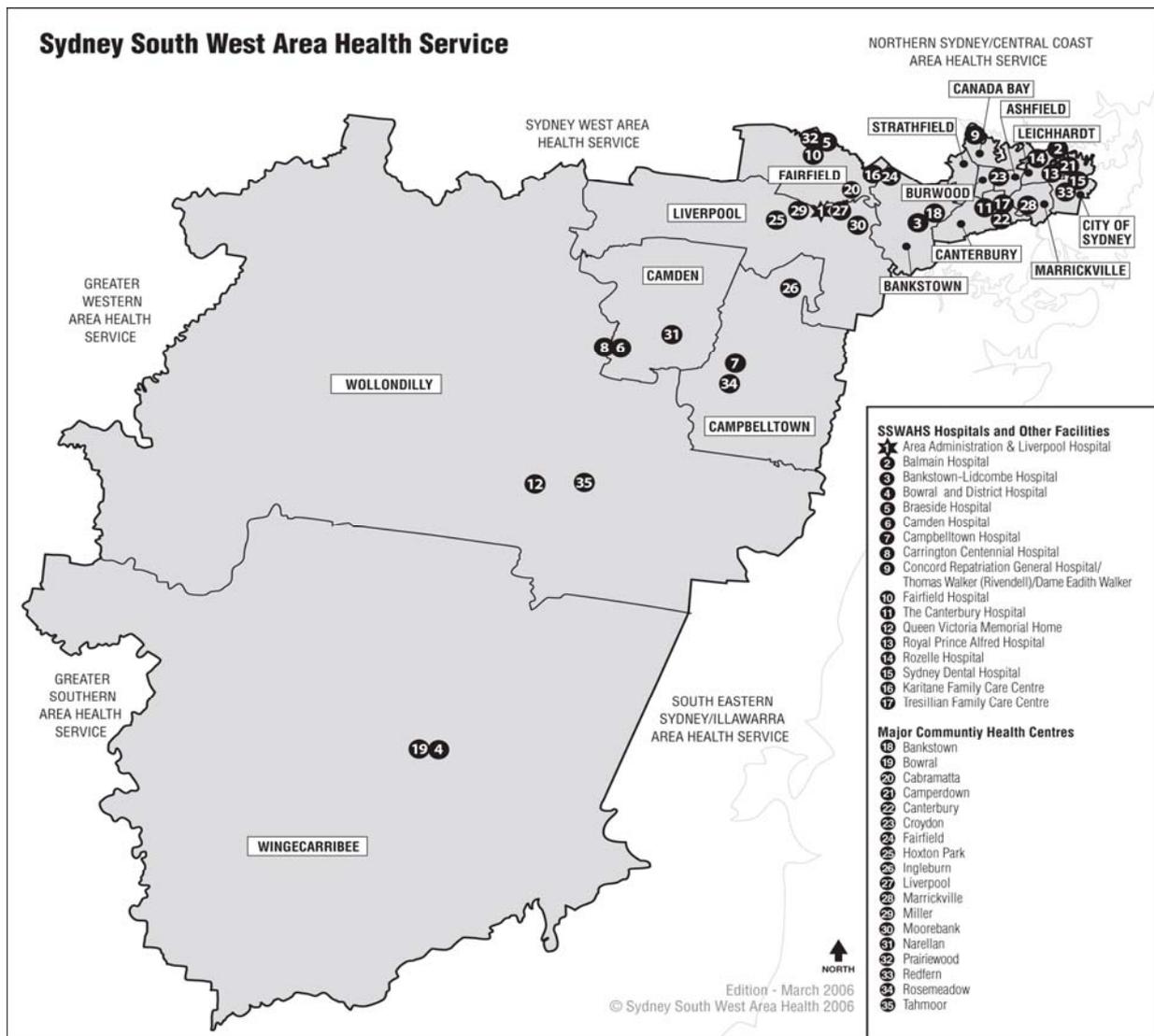
2.1 Sydney South West Area Health Service

Sydney South West Area Health Service (SSWAHS) is one of eight area health services in NSW. It is responsible for planning, delivering and coordinating local health services for residents of Sydney South West. SSWAHS covers fifteen (15) local government areas (LGAs): City of Sydney (part); Leichhardt; Marrickville; Ashfield; Burwood; Strathfield; Canada Bay; Canterbury; Bankstown; Fairfield; Liverpool; Campbelltown; Camden; Wollondilly; and Wingecarribee. A map of the area covered by SSWAHS follows.

2. South West Sydney

- SSWAHS covers 15 LGAs and a very diverse population of almost 1.3m people
- There are more than 100,000 unpaid carers in the Area
- Some SSWAHS employees will also be carers at some time in their working life

Figure 2: Geographical area covered by Sydney South West Area Health Service



2.2 The Sydney South West Community

Approximately 1,300,000 people live in the geographical area covered by South West Area Health Service i.e. almost 20% of the NSW population (ABS 2006 Census). The population combines a generally older population in the inner west of the Area, with a younger population in the south west. Local councils with the highest proportion of young people (0-14 years) are Camden, Liverpool, Wollondilly, and Campbelltown. Councils with the highest proportion of people aged 65 years and over are Wingecarribee, Burwood, Ashfield, Canada Bay and Bankstown.

Over the next fifteen years, the number of people in SSWAHS is expected to increase by between 250-300,000 people - a population the size of Canberra. Those aged 65 years and over are projected to increase by 45%, and people aged 85 years and older is projected to almost double. This large population will place many demands on our health services.

There are 14,080 Aboriginal and Torres Strait Islander people living in South West Sydney, with 27.5% living in the Inner West and the remainder living in the south west. The largest of the Aboriginal and Torres Strait Islander communities reside in the LGAs of Campbelltown, Liverpool, Fairfield, Bankstown, Marrickville and the City of Sydney.

SSWAHS has the most culturally diverse community in NSW, with approximately 40% speaking a language other than English at home (compared with 26% in NSW). Most notable are Fairfield and Canterbury LGAs, where over 60% people do not speak English at home. The greatest number of people who speak a language other than English at home (LOTE) are Arabic, Vietnamese, Cantonese, Italian and Greek.

Although traditionally an area of settlement for people from southern Europe and Asia and the Pacific, recent refugees (or humanitarian arrivals) have increasingly arrived from Africa. Other emerging communities include Afghani and Bangladeshi groups.

Although the ABS does not collect data on sexual identity, the cultural diversity of SSWAHS includes a significant Gay, Lesbian, Bi-sexual and Trans-gender population, particularly in the Inner West.

Family households vary with the highest proportion of lone person and group households located in the inner city areas of Sydney, Leichhardt and Marrickville. In contrast, the highest proportions of multiple family households are in Fairfield, Liverpool and Bankstown, and single family households in Camden, Wollondilly and Liverpool.

South West Sydney has some of the poorest communities in NSW, with a large number of recent arrivals, and pockets of high unemployment and a higher proportion of families living on welfare. The local government areas with the greatest socio-economic disadvantage (in order of ranking) are Fairfield, Canterbury, Liverpool, Bankstown and Marrickville.

2.3 Carers in Sydney South West

The *Review of the 1999 NSW Carers Statement: Background Paper* identified carers with specific needs. They were: carers in rural and remote areas; Aboriginal and Torres Strait Islander carers; carers from culturally and linguistically diverse backgrounds (CALD); young carers; ageing carers; hidden carers; gay and lesbian carers; and carers who are frail, have a disability, or have a drug and alcohol issue themselves.

The Australian Bureau of Statistics (ABS) included questions about carers in the 2006 Census. The Census indicates that there were 100,743 people (9.7%) aged over 15 years in SSWAHS who provided unpaid help, care or assistance to a family member or other because of a disability, long term illness or problem relating to old age. The proportion of carers in SSWAHS is similar to the proportion of carers in metropolitan Sydney.

The following table indicates the LGAs where unpaid carers live in SSWAHS. Not only are there more carers in the south west of the Area i.e. approximately 40% of carers in SSWAHS reside in Bankstown, Fairfield or Liverpool LGAs, but there is also a higher proportion of carers in the

South West than in the Inner West. The ABS 2006 Census also provides detailed information about our carers.

Table 1: Residence of Unpaid Carers aged over 15 years in SSWAHS (ABS Census 2006)

Unpaid Carers in the South West	Total Unpaid Assistance (People Aged 15+ years)	Total SSWAHS Population aged 15+ yrs	Proportion of Unpaid Carers
Ashfield	2,987	33,536	8.9%
Bankstown	14,159	133,081	10.6%
Burwood	2,521	26,139	9.6%
Camden	3,660	36,960	9.9%
Campbelltown	11,262	109,056	10.3%
Canada Bay	5,453	54,916	9.9%
Canterbury	10,575	103,576	10.2%
Fairfield	14,184	141,111	10.1%
Leichhardt	3,661	41,777	8.8%
Liverpool	12,220	123,677	9.9%
Marrickville	5,309	61,849	8.6%
Strathfield	2,616	26,240	10.0%
Wingecaribee	3,803	33,502	11.4%
Wollondilly	3,323	30,553	10.9%
Part of City of Sydney ¹	5,010	80,346	6.2%
Inner West Subtotal	38,132	428,379	8.9%
South West Subtotal	62,611	607,940	10.3%
Total	100,743	1,036,319	

Note

1. Estimate only using the West and South Statistical Local Areas

Sex of Carers

Consistent with the NSW average, women in SSWAHS are more likely to be a carer (61.2% of all carers). There are approximately 39,100 male carers. The proportion of male carers is highest in the southern part of the City of Sydney where 45.5% of carers are men.

Rural Carers

Although SSWAHS is primarily a metropolitan Area Health Service, rural areas are also a feature of the Area. The highest proportion of unpaid carers live in the rural and fringe metropolitan shires of Wingecaribee (11.4%) and Wollondilly (10.9%).

Indigenous Carers

There are approximately 8,840 Aboriginal and Torres Straits Islander people aged over 15 years residing in SSWAHS. Of these, 1,192 (13.48%) are carers. This proportion is significantly higher than the proportion of carers in SSWAHS overall.

Young Carers

There are approximately 9,220 young carers aged 15 - 24 years living in SSWAHS ie 9.2% of all SSWAHS carers. This is higher than the NSW average of 7.6%.

Older Carers

Older carers (aged over 75 years) represent 4.8% of all SSWAHS carers. This is lower than the NSW average of 6.1%.

Carers from Culturally and Linguistically Diverse (CALD) Communities

SSWAHS comprises a large proportion of culturally and linguistically diverse communities (CALD). Although 2006 Census data is not yet available on CALD carers, they can be profiled by their isolation, stigmatisation of the people they care for, language and communication barriers, and lack of information (Carers NSW website: www.carersnsw.asn.au)

Gay, Lesbian, Bisexual and Transgender (GLBT) Carers

As noted previously, the ABS Census does not identify sexuality, however the *Review of the 1999 NSW Carers Statement: Background Paper* noted that GLBT carers have specific needs. These include care related to people with HIV/AIDS and ageing GLBT people, and overcoming barriers to access already known to affect GLBT carers.

Carers in Our SSWAHS Workforce

There is no information available about the number of SSWAHS staff who are also carers.

In considering the statistics above, it should be noted that although the ABS Census provides broad information about the number of carers and their characteristics, it does not provide detail about the capacity of each carer to meet the demands of their caring role. This can only be identified on an individual basis.

3. Health Services in Sydney South West

3.1 SSWAHS Health Facilities and Services

SSWAHS provides the majority of its health services through public hospitals and community health centres. Public hospitals in SSWAHS are:

- Royal Prince Alfred Hospital (RPAH)
- Concord Hospital
- Canterbury Hospital
- Tresillian Family Care Centre
- Balmain Hospital
- Institute of Rheumatology & Orthopaedics (IRO)
- Sydney Dental Hospital (SDH)
- Dame Edith Walker
- Thomas Walker Hospital (Rivendell)
- Bankstown-Lidcombe Hospital
- Fairfield Hospital
- Braeside Hospital
- Liverpool Hospital
- Karitane
- Campbelltown Hospital
- Camden Hospital
- Bowral and District Hospital
- Carrington Centennial Hospital
- Queen Victoria Memorial Home

3. Health Services

- *20 public hospitals and more than 160 community health facilities*
- *There is a strong community participation framework in place in SSWAHS*
- *A SSWAHS workforce of more than 23,000 staff*
- *SSWAHS services work with General Practitioners. Private health services complement public health services*

Community health services are provided through 160 community health and related facilities. Large community health centres are located at: Redfern; Camperdown; Marrickville; Canterbury; Croydon; Bankstown; Carramar; Cabramatta; Prairiewood; Liverpool; Miller; Moorebank; Hoxton Park; Ingleburn; Campbelltown; Rosemeadow; Narellan; Tahmoor; and Bowral. Services provided include early childhood, community nursing (including both primary and specialist palliative care), child adolescent and family, oral health, drug health, mental health, and aged care.

SSWAHS employs more than 23,000 staff to provide health services to the local community. These staff include doctors, nurses, allied health professionals, and support staff. In 2005-2006, there were approximately 281,065 inpatients treated in SSWAHS hospitals, 298,203 attendances at Emergency Departments, and 4,142,227 non-inpatient occasions of service.

SSWAHS staff work with general practitioners, other health providers, government departments, non government organisations, and groups to meet the needs of the patients and clients and the wider community.

To improve coordination of health care, SSWAHS has grouped medical specialties and health services into clinical streams. Clinical streams bring together health professionals with specific skills and expertise in similar health problems, or a focus on specific target populations, with a focus on developing and implementing better health care.

Clinical streams in SSWAHS are: Women's Health and Neonatology; Paediatrics; Gastroenterology and Liver; Cardiovascular; Neurosciences, Bone and Joint, Plastics and Trauma Surgery; Cancer; Mental Health; Critical Care; Oral Health; Drug Health; Laboratory Services; Aged Care and Rehabilitation; Complex Care, General Practice and General Medicine; and Medical Imaging. In addition, Allied Health and Community Health service a range of communities and needs.

Although clinical streams operate across the entire Area (commencing 2008), they may not provide a service in all hospitals or community health centres. Services may be provided through inpatient units, outpatient (or ambulatory) clinics, community health centres, homes or other settings.

SSWAHS has developed and implemented a Community Participation Framework which ensures the involvement of consumers and carers in decisions about individual health care, as well as the involvement of communities in decisions about the provision of health care services. This commitment to participation results in improved health care and health outcomes that are transparent, accountable and reliable. There is a structured and coordinated approach to participation through involvement of consumers, carers and community in decision making and evaluation of services, and through the ongoing establishment of partnerships between consumers, carers, communities, health services and professionals.

3.2 Other Health Services

General practitioners underpin the health system by providing primary health care to residents of SSWAHS. Increasingly, practice nurses are being employed by general practitioners to improve patient care and support. Divisions of General Practice have been developed to support the work of general practitioners and to build their clinical capacity.

SSWAHS services and staff work with general practitioners and local Divisions of General Practice to improve the overall health of the community, and to address the health care and related needs of individual patients.

There is also a range of other non government organisations and private practitioners operating in SSWAHS who address specific health needs of individuals and families. They include dentists, medical specialists, private allied health practitioners, local community pharmacists, and community based health and welfare organisations.

Private hospital and day procedural centres operate across SSWAHS. The majority of these private facilities are located in the Inner West of SSWAHS.

Both government and non government provide community based models of health service delivery that play an important part in preventing ill health, peer engagement and reduction of social isolation, all of which have significant positive health outcomes at the individual and population level.

4. Services for Our Carers

SSWAHS has a number of services which are specifically targeted to providing information and support to carers. The major services which provide support to carers are the SSWAHS Carers' Program, the SSWAHS Family Friendly Mental Health Program (Area Mental Health Services), Aged Care and Rehabilitation Services, and Cancer Services.

Clinical streams such as Gastroenterology and Liver; Cardiovascular; and parts of Neurosciences, Bone and Joint, Plastics and Trauma Surgery have developed strong carer-focused support in response to the perceived and expressed needs of carers with whom they come in contact. Allied Health professionals such as Social Workers, Occupational Therapists, Physiotherapists and Speech Pathologists also provide individual and group interventions for Carers. Community Nursing and other community health services have long histories of working with Carers even though in the past this work may not have been well articulated as part of their core business.

Some services, such as the Special Care Dentistry Department at Sydney Dental Hospital, work specifically with people with disabilities. These services usually have a stronger focus on carers.

SSWAHS services, together with other government and non-government organisations (NGOs), and voluntary support groups, provide a range of support for carers. The following provides information about specific carer services in Sydney South West.

4.1 SSWAHS Carers' Program

Carer Support Services were established in 2003 in the former Central Sydney AHS and South West Sydney AHS, funded by the NSW Health Department. The original NSW Health brief for all Area Health Carer Support Services was "to provide professional support (to carers) in the public health system and initiate strategies at the local level to improve the responsiveness of the public health system to the needs of Carers." These services have worked closely together since the amalgamation of the two Areas into SSWAHS in January 2005.

The Carers Information and Support Service, formerly based at Liverpool Hospital (and now relocated to Camden Hospital), and the Carer Support Service at Concord Hospital were amalgamated as the SSWAHS Carers' Program in 2007. The service employs 4.9 full time equivalent staff.

The SSWAHS Carers' Program mission is to: "foster an Area Health Service that supports and includes carers by: raising awareness amongst SSWAHS staff and residents about carers and their role, promoting the contribution of carers in all their diversity, supporting the improvement of access and service delivery to carers; supporting the enhancement of carer wellbeing, promoting an environment that supports the caring role and; advocating for carers at an organisational level".

Prior to 2007, NSW Health required Area Carer Support Services to work to individual action plans. Accordingly, the SSWAHS Carer Support Services worked to improve the responsiveness and inclusiveness of Area facilities to carers. Actions were strategic and practical in their implementation, practical in terms of engaging health workers who provide services involving

4. Services for Carers

- *SSWAHS services include the SSWAHS Carers' Program, Family Friendly Mental Health Services Program, and a range of Aged Care and Rehabilitation Carer support services.*
- *Some other SSWAHS specialist services have a strong emphasis on carers*
- *A range of government and non-government agencies provide financial and practical support to carers*

carers, and strategic in regard to the desired impact the actions would have across a large and diverse organization. Earlier action plans focused on:

- Consulting with Carers, AHS workers and Community partners regarding the needs of carers and how these needs can be best met - especially carers with high needs and hidden carers;
- Improvement in the provision of support and education services to carers both through the tendering, dissemination and administration of NSW Health Local Carer Grants to NGO's and the direct provision of education to carers in SSWAHS;
- Training of health care workers and education of the community about the issues facing carers and their needs;
- Promotion of practice improvement and service initiatives that better meet the needs of carers, particularly in acute care settings ;
- Lobbying for the development and adoption of Area-wide policies and practices that are carer friendly and carer inclusive;

As a result of these actions, effective working relationships have been established with specific Area services and the community sector, and progress has been made towards achieving better outcomes for carers.

The SSWAHS Carers' Program receives approximately \$400,000 in recurrent funding from NSW Health. This funding supports development of a carer focus across all clinical services.

In addition, \$148,578 pa has been allocated by NSW Health for implementation of the Carers' Action Plan to 2010/2011, and non-recurrent funding was provided in 2007/7 for Aboriginal and CALD targeted activities. Costing related to the expenditure of this funding has been included in the Summary Action Table (p 35) to June 2009. In keeping with NSW Health parameters for development of AHS Carer Action Plans, this costing will be reviewed and updated annually.

4.2 SSWAHS Family Friendly Mental Health Services Program

The SSWAHS Family-Friendly Mental Health Services Program (FFMHSP) is a two year funded (\$200,000pa) initiative of the NSW Centre for Mental Health and addresses the needs of families and carers. The program, which commenced in June 2006, seeks to improve the health and quality of life of families and carers, and also of people with a mental illness, by:

- Promoting the optimum health and well-being of families and carers of people with a mental illness;
- Enabling families and carers of people with a mental illness to maintain their caring role and/or to make choices about their continuation in the caring role;
- Improving family and carer participation in service planning and delivery; and
- Assessing a family's or carer's capacity and willingness to provide the care required, and also their information, education and support needs.

The overall goal of the FFMHSP is: "To ensure that families and carers of people with a mental illness are adequately supported and have sufficient information and skills to fulfil their caring roles".

The FFMHSP focused on the establishment of a small team of specialist staff to facilitate changes needed to make Area Mental Health Services more family friendly. It is working towards its goals through: coordinating and delivering local staff training and resource development; providing specialist clinical consultative advice and support about family intervention; coordinating with mental health carer support programs and generic services from NGOs; developing local participation by families and carers in service development; and facilitating local systemic change management.

A family friendly mental health service is one in which clinicians and other health professionals are at all times supported to:

- Consider the family and carer throughout the consumer journey;
- Support consumers to involve their families and carers in the most appropriate way for both the consumer and the family and carer;

- Provide general information to families and carers, such as how the mental health system works, and fact sheets about different mental illnesses, treatments, etc;
- Recognise family and carer needs, and provide information to help them access support, information, education and advocacy, eg. through NGOs; and
- Recognise that the needs of families and carers change over time, and to respond to these changes.

Key initiatives in the first year of operation of this program (2006/7) include:

- appointment of a program coordinator and program officers;
- establishment of a steering committee to oversee development and implementation of the program, and working parties;
- a survey of staff about their current skills, knowledge and practice in working with families and carers, supported by a review of service activity data;
- implementation of “family sensitive” training for staff across the Area;
- the establishment of strong productive links with our partner NGO, Carer Assist and with the Commonwealth Carer Respite Service; and
- small group clinical supervision in Family Work in parts of the Area.

4.3 SSWAHS Aged Care and Rehabilitation Services Carer Support

Carers play an extremely important role in Aged Care and Rehabilitation Services (AC&RS), with many frail aged and disabled people extremely reliant on their carers for ongoing care and support. In addition to referring patients and clients to services provided by non-government carer support services, SSWAHS AC&RS operate a variety of carer support services. A key focus of AC&RS is to provide practical and flexible support to carers. These services are funded through NSW and Commonwealth programs and include:

- Generalist Day Care Centres at Camperdown, Concord, Canterbury, Bankstown, Panania, Greenacre, Villawood, Carramar, Lurnea, and Picton; Aboriginal Day Care at Hoxton Park and Minto; Ethnic Day Care at Concord, Bankstown, Fairfield, and Liverpool; and Dementia Day Care at Camperdown, Concord, Canterbury, Fairfield (Aimee’s Place), Rosemeadow CHC and Camden;
- After hours and weekend respite;
- Dementia Advisory Services which provide strategic support, education and coordination for people with dementia and their carers, often in conjunction with other services.
- Transcultural Respite which provides out-of-home respite to people from non-English speaking backgrounds;
- Reslink which provides flexible respite for carers of people with dementia and challenging behaviours;
- Out-of Hours and Weekend centre based day care for people with dementia;
- Dementia Support Service providing in-home respite for people with severe dementia

Aged Care Assessment Teams (ACATs) also have a critical role in assessing people for respite in residential aged care facilities.

AC&RS receive approximately \$2.6 million in Home and Community Care (HACC) funding and \$1.7 million in National Respite for Carers’ Program funding to provide these services. SSWAHS also contributes General Health program funding to the operation of these respite services.

4.4 SSWAHS Cancer Services

Area Cancer Services at Bankstown, Campbelltown and Liverpool hospitals, and cancer services at RPA, Concord and Canterbury hospitals (which comprise The Sydney Cancer Centre) work closely with both patients and carers to provide ongoing support during the patient’s cancer journey. Carers are encouraged to take an active role in conjunction with the patient in health service treatment decisions and care planning including family conferences.

The Sydney Cancer Centre's (SCC) Cancer Information and Support Centre offers the full range of Carers NSW brochures and information for carers. The Centre's library has various books, CD's, DVD's and other library resources targeted specifically at carers. Carers are encouraged to visit the Centre and make use of all its facilities. The Information and Support Coordinator's brief includes enhancing and extending the care and support extended to both patients and carers. Carers are able, and encouraged, to contact the SCC Info Line with questions and concerns.

While differences exist in the services provided across facilities depending on staff and resources, services in SSWAHS include:

- General information on psychological, financial and practical support including local carer support groups and national carer support programs (including face to face, telephone and internet support) and information packages (Cancer Council);
- Assistance from Social Workers for counselling and/or referral for counselling (including bereavement counselling) and in accessing respite for carers;
- Assistance with access to other Allied Health professionals such as dieticians and clinical psychologists and to community services, transport and parking vouchers;
- Provision of regular education programs including information days for carers (and patients);
- Relaxation and meditation sessions for carers (and patients); and
- Access to Cancer Council supports such as telephone and web based services.

There is no specific budget for carers in Cancer Services.

Palliative Care Services also:

- Promote and access in house carer respite where possible;
- Access trained palliative care volunteers to support both carer and patient at home, as well as a visiting program in Camden, Braeside and Liverpool Hospitals;
- Provide a 1300 number in the south west that allows access to services 24/7 using just one number to make it easier for carers. It also allows out of hours advice and support via the two inpatient units at Braeside and Camden;
- Access specific carer resources via the Palliative Care Australia website.

4.5 SSWAHS Community Health Services (CHS)

Multicultural Health Services support carers from Culturally and Linguistically Diverse (CALD) backgrounds through ethno-specific carer support groups. These groups operate across the Area. There is no budget allocated specifically for carers within CHS.

4.6 Support for SSWAHS Working Carers

In addition to working for SSWAHS, many SSWAHS employees are unpaid carers. Although accountable for ensuring that health services are provided to our local communities, SSWAHS and its managers try to balance service delivery needs with the employee's caring role. Flexible hours, carers leave, and family and community service (F&CS) leave are available to support staff with this additional responsibility.

4.7 NSW Health NGO Program Grants in SSWAHS

NSW Health has a long history of funding NGOs to provide a range of health and related services through the SSWAHS NGO Program. Some of these services have traditionally targeted carers. Examples include the Ella Centre which receives funding for respite services, and Stanford House which provides respite and temporary accommodation for people with HIV.

In 2004/5, NSW Health provided one-off Local Carer Grants to NGOs to provide direct services to carers. Agencies that received local Carer Grant funds for 2-3 year projects in South West Sydney and the Inner West are listed in Appendix B (p45). Funding for these grants was provided from dedicated NSW Health Local Grant funding and some Carer Support Services recurrent funding from previous years.

In 2007, as part of the Family and Carer Mental Health Program, the NSW Mental Health and Drug and Alcohol Office provided new state-wide funding to four organisations to provide greater support to carers of people with mental health problems, in partnership with Area Health Mental Health Services. The Schizophrenia Fellowship of NSW received this funding for Carer Assist, a unit of their organization, to provide information, education, advocacy and support to family and carers of people with mental illness in SSWAHS. Funding for this initiative is \$600,000 pa to 2011.

4.8 Community Based Carer Support Services and Programs

A variety of government organisations and NGOs at a local, state and national level provide direct information, advice and support to carers. Many more provide indirect support via services targeting their care recipients. These services may be wholly, partly or jointly funded by State or Commonwealth Governments and are critical to ensuring that carers are supported. SSWAHS works with these organisations to develop and deliver specific programs and services targeting carers.

At a national level, the Commonwealth Government Centrelink services provide carer payments and carer allowances. Carer Payment is an income support paid at the same rate as other social security pensions for people whose caring responsibilities prevent them from working. Carer Allowance is an income supplement for people who provide daily care and attention at home to a person who has disabilities or a severe medical condition.

There are several major Australian Government Programs that impact on the provision of services for Carers, including the National Respite for Carers' Program (NRCP), the Commonwealth State Territory Disability Agreement (CSTDA), the Residential Aged Care Program, the Aged Care Assessment Program (ACAP), the Transitional Aged Care Program (TACP) and the Home and Community Care Program (HACC). Of these, HACC and TACP involve joint Commonwealth/State funding agreements.

The Commonwealth Department of Health and Ageing (DHA) **National Respite for Carers' Program (NRCP)** provides respite care as well as other information and support for carers (including working carers), designed to support and assist relatives and friends caring for people at home who are unable to care for themselves because of chronic illness, disability or frailty. The Program funds Commonwealth Carer Respite Centres, Commonwealth Carelink Centres, Commonwealth Carer Resource Centres, and the National Carer Counselling Program provided by Carers NSW. Commonwealth Carer Respite Centres coordinate access to respite services, and provide emergency respite and other service information to carers at a local level via access to an 1800 telephone number. Commonwealth Carelink Centres are information centres for older people, people with disabilities, and those who provide care.

The DHA **Aged Care Assessment Program** provides flexible, coordinated "packages" to people who are frail aged or disabled who have complex needs. These packages may have direct or indirect benefits for the carer. The Extended Aged Care at Home (EACH) program assists frail aged people to remain in their homes, supported by high level care through an approved service provider. EACH Dementia (EACHD) packages provide the same range of services but include strategies to meet the specific needs of people with dementia.

DHA also provides Community Aged Care Packages (CACPs) via its **Residential Aged Care Program** to help older Australians with low care requirements to remain in their own homes.

Aged Care Assessment Teams (ACAT) funded under ACAP have an essential role in assessing the need for these and other services and may be located either in the community or hospitals. ACATs help older people and their carers (and in some instances, people with disabilities) work out the type of care to best meet their needs when they are no longer able to manage at home without assistance.

The **HACC Program** is a joint Commonwealth and State funded initiative providing community services to the frail aged, people with disabilities, and their carers. The HACC Program funds a

range of non-government, local and state (including health) services (such as the Home Care Service of NSW, NSW Meals on Wheels Association Inc, and the Community Transport Organisation Inc.) to provide this care. At a local level, these organizations will sometimes plan, coordinate and deliver the services directly, while at other times a variety of organisations may provide the individual services on their behalf. In NSW the HACC program is administered by the NSW Department of Ageing Disability and Home Care (DADHC).

The HACC Program provides services such as nursing, allied health care, meals and other food services, domestic assistance, personal care, home modification and maintenance, transport, respite care, counselling, support, information and advocacy and assessment. Community Options, also funded under the HACC Program, provide ongoing case management services for clients whose more complex needs cannot be met by other mainstream HACC services.

The Department of Families, Housing, Community Services and Indigenous Affairs (FaHSCIA) Commonwealth State Territory Disability Agreement provides the national framework for the delivery, funding and development of disability services for people with disabilities and their carers. Considerable government funding has been provided recently under this agreement, particularly for Ageing Carers of Adult Children with Disabilities, Carers of Children with Autism, Young Carers, and Carers of People with Mental Health Problems. The details of new service provision under this agreement in some instances are still being addressed. Under the terms of this agreement the Commonwealth Government has responsibility for the planning, policy setting and management of specialised employment assistance, while state and territory governments have similar responsibilities for accommodation support, community support, community access and respite.

In addition to its role with the HACC program, DADHC provides support to carers and their care recipients via its **Ageing Program** (for example Dementia Advisory Services and allied health services), and **Disability Program** (for example Residential care and respite services)

As part TACP joint funding with DHA, NSW Health provides time limited, supported discharge services either in community or residential settings to patients leaving hospital while longer term provisions are considered and put in place. These services, such as ComPacks and Transitional Aged Care Packages, may also support carers.

NSW Health also funds the Transcultural Mental Health Centre (TMHC) to promote access by CALD communities to mental health services. The TCMHC Carers Support Program provides support and information to carers of CALD background, who look after a family member or friend with a mental health problem. Bi-lingual facilitators are trained to run language-specific support groups - a number of which operate in SSWAHS.

Within SSWAHS state, local government and non-government organizations provide direct and indirect services to carers funded by Programs such as those mentioned above. Examples of these organisations are Newtown, Rozelle, May Murray, Bankstown and Fairfield Neighbourhood Centres, AFFORD (Australian Foundation for Disability), Hope Health Care, Bankstown Baptist Community Centre, Woodville Community Services, FRANS, Ethnic Child Care Family & Community Services, Koorana Family Services, Families in Partnership, Uniting Care, Disability South West Inc, Multicultural Home Respite Inc, and Centacare.

At a state level, organisations such as Carers NSW (the peak organisation for carers in NSW) provide information, support and advocacy to all population groups. Other agencies such as ACON (AIDS Council of NSW), Alzheimer's Australia, the Cancer Council, the Muscular Dystrophy Association, Parkinson's NSW, Vision Australia, Multicultural Disability Advocacy Association, and Multiple Sclerosis Society support carers of people with specific health problems.

5. Developing Our Plan

5.1 The SSWAHS Service and Planning Context

SSWAHS aims to achieve the NSW Health Vision 'Healthy people - Now and in the Future'. This vision has four overarching goals:

- To keep people healthy
- To provide the health care that people need
- To deliver high quality services
- To manage services well

5. Our Plan

- Informed by the NSW Carers Plan, reports on carers needs, statistics, local information, and consultation with carers and service providers

The Area Health Service works to achieve the NSW Health seven strategic directions:

1. Make prevention everybody's business
2. Create better experiences for people using health services
3. Strengthen primary health and continuing care in the community
4. Build regional and other partnerships for health
5. Make smart choices about the costs and benefits of health services
6. Build a sustainable health workforce
7. Be ready for new risks and opportunities

SSWAHS operates within the context of NSW Health Department policy which seeks to strengthen clinical and operational practice. NSW Health Policy Directive *Discharge Planning: Responsive Standards (Revised) (PD2007_092)* which provides a responsive and standardised approach to discharge planning has a very strong focus on carers. Appendix B lists other relevant policies.

SSWAHS is developing plans to better meet the needs of the community. *A New Direction for Sydney South West Health Service Strategic Plan - Towards 2010 (2006)* provides direction for SSWAHS activities from 2006 to 2010. It outlines our vision, values and objectives, and guides further corporate and health service planning and reporting across all levels of the organisation. The Strategic Plan requires that a Carers Action Plan be developed.

The development of this Carers Action Plan should not be considered in isolation, but within the context of considerable efforts to plan and develop clinical services in SSWAHS. Other plans under development by SSWAHS cover Community Health, Aboriginal Health, Overweight and Obesity Prevention and Management, Aged Care and Rehabilitation Services, Mental Health, Maternity Services, HIV/AIDS, and Youth Health. These plans consider the needs of carers as part of a comprehensive approach to service development.

5.2 Plan Development

The SSWAHS Carers Plan Steering Committee was established in August 2007 to oversee development of this plan. The committee comprised representatives from SSWAHS clinical and support services, carers, and a non-government organisation. A working party supported identification of issues, strategies, timeframes and responsibilities. Terms of reference and membership of the committee is in Appendix C.

Previous consultations, plans of the former CSAHS and SWSAHS Carer Support services, and information from SSWAHS clinical services informed this process, as did information from other available sources such as the 2003 ABS Disability and Carers Survey and the 2006 ABS Census. Information collected about complaints through the NSW Health Incident Information Management System (IIMS) and the Annual NSW Health Patient Surveys was also considered, and will continue to be used to review progress and guide service development.

5.3 Consultation

The plan has considered the findings from a range of general and targeted consultation processes that occurred over the past three years. This includes:

- six consultations with 297 carers in the south west of SSWAHS (Oct 2004 - April 2005) including Bowral and Macarthur carers, carers of people with mental health problems, carers in aged care, carers of people with dementia and Khmer carers;
- consultations with 50 carers from the Inner West of SSWAHS (2004-2005), including carers of people with diabetes, Italian carers, and carers of young people with disabilities, and carers of people with dementia and neurosurgical patients;
- consultation with representatives from 13 Inner West community organisations (2005);
- consultations with health service consumers where issues about carers were raised;
- consultation with Aboriginal service providers and consumers (October & November 2007) focusing on issues and strategies in access and use of health services by Aboriginal older people, carers and people with disabilities;
- consultation with parents/carers of children with disabilities in Macarthur (2007);
- a workshop with SSWAHS Carers Plan Steering Committee members (November 2007) regarding issues and strategy development;
- a survey of SSWAHS Clinical Groups and Facilities (Aug 2007) regarding the issues affecting carers, current initiatives and potential strategies; and
- distribution of the Draft Plan to SSWAHS clinical services and facilities, and the SSWAHS Community/Consumer Councils and Networks, and to local councils, Aboriginal Medical Services, local carers, Divisions of General Practice, key government departments, peak agencies, and local non-government organisations.

6. SSWAHS Carers Plan

This Plan will help SSWAHS facilities and clinical services to improve support provided to carers.

6.1 Our Vision

The SSWAHS vision for carers is:

SSWAHS supports and values carers recognizing the cultural diversity of our communities. Carers are key partners and providers in care and service development

6. SSWAHS Carers Plan

Priorities in this plan are:

P1: Carers are recognised, respected and valued

P2: Hidden carers are identified and supported

P3: Services for Carers and the people they care for are improved

P4: Carers are partners in Care

P5: Carers are supported to combine caring and work

6.2 Our Principles

SSWAHS has adopted the principles outlined in the NSW Carers Action Plan 2007-2012:

- Carers' physical, emotional and career needs are identified acknowledged and responded to.
- Carers are supported by quality services that are affordable, flexible, culturally competent, coordinated, accessible and available.
- Strategies are developed to identify and support people who do not identify as carers and who may be disadvantaged by social, cultural or economic circumstances or location.
- Carers are able to exercise choice in their role as a carer and are supported in transitioning into/from their caring role when this is necessary.
- Caring relationships are recognised as diverse, dynamic, complex, with changing needs over time.
- Carers are recognised, valued and respected.
- Carers have access to information, resources and opportunities to develop their skills to provide quality care.
- Carers are included in every stage of assessment and care planning with the agreement of the care recipients and are consulted in the planning, delivery and review of services that impact on their role.
- Carers are supported by family friendly policies in the workplace.

6.3 Carer Friendly Model of Care for SSWAHS

Over the past several years, carer recognition and involvement in services has increased across Sydney South West Area Health Service. The level and type of recognition and involvement of carers varies significantly between services and facilities. SSWAHS is committed to developing the capacity of all clinical services and facilities to work with carers.

The development of a Generic Carer Friendly Model of Care for SSWAHS is a means of addressing identified gaps and ensuring a planned systematic approach is used in the development of a family friendly service. The model is compatible with the Australian Council of Health Care Standards' EQuIP criteria relating to Carers.

Critical elements of the SSWAHS Carer Friendly Model of Care are:

- A structure and policies which ensure carers participate in development of programs and services;
- Guidelines for clinical services to improve identification, support and involvement of carers in day to day practice (Refer Appendix E);

- Training in the use by all services of these guidelines;
- Staff education commencing at orientation about the importance of carers;
- Carer friendly hospital policies which are consistent and support carers;
- A culture of carer friendly services lead from senior management;
- Health promotion initiatives, such as carer education, which focus on carers;
- Employment practices that recognise caring responsibilities and support flexibility where reasonable;
- Health facility design and health services which support carers; and
- Partnerships with agencies and NGOs to advocate for and support carers.

6.4 Priorities for Action

The SSWAHS Carers Action Plan 2008 - 2010 focuses on the five Priorities for Action in the *NSW Carers Action Plan 2007 -2012*. These priorities are fundamental to improving the quality of life for carers and the people they care for:

1. Carers are recognised, respected and valued
2. Hidden carers are identified and supported
3. Services for carers and the people they care for are improved
4. Carers are partners in care
5. Carers are supported to combine caring and work

7. Priority Action Areas

Strategies have been developed to ensure that all clinical services and facilities focus on the needs of carers. The strategies address priority actions identified in the NSW Carers Action Plan and are listed as "What we are going to do" and in the Summary Action Table in Section 8. Many strategies will impact on more than one of these priority action areas. Potential measures for success identified in the NSW Carers Plan to which SSWAHS can contribute have also been identified.

7.1 Priority for Action: Carers are recognised, respected and valued

Carers play a vital part in supporting people with a range of health and related problems. They provide help with daily living tasks, supporting health care, follow up on paper work and emotional support. Their value to the person they are caring for is priceless and economic value to the nation significant.

Yet countless carers do not feel their role is seen as worthwhile and others do not recognise that they are providing valuable care. They perceive themselves as a daughter, or friend who is helping out, without acknowledging fully the importance of their caring role.

Many health workers, including general practitioners, do not identify Carers as a critical person in the patient's life or source of information about the patient, and fail to involve them in care planning decisions.

Why do we need action?

- Carer consultations indicated that many carers did not identify with the term "carer", particularly in the early stages of care. A number of carers felt that staff did not pay attention to their knowledge of the patient during assessment, and/or listen to concerns expressed by carers about the diagnosis and/or proposed treatment and care.
- SSWAHS clinical services report that current admission forms and electronic medical records do not require identification of the carer; and that many staff do not have a good understanding of the term "carer".
- Many complaints from carers focus on lack of acknowledgement of their role, and failure of staff to listen to them and value the information they can provide about the patient's symptoms and care needs. General rudeness by staff, such as failing to answer or return phone calls, distressed carers and added to their general feeling of dissatisfaction.
- Similarly, the NSW Patient Survey 2007 identified communication as a major issue for patients and carers. A need to discuss patient anxiety and fears with nurses, confidence and trust in nurses, and patients having enough to say about their treatment were identified as the major concerns.

What are we building on?

- Participation in Carers Week events in hospitals, community health centres and community settings by the SSWAHS Carers' Program and other services since 2004;
- Development and distribution of a Carers brochure "*Who Cares?*" to new SSWAHS employees at Orientation. This pamphlet includes statistics about Carers, their importance to the community, information on carer leave entitlements for employees who are carers, and information about the Carers' Program;
- Publication of the "*Carers Voice*", a regular newsletter for Carers in SSWAHS;
- Development and distribution of a *SSWAHS Family and Carer Mental Health Information Kit* providing information on mental health services in the Inner West;
- Development of a flip chart for carers about dementia by Aged Care and Rehabilitation Services in Macarthur, and provision of special bereavement packages on coping with special events for children.
- Implementation of staff education packages which incorporate feedback from consultations with Carers on subjects such as Carer Awareness, End of Life Issues, and Working with Carers from CALD backgrounds.

- Annual surveys of patient and carers experiences and regular consultations with patients and carers, provide greater opportunity to hear about patient and carer needs

What are we going to do?

- Promote carers week in all facilities, and initiatives focusing on carers in local media. Include information about carers in other promotional activities
- Increase staff awareness and knowledge about carers through training, clinical education and promotional materials
- Use new knowledge and information to inform development of services;
- Develop resources for carers which is relevant to their needs and the health problem of their care recipient, eg realistic information about services available and rights and responsibilities
- Incorporate responsibilities for carer support into performance agreements and position descriptions
- Reflect consideration of carers in SSWAHS plans, policies, guidelines, programs, and priorities (Refer priority 4)
- Incorporate legislative requirements from the new Mental Health Act into clinical practice, and evaluate mental health initiatives
- Implement the NSW Patient and Carer Experience – SSWAHS Action Plan, and consider how the Carers Program can support this plan

Have we made a difference?

Measures identified in the NSW Carers Plan which SSWAHS may be able to contribute to are:

- Positive media coverage of Carers Week and caring issues
- Increased number of policies that include analysis of the impact on carers
- Increased number of policies and programs that include a response to carers needs

7.2 Priority for Action: Hidden carers are identified and supported

Hidden carers are often overlooked because of their isolation, cultural values, or because they do not fit the usual label for carers. These carers are less likely to obtain financial or service support from government and non-government services, and may also be less likely to get support from their families. “Hidden” carers include Aboriginal carers, carers from culturally and linguistically diverse communities, young carers, and rural carers.

Why do we need action?

- In comparison with the broader community, Aboriginal people have poorer health and premature mortality, and are less likely to access and use health and other services. SSWAHS has a large Aboriginal population comprising 10% of all NSW Aboriginal residents.

A high proportion (13.5%) of Aboriginal people in SSWAHS self identify as a carer (ABS Census 2006). Despite this, Aboriginal residents and workers indicate poor identification with the term “carer”, limited knowledge about services available, and service barriers such as discrimination and service inflexibility as reasons for poor access and service use. These factors increase the burden of care, with significant implications for the health of Aboriginal carers. Increased knowledge about services available will improve access to services by Aboriginal people, and improve their ability to navigate the health system.

- SSWAHS has a significant population of people from non-English speaking countries. It is anticipated that the number of carers from culturally and linguistically diverse communities will increase with the ageing of the population. CALD carers include immediate family

members, such as the spouse, and secondary carers, including older children who speak English. Male CALD carers tend to be responsible for financial aspects of care and female CALD carers for physical and emotional care.

Consultation with local Khmer and Italian carers indicates poor identification with the term "carer" (influenced by cultural attitudes about caring as an obligation), poor knowledge of where to go to get help (including little promotion about carers in ethnic radio), and language barriers (including difficulty accessing interpreters and lack of information or education in alternative languages). These comments are consistent with findings from other parts of Australia. Local HACC forum consultations indicate that CALD carers seek carer support, carer support groups and education, and case management.

- SSWAHS has approximately 9,200 young carers aged 15-24 years. There are also likely to be carers under 15 year who have not been counted, who may be caring for a parent or older relative with a mental health or physical health problem. At the same time, they may be caring for younger siblings, or completing their education. They are less likely to be aware of their rights.
- NSW Health research indicates that families and carers of people with drug and alcohol problems, and the children of people with drug and alcohol problems require greater understanding about their circumstances, confidence in addressing the issues, and improved education and emotional support.
- SSWAHS has a significant number of rural carers living in Wingecarribee and Wollondilly. Patients and carers from rural and remote NSW also travel to SSWAHS hospitals for tertiary care. Lack of (and distance from) local services and supports, including respite, and cost to access services, associated with travel and accommodation, are significant concerns. These concerns are amplified for rural Aboriginal patients and carers, who may be unaware of financial supports available to rural patients and ill-prepared for longer term stays, and may require accommodation for more than one family member.

By addressing the financial concerns that Aboriginal and other socio-economically disadvantaged groups experience, one of the barriers to access to services will be removed.

- While not identified as hidden carers in the NSW Carers Action Plan (2007 - 2012), the large population of GLBT people residing in SSWAHS (including people with HIV/AIDS and ageing GLBT people) indicates a carer group who may have difficulty obtaining support and information due to pre-existing attitudes and beliefs that create barriers to access.
- SSWAHS services have expressed concern about the relatively little attention given to identify or support hidden carers, particularly given the size of these populations. Poor use and access to interpreters, poor literacy levels, and lack of targeted support were identified as specific issues.
- No data is currently collected about the number of carers supporting SSWAHS patients.

What we are building on?

- Aboriginal Patient Liaison Officers at RPAH, Liverpool and Campbelltown Hospitals identify and support Aboriginal patients and carers in hospital;
- Redevelopment and publication of a pamphlet for Aboriginal rural patients, family and carers about RPAH services (an initiative of SSWAHS Aboriginal Liaison Officers, RPAH Social Worker Department, Carers' Program and the Health Promotion Unit);
- SSWAHS Respite services for older Aboriginal people in the South West, and ethnic specific clusters in the Inner West;
- CALD Carer education programs held in memory loss, falls prevention, and accessing aged care services;
- Increased use of telemedicine with rural patients and families, including training of Aboriginal Liaison Officers in the use of RPA teleconferencing facilities;
- With Carers NSW, training of SSWAHS staff to support Carers from CALD backgrounds;
- Development of a poster "Culturally Diverse Carers Need Your Help" for Inner West facilities to enhance identification of carers;

- Funding for local NGOs working with CALD and indigenous communities to improve support and information to carers;
- Children of Parents with a Mental Illness (COPMI) camps and programs have been conducted for almost a decade providing young people with peer networks, knowledge of mental illness, and dealing with feelings. Occasionally young people participating in FFMHSP steering committees, ensuring that the needs of young people are considered.

What we are going to do?

- In conjunction with Aboriginal NGOs and Aboriginal health staff, improve information and support available for hidden carers, participate in and support carers week events, develop an Aboriginal Carers Information Kit, survey current knowledge of Aboriginal staff, and provide training in carers issues and needs
- Support CALD carers by: capacity building in ethno specific services and communities to understand the term "carer", and promoting services available and how to access these services. Promote carer information in community languages, evaluate the multimedia interpreter service trial which focuses on improved access to Interpreter services, and work with Multicultural Health Services in developing strategies to address the needs of CALD Carers
- Incorporate information about ways to support rural carers in guidelines for clinical services
- Identify carers on admission and discharge forms, electronic records, and other medical records
- Expand and build on COPMI (Children of People with Mental Illness) programs, with a stronger focus on Aboriginal and CALD children and adolescents
- Implement NSW Health initiatives on hidden carers, including young carers and carers of people with drug and alcohol problems
- Incorporate strategies on carers in the SSWAHS Youth Health Plan and Drug Health Strategic Plan
- Work with NGOs, including Carers Respite Centres, in identification of hidden carers and improvement of their access to services and support
- Assess the feasibility of identification of carer needs/stress in the electronic medical record (EMR) record

Have we made a difference?

Measures identified in the NSW Carers Plan which SSWAHS may be able to contribute to are:

- Increase in provision of services for CALD, young, Aboriginal and ageing carers

7.3 Priority for Action: Services for carers and the people they care for are improved

Carers and their care recipients seek support from a range of services. Respite provides some of this support, however there are other services that may be required. Many health services provide a uniform service, neither tailoring their services to the carer or care recipients. Services need to be flexible, available, affordable, culturally competent and of a high quality.

Why do we need action?

- Carers indicate that they receive variable information, advice, support and assistance from health professionals. This can result in misconceptions or unrealistic expectations. They

report the standard of service received sometimes appears to depend on the presentation of the carer - whether they are English speaking, their degree of "health literacy" and assertiveness, as well as whom they encounter.

- Information provision to carers needs to be timely and accurate and in a suitable medium for the carer to understand and absorb, with health staff being aware of the effect of information overload in circumstances when the carer is under stress or traumatized.
- Service policies and practices vary from facility to facility, with little attention given to carer needs. Some support services are not carer friendly. A lack of parking, high parking fees, discharges made late at night, limited visiting hours, variable policy in staying overnight with a patient, paucity of overnight stay facilities, and cost of meals for carers remaining with the patient make circumstances more difficult for the carer and patient. This is a particular concern for financially disadvantaged people, including patients and carers from rural and disadvantaged communities and those on a Carers Payment.
- Carer's complaints when they are acting as advocates on behalf of their relative/care recipient, are often about patient care provided. Carers also report time delays between the patient's discharge from hospital and provision of community services, and confusion about who will implement services.

What we are building on?

- A range of services targeting carers provided by Aged Care and Rehabilitation Services, Cancer Services and other clinical groups. This includes respite programs, support groups for carers, and other specific services for carers of people with Dementia;
- SSWAHS was funded through the Family Friendly Mental Health Program \$200,000 pa for two years (2006/7 and 2007/8). This funding is being used to develop the FFMHSP model of care and in staff education. Recent initiatives in the South West to respond to the needs of carers have resulted in, for example, the employment of a carer advocate at Liverpool Hospital;
- Carer education and information seminars and workshops provided by SSWAHS clinical services over many years. Recently, education provided by the Carers' Program in partnership with health services, other government and NGOs (e.g. the series of seminars on Dementia in Lakemba and Concord in 2006/7), and participation by Palliative Care Services in a National Health and Medical Research study which will evaluate the effectiveness of a hospital based carer education group program;
- Consultations with Carers, health and community workers over the past 4 years have identified carers needs and concerns;
- Better Practice Project Grants to Inner West clinical services (2005 & 2007) have fostered the provision of services and education to carers across acute and community health care;
- Networks and partnerships with other government and non-government services, such as HACC services and forums, to exchange information about gaps in services for carers and care recipients;
- Some inpatient units eg at RPAH and CRGH, and palliative care units in the South West, have capacity to enable carers to stay overnight with their care recipient. Capital works project plans at Liverpool Hospital and RPAH include culturally appropriate overnight accommodation for rural patients and carers;
- A successful framework for consumer consultation and participation, including carers.

What we are going to do?

- Use new and existing information, including NSW Health patient surveys, patient complaints information (IIMS), Carer Assist surveys about mental health clients, and HACC Minimum Data Set (MDS) about older people and people with disabilities, to inform service development
- Continue to implement the Family Friendly Mental Health Program in partnership with NGOs through training mental health staff through Train the Trainer workshops in carer and family friendly practices, working with Carer Assist to provide support and education to carers of mental health consumers, and incorporating requirements of the Mental Health Act into service policies and procedures
- Provide education and support for all new families and carers of young people with early psychosis, eating problems or personality disorders
- Develop guidelines for use by all services to review and develop carer friendly services, and provide training in their use to senior managers
- Work with SSWAHS Pharmacy Departments to improve information on medications provided to carers
- Work with the Divisions of General Practice to develop and implement strategies to improve GP and practice nurse awareness and response to carer needs and support
- Include a focus on carers where SSWAHS has responsibilities in student training. Advocate for universities and training bodies to improve course content about carers
- Continue to monitor and support existing grants to local NGOs. Fund Better Practice Projects to heighten awareness of carer needs and foster service improvement
- Improve support given to people with specific needs and their carers, and in particular, carers of people with multiple problems or disabilities (including dual diagnosis), carers of younger patients, and carers of Aboriginal patients. Consider issues such as carers who wish to stay overnight with their care recipient
- Consider the implications of corporate services on carers (including financial and other constraints) by reviewing accommodation charges applied to rural patients and carers, parking fees, cost of hospital meals, availability of health related transport, and access by public transport
- Incorporate carer accommodation into hospital capital works developments
- Work with DADHC and other agencies, and volunteer organisations in supporting planning and development of services, programs and information which support carers and their care recipients. Implement the HACC Minimum Data Set (MDS).

Have we made a difference?

Measures identified in the NSW Carers Plan which SSWAHS may be able to contribute to are:

- Greater number of people with complex health care needs accessing centre based respite
- Greater number of people supported through day programs receiving higher level of support
- Greater number of mental health carers attending carer groups/courses

7.4 Priority for Action: Carers are partners in care

As the number of aged and people with disabilities increase, so too has the importance of the role of carers. To provide the best care in our health system, it is imperative that clinicians recognise the information and skills held by carers, and work with them as partners in care.

Carers hold expert knowledge about the person that they care for, including medical history, needs, and community and financial supports. This information is critical to ensuring that the diagnosis is accurate and the care plan feasible and appropriate. If our services are to be responsive to carers' needs, we need to ensure that new and existing services and programs have been informed by carers' advice. Services should use the opportunity created by this plan to review existing services and policies in consultation with carers. Services also need to recognise that the health and community support system is complicated, and that carers will require information and support to navigate this system effectively.

Many existing policies may directly or indirectly disadvantage carers. These policies need to be reviewed by carers to ensure that this does not happen. Carers who review our policies and programs will also need support, information and skills to ensure that a successful process.

Why do we need action?

- While many services already work with carers in providing care to their care recipients, improvements can be made to ensure that this is systematic and inclusive.
- Traditionally, health staff have not consulted with carers in developing patient care plans or in development of new programs and services. As a result, carers have often been ignored, and health care provided less effective. NSW Health Policy "Responsive Discharge Standards PD 2007_ 907" mandates that clinicians consider the needs of carers, consult with them from the point of admission and involve them in care and discharge planning. SSWAHS services need to ensure that local policies and procedures reflect this policy.
- Our services need to be both effective and efficient. In the past, new services (such as respite services) have been established to support carers but may have been poorly utilised as they did not meet carer needs for flexibility in type and hours of support, education, and transport. These services now consult with carers and reorient their services to respond to patient and carer needs. These initiatives need to be built on and sustained.
- Opportunities to work together indirectly improve understanding and knowledge of the constraints that operate for carers and staff. Greater opportunities for staff and carers to work together are more likely to challenge and change long held misconceptions.

What we are building on?

- Some clinical services have a long standing focus on consulting with carers in the development of individual patient care plans and provision of services. These include Aged Care and Rehabilitation Services, Cancer Services, Gastroenterology and Liver Services (particularly with transplant patients), Allied Health Services and Community Health Services (particularly with children and families in addressing specific health needs);
- The provision of information and education to carers already noted under Priority 7.3 which inherently recognises the important role of carers in providing care to SSWAHS patients and in some cases has also involved carers in the development and presentation of the education;
- Current initiatives in the SSWAHS Family Friendly Mental Health Program in partnership with Carer Assist to improve support to carers, and in training mental health staff to work better with Families and Carers of people with mental health problems;
- The revised NSW Health Policy *Discharge Planning: Responsive Standards (Revised) PD2007_003* will require clinical services to improve the response to carers' needs. It provides guidelines about inclusion of carers in preadmission and discharge planning;
- The introduction of patient surveys and patient and carer interviews by NSW Health in 2007 will ensure that patient and carer needs inform clinical service development;
- The IIMS system which records complaints and adverse incidents provides a systematic way for SSWAHS to identify clinical issues and use this information to improve care;
- The SSWAHS Community Participation Framework includes Carers as a group for consultation;
- Consultation with carers in capital works, for example, carers of people with mental health problems in the design of new mental health units.

- Plans under development such as the SSWAHS Aged Care and Rehabilitation Clinical Services Plan 2007-2012, the SSWAHS Strategic Framework for HIV/AIDS and Related Programs Funded Services 2008-2012, and the SSWAHS Overweight and Obesity Prevention and Management Plan 2008-2012 include strategies focused on carers.

What we are going to do?

- Consult with and involve carers in all aspects of service planning, review, and policy development. Develop and implement a framework for consultation with carers, which includes ways to support them during the consultation process
- In partnership with NGOs, provide education to carers (in a range of settings) about services available, ways to access services, and ways to improve their caring skills
- Monitor changes implemented in SSWAHS which impact on carers, including the degree to which carers have been involved in service and policy development
- Include carers in SSWAHS business processes and education programs, and provide carers with opportunities to increase their knowledge, skills and capacity to effectively participate. Include mentoring and support for their involvement in the community participation framework, assist their development of communication and negotiation skills, and address financial and other needs arising out of their participation in SSWAHS business
- Provide health staff with support, and encourage staff to attend relevant courses which will improve their knowledge about carer needs and issues
- Develop a resource on advanced care directives, which includes carer information
- Implement NSW Health initiatives as they arise

Have we made a difference?

Measures identified in the NSW Carers Plan which SSWAHS may be able to contribute to are:

- Increased number of carer representatives actively participating in policy development and review;
- Increased percentage of carers reporting positive experiences in their contacts with SSWAHS;
- Increased number of carers attending carers training;
- Increased number of health staff attending Carers NSW biannual conference

7.5 Priority for Action: Carers are supported to combine caring and work

Caring can be very time-consuming. Carers are less likely to be employed, and do not participate in the workforce to the same level as non-carers (ABS SDAC). This has financial implications for them in the short term (income level) and in the long term (barriers in returning to the workforce and superannuation). Many carers would enjoy opportunities to work in the paid workforce. This requires flexibility in employment, such as part-time work and staff leave.

Currently, carers are underrepresented in the Australian workforce, finding it difficult to combine part or full-time work with caring commitments they have outside work.

Why do we need action?

- Access Economics (Fig 1, p5.) provides a daunting picture of the future with a growing number of people requiring care and a reduction in the number of carers available. As our ageing population increases and more women return or remain in the workforce, there will be a need to facilitate the combining of individual's work and caring responsibilities.
- It is anticipated that carers will continue to be predominantly female. With a health workforce that is mostly female, managers will need to become more flexible in how they

deal with the caring responsibilities of staff. This will be particularly important if they want to retain experienced staff. SSWAHS workforce planning needs to respond to these circumstances and be flexible and creative in how it addresses this emerging challenge.

- We need to understand the needs and concerns of employees who are also carers, including views about how caring will impact on their job and future progression in the workforce.

What we are building on?

- SSWAHS staff can access Carers' leave as FACS Leave. There is capacity for carers to take more carers' leave from sick and annual leave entitlements;
- Information is available to employees about existing employment policies and conditions on the SSWAHS Workforce Website, improving access to information about work entitlements;
- Staff receive information at orientation about leave entitlements related to caring responsibilities;
- Provision of carer education at night to support working carers e.g. carers of people with dementia and carers of children with disabilities. ;
- A survey of Canterbury Hospital and Community Health staff focusing on their caring responsibilities outside work completed in 2007, found that 48% of carers felt their caring role impacted on their health and well being, particularly their emotional well being. The majority of carers surveyed felt supported by their managers (61%), though a significant number reported their employer (55%) and manager (24%) were unaware of their caring role.

What we are going to do?

- Finalise the SSWAHS Workforce Plan which focuses on strategies to attract, develop and retain staff, and ensure that strategies focusing on staff who are carers are included
- Review the SSWAHS Employee Orientation brochure focusing on Staff as Carers
- Extend the survey of employees who are carers to the rest of the AHS. This will provide a clear picture of SSWAHS employees who are carers and provide feedback on how they perceive the support provided by SSWAHS as an employer. The survey results will be used to inform and develop further workforce policy and strategies, to enable carers to participate more fully in the SSWAHS workforce
- Ensure that SSWAHS management education courses incorporates information about working carers
- Review the policy on carer leave entitlements and flexibility and provide expanded information
- Include a focus on extending carer friendly workplaces in strategies implemented by the SSWAHS Health Promotion Unit to improve the health of the community
- Disseminate relevant information eg Working Carers Gateway website through internal newsletters, the intranet, and other communication channels.

Have we made a difference?

Measures identified in the NSW Carers Plan which SSWAHS may be able to contribute to are:

- Increase in family/carer friendly practices in SSWAHS
- Increase in working carers reporting improved support to combine care and work

8. Implementation Plan

The SSWAHS Carers Action Plan has implications for all services within SSWAHS. It will be promoted by internal circular, the SSWAHS newsletter, SSWAHS internet and intranet, and community networks.

All services and facilities will be required to implement this plan. Performance agreements of senior staff will include responsibilities from the Carers Plan. Directors and senior managers of clinical services, facilities and area programs will be required to report on a half yearly basis progress on implementation. Performance indicators will be used to guide their response on progress and evaluation of progress.

From July 2008, SSWAHS will report on progress annually to NSW Health against actions, performance measures and time lines incorporated into this plan. Reports will also be sent to the SSWAHS Clinical Council and Management meetings.

The NSW Carers Action Plan 2007-2012 has identified a range of measures to evaluate progress. Using relevant measures in the NSW Plan, this Plan identifies those measures which could potentially be used at a local level. Not all data and information is readily available nor are definitions clear. Data collection systems will need to be developed over the life of the Plan.

A SSWAHS Carers Plan Committee will be established to monitor the implementation of the plan and to provide ongoing advice regarding the needs of carers. The committee will be chaired by a Senior Executive. The role of the steering committee will be to:

- consult with NSW Health regarding the definitions of performance measures, and work with NSW Health in developing appropriate data collection systems*;
- establish baseline information about the quantum of services delivered;
- develop a report format to be used by SSWAHS services to describe progress and implementation*;
- ensure that responsibility for implementing NSW Health initiatives is identified and allocated;
- analyse information from established reporting systems to identify issues and areas of further development;
- monitor implementation of the plan; and
- develop the SSWAHS annual report to NSW Health.

Needs and issues identified by the committee throughout implementation will be reported to the SSWAHS Clinical Council, SSWAHS Managers Meeting, and Area Executives.

Roles which need to be undertaken in Year 1 are asterixed (*).

Actions incorporated in this plan have been costed where feasible in the initial years. It is anticipated that as the plan is rolled out, strategies will be reviewed and new strategies developed. Estimates for the costs associated with new strategies have not been included in the plan at this stage. Estimates for cost will be determined annually.

At the end of the 2012, the Action Plan will be reviewed. As part of the process for review, consultation will occur with clinical services, carers (including peak agencies), and local agencies, regarding effectiveness of implementation, and identification of issues and potential strategies.

9. Summary Action Table

The table following summarises the strategies which will be implemented in SSWAHS to support carers. Responsibility has been allocated across SSWAHS clinical programs and services. Most strategies will be achieved from within the existing budget eg Carers' Program, Family Friendly Mental Health, HACC, NSW Carers' Program, NSW Health NGO Program, and general health funds. Where it has been feasible to quantify costs in initial years of the plan, a notional estimate has been made (from within the existing budgets). Where the future of funding is uncertain, this has been identified. The plan will be regularly updated and costed.

AHS Strategies	\$ Funding (if any) & Source	Timeline	Responsibility	Progress in 2007/8
1. Priority for Action: Carers are recognised, respected and valued				
1.1. Promote Carers Week in all facilities, and include Carer information into events targeting specific health problems/issues (eg Alzheimers Week)	Within existing resources Carers' Program \$5000 to June 09	Annual	Carers' Program; GMs; Clinical Directors; HPU	Promotional activities at Camden, Canterbury, Concord, RPA and Fairfield H and partnerships with 6 LGAs in Carers week events at Burwood and Canterbury and in Oct 2007
1.2 Develop and regularly review promotional information for Carers eg brochures, fact sheets, information panels, poster, webpage	Carers' Program \$12,000 to June 09 FFMH \$10,000 (2008 only)	2009	Carers' Program; FFMHSP; Clinical Directors; ISD	Poster, information panels and web page drafted by the Carers' Program. Family & Carer Information packs with information sheets in used the NE cluster and due for release in SW cluster in June 08
1.3 Incorporate legislation requirements from the new NSW Mental Health Act 2007 into existing service delivery	Within existing resources	Ongoing	Clinical Director AMHS	
1.4 Incorporate carers issues in health promotion priorities and plans	Within existing resources	2009	Director HPU	

AHS Strategies	\$ Funding (if any) & Source	Timeline	Responsibility	Progress in 2007/8
1. Priority for Action: Carers are recognised, respected and valued				
1.5 Develop a comprehensive staff education and training program which focuses on: <ul style="list-style-type: none"> - 1.5.1 Staff Carer Awareness Training and advanced training around Carer issues - 1.5.2 Carer content in Facility Based Clinical Education Programs eg Grand rounds and in-services - 1.5.3 Conduct SSWAHS Workforce Development programs eg Orientation, mandatory and general programs. Consider development of a self directed on line learning program 	Carers' Program (recurrent funding); FFMHS Within Existing Funds Within Existing Funds	Ongoing 2009 2010	Carers' Program; FFMHS; Centre for Education and Workforce Development DOMS; Clinical Directors Centre for Education and Workforce Development	Continuation of previous years' training packages by Carers' Program - 278 clinical staff attended training 06 - 07 FFMHSP: 120 clinicians, consumers and carers completed the FaST (Family Sensitive Training) 2007: Carers Brochure provided to all SSWAHS Orientation Program Participants
1.6 Incorporate carers responsibilities into performance agreements and job descriptions of managers	Within Existing Funds	2008	Performance Unit; Clinical Directors; Area Executive	
1.7 Implement the annual NSW Patient and Carer Survey – SSWAHS Action Plans	Within Existing Funds	Ongoing	Director Clinical Governance	
1.8 Consider how the Carers Program can support implementation of the NSW Patient and Carer Survey – SSWAHS Action Plans	Within Existing Funds	Ongoing	SSWAHS Carers Program; SSWAHS Carers Plan Implementation Committee	

AHS Strategies	\$ Funding (if any) & Source	Timeline	Responsibility	Progress in 2007/8
2. Priority for Action: Hidden carers are identified and supported				
<p>2.1 Improve identification and support to Aboriginal carers:</p> <ul style="list-style-type: none"> - 2.1.1 Consult with Aboriginal consumers, carers and agencies about concerns and potential strategies - 2.1.2 Participate in Carers Week events targeted at Aboriginal carers in partnership with Aboriginal Health staff and Aboriginal Health Services - 2.1.3 Survey Aboriginal staff about their knowledge of Carers. Develop and implement cultural training to address identified needs - 2.1.4 Support initiatives which improve assistance to Aboriginal carers including development of: <ul style="list-style-type: none"> • Aboriginal Carers information. Distribute to Aboriginal health staff, Aboriginal Medical Services and other local Aboriginal services • an Aboriginal Carers Directory; • an Aboriginal Aged Care and Disability Forum; • clearer pathways for patients and carers; • culturally sensitive workforce education programs, including the role of carers in Aboriginal communities 	<p>General Health Funds (Aboriginal Health); Carers' Program</p> <p>Carers' Program \$5000 annually</p> <p>Carers' Program Recurrent Funding</p> <p>Carers' Program \$65,000 by June 09</p>	<p>2007</p> <p>Ongoing</p> <p>2009</p> <p>Ongoing</p>	<p>SSWAHS Aboriginal Health Services; AC&RS; Carers' Program; Planning</p> <p>Carers' Program; Aboriginal organisations'/staff</p> <p>Carers' Program; Centre for Education and Workforce Development</p> <p>Carers' Program; Director Aboriginal Health; Aboriginal Medical Services</p>	<p>Consultation occurred Oct/Nov 2007. Strategies identified have been incorporated into this plan and into the SSWAHS Aboriginal Plan</p> <p>Carers' Program participated in a Carers Week event at Cabravale Leisure Centre in the South West. Funding provided to Newtown NC to promote and support Aboriginal Carers</p>

AHS Strategies	\$ Funding (if any) & Source	Timeline	Responsibility	Progress in 2007/8
2. Priority for Action: Hidden carers are identified and supported				
<p>2.2 Improve identification and support to CALD carers:</p> <ul style="list-style-type: none"> - 2.2.1 Work with councils and other agencies in promoting Carers Week for the CALD community - 2.2.2 Evaluate the Multimedia Interpreter Service Trial and implementation across the area if effective. - 2.2.3 Work with SSWAHS Multicultural Health Services in developing strategies and partnerships focusing on targeted CALD Carers. Develop the capacity of NGOs to work with CALD Carers including: <ul style="list-style-type: none"> • develop language specific information; • provide seminars and workshops to Carers; • conduct general community awareness raising strategies; and • provide education/training for NGO services about Carers and health services. - 2.2.4 Source translated information and/or translating Carers Information into five community languages and distribute to key CALD NGOs and Commonwealth CRCs. 	<p>Carers' Program \$2,000 to June 09</p> <p>Within Existing Funds</p> <p>\$65,000 Carers Program</p> <p>Within existing budgets</p>	<p>Ongoing</p> <p>2008</p> <p>2008/9</p> <p>2012</p>	<p>Carers' Program Multicultural Health Services</p> <p>Director Allied Health; Director Interpreter Services</p> <p>Clinical Directors; Director Multicultural Health Services</p> <p>Clinical Directors</p>	
<p>2.3 Improve identification and support to young carers:</p> <p>2.3.1 Consult with young carers about their needs and concerns</p>	<p>To be determined</p>	<p>2008</p>	<p>Youth Health Services (including Youth Health and Child and Family, Mental Health and youth Medical Consultancy)</p>	<p>Consultation by AMHS about young carers (refer Section 5)</p> <p>"Young Carers" needs specifically included in FFMHS FaST workshops</p>

AHS Strategies	\$ Funding (if any) & Source	Timeline	Responsibility	Progress in 2007/8
2. Priority for Action: Hidden carers are identified and supported				
- 2.3.2 Incorporate strategies focusing on young carers in the Youth Health Plan. Consider young Aboriginal carers.	Within existing resources	2008	Health Services Planning Unit, Carers' Program	
- 2.3.3 Implement strategies to improve support to young carers, such as resources and education for staff	\$2,000 to June 09	2010	Youth Health Services; Carers' Program;	
- 2.3.4 Expand and build on COPMI programs, with a stronger focus on Aboriginal and CALD children	Within Existing Budget (AMHS)	Ongoing	AMHS	
2.4 Enhance support for rural carers:				
- 2.4.1 Consult with rural AHSs, and review of research about the needs of rural and remote carers. Incorporate into the model of care	Within existing resources	2009	Carers' Program; Director Social Work	
- 2.4.2 Implement programs, such as Housing and Support Initiatives (HASI) in the Home and Resources and Recovery, for people with a mental illness and their carers	NSW Health funding	Ongoing	AMHS	
2.5 Incorporate a carer focus into the Drug Health Strategic Plan	Within existing resources	2009	Drug Health Services; Area Planning	
2.6 Improve identification of carers:				
- 2.6.1 Review inpatient, outpatient and community admission and intake forms. Train staff in their use	Within existing resources	2009	Director, Clinical Redesign; GMs	
- 2.6.2 Include in the electronic medical record. Train staff in its use	To be determined	2011	Director ISD; Clinical Directors	
- 2.6.3 Assess feasibility of having identification of "need/stress" in admission/intake/EMR record	Carers' Program \$1000 to June 09	2012	Carers' Program, Directors of Social Work	
2.7 Identify and promote carer focused NGOs which can advocate for carers	Within existing resources	2009	Carers' Program; Clinical Directors	
2.8 Work with other agencies in developing strategies to improve identification and support for Hidden Carers	To be determined	2012	All Clinical Groups	

AHS Strategies	\$ Funding (if any) & Source	Timeline	Responsibility	Progress in 2007/8
3. Priority for Action: Services for carers and the people they care for are improved				
3.1 Analyse and use existing and new data (eg NSW Health Patient Surveys, IIMS, and research) to inform strategy development and practice	Within existing resources	Ongoing	All clinical services; GMs; Carers' Program;	
3.2 Work with government and non-government agencies in developing resources and programs which support carers	To be determined	Ongoing	All clinical groups	
3.3 Continue to implement the FFMHSP: <ul style="list-style-type: none"> - 3.3.1 Implement the FFMH Training for Area Mental Health Service staff - 3.3.2 Evaluate the effectiveness of Mental Health Carer Support Worker position, and subject to evaluation, considering extension to other services 	\$200,000 FFMHSP. Ongoing training beyond 2007/8 dependent on funding Within existing resources (AMHS)	2007/8 2009	FFMHSP AMHS	Eighteen clinicians have attended FaST Train the Trainer workshops in preparation for supporting future training initiatives by FFMHSP team.
- 3.3.3 Continue to work with Carer Assist to provide support and education to carers of mental health consumers	NSW Centre for Mental Health - \$600,000 pa	2008-2011	AMHS	Carer Assist/AMHS Steering Committee established in mid 2007 and continues to meet bi-monthly
- 3.3.4 Develop a service level agreement with Carer Assist	Within existing resources	2008	AMHS	Work in progress – to be finalised by June 2008
- 3.3.5 Incorporate requirements of the MHA into all service policies and procedures, including admission, discharge and ongoing client planning processes	Within existing resources	2008 and ongoing	AMHS	
- 3.3.6 Systematically implement education and support for all new families and carers of young people with early psychosis, and families of people with eating disorders and personality disorders	Within existing resources	2009	AMHS	

AHS Strategies	\$ Funding (if any) & Source	Timeline	Responsibility	Progress in 2007/8
3. Priority for Action: Services for carers and the people they care for are improved				
3.4 Strengthen clinical care and support : - 3.4.1 Develop the model of care and incorporate into "SSWAHS Guidelines for Carer Friendly Services". Train senior managers in its use - 3.4.2 Use the Carer Friendly Guidelines to review and update clinical care policies and procedures, information and education to incorporate carers' needs.	Carers' Program \$2,000 to June 09 Within existing resources	Dec 2008 2009	SSWAHS Carers' Program; Centre for Education and Workforce Development Clinical Directors; General Managers	
3.5 Work with SSWAHS pharmacies to improve information on patient medication given to carers	Carers' Program \$3000 to June 09	2011	Directors Pharmacy; Carers' Program, Parkinson's NSW	
3.6 Work with Divisions of General Practice to incorporate carer content into Clinical Medical Education Programs for GPs and Practice Nurses, and develop strategies to improve GP surgeries' focus on carers	Carers' Program \$10,000 to June 09	2010	Clinical Directors; Carers' Program	
3.7 Incorporate information about carers into students training through: advocacy in undergraduate training courses; input into curriculum development; and student placement	Within existing resources	2011	Clinical Directors	
3.8 Implement "Caring for Carers Better Practice Project" and seeding grants across the SSWAHS. Review the effectiveness of this strategy annually	Carers' Program \$60,000 pa.	2007-2012	Carers' Program	Implemented again in Inner West in 07 South West in Feb 08
3.9 Administer, monitor and support Local Carer and related Grants to NGOS	Carers' Program Committed Funding from previous years	June 2008	NGO Coordinators; Carers' Program; AMHS; AC&R	Carers' Program has continued to monitor and support NGOs receiving local grants through to June 2008

AHS Strategies	\$ Funding (if any) & Source	Timeline	Responsibility	Progress in 2007/8
3. Priority for Action: Services for carers and the people they care for are improved				
3.10 Improve support for patients with specific needs: <ul style="list-style-type: none"> - 3.10.1 Consult with carers of people with multiple disabilities and NGO's to identify carer concerns about clinical care and support - 3.10.2 Develop clinical care guidelines for the care of people with disabilities and provide training to clinical services in their use - 3.10.3 In partnership with Commonwealth CRCs and other agencies, develop and implement projects that improve the provision of services to carers, particularly Aboriginal carers, and carers (especially older parents) of people with disability (incl. intellectual and mental health disabilities) - 3.10.4 Review current guidelines and practices focused on carers of young patients who are transitioning from paediatric to adult services and facilitate their implementation in SSWAHS 	Carers' Program \$5000 to June 09	December 2009	Directors Clinical Services, Directors of Social Work, Carers' Program	
3.11. Work with DADHC and other agencies, including volunteer organisations, in planning and developing services, and implement initiatives such as use of the new MDS to provide information regarding carers	Within existing resources	Ongoing	AC&RS	
3.12 Incorporate a carer focus into performance agreements of NSW Health NGO Program funded services	Within existing resources	2011/12	NSW Health NGO Program Coordinator	
3.13 Should additional funding become available, use and/or submit for funding consistent with role, identified needs and priorities	To be determined	Ongoing	All services	

AHS Strategies	\$ Funding (if any) & Source	Timeline	Responsibility	Progress in 2007/8
3. Priority for Action: Services for carers and the people they care for are improved				
3.14 Improve provision of corporate support services: <ul style="list-style-type: none"> - 3.14.1 Incorporate culturally appropriate carer and patient accommodation into hospital redevelopment - 3.14.2 Review policies for accommodation, access to meals, parking and overnight bedside stays for all patients and carers, with particular reference to disadvantaged communities - 3.14.3 Promote SSWAHS Central Transport Unit and phone number 	To be determined Within existing resources Within existing resources	Ongoing 2009 2008	Director Clinical Operations; Director Capital Works; Director Planning Area/Facility Directors Corporate Services; Area Director of Nursing; Area Transport Unit; Director Allied Health SSWAHS Transport Unit	Aboriginal friendly Carer/Patient accommodation incorporated into capital project plans for Liverpool Hospital Stage 2, & RPAH North West precinct (2007)
4. Priority for Action: Carers are partners in care				
4.1 Include carers in service planning, review and development: <ul style="list-style-type: none"> - 4.1.1 Review the Community Participation framework to ensure effective consultation with Carers - 4.1.2 Include information about Carers in the Community Participation Framework literature 	Within existing resources Within existing resources	July 2008 December 2008	Consumer Participation Program Consumer Participation Program	

AHS Strategies	\$ Funding (if any) & Source	Timeline	Responsibility	Progress in 2007/8
4. Priority for Action: Carers are partners in care				
- 4.1.3 Consult with carers in service and policy development and evaluation processes such as: service plans; Clinical redesign; Health Impact Assessment; and capital works redevelopment	Within existing resources	2008	Clinical Directors; General Managers; Planning Units	FFMHSP: Carers represented on key mental health committees eg Serious Incident Review Committee; Cluster Level Analysis of Incidents Meeting and Area Clinical Quality Council; and have some input into policy and procedure development/review, and planning/ evaluation of service delivery.
- 4.1.4 Support carers who participate in SSWAHS service planning, review and business processes	Within existing resources	Ongoing	All clinical services; GMs; Community Participation Unit	
4.2 Continue to run carer education programs in partnership with NGOs. Include flexible courses which accommodate working carers	Carers' Program \$3,000 to June 09	Ongoing	All clinical services; Carers' Program	Carer education in Dementia in Concord (2007) – one planned for Camperdown in 2008 2007: Carers' Program has provided carer education in partnership with St Basils Homes, Inner Western Cycle Inc, and Earlwood Day Care Centre
4.3 Work together to develop resources on Advanced Care Planning which includes carers	Carers' Program \$4,000 to June 2009, + other NSW Health funds	2010	Aged Care and Rehabilitation Services; Carers' Program; Social Work; Palliative Care	
4.4 Support SSWAHS staff to attend courses on issues relating to Carers support and involvement	Within existing resources	Ongoing	Director Clinical Groups	
4.5 Implement NSW Health initiatives as they arise	To be determined	Ongoing	All Services	

AHS Strategies	\$ Funding (if any) & Source	Timeline	Responsibility	Progress in 2007/8
5. Priority for Action: Carers are supported to combine caring and work				
5.1 Finalise the SSWAHS Workforce Strategic Plan, including development of strategies which support working carers.	Within existing resources	Ongoing	Director Workforce Planning & Development	
5.2 Review and enhance information about existing policies on carer leave, FACS Leave entitlements and workplace flexibility, and incorporate this information into existing staff development programs	Within existing resources	2009	Centre for Education and Workforce Development	
5.3 Review the current SSWAHS Employee Orientation Brochure about carers	Carers' Program \$4,000	June 2008	Carers' Program;	
5.4 Extend the Staff as Carers Survey - Caring and Work Responsibilities across SSWAHS	Carers' Program \$15,000	2010	Area Director Corporate Services; Carers' Program Facility Managers	Completed at Canterbury H and Canterbury CHC (950 surveys distributed)
5.5 Promote resources for working carers eg Working Carers Gateway through promotional information	Within existing resources	Ongoing	Carers Program; Human Resources	
5.6 Include information and strategies on carer friendly workplaces, into work done with businesses to improve employee health	Within existing resources	Ongoing	Health Promotion Unit	
Implementation Plan				
6.1 Establish a SSWAHS Carers Plan Steering Committee and develop a workplan	Within existing resources	April 2008	Director Clinical Operations	
6.2 Monitor implementation of this plan and carer involvement in service planning	Within existing resources	Ongoing	SSWAHS Carers Plan Steering Committee, Community Participation	
6.3 Support evaluation of the plan and programs as appropriate	Within existing resources	Ongoing	SSWAHS Carers Plan Steering Committee; Clinical Directors	

10. Appendices

Appendix A: NGOs provided with Local Carer Grants

Sydney South West:

Bankstown Women's Health Centre: "Time Out for Carers" - a project providing workshops, information and ongoing support networks for female carers from Aboriginal and CALD backgrounds;

Headway Adult Development Program Inc. "Carer Support Project" for Carers of people with acquired brain injury (including specific services for Arabic Vietnamese and Indigenous backgrounds);

Woodville Community Services Inc.: "Multi-cultural Carers On-Line" a project to provide computer and internet based skills to carers from ethnically, culturally and linguistically diverse backgrounds to enable them to access information and resources on caring issues and services in their own language and in English; and

Macedonian Australian Welfare Association of Sydney Inc: "Carers Support for the Macedonian Community in Sydney" a project providing support, education and information to Macedonian carers.

Inner West:

Canterbury Multicultural Aged and Disability Support Service: "Non-English Speaking Background Support Groups" a project providing support groups for Carers of people with a physical disability, frail aged, dementia and chronic illness;

Chinese Australian Services Society: "Carers Support Project" providing support, information, education and referral for Chinese and Korean language speaking carers aged 18 or over of people with an intellectual disability, frail aged, dementia or chronic illness;

Ethnic Child Care Family & Community Services: "CLDB Carers Support Network Project" providing support, information and education for Carers from CALD backgrounds aged 25 years or more, of people with an intellectual &/or physical disability &/or mental illness;

Family Resource and Network Support Inc: "FRANS CARERS LIFE ENHANCMENT PROGRAM (FCLEP)" providing education and support for Carers aged 18 - 70 years of People with physical disability, intellectual disability or acquired brain injury from any cultural background;

Newtown Neighbourhood Centre: "The Multicultural Carers Support Project" providing information and network support for Carers aged 40 or more of people with a physical disability, Frail Aged, Dementia or Chronic Illness from Chinese, Vietnamese, Greek, Arabic, the former Yugoslav Republic (Croatian, Macedonian, Serbian) and Indigenous backgrounds;

Roselands Sports & Aquatic Club: "Parents & Carers Support Group" for Carers of any age and culture of People with a Disability (including people with mental health issues); and

Rozelle Neighbourhood Centre: "We Are Community" providing activity and education sessions for carers from Greek, Chinese, Arabic and Italian backgrounds.

Appendix B: Relevant NSW Health Policy

Discharge Planning: Responsive Standards (Revised) (PD2007_092): This policy presents a responsive and standardised approach to discharge planning, from preadmission to post discharge. It includes a requirement to undertake a discharge risk screen (DRS) to identify patients who require further assessment and follow up prior to discharge from hospital, standardised discharged planning and communication strategies.

Disability - People with Disabilities: responding to their needs during hospital (PD2008_010): This policy aims to increase the sensitivity and adaptability of services provided during hospitalisation including the hospital experience, roles and responsibilities for caring for people with disabilities in hospitals, preadmission and discharge planning; communication and consent; accessibility; inservice education and training; protocols and quality improvement.

Transport for Health NSW Policy Framework (PD 2006_068): This policy seeks to integrate all non-emergency health related transport into one program, and requires area health services to be more strategic in identifying, consolidating and integrating transport services for transport disadvantaged patients. This includes people with disabilities.

Program of Appliances for Disabled People (PADP) (PD2005_563): This policy defines the conditions and arrangements for the provision of equipment, aids and appliances to assist eligible residents of NSW who have a disability of a permanent or indefinite nature to live and participate in the community.

Consent to Medical Treatment - Patient Information (PD2005_406): This policy focuses on ensuring that patients are provided with adequate information to enable them to make informed decisions. This includes people who are incapable of providing informed consent who are covered by the Guardianship Act 1987. Information Bulletin: IB 2005-054 Substitute Consent Form Amendment - Patient Information and Consent to Medical Treatment provides the form relevant to people under the Guardianship Act.

Privacy Management Plan - NSW Health (PD2005_554): This policy addresses information privacy including protection of personal information, privacy of the individual and requirements for consent.

Standard Procedures for the Use of Health Care Interpreters (PD2005_281): This policy stipulates the use of interpreters at key points in the patients care.

Family and Community Services Leave and Personal/Carers Leave (PD2007-031): This policy outlines the conditions under which employees can take leave.

Discharge Planning for Adult Mental Health Inpatient Services (PD2008-005): This policy outlines the process to be used for managing patients with a mental health problem from admission to hospital to post discharge.

Appendix C: SSWAHS Carers Action Plan Steering Committee Terms of Reference

Purpose: To provide advice to Sydney South West Area Health Service (SSWAHS) regarding the development, implementation, monitoring and evaluation of the SSWAHS Carers Action Plan.

Reporting To: SSWAHS Director of Clinical Operations.

Scope of Plan:

To consider:

- Key priorities for action in the NSW Carers Action Plan 2007 - 2012. These are:
 1. Carers are recognized respected and valued
 2. Hidden carers are identified and supported
 3. Services for carers and the people they care for are improved
 4. Carers are partners in care
 5. Carers are supported to combine caring and work
- Existing services including: SSWAHS Carers' Program, SSWAHS Family & Carer Mental Health Program, carer focused services provided by other clinical services and streams in SSWAHS, NGOs providing services to Carers funded through the NSW Health NGO Program;
- SSWAHS Carers' Program initiatives in the past four years;
- Other NSW Government Plans such as Stronger Together and Better Together (DADHC);
- Relationship to other SSWAHS current and future plans e.g., Disability Plan, Mental Health Plan, Aged Care/Rehabilitation Plans and the annual Patient and Carer Experience Improvement Action Plan (a requirement under NSW Health's Sustainable Access Plans);
- Existing NSW Health policy directives & program initiatives eg Discharge Planning: Responsive Standards, clinical redesign, 2007 patient survey and Sustainable Access Plan;
- Available budget;
- Current gaps and challenges in SSWAHS;
- Consultation processes with internal and external stakeholders including consideration of previous consultation findings;
- A 5 year timeframe for implementation from 2007 to 2012 commencing in 2007/8;
- Strategies and actions that result in sustainable organizational change to mainstream services so that carers are supported;
- Build on existing relationships with other agencies and service providers.

Timeframe for Plan Development

NSW Health has advised that a progress report on the Draft Action Plan will be required by mid-February 2008, and that regular progress reports on implementation will be required at the end of September annually. It is envisaged that the plan will be developed by April 2008.

Responsibilities and Activities of the Steering Committee

1. Determination of an appropriate process for developing the SSWAHS Carers' Action Plan.
2. Identification of key information required.
3. Clarification of the consultation process and key consultation groups.
4. Identification of major gaps and the main priority areas for action for SSWAHS.
5. Identification of staff and services which can support development and implementation of the action plan.
6. Provision of advice regarding strategies and actions for the Plan as well as performance indicators, resources required and timeframes for completion.
7. Provision of recommendations for the process of monitoring and evaluating the effectiveness of the implementation of the SSWAHS Carers Plan 2008 - 2012.

It is expected that all members of the steering committee will contribute fully to the development of the action plan by seeking out information, consulting with their peers and relevant services, and providing other information as required.

Chairperson: SSWAHS Director Allied Health Services

Membership: Membership will include the following representatives/representation:

- SSWAHS Director Allied Health Services
- A/Manager, Carers' Program
- Director, EZ Social Work
- Director, WZ Social Work
- D/Director Aboriginal Health Services
- Mental Health Service representative
- Coordinator Aged Care Services
- Discharge Planner
- Representative from Centre for Education and Workforce Development
- Representative from SSWAHS Area Cancer Services
- A/Director Community Health Fairfield/Nurse Manager Community Nursing WZ
- Community/Consumer Council Carer representatives
- Representation from the CALD community
- An NGO representative
- Area Planner

Frequency of Meetings: To be determined by the Committee

Quorum: A quorum should be 50% of the committee membership

Minutes: Minutes are to be in the form of Action minutes and are the responsibility of the A/Manager, Carers' Program.

Appendix D: Membership, SSWAHS Carers Action Plan Steering Committee and Working Party

1. Steering Committee

Service/Clinical Stream	Name	Position
Allied Health	Katherine Moore	Chair - Director of Allied Health
Aged Care	Adele Lubiana	A/Service Development Manager Aged Care
Aged Care	Janice Margin	Macarthur Dementia Advisory Service
Mental Health	Barry Kinnaird	Deputy Director Mental Health Services
Workforce Development	Florence Olugbemiro	Workforce Planning & Development Analyst
Cancer Services	Daniel Barakate	Cancer Support Services Coordinator
Social Work	Nadine Meredith	Director of Social Work, Inner West
Social Work	Lorraine Merheb	Senior Social Worker Aged Care
Aboriginal Health	Brendan Kelaher	Assistant Director of Aboriginal Health
Discharge Planning	Kerry Womsley	Clinical Nurse Consultant, Complex Care
Community Health	Eve Bigelow	A/Director Community Health (Fairfield); Nurse Manager (Community Nursing)
NGO Representative	Bob Lester	Community Development Officer, Families in Partnership
Community Participation	Marie Patterson	Carer Representative
Community Participation	Janette Dubuisson de Perrine	Carer Representative
Community Participation	Janice Slavik	Carer Representative
Community Participation	Lynda Johnston	Area Manager
Carer's Program	Tony Phiskie	A/Service Manager, SSWAHS Carers' Program
Multicultural Health	Yvonne Santa Lucia	Area Ethnic Aged Health Adviser
SSWAHS Planning	Gay Horsburgh	Senior Planner, Health Services Planning Unit

2. Working Party

Service/Clinical Stream	Name	Position
Aged Care	Adele Lubiana	A/Service Development Manager Aged Care
Aged Care	Janice Margin	Macarthur Dementia Advisory Service
Mental Health	Barry Kinnaird	Deputy Director Mental Health Services
Cancer Services	Daniel Barakate	Cancer Support Services Coordinator
Discharge Planning	Kerry Womsley	Clinical Nurse Consultant, Complex Care
Community Participation	Janette Dubuisson de Perrine	Carer Representative
Carer's Program	Mary Kang	Carer Project Coordinator
SSWAHS Planning	Gay Horsburgh	Senior Planner, Health Services Planning Unit

Appendix E: SSWAHS Family Friendly Guidelines and Checklist for Clinical Services and General Practitioners - Preliminary Coverage

- The breadth of the definition of carers, the implications of the diversity of our community in determining needs (eg legal status of unrelated carers such as GLBT partners, need for interpreters), and the importance of an assessment to meet the needs of each individual carer;
- Relevant policy and program materials that would support specific clinical group;
- Early identification of carers at admission/intake;
- The importance of timely comprehensive and accurate advice to carers and consultation with carers, who are responsible for ensuring compliance with medical and care directions, and the implications for the carer and patient if quality support is not provided by health professionals eg reduced quality of life for the patient and carer, readmission to hospital, and additional health complications; the importance of carers understanding the signs and symptoms of a worsening condition, and what to do in these situations; and knowledge of the health system so that carers have realistic expectations.
- Recording of carer details and inclusion in the electronic medical record in order to (1) raise the profile of carers and awareness and knowledge about them and; (2) ensure their involvement in assessment/diagnosis, carer planning and discharge planning
- Consultation with carers in the review and development of policies, programs and plans
- Discharge processes such as support services required in the community, time of discharge, the information to be provided on discharge, etc;
- Provision of information and education for carers in clinical and community settings in culturally appropriate language and formats, on accessing relevant services, disease progression of care recipients (where relevant); and improving standards of care (including carer self-care)
- Assessing the use of a carer assessment tool (*Care Giver Strain Assessment*) to identify carer support concerns and needs, in conjunction with pathways to address identified needs;
- Working more closely with general practitioners;
- Supporting rural carers: including identification of transport and accommodation needs; use of IPTAAS; flexibility in appointment times;
- Supporting people from CALD communities: using interpreters and/or ethnic health staff, or exploring and utilising alternative methods of communication to support carers, such as teleconferencing; internet communication; availability of multicultural organisations
- Supporting Aboriginal People: financial, equity and cultural issues; availability of Aboriginal liaison staff in family conferences; addressing transport and/or accommodation needs; role of carers in the Aboriginal community; available support services including financial support; need for clearer pathways for Aboriginal patients and carers.
- Supporting Young People: supports available including school networks, web-based programs, and young carer programs; unique needs related to their age and developmental stage;
- Identify carers requiring access to specific services within clinical streams and services who may be hidden or have special needs; adopting more flexible approaches to support such carers who may be working, aged, young, or are from diverse communities, including people such as GLBT;
- Services available to support carers including: Carers Payment and Carer Allowance, Carers NSW (and peak organisations), Commonwealth CRC and Carelink (including availability of emergency and short term respite) and other targeted Commonwealth programs eg Mental Health respite, HACC and NGO services, and relevant GP services/items which are funded through Medicare or private health insurance; and brochures and other information provided by peak agencies;
- Consider issues such as succession planning for ageing carers, and the needs of carers who are exiting the carer role;
- Implications of legal and privacy responsibilities identified in legislation such as the Guardianship and Privacy Acts.
- Need for each clinical service to consider hidden carer groups in developing carer strategies

Abbreviations

ABS	Australian Bureau of Statistics
AC&RS	Aged Care and Rehabilitation Services
ACAP	Aged Care Assessment Program
ACAT	Aged Care Assessment Team
AHS	Area Health Service
AMHS	Area Mental Health Service
CACP	Community Aged Care Packages
CALD	Culturally and Linguistically Diverse Communities
CHS	Community Health Services
CRC	Commonwealth Carer Respite Centres
CSTDA	Commonwealth State Territory Disability Agreement
DADHC	Department of Ageing Disability and Homecare
DFHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
DHA	Department of Health and Ageing
EACH	Extended Aged Care in the Home
EMR	Electronic Medical Record
FFMHSP	Family Friendly Mental Health Services Program
HACC	Home and Community Care Program
LGA	Local Government Area
MHA	Mental Health Act 2007
NGO	Non-government organisation
NRCP	National Respite for Carers' Program
RPAH	Royal Prince Alfred Hospital
SDAC	Survey of Disability and Caring
SSWAHS	Sydney South West Area Health Service
TACP	Transitional Aged Care program
TMHS	Transcultural Mental Health Service

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