

# The St George Dementia Network Model

Paper Developed by the St George Dementia Network in collaboration with Glen Sorensen, Age Communications

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## Background

The St George area is located in south–eastern Sydney. It consists of the local government areas of Rockdale, Kogarah and Hurstville. The three LGAs had a combined population of approximately 209,500 in the 2001 census of whom 15.5% were aged over 65 years. The area has a sizeable proportion of people from culturally and linguistically diverse backgrounds with approximately half the population speaking a language other than English at home. The most common languages, other than English, spoken at home in the 2001 Census were the Chinese languages, Greek and Arabic.

St George has an extensive network of community care services including a number of agencies targeting people with dementia, their carers and families. In recent times, the St George HACC Forum has been interested in establishing a formal network of dementia services that will provide a seamless service pathway for people with dementia and their carers.

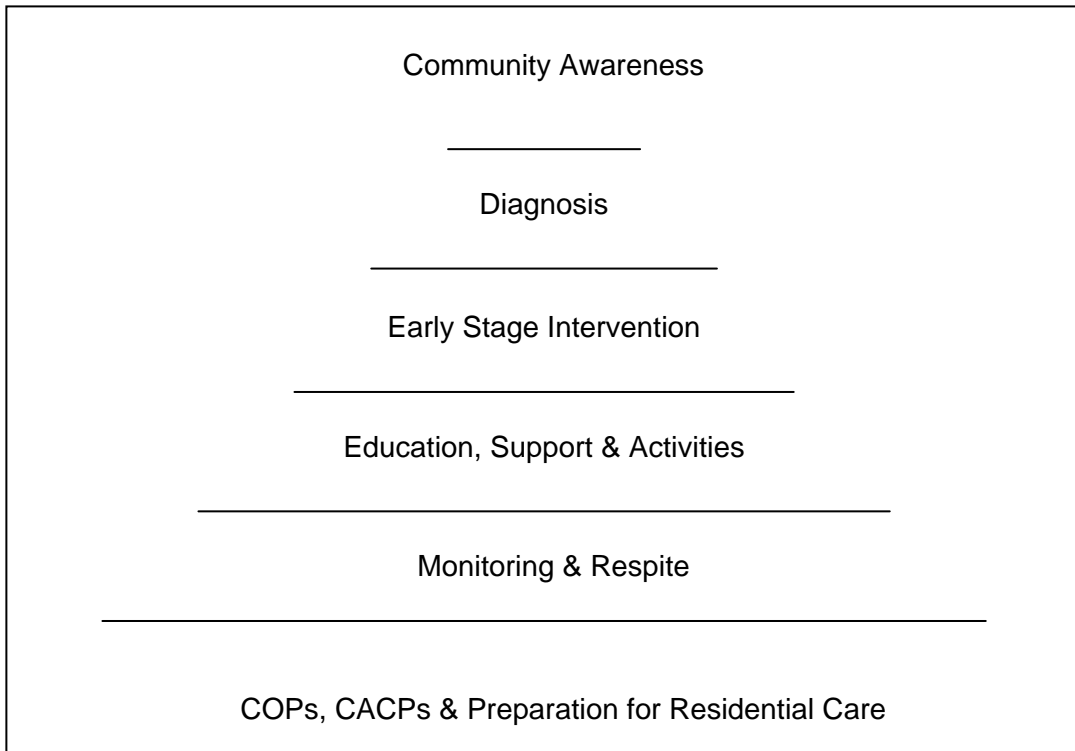
To assist this process, community care services have adopted a Dementia Network Model for implementation in the St George area. The overall aim is to develop clear links between the different levels of care in the model, therefore enhancing service providers' ability to respond to client and carer needs.

## The Dementia Network Model

The Dementia Network Model (Figure 1) is a pyramid divided into six community care tiers that, from top to bottom, follow a logical process from broad community awareness about dementia and the availability of support services to Community Options (COPS) and Community Aged Care Packages (CACPs). Ideally, people with dementia and their carers will enter the service system via the top of the pyramid and, as the dementia progresses, move down from tier to tier until case managed, more intensive community care services, like COPS or CACPs, are in place to help people stay at home or the client makes the transition to low or high care in a residential setting. The model also recognises that clients and their carers may enter the pyramid at any of the six stages.

Members of the St George Dementia Network view the model as one journey for the client and carer that takes its starting point from their point of entry in the pyramid and proceeds in a seamless way through the tiers and across services. The emphasis throughout the process is on ensuring that the client and carer retain maximum power over decision making and control in the meeting of their care and support needs.

The Dementia Network Model is also consistent with the three stages of dementia. The early stage that may be characterised by the beginning of short term memory loss and confusion may occur even before the diagnosis is made. The middle stage of dementia, after diagnosis, is orientated towards strategies for living at home, behaviour management, carer respite and the provision of community support services. The later stage of dementia, when care needs become more complex, is often about developing a package of services designed to meet the unique needs of the situation.



**Figure 1: The Dementia Network Model**

## The First Tier – Community Awareness

The aim of community awareness strategies is twofold; to improve awareness of dementia itself as well as to broadcast the existence of support services. One desired outcome, particularly for people from culturally and linguistically diverse (CALD) backgrounds, is an increase in the consumers seeking diagnosis in the early stage of dementia.

A comprehensive community awareness strategy targets:

- the general community with different messages for younger and older people
- local media
- vital services involved in frontline intervention, such as the Police, ambulance and drug and alcohol services
- health professionals, such as general practitioners
- community support services, including HACC, disability, ethno-specific and community information services.

Effective community awareness strategies challenge the misconception that dementia equals no quality of life. They emphasise that early diagnosis and appropriate intervention can reduce anxiety and depression amongst clients and their carers. They mention the full range of services where possible, recognising that the Dementia Network Model has a number of points of entry. They advertise available resources like the Alzheimer's Australia Help Line and the Carer Resource Centre.

There is no need to develop all local community awareness strategies from scratch. Local strategies in the St George area will:

- draw on available resources, like the Help Sheets prepared by Alzheimers Australia and carer kits produced by Carers NSW
- use existing communication pathways like local newsletters, newspapers, ethnic radio and information kiosks and services
- piggyback on to local, state and national initiatives and events such as the Carers Resource Centre database, Dementia Awareness Week, Carers' Week and Seniors Week.

The Benevolent Society Community and In Home Flexible Respite Service, CRAGS (the local ACAT), the Dementia Advisory Service and the St George Carers Support Service acknowledge that they have a role in the community awareness tier of the model. Their strategies include the production of information booklets for people with dementia and their carers, community presentations and displays, production of a dementia specific brochure for GPs as a referral aid, education of professionals, newsletter articles and health education sessions.

## The Second Tier – Diagnosis

Eligibility and availability for some services can be dependent on gaining a dementia diagnosis first. Diagnosis is strengthened when service providers, including volunteers, and health professionals, such as GPs, have the skills to notice the signs of dementia when dealing with clients and patients. It is hoped that effective community awareness strategies will also lead to an increase in clients and their carers noticing that something is wrong, taking the initiative and asking for a diagnosis when they visit their GPs.

General practitioners are major stakeholders in the diagnosis tier of the Model and can play a critical role in linking clients and their carers to the other tiers. The Dementia Network recognises that, although formal diagnosis is more the role of specialists such as geriatricians, psychogeriatricians and neurologists, the link to diagnosis is often through the GP.

The Division of General Practice and the Dementia Advisory Service has found that GPs are open and want to learn more about dementia and the Network Models. The Division of General Practice has focussed on ways to make it easier for GPs to link with diagnostic and support services. These include targeting education through the Division of General Practice and the production of guidelines for GPs. Future Dementia Network strategies, now under consideration, include education of practice nurses, particularly those conducting Enhanced Primary Care health assessments with the over 75s, the establishment of a one-stop contact number with information about access to all tiers of the Model and the introduction of memory clinics.

CRAGS also plays a key role in the diagnosis tier of the Model. It encourages memory loss to be mentioned at point of intake by the referrer and, after initial assessment by a nurse, can bring in specialists or order further tests to assist with the diagnosis. Assessments are usually conducted within two weeks of referral or sooner for cases highlighted as urgent.

The Dementia Network acknowledges that there are gaps in the diagnosis tier at present. There is a need:

- for a dementia specific brochure to assist with the linkage between diagnosis and the other tiers of the Model
- to ensure that assessment is comprehensive, inclusive of the carer and considers all aspects of the person and their situation
- to be mindful and realistic about bottlenecks in getting diagnoses
- for the Network to ensure that clients awaiting diagnosis have access to support services in the interim if needed.

## The Third Tier – Early Stage Intervention

As an ideal, early stage intervention takes up where diagnosis leaves off. The theory is that, if enacted properly, early stage intervention will lead to clients and their carers being better adjusted to the situation as they progress through the tiers of the pyramid.

The focus in early stage intervention is on empowering the person with dementia and the carer and equipping them with the essential tools to cope effectively with the situation. Most usually this means providing them with information about dementia and available support services as well as assisting them to develop strategies for coping at home.

In this early stage, clients and their carers may simply need reassurance that the situation is under control and being monitored. They may not need nor be ready for practical support from community care services. The emphasis for the person with dementia can be on supporting them to maintain their networks and links to the community. The emphasis for the carer can be linking them into information and carer support networks.

CRAGS, the Dementia Advisory Service, Rockdale Community Services, Georges River Neighbour Aid, St George Home Visiting and Dementia Monitoring Service and the St George Carers Support Service all play a role in early stage intervention. Specific strategies include:

- conducting Living With Memory Loss workshops
- linking carers attending these workshops into the Carer Support Group
- outings for clients of the Georges River Community Service
- monthly bus trips for clients in the early stages of dementia.

The Network has identified significant gaps in early intervention strategies. Comparatively little is available for people with dementia as strategies tend to focus on empowering and supporting the carer. Younger people with dementia, in particular are disadvantaged as all services are geared for older people. Organisations and services for younger people with disabilities may also be inappropriate for their support needs.

## The Fourth Tier – Education, Support and Activities

Activities in this tier encompass both emotional and practical needs for support. The initial focus is often on setting up emotional support systems and empowering the carer while some practical assistance makes life at home easier. This does require the carer to accept that they are a carer and be prepared, if needed, to get assistance from community care services. It is important at this time to provide what the client and the carer need rather than to overburden them with too much information or support.

At present, avenues for emotional support seem more plentiful than practical assistance. The key issue here seems to be the lack of availability of low level domestic assistance. The Home Care Service of NSW, the major supplier of domestic assistance services, has not been able to provide low level domestic assistance in recent months due to higher level support demands. The inability to gain affordable public liability insurance, has meant that Neighbour Aid Services can no longer co-ordinate low level domestic assistance. One alternative being considered by the Network is to link this gap back to community awareness strategies and encourage families to assist with domestic tasks like vacuuming.

It is usually critical to engage the carer at this time. The ideal is that the service provider co-ordinating the activity uses it as an opportunity to build a working relationship with the carer. Activities that offer both knowledge and skill development as well as something for the carer themselves tend to be most effective in retaining carer engagement in fourth tier activities.

A number of agencies in the St George area provide services in this tier. They include the Benevolent Society's Community and In home Respite Service, Dementia Advisory Service, St George Carers Support, Rockdale Community Services, Georges River Neighbour Aid Dementia Monitoring, Kogarah Community Services Home Visiting and Dementia Monitoring Service, Chesalon Dementia Flexicare, St George and Sutherland Live at Home Service, Bobby Goldsmith Foundation and CRAGS.

The components of this tier include:

- regular and ongoing carer support groups
- short courses for carers on issues like stress management, dealing with challenging behaviours and practical strategies for home
- dissemination of written information covering issues such as how relationships change with dementia
- production, by CRAGS, of a resource kit of dementia information for distribution to carers of clients attending the Warrina Dementia Day Care Service
- information and education sessions for community care service providers, volunteers and health professionals on issues like the roles of the Dementia Network and its members, the Living With Memory Loss Program, dealing with challenging behaviours
- basic HACC and HACC-like services including assistance with meals, shopping, transport, home maintenance and modification, home visiting and domestic assistance
- socialisation activities and weekends away for groups of carers. The latter has been identified as a current gap.

## **The Fifth Tier – Monitoring and Respite**

As the dementia progresses, monitoring of the situation and the provision of respite for the carer become increasingly important. The Dementia Network believes that carers of people with dementia need to have access to:

- respite that is planned, regular and on-going
- emergency and short-term respite when needed
- a range of respite options in and outside the home
- respite that is affordable
- informal respite provided by family or friends.

General Practitioners, the Benevolent Society's Community and In Home Respite Service, St George Carers Support, Rockdale Community Services, Georges River Neighbour Aid Dementia Monitoring, Kogarah Community Services' Home Visiting/Dementia Respite, the NESB Dementia Monitoring and Support Service, Chesalon Dementia Flexicare, St George Live at Home Service, Bobby Goldsmith Foundation, Warrina Dementia Day Care and CRAGS play some role in monitoring and respite. Bilingual workers and ethno-specific activities provided through Warrina Day Care Centre also reach Arabic, Chinese, Greek, Italian, Macedonian and Spanish speakers.

At this stage of dementia situations can become more complex. They may require intensive case management and tailored care and support packages and solutions to address need.

When this is the case, referral for comprehensive assessment becomes necessary to determine eligibility for Community Options or CACPs. In the St George Area, CRAGS is the authorised service for the completion of the Commonwealth Department of Health and Ageing Aged Care Client Record (ACCR) necessary to determine eligibility for entry into residential care. This means that all suppliers of monitoring and respite services need to have a detailed understanding about available comprehensive assessment services and the availability of CRAGS, COPs and CACPs and the preparation for residential care services. Participation in the Dementia Network contributes greatly to this understanding.

The Network has identified a gap in the availability of monitoring and home support services for people with dementia who do not have carers. Monitoring of these people often falls by default to non-dementia specific HACC services providing care and support.

## **The Sixth Tier – COPs, CACPs and Preparation for Residential Care**

Transition from the fifth to the sixth tier of the Model requires across and within agency teamwork to ease stress on the situation. Clients and carers who have developed strong, trusting, working relationships with service providers in the early and middle stages of the dementia can now find that they have to deal with different suppliers of case management and support services in the later stages of dementia. It can be particularly distressing for the person with dementia if the transition is not planned and well co-ordinated.

The Dementia Network Model emphasises the 'shared care' concept in this handover period and the role of CRAGS as the delegated authority for assessment of people for residential care, respite in residential care and for CACPs. Through this delegation comes the Placement Service which keeps an updated list of all vacancies in the residential care sector. This information is given to carers and clients in preparation for low or high level residential care. Basic community care services that have an existing relationship with the client and carer can share the support role with COPs or the CACP provider during the interim handover period.

At first this might mean that existing provider plays the primary support role, introducing the new players to the client and carer. The existing service provider may help them prepare for and even provide support during comprehensive assessment process. Volunteers and people providing in-home respite may continue to visit during the handover period. The COPs or CACP case manager may initially play the

secondary support role, taking a back seat as the client and carer develop a good working relationship with them. Gradually, the roles rotate as the case management and service co-ordination role takes over. The secondary support role often gradually fades away though, in many cases particularly with volunteers, contact is on-going.

Essential components to maximise the effectiveness of this tier are that:

- existing service providers have an accurate knowledge of what COPs and CACPs offer and can explain it to clients and carers
- the carer has a clear understanding of the purpose and process of comprehensive assessment
- the carer has a clear understanding of the role of the case manager and the process of case management, if needed
- the client and carer know about any fees for service
- the client and carer know the full range of care options and can make an informed choice
- there is a planned, gradual and well co-ordinated transition and handover process
- quality case management is provided
- residential respite is available to give the carer longer breaks
- the carer and client have access to educational or experiential opportunities that help prepare for low or high care in a residential setting.

Network members have identified that preparation for residential care is a current support gap within this tier of the Model. Some members have been developing a report that will discuss this gap and identify possible solutions.

## Role of the Dementia Network

The St George Dementia Network will be a formal network of major community care stakeholders involved in raising community awareness about dementia and delivering a range of services to people with dementia, their carers and families. Collectively, they cover all tiers of the Model. Table 1 maps their role across the six tiers of the Model.

The St George Dementia Network intends to meet quarterly. It has identified its major roles as being to:

- exchange information about and monitor of the full range of quality services to people with dementia, their carers and families
- raise awareness of the Dementia Network Model, its tiers and the linkages between the tiers amongst health care professionals and community care service providers
- advocate for broader community understanding of dementia and sensitive service provision by the private sector when dealing with people with dementia and their carers
- develop and maintain clear referral pathways that maximise a seamless transition between the tiers for clients and their carers as the dementia progresses
- identify gaps, problems and blockages in the service system for people with dementia and their carers
- act as a problem solving forum to address gaps, problems and blockages
- where appropriate, lobby for needed resources and services for people with dementia and their carers.

The Network has identified the need for the production of a dementia specific brochure outlining the role, membership and services of the agencies forming the St George Dementia Network.

## Conclusion

The Dementia Network Model provides a comprehensive framework for identifying the range of information and support services available to assist clients and carers as they progress through the early, middle and later stages of dementia. The Model is client focussed in that it recognises that clients and their carers not only need different types of support as the dementia progresses but also as smooth a transition as possible as they move through the six tiers of the Model.

The Dementia Network itself ensures that there are strong, informed and collaborative links between health care professionals and agencies providing specific support services to people with dementia and their families. Its work in identifying and responding to service gaps, problems and blockages should ensure that people in the St George area who are living with dementia, their carers and families receive quality, appropriate and flexible support services.

The St George Dementia Network

	<b>Community Awareness</b>	<b>Diagnosis</b>	<b>Early Stage Intervention</b>	<b>Education, Support, Activities</b>	<b>Monitoring and Respite</b>	<b>CACP, Community Options</b>
CRAGS (ACAT)	<b>V</b>	<b>V</b>	<b>V</b>	<b>V</b>	<b>V</b>	
Dementia Advisory Service	<b>V</b>	<b>V</b>	<b>V</b>	<b>V</b>		
Benevolent Society, Community & In Home Flexible Respite	<b>V</b>			<b>V</b>	<b>V</b>	
St George Carers Support Service	<b>V</b>		<b>V</b>	<b>V</b>	<b>V</b>	
Rockdale Community Services			<b>V</b>	<b>V</b>	<b>V</b>	
Georges River Neighbour Aid Dementia Monitoring			<b>V</b>	<b>V</b>	<b>V</b>	
Kogarah Community Services Home Visiting/Dementia Respite			<b>V</b>	<b>V</b>		
St George Division of General Practice				<b>V</b>	<b>V</b>	
Chesalon Dementia Flexicare				<b>V</b>	<b>V</b>	
NESB Dementia Monitoring and Support Service					<b>V</b>	
Warrina Cottage Dementia Day Care					<b>V</b>	
Bobby Goldsmith Foundation				<b>V</b>	<b>V</b>	
St George & Sutherland Live At Home Service					<b>V</b>	<b>V</b>
Benevolent Society, St George Help At Home CACPs					<b>V</b>	<b>V</b>
Chesalon Care At Home CACP						<b>V</b>

**Table 1: The Members of the St George Dementia Network and Their Place in the Model**

