



Evaluation of the Barwon-South Western Region Dementia Strategy

Final Report

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1. Executive Summary

Background

The Department of Health (DH) Barwon-South Western (BSW) Region Dementia Strategy was developed with the support of regional health professionals in response to the Regional, State and National Health Departments' priority to improve services for people affected by dementia. The National Ageing Research Institute (NARI) was commissioned by DH BSW in 2010 to conduct an evaluation of the BSW Region Dementia Strategy.

Aim

The aim of the evaluation was to determine the effectiveness of the BSW Region Dementia Strategy initiatives with particular reference to their impact on:

- People living with dementia, their families, carers and the community
- The added value to the current dementia services in the BSW region

Method

The main stakeholders consulted for this evaluation were health professionals in the BSW region working within the initiatives, the dementia networks and the Dementia Strategy Steering Committee, which included carer and consumer representatives. Components of the evaluation included reviewing documentation and consultations with the Dementia Strategy Steering Committee. Other components included:

- Three focus group consultations conducted in the BSW region in March 2011;
- Analysis of evaluation surveys sent to service providers in the BSW region at two time points;
- Consultation with service providers at the Regional Dementia Forum run in August 2011 and;
- Dementia service mapping for the BSW region.

Findings

Focus Group Consultation

The 20 participants in the three focus groups identified many improvements in the service system for people with dementia during the BSW Region Dementia Strategy period, including many of the areas the strategy aimed to improve. These included educational opportunities, information sharing and collaboration, the availability and suitability of residential aged care, the dementia networks and service development including the Remember Exercise Matters pilot. However focus group participants also identified areas in which there was still room for improvement. They were particularly concerned about the management of people with dementia in hospitals and the participants in Colac, Hamilton and Warrnambool identified some key gaps in the service system such as access to geriatricians and geriatric psychiatrists. Those participants who were involved in the dementia networks, and therefore aware of it, were very keen to see the "Memory loss and dementia directory" completed and disseminated with an accompanying education strategy. Other areas that participants identified as priorities for the rest of the current BSW Region

Dementia Strategy timeframe were more community education, including broad based education through newspapers and schools and more of a focus on rural parts of the region. They were also keen to see service gaps addressed including a Geriatrician who could service the Southern Grampians/Glenelg area, more emergency respite for carers and further service development, such as the development of nurse practitioner and clinical nurse specialist roles.

Evaluation Surveys

Fourteen middle-stage evaluations from approximately 40 distributed were returned from service providers in the Geelong, Hamilton, Portland and Warrnambool regions. These service providers were undertaking 108 dementia related services, programs or activities. These were categorised as home support, carer services, activity and support programs, cognitive assessments/initiatives and education. Six pre-stage evaluation surveys were completed and returned by service providers in the BSW region prior to the implementation of the BSW Region Dementia Strategy. Only two service providers completed both the pre-stage and middle-stage evaluation surveys therefore it was not possible to gauge the impact of the BSW Region Dementia Strategy on dementia related services, programs and activities currently being run in the region. However, there did appear to be an increase in awareness of the importance of dementia related services as indicated by the programs the service providers were running and their priorities for these services in the next action plan. The increase in returned evaluation surveys in the middle stage also indicated an increase in awareness of the BSW Region Dementia Strategy.

Regional Dementia Forum Consultation

Approximately 50 service providers in the BSW region attended the Regional Dementia Forum and participated in the consultations. Participants were asked to discuss what they had found most helpful/valuable about the BSW Region Dementia Strategy and how they thought the BSW Region Dementia Strategy could be sustained in the future without a Dementia Strategy Project Officer. The main aspect of the BSW Region Dementia Strategy that the participants in the Regional Dementia Forum consultations found valuable was the Dementia Strategy Project Officer role. Other aspects seen as helpful were the networking opportunities, the reinvigoration and development of dementia networks, the increased knowledge of services and resources and service development outcomes. In terms of sustainability the participants were keen to see the role of the Dementia Strategy Project Officer or a similar central role continue. It took considerable prompting for participants to consider alternate options other than the continuation of the Dementia Strategy Project Officer role for ongoing sustainability of the BSW Region Dementia Strategy. However they did identify having several key people (one for each sub-region) as a possible alternative.

Service Mapping

Finalised service maps of dementia specific services available in the BSW region were produced for: Geelong, Hamilton, Portland, Colac, Warrnambool and Camperdown. For each service map service organisations in each area were listed with an outline of what dementia specific services they offer. Another service map was produced outlining the service

providers that provide care packages to the local government areas of the City of Greater Geelong, Surf Coast Shire, Colac Otway Shire and Borough of Queenscliff.

Summary

The evaluation has illustrated that there has been considerable development in dementia services and networks in the BSW region during the period of the BSW Region Dementia Strategy. Some of this development can be attributed to the BSW Region Dementia Strategy particularly the work of the Dementia Strategy Project Officer, the dementia networks and the Dementia Strategy Steering Committee and some of it can be attributed to other State and National initiatives (COAG-LSOP initiative, Dementia Management in Hospitals Program, the National Dementia Initiative, HACC Active Service Model and the Respecting Patients Choices Program) that were introduced during the same period. There were some limitations to the evaluation of the BSW Region Dementia Strategy including limited opportunities to consult with consumers and people who were not engaged with the BSW Region Strategy. However the evaluation did involve considerable consultation with service providers in the BSW region which allowed the impact of the BSW Region Dementia Strategy and its outcomes to be determined on services, programs and clients in the region.

For ongoing sustainability of dementia service development in the BSW region the following recommendations were suggested for consideration by the Department of Health based on the findings of this evaluation:

- Ongoing employment of a Dementia Strategy Project Officer or similar role to act as a central person to drive communication and act as a link between the four dementia networks in the BSW region;
- Identification of key people within each dementia network in the BSW region to act as ongoing drivers. This could include creating role descriptions for a “dementia champion” in each sub-region of the BSW region;
- Provision of terms of reference for each dementia network in the BSW region;
- Continuation of the Dementia Strategy Steering Committee;
- Production of a dementia newsletter with information on dementia funding opportunities, initiatives, presentations, expos and forums occurring in the region that could be disseminated to service providers in the BSW region quarterly
- Dissemination of the service maps to service providers in the BSW region
- Completion and dissemination of the "Memory loss and dementia directory - Barwon South Western Region"
- Further development and potential regional dissemination of Remember Exercise Matters
- Presentation of findings of this evaluation to state DH and other regional steering committees (or alternative forums)

2. Background

The Department of Health (DH) Barwon-South Western (BSW) Region Dementia Strategy was developed with the support of regional health professionals in response to the Regional, State and National Health Departments' priority to improve services for people affected by dementia.

The aim of the BSW Region Dementia Strategy was to increase the community's awareness of dementia, and the services available to enable people living with dementia and their carers to: gain a diagnosis; access appropriate support, respite and care when required; navigate the services effectively; and have a continuity of care throughout their journey of dementia. This included providing the health services with strong networks, referral pathways, and education and training opportunities.

In order to facilitate implementation of the BSW Region Dementia Strategy and networks, BSW DH employed a Dementia Strategy Project Officer working two days a week, spanning a three year period, with completion in September 2011.

A Regional Dementia Strategy Steering Committee and three sub Regional Networks within the Primary Care Partnerships (PCP) catchments of Barwon, South West and Southern Grampians - Glenelg were established. The Dementia Strategy Steering Committee and networks met quarterly.

The Dementia Strategy Steering Committee and networks were guided by the four key themes of significance for dementia service provision, which were identified through regional consultation, and included:

- 1) Dementia education
- 2) Services System Development and Coordination
- 3) Dementia Pathway Planning
- 4) Gaps in Service.

The National Ageing Research Institute (NARI) was commissioned by DH BSW in 2010 to conduct an evaluation of the BSW Region Dementia Strategy. The aim of the evaluation was to determine the effectiveness of the BSW Region Dementia Strategy initiatives with particular reference to their impact on:

- People living with dementia, their families, carers and the community
- The added value to the current dementia services in the BSW region

3. Evaluation Method

The main stakeholders consulted for this evaluation were health professionals in the BSW region working within the initiatives, the dementia networks and the Dementia Strategy Steering Committee, which included carer and consumer representatives.

Components of the evaluation included: reviewing relevant documentation including the BSW Region Dementia Strategy; attendance, reporting and advice to the Dementia Strategy Steering Committee and verbal reports on findings to the Dementia Strategy Steering Committee throughout the course of the evaluation period.

Other key components of the evaluation method described below included:

- Focus Group Consultation
- Evaluation Survey Analysis
- Regional Dementia Forum Consultation
- Service Mapping Process

3.1 Focus Group Consultation

Prior to the commencement of the BSW Region Dementia Strategy, the Department of Health facilitated six focus groups across the BSW region in 2006 with the aim to inform the development of the BSW Region Dementia Strategy. Prior to the evaluation documentation used to run the 2006 focus groups including questions asked, surveys used and attendance lists were reviewed. The report produced on the focus groups was also reviewed in order to identify key themes and issues in the BSW region prior to the implementation of the BSW Region Dementia Strategy.

For this evaluation, focus group consultations were conducted with service providers in the BSW region in March 2011. An invitation to attend the focus groups was created by NARI and distributed to service providers in the BSW Region by the Dementia Strategy Project Officer. The aims of this consultation process were to gather information about service providers' perceptions of the changes that had occurred in the BSW region since the previous round of focus groups and to identify priority areas for the rest of the BSW Region Dementia Strategy timeframe.

The focus groups were run at three locations in the BSW region: one in Geelong (with eight participants); one in Colac, with a video link to Hamilton (with 10 participants, six from Colac and four from Hamilton); and one in Warrnambool (with two participants). The participants consisted of workers from residential aged care, aged care assessment, health services and community aged care settings. Table 1 below shows the service area represented and Table 2 shows the agencies represented at the focus groups.

Table 1 Service Areas Represented in the Focus Groups

	Geelong	Colac	Hamilton	Warrnambool
Service Area Represented	<ul style="list-style-type: none"> • Community, residential aged care • Respite • Assessment • Community • Aged Support • Aged and Disability services • Community aged care and disability 	<ul style="list-style-type: none"> • Aged Care • Acute • Emergency • Community • Rehabilitation • Residential aged care 	<ul style="list-style-type: none"> • Acute care • Community aged care 	<ul style="list-style-type: none"> • Aged care and community • Residential and community care

Table 2 Agencies represented in focus groups

	Geelong	Colac	Hamilton	Warrnambool
Agencies	<ul style="list-style-type: none"> • St Laurence • Barwon Regional ACAS • DoCare Geelong • Alzheimer's Australia Victoria • Diversitat • City of Greater Geelong • Karingal Inc • Barwon Regional Aged Care Assessment Service 	<ul style="list-style-type: none"> • Mercy Place and Aged Care • Timboon & District Healthcare Service • Colac Area Health 	<ul style="list-style-type: none"> • Western District Health Service 	<ul style="list-style-type: none"> • Lyndoch • Moyne Health Services

Participants were asked to comment on four main areas. These were the areas identified as the main areas of focus for the BSW Region Dementia Strategy in the focus groups conducted in 2006:

- Dementia pathway planning
- Gaps in Services
- Service system development and coordination
- Dementia Education

Participants were asked whether they felt there had been any progress in each of these areas over the past four years and whether there were still gaps to be addressed. Please see Appendix A for the focus group agenda.

The three groups were facilitated by the same NARI senior researcher, a NARI research assistant took notes and they were also audio taped with permission of participants. In the first two groups, the research assistant read through the notes at the end of the discussion and sought agreement from participants that this was an accurate summary of the

discussion. The third group declined this opportunity as they said they trusted that the research assistant would have recorded them accurately. The notes were also sent to the Colac/Hamilton participants and some additional comments were sent back to the NARI team.

3.2 Evaluation Surveys

Evaluation surveys were sent out (via mail or email) to service providers in the BSW region in December 2010 by the Dementia Strategy Project Officer. An estimated 40 surveys were distributed, and the response rate was 35%. The completed surveys were returned to NARI via reply paid envelopes or email. The aim of this process was to collect information about what dementia specific services, programs and activities were being run in the BSW region at this time point.

The surveys used the *Dementia Framework for Victoria Implementation Plan 2006/2008*¹ as a guide for the evaluation. This framework allowed service providers to list their current services, programs and activities, the area on the pathway they covered, the strategies involved in implementation as well as their priority actions for the future. The evaluation surveys asked service providers to indicate which key strategy action area each of their dementia services best addressed. The key action areas were drawn from the directions paper *Pathways to the Future, 2006 and Beyond Dementia Framework for Victoria* which nominated strategies considered of most importance for each stage on the dementia pathway. The key action areas were:

1. Promoting positive ageing and social connectedness
2. Life planning
3. Education and information for the public
4. Service development and enhancement
5. Support for people with dementia and their unpaid carers
6. Respite and residential accommodation
7. Transitions from living at home to residential aged care
8. Meeting specific needs including younger onset dementia, rural and remote isolation, homelessness, Down syndrome, Aboriginal and Torres Strait Islander (ATSI), and culturally and linguistically diverse needs (see Appendix B for more information).

The same evaluation survey was completed by six service providers at the beginning of the BSW Regional Dementia Project in July 2009. The two stages of data collection were analysed and compared to establish what dementia specific services, programs and activities were being run in the BSW region and what changes had occurred to the services and program's offered within the BSW region since the beginning of the BSW Region Dementia Strategy.

¹ The *Dementia Framework for Victoria Implementation Plan 2006/08* accompanies the directions paper *Pathways to the Future, 2006 and Beyond - Dementia Framework for Victoria*, or *Pathways*, on <http://www.health.vic.gov.au/agedcare/>

3.3 Regional Dementia Forum Consultation

Final consultations were conducted with service providers in the BSW region at the Regional Dementia Forum run in August 2011 in Camperdown. The aim of this consultation process was to gather information about service providers' perceptions on the BSW Region Dementia Strategy and its direction for the future.

Approximately 50 service providers in the BSW region attended the Regional Dementia Forum and participated in the consultations. The agencies represented in the consultations are shown below in Table 3.

Table 3 Agencies represented in the Regional Dementia Forum Consultations

Group One	Group Two	Group Three	Group Four	Group Five	Group Six
<ul style="list-style-type: none"> • Barwon Health Carer Respite • Alzheimer's Australia Vic • South West Healthcare • Barwon Health- day programme Planned Activity Groups (PAG) • Cognitive, Dementia and Memory Service (CDAMS) 	<ul style="list-style-type: none"> • Camperdown PAG • Timboon and District Healthcare • Surfcoast Shire • St Laurence 	<ul style="list-style-type: none"> • Colac Otway Shire • NRCP Warrnambool City Council • Corangamite Shire • Cobden District Health Services • David Newman Centre- Camperdown 	<ul style="list-style-type: none"> • Mercy Health Best of Care- Geelong, Colac • DBMAS • St Laurence • Uniting Aged Care 	<ul style="list-style-type: none"> • Western District Health Service Hamilton - Aged care, District Nursing Service, PAG, project officer Long Stay Older Patients (LSOP) 	<ul style="list-style-type: none"> • Colac • Geelong Respite • Winchelsea Dementia Unit

The participants were asked to comment on two main areas. These were:

- What they had found most helpful/valuable about the BSW Region Dementia Strategy and
- How they thought the BSW Region Dementia Strategy could be sustained in the future without a Dementia Strategy Project Officer.

NARI researchers gave a brief presentation on the evaluation and explained what the consultations were aiming to achieve. Following instructions participants formed groups and conducted round table discussions on the above points with one participant acting as a scribe. The participants were given ten minutes to discuss each point as a group and then were brought together as a large group where a NARI researcher facilitated a group

discussion. Another NARI researcher took notes during the group discussion and sought agreement from participants that this was an accurate summary of their views at the conclusion of the consultation.

3.4 Service Mapping Process

Service maps were produced using information provided to NARI throughout the evaluation period. This included information gained through focus groups, the pre and middle stage evaluation surveys, the Regional Dementia Forum consultation and information gained through the Dementia Strategy Steering Committee. The service maps were designed to give people a snapshot of what dementia specific services were available in the BSW Region. Service maps were produced for the areas of Geelong, Warrnambool, Hamilton, Colac, Portland and Camperdown. For each of these areas two service map formats were produced one outlining the dementia service organisations with a description of what dementia specific services are available and the other outlining the dementia specific services available categorised by type of service. A further service map was produced outlining service providers that provide Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH) and/or EACH Dementia Packages (EACH-D) to the local government areas of the City of Greater Geelong, Surf Coast Shire, Colac Otway Shire and Borough of Queenscliff.

4. Consultation Findings

The following section reports the main findings from each evaluation component; the focus consultations; the evaluation surveys; the Regional Dementia Forum consultations and the service mapping process.

4.1 Focus Groups

This section reports on the summarised findings from the three focus groups conducted in the BSW region in March 2011. The section is broken into key areas including progress and gaps evident in the service system, the impact of the BSW Region Dementia Strategy/networks and suggested priorities for the BSW strategy as reported by focus group participants. A detailed report produced by NARI on the findings of these focus groups has been provided to the DH BSW.

Progress and gaps still evident in the service system

The 20 participants in the three focus groups identified that many improvements had been made in the service system for people with dementia during the BSW Region Dementia Strategy period, including many of the areas that the strategy aimed to improve. This included improvements in educational opportunities with particular mention made of the role played by Alzheimer's Australia Victoria (AAV) in the region. There were also improvements noted in the availability and suitability of residential aged care as well as improvements in continuity of care between (public sector) residential aged care and hospital settings. In terms of regional initiatives, the Expos and the dementia networks were mentioned in both Geelong and Warrnambool, the Exercise Matters Group in Geelong and there it was also mentioned that there has been limited progress with using technology to meet some service gaps.

There were also some improvements noted as a result of various other State and Australian Government Initiatives that have been implemented since 2006. These include the Council of Australian Government's Long Stay Older Patients (COAG-LSOP) initiative, including the Dementia Management in Hospitals Program (referred to as the Cognitive Identifier); the National Dementia Initiative that initiated the Extended Aged Care in the Home – Dementia Packages (EACH-D) and the Dementia Community Grants program; and the Home and Community Care (HACC) Active Service Model. The Respecting Patient Choices Program was also mentioned in both the Geelong and Colac/Hamilton groups.

Focus group participants also identified areas in which there was room for improvement. They were particularly concerned about the management of people with dementia in hospitals. Other key gaps in the service system identified by participants in Colac, Hamilton and Warrnambool included limited access to geriatricians and geriatric psychiatrists and the need for more GP education and awareness of dementia. Geelong participants identified the need for more of a focus on social support; increased flexibility of services; and the need for services for people with early onset dementia. The need for episodic case management was also identified and strongly enforced in the Geelong group as they felt it was very difficult for people living with dementia to navigate the system and they need access to someone who

can help them with this on a periodic basis. The need for clearer pathways, carer education, increased availability of EACH-D packages and the need for continuity of care from community care to residential care were also raised by focus group participants.

Impact of BSW Region Dementia Strategy/Network

Focus group participants were asked to identify what they saw as the impact of the BSW Region Dementia Strategy and the areas that should be made a priority over the next few months.

The Geelong group identified a number of ways in which having an overall strategy and a Dementia Strategy Project Officer had helped to progress the support of people with dementia and their families in the local area. They identified some specific initiatives, such as the “Memory loss and dementia directory”, the Exercise Matters Program and the Expos, and they also felt that the support to the network group had given it more validation and strength. They also felt that collaboration within the community sector had been strengthened but that there had been limited impact on residential care or the acute health sector. They were very appreciative of the role played by the Dementia Strategy Project Officer and thought that having someone in that role on an ongoing basis would be important for future development of dementia support in the region.

The Warrnambool participants also valued being part of the local network as it had enabled organisations to get together and learn more about each other and what each other do. They said that the network also gave them an opportunity to get together and discuss their dementia work, to find out what the rest of the region are doing, about Head Office policy and strategy and a “heads up” on funding opportunities. It had also helped with knowing that they were going in the right direction and reduced the level of duplication of effort as they could learn from each other and move forward.

They also found that the Dementia Strategy Project Officer had been a great asset. One participant said it was *“great to have someone at a regional level to communicate with, who lets you know about new initiatives and what other people are doing. It would be a pity to see that level of person disappear. Good to have a driver”*. Both focus group participants were in the local network.

The Colac participants were not aware of any specific initiatives associated with the BSW Region Dementia Strategy. They felt that there had been changes but these were more at an individual professional level, not due to the strategy. They said that the assessment of dementia in aged care had been pushed by Aged Care Funding Instrument (ACFI), which prompts completion of both a cognitive and mood assessment. They also felt that there had been an increase in public awareness. In Hamilton they saw the progress in the acute sector as due to the COAG LSOP initiative. None of the Hamilton or Colac participants were involved in the dementia networks or Dementia Strategy Steering Committee and one participant was a COAG LSOP project officer.

Priorities for BSW Region Dementia Strategy

The main priority identified by group participants for the BSW Region Dementia Strategy was to finalise the “Memory loss and dementia directory”, and to broadly disseminate it, accompanied by education.

Other priorities identified included:

- Broader Community education- potentially at school level
- Need to target teenagers- if they are informed it can help demystify dementia and help increase awareness
- Emergency respite needs to be available – has to include the carers
- Fund more regional projects in rural settings
- More Geriatricians
- Funding to take early onset dementia patients
- Health promotion funding
- Build nurse practitioner role - still just developing
- Clinical nurse specialist/regional team for dementia to act as a link based on palliative care model
- Portfolio for dementia worker- being looked at in Colac
- Use local media to educate about dementia and services available – for example, a bi-annual piece in local paper (Colac Herald) and (Hamilton) Annual Radio talk about COAG LSOP

4.2 Evaluation Surveys

This section reports on the summarised findings from the middle stage evaluation surveys and compares them to the pre-stage evaluation surveys. A detailed report produced by NARI on the findings of the evaluation surveys has been provided to the DH BSW.

Middle stage evaluation survey analysis

Fourteen service providers in the BSW region completed and returned middle stage evaluation surveys. This included service providers from the Geelong, Hamilton, Portland and Warrnambool regions. These service providers were undertaking 108 dementia related services, programs or activities. The programs, services or activities the service providers were undertaking were categorised as home support, carer services, activity and support programs, cognitive assessments/initiatives and education.

Service providers in Geelong, Hamilton, Portland and Warrnambool reported providing home support services to clients. This included HACC assessments and HACC based services, Community Aged Care Packages (CACPs), Aged Care Assessment Services (ACAS), home visiting programs and in-home support services (e.g. domestic assistance). Key dementia specific activities undertaken included: dementia specific HACC planned activity care (Geelong), EACH-D (Geelong) and the Hospital Admission Risk Program (HARP) (Hamilton).

Carer support programs were reported by service providers in the Geelong, Hamilton and Warrnambool regions. This included planned and unplanned respite in various

environments, carer support groups, family meetings, and direct carer involvement in assessment care planning and discharge planning in an acute environment.

Service providers from all regions (Geelong, Hamilton, Portland and Warrnambool) outlined activity or support programs they were offering to clients in the BSW region. This included Planned Activity Groups (PAGs), monthly social groups, aged care exercise programs, pet therapy, music therapy, diversional therapy, social interaction groups, volunteer implemented patient engagement programs (activity groups or individual visits), activity trolleys, communal dining and counselling and support services. Key dementia specific activities undertaken included: two dementia specific pilot programs; Remember Exercise Matters and Artists Within (Geelong), individualised one on one therapy for dementia specific residents (activities based on past lifestyle and preference) (Hamilton), individualised exercise programs within PAGs for people with dementia (Hamilton) and activity programs with activities designed specifically for people with dementia (including walking programs) (Portland).

Another key dementia specific activity reported by service providers was the use of cognitive assessments and the development of cognitive initiatives. This included a clinical cognitive assessment on medical referral (Geelong), cognitive risk screens (Hamilton, Warrnambool), behaviour management plans (Hamilton), dementia passports (Warrnambool) and use of the “cognitive impairment identifier” (Warrnambool).

Service providers in the Hamilton and Warrnambool regions reported conducting dementia related education sessions or reported staff attending training and education sessions to improve their knowledge of dementia. This included education for staff on how to deal with challenging behaviours (Hamilton), advanced dementia training (Hamilton), dementia training including criteria for cognitive identification (Hamilton), dementia awareness campaigns; Alzheimer’s Week and COAG-LSOP radio talks (Hamilton) and raising community awareness of dementia through information sessions and the promotion of a school education kit (Warrnambool).

Strategy action areas

The evaluation surveys asked service providers to indicate which strategy action area they believed their initiatives best addressed. The eight key action areas of which the service providers could choose from were nominated in the Pathways to the Future, 2006 and Beyond - Dementia Framework for Victoria document (refer Appendix B).

Promoting positive ageing and social connectedness and support for people with dementia and their unpaid carers were the strategy action areas that all service providers believed were best covered in the BSW region. The strategy action area that service providers in Hamilton, Portland and Warrnambool did not believe to be as well addressed in the BSW region was life planning. In the Geelong region service providers reported that transitions from living at home to residential aged care was the strategy action area that was not as well addressed by the actions currently being undertaken in Geelong.

Pre-stage and middle-stage comparison

Six pre-stage evaluation surveys were completed and returned by service providers in the BSW region prior to the implementation of the BSW Region Dementia Strategy. As reported above 14 middle-stage evaluations were returned- an increase of eight surveys on the pre-stage data collection stage. Key dementia related services, programs and activities reported in the pre-stage evaluation surveys included: the Mind your Mind Program (Warrnambool); the Living with Memory Loss program (Warrnambool); counselling, information and education sessions for the carer and person with dementia (Geelong, Warrnambool); dementia specific PAGs and activity programs (Warrnambool, Geelong); assistance and direction with specialist diagnosis of condition and support services available (Warrnambool); and respite services (Geelong, Warrnambool).

Only two service providers (Terang and Mortlake Health Service and South West Healthcare Warrnambool) completed both pre-stage and middle stage evaluation surveys and therefore it was only possible to measure change from these two service providers. Key changes reported from South West Healthcare Warrnambool included the implementation and continued use of the “cognitive impairment identifier”, the introduction of a cognitive risk screen and the utilisation of The Dementia Behaviour Management Advisory Services (DBMAS). Terang and Mortlake Health service outlined a comprehensive action plan for developing dementia specific activities within their PAGs that they planned to implement in 2011.

One service provider in Geelong (Surf Coast Shire) also noted that participation in the BSW Region Dementia Awareness Network Group had resulted in the ongoing sharing of information and resources and had also promoted a partnership approach to dementia specific initiatives and programs. It had also allowed them to run an annual community forum to promote awareness of the dementia journey and develop interagency protocols to facilitate shared care planning. This response indicates development in this health service since the implementation of the BSW Region Dementia Strategy.

4.3 Regional Dementia Forum Consultations

This section reports on the findings from the consultation conducted at the Regional Dementia Forum in August 2011. The section is divided into two key areas including what participants found most helpful/valuable about the BSW Region Dementia Strategy and how participants thought the BSW Region Dementia Strategy could be sustained in the future without a Dementia Strategy Project Officer.

Most helpful/valuable about the BSW Region Dementia Strategy

The main aspect of the BSW Region Dementia Strategy that the participants in the Regional Dementia Forum consultations found valuable was the Dementia Strategy Project Officer role. Participants identified that the Dementia Strategy Project Officer had been especially helpful and valuable in implementing the BSW Region Dementia Strategy. Key components of this role found helpful by service providers included: the facilitation of better coordination

and linking between dementia services, and the development of networking opportunities and dementia resources (e.g. the "Memory loss and dementia directory - Barwon South Western Region"). Participants further noted that they had "*confidence in the project officer position*" because it allowed them to see the bigger picture; it created synergy with the department and the services; and it produced a central point of contact which was thought to be essential in such a large and diverse region.

The second key element identified as helpful was the networking and collaboration opportunities that arose from the BSW Region Dementia Strategy. One group stated that the BSW Region Dementia Strategy was "*a great platform for networking and holding working relationships and partnerships*". The reinvigoration of existing dementia networks and the formulation of new dementia network in Colac (Colac Otway dementia network) were seen as especially valuable outcomes. Third, increased community awareness and increased service provider knowledge of what dementia services and resources are available and how the services can be linked into were seen as positive outcomes from the BSW Region Dementia Strategy. Increased collaboration between community and residential care settings was also noted as a positive outcome.

Participants also stated that the BSW Region Dementia Strategy had allowed them to look at a broader, more strategic approach to dementia care and initiatives. It was noted in several groups that the BSW Region Dementia Strategy had allowed a dementia services focus rather than an agency focus. This comment was further redefined in some groups with statements that the BSW Region Dementia Strategy had allowed them to "*focus on the individual's journey not just the service*".

Other comments included that the BSW Region Dementia Strategy had produced "*optimism*" and "*cohesion*"; allowed a "*reconceptualization of the field*"; and was changing the way that services are delivered. Participants also stated that it had helped to facilitate "*innovative care*" and had generated a lot of interest, ideas and activities relating to dementia care. This included tangible outcomes such as the St Laurence Remember Exercise Matters pilot, the regional expos and the "Memory loss and dementia directory - Barwon South Western Region". The funding and training opportunities that were available from the BSW Region Dementia Strategy were also reported as valuable outcomes.

There were approximately 12 people at the Regional Dementia Forum who were unaware of the BSW Region Dementia Strategy. This group of people felt that the regional forum was a great avenue for them to learn about the BSW Region Dementia Strategy, collaborate with other service providers in the region and increase their knowledge on what dementia services and resources are available.

Sustaining without a Dementia Strategy Project Officer

Participants in the Regional Dementia Forum consultations noted that there was a risk that the BSW Region Dementia Strategy may not be sustained with a Dementia Strategy Project Officer. Participants noted that the Dementia Strategy Project Officer position was

“neutral and can bring state-wide ideas to each region” and that they did want to lose the *“knowledge, expertise and extensive networks”* that came with the position.

There was agreement between participants that if there was not going to be a Dementia Strategy Project Officer position there was need for a central position that could drive communication and act as a link between the four networks in the BSW region. One group stated that there is a *“need for an ongoing, passionate, enthusiastic, advocate within the department who has regular contact with grass roots”*. Other participants noted that due to *“sheer physical area”* spread over the region that the logistics involved in sustaining the BSW Region Dementia Strategy made it essential for a central person to be employed. Participants suggested that funding should be provided in order to continue the Dementia Strategy Project Officer or similar role. Another suggestion was that this position could be *“job-shared”* so that the responsibility could be shared within the region.

It took considerable prompting from the facilitators of the group discussion to get the participants to consider alternative options other than the continuation of the Dementia Strategy Project Officer role as they were very keen to see that role continue. After prompting a number of suggestions were made in relation to the continuation of the BSW Region Dementia Strategy and the dementia networks. Participants stated that there needs to be commitment from current stakeholders to continue in their roles to ensure sustainability of the BSW Region Dementia Strategy. Other suggestions related to maintaining the dementia networks included reviewing the terms of reference, having a rotating chair and/or appointing a key person to lead each network. Increased communication and networking was thought to be vital for ongoing sustainability. One group suggested that enhanced geographical networking and communication could be achieved via emails, newsletters or presentations between each network. Participants also noted the importance of funding and suggested that funding be allocated to existing networks/groups in order to enhance sustainability.

Continued support and collaboration between all stakeholders including dementia organisations and the DH was thought to be vital to the ongoing sustainability of the BSW Region Dementia Strategy. Suggestions included: the continuation of department reports on the dementia initiatives occurring in the region; a dementia advocacy link between the department and the region and the possibility of the department providing funding for a major project each year which would help facilitate the continuation of the dementia networks. Participants also noted the importance of building in processes and policies and reporting/auditing within the networks so that current practices can be maintained.

4.4 Service Mapping Process

This section reports on the finalised service maps produced for the BSW region. It includes a brief description on what service maps were produced and the information they provide.

Finalised service maps of dementia specific services available in the BSW region were produced for:

- Geelong (see Appendix 1)

- Hamilton (see Appendix 2)
- Portland (see Appendix 3)
- Colac (see Appendix 4)
- Warrnambool (see Appendix 5)
- Camperdown (see Appendix 6)

For each service map (Geelong, Hamilton, Portland, Colac, Warrnambool and Camperdown) service organisations in each area are listed with an outline of what dementia specific services they offer. For each of these areas two service map formats were produced one outlining the dementia service organisations with a description of what dementia specific services are available and the other outlining the dementia specific services available categorised by type of service. Type of service included respite, activity and support programs including PAGs, residential care, home support including HACC services, CACPs, EACH-D and/or education and information sessions.

A further service map was produced outlining the service providers that provide Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH) and/or EACH Dementia Packages (EACH-D) to the local government areas of the City of Greater Geelong, Surf Coast Shire, Colac Otway Shire and Borough of Queenscliff (see Appendix 7).

A draft version of the Geelong service maps were taken to the Regional Dementia Forum in August 2011 and feedback was sought on the format. Participants were also given a chance to provide further information to NARI for inclusion in the service maps. The finalised service maps provide a snapshot of the dementia specific services available in the BSW Region generated from the information provided throughout the evaluation period. They are not intended to provide a comprehensive picture of the dementia specific services available in the BSW Region.

5. Summary

The aim of this evaluation was to determine the effectiveness of the BSW Region Dementia Strategy initiatives with particular reference to their impact on: people living with dementia, their families, carers and the community and the added value to the current dementia services in the BSW region.

The evaluation has drawn together information from a number of different data sources including pre- and post- BSW Region Dementia Strategy focus groups and evaluation surveys with service providers as well as consultations with the Dementia Strategy Steering Committee and service providers at the Regional Dementia Forum. The main achievements of the BSW Region Dementia Strategy and their impacts included:

- Development of dementia networks and reinvigoration of existing dementia networks. This has resulted in service providers in the BSW region reporting that:
 - They were better informed and had increased knowledge of dementia services and resources, funding opportunities, and what other agencies in the region were doing;
 - There was increased collaboration between services and the dementia networks through the promotion of a partnership and strategic approach to dementia specific initiatives and programs;
 - There were increased opportunities to come together to discuss dementia work which resulted in ongoing sharing of information throughout the BSW region;
 - The extra support provided to the dementia networks through the BSW Region Dementia Strategy period had given the dementia networks more validation and strength and;
 - It had allowed them to focus on the individual's journey of dementia not just their service.
- Service development including:
 - The "Memory loss and dementia directory - Barwon South Western Region" developed as part of the BSW Region Dementia Strategy. The directory was designed for people with dementia, their families and carers and includes general information and contact details of the types of services and programs available in the community for people with dementia. The directory is available via the Department of Health website <http://docs.health.vic.gov.au/docs/doc/Memory-loss-and-dementia-directory-Barwon-South-Western-Region> and;
 - The dementia specific Remember Exercise Matters pilot program run by St Laurence Community Services Ltd

The consultation process undertaken at the March focus groups and at the Regional Dementia Forum revealed that workers in the BSW region attributed the success of the BSW Region Dementia Strategy to the Dementia Strategy Project Officer role and were all keen to see continued funding for this role. This is one option for continued sustainability of

dementia service development in the BSW region. When prompted alternate solutions were suggested to promote ongoing sustainability of dementia service development in the BSW region this included:

- Commitment from current stakeholders to continue in their roles for example those involved in the dementia networks and the Dementia Strategy Steering Committee;
- The maintenance of dementia networks by reviewing and developing terms of reference, having a rotating chair and/or appointing a key person to lead each network;
- Increased communication and networking between services in the BSW region via emails, newsletters and presentations;
- The allocation of funding to existing dementia networks;
- Continued support and collaboration between dementia organisations and DH and;
- Building in processes, policies, reporting and auditing within the dementia networks so that current practices can be maintained.

There were some limitations to the evaluation of the BSW Region Dementia Strategy. There was limited opportunity to consult with people not engaged with the BSW Region Dementia Strategy. However the focus group conducted in Colac in March 2011 and the Regional Dementia Forum conducted in August 2011 did include people who were not previously engaged with the strategy. Another limitation was that there was no direct consultation with consumers in the BSW region which limited the ability to directly determine the impact of the BSW Region Dementia Strategy on carers and people living with dementia. Lastly the evaluation relied on information provided to NARI and responses from participants in the evaluation and therefore the service maps are unlikely to provide a comprehensive picture of the dementia services available in the BSW region.

The evaluation has illustrated that there has been considerable development in dementia services and networks in the BSW region during the period of the BSW Region Dementia Strategy. Some of this development can be attributed to the BSW Region Dementia Strategy particularly the work of the Dementia Strategy Project Officer, the dementia networks and the Dementia Strategy Steering Committee and some of it can be attributed to other State and National initiatives (COAG-LSOP initiative, Dementia Management in Hospitals Program, the National Dementia Initiative, HACC Active Service Model and the Respecting Patients Choices Program) that were introduced during the same period. It is hoped that this evaluation can help enhance the ongoing sustainability of the BSW Region Dementia Strategy which was highly valued by participants consulted throughout the evaluation period.

Recommendations

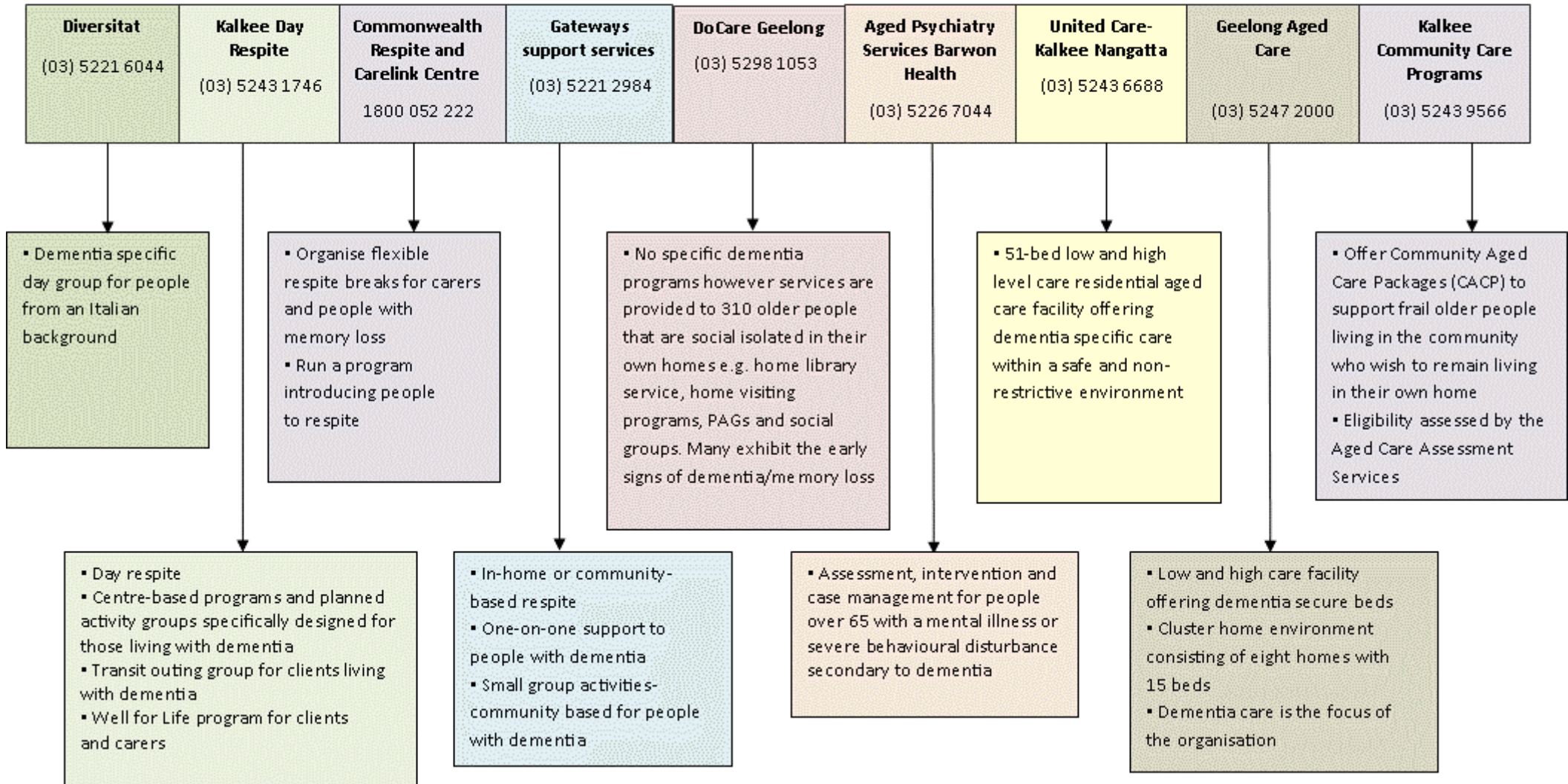
Based on the findings of the evaluation, in order to promote ongoing sustainability of dementia service development in the BSW region, it is recommended that the Department of Health consider:

- Ongoing employment of a Dementia Strategy Project Officer or similar role to act as a central person to drive communication and act as a link between the four dementia networks in the BSW region;

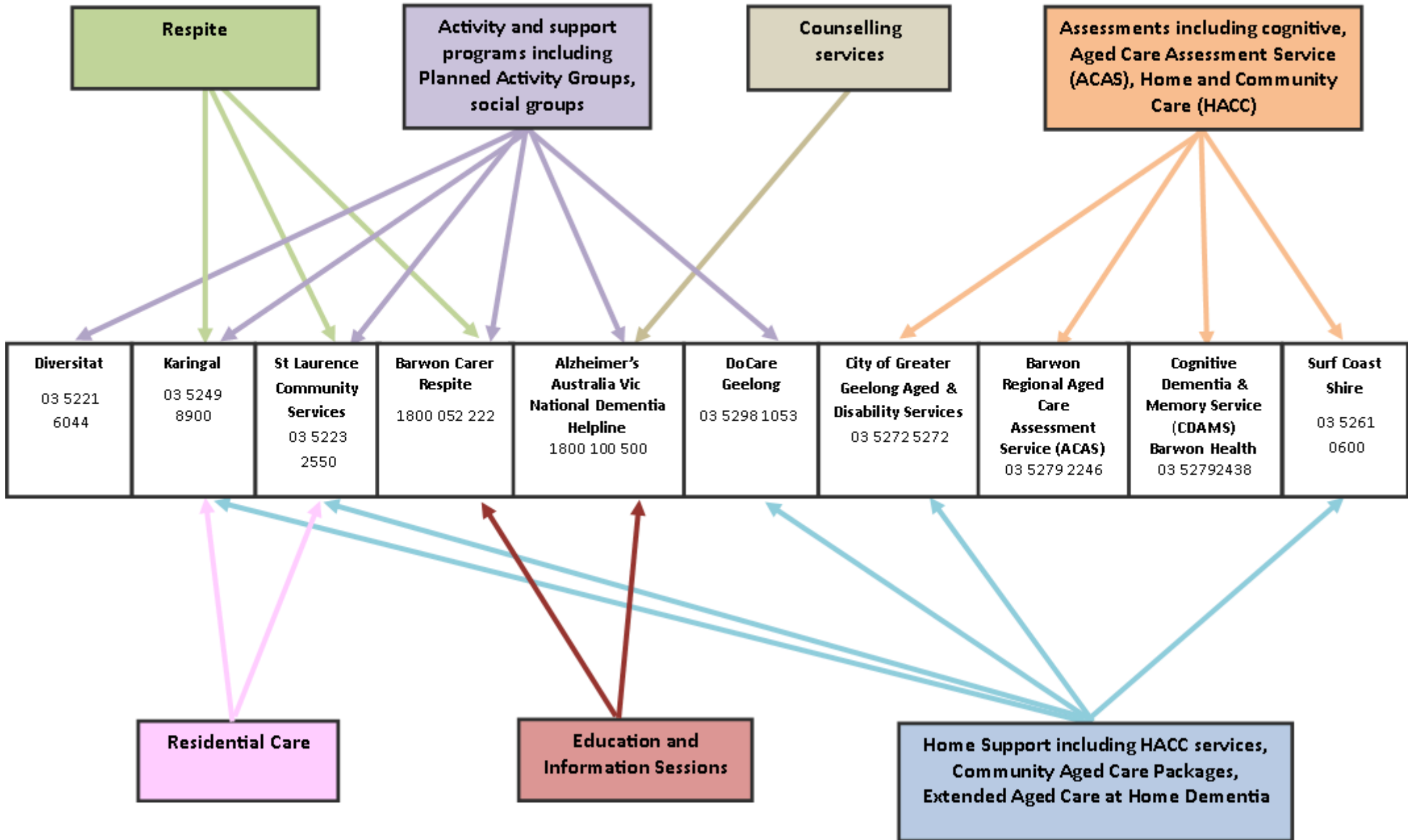
- Identification of key people within each dementia network in the BSW region to act as ongoing drivers. This could include creating role descriptions for a “dementia champion” in each sub-region of the BSW region;
- Provision of terms of reference for each dementia network in the BSW region;
- Continuation of the Dementia Strategy Steering Committee;
- Production of a dementia newsletter with information on dementia funding opportunities, initiatives, presentations, expos and forums occurring in the region that could be disseminated to service providers in the BSW region quarterly
- Dissemination of the service maps to service providers in the BSW region
- Completion and dissemination of the "Memory loss and dementia directory - Barwon South Western Region"
- Further development and potential regional dissemination of Remember Exercise Matters
- Presentation of findings of this evaluation to state DH and other regional steering committees (or alternative forums)

Some service organisations for people with dementia in the Geelong area

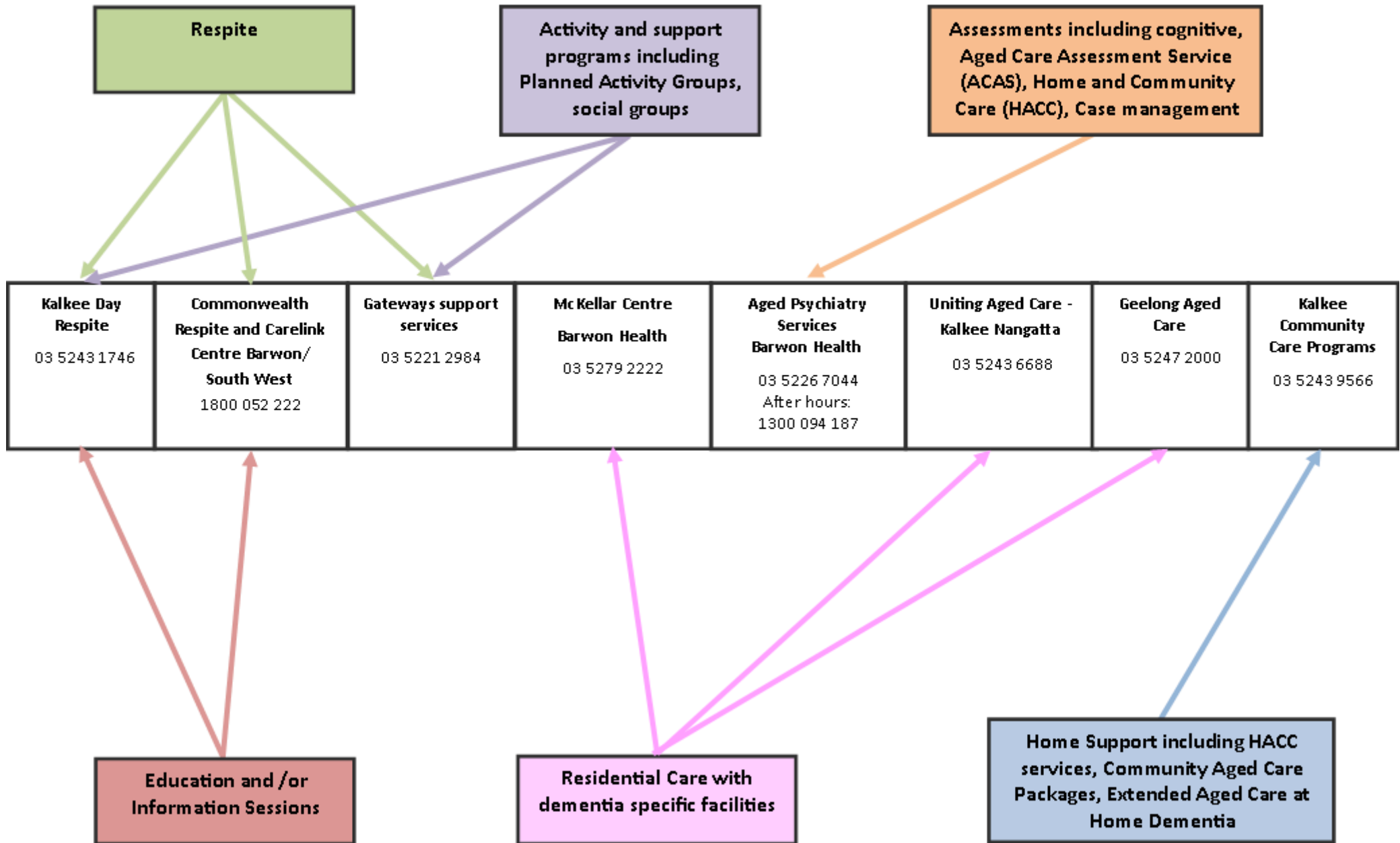
Appendix 1 Geelong Service Maps



Some Geelong services for people with dementia by type

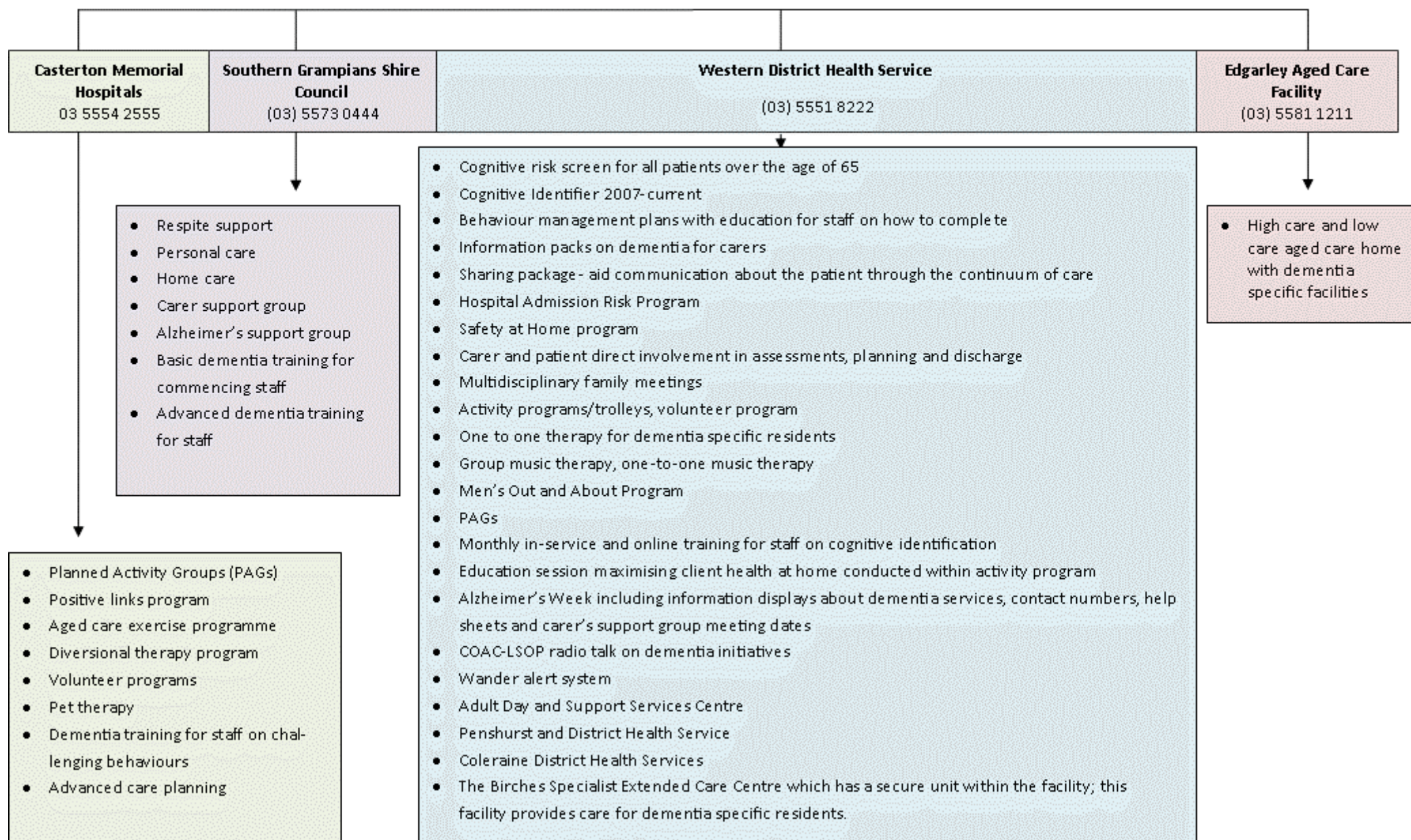


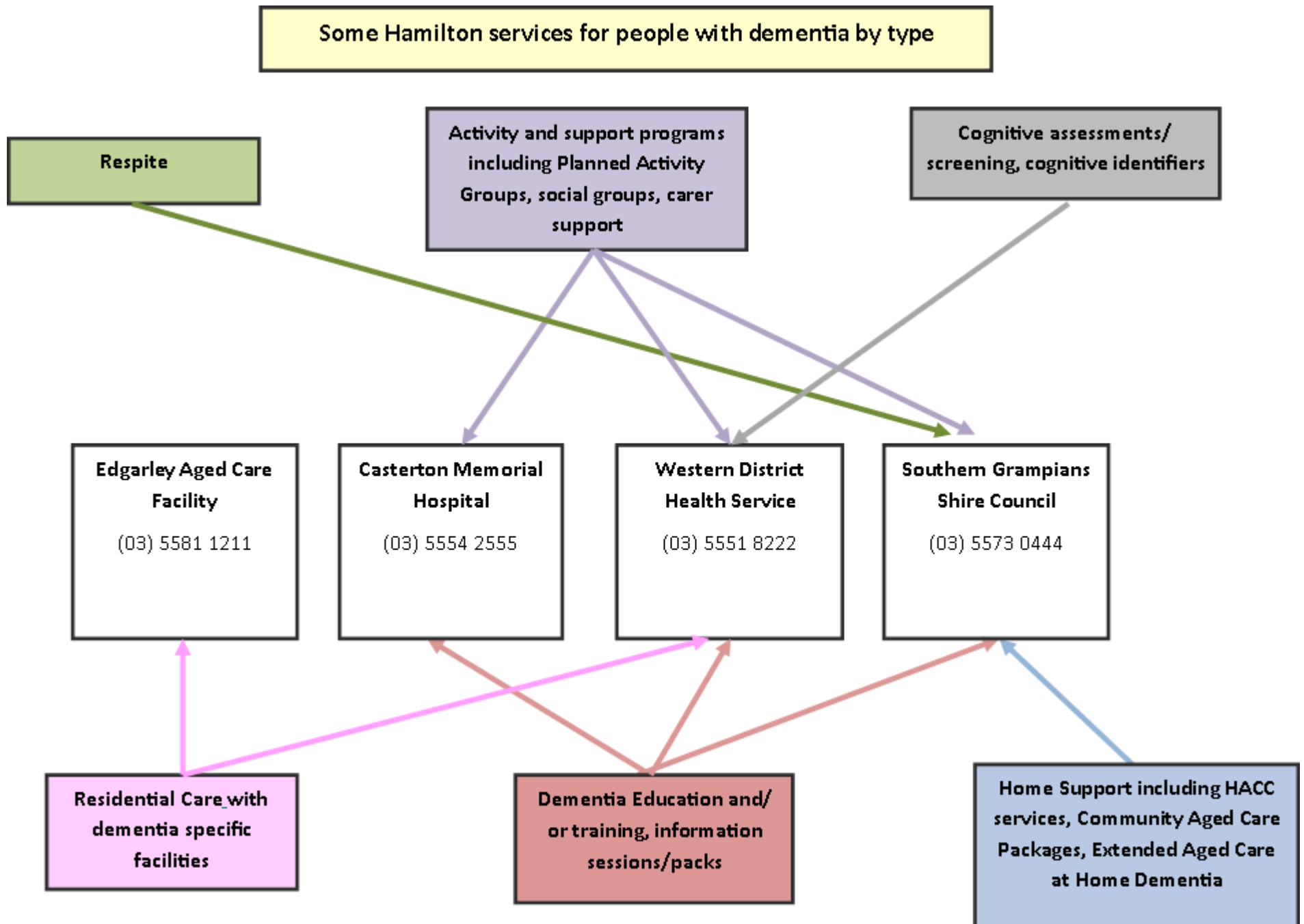
Some Geelong services for people with dementia by type



Some service organisations for people with dementia in the Hamilton area

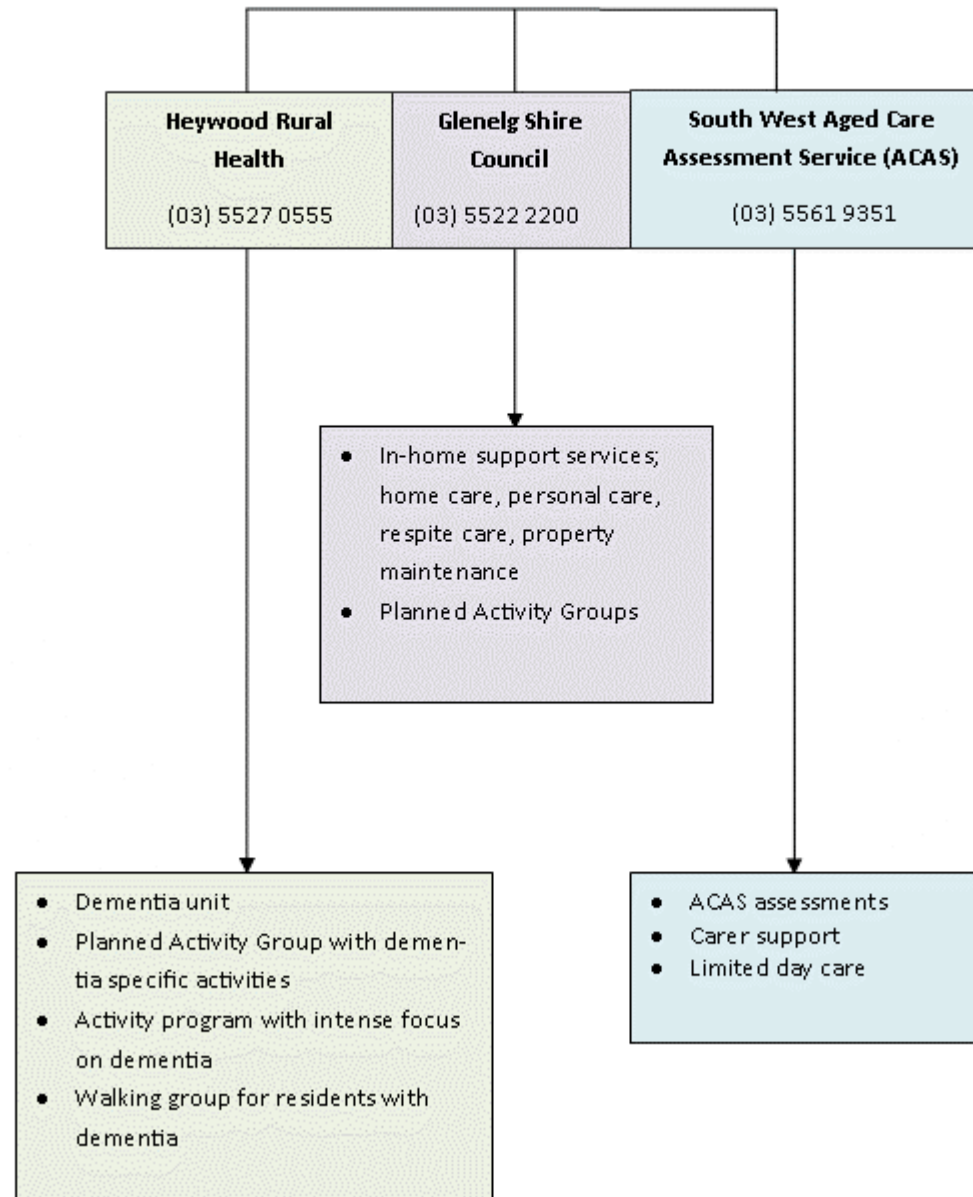
Appendix 2 Hamilton Service Maps

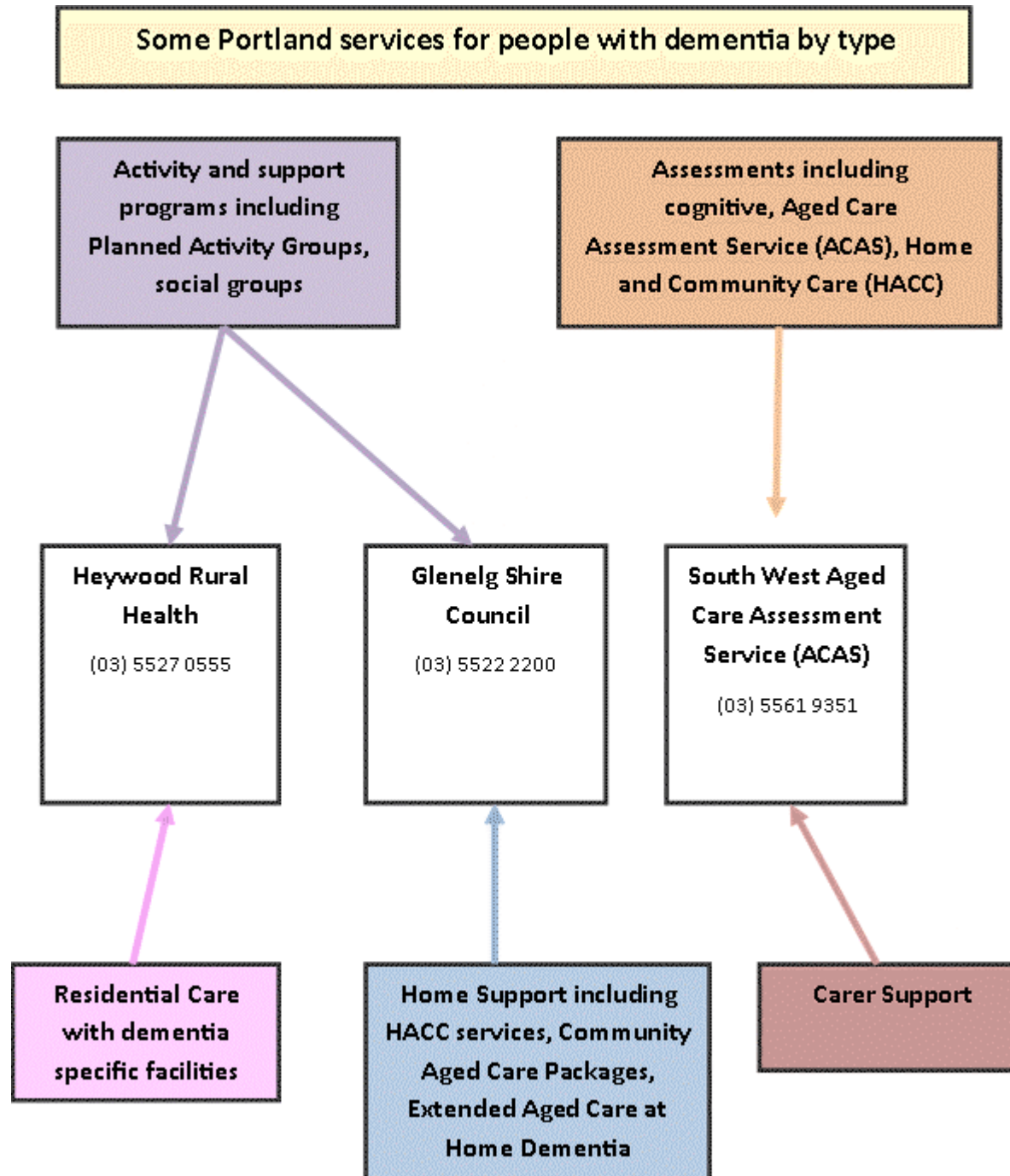




Some service organisations for people with dementia in the Portland area

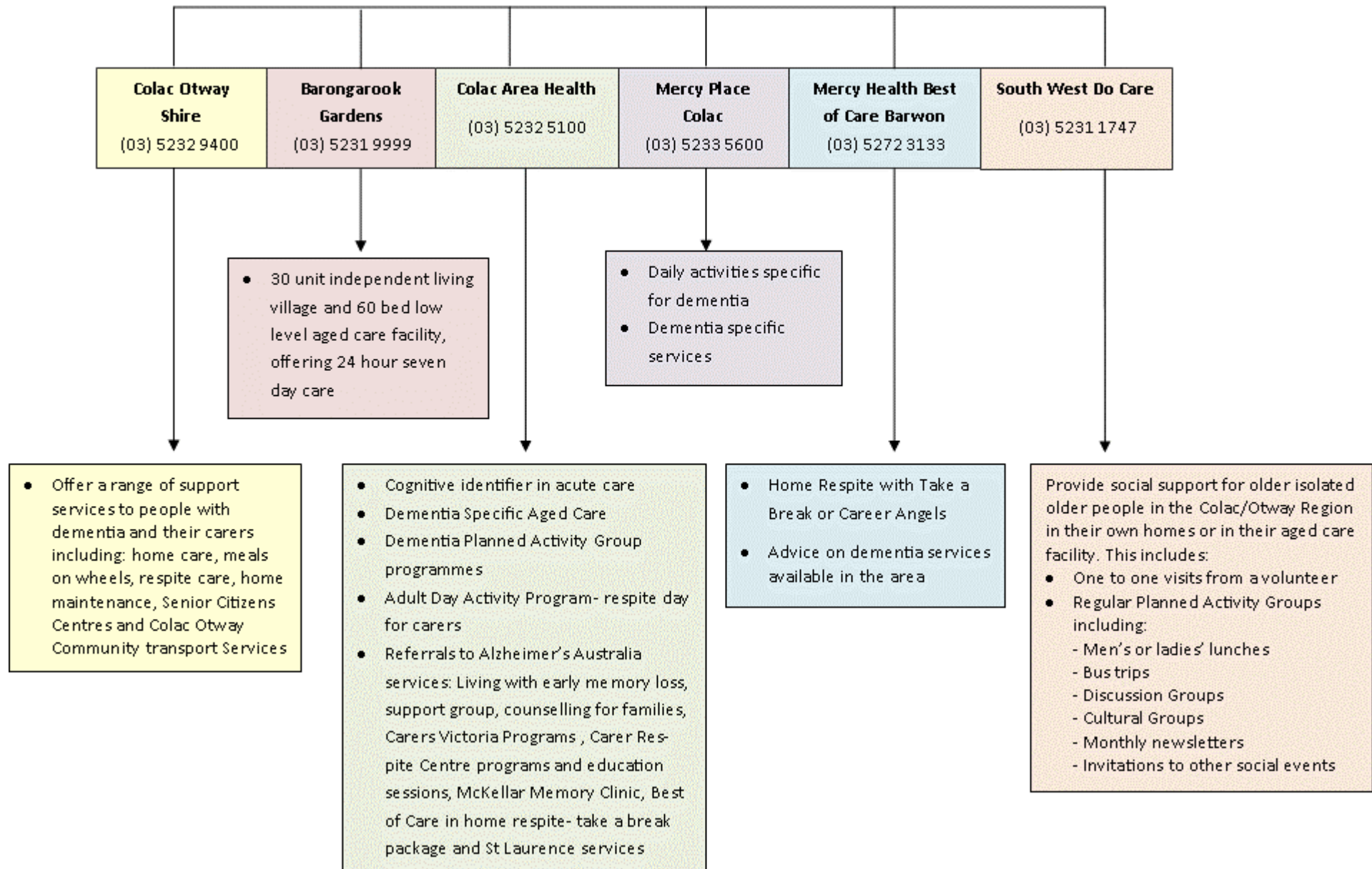
**Appendix 3
Portland Service
Maps**

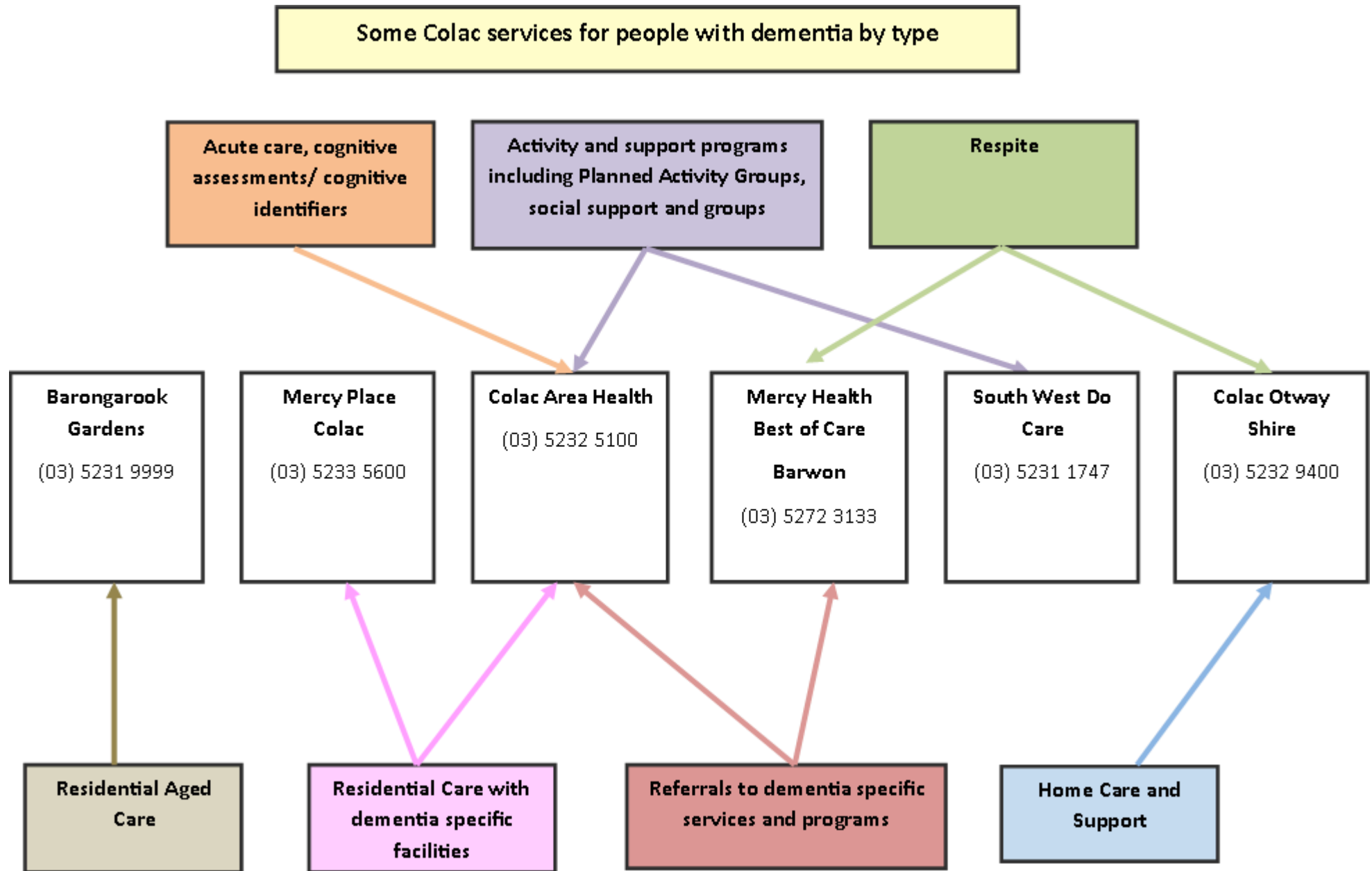




Some service organisations for people with dementia in the Colac area

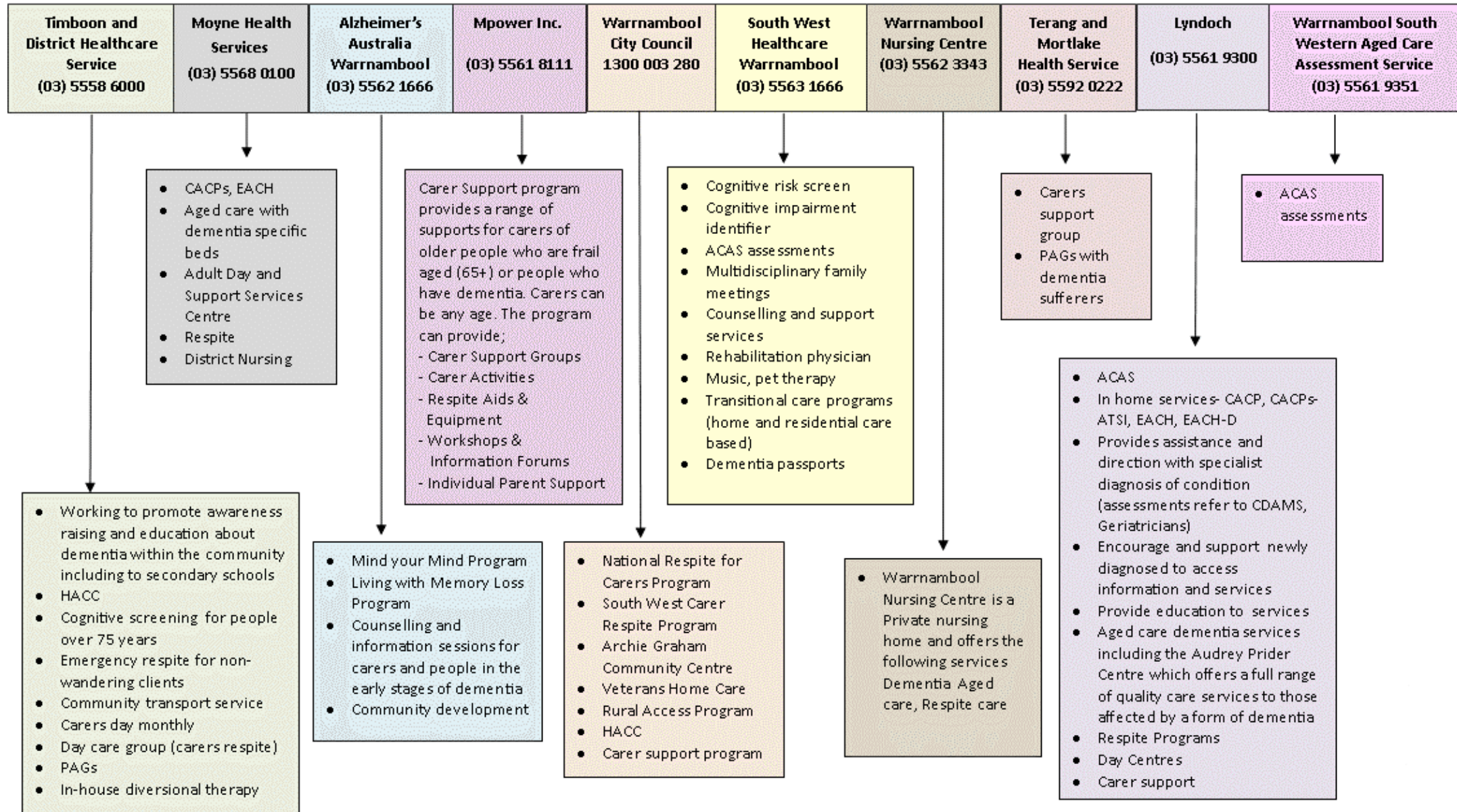
Appendix 4 Colac Service Maps



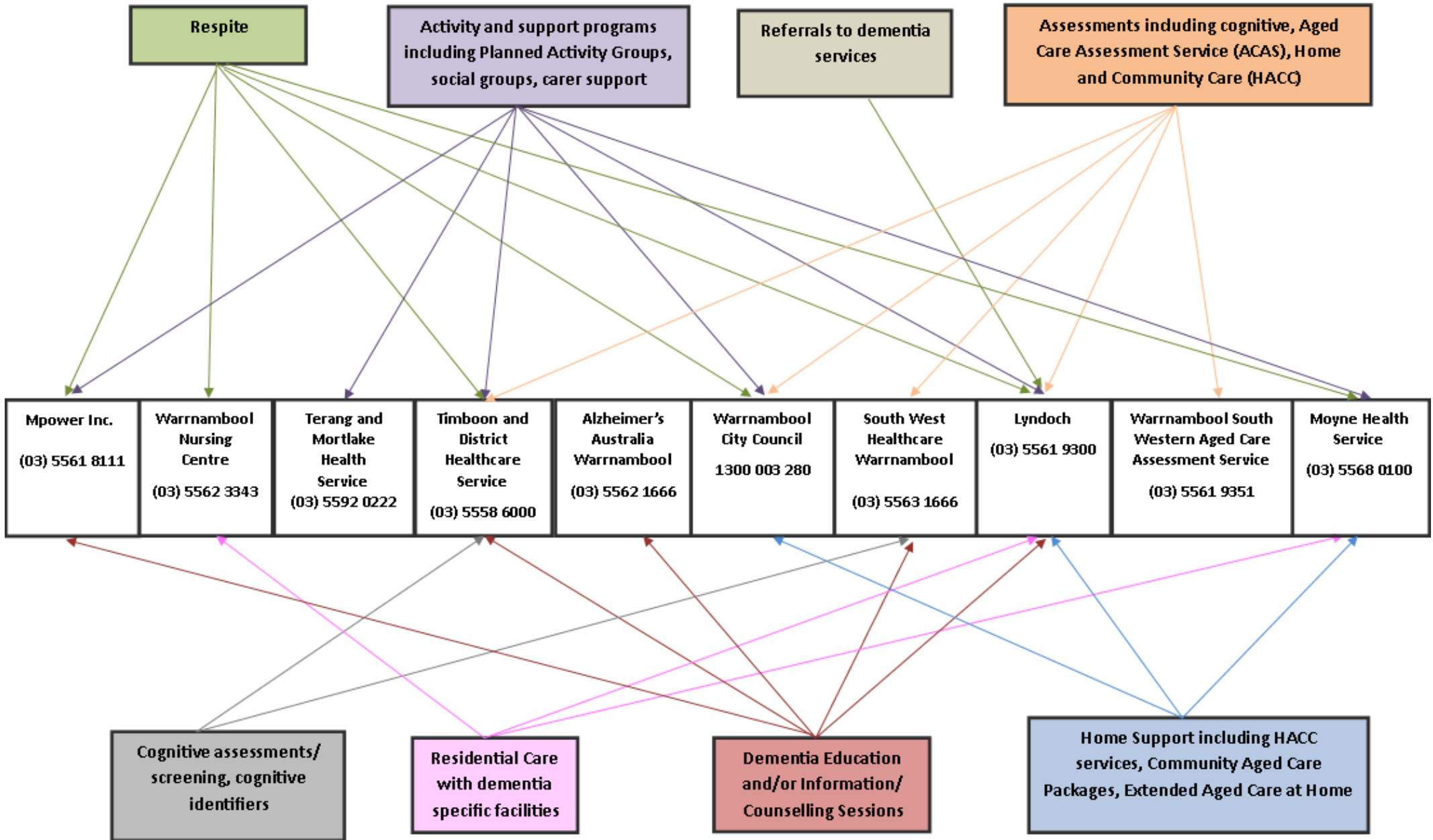


Some service organisations for people with dementia in the Warrnambool area

Appendix 5 Warrnambool Service Maps

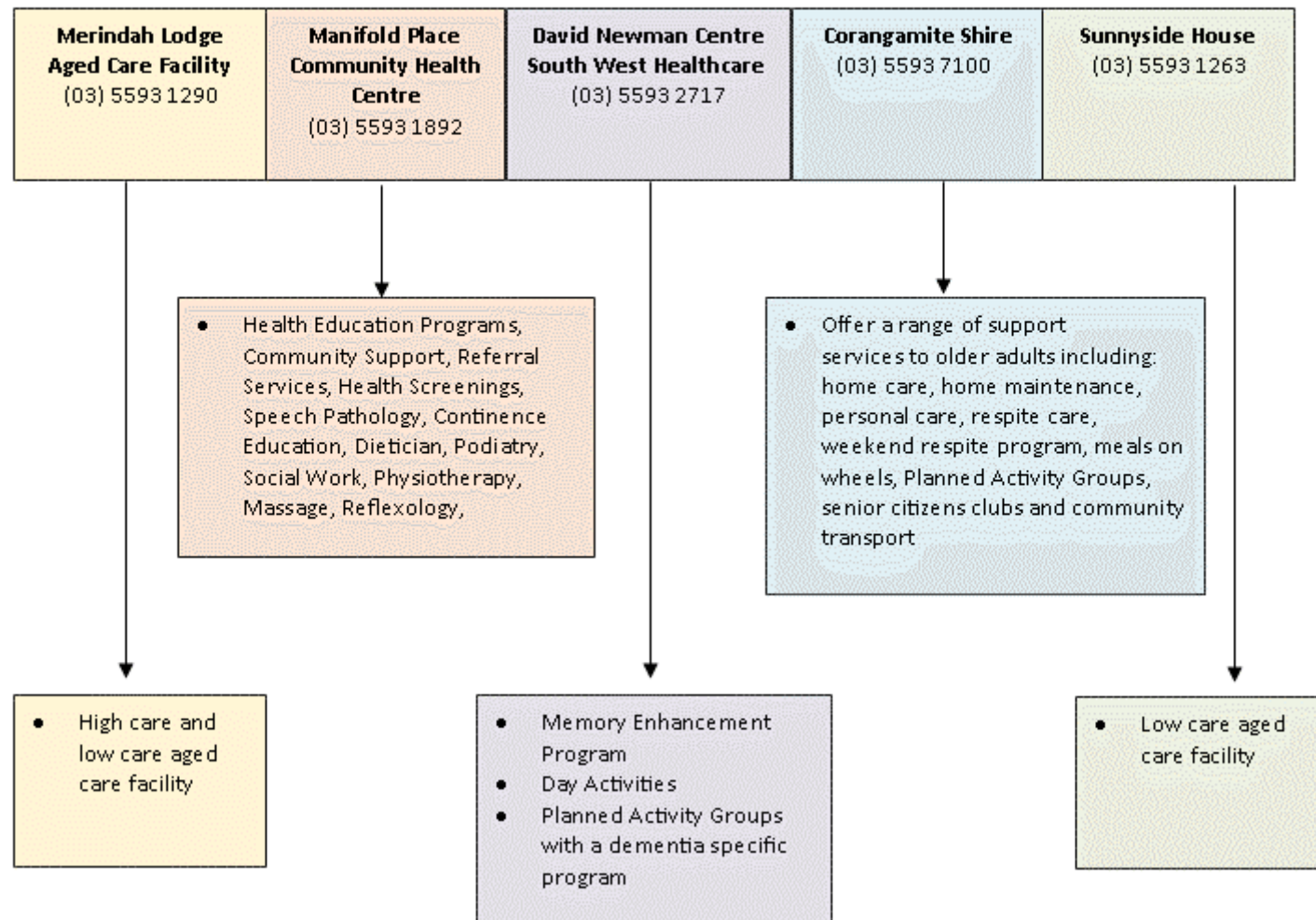


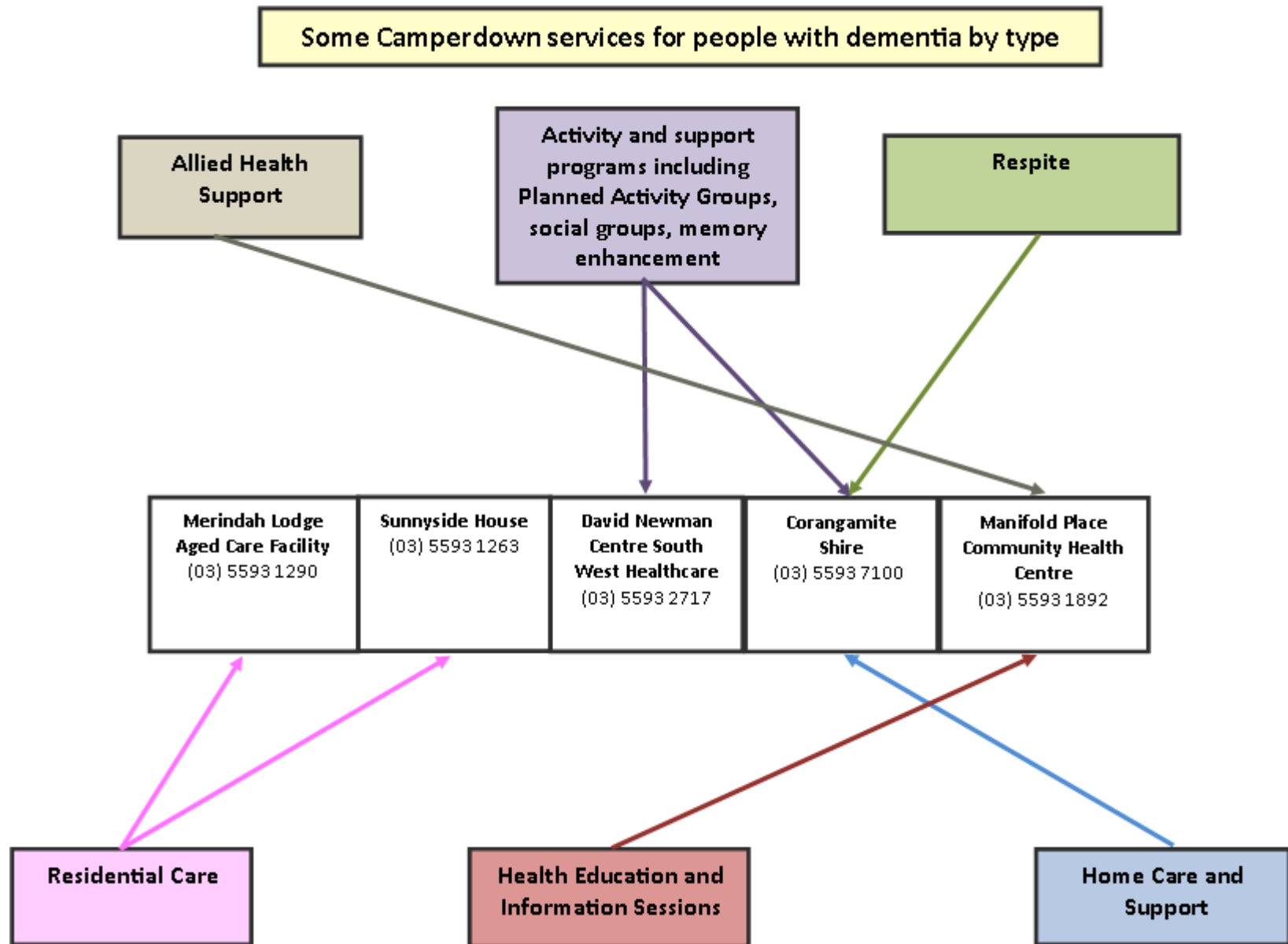
Some Warrnambool services for people with dementia by type



Appendix 6 Camperdown Service Maps

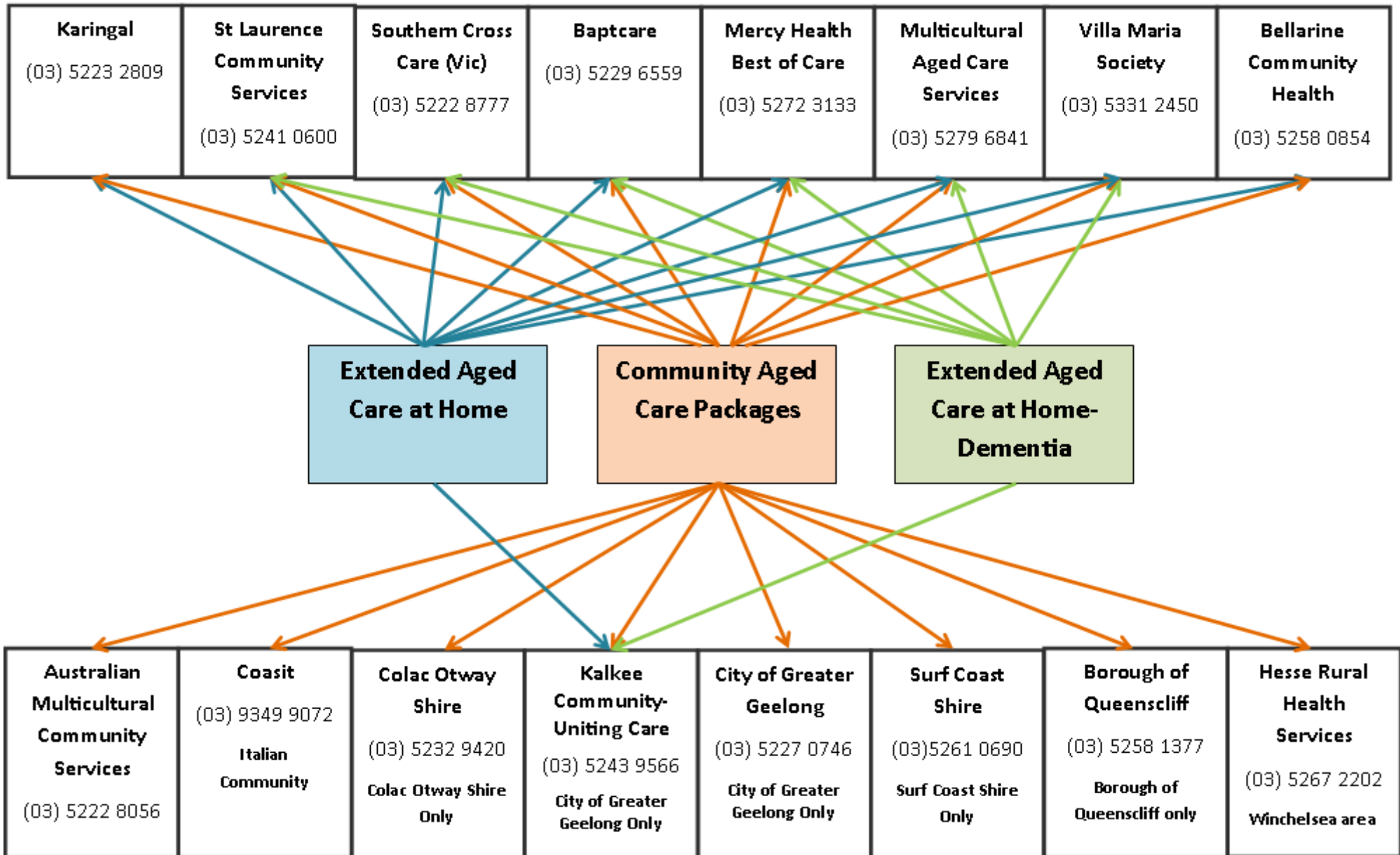
Some service organisations for people with dementia in the Camperdown area





Care Package Providers in the Barwon South Western Region

Appendix 7 Care Package Providers in the Barwon South Western Region



Appendix A Focus Groups Agenda

Barwon South Western Region Dementia Strategy Evaluation 2007-2010

Focus Groups March 2011 Agenda

1. Introductions and survey completion (30 minutes)

Introduce selves

Purpose of these meetings

Surveys to complete to help with service mapping process – explain and complete

2. Focus group discussion (60 minutes)

Explain about previous focus groups and what has been done since – development of Dementia Strategy, project officer since Sept 2008, sub-regional and regional planning committees, a number of initiatives

Today we are going to focus on the issues that were identified in the focus groups run in 2006 to see what progress has been made since then and what still needs to be done.

Issues that emerged in the previous focus groups were:

Dementia pathway planning –

Previous focus groups noted that pathways did not exist but were needed – they identified the following as possible future directions:

- One primary entrance point into dementia responsive services
- A simple pathway to map assessment, diagnosis and referral services
- Regional coordination
- A clear pathway to assist clients and services to coordinate care especially when that care is not in their home town
- Case management was also mentioned

Questions -

- Has there been any progress with this over the past 4 years – if yes, what progress has been made?
- Are there still gaps/areas to be addressed?

Gaps in services

Previous focus groups identified a number of service gaps, including

- Difficulties accessing services due to limited local availability – specifically
- Lack of local geriatricians
- Lack of respite care for carers
- Inadequate nursing ratios
- Lack of access to appropriate assessment (limited CDAMS and ACAS to parts of the region)
- Lack of choice in residential care, especially for people with special needs

Some suggestions for addressing these gaps were:

- Information packages for healthcare professionals (especially GPs)
- Coordinated approach at regional or subregional level with clear documentation of client's care needs and continuity of care
- Client's history should be able to follow the client, especially after EACH or CACPs stops

Questions -

- Has there been any progress with this over the past 4 years – if yes, what progress has been made?
- Are there still gaps/areas to be addressed?

Service system development and coordination

There were a number of areas where service development and further coordination was seen as needed. These included:

- Prevention and risk reduction – community focussed health promotion
- Early detection and diagnosis
- Self-management and care
- Information and knowledge about existing services
- Coordination of existing services
- Lack of public transport
- Flexibility and access
- Technological approaches to service delivery

Some suggestions for future directions included:

A map or directory of services

- Service available
- How to refer
- What each service provides
- Specific contacts (positions not names)

Questions -

- Has there been any progress over the past 4 years with any of the issues identified– if yes, what progress has been made?
- Are there still gaps/areas to be addressed?
- As this is somewhat repetitive of the above – we will focus on any progress in prevention and risk reduction

Dementia education

Although many of the previous focus group participants had received some dementia specific education, none had dementia specific qualifications. They identified the following barriers to take up of training:

- Cost
- Distance

Areas that participants sought more education on included:

- Understanding changes in symptoms and stages of dementia in order to effectively manage medication and care
- Identifying and better management of patients in the acute care setting

Future directions suggested were:

- Executive level support for ongoing education and regional networking
- Prioritisation of dementia education, including behaviour management, effective communication, time management and care planning documentation
- Establishment of a clinical nurse specialist role\

Questions -

- Has there been any progress with this over the past 4 years – if yes, what progress has been made?
- Are there still gaps/areas to be addressed?

Are there any other achievements that I haven't mentioned or any other issues that you would like to raise in relation to the regional dementia strategy and its implementation? Are there any other areas where have suggestions for changes that we haven't already covered? Summarise key points and seek validation. Thank participants – flag another focus group later in the year

Appendix B Evaluation Survey Template

Strategy Action Area: Given Victoria’s achievements to date on dementia care, changing demographics, and opportunities for action, Pathways nominates strategies considered of most importance for each stage on the dementia pathway. The strategies are grouped into the following key areas for action:

1. **Promoting positive ageing and social connectedness**
2. **Life planning**
3. **Education and information for the public**
4. **Service development and enhancement**
5. **Support for people with dementia and their unpaid carers**
6. **Respite and residential accommodation**
7. **Transitions from living at home to residential aged care**
8. **Meeting specific needs including younger onset dementia, rural and remote isolation, homelessness, Down syndrome, Aboriginal and Torres Strait Islander (ATSI), and culturally and linguistically diverse needs.**

EXAMPLE

Actions List the service’s, program or activity your agency conducts	Implementation Brief description of what occurs in the program	Stage/s of dementia pathway to benefit	Strategy Action Area Provide a brief description of the strategies	Key Action Areas Check the number listed above that the area covers,	Priority for next Action Plan
Planned activity group’s that are dementia specific	Conduct 1 weekly dementia specific program; provide support and education where applicable. Accept referrals from;	Middle – late	Conduct suitable programs that are engaging, and utilize the skills and abilities of the clients and provide social connections	<input checked="" type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input checked="" type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8	Conduct more dementia specific PAG’s
Work with stakeholders such as the Department of Education and TAFE to promote awareness raising in secondary schools and tertiary institutions, regarding symptoms, what to do about them, and availability of information.	AAV – development, distribution and promotion of a school kit to raise awareness of school children, parents and teachers, and teach strategies for communicating between families where a person has been diagnosed with dementia, to maintain social inclusion.	Healthy active & early	Promote awareness raising and education about dementia within the community, including to secondary schools and tertiary institutions, for example about symptoms, what to do about them, and availability of information.	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input checked="" type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8	Promote awareness in the primary and secondary education sector of the various creative ways the kit is being used to raise awareness in young people and promote social inclusion of people with dementia, e.g. the use of memory boxes.

Strategies

Strategy Action Area: Given Victoria's achievements to date on dementia care, changing demographics, and opportunities for action, Pathways nominates strategies considered of most importance for each stage on the dementia pathway. The strategies are grouped into the following key areas for action:

1. Promoting positive ageing and social connectedness

2. Life planning

3. Education and information for the public

4. Service development and enhancement

5. Support for people with dementia and their unpaid carers

6. Respite and residential accommodation

7. Transitions from living at home to residential aged care

8. Meeting specific needs including younger onset dementia, rural and remote isolation, homelessness, Down syndrome, Aboriginal and Torres Strait Islander (ATSI), and culturally and linguistically diverse needs.

Include here general actions you have undertaken to support people with dementia and their families and carers.

Actions List the current services, programs or activities your agency conducts	Implementation Brief description of what occurs in the program	Stage/s of dementia pathway to benefit (healthy active living, early, middle or late stage dementia)	Strategy Action Area Provide a brief description of the strategies	Key Action Areas Check the number listed above that the strategy covers, 1 – 8.	Priority for next Action Plan
				<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8	
				<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8	

Thank you for your time and your contribution. Please return the completed survey to Emma Renehan e.renehan@nari.unimelb.edu.au by

28 January 2011.



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