

- **Contenance and Stoma clinics** (clinic and community in-home visits)
- **Assessment clinics** (ie HSA centre based) trial with GP EPC
- **Home Help** (domestic assistance)
- **Home Maintenance** (CACP clients only)
- **HIP** (Home Independence Program)

For the dementia client, the journey through this maze and options from other Health Providers can be an arduous task. How easily the person with dementia and their care can become *fragmented* and they can feel *forgotten*. In dementia, the issues with continuity of care, carer fatigue, knowledge and service access continually come to the fore. This is demonstrated in examples such as for community clients where the carer is unable to cope and when profiled they have been accessing very little, if any services and struggling to support the high dependency dementia client alone. We know this is backed up nationally by the poor access to respite services and the availability of high care services at home in the community.

For example in our community we have no EACH (Extended Aged Care at Home) packages.

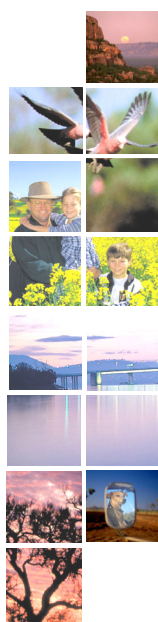
Often we see the gaps in the level of care that clients have been receiving through community and the correlation of that to the care required when they have reached residential level. It is extremely out of context when you profile the community care client who is receiving services through HACC (Home and Community Care) at low care and then is a level 2 at the RCS (Resident Classification Scaling).

In the Albany area, the number of people with dementia among the ageing population is increasing and our research has estimated a total of 296 persons with dementia living in the City of Albany alone.

Dementia not only causes personality changes, but also impairs the individual's ability to remember, think and learn. These effects interfere with the social and occupational functioning of the person. Also, dementia not only affects the physical, social and emotional life of the individual, it impacts on their carer, family and friends.

Silver Chain knows that there is a strong commitment from local providers in Albany to address gaps in dementia care. In April 2002, Silver Chain conducted a consultation forum with key providers in Albany including feedback from the Health Consumers Forum, which meets regularly at the local hospital. The outcome was a two day planning group workshop in August 2002 and the formation of a Dementia Advisory Group who call themselves the OWL group because they are intent on being a wise group. A project officer (part time position) was appointed with the support of the Department of Health for one year. The project aims to capture and identify issues relating to the dementia care of an individual during their journey or pathway of care.

The project is capturing this journey in a story which they are calling *JUNE's Story*. JUNE stands for "Journey of Understanding my Needs and Empowerment". This story looks at the early intervention phase through to diagnosis, care planning, community care, hospitalisation, residential and respite care. *JUNE's Story* is an

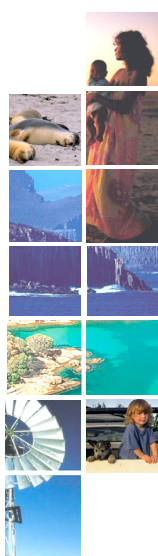


important resource for policy makers, providers and carers who are supporting the care of people with dementia.

The consultation process in Albany identified the following key issues:

- A lack of funding and resources for community-based high care provision in dementia.
- The limitations of Community Aged Care Packages (CACP) to support high dementia care.
- Different funding models create duplication and restrict the continuity of care.
- The lack of a co-ordinated approach due to fragmentation and duplication of dementia care – this is becoming clear as *JUNE's Story* is evolving.
- The complexity of demand underestimated and poorly understood by local providers.
- Carer breakdown due to lack of knowledge and support.
- Inappropriate use of planned or emergency respite, eg hospital beds used for acute respite.
- When people are readmitted to the community after a period of respite there is frequently a loss of information pertaining to their care.
- Concerns regarding dementia misdiagnosis. A poor diagnostic process results in frequent misdiagnosis.
- Lack of early intervention in dementia diagnosis.
- Lack of knowledge by the community and providers of service range and availability – this is well-documented in *JUNE's Story*.
- Reduced use and availability of flexible planned/emergency respite in both community and residential settings.
- Ownership of dementia specific care planning that includes both clients and carer.
- Lack of information and support to people with dementia that go into acute and residential settings. This gap can be supported by a mobile package of care that supports the changing needs of the dementia client across a range of settings, ie care provision by the same team in community, hospital and residential for respite and ongoing care.
- A lack of early detection of the deterioration of person with dementia's lifestyle and ability. For good care outcomes it is necessary to know who they were before deterioration and the individual's profile, present and past should be well documented.

This is in partnership with a range of clients and carers telling the story of **JUNE** through their eyes and how the journey is and the resources that are available to



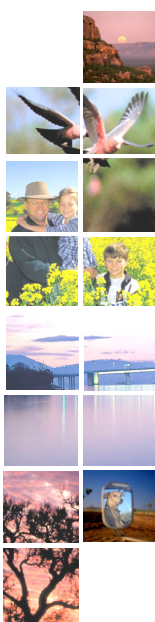
empower and make this journey one of understanding the needs of the person with Dementia.

JUNE's story is to be written that is in a language that is easy to access and understand by the client, carer and provider.

JUNE'S story—the Journey of Understanding the Need's and Empowerment of the person with dementia

Establishing an "Owlistic" Service Landscape

PRE DIAGNOSIS	TRANSITION & DIAGNOSIS	PLAN OF CARING & PLAN OF CARE	COMMUNITY CARE	RESIDENTIAL CARE
The person is preserved.				
Personal history recorded	Assessment	Holistic—sharing of information		
Problem solving/education to all levels		→		
Carers/Home Help as detectives for early intervention		Plan of caring for the carer		
Training for Carers/Home Help/Nursing staff/ Knowledge +ve aging	Informed Decision Making	Decrease the burden →		
Community Awareness/PR Education		Care plan that will work across all providers		
Same language	Documentation →			
Seamless—Client journey tracked			→ Transition for client/carers/home care	
Case management				
Research				



HOW INTEGRATED CARE CAN ASSIST IN REMOVING FRAGMENTATION

An integrated service offers the opportunity to trial and test better models of care that are impossible to attempt under current funding and service streams.

In Albany we are currently looking at LEAP (Lifestyle Enrichment Activity Program) packages of care in the current innovative funding program which will enable the following vision to become a reality an owlistic (wise and complete) service

LEAP and how LEAP can make a difference

LEAP can assist in addressing the gaps and needs identified in the care of people with dementia. Silver Chain is proposing a model called LEAP (Lifestyle Enrichment Activity Program) which is different from the traditional community package of care.

This model has evolved out of the consultation process to identify the dementia service gaps between community and residential settings in Albany.

The main goal of the LEAP model is to delay or prevent residential admission and it has four important components:

- lifestyle enrichment
- home independence
- high carer focus
- nursing home in the home.

Silver Chain is looking at developing and delivering LEAP packages to people, with a dementia related ACAT assessment for high level residential care, who would benefit from an alternative approach to their care needs.

LEAP, which has a strong carer focus, is intended to assist clients requiring dementia specific services to *leap* through obstacles that hinder them remaining in their own home, or place of choice in Albany, with quality and dignity in their life. A key focus of our LEAP package is on regular respite for carers. The specific interventions used in LEAP will be determined by the individual's needs and the goals they identify for themselves when on the program.

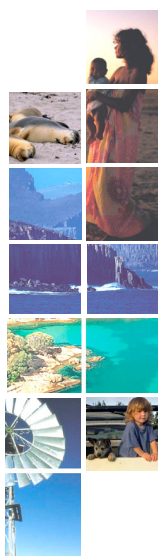
LEAP will be flexible and tailored to meet the needs of both the client and carer and will deliver the following innovative products:

MY PLAN OF CARE

"My Plan of Care" was initially developed by the Silver Chain Albany Integrated Service to support residential care planning at Gwen Hardie Lodge. My Plan of Care is a partnership between the resident/client and care staff. This approach will be used for LEAP in the community and will be modified where necessary to include pathways between care needs and service provision for this project.

Although clients are involved in the traditional model of care planning, care plans tend to be provider focused rather than client focused. With "My Plan of Care", the care plan is based on what clients believe is of importance to them. This is quite different from what providers tend to do, which is develop care plans according to assessed need, which is important, but does not necessary take into account what is important to the person who will receive that care. Consequently this affects the general well-being or quality of life of the individual.

The proposed method of care planning reflects the social, psychological and physical needs of the individual with dementia. My Plan of Care is written and delivered in a way that is easily understood by the client and results in greater ownership of care outcomes because the agenda is not solely driven by the provider.



MY PLAN OF CARING

We recognise that the health and well-being of carers is critical to the people with the dementia that they support. For this reason we will develop “My Plan of Caring” for carers as part of the LEAP package. This will be done in consultation with carers to support their social, physical and psychological needs.

The care plan will focus on the carer and their lifestyle and health management. We will also interface the carer’s care planning with our Home Independence Program (HIP) when deemed appropriate. HIP is an early intervention program which may be appropriate to supporting and maintaining the health and well-being of the unpaid carer.

HOME INDEPENDENCE PROGRAM

In 1999, Silver Chain commenced an evidence-based research project, which resulted in the Home Independence Program (HIP). This is a home-based early intervention program directed at preventing, reversing or slowing down the disablement processes from ageing or a medical condition associated with ageing. The study demonstrated that not only did the majority of clients (71%) report that they found it easier to perform at least one daily living activity but that this was then translated into 39% needing a reduced level of service and 33% requiring no ongoing home care at all. As previously mentioned HIP can be used as an early intervention program for carers. Our experience has shown that carer fatigue and the resultant health issues frequently lead to an inability to cope with managing high dependency individuals at home.

PROCARE

PROCARE is an innovative problem solving tool developed by Silver Chain for dementia care provision. This tool will be used extensively to support LEAP.

The acronym **PROCARE** means:

P – Problem

R – Response

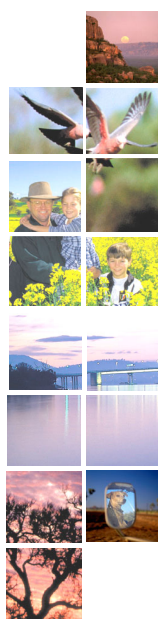
O – Outcome to be achieved

C – Collecting evidence

A – Action

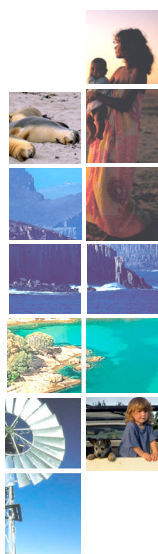
R – Result

E – Evaluation



MOBILE RESPITE

Continuity of care is a critical factor in caring for people with dementia because it provides for familiarity. Wherever possible care should be provided by the same care team preferably in the same location. However keeping people in one location is not always possible. For this reason LEAP respite will be mobile and cross the boundaries of home, community and residential settings. We will introduce care plans and home notes to follow the individual including care provision by their LEAP provider. This means the LEAP provider will continue to provide personal care/activities to the same client even during respite in another settings. We believe this is a critical success factor for continuum of care and reducing complications that may be caused by inconsistency of care which leads to a fragmented service delivery. Our experiences have indicated a lack of ownership of care during respite period due to change of carer and the client often lapses into complications when the care is not co-ordinated and delivered by the same carer.



OUTCOMES TO BE ACHIEVED THROUGH THIS TYPE OF CARE

People with dementia and their carers need services, education about dementia and information that assists them to manage their conditions. We acknowledge that the Commonwealth Government funds several dementia projects providing telephone helplines, early stage support and education, and psychogeriatric interventions. However, our experience has shown that the current Commonwealth programs such as specialist dementia education, training and management support do not reach the majority of clients and their carers. In addition, some of these programs are limited in Albany. There are also gaps in early intervention services for people with dementia, their carers and families.

Earlier and more accurate diagnosis of dementia and other medical issues will offer a range of benefits to people with dementia and their carers. In Albany, we have had cases where misdiagnosis has resulted in major implications for the person with dementia, their carer and service providers. Under the proposed LEAP model, Silver Chain will be the gatekeeper, working closely with health care professionals and ACAT teams in Albany to ensure diagnosis and appropriate assessment.

The LEAP model of care and JUNE's story focus on early and accurate diagnosis, assessment, and early intervention and care management for people with dementia and their carers. The individually tailored LEAP packages may consist of any combination of activities or services such as home nursing, personal care, domestic assistance, nutrition, HIP, lifestyle activities, training or respite based on assessed needs.

The LEAP model and JUNE's story will deliver:

- Mobile transitional support across community, hospital and residential settings will ensure personal care and activities/lifestyle support to be provided by LEAP providers which allows an holistic approach.
- Better linkages between care settings resulting in continuity of care.
- Better understanding of the client, carer and their needs for future planning.



- An integrated plan of care.
- Improved community readmission (discharge planning).
- Better coping and health outcomes for the primary carer.
- Reduced emergency respite admission to residential facilities and hospital.
- Prevention or delay of permanent admission to residential and care awaiting placement in an acute hospital setting.
- Less stressful respite and permanent admissions for people with dementia and their primary carers.
- Easier transition for the client and carer as the disease progresses.
- Better planning of short and long-term goals of care arrangements before crisis.
- Linkages to appropriate resources that enable the client and carer to access support services

Silver Chain Integrated Health and Community Care Service in Albany provides a centre-based day care to the Noongar elders in Albany which included take-away sit down meals and a “New Dreaming Activity Program”. LEAP would be available to assist Noongar Elders to age at home better supported by a program that is more closely aligned with their caring culture, particularly in light of the fact that residential facilities are poorly accessed by Elders in Albany.

SERVICE MIX

All clients admitted to this LEAP pilot program would have a health, lifestyle and functional assessment to determine their health status, their lifestyle choices, level of independence and capability. The assessment outcomes will form the basis for setting goals of care for LEAP.

Our LEAP package, as indicated in Diagram 1 below may include the following services that assist the individual to remain at home:

- Home Care – nursing/personal care/home help/shopping/transport.
- Respite – in home/community house/residential.
- Physical activities – walking/hydrotherapy/isometric exercises.
- Lifestyle activities – fishing/boating/farming.
- Education – personal development, memory recall, problem solving.
- Case planning and co-ordination – network support, OWL group, JUNE’s Story.

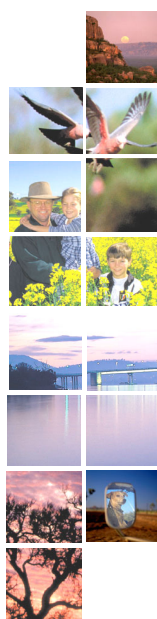


DIAGRAM LEAP PACKAGES

(Lifestyle Enrichment Activity Program) for people with dementia and their carers

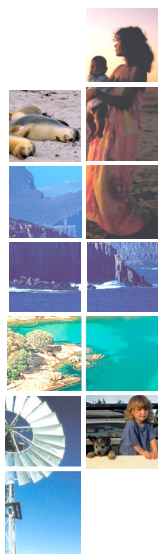
Silver Chain has extensive health and community service experience including the Home Independence Program (HIP), Enhanced Primary Care assessment (EPC) and Health Services Assessment Clinics (HSA). We are confident of our ability to deliver the LEAP model with successful clinical and quality of life outcomes.

Silver Chain will provide a dedicated and comprehensive service and will work closely with other providers creating a team of competent and experienced professionals consisting of:

- Nursing – Registered Nurses (RN) and Enrolled Nurses (EN).
- Medical – General Practitioner (GP), Geriatrician.
- Allied Health – ACAT, Physiotherapist, Occupational Therapist, etc for HIP.
- Home Support staff.
- Diversional therapist.
- Other local providers, eg Alzheimer's Association, ACAT, Lions day care mental health services.



Clients and their carers and family, the physician, the General Practitioner and our multi-disciplinary LEAP team will contribute to the development of a LEAP package based on the goals of care. A copy of the agreed client oriented pathway and care plan will be provided to the client and carer as part of their home notes.



LEAP SERVICES

The LEAP project if successful will have a project co-ordinator and a team of expert staff to deliver the services in Albany. Team composition is outlined above. All newly employed staff will be able to learn and share experiences with our existing staff in our current dementia special care unit at Gwen Hardie Lodge and the HIP program.

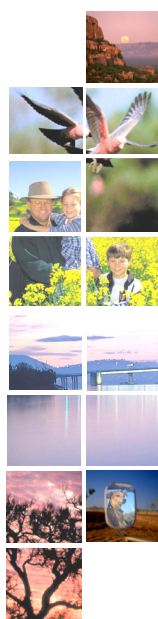
We will standardise assessment tools to ensure consistency in outcome assessment, and will use appropriate tools for outcome evaluation. Some of the proposed tools are:

- Assessment for eligibility – ACAT assessment.
- General health assessment – full medical, eg history of medical conditions, nutrition, elimination, sensory, motor etc.
- GDS – Geriatric Depression Scale.
- Hierarchic Dementia Scale – to ascertain perception, attention and memory, language, purposive movements, spatial constructive ability and primitive reflex motor function.
- Barthels or FIM.
- Body Mass Index (BMI).
- Quality of Life.

OUTCOME OF LEAP AND JUNE'S STORY

- To have a continuum of care that follows the dementia client across from the early intervention phase but which can be accessed at any point on the journey by the client and carer.
- Resource story for people with dementia and their carer's to access.
- To achieve a healthy life plan for the Client and carer that enables quality of life to be maintained for as long as possible in the home environment.
- Delay premature permanent residential admission.
- Increased use of respite services.
- Cross pollination of community services into residential care.
- Shift of residential culture to more of a community culture of care
- Improved ease of transition of care for dementia client
- Better health outcomes for carer

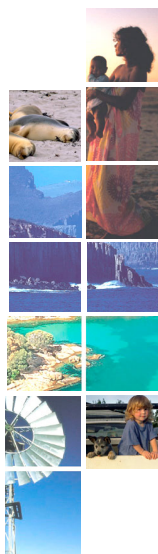
Providers across a range of agencies will continue to work together with portfolios that enable the JUNE's story and hopefully the concept of LEAP to become a reality at the end of the project.



This will enable LEAP package of care to have the focus on maintenance of lifestyle for the person with dementia that keeps them well through out their disease. For the carer lifestyle skills that enable them to manage the high dependency client at home then is referenced into their package of caring.

Fortunately the vision for the diversity in the range of options offered by the Integrated Health Service is now beginning to allow for the Dementia client's individual needs to be co-ordinated at time of referral.

This enables the concept of integrated seamless care between programs and other services not to be just a vision but a reality. Centre-based and community services can be enhanced with co-ordinated care occurring between programs. This also allows services for people with Dementia to have options between residential and community that have not been possible before, removing the fragmentation and improving the quality of life to those clients.



PRESENTER

Lesley Pearson is a Registered Nurse with 15 years' experience with Silver Chain as Manager of a Medical Centre, Nursing Post and two Residential facilities. Since December 2000, Lesley commenced her journey on the development of the Integrated Health Services model in Albany. In addition to her clinical qualifications Lesley has a Health Services Management Certificate and is working towards her Bachelor of Commerce.

