SUBMISSION TO THE SENATE STANDING COMMITTEE ON COMMUNITY AFFAIRS

- INQUIRY INTO PALLIATIVE CARE IN AUSTRALIA -

Submission from Silver Chain, March 2012

Introduction and Background

Silver Chain welcomes the opportunity to make the following submission to the Senate Standing Committee on Community Affairs Inquiry into Palliative Care in Australia.

For more than 100 years, Silver Chain has a rich history of service provision in Western Australia, and is a not for profit organisation which provides care to people living in metropolitan, rural and remote areas. Today, we are one of the largest providers of community, clinical and health care services to the Western Australian and South Australian communities, and a growing entity in Queensland.

Silver Chain provides a diverse range of services including palliative care, and its Hospice Care Service in Western Australia is one of Australia's largest providers of *specialist community palliative care* services.

As a service provider across a number of states, we believe we have a detailed understanding of the diverse range of palliative care models of care as they are interpreted and implemented across the triangle of care - community, inpatient and consultancy - along with the differing funding mechanisms and resources, and the disparate outcomes which arise from service provision across the nation.

We acknowledge that many respondents to this Senate Inquiry into Palliative Care in Australia will provide a detailed understanding of their challenges in supporting their communities at a local level. Many of these organisations are not provided the resources they require to meet community need. Many are not well integrated across geographic areas to leverage best practice outcomes for their community. Many rely heavily upon medical and hospital driven models of care. They are well placed to provide comment on traditional inpatient and institutional care provision, but are not, however, good analysts to how best return the care of the dying to where the majority of people want care to be delivered – in the home.

It is for this reason that Silver Chain's submission will focus on what has been identified as a best practice model of specialist community palliative care provision and its enablers – highlighting what we believe works, why it works, what the outcomes for a community can be, and what the challenges are that still remain.

Silver Chain supports Palliative Care Australia's National Palliative Care Consensus Statement which accords with the Australian Government's National Palliative Care Strategy 2010 in recognising a need for Commonwealth, State and Territories to work cooperatively and collaboratively in achieving common and agreed goals to achieve what Australians want - a system that supports all of us to live well at the end of life.

In particular, we highlight the following priorities:

- All Australians must have reasonable access to resources to support them to die in the location of their choice.
- All Australians have a right to equitable access to quality palliative care when and where needed
- Appropriate funding must be made available by all levels of government to palliative care services on an equitable population needs basis.

The modern palliative care movement is attributed to the tireless efforts of many, and in particular Dame Cicely Saunders, through St Christopher's Hospice in the 1960s. This modern palliative care concept – with an interdisciplinary team at its core, focussed on quality of life, cessation of burdensome treatment, and management of symptoms – still pervades today, and is replicated in hospices, community and consultancy services throughout the world.

It is interesting to consider the evolution of palliative care here in the many states of Australia. Palliative care beds in the hospice and hospital setting were the primary location for this evolution – rightly they were in many cases centres of excellence for developing the specialty.

Whilst much has changed in this time, it is our belief that we need to really consider this:

> *70-75% of people express the desire to be cared for, and die at home – yet most will die in inpatient facilities across the country.*

Why?

'If we want to tackle a problem that affects all of us, let's think big. If we want to transform health care, let's change the way we die.'

-Ellen Goodman, Harvard Business Review

From our experience, it is clear that there is a direct correlation between the resources provided to support a large scale integrated community palliative care service and the positive outcomes derived that are in line with community expectation for end of life care.

We need to reconsider health care in an entirely new paradigm, one that is viewed through the eyes of the individual, one where the individual is rooted in a community setting.

We would welcome the opportunity to provide further information regarding our submission, and in particular greater detail about our model of care and its many outcomes highlighting capacity to meet community need. The model is not perfect,

but it does clearly demonstrate significant difference in outcomes to the other states of Australia – outcomes that more readily meet individually expressed desire to die at home, and is intrinsically integrated within primary health care.

Key Messages

People want to die at home

There are barriers to dying at home

Silver Chain has a viable community palliative care model – with defined links, roles and responsibilities within primary health care, aged care, rural and remote communities

Funding is a key lever but not currently supportive of community models across the country

Significant cost and outcome benefits are possible with large scale coordinated community palliative care

Addressing the Terms of Reference

The provision of palliative care in Australia, including:

1. The factors influencing access to and choice of appropriate palliative care that meets the needs of the population

1.1 Consumer Preference re Place of Death

It is widely reported in the literature that 70-75% of the community when asked where they would prefer to be cared at the end of life, nominate home – yet we know that most will die in inpatient settings across the country. While 70% of people will die in an institution, up to 90% of people with a terminal illness spend most of their final year of life at home. The bulk of end of life care is delivered in the community.

Place of death is related to, and affected by, various demographic factors including age, diagnosis, preferred place of care, and availability of a carer(s). Many people who wish to die at home are unable to do so. Of particular importance in support of preference for place of care, are the kinds of health services available to influence this outcome – where palliative care is available in the community, people are more likely to die at home than in an inpatient setting.

Inpatient settings are typically poorly placed to address the social determinants of health and the complex family and social dynamics that complicate a terminal illness. General Practitioners, with the support of community based organizations, have for many years managed very large numbers of these types of clients in both palliative care and complex co-morbid medical services.

In a study by McNamara and Rosenwax (*Factors affecting place of death in Western Australia, 2007*), the Western Australia Data Linkage System enabled analysis of the Mortality and Hospital Morbidity data sets along with the Silver Chain service data (90% of community-based palliative care provision in Western Australia) across a 2.5 year study period. This study highlighted that there is a seven times higher chance of dying in the usual place of residence if the patient received community-based specialist palliative care when compared to no specialist palliative care from any source. We also know that patients who are enrolled in a palliative care program are less likely to present to emergency or be admitted to a hospital via the emergency department, consequently placing less strain on emergency departments and health resource funding for overnight admissions in acute settings.

We believe there is real opportunity to bring fundamental positive change to the quality of care and outcomes for Australians living with a terminal disease. This also

supports general practitioners to continue to be involved in advanced patient care in the community and allowing hospitals to discharge all patients who do not necessarily need inpatient care. The capability to manage complex patients in the community is not a casual undertaking.

We believe there is an opportunity for a better health system for all patients who can be managed in the community to achieve systemic improvements such as we have achieved alongside hospital based clinicians for palliative care in Western Australia. We need to seize the opportunity to build more capability in the community care system through community based services and the general practice sector to significantly improve both patient care and reduce healthcare costs.

1.2 A Best Practice Model: Silver Chain Hospice Care Service

Silver Chain has effectively managed to integrate specialist community provision of palliative care within this primary health care infrastructure – the primary care infrastructure is a part of the team explicitly through more than 30 General Practitioners who are employed within the model.

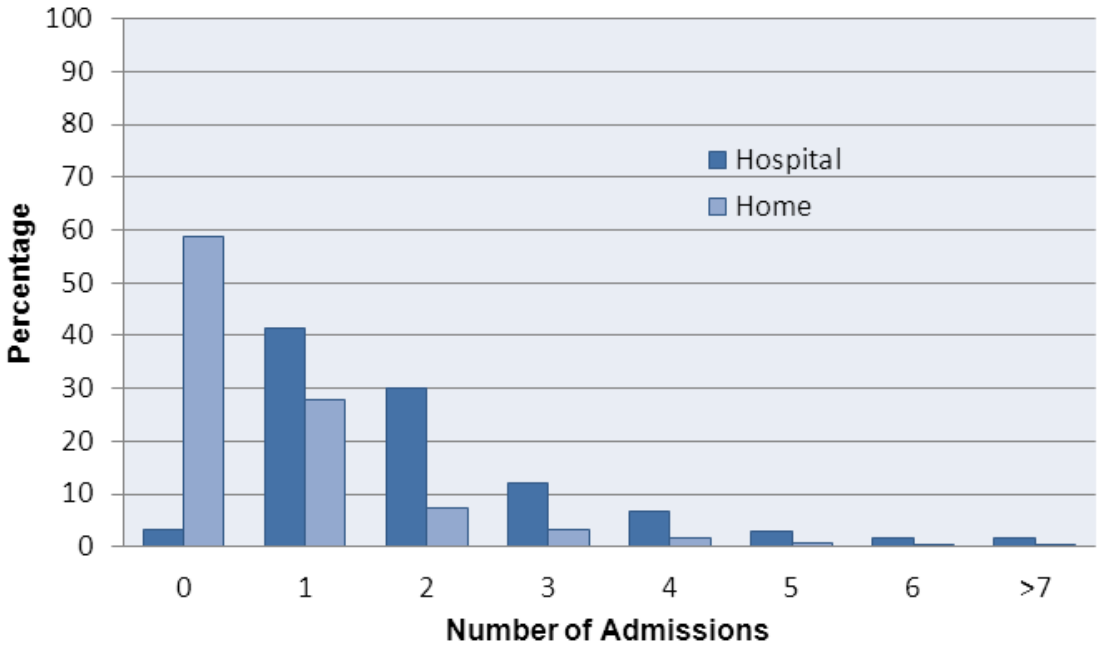
Silver Chain is the predominant specialist community palliative care provider for the Perth metropolitan area – greater than 5,000 square km with a population of 1.6 million people. This service is delivered through an interdisciplinary team consisting of specialist nurses, medical consultants, registrars, general practitioners, allied health professionals, care aides, and volunteers.

The service admits approximately 3,000 people annually, with more than 660 people receiving care on any given day, and an average length of stay of 84 days. Sixty per cent of admitted clients are supported to die at home (compared to national average of 25-30%). Recent analysis of Silver Chain data over the last two years demonstrates that the majority of those who died at home had no hospital admissions during their episode of care with the service. Client satisfaction is at 98%.

The table below shows that on average clients who died in hospital are admitted to hospital twice across their episode of care. Those who die at home have significantly fewer admissions – 0.66 per episode of care.

	Mean	Standard Deviation	Median
Hospital	2.05	1.54	2
Home	0.66	1.12	0
Total	1.28	1.49	1

The graph below shows the percentage of clients having 0 – 7+ admissions to an inpatient facility during their episode of care with Silver Chain. Almost 60% of those who died at home had no admissions and a further 28% had only one. Seventy-one per cent of clients who died in hospital had one or two admissions.



All demographic, service and hospital related variables from the Silver Chain palliative care data set were included in a logistic regression calculation to determine whether any factors are able to predict whether or not a client will die at home. These variables included gender, living arrangements, carer information, referral source, Silver Chain episode length (LOS), total amount of time spent visiting clients during the episode, number of hospitalisations during the episode, total number of days spent in hospital in the last 28 days and the last seven days. Variables that were found not to be significant contributors to the regression equation were removed.

As would be expected, the majority of the variance (60%) was due to the number of days in hospital in the last seven days. For each day spent in hospital during the last week of life, the odds of dying at home decrease by 67%. In addition, for every hospital admission during an episode of care at home, the odds of dying at home decrease by 43%. The only factor that was found to increase the odds of dying at home was the total time spent by Silver Chain visiting at clients during an episode. For each additional minute, the odds of dying at home increased by 0.1% - a very small but significant factor.

There is not one single reason or component of the model that is responsible for the outcomes achieved by the service – it is very much about how these components

come together to form an integrated model focussed on meeting the client's and community's needs. An overview of the model is provided:

Silver Chain provides three specific service offerings:

1. ***Metropolitan Community Palliative Care Service:*** Provision of in-home specialist palliative care to clients within the metropolitan area and to all metropolitan care facilities that do not have a registered nurse managing care 24 hours a day.

2. ***Palliative Nurse Consultancy Service:*** Provision of a palliative nurse consultancy service to metropolitan public/private hospitals and residential facilities where client care is managed by a registered nurse 24 hours each day. The service provides specialist nursing advice, assessment, procedures, specific staff education and telephone follow up to meet the care needs of a specific client. Referrals are accepted from medical practitioners, registered nurses and allied health staff that are providing care within the facility. Involvement is limited to a period of five days following which the client is separated from the service. The client can be re-referred and there is no charge to the facility or the client.

3. ***Palliative Rural Telephone Advisory Service:*** Clinical Nurse Consultants who have specialist skills and knowledge provide telephone advice to rural service providers regarding managing the palliative care needs of a specified client. This service is available via a free call telephone number 24 hours per day, seven days per week.

Silver Chain's service model is guided by the following principles:
- Build capacity within families to care for their own;
- Integration and service coordination;
- Interdisciplinary care planning;
- Evidence-based, client-centred care.

In comparison to many community palliative care services, Silver Chain's model varies in a number of distinct ways including:

1. Whole of Metropolitan Service
- Improved workforce development and planning across a significant number of staff and disciplines;
- Improved resource utilisation and allocation;
- Reductions in administrative overhead and burden;
- Single point of referral;
- Population-based approach to service development and planning;
- Coordinated service provision across specialist, primary care and primary health care where Silver Chain is a major provider in all areas.

2. General Practitioner Engagement

Silver Chain employs 32 up-skilled General Practitioners across Perth who support each of the 8 geographically based care teams. These doctors serve as a bridge between specialist community palliative care and primary care, and work closely with the client's general practitioner to discuss and plan ongoing care. The client's general practitioner has the following clinical governance options:

- *Full Care:* Where the general practitioner is available to the client, family and Silver Chain team 24 hours per day.
- *Shared Care:* Where the general practitioner is available during business hours, while the Silver Chain doctors provide services out of business hours.
- The Silver Chain doctor is the only medical decision-maker.

3. 24/7 Service

The large scale of the service enables staff to be available 'out on the road' to respond 24/7 with shift that cover day, evening and night, and enables:

- Rapid response to crisis events;
- Planned after-hours support for client, carer and family where required;
- Symptom assessment and management 24/7 at home;
- Back up support (on-call) by senior nursing and medical staff in support of rostered staff 24/7;
- Customer Centre Representative availability 24/7;
- Provision of equipment 7 days a week via CarePlus;
- Consultancy support to rural and metropolitan providers.

4. Personal Care and Respite Provision

Care Aides are employed as members of each team for the support / provision of personal care at home and respite care. As members of the team, full care provision can be coordinated internally to support the client's wishes to remain at home. Where respite care is provided (average duration of 4 hours each) in the last weeks of life, 80% of those clients are supported to die at home.

Silver Chain has taken a population based approach in development of its community palliative care model, together with an understanding of differing care pathways that are responsive to the needs of specific populations – with enhanced integration of services within Silver Chain to meet the needs of people with malignant and non-malignant disease. This is coupled with a workforce with skills and capabilities to meet community expectations of safe and quality care.

Silver Chain utilises an integrated IT solution across all areas of operation – ComCare. This purposely designed software assist us to deliver a better level of care while reducing costs and improving productivity. All staff utilise hand-held

technology allowing access to required information in all environments, supporting care decision-making and delivery, and collection of required clinical information that assists targeted care delivery, internal and external benchmarking activities

There is no charge for the service, and includes the provision of equipment and medical devices from Silver Chain's supply chain management service, CarePlus. This is a comprehensive service and demonstrates that where such a focus is provided people can be well supported to die at home.

Silver Chain's model of care increases the provision of palliative care delivered in the home and create a shift from unnecessary and undesirable admission to acute care.

The core competencies of inpatient services are to deliver where resources required exceed those able to be delivered in the community. Silver Chain's core competency on the other hand is to deliver increasingly complex care to patients in the community. The tools, software, logistics, clinical governance systems are uniquely tuned to deliver precisely this service.

Growth of aged care services for older people with chronic and complex conditions will need to be complemented by an expansion of the capacity and competence of primary health care services to provide generalist palliative care for people living in the community and in aged care homes, supported by increased collaboration and networking with expanded specialist palliative care services (Palliative Care Australia). As a provider of specialist and primary health care services, Silver Chain's model of care is principally focussed on collaborative efforts supporting the delivery of palliative care in the community, and enablement of access to services 24/7 through developed internal and external integrated pathways.

1.3 Barriers to Reform

Funding
There is an inequitable and haphazard approach to the funding of community palliative care service provision across the country. The outcomes that our communities want, and indeed expect of us – to be well supported and cared for at home – are at odds with how the resources are currently distributed. The provision of resources for community palliative care that are provided at a whole of population level can vary across the country from $1 to $10 per person/annum – a 1000% differential!

Inpatient facility capacity
Our communities require the provision of appropriately resourced palliative care beds to specifically meet the complex needs of people who are unable to be supported at home. But, how many beds does a community require? Resources to support the palliative care sector will always be limited. We need to be prudent in

our allocation. It has been our experience that where there is not an adequately resourced community service, there is of course a greater requirement for more beds to address the unmet palliative care needs in the community. Without addressing the core issue – community resource distribution – it is a self-perpetuating argument. We need to address the core issue at the community level ensuring resources are targeted to achieve community-driven outcomes.

Governance concerns
The issue of quality and safety in a community sector is a pervading concern to traditional inpatient service clinicians concerning clinical governance around complex care. Indeed, community centric services are more satisfying to clients, provide safer outcomes, and are more connected to other support services in the environment in which they operate.

The clinical governance delivered by the community clinical provider occurs within the context of the broader governance role, which includes financial and corporate functions, setting strategic direction, managing risk, improving performance and ensuring compliance with statutory requirements.

Large scale community models of care
The community infrastructure currently in place to provide palliative care services across Australia is as broad and diverse as the country itself. Whilst many services have developed in response to local community need, most have not been specifically designed in accord with a population based approach at the service level. We believe that large scale models of care are required to enable coverage, quality, engagement, integration, and good governance – all 24/7.

2. Funding arrangements for palliative care provision

2.1 Cost of End of Life Care

It is estimated that 5% of people accessing the Australian healthcare system consume almost 25% of its entire funding in the last 12 months of their life.

The AIHW Report 2011: *Trends in palliative care in Australian hospitals* highlights that during 2008-09 there were 52,347 palliative care separations across Australia resulting in 653,468 patient days (approximately 70% of these are public funded). At a conservative rate of $550 per bed day, this equates to approximately $250M.

Palliative care separations by states and territories highlights further the disparities across the country. New South Wales and Victoria have the highest age-standardised rate of separations (number of separations expressed per 10,000 persons) at 24.9 and 24.7 respectively. Western Australia, by contrast, has an age-standardised rate of 15.6 separations – a significant reduction in health care costs, and when coupled with a death at home rate of 60% for all clients admitted to Silver Chain's community palliative care service, highlights the many positive outcomes that can be achieved.

2.2 Balancing Palliative Care Funding

It has been our experience, here in Western Australia, that there is a fine balance that exists in the palliative care sector between the number of funded palliative care beds and resources that can be provided in support of community palliative care. This is not mutually exclusive. The success of the palliative care system is not found in one part alone, and they are absolutely dependent upon each other. It is our observation that many states across Australia spend significant resources on palliative care beds as the front line to its community's needs.

Western Australia has taken a different approach in its allocation of resources with funded beds at approximately 30 beds/million population in contrast to a number of states with approximately 50 beds/million. This allocation in Western Australia has encouraged and enabled a better resourced specialist community palliative care model to evolve over the past 30 years through Silver Chain.

The different approaches to funding and delivery of palliative care create quite different outcomes for individuals depending on where they live. Here in Western Australia the state government provides significant funding for community palliative care through our service, and the service is often quoted as best practice with 60% of admitted clients dying at home. Western Australia also has a lower rate of people dying in hospital.

Arguably, resources that would otherwise have been distributed towards more inpatient services if directed towards integrated community and primary health care models of care will result in significant improvements and outcomes for the community.

2.3 Need for Large Scale and Coordinated Funding for Community

Investment in sophisticated approaches (not expensive approaches) in community health care services will improve and enable primary health care infrastructure to address the needs of the small proportion of the population who use significant percentage of health care expenditure.

Complex care in the community is not a casual undertaking it must be the **core** business of the provider. Such care provision is patchy and inefficient when delivered as an isolated outreach program from a hospital setting. Best practice community service care needs to be a systemic approach that supports the population; and requires sophisticated technology, logistics, HR systems, quality systems and organisational and clinical governance designed for the community.

The provision of high quality care at the end of life is not possible without adequate and equitable resourcing. The current mix of federal, state and territory funding for palliative care works against the integration of both GPs and specialist palliative care providers into the primary care team, only further exacerbating the problem.

In a recent Harvard Business Review article, Pulitzer Prize winner, Ellen Goodman, noted "*the public debate about health care is framed in the language of cost cutting and rationing – as what health reform will take away from you. But what if we could break out of that frame? This is one area in which letting patients' choices drive decisions could result in lower costs – financial and emotional ones. We may even be able to rebuild trust in the medical system by respecting patient's wishes. Most important, we can ensure more humane deaths*."

There is, of course, a limited resource that can be spent on health care in all our communities. As we have already noted, the funding and delivery mechanisms for community based services vary markedly throughout Australia. A guiding principle underpinning funding is that there should be quality and equitable palliative care and support available to all Australians. However, as highlighted previously, the provision of resources to community palliative care services at a whole of population level can vary across the country from $1 to $10 per person/annum.

2.4 The Likely Impact of Current Funding Reform

The introduction of new funding arrangements through Activity Based Funding (ABF) creates opportunities for community based service organisations to be better configured to respond to health needs within the community, and should promote lower cost community solutions where appropriate. However, there is a competing risk that inpatient facilities will pursue additional funding potential by extending their outreach services (inherently inefficient) that sustain the inpatient centric culture that pervades first world health systems.

The primary role of ABF is to efficiently use the most expensive resource in the health system - hospitals. To this end, an outcome of ABF will be to rebuild the primary health care infrastructure to more adequately assist the GP to support higher needs people within their social context.

3. The efficient use of palliative, health and aged care resources

3.1 A More Efficient and Effective Model

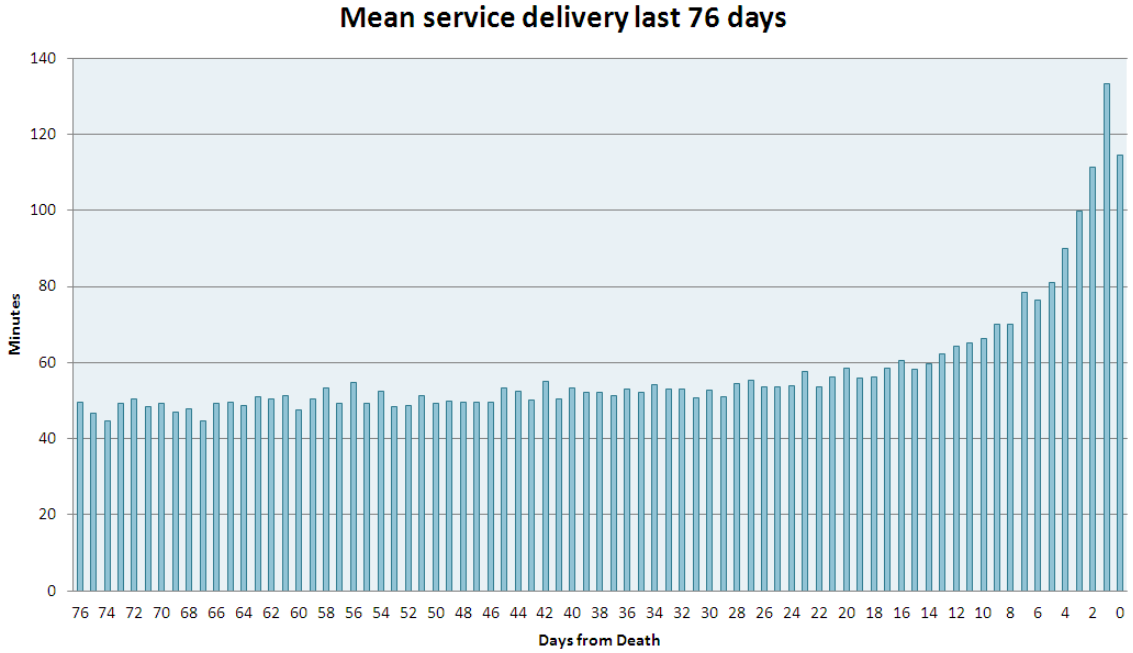
Improved access to community palliative care services has the potential to improve both the effectiveness and the efficiency of healthcare services for people with a terminal illness, and the healthcare system as a whole:

Efficiency – the avoidance of inappropriate and preventable admissions to emergency and inpatient facilities, along with minimising or avoiding investigations, treatments and procedures that offer no improvement in quality of life provides a more cost-effective use of health resources.

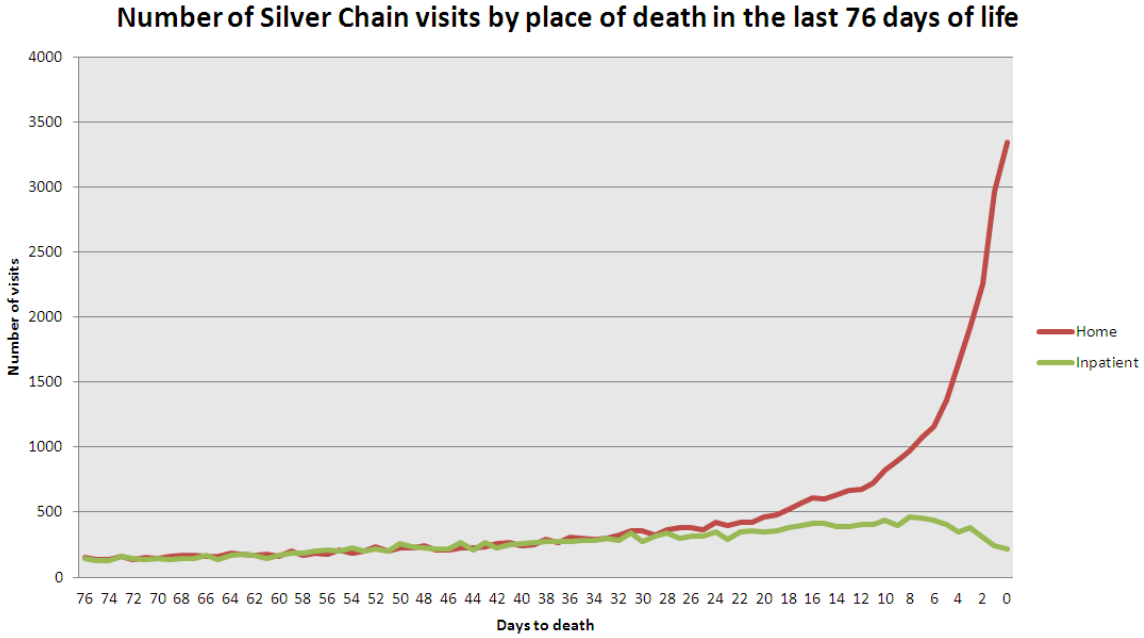
Effectiveness – by providing better outcomes for clients and their families.

As highlighted previously, 60% of all people admitted to Silver Chain's Hospice Care Service die at home. Of this group, a further 60% will have no admissions to an inpatient facility during their whole episode of care, and a further 28% will only have one admission.

The graph below highlights that Silver Chain clients do not receive visits every day of their episode of care – there is a real focus on building capacity within families to care for their own. For those that received services on any particular day from death, the actual duration of their visits remain under one hour up until 14 days from death and then they increase significantly until death.



The graph below highlights the number of visits by place of death in the last 76 days of life. At approximately 16 days prior to death there is a dramatic increase in the number of visits provided by those who will die at home. Our analysis highlights that with every admission to an inpatient facility from the community, there is a 45% less chance that the person will then die at home – our strategies then focus on reassessment of needs and redirection of resources in support of all people following discharge from an inpatient facility to support them to remain at home, where this is their wish.



Helping to meet people's wishes to die at home makes economic sense. A 2009 review in found it is about five times less expensive to care for a person with a life threatening illness at home than it is to care for them in hospital. This is also confirmed by overseas studies that show palliative care can reduce costs by reducing hospital admissions and use of acute beds, length of stay and pharmacy costs, and improve health-system efficiency without compromising client care.

It is clear that the challenges we face are:

- Australia's population is growing and ageing
- The way we live in old age, and the way we die, has changed
- Meeting people's wishes to be cared for and die at home

People aged over 70 are admitted to hospital more often, stay longer in hospital and use more healthcare bed days than younger age groups. It is likely that this group will have more complex needs and require more specialised care from a wider variety of specialists, including palliative care. The major causes of death for Australians have changed. There is a clear trend in the increasing prevalence of chronic diseases, including cancer, as the main causes of death.

It is clear to us that there is a direct correlation between the resources provided to support a large scale integrated community palliative care service and the positive outcomes that are in line with community expectation for end of life care – assisting us to meet these challenges.

We need to reconsider health care in an entirely new paradigm, one that is viewed through the eyes of the individual, one where the individual is rooted in a community setting.

We believe there is real opportunity to bring fundamental positive change to the quality of care and outcomes for Australians living with a terminal disease. This also supports general practitioners to continue to be involved in advanced patient care in the community and allowing hospitals to discharge all patients who do not necessarily need inpatient care.

We believe there is an opportunity for a better health system for all patients who can be managed in the community to achieve systemic improvements such as we have achieved alongside hospital based clinicians for palliative care in Western Australia. We need to seize the opportunity to build more capability in the community care system through community based services and the general practice sector to significantly improve both patient care and reduce healthcare costs.