



## DTA Guest Lecture: Palliative Dementia Service: A New Initiative from Silver Chain, Responding to a Community's Needs - 23 July, 2020

### Audience Q&A's

QUESTIONS	ANSWERS
How do you recognise the vulnerable population and how do you support them?	Considered vulnerable by the Palliative Care Standards is in part due to the long and unpredictable course of the disease. Issues regarding capacity for decision making along with difficulties in communication are compounded by a lack of community understanding of both the disease and role of palliative care. A legal and moral requirement to obtain a proxy, consent and direction for care means that patients are afforded every possible opportunity to contribute as they are able to their care planning and decision-making process, needing to happen early in the disease process.
How do you suggest we help those who care for people with dementia in residential aged care to better prognosticate and recognise end of life. I find that it is poorly recognised and therefore not well prepared for?	Identification of triggers for sustained change and deterioration; discussion within the team and use of the GP and MPaCCS if in WA.
Once the pilot is complete, will this be rolled out nation wide?	There are many steps and hoops to go through for this to happen. We hope so. We will need to complete the final evaluation first.
Is this service available for consumers living in residential aged care facility?	The Silver Chain Palliative Dementia Service is only for people living at home. There is a palliative care service in the Perth metro area specifically for RACF's called MPaCCS (Metropolitan Palliative Care Consultancy Service). They provide a general palliative care consultancy service - they are not specific to dementia but certainly would see client's with dementia.
People with dementia find it difficult to express their pain, especially when they are in palliative care. Could you please provide us with some ideas on how to better assess their pain.	There are many ways of recognising pain in a person with dementia. A thorough medical history is important as they may have conditions which are painful such as osteo arthritis, a specific pain scale such as the Abbey Pain Scale can be used. There is great information on this topic on websites such as Dementia Australia. A new innovative system called PainChek is an app on a phone (to consider privacy etc) uses facial expression and a set of questions.
Do you have many clients who have expressed the desire to remain at home until the end and have asked carers to make sure they are given 'something' ie medications to ease their transition. Do you come to the home to administer medication?	This is part of our assessment and future planning. Yes most of our client's and their carers wish for them to be cared for at home until death. When the client's reach the terminal phase we can refer to the Silver Chain Palliative Care Service who provide 24hr palliative care home service with a multidisciplinary team. They can administer medication if necessary for symptom management. Both symptom management and an understanding of the terminal phase are extremely important discussions we have through this time. If you are referring to Voluntary Assisted Dying - people with Dementia will not have access to this in current legislation in Western Australia.
Where does the funding for the client come from - is it the age care packages?	The service is free.
Do you have any ideas about how you can start the conversations around palliative care with people living with dementia and their carers when they come into an acute health care setting? We have clients with significant care needs on a background of BPSD who come to us due to these symptoms and staff find it hard to raise this as a concept. Any thoughts would be appreciated.	Time is always an issue but opening family to potential deterioration starts the conversation- open questions allow family to think.... how has their loved ones health been over the last few months? And if things were not to go well on this or a future admission have you had any conversations related to this or have they ever made any comments about past situations involving family or friends?

Are you anticipating moving towards a more multi D approach if the program continues?	Yes absolutely! Our wish list includes Social Worker, OT, Geriatrician, Spiritual Care Worker.....many more!
How many participants were involved in the pilot study? And from a treatment perspective, what were the main roles of RN/NP in this initiative?	The pilot is still ongoing. The care providers are 2 Palliative Care Nurse Practitioners only
Is there any access to Silver Chain in Queensland?	The Palliative Dementia Service is only in Western Australia
I do not work in a clinical situation and am interested in whether the Focus on the Person form is in general use?	It is freely available on the internet. The intent is for the family/carer to complete it. We would encourage people to use it, the team that developed it just like to have feedback from those who have used it and in what context.
Even level 4 packages don't have sufficient funds to pay for many hours of weekly care - what happens when the funds are spent /are there alternative funding options?	There are additional pockets of funding for care like a Dementia supplement, emergency respite but we would have to defer to a SW to get some extra advice. Many of our clients do not have a level 4 package, it is very difficult for some families.
How/who has the pilot to date been funded by? How would such an important initiative be funded in the future?	The pilot has been funded by community donation through the Silver Chain Winter Link appeal.
Both case studies related to elderly clients . Dementia affects younger people too. Do you have a model of care for younger people with dementia?	One of the case studies was 62 with Young Onset Dementia. We recognise the needs of a younger age group are different. We don't have a specific model of care - we recognise the complexities such as carer may still be working, younger children, change in social situation, loss of roles, new roles, behaviours involving a client with greater strength.
When do you discharge patients from your service? What criteria do you use?	Discharge criteria includes when the person is admitted to a RACF, when referred to the Silver Chain Hospice Service. If they are stable we can spread the visits out (eg. 2 monthly)- they have a 24 hour number they can contact us on if they require assistance.
What is the memory clinic?	A Memory Clinic is an outpatient medical clinic specialising in memory disorders, that involves review by a Geriatrician/ Registrar.
I would like to know when palliative care starts? Who decides?	Ideally Palliative Care starts on diagnosis as Dementia is a life limiting illness. This would enable Advance Care Planning, not only about end of life but improve understanding of the future to facilitate end of life plans eg. A holiday, writing letters to grand children, children, potential grand children, building bridges with family or friends. Considering what is important in their lives. Unfortunately people often see Palliative Care as End of Life Care therefore they do not want to engage too early. This should occur for all with a life limiting condition.
How do you manage with families wishing to provide care at home, however display an inability to provide the care necessary? i.e. evidence of pressure injuries / failed trial of care on ward / dismissing of education and support offered. Especially when the patient does not have capacity but clearly state they wish to remain in the care of family. Ultimately care is required to be safe with the addition of caring community services and raising awareness with the GP.	Our experience has been varied. The complexities people manage at home has to be seen to be believed. Many of our clients have settled after a few weeks at home - routine and familiarity makes a difference. Carers usually come to the point where they realise the situation cannot continue. Our role is to support them making this decision as often there is much guilt. We can also assist with the transition re Focus on the Person form, speaking to the facility.
Would Silver Chain be working with old age mental health services as well - as an old age Psychiatrist, I think it would be greatly appreciated, at least in WA, we manage a lot of end stage dementia patients.	Yes we would. The client must be living at home. Some of our clients have OAMHS involved in their care. Collaborating with specialist services is so important - we don't have all the answers, we are part of the community puzzle.

How do you address palliative care plans when client and families are refusing to discuss due to cultural and religious beliefs.	This is a scenario we encounter often in general Palliative Care situations - Dementia adds another layer. It is important to build a trusting relationship, acknowledge, respect and understand their culture and beliefs, and what the barriers to the discussion are. Give information in a sensitive manner perhaps over time in manageable amounts. Understand the need for a family meeting with nursing, medical and Allied health involvement if needed. Raising awareness to the clients changing conditionWe also need to consider telling someone with memory loss they are dying or have a terminal illness each day may not be helpful.
Is there a way people needing higher needs due to dementia and palliative care can not have to be on the waitlist but receive immediate care? Sadly many palliative and dementia clients get adequate packaging a little too late. As a care aid, seeing stress on family and family misunderstanding/ignorance shows just how our presence and assistance is quite imperative to everyones sanity/wellbeing.	Your presence and support to families is invaluable. Often just having someone who listens, who acknowledge the difficulty of the caring role and who provide reassurance that they are doing a great job goes a long way. We are not experts in care package management - I don't think it can be sped up unfortunately. No matter what level of home package they have they will be entitled to a Dementia and cognition supplement.
Helpful resources	CareSearch, ELDAC, palliAGED, Palliative Care WA, Palliative Care Australia