The relationship between Palliative Care and VAD

Our family experience.

The What

Is Palliative Care

Palliative care helps people with any life-limiting or terminal condition to live their life as fully and as comfortably as possible. It is not just for people with cancer.

Palliative care identifies and treats symptoms which may be physical, emotional, spiritual or social. It also provides practical and emotional support to family and carers.

(Palative Care Australia)

The Who

(Not the band)

Providers of Palliative Care

doctors

nurses

social workers

psychologists

physiotherapists

pharmacists

occupational therapists

speech therapists

nutritionists

FAMILY & FRIENDS

Pets

Carers and neighbours

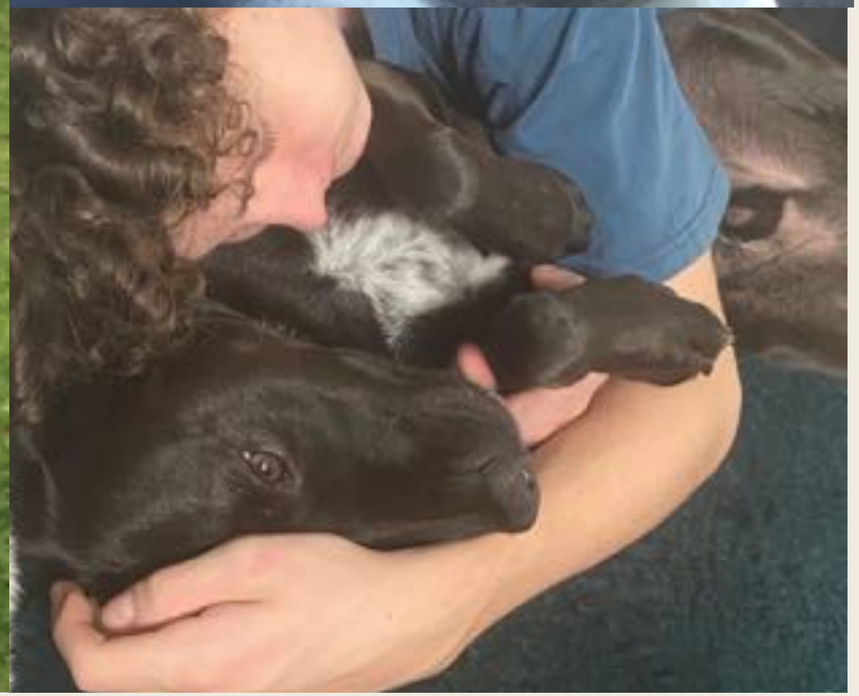
Colleagues

Family

Friends

The person involved

Milli & Buddy wheelchair sled dogs



where?

Guide to Specialist Palliative Care Services

Admission criteria by service type

Patient must meet the Generic Referral Criteria for Specialist Palliative Care prior to commencing referral for admission to any of the following services

Outpatient Clinic	Community	Consultation – Facilities*	Consultation – Hospital	Specialist Palliative Care Unit
Specialist advice required	Specialist advice and/or care at home required	Specialist advice required	Specialist advice required	Specialist care required
Patient is within catchment (for public services only)	Patient is within catchment	Patient is within catchment		Patient cannot be optimally managed in current environment
Able to attend clinic	Patient and carer have consented to care at home			
Patient has consented to referral	Patient and carer aware of referral and have understanding of palliative care	Patient and carer aware of referral and have understanding of palliative care		Patient and carer aware of referral and understanding of palliative care
Referral by doctor, nurse practitioner or palliative care service	Referral by doctor, nurse practitioner or palliative care service	Referral by doctor, nurse practitioner or nurse in consultation with GP	Referral according to individual hospital criteria	Referral by doctor, nurse practitioner or palliative care service

Services provided by admission type

All services have links with and can refer to other Specialist Palliative Care Services

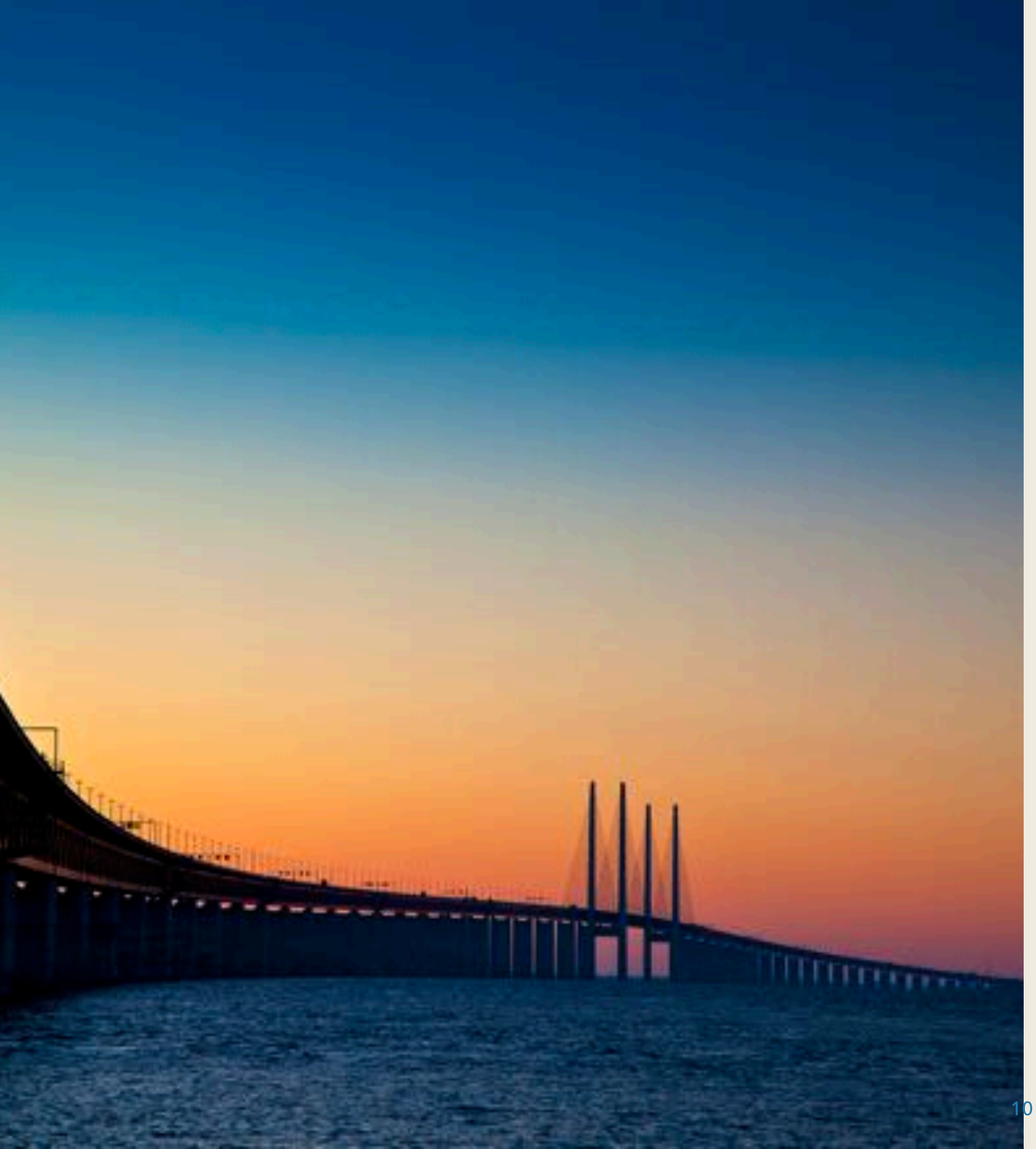
Comprehensive assessment	Comprehensive assessment	Comprehensive assessment	Comprehensive assessment	Comprehensive assessment
Care planning and co-ordination	Care planning and co-ordination	Care planning and co-ordination	Care planning and co-ordination	Care planning and co-ordination
Symptom management	Symptom management	Symptom management	Symptom management	Symptom management
Access to multidisciplinary team	Access to multidisciplinary team	Access to multidisciplinary team	Access to multidisciplinary team	Access to multidisciplinary team
Psychosocial support for patient and family	Psychosocial support for patient and family	Psychosocial support for patient and family	Psychosocial support for patient and family	Psychosocial support for patient and family
Shared care with other care providers	Shared care with other care providers	Shared care with other care providers	Shared care with other care providers	Shared care with other care providers
	Access to equipment and resources			Care in specialised facility
	Practical support	Advisory/educational support to doctors, nursing and allied health care workers	Advisory/educational support to doctors, nursing and allied health care workers	
	Terminal care	Terminal care	Terminal care	Terminal care
	Bereavement support	Bereavement support	Bereavement support	Bereavement support

CP-012811 APR'16

The Picture in Perth/WA

- 70% of people who are dying wish to die at home. The Australian average of people who do is 14%
- Perth has the lowest number of inpatient care beds per head of population (but has the most well funded community palliative care services and the highest number of private palliative care beds)
- 70% of Hospice at Home patients die at home in WA. (80% in a place they want) (silverchain 2015)
- Silver chain has 650 Palliative Care patients per day.

- 28 Public Specialist Palliative Care beds. (Kalamunda and Albany)
- 88 Private Specialist Care beds. Accessible by public funding. (10 NOR). 10 further beds funded
- Regional palliative care provided by regional palliative care service. 61 extra FTE staff funded
- There are 80k Palliative care/end of life hospital admissions per year. 50% aged of 75 years



LIZZ CLARKE FOR DYING WITH DIGNITY OCT 2020

Relationships - Palliative Care and VAD

In June this year Colin died at Murdoch Hospice. We miss him.





VAD is not part of palliative care?

Why Not

- WHO Definition of Palliative Care - Intends to neither hasten or postpone death.
- External -Fear/Identity People will associate Palliative care with dying and may be less likely to approach services for help.
- Internal -Moral Injury - Psychological distress which results from actions or the lack of, which violate moral or ethical code.

- But there is good news

Oceanic Palliative Care Conference 2019

Plenary session Ethics in Palliative Care

Broad Agreement that palliative Care and VAD are not mutually exclusive

Its about the individual not the core providers or those making guidelines.

The solution then is accepting there is no one solution.

The autonomy of the individual, to live and die with dignity, be as free as possible from distress and discomfort, must be our aim.

Challenges to VAD in Palliative Care

- Silverchain is Neutral but will not seek to be a VAD service provider.
- Admitting rights to private hospice. Are they expected to abide by SJOG bylaws?
- Majority of hospice beds are in religious affiliated private.
- SJOG - 40. Ramsey (Ascension) 25. Bethesda 23 public beds 28.
- Medical Practitioner By-laws ie: SJOG. -

3.1 Medical Practitioners who provide Health Care Services at Hospitals/Services of SJGHC are required to respect and comply with the moral teachings of the Catholic Church

- Religious Discrimination Bill

* All hospice providers contacted. No current statements issued on how VAD requests will be facilitated/managed. Or what restrictions will be imposed on health care professionals.

Anyone need a break?

Palliative Care-Our Story

A survivors guide

Our experience

Palliative Care centres around the person with the life limiting illness. It is not a precursor to death or necessarily the end of active treatment. Care is coordinated holistically, based on what best suits the person. Discussions and interventions are frank and directed to the desire and needs of the patient and their family. Perhaps for the first time efforts are made by the health professionals involved to coordinate services with the patient at the centre, rather than at the needs of the service.

Palliative Care@home.
The carers experience - its exhausting

Advantages

Comfort
Quality time is easier
No visiting restrictions
Private
Family time
No travel time
Peaceful
Autonomy
Kitchen availability
More Control

Challenges

Becoming a scheduling genius
Responsibility for everything
Amount of people in your house
Visitor Management skills
Organisation of help
Laundry
No time off
Equipment
Disposal of medical waste
Availability of help

I’m so angry at the inevitability of what’s happening. Last week, this lovely man whilst terminally ill and accepting of the restrictions imposed on his body by cancer, was able to chat to his children, watch movies with them and eat a simple meal.

The ravages of this cancer are all too apparent. We moved into a hospice two days ago, I can no longer maneuver him alone. We both need the help.

We all know that death is near, he has no respiratory reserve. He tells us “I want to die”. “This isn’t what we wanted”.

But still we have to wait.

It’s clear that he will get an infection. Most likely in his chest, because he aspirates gastric fuid several times a day. Or maybe at one of the numerous drain sites littering his abdomen where fluid build up has been drained. Sometimes four litres at a time.

It is clear he will get an infection. But still we wait.

We wait for the infection to take hold, to make him sicker.

We wait for delirium and incontinence, it's par for the course.

And yet still we wait.

We wait for his organs to stop working, for the skin injuries to become more painful.

We hear the rattle of sputum. He no longer has the reserve to move it from his lung.

We know it's a good reserve for bacteria, and yet still we wait.

We wait for this young man, their father, my husband, both a big and little brother, and son to his anxious parents watching close by. We wait.

We wait for all traces of independence to be lost. Dignity and privacy are preserved outside the room.

The kindness of everyone in this place is unquestionable and reassuring.

But here, he is laid naked to unfamiliar hands. Personal care is no longer that, but remains necessary. But still we wait.

I’m angry. I ask why we have to wait? His wishes were well known and documented. Why it is that we can sedate and wait, but we cant add just a little more,

Stop this now? But still we wait.

We watch his personhood leave the room, but we wait for the final indignities. One more change and refresh, one more time being rolled with unfamiliar hands on skin.

One more reassuring touch to his arm, empty in its promise. Yet, still we wait.

Why? For what purpose? To prolong this inevitable end? To extend the indignities a little longer? And yet still we wait.

Tips on getting what you need

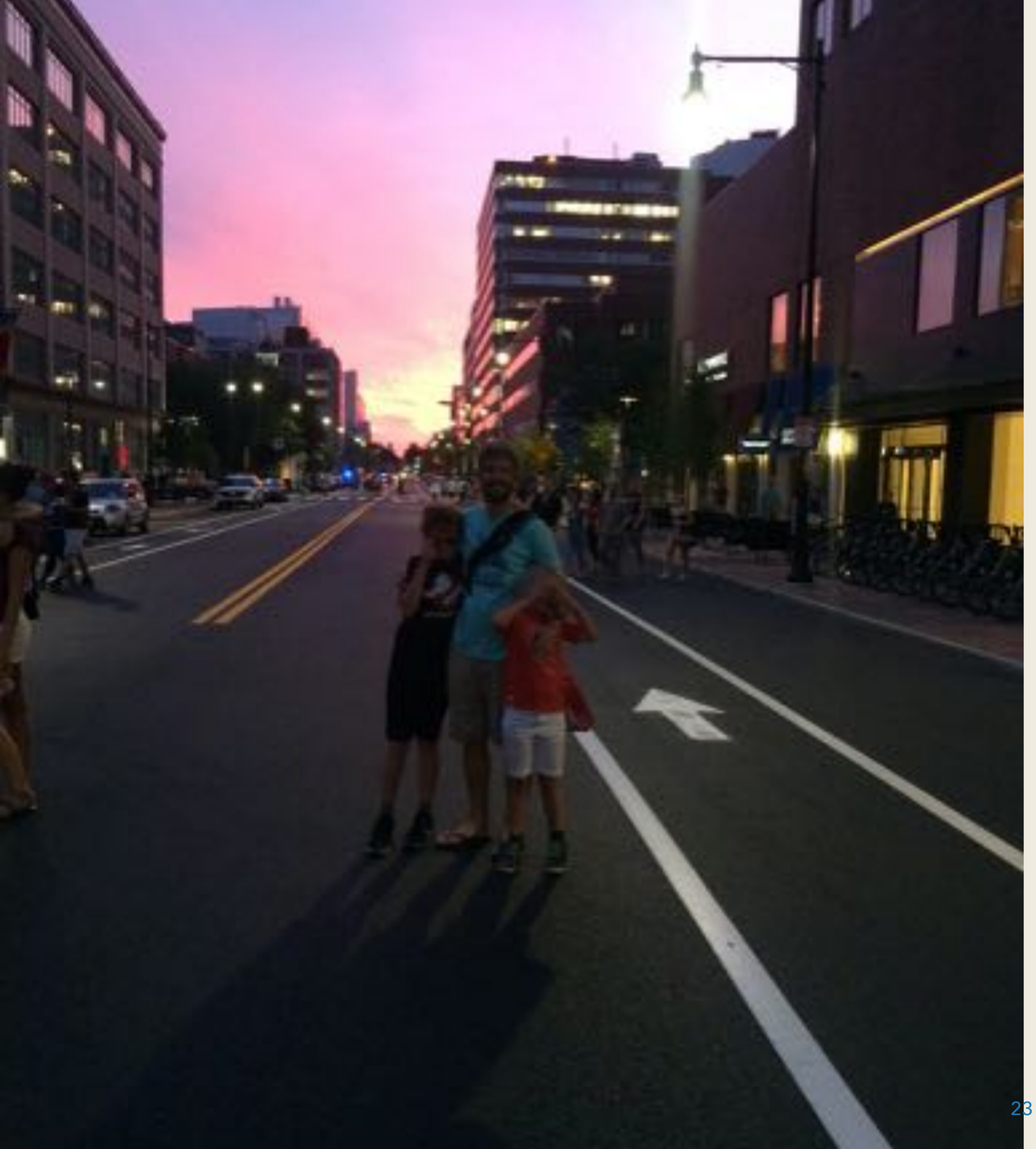
- Polite persistance
- Dont be fobbed off with answers your not happy with. Ask for another opinion.
- Be honest and upfront. Be clear about your intentions with family and health care providers.
- Drs are not god, especially not the ones that think they are.
- Be reasonable about what can happen and when.

- Invite and revisit conversations especially hard ones
- Ask about alternatives
- Ask for timelines
- Be clear about your boundaries
- Consider a patient advocate.
- Dont wait until your desperate to get help.

Top Tips

There is no normal - Only today.

- www.gathermycrew.org.au
- Program phone/message lists
- Food delivery www.youplateit.com.au
- Communications manager
- Social activities director
- Funeral Planing can be fun. (Honest)
- Hospital Visits - Transport
- Equipment. The hospital OT is your best friend.
- Be honest, be rude, be frank.
- Write questions down as you think of them
- Dont wait until you need it, to organise.



My wish list

Looks suspiciously like Palliative Care WA submission to the Joint Elect Committee in July 2020.

- Navigators for all complex patients
- Better support for carers
- Early, proactive intervention by wider allied health
- Goals of patient care to be completed and revisited regularly.
- Workforces training particularly in dying/death language.
- For everyone that chooses to access VAD to be able to do so without judgment or obstacle.

One last thing

Make sure the bloody tax return is done!