

Friday 10 July 2020

To members of the Joint Select Committee on Palliative Care in Western Australia

“From the very first second we walked into [the hospice] we felt that as a family we would be well looked after. I knew my dad was being cared for by the very best and treated with so much dignity, nothing was ever a bother. Myself, my mum and my sister spent all of our time in the Hospice and my mum even slept over in his final week. We took my three children there daily and we never felt a burden.”

Comments about a UK hospice

“In the days before Liam died, I was feeding the baby in Liam’s room, back in the palliative care unit. Liam was sedated. His mother had arrived from her home in Scotland and was sitting with Liam.

A doctor came into the room and started to discuss the medications they were considering for Liam and the effects they would have on him, including the fact that they would hasten his death. His mother became angry and upset and had to leave Liam’s side to leave the room. I could do nothing or go nowhere. I couldn’t get upset. I had a baby to look after and had to think of everyone I still had to care for.”

Kate McLaughlin, Founder, LJM Memorial Hospice
talking about her experience of end of life care in the
northern suburbs of Perth in 2018

[About LJM Memorial Hospice](#)

LJM Memorial Hospice was established in 2018 by Kate McLaughlin. The charity was established to give back to the WA community after they had provided so much support to Kate and her husband Liam when he developed a brain tumour. Based on Liam and Kate’s experience at that time, LJM Memorial Hospice’s vision is:

“Empathetic, humane and family-orientated not-for-profit hospice care for people of all demographics.”

We know the impact that poor quality end of life care can have on the health of the patient as well as their family. Through our submission, we hope to contribute to a more positive experience for the WA community.

Summary

This a summary of our response to the terms of reference of this inquiry:

(a) the progress in relation to palliative care, in particular implementation of recommendations of the Joint Select Committee into End of Life Choices:

Recommendation 7: Hospice care in the northern suburbs

- We welcome the recommendation in the My Life, My Choice that the Minister for Health should facilitate the establishment of an inpatient specialist palliative care hospice providing publicly funded beds in the northern suburbs of Perth. We welcome the WA Government's response to this recommendation that it was supported, noting dependencies. We believe this will be an important service offering more choice and options to consumers in that area.
- We request that, if this hasn't happened already, that consumers and community members have the opportunity to be actively involved as partners in scoping, designing, planning, delivering and evaluating this hospice service, as per Recommendation 4 in the Sustainable Health Review (SHR)¹
- We are not aware of any progress in regards to this recommendation. We note a tender is planned by North Metropolitan Health Service in August 2020 for specialist inpatient palliative care beds, but we have been unable to determine if this tender relates to this recommendation. See below for further comments on this.

"I contacted our cancer support nurse... who couldn't assist... and who suggested that I speak to our GP.

The GP suggested Silver Chain and tried her best to link us to them. A friend we made at the cancer centre – a fellow patient – told us the Neurodegenerative Conditions Coordinated Care Program (NCCCP). I ended up making contact with NCCCP myself and thankfully they did the work required and made the link for us needed to access care with Silver Chain..."

Kate McLaughlin

Recommendation 8: adequate funding for community palliative care providers

- We strongly support this recommendation but are unaware of any progress in implementing it.
- Additionally, we encourage the WA Government to do more to address the experience many people have of fragmented care that is difficult to access. At a critical time in a family's life – when a member is approaching the end of their life – it should not be necessary for family members who are caring for their loved ones to have to try to navigate the labyrinth of services. While care navigation and coordination is a challenge in all areas of healthcare, it is particularly important at this time.

¹ [Sustainable Health Review](#), WA Government, accessed 09/07/20

Building on community capacity and strengths

- We note the absence of any reference in the My Life, My Choice report recommendations to building capacity amongst the general community to support people who are living with a life-limiting condition, caring for someone who is, or dealing with grief and loss after a bereavement.
- We also note the early work underway to establish a network of compassionate communities in the South West of the state.
- We encourage the Government to proactively support the establishment of a network of compassionate communities in the northern suburbs by providing resources to enable this approach to be further explored and rolled out in this area to wrap around the inpatient specialist palliative care hospice that has been recommended.
- We propose that the Government provide financial and project coordination support to establish a network of Compassionate Communities in the northern suburbs of Perth. This could include:
 - A paid coordinator position who is able to establish relationships with local community members, local community groups, local governments, and with local health service providers.
 - Funding to evaluate this initiative including carrying out baseline research to establish levels of health and wellbeing prior to the establishment of compassionate communities.
 - Funding to recruit and support a network of volunteers throughout the northern corridor to explore the potential for compassionate communities in local communities.

(b) the delivery of the services associated with palliative care funding announcements in 2019–2020

- We welcome the announcements of additional funding for palliative care in 2019-2020.
- As members of the community, we have not found information relating to how those funds will result in practical changes to services or people's experiences on the ground.
- We look forward to learning how interested consumers and community members are being, or can be, actively involved in scoping, designing, planning, delivering and evaluating the services that will result from these additional funds in line with the recommendation in the SHR².

² [Sustainable Health Review](#), WA Government, accessed 09/07/20

(c) the delivery of palliative care into regional and remote areas

- If they have not done so already, we encourage the WA Government to look at the Queensland Health model which provides “pop-up” respite paediatric palliative care services to regional people. We believe this model could have some lessons for adult service provision in some regional areas.

<https://www.childrens.health.qld.gov.au/latest-news-enhancing-paediatric-care-across-australia/>

(d) the progress on ensuring greater equity of access to palliative care services between metropolitan and regional areas

- We support the drive to ensure greater equity of access to palliative care services between metropolitan and regional areas. We believe there are still high levels of unmet demand in the metropolitan area and believe that services in both regional and metro areas need to be increased and for them to be much easier to access more quickly.

“The MSWA carers stayed beyond their care hours, and a Silver Chain nurse helped me initially settle Liam before she had to leave. She gave me all the contacts I would need if I should need assistance.

As things escalated, I was alone and had to wait for a friend to be able to come and help me. Out of hours care arrived later and relayed information from a palliative care doctor. But nothing was working to settle Liam safely at home.

I literally had to ask for the doctor to get Liam taken to a hospital. I was so concerned over what was happening to him – we had never experienced this before.

I knew then that Liam wouldn’t return home. I was left on my own with our babies and my husband was on his own not understanding what was happening, where he was going and like me had no comfort or consistent adequate care.”

Kate McLaughlin

Additional information relating to our response to the Inquiry

Hospice care or palliative care

We believe that hospice care, as referred to in Recommendation 7, is very different to care at home as it is currently experienced by some people in WA.

We note that while there is a lack of formal definition of “hospice” in the Australian context, we believe that it would be community’s expectation that this would mean the care is provided in a setting that is not an acute hospital setting. We understand in Western Australia that hospice care is considered to refer broadly to palliative care, whether it is provided in a standalone facility or not.

While many people in Western Australia are proud of the community-based hospice services provided by Silver Chain we believe there is significant unmet need in the community and a lack of choice for many. We believe there is an opportunity for the community to be involved in conversations about alternatives to the current binary options for end of life care of either home or hospital. We note the national consensus statement on carer and consumer engagement in palliative and end of life care³.

Our expectation of hospice care is that it enables people to live well, die well and grieve well. We believe hospice care has a focus on making the most of life, right up to the point of death. Where the unit of care extends beyond the individual patient to their family, and supports people as they care for and grieve the lost of their loved ones, as well as for the patient who is approaching the end of their life.

We believe hospice care is very different to care in a hospital. We understand that a tender is about to be issued for specialist inpatient palliative care beds by North Metropolitan Health Service. We have been unable to find out anything about the specifications of this tender and so are unclear whether this tender relates to Recommendation 7 in the Report.

We hope that the specifications have been developed with input from consumers and community members as partners, in line with Recommendation 4 of the SHR⁴. If this is not the case, we hope there will be opportunity for input from consumers and community members into the procurement and implementation process from this point forward.

We know that there is currently a survey open seeking community input on people’s experience of palliative care services. We believe that many community members in Australia don’t have experience of the benefits of good quality hospice-based care because there are so few facilities in Australia, and will therefore be unlikely to mention it in this survey.

³ https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/05/PalliativeCare-Consensus-statement.pdf accessed 09/07/20

⁴ [Sustainable Health Review](#), WA Government, accessed 09/07/20

What is possible?

We are aware that there are already two facilities in WA that offer a service that is close to the model we would advocate: Albany Community Hospice and Murdoch Community Hospice. We believe there is an opportunity to build on the strengths of existing models in WA and extend access to this kind of service to more people.

We are aware of other facilities that are listed as offering inpatient palliative care north of the river, but based on personal experience of one of those services we are clear they do not provide the holistic person-centred care we are advocating.

A number of our Board members have personal experience of the positive difference that access to friendly high quality hospice care can make to a person with a life-limiting illness and their loved ones. The model we have experienced is that of [Strathcarron Hospice](#) in central Scotland.

This 24-bed facility offers specialist inpatient palliative care, as well as community-based palliative care and end of life services. Strathcarron Hospice is embedded within its local community and benefits from the active involvement of many in the community both as volunteers and as donors.

While we recognise that establishing a standalone hospice facility is a significant undertaking for the WA community, we believe that hospice care should include these elements as a minimum – whether or not they are provided in a standalone facility:

- 24/7 access to specialist palliative care medical, nursing and allied health care
- Be experienced in a home-like environment – this includes:
 - A non-clinical feel
 - Soft furnishings
 - Space for people to gather informally
 - Access to gardens and outdoor space
 - Access to kitchens and lounge areas
 - Ability to have pets stay
 - No limit on visiting (other than any limits requested by the patient)
 - Free parking
 - Where families can “hang out” and be families together
- Holistic care
 - Clinical – medical, nursing and allied health
 - Spiritual
 - Psychological
 - Complementary therapies
 - Music and art therapy
- That care be integrated with
 - Other elements of life for the patient such as
 - Family support and activities – including fun, love and laughter – as well as tears and sadness
 - Community support and activities

- Other palliative care or clinical care that may be being received
- That there be strong links with the community
 - In the governance
 - Board level
 - Advisory groups and mechanisms including evaluation
 - In the running – through volunteers
 - In the support – linking with new and existing community supports and groups – for example, a network of compassionate communities in the area (see below)

“I couldn’t leave him in the care of the palliative care unit willingly. It was supposed to be respite. Instead, I feel it has left trauma issues for me that are still present over two years later.”

Kate McLaughlin

Building on community capacity and strengths

“People want a life, not a service”

Cormac Russell, Power to the People Conference
Melbourne 2015

Asset-based community development (ABCD) ⁵ encourages us to consider:

- What do communities do best?
- What do services do best?
- How can they work together?

We believe an ABCD approach is a useful framework when considering how we organise palliative and end of life care.

Allan Kellehear, Professor of End of Life Care at the University of Bradford, commented at the launch of the South West Compassionate Communities Network⁶ that people living with, or caring for someone with, a life-limiting condition typically only spend 5% of their time in front of a health professional. The rest of their time is spent in community – with family, friends, neighbours, work colleagues, sports club members, fellow students and so on.

We believe there are opportunities to build on community strengths and extend the Compassionate Communities approach to the northern suburbs. We believe that this would add value to the community by making it easier for people to navigate the maze of existing services – many people find out about health and social care services by speaking with people who have been in a similar situation themselves – as well as helping to create an environment that is more open to discussing death, grief and loss.

We believe the community would benefit from any palliative care or end of life service – such as the hospice facility that is recommended in the report – being embedded within a broader community which “as individuals and collectively, values and embraces death and dying as an integral part of life”⁷.

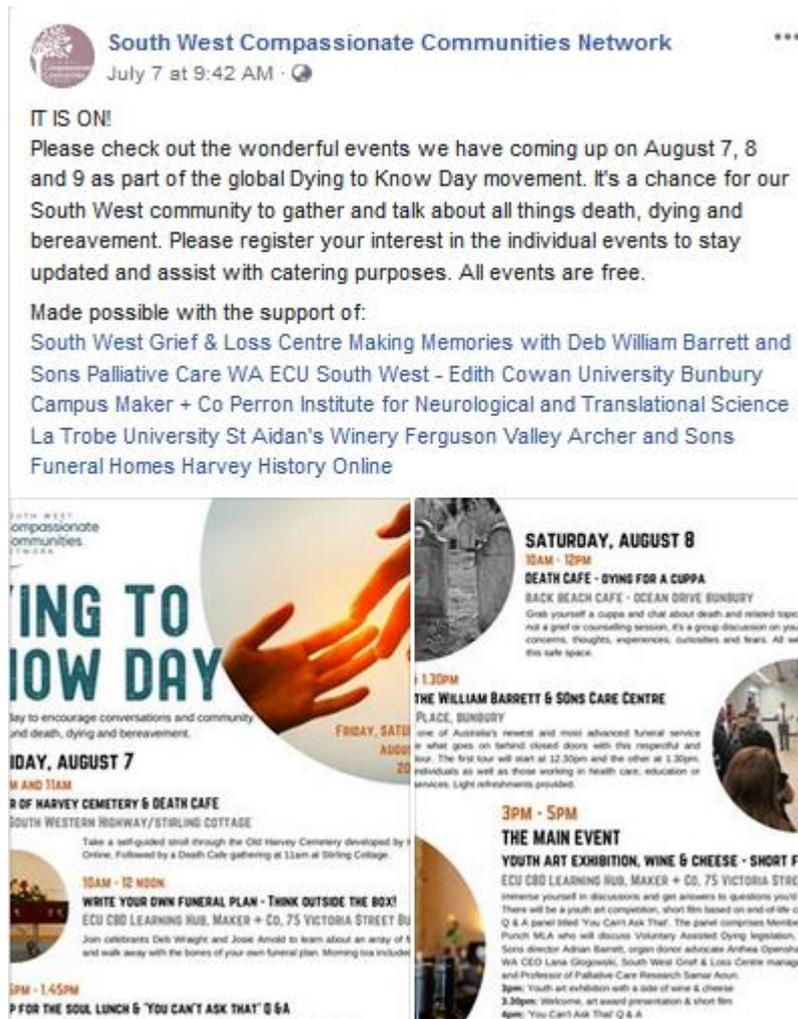
For this reason, we encourage the Government to proactively support the establishment of a network of compassionate communities in the northern suburbs. This will require paid staff time to establish relationships, research existing arrangements and support and encourage volunteers. It would also require resources to support community conversations

⁵ <https://www.nurtureddevelopment.org/about-abcd/> accessed 09/07/20

⁶ <https://www.comcomhub.com/about> accessed 09/07/20

⁷ Albany Hospice Inc. Constitution, Accessed 05/07/20,
http://www.albanyhospice.org.au/news/pdf/Constitution_AlbanyHospiceNov2018.pdf

and connections through facilitating and organising local events – such as those planned in the South West for Dying to Know Day in August⁸



South West Compassionate Communities Network
July 7 at 9:42 AM · 🌐

IT IS ON!
Please check out the wonderful events we have coming up on August 7, 8 and 9 as part of the global Dying to Know Day movement. It's a chance for our South West community to gather and talk about all things death, dying and bereavement. Please register your interest in the individual events to stay updated and assist with catering purposes. All events are free.

Made possible with the support of:
South West Grief & Loss Centre Making Memories with Deb William Barrett and Sons Palliative Care WA ECU South West - Edith Cowan University Bunbury Campus Maker + Co Perron Institute for Neurological and Translational Science La Trobe University St Aidan's Winery Ferguson Valley Archer and Sons Funeral Homes Harvey History Online

South West Compassionate Communities Network
DYING TO KNOW DAY
Day to encourage conversations and community and death, dying and bereavement.

FRIDAY, AUGUST 7
10AM AND 11AM
R OF HARVEY CEMETERY & DEATH CAFE
SOUTH WESTERN HIGHWAY/STIRLING COTTAGE
Take a self-guided stroll through the Old Harvey Cemetery developed by Edith Cowan University. Followed by a Death Cafe gathering at 11am at Stirling Cottage.

10AM - 12 NOON
WRITE YOUR OWN FUNERAL PLAN - THINK OUTSIDE THE BOX!
ECU CBD LEARNING HUB, MAKER + CO, 75 VICTORIA STREET BU
Join celebrants Deb Wright and Joze Arnold to learn about an array of funerals and walk away with the bones of your own funeral plan. Morning tea included.

3PM - 1.45PM
FOR THE SOUL LUNCH & 'YOU CAN'T ASK THAT' Q & A

SATURDAY, AUGUST 8
10AM - 12PM
DEATH CAFE - DYING FOR A CUPPA
BACK BEACH CAFE - OCEAN DRIVE BUNBURY
Grab yourself a cuppa and chat about death and related topics. It's not a grief or counselling session, it's a group discussion on your concerns, thoughts, experiences, customs and fears. All welcome in this safe space.

1.30PM
THE WILLIAM BARRETT & SONS CARE CENTRE
PLACE, BUNBURY
one of Australia's newest and most advanced funeral service centres that goes on behind closed doors with this respectful and kind. The first tour will start at 12.30pm and the other at 1.30pm. Individuals as well as those working in health care, education or services. Light refreshments provided.

3PM - 5PM
THE MAIN EVENT
YOUTH ART EXHIBITION, WINE & CHEESE - SHORT FILM
ECU CBD LEARNING HUB, MAKER + CO, 75 VICTORIA STREET
Immerse yourself in discussions and get answers to questions you'd like. There will be a youth art competition, short film based on end-of-life care Q & A panel titled 'You Can't Ask That'. The panel comprises Member of Parliament MIA who will discuss Voluntary Assisted Dying legislation, Ill Sons director Adrian Barrett, organ donor advocate Anthea Openshaw, WA CEO Lena Glogowski, South West Grief & Loss Centre manager and Professor of Palliative Care Research Samar Anon.
3pm: Youth art exhibition with a side of wine & cheese
3.30pm: Welcome, all second generation & short film
4pm: 'You Can't Ask That' Q & A

Conclusion

We believe that death, dying and loss is a critical public health issue that affects us all⁹. We know from lived experience the negative impact that a poor quality end of life experience can have on a patient and their family.

We welcome the opportunity to be part of the solution going forward. We hope we will have the chance to contribute to the rollout of new approach and proactively engage with consumers and community members to improve the experience of palliative and end of life care in the WA community.

LJM Memorial Hospice Management Committee

July 2020

⁸ South West Compassionate Communities Network, [Facebook post](#), accessed 09/07/20

⁹ Julien Abel, [Video on the Compassionate Communities Network page](#), accessed 09/07/20