Latrobe Health
Advocate

Achieving Victoria's best end of life experience for people in Latrobe.

Latrobe Health Advocate

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The Latrobe Health Advocate respectfully acknowledges Aboriginal people as the Original Custodians of the land we walk on today – the land of the Braiakaulung people of the Gunaikurnai nation and passes on respect to their Elders past and present, future and emerging.

Jane Anderson, Latrobe Health Advocate.

As the Latrobe Health Advocate, Jane Anderson reports directly to the Victorian Minister for Health. Jane's role is to provide independent advice to the Victorian Government on behalf of Latrobe Valley communities on system and policy issues affecting their health and wellbeing.

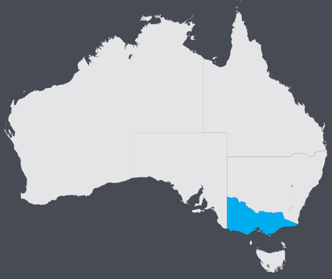
Jane maintains a focus on strategic outcomes and systemic change, ensuring advice and activities within the Latrobe Health Innovation Zone are informed and underpinned by a strong collaborative approach.

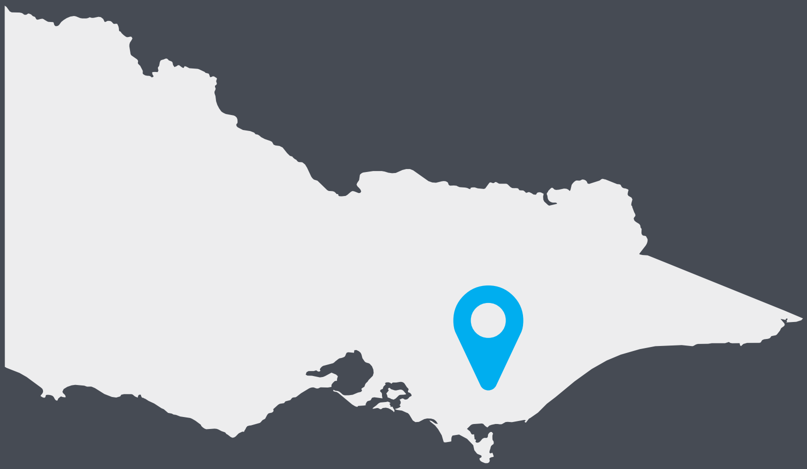
Jane listens to and analyses community voice and identifies health and wellbeing priorities that impact people in Latrobe. Jane collaborates with others including the Latrobe Health Assembly and local health services with a view to bring about change and improve health and wellbeing outcomes.

Latrobe, Gippsland, Victoria.

The local government area of Latrobe City is located approximately 150kms east of Melbourne. It is recognised as one of Victoria's major regional centres and is one of six local government areas that make up the broader Gippsland region.

Latrobe is home to more than 75,000 residents and is made up of four central towns; Churchill, Moe, Morwell and Traralgon, and several rural townships; Boolarra, Glengarry, Toongabbie, Tyers, Traralgon South, Yallourn North and Yinnar.





Message from the Latrobe Health Advocate.

To the Hon. Jenny Mikakos, Minister for Health,

I am pleased to provide this report which includes recommendations to improve the end of life and palliative care experience for communities in Latrobe. When I commenced as the Latrobe Health Advocate last year, I included end of life palliative care as a priority project for system change within my Statement of Intent. The voice of Latrobe communities was strong at the time and it has become stronger over the past twelve months.

My office has undertaken extensive community engagement and desktop research to hear the voices of people in Latrobe, understand the underlying issues and identify opportunities for improvement. The engagement process itself has been a catalyst for change. In bringing communities, governments and services together to share perspectives and co-design solutions, improvements to the system are already being made at a local level.

> "…I see an opportunity in Latrobe to build and deliver Victoria's best palliative care system."

However, there is more to be done, as the engagement and research has identified that the palliative care system as it is experienced by people in Latrobe is not on par with what is described in Victoria's end of life and palliative care framework. In response to this the local system needs to be reformed to ensure that what is described in the state-wide policy is being implemented and monitored effectively in Latrobe.

The Latrobe Health Innovation Zone was designated by the Victorian Government to support communities in Latrobe to improve their health and wellbeing. It is a place where the community is being empowered to lead and influence change. It is within this context that my recommendations are framed as I see an opportunity in Latrobe to build and deliver Victoria's best palliative care system.

In responding to my recommendations, I urge the Victorian Government to consider the resources required to adequately deliver palliative care services in Latrobe. I offer the engagement process I have implemented as a model that could be applied in other locations across Victoria to ascertain how palliative care services are being experienced by other communities into the future. I suggest the establishment of a **Latrobe Palliative Care Taskforce** to bring together communities, services and governments to determine a plan of action and way forward.

I acknowledge the people who have generously contributed to this work by sharing their very personal stories of grief, gratitude and despair and thank them for their willingness to hear and learn from the perspectives of others.

J. Anderson

Jane Anderson
Latrobe Health Advocate

A future vision for palliative care services in Latrobe.

Latrobe communities have been clear in what they are asking for and why it is important to them. At the heart of it, their aspirations are about respect, dignity and kindness. They are looking for services that work together as one to provide a model of care where quality of life and death is possible and where the impact of death is lessened through care and support available for and from the community.

> “This vision is founded in the voices of Latrobe communities who have courageously shared their stories of hope, gratitude and despair.”

With the Victorian Government’s designation of the Latrobe Health Innovation Zone, the will of Latrobe communities and responsiveness from local services, the conditions for systems change exist. There is an opportunity in Latrobe to build a system that delivers Victoria’s best end of life experience. A system that offers optimal care and truly empowers patients and their loved ones. An experience that is in harmony with the needs of the local community. An experience that becomes the benchmark for the rest of Victoria.

This vision is founded in the voices of Latrobe communities who have courageously shared their stories of hope, gratitude and despair. It brings together community voice and research within the strategic context of the Latrobe Health Innovation Zone, Victoria’s end of life and palliative care framework and the National Palliative Care Strategy.

The Latrobe Health Advocate has identified five key areas for reform and twelve recommendations for action. These recommendations are for the Victorian Government, Latrobe Regional Hospital, Latrobe Community Health Service, Gippsland Regional Palliative Care Consortium, Gippsland Regional Palliative Care Consultancy Service, Gippsland Primary Health Network and the people of Latrobe. They are also relevant for other government services, agencies and peak bodies with an interest in end of life care for Victorian communities.

Achieving this vision will position governments and services to respond to the immediate and future needs of Latrobe communities. The benefits will expand beyond Latrobe to the broader Gippsland region and across Victoria.

Collaboration and community are key. When true collaboration is realised, governments, health services and communities will benefit from trusted relationships, where community voice is valued alongside health expertise and clinical evidence. The outcomes will be stronger and longer lasting. People in Latrobe will have peace of mind that when they die or lose a loved one, the care will be optimal, and the experience will be as good as it can be.

Achieving Victoria's best end of life experience for people in Latrobe.

Offering people in Latrobe their place of choice.

Latrobe communities experiencing a system that works in harmony with their needs.

Latrobe as the epicentre for those who have the heart for palliative care.

A public health approach that brings death and dying out from the shadows.

Contemporary governance that brings health services and communities together.

Latrobe Health Innovation Zone

National Palliative Care Strategy

Victoria's end of life and palliative care framework

Summary of recommendations from the Latrobe Health Advocate.

Reform priority 1

Empowering people in Latrobe to die in their place of choice and offering places to choose from.

Recommendation 1
A hospice as a place of choice for people in Latrobe.

Recommendation 2
A shift in thinking and a commitment to achieving a home-like environment within the hospital setting to significantly improve the experience for patients and their loved ones.

Reform priority 2

Latrobe communities experiencing a system that works in harmony with their needs.

Recommendation 3
Palliative care services available every hour of every day as a matter of course.

Recommendation 4
Timely access to medicines to prevent patients, families and carers from suffering unnecessarily.

Recommendation 5
Services unite to provide a model of care that is experienced by every patient in every place.

Recommendation 6
A unified model of care where records are shared across the system for the benefit of patients.

Reform priority 3

Latrobe as the epicentre for those who have the heart for palliative care.

Recommendation 7
Immediate and ongoing investment to build, grow and nurture the Latrobe palliative care workforce

Recommendation 8
Volunteers in Latrobe are well utilised, valued and acknowledged.

Recommendation 9
The system fosters compassion for staff and volunteers to enable them to truly give this to others.

Reform priority 4

Latrobe communities benefitting from a public health approach that brings death and dying out from the shadows.

Recommendation 10
Localised education and awareness campaigns to shift community views and experiences with death.

Recommendation 11
Local grief and bereavement supports to ease the pain of death for Latrobe communities.

Reform priority 5

Contemporary governance brings health services and communities together to share their collective expertise.

Recommendation 12
Effective leadership and accountability structures where health services and communities come together to share their collective expertise.

Project overview

Project objective

To determine how best to improve end of life and palliative care services available within Latrobe and to advocate for change as required.

Desired outcomes

- ✓ Gain a deeper understanding of the current local palliative care system from both a community and service provider perspective.
- ✓ Research known and emerging issues, alternate models and options.
- ✓ Listen to community and stakeholder aspirations about system improvements and innovation.
- ✓ Make recommendations to community, local services and government.

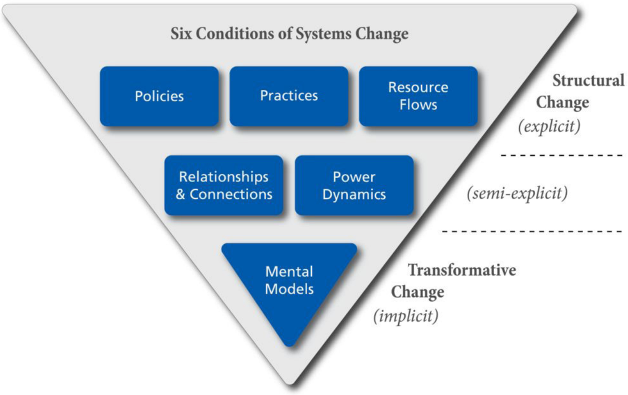
Changing the conditions that are holding problems in place.

Identify, through research, known and emerging issues.

Explore the user experience and engage with communities to deepen understanding of issues.

Collaborate with communities to identify changes required to policies, practices, resources, connections, assumptions, beliefs and values.

Advocate for system changes and gaps.



The Water of System Change 'inverted triangle' framework. (FSG, 2018.)

Project methodology

A call from Latrobe communities to prioritise end of life care.

End of life care listed as priority for systems change in Latrobe Health Advocate Statement of Intent 2018-19.

Initial desktop research and project planning.

Ongoing community conversations seeking to understand barriers, suggestions and aspirations.

Informal research interviews and briefings with key stakeholders.

In depth interviews with local palliative care staff and community groups.

Interactive workshop bringing together services and communities to share perspectives and vision a future end of life experience in Latrobe.

Further desktop research and development of draft recommendations.

Site visits.

Key stakeholder briefings.

Latrobe Health Advocate makes recommendations to government, services and communities.

Strategic and policy context for palliative care services in Latrobe.

The local government area of Latrobe City has a population of more than 75,000. The local hospital and local community health service are funded by the Victorian Government to deliver palliative care services to Latrobe communities. Whilst it is difficult to ascertain the precise demand for these services, figures indicate that between 2012 and 2016, an average number of 650 people died in Latrobe each year. For each death, there is likely to be a number of bereaved people in need of psychosocial supports to varying extents and for varying periods of time.

When death and dying is considered from a whole-of-community perspective there is a strong case for policy makers and services to consider a public health approach to palliative care. One that provides maximum benefit for the largest number of people. An approach that considers the ongoing health and wellbeing of the broader community, ensuring quality of life and quality of death. An approach that considers the impact that death can have on the community and the difference that quality palliative care services, grief and bereavement supports can make.

The World Health Organisation defines palliative care as an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

Government policies and investments for palliative care have evolved in recent years and continue to do so. Efforts are being made at all levels to continually improve how palliative care services are designed and delivered.

Victoria's end of life and palliative care framework 2016

Palliative care services in Victoria are delivered within the context of Victoria's end of life and palliative care framework. This framework was released in 2016 and seeks to provide clear expectations for how services are delivered, identify actions to ensure services are sustainable and provide all Victorians with safe and effective end of life care.

It is likely that palliative care services offered in specific locations across Victoria are influenced by existing infrastructure, historical funding arrangements and relationships between services and governments. There is an obvious rationale and benefits for this, building on local strengths and working to improve the delivery of existing services. However, true reform may require a more objective view, considering first, what the needs of a community are and then designing or rebuilding a local system that can meet these needs.

Voluntary Assisted Dying

Victoria was the first state in Australia to pass voluntary assisted dying laws. In November 2017 the Victorian Parliament passed the Voluntary Assisted Dying Act 2017. It has been described as providing a safe legal framework for people who are suffering and dying to choose the manner and timing of their death.

In June 2019 the Voluntary Assisted Dying Act 2017 came into effect. Victorians who are at the end of life and who meet strict eligibility criteria can now request access to voluntary assisted dying.

Productivity Commission Inquiry into Human Services 2017

In 2017 the Productivity Commission undertook an inquiry that looked specifically at palliative care services across Australia. The inquiry found that palliative care services in Australia can be excellent, however they are not necessarily afforded to everyone that needs them and that there is scope for improvement in all settings;

> *Where it is available, the quality of end-of-life care services in Australia is often excellent. But services are not available everywhere and to everyone who would benefit. Delivery of more effective end-of-life care will require investment and coordinated action across the Australian, State and Territory Governments.*
>
> *In light of the constraints on the supply of the types of care that users would prefer, particularly skilled palliative care at home, in hospices and in residential aged care, it is unsurprising that many people who would benefit from end-of-life care do not get the right care, in the right place, and at the right time.*
>
> *As a report published by the Australian Centre for Health Research put it: … too many people are dying in a way they wouldn't choose, and too many of their loved ones are left feeling bereaved, guilty, and uncertain. The care most Australians receive at the end of life often does not reflect their values, goals, or informed choices.*

> *There is scope for improvement in end-of-life care in all settings (including hospitals, community-based palliative care services and residential aged care facilities), and in the integration of care between settings. (Productivity Commission, 2017)*

National Palliative Care Strategy 2018

In 2018 the Australian Government released a new National Palliative Care Strategy. The purpose of this strategy is described below;

> *The National Strategy is intended to be used by all Australian governments, as well as organisations and individuals, in guiding the improvement of palliative care across Australia so that people affected by life-limiting illnesses get the care they need to live well. The National Strategy provides a shared direction and an authorising environment for the continual improvement of palliative care services throughout Australia. (Australian Government, 2018)*

The Australian Government acknowledges that cooperation across governments is required to deliver the highest possible level of palliative care. There is recognition that the services in Australia are some of the best in the world, however there is more to be done and that demand for palliative care is increasing.

> *The National Palliative Care Strategy represents the commitment of the Commonwealth, state and territory governments to ensuring the highest possible level of palliative care is available to all people.*
>
> *There is more to be done to maintain Australia's high standards of palliative care and to ensure that care is available to those who need it as well as their families and carers, including bereavement support following the death of a loved one. (Australian Government, 2018)*
>
> *Demand for palliative care is increasing;*
>
> - *It is anticipated that by 2066 around 25% of the population will be over 65.*
> - *As around 80% of Australians who die in any given year are over 65, the number of people dying each year will increase consistently.*
> - *The number of people receiving a palliative medicine specialist service through the Medicare Benefits Scheme increased by almost 85% in the five years to 2015–16. (Australian Government, 2018)*

The Australian Government further notes that palliative care services need to be suitable for the diverse needs of people within a community.

> *Palliative care may be required at any age. The needs of children and young people, and their parents and families, are often quite different from those of people facing the end of life at a much older age. Cultural factors, such as kinship and community, and end-of-life practices and rituals of Aboriginal and Torres Strait Islander people need to be considered to enable cultural capability of palliative care services for Aboriginal and Torres Strait Islander people. People with differing illnesses (such as cardiovascular disease, dementia or cancer) will have differing physical, psychosocial and spiritual needs over various timeframes. (Australian Government, 2018)*

Palliative Care Australia's vision for 2030

In February 2019 Palliative Care Australia released a report that looks to the future and envisages what high quality palliative care in Australia will look like in 2030. Palliative Care Australia notes the expected increase in demand for palliative care services and describes a future service grounded in collaboration, population and needs-based planning.

> *Currently approximately 160,000 people die in Australia each year and by 2030, this will be over 200,000. Within 40 years' time, the figure of 160,000 will have doubled. In 2030 silos and system impediments will have been minimised via collaborative population-based planning across all levels of government, Commonwealth and State and Territory. There will be improved data collection and data sharing leading to ongoing quality improvement and carefully considered policy and funding decisions.*
>
> *Australians will have different expectations about how they can have quality of life and a good death, including choosing the setting of their care as they approach the end of their life as well as the preferred location for their death. (Palliative Care Australia, 2018)*

Latrobe Health Innovation Zone

In response to the 2014-15 Hazelwood Mine Fire Inquiries the Victorian Government designated the Latrobe City local government area as a health innovation zone. This included the establishment of the Latrobe Health Assembly and the Latrobe Health Advocate.

The Latrobe Health Innovation Zone is intended to give voice to community aspirations in the planning and delivering of better health and wellbeing outcomes, and where a process of co-design with individuals and organisations is actively encouraged.

There is an opportunity in Latrobe to think and act differently across all areas of health and wellbeing including the design and delivery of palliative care services. It is possible to do this within the context of state and national policy directions. In fact, a commitment to innovation and rapid reform of the local palliative care system could be of significant benefit to the broader Victorian community. The Latrobe Health Innovation Zone could be viewed as a mechanism to trial new ways of working, bringing communities and the health sector together to strengthen the delivery of palliative care services. Learnings could be shared across the broader system to inform future policy design and investments and accelerate future responses to increasing demand and population growth.

In its 2017 report the Productivity Commission stated;

> *In 2025, the services available to people approaching the end of life will also need to be substantially different to those currently available, as current services are not meeting the needs of people approaching the end of life. (Productivity Commission, 2017)*

The United Kingdom's National Palliative and End of Life Care Partnership has established a national framework for local action. This framework highlights the need for localised solutions and a commitment for governments and organisations to work together in the spirit of collaboration and doing things differently;

> *We need a collective response. The will, determination and innovation of organisations working collaboratively to find new ways of delivering better care will, and must, make a difference. The essential challenge is to learn how to work together, collectively and differently to achieve these ambitions and the standard set out in the NICE Quality Standard for End of Life Care (2011). It is up to us. Engaging with the task, sharing good practice, using what we know and being prepared to learn what we haven't yet understood. (UK Partnership, 2015)*

There is alignment between the principles of the Latrobe Health Innovation Zone and the Victorian and Commonwealth palliative care policy directions. There is also an opportunity to work towards Palliative Care Australia's vision for 2030. It is within this strategic and policy context that the voice, experiences and aspirations of Latrobe communities should be heard and considered.

Latrobe Health Innovation Zone – the first of its kind in Australia.

Guiding principles of the Latrobe Health and Wellbeing Charter:

Latrobe Valley communities, organisations and government who commit to the Charter will:

Use a community-led approach to ensure all people, including those who are marginalised and under-represented, have choice, control and a voice in developing the supports and services they need in their lives.

Work with First Nations communities and health service providers to improve health and wellbeing.

Do something different, try new approaches and learn from mistakes to create new and innovative health and wellbeing models and programs.

Be fair and transparent by doing as we say to follow through on commitments to Latrobe Valley communities.

Communicate in plain language to build trust and respect among individuals, families, communities and service providers.

Work to improve the lives of everyone, especially the most vulnerable and disadvantaged.

Develop equitable access to the most appropriate supports and services for all people in Latrobe Valley communities.

Grow and nurture collaboration and coordination between agencies to develop new ways of delivering services that cut across boundaries to best meet the needs of each person.

Use a co-design model to shift how we think about and organise health services in the Latrobe Valley, and create innovative approaches to their design and delivery.

	National Palliative Care Strategy.	Victoria's end of life and palliative care framework.	Palliative Care 2030. Working towards the future of palliative care for all.
Vision	This National Palliative Care Strategy provides an overarching vision for palliative care in Australia: that people affected by life-limiting illnesses get the care they need to live well.	All Victorians and their families receive the best possible end of life care that places them at the centre where preferences, values, dignity and comfort are respected and quality of life matters most.	A future focus for palliative care - what should we expect in 2030? Palliative care is now a national health priority. There has been a commitment since the release of the National Palliative Care Strategy in 2018/2019 for a whole of government approach to robust population and needs-based planning and adequate funding of palliative care and specialist palliative care services.
Guiding principles	The National Palliative Care Strategy has six guiding principles; Palliative care is person-centred care. Death is recognised as a part of life. Carers are valued and receive the support and information they need. Care is accessible. Everyone has a role to play in palliative care. Care is high quality and evidence based.	The Department of Health and Human Services will work with communities and services to deliver the right care at the right time and in the right place by: Focusing on people and outcomes. Enabling local solutions. Equipping the service system to deliver earlier and more connected support. Ensuring safety, quality assurance and innovation. Using data and evidence for service development and monitoring.	**These guiding principles are proposed to assist policy planners to prepare for the future and work towards ensuring Australians have assured access to high quality palliative care in the future. High quality care for all Australians Patients, their carers and family can determine which services they access at any given time There is benefit in providing palliative care concurrently with disease-modifying therapies. Palliative care is available for all ages including children. Grief and bereavement support is an integral component of all healthcare. Culturally safe and culturally aware palliative care services is common place. Appropriate privacy provisions are in place when new technologies are developed.
Goals	**Goal 1:** Understanding People understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care. **Goal 2:** Capability Knowledge and practice of palliative care is embedded in all care settings. **Goal 3:** Access and choice People affected by life-limiting illnesses receive care that matches their needs and preferences. **Goal 4:** Collaboration Everyone works together to create a consistent experience of palliative care across care settings. **Goal 5:** Investment A skilled workforce and systems are in place to deliver palliative care in any setting. **Goal 6:** Data and evidence Robust national data and a strong research agenda strengthen and improve palliative care. **Goal 7:** Accountability National governance of this Strategy drives action.	To achieve this vision, the government has developed the following goals in consultation with community and expert representatives: People experience optimal end of life care. People's pain and symptoms are managed using quality interventions. People's preferences and values are recognised and respected in their end-of-life care. Carers are better supported. People are cared for in their place of choice. Where possible, people can choose to die in their place of choice.	Palliative Care Australia suggests seven key areas for action to achieve its vision; Whole of Government. Workforce. Community awareness and mobilisation. Research, data and advances in technology. Best practice innovative models. Funding models and flexibility. Grief and bereavement. Safe access to appropriate medicines.

***Principles have been described simply for the purpose of this report. For full descriptions refer to complete Palliative Care Australia report.*

Empowering people in Latrobe to die in their place of choice and offering places to choose from.

Recommendation 1

A hospice as a place of choice for people in Latrobe.

Most palliative care patients in Latrobe currently have two choices…to stay at home or to die in the hospital. In many instances either by choice or circumstance people die in the hospital.

Palliative care outcomes and community experiences in Latrobe could be significantly improved through the establishment of a dedicated palliative care facility that will truly give people choice of place for their care and death.

With the right design, philosophy of care, and integration with the broader system, a hospice in Latrobe could become the keystone of a contemporary and local palliative care system. It could offer a home-like and nurturing environment with specialist care for patients and their families.

Community voice

There has been an overwhelming voice from communities for the establishment of a hospice in Latrobe.

Numerous people have made this suggestion. Most of the time when the concept of a hospice is shared with others it is strongly supported, particularly by communities and local palliative care staff.

Some people suggest aged care facilities or nursing homes as a suitable alternative to a hospital and others talk about the stigma that can be associated with them. People often express concerns about younger people including children, or adults under 65 years who may be faced with no choice but to go to an aged care facility.

Some have suggested that a hospice would encourage greater community contribution to and participation in palliative care services, through increased volunteerism and local fundraising activities.

A hospice has been described by communities as having;

- Visiting hours around the clock, where no one has to be alone.
- An atmosphere of peacefulness and caring.
- Dedicated and specialist palliative care staff and volunteers.
- Space for families and carers.
- Education for patients and families.
- A calming environment; slower pace; family amenities and support; pleasant surroundings and garden; doors open to the garden; overall design.
- A 'home' type environment, with gardens, nature, respite, non-clinical.
- A therapeutic and nurturing environment.
- A place where pets are allowed, and where 'my dog can be by my side.'
- Direct access to spiritual support.
- Respite options for patients, families and carers.

Quotes from Latrobe communities

"A hospice would provide the real care that a patient and family need."

"I would like to see if Latrobe Valley can finally get a palliative care hospice."

"There's a huge cavern between hospital and home."

"The only alternatives are hospital or an aged care facility."

Desktop research

In some locations, hospices and community-based palliative care services largely succeed in supporting those who wish to die at home to die at home or in home-like environments. (Productivity Commission, 2017)

Preferences about place of death can also change over time. While the direction of the change can vary, a review of 210 studies across 33 countries found preferences most commonly changed 'from hospital to home, home to hospice and from home to hospital'. (Productivity Commission, 2017)

Australia's end-of-life care services, where they are available, are among the best in the world in terms of quality and affordability (EIU 2015). Services are not, however, available everywhere and to everyone who would benefit. (Productivity Commission, 2017)

Often, people who would benefit from certain types of end-of-life care — such as specialist palliative care or support to die at home — miss out. Many, perhaps tens of thousands of, people cannot access desired support to die in their own home and die in hospital instead. (Productivity Commission, 2017)

The unprecedented increase in deaths from dementia means that a change in focus towards people living with dementia will be required. (Palliative Care Australia, 2018)

Comorbidity will be an increasingly significant factor in palliative care due to multi-morbidity, chronic progressive illnesses with longer disease courses, and diseases with complex symptoms and high symptom burden. (Palliative Care Australia, 2018)

If the place of death and care preferences of people approaching end of life are to be realised then a much greater investment is needed in the provision of specialist palliative care services in Australia. (Palliative Care Australia 2017)

Cancer Council Australia describes the benefits of a palliative care unit or hospice as;

- A warm and comfortable physical environment.
- 24-hour care with expert pain and symptom control.
- Focus is on quality not length of life.
- Direct access to a team of professionals and volunteers trained to meet the needs of the dying patient and carers.
- Allows the patient and their family and friends to focus on being together.
- Carers can leave at the end of the day and get some rest.
- Some families prefer not to live in a house where someone has died (although others find this a comfort).

End-of-life care needs are also changing, with a smaller proportion of people dying suddenly and dying from illnesses with a predictable trajectory (such as cancer), and more people experiencing a prolonged period of disability, frailty and illness and then dying 'with unpredictable timing from a predictably fatal chronic disease' (such as heart disease, lung disease, frailty and dementia) (ACSQHC 2013, p. 10). (Productivity Commission, 2017)

Opportunities and considerations

The establishment of a hospice in Latrobe should not be seen as 'the solution' to existing challenges within the system. Rather, it could be designed as a hub of excellence, where an agreed ethos and model of care for Latrobe communities is implemented in a way that sets the standard for all other settings in Latrobe.

It could become the home of the Gippsland Regional Palliative Care Consortia and Consultancy Service. It could act as the 'home base' for the local palliative care workforce with multi-agency access and supports for staff and volunteers that work across the system. It could be the training ground for volunteers, the general and palliative care workforce. A place where continual improvement, innovation and learning is common place.

It is important for a hospice to be considered as part of the broader palliative care, health and social system. It would need to function in a way that enables patients to experience a seamless transition in and out of other settings or services.

In sharing their aspirations for a hospice in Latrobe people often talked about a home-like environment with specialist care. Pets, community gardens, family kitchens and good access to transports were commonly associated with a hospice.

Further work needs to occur to consider, in more detail, the option of a hospice for Latrobe. This would involve reaching a shared understanding between communities and the Victorian Government about the definition of a hospice along with feasibility studies that look at costs associated with the establishment and ongoing delivery of such a facility. It would be of benefit to think innovatively about funding models with an openness to redirecting existing funds as well as consideration of alternate models such as public-private partnerships. Involving Latrobe communities throughout the entire process of determining feasibility, considering options and designing a facility is essential.

Recommendation 2

A shift in thinking and a commitment to achieving a home-like environment within the hospital setting to significantly improve the experience for patients and their loved ones.

Latrobe Regional Hospital is funded to provide a small number of palliative care beds and where possible, a dedicated bed on a sub-acute ward is offered. On occasion, when this is not an option staff need to do what they can to find a bed somewhere else within the hospital.

The environment of a hospital is clinical in nature. The philosophy of care is about treatment and cure. There is little room for families and loved ones. The staff are busy and may not have the skills or confidence to provide the care that is needed at the end of life.

Despite this, Latrobe Regional Hospital needs to take immediate action to innovate ways to create a space, environment and model of care that is more suitable for palliative care patients. This needs to take into account the physical environment and the psychosocial needs of a patient and their loved ones.

Community voice

There is a common view that the hospital environment is not suitable for end of life care and that this has a negative impact on patients and their families. People may initially plan to be at home, however if they change their mind the hospital is not considered to be a suitable or pleasant alternative. Some people don't want to be at home and the hospital is their only other option.

The hospital has been described as an acute service with a completely different ethos to what patients and families might be seeking at end of life. Communities have described the hospital as busy and clinical, with limited space or time to contemplate end of life and share those precious moments with family and friends. There is limited privacy in the hospital.

Quotes from Latrobe communities

> "The hospital setting would benefit from a specialist palliative care ward and palliative care nurses to care for patients and their families appropriately."

> "I wanted somewhere where I could create memories with my boy before he died."

> "We need continuity of a peaceful environment, from home to hospital."

> "There is nowhere for younger adults to be cared for…an acute hospital bed is not the right place."

Desktop research

There is significant investment in acute care. However the acute care system is set up for a 'treatment first' approach and thus it can result in unnecessary cyclic pathways for people at the end of life. (TACSI, 2017)

Most Australians currently die in hospital, and many receive end-of-life diagnoses or referrals to community-based palliative care services while in hospitals or outpatient clinics. Hospitals therefore play a critical role in the delivery of quality end-of-life care. Reform is needed to address the many systemic issues that can make it difficult for hospital staff to deliver good end-of-life care. (Productivity Commission, 2017)

Once they are in hospital, patients approaching the end of life, and their families and carers, can find it hard to understand whether or not hospital is the best place for them and, if they would prefer to forgo certain medical interventions, can find it hard to express those preferences. This inhibits user choice and can lead to poorer care. (Productivity Commission, 2017)

In acute hospitals, the overall momentum of care delivery is toward life extension, and many clinicians regard patient death as their 'failure' or a result of their inadequacy (Bloomer, Moss and Cross 2011). This is appropriate. Nevertheless, patients often rely on clinicians to initiate conversations about end-of-life care, but many clinicians are inadequately trained about, and are intimidated by, holding such conversations (Bartel 2016). (Productivity Commission, 2017)

Patients with palliative care needs and their families have been consistent in what they consider to be most important in relation to end-of-life care within the hospital setting. The need for expert care (inclusive of physical care, symptom management and integrated care), optimal communication, respectful and compassionate care, valued family involvement in care planning and delivery, maintenance of self-identity for patients, environmental privacy for families, ensuring patient safety, supporting patient choices, preparing families for death and providing contact for families after a patient has died, cannot be over stated. (Palliative Medicine, 2016)

A comfortable death can help those who are bereaved to adjust to their loss in ways that secure their future health and wellbeing. (UK Partnership, 2015)

Opportunities and considerations

It is likely that there are immediate and longer-term improvements that Latrobe Regional Hospital could make. It may be of benefit for Latrobe Regional Hospital to bring together communities and the local palliative care workforce to consider possibilities and opportunities. The outcomes of these discussions could be enhanced with the involvement of other hospitals or palliative care staff from elsewhere in Victoria. In particular, hospitals that are regarded well by their communities for having a dedicated space for palliative care or creating an environment and model of care that is alternate to the typical hospital environment that has been described above.

Consideration needs to be given to the experience that palliative care patients have within the emergency department. Latrobe communities have suggested an alternate 'way in' to the hospital for palliative care.

In the longer term there are expansions already planned for Latrobe Regional Hospital. It would be of benefit to consider what opportunities this creates to enhance the options available to palliative care patients. There may be existing locations or infrastructure within the hospital grounds that are more suitable for end of life than a sub-acute ward. The hospital grounds may also be suitable for a dedicated palliative care unit, similar to what is available to communities in the Mornington Peninsula through Peninsula Health.

These efforts can only be successful if both the physical environment and the model of care or ethos are considered together.

Latrobe communities experiencing a palliative care system that works in harmony with their needs.

Recommendation 3

Palliative care services available every hour of every day as a matter of course.

Latrobe communities have expressed concerns about the limited availability of palliative care services. They have described their feelings of being an inconvenience and their distress at needing support outside regular business hours and how this has impacted them.

Immediate action needs to be taken to ensure that current and future services have the capacity to deliver optimal palliative care for patients in the home, hospital or hospice regardless of the day or hour.

Consideration needs to be given to the quality of care that can be offered in person compared to the value of advice that is offered to patients and carers remotely over the telephone.

Community voice

People want services to be available at times that patients and families need them, and not when health services choose to deliver them. They have suggested better coordination, communications and protocols between services to assist with this.

A common area of feedback is that local palliative care services are limited to business days and hours and that this has a significant impact on patients, their families and local staff.

It has been suggested that funding is provided for palliative care supports to be offered outside business hours. However it seems that some of these supports are in high demand and therefore less available and other supports are underutilised.

Quotes from Latrobe communities

“Do people not die on a Sunday?”

“Palliative care needs an immediate fix. We need 24-hour care 7 days a week.”

“There is no local after hours support and the support available is advice only. Some patients go to the emergency department for help.”

“Most problems occur after hours.”

Desktop research

Every person at the end of life should have access to 24/7 services as needed as a matter of course. The distress of uncontrolled pain and symptoms cannot wait for 'opening hours'. This is a necessary system-wide expectation and good end of life care cannot be achieved without it. (UK Partnership, 2015)

We know that 24/7 expert palliative and end of life care services need to be available and that their availability around the clock is key to building a system of high quality care. (UK Partnership, 2015)

Opportunities and considerations

There are multiple factors that may be impacting the availability and utilisation of local palliative care services. These include workforce capacity and availability, funding, potential discrepancies between funding expectations and service implementation, lack of knowledge or underutilisation of services available, inadequacies of remote services such as telephone supports, high demand and discrepancies between community needs and expectations, policy directions and service provision.

> **"Support is not available when families are most vulnerable. Loved ones only die once, it should not be so traumatic."**

Recommendation 4

Timely access to medicines to prevent patients, families and carers in Latrobe from suffering unnecessarily.

When a patient is unable to access medicine in a timely manner this can significantly impact their pain and symptoms. It places additional burdens on caregivers and can result in avoidable emergency department presentations.

Local nurses and doctors have said that some GPs have limited knowledge of palliative medicines and that they won't prescribe without first seeing a patient, however they are reluctant to do home visits. Nurse Practitioners are seen as a valuable part of the palliative care team, however there are limitations on what they are able to prescribe.

There is an opportunity in Latrobe to pilot a program working with health services and pharmacies to improve access to medicines for palliative care patients. The objective of this program would be to address the underlying issues currently preventing patients in Latrobe from having adequate and timely access to medicines. Further, the outcomes of the work could be shared and applied more broadly across Victoria.

Community voice

Latrobe communities, along with palliative care doctors and nurses have shared their frustrations about not being able to get scripts or access medications in a timely manner and the negative impact this can have.

Pharmacists have indicated that the palliative care section on the PBS is a challenge as it doesn't cover all medication required by palliative care patients. They have said that accessing prescriptions is often challenging.

Some people have shared their experiences of having to go to the emergency department for assistance with managing their pain when they have not been able to access medication.

Quotes from Latrobe communities

"We need pain management specialists in Latrobe."

"We need timely access to medication."

"Pain management is of the utmost importance."

"People don't have to die a painful death."

"Patients should not have to wait until Monday morning."

Desktop research

In their vision for the future Palliative Care Australia has described their aspirations for a person and their family or carer to be able to access appropriate medicines as and when required within a quality use of medicines safety and regulatory framework, but without the red tape and systems issues that were present in 2018. (Palliative Care Australia, 2018)

Opportunities and considerations

Engagement with communities has highlighted the importance of improving communications and interactions between doctors, nurses and pharmacists to ensure that the experience for patients is as problem free as possible. It is likely that with improved collaboration and more proactive planning some of the existing challenges could be alleviated.

There is an opportunity in Latrobe to work together with health services and pharmacies to:

- Improve access to essential, affordable end-of-life medicines to support people wishing to die in the community
- Reduced burden on community caregivers during the terminal phase through improved access to medicines for end-of-life care
- Increase understanding by general practitioners and community pharmacies on the importance of anticipatory prescribing
- Increase collaboration between general practitioners and community pharmacies around the provision of medicines for community-based end-of-life care.

> “Difficulties with access to medicines in the terminal phase can act as a barrier for people wishing to die at home and place additional burdens on caregivers.”

Recommendation 5

Services unite to provide a model of care that is experienced by every patient in every place.

It is evident that the palliative care system as it is experienced in Latrobe is disjointed and overly complex. This has been described by patients and families as well as staff that work within the system. Communities are clear in their view that for patients and families, who the service provider is and what they are funded to deliver is irrelevant. What matters most, is that they receive a consistent quality and continuity of care and that the system can function effectively to meet their needs.

Immediate and ongoing action needs to be taken to address the barriers that patients, communities and staff experience in trying to navigate and work within palliative care services in Latrobe. This requires a real and visible commitment from both the Boards and Executives at the hospital and community health service.

The provision of a consistent model of care needs to be underpinned by ongoing opportunities for staff and volunteers to establish good working relationships and the rigorous implementation of regular communication and multidisciplinary meetings.

Community voice

Communities, volunteers and local palliative care staff have all identified challenges that come about as a result of limited collaboration and coordination between local services. Some have described the palliative care system as fractured and suggested it needs to be more community friendly.

There is a desire to see a more coordinated end of life care system in Latrobe. Patients and families are looking for a single point of coordination or one phone number to call.

Local health services have initiated weekly meetings and other regular communications between staff. These are proving to be useful.

The local consultancy service (located at the hospital) has reported a great working relationship with the acute staff from the hospital and has said that the acute staff are responsive to their advice about palliative care.

Local staff have said that when they have good working relationships with their colleagues it results in a better experience for their patients.

Quotes from Latrobe communities

"The overall system must operate better…doctors, nurses, volunteers, church."

"As carers and volunteers we want to see improved collaboration and cooperation at all levels."

"There is system confusion and model breakdown, with a disconnect with providers in community and medical. It needs to be more family focused."

"Our inter-agency relationships need to work properly."

Desktop research

Fragmented and disjointed care is a source of frustration and anxiety for the dying person and for all those important to them. (UK Partnership, 2015)

Navigating a complex system and advocating either for yourself or for a loved one at a stressful time of life can be both difficult and lead to less than optimal outcomes. (TACSI, 2017)

While Governments have recognised community concern about end-of-life care, progress is being hindered by poor stewardship, including conflict over responsibilities and how service provision is coordinated across different settings. Reforms are needed to put users' needs and choices at the heart of end-of-life care services, and to ensure those services have the capacity to meet users' needs. (Productivity Commission, 2017)

An 'integrated system' is one that provides supported transitions from pre-diagnoses through to diagnoses, curative care, palliative care, death and bereavement. Supported transitions between parts of the system are important for ensuring a good outcome for both the person dying and their loved ones. This is not the current experience of many people and families. (TACSI, 2017)

Service models must allow providers to respond quickly when an individual's condition changes, to avoid inappropriate or unnecessary emergency department presentations at the end of life and support people to remain in their home, if they choose, for as long as possible. (Australian Government, 2018)

The accountability for ensuring environments that support all professionals to give their best lies with the executive governance of the organisation. Every organisation should have clear governance at Board level for high quality palliative and end of life care and environments in which all staff can provide the best of their professionalism and humanity. (UK Partnership, 2015)

Opportunities and considerations

This work presents an opportunity for services in Latrobe to come together to determine an agreed ethos and model of care. If this is truly achieved, patients and their families will experience continuity of care and a more consistent experience, regardless of which setting they are in or with which service they interact.

Local staff have indicated that there have been recent efforts to achieve a more united approach through multi-disciplinary meetings and client reviews however this has been impacted by other pressures in the system such as workload, workforce capacity and differences in workplace culture.

The concept of a discharge coordinator has been suggested to address a current gap in the system where patients are discharged from the emergency department and file notes are sent to a general practitioner but not the palliative care nursing team.

Recommendation 6

A unified model of care where records are shared across the system for the benefit of patients.

Presently in Latrobe, the hospital and the community health service are operating with separate palliative care databases. Staff based in either service are unable to access a patient's entire records. There is no systemised way for staff based at the hospital, including the emergency department to identify that a patient may be receiving home based palliative care services and medicines.

A centralised palliative care patient records system needs to be implemented immediately. This will not only enable staff across multiple services to provide continuity of care for patients in Latrobe, it will enhance the reporting and planning functions of the system to ensure ongoing capacity to respond to changes in demand and population growth.

Community voice

Local palliative care staff have suggested it would be much easier to offer continuity of care with a single shared database between health services. They have also identified the importance of good working relationships and communications between staff and services as crucial.

Desktop research

Improving the integration of care is important not just for those approaching the end-of-life, but also for the health system more broadly. Designing and implementing integrated patient-centred care throughout the health care system will require several changes to structures and funding arrangements to improve coordination of care. (Productivity Commission, 2017)

Opportunities and considerations

The Department of Health and Human Services is currently working with Gippsland Regional Palliative Care Consortium to implement a centralised database that is utilised across Gippsland. In order for this software to fully meet the needs of communities and the broader palliative care workforce it is important for it to be available and accessible across the entire system. This includes palliative care specialists, nurses, general practitioners and other relevant staff. Into the future consideration could also be given to how volunteers, through an authorised coordinator could access and contribute to the database to ensure a complete picture of the patient experience.

Quotes from Latrobe communities

“The system is confusing; the model is broken.”

“Having a full history of patients helps us to understand where the patient is up to. This is not always available to us which can create a lot of follow up work. This takes time that we don’t have.”

“We need all of our clients in one database that can be accessed by staff at the hospital, local GPs, and the community palliative care team.”

Latrobe as the epicentre for those who have the heart for palliative care.

Recommendation 7

Immediate and ongoing investment to build, grow and nurture the Latrobe palliative care workforce.

Palliative care staff in Latrobe are few in numbers. They are in high demand and experience a never-ending tension between their desire to provide what they know is optimal care and the need to get to the next patient. It is likely that the local staffing profile is not commensurate with what is described in the Victorian Government's palliative care service capability framework. It is important to consider, not only what positions have been funded, but whether staffing positions are filled and in place on the ground.

Inadequacies within the palliative care workforce can compromise the entire system, place unnecessary pressure on the limited staff in place and impact a patient's opportunity to receive optimal care.

Striving to deliver Victoria's best palliative care system requires upfront and ongoing investment to implement a localised workforce development strategy. Implementation of this strategy needs to attract and retain increased numbers of palliative care staff. It needs to significantly increase the capacity of local services to enable them to achieve both the provision of optimal care across all settings and meet the ongoing learning and development needs of the palliative care and broader health and social workforce.

Community voice

The local palliative care staff and volunteers are committed to their work and share a genuine care for their patients. They are working within their means to do what they can.

Nurses and specialists have said that the training and education provided by Gippsland Regional Palliative Care Consortium is helpful.

Local nurses have described the pressures that they are under due to high demand for their services and limited staffing capacity within their teams. It has been suggested that there have been numerous vacancies over an extended period of time that can add to this pressure. This impacts the confidence levels of staff within services who become hesitant about taking new clients or referring an existing patient to another service when they know they are already at capacity.

Quotes from Latrobe communities

"Generalist palliative care is inadequate; therefore we need specialist palliative care staff."

"We have a fractured clinical and non-clinical workforce."

"We have a shortage of staff and qualified workforce."

"We continue to take patients even though we have no capacity. Issues can occur after-hours because nurses can't manage their caseloads."

"We need to be able to provide adequate care to residents in a facility-based age care environment regardless of funding and staffing issues."

"It is difficult to recruit palliative care specialists."

Desktop research

Investment at national, state and territory levels will be required to ensure that the systems and people are available to provide quality palliative care where and when it is needed. This will include palliative care specialists who play an important role in not only the delivery of care but building the capacity of other providers of palliative care. (Australian Government, 2018)

Workforce planning will need to take into account the current services available, the anticipated increase in demand, how people are likely to want to receive care in the future, and the competencies required to provide high quality palliative care. (Australian Government, 2018)

Current models of palliative care rely heavily on a critical number of specialist palliative care providers working within primarily metropolitan-based in-patient environments, while individual preferences and funding constraints point to an increasing need for service delivery in the community, within homes, and in residential aged care facilities. (Australian Government, 2018)

General practitioners and practice nurses could play a much larger role in helping people to articulate their preferences for end-of-life care through advanced care planning. Changes to Medicare item numbers are needed to enable this. (Productivity Commission, 2017)

Investment at national, state and territory levels will be required to ensure that the systems and people are available to provide quality palliative care where and when it is needed. This will include palliative care specialists who play an important role in not only the delivery of care but building the capacity of other providers of palliative care. (Australian Government, 2018)

Opportunities and considerations

Work needs to be done to determine what an ideal palliative workforce in Latrobe comprises of. This could be contrasted with the current staffing profile across all settings to identify gaps. Ongoing and future needs of a palliative care workforce also need to be taken into account.

Some of the suggestions made throughout the engagement process include;

- Introducing skilled mental health practitioners to assist in providing grief and bereavement supports
- The establishment of a dedicated team of specialist palliative care physicians that work across the system in all settings. This team might include 2-3 physicians, one of which would be the chief or lead clinician for all palliative care in Latrobe
- Increasing the number of Nurse Practitioners in the local workforce
- Adding a palliative care physician to the team at Latrobe Community Health Service
- Greater education for general practitioners about palliative care, noting that it can be hard at the moment to persuade some GPs to attend home visits
- Increased investment into local training and education is likely to result in longer term retention of staff
- Introduction of palliative care navigators
- Appropriate training specific to paediatric palliative care
- Flexibility for palliative care staff with provisions in place to allow and encourage them to work across multiple settings.

The Latrobe Valley Authority, in partnership with Latrobe City Council and the Latrobe Regional Hospital has recently commissioned some research that relates to the development of a future health workforce strategy for Latrobe Valley. This research could be used to inform the development of a dedicated palliative care workforce strategy for Latrobe.

Recommendation 8

Volunteers in Latrobe are well utilised, valued and acknowledged.

Volunteers in Latrobe come from a community characterised by care, generosity and goodwill. A community where health and wellbeing, looking after family and friends is important. Local palliative care volunteers have described how their involvement with the ‘system’ has changed over time. They often compare past to current experiences and share frustrations about what they describe as red tape and bureaucratic processes. They feel restricted and underutilised.

Interestingly, in many discussions with local palliative care nurses, it was hard to get a sense of how involved volunteers are or what their connection is to the local palliative care workforce.

Volunteers are an invaluable asset and need to be seen as a core component of the palliative care system in Latrobe. They can assist greatly in providing continuity of care and relationships across settings. Further, volunteers can assist in bridging the gap between the community and the palliative care system.

Community voice

Communities are wanting to be more involved and want to be supported by health services to be involved. They have said that often patients need someone to sit with them overnight. Volunteers and fundraising committees want to see their efforts contribute directly to the patient experience and not become lost in the health system.

Volunteers have said that they used to be more involved. They have asked questions about the role of Latrobe City and have suggested that ‘red tape’ within health services has limited their ability to be involved. It has been suggested that some people and their families have limited networks and are often hesitant to call on others for support.

It has been suggested that Latrobe has a well-developed training program for volunteers that is designed to select, screen and train the right people.

Both the hospital and community health service have indicated that their volunteer numbers are low, and that work needs to be done to address this.

The local palliative care fundraising committee has expressed a desire for greater influence over how its funds are allocated and wants reassurance that 100% of funds raised are directly benefiting palliative care patients.

Quotes from Latrobe communities

“Support volunteers to enable them to fully share their passion and support families.”

“We used to go in and speak with relatives and become part of their lives. We supported them.”

“It has gone backwards… we used to share care… with limited resources and it was good.”

Desktop research

Volunteers are a significant resource in creating good end of life care and must be valued more highly and used more effectively. (UK Partnership, 2015)

In addition to specialist and non-specialist palliative care providers, there are many volunteers and community organisations that support the holistic needs of people affected by life-limiting illnesses. Their contribution needs to be acknowledged and support provided for these essential services. (Australian Government, 2018)

Communities need greater recognition and support for the help that they can provide for people with end of life care needs. Local health, care and voluntary organisations should find new ways to work alongside families, neighbours and community organisations as well as to give them practical support, information and training. (UK Partnership, 2015)

The volunteers' contribution can be used to far greater effect. (UK Partnership, 2015)

Carers and informal support networks are not always acknowledged or meaningfully included as people encounter parts of the system they need to navigate at end of life. (TACSI, 2017)

Opportunities and considerations

Local services all agree that there is great value in working with palliative care volunteers. However they note that good volunteer management does come at a cost which is often not factored into funding models and staffing profiles.

There is an opportunity in Latrobe to rebuild the local volunteer workforce with a view to achieve a more centralised model where volunteer recruitment and training standards are consistent across the system and where volunteers can freely work across all palliative care settings.

It has been suggested that the presence of volunteers can increase the accountability of local services and help services to have greater connections with the local community.

Recommendation 9

The system fosters compassion for staff and volunteers to enable them to truly give this to others.

The impact of working in palliative care has been described as cumulative. Like all other health professionals, palliative care staff will be best placed to look after others when they are supported to look after themselves. Staff and volunteers within the system need to know that they too are cared for. Their workplaces need to provide space, time and opportunities to enjoy good mental and physical wellbeing.

Fostering a culture of compassion and wellbeing within the local palliative care workforce is likely to result in benefits for community and the health system. A workforce that is healthy and happy will be more engaged and perform to a higher standard. Recruitment and retention rates will be greater. And, as a result, communities will benefit from the best possible care.

It is possible that palliative care staff by their nature would have a tendency to put the needs of others before themselves. For this reason, it is important that all employers within the system work collectively to create a culture where staff and volunteers know that they are cared for regardless of which palliative care setting they are in.

Community voice

People in Latrobe have expressed their gratitude for the work that local palliative car staff and volunteers do. They often preface feedback about the system by first acknowledging the support they have received.

Many people in Latrobe shared personal stories and memories of times when nurses and medical staff showed empathy and compassion, describing the positive difference that this made.

Local staff have talked about the importance of feeling listened to and being able to contribute their ideas to improve the local system. They have shared their frustrations about high workloads, limited resources and staff turnover and the personal impact this can have them as well as the community.

Quotes from Latrobe communities

> "Sometimes we feel guilty that we can't give patients more time, but we have limited capacity."

> "I just want to be able to provide good care to patients and families, that is what I have been trained to do and that's what I find rewarding."

Desktop research

Staff can only provide compassionate care when they are cared for themselves and must be supported to sustain their compassion so that they can remain resilient, and use their empathy and apply their professional values every time. (UK Partnership, 2015)

All individuals involved in palliative care need to be supported to maintain their own resilience and well-being while working in this often challenging area. (Australian Government, 2018)

Opportunities and considerations

The benefits of good employee health and wellbeing programs are well researched as is the impact that a workplace or organisational culture can have on staff. There is an opportunity in Latrobe to build stronger working relationships and professional networks within the local palliative care workforce. Work could be done to involve the local workforce in discussions about how a localised model of care and ethos for the community can be reflected by shared values and ways of working.

Designing and systemising an agreed approach to mentoring, clinical supervision and shared opportunities to debrief and reflect would be of benefit. This is more likely to have impact if the approach is consistent for palliative care staff across all settings, regardless of who their employer is. Staff and volunteers need to be given permission and time to invest into these important activities.

It is important for palliative care staff and volunteers from all settings to have ongoing opportunities to come together and socialise. This is likely to strengthen their working relationships and will help to build the desired workforce culture.

> **"I just want to be able to provide good care to patients and families, that is what I have been trained to do and that's what I find rewarding."**

Latrobe communities benefitting from a public health approach that brings death and dying out from the shadows.

Recommendation 10

Localised education and awareness campaigns to shift community views and experiences with death.

In Latrobe, not unlike many other Victorian communities, death and dying might be considered a taboo subject. This can impede the likelihood of the development of Advanced Care Plans and prevent people from having discussions about their death.

Further, there is little awareness of the palliative care services that are available to Latrobe communities. Even those that have experienced or worked within the system have struggled to describe what is available and what the model of care is for people in Latrobe.

Localised delivery of communications campaigns and community engagement activities would assist to educate and mobilise the Latrobe community around death and dying. Palliative care staff and local communities should be involved in planning and implementation; however it would be beneficial to utilise communications and engagement experts to achieve stronger outcomes.

Community voice

Many of the people that have shared their experiences about palliative care and end of life have talked about how important it is to raise awareness of death and dying. They recognise that death is inevitable and that when it is hidden away from communities it makes it harder to talk about.

Latrobe communities have also talked about the importance of being able to understand what services are available and how they can assist. People have noted that palliative care services are often feared, and that community education and awareness could alleviate this.

Quotes from Latrobe communities

“We need to increase awareness of palliative care services.”

“The support of family and friends is essential…particularly when caring for someone at home…and after too.”

“We need better information available to the public.”

“We need to demystify palliative care. Some patients are terrified.”

Desktop research

Not all of those who could benefit from end-of-life care know of its existence, or how to access it. (Productivity Commission, 2017)

We will all die. Before the advent of our modern hospitals, more people died at home and death was more visible in the daily life of families and neighbourhoods. Today, the experience of dying is largely hidden from view. (Australian Government, 2018)

End of life care has relatively low profile in Australia. Information provision is often transactional and information not always readily accessible. Particularly for certain groups of people. (TACSI, 2017)

The nature of the information and who provides it can also create barriers for engagement. As a result, conversations about dying are happening too late in people's journeys, or not at all. Yet, the later we engage in conversations about values and choices in someone's end of life journey the more their options are diminished. (TACSI, 2017)

There was a shared view that education efforts go beyond information provision and build both capability and confidence to take action are critical to creating change that leads to better end of life outcomes for people. (TACSI, 2017)

Latrobe University and the Municipal Association of Victoria are currently working together to consider the role of local government in relation to building the capacity of communities to better accept and respond to death and dying. In their work they note that:

The social, economic and physical environments that impact on living well also impact on dying well. The public health approach to end-of-life recognises that while clinical support for people with a life limiting condition may be vital for many, ensuring their comfort, their care and their wellbeing depends on the community.

Research indicates that in many societies, communities or families, dying, death and bereavement can be 'taboo' subjects or difficult areas to have conversations. Research also shows that many people, as they approach their end of life, wish to remain connected with family, friends and community. Respecting individual choice is embodied in person-centred approaches and upheld by policy and service directions now commonly in place across health and other community services.

Opportunities and considerations

Consideration needs to be given to population demographics of Latrobe communities. There are people in Latrobe, who may already be experiencing disadvantage or may be, for a range of reasons, experiencing exclusion have little to no knowledge of the services available or what their options are.

This work highlights an opportunity for services in Latrobe to partner with peak bodies and other agencies such as Palliative Care Victoria, Very Special Kids, Go Gently and the Council of the Aging. These agencies and others could add value to the design and delivery of a palliative care system that becomes the benchmark for Victoria. Latrobe could be a location where new campaigns and initiatives are piloted, particularly if there is a component of community and workforce engagement.

The recent introduction of Voluntary Assisted Dying in Victoria presents an opportunity to raise the profile of palliative care services and encourage conversations amongst communities about death and dying.

Recommendation 11

Local grief and bereavement supports to ease the pain of death for Latrobe communities.

In Latrobe there is a notable absence of grief and bereavement supports. This is significant, with the impact being somewhat immeasurable and likely to linger within the community for extended periods of time. It goes beyond the realm of grief and places ongoing mental health burdens on the community.

Work needs to be done to ensure that grief and bereavement supports are embedded throughout the palliative care system. They need to be routinely available to patients and their families before, during and after death. The system needs to be designed in a way that embraces the varying cultural and spiritual needs of the community.

Community voice

People in Latrobe have shared their concerns about the lack of grief and bereavement supports available to them. They struggle to understand why more supports are not provided as a standard part of a palliative care services.

Local clergy and spiritual leaders have expressed their desire to be more involved and asked questions about how the system can be more inclusive for all spiritual and cultural needs.

Local organisations have described limitations on funding and suggested that communities may struggle or choose not to access telephone supports that are based elsewhere in Victoria.

Quotes from Latrobe communities

“I have not heard from anyone since the day my son died.”

“We need more bereavement support before and after passing.”

“Can we have Chaplaincy and a chapel in the hospital?”

Desktop research

Good palliative and end of life care includes giving care and support to families, friends, carers and all those who are important to the dying person. This must encompass good bereavement and pre-bereavement care, including for children and young people. (UK Partnership, 2015)

Bringing comfort has to include managing physical pain and symptoms but must also encompass and seek to alleviate all the different forms of distress. The experience of suffering associated with physical symptoms may be exacerbated, or sometimes caused, by emotional or psychological anguish, or social or spiritual distress. (UK Partnership, 2015)

The gaps in knowledge from 2018 have reduced significantly in relation to the level of grief and bereavement support needed in different situations and for what length of time. There is a greater understanding and awareness of the impact that grief and bereavement support services have on improving physical and mental health wellbeing and ability to maintain active engagement in the workforce, study and other community obligations. (Palliative Care Australia, 2018)

The literature around therapy animals in palliative care, as well as other health care services (McNicholas et al. 2005), supports the contention that animals can have positive impacts for patients as well as their friends, family, staff and volunteers.

Another report indicated that patients, staff and volunteers in day hospice services enjoyed daily visits from therapy animals highlighting that the animals relaxed patients, lightened the mood, created a non-clinical atmosphere and brought people together (Phear 1996). In addition, many patients indicated that they would like to keep a companion animal full time if not limited by accommodation restrictions (Phear 1996).

Opportunities and considerations

Work needs to be done to consider the current capacity of the local system with regard to grief and bereavement. Adequate staffing needs to be a consideration for a palliative care workforce strategy. Grief and bereavement should be taken into account when designing local governance structures associated with palliative care.

There may be existing services and staff within local organisations that could be better utilised or integrated within the palliative care system. Grief and bereavement support needs to be both systemised and individualised. It needs to be routinely offered throughout the entire palliative care journey and delivered in a way that is meaningful and of value for the patient and their family.

Further consideration must be given to the diverse spiritual and cultural needs and preferences of people in Latrobe. Palliative Care Victoria has recently implemented two projects that may be of relevance. One is a Cultural responsiveness Strategy and the other is an Aboriginal Palliative Care Program.

A number of people in Latrobe have talked about the value of pets and the therapeutic influence they can have. Further work could be done to explore how the inclusion of pets could ease the suffering of patients and their families.

Contemporary governance brings health services and communities together to share their collective expertise.

Recommendation 12

Effective leadership and accountability structures where health services and communities come together to share their collective expertise.

It is apparent that oversight for the delivery of palliative care services in Latrobe is distributed across multiple services and settings. Within both the hospital and the community health service palliative care is funded alongside numerous other services. Emphasis on palliative care will inevitably be diluted within this context. Consideration for the needs of Latrobe communities may be diminished with funding and service allocations applicable across the broader Gippsland region.

The influence of the Department of Health and Human Services is unclear. It is evident however, that there are discrepancies between policy directions, funding expectations and what Latrobe communities are experiencing.

The establishment of a dedicated governance structure with oversight for all palliative care services in Latrobe could significantly enhance local leadership and accountability. With a contemporary approach that is inclusive of communities; innovation and continual improvement is more likely to occur.

> **“All health and social care systems should involve people who have personal experience of death, dying and bereavement.”**
>
> **(UK Partnership, 2015)**

The membership of the governance structure would need to bring together a diverse mix of stakeholders including governments, service providers, palliative care staff, volunteers, relevant peak bodies and importantly, communities. Such a structure would need enough authorisation, resourcing and collective will from all organisations involved to ensure its success.

Key responsibilities of a contemporary governance structure could include;

- Stewardship of an agreed model of care and palliative care ethos to ensure it is consistently realised across all settings in Latrobe.
- Visible leadership and accountability for palliative care services in Latrobe
- Meaningful and ongoing engagement with Latrobe communities and the local palliative care workforce
- Ongoing innovation, learning and development to achieve Victoria’s best end of life experience for Latrobe communities
- Exemplary levels of organisational collaboration to ensure that from a community and workforce perspective, the system is functional and seamless
- Utilising data and evidence from within the local palliative care system as a way to continually monitor and improve outcomes for patients and communities

Desktop research

Systems of end of life care are best designed in collaboration with people who have personal and professional experience of palliative and end of life care. New partnerships will create the new impetus for developing the care that people need at the end of their life. All health and social care systems should involve people who have personal experience of death, dying and bereavement. (UK Partnership, 2015)

We live in a world where improvement no longer comes about as a consequence of central direction. It is local leadership, in all that local leaders do, say and exemplify, that is vital to finding new ways of organising care and support for people. (UK Partnership, 2015)

When governments engage community-based palliative care providers to deliver end-of-life care, they must also put safeguards in place to ensure that those providers deliver high-quality care. Safeguards are particularly important in end-of-life care, given the vulnerability of users, the time-critical nature of their care needs and the stress that an end-of-life diagnosis entails for users, their families and carers. (Productivity Commission, 2017)

The design of appropriate safeguards depends on the risks that are being guarded against. In community-based palliative care, a critical risk is that the service provider may not respond to urgent care needs in the correct manner (for example, by failing to provide necessary medications, to answer an after-hours phone line or to respond to patient concerns in a timely manner). There is a need to ensure that quality care continues to be provided, and that oversight is maintained, as the volume of services provided increases. (Productivity Commission, 2017)

The leadership of CCGs and Local Authorities and, in particular Health and Wellbeing Boards, is needed to create the circumstances necessary for action. This would include identifying the local work needed to bring these ambitions into place, such as driving forward the use of personal budgets and working to support cross-organisational leadership and collaboration. It would mean championing an approach to commissioning that is collaborative, population based and proactive, and supporting the work of those who promote the public discussion of dying, death and bereavement. (UK Partnership, 2015)

Cross-organisational collaboration is vital to design new ways of working that will enable each community to achieve these ends. These systems must reach out beyond the usual networks of organisations and communities to call upon contributions, ideas and actions from a wider spectrum of people. We need integrated health and social care systems that work with people, as well as for people. (UK Partnership, 2015)

Opportunities and considerations

The contemporary governance structure described above is not to be confused with or proposed to replace existing clinical governance arrangements within health services. It is more about bringing services together through collaboration, valuing the perspectives of communities through meaningful and ongoing engagement, and providing leadership for the ethos and model of care that can be achieved across all palliative care settings in Latrobe.

In England, the Office for National Statistics runs an annual National Survey of Bereaved People (known as the VOICES survey), which collects information on people's views on the quality of care provided to a friend or relative in the last three months of life.

The survey includes questions about the physical and practical experiences of dying, including perceived pain relief and coordination of care, but also about some of the psychosocial aspects, including the perceived level of deprivation, dignity and respect, and the level of support for relatives, friends or carers at the end of life. The results of the survey are used to inform policy decisions and to enable evaluation of the quality of end-of-life care in different settings, across different ages and different causes of death.

Other considerations

Throughout the engagement process the following areas were identified for further research and consideration;

- The experiences and needs of Aboriginal communities, multicultural communities and children
- Residential aged care settings and how they integrate with and form part of the local palliative care system
- Implementation and impact of the Voluntary Assisted Dying Act 2017
- Health equity and the impact of death on social and economic circumstances

Next steps and implementation

This work has gone some way to surfacing and raising awareness of how people in Latrobe are experiencing local palliative care services and what their aspirations are for the future. Attention now needs to be given to how the vision and recommendations in this report can be achieved. This will require a willingness for change to occur and the backing of the Victorian Government to enable local solutions.

The establishment of a **Latrobe Palliative Care Taskforce** can bring together communities, services and governments to determine a plan of action and way forward. Local stakeholders including the Latrobe Regional Hospital, Latrobe Community Health Service, Gippsland Palliative Care Consortium and Gippsland Primary Health Network have already expressed their support and commitment to improving palliative care services in Latrobe.

The Latrobe Health Assembly has indicated that it can play a key role in guiding the establishment of the Latrobe Palliative Care Taskforce and to enable collaborative discussions to occur. The Latrobe Health Assembly has a remit to improve health and wellbeing outcomes for Latrobe communities through delivery of new initiatives as well as influencing how existing funds and services are directed.

The Latrobe Palliative Care Taskforce membership should comprise of;

- Latrobe Health Assembly
- 2-3 community representatives
- Gippsland Regional Palliative Care Consortium
- Latrobe Regional Hospital
- Latrobe Community Health Service
- Department of Health and Human Services
- Gippsland Primary Health Network
- Pharmacy Guild of Australia – Victoria
- 1-2 General Practitioners

One of the primary responsibilities of the Latrobe Palliative Care Taskforce would be the development of an action plan that considers costs, timing and priority allocation of work in response to the Latrobe Health Advocate recommendations.

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Appendix

Summary of engagement and co-design workshop.

Improving palliative care services in Latrobe.

Community engagement and co-design workshop.

On 2 July 2019 the Latrobe Health Advocate brought together communities, professionals and governments to share experiences and suggestions to improve palliative care services in Latrobe.

This workshop was the culmination of twelve months of engagement with people in Latrobe who had already shared their experiences, suggestions and aspirations about end of life and palliative care. It was an opportunity to bring everyone together to share the views of Latrobe communities and to contribute to the development of the Latrobe Health Advocate's recommendations.

The workshop was designed to achieve three things:

1

Shared perspectives.

Creation of an environment where everyone could come together, and, in the spirit of working together as equals and without judgement learn about what is working well and identify opportunities to improve the end of life of experience in Latrobe.

2

Consider a different end of life experience.

In doing so, identify some areas to improve the experience at home or in the hospital. Identify perspectives that had not yet been considered and questions that had not yet been asked or answered.

3

Shaping the Advocate's recommendations.

Reflect on the discussions in the lead up to and during the workshop. Consider the aspirations of Latrobe communities for a future end of life experience and identify what it might take to realise these and bring about change.

Participants were given the opportunity to share their own views and to listen to the views of others. They were encouraged to share with courage and to be generous with their listening.

This report includes a summary of the engagement activities from the workshop, along with the feedback, questions and suggestions from workshop participants.

The Latrobe Health Advocate asked…

Why is it important for you to be here today?

"To assist in finding a way to improve access to resources and support for people living with a life limiting illness and their loved ones."

"To make sure we can enable a good death where possible."

"I would like reassurance that the current issues are being heard as it is my opinion it is at crisis point."

"To provide real input to improve palliative care services in Latrobe."

"As a community we need the opportunity to have our voices heard. It will affect all of our families at some stage."

"I am reaching an age that I need to think about dying and I hope that Latrobe Valley has better options."

"To listen to our community."

"To be a voice for rural families who's children have a life threatening condition."

"To hear what others have to say."

"I've seen my mother, brother and best friend go through palliative care and I'm now going through it with my father. We need to do it better in Latrobe."

"To connect our perspectives and explore opportunities."

"To work together with other stakeholders."

"I see patients in the last days of their lives. I witness the struggles of patients and families."

What questions or comments are important for you to share today?

"How are the State and Federal issues to be resolved?"

"What can be done immediately to ensure palliative care services can improve?"

"Pain management is of the utmost importance."

"How can we advance the immediate palliative care hours of operation to be more user friendly?"

"Why is Latrobe Valley so far behind in palliative care availability and options?"

"When will we have a hospice in the Latrobe Valley?"

"How can we provide a better environment for care for those who cannot be at home?"

"My husband and family felt let down by the system."

"How can we make hospitals more user friendly for terminally ill people and their families?"

"Why don't people listen to those who are closest?"

"I would like to see if Latrobe Valley can finally get a palliative care hospice."

"The current palliative care system is absolutely fractured".

"The lack of current infrastructure in regional palliative care is frustrating and makes the provision of timely and holistic palliative care very difficult."

"The current palliative care set up causes me moral distress and undue stress and suffering within the community."

"We need to improve the system to make end of life respectful, dignified and personal. Not one that triggers bad memories."

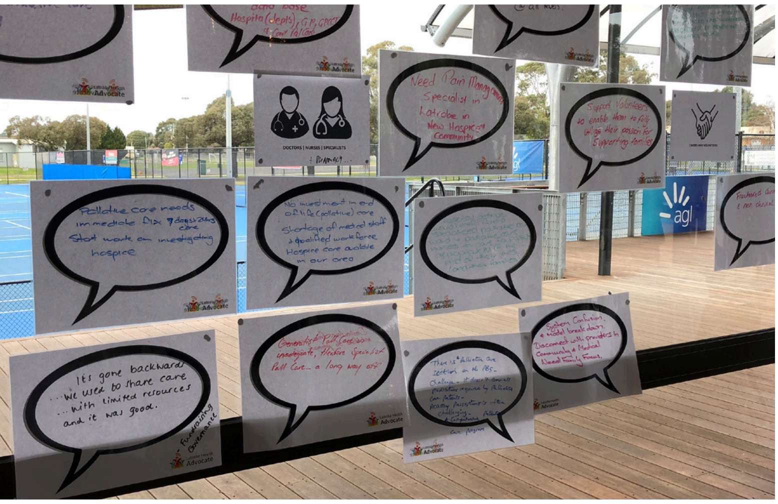
"We are still hoping for palliative care as it is described in the pamphlets."

"My brother's passing in Geelong was a very soft experience. My mother's passing in Latrobe was jarring and harsh."

Shared perspectives…

The Latrobe Health Advocate shared insights into what communities, health services and health professionals had already talked to her about. This was an opportunity for participants to learn about the perspectives of others and to reflect on how it related to their own experiences with end of life care in Latrobe. Together participants defined the end of life experience in Latrobe from multiple perspectives, thinking about what is working well and what could be improved.

Family and friends	**Patients**	**Nurses, Doctors, Specialists, and Pharmacists**	**Carers and volunteers**
"We need more bereavement support before and after passing." "We need the overall system to operate better." "The support of family and friends is essential…particularly when caring for someone at home…and after too." "Support is not available when families are most vulnerable. Loved ones only die once, it should not be so traumatic."	"A hospice would provide the real care that a patient and family need." "There is nowhere for younger adults to be cared for…an acute hospital bed is not the right place." "Hospital settings would benefit from a specialised palliative care ward and palliative care nurses to care for patients appropriately at the end of their lives (and their families)." "Accessing prescriptions is often challenging."	"We need all of our clients in one database." "We need stronger service coordination and better communication." "We need to increase awareness of our palliative care services." "Palliative care needs an immediate fix 7 days x 24 hours care. "Can we start work on investigating a hospice?" "Generalist palliative care is inadequate; therefore we need specialist palliative care."	"We need improved collaboration and cooperation at all levels." "We need pain management specialists in Latrobe." "We want to be able to provide adequate care to residents in a facility based age care environment regardless of money and staffing issues." "Volunteers need to be supported to fully utilise their passion for supporting families." "There is system confusion and model breakdown." "There is a disconnect with providers and the community." "It has gone backwards…we used to share care…with limited resources and it was good."



A future end of life experience in Latrobe...

Together participants considered what is important to people in Latrobe. They used storytelling and creative co-design activities to describe what a future end of life experience might be. In doing so, they imagined what could be different and the impact this might have on Latrobe communities.

- Nurses enabled to administer pain medications
- Time spent with friends and family
- Good transport connections
- Improved staff: patient ratios
- Every patient is afforded the same opportunities for care
- Introduction of palliative care navigators
- Enhanced training and professional development for staff
- Better and more flexible access to pain medications
- Government funding is appropriate and ongoing
- Pet therapy and access to animals
- Advance Care Plans are common place
- Individualised care
- Respite is available for carers
- Dedicated private spaces at health facilities
- A patient's final wishes are granted
- Patients have choices of place to pass
- A consistent homely environment across all settings
- Access to, and choice of doctor
- Flexibility for staff to work across multiple settings within one system
- Services are linked together
- Different delivery models with Nurse Practitioners a standard part of the team
- Volunteers utilised and moving freely between settings
- A place-based approach for Latrobe
- Mobile palliative care services for communities
- Alternate access and direct admission to hospital
- Doctors readily available
- 24-hour care, 7 days a week
- Privacy and intimacy
- Extra space
- Quality of life
- Peace
- Holistic care and a more comprehensive approach
- Appropriate training specific to paediatric palliative care
- A hospice available for Latrobe communities
- Kitchens for patients and families
- Community gardens
- Direct access to spiritual support
- A hospice with its own identity

Shaping the Advocate’s recommendations

Participants were asked to consider the existing system and community aspirations for the future. They were encouraged to identify opportunities for immediate improvement, questions and perspectives that had not yet been considered.

	What are the immediate opportunities for improvement?	What else needs to be considered?	What questions are we still holding?
End of life care in the hospital.	Better record management with access between health services - one client management system. Inclusion of pastoral care and spiritual supports. Alternate access for palliative care into the hospital. Palliative care training in graduate nurse and personal care assistant programs. Staffing increase to improve ratios. More education for hospital staff. More dedicated palliative care staff in the hospital.	Increasing existing service integration with palliative care. Medication management and safety. Palliative care interface with Voluntary Assisted Dying.	Who helps the person transition from life to death? Are there plans for a dedicated ward at the local hospital?
End of life care at home.	Increased support in the home environment. Immediate action to achieve 24/7 care. Note that we may need funding and workforce to go with that. Availability of services increase from 5 to 7 days. Timely access to medication.	Pain specialists and reporting mechanisms. Management of medicines. New Voluntary Assisted Dying legislation and role of care navigators.	What are the barriers to making palliative care 24/7? How long do we have to wait for a hospice?

	What are the immediate opportunities for improvement?	What else needs to be considered?	What questions are we still holding?
The broader palliative care system.	Increase in funding for an appropriate workforce. Social marketing campaign to promote and normalise end of life planning. Marketing campaign to promote existing services. System review and gap analysis. - Counselling - Health system review - Support system - Social and economic resources - Education - Training - Workforce supply - Clinical and referral pathways Determine a mechanism, fulcrum point, person or organisation that can mobilise the correct authorities to bring about change. Integrated allied health support and communication. Priority services and supports for those impacted by end of life. Can we define and explain what palliative care services are available in Latrobe and demonstrate how the 'system' currently works? Staff to patient ratios in aged care environments. Improved palliative care education to healthcare providers.	Hospice location accessible to transport and specialist services. Advance Care Planning and health literacy. Aging population and the impact on current resources and services. Impact of Voluntary Assisted Dying on current services and perceptions of. Specialist education and training. Relaxing the prescribing rules for nurses and nurse practitioners. Funeral director involvement - Before death - Integrated with care staff Better marketing of existing services. - Public menu - Training - Service coordination Could we centralise palliative care services to one organisation? Role of Centrelink. Impact on social and economic circumstances when dealing with death. - Financial - Employment - Cost of living - Housing Financial support for families following death.	Why are we not resourcing end of life care? Who will pull all the information on palliative care services together and market this to the community? Can the Latrobe Health Assembly fund a project to do this? Who is responsible for the removal or disposal of medications from the home? What can we learn from experiences in other regional areas in Victoria or internationally? What commitment is there to follow through on Latrobe Health Advocate recommendations? What are Government's current thoughts / priorities for funding? Can we connect with the Victorian Paediatric Palliative Care Program? Do we need policy reform and system change to enable people to access financial support? Can we repurpose an existing building for a hospice or palliative care unit?

Fireside chat

At the end of the workshop everyone sat by the fire and the Latrobe Health Advocate shared her reflections and invited participants to do the same.

"I loved the interactive building and working together. Meeting new people from all over."

"I liked how we could all express our opinions in different ways."

"Really well done, everyone was included."

"It was easy to have my say and there was no judgement."

"A great day spent learning more about such an important subject."

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