

14th September 2021

The Honourable Anastacia Palaszczuk MP, Premier and Minister for Trade
The Honourable Dr Steven Miles MP, Deputy Premier and Minister for State Development,
Infrastructure, Local Government and Planning
The Honourable Cameron Dick MP, Treasurer and Minister for Investment
Parliament House
George Street,
BRISBANE QLD 4000

Dear Premier, Deputy Premier and the Treasurer,

Re: True Choice for all Queenslanders during the debate on VAD

Palliative Care Queensland (PCQ) is neutral in relation to the Voluntary Assisted Dying (VAD) Bill, however as highlighted throughout the 57th Parliament Health and Environment Committee Parliament's VAD Bill 2021 Inquiry Report¹ the continual lack of funding for palliative care and systemic issues surrounding palliative care create barriers for Queenslanders to access quality palliative care when and where they need it. Further, this will continue to be the case without significant investment in the palliative care sector.

Data from other jurisdictions indicate that the option to access VAD would be taken up by less than 2% of the population, whilst Palliative Care is appropriate and beneficial for 100% of the population. This cannot continue to be ignored or unacknowledged in the VAD debate. The current Queensland Government commitment of \$171M over six years (approximately \$28M per year) is a small start, but it is **not enough funding**, and it **will not be delivered quickly enough** to meet the needs of Queenslanders who are experiencing serious illness, dying, death and grief. This funding has been labelled a 'reform' for Palliative Care, yet it fails to meet the majority of the recommendations found in the 2013 and 2020 Queensland's Parliamentary Inquiries into palliative care and is only 10% of what the Palliative Care peak body (PCQ), AMAQ (Australian Medical Association – Qld Branch) and Palliative Care Medical Directors have identified what is needed. PCQ has had very little consultation by Government in the formation of the "reform package". We have heard indication that future funding is being considered, and that our sector funding will gradually increase, however with more people migrating to Queensland and a rapidly ageing population, our members are concerned that this is not a **true reform**.

We believe there has been chronic under-funding of the palliative care sector in Queensland, which has resulting in a postcode lottery, workforce issues and an increase in unnecessary suffering. Everyone has the right to specialist and generalist palliative care, and this is not currently being delivered in Queensland. **Palliative care services must be resource, prioritised and funded.** Appropriate funding will deliver an exponential return on investment in terms of appropriate health care utilisation, quality of life, reduction in suffering, increased support for carers and bereavement pathways for families.

¹ <https://documents.parliament.qld.gov.au/TableOffice/TabledPapers/2021/5721T994.pdf>



True Choice is needed for ALL Queenslanders at the end stage of life

The Queensland Parliament's Health and Environment Committee Voluntary Assisted Dying Bill 2021 Inquiry Report¹ noted the following in relation to palliative care:

*"It (the previous Committee) also found that some Queenslanders experienced profound suffering as they die, in part **due to the challenges of accessing palliative care**"* (page 6)

*The terms of reference from the Parliament to the Queensland Law Reform Commission regarding development of an appropriate legislation scheme for voluntary assisted dying for Queensland included: "The provision of compassionate, high quality and accessible palliative care for persons at their end of life is **a fundamental right for the Queensland community.**"* (page 7)

*"In addition to the requirement to inform a person considering voluntary assisted dying about palliative care, the Bill includes the principle: ... **every person** approaching the end of life **should be provided with high quality care and treatment, including palliative care**, to minimise the person's suffering and maximise the person's quality of life.*

*The QLRC argued that 'any scheme for voluntary assisted dying **should complement, not detract from, the provision of high quality and accessible palliative care**', stating: The resources required to ensure that any legislated scheme for voluntary assisted dying operates safely and compassionately **should not be at the expense of palliative care services.*** (page 107)

The call for a significant increase in funding for palliative care services in Queensland was supported by numerous submitters. The need for increased palliative care resources to be provided in rural, regional and remote areas of Queensland was also noted by submitters, regardless of their stance on voluntary assisted dying.

The Clem Jones Group argued: We believe that the State Government needs to address any inequality in access to palliative care in the regions of Queensland as well as metropolitan areas. Hospices, in particular, are largely concentrated in South East Queensland and ought to be more available in regional Queensland. (page 108)

*While the committee appreciates the difficulties some Queenslanders can face accessing palliative care, particularly in rural, remote and Indigenous communities, it notes the work by the department in developing its Palliative and End-of-Life Care Strategy and the extra funding dedicated to palliative care which will support **gradual and targeted growth in the area**. Ultimately, a good death supported by properly resourced, accessible, high-quality palliative care should be available to every Queenslander.* (page 111)

PCQ calls for the Queensland Government to immediately and publicly address the following six areas during the public debate on the VAD legislation to ensure true choice for all Queenslanders at the end stage of life:

- 1. Publicly release a current transparent report on the Queensland Government's funding for palliative care, providing the actual spending from 2018-2021 and the budgeted funding for 2021-2022 (using the template provided in attachment 1).**
- 2. Publicly commit to a significant increase in ongoing service delivery and capacity building investment for palliative care (specialist and generalist) in the next budget, in addition to the current, inadequate investment of \$171 million over six years (or approximately \$28million per year).**
 - a. Including the Government's commitment to work with PCQ to advise on the investment
 - b. To ensure equal access to specialist palliative care, as to VAD (in the proposed VAD bill clause 10), which indicates access at 12 months, when most specialist palliative care services throughout Queensland are only available for 3- or 6-months prognosis due to resourcing. This includes equipment becoming available at 6 months.

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3. **Make the following two amendments to the Qld VAD bill to ensure adequate bereavement support and greater funding transparency:**
 - a. Amend Clause 5 (d) to include the words “Every person and their families should have access to bereavement care from diagnosis of a life-limiting illness to a minimum of 12 months after the death” (and preferably for as long as is required).
 - b. Include greater statutory reporting requirements of the Attorney-General or Health Minister, requiring them to report to Parliament on the amount the Queensland Government spends on palliative care during each financial year, and the aggregated amounts spent by the Queensland Government on palliative care during the preceding five financial years (this is similar to the South Australian draft VAD Bill which has been passed).

4. **If the VAD Bill is passed, PCQ requests the Government announce immediate support for both palliative care and the community through the following new projects from 2021-2024 (3 years) to demonstrate the Queensland Government’s support for palliative care and the general community during this significant period of societal change by providing new funding of \$14,750,000 over 3 years:**
 - a. **PCQ response to VAD project** - Focusing on supporting the palliative care sector to respond and adapt to this new legislation particularly in relation to policy, strategy, communication, and staff self-care (including QHealth and NGOs services). This will ensure that palliative care is not removed from the frontline to provide input into the VAD implementation [**Cost \$750,000 over 3 years**]

 - b. **Queensland Bereavement Care Program** - To support grief and bereavement issues that arise due to the public VAD discourse. This will also support the impact of COVID grief and loss and enable to palliative care sector to provide bereavement support to carers and family (which is currently a significant gap identified in the [Palliative Care in Qld 2021: Bereavement Care report](#)). This will provide online and face to face support, care, education and capacity building for the sector and community in relation to bereavement care [**Cost \$6M over 3 years**]

 - c. **Queensland Spiritual Care Program** - To support spiritual issues related to serious illness, dying and grief that arise due to the public VAD discourse, this will also support the impact of COVID and existential questions and enable palliative care sector to provide spiritual support to people in palliative care settings, carers and family (which is currently a significant gap identified in the [Palliative Care in Qld 2021: Spiritual Care report](#)). This will provide online and Face to face support, care, education and capacity building for the sector and community in relation to spiritual care in palliative care [**Cost \$3M over 3 years**]

 - d. **Queensland Palliative Care Volunteer Village Program** - A statewide palliative care ‘Volunteer Village’ to support palliative care services (specialist and generalist) and community groups, based on existing programs in NSW, VIC and ACT. Including Volunteer Coordinators in Specialist Palliative Care Services and programs similar to no-one dies alone [**Cost \$5M over 3 years**]

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5. **Clarify if VAD is going to be included in End of Life Care aspect of the Queensland “Queensland Palliative and End of Life Care Strategy”** (which is currently under development by Queensland Health). PCQ recommends that while palliative care can co-exist with VAD, they are not the same and therefore palliative care funding should not be used to develop a VAD Strategy. PCQ recommends that the Strategy is renamed Queensland Palliative Care Strategy and includes a detailed strategy for the improvement of both specialist and generalist palliative care across the state (and not just limited to the current commitment of \$171M over six years)
6. **Provide navigation support to the community during the public discourse on VAD.** Recognise the potential negative impact that this public discourse/messaging can have on individuals who are currently dying or bereaved. Whenever communications/marketing occurs regarding VAD (ie on social media) it is recommended that just as people do with suicide, that a line similar to below is included: *“if this discussion has brought up any issues for you, please contact Lifeline”*

PCQ is the peak body for palliative care in Queensland. Our priorities are that all Queenslanders are able to live every day until their last, are able to have a dignified death, regardless of their illness, age, culture or location, have access to a supportive social network at the end stage of life; and have the choice of quality palliative care. *Because the way we care for our dying is a significant indicator of the kind of society we are.* **If the Queensland Government is adding more choices, they also need to ensure that palliative care is a choice for all Queenslanders as well.**

Sincerely yours,



Marg Adams
President, Palliative Care Queensland
president@palliativecareqld.org.au



Shyla Mills
CEO, Palliative Care Queensland
ceo@palliativecareqld.org.au

CC: All Queensland MPs, Queensland Health, PCQ members and available on the PCQ website

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Attachment 1:

Why is PCQ calling for a transparent funding report on palliative care?

“Queensland Health does not systematically collect referral data in regard to palliative care. However, I can advise that episodes of palliative care, both non-admitted patients and those in public acute hospitals, have been increasing for a number of years.” (QON 2010²)

“Palliative care services are delivered in a range of settings within each Hospital and Health Service. Some patients receive care in the hospital setting but outside designated palliative care units and may therefore not be captured as a palliative care patient for the purposes of reporting. To accurately answer this question would be a significant task for Hospital and Health Services and divert resources away from front line services.” (QON 2020³)

What has been reported as spent on palliative care?

What has been stated in Hansard, media or to the palliative care medical directors

- 2015: \$100Million⁴
- 2018: \$95Million⁵
- 2019: \$123Million
- 2020: \$110Million
- 2021: \$162.9Million⁶
- 2020 Labor Election promise: \$171M over 6 years

When PCQ requested detail of the above expenses it was described as being a mix of budgeted and actual expenses based on when the statement was made.

PCQ is now requesting a transparent, detailed report on the funding provided by the Queensland Government using the template below.

- Including the actual annual figures from 2018-2021 and the budgeted expenses for 2021-2022
- If these are unable to be provided, please note the reason why and propose an alternative reporting measure that is collected
- If these are not currently provided, then please write “not provided”

General Area	Detail
State funding for statewide government initiatives non service delivery	QHealth Strategy and policy team
	QHealth Clinical Excellence Team (<i>ie Care@EoL etc</i>)
	Office of ACP
	SPARTA Project
	PallConsult
	SPACE Project
	Statewide Paediatric Palliative Care Collaborative Outreach Service
	CPCRE

² Question on Notice 17 October 2010 No 2163

³ Question on Notice 5 September 201 No 1352

⁴ Media Release 24 May 2021, Minister for Health and Ambulance Services) **current funding for palliative care was approximately \$100M** “Since coming to office in 2015, we’ve increased funding for palliative care to almost \$150 million a year, or around 50 per cent”

⁵ **2018 (15 June) the funding was noted as \$95M** (QON - see attached), which states it is including more than \$7M for NGOs

⁶ **2020-2021** (Media Release 24 May 2021, Minister for Health and Ambulance Services) **current funding for palliative care was \$162.9M (\$150M +\$12.9M for NGOs)**

“Since coming to office in 2015, we’ve increased funding for palliative care to almost \$150 million a year, or around 50 per cent”

“The government is also providing \$12.9 million a year to non-government organisations to deliver palliative care services in the community.

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General Area	Detail
	Specialist Palliative Care Medical Training Program
	Specialist Palliative Care Nursing Training Program
	Specialist Palliative Care Allied Health Training Program
	Statewide Palliative Care digital health program (<i>inc telehealth etc</i>)
	MASS
	Other funding provided (<i>for example Care in the right setting funding</i>)
	Actual workforce FTE in this area (and their roles)
	Actual number of palliative care trained volunteers
Hospice & community funding service delivery	Actual number of annual volunteer hours provided by palliative care trained volunteers
	Queensland NGO Hospices funding through the CSFB
	Funding for the development of new Hospices in Queensland
	Other funding provided (<i>for example CSFB service delivery, non-project funding</i>)
	Actual workforce FTE in this area (and their roles)
	Actual number of palliative care trained volunteers
	Actual number of annual volunteer hours provided by palliative care trained volunteers
HHS funding	Number of designated palliative care beds
	Number of designated Palliative Care episodes of care provided
	Actual funding per HHS (<i>including a breakdown of inpatient, outpatient, consult services, outreach services, scripting, HITH and telehealth</i>)
	Other funding provided
	Actual palliative care designated workforce FTE per HHS (and their roles)
	Actual number of palliative care trained volunteers
	Actual number of annual volunteer hours provided by palliative care trained volunteers
	Palliative care specific projects funded by HHS
Targeted NGO programs	Number of designated palliative care beds
	Number of designated Palliative Care episodes of care provided
	NGO funded projects related to First Nations Palliative Support
	NGO funded projects related to Bereavement Support
	NGO funded projects related to Spiritual Care in Palliative Care Program
	NGO funded projects related to Palliative Care Volunteering Program
	NGO funded projects related to building Compassionate Communities & public health approaches to palliative care (<i>capacity building, community engagement, development understanding and public education</i>)
	Ambulance Wish Queensland program
	PalAssist program
	Recurring Peak body support for strategy, policy, priorities, sector / consumer engagement and awareness
	NGO funded projects related to (one-off) strategy, policy, priorities, sector / consumer engagement and awareness
	NGO funded projects related to Palliative Care Data Registry
	NGO funded projects related to related to palliative care underserved populations program
	NGO funded projects related to young adult palliative care transitioning program
	NGO funded projects related to related to paediatric palliative care
	Other (NGO funded projects related to palliative care)
Other	Actual palliative care designated workforce FTE per project (and their roles)
	Actual number of palliative care trained volunteers
	Actual number of annual volunteer hours provided by palliative care trained volunteers
	Other Queensland Government palliative care funding support
	Other Commonwealth Government funding that Queensland Health administers and how this is distributed to different states (e.g. Care@Home, QuoCCA).

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Attachment 2:

Facts about Palliative Care: 10 reasons why we urgently need True Choice and Radical Reform in palliative care in Queensland

1. Palliative care benefits all Queenslanders living with a serious illness, regardless of diagnosis, age, location, or intent of treatment, from diagnosis through to bereavement care for loved ones. If VAD becomes legal in Queensland, this fact does not change. Regardless of which path people choose for their last hours of life, palliative care is needed for the months, weeks and days before that moment in time when death occurs. Currently, palliative care is only available to less than half the people who need and would benefit from it. ***We urgently need True Choice and Radical Reform in palliative care in Queensland.***
2. If VAD becomes legal in Queensland, the opportunity to access VAD will commence in January 2023. This is a golden opportunity for our Queensland Government to ensure policy and funding enables all Queenslanders to access quality palliative care when they need it, regardless of their diagnosis, age, location, or intent of treatment. ***We urgently need True Choice and Radical Reform in palliative care in Queensland.***
3. If VAD becomes legal in Queensland, less than 2% of Queenslanders will access it. Palliative Care is for 100% of Queenslanders, including those who choose VAD. ***We urgently need True Choice and Radical Reform in palliative care in Queensland.***
4. Palliative care in Queensland has been underfunded for decades, resulting in fewer and fewer Queenslanders being able to access palliative care when they need it. The demand for palliative care from our rapidly growing older population in Queensland has reached crisis point. The currently proposed palliative care reform meets only 10% of what is needed now. ***We urgently need True Choice and Radical Reform in palliative care in Queensland.***
5. The COVID19 pandemic has brought sharply into focus what can happen when people become seriously ill and there are not enough skilled health professionals to care for them. The specialist palliative care workforce is currently working beyond capacity. We need more skilled doctors, nurses and allied health staff to meet the palliative care needs of Queenslanders when they need it. In ICU ventilators are useless without the staff to operate them; in palliative care the medications and holistic care plans are irrelevant without skilled health professionals to deliver them. ***We urgently need True Choice and Radical Reform in palliative care in Queensland.***
6. Whilst the 2020-2021 budget announcement of a palliative care funding boost of \$171 million may sound like a big number, this is spread across six years, leaving an investment of just \$28 million per year for palliative care across the whole state. Palliative Care Queensland and the Queensland Palliative Care Medical Directors Group believe this is just 10% of what is actually needed. Furthermore, there are major gaps in the plan for this funding, including no additional funding for hospices, bereavement care, spiritual care, volunteers or compassionate community building. ***We urgently need True Choice and Radical Reform in palliative care in Queensland.***

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7. If VAD becomes legal in Queensland, it will be available for people who are expected to die within 12 months. Due to an overwhelming lack of funding and resources, most specialist palliative care programs in Queensland can only be accessed between 3 and six months before death is expected. This means people will be able choose VAD way before they have an opportunity to access palliative care services, and therefore disadvantages up to 98% of the population. This inequity needs to be addressed immediately. ***We urgently need True Choice and Radical Reform in palliative care in Queensland.***
8. Palliative care services, including hospices, receive very few donations, bequests and philanthropic grants compared to other similar charities. For example, whilst Cancer Council Queensland received **over \$19 million** (over 62% of their total gross income) in donations and bequests in 2020-2021, Palliative Care Queensland received **less than \$36 thousand** (less than 2.5% of their total gross income) in the same period. Yet, palliative care is for all Queenslanders, not just those with a cancer diagnosis. ***We urgently need True Choice and Radical Reform in palliative care in Queensland.***
9. No legislation or service can prevent all suffering for all people, including palliative care and VAD. However, palliative care can make a profound difference to the lives of those with a serious illness. We are a specialist sector with specialist knowledge and skills. Dying is sad. Caring for somebody who is dying is exhausting. Leaving a legacy takes effort and grieving is hard. The physical, emotional, social and psychological support provided by palliative care could be available to so many more Queenslanders who need it, if we were better funded and resourced. ***We urgently need True Choice and Radical Reform in palliative care in Queensland.***
10. Dying is a normal part of life. Dying well is a basic human right and takes planning and community support. It is not simply about the last breath, it is about how we educate our children to accept death, how we support our neighbours who are carers, how we provide last aid for a colleague, how we support our front-line specialist and generalist palliative care staff, how we support a loved one who is grieving; and how we play a role in making our own community, a compassionate community. ***We urgently need True Choice and Radical Reform in palliative care in Queensland.***

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Attachment 3:

What does True Choice and a Radical Reform in palliative care in Queensland look like?

PCQ has worked with the palliative care sector, Palliative Care Medical Directors and AMA Queensland to come up with a funding model for palliative care which was released in 2020. This called for an additional \$275million per year investment in palliative care to reach World Health Organisation standards and provide equal access to Queenslanders experiencing a serious illness, dying, death and grief. This is **\$53 per capita per annum**, a small investment to meet a universal need and address a human right.

*Details of this funding can be found in the PCQ Pre- Budget Submission 2021-2022:
<https://palliativecareqld.org.au/positionstatements/>*

The Government response was the election announcement of approximately \$28 million per year for palliative care, which leaves a **shortfall of \$247 million per year**.

While PCQ welcomes an investment to start the reform process and acknowledge that this will fill some gaps over the next 6 years, we recognise it is only 10% of what is needed and encourage the Government to commit to much needed project and program funding while debating the VAD legislation, as well as announce a significant investment will be announced in the next budget.

What is included in the shortfall of \$247million per year:

- *Statewide Palliative Home Care Packages*
- *Specialist palliative care workforce growth (Including allied health and administration)*
- *Statewide First Nations Palliative Support Program*
- *Increased support for Queensland Hospices*
- *Statewide Bereavement Support Program*
- *Statewide Spiritual Care Program*
- *Statewide Volunteering Program*
- *Increased Palliative Care Digital Investment*
- *Specialist and Generalist Workforce training Program*
- *Public Statewide Palliative Care Database and Registry (including progress measures and palliative care report cards)*
- *Increased palliative care research funding*
- *Increased funding for Palliative Care Queensland (peak body, policy)*
- *Queensland Compassionate Community Program (build community capacity and awareness)*

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Attachment 4:

What is palliative care?

Palliative Care Queensland's policy guiding principles

Palliative Care is about the whole person for the entire dying journey

for every age and every stage

about the community of care

about choice, autonomy & dignity

about living

not 'one-size fits all'

Everyone's business

care for the carer

a Human right

Palliative Care *It's more than you think.*

palliativecareqld.org.au

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