Position paper: Taking a palliative approach

May 2016

Churches of Christ in Queensland

Bringing the light of Christ into communities

About Churches of Christ

Churches of Christ in Queensland has a significant presence in Queensland, Victoria and Vanuatu with over 200 services in more than 100 communities, touching tens of thousands of lives each year.

We operate a range of missional and community care services to assist families, the elderly and people in need through church communities and our care services groups operated through Churches of Christ Care.

We provide a range of services for seniors including retirement living, home and community care, home maintenance and modifications programs, and residential care.

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Summary

Key points

- Dying is an inevitable part of life.
- We believe that by offering people dignity in death, we honour the importance and sacredness of their life.
- Supporting people to have a good death is a significant clinical practice and policy challenge that we must face as the population ages.
- Churches of Christ Care supports the Grattan Institute's view that "a good death gives people dignity, choice and support to address their physical, personal, social and spiritual needs."[1]
- Churches of Christ Care has adopted the palliative approach as a framework for increasing the dignity and choice for people at the end of life.
- A palliative approach promotes open communication between a person, their family and the care teams.
- A palliative approach acknowledges a person's choice through documented advance care plans for improved end of life care and can reduce unwanted hospital transfers.
- A palliative approach begins soon after a person comes into our care, not just in the last days or weeks of somebody's life. The approach begins early, when people are able to communicate their needs and wishes openly.
- Knowing that their choices will be upheld at the end of their lives, increases a person's sense of positive wellbeing.
- For those tasked with caring for a loved one who is dying, being aware of the person's wishes and having access to services to support them as carers can relieve significant stress.
- A palliative approach places death and dying in the context of positive wellbeing and involves a person's family and friends. This approach provides an experience of death that moves beyond the person dying and influences how their children, family and community view dying well.
- Churches of Christ Care supports the National Palliative Care Strategy and the guidelines for a palliative approach in residential and community-based care.
- Churches of Christ Care commends the Commonwealth Government for its support in rolling out the Residential Aged Care Palliative Approach Toolkit through the Department of Social Services Encouraging Better Practice in Aged Care initiative.

Recommendations

Churches of Christ Care recommends:

- The federal government investigates providing community-based palliative care packages to support people's choices around receiving care and dying in a setting of their choice.
- Any review of health and aged care funding models pays particular attention to increasing palliative care options for people in regional and remote communities.
- Any changes to the funding model for community-based palliative care are implemented alongside support for providers to take a palliative approach.

1 Swerissen. H. and Duckett. S. (2014). Dying Well. Grattan Institute. Retrieved from: http://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf p.2.

Background

Churches of Christ Care holds people at the centre of our services. In our Seniors and Supported Living services, we focus on giving people choice. To improve how we give people choice, we are implementing our award-winning Positive Wellbeing Model of Care. This model draws out people's strengths, needs and preferences for care, while involving the people who are important to them. Doing this allows us to deliver holistic care that improves quality of life and allows people to be active and engaged. This approach encourages people to have early conversations about what they would like to happen at the end of life, giving them greater opportunity for choice.

Dying is an inevitable part of life, and our goal is to enable people to die with dignity, in a setting of their choice. We want those in our care to experience the light of Christ in every aspect of their lives. We believe that by offering people dignity in death, we honour the importance and sacredness of their life.

The question of what makes a good death can be overlooked in health policy and practice, and can be hindered by a fragmented health system. In Australia, considering and talking about the detail of our deaths is uncomfortable and almost taboo, yet the reality is that most people would prefer to have a say in the matter. And while we do not control when a person will die, we can offer them choice around how they will be cared for, what kind of treatments they have and where they will be when they die. Supporting people at end of life is a significant clinical practice and policy challenge that we must face as the population ages. This paper examines how taking a palliative approach can help ensure that people are offered as much choice as possible at the end of their lives.

Dignity, choice and a palliative approach

As death approaches, people's needs and choices vary. By identifying people's choices early, we can adapt and individualise the care we provide to allow people to have a good death. Research tells us that:

> A good death gives people dignity, choice and support to address their physical, personal, social and spiritual needs[2].

To ensure that those receiving care from us at the end of their life are able to have their needs met, be treated with dignity and exercise their choice, Churches of Christ Care has implemented the *Residential Aged Palliative Approach Toolkit*[3]. A palliative approach can also be applied to caring for people in their homes and we are looking to roll this out across our community care services.

A palliative approach does not start in the last days or weeks of somebody's life. It begins early, when people first come into our care. A palliative approach brings people, their families and care staff, such as General Practitioners and nurses, together to have open and regular conversations about people's choices around death. This approach normalises talking about death and dying, and increases people's confidence when asking health professionals questions about their care. Taking a palliative approach means that we know and respect people's care choices at end of life[4].

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2 Swerissen. H. and Duckett. S. (2014). p.2.
3 For more information visit http://www.caresearch.com.au/caresearch/tabid/2917/Default.aspx
4 University of Queensland/ Blue Care Research and Practice Development Centre. (2012). *The Palliative Approach Toolkit*. Available at: http://www.caresearch.com.au/caresearch/Portals/0/Documents/WhatisPalliativeCare/PA-Toolkit/01809-CEBPARAC_module%201%20web.pdf

Providing spiritual care

> When people are overwhelmed by illness, we must give them physical relief, but it is equally important to encourage the spirit through a constant show of love and compassion. It is shameful how we often fail to see that what people desperately require is human affection. Deprived of human warmth and a sense of value, other forms of treatment prove less effective. Real care of the sick does not begin with costly procedures, but with the simple gifts of affection, love, and concern.
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> - His Holiness The Dalai Lama[5]

Taking a palliative approach means not shying away from people as they contemplate the big questions at the end of life. What has my life meant? Have I made a difference? And what happens next?

At Churches of Christ Care, we view spiritual care as being as important as physical care, and even more so at the end of life. Working as a team our nurses and chaplains along with family members are able to be attentive and listen to people as they near the end of life, offering them comfort and compassion. By doing this, we foster a sense of openness and spiritual wellbeing for those in our care, which is part of offering people dignity at the end of life.

The role of Advance Care Plans

A palliative approach also encourages the development of Advance Care Plans. These are designed to give people choice around their future care and give them time to consider the tough questions while they are still able to do so. The Advance Care Plan process allows people to consider what's important to them, their beliefs, goals, values, preferences, quality of life as defined by them, and how they want to be cared for. The plan is about thinking ahead in case they are unable to communicate decisions about their own future care[6].

Having a written advance care plan can improve end of life care and reduce unwanted treatments and hospitalisation.

The benefits of a palliative approach

Individuals

A palliative approach facilitates early conversations to draw out what may have been unspoken and encourages people, their families and staff to explore issues beyond day-to-day care. These conversations provide people with information and choice, which can decrease or even stop unwanted transfers to hospital. People often chose to stay in familiar surroundings with familiar faces and the familiar touch from those providing regular care for them[7]. Knowing that they will be cared for and their choices will be respected increases people's sense of positive wellbeing, and also has a positive impact on their family and friends.

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5 Puchalski, C. M. (2009). "Compassion: A Critical Component of caring and Healing". in Swinton J and Payne R. *Living Well and Dying Faithfully* Chapter 9.

6 Australian Government. (2015). *Palliative Care – Advance Care Planning.* Available at: http://www.health.gov.au/internet/main/publishing.nsf/Content/acp

7 University of Queensland/ Blue Care Research and Practice Development Centre. (2012).

Molly's* Story

We work hard to give people good quality of life in their time with us – we want them to make the most of the time they have left.

Molly came to live at one of our residential aged care facilities not long after being diagnosed with pancreatic cancer. Very early on we began discussing with her and her family what would happen as her illness progressed. Our staff worked closely with the local palliative care team to plan with Molly and her two sons. We regularly work with this team, who are employed by Queensland Health, to provide specialist consultancy services at our residential aged care facilities.

Through these conversations and planning, Molly and her family had access to relevant and appropriate information, how pain would be managed and what else could be done to provide Molly quality of life. These are hard conversations and at times Molly felt depressed. But talking about the plan and providing reassurance about how she would be cared for helped give her some comfort. We also connected her with our chaplain to discuss what was happening and how she was feeling. Molly was a very social person, so we made sure she had frequent company by getting our volunteers involved and encouraging her to come along to activities – although that wasn't too hard, she always joined in with a smile.

By taking a palliative approach we created a care plan for Molly that took care of her medical needs, facilitated her choices and included plenty of social interaction. Molly was fully aware of her condition and prognosis but enjoyed every single remaining moment of her life with her family, our staff and the other residents. Molly was always quick to smile and never seemed to be overwhelmed by worry and fear.

The impact of this was felt not just by Molly, but her sons and our staff. Her sons, who were frequent visitors, were very happy with the care we provided Molly. After she died they came in to say thank you and still pop in from time to time to say hello to our staff.

*Names have been changed

Carers and families

About 70 per cent of people want to die at home and as we work to support this choice, we must consider the added pressure this puts on the informal care provided by family and friends[8]. Caring for someone who is dying is a 24-hour job that can cause significant stress and anxiety, with many carers who do not anticipate the impact it will have on their own well being[9].

Through the regular open conversations facilitated by a palliative approach, we are able to identify when carers are experiencing distress and provide additional support. In this way a palliative approach provides holistic support that includes families and carers.

8 Swerissen. H. and Duckett. S. (2014).

9 O'Connor, L., Gardner. A., Millar. L., Bennett. P. (2009). "Absolutely fabulous—But are we? Carers' perspectives on satisfaction with a palliative homecare service." *Collegian.* **16**(4): 201-209.

Antonio and Ricci's* Story

The timing of palliative case conferences is essential. It can mean the difference between the conversation going well or badly.

Antonio was a resident at one of our aged care facilities and he had many pre-existing conditions and co–morbidities. His prognosis was poor and the terminal phase of his care was imminent. Antonio's son, Ricci, is extremely proactive and actively participates in all of his fathers care needs.

After Antonio was admitted to hospital with a life-limiting condition, Ricci become very distressed. The medical officer at the hospital had told Ricci that due to multiple co-morbidities, his father's prognosis was very poor and he may need to think about what medical interventions were appropriate for his deteriorating condition.

Ricci was upset, confused and not sure what he should do, and there were no other family members close by to provide any support. When Antonio was transferred back to the facility he was on continuous oxygen and medication for pain. Ricci was clearly distraught, tired and frustrated. He asked repeatedly what he should do.

We took Ricci to a quiet place where we would not be disturbed and had some coffee to help him relax. We began talking about the palliative approach. We explained Antonio's pre-existing and current life-limiting illnesses, helping Ricci to understand about advanced disease progression. We arranged a palliative case conference so that Antonio, Ricci, the care team, Antonio's GP, the chaplain and other nurses could come together to talk about Antonio's care. The aim of this meeting was to identify clear goals of care for Antonio, including a review of his advanced care plan.

At the case conference we discussed Antonio's cultural, psychological, social and spiritual care needs. Antonio is Italian and a practising catholic, which was very important to him – he has a cross on rosemary beads that he keeps with him at all times. He asked that the priest be present to give him last rights and also to be visited by him regularly. Antonio also expressed a desire to be warm with dimmed light and gentle Italian music playing. He wanted the knitted quilt his wife made over him and not to be left alone.

End of life care is very confronting when not explained well. After the case conference Ricci was given the opportunity to ask more questions and was given a copy of the Advance Care Plan. He appeared more relaxed and said that although it is upsetting to discuss the end of life care for his father, it was explained well and he now had a better understanding of everything.

By taking a palliative approach and using a case conference to develop an advance care plan, we avoided the risk of having to make these hard decisions when Antonio would no longer be able to participate in the process. This process also eased Ricci's distress, giving him a clear picture for what was happening and knowing that his fathers wishes would be met.

*Names have been changed

The community

Our views on death are influenced by our culture, religious beliefs and by how our loved ones experienced death. By improving the way we approach the end of life, focusing on giving people choice and dignity, we have the opportunity to transform people's perceptions of death and dying.

A palliative approach places death and dying in the context of quality of life and positive wellbeing and is inclusive of a person's family and friends. When done well, this approach provides an experience of death that moves beyond the person dying and influences how their children and family begin approaching their own lifespan and journey to dying well. It can create a ripple effect, getting conversations about death and dying happening even earlier and starting to change minds across generations about what death can look like and mean. As these positive experiences are shared with others, slowly the experience of death can transform from something unthinkable to something that can be experienced with dignity.

Below is an example of some of the new practices happening across our residential aged care services after implementing a palliative approach. This approach has encouraged our staff to find ways of showing dignity and respect to people once they have passed away, and to give everyone a chance to say goodbye. Doing this is having a significant flow on effect to others, especially our residents, who gain a stronger understanding of what will happen when they pass away.

Saying goodbye to Greg* – from a service manager

Recently a resident, Greg, passed away at our facility and although sad it turned into a beautiful procession of respect and love.

When Greg passed away, the staff, fellow residents, his family and volunteers were able to say goodbye to someone they had either cared for or shared a home with.

When leaving the facility, staff, other residents and volunteers formed a guard of honour at the front door and had an opportunity to say goodbye. Someone played music on the organ and our staff and volunteers sang Greg's favourite song. This added so much meaning and made the farewell even more beautiful.

Saying goodbye is always difficult, but doing it this way shows respect for the person who has died and gives friends and neighbours the opportunity to show their respect. This is important as while living in such close proximity to each other, residents form friendships that develop and grow.

Some cried while others supported residents and family in their grief. Later, Greg's family expressed their gratitude and were overwhelmed with the love and respect shown to him. They are looking forward to retuning for the end of life celebration, which remembers all residents who have passed in the last six months. They expressed a feeling of belonging and feeling like part of the family at our facility.

We placed a memory book with Greg's biography, a candle representing his soul and fresh flowers at the entrance to our facility. The book will stay there until everyone has had a chance to place a memory of their time with Greg. Then the book will be given to his family so that they can have fond memories of their time with us.

Being involved and showing respect at the final goodbye is a wonderful tribute, it is not about religious belief as we are a multi-denominational service, and do not discriminate against personal beliefs. This way of saying goodbye shows residents still with us that they too will be shown respect and love when it is their time and they too will be remembered. Many have said it has made them more at ease with the process of dying as they know what to expect when their time comes.

*Names have been changed

Government as funders of health services

A palliative approach reduces the likelihood of hospital admissions as most people would prefer to die in a known environment with people they know[10] [11] [12]. Research is starting to show that supporting people's choice to die at home, in residential aged care or hospice facilities can contribute to reducing the high health care costs associated with the end of life[13]. However, Palliative Care Australia notes that access to community-based palliative care services vary based on people's location and what is available in the area[14]. This indicates that there are gaps and inconsistencies in the current health system that restricts people's ability to die where they choose.

The role of government

Churches of Christ Care commends the Australian Government for its support in rolling out the *Residential Aged Care Palliative Approach Toolkit* through the Department of Social Services Encouraging Better Practice in Aged Care initiative. As an aged care provider, this has supported our work towards implementing a palliative approach across all of our residential aged care services. Other capacity building projects under the National Palliative Care strategy are also commended. There is now an opportunity to build on this work to encourage widespread use of a palliative approach in community-based care services.

Community-based aged care services support people to stay in their homes for as long as possible. Recently, the 2012 Senate Affairs References Committee Inquiry into Palliative Care in Australia, the 2014 Grattan Institute report, *Dying Well* and Palliative Care Australia have recommended that community based care funding be extended to include in-home palliative care services. **Churches of Christ Care supports these recommendations**, as providing community-based palliative care packages can support people's choice to die at home.

Churches of Christ Care also recommends that any review of health and aged care funding models pays particular attention to increasing palliative care options for people in regional and remote communities. Choice for people in these communities is often limited due to a lack of access to palliative care services in hospitals and residential aged care facilities - access to palliative care services to support people to die at home is even more limited.

Churches of Christ Care strongly recommends that any changes to funding models to support community-based palliative care are implemented alongside support for providers to take a palliative approach.

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10 Palliative Care Australia. (2015). *2015-2016 Federal Pre-Budget Submission*. Retrieved from: http://www.palliativecare.org.au/Portals/46/Policy/Submissions%20and%20reports/2015-16%20Federal%20Pre%20Budget%20submission%20final.pdf

11 Swerissen. H. and Duckett. S. (2014).

12 University of Queensland/ Blue Care Research and Practice Development Centre. (2012).

13 Palliative Care Australia. (2015).

14 Palliative Care Australia. (2015).