

Queensland Aged Care, Palliative Care and Voluntary Assisted Dying Submission

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Without going into all the statistics of current and future demand it is a changing community expectation that RACFs will need to adapt to providing more individualised care in settings offering healthier meals, greater opportunities for exercise and more diverse entertainment. People entering a facility with full cognitive ability will expect greater autonomy in their wake and sleep times, meal times and other aspects of their day to day care. Those approaching their 50's and 60's have enjoyed all the comforts of luxury living (by 3rd world standards) and rampant consumerism and are used to having what they consider as normal requirements in life. As a person very close to the end of their 7th decade and having worked in aged care around the millennium I have no desire to ever enter a RACF and there are many liked minded people of whom I am aware.

Another aspect of those entering their elder years is the often false expectation that there is always another care option available from the medical service and pharmaceutical business. This misunderstanding, especially in people with chronic disease and multiple co-morbidities leads to a life of quantity at the price of quality as their disease burden continues to restrict and reduce their quality of life (QOL). Caring for these folk then produces huge costs on the health budget. These are the people putting a high demand on the the aged care sector and given poor health choices by those in their 50's and 60's the demand on aged care services will loom as an increasing burden on the health care system.

It is extraordinarily hard on the aged care workers in RACF to fulfil the level of personal care and attention they wish to give, multi task to reduce costs to the facility and report in a standard acceptable to the accreditation industry. As accreditation came into being in the new millennium it certainly showed how time consuming and demanding it is meeting the 44 standards. It seems to me this now drives the system of care rather than the actual delivery of health care and while I recognise there are genuine concerns of inadequate and inappropriate care in some facilities the lack of staff and the low ratio of RNs to basically trained aged care workers is now endemic. As an RN working in the system the pressure of trying to meet the needs of everyday care let alone the unexpected fall and trauma, sudden health changes and difficult behaviours exhibited without warning are beyond challenging and give no work satisfaction, when it can be a most enjoyable and satisfying job caring for the senior members of our society. In my Mother in law's (MIL) situation 10 years ago in the NSW border town of Tweed Heads I was amazed and appalled by the lack of a RN in the facility at all. The care staff were mostly friendly and developed relationships with the residents but from my experience their total lack of advanced training meant that my MIL developed health conditions and experienced unnecessary pain due to their lack of skill in recognising the symptoms. This impacted by having more frequent hospital admissions that could have been avoided by more skilled care. Inadequate and inappropriate care costs the health system more with

the need for either hospital admissions at a cost of \$4,000 to \$10,000 to treat an infection that could have been treated more easily, quickly and efficiently if the symptoms were recognised at an earlier stage or treatment costs with expensive dressings or similar.

Skilled and well trained RNs in community, aged and palliative care will save thousands of dollars by keeping people out of hospitals. There needs to be sufficient numbers of these well skilled RNs with time to do thorough assessments, care and surveillance across our communities, especially in regional, rural and remote areas to effectively improve peoples health status.

There needs to be a total turn around of health funding and promotion so that huge amounts of funding is available for primary health and disease avoidance with the understanding clearly voiced to people of the need to take full responsibility for their own health status. The medical profession needs to be more responsible in discussing the limited options available as chronic health conditions and disease proceed and also to talking more categorically to people about dying and death being an appropriate choice at some stage during their lack of health journey. Discussion must be clear in how inappropriate it is to have a very old person and / or one with a very high disease burden being sent to hospital and treated in intensive care (ICU) or critical care. Statistics show these people usually die in hospital after a lengthy stay on discharge from the ICU.

Figure 1. Average number of admissions# and length of stay in Queensland hospitals in the last 6 months of life for those who died from selected chronic conditions between January 2010 and November 2011*

Source: Queensland Death Registrations, Queensland Cause of Death Unit Record File, Queensland Hospital Admitted Patient Data Collection

*h t t p s : / / w w w . g o o g l e . c o m / u r l ?
s a = t & r c t = j & q = & e s r c = s & s o u r c e = w e b & c d = 6 & v e d = 2 a h U K E w j R p K -
U 8 b r h A h X S X i s K H V K q B I 8 Q F j A F e g Q I B h A B & u r l = h t t p s % 3 A % 2 F % 2 F w w w . a i h w . g o v . a u % 2 F r e p
o r t s % 2 F h o s p i t a l s % 2 F d e a t h s - i n - a u s t r a l i a n -
h o s p i t a l s - 2 0 1 4 - 1 5 % 2 F c o n t e n t s % 2 F s u m m a r y % 2 F d i d - t h e - p a t i e n t - s p e n d - a n y - t i m e - i n -
i n t e n s i v e - c a r e & u s g = A O v V a w 3 P F A 1 j q g k 4 l x o 7 L O W 2 X G b x*

As a highly skilled and still practising specialised palliative care RN and working in the community setting for 20 years I strongly applaud the provision of aged care packages to allow older people to remain in the comfort of their own dwelling and in the neighbourhood they know. My experience from discussing the need with our patients to apply for My Aged Care (MAC) is often one of “I don’t need that yet” and then checking on what advanced care planning they have in place to find there is nothing and the person does not wish to discuss that as it is about the end of their life and they don’t want to consider that subject.

This indicates there is still a lack of public knowledge on the needs for these subjects to be so well known, that older people especially, have acted accordingly. I consider TV and

radio advertising in equal frequency to the current advertising for funeral planning needs to be an opportunity for really getting people to be more comfortable about their death at some time and to be less complacent on having appropriate plans and personal choices in place for the journey between now and then. At this point there is a lot of time, effort and money put forward by the government in up-skilling health professionals “at the coalface” in advanced care planning but it takes a lot of time convincing people to act. As someone at that most crucial coalface it becomes very time consuming and burdensome to help those in the care of my service Little Haven Palliative Care (LHPC) to achieve this planning, especially as it is reportable to QH on the level of care planning achieved. Despite much time and effort in discussion it is not followed through at what would be called a successful level of achievement and can be at the expense of developing a strong and therapeutic relationship that is required for palliative and ultimately end of life care. It is not fair practice for QH to pass on the responsibility of Advanced Care Planning to NGO and NFP community services without funding the time it takes to achieve an adequate uptake.

The other huge difficulty for our small service of specialised palliative RNs in an inner regional area is trying to get supportive services into the home at a timely and appropriate level to meet the changing needs of a person with a terminal illness. As our area has only just received the NDIS we have no experience of assistance for those people accessing our service who are under 65. Currently we try and get extra help in the home through Community Care Services but this may or may not be successful and often it is the lack of availability with the domiciliary nursing services to have capacity to assist.

Having extra support and care services in the home when needed (some people have rather quick deterioration) is the help that can make the difference in people with a palliative diagnosis being able to remain in their own home that is most often their chosen place of care and dying. If someone is over 65 but has not applied for MAC and their prognosis is 3 months or more then applying for and then receiving a level 2, 3 or 4 package is unlikely in their remaining life.

From my experience since the change to MAC and NDIS there is a rift in provision of services for palliative patients with limited prognoses. There is nothing truly supportive to assist people to stay in their own home (national desire is 80% wishing to die at home) in the limited span of their life that is available when it is needed. Also, from my experience being funded from the QH HHCS provisioned palliative care service in the region I work in is very restricted to the last week or two of life as they have increasing demands from the increasing numbers of palliative patients in their area of operation and responsibility. This funding covers nursing visits only and is restricted to an hour per day unless applied for exceptional cause. This funding does not cover travel time as many of our patients can live up to 76 kilometres from our centre and can add several hours a day of non productive time in travelling, all to keep that person at home with their symptoms appropriately managed.

The best palliative care starts at a community level by a group of people wanting better choices for their loved ones as did LHPC when around 1980 a forward thinking woman name Phyl Little determined her community needed to do better in helping people with a terminal illness receive the best supportive care and equipment possible, initially in the home but also in hospice if necessary. She formed a supportive group of people around her who were able to carry on her vision, philosophy and support to patients / families after she left the area. This service gained traction and due to committed fund raising they were able to cover the cost of commissioning 2 palliative care beds in the local hospital long before city hospitals were even thinking of palliative care being a viable option in the care trajectory of a person with a life limiting disease. This was in lieu of a hospice at the time. The funding also included education opportunities for RNs to up-skill in palliative care. Ultimately in 1999, the committee was successful in receiving initial funding from QH to deliver a nursing service dedicated to the provision of palliative care in the home with 24 hour access. From there the service has grown and attempts to admit all those who seek our assistance. Through the dedication of the Board, the staff and the many volunteers who assist with respite care and fund raising our service has reached the stage of assisting over 200 people + families /carers requiring palliative care per year, keeping up to 67% of our patients in their home to die and often without the need for a hospital admission. This is closely followed by patients who are admitted to hospital as a matter of choice or need, dying within 5 days of admission. The support continues for the grieving in supporting them for the time they need to readjust to life as it is now.

This model of care developed in our community has been recognised by the National Productivity Commission into Palliative Care as being the Gold Standard of palliative care and QH now wish to see similar types of community palliative care services available in all communities.

Our community of statistically low incomes has consistently been educated about palliative care due to the need to continue funding the service way beyond the assistance from government. The service excels in the provision of home based care, wholistic support to the palliative person and their carer/s so that the physical, mental, emotional and spiritual wellbeing concerns are identified and supported in a timely and responsive manner. Our nurses have the capacity to prioritise need and stay with a patient / family when there is a lack of education and awareness, overwhelming distress or symptom management or the imminent dying / death of the patient. Along with the ready supply of purposed equipment, access to a social worker, the benefit of complementary therapies, reassurance a nurse is always on the end of the phone no matter what time of day or night and the relationship of non judgemental support, advocacy and respect of their autonomy from the staff and volunteers is the fact that our carer surveys register high quality of support and satisfaction of our service. Our carers are up-skilled, educated in the use of medications for symptom control, monitored and supported as required so

they can successfully give appropriate medications to control symptoms in the home at the time it is needed. This ultimately may be experienced as an unpleasant memory but the knowledge that they were able to give the very best of loving care lives strongly with them afterwards. Unfortunately many hospital doctors and nurses do not believe that family members are able to provide such a level of care even when there are excellent support services available.

As part of the care and support available is the GP who is the team leader of symptom management and medical support. The GP and LHPC also have the support and guidance of the specialised Palliative Care Service who often are involved in more complex patient management. Our service and the Palliative Care Service has assisted many of the local GP's increase their understanding and involvement in successfully caring for a palliative patient in the community. The GPs work readily with our service as our nurses successfully identify and manage symptoms as they arise and fortunately there are still a fair number who are prepared to make regular or when needed home visits if at all possible. As I understand it there is no Medicare allowance for that and it is down to the goodwill of the GP and their relationship with their patient.

From my experience there is something wondrous about being present and holding space for those transitioning in either birth or death. Being present when a person is passing from this life is an honourable gift and a beautiful experience as we put so much effort into managing symptoms to allow it to be as peaceful as possible. It is part of the journey we travel with our patients and their families in helping them accept and prepare for this event. With good support it becomes possible to have what is referred to as a "good death" no matter how it may look to others as a death will be just as individual in its makeup as the person is who is dying and those around who are part of their journey in life. The other wondrous thing is seeing family /carers becoming empowered so that their increased strength and resilience becomes their staff in times of distress and hardship. This all happens as strong therapeutic relationships are built over the short or longer term and has led to many of our carers choosing to be a LHPC volunteer sometime after their loved one has died. This further strengthens the ties with the community with a sense of community pride and ownership of its very own palliative care service.

This is what community palliative care should be and if this was practised across the board then it would save the horror stories so many people seem to have of how they felt palliative care failed them and their loved ones.

On voluntary assisted dying (VAD) I understand the angst people feel as they become increasingly trapped in a failing body. I think many people do not have personal awareness or the capacity to imagine what living with unresolvable pain, overwhelming mental distress or increasing dependence on others for the smallest actions in life and how undignified that can be. Also from my 30 plus years in palliative care I have seen

people who have made the choice to end their own life at some point when it becomes untenable to them, then decline that path as great supportive care has given them the desire to allow nature to take its course. When death is days or weeks away and cannot be altered I can understand some people wishing to avoid that last part of total dependence and maybe suffering or perceived suffering and wish they could finish their life sooner. I understand the grief those who love them feel when they watch a loved one go through the normal process of normal dying (as opposed to a rapid death) and are concerned they are being starved or left without adequate hydration and maybe have some inadequately controlled pain. They say “ if this loved one was a dog they could put them down” to save the suffering.

How much of this disquiet is due to a lack of spiritual sustenance, community avoidance about the subject of death and dying and lack of awareness, education, proper care services and support in a holistic manner in the processes of dying?

If VAD is accepted as a legal action my thoughts are that a doctor or other is not the person taking the final action but the patient having the requirements to hand to self administer. This makes sure the onus of dying is on the person requesting the assistance and the wherewithal to do so after all the appropriate checks and balances have been attended.