



Inquiry into End of Life Choices

August 2015

Introduction

Ballarat Health Services (BHS) recognised that the care that people receive at the end of their life was not routinely meeting their needs or the needs of their loved ones. In 2013, the organisation commenced a project to develop an End-of-Life Framework in response to adverse incident data, patient feedback and concern from health care providers. A range of elements had been discussed in the quest to improve the way health care providers manage end-of-life care. Advance care planning had been in the space for some time with the purpose of respecting the wishes of people to determine their future health care needs (Respecting Patient Choices®). The Liverpool Care Pathway had been suggested as a way to offer effective palliative care outside the specialist palliative care setting. The organisation had participated in an improvement group on end of life care facilitated by the Health Round Table and the Australian Commission on Quality and Safety in Health Care (ACQSHC) had in draft a consensus statement on end-of-life care. Ballarat Health Services had previously piloted some of these elements in some areas of the health service. It was determined that we needed an integrated approach to managing end-of-life care across the whole health service. That is, across the Acute, Subacute, Mental Health, Community and Residential Aged Care settings.

Despite having some of the best palliative care services in the world, half the deaths in Australia occur in an acute hospital setting and a further 30% occur in a residential aged care setting¹. It is estimated that 70% of people who die in hospital receive curative treatment right up until the moment of death which may not be in accordance with their end of life (EOL) choices. The acute care sector focus is traditionally on treatment and cure, along with increasing survival rates and reducing mortality and our challenge is to ensure that the dying patient and their family receive optimal care in accordance with EOL choices.

The BHS End-of-life Framework project

In August 2013, after agreement at Executive and Board level, BHS commenced the End-of-Life Framework project. Almost 2 years into the project, the organisation's commitment has extended to another 12 months of work to ensure the framework elements are embedded.

The Framework elements that we believed were needed were:

- Advance Care Planning
- Tools to assist in recognising people at risk of deteriorating and dying – to identify those with whom we need to be having a discussion about limitations of treatment
- Goals of Care planning – for discussing and documenting limitations of treatment
- Care of the dying management plan – effective palliative care that can be used outside the specialist palliative care setting
- Bereavement considerations and supports.

The voices of those who have been involved in end of life care whether from a personal perspective or experience or as part of their professional activity were considered critical. With ethics approval, focus groups of health care providers and consumers were conducted. Interviews (semi structured interviews) with the first next-of-kin of people who had died at BHS in our acute and subacute facilities in 2013 were also undertaken. The results of this work informed the development of the framework. While our findings are yet to be published, aspects of the work will be discussed in this submission as

¹ Swerissen H, Duckett, S. 2014. Dying Well, Grattan Institute. <http://grattan.edu.au/report/dying-well/>



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it was a significant guide for the End-of-life project steering group in determining what the framework would look like.

Analysis of interviews with the first next-of-kin identified the following main themes:

- **Conversations and communication:** this included discussions or communication with nurses and medical staff on the current health status of their loved one. This may have included formal family conferences or bedside conversations.
- **The care experience:** the care received by their loved one (the person dying) and themselves by members of the health care team.
- **Family's preparation for death:** conversations with nurses and medical staff about the dying process. This may also include conversations between family members and their loved one
- **The dying experience:** this is the description of death, whether the participant was present or not. It included viewing of the body on the ward.
- **Follow-up after death:** conversations, meetings or any contact from the health care service after the death of a loved one.

There was participation and involvement of professionals and consumers from a wide range of backgrounds in our focus groups. All participants involved as stakeholders in the consultative process expressed a passion and desire to improve end of life care.

The overwhelming themes that emerged from the discussion revolved around communication, conversations and choice. Health professionals saw advance care planning as a means of addressing shortfalls where the care delivered did not meet the expectations of patients and family. Consumers expressed a desire to be listened to and that their knowledge of their loved one's wishes be acknowledged and respected.

Analysis of the consumer focus group data by Dr Wendy Penney (Head of Discipline, Nursing & Midwifery, Federation University) stated: Much of the discussion related to being able to choose not to be treated and this was at times emotional as consumers shared occasions when choice was not an option.

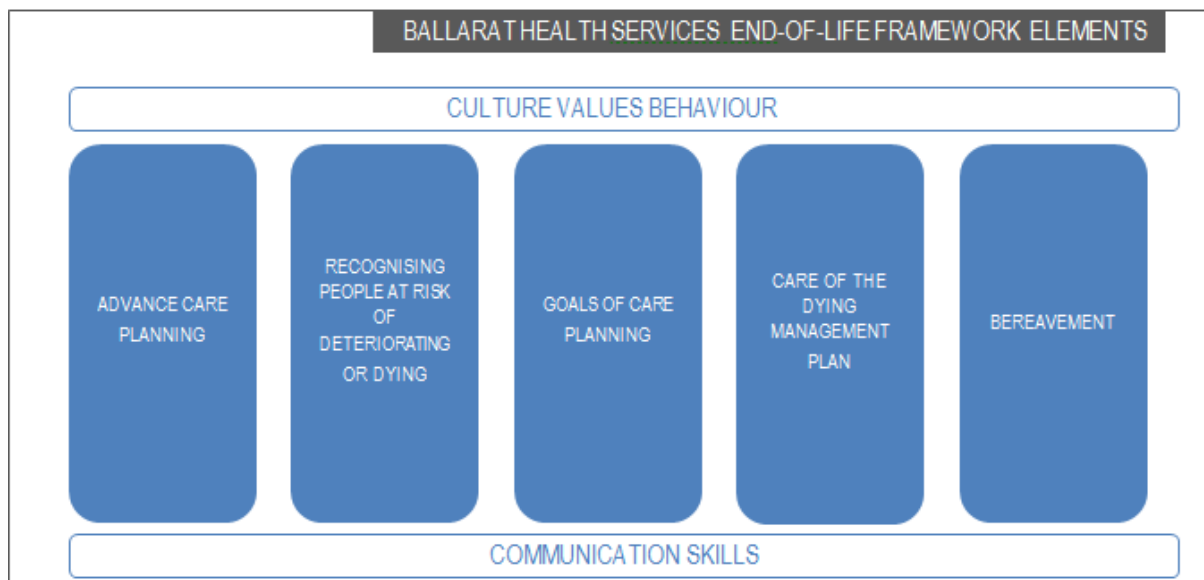
(CONSUMER) ... but it was difficult to get them in the last two days to stop feeding him. In the end, it was a bit like you were saying, some staff would go with that notion and so would the doctor, and then other staff would come on and say, he hasn't had any nourishment today. So I found myself in a battle all the time and that made it really difficult to manage that stuff.

For consumers, a good death was described in terms of having choice, being comfortable and pain free, as well as with dignity and surrounded by family who knew them best. Choice for people at the end of life can be difficult if the health care provider does not recognise that choice is an option, or what best-practice palliative care looks like. The experience of patients in the acute setting reflects the acute hospital focus on treatment and cure.

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The tone and intent of the framework was to be informed by the research from the focus groups and the bereavement interviews, however, the strong theme around communication meant that this needed a particular place in our framework. Rather than being a stand-alone element, communication underpins all of the parts of the framework (Fig 1).

Figure 1



Communication

Dr Penny Cotton, Palliative Care physician at Ballarat Health Services has developed an evidence-based workshop for health care providers in response to the concerns raised about how well we are able to manage the 'difficult' conversation. The following is taken from the introduction to the participant information for the **Discussing goals of care workshop**:

There is now good evidence that the way in which we communicate can influence both physical and psychological health outcomes for patients, as well as for health professionals. Patient and families rate health practitioners highly when they are able to communicate openly and discuss matters both good and bad with them. Communication is therefore a cornerstone skill for all medical practitioners.

Effective communication is a set of skills. It can be learned and practiced in the same way that we develop other skills in medicine such as suturing or paracentesis. The literature demonstrates that communication skills can be improved through understanding theory, mentored exposure to practice, repetition, feedback and reflection. This leads to increased confidence and satisfaction of health practitioners with reduced rates of stress and burnout.

Dr Cotton goes on to point out that while discussion of goals of care, limitations to medical treatment and resuscitation are challenging for medical professionals, there is consensus in the literature that people who have a life limiting medical condition want the opportunity to discuss their future care and treatment preferences. The literature and our interviews would suggest that these difficult discussions happen infrequently in practice. Dr Cotton notes that 'surveys of clinicians identify that a lack of confidence, skills and knowledge about how to initiate these conversations means they are often avoided or delayed'.

While communication is taught in the undergraduate medical degree, great communication is not routinely modelled once they reach the clinical domain of a busy hospital. Opportunities for junior medical staff to observe skilled communication by senior clinicians is limited and because it is not



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routinely modelled, it is easy for the new medical practitioner to default to what they see in practice rather than what they may have learned in a classroom. A number of hospitals in Victoria have recognised that this is a problem and have developed their own in-house training programs.

The communication workshop at BHS is designed around our Goals of Care Summary Plan and the discussion that occurs to enable a doctor to complete this. The workshop aims to increase confidence and skill in discussing goals of care with patients by providing participants with a toolkit of strategies to use for the challenging conversation. The workshops at this stage are for the senior medical trainees as they will then be in the position to both have the conversations with patients and also to mentor the junior trainee cohort. The challenge for BHS has been to provide training for all registrars in a program that runs for 3 hours, after hours, when the registrar group are only in our organisation for a 3 month period due to the frequency of training rotations with competing training requirements over a short contact period.

Recommendation

1. That consideration is given to the development of a state-wide approach to explicit, experiential and evidence-based communication skills training that is accredited and given similar weight to achievement of skill as other procedures.

Advance care planning.

When the time came it was so easy, because again, I knew what he wanted, and didn't have to think, 'Oh, would he like this?' Annie, daughter (from BHS project interviews)

Advance care planning improves end-of-life care and patient and family satisfaction and reduces stress, anxiety and depression in surviving relatives.²

There is increasing interest from consumers in being able to have their wishes for future health care discussed and documented so that they are respected when that person cannot speak for themselves. Our health service believe that these conversations are best had when the person is not in crisis and as such, our efforts have been focused on the chronic illness setting, community programs and primary health care (where we have recently collaborated with Decision Assist to pilot a GP training program). There are several barriers to having an advance care plan completed, being available when needed and then activated.

Completing an ACP - The discussion and documentation:

There are numerous online resources for assisting with completion of an ACP however our experience is that people need the support of someone who is health literate to assist in documenting meaningful goals and values that are then able to be translated in to action when the time comes to activate the plan.

While we believe there should be a focus on training GPs and GP practice nurses, this is somewhat outside our sphere of influence. We have partnered with one interested GP practice, but a robust training program for all GPs and GP practice nurses best sits with the Decision Assist 'train the trainer' programme which is reliant on the local interested GPs in turn to run training for the other GPs in the region. This approach may make the ability of people accessing assistance with ACP development in to the primary care setting slower than the developing community need.

² Detering et al 2010. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial BMJ. 2010; 340: c1345



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The health service has a number of ACP facilitators trained to assist the clients in their specific area – Dialysis, HARP, ACAS as part of their usual care. However, our health service does not have facilitators available to have a discussion with people who make an ad hoc approach to the health service to have an ACP done or patients who sit outside these funding streams. While we can and do refer them back to their GP for ACP support, many GPs at this stage are not informed or trained to be able to provide that support for their patients. It is also a barrier if people don't have a regular GP.

BHS is currently seeking a sustainable and achievable approach to funding and supporting an ACP program. A program co-located in a large regional health service such as ours would consider and facilitate the range of options community members have to complete ACPs while ensuring a level of quality and usability of plans that might come from a range of sources.

A robust ACP system would ensure that:

- The ACP was quality checked so that it makes sense when the time comes for it to be activated,
- There is a system to alert the person with an ACP that they might like to review their plan;
- Those with an interest in a person's ACP (treating medical teams, private hospitals and clinics for example) have easy access to the ACP if the person desires.

Activation:

When a person loses capacity to make or communicate their decisions, their advance care plan can guide health care providers with a course of action.

The first barrier to having the person's wishes respected, is for the health care practitioner to have the advance care plan available to consider as part of their planning of care and treatment. Advance care planning and the Enduring Power of Attorney (medical treatment) documents should be supported to link to the PCEHR and digital medical records of health services so that medical practitioners have access to the most up to date information at the time they need it.

Advance care plans carry weight under common law however, many medical practitioners are nervous about the extent to which they need to interpret and follow the plan. The quality of the written plan will often determine to what extent the practitioner will follow it. Vague statements or highly prescriptive descriptions can limit the way the ACP is followed. As such, the way the plan is written is significant and there should be systems in place to have an experienced facilitator either assist in the documentation or to quality check the completed document.

Recommendation

1. That end of life choices documents are able to be shared digitally between health services on platforms such as the PCEHR
2. That there be a system-wide approach to assisting people to have their advance care plans completed or quality checked by an appropriately qualified, medically literate facilitator so that the plan is in the best position to be followed if needed.



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Goals of care planning

Our organisation now uses the Goals of Care approach³ to medical decision making with Goals of Care plans developed for use in the both the acute and residential aged care settings. The goals of care approach acknowledges the importance of establishing a medical management plan as early as possible in the admission. Together with an increasingly robust mortality review process, the introduction of the Goals of Care Summary form has seen a significant improvement in the timely discussion and documentation of a goals of care plan. Whilst any patient can have a goals of care form completed, we have a set of minimum inclusion criteria:

- Age > 75
- Any patient who requests limitations of treatment on an advance care plan
- Any patient meeting the indicators of deteriorating health according to the Supportive and Palliative Care Indicators Tool (SPICT™)⁴

Care of the Dying Person

...but that was really his last cognisant evening and we all stayed at the hospital with our partners and we just sort of sat around the bed and he had a lovely time. He chatted, I mean his words were a bit slurred sometimes or he'd forget words. He was talking about old cars and holidays and how things would go wrong with the cars and all the weird and funny things that happened. He just had a lovely time that last night. Dom, family member (from BHS project interviews)

There is only one chance to get management of the last days of life right. The increasing numbers of people dying in the acute hospital setting is a challenge to the beliefs, practices and training of acute care health practitioners who understood the hospital to be a place where people go to be cured. The change in demographic of our patients has seen the need to change our approach to a range of choices that are in line with the wishes of the person:

- A goal of care to cure or restore function;
- A goal of care to manage symptoms, and to optimise quality of life (Palliative phase for frail elderly or those with a life limiting illness);
- A goal of care to allow a natural death and to optimise comfort for the dying person

The numbers of people dying in the acute setting has increased and will continue to increase in coming years. Palliative care training has been the domain of the specialist palliative care practitioner but many of those who die in the health service do not have complex palliative care needs when they are dying. They can be managed by a care team who has had some palliative care training to ensure that they have the skills and confidence to discuss palliative care with patients and their loved ones. We have introduced the Care of the Dying Management Plan (CDMP) which is a document based on the Liverpool Care Pathway but customised in response to feedback after the trial of the LCP. The CDMP aims to enable best practice evidence-based terminal care to be delivered in clinical settings outside a specialist palliative care unit. The challenge has been in having time allocated for the Palliative Care specialist staff to train and support the clinical workforce to use the CDMP and to manage other aspects of end of life care delivery including referral.

The demand on our specialist palliative care consultancy service has grown significantly over the last 2 years. Some of this growth will have been due to the changes in the conversations around our

³ Thomas R et al. Goals of care: a clinical framework for limitation of medical treatment. Med J Aust 2014;

⁴ University of Edinburgh. Supportive and Palliative Care Indicators Tool (SPICT™). NHS Lothian.

www.spict.org.uk



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organisation with the end-of-life project and the responsibility we have to optimise the last days and hours of a person's life. The area that remains a challenge for referring clinical staff is that palliative care is not just terminal care. It is for people who have a life limiting illness who need excellent symptom assessment and management. Recent publications have found, indeed that early referral to palliative care increases life expectancy.⁵ There is however, a tendency for the treating medical teams to wait until the person is actively dying before a referral is made to the specialist palliative care team. The first question on our CDMP is 'Do you want to die at home?'. This is offered to people in hospital subject to the availability of the community palliative care service. While there has been several instances of us discharging people home to die from the intensive care unit (not due to the CDMP but due to in hospital palliative care referral), there have been instances (especially after hours and on weekends) where this has not been possible, even though it was wished for by the patient or that person's family because of workforce limitations.

Recommendation

1. Palliative care training should be part of the education for all members of the multidisciplinary team so that the healthcare workforce can meet the needs of those who are in the palliative phase or who are actively dying.
2. There should be greater communication to the wider public of the role and function of palliative care in health care so that fears that the public have around palliative care just being for people who are dying are allayed.
3. Funding for palliative care should allow for delivery of services that meet the needs of the individual person in the setting of their choice.

Bereavement

As part of the End-of-Life project, BHS asked retired palliative care physician Dr David Brumley to undertake a literature search on bereavement in order to ascertain the organisation's responsibility towards the loved ones of the person who has died. Dr Brumley wrote in his report 'The bereavement period can be broadly defined as the entire experience of family members and friends in the anticipation, death and subsequent adjustment to living following the death of a loved one'. In his report, Dr Brumley notes that there has not been a lot of research done around the role of the health service with bereavement. The BHS framework document states 'Care does not end until the family has been supported with their grief responses and those with complicated grief responses have been helped to get care'. The ACQSHC National consensus statement guiding principle includes 'Care of the deceased person, and care for families and carers extends to the period after the patient has died'.

Our health service has minimal involvement with the bereavement phase at this stage, however the literature review, feedback from our interviews with the first next of kin and also the consensus statement indicate that this is a key part of an end-of- life framework. We would be happy to hear of others experience in this space, or have some guidance at state level about how we can support the loved ones of those who have died in our health service, sometimes after a long period of ill health where the hospital staff have become part of the social life a loved one who has been left behind. We believe at this stage, that this element can be addressed through identification and then referral if needed to specialist bereavement services.

⁵ Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med 2010;363:733-742



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Bereavement cont.

Recommendation

1. That consideration is given to the role of health services in supporting the loved ones of those who have died in our care.

Ms Denise Fitzpatrick
T: [REDACTED]
E: [REDACTED]
End-of-Life Project Coordinator
Ballarat Health Service
Ballarat Health Services
Drummond Street North
BALLARAT
3350