



Government of **Western Australia**
Department of **Health**
Palliative Care Network

The consumers' & carers' perspective: Communication at end-of-life in hospital

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Focus Group

- 19 February 2015
- 8 carers / consumers
- **Participants:** Adults with advanced life-limiting illness (or their families) who are receiving or have received end-of-life care in a WA hospital in the last five years.


- **Topic:** Communication at end-of-life in WA hospitals
- **Scope:** Time period from diagnosis or decline to before the terminal care phase.



What do you think is a definition of a good death?

- “Pain free”
- **“Timely, consistent information** so then the family can make the best decision for their care when they are dying.”
- “Time. Letting the patient have as long as the journey takes. Respecting what the patient wants.”


1. Patient focus - Respecting what they want



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want

- “My concerns extend to hospital. When I go to emergency (with my father). **They don’t understand his wishes.**”
- “They had a paragraph in their Living Will that **discussed what they wanted as a good death.....**It made a real difference with care in the hospital.”

2. Lack of general palliative care knowledge



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- “The GP signed her onto palliative care and we were very happy about the fact that she was on palliative care, then the Consultant said **“it’s far too early, sign her off”** and hung up.”
- “Once we got to specialist palliative care, it was generally good, but the lead up to it in terms of end-of-life care, **we felt we were fighting.**”

- “Palliative care is associated with cancer, but palliative care is to do with **all life-limiting illnesses**. Many don’t understand that.”
- “Palliative care is associated with terminal care. There needs to be education of what palliative care is, that it is **not just short-term end-of-life care**, and better conversations about end-of-life wishes and Living Wills.”

3. Communication - upfront, timely and respectful

- “Conversations and information on end-of-life need to be **tailored** and a **choice given about how and when it’s received**, so whether it is given bit by bit or all at once is dependent on the patient.”
- “The **system coming to us** rather than us forcing their hand (to communicate what’s going on).”

3.1 Upfront

3.
Communication -
upfront, timely,
respectful

“I thought I knew what the final stages would be...she then went into a funny breathing rhythm, her hand was floppy, she took staccato breaths. I asked the junior Doctors ‘is it ok to leave (to go home)’. They said ‘**no go home, she’s just sleeping**’. The Nurse called at 1am and explained that **she stopped breathing**”.

3.2 Timely

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Communication -
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respectful

“Five of us waited for five hours for the information. We were told that the Consultant was going to give us this information. They stuck their head in and said they were going to do handover and then speak to us. We later found out **the Consultant went home**. I think the conversation was **too hard** for them.”

3.3 Respectful

“Human determination and how they accept their own pending death needs to be considered within palliative care, for example end-of-life and the period in which people are dying, it’s not just a medical experience ... **it’s a human experience.**”

4. Early conversations on end-of-life - at diagnosis

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“My experience with specialist palliative care is fine, but at the Consultant level to do with their **diagnosis and hospitals and specialists**, it was **not** a good experience.”

4.1 When is the best time to have these conversations?

4. Early conversations on end-of-life - at diagnosis

- “At diagnosis, early.”
- “When it’s cancer, they’re interested in having the conversation. They’re **not interested** in their wishes when it’s dementia.”

5. Involved in decision-making process

- “We need to **involve** carers and consumers in the decision-making process, or **at least try to**. I noticed they had stopped giving him fluids, and they hadn’t told us. But they put the emphasis on ‘turning off the ventilator’ when **they had already stopped giving him fluids.**”
- “It’s hard for experts to listen to non-experts, when **they are the experts** of their loved one. Listen to the carers and consumers a bit more.”

6. Continuity of care across health services

- “They kept asking about the Advance Health Directive, but **they didn’t check (for it)**. There needs to be more robust measures to check about who has it. They are not checking whether or where the Advance Health Directive is (located).”
- “Health professionals **won’t write it in the patient’s file properly**, or put it at the front of their file (Enduring Power of Guardianship).”

7. Workforce capacity

- “Health professionals are **people** and have **feelings** too, we forget that sometimes.”
- “There is education on the front-line about how to share that information, but **it might be their first time** having to deliver this information to families and patients.”

“It’s a failure of the system, not individuals.”

Learnings from a lived experience

- Experience in the time leading up to my mother entering palliative care:
 - Conversations & information that worked
 - Conversations & information that didn't work
 - What can be improved