



## **Being Part of the Care Process: How Careworkers Contribute to a Palliative Approach in Residential Aged Care**

Hi, I'm Gina. I've been a careworker in residential aged care for about twelve years and really like it.

Careworkers are essential in providing the best possible day-to-day care and support for residents and their families. This is particularly important when residents are coming to the end of their lives and require what's called a 'palliative approach' – which means the focus of care is on residents' comfort and quality of life, rather than on curing their health conditions.

A 'palliative approach' to caring for a resident can be started whenever treatments given to cure a condition aren't working any more, or aren't chosen by the resident. Choosing to use a 'palliative approach' is a decision made between the resident, their family and the doctors and nurses involved in the resident's care. But the focus is always on making sure that the resident's wishes for their care are respected. And, because everyone's wishes and needs are different, there's no set timeframe for a 'palliative approach' to care – sometimes it's started a few years before a person dies and other times just in the last few days.

Keeping in mind that a 'palliative approach' isn't just about the last days or weeks of a resident's life, how can careworkers best support residents needing this type of care?

Part of the answer is for careworkers to be aware of their role in three key processes that are important when using a 'palliative approach' in residential aged care. The three key processes are:

- advance care planning
- palliative care case conferences, and
- end of life care pathways.

In this short video I'll talk about how careworkers contribute to each of these key processes. I'll use Betty Freeman, a resident we recently looked after here, as an example.

Betty was eighty-seven when she came to live here. About a year earlier, Betty had had a stroke that made it hard for her to walk and use her left arm. She also had lots of other health problems including diabetes, osteoporosis and kidney failure. Betty's husband had cared for her at home. But, after he died, Betty wasn't able to live by herself and she moved here so we could help her with her daily care needs.

Soon after Betty moved here, she and her family were invited to complete what's called an 'advance care plan' with help from our nurses. Offering the opportunity to complete an advance care plan is one of our facility's policies and the first key process I want to talk to you about.

Advance care planning's all about what a person wants for their healthcare in the future. It's about talking to those important to them about their choices. And it's best to write down those choices. That way, if something happens to them and they can't tell people how they'd like to be cared for, it's all written down. That's really helpful for their family and carers. And helps make sure treatment is in line with what they want.

An advance care plan might include things like how and where a resident wants to be looked after as they approach the end of their life, if there are any specific treatments they don't want, and who they want to make decisions for them if they're not able to. That person's called the resident's 'substitute decision maker' and isn't always a family member.

Many facilities have policies and procedures about advance care planning and use specific forms to make sure a resident's wishes are written down so staff can be aware of them.

Betty was keen to do an advance care plan so that decisions about her care didn't have to be made 'on the run' when a crisis developed. As a careworker, I've found it very useful to know what care a resident wants - it helps me get to know them and meet their needs better. Talk to your nursing staff to find out if there's anything in a resident's advance care plan that you need to know as part of providing good care for that resident.

Residents often mention their hopes and concerns to careworkers - about going back to hospital for instance - before mentioning them to anyone else. So it's important to listen for these comments and to report back to nursing staff. When you do report back, try to use the same words that the resident used.

Advance care planning works best when there are ongoing discussions between the resident, their family and the care team. This is important because, as a resident's condition becomes worse, they might change their mind about the care they want. If the resident does change their mind about any part of their future care or treatment, their advance care plan must be updated.

Remember, advance care planning is about planning ahead, discussing wishes and then writing those wishes down.

In Betty's advance care plan she said that she wanted all her future care in the facility, her home, and she wanted her GP to look after her.

After twelve months, Betty had become more fatigued, she'd lost six kilos, her kidney tests were worse, and she was pale and showed little or no interest in anything. After discussing the goals of her care, the care team decided to organise a palliative care case conference - and this is the second key process in a 'palliative approach' to care that I want to tell you about. It's a meeting between a resident, their family, their substitute decision maker, if there is one, and the care team. It's a good opportunity to discuss the resident's condition, to re-check their advance care plan, and for everyone to agree on the 'goals of care'. This means what care will be provided when the resident's health gets worse.

As a careworker, you might be invited to attend a resident's palliative care case conference and your contribution is really important. Because you provide the direct day-to-day care for the resident, you may notice changes in their mood, symptoms (for example their breathing), how they're coping with daily activities like walking, eating and drinking, before anyone else does. It's important for you to share this information with others in the care team to help prepare a future care plan for the resident.

Having a plan in place that everyone has agreed to can be very reassuring for the resident and their family - and contributes to a better outcome for everyone involved. It'll help you know what to expect and how you can help.

After another 16 weeks, Betty was experiencing signs and symptoms suggesting she may be dying - she'd lost more weight, she didn't want to eat, she couldn't swallow her tablets, she was making very little urine and most of the day she seemed to be asleep. Her ankles were very swollen and her breathing was very irregular and rattly. She no longer got out of bed. At this stage, it was decided to start Betty on an 'end of life care pathway'. This is the third and final key process in a 'palliative approach' to care that I want to tell you about.

An end of life care pathway is a document that acts as a sort of 'road map' to guide the care provided by doctors, nurses and careworkers in the last days or week of a resident's life. The decision to start a resident on the pathway will be made by the doctor and care team after talking with the resident and their substitute decision maker.

A resident will be started on an end of life care pathway when they show behaviours, symptoms or physical changes suggesting that they may be dying. So it's important for careworkers to be familiar with these things.

You may notice:

- a rapid day-to-day deterioration where the resident's condition keeps getting worse
- that the resident needs more frequent care or interventions
- that they're becoming semi-conscious or less aware of their surroundings, and there may be times when they're unconscious

- that they're finding it harder to swallow
- perhaps they're refusing or unable to eat, drink or take oral medications
- that they've lost a lot of weight
- they're very weak now, and
- you may notice changes in their breathing.

Find out if your facility uses an end of life care pathway and, if so, what your role is. The nurses will be able to help you learn what your role is and how to complete any forms related to the end of life care pathway, if that's part of your role.

Often, your role will be to provide care that keeps the resident as comfortable as possible. For example:

- helping the resident get into a comfortable position
- providing mouth, eye and skin care, and
- helping with incontinence and bowel care.

Family members often spend many hours with the resident at this time and they may ask you questions about what's happening to their loved one. It's OK for you to answer these questions as long as they're within your scope of practice. If you aren't sure what to say, try to reassure the family and tell them you'll ask the nurse to come and speak with them.

Sometimes a resident's condition may improve. If this happens, the resident will be taken off the end of life care pathway and the care team will continue with their routine care.

**Dave** (registered nurse): Before we finish handover, I want to let you know that Betty Freeman died this morning, peacefully, with her family present. Because we'd planned ahead and had things in place to support the best possible end of life care for Betty, we were able to respect her wish not to go back to hospital. We were able to keep her very comfortable up until she died. As she'd wanted, Betty died here, her home, in familiar surroundings and being cared for by staff who knew her well.

Betty's daughter Carol asked me to pass on a thank you to everyone involved in caring for her mum over the last 18 months and I'd also like to thank you.

In looking back through Betty's medical record, it's clear our use of a 'palliative approach' ensured Betty's comfort and quality of life were maintained and that she'd had a 'good death'.

The success of each of the three key processes in a 'palliative approach' is based on good communication between the resident, their family and substitute decision maker, and the care team.

You'll find that the Residential Aged Care Palliative Approach Toolkit – or PA Toolkit for short – includes a lot of useful tips for careworkers. In particular, you'll find that the 'Careworker self-directed learning package' and the 'Introduction to a palliative approach' flipchart provide practical information about the three key processes in a 'palliative approach' and what careworkers can do to best support each of these processes. PA Toolkit resources can be accessed and downloaded at no cost from the website: [www.caresearch.com.au/PAToolkit](http://www.caresearch.com.au/PAToolkit). Or your facility should have received a Toolkit, so ask your manager about it.

This is a transcript of a Palliative Approach (PA) Toolkit video *Being Part of the Care Process: How Careworkers Contribute to a Palliative Approach in Residential Aged Care*.

To view the video visit [www.caresearch.com.au/PAToolkit](http://www.caresearch.com.au/PAToolkit)

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