

Embracing Family Carers

Recognising and supporting their expertise during end of life care

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Reflection

Today's workshop is an opportunity to:

- Explore end of life care from the perspective of the family carer
- Recognise and appreciate Carers' expertise
- Consider meaningful ways of interacting in a more collegial, yet supportive relationship
- Consider work practices that holistically and genuinely embrace family carers as valued members of the end of life care team

Family Carers

Most people who have chronic or acute health conditions, mental illness, disabilities, or aged frailty require varying degrees of assistance from a family member.

The family member who provides this care is a family carer.

Increasing Care Needs

As the illness or condition worsens, the amount and type of care and assistance provided by family carers increases and intensifies.

Every Death Has a Story

In Australia approximately:

- 133,000 deaths are registered each year
- 100,000 of those are expected or predictable
- 275 expected deaths occur each day

Source: Palliative Care Australia website quoting ABS statistics

Illness & Death

Expected or predicted deaths are defined as:

“when a person has an eventually fatal condition and their death in the foreseeable future would not be a surprise”

Source: Palliative Care Australia, 2008

A significant level of care prior to death is associated with expected deaths.

Quality of Life

The goal of palliative and end of life care is to achieve the best possible quality of life for the dying person and their family, based on a positive and open attitude to death and dying.

End of life care may occur over days, weeks or months.

The Carers Experience

During end of life care:

Q: What do you think the family carer's experience of end of life care might be?

Q: What expectations, thoughts, feelings, hopes and fears, might they have?

History & Longevity of Care

Family carers have an emotional investment in, and a relationship with, the person they care for.

Family carers provide care over an extended period, often many years, and they develop an enormous range of skills, knowledge and expertise.

Expertise: Complexity of Care

Q: What type of skills, knowledge and expertise might carers develop over the course of an illness, and/or in response to their role as a family carer?

Carer Expertise

Carers develop great expertise in:

- The person they care for – personality, history, etc
- The illness – and how it manifests in that person
- Dual or multiple diagnosis and their interactions
- Managing medications and treatment regimes
- Maintaining an environment to enhance quality of life, health and wellbeing
- Managing family dynamics
- Managing home and financial requirements
- Navigating health & service systems
- Etc, etc, etc ...

Utilising Carer Expertise

Q: Did you realise the extent of carer expertise?

Q: To what extent is the depth and diversity of the carers' expertise currently recognised and utilised by yourself and the service you work for?

The Challenge

With your raised awareness of the carers expertise and dedication:

Q: How can you meaningfully interact in a more collegially respectful relationship with family carers, while remaining supportive and not overburdening them?

Holistic Care for All

Q: How does recognising and respectfully supporting and utilising the carers expertise enhance quality outcomes for all - carer, dying person, and service provider?

Your Task – Value Adding

Enhancing your work practice.

To genuinely and holistically embrace family carers as valued members of the end of life care team

Identify one work practice:

- that you are currently doing
- that you can add to extend your carer inclusiveness

Thank You

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