Victorian Institute of Forensic Medicine

# Residential Aged Care Communiqué

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## EDITORIAL

Welcome to the special supplement of the final issue of the RAC Communiqué for 2014. This contains two new cases about goals-of-care and end-of-life in Residential Aged Care Services to consider and reflect upon. The supplement also contains the two extra commentaries and a detailed list of resources.

## CASE #1 MY SISTER

GLTCRC 2012(2012-19/2)
Case Précis Authors:
C Young RN, Ballarat Health &
JE Ibrahim, Monash University

### Clinical Summary

Ms L was a 69 year old female resident who had arrived directly from an acute hospital (where she was an inpatient for 2 months) to live at this RACS. Past medical history included depression, alcohol abuse that had led to end-organ damage with cirrhosis of the liver, gastrointestinal bleeds requiring multiple blood transfusions, hepatic encephalopathy and cognitive impairment. Other ongoing medical conditions included osteoarthritis requiring total knee replacement; heart failure, angina and chronic obstructive pulmonary disease.

Ms L overall function improved in the first year at the RACS becoming continent, more mobile and sociable. Ms L's sister, a trained nurse was very much involved in the care of Ms L, taking her out to appointments and assisting with feeding when required.

Around a year after entering the RACS, Ms L's health began to decline both physically and cognitively.

In February, Ms L's sister changed the medical practitioner to see if anything could be done to address the decline. In March the sister became frustrated that 'nothing was being done' even though Ms L had undergone further clinical investigations, been referred to a medical specialist, had therapeutic paracentesis (to drain ascites) and another blood transfusion. Despite this treatment, Ms L's condition remained poor and had a prognosis of less than three months towards the end of March. The RACS staff observed signs of caregiver burnout in Ms L's sister and identified this was interfering with their ability adhere to Ms L's plan of care. It was also clear that Ms L's sister wished to remain in control of any care decisions. By this time, Ms L required full nursing care, was doubly incontinent and bedbound.

In mid-April, Ms L was less responsive with very low haemoglobin and the medical practitioner discussed the futility of treatment and the need to alter the Advanced Directives from "transfer to acute care and full resuscitation" to "remain at RACS with treatment for comfort".
Ms L's sister requested to stay at the RACS to provide direction to staff on what medication to use. About two weeks later Ms L died and appeared comfortable during the last few hours of life.

### Pathology

The cause of death was reported as cirrhosis of the liver due to alcohol abuse, with other significant conditions – heart failure, chronic obstructive pulmonary disease, anemia and gastrointestinal bleeding. No autopsy was done.

### Investigation

Further investigation was required because the sister lodged a formal complaint. A range of statements and documents were examined. These confirmed that in the last few weeks of life, Ms L had frequent assessments, interventions and monitoring was offered and/or provided for end-of-life comfort measures as requested and needed.

It was also clear that Ms L's sister was upset with the decline and expressed difficulty in making the requested decisions at one point. The sister received significant emotional support, reassurance and explanations from staff during this very difficult time. Staff indicated that in the last few weeks, Ms L's sister was indecisive and insecure about end-of-life decisions.

### Coroner's Comments and Findings

The case was closed following the review with a finding that there was no evidence of systemic care related issues in the death.

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FEEDBACK

The editorial team is keen to receive feedback about this communication especially in relation to changes in clinical practice. Please email your comments, questions and suggestions to:
racc@vifm.org

DISCLAIMER

*All cases that are discussed in the Residential Aged Care Communiqué are public documents. A document becomes public once the coronial investigation process has been completed and the case is closed.*

*We have made every attempt to ensure that individuals and organisations are de-identified. The views and conclusions are those of the authors and do not necessarily represent those of the Coroners, Department of Health, Victorian Institute of Forensic Medicine or Monash University.*

Residential Aged Care Communiqué [electronic resource]: Department of Forensic Medicine, Monash University,

Available at:
www.vifmcommuniques.org/previous-editions/residential-aged-care-communique-editions/

# COMMENTARY #1

# HELPING THE HELPERS

Dr. Penny Cotton, MBBS(Hons) BMedSci FRACGP FAChPM Grad Dip Clin Ed.
Palliative Care Physician,
Ballarat Health Service

This evening, you're feeling sad about walking into Joan's room, where you see she barely makes a bump in the sheets lying in bed. You remember a happier time, over two years ago when Joan moved into the RACS, she liked to sing and even though her memory was failing she still knew all, well mostly all, the words. Joan's failing kidneys, heart disease and underlying Alzheimer's dementia were all stable then.

> *Recognising that someone is dying is the first and often the most challenging decision in caring for someone at the end of their life.*

It's been many months since you'd heard Joan sing and over the last two weeks Joan has been getting weaker not eating much, not saying much, looking so thin, so frail and so sick. Joan's General Practitioner prescribed a course of antibiotics for a urine infection but this still hasn't made any difference.

Tonight, Joan isn't responding when you call her name and when you touch her arm she moves a little. Joan is not getting any better, what if she is dying? How do you know what to do?

Recognising that someone is dying is the first and often the most challenging decision in caring for someone at the end of their life. What if we missed something that could be treated? Is this decline in Joan reversible? Should we send Joan to hospital? Should we look after Joan, here? What do we say to her family?

These are just some of the thoughts running through your head. It is hard to sort this out anytime but especially late at night. Joan's advanced care plan documents what she would want if she was dying. But, how do we know she is dying?

Well, Joan is getting sicker, has not responded to antibiotics in the setting of multiple advanced and end stage disease processes (including heart failure, kidney failure and dementia). Joan's deterioration has occurred over a few months with no reversible features and her GP commented on a recent visit that a palliative approach would eventually be needed, but she wasn't dying then.

You ring her family. Joan's daughter is upset and worried about her mum. She is not sure what to do. She wants to make sure her mum gets the best care possible "should that be in hospital?" she asks.

How should you respond? What do you say?

You explain how we will care for Joan, make sure she is comfortable, that we will use medication to control symptoms, provide good pressure care and oral hygiene and mouth care.

> *By treating Joan with respect and dignity the family are likely to feel that you genuinely care for Joan.*

But how do we respond to a family who are grieving?

Listen, acknowledge the emotion: this is tough, even though Joan is 99 years old, and you know older people die, this is their mum. Practical support: what to do next, a glass of water, a box of tissues. These small things help someone to feel supported. By treating Joan with respect and dignity the family are likely to feel that you genuinely care for Joan. For some families this time is very distressing which creates a challenging environment for staff.

Recognise you won't win them all over. Recognise you won't always know what to do. When this happens call the Decision Assist Program.

The Decision Assist Program is available to support all health professionals involved in aged care in Australia to care for people at the end of life through Specialist Palliative Care and Advance Care Planning Advisory Services.

This initiative includes a 24 hour phone advisory service for advanced care planning and specialist palliative care advice: phone 1300 668 908.
Visit www.decisionassist.org.au for further information and resources on symptom management and advanced care planning.

# CASE #2 BE CAREFUL THE DAUGHTER IS HERE

GLTCRC 2012(2012-19/1)

Case Précis Authors:
C Young RN, Ballarat Health &
JE Ibrahim, Monash University

## Clinical Summary

Ms K was a 94 year old female resident requiring high level care in a Residential Aged Care Service (RACS) for the past three years. Past medical history included Alzheimer's type dementia with visual hallucinations (MMSE was scored as zero on entry to this RACS, the previous recorded MMSE had been 8/25 when she was 88 years old), an acquired brain injury, aphasia; dysphagia and gastroesophageal reflux; impaired hearing and vision (legally blind), urinary tract infections, diverticulitis, relapsing C. Difficile colitis and osteoarthritis. Ms K was dependant on staff for all personal care, being dual incontinent, requiring two persons for transfer and a tilt wheelchair. She was losing weight often refusing to eat or drink and would occasionally spit out the texture modified food and medications. Ms K's daughter visited regularly, was very supportive, actively engaged and a strong advocate in the care of her mother.

*It was clear from the documentation that the daughter had identified multiple concerns to the staff and management on various occasions.*

One day in mid-January Ms K's daughter was worried that her mother was not eating or drinking and was complaining of 'burning'. Ms K's daughter spoke to RACS staff who in turn contacted the medical practitioner. The doctor offered to organise admission to an acute care hospital for investigation and treatment. The daughter declined and was agreeable to monitoring Ms K for any new symptoms or signs with no other changes in care. The following day the RACS staff commenced paracetamol, though it took some effort to convince the daughter about the benefits of this, and a urine specimen was collected to exclude a bladder infection.

About a week later, RACS staff raised concerned that Ms K's daughter was insisting on her mum having a regular diet rather than the prescribed modified texture, and asked about the need to obtain a formal signed statement of consent.

Three days later, on a Saturday, Ms K was agitated and had spiked a fever (T 38.2C). Ms K's daughter declined the suggestion of Ms K to acute care but agreed for the on-call doctor to visit in the RACS. Two antibiotics were prescribed, one to cover a possible bowel infection and the other for a possible UTI. The daughter initially agreed but on learning the urine specimen had no growth withdrew consent for administration of antibiotics.

The next day, Sunday, a different on-call doctor assessed Ms K and ordered further investigations (chest X-ray, FBE) and reiterated the need to closely monitor, encourage fluids and use paracetamol for fever and malaise.

*It is important to recognize that there is no obligation to provide futile care even when requested by the patient or family.*

On the Monday Ms K was reviewed by her regular doctor, who considered the most likely cause of the change was due to diverticulitis (white cell count elevated almost double the reference range; chest x-ray clear) and prescribed antibiotics. Ms K's daughter at first agreed to the plan but when nursing staff tried to administer the antibiotics to Ms K, the daughter declined. Also that day, the dietitian confirmed that the family were aware and had signed a "negotiated risk' form about the risk of having a textured diet.

On Tuesday morning, Ms K. was resting comfortably and unable to be roused. The daughter was concerned at her mothers decline, changed her mind and requested that the antibiotics be started. The DON and RN discussed the situation with the daughter who was distraught and threatened to lodge a formal complaint about the care provided.

Just after lunch, that same day Ms K's son-in-law rang requesting that she be transferred to an acute hospital and commenced on intravenous antibiotics. The request was declined in consultation with the medical team and Ms K died at the RACS a few days later.

## Pathology

An autopsy was not done.
The death certificate was completed by the medical practitioner and listed the cause of death as sepsis and dementia, anemia and failure to thrive.

## Investigation

Further investigation was required because the family lodged a formal complaint identifying multiple issues at different times about the RACS. The family raised concerns about care provided and potential non-compliance with the law.

A range of statements and documents were examined, some of which included RACS and hospital records; assessment, care plans and treatment charts.
It was clear from the documentation that the daughter had identified multiple concerns to the staff and management on various occasions. It was also clear the RACS staff had discussions with the daughter and attempted to resolve the concerns on multiple occasions.

## Coroner's Comments and Findings

The case was closed following the review with a finding that there was no evidence of systemic care related issues in the death.

## Author's Comments

The RACS in this case handled the issue of risk of choking well with a clear explanation and documentation reflecting the resident's preference about quality of life and acceptance of the potential dangers.
This case also illustrates that it is reasonable for health professionals to decline to provide futile care. It is important to recognize that there is no obligation to provide futile care even when requested by the patient or family. There is an obligation to discuss, explain and support the family and resident when this type of situation occurs. It is also important to document the key issues and nature of discussion so there is information that assist in resolving concerns or complaints about care raised by family, professional bodies, regulatory authorities and the Coroner.

Another clue in this case is that multiple complaints appear to be a sign of distress and conflicted emotions in the family. Often our initial response to complaints is to become defensive and focus on resolving the immediate issue, and we then become frustrated as each issue is resolved and the family continues to present new and different concerns. Perhaps next time, we should pause and think about whether this is a form of communicating personal distress/carer stress.

# COMMENTARY #2
# AM I DYING NURSE?

Emeritus Professor Rhonda Nay

Death and dying remain taboo subjects in our communities; families do not want to think about their parents or spouse dying and shy away from discussing the subjects. I have even met nurses who refuse to speak with residents about dying even when it is obviously relevant and the resident raises the issues. More likely the resident who asks: 'Am I dying nurse?'' will receive a cheery response such as 'Only the good die young – you will be right'.

> *Death and dying remain taboo subjects in our communities...*

Even if a person has an advance care plan (also referred to as a living will or end of life Statement of Choices) it is often ignored, especially if there is an emergency situation and the person is transferred to hospital.

Nurses and other health professionals fear litigation so will tend to preserve life even when the resident wishes for nature to take its course. Fear may also leave pain untreated as nurses avoid morphine lest it hasten death. Families have different reasons for holding on and requesting interventions that may prolong life. They are unable to let go and face that final moment of death.

> *Families have different reasons for holding on and requesting interventions that may prolong life. They are unable to let go and face that final moment of death.*

The language around end of life exacerbates concerns. For example, we speak of withdrawing treatment – which is very negative and incorrect. What we are usually doing is withdrawing medical treatments that are not assisting the resident's quality of life.

In fact what usually occurs is that a decision is made to change to more appropriate treatment such as pain management, non-pharmacological interventions and other comfort measures. Euthanasia is illegal and is the source of many acrimonious debates. A palliative approach to care may then be perceived as euthanasia.

In my view every person should discuss and document their wishes (with family, GP and anyone else who is likely to be involved in end of life decisions) when they do their will. Whenever the Will is reviewed so too should be the Advance Care Plan (ACP) documents. Although it may be a difficult topic it is much better to have the discussions before any crisis and emotion charged situation.

> *Overcoming our own fears is necessary if residents are to receive a palliative approach to care and a 'good death'...*

All people entering RACS should have their wishes documented and all staff expected to adhere to those wishes.

Each CASE (Care and Support Engagement) conference can then ensure any wishes are known and communicated to the GP. ACPs should accompany the resident if admission to hospital should be necessary. Too often transfer to acute care causes increased confusion and deconditioning. In my view it should be avoided unless it is impossible to provide care in the RACS.

Overcoming our own fears is necessary if residents are to receive a palliative approach to care and a 'good death'; relieving pain is not euthanasia, a palliative approach to care is not euthanasia. Rather taking account of the resident's wishes and taking the time to ensure the family understand that a palliative approach does not mean withdrawing treatment is better practice and person centred.

## LIST OF RESOURCES

1. There is an enormous number of resources and commentary around on these topics. Often the best place to start is by contacting your regional palliative care service to see what they have to offer. Below are some of our suggestions. The Royal Australasian College of General Practitioners (AU). Medical care of older persons in residential aged care facilities (silver book) [Internet]. Available from: http://www.racgp.org.au/your-practice/guidelines/silverbook/general-approach-to-medical-care-of-residents/principles-of-medical-care-of-older-persons-in-racfs/
2. Guidelines for a Palliative Approach in Residential Aged Care [Internet]. Available from: http://agedcare.palliativecare.org.au/Portals/35/Symptom%20Management/SymptomManagementResource.pdf
3. Palliative Care Australia (AU) has many valuable resources on their website. Consider some of the following:
    - Facts about morphine and other opioid medicines in palliative care [Internet]. Available from: http://pallcare.org.au/
    - About Pain and Pain Management [Internet]. Available from: http://pallcare.org.au/
    - Pain Assessment and Management. Available from: http://agedcare.palliativecare.org.au/PainAssessmentandManagement.aspx
4. CareSearch Palliative Care Knowledge Network (AU). Symptoms [Internet]. Available from: http://www.caresearch.com.au/caresearch/tabid/2392/Default.aspx
5. Limitations of Care resource by the Dementia Training and Studies Centre contains an animated video and a short package to facilitate discussion amongst care providers about resuscitation in persons with dementia website (www.dtsc.com.au/limitation-of-care-orders-making-an-informed-choice)
6. Use of 'not for resuscitation orders' (see Resuscitation Council UK website at https://www.resus.org.uk/index.html)
7. Commonwealth Guidelines for a palliative approach in Residential Aged Care, available at http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-workf-guide.htm
8. The Department of Health Victoria's Advance care planning strategy 'Advance care planning; have the conversation: A strategy for Victorian health services 2014-2018 provides direction to Victorian health services to develop, review and activate advance care plans across and beyond their organisations' available at http://www.health.vic.gov.au/acp/strategy.htm