WHEN DYING ISN'T DYING: REASSESSING DECLINE IN PATIENTS WITH CHRONIC KIDNEY DISEASE IN AGED CARE

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EXECUTIVE SUMMARY

Residents with chronic kidney disease (CKD) in Residential Aged Care Facilities (RACFs) can experience sudden deterioration. Reduced oral intake, tiredness, weakness, functional decline and reduced responsiveness are often interpreted as signs that a resident is dying. However, these changes may have reversible causes. If these are not considered, residents may be moved to end-of-life care too early.

The Renal Supportive Care (RSC) service has had extensive involvement in RACFs since 2021. A core component has been education and support for registered nurses (RNs) in CKD care, recognition of deterioration and appropriate referral to the RSC team.

YEAR CASE STUDY OCCURRED

2023 to 2025

CASE STUDY DETAIL

Residents with CKD can develop non-specific changes such as reduced appetite, lethargy, weakness, functional decline and reduced responsiveness. These changes can be particularly difficult to assess in residents with dementia who may be unable to communicate their symptoms.

Possible reversible causes include dehydration, infection, electrolyte abnormalities such as hypercalcaemia or hyperkalaemia, and medication-related problems. Medication management is particularly important in CKD because reduced kidney function can affect drug clearance.

The RSC approach included clinical review, medication reconciliation, review of blood results and symptom assessment, with RNs encouraged to seek RSC advice when deterioration was unclear or potentially reversible.

The case study occurred between 2023 and 2025 and involved two residents initially thought to be approaching the end of life.

The first case involved an 80-year-old man who, in 2023, developed confusion, reduced oral intake and increasing weakness. He was initially thought to be dying, and his family was told that care would focus on comfort. The RACF RN recognised a significant change and contacted the RSC team. Blood tests showed significant hypercalcaemia. He was transferred to hospital for treatment and improved significantly, with improvement in cognition, appetite and strength. He did not die at that time and continued to live for another two years, dying in 2025. This reinforced that his deterioration in 2023 was not necessarily a sign that death was imminent.

The second case involved a 69-year-old man with frontotemporal dementia who became drowsy, less responsive and stopped eating. End-of-life care was being considered, and his family was informed that he was likely approaching death. The RACF RN recognised a significant change from baseline and contacted the RSC team. Raised inflammatory markers suggested infection. Although a urine sample could not be obtained, antibiotics were commenced in the facility, and he subsequently became more alert and resumed eating. He later remained well for approximately seven months before his condition gradually declined due to progression of his dementia, and he subsequently died. His recovery from the initial episode caused confusion and anger within the family, highlighting the impact of premature prognostic discussions and the importance of reassessment when deterioration is uncertain.

In both cases, reassessment changed the initial plan. A treatable cause was identified and managed, and end-of-life medications were not required. RACF nurses' knowledge of CKD and recognition of changes from baseline contributed to timely RSC referral.

Although these may appear to be simple cases and are not necessarily extraordinary clinical events, they represent situations that occur frequently in residential aged care and can be easily overlooked or under-recognised. Their importance lies in the reminder they provide that clinical deterioration in older people does not always mean that death is imminent. Recognising and treating potentially reversible causes remains important, even when a resident has significant frailty, dementia or advanced CKD.

The experience highlighted the value of building CKD knowledge within the RACF nursing workforce. Nurses are often the first to notice changes in a resident's condition and can play an important role in identifying when further assessment is needed.

The cases also reinforced the importance of careful communication with families when prognosis is uncertain. Allowing time for reassessment may prevent unnecessary distress and confusion. Prognostic discussions should acknowledge uncertainty when the cause of deterioration has not been established.

These cases highlight an important principle of palliative care: providing comfort-focused care does not mean unnecessarily prolonging life, nor does it mean anticipating or hastening death. Rather, palliative care focuses on relieving symptoms, addressing distress, and supporting the person's goals, values, and quality of life. Importantly, this approach can coexist with the assessment and treatment of potentially reversible causes of deterioration, including in people living with advanced dementia and significant functional impairment. Where a reversible cause is suspected, proportionate investigation and treatment may therefore be appropriate and remain consistent with good palliative care, provided that decisions are guided by the person's goals of care and overall clinical context.

Overall, this work highlights the importance of pausing and reassessing before assuming that a resident is dying. Supporting RACF nurses with CKD education and access to RSC advice can help identify reversible causes of deterioration and support appropriate end-of-life and goals-of-care decisions. These common, often unreported clinical situations remind us that good palliative care means neither unnecessarily prolonging life nor rushing death, but treating symptoms, addressing potentially reversible causes and allowing the person's illness to take its natural course with dignity and appropriate goals of care.