The Kidney Supportive Care Program

Frail & Complex Stream

Louise Purtell
Kidney supportive care

• People with advanced CKD are frail, elderly and/or complex
• Require a care pathway that addresses their needs
“We are inappropriately dialysing patients, I think; prolonging their suffering and not providing them alternative routes to manage their symptoms appropriately.”

~Staff member

“Patients who were electing to have conservative management in end stage kidney stage, or who were struggling on dialysis [and] were very symptomatic, really often weren’t able to access appropriate palliative care support.”

~Staff member
What are the needs of elderly, frail, complex CKD patients?

Symptom management

Psychosocial, spiritual support for person and family

Support for dialysis decision-making

Planning for end-of-life

Personalised care

Advance care planning is associated with improved end-of-life care. For people >75 on dialysis, the leading cause of death is withdrawal for psychosocial reasons.
“[What’s] always been a big thing for me is the doctor’s check-up. Oh yeah, all your bloods are good, your fluids, you’re doing wonderful, you’re taking your tablets, all that, so you must be really feeling well, and you go “No, I feel like crap”. One thing that doctors should say is it doesn’t matter what it says on the paper work—it’s easiest just to say how do you feel? How are things going with you? Bugger all the bloods; bugger all what fluid and that but how do you feel in yourself? And that’s when you get down to how a person is going.”

~Patient
KSCp model of care

How do we know if it’s working?
“Evaluating the Implementation of a Kidney Supportive Care Program into a Hospital and Health Service”
Research methodology

• Implementation science framework
• Longitudinal mixed-methods study
  – Quantitative data
  – Qualitative data
• Research study embedded into clinical practice
• Collaboration with Health Economics CKD.CRE stream
Symptoms at baseline

Most prevalent symptoms

- Weakness (90%)
- Pain (82%)
- Poor mobility (80%)
- Drowsiness (74%)

Symptoms per patient

- Median = 12
- IRQ=10–14

Most severe symptoms

- Weakness
- Pain
- Poor mobility
- Drowsiness
- Difficulty sleeping

Overall symptom burden

- Mean score = 22.9±9.7
**Symptom management**

**Change in overall symptom scores between visits**

- **First visit**
- **Most recent visit**

Overall IPOS score

![](chart.png)

* p=0.02

**Change in individual symptom scores between visits**

- **Decreased**
- **Increased**

**Symptom management**

69% of KSCp patients reported improvement in overall symptom burden
Summary

- KSCp care is associated with reduced symptom burden
- KSCp has progressed from pilot program to usual care service
- Analysis and dissemination are ongoing
“I’m grateful because we’ve done a lot of things together that we wouldn’t have been able to do because we’d be sitting at home bloody fretting. We’re going out to see the family and going out to go shopping and do stuff and things that we just weren’t going to bother doing, because what was the point?”

~Carer 1
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