

# GCPHN Community Advisory Council (CAC)

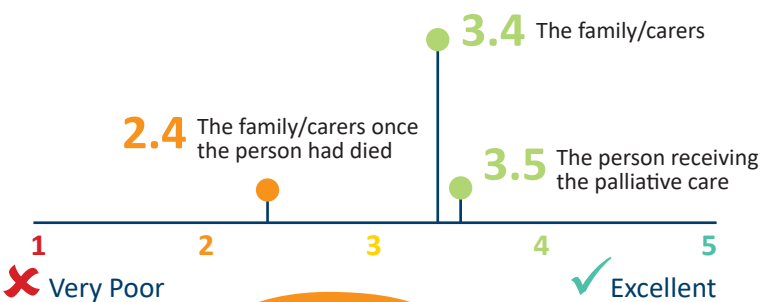
MEETING 03.09.21

## Greater Choices at Home Palliative Care

**73%** (8 out of 11) CAC members had an experience supporting a close family member or friend who was palliative.



These CAC members rated the overall experience for:



Experiences of palliative care was positive in private and public hospitals.

Care for family members during and after the experience was limited, and more support for immediate family was needed.

The care provided by some aged care homes was not sufficient.



**Positive experiences included:** good rapport with medical staff who were attentive, slow pain relief given and maintained, the patient was checked on and bathed regularly, family were kept up to speed on what was happening.



**Negative experiences included:** gaps in knowledge of staff, nursing homes being understaffed and poor quality of care. CAC members strongly expressed the need for reviews of the current systems in place in aged care facilities, discussing how it is likely the current system doesn't have capacity for good palliative care in nursing homes.

### What would improve at home palliative care for the patient, family, and carers?

Additional training for all staff to include assessments of the situation e.g. a run-down of what works vs. what doesn't work. Give staff and volunteers the opportunity to reflect and look for quality improvement.

It would be ideal to have more social workers and volunteers in hospitals and palliative care.

Further education is needed on different types of death.

Carina Hospice and North Stradbroke were recommended as great models of care. CAC members suggested that some of the smaller models could help influence the larger ones.

It was recommended that the same set of rules should be in place for all palliative and end-of-life, not different ones for aged care, for kids etc. overarching standards for everybody.

Further education and information for families is needed on using Ryan's Rule, contacting the Office of Health Ombudsman and using the Australian Charter of Healthcare Rights to help address substandard care.

### How can we better support family and carers when a patient has chosen to die at home?

CAC members suggested the idea of death doula in the community for those who refuse treatment and don't want to use hospital.

Have volunteers and people with lived experience in palliative care, help support the family.

Family members need simple things such as breaks and someone else to bring them food. More practical and emotional support that encompasses these things is needed.

Information and training should be available in different formats for different accessibility options.

There is the need to promote existing dying-at-home resources in the community.



### Recommendation to the GCPHN Board:

That the Board note the CAC feedback, which will be considered as part of development of this project.