
CONFERENCE ABSTRACT

Peace of Mind project: an integrated model to improve the end-of-life journey for patients with dementia

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Introduction: Dementia is a terminal illness, third cause of death among Australians (ABS, 2017) and South Western Sydney (SWS) has one of the highest prevalence in NSW (9,769 people – 2016). This group of people experience barriers to accessing Palliative Care (PC) services and having their end-of-life (EoL) wishes granted. Differently from many conditions, patients with dementia have both their cognitive and decision-making capacity progressively impacted. Therefore, Advance Care Planning (ACP) and engagement with PC services should commence soon after diagnosis.

Short description of practice change implemented: SWSPHN is developing an integrated, person centred model of EoL planning and PC delivered in the place of residence for people aged 70 years and over with intact decision-making capacity at the time of dementia diagnosis.

Aim and theory of change: Improve the EoL journey for people with dementia through early diagnosis and engagement with PC education, planning and choices while the patient's capacity is intact.

Target population and stakeholders: Patients diagnosed with dementia, aged 70 years and over with capacity to undertake ACP intact from Campbelltown, Camden, Liverpool, Fairfield. Collateral target groups include the broader community, service providers, and primary and tertiary clinicians.

Timeline: Diagnostic (Jan-Jul/2018): identify barriers and facilitators during EoL journey for patients with dementia; Solution design (Jul 2018/19): co-design of an integrated pathway with consumers, carers and service providers; Implementation (Jan – Dec/19): capacity building of community and integrated Pathway pilot; Evaluation (Jan-Jul/2020).

Highlights:

- Development of a Dementia specific HealthPathway from pre-diagnosis to PC and EoL
- Raise community and providers awareness of Dementia as a terminal illness
- Improve ACP uptake
- Educate communities on improved social networks to promote emotional, social, physical and spiritual wellbeing for people experiencing dying, grief and bereavement (Compassionate Communities model)

Comments on Sustainability: Sustainable capacity building of community on how to identify, establish and maintain networks between community and health services to support people during EoL. Conjoined community and health providers sessions for continuous partnerships arrangements. Implementation and training of service providers in the new pathway.

Comments on Transferability: The activity could be expanded geographically and to include other sub-population groups such as younger people with an Early Onset Dementia diagnosis and people with chronic illnesses.

Conclusions: Dementia is early diagnosed but not well recognised as a terminal illness by both community and health professionals, impacting in patients EoL journey. Dementia is rarely the principal diagnosis on referrals to PC services, but is frequently a listed comorbidity during hospitalisation.

Discussions: The development of the model will empower primary and community care providers to support patients to access the right care, in the right place at the right time and reduce unwanted hospitalisations. Through timely diagnosis of Dementia, early engagement with EoL planning and a palliative approach to care, patients, carers and families will benefit from an easier to navigate system and greater preparedness for EoL.

Lessons learned: Health Providers confidence to instigate and hold ACP discussions is low. Informal partnerships between community and health providers are few impacting on patients journey during EoL.