Providing early care and support to people with life-threatening illness

Palliative Care South East established an early intervention palliative and supportive care clinic to provide terminally ill but stable clients with access to support sooner, enhancing their quality of life.

## Background

Palliative Care South East (PCSE), which provides home-based care to southeast Melbourne residents who have been diagnosed with a life-limiting illness, receives more than 500 referrals each year. In 2017, referrals were triaged according to immediate need. Clients with urgent needs were prioritised, and those considered to be relatively stable were placed on a wait list.

In 2016–17, approximately 20 per cent of the 444 clients referred to PCSE had to be placed on the wait list and it became clear that these clients were deteriorating at a faster rate than they would have had they been able to access the service earlier.

After conducting a literature review about early intervention palliative care clinics in Australia, Canada, New Zealand, the UK and the US, PCSE decided it needed to establish a new service to meet the needs of clients and carers early in the palliative care trajectory. Studies showed that earlier intervention tended to improve quality of life, increase the chance of people dying in their preferred place of death due to better planning, and reduce overall health system expenditure.

PCSE piloted an early intervention palliative and supportive care clinic with the primary goal of improving service access for people who were early in their illness and in a stable condition. By providing early access to community palliative care services, PCSE aimed to improve clients’ wellbeing, help them better plan for states of deterioration and end of life, and reduce the number of ‘crises’ and unnecessary hospitalisations. The organisation also sought to improve carer wellbeing as carers are subject to considerable stress.

Early intervention palliative and supportive care clinic

**Lead** Palliative Care South East

**Partners** Bolton Clarke, Monash University

**Duration** September 2017 – January 2019

**Key outcomes**

* Increased the number clients accessing the service while stable, with 94 per cent of clients accessing the services earlier
* Decreased wait times from referral to initial visit from 52 days to 38 days
* Reduced self-reported client presentations to the ED from 51 per cent to 19 per cent
* Engaged 93 per cent of clients in advance care planning discussions, with 70 per cent having elements of a formal plan in place
* Found that 65 per cent of deteriorating clients had stabilised six weeks after admission
* Received positive consumer feedback, with 75 per cent of clients agreeing their quality of life had improved and 89 per cent of carers reporting that the support information provided was beneficial

‘[I now have] access to services I didn’t know existed.’

**– EPIC client**

‘This clinic has opened our eyes to what we need to have in place for our life.’

 **– EPIC client**

## Key activity

PCSE opened the Early Palliative Intervention Clinic (EPIC) to clients in May 2018, operating one day a week.

The EPIC model of care involved:

* a multidisciplinary team providing holistic care and support, including nurse practitioners, registered nurses, allied health practitioners, a social worker, a counsellor, and volunteers
* an initial needs assessment with clinicians during the client’s first visit to ensure their care plan was tailored to their goals, preferences and priorities
* follow-up appointments scheduled across the multidisciplinary team in either two-, four- or six-week intervals, depending on need and preference
* 24-hour phone support
* transition to PCSE’s home care services when a client became too unwell to attend the clinic.

The clinic offered:

* client education on their illness and options
* specialist symptom, pain and medication management
* decision making and advance care planning support
* emotional support through counselling and spiritual care
* services to support relaxation and enhance quality of life, such as massage therapy and opportunities to talk with others in a similar situation
* practical support for daily living, such as access to Centrelink, referral and advocacy for financial and legal matters, referral to home care and respite care services, and equipment and education
* a carer wellbeing program, including education workshops providing information on available support and skills to help carers in their role, complimentary therapy sessions, and a carer support group.

‘[Other service providers have told us] we can apply for a carer’s allowance, but nobody told us how to do it. It is amazing that with one visit [to EPIC], we get things done so quickly.’

**– EPIC client**



## Outcomes

During the initial pilot, EPIC had 63 clients and 396 appointments. Within the six-month trial, the clinic:

* saw 94 per cent of clients access palliative care services earlier, with 46 per cent of EPIC clients being stable at admission. This was a higher proportion than PCSE’s home-based service (32 per cent) and the Australian average (43 per cent)
* reduced the time from referral to initial visit for all clients from 52 days pre-clinic to 38 days post-clinic. Time to initial visit was further reduced to 21 days for clients who met the EPIC criteria. While the number of clients on the wait list reduced initially, there was an overall increase due to successful promotion of the clinic leading to an increase in referrals
* saw 93 per cent of all clients discussing plans for their future care. 70 per cent had elements of a formal advance care plan in place post-clinic compared with 48 per cent pre-clinic
* reduced the proportion of clients making unplanned emergency department (ED) presentations from 51 per cent pre-clinic to 19 per cent post-clinic, potentially avoiding 131 ED presentations per year (although this data was self-reported and not verified with the hospital).

A comparison with ‘usual care’ showed that while the cost of non-hospital care in an early intervention clinic such as EPIC was slightly higher, significant cost savings could be achieved through reduced hospitalisations. Further revisions of the model and support systems have since reduced the cost base to a sustainable level.

### Client experience

* 65 per cent of deteriorating EPIC clients had stabilised six weeks after admission and remained stable during the trial.
* 12 of 16 clients surveyed (75 per cent) agreed their quality of life had improved by attending EPIC, with the remaining four remaining neutral.
* Benefits of EPIC reported by clients included:
	+ improved daily function, knowledge and confidence
	+ increased familiarity with early palliative management and the holistic support services available
	+ enhanced access to quality pain management and equipment such as wheelchairs
	+ improvements in wellbeing, including reduced isolation and anxiety due to access to 24/7 support
	+ therapeutic benefits from massage therapy
	+ feeling supported through difficult processes and being able to talk about their experiences.
* 24 of the 63 clients died during the trial. Of those who died, 67 per cent died in their place of choice. 21 per cent did not die in their place of choice. This was because it was no longer a viable option due to their condition.
* While no EPIC carers took up the offer of the carer wellbeing program (it was only accessed by carers of PCSE home care clients), they were positive about the carer support kit provided as part of the EPIC client welcome pack, with 89 per cent saying they found the information in the kit beneficial.

‘Having someone to contact at any time is a great help with anxiety.’

 **– EPIC client**

## Key learnings

* The reduction in self-reported unplanned ED presentations combined with the tendency for EPIC clients to stabilise suggests early provision of person-centred multidisciplinary care can reduce the likelihood of clients deteriorating early in their illness.
* PCSE found that building client and carer confidence and alleviating their anxiety helped to avoid unnecessary hospitalisations as they could make calmer, more informed decisions.
* The highest contributing factors towards clients’ perceived quality of life were symptom and pain management, feeling that someone was listening to them, and achieving goals.
* Many clients were not ready to complete a formal advance care plan so early in their illness, choosing to discuss their options instead. Advance care planning discussions need to be ongoing to prepare clients for when they near the end of their life.
* Massage therapy became an important part of the service. 91 per cent of clients and 100 per cent of carers reported reduced anxiety and better symptom management as a result of the therapy, and they were more likely to discuss feelings and concerns.
* When clients are stable and well, their carers are less likely to accept support, so in the early stages of illness, providing written or online information that carers can read at their leisure may be more effective than workshops. However, as clients deteriorate, the need for carer education and support increases, so it is important to continue discussing options and provide support when needed.
* Operating the clinic one day a week impacted some clients’ ability to attend. Clients early in their illness are often still having treatment and regular appointments with specialists.