



Palliative care in South Australia

Supporting all South Australians who are facing death and bereavement to live, die and grieve well



PalliativeCare
SOUTH AUSTRALIA

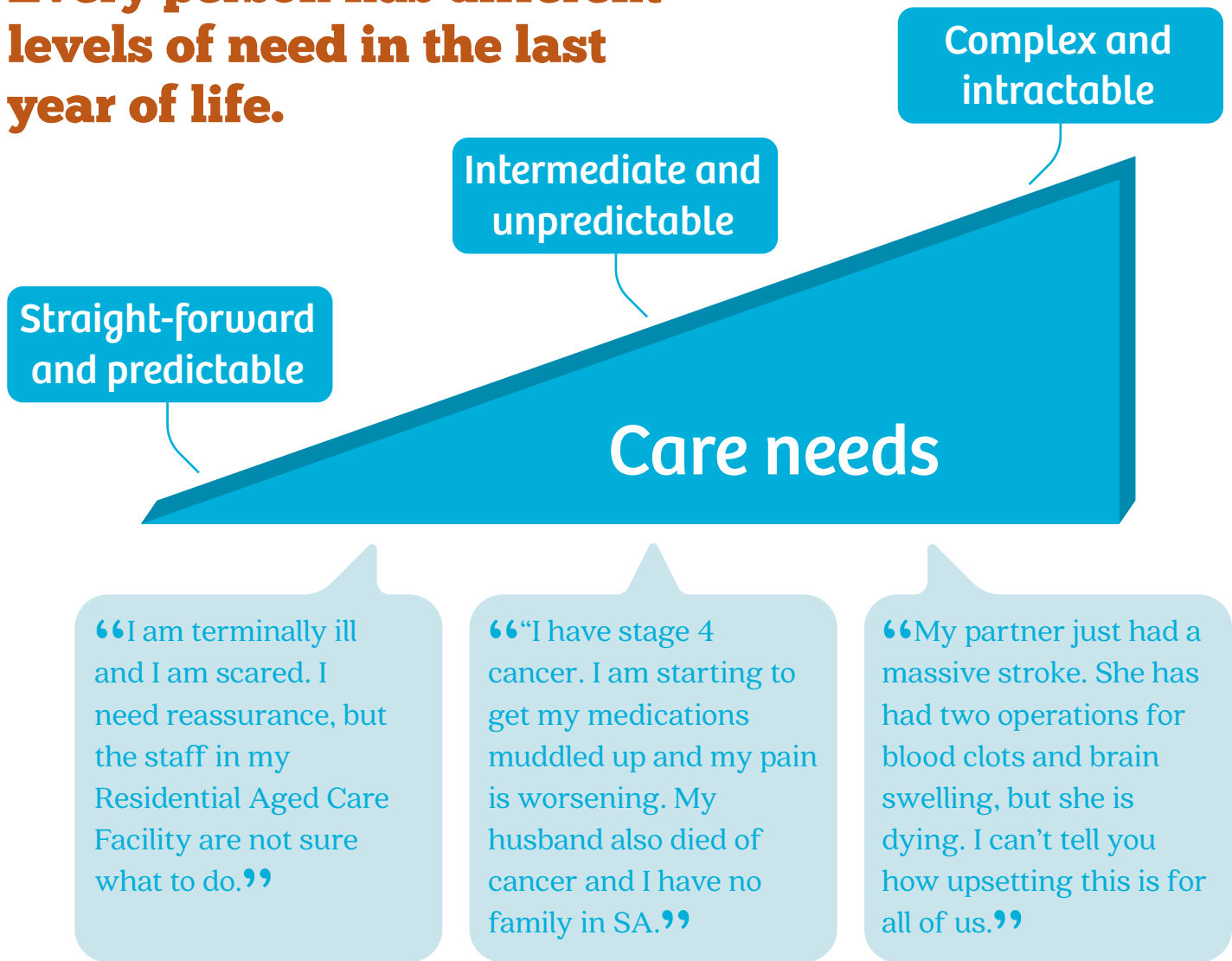
13,337

South Australians died in 2016

Some South Australians get the help they need to live, die and grieve well.

Some South Australians don't.

Every person has different levels of need in the last year of life.



We need to decide who gets their needs met, and when and how.

When is it OK to say NO?

NO,
we will not give you the support to improve your experience

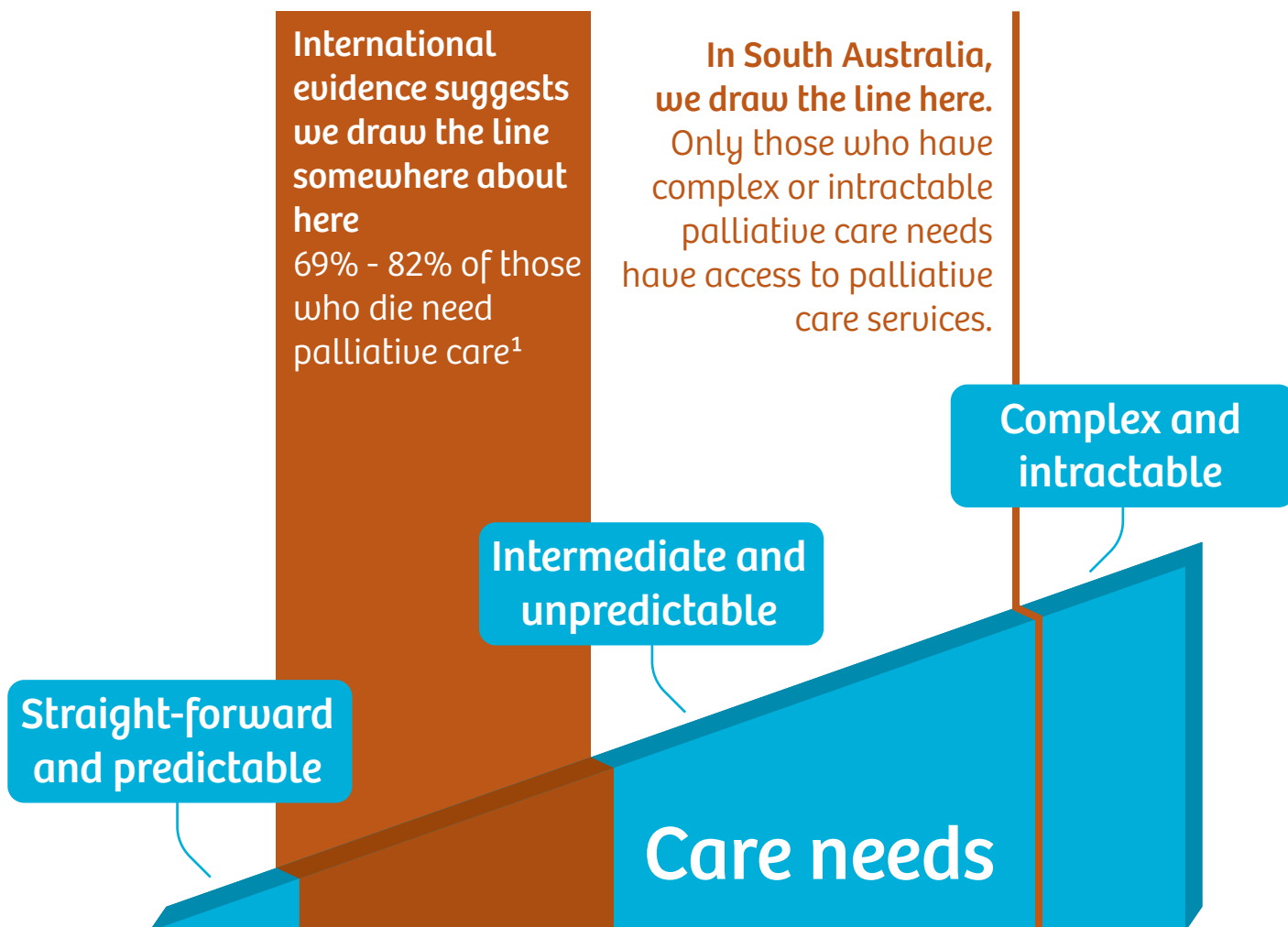
NO,
we will not give you access to the supports you need

NO,
we will not connect you to services at the time and place you need it

NO,
we will not give you personalised service tailored to your needs

NO,
we will not ensure you have the right resources to live, die and grieve well

Palliative care focusses on improving symptoms, improving wellbeing and helping people achieve their goals and the life they want to live as they approach the end of their life



Where do you believe we should draw the line?

Who do you think should be supported to live, die and grieve well?

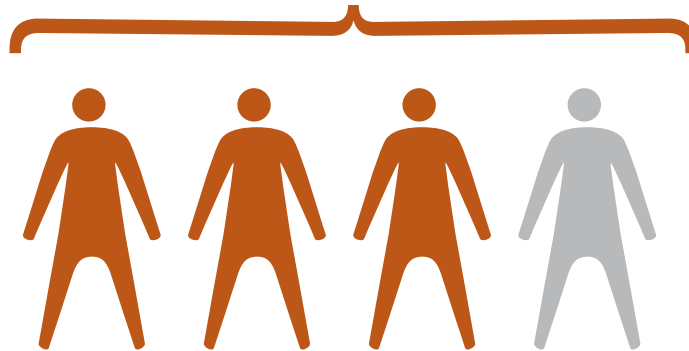
1. Murtagh FEM, Bausewein C, Verne E, Groeneveld EI, Kaloki YE and Higginson IJ. How many people need palliative care? A study developing and comparing methods for population-based estimates. Palliative Medicine 2014, Vol 28(1) 49 –58.

You only die once.

If it is a bad experience, it is bad for everyone...

3 out of 4

Australians do not get the care they need



...forever

“We have someone dying in our family. We didn’t know where to go for help, so we called our Federal MP.”

“I have breast cancer. I want to be at home with my young family but the pain got too much. They told me I was not serious enough. They wouldn’t help me move, or shower or go to the toilet. They won’t give me anything to make me more comfortable. My sister has to stay to help me toilet.”

“I wanted to be at home. This was so sudden. I know I am dying but they want to keep me in to do tests and chemo. What for? I have moved wards three times. I am treated like an idiot. They sent me home eventually. But there is no plan. We don’t know what we are doing, what the meds are for. My daughter can’t go to work. I am a full-time job right now. There is no one to help her.”

We want to say **YES** to all South Australians

YES, we will give you support that improves your experience

YES, your care will be personal and high quality

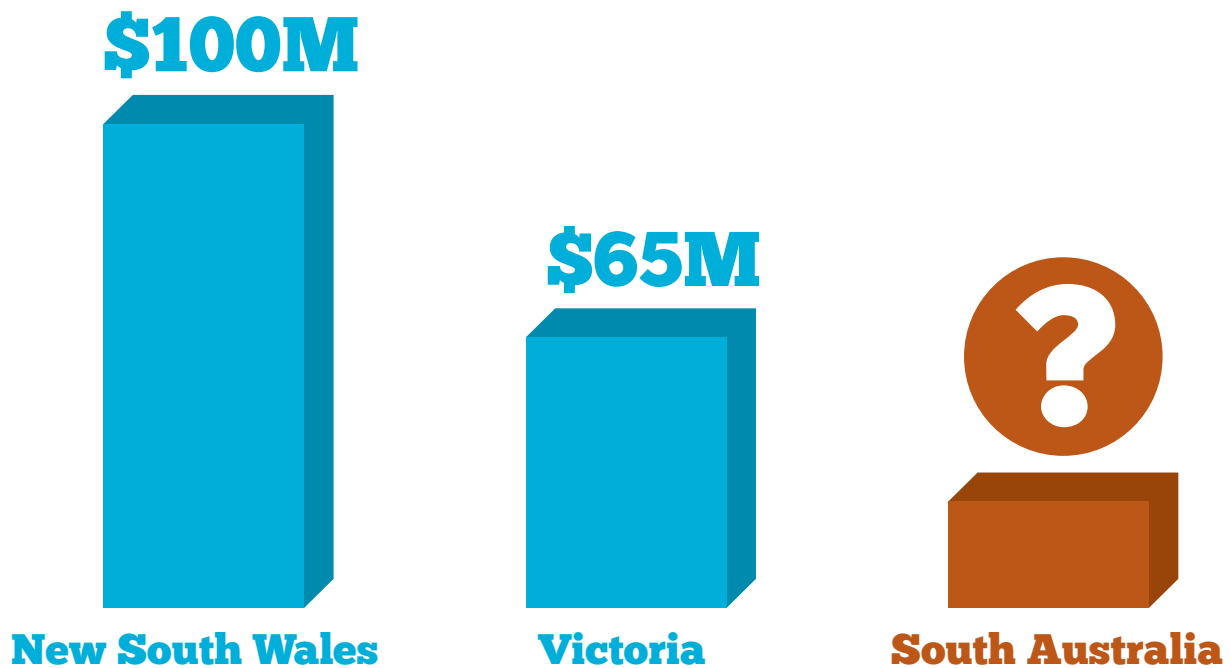
YES, you can access the support you need

YES, we can resource your care needs

YES, you will receive the right care at the right time

YES, we will support you to live, die and grieve well.

Other State Governments agree and have invested in palliative care:

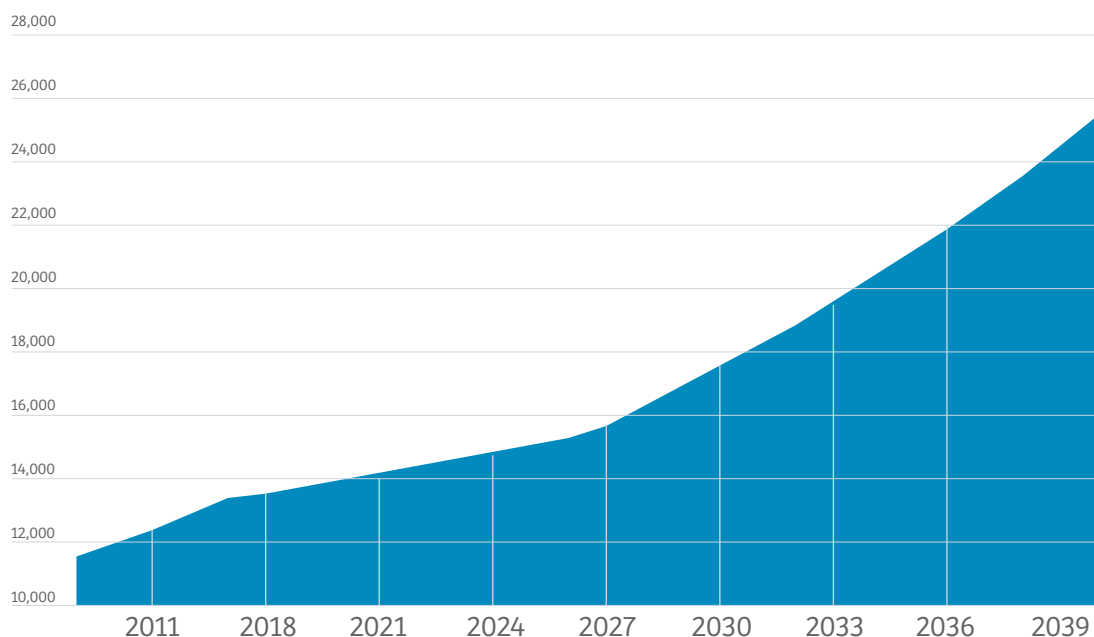


The number of South Australians dying each year will continue to grow.

In SA we want to make smart choices, that give good health and social outcomes for a good price. We want to use investment wisely.

South Australia Annual Number of Deaths

Historical & Forecast (Source Adelaide Cemeteries Authority SA)



Access and Equity

"I can access the support I need, regardless of my circumstances"

We want to open up access to palliative care services

If we reframe the access point to palliative care, many more South Australians will be able to receive the support they need to live, die and grieve well.



Currently, people have to be seen by specialist or hospital palliative care to receive metropolitan community palliative care supports to stay at home. This is one reason South Australia draws the line so far from where international experts recommend.

Reframing the access point to community palliative care supports will allow more people to have the support they need.



The access point should allow people who want their care to be in the community setting and those who don't yet require specialist palliative care services to be assessed and receive on support they need.



Seamless, timely and responsive care


"I receive the right support at the right time, and all parts of my support feel connected."

We want people to have access to the types of support they need after hours and on weekends.

{ Most people want to live well in the last year of life.

{ Most people want to live in their home with family and friends around them.

{ Living with a terminal illness does not stop after hours or on weekends, but many palliative care services in South Australia do.



"Whether it is day or night, I want to have personal help from someone who knows my story."

Personalised, high quality care

“My supports are effective and I feel safe.”

“I have breast cancer. I want to be at home with my young family but the pain got too much. They told me I was not serious enough. They wouldn't help me move, or shower or go to the toilet. They won't give me anything to make me more comfortable. My sister has to stay to help me toilet.”

“I have bladder cancer and it is now in my liver. When I left hospital, they gave me wound care at home. I don't feel right. I am worried. They talked about palliative care, but I never got it.”

“She is in hospital. She's stopped eating. They say it is organ failure. But there are no palliative care beds. She is stuck where she is. They have taken out the drip now. We are just waiting now—in a crappy ward.”



“We have someone dying in our family. We didn't know where to go for help, so we called our Federal MP.”

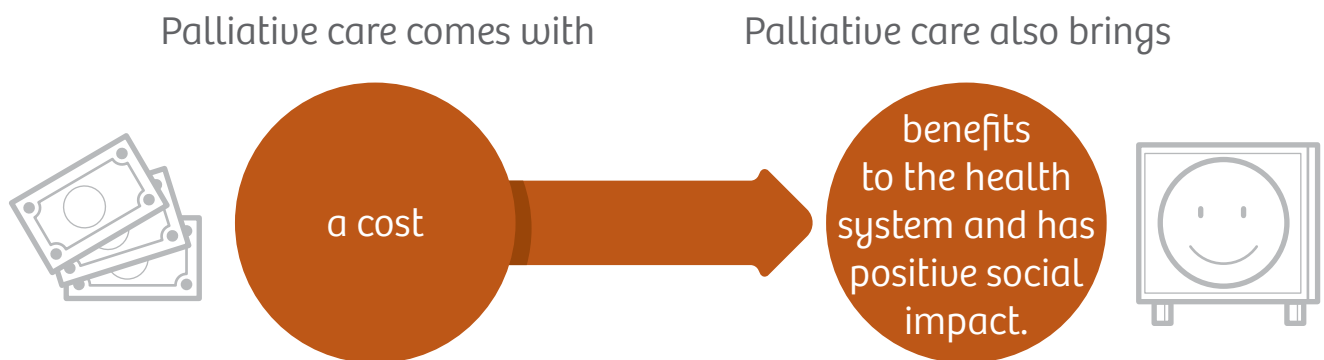
“I wanted to be at home. This was so sudden. I know I am dying but they want to keep me in to do tests and chemo. What for? I have moved wards three times. I am treated like an idiot. They sent me home eventually. But there is no plan. We don't know what we are doing, what the meds are for. My daughter can't go to work. I am a full-time job right now. There is no one to help her.”

“My Mum had a stroke. It turned out awful. She had no comfort care. No palliative care. No pump to manage her pain because they couldn't find one. It shouldn't have been this way. Mum deserved better!”

Appropriate resources are identified and agreed

"I have the supports I need to ensure my wishes, rights and dignity are respected, my symptoms are well-managed and my quality of life is maximised."

We want transparent, efficient and effective palliative care services across the state



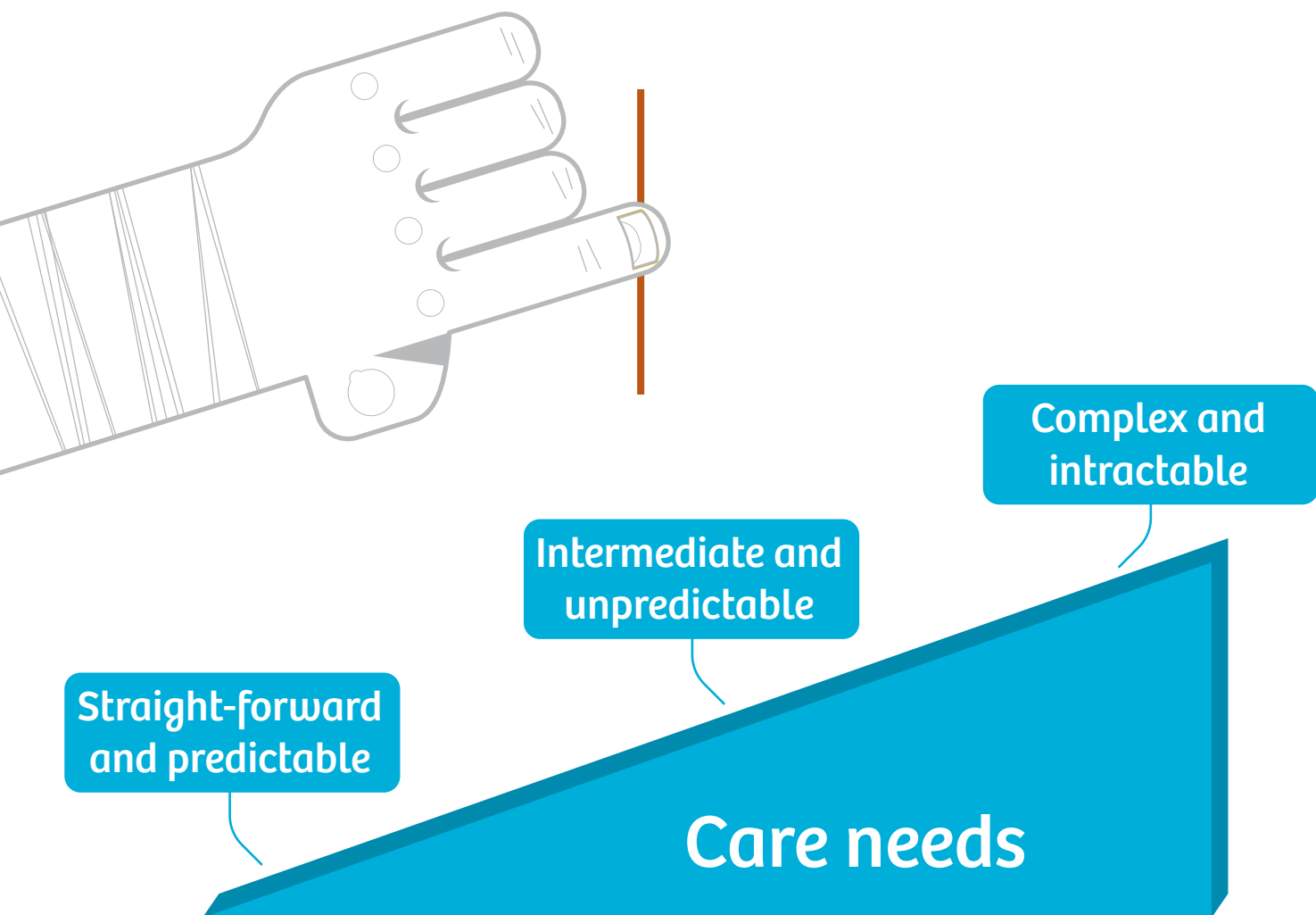
Did you know?

- { Good palliative care improves family experience after a death¹.
- { Caregivers who feel the needs of the dying person are met find it easier to 'grieve' after the death².
- { A strong relationship between the patient and palliative care staff can positively affect the mental health of family carers after the death³.
- { Access to community palliative care leads to less hospital admissions⁴.
- { Access to community palliative care leads to less ED presentations⁵.

It will be important to demonstrate that with continual assessment and improvement, palliative care can be an enabler to SA Health, sustainable in the face of growth and increased demand.

1. Aoun SM, Ewing G, Grande G, Toye C, Bear N. The impact of supporting family caregivers pre-bereavement on outcomes post-bereavement: Adequacy of end of life support and achievement of preferred place of death. *J Pain Symptom Manage*. 2017 Oct 10. pii: S0885-3924(17)30526-2. doi: 10.1016/j.jpainsymman.2017.09.023. [Epub ahead of print]
2. Burns E, Prigerson HG, Quinn SJ, Abernethy AP, Currow DC. Moving on: Factors associated with caregivers' bereavement adjustment using a random population-based face-to-face survey. *Palliat Med*. 2017 Jun 1;269216317717370. doi: 10.1177/0269216317717370. [Epub ahead of print]
3. Trevino KM, Maciejewski PK, Epstein AS, Prigerson HG. The lasting impact of the therapeutic alliance: Patient-oncologist alliance as a predictor of caregiver bereavement adjustment. *Cancer*. 2015 Oct 1;121(19):3534-42
4. Spilsbury K, Rosenwax L, Arendts G, Semmens JB. The impact of community-based palliative care on acute hospital use in the last year of life is modified by time to death, age and underlying cause of death. A population-based retrospective cohort study. *PLoS One*. 2017 Sep 21;12(9):e0185275. doi:10.1371/journal.pone.0185275. eCollection 2017. 5. Spilsbury K, Rosenwax L, Arendts G, Semmens JB. The Association of Community-Based Palliative Care With Reduced Emergency Department Visits in the Last Year of Life Varies by Patient Factors. *Ann Emerg Med*. 2017 Apr;69(4):416-425.

So, where would you draw the line?



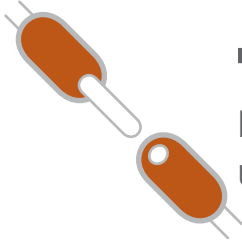
Who do you think should be supported to live, die and grieve well?

Key Messages



A Fair Go

three quarters of people are not getting access to palliative care



Transitions

Brand new system but not connected up **PALLIATIVE CARE IS THE ENABLER**

Solutions



Reframe the access

point **\$14M/year**



Open access 24 hours

7 days **\$4M/year**



Coordinated **\$6M/year** integrate palliative care into **chronic disease clinics**



Awareness **\$400K/year** Information review, reproduction and dissemination

\$24.5M SA

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