

State  
Election  
2015  
Call for  
Action

A DIGNIFIED  
DEATH  
=  
CHOICE



**PalliativeCare**  
NEW SOUTH WALES

## OUR VISION

That every person in NSW who is diagnosed with a condition that will result in their death in the foreseeable future will have access to quality care that addresses their physical, psychosocial and spiritual needs.

## CALL FOR ACTION

Every resident of NSW who is living with a life-limiting illness should be supported in choosing where they die.

It could be in their own home. It could be in their Residential Aged Care Facility. In a long-term in-patient Palliative Care facility. In a hospital. Under a tree.

But too few people have that choice.

The NSW government has taken very welcome first steps to ensuring that you have the choice to die at home, if that is what you and your family want. There is more to do however to make genuine choice a reality for all and ensure a safe and dignified death for everyone.

## WHAT IS NEEDED NOW

Increased investment in Palliative Care by \$8 million per year:

- \$4 million per year to address current major gaps in Palliative Care services.
- \$4 million per year to meet the growing need for Palliative Care.

## WHAT IS NEEDED IN THE FUTURE

- An ongoing commitment to supporting real growth in the Palliative Care service system, including Specialist Palliative Care services in metro and rural/remote areas.
- Increased funding so that capacity growth is ahead of the ageing and chronic disease curve – not behind it.
- Government policy that encourages professional development programs incorporating end of life care so that hospital clinicians, General Practitioners and other care providers feel more confident in providing appropriate end of life care. GPs for example can feel confident and supported in starting end of life conversations with the growing number of patients and their families.

### Case Study: More resources needed

*Mavis Strong is a patient at a major Palliative Care in-patient facility in Sydney. Mavis is on a pension and is on a waiting list for incontinence pads. The waiting list is six weeks. Doctors have given Mavis five weeks to live.*

### Case Study: Young and homeless

*Jody Bell is a homeless young person with advanced liver disease and an in-patient in an acute hospital. She is too young for an aged care facility and her prognosis is too uncertain for a timely admission to a Palliative Care unit. There is nowhere to go until she gets sicker.*

## OUTCOMES

**PRIMARY CARE HEALTH PROFESSIONALS** will be able to provide excellent end-of-life care and recognise when to refer patients and families on to specialist Palliative Care.

**THERE WILL BE A CONTINUATION** of the increasing trend in home deaths and associated decline in unnecessary acute hospital deaths.

**LONG-TERM IN-PATIENT** Palliative Care facilities will be fully supported to provide the choice that many people want – to die in a comfortable but professionally supported environment.

**CARERS** – the missing voice in this conversation – are better supported in their role with in-home after-hours respite.

**VOLUNTEERS** across the state are fully supported and educated to provide essential support to the this group of people and their families.

**IMPROVED ACCESS** to Palliative Care by groups who currently miss out, especially CALD groups, Aboriginal and Torres Strait Islander groups, the young, the homeless and those with mental health challenges.

**SPECIALIST PALLIATIVE CARE SERVICES** will have sufficient and well trained staff to enable them to respond to the growing need and care choices.

**MORE EFFICIENT** and less costly delivery of health services.

## RECOMMENDATIONS

1. **FUND KEY SPECIALIST POSITIONS** including Nurse Practitioners in the areas of greatest need now – Western Sydney, all of rural and regional NSW, South West Sydney, Central Coast, Hunter region. Total cost: **\$3 million per year.**

3. **INCREASE COMMUNITY AWARENESS** and capacity so that people know there are services available both for themselves and for their carers or families: fund a community engagement programme to raise awareness of end of life and specialist Palliative Care. This programme will build community capacity in dealing with issues of dying, death, bereavement and to encourage people to discuss, clarify and document their advance care wishes. **\$300,000 per year.**

2. **WORK WITH PALLIATIVE CARE NSW** and other key agencies to develop a workforce strategy for Palliative Care to attract health professionals including allied health professionals to specialise in Palliative Care in both metro and rural areas. Fund a program of education on Palliative Care and communication skills, including the use of key triggers for referral to Palliative Care with a focus on those health professionals working patients with chronic illness. **\$400,000 per year.**

4. **RECOGNISING** that most people in NSW with a life limiting illness currently die in a NSW acute public hospital, PCNSW calls for a commitment to improve the quality and safety of dying in these important facilities. To achieve this NSW A1 hospitals require seven day 24 hour access to Palliative Care consultations and advice, and five day access to Palliative Care consultations and advice in all NSW B hospitals is urgently required. Cost is dependent on staff mix required. Estimated cost: **\$3 million per year.**

5. **TIMELY, FREE AND EQUITABLE** access to appropriate equipment to support end of life care and specialist Palliative Care is required urgently eg electric beds, pressure relieving equipment and incontinence pads – regardless of place of care. **\$1 million per year.**

6. **CONTINUE TO FUND** the Volunteer Support Program to ensure that volunteers across the state are fully supported and educated. **\$300,000 per year.**

## **WHAT IS PALLIATIVE CARE?**

*'Palliative Care provides a safe pair of hands for people without influencing or shaping the traveller'*  
Professor Norelle Lickiss, PCNSW State Conference 2014.

Palliative care is an approach that improves the quality of life of patients and their families facing the challenges associated with life limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

## **WHO CAN BENEFIT FROM PALLIATIVE CARE?**

Palliative care is beneficial for people of all ages with a wide range of life limiting conditions, including cancer, end stage organ failure, dementia, other neurodegenerative conditions and genetic disorders. It is provided on a needs basis from diagnosis and including bereavement.

## **PALLIATIVE CARE NEW SOUTH WALES**

Palliative Care New South Wales is an independent not-for-profit peak body in NSW. Established in 1981, we represent Palliative Care providers, consumers and their families and those with an interest in Palliative Care. We are a member of the national peak body, Palliative Care Australia.

Our mission is to provide effective support to services, professionals, carers, and the community in achieving our vision.

Quality Palliative Care is realised when strong networks exist between specialist Palliative Care providers, primary generalist and primary specialist and support care providers and the community: enabling them to work together to promote an optimal quality of life and a good death.

## **FOR MORE INFORMATION CONTACT**

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