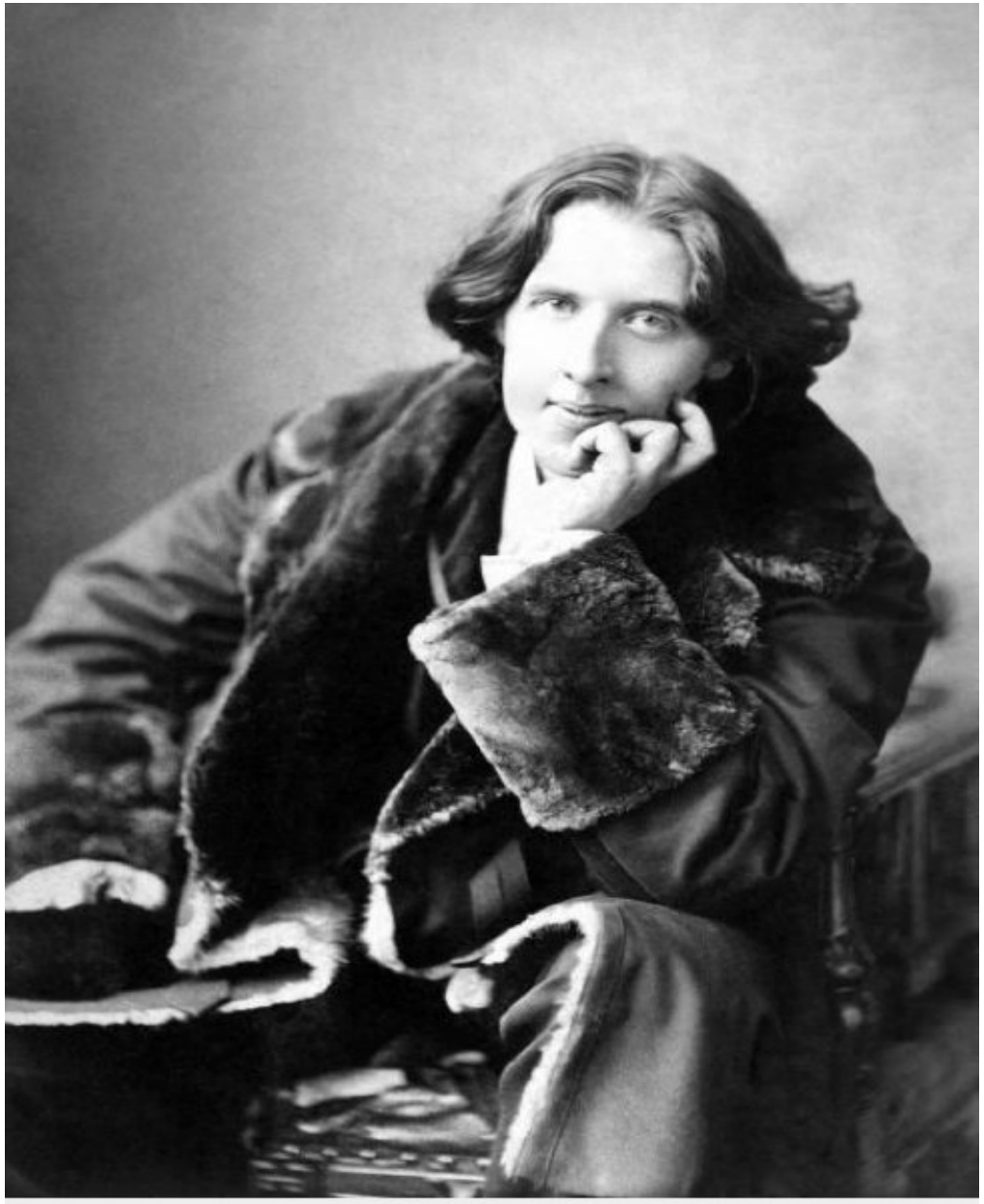
Bringing our dying home: the role of advanced practice clinicians in strengthening community capacity

Kate Swetenham

Oscar Wilde

“To live is the rarest thing in the world. Most people exist, that is all”



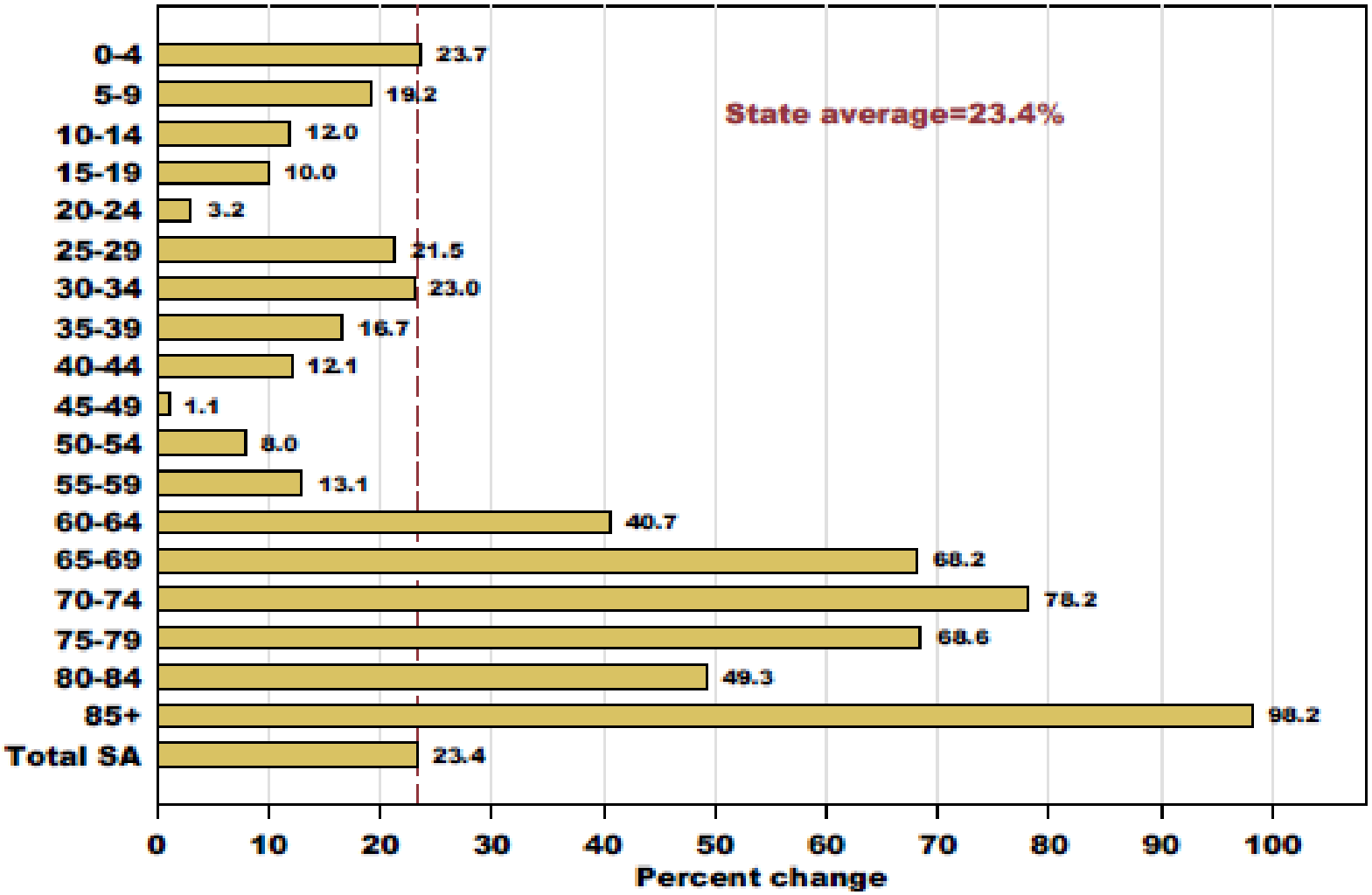
When asked 70% of people say they wish to die at home

“I want to be at home as long as possible”

Challenges ahead

- Increasing demand for end of life care in the coming years
- Population of people will be older, living alone, with fewer available caregivers in a climate of an ageing workforce.

Figure 10. Projected South Australian Growth 2006 to 2026, by Age Group



Source: Based on Department of Planning and Local Government 2010a

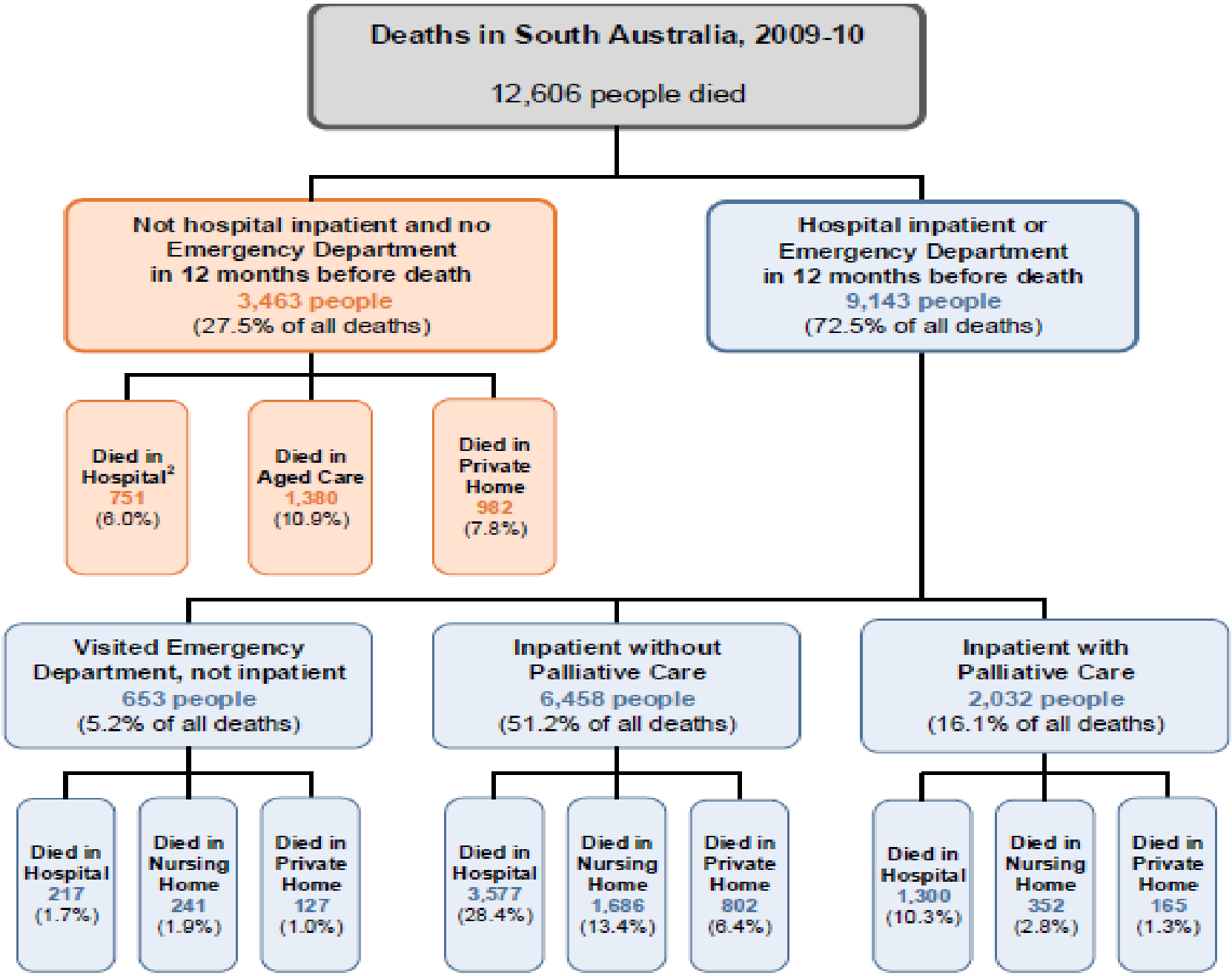

Deaths in South Australia, 2009-10
12,606 people died
Not hospital inpatient and no Emergency Department in 12 months before death
3,463 people
(27.5% of all deaths)
Hospital inpatient or Emergency Department in 12 months before death
9,143 people
(72.5% of all deaths)
Died in Hospital[2]
751
(8.0%)
Died in Aged Care
1,380
(10.9%)
Died in Private Home
982
(7.8%)
Visited Emergency Department, not inpatient
653 people
(5.2% of all deaths)
Inpatient without Palliative Care
6,458 people
(51.2% of all deaths)
Inpatient with Palliative Care
2,032 people
(16.1% of all deaths)
Died in Hospital
217
(1.7%)
Died in Nursing Home
241
(1.9%)
Died in Private Home
127
(1.0%)
Died in Hospital
3,577
(28.4%)
Died in Nursing Home
1,686
(13.4%)
Died in Private Home
802
(6.4%)
Died in Hospital
1,300
(10.3%)
Died in Nursing Home
352
(2.8%)
Died in Private Home
165
(1.3%)

Table 2. Public Metropolitan Emergency Department and Public Hospital Use in Last Year of Life by Top Three Causes of Death, 2009-2010

Cause of Death	Died	Presented to ED	Average presentations if presented to ED	Separated from hospital	Average separations if separated	Average bed days if separated	Separated from ICU	Average time in ICU if admitted to ICU	Received ventilation	Average time of ventilation if ventilated
Cancer	2,803	1,589 (56.7%)	2.6	1,991 (71.0%)	3.7	38.8	212 (7.6%)	2.96 days (71.1 hrs)	62 (2.2%)	2.8 days (67.8 hrs)
Cardiovascular	2,667	1,356 (50.8%)	2.3	1,549 (58.1%)	3.9	27.2	258 (9.7%)	4.4 days (104.3 hrs)	150 (5.6%)	3.96 days (95.0 hrs)
Respiratory	2,589	1,606 (62.0%)	2.5	1,888 (72.9%)	3.6	38.3	405 (15.6%)	7.3 days (174.2 hrs)	171 (6.6%)	7.4 days (176.9 hrs)
All deaths	**12,606**	**7,219 (57.3%)**	**2.5**	**8,490 (67.3%)**	**4.2**	**36.1**	**1,593 (12.6%)**	**5.7 days (136.9 hrs)**	**818 (6.5%)**	**5.5 days (132.3 hrs)**

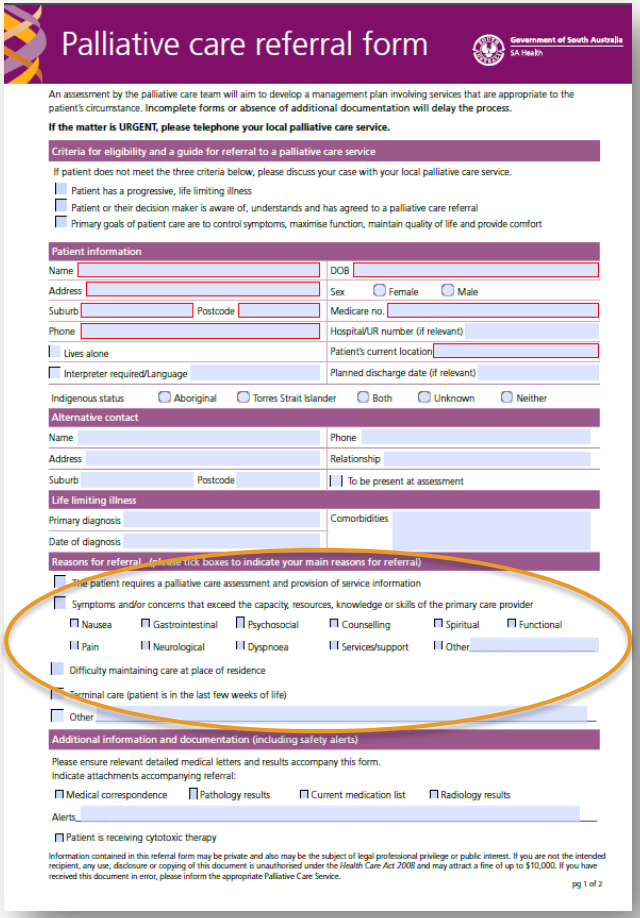
Source: Based on SA NT Datalink 2013, Customised Report
*Note percentages are of all people who died of that cause

Community consultation

- During consultations, community members expressed concerns that people with non-cancer terminal illnesses are less likely to receive appropriate end of life care and access to specialised palliative care.
- In South Australia in 2009-10, 81.6% of palliative care separations were for someone whose principal or other diagnosis was cancer, higher than the 76% nationally (AIHW 2011). Nationally, renal failure was a far second at only 13% of palliative separations; heart failure and chronic obstructive pulmonary disease were also a minority of palliative care, at 8% and 6.4%, respectively.

- *'GP [was] not willing to have Palliative Care staff involvement – 'only for those dying in pain with cancer'' (Family member)*

Referral & eligibility criteria to SPC



Palliative care referral form

Government of South Australia
SA Health

An assessment by the palliative care team will aim to develop a management plan involving services that are appropriate to the patient's circumstance. **Incomplete forms or absence of additional documentation will delay the process.**

If the matter is URGENT, please telephone your local palliative care service.

Criteria for eligibility and a guide for referral to a palliative care service

If patient does not meet the three criteria below, please discuss your case with your local palliative care service.

- ☐ Patient has a progressive, life limiting illness
- ☐ Patient or their decision maker is aware of, understands and has agreed to a palliative care referral
- ☐ Primary goals of patient care are to control symptoms, maximise function, maintain quality of life and provide comfort

Patient information

Name | DOB
Address | Sex ☐ Female ☐ Male
Suburb | Postcode | Medicare no.
Phone | Hospital/UR number (if relevant)
☐ Lives alone | Patient's current location
☐ Interpreter required/Language | Planned discharge date (if relevant)
Indigenous status ☐ Aboriginal ☐ Torres Strait Islander ☐ Both ☐ Unknown ☐ Neither

Alternative contact

Name | Phone
Address | Relationship
Suburb | Postcode | ☐ To be present at assessment

Life limiting illness

Primary diagnosis | Comorbidities
Date of diagnosis

Reasons for referral (please tick boxes to indicate your main reasons for referral)

- ☐ The patient requires a palliative care assessment and provision of service information
- ☐ Symptoms and/or concerns that exceed the capacity, resources, knowledge or skills of the primary care provider
  - ☐ Nausea ☐ Gastrointestinal ☐ Psychosocial ☐ Counselling ☐ Spiritual ☐ Functional
  - ☐ Pain ☐ Neurological ☐ Dyspnoea ☐ Services/support ☐ Other
- ☐ Difficulty maintaining care at place of residence
- ☐ Terminal care (patient is in the last few weeks of life)
- ☐ Other

Additional information and documentation (including safety alerts)

Please ensure relevant detailed medical letters and results accompany this form.
Indicate attachments accompanying referral:

☐ Medical correspondence ☐ Pathology results ☐ Current medication list ☐ Radiology results

Alerts

☐ Patient is receiving cytotoxic therapy

Information contained in this referral form may be private and also may be the subject of legal professional privilege or public interest. If you are not the intended recipient, any use, disclosure or copying of this document is unauthorised under the *Health Care Act 2008* and may attract a fine of up to $10,000. If you have received this document in error, please inform the appropriate Palliative Care Service.

pg 1 of 2

Reasons for referral to specialist palliative care include:

- Palliative care assessment and provision of service information;
- Symptoms and/or concerns exceed the capacity, resources, knowledge or skills of the primary care provider;
- Difficulty maintaining care at place of residence; and/or
- Terminal care (person is in the last few weeks of life).

Criteria for eligibility and a guide for referral to a palliative care service

If patient does not meet the three criteria below, please discuss your case with your local palliative care service.

- ☐ Patient has a progressive, life limiting illness
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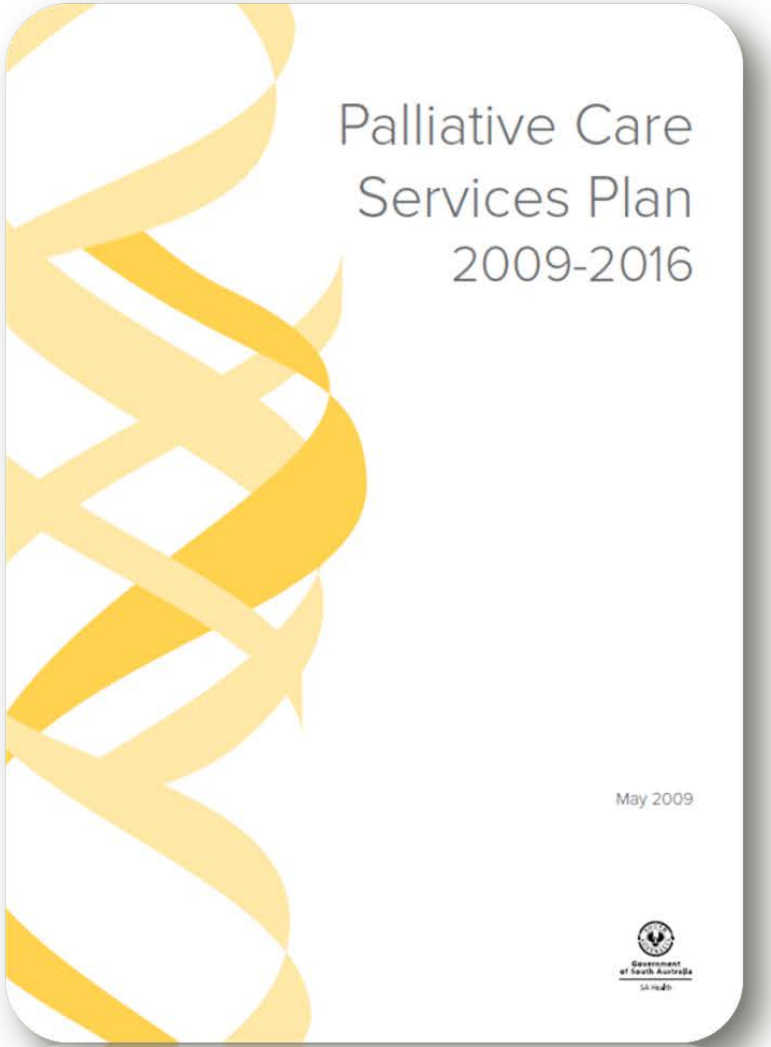
  ☐ Nausea ☐ Gastrointestinal ☐ Psychosocial ☐ Counselling ☐ Spiritual ☐ Functional

  ☐ Pain ☐ Neurological ☐ Dyspnoea ☐ Services/support ☐ Other_____
- ☐ Difficulty maintaining care at place of residence
- ☐ Terminal care (patient is in the last few weeks of life)
- ☐ Other _____

What the plan means for palliative care services in South Australia - as proposed in 2009



- Expanded and diversified teams
  - New disciplinary contributions and roles
  - Optimising the use of existing roles

The Plan – KPIs

- DEVELOPING A STATEWIDE PALLIATIVE CARE WORKFORCE STRATEGY
- PROLIFERATING ADVANCED PRACTICE ROLES
- ESTABLISHING A STATEWIDE PALLIATIVE CARE COMMUNITY PHARMACY NETWORK
- DEVELOPING A RAPID RESPONSE SERVICE
- DEVELOPING THE ROLE OF THE GP WITH A SPECIAL INTEREST IN PALLIATIVE CARE.

Building the NP workforce

- Election promise provided scholarship for nurses to train as NPs-Palliative Care identified as an area of investment.
- NPC Training program aligned with the strategies of the Plan to enhance community based care.
- NPs now make up the workforce of specialist palliative care teams.

NP- contribution to the SPC team

Provision of nursing leadership and expertise particularly in the area of complex case management,

- Nurse led intake clinic
- MND
- Mental Health
- Disability

Resource to nursing colleagues via expanded scope of practice

Consumer expectations regarding EOLC

Advanced Care Planning

- End of life issues identified and accepted by clinicians who initiate discussions with
- patients and their families.
- People make known their wishes about treatment.
- Treating health professionals are aware of and respect people's wishes.

Access to Services

- Patients and carers have 24/7 access to symptom management, support and advice
- as needed.
- There is equitable access to end of life care options delivered in the community or
- hospital by a skilled workforce in accordance with advanced care plans.
- Patients do not have unnecessary visits to hospital or unwanted, invasive treatments.

A Good Death

- A dignified death in a place of the person's choosing.
- Access to grief and bereavement support for carers and family.

Advanced Practice Pharmacist

CSIRO PUBLISHING
Australian Health Review
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Perspective

Clinical networks influencing policy and practice: the establishment of advanced practice pharmacist roles for specialist palliative care services in South Australia

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David Stephenson[3] RN, BN, MPallC, MNP, PhD, Nurse Practitioner

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Abstract

Objectives. To operationalise the concept of 'advanced practice roles' in pharmacy within the new integrated regionalised palliative care service model outlined in the Palliative Care Services Plan 2009–2016, SA Health.

Methods. A working group was established under the auspices of the Palliative Care Clinical Network to progress the development of advanced practice pharmacist roles for regionalised palliative care services. A pharmacy stakeholder forum was conducted in December 2010 to provide further guidance on the advanced practice pharmacist roles in the following domains: education; network links and partnerships; quality and safety; and research.

Results. Advanced practice pharmacist positions were created for each of the three regionalised palliative care services in South Australia (SA). Funding was obtained for a Statewide Palliative Care Pharmacy Network project, to build a sustainable community-based palliative care pharmacy network. Advanced practice pharmacists commenced in the regionalised palliative care services of SA on 4 October 2011.

Conclusions. The Statewide Palliative Care Clinical Network and the SA Palliative Care Plan provided a policy framework that supported involvement and advocacy in the planning of the advanced practice pharmacist roles. Collaboration between leaders in workforce reform, service planners, specialist palliative care providers and the pharmacy sector was a key enabler for developing the advanced practice pharmacist positions for regionalised palliative care services.

What is known about the topic? The advanced practice palliative care pharmacist role reflects a new direction for the discipline of pharmacy and has been embraced at a time when a nationally endorsed Advanced Pharmacy Practice Framework has been published, while recognising that registration for pharmacists in Australia currently does not have specific endorsement for advanced practice.

What does this paper add? This paper outlines the value of collaboration across settings and sectors. There is an opportunity for these roles to align with the new nationally endorsed framework for advanced practice in pharmacy.

What are the implications for practitioners? These new positions strengthen the links between the hospital and community pharmacy sectors to enhance a quality use of medicines approach with improved access to end-of-life medicines for home-based palliative care clients, which actively facilitates a home death for those who choose it.

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Advanced Practice Pharmacist

- The scope of the role is that of a leadership position which encompasses clinical practice, teaching/education, curriculum development, clinical research within the field of palliative care pharmacotherapeutics and contribution to relevant policy development.

How the pharmacist can contribute

- Hussainy et al identify seven key areas where the pharmacist can contribute.
- Medication review
- Education for patients and carers regrading specific medicines and modes of delivery
- Ensuring ongoing access to medications
- Information provision to team members particularly regarding ‘off label’ medicines.
- Consultation and collaboration with team members regarding updating of medication chart.
- Liaison with other health care professionals to ensure continuity of patient care.
- Symptom management protocols.

Hussainy SY, Box M, Scholes S. 2011. Piloting the role of the pharmacist in a community palliative care multidisciplinary team: an Australian experience. BMC Palliative Care 2011 10:16.

The Community Pharmacy Network

- Facilitate a quality use of medicines approach across community, aged care, disability and acute care settings.
- Expand the number and the capacity of community pharmacists across the state providing home medicine reviews for palliative care patients in the community.
- Explore a systems approach to improve access to medicines around the clock to those who need them, and the safe disposal of those medicines when no longer required.
- Explore and overcome barriers that inhibit greater contribution to the planning and delivery of coordinated multidisciplinary palliative care by community pharmacists in the community setting.
- Bring together community pharmacists with an interest in palliative care to explore and develop opportunities for increased community pharmacy involvement in quality end of life care in the community.
- Developing a quality and safety framework.
- Establishing and maintaining networks, links and partnerships across the sector.
- Identification of key performance indicators for evaluating the impact of this service

Consumer Feedback

'Coordination between health-care specialists seemed to be patchy and to rely, to an unacceptable extent, on us (untrained, lay people) carrying messages between them (the medical specialists). It seemed hard, too, to have much confidence that the mass of medications being prescribed were being coordinated to ensure against adverse cross-medication reactions.' (Family member)

'Patients mostly want to die at home and this is a much cheaper option if all the supports are in place. Coordinating the supports has proved difficult.' (GP)

Issue 2- June 2012

SA Palliative Care

Community Pharmacy Update

A joint initiative of SA Palliative Care Services and Ambulatory & Primary Health

There are several symptoms that can present during the last few days of life. A pharmacist can contribute in part through the provision of prompt access to treatments.

End of Life Care

A person is identified in the terminal phase of life when death is likely within days. While they may receive treatment within a health facility, it is also likely that they could be cared for in their home environment. Thus medications that would normally be accessed through a hospital or hospice may need to be obtained through their usual community pharmacy.

The terminal phase is associated with physical changes, including weakness and the inability to swallow. Thus the patient will require switching between oral dosage forms to subcutaneous infusions.

Patients with substantial pain require strong opioid analgesics for adequate symptom relief. Morphine is first line treatment. While hydromorphone and oxycodone are also available in injectable forms, the latter is not currently on the Schedule of Pharmaceutical Benefits (PBS) and thus has limited access in the community.

Nausea and vomiting can have a variety of causes and this will influence the choice of medication prescribed. Prescribers have access to injectable forms of haloperidol, metoclopramide and dexamethasone through the PBS.

Dyspnoea is upsetting for patients and both physical and psychological factors can contribute. The regular use of small doses of opioids is first line treatment. There is evidence to support the use of benzodiazepines such as midazolam and clonazepam in dyspnoea as well.

Noisy breathing results from the inability of the patient to clear secretions through coughing or swallowing. Anti-cholinergics such as hyoscine butylbromide, hyoscine hydrobromide and atropine are the basis of treatment.

Agitation can be distressing for the carer as much as the patient. Resolving other symptoms (i.e. pain and dyspnoea) can impact on the level of agitation. Treatment options include parenteral clonazepam or midazolam.

Delirium is the acute onset of intermittent confusion and altered consciousness and can be caused or compounded by other medications (particularly with a primary central nervous system action). Initial therapy for delirium is with haloperidol.

A small number of medications are required for symptom control, within the terminal phase. Often several symptoms will occur at once. Knowing the range of treatment options will assist the pharmacist to anticipate which medications to have available.

Useful resources

General resources and reading

- Seidel R, Sanderson C, Mitchell G, Currow DC. Until the Chemist Opens. Palliation from the Doctor's Bag. Aust Fam Phys 38:4 225-231

For more information

Contact the Advanced Practice Pharmacists

- **Lauren Curtis, Northern**
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  0478 457 974
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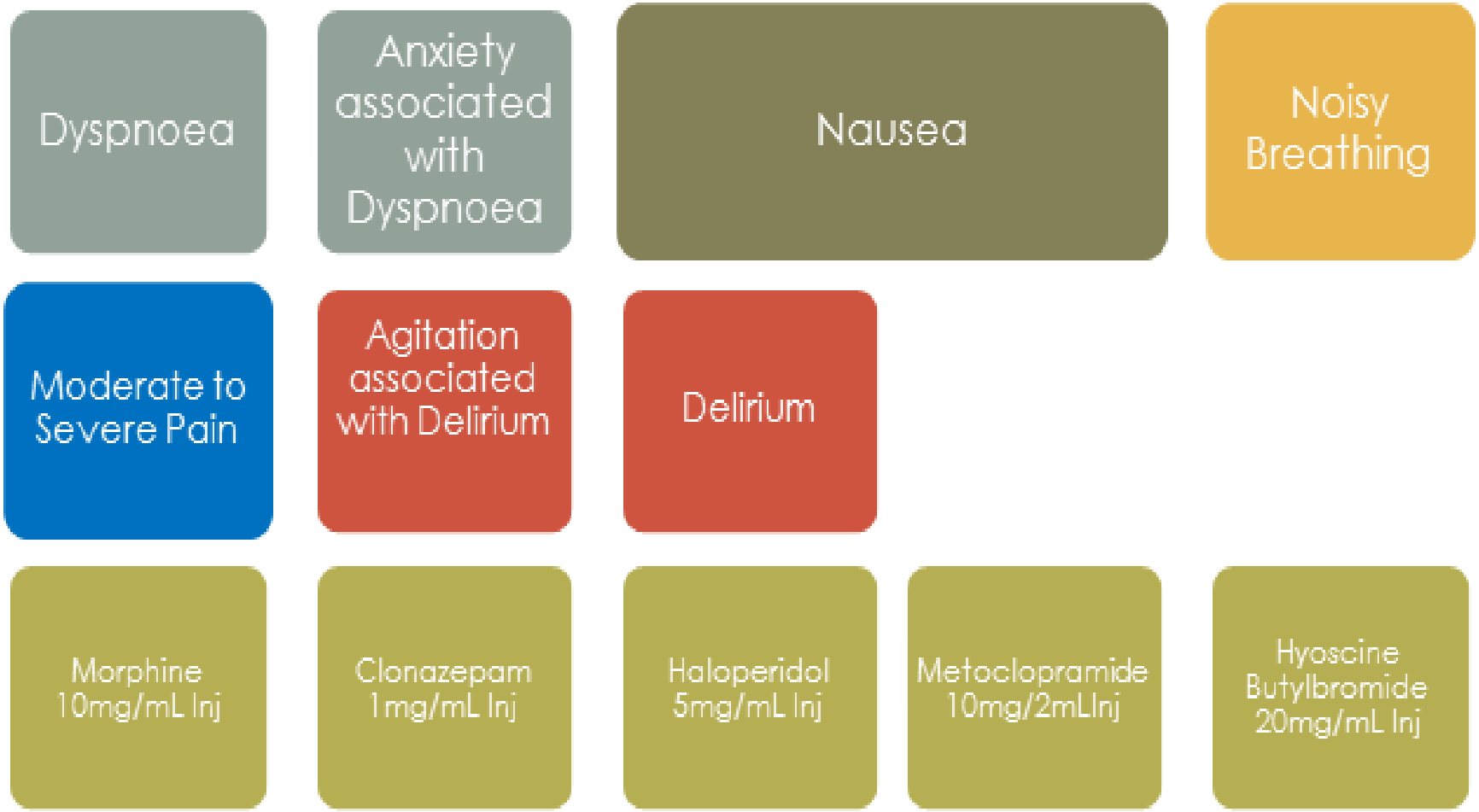
  paul.tait@health.sa.gov.au
  0478 457 977

This update is intended to provide practical up to date and factual information relating to pharmacy and medicines management in the setting of Palliative Care and is based on critical review of available evidence. Individual patient circumstances must be considered when applying this information. Please feel free to distribute this update further to interested colleagues.

Developing a core medicines list for EOL



Discussion/opinion paper

Breaking down the silos: Collaboration delivering an efficient and effective response to palliative care emergencies

Kate Swetenham[1], Hugh Grantham[2], Karen Glaetzer[1]

[1]Southern Adelaide Palliative Services, Daw Park, SA, Australia, [2]Flinders University Paramedic Unit, Sturt Campus, Flinders University, Adelaide, Australia

Objectives: The objective of this article is to explore the introduction of a rapid response team as outlined in the South Australian Palliative Care Services Plan 2009–2016. The Plan identifies this service as being provided by nurse practitioners. This workforce is not yet fully developed so a partnership model utilizing the extended care paramedic has been explored for the provision of out-of-hours emergency care to palliative patients.
Methods: A working group was established under the auspices of the Palliative Care Clinical Network to progress the partnership model of care. Key stakeholders from SA Ambulance, the Royal District Nursing Society, Flinders University, and Specialist Palliative Care Services (SPCS) made up the steering committee. Satisfaction telephone surveys were conducted following the trial phase to assess the community acceptance of this model.
Results: Data were collected from across the metropolitan area of Adelaide. There were 40 paramedic visits during the 118 days of the trial, which equates to 10 days per month. About 78.5% of the patients requiring this service were registered with a SPCS. Satisfaction from patients, caregivers, and the extended care paramedics was high.
Conclusions: This partnership model has enabled an emergency after-hours service to be provided between the SPCS and the ambulance service. This unlikely alliance has been very well received by patients and family members wishing to remain at home. Early data reveals that 90% of unnecessary and unwanted admissions to hospitals have been avoided in the palliative care population.

Keywords: Palliative care, Paramedics, Emergency response, Out-of-hours care

Rapid Response

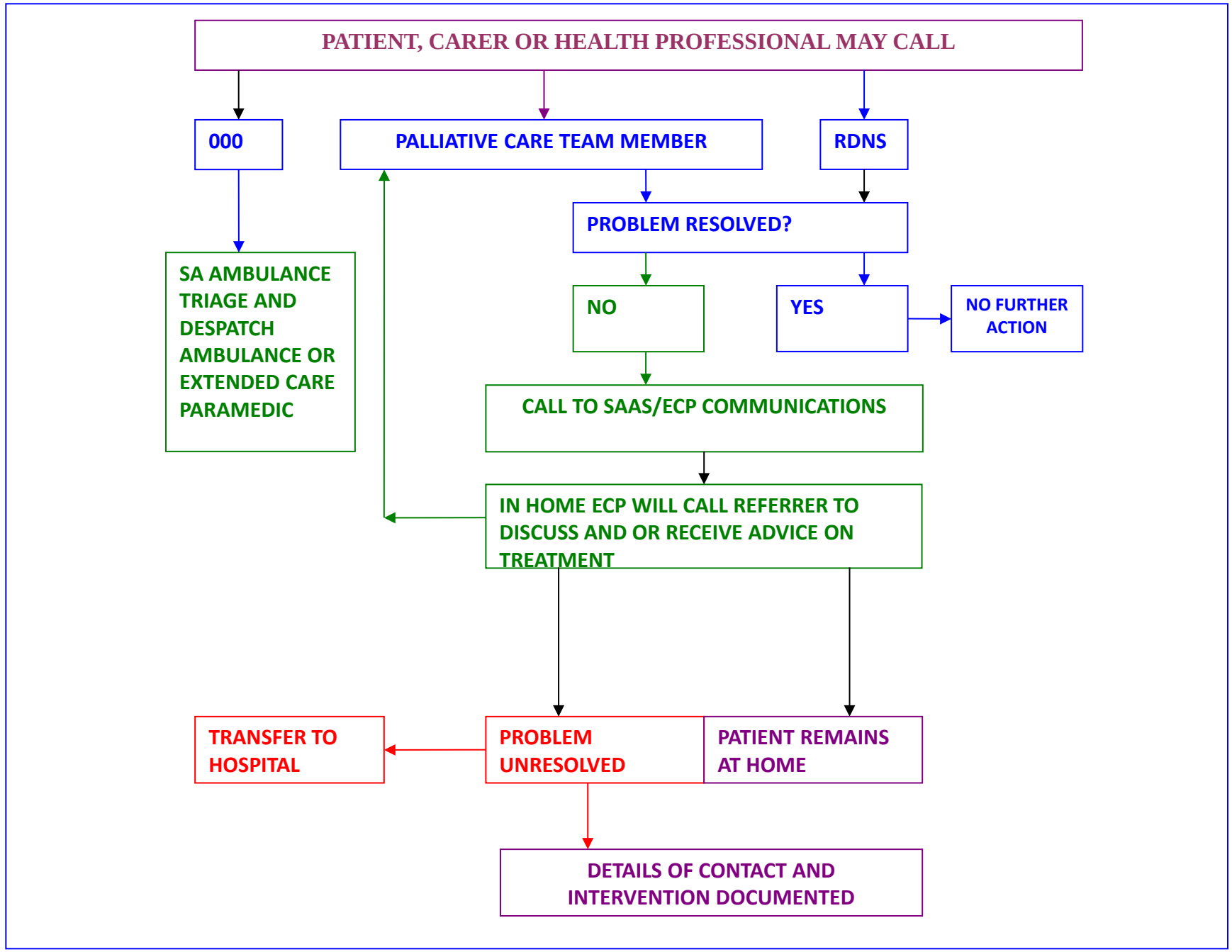
Identified need for after-hours rapid response service for palliative care patients
SA Statewide Palliative Care Services Plan

Goal:
increase number of patients who are able to die in place of residence
as per omnibus survey (70%)

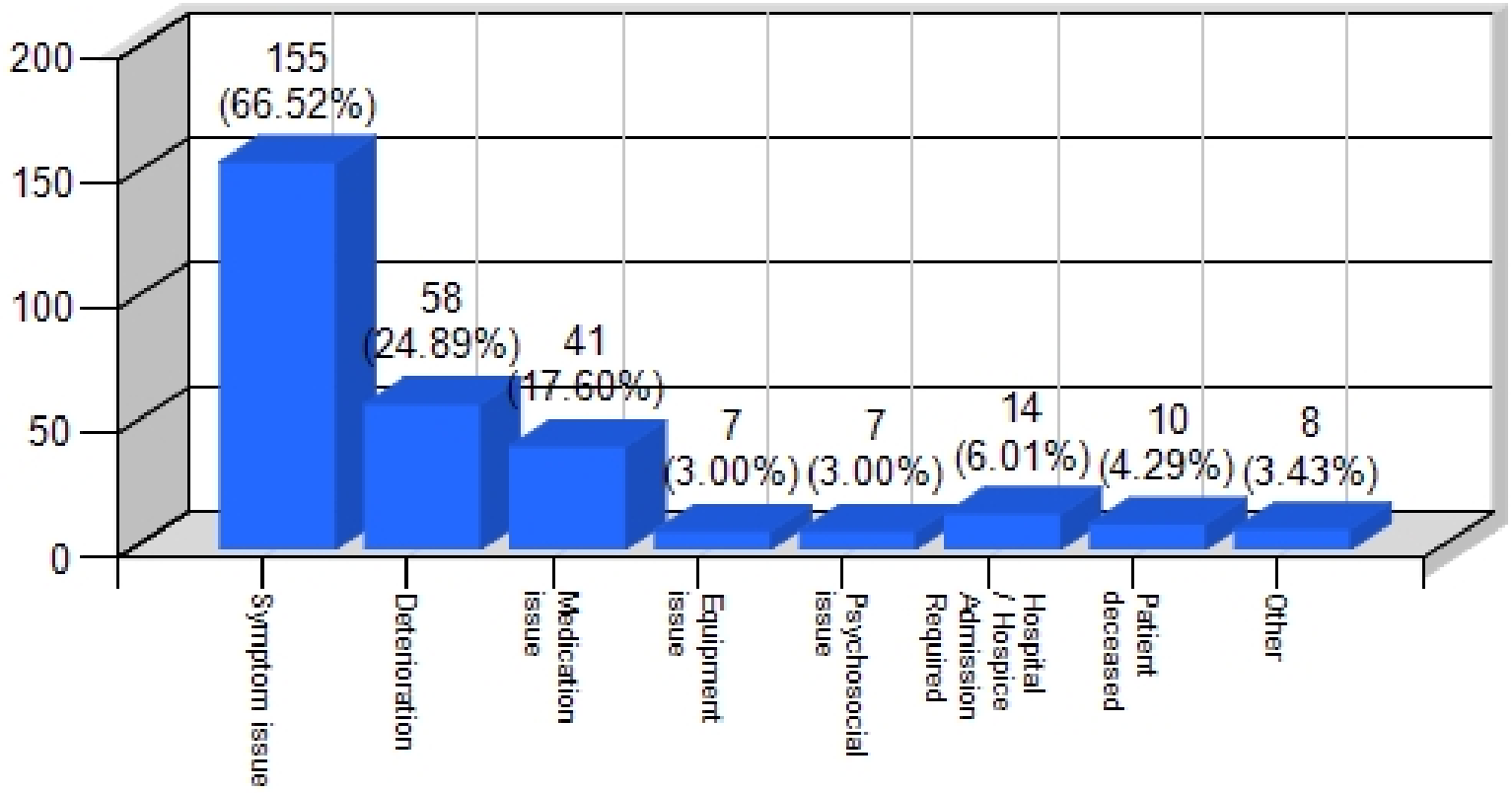
Extended Care Paramedics (ECP) already providing this service
BUT quality and effectiveness not evaluated

What is an ECP?

- In South Australia, experienced Intensive Care Paramedic, up skilled and trained in a multi disciplinary environment
- Complementary to primary care – provides options other than ED/hospital admission where appropriate
- Training emphasises complex problem solving, knowledge/assessment, collaborative solutions/consultation where required.
- Safety proven by pilot study, audit and multidisciplinary review


PATIENT, CARER OR HEALTH PROFESSIONAL MAY CALL
000
PALLIATIVE CARE TEAM MEMBER
RDNS
PROBLEM RESOLVED?
SA AMBULANCE TRIAGE AND DESPATCH AMBULANCE OR EXTENDED CARE PARAMEDIC
NO
YES
NO FURTHER ACTION
CALL TO SAAS/ECP COMMUNICATIONS
IN HOME ECP WILL CALL REFERRER TO DISCUSS AND OR RECEIVE ADVICE ON TREATMENT
TRANSFER TO HOSPITAL
PROBLEM UNRESOLVED
PATIENT REMAINS AT HOME
DETAILS OF CONTACT AND INTERVENTION DOCUMENTED

Main reason for call:
(233 Responses)



Timing of Assistance

Patient's satisfaction with the timing of ECP attendance 78%

"They came very quickly"

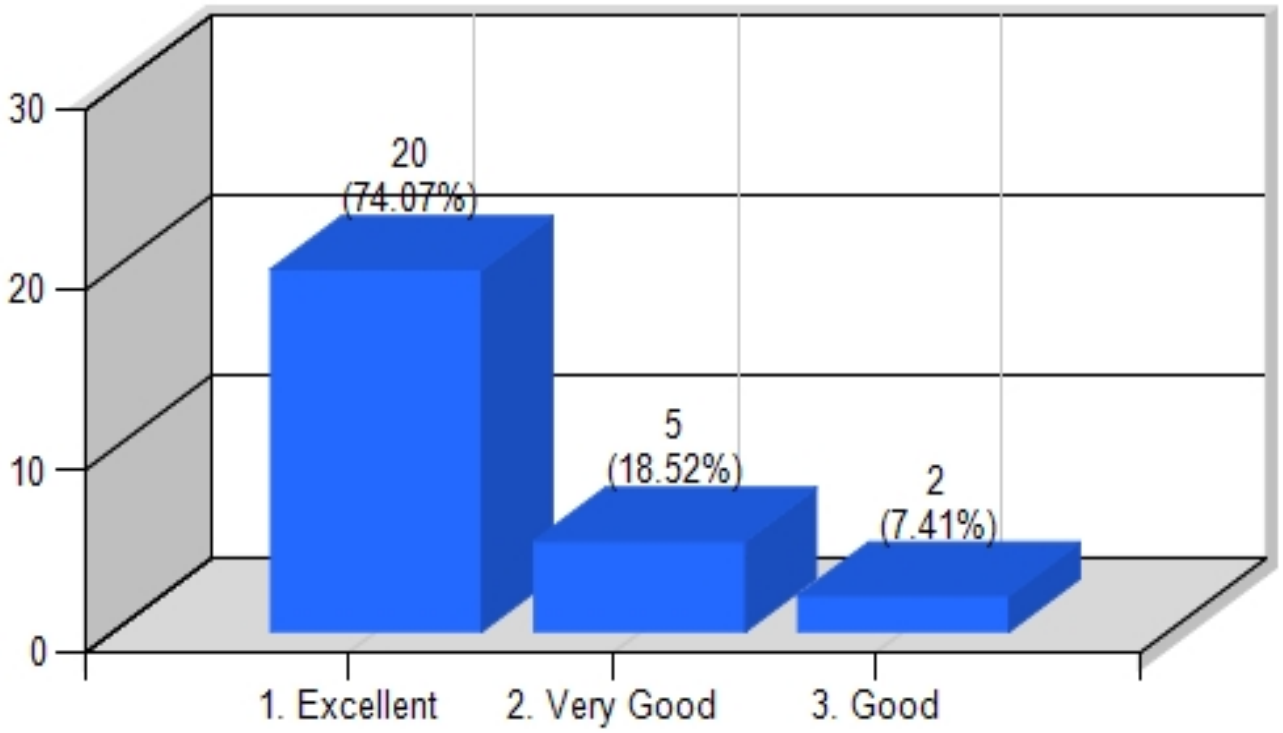
"A bit long. Approximately 50 minutes"

"They took 30 minutes but I knew they were on their way so I didn't mind"

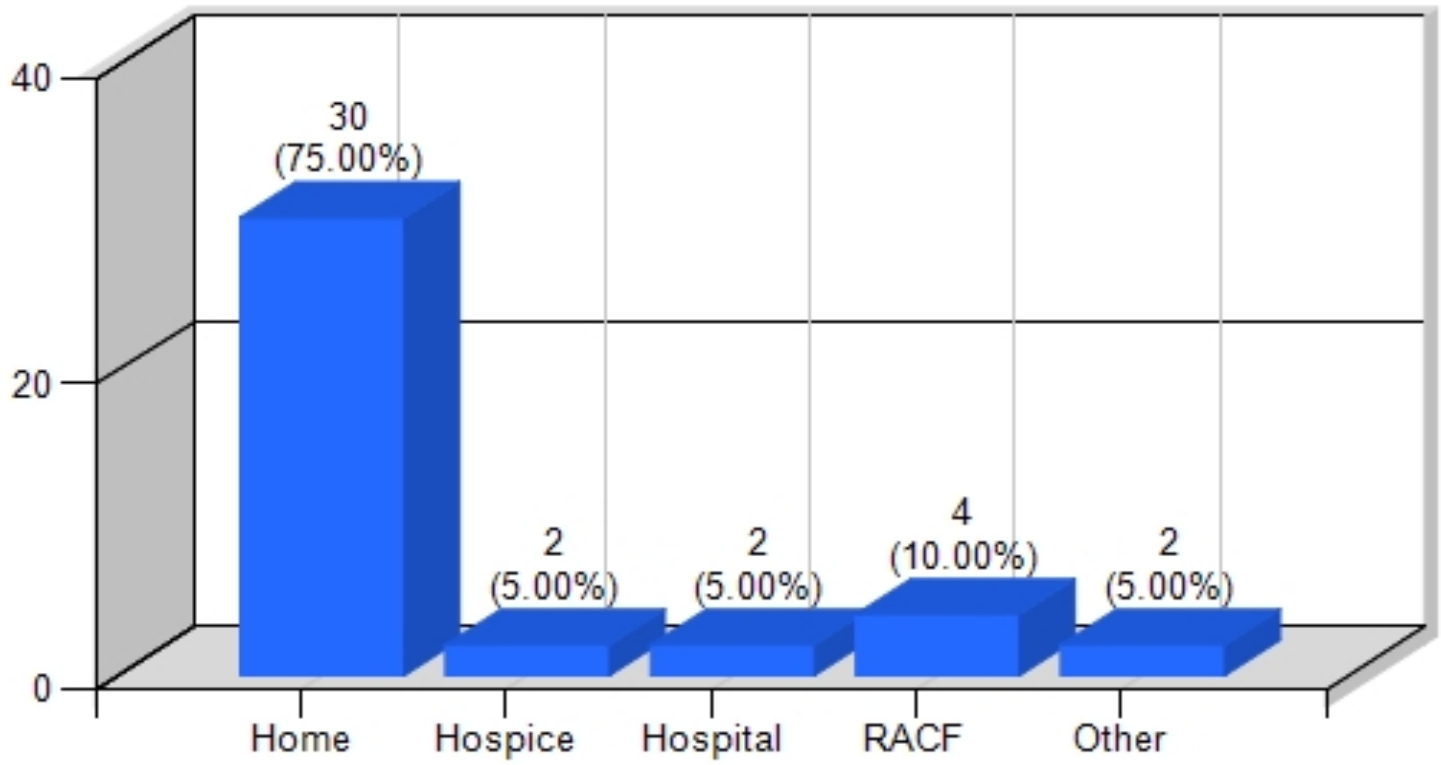
"Quick response"

"It took two hours for the ECP to get there. In the mean time, the ambulance phoned back and offered to take him to hospital sooner but we really preferred that he stay home if possible so refused and said we would wait for the ECP"

7. Overall, how would you rate the service you received?
(27 Responses)



Site of care at completion of contact: (40 Responses)



GP partners AUSTRALIA

supporting GPs to care for the community

Government of South Australia

SA Health

GP Palliative Shared Care Program Framework

For General Practitioners

GP Shared Care Program

- Completion of full day orientation seminar for GPs to be registered with the program (40 CPD points)

Education package includes

- ACD legislation
- NAT-PD
- 7 Step Resuscitation Pathway
- Case conference planning and billing requirements on MBS.
- Education in PCOC tools

Ongoing participation in the program

To maintain participation in the GP Palliative Shared Care Program a GP needs to demonstrate over the 3 year period that they have completed:

- a) a **GP Palliative Shared Care Orientation Seminar** or **GP Palliative Shared Care Refresher Day**; and
- b) a **minimum of two (2) RACGP or ACRRM accredited CPD activities** relevant to Palliative Care.

Available CPD Activities

- GP partners Australia provide regular CPD events for participating GPs to further develop their skills and knowledge in caring for people with a life limiting illness. The details of RACGP and/or ACRRM accredited palliative care CPD activities delivered by GP partners Australia and other education providers are available at www.gppaustralia.org.au/psc.

Are we Fit for the Future?

- SA Health has disbanded all Clinical Networks in favour of a system wide Transforming Health Agenda.
- Challenge for the future will be continuing to ensure EOLC is a priority for work being undertaken in the TH space.
- TH is focusing on acute hospitals only- How can we expand the GP interface?

Oscar Wilde

“Live! Live the wonderful life that is in you! Let nothing be lost upon you. Be always searching for new sensations. Be afraid of nothing”