



# The National Rollout of the Palliative Approach Toolkit for Residential Aged Care Facilities

May/June 2015

Issue 6

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## Additional funding

We have negotiated a Deed of Variation to our current PA Toolkit Funding Agreement with the Australian Government Department of Social Services. Additional funding has been provided to develop 15 fact sheets and 4 short educational videos.

The resources will be developed primarily for careworkers in residential aged care and will highlight messages relevant to palliative and end of life care using the PA Toolkit resources as base material. The resources will be online towards the end of 2015.

### Ongoing support

You can continue to contact the project team up until the end of 2015.

Phone: 07 3710 2226

Email: [patoolkit@health.qld.gov.au](mailto:patoolkit@health.qld.gov.au)

Web: [www.caresearch.com.au/PAToolkit](http://www.caresearch.com.au/PAToolkit)

## Message from Professor Liz Reymond

Welcome to the final issue of the project newsletter for the *National Rollout of the Palliative Approach Toolkit for Residential Aged Care Facilities*.

What a busy, but rewarding two years we have had! Our final workshop was held in Longreach in November 2014. We ran workshops across all states and territories of Australia. This means over 2,100 RACF staff from 1,200 facilities have received training in how to use the PA Toolkit resources to implement a palliative approach. An additional 500 staff from 220 facilities have been trained by Victorian Palliative Care Consortia staff. This far exceeds the project deliverable of training staff in 1,000 RACFs.

We have heard from many facilities that, since attending a workshop and getting a PA Toolkit, they have reviewed their palliative care strategies and processes and have developed, or begun implementing, a comprehensive, sustainable palliative approach. That's a fantastic result

and we wish you well as you enhance the palliative care you provide for your residents.

Even though the project is finishing, you will be able to access the project website for at least another year. Please continue to visit the website for updates, as new resources will be uploaded. In fact, we have just given our website a makeover—you can read more about this inside!

Keep an eye out for our new clinical newsletter and our new webinar—these have been uploaded to our newly redeveloped project website.

Many individuals and organisations have made a significant contribution to the PA Toolkit project over the past couple of years and we are deeply grateful to you all. Thank you all for your support of the PA Toolkit project.

Best wishes,  
Liz

## New clinical newsletter

The fourth clinical newsletter developed by PA Toolkit Trainer and Nurse Practitioner, Kris McAnelly, provides information about nutrition and hydration for residents receiving a palliative approach to care. Visit the project website to access all our clinical newsletters:

- [A palliative care approach to nutrition and hydration](#)
- [Management of pain in residents requiring a palliative approach](#)
- [Predicting prognosis within a palliative approach framework](#)
- [Recognising and managing delirium in residents with dementia](#)



### A palliative care approach to nutrition and hydration

CLINICAL NEWSLETTER OF THE NATIONAL ROLLOUT OF THE PALLIATIVE APPROACH TOOLKIT FOR RESIDENTIAL AGED CARE FACILITIES  
16 March 2015

Managing the practical, ethical, and emotional issues associated with loss of appetite and weight loss in residents who have an advanced life-limiting illness can be complex and challenging for the residential aged care team. Family members often experience distress when they see their loved one eating and drinking less, losing weight, and becoming increasingly frail, and may say to care staff "Why is this happening and can anything be done?", "How will staff be able to care for my loved one when they can no longer eat or drink?", or "You can't just let them starve to death!"

Causes of nutritional deficiency in older people  
Poor nutritional status and unintentional weight loss are common in older people with advanced life-limiting illness. The causes, which are multifactorial and not well understood, may include a decreased sense of smell and taste, reduced chewing efficiency, gastrointestinal changes, and dysphagia.<sup>1</sup> Swallowing deficits are a feature of advanced neurological disorders (e.g. Parkinson's disease, stroke, dementia) and are due to sensory and motor disturbances in the brain as well as progressive weakness of the muscles of the face, mouth, tongue, and oropharynx. Alterations in the production of particular chemicals and hormones also impact on nutritional intake by prolonging feelings of gastric fullness and decreasing the sensation of hunger.<sup>1,2</sup> A study of individuals receiving a palliative approach explored whether a decrease in oral intake adversely affected their quality of life; however, they reported that they did not experience hunger and remained comfortable on sips of fluid only.<sup>2</sup> While many of the factors that contribute to loss of appetite and weight loss are due to irreversible age-related physiological changes, there are other causes such as poor dentition, sore mouth, poorly controlled symptoms, depression, and medications (e.g. opioids, anticholinergics), which, if identified, may be managed.<sup>3,4</sup>

Access the PA Toolkit at: [www.caresearch.com.au/PAToolkit](http://www.caresearch.com.au/PAToolkit)

**Assessment and management of oral feeding problems**  
The resident's nutritional care plan should consider the resident's prognosis and the severity of the oral feeding problem, and must be in line with the resident's and family's stated goals of care.

**Use of oral supplements**  
Studies have not been able to demonstrate improvements in physical function, morbidity, or length of survival in older institutionalised people following the introduction of nutritional supplements.<sup>5,7</sup> A randomised control trial with nursing home residents compared the effect of multi-nutrient oral supplements with a non-nutritive placebo.

Kris McAnelly, Nurse Practitioner - Brisbane South Palliative Care Collaborative  
Tel: 07 3710 2226. Email: [patoolkit@health.qld.gov.au](mailto:patoolkit@health.qld.gov.au)

## PA Toolkit resources available for order

All 3,000 copies of the PA Toolkit have been distributed. Almost 2,800 have been distributed to RACFs and the remaining PA Toolkits have been distributed, on request, to specialist palliative care services, aged care trainers, and other organisations to support the national rollout.

The PA Toolkit is now only available online. However, a limited number of hard copies of the following three PA Toolkit resources are available to order free of charge. If you would like a copy please complete the [order form](#) or email [patoolkit@health.qld.gov.au](mailto:patoolkit@health.qld.gov.au).

1) [All on the same page: palliative care case conferences in residential aged care](#) This 12-minute video uses a fictional scenario to demonstrate key principles and issues to consider in convening effective palliative care case conferences.

2) [Guide to the Pharmacological Management of End of Life \(Terminal\) Symptoms in Residential Aged Care Residents](#) This guide includes clinical and educational resources to support the development of policies and procedures to ensure timely access to appropriate medications for managing common end of life (terminal) symptoms experienced by dying residents.

3) [How to use the Residential Aged Care End of Life Care Pathway \(RAC EoLCP\)](#) This multimedia resource focuses on when and how to use the RAC EoLCP to support the high quality care of dying residents, and includes:

- a 26-minute training video of a fictional scenario that demonstrates use of the RAC EoLCP in the end of life (terminal) care of residents
- a companion Learning Guide
- the RAC EoLCP form
- an information brochure for relatives and friends

There has been information in the media recently about the Liverpool Care Pathway in the UK being replaced in 2015 with a model Integrated Care Pathway for Best Care of the Dying Person. This does not affect your use of the RAC EoLCP. The RAC EoLCP was developed uniquely for Australian RACFs. Evidence shows that the RAC EoLCP improves outcomes of care for dying residents and results in fewer residents being inappropriately transferred to acute care facilities. It is important that the implementation of the RAC EoLCP is supported by education to all facility staff involved in the end of life (terminal) care of residents.



## PA Toolkit resources to support RACF-GP collaboration

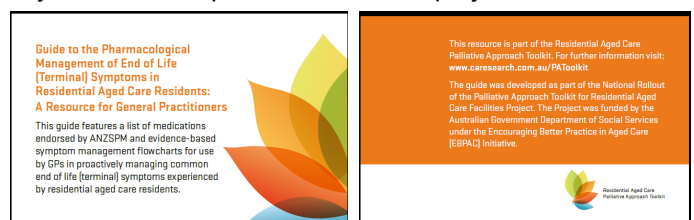
To support proactive collaboration between RACFs and GPs in regards to best practice symptom management for residents at end of life, the PA Toolkit project team has developed a '[GP version](#)' of the [Guide to the Pharmacological Management of End of Life \(Terminal\) Symptoms in Residential Aged Care Residents](#).

The new version focuses specifically on the GP/NP scope of practice. Similar to the original guide, the 'GP version' includes:

- A list of medications, endorsed by The Australian and New Zealand Society of Palliative Medicine (ANZSPM), suitable for use in residential aged care for the management of terminal symptoms.
- An educational table summarising the uses, doses, and routes of administration of the medications endorsed by ANZSPM.
- Flowcharts summarising the pharmacological management of four common terminal symptoms: nausea and vomiting, pain, respiratory distress, and restlessness and agitation.

### USB business cards for GPs

In addition, a limited number of USB business cards containing the 'GP version' of the guide have been produced for distribution to GPs. The USBs are being distributed to GPs at Decision Assist workshops that are held nationally throughout 2015. If you would like some USB business cards to give to GPs involved in the care of your residents please contact the project team.



### Workplace Implementation Guide

Don't forget that the PA Toolkit [Workplace Implementation Guide](#) includes information and templates to support your facility to collaborate with external stakeholders including GPs.

## New look for the PA Toolkit website!

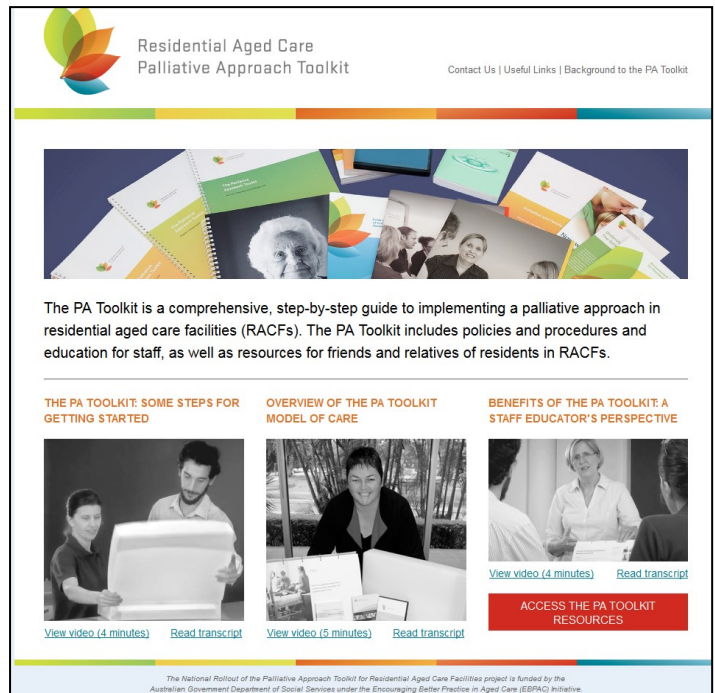
New year...new look website! With the help of the CareSearch team at Flinders University, we've given the existing PA Toolkit website a makeover.

We hope users will find the website easier to navigate and use. The site focuses on the PA Toolkit resources and offers users more detailed information about the resources including suggestions on how to use them and the target audience. Users can also search by resource, care issue, and user.

The redeveloped website features:

- new resources for [educators](#)
- instructional video clips that give tips and advice for using the PA Toolkit resources
- an online version of the Self-Directed Learning Package for careworkers. Users can rate their knowledge by completing an online test, and generate a certificate of completion.
- fillable versions of clinical forms in Modules 2 and 3

The website will remain accessible until at least December 2016: [www.caresearch.com.au/PAToolkit](http://www.caresearch.com.au/PAToolkit)



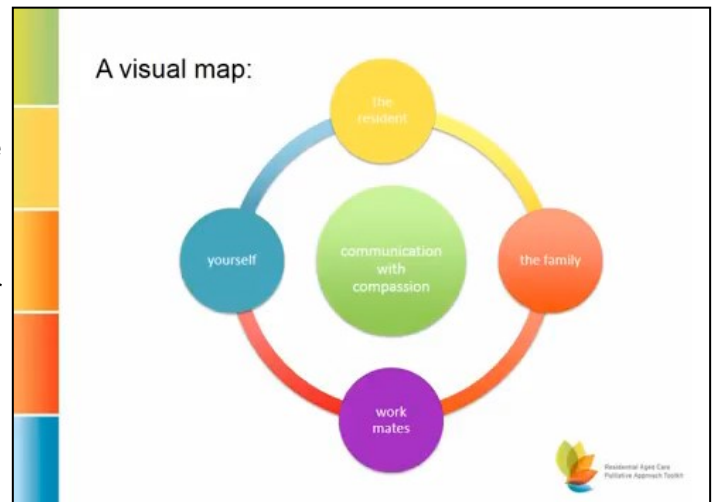
## New webinar: “Someone is dying. What do I say?”

Effective and sensitive communication with a resident and their family is a crucial aspect of successfully delivering end of life care. And yet, it's often hard to feel confident or skilled enough to know what to say or how to begin a conversation with the resident who is dying or the family members who are experiencing their own struggles.

This webinar explores some of the barriers and difficulties that arise in practice and offers suggestions for ways to deliver what the dying person wants.

This 45-minute webinar is presented by Julie Sutherland, Counsellor, Metro South Palliative Care Service, Metro South Health. Julie has worked for many years as a nurse. The last 15 years Julie has worked as a counsellor in health care settings. Through her work in palliative care units, private homes, and RACFs, Julie has collected a wealth of experience and stories from dying people and from their bereaved family members. She knows the difficulties of squeezing many tasks in a shift while attending to the emotional and spiritual needs of a dying person.

The [“Someone is dying. What do I say?”](#) webinar is available on the PA Toolkit website.



*“We don't remember whole days,*

*we remember moments”*

Cesare Pavese, Italian poet

## PA Toolkit audits

Thank you to all RACFs that provided completed PA Toolkit audits. A total of 486 pre-implementation and 524 post-implementation [After Death audits](#) were entered into the online system. We received 82 pre-implementation and 14 post-implementation [Organisational Policies and Structures audits](#). RACFs that provided **both** pre- and

post-implementation After Death audits have been sent a report based on their responses, as well as a report of de-identified responses from all participating RACFs. We hope that you continue to use the audits within your facility. Remember that you can download the audit templates from the project website.

### TriCare facilities implement a palliative approach

TriCare has embraced a palliative approach to care in their 14 Queensland RACFs. In August 2014, TriCare officially launched their palliative approach project. TriCare has implemented a palliative approach in the following key areas:

#### Psychological and spiritual support

Support for residents, family, and friends during the palliative and the end of life phase is provided by staff. TriCare carers report that they provide continuity of care through rosters that assign staff to the same area for significant amounts of time.

Specific 'follow through' strategies that are taken after the death of a resident include respecting the resident's room and property, sending the family a sympathy card, attending the funeral, and holding recurring memorial services that are attended by family, friends, and staff.

#### Environment

Strategies followed include placing the resident in a room by him/herself for the end of life phase where family and friends can come and go, and using soft lighting, music, candles, and resources from a 'palliative care trolley' or 'kit'.

#### Symptom management and provision of care

Some GPs affiliated with TriCare RACFs hold palliative care case conferences with family, RACF staff, power of attorneys, and residents early in the admission process to discuss advance care planning. Niki pumps, pressure ulcer care, and oral care. Conferences are also held for residents when they are nearing the palliative stage. Some TriCare RACFs have found referral to external specialists, such as palliative care teams, to be helpful.

### Acknowledgements

The national rollout of the PA Toolkit was led by the Brisbane South Palliative Care Collaborative in direct partnership with key clinical, industry, and academic organisations. We thank the following for their significant contribution to the success of this project:

- Members of the PA Toolkit project Steering Committee: The University of Queensland / Blue Care Research & Practice Development Centre, The Australian and New Zealand Society of Palliative Medicine, Leading Age Services Australia, Royal Australian College of General Practitioners
- Members of the PA Toolkit project Clinical Education Reference Group: Aged & Community Services SA & NT, Australian Catholic University, Calvary Health Care, CareSearch, Griffith University School of Pharmacy, Mercy Aged Care, Metro South Health (Queensland Health), Palliative Care Queensland, Queensland University of Technology (Health Law Research Centre), Respecting Patient Choices Program (Austin Hospital), Resthaven Inc. SA
- Australian Government Department of Social Services
- Victorian Palliative Care Consortia, particularly the Palliative Aged Care Support Nurses
- Cancer Council WA - Palliative and Supportive Care Education Team Manager
- WA Cancer & Palliative Care Network, WA Department of Health
- Metro South Palliative Care Service staff

### Decision Assist Phone Advisory Service

General practitioners and aged care staff around Australia, including nurses, allied health professionals and personal care workers, are continuing to access the latest, expert information and advice about advance care planning and palliative care over the phone.

Since the start of the service last year, both the Advance Care Planning line and the Specialist Palliative Care line are reporting more than half of the calls coming in during office hours, with after hours and weekend calls making up the remainder. Calls have been received from all states and territories across Australia. While both lines report an increase in calls, in the latter part of 2014 the advance care planning service reported a 50% increase

in calls leading up to the Christmas break. The majority of calls are from nurses working in aged care: around 70% of calls to the Specialist Palliative Care line and nearly 50% of calls to the Advance Care Planning line. Click [here](#) for a video of an aged care nurse talking about her experience of calling the advisory service.

For information about Decision Assist and the range of services provided, including the training workshops, visit [www.decisionassist.org.au](http://www.decisionassist.org.au).

Aged care staff and GPs can phone the advisory service for information and advice on **1300 668 908**.

#### ACKNOWLEDGEMENT

The National Rollout of the Palliative Approach Toolkit for Residential Aged Care Facilities project is funded by the Australian Government Department of Social Services under the Encouraging Better Practice in Aged Care (EBPAC) Initiative.