

LAST DAYS OF LIFE TOOLKIT

SUMMARY REPORT FROM PILOT PROGRAM

MARCH 2017



Last Days
of Life

The Last Days of Life Toolkit

While clinical needs are similar, the approach to management of the dying patient varies across New South Wales (NSW) health facilities. To improve and support the care of the dying patient the Clinical Excellence Commission (CEC) End of Life (EOL) program, in collaboration with clinicians and consumer advisors, developed a last days of life (LDOL) toolkit. The toolkit provides tools and resources to ensure all dying patients are recognised early, receive optimal symptom control, have social, spiritual and cultural needs addressed, both patient and families/carers are involved in decision-making, and bereavement support occurs.

Pilot Program

A pilot was undertaken between September and December 2016. Tools piloted included:

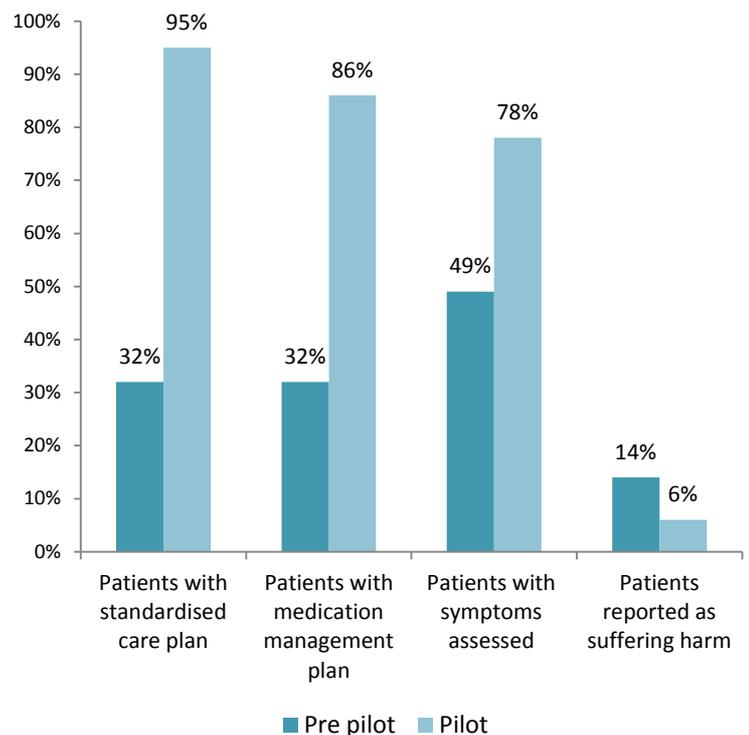
- Initiating last days of life planning
- Comfort observation and symptom assessment chart
- Anticipatory prescribing guide for medications
- Five guides/flowcharts for the most common symptoms of dying patients
- Accelerated transfer to die at home plan

Education and facilitator training was provided to each participating site.

Pilot Findings

Initiating Last Days of Life Planning

During the pilot 152 patients were managed using the various tools across nine sites. One of the main findings was that patients who were cared for using a standardized approach had a higher percent of their care being more structured i.e. symptoms and comfort assessed routinely and receiving medications within a best practice model. This also saw a decrease in the harm to patients (see figure below).



"A common discussion amongst staff were 'not more paperwork' but when they used the forms, especially the observation form all agreed that it covered all aspects of caring for the patient and their families at end of life care"

"The nursing staff expressed that the instructions for symptoms assessment and rating were easy to read and some staff stated that without this chart they would have not known to call a clinical review or rapid response for carer distress. The chart was easy to read and follow and proved a valuable tool when caring for a palliative patient."

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Medication Management Guides

The medication guides were some of the most popular tools developed and piloted. The comments were positive in relation to their ease of use and usefulness in determining what medication and dose to prescribe. Barriers mainly related to lack of education / explanation around the use of the tools.

"Some of the doctors were very open to using this, but some needed a bit more direction with medications and especially converting doses."

"Medical staff were observed to be photocopying, and recording the anticipatory prescribing guidelines onto their "smart" devices, so that the information could travel with them."

Throughout the pilot there were suggestions to add HYDROMORPHONE to the guides especially in relation to its use in patients with renal failure. Due to a number of incidents occurring in NSW that related to HYDROMORPHONE a decision was made not to recommend its use and reiterate the need to seek specialist advice if required.

Communication Tools

While not officially piloted all sites were given access to the communication tools and encouraged to use as appropriate.

"The communication handouts were fantastic, they answered a lot of questions that the families had, and may not have known to ask. These handouts also were helpful for our new staff, who had not had experience with palliative care"

Further Information

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Conclusion

Overall the response was very positive and the tools were seen as appropriate and suitable for the care and management of the dying patient.

*"I have worked in the health care area for 40 years and not encountered a set of tools that have been as well received by clinicians as those included in the Last Days of Life Toolkit. My experience was that once site staff across our LHD heard about the tools being trialled they were regularly contacting me to request access to the tools" **Rural Palliative Care CNC***

*"Overall rolling out the Last Days of Life toolkit has been a positive change for our Hospital. It has been embraced by the majority of clinicians with many very happy to see recognition and action that we are working towards improving the end of life care provided to our community" **End of Life Care Project Officer***

Next Steps

1. The charts have been updated and are undergoing another round of consultation through the State Form Management Committee process.
2. Documentation which includes guidance documents and education material will be developed to support implementation
3. Once completed the toolkit will be launched in April / May 2017 and be available for use statewide

Acknowledgement

The Last Days of Life Toolkit was developed by NSW multidisciplinary specialists and generalist clinicians and consumer advisors. The CEC would like to acknowledge all who gave their time and expertise to this project.
The CEC would also like to acknowledge the clinicians and support staff at the pilot sites.