Development of End-of-Life Goals of Care Form

To meet the requirements of the National Safety and Quality Health Service (NSQHS) Standards actions for Comprehensive Care at the end-of-life, Alice Springs Hospital (ASH) undertook auditing as a tool to identify areas for improvement.

The results of the audit and discussions with key stakeholders across ASH led to the implementation process of a End-of Life Goals of Care Form (replacing the existing Do Not Attempt Resuscitation (DNAR) Form).

Overview

This Case Study explores the learnings of the hospital, covering the following areas:

- Audit on Advance Care Plans and Do Not Attempt Resuscitation Forms
- Development of the End-of-Life Goals of Care Form
- Piloting the new Form
- Governance Structure
- Education to support the End-of-Life Goals of Care Form
- Challenges to implementation
- Key learnings and outcomes
- Next steps and areas of focus after accreditation against the NSQHS Standards (2nd edition)

Advice for other Hospitals

A key factor contributing to the development and implementation of the Form has been the widespread recognition and acceptance from health professionals (across all levels) that there were opportunities for improvement in the planning and delivery of quality end-of-life care to patients.
This was evident by the number of health professionals that expressed a keen interest to be involved from the beginning of this journey and the continued feedback and support throughout the development and trial of the End-of-Life Goals of Care Form.

The new Form supports clinicians working outside of the Palliative Care Unit to deliver quality end-of-life care to patients.

Audit on Advance Personal Plans and Do Not Attempt Resuscitation Forms

The hospital began by conducting a hospital wide audit on Advance Personal Plans (APPs) and DNAR forms. The audit aim was to review the completion, filing and communication of APP and DNAR forms.

The results of the audit confirmed that APPs and DNARs were not routinely completed well which led to confusion, with evidence of incomplete forms and inconsistencies with documentation outlining treatments to be undertaken as opposed to treatments not to be undertaken. Staff awareness and knowledge of the intent of the forms were variable and highlighted the gap in education and training to support the effective completion and application of the forms.

Development of the End-of-Life Goals of Care Form

The results of the audit led to a discussion with key stakeholders of ASH to identify existing practice in other jurisdictions.

It was noted that NT Health's Top End Region had implemented a Goals of Care Form.

This concept was adopted and adapted by ASH, leading to a two-year project to develop the End-of-Life Goals of Care Form. The form is a tool to guide staff in discussion of a patient's goals of care at the end-of-life and providing a documented agreed plan.

End-of-Life Care Working Group

The development of the form was driven by the ASH End-of-Life Care Working Group which consisted of representatives from a range of disciplines. Members were recruited through an expression of interest, seeking staff with a passion for:

- quality improvement;
- positive patient outcomes; and
- ensuring systems are in place for the patient wishes at the end of life to be clearly articulated and respected.

Key elements of the End-of-Life Goals of Care Form

The End-of-Life Goals of Care Form includes:

1. Possible **triggers for Goals of Care** discussion (developed by the medical officers).
2. **Asking the patient who they wish to be involved in the shared decision making process,** such as family, ALOs, social workers, NGOs and Chaplain.
3. **Identifying the end-of-life wishes of the patient** and/or their families that can be appropriately met by the service.
4. **Resuscitation status.**
5. Description of any **treatment limitations**.
6. **Permission of the patient to share the resuscitation plan** with GP, health centre, nursing home, St John Ambulance or other health professionals.
7. Whether the discussion is an update or to revoke previous goals of care form.
8. Details about whether an **APP or guardianship is in place**.
9. **List of people involved in the discussion,** including the patient, family and staff.
10. Description of the **patient's wishes and priorities** and what follow-up is required to facilitate this (includes specific documentation of patient's wish to finish up on Country/at home, which is culturally significant in the hospital).

Format of the End-of-Life Goals of Care Form

After reviewing evidence of other practices in Australian health services, the working group decided to format the goals of care form into four distinct goals and resuscitation plans of care.

END-OF-LIFE GOALS OF CARE FORM: GOALS AND RESUSCITATION PLANS

CURATIVE

Full ICU Care

RESUSCITATION STATUS

FOR CPR AND FOR MET CALL

RESTORATIVE

Limited ICU Intervention

RESUSCITATION STATUS

	Yes	No
FOR CPR	☐	☐
FOR MET CALLS	☐	☐

WARD BASED CARE

Not for escalation to ICU

RESUSCITATION STATUS

NOT FOR CPR

FOR MET CALLS

☐ Yes ☐ No

COMFORT BASED CARE

All treatments have the aim of improving comfort and quality of life

RESUSCITATION STATUS

NOT FOR CPR

NOT FOR MET CALLS

In addition, the form provides a section to describe the patient goals of care, ensuring clear individualised agreed care plans.

Piloting the new form

In November 2021, ASH began the six-month hospital-wide trial of the End-of-Life Goals of Care Form. However, the trial was interrupted as a result of the influx of COVID-19 cases and therefore extended until the end of 2022.

Hospital Insight: The hospital implemented a hospital-wide trial of the End of Life Goals of Care Form, as opposed to trialling the form within a specific ward. As the hospital is relatively small, the approach was carefully considered, recognising that many staff worked between different wards and did not want staff to complete different forms on different wards.

The hospital administered surveys through Microsoft TEAMS to obtain and collect feedback from health professionals on the utilisation of the new End-of-Life Goals of Care Form. To date, positive feedback has been received from both medical officers and nurses on the new form.

In particular, staff found the form easy to use and appreciated the collation of information in one place on the patient's wishes at the end of their life.

Governance structure

The NT Health Regions are considered to be relatively small, however cover large geographical areas. The Regions aim to work collaboratively to make the best of limited resources and to attempt to provide the same care everywhere. With this approach establishment of a NT working group was essential to the success of the health regions in meeting the national standards requirements. The NT-wide policies and guidelines were initially developed, reviewed and updated by a NT working group. These documents received final endorsement and approval for use across NT Health Regions.

There was a requirement for some variation of the End-of-Life Goals of Care Form between the regions to ensure we are able to meet the culturally appropriate needs of our consumers and variation in local service delivery capabilities.

The NT-wide working group has now been disbanded as the objectives of the working group have been achieved.

The local End-of-Life working group continues to meet regularly, although currently electronically or one-on-one, with the plan to resume face-to-face group meetings.

Education to support to new End-of-Life Goals of Care Form

To support the roll-out of the new End-of-Life Goals of Care Form, education to both medical officers and nursing staff was and continues to be a key focus.

The hospital's Palliative Care Consultant provides education to the heads of each department and the medical teams, including junior medical officers.

In addition, the Clinical Nurse Consultant is responsible for delivering education to the nurses and educators, which often occurs on the wards, with a plan to embed the education into the established education programs.

Formal feedback is sought by participants on the education sessions to ensure it meets their needs.

Challenges to Implementation

The hospital identified the following challenges in the process of development and implementation of the new End-of-Life Goals of Care Form:

- **COVID-19.** Impacted on defined trial timelines resulting in the pilot of the form requiring an extension of an additional six months . The new trial end date is 12 months from the initial commencement date due to redeployment of key stakeholders to COVID support roles and front line staff's inability to contribute due to clinical demands.
- **High turnover of staff.** An ongoing issue, which needs to be managed, therefore education about the form is a continuous requirement for inclusion in the medical, nursing, and allied health staff training calendars.
- **Location of End-of-Life Goals of Care Form.** As patient files are still paper-based, an agreed standardised process for the appropriate filing location of these forms is currently being problem solved. Ideally, the form would be located at the beginning of each patient's file. This would ensure the form is easily located at every episode of care enabling staff to identify the agreed plan, and the patient to receive care based on their wishes.

Key Learning and Outcomes

Through the development and release of the End-of-Life Goals of Care Form, the hospital has identified the following key learnings:

1

Importance of having goals of care discussions and clear documentation for patients throughout their illness trajectory.

The new form recognises patients might have multiple transitions in their goals of care, for example a patient has an acute episode, recovers, followed by another acute episode.

2

Value of Advance Personal Plans (APPs)

It has been identified that there is a lack of knowledge by both staff and patients in regard to APPs. The auditing of APPs provided insight into the need for patients to be well supported by medical, nursing and social work staff to complete the plans in a way that was clearly understood, both by health professionals providing the care and by the patients receiving the care.

3

Acknowledge, ensure and document cultural safety in the planning and discussion of end-of-life care with Aboriginal and Torres Strait Islander people.

It is imperative that staff involved in these discussions include the appropriate Aboriginal Liaison Officers and an interpreter, as required.

Next steps and areas of focus after accreditation against the National Safety and Quality Health Service Standards (2nd Edition)

Following the hospital being successfully accredited to the NSQHS Standards, the following key areas for improvement were identified:

1. **Processes to ensure that current advance care plans can be received from patients and are documented in the patient's healthcare record** (Action 5.17). The hospital is working on processes to ensure patients are routinely asked if they have an APP; where the APP is to be filed; and if the APP is communicated to all members of the health care team.
2. **Continue to support patients, carers, and families to engage in shared decision-making about end-of-life care** (Action 5.20). The multi-disciplinary teams continue to conduct family meetings as needed, to ensure the goals of care are updated and clear to all the team, the patient and their significant others. The form allows for the documentation of revisions and when they occurred. If there are significant changes, a new form will be commenced.
3. **In line with Action 5.14 relating to the use the comprehensive care plan**, the hospital has revised the adult comprehensive care plan to include "Goals of care and Resuscitation Status". The process also includes for the form to be checked every shift by every nurse caring for the patient (alerting clinicians to the existence of this form - Action 5.14).
4. **Clinicians used shared decision making process to develop person centred and goal directed comprehensive care plans that meet identified patient needs** (Action 5.13). In addition to developing the End-of-Life Goals of Care Form, the hospital has revised and updated the Nursing Adult Admission and Discharge Assessment form and the adult Comprehensive Care plan which cover a broad range of screening, assessment and management information. Often more detailed patient assessment, goals of care and care planning is documented in the patient's progress notes. The hospital is establishing processes to ensure clinicians are able to easily identify which screening and assessment forms are required on admission and throughout the patient's episode of care.