

Delaware Health Care Commission End-of-Life Workgroup

Workgroup Meeting
February 12, 2016



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DELAWARE

Agenda

Topic	Time
Recap of Last Meeting	10
Listening Sessions	35
Final Report Outline	30
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Recap of Last Meeting

- Presented 'key themes' document capturing information shared to date
- Reviewed DE data and PCC survey findings
- Discussed preparations for listening sessions
- Presented the draft outline of the final report to HCC



Listening Sessions

- Held in New Castle, Dover, Lewes and Seaford
- Attendance averaged 20-25 per session, with a mix of personal and professional interest
- All comments have been captured and the majority have been categorically grouped relative to our charge
- The group will need to determine how to address items outside of our scope

Listening Sessions: Key Themes

- **Each person must decide what is best for him or herself**
 - DE has an opportunity to encourage and support those decisions by sharing information and resources in an unbiased manner
 - Consider the various audiences who need to hear that message: patients, providers, policy makers, decision makers, other members of the support system



Listening Session Key Themes

- **Talk early and often with loved ones, caregivers, providers and others about personal wishes to encourage clear understanding.**
 - Family members and loved ones often feel powerless when left to make a decision on behalf of a loved one, especially when they are unsure of what the person would want
 - Doctors don't always know what is best for a patient
 - Many expressed concern about not being able to articulate their own end-of-life preferences
 - People need education about what it means to be a surrogate and making decisions as this is difficult to do even with direction

Listening Session Key Themes

- **Patients and their families often struggle to receive/provide the necessary care once an individual is released from the hospital**
 - Delaware does not offer 24/7 care in the home setting and most families can't afford to pay for additional nursing care, especially when someone is out of work. Aides and family can offer some supports but not all (e.g. medicine)
- **Delaware has many existing resources that can and should be leveraged for outreach and education purposes (Senior centers, community centers, churches, Navigators, Federally Qualified Health Centers, etc.)**

Listening Session Key Themes

- **DMOST and Advance Care Directives**
 - People are confused about the distinction between these two documents
 - Many people expressed concern about putting something in writing that would force them to forgo treatment that could potentially help or save them
 - Participants were divided on the effectiveness of ADs, with some saying that they provided clarity on critical decisions while others noted that even with an advance directive in place, the provider did not always adhere to it

Listening Session Key Themes

- **Providers need to receive education and training around end-of-life and palliative care so that they can properly and thoughtfully address patient needs. The importance of cultural competency was noted**
- **Providers also need to participate directly in advance care planning discussions so that all parties understand options and implications of each choice**
- **Palliative and hospice care are critical to supporting a good quality of life for patients with serious or terminal illness and providing support to caregivers. These services should be accessible regardless of ability to pay**

Listening Session Key Themes

- Many participants expressed concern about cost factoring into end-of-life decisions and noted that this is especially difficult for patients and families with limited resources
- Some participants expressed concern that conversations around withholding certain treatments put Delaware on a ‘slippery slope’ towards talking about euthanasia or physician assisted death, especially for those who may be considered a burden

Listening Session Key Themes

- There was much discussion around the importance of the compassionate care offered through palliative medicine and its role in improving quality of life for seriously or terminally ill patients. This is care designed to support patient and family preferences, offer options and ultimately provide whatever the patient wishes.

Final Report Outline

- What components are necessary to convey a comprehensive understanding of the issues?
- How do we ensure that this report lays the groundwork for a strong system of care and education?
- How do we address items outside of our charge?
- **What recommendations are essential to include?**



Recent Publications

- The DE Journal of Public Health issued its January issue, which included several articles related to palliative and EOL care. Of particular note:
 - Interview with Dr. Goodill
 - The Importance of Advance Health Planning
 - The Increasing Importance of Advance Care Planning
 - Impact of DMOST on Hospice and End-of-Life Care
 - DMOST: Keeping Control of Treatment Decisions
 - Glossary of Terms
- The full issue can be found at <http://issuu.com/dam-dpha/docs/final-de-jph-january>

Recent Publications

- The Journal of the American Medical Association (JAMA)'s January 19 issue included several articles related to end-of-life issues including:
 - Death, Dying and End of Life
 - A Policy Prescription for Hospice Care
 - The Problems with POLST
 - Toward Better ICU Use at the End of Life

Also included are various perspectives on right to die and physician assisted death. To access the full issue: <http://jama.jamanetwork.com/issue.aspx?journalid=67&issueid=934869>

Timeline Review

Due Date	Task/Deliverable
January 4	Draft outline of final deliverable
February 5	Listening sessions throughout DE (final session 2/10)
February 19	Complete first draft of report
March 4	Public comment period (completion)
March 11	Review and incorporate public feedback into report; complete and circulate second draft to workgroup
March 21	Receive and incorporate workgroup feedback into report
March 28	Complete final draft of report
March 31	Submit final report to HCC

Other Updates

- Resources continue to be added to the EOL webpage. Feel free to send along items for review.
- Next workgroup meeting: **Friday, February 26 from 10-12 a.m.**
- Reminder: the dedicated e-mail address for the workgroup is endoflife@choosehealthde.com

Public Comment

