End of Life Care
Is Everyone’s Business:
Examples from the 3 Wishes Project

Deborah Cook
Objective

To revisit and reawaken compassion in health care at the end of life
The World of a Person in the Community

- Family
- Friends
- Workmates
- Other Community Members
A Patient’s World in the ICU

Patient

Nurse

Physician

Physiotherapist

Respiratory therapist

Social worker

“Visitor”

Dietician

Chaplain

Pharmacist Psychologist Occupational therapist etc
FROM THE INSIDE

Ángela Alonso-Ovies
Gabriel Heras La Calle

ICU: a branch of hell?
Language is Dehumanizing

- ‘Bed 3’
- ‘The lady with sepsis’
- ‘That bad GI bleed’
- ‘The PRISMA guy’
- ‘She bought herself a tube’
Stories Are Dehumanizing

- Scripted case histories
- Abbreviations
- Template notes
- Digital documentation
- E-handovers

Silverman, JAMA Int Med 2017
Do You Really Know Your i-Patient?
Critical Illness Triggers.....

• Existential questions about
  – purpose
  – meaning
  – relationships
  – destiny

• Spirituality
  – matters of suffering beyond the range of physical human experience
<table>
<thead>
<tr>
<th>Clinician Response</th>
<th>Sympathy</th>
<th>Empathy</th>
<th>Compassion</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ego-based</td>
<td>Emotional</td>
<td>Altruistic</td>
</tr>
<tr>
<td>Attributes</td>
<td>Verbal</td>
<td>Verbal Affective</td>
<td>Virtuous &amp; Action-oriented</td>
</tr>
<tr>
<td>Regarding Suffering</td>
<td>Acknowledge</td>
<td>Acknowledge</td>
<td>Ameliorate</td>
</tr>
<tr>
<td></td>
<td>understand &amp; resonate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Response</td>
<td>Pitied &amp; Patronized</td>
<td>Heard &amp; validated</td>
<td>↓ Suffering, ↑ Well-being</td>
</tr>
</tbody>
</table>

Adapted from Sinclair et al, 2016
The top attributes of excellence of intensive care physicians

1. Compassion
2. Knowledge
3. Outstanding clinical skills
4. Commitment
5. Enthusiasm
6. Communication
7. Integrity & Professionalism
8. Teamwork
9. Leadership skills
10. Outstanding teaching skills
Overall Goal of The 3 Wishes Project

To improve the quality of the dying experience for patients and their families
3 Specific Objectives

• For patients, to dignify their death and celebrate their life

• For family members, to humanize the dying process and create positive memories

• For ICU clinicians, to foster patient and family-centered care and inspire a deeper sense of our vocation
Premise of the 3 Wishes

• Bringing a set of 3 wishes to fulfillment in the hope of bringing peace to the final days or hours of a patient’s life

• Wishes may be those of
  – the patient
  – their family members
  – ICU clinicians
  – 3 Wishes team
Qualitative

- Semi-structured family & clinician & manager interviews
- Wish categorization

Quantitative

- Patient demographics & life supports
- Family & clinician demographics
- Cost & donation data
With heartfelt condolences,

3 Wishes Project
Humanizing The Room
Momentos & Keepsakes
Rituals
## The Process: Examples

<table>
<thead>
<tr>
<th>Elicited By</th>
<th>Wished By</th>
<th>Wish</th>
<th>Implemented By</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 Wishes Team</td>
<td>Family</td>
<td>Classical music</td>
<td>Bedside nurse</td>
</tr>
<tr>
<td>Bedside nurse</td>
<td>Patient</td>
<td>Bring in pet dog</td>
<td>Family member</td>
</tr>
</tbody>
</table>
Spiritually enhanced environment
A Breath of Fresh Air
“A really big thing I took away was that, you know, those requests can be so simple and sometimes we don’t ask the question because we’re afraid of the effort…we’re afraid that we can’t deliver…the biggest thing I’ve learned is that a lot of these things we can deliver, so why not ask the question?..”
“Instead of remembering this horrific 2 month course... they might focus on, you know, ‘here we are with Dad, we had flowers in the room and a nice toast over his life’. I think that would stick out more in their minds than the pretty horrible days that preceded that.”
Dear papa Lou,

You have always been an inspiration to me. I have always been inspired by your strength and attitude. Throughout my whole life, and even before then, you have been modelling true perseverance and strength to me, our family and anyone else who crosses your path. For years I have kept a picture of you and grandma Nell close to me, simply because I hope to be just like the two of you.
“This was the work of spiritual care embodied. The wishes were a concrete means to engage something that was greater than everything else that was in the room… The wishes were a medium through which the family could re-engage him…. the life they shared together. It was deeply honouring.”
Personalizing Dying in the ICU

Dignifying The Patient

Giving Voice To The Family

Calling Forth Clinician Compassion
Wish Categories

- Humanizing the Patient
- Humanizing the Environment
- Family Care
- Keepsakes & Tributes
- Celebrations With Food & Beverages
- Preparations & Final Arrangements
- Paying it Forward
- Organ & Tissue Donation
- Miscellaneous
- Rituals & Ceremonies
- Word Clouds
- Music Therapy

Word Clouds
- Music
- Therapy

Humanizing the Patient

Connections

Rituals & Ceremonies

Organ & Tissue Donation

Miscellaneous
Post-Mortem Connections: Finding Fish a New Home
Family → Staff
A Community of Compassion
What is a Wish?
A wish is a Process…. And a Product
• A conversation starter
• A means to recognize the patient
• An example of dignity-conserving care
• An opportunity for reflection
• A manifestation of hope
• A therapeutic connection
• A vehicle for inter-professional care
• A transitional activity
• An expression of spirituality
• A secular prayer
• A tangible expression of empathy
“One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient.”

Francis Peabody (1881-1927), Boston City Hospital, JAMA 1927
To Care Is Human — Collectively Confronting the Clinician-Burnout Crisis

Victor J. Dzau, M.D., Darrell G. Kirch, M.D., and Thomas J. Nasca, M.D.

• What can be done to
  – Reduce burnout
  – Promote well-being
  – Help clinicians carry out the sacred mission that drew them to the healing professions – providing the very best care to patients?
Nurse

“The most significant, meaningful aspect, or memorable aspect to me was collaborating with my team and presenting this concept to the family, which completely overwhelmed them. Then going through with the plan and participating in this celebratory last supper with them. It was a phenomenal experience.”
“Full steam ahead. Don’t give up. Never give it up because if you give it up then you’re just going to be … a standard hospital… and nothing extraordinary will come from here. And when something extraordinary is in the making you don’t give it up.”
Thank You!