Disclosure
#Palltech: Leveraging Digital Resources in Hospice and Palliative Care
Learning Objectives:

• Describe the current culture and climate for technological innovation within our changing healthcare system.

• Identify how digital resources can promote the work of hospice and palliative care clinicians.

• Examine gaps within hospice and palliative care that can benefit from technological innovation.
Ways to Interact

#PallTech

www.palltech.org
Technology in Palliative Care Use Cases

Clinicians

Patients

Families
Clinicians
https://www.youtube.com/watch?v=aZkU5gB2bNc
Tips For Using That Dragon, Cancer

- Empathy builder for ourselves (projective identification)

- Teaching tool for learners (especially family meeting session)

$4.99 appstore, android
Palliative Care FAST Facts App
Education Resource Email #5: Fast Facts and Concepts

Fast Facts and Concepts for Ed-SIG

http://www.eperc.mcm.edu/EPFLC/FastFactsandConcepts

Fast Facts and Concepts (FF) are a series of short, peer-reviewed monographs on a wide variety of palliative care topics. They are published on the EPERC website at the Medical College of Wisconsin, as well as co-published in the Journal of Palliative Medicine. FF were started in around the year 2000, as part of the Robert Wood Johnson Foundation palliative care residency education project that David Weissman MD ran. Drew Rosielle MD has edited them since 2007, with assistance from Sean Marks MD since 2013. More information about the editorial board and process is available on the FF website.

Using FF as an educational-resource:

1. FF are developed to be practical & clinically relevant point-of-care resources. We write/edit them with residents in mind, although we hear that they are used widely by medical students, residents, attending & faculty physicians, nurses, social workers, and administrators. They are aimed at non-palliative specialists, but would be relevant for palliative learners such as fellows, especially in the first 6 months. The idea behind FF is to give the reader both a broad overview of a topic, as well as practical tips in approaching a patient or certain situation, whether it's elucidating a patient to 'comfort care', going into a family meeting one worries is going to be contentious, to seeing a cancer patient in clinic who complains of severe fatigue.

2. FF are based on evidence, as well as evidence-based. While always peer reviewed, as FF (and the field of HPm in general) evolved, it became more important for them to be evidence-based. The current editorial stance is that they have to be as evidence-based as much as there is evidence, and transparent about the level of evidence behind any recommendation. That said, much of our practice remains empiric, and we continue to believe there's a role for common sense and the wisdom of clinicians, and FF include a lot of that, as well. They are 'evidence-based', insofar as they've been investigated and shown to improve medical residents' palliative knowledge: (http://www.ncbi.nlm.nih.gov/pubmed/23195446).
Getting The Most Out Of Fast Facts App

- Using as a quick reference for medication selection, dosing, guidelines

- Use as a teaching tool for learners (quick reference)

- Can use as an “academic detailing:” to give to colleagues when working as a consultant
### Fast Facts App Examples

**Symptom Control For Ventilator Withdrawal In The Dying Patient**

**Authors:** Charles F. von Gunten MD, David E. Weisberg MD  
**Category:** ICU, Critical Care

**Introduction:** This is the second of a three-part series. *Fast Fact* 34 reviewed a protocol for removing the ventilator, and *Fast Fact* 35 will review information for families. The most common symptoms related to ventilator withdrawal are breathlessness and anxiety. Opioids and benzodiazepines are the primary medications used; concerns about unattended hastened death are exaggerated, particularly if established dosing guidelines are followed (see *Fast Fact* #3). There is no medical or ethical justification for withholding sedating medication when death from ventilator withdrawal is the expected goal. However, increasing doses beyond the levels needed to achieve comfort, sedation, with the intention of hastening death is unethical and is not acceptable legal medical practice.

**Medication Protocol**

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Discontinue sedatives (e.g., morphine) and titrate withdrawn</td>
</tr>
<tr>
<td>2.</td>
<td>Administer IV fentanyl and or IV continuous infusion of sedating medication (see below). Do not rely on anesthetics or oral drug administration as these take longer to work. For children, obtain dosing advice from a pharmacist or pediatric intensivist.</td>
</tr>
<tr>
<td>3.</td>
<td>Titrate drugs to control labile respirations and achieve the desired state of sedation prior to extubation. Testing the newest reflex is a common method of quickly assessing level of consciousness.</td>
</tr>
<tr>
<td>4.</td>
<td>Have additional medication drawn up and ready to administer at the bedside if needed.</td>
</tr>
<tr>
<td>5.</td>
<td>After ventilator withdrawal, if distress causes immediate symptom control is needed. For additional sedating medication (e.g., morphine 2-10 mg IV push q 15 min, and/or midazolam 1-2 mg IV push q 15 min, until distress is relieved). Adjust infusions rates to maintain relief.</td>
</tr>
<tr>
<td>6.</td>
<td>Specific dosages are less important than the goal of symptom relief. A goal should be to keep the respiratory rate &lt; 30 and eliminate grunting and agitation.</td>
</tr>
</tbody>
</table>

**Medication Protocol**

1. Discontinue paralysis; do not use paralytic agents for ventilator withdrawal.
2. Administer an IV bolus dose and begin an IV continuous infusion of sedating medication (see below). Do not rely on anesthetics or oral drug administration as these take longer to work. For children, obtain dosing advice from a pharmacist or pediatric intensivist.
3. Titrate drugs to control labile respirations and achieve the desired state of sedation prior to extubation. Testing the newest reflex is a common method of quickly assessing level of consciousness.
4. Have additional medication drawn up and ready to administer at the bedside if needed.
5. After ventilator withdrawal, if distress causes immediate symptom control is needed. For additional sedating medication (e.g., morphine 1-2 mg IV push q 15 min, and/or midazolam 1-2 mg IV push q 15 min, until distress is relieved). Adjust infusions rates to maintain relief.
6. Specific dosages are less important than the goal of symptom relief. A goal should be to keep the respiratory rate < 30 and eliminate grunting and agitation.

**References**

What Do I Tell The Children?

Authors: Robert J. Arnold, MD, Paula Rauch

Background: The death of a young adult is always difficult, even more so when there are young children survivors. A common question asked by dying adults or their family members is, "What do I tell the children?" Physicians and other health care providers can provide leadership and guidance to help young families through this crisis.

I. Screening and Awareness

- Ask if the ill person has children at home. Ask about their age, personality, and coping style.
- Ask what the ill person has told the children about the illness.
- Ask if they have a specific worry about the child.
- Ask if the child has had recent problems in school, at home or with relationships.
- Ask who they would like to talk to if they have concerns?

II. Give them some words

- Often a parent's biggest worry is what to say if the child asks if he or she is dying. Here are two examples of words a parent might use. Asking a parent if these words would feel comfortable to say can begin a dialogue between patient and clinician to arrive at language that is honest, and life affirming.
- "X" can kill people, but I am taking the best care of myself I can. I am following the doctor's plan so that I can live as long as possible.
- Even with trying my hardest and getting the best possible care, my ____ is getting worse; still I plan to live every day.

III. Give child/youth some examples to guide their interactions.

- Express interest in the child's day.
- Work to maintain normal routines (e.g. maintain family rituals, Friday night supper, Monday night pizza, watching television together).
- Welcome all questions but do not force discussions. Make sure you understand the real question before answering. Take your time to think about how you want to answer.
- Overhearing bad news is the worst way to hear it. Talk with children from diagnosis onward, being sure to give updates when there are changes in prognosis or treatment.
- Avoid euphemisms (e.g. lump, boo-boo, or sickness) that may confuse children.
- Ask children to share what they are thinking, or hear from others, so they do not worry alone.
- Prepare children for visits with the sick person. Describe what they are likely to see.
- Bring along another adult who is comfortable to stay only as long as the child wants.
- Bring along markers and paper, so children can leave the parent with a picture or message.
Patients
Go Wish - Go Wish Interactive
www.gowish.org/staticpages/index.php/thegame
SOMETHING. Important. VERY. NOT. CLICK TO DRAW. Here is where I will put my comments. I can type on and on and on until I get to the end. pg 1 of 3. How to ...

Go Wish
www.gowish.org/
The Go Wish card game is designed to help you find words to talk about what is important if ... Click on this link to play the online interactive version of the game.
Go Wish FAQs · Purchase · Stories · How To Play

Go Wish - Purchase Go Wish Here
www.gowish.org/article.php/purchase
Decks of Go Wish cards are available in English OR Spanish to purchase from Reach And Teach (the developers of this web site) and the Coda Alliance.

Go Wish - Resources > Go Wish Stories
www.gowish.org/index.php?topic=resources_stories
Video of Different Ways People Use Go Wish Email Article To a Friend View Printable ... The chaplain suggested they use the Go Wish cards as a segue into the ...
How to play Go Wish

CLICK (don't drag) on the face down pile to your left to draw a card and place face up. Now CLICK on any of the face down cards below to place the drawn card into that spot. Note that there are three card categories:

Very Important, Somewhat Important, Not Important.

To pick up a card and place it somewhere else, click on that card and then click on the new location for the card. Keep sorting as many times as you like until you are satisfied.

Object of the game
Apps Review

CreateToHeal
Getting Started

Select a music track from the Music section and meditation track from the Meditation section by swiping.
Using Virtual Reality In HPM
A Virtual Bucket List
Families
Bereavement Care

• How can we use technology to better support bereaved individuals and families?
  • Technology has great potential to:
    • provide access to basic psycho-educational material, 24/7
    • offer a ‘preview’ about what recently bereaved individuals might expect from the program if they were to opt-in
    • decrease isolation by connecting bereaved individuals
Bereavement Care

• At Dana-Farber Cancer Institute, we have:
  • Information about coping with grief on the website, including a PDF of the grief guide, *When Grief is New* that we mail to families [Guide](#)
  • Interviews with bereaved family members that allow recently bereaved individuals to learn about grief and what they might expect from the bereavement program [Janet's Interview](#) (Time: 2.20-3.57)
Bereavement Care

• CancerConnect - Private Online Bereavement Community
  • Part of CancerConnect platform by Omni Health
  • HIPPA compliant and secure
  • Bereavement community launched in August 2013
  • Helps connect people to tackle isolation
  • 170 members
  • Moderated community
  • 127 discussion topics to date and 740 replies
  • 5331 page visits
  • Welcome email and a daily digest email notifications
Live Webchat: Parenting During Cancer Treatment

Watch Archived Chat

Hello, I'm your moderator. Please let me know if you have any questions.

Dana-Farber Cancer Institute provides expert, compassionate care to adults and children, while advancing the understanding, diagnosis, treatment, and prevention of cancer and related diseases. Dana-Farber, with our partners, is ranked among the nation’s very top cancer centers, and is one of the world’s leading centers for research into the causes of — and new treatments for — the disease.

Contact Us
Remembering

I posted a while ago that she was a social lubricant for me, cuing when my directness was not appropriate, or it was the wrong story to tell. She also reminded me to slow down at traffic circles or and remembered all the things I had done wrong (by her estimation) in forty years of marriage. But now as my life is crowded with work, family and routine, I have to stop to remember. At times it is almost like I am searching for the grieving as a way fully remember. Solving the daily problems of living alone, with the exception of folding fitted sheets, sets new routines. Three months since her passing seems both distant and current. People have posted that even after years they still grieve. Is my process unique?

Posted by @danielk, Fri, Sep 29 5:03am

Liked by pijpeocher

Hi Danielk,
I think everyone’s grief process is unique. I also agree that time gets distorted. On one hand, it can seem like just yesterday since someone died, and on the other hand, it can seem like an eternity. When people are busy with work and family life as you are, I do encourage them to carve out time to grieve – which is why writing or attending a group can be a way to do this. Thank you for ‘remembering’ here, Sue

Posted by @suemorris, Fri, Sep 29 8:38am
Longing to hear his voice

Posted by @seashells, Sun, Oct 1 10:50am

My husband passed away in August from three years with follicular dendritic cell sarcoma which is a rare form. So of course the pain is new and I have my ups and downs. Trying to keep busy but it’s just so hard

Reply

Manage + Follow

Search entire site...

Dana-Farber Private Groups

--Select--

You are a member of Dana-Farber CancerConnect Community on CancerConnect. Click here to post to Dana-Farber CancerConnect Community members only.

Posted by @njg, Sun, Oct 1 2:58pm

I can relate to your wanting to hear your husbands voice. I saved my husbands last voice mail to me however it took me a long time before I could listen to it….and I’ve only listened to it a couple of times during the last two years. Somehow it’s comforting to me knowing that I could listen to his voice if I want.

I’m ahead of you in the grieving journey my advise: keep talking and yell and scream once in a while too.

My best to you and my deepest sympathy on the loss of your husband.

Ciao

REPLY
Bereavement Care

• What are the barriers to using technology?
  • Cost for initial implementation and maintenance
  • Often a clinician has the idea but not the ‘know-how’
  • May require a moderator, especially if related to mental health
Bereavement Care

• How would we like to use technology in the future?
  • Include stories on website to reflect different losses e.g. bereaved parents
  • Internet-based therapist-assisted program for the treatment and prevention of prolonged grief disorder (Litz et al., 2014)
  • Develop a platform to connect people to community resources because people often don’t know what they need or what is available
VR/AR
Websites
Mobile Apps
Video
Games

VISIBILITY

Peak of Inflated Expectations
Plateau of Productivity
Slope of Enlightenment
Trough of Disillusionment
Technology Trigger

TIME