



hope
is the thing . . .
the challenges of
communicating hope

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Hope





-
- Individual experience
 - Subjective experience
 - Universal elements
 - Culturally expressed

“It is an orientation of the spirit, an orientation of the heart; it transcends the world that is immediately experienced, and is anchored somewhere beyond its horizons. -- *Vaclav Havel*



Learning objectives

- Expresses the emotional and spiritual essence and benefits of joining with families in the context of hope from initial contact with families, throughout treatment and into bereavement.
- Reviews interventions published and those practically applied by Stepping Stones Care Team to foster hope.



Learning objectives (cont.)

- Apply to clinical practice language families and providers have identified as helpful in communicating and holding hope.
- Examines the natural fit of “holding hope” with families from time of diagnosis into bereavement.

Watching Furious Peace



Looking at the world around...

Seeing windy dreams blow by...

How can wonders cease to feel the sting of autumn's cry?

I look out from my cozy niche...out at an autumn storm.

How can it be so beautiful – the kiss of season's thorn?

A thought to think, to wonder why the rolling, blowing leaves
can paint a picture sharp and clear.

My heart warms from this lucent eve.

I see and feel the beauty come from wispy, blowing gusts.

A mystery I shall never solve:

Hope comes from storms I've learned to trust.



Kristen

Now 20 years old with a progressive, rare neurological condition – non verbal – full care.

- Change in communication over time
- Longevity in relationship – uncertainty in prognosis
- Eventual openness to spiritual care by parents
- Parent meetings – meaning in their relationship

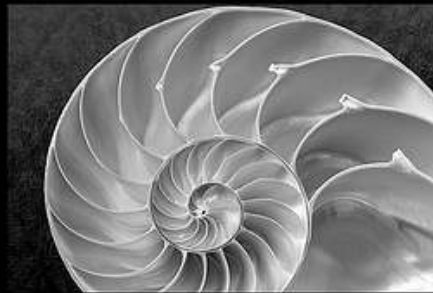


Anna

9 year old with recurrent cancer; on hospice
for 3 weeks at home

- Family Advisory Committee
- Mom's honoring of child's hope/desire to be @ home.
- Father volunteering @ Bereavement Camp
- "I wish someone had told me I would be ok"
- Mom requested – "standard of practice to refer to community palliative care program"

The Continuum of hope





Part of the package

Premise – Hope thrives in families with a seriously ill child...

- Integral
- Established roots – changes over time
- Allows for/supports daily survival
- Dynamic Life Force







The gift

- Adult context may carry a very different frame
- Supports survival across the experience
- Special Considerations –
 - Moments of hopelessness – not the usual undercurrent
 - Assessing mental health across care





Hope and prognostic disclosure*

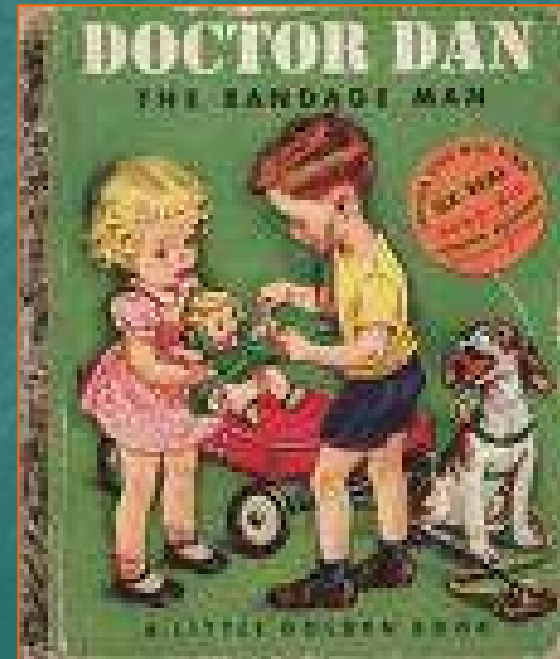
- Study found no evidence that prognostic disclosure makes parents less hopeful. Instead, disclosure of prognosis by the physician can support hope, even when the prognosis is poor.
 - Importance of relationship and connection
 - Realistic perceptions of prognosis can transform hope – perhaps into a meaningful end of life period
- * (Mack, et al, 2007)



“Tell us the truth...”

- ...we'll believe what we need to believe.
- “...bandages don't fix the wound in my soul.”
- Parents want accurate, clear, and timely information even if stating the situation is uncertain.

(When Children Die – IOM)





Enabling concurrent care

- Essential to integrate team focused on active treatment, palliative care team and home based palliative team from time of diagnosis into bereavement.

(When Children Die – IOM)

- Imperative for team of health care providers to find ways to redefine and reframe hope without removing it
- Hope for a miracle never fades

(...There are people who make it...JAMA 2004)



Parent & child statements

- “It was so helpful when you said we could graduate from hospice.”
- “Now, two years later, I’m beginning to see how everything happened as it needed to happen.” (hindsight, visitation of the hummingbird)”.
.”
- “I wish someone had told me that I was going to be ok”.



Parent statements (cont.)

- “That night I had another powerful dream. . . (my son had written) -‘I understand that I was completely beloved in my family’. I felt it was a definite message to stop feeling so bad, and it signaled the beginning of my healing”. *(Speich)*





In their own words

“Sometimes when she is sleeping she seems completely at peace. When I wake her up in the morning she opens her eye as if all of sudden noticing she is not able to move again - she cries. She cries every morning and sometimes I wish and hope death will come fast and unexpected when she is peacefully sleeping.”



Shifting hope - supporting

- “If we had known we would have aborted. Now I have a chance to appreciate her moment to moment”.
- “I haven’t lost my hope, I’m just changing my hope.”
- “Michael’s MD worked the entire way knowing that if he didn’t make it, we were still going to have to get through it, so she treated us as well as she treated him.” *(Rose Conlon, parent, 2001 – IOM)*



Gloria's Angels

- “One year later Gloria continues to give us all a Glimpse of Heaven.”
- “I am honored to be her father and grateful for her example of love, hope and faith.”





Borrowed & shared strength

- “I borrowed the strength from those who stood with him”.
- “We did it because we had too...and we knew you were there”

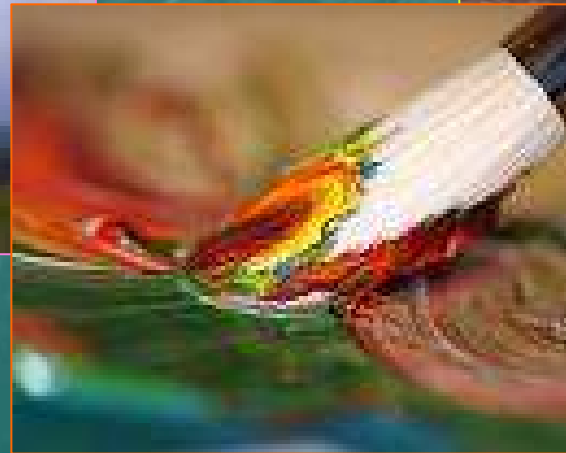


Clinical practice strategies – communicating with words

- Refrain from pushing our own agenda
 - EOL discussion/planning – let parent & child lead
- Promote personal control and self-report
- Practice truth-telling
- Practice non-judgment
- Provide consistent and comprehensive information BUT...
 - consider appropriate cultural context
- Hope is subjective – self report – watch also for behavioral cues, i.e.: depression.

“hope - expression of desire
in imagination”

(Adrienne Martin, Ph.D.)





Hoping with Children – clinical wonderings

- What are you looking forward to most?
- Who do you like to spend the most time with?
- What is your mom/dad/sister looking forward to most?
- Do you sometimes worry or feel afraid?
What makes you afraid/worried?



Clinical wonderings/questions

- As you think about your child's illness what are your hopes? What are your worries?
- What are you hopeful for right now?
- "I know you are hoping that the disease will be cured and I am hoping for that too. But I would also like to know more about your hopes and goals if a time comes when a cure is not possible".



Clinical wonderings/questions (cont.)

- Although we cannot predict exactly what will happen to your child most children with this disease usually have _____. It that happens our goal will be to make him as comfortable as possible and to assist you in being with him and caring for him.



Hoping for the best – preparing for the worst

- Have you thought about what might happen if things don't go as you wish? Sometimes having a plan that prepares you for the worst makes it easier to focus on your hopes.
- What sorts of things are left undone for you? Let's talk about how we might be able to make these happen.
- What is your sense/understanding of what is happening?



Program considerations – responsibility

- Assuring that your program offers parent support groups.
- Anticipatory support for siblings, significant other children in patients life.
- Referrals to *Make a Wish*, photography opportunities
- Have team introduce bereavement specialist, before death if possible (*Australian Study*)



Program considerations – responsibility (cont.)

- Recognizing team clinicians can participate in bereavement offerings
- Annual Day of Remembrance
- Attending family invitational events
- Family Advisory Committee
- Camp Erin





Continuing a life long bond

- The fundamental belief that purpose of grief is to let go of the deceased in order to move on and form new attachments is the antithesis of many bereaved people's experience.
- Anne Finkbeiner's findings demonstrate unequivocally that far from letting go of their dead children, bereaved parents strive to find ways of sustaining a life long bond with their child.



Finding meaning after death

By 12 months post death 12% of sample had found meaning in their child's death. By 60 months post death 57% had found meaning in their child's death. Parents who attended a parent support group were 4 times more likely to find meaning and reported lower scores on mental distress, higher scores on marital satisfaction and higher scores in general health. *(Murphy, et. Al, 2003)*



Finding meaning after death

Early provision of info on how to practically and emotionally prepare for the death of their child, contact with other bereaved parents and formal grief support for siblings are what parents identify as helpful from their medical team.

(deCinque, et al. 2006)



Incorporating ritual

- Celebrating birthdays post death - Wrapped and delivered birthday presents to Children's Hospital
- Reading chapters of books with child
- Daily 1:1 specific time (reading, saying goodnight) with well and ill child
- Decorate a child's room prior to bone marrow transplant
- Raise donations for a bench in the park



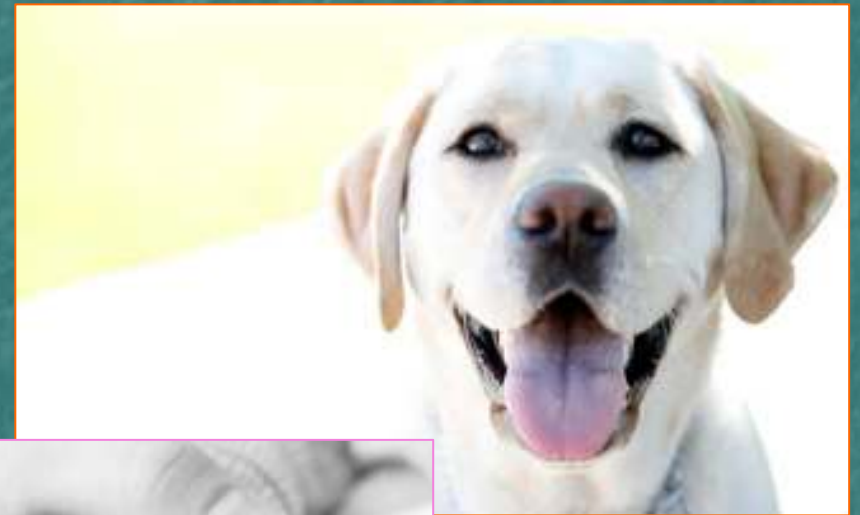
Incorporating ritual

- Prayer gatherings at family home or other homes
- Raise donations for cause – illness-specific race or walk
- Create a local summer camp
- Assemble folks to hike up to point to scatter ashes, and scatter in significant places around the world
- Create parent survival kits while for hospital



Clinical Communication – beyond words

- Animal Assistance
Activity/Therapy Program



- Light Touch Therapy





Encouragement

- Be gentle with yourself
- We grow and learn with our families
- Our very core – cell structure is changed having experienced the living of the children we come to know



Hope

Hope is the thing with feathers
That perches in the soul,
And sings the tune--without the words,
And never stops at all,
And sweetest in the gale is heard;
And sore must be the storm
That could abash the little bird
That kept so many warm.
I've heard it in the chillest land,
And on the strangest sea;
Yet, never, in extremity,
It asked a crumb of me.

-Emily Dickinson