

## Hospice and the Holidays... Helping Others, Helping Yourself

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### Why this topic is important?

- ▶ In 2015, statistics showed that 92% of Americans say they celebrate Christmas. \*Pew Research Study; 2013. The same study also showed that:
  - ▶ 81% of non-Christians in the US also celebrate Christmas, inc. 87% of people with no religion, 76% of Asian-American Buddhists & 73% of Hindus.
  - ▶ Nearly 1/3 (32%) of US Jews (many of whom have non-Jewish spouses) said in a 2013 survey that they had a Christmas tree in their homes during the recent holiday season.
  - ▶ Among Americans overall, 51% say they celebrate Christmas as a religious holiday and 1/3 said they celebrate it as a cultural holiday.

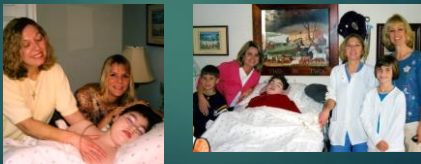
### Who is missing out on hospice care during the holidays?

- ▶ Those who might need it most...Halcyon Hospice has reported that many physicians are slow(er) to refer during the holidays, due to the incorrect perception many physicians have that hospice = a death sentence.
- ▶ However, there are over 1.5 million families with a loved one on hospice care. Statistics also show there are over 2 million seriously ill children in our country, many who are on palliative and hospice care.
- ▶ Regardless of who you provide care for – Christmas, Hannukah, and Kwanzaa can be incredibly complicated for all patients and families.

Because as you can imagine, life is often fraught with uncertainty and difficulty when meshed with expectation & ritual. So how can we help families and ourselves during this time?



Ask direct questions that inquire about expectations. Our team helped us to release expectation that the holidays would be horrible, which opened us up to the idea that "magical moments" could occur, too.



They also explained that one person cannot be all things to all people, at all times...and they decided to create a larger "circle of care" which focused more on community support.



This enhanced "circle of support" lessened the pressure on all involved. It included more focus on:

- ▶ The family chaplain and church support team, including the youth groups.
- ▶ My daughter's teacher, who included the class in a special project for our family
- ▶ Local musicians who would come to share their music at our home
- ▶ Neighbors who would Christmas shop with my daughter and for our family, because kids, too, worry about getting a present for mommy.
- ▶ Hospice volunteers; Were needed more than ever – which meant that I had to lower my resistance to having outside help from strangers.

But first, before anyone did anything, we created a list. It included answers to these questions:

- ▶ 1. What were/are our rituals?
- ▶ 2. Which rituals no longer served our current situation?
- ▶ 3. What new rituals may find their way into our holiday season?
- ▶ 4. What could our care team add to the mix? Who was the musician, baker, chief story teller?
- ▶ 5. Were we comfortable with our care team becoming an instrumental part of our holiday experience? In our case: Absolutely. Our own family just "couldn't handle" the concept of a dying child at Christmas. We needed all the love and support we could get!

Together we discussed  
"the cues"... The Five Senses

- ❖ *What sounds did we like over the holidays? Music?*
- ❖ *Visually, what was important to us?*
- ❖ *Scents that did we like (while keeping in mind that not all scents are still good to the patient)?*
- ❖ *How about touch? Might a massage help even more during the holidays?*
- ❖ *What about our sense of taste? What foods/ flavors might be important to the healthy family members? How could we adapt even pumpkin pie, so that my son could participate?*

I also learned it was important to remain flexible regarding who would help us and how. For example, children can be a very important part of the holiday experience.



Our team also talked to us about what we may feel during the hospice holiday experience.  
For example:

- ▶ 1. Feelings of deep joy AND sorrow. The depth of both was very confusing. We also discussed the book "The Prophet" by Kahlil Gibran and how our joy and sorrow are interconnected. This helped a LOT!
- ▶ 2. Feelings of isolation from our biological family, friends, other families and community. Not everyone can emotionally handle being around seriously ill patients at the holidays. Explaining this WILL help families to not feel shunned and abandoned.
- ▶ 3. The importance of embracing small moments of joy, versus seeing the sometimes overwhelming "big picture" of the holidays.

And we also heard what others might say to us... and this helped me to prepare!

- ❖ Well meaning people tell us that our loved ones would want us to have a happy holiday. "Go and have a good time" was not in my plan.
  - ❖ *While I appreciated their well wishes, there was no place I else I wanted to be.*
  - ❖ *Also, we received more food than anyone could have ever eaten. I wish someone would've given me a printed list of food banks and shelters that would've accepted the food!*
  - ❖ *Or better yet, I would love for someone to have offered to take the food.*
  - ❖ *We heard a lot of "advice"... I think in the end, it was helpful for our case manager to explain that people basically don't know what to say or what to give during the holiday hospice experience. I felt better once she explained this.*

Also, our "holiday talk" included caregiver help... and I was thankful for the direct dialogue. We discussed:

- ▶ Over use of alcohol to relax
- ▶ Feeling guilty about not being able to do it all
- ▶ Taking the time (or not) to attend parties or social events
- ▶ The benefits of exercise
- ▶ The benefits of sleep
- ▶ And she described that these things applied to her, too, which I really appreciated because it made me feel that we were a team.

She also added in these pointers:

- ▶ Try not to over do it
- ▶ Reach out to others for help
- ▶ Remind yourself that the actual holiday is only one day
- ▶ The anticipation of the holidays can be worse than the day itself... which was really helpful to know, because I didn't understand what I was feeling!

Our team also encouraged us to:

- ❖ Let people know as early as possible that we will would not be doing our usual holiday activities.
- ❖ Pick those holiday events we did want to attend and select friends to attend with us
- ❖ Connect with others
- ❖ Take a break and go for a walk
- ❖ Remember that we hurt so much because we love so much!

We also discussed how technology was a friend to both of us, whether shopping...

<https://www.lifewire.com/holiday-shopping-christmas-list-apps-3486568>



Or de-stressing:

- ▶ [www.https://www.calm.com](https://www.calm.com) (It's FREE):



And about those expectations:

Our case manager also asked us to park our expectations at the door! In doing that, we all opened ourselves up to moments that may never have occurred otherwise.

For example: A Florida ice company coordinated with a trucking company to dump three tons of "Christmas snow" in a friend's yard....



And we all (including my terminally ill son) had three tons of FUN...which we will always remember...



Yet, I also saw that you all, as care providers, are people, too... and need your emotional well refilled from time-to-time during the holidays.

How do you take care of me, if you do not take care of you...and do not find your own "holiday in your heart"?

For those of you who studied the work of hospice pioneer Dr. Elisabeth Kubler-Ross, here's a thought for you:

- ▶ Elisabeth, who wrote 24 books which were translated in 34 languages, was a HUGE fan of Christmas! She would shop, bake, decorate, you name it. In fact, the holidays were a part of her life in a very BIG way...

Meet hospice pioneer, Dr. Elisabeth Kubler-Ross & her 15' tree!



Her thoughts on Grief and the Holidays...

- ▶ "For some, it makes sense to just ignore the holidays as if they didn't exist. Why not just cancel them for a year?"
- ▶ However, others choose to celebrate as a symbol of life continuing.
- ▶ "You can integrate the loss into the holiday by giving it a time and a place. Perhaps the prayer before dinner includes your loved one. A simple gesture of recognizing your loved one can reflect the continued presence in your heart."
- ▶ "Making time for your loss (and the process) and acknowledging it is often easier than resisting it."

Regardless of how near or far away they are...



Most of all, please remember to take care of yourselves... because you are important to your patients and families. Here are a few resources:

- ▶ <https://www.aarp.org/home-family/caregiving/info-12-2013/caregiving-holiday-stress-gover.html>
- ▶ **Ways to Take A Quick Break** (which helps reduce stress): <http://daily.caring.com/10-ways-caregivers-can-take-a-quick-break-right-now/>
- ▶ <http://www.holidaytouch.com/retirement-101/senior-living-articles/four-apps-to-support-caregiving-from-a-distance>

My closing holiday story for you...



Thank you...

