This Q & A article is from BDSRA’s “Ask An Expert” Facebook Chat in the BDSRA Closed Facebook group for parents and caregivers.

\*Please note: the information contained in this material is intended to provide

basic information to Batten families and caregivers. It is not intended to be, nor is it, clinical advice for individuals. Parents and caregivers should consult their own physician or mental health professional prior to changing medication, treatment, or daily activities.

“Coping with Grief & Loss during the Holiday Season”

Featured Expert:

Doug Cluxton, MA, LPC, Manager of Bereavement Services

OhioHealth Hospice

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Q: We encourage parents and caregivers to share your thoughts about coping with grief and loss during the holiday season. Is anyone willing to comment about how they feel about the impending holiday season? I often hear from bereaved family members that they wish they could simply skip the holidays altogether. There’s often a feeling of dread. They often say that the expectation to be around family and friends feels overwhelming.

Just so everyone is aware, “Fred Batten””) is Doug Cluxton answering the questions. Last time it was “Docktor Batten” but Facebook was giving us a hard time with this account.

Q: My daughter passed away in 2009 and I am just starting to enjoy Christmas again. It is very hard to enjoy the holidays as I don’t feel like my family is complete without her.

A: I think an important consideration is to try to define what YOU need at this time. What is your energy like? What do you want or are able to do? What is simply too much? I can imagine Phyllis. Are there any specific things you do at the holidays to keep your daughter’s memory alive?

A: I’m trying to do a Christmas village with pieces in the village that remind me of her.

A: Sometimes we recall the person by name at family gatherings or light a candle in the child’s memory by a photo, etc. The Christmas village is a great idea. Wonderful way to keep her a part of your family’s memory, as she will always be! Another idea is to have available a Christmas stocking that family members can write a note about their lost loved one and recall funny memories or holidays past, both poignant and sad but often full of laughter as well. Sometimes traditions like church attendance at the holidays are particularly difficult, so they may mix it up a bit. For example, they may attend a different church or a different time of service. Makes it a bit more manageable for some.

Q: Do you find that family and friends have given you space without lots of expectations about your participation if you haven’t felt up to it?

A: Yes, my family has been very understanding.

Happy to hear that. One challenge that some families describe is attending a school holiday performance of kids when their affected child is unable to participate. That is hard. I always encourage people to be gentle on themselves and not to over expect. Pacing themselves is good. Acknowledging the pain and sadness when others are experiencing joy is difficult. Just be with it and find supportive others to offer their listening ears.

Q: Does anyone have a favorite song or tradition that their child always enjoyed? Those are important to keep alive and celebrate. It’s a lot about maintaining a relationship with the child in memory. Gone but not forgotten as some have said.

Comment: I haven’t lost my child yet, but I just want to say that I appreciate all your suggestions. I’m writing them down for later.

A: Try to outline what friends can do for you and with you. What do you need and want to do or are able to do? Thank you – I hope these suggestions are helpful. I’m very pragmatic….there’s no blueprint in this kind of loss and everyone finds their own way. Support of friends and family seems to be a key for most. Also, a person’s faith or spirituality seems to be a great source of comfort for many folks.

Q: I really hate Christmas now. My brother passed away 3 years ago on Christmas Day. They my worst year last year. My father-in-law passed on Dec. 27th and 6 months later my daughter passed away on Father’s Day, 5 months later we brought my mother-in-law here in final stages of cancer. Last Christmas was terrible. We had purchased a Pandora bracelet for Melissa's last Christmas with us and never got that many charms on it so every holiday we purchase a charm for it. It is kinda like I still get to buy her presents.

A: Joyce, I’m so sorry for all those series of losses. That is so difficult and can complicate the whole process. You have a wonderful way to keep Melissa alive and a part of your life. The bracelet idea is really great. Paying attention to one’s own needs and trying to maintain inner balance is helpful. This kind of self-monitoring can enable some to say, I simply can’t join you this year or I don’t have the energy to send out holiday cards, for example.

Comment: I think that Pandora bracelet thing is great. For me, Christmas has not been all that enjoyable since my daughter was not able to enjoy it, so the holiday itself has not bothered me much yet. I am having trouble getting motivated to decorate or do cards, so I guess in that way, maybe it is bothering me.

A: With the difficulty motivating yourself, can you invite another person to help you? Sometimes sharing those tasks or holiday responsibilities can be a help. Some people simply give themselves permission to take a break…”maybe next year” becomes their new mantra.

Response: I could I guess. I do have a 10 year old who is begging to “go big” with the decorations so I am sure once I get started I will be fine.

Comment: Parents, do you attend any social gatherings at the holidays or is that too painful? Might be worth a try if you feel up to it or on the other hand, like I said earlier, allowing yourself to take a break is sometimes in order. Only you will know.

Comment: We look forward to decorating (name’s) garden and we have been told by neighbors that they look forward to driving by and seeing the lights. At first it felt difficult that he couldn’t be there to enjoy them with us and now we try to outdo ourselves each year thinking “the bigger the better” – that’s how he would have loved it!

A: That is so generous of you and your family. It sounds like this results in a lot of joy for you and your family, and also for the neighbors and community. I can imagine that as you’re hanging the lights, there are both tears and lots of laughter. Following a death, some people have decided to reach out to others who are also having difficulty and sometimes that makes the burden less painful. For example, taking a child’s favorite type of toy to other children who are ill or in the hospital during the holiday season.

Q: My boys have not passed, but every year I can’t help but wonder if this will be their last Christmas with us. This year I bought a Mickey Mouse Christmas train for my son and we will put it around the tree. He loves Mickey and sharing Disney with him has always been a favorite thing. I know he won’t play with it, but I’m hoping it’ll be a happy reminder of him every year we put it up during Christmas.

A: That too is a great example of keeping your loved child alive and a part of your family. Wonderful idea! With the difficulty in this type of progressive chronic illness and not knowing what the next day, month or year holds in store, it’s vital to savor the moment and live in the present. That’s all any of us have, isn’t it?

Trying to stay balanced and intentional about the holidays is a key in coping. I remember one bereaved mom who said, the key for her was to be “open to joy” in the midst of the pain. Often too, bereaved family members will tell me the anticipation of the holidays was actually worse than the actual holidays. My hope for all of you is that you find peace in these days ahead and “surprised” by deep moments of joy. My thoughts are with you. Thanks for this opportunity to be with you this evening.

Comment: Thank you!

Comment: Thank you for this valuable information and support!

Q: I lost my son 6 months ago. I too did not want to put Christmas decorations up but I knew I would do some. When the decorations came down from the attic my 13 year old started decorating and now we have a “Christmas” Christmas house.

A: Thank you for sharing this nice reminder about our resilience and ability to find some happiness even then initially reluctant.

Q: Christmas has become so family-oriented. Hard to celebrate when all 3 of your children have died. Saddens me so many Christmases without them. We put up the “tree of memories”. All the ornaments have meaning. So as we put the ornaments on the Christmas tree. We are remembering our children as we place them.  
Yes it is a roller coaster of emotions. Thus that’s what Christmas is for us now days of up and down for us. We make it the best we can with what's left us...   
This celebration at Christmas just makes missing them extremely harder than a normal day... Miss them terribly always and love them forever. Never forgotten, my three children (names)...may we all find peace in Christmas memories of past or new ones.

Comment: To lose all of your babies is just unimaginable. So sorry, for all of your losses.

A: Beautifully said. I know that will always be precious to you and your family.

Comment: My heart breaks for all of you…sending hugs so tight to all of you!

Comment: Thanks to all of our parents for sharing in this Facebook chat and for Doug Cluxton, for sharing his support and expertise in coping with grief and loss during the holidays. As always, please contact us at BDSRA if you think of ways we can be more supportive in other ways to bereaved families year-round or if you need help in coping with grief and loss individually. Thinking of you this holiday season.