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, medical advice for individual children. Parents and caregivers should consult the patient’s physician prior to changing medication, medical treatment or daily activities.*

**“Supporting Siblings Through the Grieving Process”**

Featured Expert:

**Angela Hamblen Kelly** **L.C.S.W.**

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Welcome to our monthly Ask-an-Expert Facebook Chat! Tonight we are joined by Angela Hamblen Kelly. Angela is the Executive Director of the Kemmons Wilson Family Center for Good Grief with Baptist Memorial Health Care.

1. To start off, Angela could you tell us a little about your background?
   1. Hi. Thanks for having me here with you. I am an LCSW with a specialty in the field of death and dying. My interest developed through working with healthy siblings when I was in college. I have been a grief therapist for over 20 years and we work with children, teens and adults through individual and group counseling.
2. Sometimes grief is a difficult thing to handle as an adult let alone as a child or teenager what can parents or family members be doing to help their children throughout the process?
   1. Grief is very complex and ever changing and family members are rarely in the same place at the same time. And children grieve so differently. First, I think we must remember that children grieve in spurts and then they will naturally turn their grief off and go play. That's confusing for us as adults because we often get stuck in our feelings. so, it's important to keep conversation open. You can do that by being open yourself. You don't have to tell your children everything you are feeling. But do tell them that you are confused, or sad, or just having an angry kind of day. Hep them know that you are feeling things too - model that for them. If you do that, that will more than likely share too. Then, help your child identify other sources of support. Maybe an aunt, a teach, or a therapist. Help them build a support network around them.
3. Is grief exhibited by teens different than younger children?
   1. Yes, teens are stuck between being a child and being an adult. Often times healthy teens become more adult like in some of their behaviors, but then they will regress in others. With teens, I think we must remember to show them respect through communication and expression - but also remember that they need nurturing too. Teens can be hard also, because developmentally they start drifting more towards peers and away from family.
4. What should parents look for as signs a teen (or younger child) is struggling with their grief?
   1. I usually start within anything more or less than their normal. More or less sleeping, eating, exercising, etc. Often people only look at the "bad" ways of coping for signs of trouble - meaning decrease in grades, drinking, etc. But you also need to watch out for those who swing the other direction with over pleasing behaviors. Sometimes we view these as "good", but they are often cries for help that go unnoticed. Also, look for self-destructive forms of coping - cutting, risk taking behaviors, suicide ideation - those need immediate attention. For younger children - they usually show us their grief through their behaviors and play. Children and teens might also regress - baby talk, whining, etc These are normal signs of a need for safety.
5. So what things might we do to provide more safety?
   1. Emotional safety needs are met through open and honest (age appropriate) communication; signs of affection - hugging, sitting in your lap, etc and reassurance that the child is loved and not alone. We run the risk of shaming children when they regress...stop talking like a baby, you are a big boy. We want to avoid shame and hear that as a call for communication, touch and assurance.
6. My twins are fraternal, the unaffected one knows their sibling has batten disease, that they go to the doctor etc, but doesn't know the extent of it all. When is an appropriate time to have that conversation? This disease takes so much from the unaffected, and we want to minimize, as best we can, its effect on her. The day we have that conversation, their life changes.
   1. You are so correct about that conversation. Thank you for asking this tough question. It sounds like your unaffected child is content with the information they have now. Is that correct? If so, I would keep doing what you are doing. Keep being open and honest about their sibling having a disease and treatments - they will probably guide you. Meaning - if they ask a question about prognosis, etc that is the time to softly and age appropriately answer. I wouldn't encourage you to sit them down and have a conversation unless they nudge you that direction with their questions. It would be appropriate to sit them down if their brother's condition made a significant change quickly. Otherwise, let them guide you. They will more than likely ask when they are ready for the information.
7. Sometimes the grief manifests itself in poor behavior, which creates its own challenge, especially around others who don't have the hands-on knowledge of managing the disease. Is this behavioral or grief related or are they connected?
   1. It is! She will often show her protest for this disease through acting out.....at her age, she doesn't have all of the language built to express it yet. So therefore, it comes out through her behavior. So, it's important to understand where it comes from, but that is not an invitation to let healthy sibling just have their way. One of the best ways you can help your child is by maintaining rules and consequences. Obviously, we balance that with grace and love. But sometimes that is hard, and it doesn't always look pretty!
8. Do some kids never want to talk about their grief or what is happening? We have a 9 year old son who never really asks questions about his sister and we don’t push him to talk. He has been around the Batten community since he was 6 and attended funerals of children with Batten. We talk fairly openly in the hopes he will ask questions if he needs to. Do some kids just not want to talk? He obviously knows what happens to a child with Batten disease.
   1. Yes. Just like adult, some children are more open and verbal and some process more internally. It sounds like your family works hard to keep communication open. I would encourage you to keep that up. I would keep an eye on him and maybe reach out to others who make up his support network. He might want to protect you - but maybe would talk to a teacher, etc. I would just encourage his support system to stay involved with him. It is okay at times, to ask him directly how he is coping with his sister's illness. I wouldn't do it every day, but you might want to sit down and just say - I want to check in and just have some time with you. How are things going with soccer (example)....talk about the things...then say, I have been feeling overwhelmed (example) lately, I was wondering how you are doing? But also watch for signs of anxiety, irritability, behavior changes.....those types of things will help you see if he is internalizing too much.
9. Thank you! He has seen a therapist specializing in helping families dealing with cancer and sickness. We started because he was having a lot of anxiety and what I would consider irrational fears. He decided after a few visits that he didn’t want to see him anymore and we were ok with that because his anxiety has lessened greatly. Is he old enough to make a decision to stop seeing a therapist?
   1. I think it's important to listen to kids about their beliefs about therapy - and since you were seeing a decrease in the anxiety, that sounds good. But, keep the door open. Reserve the right to say it might be good for a check in session. Especially with Batten's, I think it's good to maintain a connect with a therapist just to be able to check in as the disease progresses, etc.
10. How do you know if a therapist is a good fit for your child? I’m sure just because I like someone on the phone doesn’t necessarily mean they are the right person for my child.
    1. Great question. Your child will usually tell you. Nobody really looks forward to therapy, but they shouldn't dread it. Ask the therapist about their experience working with children...do they use play therapy, sand trays, etc and not just talk therapy.