

Welcome!

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How Families Can Support Children and Youth in School Settings

Guest Speaker:
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Hosted by:
The ALS Association
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How families can support children and youth in school settings

Melinda S. Kavanaugh, PhD, MSW, LCSW
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"I am so glad that you all think of not only the patient who's affected, but also the children involved. As well know having ALS affects the whole family"

- Children and youth are the hidden population in ALS
- Requests by families for more attention paid to the family experience of ALS
- School is the place all children and youth spend the majority of their time.
- Start of the school year may bring up emotions and support needs for children/youth and their families

Youth and ALS: How many?

- Difficult to track
- Study of 111 people living with ALS
 - 62 had a youth under age 18 in the home
- Issues faced by families with youth
 - Talking about ALS
 - School and ALS
 - Death, dying and grief



CHAPTER 1



TALKING ABOUT ALS WITH CHILDREN AND YOUTHS

"I think just, like, talking to her, I think is probably the best thing. Just kind of like good communication and stuff like that ... so I think having a conversation with her helps a lot."

18-year-old living with a parent who has ALS

Family resource guide

CHAPTER 2



CAREGIVING CHILDREN AND YOUTHS

"It's challenging. It's just kind of ... it's always there reminding you, kind of just sort of that sort of thing. You kind of have to put your own care aside because you really have to be there to help out."

14-year-old living with a parent who has ALS



Families and ALS:

A Guide for Talking with and Supporting Children and Youths

ALS.org

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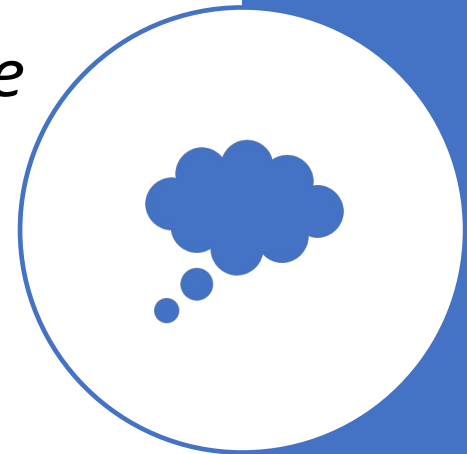
Children, youth , ALS and School

Transition back to school after summer is tough for all youth, but might be more difficult for youth in families with ALS

- **Is ALS a new diagnosis?**
- **Has ALS Progressed?**
- **Is your child moving to a new school?**
- **Change in friends?**

Before any of these changes take place, make sure you have talked about ALS – but many families struggle with the conversation

“I think just like talking to her I think is probably the best thing. Just kind of like good communication and stuff like that. . . so I think having a conversation with her helps a lot.”



18-year-old living with a parent who has ALS

Why some parents struggle to talk about ALS

“I don’t want them to think about it”

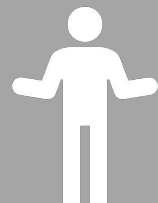
“They are too young”

“I don’t know what to say”

Question:
*What if my
child does
not want to
talk about
ALS?*



Tell them they can come to you at any time – when they are ready.



Make the conversation normal with no pressure.



Something to consider – they may not want to talk about it because you don't talk about it. It is very important to know where you stand before you talk to your child, so that you are modeling open and honest discussion.

Question: *What if they ask a question I am not prepared to answer?*



How would you like to talk about it? What would make you comfortable?



Show your willingness to discuss difficult issues, and they may as well.

Start with saying something about ALS that makes you uncomfortable – perhaps how something has changed



Answer honestly, and don't be afraid to say you don't have answers – or that *“we will find out as we go along.”*

Question:
***Aren't I
protecting
them by not
telling them
about ALS?***

Not necessarily. Think
about why you want to
protect them:

You don't know what to say

- talk to someone at the ALS Association or a counselor/therapist for guidance.

You know your child and they will not handle it well.

- engage with a trusted family member, friend, or therapist to help guide your conversation.

You don't want them to know

- This can foster resentment and isolation in the child for many years to come.

The key is to talk – keep communication open

Important takeaways



**YOUTH WANT TO TALK ABOUT ALS,
BUT PARENTS ARE OFTEN CONCERNED
ABOUT WHAT TO SAY AND HOW MUCH**



**YOUTH KNOW SOME OF ALS, BUT OFTEN NOT
ENOUGH TO ALLAY FEARS OR CONCERNS –
PARTICULARLY ABOUT HOW ALS MAY IMPACT THE
PARENT**

Talking to the school

- Before you talk with the school – talk with your child. Ask them what they think, and if they want to be a part of the conversation
- **This helps your child knows what will be said and to allow them the opportunity to help craft the conversation.**
 - Engaging children in talking to the school helps him or her feel a sense of control at a time when he or she has very little control.



Suggested questions to ask your child/youth

- Who would be best to bring into conversation – school personnel they like and trust?
- Would they prefer a group meeting, or would he or she like to talk to the teacher/counselor alone?
- Have they talked to teachers, social workers, coaches, or any personnel in the past?
- **Why bring in the child/youth?** it is important to let them know what is happening so he or she can be prepared and not caught off guard if asked a question or engaged by school personnel.



Helping your child talk about ALS to peers

Children often say they worry about how to talk to their peers – or IF they should talk to their peers.

Talking about ALS may be very natural for some youth. But for others, it is scary and they are not sure how.

Class presentations about ALS

- By telling their story first, it can break down barriers and misconceptions about the parent with ALS and lessen the possibility of bullying.
- Allows the child/youth to tell his or her side of the story and put the information out there before someone can use it against the child.
- The ALS Association can be a valuable tool in providing information, details, and charts about ALS for the youth to use.
- IDEA: Have your child/youth interview your neurologist

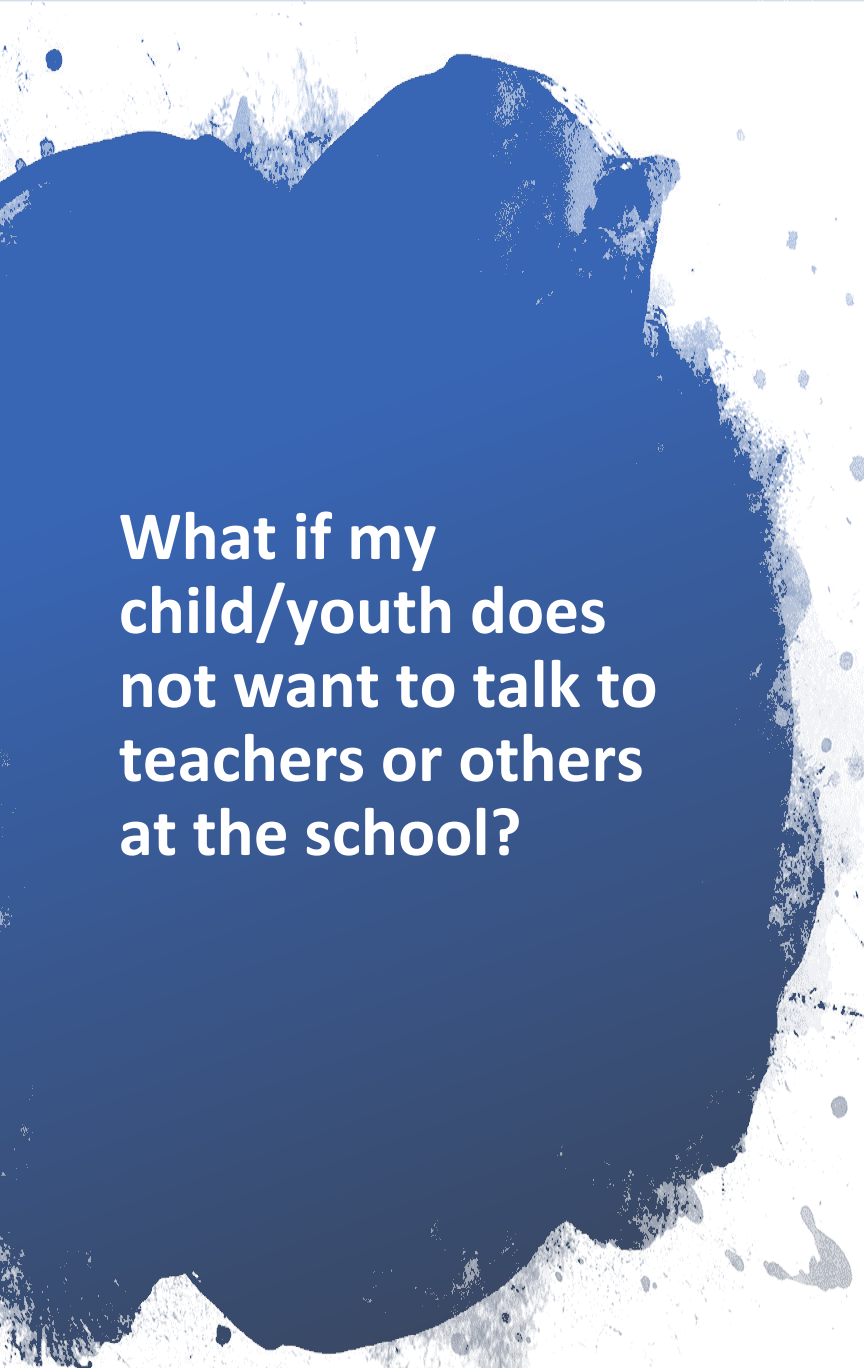


School-engaged advocacy

Children and youth want to be involved!!



- Does your chapter host a walk? Will the school post information?
- Getting involved by promoting the walk, while raising awareness about ALS.
- Encouraging youths to share their Chapter's Walk or other advocacy activity with their class. This provides an opportunity to encourage classmates to attend a family-fun activity and to volunteer.
- Peers can help with a kids games table, at the registration table, or some other volunteer opportunity. This may help your child living in an ALS family to feel more connected to peers and provide the peers with a means to connect personally with their peer's family member with ALS.



**What if my
child/youth does
not want to talk to
teachers or others
at the school?**

- **Worry it will make him or her more separate from peers.**
- **School may be the only place they feel like himself, or “normal”—where the child doesn’t have to think about ALS.**
- **Let them know they can reach out to the social worker or talk to the teacher in their own time.**
- **Talk about confidentiality of the adults in the school, which may help to alleviate fears.**



Death, dying, grief and school

Talking about death, dying, loss and grief

“I don’t know how to describe it. Kinda made me really upset because, yeah everybody’s gonna die, but like my mom is gonna die, like, more than likely way before the average person. And, like, I don’t know. Like, dealing every day, like, knowing that each day she’s, like, getting worse and worse . . . it just . . . I don’t know. It makes me . . . upset.”

17-year-old living with a parent who has ALS

Should you talk about death and dying?

Talking with your children and letting them express their feelings and grief helps them feel less anxious about death ^{1, 2}.

Helps them process the loss of their parent ³.

Children benefit from clear information in order to feel comfortable in expressing their feelings ^{4,5,6} and parents are the ideal ones to start and have the conversation.



Death and loss and schools

- Make sure school knows of the loss of a loved one
- Ask about grief groups in school
 - Many schools sponsor these, or have connections to organizations who can help
- Personnel trained in dealing with death and loss?
- Consider making an appointment

Complicated grief in school

- Loss of interest in daily activities and events
- Inability to sleep, loss of appetite, fear of being alone
- Regression – or acting younger than they are
- Excessively imitating the person who has died
- Repeated statements of wanting to die to be with the person who has passed away
- Avoiding peers and friends
- Extreme change in school performance, or avoiding school



Important to work with the school to recognize and get help for you and your child



School Social Work
Association of America

- Works directly with youth in schools to support youth and families in need

Organizations to support children/youth in schools

National Alliance for Grieving Children

- programs for grief and complicated grief
- school based education
- Family support
- “When someone dies” handbook



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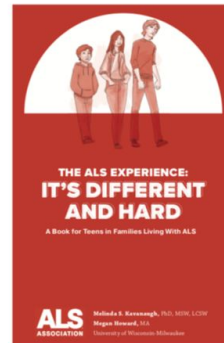
National Alliance for
Grieving Children

**School, Friends,
Work, and ALS:**

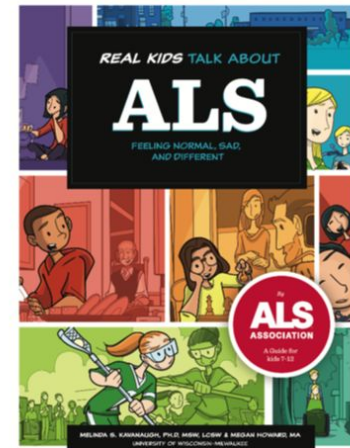
A Young Adult Guide to Balancing Life With ALS



ALS
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**ALS Specific Materials
to support
Children/youth**

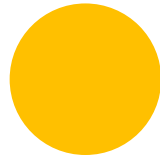
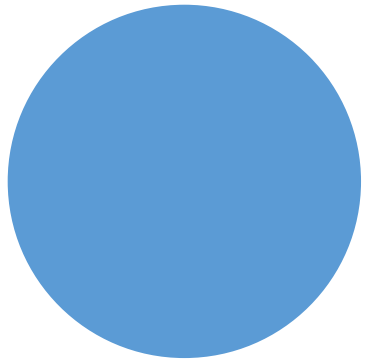


In closing, in their own words...

“If I had to tell somebody that was my age if they had a family member with ALS, I would tell them that you just have to be patient . You have to get used to the new things. And you kind of just got to accept that that happened. And there's nothing you can do about it but be there for them and for you “

The End.





Questions?

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