I have ALS and a child or youth: Now what? Bringing children and youth into the conversation

Melinda S. Kavanaugh, PhD, MSW, LCSW
Assistant professor, social work
August 21, 2017
Notes about the webinar

• More attention paid to the family experience of ALS

• Data drawn from two studies of youth in families with ALS

• Quotes directly from youth who live in families with ALS, detailing their experiences and needs
“...sometimes I just feel kind of like always helping other people, and no one's there to help me, I guess. That would be the best thing is just kind of have someone go, hey, good job, whatever. You know, sometimes”
Youth and ALS: How many?

How many families have children and youth in the home?

- Difficult to track

- Study of 111 people living with ALS
  - 62 had a youth in the home

- Issues faced by families with youth
  - Talking about ALS
  - Caregiving by children and youth
  - Death, dying and grief

- Starting the discussion with the webinar
TALKING ABOUT ALS WITH YOUR CHILD AND YOUTH
“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”
What do children and youth know about ALS?

**Minimal knowledge**

- “Affects how the body works – pretty much all I know”
- “I know it stops the body from moving”
- “He can’t move”
- “Starts in the legs and moves up”
- “Rare for a girl to get it”

**More thorough**

- “I know that ALS is a disease that makes the nerves in his body not work as well and that it's going to slowly paralyze him I believe.”
- “It's a muscle disease that affects the way nerves travel throughout the body and it can cause paralysis in certain areas.”
- “It's a disease of the brain which shuts down the neurons that transmit neurons that cannot move”
• 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

• Next section provides suggestions and frequently asked questions about talking to your child about ALS
Talking with children and youth

Start the conversation - Find a time when you are doing something “normal” and not stressful, like watching TV or relaxing at home. This models the normalcy of the conversation and puts less pressure on it being a “big talk.”

- Be honest
- Begin with basic information
- Seek out experts – ALS Association, clinic, family therapist
- You know your child best
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.**
  - Find a tie when you are doing ”normal” activities.
  - Start open and broad – let them drive it

- **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
Neurologist view

“For our patients, I talk about these issues. And I do explain the disease to the children when they come to clinic. I know that most (parents and providers) ignore it because it is difficult.” (ALS Neurologist)
Implications for chapters and health professionals

- Engage whole families around how to talk about ALS
  - Kids want to know more
  - Want to feel involved

- Build trust and community with the family
  - Sessions for parents “how to talk to kids”
  - Make it ok to talk to kids
  - Youth programming
CHILDREN AND YOUTH AS CAREGIVERS
Caregiving by youth

“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
Caregiving by youth

Over the years, this is one of the most difficult aspects to discuss with families

• Questions about abuse and neglect

• Parents feel “bad” about youth providing care
  – “Sad that they have to do all the things they do, but they are caring boys”
  – “I wish they didn’t have to, but I need it”

caregiving by youth is not inherently bad. But, when there is no communication, support, or guidance around caregiving and the needs of the caregiver, it can result in negative outcomes for all involved.
Caregiving by children and youth

• Studies of youth and ALS, included interviews with 57 youth who provide care to a family member with ALS

• Tasks identified by the parent:
  – Feeding, bathing, transferring, dressing

• Youth provide care for:
  – Parent: 40
  – Grandparent: 11
  – Other relative: 6
Caregiving tasks by age (Kavanaugh, Cho and Howard, 2017)

- **Medication**
  - 8-12 year: 4
  - 13-15: 9
  - 16-18: 4

- **Food/eating**
  - 8-12 year: 7
  - 13-15: 11
  - 16-18: 8

- **Toileting**
  - 8-12 year: 5
  - 13-15: 5
  - 16-18: 4

- **Transferring**
  - 8-12 year: 7
  - 13-15: 11
  - 16-18: 6
Talking about caregiving by youth

- Let them know you are appreciative of the care they provide and that you love them regardless of the care they do or do not provide.

- Let your youth know they can talk about feelings and experiences of caregiving at any time with you – without hurting your feelings.

- Model the conversation by telling them how you feel
  - maybe it is hard at times to have your child help you, but sometimes you need it.
  - That way they may feel comfortable also saying that sometimes it is difficult
What is it like being a caregiver?

Positive

• It makes me feel better about myself and stuff
• It's like you're doing a good deed for someone
• It does feel good inside
• It makes him feel happy and it makes me feel happy

Negative

• Hard
• Stressful
• I think it's kind of sad and a little stressful
• Sometimes it's really hard depending on the task
• It made it hard to do other things because she needed help a lot
Caregiver training and guidance

Have children and youth received caregiver training?
- only 30% have received any training

How do they know what to do?

• “Wing it”

• “Use common sense”

• “Rely on the person living with ALS to tell them what to do”

(Kavanaugh, Cho and Howard, 2017)
Youth caregiver support needs
(Kavanaugh, Noh and Studer, 2015)

**Instrumental support**
- Give information and advice
- Help with actual caregiving
- Others spend time with parent

**Emotional support**
- Understanding attitude
- Friends who get it
- Treat family normal
- Support groups
- Care about caregiver

Youth caregiver support needs (Kavanaugh, Noh and Studer, 2015)
TALKING ABOUT DEATH
DYING GRIEF AND LOSS
“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.
What children and youth say about death and dying (Kavanaugh, Noh and Studer, 2016)

“I think it makes [the parent] uncomfortable, which makes me uncomfortable.”

“Unless she brings it [discussion of death] up, like, I’m not ‘gonna’ bring it up....‘Cause I don’t wanna make her any sadder than she already is”

• They often take the lead from the parent
• Take the time to know how you feel
• Conversations vary by age of the child
Children, youth and grief

• Check in with your child:
  – how they feel about the changes and/or progressions?
  – What might they be grieving the loss of?

• Let them know you are also sad and grieving as well.

• Consider engaging with a priest, clergy or mental health therapist to help guide the process and provide support.

*It is important to acknowledge that your child will grieve in their own way. What they need most is support, the space to grieve, and an open door to talk about it.*
What to know about grief and children/youth

- Grief is normal
- Children need to know the truth
- Grief is unique to a person
- Grieving children can feel alone
- Grief comes and goes
- Children can grow from grief
- Grieving children respond to being with other grieving children
Complicated grief

• Grief is normal and can last for some time. It comes and goes, but diminishes over time. When it doesn’t:

Complicated grief

• 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 recognize and get help for you and your child
Youth programming and supports

- Respite programs
- Camps
- Support groups
- Youth activities
- Educational materials
- Website

If your chapter does not have youth programming, just ask!
Family resource guide

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 she needs communication and stuff like that... so I think having a conversation with her helps a lot.”

A 15-year-old living with a parent who has ALS

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 think of how to put your own care aside because you really have to be there to help her.”

A 15-year-old living with a parent who has ALS

Families and ALS:
A Guide for Talking with and Supporting Children and Youths

ALSA.org
Coming soon - Youth guides and web based programming

- Positive feedback from family resource guide
- Request for materials for youth
- Targeting children and youth across ages and developmental stages
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 because sometimes their speech isn't that good. And you kind of got to wait for them to get the whole point across. And if they got it, and you were used to having a parent who could do regular stuff, it's just going to be a time of adapting.

And that you can't just, it won't just be like overnight. 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.”
Thank you for being a part of this webinar

Questions?