Resources for Helping Youth Cope with Dementia in the Family

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Outline

1. Introduction  
2. Personal Experience  
3. The Youth Experience  
4. Overview of Online Resources  
5. Conclusions and Questions
Introduction

- Having a family member with dementia can introduce many changes for the family as a whole
- How children and teenagers cope with this is especially unique as they go through important phases in development
- The Covid-19 pandemic has introduced new challenges
  - Those living at home interacting with family more often
  - Those in long-term care struggling to stay connected with their families
Personal experience

- Grandmother started experiencing symptoms in her late 60s
- My interaction with her was intermittent, though in depth for extended periods of time in the same home
- Early symptoms: difficulties with language, short-term memory loss, completing tasks at a slower pace
- Later symptoms: recognition of faces, loss of language, increased need for help, getting lost and difficulty getting around
Personal Experience

1. Confusion
2. Fear
3. Coping
4. Acceptance and Commitment
Personal Experience

What was done right:
- Emphasis on time together
- Doing activities we both love
- Encouraging patience

What could have been done better:
- Didn’t explain dementia
- Didn’t “sit down” to explain or process
- Not recognizing my emotions and reactions
The Youth Experience: Stages of Development

- **Infancy**: Trust vs. mistrust
- **Early Childhood**: Autonomy vs. shame and doubt
- **Preschool**: Initiative vs. guilt
- **School Age**: Industry vs. inferiority
- **Adolescence**: Identity vs. role confusion
- **Middle Adulthood**: Generativity vs. stagnation
- **Young Adulthood**: Intimacy vs. isolation

The Youth Experience:

- Confusion
- Grief and sadness
- Anxiety and irritation
- Embarrassment
- Fear
- Rejection
- Sense of connectedness
- Increased maturity
- Greater assertiveness
- Sense of pride and identity
- Increased coping skills
- Greater empathy
Online Resources
Do You Know Someone with Alzheimer’s?

Alzheimer’s affects every member of the family, including children and grandchildren. Our resources help you connect with the person living with Alzheimer’s and adjust to your “new normal” in ways that are beneficial to everyone involved.

For Kids
When you find out that someone has Alzheimer’s disease, you may feel confused or scared. That is normal. Learn about Alzheimer’s by checking out our books, links and videos and hear from others like you.

For Teens
Finding out that someone you love has Alzheimer’s can be difficult, but we have information that can help you cope. Use our resources to educate yourself and help support the person with the disease.

For Parents & Teachers

Videos
3. COMMON QUESTIONS

Encourage your child to ask questions. Answer honestly and using age-appropriate explanations. The Alzheimer’s Association® can provide you with information to help answer these questions and suggestions for coping with changes that accompany the disease.

Possible answers to questions your child may ask:

Q: What is Alzheimer’s disease?
A: Alzheimer’s is not just memory loss; it’s a disease that affects how the brain works and how a person thinks. Over time, it also changes the way a person’s body functions.

Q: Will my mom get Alzheimer’s, too? Will I?
A: Many scientists believe that there’s a greater chance of getting the disease if someone in your family has it, but not everyone who’s related will get it. Most people who develop Alzheimer’s are older.

Q: Why does my grandpa call me by my dad’s name?
A: Changes inside your grandfather’s brain may make it difficult for him to remember things like your name. This is not your fault or his. You may remind him of your dad at your age. It’s best not to correct him, as that could upset or frustrate him.

Q: Will my grandma die from Alzheimer’s?
A: We don’t know for sure. Some people with Alzheimer’s do die from the disease, while others may pass because of another serious health condition.
My Name is Lisa
This powerful fictional film depicts a 13-year-old girl coping with her mother's Alzheimer's. This video won best short film on YouTube in 2007, drawing the attention of millions.

My Name is Brittany
Brittany's mom has younger-onset Alzheimer's disease. She tells her story of how Alzheimer's affects her mom and her in this video.
AFA Teens for Alzheimer’s Awareness College Scholarship Essay Contest

AFA’s Teens for Alzheimer’s Awareness College Scholarship Essay Contest is an annual competition for college-bound high school seniors. Applicants are asked to write a 1,200 to 1,500-word essay that describes the impact of Alzheimer’s disease on themselves, their families or their communities, and what they have learned in light of coping with the brain disorder. The grand prize winner receives $5,000, with additional prizes awarded for runners up.

AFA On Campus

AFA on Campus is a division of the Alzheimer’s Foundation of America (AFA) that caters exclusively to students at colleges and universities across the country in an effort to engage them in awareness-raising activities and to groom tomorrow’s leaders in the Alzheimer’s community. Initially founded as an offshoot of our AFA Teens division, AFA On Campus provides an opportunity for individuals who have been involved in the cause during high school to continue their efforts.

In 2014, AFA kicked off its Raise Your Voice for Care college tour at Frostburg State University, bringing a full day of educational programs and workshops, displays of the AFA Quilt to Remember and live music to campus communities across the country.
Looking to learn more about dementia? Dementia Explained has been developed by Alzheimer’s Research UK to help children and teenagers understand dementia, how it affects someone and how this could impact their lives.
Young kids (up to around age 6)

Discover your amazing brain
Find out about your brain with our fun activities
Learn more

Beautiful brain cells
Craft activities introducing brain cells.
Learn more

Grandad’s Hat colouring page
Have a go at colouring in Grandad’s Hat.
Download
Understanding dementia
Learn about dementia and show what you know with this worksheet and crossword.

Download

How does dementia affect people?
Grow your understanding of how dementia affects people with our videos and worksheet.

Download

Make your own awareness campaign
Help separate fact from fiction and make a campaign about brain health.

Download
Common Themes

- Recognizing, acknowledging and reassuring emotions
- Communication
- Education
- Activities to do together
ASK ABOUT ALZHEIMER'S

A group for students in grades 6 - 8 who are coping with a loved one with memory loss or dementia

4 - 4:45 P.M. EVERY OTHER WEDNESDAY:
1/6, 1/20, 2/3, 2/17, 3/3, 3/17, 3/31, 4/14, 4/28, 5/12, 5/26, 6/9

ONLINE USING ZOOM

Connect with others who understand what it's like to have a family member with memory loss. Come together to connect, share and learn from each other. Join as often as you like.

Register here: https://tinyurl.com/AskAboutAlz
Conclusions

● Important to recognize how youth adjust to having a family member with dementia
● How youth adjust to these changes is unique for a variety of reasons
● Among youth, there are many different ways a child or teenager may react to these changes
● Thankfully, there are wonderful resources out there that are created and targeted for youth
Questions


