

What Comes Next: Supporting Kids, Teens, & Young Adults after an FTD Diagnosis



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**THE UNIVERSITY OF
CHICAGO MEDICINE**

Center for Comprehensive Care
and Research on Memory Disorders

About Lorenzo's House

*Lorenzo's House, is a nonprofit designed to **empower families everywhere who is living with or has lived with younger-onset dementia** through our holistic model, ensuring we walk this journey united – never alone.*



What is Light Club?

*A **safe, brave** virtual hangout for **tweens, teens and young adults who have a parent who is living or has lived with younger-onset dementia.***

*The Light Club brings together youth from all across the globe - providing a space to **connect with others who understand, have fun, share common stories and build an alliance.***

Meets on the 2nd Wednesday of each month for age specific session & the 4th Wednesday of each month for all ages of youth sessions.

What is Youth Summit?

A single day virtual experience that unites tween, teens & young adults from all across the globe who have a parent living with or has lived with younger-onset dementia.

Together we will:

- ***Exchange caregiver strategies***
- ***Share pieces of our common stories***
- ***Expand our brain health knowledge***
- ***Build our growing youth alliance***

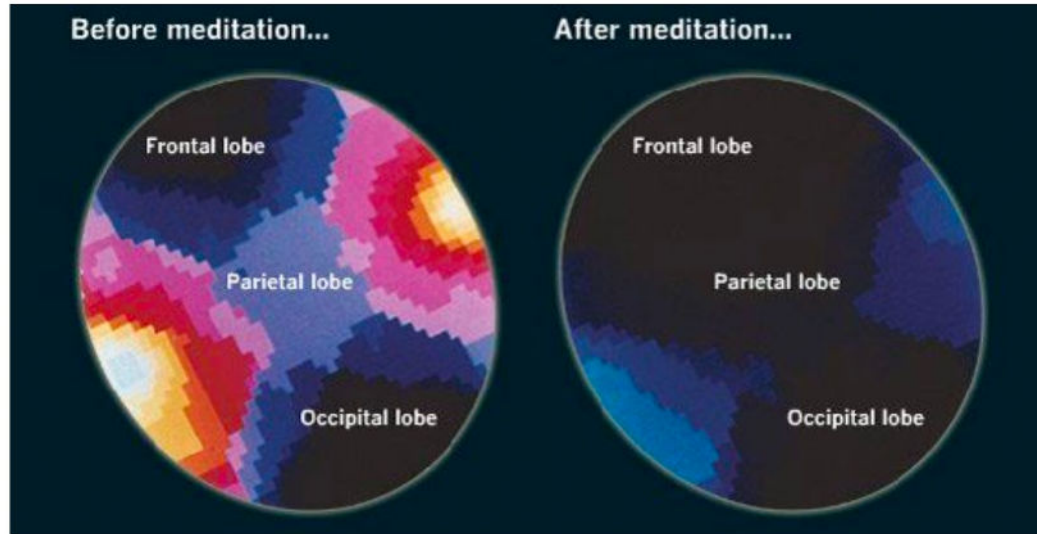
***Join us on Saturday, June 17th
Reserve your spot at www.lorenzoshouse.org***

Before we begin . . .

A moment to pause

How did that feel?

taking time out to slow down, pause, and breathe
literally creates room in your brain to think more clearly

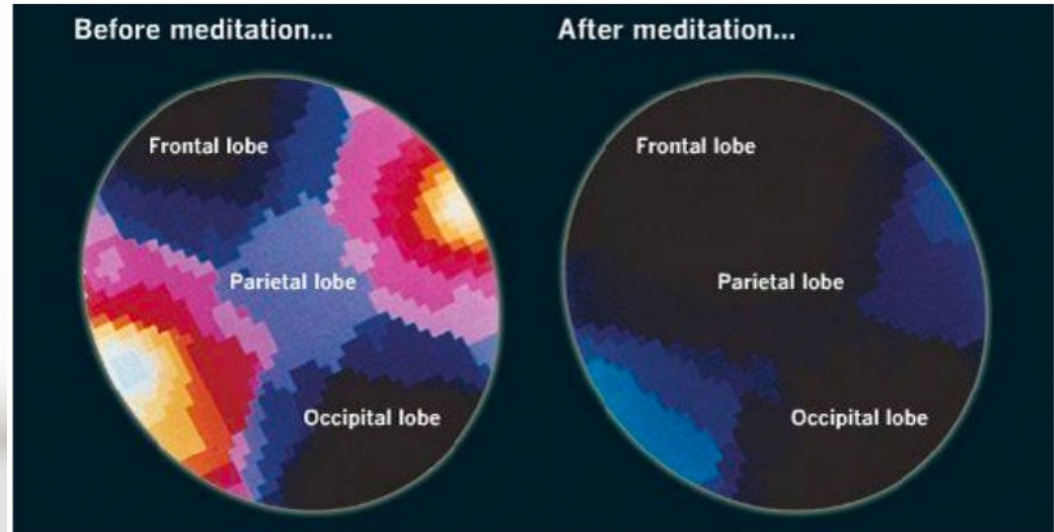


Why does it matter?

OXYGEN!



taking time out to slow down, pause, and breathe literally creates room in your brain to think more clearly



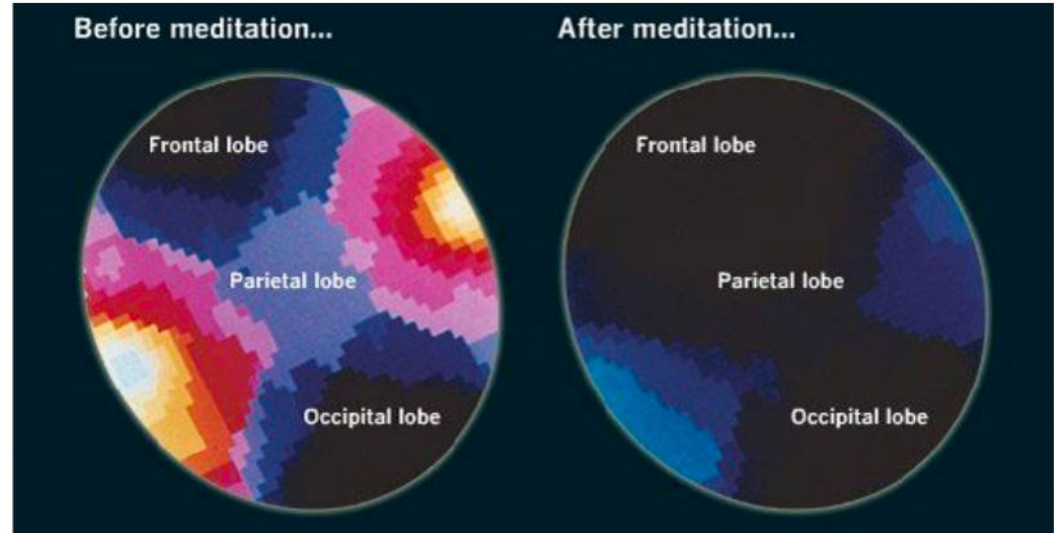
Sources: National Institute of Health, *Frontiers in Psychology Journal* and Dr. Gregg Jacobs, Harvard Medical School, *The Ancestral Mind*;
<https://www.nytimes.com/2019/02/12/well/family/how-to-help-teens-weather-their-emotional-storms.html>

Why does it matter for our youth?

Our youth carry so much day-to-day:

- Long days & short fuses
- Balancing school & caregiving & personal life
- Craving connection with peers who 'get it'
- Not wanting to disappoint the other parent
- Not knowing how to curate meaningful moments or communicate through tough interactions with the parent diagnosed
- Can benefit from self-regulation/coping skills
- Curiosity to understand what's going on

taking time out to slow down, pause, and breathe literally creates room in your brain to think more clearly



AGENDA: Key Questions

- **What should we be looking out for in our youth?**
- **What do the youth have to say about their journey?**
- **What types of resources can help us help our youth?**

Youth and the FTD Journey

- 5.4 million caregivers under the age of 18 in the U. S.
- Young-onset nature of FTD means more youth needing to take on caregiving, and/or other household roles
- Misunderstood and stigmatized symptoms of the person diagnosed means youth have difficulty connecting with peers

Anxiety and Depression Rates Tend to Be Higher with Youth Caregivers

- Many youth caregivers report feeling stressed and overwhelmed by their caregiving responsibility
- 25% of youth caregivers report symptoms of depression
- Youth caregivers who lack social support are more likely to experience symptom of depression
- Youth caregivers experience high levels of stress, anxiety, and depression, with 42.5% reporting clinically significant depressive symptoms.

The Big Idea: What we are learning in Light Club

When Youth with a parent diagnosed **feel a sense of community** with others, **share a common experience**, **learn healthy coping strategies** through various modes of creative arts and movement expression, **and gain knowledge plus resources** in dementia care. . .

. . . not only do they emerge with practical tools, **their very beings change, physically and emotionally.** They discover a newfound sense of calm, wellness, of belonging, and a deeper connection with the one diagnosed & themselves.

Youth Impact: Their Own Words

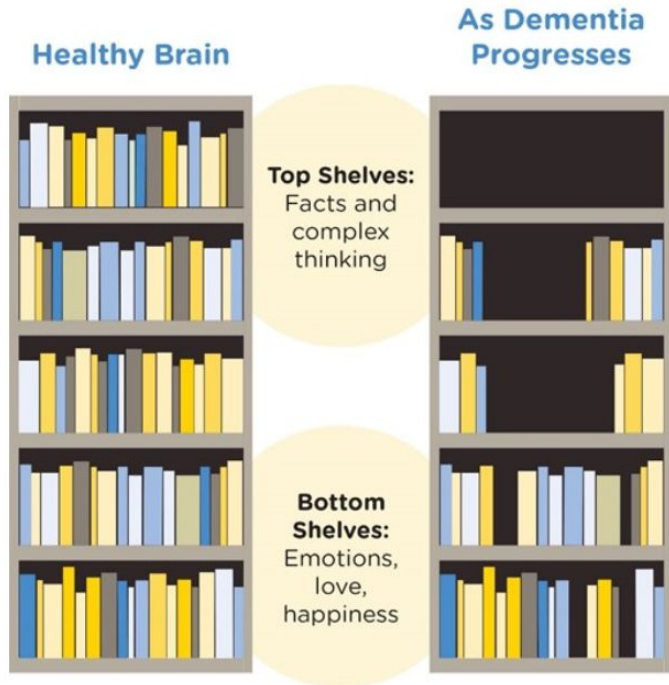
“Being here helps to me helpful when around family and this place is helpful for me to be around others. It is a place to talk about it where people understand.”

“I feel calm and excited to meet others sharing a similar pain.”

“I want to learn healthy habits to process the disease in this environment.”



Helping them understand how FTD feels



"We may have forgotten your name...
But we remember love."
Tim Brennan, living with dementia

"I'm still myself."
B. Smith, living with dementia

Teaching communication strategies

Ask yourself. . .

For every interaction

For every encounter

Will this comment, gesture, or facial expression
make this person want to **avoid** or **approach** me?

Think: *They just want to connect.*

Everything is interpreted by how it comes off & how it makes them feel.

Teaching communication strategies

De-escalating the tough moments

How does the word 'No!' feel to you? Those with memory loss are hyperfluent in body language, & can sense frustration & impatience...

correction

quizzing

increased connection

"No, but..."

vs.

"Yes, and..."

trigger stress response

(fight, flight, freeze)

anger, tearfulness, withdrawal

reduced

conflict

5-min timer in

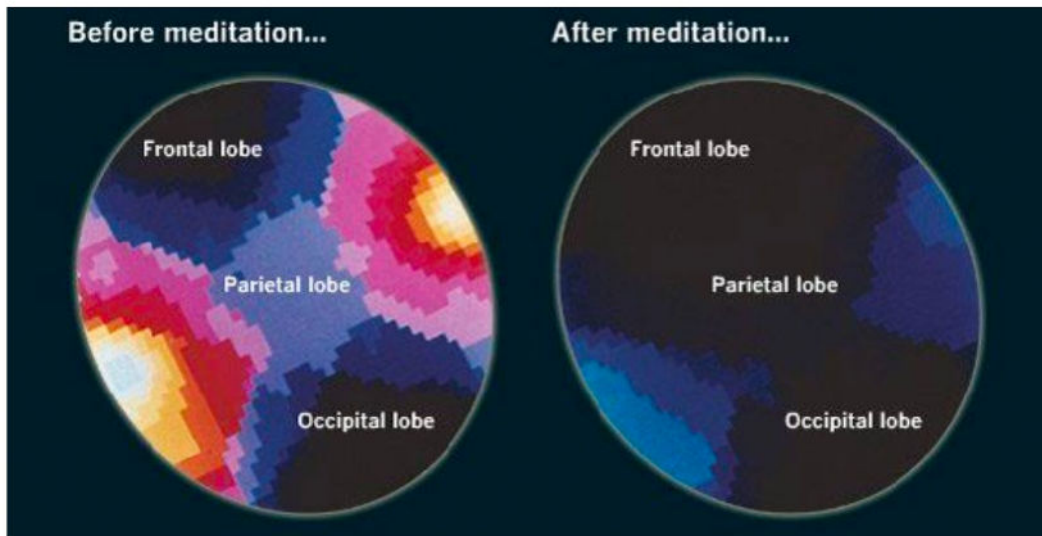
back pocket

...just as one can sense warmth, joy, connectedness

Teaching healthy habits & coping skills

through various modes of creative expression: mindfulness, journaling, and the arts

taking time out to slow down, pause, and breathe
literally creates room in your brain to think more clearly



“I will deep breathe when I
have anxiety.”

refreshed
happy relief peaceful
calm relaxed

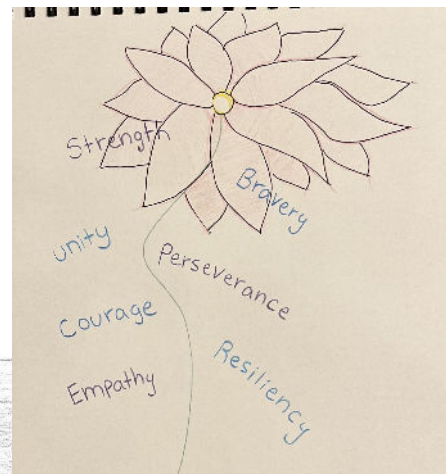
“I am calmer than I was before.”

Mindfulness based interventions on caregivers for dementia “showed greater improvement in overall mental health, stress, and depression” and they “improved anxiety, social support, and burden.”

Teaching healthy habits & coping skills

through various modes of creative expression: mindfulness, journaling, and the arts

This is hard to handle and manage. Living without a family member is hard, especially if it's your mother or father. This disease ravages their mind and causes rough times for the caregiver and the children of the family. But the one piece of support I have for you today is: Don't dwell on your troubles and cry about them at night; focus on the good things you can find in your life, big or small. That will help you get through this much easier than sadness and frustration.



VOICES FROM THE YOUTH:

“Mom went on a much needed vacation. So we were home with dad. At first we were nervous, but then **we gave him lots of 1:1 time and hugs and kisses, and he was so happy.** He was in such a good place!”

“**I feel like I have concrete things to connect with Dad when I visit him** at the memory care center, using our 5 senses and the Last Word technique!”

“I didn’t feel like I had much to say today, but **I liked the writing we did because I wrote a whole page!**”

“Sometimes I have a hard time. It is easy to get mad at Dad. So **I take my anger out by drawing a picture** of what I think [his disease looks like], hung it on the wall, and **I choose to get mad at that instead.**”

“**I used the breathing technique at school!!**”

“The **art we made today felt so good** as a form of expression!”

“I learned **I will breathe when I’m overwhelmed.**”

Social Impact on Youth

- Often hidden within schools (thus not supported)
- Conflicting responsibilities
- Counters developmental progress
- Time restraints for school and activities
- Financial responsibilities with one-parent income
- Loneliness and isolation

What YOU can do to support our youth

“Most people avoid us. **Stopping by to say hi means the world.**”

“Often **we don’t have the room to reach out on our own. Just show up. With your time.** With a bag of groceries. Every little bit helps.”

“Sometimes it’s hard to tell people because they don’t understand without going through it. **Be compassionate. Check in. Research.** Open up to help with your own feelings.”

“**Be patient to make everybody feel better,** because it’s worth it.”

ACTIVITY:

Reducing isolation | Enhancing meaningful connections

Make a list of your favorite people:

Reach out! By text, video, email, phone, letter, meet

Send invites on your calendar for recurring encounters

(nurturing meaningful connections w/mentors, teachers, friends, family)

Use all 5 Senses to engage with your person diagnosed:

TOUCH | TASTE | SMELL | HEAR | SEE

(as verbal capacity is diminished, we can still enjoy how things FEEL)

“You can’t find a community where so many other young people actually get what you are going through. I now know it’s important to find that place where you can express yourself.”

“I feel more equipped now.”

“I have practical tips for connecting with my dad.”



“As a daughter who suffers from younger-onset dementia, it can be really hard. Telling others about this piece of myself is difficult because they won’t fully understand. **Opening up and letting my feelings out at the Light Club has been really helpful for me.** And meeting more people and friends who understand at Lorenzo’s House has been really helpful.”
- Light Club, youth



“I feel understood.”

3 KEY TAKEAWAYS FOR HEALTHY COPING & WELLNESS

1. SOCIALIZE!

Make a list of your favorite people: (text, video, email, phone, letter, meet)
(nurturing meaningful connections w/mentors, teachers, friends, family)

Use all 5 Senses to engage with your person diagnosed:
(as verbal capacity is diminished, we can still enjoy how things FEEL)

2. LEARN & GROW!

Knowledge is power: Learn the diagnosis (AFTD) | Teepa Snow | DementiaFriends

Build healthy habits: *Nutrition, Exercise, Sleep, Hydration, Stress Management*

3. BE WELL!

Use a meditation app daily: Insight Timer | Calm | Headspace
(stress management, in-the-moment self regulation, brain training)

Get it out of your body: journal | movement | art | music | breathwork

Remember: The Big Idea

When Youth with a parent diagnosed **feel a sense of community** with others, **share a common experience**, learn **healthy coping strategies** through various modes of creative arts and movement expression, **and gain knowledge plus resources** in dementia care. . .

. . . not only do they emerge with practical tools, **their very beings change, physically and emotionally**. They discover a newfound sense of calm, wellness, of belonging, and a deeper connection with the one diagnosed & themselves.

Additional Sources

[Armstrong-Carter, E, Johnson, C, Belkowitz, J, Siskowski, C, Olson, E. From the Editor Intro for SPR 34.2 “The United States should recognize and support caregiving youth”. Soc Policy Rep. 2021; 34: 1– 24. https://doi.org/10.1002/sop2.14](https://doi.org/10.1002/sop2.14)

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<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6008507/>

<https://www.freemeditation.com/articles/2009/09/10/calming-the-mind/> | <https://buffer.com/resources/how-meditation-affects-your-brain/>

"Mindfulness-Based Interventions for Youth: A Review of the Evidence" by Felicia A. Huppert and Catherine A. Johnson. This article, published in the journal Mindfulness in 2010, provides an overview of the research on mindfulness-based interventions for youth, including their effectiveness in improving psychological well-being and reducing symptoms of anxiety and depression.

"Mindfulness-Based Interventions for Children and Youth" by Kimberly A. Schonert-Reichl and Eva Oberle. This article, published in the journal Handbook of Mindfulness in Education in 2016, provides a comprehensive review of the literature on mindfulness-based interventions for children and youth, including their impact on social-emotional development, academic performance, and mental health.

"The Effects of Mindfulness-Based Interventions on Cognitive Functioning in Healthy Children and Adolescents: A Systematic Review" by Lianne van der Velden, Esther I. de Bruin, and Susan M. Bögels. This article, published in the journal Mindfulness in 2015, reviews the research on the impact of mindfulness-based interventions on cognitive functioning in healthy children and adolescents, including attention, working memory, and cognitive flexibility.

"Mindfulness-Based Interventions for Youth with Anxiety Disorders" by Randye J. Semple and Jennifer Lee. This article, published in the journal Clinical Child and Family Psychology Review in 2010, reviews the research on the effectiveness of mindfulness-based interventions for youth with anxiety disorders, including their impact on anxiety symptoms, quality of life, and coping skills.

"Mindfulness-Based Interventions in Schools—A Systematic Review and Meta-Analysis" by Kaisa K. Pohjola, Nina R. Kotovirta, and Niklas Ravaja. This article, published in the journal Frontiers in Psychology in 2020, reviews the research on the effectiveness of mindfulness-based interventions in schools, including their impact on stress, emotional regulation, and academic performance.

Resources

- Links:** - www.lorenzohouse.org (Light Club & Youth Summit)
- <https://www.theaftd.org/living-with-ftd/kids-and-teens/>
- Caregiver Support Group for parents with kids and teens in the home:
(866) 507-7222 | info@theaftd.org
- The Memory Center at UChicago Medicine | www.thememorycenter.uchicago.edu

Mindfulness Models, Research Hubs, and Field Experts:

<https://mindup.org/>

<https://pureedgeinc.org/>

<https://moodmeterapp.com/> - Marc Brackett, RULER model, 'Permission to Feel'

<https://pg.casel.org/> - Kitty Rothschild

www.rand.org - arm of CASEL

https://www.rand.org/pubs/research_reports/RRA1822-1.html

<https://www.linkedin.com/in/novabiro/> - Nova Biro

<https://mcveaghlally.com/> - Pam McVeagh Lally

www.edutopia.org - George Lucas

<https://sel.lab.uic.edu/about/> - Dr. Kim Schonert-Riechl

Explore free programs at Lorenzo's House

www.lorenzoshouse.org

LIGHT CLUB

1 hr | ages 8-30s (tweens, teens, young adults) | virtual

YOUTH SUMMIT

SAVE THE DATE & RESERVE YOUR SPOT!

Saturday, June 17th | virtual

HEALING SPACES

Bright Brunch | Light Lounge | Music, Movement, & Memory

Visit the website to learn more and join