Younger-Onset Dementia: Unique Challenges Families Experience & Community that Empowers



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We heal. We advocate. We educate.
Families navigating younger-onset dementia



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Objectives:

- Introduce Lorenzo's House Mission and Vision
- Build Awareness and Understanding of Younger-Onset Dementia
- Highlight the Unique Challenges of Younger-Onset Dementia
- Showcase Family-Centered Support Models
- Invite Collaboration and Partnerships

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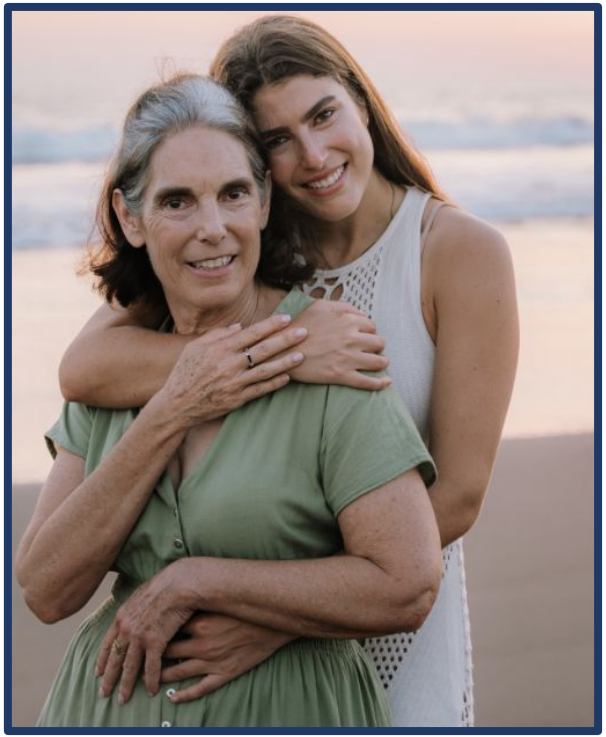


What is Younger-Onset Dementia?

Younger-onset dementia means a diagnosis of any form of dementia before the age of 65. Some individuals are diagnosed as early as their 30s, 40s & 50s.

Symptoms

- *Changes in personality, mood, or behavior*
- *Difficulty finding words or speaking clearly*
- *Problems with vision, such as depth perception*
- *Difficulty joining conversations*
- *Misplacing things*
- *Unsteadiness on your feet*



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200%
uptick
diagnosed with younger-onset dementia in the U.S.

BXBS Report 2020



600K
People Diagnosed
with younger-onset dementia in the U.S.

SSA 2025

2.4M
Family Caregivers
of younger-onset dementia in the U.S.

SSA 2025



THIS DOES NOT INCLUDE THOSE:

- *undiagnosed*
- *misdiagnosed*
- *or whose person has passed*

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10 Unique Challenges of YOD

1. *Family roles change*
2. *Long path to diagnosis*
3. *Single parent/breadwinner*
4. *Youth navigating complex brain change*
5. *No access age-appropriate support*
6. *Genetic concerns & fears about the future*
7. *Milestones disrupted*
8. *Isolation & stigma*
9. *Ambiguous loss & anticipatory grief*
10. *Delayed or non qualification for financial services, care placement, day programs & support*



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Lorenzo's House Virtual Model

Providing Support & Raising Awareness

Providing Support

MATCH - One-on-one, peer to peer connection.

CLUBS - Virtual support groups - starting at age 4 - for children, teens, young adults and primary carepartners of YOD.

SUMMIT - Global, annual, virtual, youth-led event to connect, advocate and educate.

Raising Awareness

NEXTGEN - global YOD awareness movement - building community & ending stigma.

YOD Academy - Virtual learning lab for a YOD-educated society.

YOD Global Report & Convening -a platform of lived experience, research, policy and more *(coming soon..)*

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We Provide Support



MATCH: one-on-one, carer to carer connection

CLUBS: virtual support groups starting at age 4 and above

SUMMIT: global, annual youth-led-to heal, advocate & educate

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We Raise Awareness



NEXTGEN

Global YOD awareness advocacy movement

YOD Academy

Virtual learning lab for a YOD educated society

YOD Global Report & Convening

Platform of lived experience, research, practitioners, policy & more

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Alzheimer's Disease International

The global voice on dementia

World Alzheimer Report 2024

Global changes in attitudes to dementia

Old before our years: a conversation between two sons of younger-onset dementia from across the pond

Lucas Cose[1] and Will Dean[2]

[1] *Son of a dad with younger-onset Alzheimer's, Lorenzo's House, US*

[2] *Son of a mother with early-onset Alzheimer's, UK*



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We Raise Awareness



NEXTGEN

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LORENZO'S HOUSE BY THE NUMBERS ...since 2021

SERVING
4500+
FAMILY MEMBERS

STATES
50 **40**
COUNTRIES

1000+ CAREGIVER MATCHes

150+ MONTHLY INQUIRES

200+ PARTNERS & COLLABORATORS

1000+ GENEROUS DONORS

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8 ways...**to bring light** with Lorenzo's House

- ➔ **Connect us to sons, daughters and families of YOD**
- ➔ **Join our NEXTGEN Movement**
- ➔ **Collaborate with us** - partners, experts and new friends
- ➔ **Follow us on social media** & expand our reach
- ➔ **Donate to our Mission**
- ➔ **Volunteer with Us** & be a part of the solution
- ➔ **Host a screening** of our Short Film & bring awareness
- ➔ **Sign up for** our inspiring Newsletter ***'Light The Way'***

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Bibliography

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- Earnings losses in young-onset dementia: Population-based study with admin data https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.14588
- Family carers' narratives of the financial consequences of young onset dementia https://journals.sagepub.com/doi/10.1177/14713012211009341

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