

LIVED EXPERIENCE · THE FAMILY SYSTEM

The Gap We Don't See

What a young-onset diagnosis did to a whole family — and six places a clinic team could have reached us.

Spouse of someone living with Huntington's disease · Alzheimer's Association educator

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IT STARTED WITH MY SISTER-IN-LAW'S MARRIAGE

*"Jeanie, there's nothing wrong with you.
I think your husband may be a narcissist,
or possibly controlling."*

Said after five sessions — and it wasn't careless. It was what the counselor was trained to look for first.

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GAP 1 OF 6

They looked at the marriage first

Too young, still working, still parenting — so we looked at mental health, at personality, at the relationship. Families get sent to counseling long before anyone looks at the brain.

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HOW WE FOUND OUT ABOUT HIS FATHER

The accident that wasn't an accident

He slipped in the shower in 2006 — brain bleed, surgery, then dementia. He died in 2013. For eleven years we believed the fall caused all of it.

The fall was most likely caused by Huntington's disease. He was never tested.

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GAP 2 OF 6

A family history no one knew

Three of his siblings died of it. His own sister named it out loud, years early, and was dismissed. Nobody outside the family ever asked.

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50/50

Every child of an affected parent has a 50% chance of inheriting the gene.

His children. His siblings. My husband. Our children. Our granddaughter.

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GAP 3 OF 6

A life-changing test with no roadmap

One question at a primary care visit, and the test was ordered the same day. No counseling before it. No one who owned the result after it.

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He would develop Huntington’s disease — and could pass it to our children and grandchildren.

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GAP 4 OF 6

Our children inherited the decisions, and the silence

Dating. Marriage. Testing. Which career you can afford. Whether to have children, and how. Decided by people who weren’t patients yet — in a family that couldn’t discuss it.

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FIVE SIBLINGS. TWO DIAGNOSED. THREE WHO WOULDN'T TALK.

*"Don't talk about this here.
If my kids see it on my phone,
they'll find out."*

My sister-in-law, on our family group chat. So we kept it a secret — inside our own family.

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GAP 5 OF 6

The paycheck goes before
the care plan arrives

Diagnosed in 2018. Let go in 2019. His reviews showed the disease was already there, read as a performance problem — and our income and health benefits went with the job.

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THE ONE GROUP WE WERE GIVEN

**A room where he could
watch his own future**

Built for the caregiver and the person living with the disease, together. So I couldn't say what I needed to say — and he had to sit through the next stage, and the one after that.

We went for a while. Then it closed.

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GAP 6 OF 6

The spouse is in the room
and not in the plan

Never assessed, never asked, never referred. Nine years of appointments.
And in the whole state, we could find one other younger-onset group.

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children born into our family, free of Huntington’s
disease.

Because we know the exact gene, it can be tested for. A seventh is due in March.

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MY ASK IS SIMPLE

A diagnosis doesn’t just
change one person’s life.
It changes a family —
and the generations after.

Thank you

Some names have been changed. Shared with my family’s consent.

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