

It Wasn't Alzheimer's: Our Journey To A MAPT FTD Diagnosis

By Elizabeth George: My lived experience with my mum's diagnosis at 59.

The 4 Year Road to Diagnosis

Before 2019

The silly little things that didn't make sense. We didn't realise at the time.

2019-2020

Something was going very wrong. When my Grandad passed away, my Mum didn't show any emotion.

2021- The 'Ologists'

Psychologists, Psychiatrists, Neurologists, neuropsychologists. "It's not Alzheimer's, but we don't know what's going on."

2022- It's Alzheimers

'I can confirm it is Alzheimer's disease'. I knew it wasn't. We requested a genetics test and a referral to another hospital.

2023- It's MAPT FTD

The genetics results took over a year.

Navigating Without a Map

One Appointment a Year

After diagnosis, that's often it. A yearly check-in, and you're sent away to cope alone.

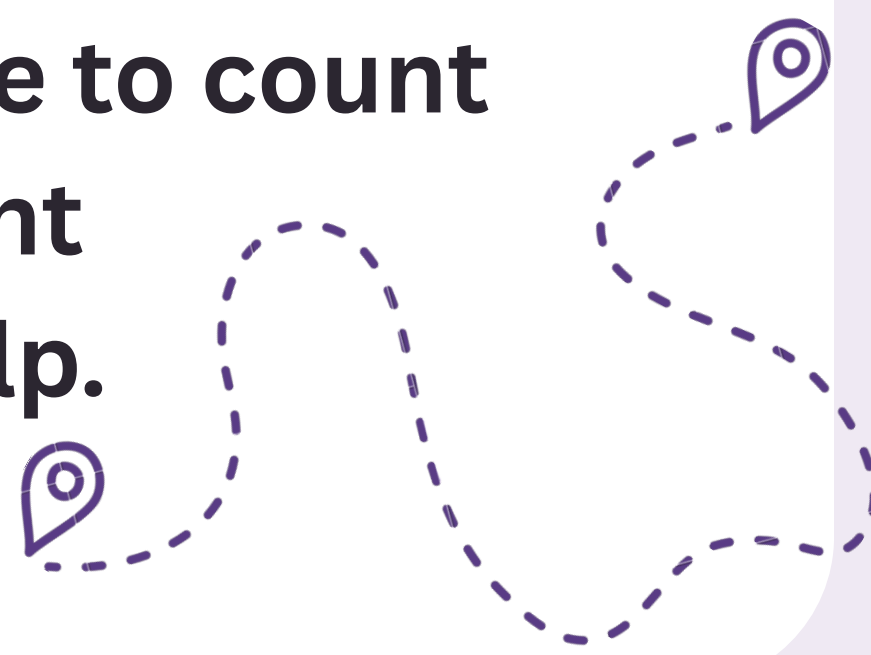
Services Not Available

It's a postcode lottery. In Suffolk especially, services are lacking and there is a disconnect between counties.

Good Luck

No signposting, no roadmap, no one to call. We found some supporting therapies and one by one they told us there was nothing else we could do.

**It is impossible to count
the hours spent
looking for help.**



Putting Support in place

Where to start?

Googling 'where to find carers', asking around for companions and personal assistants. Services built for the elderly, and a system that doesn't believe young-onset dementia exists.

It's Expensive

At the start, it cost us around £3,000 a month just to put the bare minimum in place. The PIP benefit gave us £900 a month. Families are drained financially as well as emotionally.

NHS Funding

A system that keeps breaking the people who are already fragile. Hours arguing to prove that a genetic form of dementia in someone under 65 is a medical need. Applying for this financial support is a full-time job- on top of an actual full-time job.

Looking Forward with Hope

- Improve diagnostic services and genetic testing.
- A roadmap clearly showing how to navigate a diagnosis and where to find support.
- Advocacy to include MAPT patients in anti tau trials.

Thank you to the FTD Community

We are forever grateful to our GP, Clinical Psychologist, Consultants at Addenbrookes, Cure MAPT FTD, GENFI, RDS, and all FTD advocates and researchers fighting for a cure. It is this community providing hope.

Behind every diagnosis is a lost and devastated family, waiting for a glimmer of hope.

