

# Finding Hope:

## A letter from one parent to another

Dear Parent,

### There is hope in this journey

First and foremost, there is hope. Not false hope that dismisses reality, but the genuine kind that helps us face each day with purpose.

You may have just heard the term 'childhood dementia' for the first time. I know I had never come across it before my child's diagnosis. It can be shocking and confusing to learn that dementia doesn't only affect older adults, but can also impact children through various genetic conditions. This umbrella term covers more than 140 different rare disorders, and it's completely normal if / totally understandable that you're still trying to understand what your child's specific diagnosis means.

Your child is still the same wonderful person they were before this diagnosis. While I can't promise that everything will be okay in the conventional sense, I can tell you with certainty that you will find strength you never knew you possessed. The rest of our world might have changed, but they are still our kids and we are still their parents.

One parent shared with me: "The day after diagnosis, my son was the same person he was two days before. That hadn't changed." This simple truth helped ground me when everything else felt unstable.

Please know that right now, in this difficult time you're facing, research is being carried out all across the world. We have seen remarkable progress in treatments for many chronic conditions over recent years. Your child's path may include access to clinical trials, emerging therapies, or treatments that weren't available even just a short time ago. You have every right to explore these possibilities.

## Your feelings are valid

When we received our diagnosis, I felt like I was drowning. The emotions came in waves—disbelief, rage, profound sadness, isolation, loss of control and sometimes numbness. My mind raced with questions: “Why my child?” “How will we manage?” “What will our future look like now?”

It’s completely normal if you find yourself focusing on end-of-life concerns right now. This is a common trauma response after receiving such life-changing news. These thoughts will become less overwhelming with time, but please know they are a normal reaction to what you’re going through.

Alternatively, you may be operating on a day to day basis, as the future is too daunting to consider right now. Either way, the overwhelming confusion and pain you may be feeling are completely valid. The terminology is bewildering, and the burden of becoming an expert on your child’s condition while processing grief is immense. It’s exhausting to repeatedly explain your child’s condition to well-meaning professionals who may have never encountered it before.

## Moving forward at your own pace

Right now, you don’t need to have everything figured out. You don’t need to suddenly become an expert navigator of healthcare, education, and disability systems. Some of this new language and terms can be confronting. Give yourself permission to process this information at your own pace.

What helped me through:

**Being gentle with myself.** Some days, just getting through is enough. Progress isn’t linear, and neither is grief.

**Finding my voice.** I gradually learned to trust my instincts about my child and to speak up when something didn’t feel right. Remember: you know your child best.

**Building my support network.** Not everyone will understand, and that’s okay. Seek out those who give you energy rather than drain it—whether they’re other parents in similar situations or professionals who truly listen.

**Taking care of myself.** This isn’t selfish—it’s essential. You cannot pour from an empty cup.

**Boundaries and limits are important.** You can say no. Sometimes you might need to be alone and not be asked any more questions.

## You are not alone

While it may feel isolating now, please know that there are parents like me who understand without explanation. When you’re ready to connect, we are here—people who won’t judge and who will walk alongside you.

Whatever emotions you’re experiencing—whether overwhelming grief, determination, confusion, or all of these simultaneously—know that they are normal responses to an extraordinary situation. There is no right way to navigate this path.

**With hope and solidarity,  
A Fellow Parent**

**On behalf of, and  
in collaboration  
with, families who  
have been there  
before, including:**



**Sarah, Brett, Finn,  
and Charlotte**



**Meg, Isla, and Jude**



**Renee, Hudson,  
Holly, and Austin**



**Conrad, Ana,  
and Phillip**

**childhood  
dementia  
INITIATIVE**