

## **Transcript: What is childhood dementia?** An introduction to childhood dementia

Childhood and dementia, two words that shouldn't go together, but sadly they do.

Sadder still is that, on average, childhood dementia takes a life every 11 minutes, it also takes away the future.

So what is childhood dementia? Childhood dementia results from progressive brain damage caused by over 100 genetic conditions, just like adults with dementia, children with dementia experience memory loss and confusion. They have difficulty concentrating, understanding, learning and communicating, and they can experience severely disturbed sleep and personality changes too. They can also have behavioural and emotional issues like hyperactivity, anxiety and fear.

Each child's experience with dementia is unique for some symptoms can appear when they are babies and progress quickly, while for others, they may not appear until they are teenagers. Across all childhood dementia, however, there is one common feature childhood dementia is progressive.

This means that over months, years or decades, children progressively lose skills they may have already developed, like the ability to write, read, talk, walk and play.

Over time, their brains also lose the ability to keep the body functioning properly, and eventually to keep the body alive, there has been so little investment and therefore limited research into treating childhood dementia. Because of this, most children with childhood dementia die before turning 18.

Families impacted by childhood dementia, experience many losses. Most significantly, the child loses their future. They lose the opportunity to grow up and experience their adult life.



So how common is childhood dementia? One in 2900 babies are born with a condition that causes childhood dementia. Every year, it's estimated that 50,000 babies are born with a childhood dementia disorder.

So what can be done? Well, the first step is happening right now, by making people aware of childhood dementia, we can improve diagnosis, care, research and quality of life for children and young people with dementia around the world together, we can make change.