

RESEARCH STUDY:

Childhood Dementia INsight



Researchers at The Sydney Children's Hospital Network (SCHN) and University of New South Wales are seeking volunteer research participants to help understand the psychosocial impacts of childhood dementia on parents and to identify family support needs (HREC: 2023/ETH02411).

More than **70 rare genetic conditions cause childhood dementia** (click [here](#) to see a list of these conditions). Conditions that cause childhood dementia are neurodegenerative and life-limiting. They might be described as causing 'progressive neurocognitive decline', which means progressive brain damage. Children experience a collection of symptoms that may include loss of skills, confusion, personality and behaviour changes - symptoms that are also experienced in adult dementia. Examples of conditions that cause childhood dementia are Batten disease, Sanfilippo syndrome, Niemann-Pick disease A & C, Tay-Sachs disease, metachromatic leukodystrophy, Rett syndrome and some mitochondrial disorders.

You are eligible to participate in this research if

- you are a parent of a child who has a disorder that causes childhood dementia or
- you are the parent of a child who has passed away with childhood dementia

What does participating in this research involve?

If you decide to take part, you will be invited to complete a survey. There is also the opportunity to take part in an individual interview. Both the survey and the interview will ask questions about the psychosocial impacts of childhood dementia and families' support needs. You can decide to participate in the survey online via this link

https://unsw.au1.qualtrics.com/jfe/form/SV_6hEYjxy54Qjwiou

The survey should take approximately 10-15 minutes to complete.

You can decide to participate in the interview over the phone or in person. The interview should take no longer than 30 minutes to complete.

To indicate your consent to participate in either or both component of this research please follow this link [LINK TO SURVEY & CONSENT](#)

To learn more about the research study or to enquire about participating, please contact:

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