

# 5 Requests from families

## A guide on how to work together

Hear from the other experts in the room.

Families impacted by childhood dementia share what they need from professionals who work with and support them.

**TREAT US WITH RESPECT, CARE, DIGNITY & KINDNESS. PROVIDE SOME HOPE**

“You can show respect, care and kindness by really taking the time to listen, confirm your understanding and follow through.”

“For families like ours, hope might mean something like hope that your child is not going to suffer, hope that if he’s in pain, you’ll be able to tell us.”

**ACKNOWLEDGE WE ARE THE EXPERTS REGARDING OUR CHILDREN**

“You can do this by asking us if your understanding of our circumstances is correct.”

“It’s a partnership of bringing medical information together with the expert on the child – their parent.”

**DO SOME RESEARCH TO UNDERSTAND MORE ABOUT CHILDHOOD DEMENTIA**

“Please take time to find out about our child’s condition.”

“You can do this by googling a condition you’re not familiar with.”

“It brings relief and trust if someone is humble enough to consult with another expert.”

**USE YOUR KNOWLEDGE OF MY CHILD’S DEMENTIA TO PROVIDE APPROPRIATE CARE**

“Realise that these children are often at the very extreme end of what you might treat or see on a day-to-day basis.”

“Don’t wait for us to explain to you all of the things that we have to consider when we’re treating a symptom. Have a plan for how we’re going to address that.”

**RECOGNISE THE IMPACT OF CHILDHOOD DEMENTIA ON THE WHOLE FAMILY**

“We’re all living with and caring for a child who we know is only here for a short time.”

“When you ask us how we are as a family or as parents, we feel supported, that you are with us on the journey and you care.”

This resource summarises insights collected during a series of focus groups. Childhood Dementia Initiative gratefully acknowledges all who contributed and is proud to amplify family voices.

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dementia**  
INITIATIVE

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