

Childhood Dementia Project ECHO® Community of Practice

Summary of Session 1 2026: Walking alongside families of children with dementia

This Childhood Dementia Initiative Community of Practice meeting focused on a presentation by Professor Kenneth Nunn, a paediatric neuropsychiatrist with over 40 years of experience, who shared insights on supporting families of children with dementia. Professor Nunn discussed the challenges faced by families, including uncertainty, progressive decline, and the impact on siblings, emphasising the importance of maintaining a balance between medical and personal aspects of life. He highlighted the value of playfulness and humour in coping with the situation and stressed the need for understanding and support from healthcare professionals. The session also addressed the evolution of care for children with dementia over the years and the progress made in recognizing and addressing these conditions. Attendees engaged in a Q&A session, exploring topics such as supporting younger professionals.

Presentation

Professor Nunn presented on supporting families of children with dementia, highlighting key challenges including the uncertainty of diagnosis and management, the progressive nature of the condition, prolonged anticipation of decline, and concerns about siblings potentially being affected due to the genetic nature of the conditions. He discussed how families often need to balance caring for a child with dementia while maintaining normal family life. The presentation also touched on the specific needs of well-siblings, who may be overlooked or affected by the family's situation.

Impact on Family

Professor Nunn discussed the challenges clinicians face when working with children and families affected by dementia, emphasizing the importance of supporting the family as a whole while addressing the unique struggles each member faces. He highlighted the role of playfulness and humor in managing the heavy burden and the need for clear distinction between the suffering of the child and that of the parents and siblings. He also stressed the importance of understanding that not everyone can fully comprehend these situations, encouraging professionals to focus on supporting the family and finding joys amidst the hardship.

Healthcare Professional Support and Experience

Professor Nunn discussed supporting younger professionals in healthcare by sharing his experience of navigating complex family situations and illness over many years. He emphasized the importance of maintaining presence with families during difficult times and noted that younger practitioners can learn from experienced professionals who have faced similar challenges. Professor Nunn also highlighted how many healthcare professionals have personal experience with siblings who have serious illnesses.

For more information on the Childhood Dementia Project Echo® Community of Practice, please visit:

www.childhooddementia.org/health-professionals/community-of-practice