

Childhood Dementia Project ECHO® Community of Practice

Summary of Session 4: The psychosocial impacts of childhood dementia on the whole family

The Childhood Dementia Initiative Community of Practice meeting focused on supporting children with childhood dementia and their families, with particular emphasis on the needs of siblings who often take on significant emotional and practical roles despite limited support. Presentations covered the impact of childhood dementia on siblings, practical actions for professionals to support them, and the challenges of providing psychosocial care for young people with childhood dementia. The conversation ended with a case study discussion and information about available services.

Opening presentation

Dr Shannon Schedlich presented on the needs and experiences of siblings of children with dementia highlighting how siblings of children with childhood dementia live through complex emotional terrain, coping with medical uncertainty, progressive loss, and often anticipatory grief. Yet their needs and experiences are rarely recognised or supported in service systems. Shannon drew on Australian research, including Siblings



Australia's white paper 'Why Siblings Matter to the Australian Disability Strategy', exploring the vital role of siblings, the emotional impacts of life-limiting conditions, and how services could more effectively include and support siblings across the care journey. Shannon shared practical strategies for health, education, and community professionals to engage siblings as part of a holistic family approach.

The video of this presentation is available to watch on our website.

Case presentation

Dr Azhani Amiruddin, Clinical Psychologist at Adolescent and Young Adult Hospice (AYAH), discussed the challenges of providing psychosocial care for young people with childhood dementia. Azhani shared a case highlighting the importance of early referral to palliative care thereby providing the opportunity for psychosocial support, multidisciplinary care, memory making and legacy planning. Azhani also described the facilities and services available at AYAH and has provided a quick summary of psychosocial resources at AYA which is available on our website.

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

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