

Childhood Dementia Project ECHO® Community of Practice

Summary of Session 5: ‘Cross-sector model of care’ and ‘holistic hospice approaches for children and families impacted by childhood dementia’.

This Childhood Dementia Initiative Community of Practice meeting focused on cross-sector care models, patient support services, resources and a holistic hospice approach.

Opening presentation

Anna Thetford, Project Manager for the Clinical Services at the Rare Care Centre in Perth, shared insights into the challenges and services provided for children with rare diseases. She highlighted the significant number of children affected by rare diseases in Western Australia and emphasised the need for early diagnosis, access to treatment, and coordination of care across sectors. Anna discussed the centre’s cross-sector model of care, which includes a nurse-led service and programs like Dad’s Connect. She also presented a case study to illustrate the complexities of managing a rare disease and the importance of comprehensive support for affected families.



Case presentation

The session concluded with a presentation from Hummingbird House on managing challenging behaviours in children with rare diseases, focusing on holistic assessments, positive behaviour support, and collaboration with families and other healthcare providers.

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

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