

Childhood Dementia Project ECHO® Community of Practice

Summary of Session 1 Behavioural changes in children with dementia

Opening presentation

Corrine Lewis Team Leader at Dementia Support Australia (DSA) conducted the opening presentation with a brief description of childhood dementia and behavioural and psychological symptoms of dementia.

Corrine then explained how Dementia Support Australia provides professional, tailored, practical, non-pharmacological strategies designed to support families and schools caring for the child with a focus on improving quality of life. To achieve this DSA focuses on identifying the possible causes for the behaviour, (such as pain, parent/educator approach, communication difficulties, vision/sensory changes, cognitive changes and constipation) rather than focusing on symptoms.

Case presentation

Catherine Birrell, Dementia Consultant, and Belinda Wintle, Dementia Support Coach at Dementia Support Australia, then presented a de-identified case X, a teenager with childhood dementia.

X was referred to DSA because of their verbal and at times physical responses towards those caring for them during tasks, e.g personal care.



DSA Dementia Consultants assessed X at home with their family and NDIS carers to establish potential causes for their behaviour. Anxiety and low mood related to a number of factors including fear of seizures, fatigue and cognitive changes were identified.

A dementia support coach then attended daily to help family and carers implement strategies recommended in the DSA report, focusing on validation, communication and applying the dementia lens.

Strategies included

- A personalised whiteboard that gave X more autonomy in their day, they could see what was going to happen e.g. when the medications were going to be given, and could tick activities off.
- A memory book, with videos and photos that could be used during moments of distress.

As a result significantly increased confidence and capacity in caring was achieved by family and carers, whilst X's anxiety was reduced by being able to take their whiteboard with them e.g to school.

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

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