



An Introduction to Childhood Dementia Facilitator Guide

Introduction

This information session presentation is a starting point to becoming aware of and understanding more about childhood dementia. It is the first of a number of resources about childhood dementia being developed by the Childhood Dementia Initiative with funding provided by the Department of Health. References for all statistics included are provided in this Guide as well as in the notes section of the presentation.

The PowerPoint presentation is designed to be viewed by an individual or presented by a facilitator. This guide is intended to assist the facilitator to present an information session of 30 minutes to 60 minutes in length, depending on the depth of discussion and level of interaction of participants. Please keep in mind that some people may find the content of the presentation and videos included in it confronting.

So that we can continually improve our resources, we would appreciate your feedback about this Presentation and Guide. There is a link to a feedback survey at the end of this document.

Preparation for this session

As well as familiarising yourself with the PowerPoint slides, you might like to read some background information about childhood dementia.

All these resources are accessible on our website: www.childhooddementia.org

- [Childhood dementia fact sheet](#) An infographic with statistics and key information on childhood dementia.
- [Presentation video of Burden Study Poster \(3 minutes\)](#) - Kris Elvidge (PhD) Head of Research at Childhood Dementia Initiative, summarising the results of the Burden Study:
- Childhood Dementia Initiative (2020), [Childhood dementia the case for urgent action](#) (White Paper)
- Thema Consulting Report (2020), [Childhood Dementia in Australia: quantifying the burden on patients, carers, the healthcare system and our society 2020](#) (Burden Study)
- The complete list of genetic disorders that cause childhood dementia. <https://www.childhooddementia.org/childhood-dementia-disorders>

Information Session Overview

Slide 1 – Title slide

No notes

Slide 2 – Session overview

The season will cover the following 5 topics:

What is childhood dementia?

The facts

The symptoms

Living with childhood dementia

Childhood Dementia Initiative

Section 1: What is childhood dementia? Slides 3-7

Slide 3 – Animation video (3 minutes)

Purpose / Key message

To introduce the term childhood dementia.

Introduction to video

Let's start this session by watching this video about childhood dementia..

PRESS PLAY

Optional activities

Prior to watching the video, you may like to ask:

- *What are your immediate thoughts when you hear the words "childhood dementia"?*

After watching the video you could also ask:

- *What surprised you? What do you want to know now?*

Slide 4 – Definition

Purpose / Key messages

To define the term childhood dementia and highlight that it is caused by a number of genetic conditions.

Additional information

You may like to read this information whilst showing this slide:

These 70+ conditions include disorders such as Battens disease, Sanfilippo syndrome, Niemann-Pick disease, Rett syndrome, Tay-Sachs disease, metachromatic leukodystrophy, Rett syndrome, some mitochondrial disorders and many others.

A large proportion of disorders that result in childhood dementia are due to inborn errors of metabolism. These disorders are grouped within a number of broad classifications including:

- *Lysosomal diseases*

- *Disorders of amino acid and other organic acid metabolism*
- *Vitamin-responsive inborn errors of metabolism*
- *Mitochondrial disorders*
- *Disorders of mineral absorption and transport*
- *Peroxisomal diseases*
- *Neurodegeneration with brain iron accumulation*

Optional activity

You may wish to show the full list of disorders here. If so, click on this link:

<https://www.childhooddementia.org/childhood-dementia-disorders>

References

- *Dementia Australia quote:*

https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-AboutDementia01-WhatIsDementia_english.pdf

- Thema Consulting Report (2020), *Childhood Dementia in Australia: quantifying the burden on patients, carers, the healthcare system and our society 2020*

Slide 5 – Statistics

Purpose / Key message

Although each of these conditions is rare or ultra-rare, childhood dementia is, collectively, much less rare.

- The most widely accepted definition of rare disease is that it is one that affects less than five in 10,000 people¹
- Ultra-rare diseases are defined as having a prevalence of less than 1 per 50000 people²

Additional information

You may like to add this information when you speak to these slides:

The incidence of childhood dementia is Incidence similar to that for cystic fibrosis which occurs in 1 in 2,874 live births³

¹ National Strategic Action Plan for Rare Diseases, February 2020,
<https://rva.blob.core.windows.net/assets/uploads/files/NationalStrategicAPRD.pdf> 2

² National Institute for Clinical Excellence. NICE Citizens Council Report Ultra Orphan Drugs. London, NICE, 2004
<https://europepmc.org/article/NBK/NBK401721>

³ Massie RJ, Olsen M, Glazner J, et al. *Newborn screening for cystic fibrosis in Victoria: 10 years' experience (1989-1998)* *Med J Aust* 2000; 172: 584-587

Slide 6 – Key feature of childhood dementia

Purpose / Key message

The key feature of childhood dementia is the loss of acquired skills. Childhood dementia is neurodegenerative and progressive.

Additional information

You may like to add this information when you speak to this slide:

Professor Kenneth Nunn first used the term dementia in childhood back in the early 1990s. Ken has been championing the use of the terminology and definition of childhood dementia for many years.

In their paper in 2002 Nunn and his colleagues defined childhood dementia as “global neurocognitive decline with multiple-developmental skill loss after a period of normal development”.

“One of the hallmark characteristics of childhood dementia is enduring and progressive loss of previously acquired developmental skills in contrast to static or transient loss, for example in the case of head injury, encephalitis or near drowning.” (Supported by Verity et al (2010))

Optional activity

Before going on to slide 9, which lists the symptoms of childhood dementia, you may like to ask participants:

- *What do you think symptoms of childhood dementia could be?*

Then, brainstorm ideas around symptoms with the prompt to think about adult dementia.

References

- Nunn K, Williams K, Ouvrier R. The Australian childhood dementia study. *European Child & Adolescent Psychiatry*. 2002; 11(2): 63-70.
- Verity C, Winstone AM, Stellitano L, Will R, Nicoll A. The epidemiology of progressive intellectual and neurological deterioration in childhood. *Archives of Disease in Childhood* 2010; 95:361–364. doi:10.1136/adc.2009.173419

Slide 7 - Prof Schofield explains childhood dementia (90 second video)

Purpose / Key message

The benefits of looking at the group of genetic conditions that cause childhood dementia as a group. Similarities between adult and childhood dementia

Introduction to video

Professor Peter Schofield, CEO of Neuroscience Research Australia highlights that, similar to adult dementia, childhood dementia is caused by a number of conditions. He also explains the benefits of looking at the conditions together rather than individually.

PRESS PLAY

Additional information

After the video you can add:

On the Dementia Australia website it is stated that “dementia is the umbrella term for a number of neurological conditions of which the major symptom includes a global decline in brain function. There are over 100 diseases that may cause dementia. The most common causes of dementia include Alzheimer’s disease, vascular dementia and dementia with Lewy bodies”.

Reference

- <https://www.dementia.org.au/information/about-dementia/types-of-dementia>

Section 3: The Symptoms

Slides 8-9

Slide 8 - What do children experience?

Purpose / Key message

While each childhood dementia experience is unique, there are common symptoms. Many symptoms are similar to those experienced by adults with dementia.

Additional information

You may like to add this information when you speak to this slide:

- *Note the similarities with adult dementia symptoms*
- *Keep in mind, different genetic disorders may have a different set of symptoms, but there are many common features*

Reference

- Thema Consulting Report (2020), *Childhood Dementia in Australia: quantifying the burden on patients, carers, the healthcare system and our society 2020*

Slide 9 - Unique experience, common features

Purpose / Key message

The timeline of the onset and progression of childhood dementia varies, depending on the genetic disorder and individual child, yet much of the dementia experience will be common from child to child.

Additional information

You may like to add this information when you speak to this slide

- *Symptoms of childhood dementia can progress for months, years and even decades, this has huge impacts on the whole family.*
- *Less than 5% of these 70+ disorders currently have an effective treatment.*
- *The life expectancy for childhood dementia is 28 years, as a few of the disorders have a near normal life expectancy. However, approximately 75% of children with dementia will die before they turn 18.*

Reference

- Thema Consulting Report (2020), *Childhood Dementia in Australia: quantifying the burden on patients, carers, the healthcare system and our society 2020*

Section 4: Living with childhood dementia Slides 10-12

Slide 10 – Case study: Angelina (1 minute 45 second video)

Purpose / Key message

Begin to understand childhood dementia through one young person's experience.

Introduction to video

Angelina is a young person living with childhood dementia. This video was filmed when she was in 2020 when she was 16 years old. She was diagnosed with childhood dementia caused by Lafora disease when she was 14 years old.

PRESS PLAY

Additional information

*Angelina's story and other family stories can be accessed here:
<https://www.childhooddementia.org/family-stories>*

Slide 11 - Break / pause

Purpose / Key message

We acknowledge that some participants may find the content of this video emotional or confronting. We encourage providing time for participants to pause and reflect on what they have just seen.

Optional activity

After this pause, you may like to prompt a discussion, using one or more of the following questions:

- *What are your thoughts after watching this video?*
- *What symptoms of childhood dementia did you see?*
- *What do you think are some of the impacts are on children with dementia and their families?*

Slide 12 - Initial findings from a UNSW literature review

Purpose / Key message

Insight into the impact of childhood dementia on children, siblings and families.

Additional information

You may like to add this information when you speak to this slide:

As childhood dementia is a relatively new term, there has been very little psychosocial research undertaken into the impact of it on children and families.

This literature review is the first component of psychosocial research being conducted by UNSW.

Extensive research is needed to understand both the impact of childhood dementia and the needs of these children and families, so that we can make improvements in care and support.

References for these two quotes

- Somanadhan S, Larkin P. Parents' experiences of living with, and caring for children, adolescents and young adults with Mucopolysaccharidosis (MPS). Orphanet journal of rare diseases. 2016;11(1):1-14.
- Hoffmann F, Hoffmann S, Kunzmann K, Ries M. Challenging behavior in mucopolysaccharidoses types I-III and day-to-day coping strategies: a cross sectional explorative study. Orphanet journal of rare diseases. 2020;15(1):1-14.
- Bose M, Mahadevan M, Schules DR, et al. Emotional experience in parents of children with Zellweger spectrum disorders: a qualitative study. Molecular genetics and metabolism reports. 2019;19:100459.

Section 5: Childhood Dementia Initiative Slides 13-14

Slide 13 – Childhood Dementia Initiative and parent video (2 mins 30 secs)

Purpose / Key message

Parents provide further insight into the impact of childhood dementia on children and families and why action is needed.

Introduction to video

Here, four mums talk about their children's experience of dementia and what an end to childhood dementia would mean for them and families like theirs.

PRESS PLAY

Additional information

<https://www.childhooddementia.org>

Slide 14 – Childhood Dementia Initiative

Purpose / Key message

The Childhood Dementia Initiative is a world first organisation, set up in 2020 to create increased awareness of childhood dementia, to improve care and quality of life and to accelerate the development of effective treatments.

Additional information

For further information and to keep up to date with the progress on childhood dementia you can sign up for updates on the Childhood Dementia Initiative website. You can also follow them on Linked In and Facebook.

<https://www.childhooddementia.org>

Slide 15 – Childhood dementia resources

Purpose / Key message

This is the first of 4 Information modules on childhood dementia we are developing with funding from the Department of Health.

To come:

- Working with families – July 2022
- The Clinical Perspective – February 2023
- Palliative care and end of life – February 2023

To access these modules and other resources, visit our website: www.childhooddementia.org

Optional activity

To conclude this session, you may like to ask these questions, or perhaps you have your own.

- What have you learned from this session?
- How would you explain childhood dementia to a friend or colleague?
- Do you want to find out more about childhood dementia? What will you do?

Slide 16 – Feedback

Purpose / Key message

Please encourage your participants to scan the QR code on the slide and complete our feedback survey to assist with the continuous improvement of our resources.

In the survey they can also register their details in order to receive updates and more information about our resources.

Thank you for presenting this information session!

As a facilitator who has delivered this presentation, we would really appreciate your feedback about using it and this Guide to run your information session. Your feedback will assist us with the continuous improvement of our resources.

You can also register your details in order to receive updates and more information about our resources.

To complete a short evaluation survey that will take no more than 5 minutes, please use this link: https://www.surveymonkey.com/r/CDI_Presentation_Facilitators

Or scan this QR code



This Facilitator Guide was developed by Childhood Dementia Initiative with funding from the Australian Government.

