



CORPUS CALLOSUM DISORDERS FACT SHEET

1. The corpus callosum is the **major nerve structure** connecting the two sides (hemispheres) of the brain. It allows communication between the hemispheres.
2. Most people with a corpus callosum disorder (CCD) are born missing part or all of their corpus callosum. This may be called **agenesis, dysgenesis or hypoplasia** of the corpus callosum. Some may have a thickened corpus callosum (**hyperplasia**). A CCD is a lifelong condition. Causes can be genetic, environmental or unknown, with more than 200 medical conditions or syndromes having a CCD as one component of the clinical features. Names can be confusing. You may see disorder of the corpus callosum (DCC) or corpus callosum disorder (CCD). They mean the same.
3. A CCD is a relatively common brain abnormality in newborns and occurs in approximately **1:4000 live births**, affecting approximately 6500 Australians. Accurate prognosis is difficult. Some research studies estimate that it may be as common as 1:3000 live births.
4. A CCD diagnosis is **confirmed by MRI or CT imaging**. Advancements in neuroimaging enable CCDs to be diagnosed in utero. There are relatively high termination rates. Diagnoses may also be made in childhood or in adulthood after an incidental MRI or CT scan.
5. Parents are often told to “wait and see” but early intervention is important and effective.
6. Corpus callosum disorders are **heterogeneous** in cause, presentation and management. People with apparently the same CCD may have very different impacts, requiring a holistic, personalised approach to understanding and management by professionals.
7. Professional expertise, knowledge and experiences with CCDs can be limited and sporadic. **Accurate information can be difficult to access** but there is a growing body of research.
8. A CCD affects the speed and transfer of sensory-motor processing information and may affect mobility, social skills, learning and memory, complex reasoning and other cognitive processing. **Early intervention** is effective in helping babies, children and adults meet milestones.
9. A CCD can have **cognitive, psychological, physical and social impacts ranging from mild to severe**. Some people will have very mild impacts and not need support. Most will benefit from support even if symptoms are not always apparent from simple ‘bedside assessments.’ Many people will display obvious impacts requiring targeted supports.
10. Adults with a CCD in Australia have been typically under supported and under recognised. This can contribute to isolation, mental health issues and reduced capacity to achieve in education, employment and relationships. Although the introduction of the NDIS improves access to support, many adults experience **difficulties finding health professionals who understand DCCs**.

References

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- Siffredi, V., et al., *A Neuropsychological Profile for Agenesis of the Corpus Callosum? Cognitive, Academic, Executive, Social, and Behavioral Functioning in School-Age Children*. *Journal Of The International Neuropsychological Society: JINS*, 2018: p. 1-11.