

what to expect

Development can vary significantly, ranging from normal development or mild impairments through to severe cognitive and physical disabilities. Early prognoses are difficult to provide as deficits may or may not present as children progress. A 'wait and see' attitude is often adopted by health professionals.

some of the common characteristics that may be present are:

- Delayed motor, language and cognitive development.
- Sensory processing issues
- Non Verbal Language Disorders
- High tolerance to pain
- Sleep disorders
- Difficulties with body temperature regulation
- Limited insight into their own behavior and its consequences
- Difficulties with multidimensional tasks such as using language in social situations, problem solving abilities and complex reasoning.
- Difficulties in social interactions. These can include being unaware of the thoughts and feelings of others, misunderstanding social cues such as facial expressions and tone of voice, lack of empathy, limited grasp of humor with literal interpretation of speech and not being able keep up with conversations and actions of their peers. These issues often emerge in early adolescence.

A DCC can present as a hidden disability and this can make diagnosis and access to assistance and support extremely difficult. Individuals with ACC have problems with executive function deficits, socialisation and higher order reasoning, even when simple bedside assessments do not detect any difficulties. Individuals will benefit from cognitive and behavioral therapies directed at those specific issues and often perform better when given additional time to attain a goal.



more information

Email: info@ausdocc.org.au

Website: www.ausdocc.org.au

Interactive Facebook Groups:

Australian Disorders of the Corpus Callosum (AusDoCC)

Australian ACC Adults

Facebook page:

www.facebook.com/AusDoCCInc



health professionals who may be of help:

- Paediatricians
- Neurologists
- Geneticists
- Endocrinologists
- Cardiologists
- Metabolic specialists
- Ophthalmologists
- Neuropsychiatrists
- Neuropsychologists
- Audiologists
- Therapists, including:
 - Speech therapists
 - Physiotherapists
 - Occupational therapists
 - Music therapists

membership

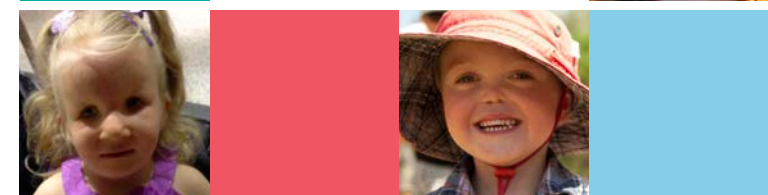
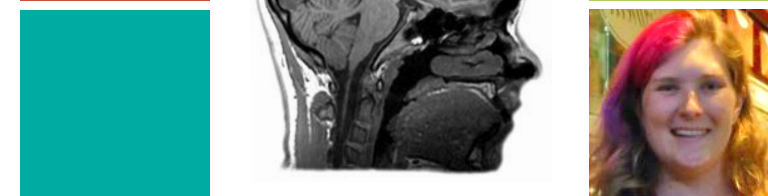
AusDoCC Inc invites you, your family and friends, other interested individuals and public or private organisations to become members of **ausDoCC** Inc. To apply for membership, please complete and return the attached application form.

benefits of membership

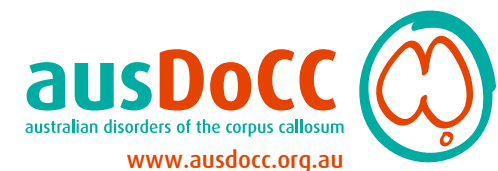
- Members receive our regular newsletter which includes family stories and information
- Invitation to **ausDoCC** Annual General meeting and voting rights at that meeting
- First to hear about events held throughout the year
- Discounted ausdocc event registration
- Members only forum
- Members only access to latest research updates and the opportunity to participate in research
- Each and every member helps raise the awareness of disorders of the corpus callosum and helps us to be a stronger body in advocating for more recognition and support of the condition.



ACC and other Disorders of the Corpus Callosum



advocating | uniting | supporting



www.ausdocc.org.au



Vision:

Supporting individuals, families and caregivers affected by a disorder of the corpus callosum

Mission:

- **Advocating** – Developing effective partnerships with key service providers.
- **Uniting** – Connecting people affected by a disorder of the corpus callosum (DCC).
- **Supporting** – Raising awareness through education, information, research and resources.

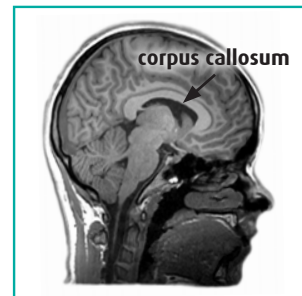
AusDocc Inc. is a not for profit organisation formed by a group of volunteer parents whose children all have a disorder of the corpus callosum (DCC). We found that there was very little information on DCCs within Australia.

Until relatively recently corpus callosal disorders have been largely underdiagnosed and overlooked in Australia. With advances in imaging technology they are now being diagnosed earlier, sometimes even prior to birth. Although most frequently diagnosed in childhood some adults are also discovering that they have a DCC. That diagnosis is providing an explanation for and an understanding of many of their lifelong difficulties.

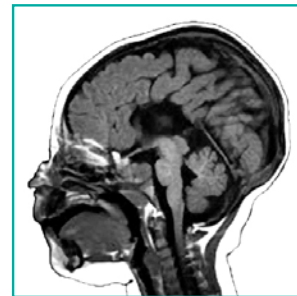
Most Australian medical and educational professionals have had little or no experience with individuals with a DCC. We are hoping to expand the knowledge and support for all Australians diagnosed with a DCC and their caregivers.



The corpus callosum is the major connection between the two sides of the brain. It consists of more than 200 million nerve fibres that enable the two sides or hemispheres of the brain to communicate and transfer information from one side to the other. A disorder of the corpus callosum (DCC) is a rare, congenital, neurological condition in which the corpus callosum fails to fully develop or does not develop at all. It is an abnormality in the development of brain structure, before birth, and is not a disease or illness. In some cases other areas of the brain may also have failed to develop normally.



MRI showing fully formed corpus callosum



MRI showing complete Agenesis (absence) of the Corpus Callosum

a disorder of the corpus callosum can further be described as:

- ACC/AgCC:**
Agenesis or complete absence of corpus callosum
- pACC:**
Partial absence of the corpus callosum
- Hypoplasia/Hypogenesis:**
Thin corpus callosum
- Dysgenesis:**
Incomplete development of the corpus callosum

other conditions present with a dcc may include:

- epilepsy
- developmental delay
- vision and/or hearing impairments
- autism spectrum disorder (ASD)
- cerebral palsy due to issues with muscle tone

associated brain malformations may include:

- colpocephaly (enlargement of the ventricles of the brain due to fluid filling the space where the corpus callosum usually lies)
- hydrocephalus (build up of pressure in the ventricles due to obstruction of fluid flow)
- microcephaly (small brain)
- Cortical malformation (abnormality in the folding or structure of the brain surface)
- abnormalities of the cerebellum or brainstem
- pituitary malformation

how it is diagnosed?

A DCC can be diagnosed prenatally via ultrasound or fetal MRI, or diagnosed later by computed tomography (CT) scan or Magnetic Resonance Imaging (MRI).

what causes a dcc?

It is hard to determine the cause of a DCC. Possible causes include genetic abnormalities (abnormalities in the structure of chromosomes or the genes within them) or non-genetic causes (such as exposure of the fetus to toxins or infections). Often the cause of a DCC is not known despite all available testing. Finding the causes of DCCs is an active area of medical research.

