

So, you're an adult and you've been told you have a disorder of the corpus callosum (DCC)?

These 10 top tips may help.

### 1. **OWN IT**

It's your diagnosis. Don't let anyone play it down or dismiss you or the diagnosis. You may have learnt to be very good at covering up to fit into the world. Find a GP and other supports who listen and work with you. You don't have to justify anything!

# 2. A DCC CAN BE AN INVISIBLE DISABILITY

Sometimes others judge disability by what they can see. Don't let people ignore your challenges or let their assumptions affect you. Learn about DCC and become sure about your true self and your knowledge of your own capabilities and your challenges.

### 3. YOU'RE NOT ALONE

You have a community. There are many other adults with DCC out there. Online communities and support groups offer connections and conferences. Become a member of AusDoCC to stay informed and join some Facebook groups for adults.

## 4. NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

Document the impacts that your DCC has had on your life as you find out more about it. Strong letters and documents from professionals will support your application. Ask others for peer support to access the scheme. It may take a few tries. Don't give up.

### 5. SUPPORT GROUPS

Finding support doesn't end with the NDIS and AusDoCC. Community groups in your local area may cater to people with similar interests and there are many online groups.

## 6. EMPLOYMENT

If you have a job, it is your choice whether you tell anyone about your DCC. Sometimes disclosing creates greater understanding and accommodations can be made. Sometimes not. You may need to inform an employer about associated medical risks such as epilepsy. Your employer **must not** discriminate against you for having a DCC. Ask a trusted health professional to write a letter of support and explanation. Reputable job agencies may be able help you to prepare for and find the right jobs.

### 7. EDUCATION

Education can be supported with explanatory letters from health professionals. Most institutions have Disability Support Units that can help you complete any education you wish to pursue. Register early and check in regularly. They want you to succeed.

#### 8. RELATIONSHIPS

You can't change who you are. Be with people who accept you for who you are. Divulge your information when and if you want to. Issues with social skills may hamper relationships, so seek advice which helps to develop skills. Find a good GP to help guide you in all areas. If you want to have children, genetic counselling can determine any heritable genes that may be passed on.

#### 9. YOU MAY NOT FEEL LIKE YOUR AGE

You may not feel like peers of the same age. You may feel behind. Know that this may be a part of you and your DCC. It is part of your journey. You are **who** you are meant to be and where you are meant to be. Be proud of everything you have achieved.

## 10. ACKNOWLEDGE YOUR JOURNEY

You have done your best and accomplished amazing things, often with challenges that had no reasons. You already know you can overcome challenges. Now you have a diagnosis. Knowledge is growing all the time & will inform and empower your future.

©AusDoCC 2020|PO Box 533|Altona|3018 | <u>www.ausdocc.org.au</u> | Reg: A0057821R



