

Management Guidelines – Adults with a disorder of the corpus callosum (DCC)

Advice for educators and health professionals

Often the universal difficulty, not recognised by professionals, is not how challenged those with a disorder of the corpus callosum (DCC) appear to be but how competent they seem. This is a common assessment in a short consultation and it may take quite some time to scratch below the surface. Not being aware of this may mean that adults with a DCC feel unheard, dismissed and disenfranchised. This is a common and frustrating error and can be very misleading with devastating results.

Transition from paediatric care to adult services is often fragmented and unsupported and adults with rare conditions typically do not fare well. It is important that families, individuals with a DCC and health/educational professionals are always working together as a team with good communication.

<u>WHO</u>	<u>WHAT</u>
<p><u>EDUCATORS</u></p> <p><u>&</u></p> <p><u>HEALTH PERSONNEL:</u></p> <ul style="list-style-type: none"> • allied health • disability • physical health • mental health • chronic health 	<ul style="list-style-type: none"> • The adult with a DCC has learnt to mask deficits to ‘fit in.’ Be astute, diligent and sensitively aware. Don’t let appearances fool you. • Listen to adults’ concerns. Really hear them. Try to read between the lines • Often the person may be having difficulty expressing his/her needs. Gently try to uncover the layers • Be patient as they process your verbal and/or written information and formulate their responses. Some things take longer. Repetition is helpful. • Respect both abilities and needs • Don’t brush off or ignore the challenges expressed by the adult with DCC. They may only be expressing the very tip of any problems and will often give up if issues are brushed aside or trivialised. It is often extremely difficult for them to communicate their needs • Anxiety and social skills deficits are two of the universal impacts for adults • Be aware of the adult with a DCC possibly feeling guilty or inadequate for who they are. Trying to change the person or asking them to conform to societal, stereotypical norms can exacerbate the issues that are caused by a physical brain malformation rather than a set of behaviours. • Respect an accompanying carer or advocate even though you may think they are not necessary • A DCC presents a very broad spectrum so try to avoid preconceived assumptions • Read the growing body of current research on DCC, outlining possible challenges experienced. Listen carefully to the individual. There is not a lot of research on lived experience. • Collaborate and communicate with other professionals who are treating the person • Often the person may have other health related issues for which services are fragmented in our health system. Consider the person as a whole and treat them with that in mind • Assist the person with support documentation for education, employment, NDIS, Centrelink and other relevant needs • Direct them towards meaningful, inclusive opportunities in the community • Try to present of at least one helpful take home strategy or idea each consultation

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Advice for adults with a DCC

- Ask as many questions as you need to. Write the questions down and write the answers too.
- If you don't understand the professional's answer, ask for it to be explained again... and again ... and again, if necessary. Repetition is very important for learning new things
- Ask the doctor to write down and explain unfamiliar words. Stop and ask her/him to expand acronyms or initialisms (letters used instead of the words, e.g. NDIS, ACC, AUSDOCC).
- Take someone with you to appointments if you wish to. It's a team effort and you're the captain.
- Plan what you need to say about taking someone in with you, so you are clear when the professional asks you if you 'want' them to come in with you. Sometimes you may be discouraged from having someone with you. Sometimes you may '**need**' more than '**want**' someone. Ask for some private time too if you need both situations.
- Discuss how you would like your support person to be in the appointment, well before the appointment. It can often be too stressful to do at the last minute
- You shouldn't have to justify your needs and/or difficulties or overexplain how you feel
- If you are not happy with your health professional it is OK to change. You need to have a good relationship with trust and respect on both sides. This can take some time to build up
- If you are not feeling heard or understood after giving it a try, talk to the professional or ask someone to talk on your behalf. If it's not working for you it is ok to change to a different professional
- Sometimes you may not realise what you're having trouble with until it actually happens or others point it out (kindly we hope!). Write lists of things to discuss with your professionals
- Don't let others patronize you by using your strengths as a reason to dismiss your challenges. Build on your strengths as much as possible to create balance but **own** these for yourself.

<u>WHEN</u>	<u>WHO</u>	<u>WHAT</u>
	CENTRELINK	<ul style="list-style-type: none"> • Disability Support Payment • Mobility Allowance • Education Supplement (PES) • Carer Payment for Carers • Carer Allowance for Carers
	OTHER SUPPORT ORGANISATIONS & SCHEMES	<ul style="list-style-type: none"> • National Disability Insurance Scheme (NDIS) • Companion Card • Multi Purpose Taxi Program (Half Price Taxi Card) • Disability parking permit • Qantas Carer Concession Cards for domestic flights with a carer • Concessions for gas, electricity, water, car registration, council rates and driving licences are available in most states. Contact your state and federal Human Services departments for advice • Disability Support Officers in higher education and training institutions
	AusDoCC	<ul style="list-style-type: none"> • Make contact through the website & become a member of AusDoCC • Join the Facebook groups – main and adults with a DCC • Attend meetups, conferences and information events • Read AusDoCC newsletters

Compiled by AusDoCC members consisting of adults with a DCC, parents, partners and friends. Reviewed by AusDoCC advisors including practitioners, researchers, clinicians, educators and allied health professionals. ©AusDoCC Inc.2018