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Communication partner training and me-
working with people with CCD and their
friends and family

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Overview

- Definitions and prevalence of Cognitive Communication Disorder (CCD)
- My experience of providing CPT in clinical practice
- CPT and me
 - **What did I do?**
 - **Why did I do it?**
 - **What did I find?**



What is Cognitive Communication Disorder?

“Difficulties with communication competence (listening, speaking, reading, writing, conversational interaction) that result from underlying cognitive impairments (attention, memory, organization, information processing, problem solving & executive functions)”.

*College of Speech-Language Pathologists & Audiologists of Ontario
CASLPO, 2015 www.caslpo.com*

ASHA, 2004 www.asha.org



What is Cognitive Communication Disorder?

- ‘Before, I used to be quite a shy person. Now, I’m less filtered. I’m more sensitive to things now; I have more anger as well. I’m more likely to perceive an offhand comment in a negative way. I’m not sure why’. (The Observer, 9th Dec 2018, ‘Life after brain damage’)
- ‘I know I’m swearing more and it’s upsetting my husband, but I just don’t give a shit’ (patient on Molly Lane Fox)
- ‘My biggest fear is being the person in the room that people just tolerate’ (brain injury survivor, presented on at the CCD Symposium)



Impact of CCD

- Families report less satisfactory, more frustrating communications. Challenges re-integrating into families and community. (*Crewe-Brown et al., 2011; Parrish et al 2009*)
- More than 50% of people report difficulties with conversation and social relationships. (*Crewe-Brown et al., 2011; Togher et al., 2014; Sveen et al., 2013*)
- 30% have difficulty returning to work after mild brain injury.
 - Communication and verbal skills are the primary factor in return to work
 - Subjective complaints and real world evaluation are better predictors than mechanism of injury, severity or standardised testing
 - (*Douglas et al., 2015; Muelenbroek & Turkstra, 2015; Reitdirk et al., 2013; MacDonald and Johnson; 2005*)



Prevalence of CCD in acquired brain injury

- TBI: 80-100% (*Cherney and Miller, 1991*)
- Penetrating brain injury: (*Coelho et al 2013*) – *all* had problems with discourse. Site of lesion insignificant
- First time stroke: 39-77% (*Hinckley 2014*)
- Right Hemisphere stroke: 66% (*Hewetson et al 2017*)



COMMUNICATION PARTNER TRAINING (CPT)

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Communication Partner Training (CPT) with family and friends

- CPT focuses on natural conversations.
- Therapy is for the person with CCD and their CP
- Outcomes are long lasting and meaningful.
- CPT is proven to be successful for families and paid carers of people with CCD.

(Togher et al, 2004), (Leanne Togher, Skye McDonald, Robyn Tate, Emma Power, and Rachael Rietdijk, 2013), (Nicholas Behn, Leanne Togher, Emma Power & Rob Heard, 2012).



Importance of working with friends

Cognitive-communication disorder results in Loss of friendships and social isolation.

Bogart et al (2012) found that friends of people with TBI facilitated natural conversations

- Personally relevant and highly familiar topics
- Overlook inappropriate comments -? Attempt to save face

Kilov et al (2009) showed that people with CCD can equally engage and enjoy interactions with their friends when given a problem- solving task to carry out with them.

- Equal roles
- Shared knowledge
- Friends took on a supportive role without any prompting from the SLT



Why should we work with friends?

- 1) to help maintain friendships post brain injury
- 2) to improve cognitive-communication competence
- 3) friends provide natural support and facilitation in conversations that may not be as easy for family/ therapists/ paid carers.
 - Personally relevant
 - Shared values
 - Shared interests
 - Shared communication medium (text, facebook, snapchat)
 - Banter
 - Highly motivating
 - Shorland J & Douglas J (2010)



CPT- WHAT DID I DO?

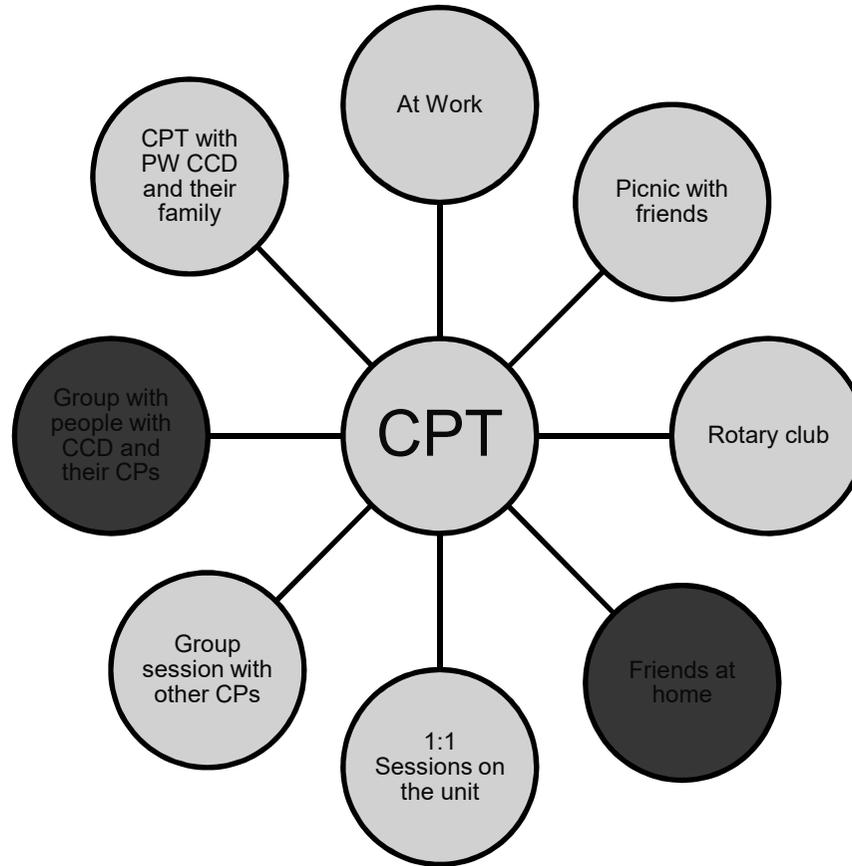


Aphasia

PPA

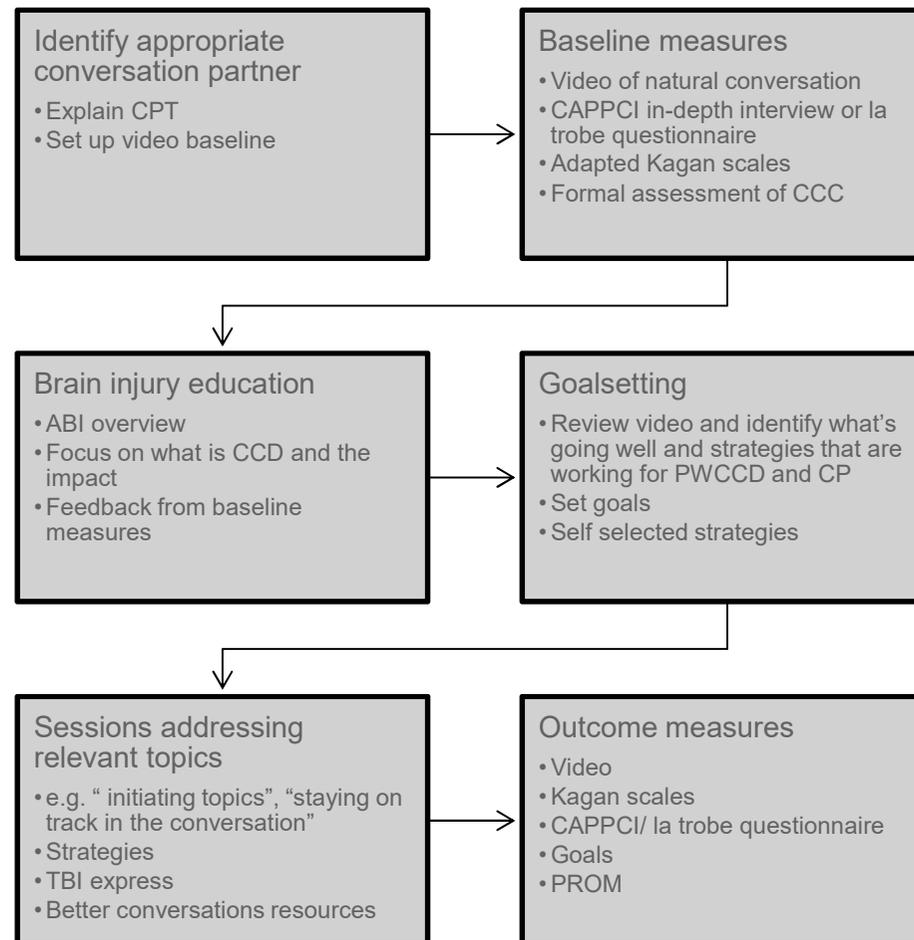
Motor
speech
disorders

CCD





CPT with friends and family: a model for providing the service within clinical practice





Case study : Angie

- Intracerebral haemorrhage on 27/4/16
- Cognitive-communication disorders characterised by
 - reduced facial expression and tone in her voice,
 - difficulties following complex conversations particularly in situations with background noise/ other distractions,
 - difficulties linking topics within conversations and between conversations due to her memory impairment
 - some disinhibition in conversation.
- Angie had some awareness of changes to her communication and was motivated to address these changes.



Goals for CPT

- To be confident to have enjoyable conversations with my husband.
 - Husband to check Angie has understood what's been said
 - To use facial expression and tone in my voice more in conversations
- To be confident to have conversations with my best friends.
 - For friends to remind Angie of relevant information that she may have forgotten
 - For Angie to explain the changes to her communication to her friends (with support from SLT if needed)
 - For Angie to confidently start conversations



CPT sessions

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1 C	Assessment: la trobe questionnaire. Discussion re video.
2 G	Assessment : CAPPCL. Video. Goalsetting.
3 G	Introductions, ABI and its effects, “what makes a good conversation? And what can go wrong?”. Video review
4 G	Cognitive changes after ABI- Effects of CCD on conversation and social relationships
5 G	Effects of CCD changes on social relationships, agree strategies to try
6 G	What is Collaboration? – own ideas. Review of video from TBI express Video
7 G	Collaboration. 1) Collaborative intent 2) Cognitive Support and 3) Emotional Support. Group conversations
8 G	Collaboration. 3) Emotional Support, 4) Positive question style and 5) Turn-taking
9 G	Overview of goals and key themes from the sessions
10 F	Session with couple and their 4 friends in their home.



Session with friends

- 1) Explanation of Conversation partner training
- 2) Ange described her cognitive and communication changes. They then led a discussion re strategies they'd used so far.
- 3) Friends suggested strategies that might help e.g. reminding Ange who you are and what you've discussed previously if relevant.



WHY DID I DO IT?



Why CPT with husband in a group?

- Strong communication skills as a couple before therapy.
- Reported changes to their communication that were changeable with CPT
- Group gave them the opportunity for more in-depth sessions, learning from other peoples experiences.
- Candidacy: both highly committed, reflective and motivated to adapt their communication.
- They loved making videos of their conversations!



Why include friends in CPT?

- Very strong relationship with husband who is main support. However, sometimes intense for both.
- Husband planned to return to work
- Premorbidly she had lots of friends and enjoyed socialising
- Reported feeling embarrassed of cognitive and communication changes in front of friends, so risked withdrawal from the conversation and consequently relationships.



WHAT DID I FIND?



Outcomes from CPT

- Angie, her husband and her friends had a better understanding of Angie's brain injury and her communication changes.
- Conversation seen as "more collaborative"
- Goals achieved. Improved scores on the Ia trobe as reported by husband
- Strategy used with husband and friends: Natural reminder of who the CP was and (if relevant) what they talked about most recently
- Videos of conversations showed strategies being used.
- Both Angie and her husband thought it would be helpful to have similar discussions with other friends independently.



Feedback from friends

Asking Ange
what helps felt
more natural
than they
expected

Focusing on
“collaboration”
really helped

Hearing about
brain injury from
Ange was more
meaningful



Future plans

- Establish a CPT clinic at the National for people with acquired communication disorders across the pathway.
- Establish CPT as part of the ICAP at the National
- Focus group with friends of people with CCD re what types of CPT they can engage with/commit to:
 - Group/ 1:1
 - Number of sessions
 - Consider skype sessions
 - Consider timing and location of therapy



DISCUSSION



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