 Cognition for Carers

The word cognition comes from the Latin ‘cognoscere, which means ‘get to know’. Our definition of cognition nowadays refers to ‘the mental action or process of acquiring knowledge and understanding through thought, experience, and the senses.’ It is also about responding to this information. Like a computer, cognition can be thought of in terms of the input, throughput and output of our control centre, the brain and can affect any aspect of day to day living.

Your loved one may or may not be affected cognitively as PSP and CBD present differently with each person. As a carer, dealing with any cognitive issues can be some of the most trying aspects of supporting someone with PSP or CBD. Managing poor insight, lack of risk awareness or inability to follow advice, can be highly stressful and worrying. There may be confusion about whether changes are due to the condition, or a reaction to the diagnosis or disability. It can also be difficult to attribute behaviours to PSP or CBD, rather than the person deliberately doing something.

When there is cognitive impairment, these are some of the common impacts of PSP or CBD and suggestions that may help:

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| COGNITIVE ISSUE | STRATEGIES FOR CARERS |
| Processing complex information | * Breakdown information into smaller chunks. * Try using clear written material instead of relying on verbalising all the details. * Take time to ensure understanding at each step. |
| Decision-making | * Focus attention on relevant issues or tasks. * Check there is comprehension of the consequences of any actions or decisions. * Give choices with one or two alternatives. * Avoid open-ended questions, instead ask questions that require yes/no answers or a simple facial response, nod or gesture like thumbs up. * Be prepared to wait a longer time for an answer. |
| Perseveration (having difficulty shifting attention away from an activity when started) | * Help to change focus by introducing a new physical task, move room or surroundings. * Change the feel of the environment for example by using music. * Surprise with something or someone different. |
| Difficulty learning new tasks or techniques | * Encourage to stop and think how to approach what needs to be done. * Workout smaller steps. * If verbal and non-verbal prompts aren’t working, try to show what to do. * Try organisational aids like phone app reminders or a calendar. * Lots of practice to reinforce new learning. * Ask professionals to demonstrate so you can refer back to what they did. |
| Impulsivity | * Encourage to pause / stop and think. * Supervise activities. * Prompt to take care, not risks. * Check answers are what the person really means e.g. as yes can get mixed up with no. * Use safety aids to help - such as seatbelts on wheelchairs. |
| Change in eating habits | * Use smaller utensils to reduce impulsive food cramming. * Encourage to put down cutlery in between mouthfuls to give enough chance to chew and clear food. * Reduce distractions at mealtimes to support concentration. * Drink between bites. |
| Word finding | * Allow for the extra time person needs to find the right word. * Use pictures to help person express or point out what they are aiming to say. * Encourage gestures. |
| Passive and withdrawn | * May be having trouble initiating activities so try modelling the responses you want to encourage, e.g. introduce to or demonstrate a task. * Use visual and verbal cues to prompt. * Have regular routine at similar times to get into a familiar rhythm of doing. |
| Egocentricity (e.g. loss of concern for others) | * Know uncaring responses are not personal but often down to thought processes changes, the symptom of apathy or altered ability to use facial expressions. * Support person’s understanding with very simple explanations behind why something matters to you or others. * Demonstrate you can’t do something, showing the person so they can see. * Your loved one may not be able to understand reasoning or argument, if so, avoid trying to help them to conceptualise or appreciate the situation. * Express your feelings simply, as matter of fact with calmness. |
| Less able to respond appropriately e.g. loss of control | * Explain to others that responses are symptomatic of changes in the brain due to the condition, so they are not misinterpreted. * Use strategies to divert or redirect your loved one’s attention. |

Further Information

PSPA have question and answer sessions with professionals on the You Tube Channel, some of these cover cognitive and behavioural changes amongst many other topics. Follow this link to explore the videos and watch <https://www.youtube.com/@pspacharity>

Adapted from PSPA’s ‘Guide to Cognition in PSP & CBD For the Primary Healthcare Team’, which can be found on PSPA’s website.

Jacqueline Ede, PSPA