 Dealing with Unusual Behaviours

Unusual behaviours do not affect everyone with PSP or CBD, however, they can generate themselves as a part of the disease process. It can be very challenging for carers dealing with strange or unexpected responses, especially if the unusual behaviour is repetitive, unsafe, disinhibited or causes distress to the individual, yourself or others. 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 place the reason for your loved one’s behaviour as down to PSP or CBD, but it is most likely they no longer have the capability to really understand the action, impact or consequence of what they are doing or be able to prevent it from happening.

This handout follows on from the ‘Cognition for Carers’, where we covered aspects like impulsivity, focus, concentration, changes in eating habits, decision-making, passivity, word-finding, and loss of empathy.

Possible Reasons for Unusual Behaviour

There are different schools of thought, however unusual behaviours are associated with the neurological degeneration process of PSP / CBD and can be viewed as:

* Neurological diseases causing what are termed as *purposeless behaviours*, such as constant chatter, seemingly without reason and involuntary.
* Other behaviours may be a result of discomfort, distress or pain.
* Or behaviours could be due to frustration, anger or at not being able to communicate.

General Strategies for Carers

1). **Diary** - Keep a note of when the behaviour happens, there may be a pattern. Look at questions such as: Does this occur at a certain time of day or night? Before or after doing something? At times of stress or excitement? Are they trying to communicate a need?

2). **Distraction** – Focus attention on something else, a different task, activity, place or person.

3). **Reassurance** – Provide a comforting presence and words in a soothing tone of voice. Being in familiar instructions

4). **Simple Instructions** – There can be a delayed response in someone being able to process the idea they need to do something or change their behaviour. Give a simple instruction and then wait, which may take some time, repeat if need be.

5). **Sleep** – Many report an increase in unusual behaviours when fatigued, overtired or not getting enough sleep. Encouraging the benefits of rest and seeking help for disordered sleep patterns.

6). **Remove the cause of distress** – If you can identify a trigger for unusual responses, minimise or take this away where possible.

7). **Source help from mental health staff** - In terms of neuropsychiatric symptoms, research recommends: *“Given the prevalence of neuropsychiatric symptoms in PSP, these patients are expected to be frequently seen by psychiatrists and other mental health professionals for symptom management and increased quality of life”.*

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| UNUSUAL BEHAVIOUR | POSSIBLE REASONS FOR | STRATEGIES FOR CARERS |
| Excessive Gripping or Grip Force:  Wrists, hands, rails, equipment etc. | The cortico-spinal tract plays a role in our level and use of grip force, which can be affected by neurological changes.  <https://www.sciencedirect.com/science/article/pii/S1053811921000124> | * Clear, simple instruction to ‘let go’, when person no longer needs to hold on, waiting for response. * Ask to hold something else or make a physical gesture e.g. wave goodbye to a carer. Again give time to respond. |
| Vocalisations:  Humming / Groaning / Grunting / Shouting / Screaming / Stammering / Chattering / Wailing | Movement Disorders Clinical Practice Journal:  ‘Voluntary Inhibition of Involuntary Groaning in Progressive Supranuclear Palsy’  Includes video example of 66 yr old gentleman with PSP  <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6336375/#:~:text=Constant%20grunting%20and%20groaning%20are,progressive%20supranuclear%20palsy%20(PSP>) | * Breathing techniques can be useful but often require much sustained effort and a work in brief periods of intense concentration. Illustrated in video: <https://movementdisorders.onlinelibrary.wiley.com/page/journal/23301619/homepage/mdc312598-sup-v0001.htm> * British Medical Journal ‘Progressive Supranuclear Palsy Diagnosis & Management’ Rowe et al <https://pn.bmj.com/content/21/5/376>   “Keening, wailing, and perpetual ‘stammer’: Some patients utter repetitive, loud vocalisations for minutes or hours on end. This is exhausting to be near, and may be the last straw for carers at home... It resembles an extreme stammer, but with a quality that might suggest distress. It helps to explain to carers that it rarely indicates distress, and that it is part of the illness. If worse at night, then sedation may help”. |
| Emotional Lability:  Sudden, inappropriate or uncontrollable crying, laughing  Also called pseudobulbar affect (PBA). Pseudobulbar affect typically occurs in people with certain neurological conditions or injuries, which may be affecting the way the brain controls emotion | British Medical Journal:    “People with PSP may suddenly cry intensely, appearing very distressed and tearful. This pseudobulbar affect is upsetting to witness but does not always reflect a patient’s inner distress. If asked, between the tears, they may deny feeling upset, or be aware of a surge of emotionality. The emotional lability can be laughter but is more often crying”. | * ‘Progressive Supranuclear Palsy Diagnosis & Management’ Rowe et al <https://pn.bmj.com/content/21/5/376>   “If it is frequent, or distressing, then consider treatment; low dose citalopram (10–20 mg) is usually very effective.” |
| Face-Related:  Frequently touching face, holding lips or cheeks. Biting inside cheeks. Sucking or licking lips. | Some body-focused repetitive behaviours are attributed to anxiety. Others due to medication side-effects. However, touching our faces is a reflex, which begins in utero when the sensory nerves develop. PSP & CBD can affect the basal ganglia which controls desired movement. | * Try general techniques listed above, particularly distraction. * Provide with objects of different textures to hold or do something with, such as folding material or kneading dough. * Ensure hydrated, with mouth and eyes kept moist. |
| Repetitive Actions / Activities:  Turning things on and off like remote controls, taps, switches etc. | From PSP Australia  “A small number of people with PSP may be affected by an inability to 'switch off' an action, resulting in repetitive movements or actions. These may include repetitive plucking at clothes or repeatedly saying the same word”. | * PSP Australia “Sometimes distraction or a change of topic may stop this behaviour”.   <https://psp-australia.org.au/docs/2.5%20Managing%20changes%20in%20personality,%20mood,%20thinking%20and%20behaviour.pdf> |

Resources

**Alzheimer’s Society** ‘Changes in Behaviour’ Handout

Covers: Repetitive behaviour — Trailing, following and checking — Hiding, hoarding and losing things — Losing inhibitions — Accusing — Agitation including restlessness — Aggressive behaviour — Sundowning, sleep disturbance and waking up at night — Social withdrawal.

<https://www.alzheimers.org.uk/sites/default/files/2018-10/525LP%20Changes%20in%20behaviour.pdf>

**MIND** ‘Responding to Unusual Behaviours Linked to Mental Illness’ Handout

Covers: Delusions – Paranoia – Low Motivation – Risky Behaviour - Anxieties

Although this refers to symptoms of mental illness, they also may be elements that your loved one experiences. This handout includes lots of ideas on techniques and approaches that could be tried, and an example of a ‘Behaviour Diary’ to note what is happening, what has helped and what hasn’t worked.

<https://www.rethink.org/advice-and-information/carers-hub/responding-to-unusual-behaviour-linked-to-mental-illness/>

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