Dealing with the Ongoing Impact of Caring for People with PSP & CBD

There are some common areas of concern raised by those caring for people with PSP & CBD. Here are some of those identified and possible ideas to meet challenges:

Areas of Concern	Solutions to Explore
Uncertainty of how long your loved will experience different symptoms, and when their presentation will next change.	Although it is not predictable and everyone is different, decide on specific questions to ask professionals involved. Some carers like to keep logs or diaries to monitor changes and spot patterns. Sometimes those who haven't seen your loved one for a while can offer helpful feedback.
Worry about accessing services as and when they are needed, getting caught in re-referral cycles and waiting lists.	Find someone who can help you to co-ordinate support, some carers have found this help through a community matron, hospice staff, GP, neurologist, community neuro team, Parkinson's Specialist Nurse or PSPA Helpline Care Navigator.
Whether paid carers who have got to you know you and your loved, coming out regularly to home or based in residential or nursing homes, will be there to keep supporting you in the future.	• If employing carers privately, try to ensure you have a minimum of three different carers supporting so they all know the needs of your loved one. • If you receive carers from an agency talk to them about having well-established staff assigned. • Be aware, if care is to be paid for by CHC funding, they come from an approved agency, which might not be who you use. Request having a handover period.
Lack of paid carers available in the local area.	Advertising on local social media has helped some find suitable carers with experience in

	neurological conditions. Asking Adult Social Care/ Social workers to recommend agencies and where to find carers. Council websites usually have an approved list.
Reduced social circles, and therefore support, due to being less able to keep up hobbies, go to work, volunteer, be out in the wider community and so on.	• Attend PSPA Carers Support Groups online or in-person if there is one in your area. • Investigate what your local carers association or hospice provide. • Call the PSPA Helpline to talk, you don't need to be ringing about a specific issue, you can just chat. • Use the online forum for PSPA Health Unlocked. • Prioritise time to speak with trusted friends or family, tell them how you feel and consider asking for help. Some people don't want to intrude and would like to help but prefer to be asked to do a specific task. Try being direct. Speak up and express what is going on for you.
The fatigue of caring increases the risk of burnout and compassion fatigue.	Have a carers assessment and ask for this to be repeated if things have changed. Carers assessments should consider breaks, respite and support for you. See article and list below to help identify the warning signs for compassion fatigue and burnout.

ARTICLE

Compassion Fatigue: When Caregivers Go Beyond Burnout

Carol Bradley Bursack

From: "Caregivers Share Their Personal Stories"

Most caregivers experience times when the fatigue and frustration of providing care for a loved one can border on caregiver burnout. Even though people handle caring for multiple elders and their unique needs reasonably well, there have been moments when they've wondered how much longer they could keep it up. During those times, I came dangerously close to burnout, but I have always gotten through with a focus on faith, respite and self-care. People have some to realise that when their caregiving days end there is another stage that is more severe than caregiver burnout—one that can be extremely scary. Many caregivers have told us over the years that they felt they had progressed beyond burnout, and it is important to understand that there is a term for this feeling: compassion fatigue.

Caregiver Burnout vs. Compassion Fatigue

Most caregivers have probably heard about burnout, but many are unfamiliar with the concept of compassion fatigue and how these two conditions differ. Dr Beth Hudnall Stamm, Ph.D., retired professor and researcher in the field of traumatic stress, defines compassion as “feeling and acting with deep empathy and sorrow for those who suffer.” Family caregivers are often compassionate individuals by nature. This characteristic is typically considered an asset, but it leaves them at risk for the negative “costs of caring” for others.

“Compassion fatigue is an extreme state of tension and stress that can result in feelings of hopelessness, indifference, pessimism and overall disinterest in other people’s issues,” explains Christine Valentin, LCSW, owner of a private counselling practice in New Jersey where she works with adults experiencing anxiety and/or depression related to work, relationships, caregiving and chronic diseases.

Unlike caregiver burnout, compassion fatigue is a secondary traumatic stress disorder that results from exposure to another person’s traumatic experience(s) and creates high levels of emotional stress. Compassion fatigue is primarily considered an occupational hazard for individuals who encounter stress and trauma in their work environments, such as nurses, mental health professionals, correctional workers and child protection workers. In fact, it is a contributing factor in why many people in these fields leave their jobs to pursue other kinds of work.

Unsurprisingly, family caregivers are also susceptible to this occupational hazard. Consider an adult child whose “job” is providing full-time care for a parent with Alzheimer’s disease and arthritis. They may not be administering high-level skilled nursing care, but they are still caring for someone in emotional and physical distress with limited options for providing comfort. While there are many similarities between professionals in high-stress jobs and family caregivers, the latter do not enjoy the same preventive measures that many employers offer, such as mental health days, peer support and professional counselling. Forgoing breaks, respite and meaningful support adds up, affecting one’s overall quality of life.

“While some may simplify and attribute compassion fatigue to frustration and/or resentment, it is important to understand that this is not something that occurs overnight," Valentin notes. "It is the cumulative result of days, weeks, months and years of managing caregiving responsibilities that are often unrecognised, seemingly endless, emotionally demanding and physically exhausting. As a result, it is not uncommon for feelings of frustration, resentment, hopelessness, guilt and/or a diminished sense of self to manifest."

Compassion fatigue also differs from burnout in that it causes caregivers to experience a weakened sense of empathy for those in their care. This is an important distinction because most family caregivers take on their role out of love. Unlike nurses and social workers who are not tasked with caring for individuals they know personally, informal caregivers look after their family members and even close friends. Family caregivers are emotionally invested in their loved ones' well-being, leaving them especially vulnerable. One study that examined 30 years' worth of existing literature on compassion fatigue in professionals acknowledged that, "Compassion fatigue occurs when a care-giving relationship founded on empathy potentially results in a deep psychological response to stress that progresses to physical, psychological, spiritual, and social exhaustion in the family caregiver."

While compassion fatigue exists on a spectrum, once one has developed a certain level of indifference or insensitivity to a care recipient, it is wise to step back from the caregiving role at least temporarily.

"With regard to caregivers, compassion fatigue can manifest through actions like yelling, hitting or neglecting a loved one," Valentin describes. "Basically, any action that is not characteristic of the caregiver's typical behaviour but is now present and consistent could be considered a result of this condition."

How to Recognise Compassion Fatigue

There are many red flags that point to the onset of burnout and especially compassion fatigue, but caregivers must know what signs to look for and be able to detect them in their own behaviour in order to act on them. Both the information and self-awareness are key to preventing long-lasting emotional issues and even stress-related physical illness.

"Being proactive is one of the best ways to combat compassion fatigue or at least prevent it from getting out of hand," urges Valentin.

Warning Signs of Compassion Fatigue in Family Caregivers

- Feeling overwhelmed, exhausted and drained
- Avoidance and not wanting to be around your loved one (choosing to work late, daydreaming about no longer having to care for them, etc.)
- A decrease in patience and tolerance
- Angry outbursts that are uncharacteristic of your behaviour
- Cynicism and hopelessness
- Heightened anxiety
- Impaired ability to make care decisions
- Difficulty sleeping
- Physical symptoms, such as headaches or gastrointestinal issues.

Using Self-Care to Prevent Compassion Fatigue

If you begin noticing any of the above signs, the next step is to make yourself a priority and tend to, at the very least, some of your needs. Remember that compassion fatigue is not black and white—it is a continuum. Each caregiver has different limits, and there are times throughout the caregiving journey when one's susceptibility to stress will increase and decrease. Many will experience these warning signs from time to time. These feelings and behaviours are undesirable but common for a demographic that is so overworked and has so few resources available. When the list above begins to describe daily life rather than fleeting behaviour on a bad day, it is absolutely time to act.

"Allocate at the very least five minutes each day to eat, pray, dance, laugh, sleep, walk, sing, read an inspirational quote, meditate or chat with a friend. Give yourself a mental and physical break from actively caring for others," Valentin encourages. "The ability to do so in small bursts can allow you to begin the practice of adequately caring for yourself and hopefully get you to increase these efforts moving forward."

While many caregivers feel that self-care is impossible, it is important to understand that if you don't allocate this time, no one else will. As mentioned earlier, in fields where compassion fatigue is prevalent, employers take care to enact policies that help prevent physical and emotional stress from negatively impacting employees' work, attitudes and personal lives. It is up to family caregivers to be their own advocates and implement care plans that allow for regular breaks, self-assessments, respite time, professional and peer support, and changes in workload. Making these changes will not only help to minimize caregiver burden but also allow you to create a more positive and rewarding caregiving experience for you and your loved one.

“Having a non-judgmental outlet to express your thoughts can be very beneficial as well,” notes Valentin. “Outlets like writing in a personal journal, talking with a confidant or seeking advice from a healthcare professional can help you with processing your feelings and offer a safe place to release pent up thoughts and emotions.”
If you find yourself already experiencing these feelings and symptoms, then seek professional help and respite care immediately. “Believing the feelings will not subside, especially while you are still actively caring for a loved one, can cause some individuals to become depressed, develop panic attacks and/or potentially put their loved ones in harm’s way,” Valentin warns.

Once you feel refreshed and regain a sense of balance and perspective, you can make some important care decisions that will help prevent future instances of compassion fatigue, such as opting for permanent placement in long-term care or fortifying your care plan with regular breaks and respite. These care decisions will help set you on the path for a different kind of caregiving experience—one that is defined by compassion satisfaction not fatigue.

Questions to think about

1. What has been/is helpful to you?
2. What are your lifelines?
3. What does successful caring look like for you?
4. Who supports you?
5. How do you look after yourself?
6. What else could you try?

List of Tips from Carers for Carers

- Speak up and express to others what is going on for you
- Reach out for support and that enables others to help. It can be hard to say how you are feeling to family and friends so talking to an ‘outsider’ can help
- Take up or continue hobbies and activities you enjoy. Have something that is just for you. Something you can get lost in
- Music can lift both mood and spirits. Music can help in a way that words can’t
- Take a breath outside. Stop and listen to the sounds around and feel part of a bigger world.

TRY VISUALISATION

WAVE IT AWAY - Lie down comfortably, resting on your bed. Use the sounds of the sea from YouTube or other internet music sites or try a CD. Imagine warm waves coming up and gently lapping at your feet, then recede again, picture this a few times, then imagine the water coming up to your ankles and away again, gradually work up to your calves, knees etc to your waist. Imagine they are washing away any stress, worries or tension. Take around 20 minutes to get the benefits.

LET THE AIR TAKE IT - Light a candle for couple of minutes to let things in your mind go, send them out and up. Then blow out the candle.

USING GRATITUDE

Have a go with the ‘Three Things’ method at the end of each day.

Think of:

1. Something that went well today...
2. Something you’re grateful for....
3. Something you’ve enjoyed....

Shift your focus from lack and loss to value and appreciation. There has been much positive research about how helpful this can be for our wellbeing.