

# TraPCAf & Parkinson's Africa Virtual Support Group Series 2024

## Session 5: Emotional Well-being in Parkinson's

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From Newcastle. **For the world.**

## Outline of session:

- Understanding Emotional Impact of Parkinson's Disease in people with Parkinson's and their caregivers.
- Coping strategies for people with Parkinson's
- Coping strategies for caregivers

## Objectives of the session:

To understand;

- How to cope with the emotional and psychological impacts of PD
- Ways to maintain a positive outlook on life
- How to maintain your emotional and mental well-being



# Ice Breaker

Share with us one thing you are thankful for today



## Understanding Emotional Impact of Parkinson's Disease in people with Parkinson's and their caregivers

Living with Parkinson's disease and providing care for someone with the condition can evoke a range of emotional experiences. Here are some varied emotional experiences that individuals with Parkinson's and their caregivers may face:

**For individuals with PD:**

- **Frustration**- difficulty in performing everyday tasks
- **Isolation**- changes in mobility and energy levels may contribute to feelings of isolation and withdrawal from social activities.



- ***Fear and anxiety***- uncertainty about the progression of the disease and its impact on daily life.
- ***Grief and loss***- adjusting to the loss of certain physical abilities or aspects of one's previous lifestyle can evoke feelings of grief.
- ***Anger***- coping with the challenges of Parkinson's may result in occasional feelings of anger or frustration.
- ***Hopelessness***- some people may experience moments of hopelessness, particularly during challenging periods.
- ***Acceptance***- over time, individuals may go through phases of accepting and adapting to their new reality.



## For Caregivers

- **Stress**- due to the demands of caregiving
- **Guilt**- caregivers may feel guilty about not doing enough or about needing respite for themselves
- **Worry**- concerns about the well-being of the person with Parkinson's and the future can be a constant source of worry
- **Exhaustion**- providing care can be physically exhausting, leading to feelings of fatigue and burnout
- **Loss of independence**- caregivers may experience a loss of personal freedom and independence



## For Caregivers cont.

- **Role strain**- juggling multiple roles, such as caregiver, family member, and professional, can create strain
- **Sadness**- witnessing the challenges faced by the person with Parkinson's can evoke feelings of sadness
- **Grief and loss**- thoughts of their loved one losing their past abilities
- **Joy and fulfilment**- despite the challenges, caregivers may also experience moments of joy and fulfilment in their caregiving role



## Coping strategies for people with Parkinson's

How do we ensure that we learn to live with Parkinson's in the best way possible? Through;

1. **Acceptance:** by allowing ourselves to grieve the loss of our previous abilities, good health and accepting that the disease is part of us now and our loved ones.
2. **Seeking support from family and health professionals such as neurologists, nutritionists and psychologists.**
3. **Embracing a positive mindset-finding joy in daily life**

By:

- ✓ Celebrating small victories
- ✓ Setting realistic goals





- ✓ Engaging in hobbies
- ✓ Focusing on abilities
- ✓ Joining a support group
- ✓ Positively affirming yourself
- ✓ Staying informed about Parkinson's- its research and treatment developments to keep hope alive.
- ✓ Expressing your emotions
- ✓ Maintaining social connections- risk of social withdrawal due to PD
- ✓ Practice gratitude journaling- example, keep a gratitude journal to focus on positive aspects of life and acknowledge small joys.
- ✓ Staying engaged in community activities to foster a sense of belonging.
- ✓ Adopting a solution-focused approach- approach challenges with a solution-focused mindset, focusing on what can be done.



## Coping strategies for caregivers

1. **Establish a support system**- have family, friends and a **support group** to help whenever you get overwhelmed, need help with the caregiving role and connect with other people.

Connecting with others means:

- ✓ Shared understanding- other people who are on a similar journey can empathise with the day-to-day struggles, offering a profound sense of understanding and validation.
- ✓ Reduced isolation- knowing you're not alone in your experiences provides comfort and strength.
- ✓ Exchange of practical tips- you will get tips and coping strategies that others have found effective.
- ✓ Emotional support- sharing emotions, fears, and triumphs with those who understand creates a safe space for emotional expression.
- ✓ Building lifelong friendships



## Importance of support groups:

- ✓ **Information sharing**- PD support groups offer platforms for sharing information on Parkinson's developments, treatment options, and practical tips for daily living.
- ✓ **Sense of belonging**- reinforces an understanding that everyone in the group is navigating similar challenges.
- ✓ **Peer mentorship**- people who have been living with Parkinson's for a longer duration often become mentors, offering guidance and reassurance to those who are newly diagnosed.
- ✓ **Stress reduction**- knowing that one is part of a community that cares often helps reduce stress.



## Coping strategies for caregivers (cont.)

2. *Balance responsibilities*- do not neglect personal well-being and set realistic goals

3. *Practise self care*- Example;

- ✓ Prioritising your health
- ✓ Taking regular breaks to rest and recharge
- ✓ Delegating- ask for help and delegate tasks to others, whether it's family members, friends, or hired assistance, to share the caregiving responsibilities.
- ✓ Maintain hobbies and interests
- ✓ Seek professional guidance- consider talking to a counsellor or therapist to navigate the emotional challenges of caregiving.
- ✓ Stay connected socially- helps to prevent isolation and provides emotional support



## Coping strategies for caregivers (cont.)

### 2. Practise self care (cont.)

- ✓ Educate yourself- stay informed about Parkinson's disease. Understanding the condition can help you anticipate and address potential challenges.
- ✓ Express your feelings- don't bottle up your emotions. Find healthy ways to express your feelings, whether through journaling, talking to a friend, or seeking professional help.
- ✓ Practice gratitude, self compassion and stay positive- focus on the positive aspects of caregiving. Celebrate moments of joy and accomplishment, and recognise the meaningful impact you have on your loved one's life.



## Practising Gratitude

Gratefulness, thankfulness, appreciation....

"In every thing give thanks: for this is the will of God in Christ Jesus concerning you." (1 Thessalonians 5:18)

Expressing gratitude and cultivating it in ourselves has been linked with increased happiness, improved physical and mental health, higher self esteem, and life satisfaction.



Examples of gratitude activities:

- **Gratitude Journaling**- keeping a daily or weekly journal where you write down things you are grateful for. One gets to reflect on specific experiences, people, or moments that brought joy or made a positive impact on their day.
- **Gratitude Jar**- have a jar/cup where you place notes inside expressing things you are thankful for. Read these notes periodically to revisit moments of gratitude.
- **Gratitude reflections at bedtime**- Before going to sleep, reflect on three things that brought you joy or gratitude during the day. This can help promote positive dreams and a restful sleep.
- **Gratitude Letters/ texts/ calls** - Write a letter, send a short message or call someone who has positively influenced your life and express your gratitude.
- **Gratitude Board**- Create a visual gratitude board by collecting images, quotes, or symbols that represent things you are grateful for. Have the board in a place you can easily see.



## Closing and Reflection

### Self compassion activity

Recite, "May I be safe. May I be peaceful. May I be kind to myself. May I accept myself as I am."

- What is your key takeaway from this meeting and what mostly resonated with you?





# Thank you!

For more information and resources visit: [www.parkinsonsafrica.org](http://www.parkinsonsafrica.org)

Get in touch if you have a query: [tania@parkinsonsafrica.org](mailto:tania@parkinsonsafrica.org)

Please complete the post session questionnaire!

