

MOOC 13 Caregiver Stress

Chapter 3: How to Be a Cheerful Caregiver?

In previous chapters, we have learnt about what caregiving is and the various burdens of caregivers. Now, let's listen to the voice of three family caregivers. What are their challenges when looking after their loved one? How do they feel?

Reflection 1


Caring for a person with dementia is unlike caring for someone with any other condition or disability, due to the complex, unpredictable and progressive nature of dementia. Refer to the sharing, there's no doubt that the caregivers felt high level of stress. Could you identify their common challenges?

Common Challenges that Caregivers of Dementia Person Face:

- Psychologically exhausted caused by countless sleepless nights due to wandering and a never-ending list of concerns.
 - Physically exhausted caused by demanding caring tasks of basic needs.
 - Stopped socializing and neglected own health caused by round-the-clock caring tasks.
 - Frustrated emotion caused by behavioral and psychological symptoms (BPSD) of dementia e.g. agitation, aggression, hallucination
 - Guilt feeling when recognizing the need for additional help, e.g. the decision on long term residential care.
- ◆ To further explore the caregiving challenges and tips about taking care of a person with dementia, please go to [The demand on your care—Care of a PERSON with dementia.](#)

Reflection 2

From the sharing, the wife of Mr. Li, Ms. Chan and Ms. Kwan have also come across a period of feeling guilty. In fact, it is not uncommon for the caregivers to have guilty feeling in the caregiving journey. They may believe that they are not doing enough for their loved ones. They may feel they've failed to meet the expectations of others and themselves. There can also be tremendous guilt when they have to place their loved one in residential care homes. Do you have any advice for them to cope with the caregiver guilt?

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Ways to cope with guilty feeling

- Acknowledge the guilt.
- Accept mistakes. Encourage them to recognize their strengths and don't focus on the negative.
- Admit the limit of informal caregiving. Set the boundaries and seek help when necessary. The choice of residential care service may be a way out. It's not necessary to feel guilty. Not to view it as a failure.
- Start the long-term care planning earlier which can help to identify the limitation of the caregivers and find ways to fill the gaps of caregiving.
- Build up a healthy coping mechanism. (Will be further discussed in this chapter)


Reflection 3

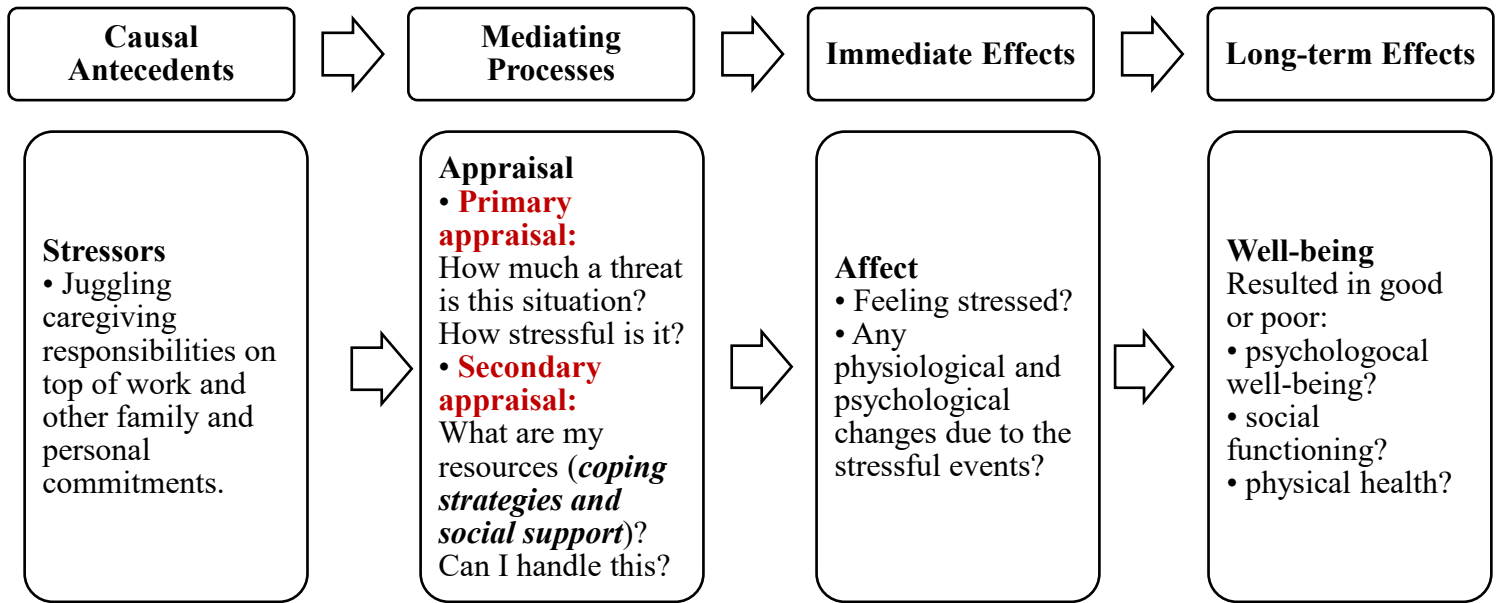
If you were the healthcare professional who was responsible for the discharge of Mr. Li's father-in-law who suffered from stroke, the mother of Ms. Chan with dementia and broken wrist after fall and the mother of Ms. Kwan with dementia and fracture after a traffic accident, apart from the pharmacological treatment, medical follow-up and laboratory investigation, do you have any advice for the caregiver in your discharge plan?

Can you try to put Mr. Li and his wife, Ms. Chan and Ms. Kwan into the Stress-coping Model before creating your plan?

Stress-coping Model

- According to the cognitive phenomenological theory of psychological stress, behavioral, physiological and psychological responses are the results of primary and secondary appraisal process between the person and the environment.
- Primary and secondary appraisals help to determine if situations are irrelevant, beneficial or threatening by taking into consideration of personal and environmental factors and coping mechanisms.

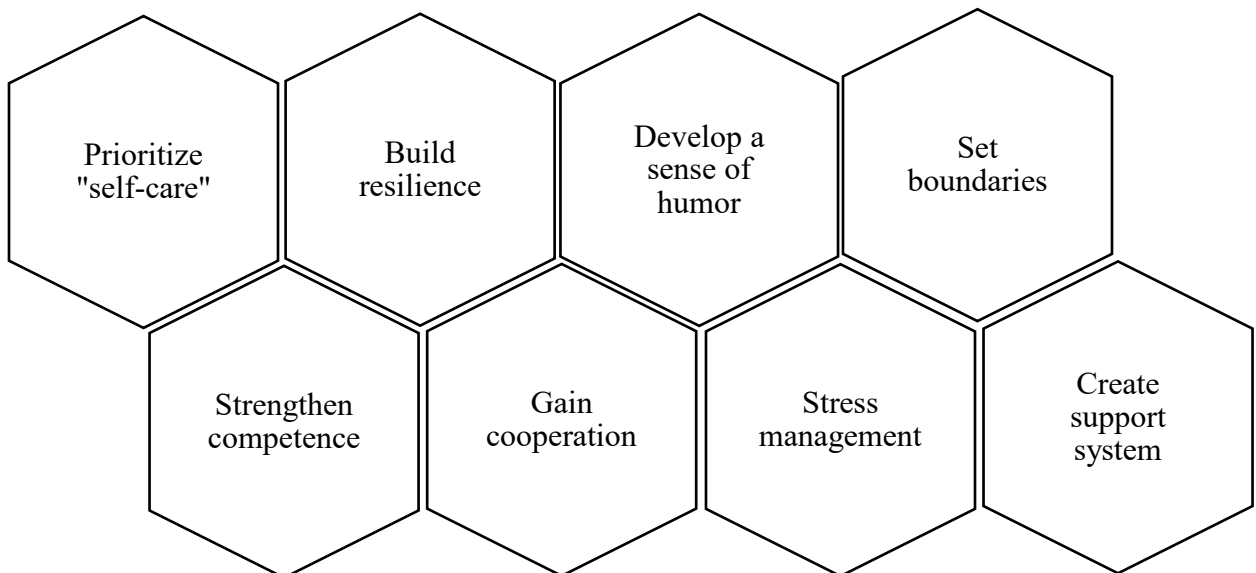
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Coping strategies are always crucial to turn the caregivers from “Stress” to “Cheerful”. After passing through the difficult period of caregiving, caregivers Mr. Li, Ms. Chan and Ms. Kwan looked back and shared some tips on coping strategies to us.

In this chapter, let’s learn about how to be a cheerful caregiver! Here we advise 8 coping strategies for caregivers.

8 Coping Strategies for Caregivers



1. Prioritize “self-care”

1.1 Why “self-care”?

We always heard that “The care you give to yourself is the care you give to your loved one”.

Unfortunately, research has shown that family caregivers struggle with promoting their health. (Acton, 2002)

Caregivers:

- have lower levels of self-care.
- are less likely to engage in preventive health behaviours.
- always neglect their own health and well-being as responsibilities and tasks pile up.

(Schulz, et al., 1997)


Without a good “self-care”, not only physical health will be negatively affected, but also leads to irritability and inappropriate anger which induces more guilt. Therefore, self-care should always be a top priority for caregivers to avoid caregiver fatigue. It helps maintain a better physical and mental condition to provide care and attention to their loved ones.

1.2 Self-care assessment

A self-care assessment often helps caregivers recognize how well they are currently taking care of themselves. As caregivers are likely too busy to manage their own health, some simple self-assessment tools can easily and instantly indicate that if they take good care of themselves or start to affect their health. It can be a good motivating factor to raise their awareness to self-care.

Quick tools:

- [How Well Do You Take Care of Yourself?](#)
- [Zarit Burden Interview- assessing caregiving burden](#)
- [【沙氏負荷量表 - 簡化版】\(Chinese version\)](#)

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1.3 How to take good “self-care”?

To maintain well-being, caregivers should:

- eat well & exercise regularly.
- get adequate sleep.
- have regular check-ups.
- avoid self-medicating with alcohol or drugs.
- schedule “Me Time” to do what you want that brings you a bit of joy.
- build up healthy coping mechanism for stress.

Remember, being kind to yourself builds the foundation to self-care.

2. Build resilience


Resilience is the process of adapting well in the face of adversity, trauma, threats or other significant sources of stress.

(American Psychological Association, 2020)

- It relates to the way people think and behave in response to these life adversities.
- Resilience is not something people are born with.
- We may develop and strengthen it through learning.
- Especially during the COVID-19 pandemic, healthcare workers who are trained in resilience have less anxiety, depression and stress related symptoms. (Baskin & Bartlett, 2021)

10 strategies to build resilience:

1. Make connections.
2. Avoid seeing crises as insurmountable problems.
3. Accept that change is part of living.
4. Move toward your goal.
5. Take decisive actions.
6. Look for opportunities for self-discovery.
7. Nurture a positive view of yourself.
8. Keep things in perspective.
9. Maintain a hopeful outlook.
10. Take care of yourself.

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Further reading:

American Psychological Association. (2020). *Building your resilience*.
<https://www.apa.org/topics/resilience/building-your-resilience>

3. Develop a sense of humor

One of the best defenses of stressors is a sense of humor. Humor is an attitude, a state of mind, a way of placing in perspective the events life hands us.


Humor and laughter can:

- ease tension
- relieve fear, anxiety, anger, and depression
- convey goodwill
- defuse negative emotions
- relieve stress and sadness
- help reassert control
- increase flexibility in problem solving by helping you see things from another perspective
- perk up the immune system
- release natural painkillers (endorphins) in the body

To keep humor in your life:

- Read funny books
- Watch funny movies
- Collect funny jokes and stories
- Send funny cards and e-mails (humor is contagious—you might get some back!)
- Look for humor in the ordinary routines of your day or the unexpected mix-ups of your life

4. Set boundaries

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5. Strengthen competence

5.1 Improve health literacy

Family caregivers:

- often feel unprepared to provide care, have inadequate knowledge and skill to deliver proper care, and receive little guidance from the formal health care providers.
- may not know when they need community resources, and how to access and best utilize available resources.
- should learn as much as they can about the illness so that they can understand what is happening. It's not only about knowledge, but also to learn caregiving tricks to make caregiving easier.
- can be empowered through learning more about age-related changes, and how to manage them through elder care training.

Reflection

Have you heard of the following feelings from caregivers?

Caregivers always feel:

- overwhelming when taking them to multiple medical visits.
- frustrated when they refuse medication and refuse to bathe.
- exhausted when receiving their repetitive phone calls.
- embarrassed when taking them out for meal or travel due to incontinence problem or frequent toileting.


Let's try to provide some caring tips to caregivers through learning [Elder Care Training Courses](#) and below readings.

Further readings:

Harvard Health Publishing, Harvard Medical School. (2023). *Caregiving*.
<https://www.health.harvard.edu/topics/caregiving>

National Institute on Aging. (2017). *Doctor's Appointments: Tips for Caregivers*
<https://www.nia.nih.gov/health/doctors-appointments-tips-caregivers>

UCLA Health. (2023). *Dementia Care- Caregiver Training Videos*.
<https://www.uclahealth.org/medical-services/geriatrics/dementia/caregiver-education/caregiver-training-videos>

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5.2 Make good use of technology


Many experts feel that technology might help support caregivers. About half of 50+ caregivers have used at least one form of technology, software or online solution to help with caregiving. (National Alliance for Caregiving and AARP, 2020)

Includes:

- Tracked the recipient's personal health records.
- Used assistive devices for their recipient.
- Checked up on the health of care recipient using apps, video, wearables devices, or other remote monitoring.
- Searched online for support services.
- Managed prescriptions on an app or website
- Placed an online order for groceries or household supplies for care recipients.
- Watched videos to learn how to do different care tasks for a recipient.
- Created an online or shared calendar to organize caregiving schedules or activities.
- Had a virtual or online visit with a healthcare provider for the care recipients.

Reflection:

Caregivers in more demanding care situations tend to lean on technology and software to help alleviate some of the intensity that goes along with their caregiving role. Do you have any ideas for caregivers to relieve caregiving stress through gerontechnology in the community?

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6. Gain more cooperation from care recipient

Caregiving can become easier if the care recipient is cooperative.

How can you overcome your care recipient's constant refrain of "NO"?

3 ways to turn a No into a Yes:

1. Be willing to compromise.

If the care recipient won't shower,

- ❖ will he at least agree to a sponge bath?
- ❖ what about asking him again when he is in good mood?
- ➔ Sometimes compromise leads directly to a "yes" .


2. Use the "three tries" rule.

Try three times in three different ways to turn a "No" into a "Yes".

- ❖ One, ask your mom to do something:
"Mom, let's go for a walk."
- ❖ If she declines, wait awhile and then ask again in different ways:
"Mom, please go out to have a walk with me."
- ❖ If she declines again, use physical touch and the offer of a reward for complying:
Take her hand and look her in the eye. "Mom, can you go out for a walk with me? We can go to Yum Cha after that."

3. Make it easy to cooperate by offering choices.

- ❖ It's easy to say "No" to requests that seem unilateral:
"Eat your lunch right now. I went to a lot of work to prepare this delicious food."
- ❖ It's easier to say "Yes" when you're given a choice.
"Would you like to eat lunch at 11:30 or at noon? Would you prefer fish or chicken?"

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7. Stress management

Caregiving can be physically and emotionally exhausting. Whether you are in the profession of caregiving or taking care of a loved one, it is important to recharge your batteries. Below are some ideas for relaxation.

7.1 Abdominal breathing & muscle relaxation exercise

7.2 Mindfulness

7.3 Horticultural therapy

- relatively new noninvasive intervention in recent years.
- the process by which gardening, and plants, are used to improve both physical and mental wellbeing of an individual.
- improve memory, cognitive abilities, task initiation, language skills, and socialization.
- strengthen muscles and improves coordination, balance, and endurance in physical rehabilitation.
- improve the quality of life and reduce the depression and burden of caregivers of the older adults with dementia. (Kim, et al., 2020)

Sharing on local horticultural therapy: (Chinese only)

[心靈綠洲與園藝治療](#)

[照顧者花園【照顧者專訪】園藝治療](#)

[香港園藝治療協會](#)

7.4 Music therapy

- A way of enhancing, improving, and contributing to quality of life.
- Music is one form of therapy that can be helpful for people with dementia experiencing difficulty with memory and communication.
- A new study shows that music therapy interventions may improve social interactions between people with dementia and their caregivers. The findings indicate that music therapy may also decrease caregiver distress. (Schafer et al., 2022)

Sharing on local music therapy about caregiving (Chinese only)

[照顧者花園【照顧者專訪】音樂治療](#)


[照顧者音樂自療手冊](#)

8. Create a personal support system

Most caregivers end up withdrawing from friends and family and feeling isolated and as if no one understands. Also, they are often reluctant to express these negative feelings for fear they will be judged by others (or judge themselves) or don't want to burden others with their problems. Support groups can be an important source of understanding and connection.

Support system may be provided in the form of:

- Physical or practical assistance (e.g. transportation, assistance with chores)
- Resource and information sharing (i.e. information on community resources)
- Emotional and physiological assistance (i.e. someone who listens to and encourages you)
- Attitude transmission (i.e. someone who helps you laugh or see things more positively)

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8.1 Long-term care plan for an older adult

- What is long-term care planning for the older adult?

A long-term care plan is a preparation for the support that the older adults and caregivers need as the health condition change. It may include:

Healthcare decision	<ul style="list-style-type: none"> - Who handle the medical needs? - What kinds of community resources available for home care? - In what situation, start to consider hiring caregivers, using home service or moving to elderly home?
Living arrangement	<ul style="list-style-type: none"> - Anyone move in to live with the older adult? - Who agree to take care of the older adult? - Any home modification needed?
Financial planning	<ul style="list-style-type: none"> - What sources of money can be used to cover the long-term care? - How much will be the expenses? - Any ideas on the household budget plan? - Any needs to prepare the will or enduring powers of attorney? - Any needs for caregiver allowance subsidized by the Government?

- Planning for future

In view of the end-of-life care planning, early discussion in the followings can be considered:

- ✓ Advance care planning
- ✓ Advance directives
- ✓ Enduring powers of attorney
- ✓ Wills

Further readings

CUHK Jockey Club Institute of Ageing. (2022). JCECC Capacity Building and Education Programmes on End-of-Life Care- EOL Resources Kit. https://www.ioa.cuhk.edu.hk/end-of-life-care/wp-content/uploads/2020/12/booklet_2022%20full.pdf

- Why create a long-term care plan?

In view of the end-of-life care planning, early discussion in the followings can be considered:


- Build up a good communication and understanding between older adult and family members through discussion.
- Early planning reduces a lot of emotional frustration and burden when the older adult getting older and weaker.
- Prepare a personal support system before the situation getting much worse.
- If something happens, both older adults and caregivers can rest assured they have control over the future.

8.2 Community resources for family caregivers

- Increasing caregivers' knowledge about community services and how to access them can increase their sense of competence and reduce depression (Toseland, et al., 2004). Can you think of any carer support service in the community?

After going through the 3 chapters...

I think you should have a more thorough understanding on carer stress and coping strategies. Referring to the [reflection](#) at the beginning of Chapter 3, can you provide guidance and support to the family caregiver when you discharge the case with a constructive framework of caregiver engagement, enablement and empowerment?

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Caregiving journey is challenging yet rewarding. Here are some suggested guiding questions for you.

Caregiver engagement	<ul style="list-style-type: none"> • How to motivate them to participate in the caring task? • How to make them build up a good self-recognition and enjoy the positive rewards in caregiving?
Caregiver enablement	<ul style="list-style-type: none"> • How to equip them with appropriate knowledge, skills, and abilities to perform the daily care tasks? • Do they have a supportive environment to back up whenever in need? • Do they get familiar with the resources available in the community?
Caregiver empowerment	<ul style="list-style-type: none"> • Do they build capacity in problem-solving? • Do they develop a comprehensive long-term care planning? If not, how to make them start the conversation? • Are they capable to manage the challenges of caregiving?

However, caregiver burden is not limited to informal caregivers. Formal caregivers who provide care to a vulnerable population of older adults with chronic medical conditions are stressful too, e.g., looking after people with dementia in residential homes, seriously ill patients in cancer units and dying patients in end-of-life care units. As discussed in *Chapter 2*, high level of caregiver stress may predispose to elder abuse.

Therefore, as a social and healthcare professional caregiver, how to equip and care yourselves for the overwhelming work demands?

- Receive adequate elder care training to increase your capability to meet with the challenges.
- Get support from peers and mentors and go through reflective journaling to regain a sense of meaning, purpose and connection in life.

Remember, not only your client needs community resources, but you need too!

Get familiar with the community resources so that you could refer the needy caregivers to appropriate supporting services.

Counselling services for social and healthcare professionals:


- [Oasis 「心靈綠洲」](#)
- [賽馬會「疫途有你」醫護及安老服務同工情緒健康支援計劃](#) (Chinese only)
- [醫護及教師資助輔導計劃](#) (Chinese only)
- [醫護同行情緒支援](#) (Chinese only)

Reflection

In this module, we have discussed the complicated challenges of caregiving and various strategies to support caregiver. However, are these sufficiently to support the caregivers? How about the public policy that can help to relief carer stress?

Here are some reflective questions for us to further investigate.

- ◆ Arouse the awareness of caregiver stress among employers?
- ◆ Promote a family-friendly workplace to support working caregivers? (e.g. family leave, flexible work arrangement, counseling service for employee...)
- ◆ Create more part-time jobs for caregivers to balance their career and caregiving?
- ◆ Enhance and extend the accessibility of respite service and home care service with Government support?


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