

CANCERF®CUS



Cancer Caregivers – The Greatest Form of Support Through the Cancer Journey



Self-care for the Cancer Caregiver



Tips to Help Yourself
Prevent Caregiving Burnout



End of Life Care

CANCER CAREGIVERS

The Greatest Form of Support Through the Cancer Journey

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C aregivers are the people who provide physical and mental support for cancer patients. They are undoubtedly an irreplaceable force and an important aspect in a patient's cancer journey.

Cancer is scary and stressful for anyone. Its diagnosis tends to be sudden and random. No one can be prepared for it.

Treatment for cancer can be a long and tiring process, both physically and mentally.

Caregivers are the ones that can give the greatest support to the patient throughout the treatment.

Being a caregiver can be stressful.

It is important for that caregiver to know what to expect in the cancer journey.





What to Expect

There maybe different types of treatment for a cancer patient depending on the type of cancer

The patient may need to go through surgery, chemotherapy, immunotherapy, etc. Patients may also need a combination of those treatment methods.



Keeping up with everything and also handling the pain and stress is a huge burden to patients. This is where the role of caregivers is very important.

They play a role in maintaining:1

- Treatment compliance
- Continuity of care
- Social support

Side Effects of Treatment

For instance, a stage 4 lung cancer patient could span over a year for the treatment.

At times treatment and check-ups have to continue way beyond that. In some cases, it could even be throughout their **whole lifetime**.

Treatments, especially chemotherapy, also have apparent side effects. Losing hair is one side effect. Along with that, patients may also experience:²

- Loss of appetite and weight loss
- Nausea
- Diarrhoea
- Weakened immune system
- Overall fatigue

Throughout that long process, caregivers are the ones there to give patients the greatest support. The moral support of simply being there at all times is really as important as the treatment itself. This is something that only family members or closest friends can do.

How Does Treatment Affect Caregivers?

Being a caregiver tends to mean that your schedule will change according to the patient's treatment. It will affect the time you have for yourself and your own social life.

In some cases, cancer patients may also no longer be able to work. The caregivers thus have to be responsible for all expenses, including the household and the treatment fees of the patient. That is a huge burden for anyone.



How can Caregivers Find Support?

Doctors and nurses at the clinic visit will always be there to guide you.

If you are still worried, there are actually official training sessions available in Singapore. For that, there is also a Caregivers Training Grant worth up to \$200 a year per patient.

To find out more: http://bit.ly/2AO8EKU





You are amazing!

Supporting someone throughout the long and complicated treatments is stressful in itself.

References: 1. Glajchen M. The emerging role and needs of family caregivers in cancer care. The journal of supportive oncology. 2004;2(2):145-155. Accessed September 12, 2019. 2. Chemotherapy for Non-Small Cell Lung Cancer. American Cancer Society. Accessed October 3, 2019.

2 cancer focus

SELF-CARE FOR THE CANCER CAREGIVER

Dr Joan Khng

Senior Social Worker

aking care of a cancer patient can often be an emotionally and mentally exhausting process. It involves adopting new responsibilities, juggling various work-related and family-related roles, navigating the healthcare system and dealing with the unpredictability that comes along with caring for someone who is sick. The demands of caregiving can be relentless and your life may even seem to revolve around your loved one's seemingly endless medical appointments, physical rehabilitation schedules, optimising their care at home and meeting the various demands of your loved one's serious illness. Sometimes you might be so focused on your loved ones that you do not realise that your own health and wellbeing is affected.

Caregivers have been found to be more stressed and depressed and have lower levels of physical health and general subjective wellbeing than non-caregivers (Pinquart & Sörensen, 2003). If left unchecked, prolonged exposure to caregiver stress can lead to caregiver burnout. Caregiver burnout is a state of emotional, mental and physical exhaustion, where one becomes overpowered by caregiver stress over time. Often, feeling a sense of powerlessness can lead to burnout and depression. It is important to understand your feelings as they relate to common signs of burnout, which may include:









Your emotional state can also affect your physical state and behaviours, which could also be indicators of burnout. For instance, you may find yourself:

- Falling sick easily,
- Using alcohol or stimulants more often,
- Losing interest in previously enjoyable activities and isolating oneself from social events.

If you observe yourself displaying any of these signs, it is important that you take it seriously and make some changes now before it is too late. While it may not be realistic to expect caring for a cancer patient to be completely stress-free, it is important to start taking action to empower yourself and avoid burnout. By paying attention to your own self-care, you avoid reaching the stage of learned helplessness, where you believe that you cannot do anything to improve on your situation.

How Then Can You Better Take Care of Yourself?

It involves taking time to care for your body and spirit. Firstly, it is important to change your attitude towards your cancer caregiving experience and yourself.

Do let go of thoughts and feelings that are unhelpful, such as blaming yourself for your loved ones' illness, and feeling bitter and resentful over handling your caregiving tasks. You may feel a sense of loss at having to give up a former lifestyle or giving up on some of your plans and/or dreams. You may even feel unhappy at having to go through the suffering of making various sacrifices to take care of the patient. While such feelings are common, do remind yourself that in every loss, there can also be some gains and that suffering is part of the common human experience. While there are sacrifices to be made when caregiving, at the same time, there are also opportunities to make meaningful memories and build deeper connection with your care recipient.

Secondly, having a self-care boundary is important, so that you will not feel overwhelmed by your caregiving tasks.

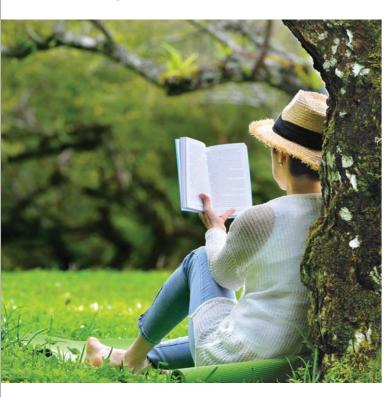
Many caregivers may set themselves up for burnout due to their unrealistic expectations of themselves and their caregiving roles. It is important to know when you say "no". Be aware of your own limitations so that you do not take on more responsibilities than you can handle.

This leads on to the next point: do not be afraid to ask for help. Sometimes you may feel a lack of control because you think that you lack the money, resources or skills to manage your caregiving roles. Be open to seek and accept the support from others, such as trusted family, friends and healthcare professionals. There are various financial assistance schemes that are available for needy patients as well as caregiver workshops to help increase your effectiveness as a

caregiver. There are also respite care services that can allow you to take a temporary break from your caregiving roles. Do alert your healthcare professional if you need help to cope with your caregiving roles.

Another way of taking care of yourself is to set aside protected time to recharge and give yourself a breathing space. It is important to make time for yourself.

Give yourself permission to take breaks and spend time away from your caregiving tasks. This may involve making a commitment to allow yourself to participate in activities or hobbies that will re-energise your spirit, such as meditation, taking short walks, exercise and reading a good book. By attending to your own needs, you will build up your own capacity to handle stress and be better able to care for your loved ones. The question you will need to ask yourself is, "if you do not care for yourself, then who else will?"



It is important to be assertive in communicating to others about your needs. Be willing to share your worries and concerns with trusted individuals. Advocate for yourself by being clear and specific about the type of help you need to better cope with your caregiving roles and responsibilities. When you go with your loved ones to their medical appointments and feel confused about information given, do not be afraid to approach the relevant medical staff for assistance to clarify your questions.

When things go wrong, express your feelings honestly to supportive others, and find out how you can improve on managing your caregiving tasks. Part of the caregiving journey is also learning to communicate well with friends and family. Sometimes it may be hard to talk to them about cancer, especially when breaking bad news. It is important to be clear on how much you and your care recipient are prepared to share, as well as how much information your loved one, family and friends are comfortable to receive. When in doubt, do not hesitate to seek for help.

Caregivers very often play a crucial role in supporting the cancer survivors' cancer journey. Yet, the needs of caregivers are often overlooked. The Singapore Cancer Society (SCS) strives to meet the needs of family caregivers of cancer patients through its services and programmes.

The team of social workers in SCS provides casework and counselling services to help caregivers cope better in their caregiving roles. Taking into account the various needs and resources of caregivers, social workers may help caregivers to apply for financial assistance schemes, medical escort services (for patients), respite care services, and hospital transport services (for patients to go for their medical treatments at the hospital). Other than such services, SCS also offers cancer caregivers training workshops periodically.

If you are interested to find out more about our cancer caregivers training workshops, you can email us at scs_pss@singaporecancersociety.org.sg.

"It is important for caregivers to accept and acknowledge what is before you and take up the challenge... Talking to and learning from others, especially those who went through similar struggles, is helpful so that you don't feel alone and you can get advice from them."

Ms Margaret Yong, Caregiver

Ms Yong has been a caregiver to many family members diagnosed with cancer. She was a caregiver to her father, mother, husband and sister.

Reference: Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. Psychology and Aging, 18(2), 250-267. doi:doi:http://dx.doi.org.eproxy.lib.hku.hk/10.1037/0882-7974.18.2.250

TIPS TO HELP YOURSELF PREVENT CAREGIVING BURNOUT

Caregiving is not a sprint but a marathon. To help yourself manage your caregiving roles for the long haul, pace yourself and be aware of your strengths and limitations. Know when to say "no".

Seek emotional support from trusted individuals who can provide you with a listening ear and encouragement.

Seek respite care services that allow you to have a temporary break from your caregiving duties.

If you find yourself unable to manage, seek professional help from professionals such as social workers and counsellors to help you better cope with your caregiving roles and responsibilities. Seek practical support from others to help you to run errands, collect medications and go for medical appointments.



Continue to participate in activities that you enjoy and give yourself permission to take breaks when necessary.

A SOFT LANDING

Jason Ho I-Ju

Social Worker, Psychosocial Services

This can't be happening to me Why is this happening?

eciding to become a caregiver to someone during end of life is a difficult choice. Caregiving for the dying requires sacrifice and commitment. If a loved one is under hospice care, it can take a toll on the entire family especially on the caregiver.

Home hospice care should start when a terminal diagnosis has been made, for which the remaining life expectancy is estimated to be less than a year. One should consider home hospice service when there are troubling physical symptoms or psychosocial issues that make care at home challenging.

Dealing with Grief and Bereavement

Grief is a natural response to a loss we experience. Grief is not something we try to get over, but something we learn to manage and get through.

This means that the grieving process is a highly personal and individual journey, thus there is no "right or wrong" way of grieving.

While grief can be caused by many other factors like (the loss of independence, privacy, sense of self, physical loss etc.), bereavement is specific to the loss of someone dear.

The way we experience grief and react to a loss can be influenced by several factors, including:

The way the death occurs

Who is to blame?

- The nature of attachment and relationship to the person we have lost
- The griever's personality
- Presence of concurrent stressors
- Previous losses and grief experiences
- The life stage that bereaved is in
- Lack of supportive social network



In 1969, Swiss-American psychiatrist Elisabeth Kübler-Ross introduced, what became known as, the "five stages of grief". These stages of grief were based on her research of the feelings of patients facing terminal illness. Since then, many people have generalized her studies to others, not just terminally ill patients, facing other types of negative life changes and losses. The five stages are experienced by those who are grieving (in no particular order and not necessarily all stages):

- Denial: "This can't be happening to me."
- Anger: "Why is this happening? Who is to blame?"
- Bargaining: "Make this not happen, and in return I will ____
- Depression: "I'm too sad to do anything."
- Acceptance: "I'm at peace with what happened."

Life's uncertainties will sometimes hit us with events that are unpleasant and it helps to know some methods to work around our grief:

- · Allow oneself to grief in own way and own pace
- · Create a schedule and a routine for self
- Take care of yourself and tend to well-being (sleeping well, eating well, exercise, going back to activities that you used to enjoy)
- Seek support from trusted family members and friends
- · Finding ways to maintain a sense of connection with loved one (rituals, going to places where both frequented)
- · Be aware of anticipatory anniversary reactions and prepare for it.

Conclusion

As Canadian Psychiatrist Harvey Chochinov, a palliative care expert, aptly states: "If life is akin to walking a tight rope, the chance of falling increases towards the end. Think, then, of palliative care as a safety net. No one escapes falling, but palliative care can provide a softer landing."

The SCS Home Hospice Services team, comprising of Doctors, Nurses, Social Workers and Therapists, work together to allow every patient and family under their care to have a softer landing.







Singapore Cancer Society (SCS) Hospice Care, the first hospice home care service in Singapore, was established in 1987. Since then, the team has provided home hospice care to support the needs of the Singapore community. In the advanced stages of cancer, patients may choose to receive care and support in their homes to maximise their quality of life for as long as possible. Many patients prefer to spend their final days with their loved ones in the comfort of their own homes. The SCS Hospice Care team applies a multi-disciplinary approach to ensure that both patients' and their family members' needs are appropriately assessed and addressed. For more info call 1800-727-3333 or email to hospice@singaporecancersociety.org.sg.

CANCER FOCUS



Established in 1964, Singapore Cancer Society (SCS), a voluntary welfare organisation has positively impacted the lives of those affected by cancer.

It actively promotes cancer awareness in the community and offers cancer screening services [Mammogram, Pap Test, Faecal Immunochemical Test (FIT)], welfare assistance, community based cancer rehabilitation, cancer support group activities and hospice homecare to support cancer patients and families.

OUR VISION

To be Singapore's leading Charity in the fight for a cancer free community.

OUR MISSION

To Minimise Cancer and Maximise Lives through effective programmes.

OUR PROGRAMMES

1. Financial Assistance

- Cancer Treatment Fund (Cancer treatment subsidies for cancer patients)
- Cancer Care Fund
- Welfare Aid for needy cancer patients

2. Free Cancer Screening

- Pap Test (For Cervical cancer)
- Health Education: Breast Self-Examination
- Mammogram screening (For Breast cancer; CHAS Card Holders)
- Faecal Immunochemical Test [FIT] (For Colorectal cancer)

3. Public Education

- Cancer awareness campaigns
- Cancer-related talks and forums
- Cancer information (via website & telephone service)

4. Cancer Support

- Cancer support groups and activities
- Psvcho-social services

5. Cancer Rehabilitation

Integrated, person-centred holistic approach with aim to return to normalcy

6. Hospice Care Services

Medical and psycho-social care for terminally ill cancer patients

7. Cancer Research

Cancer Research grants and awards

8. Volunteers Programme

Volunteering opportunities to suit people with different interests and skills

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END OF LIFE CARE

Caregiving for the dying requires sacrifice and commitment. If a loved one is under hospice care, it can take a toll on the entire family especially on the caregiver.



s Rohana Binte Ahmad was a hospice cancer patient when she was 55. She **V** I was diagnosed with pancreatic head cancer and with liver metastases.

Ms Rohana was attended by the Khoo Teck Puat Hospital's palliative team. The team then referred her to the SCS Hospice Care team. Upon discharge, SCS seamlessly settled them at home and worked with her niece Ms Eslinda Hamzah to help them better cope with the situation.

"What struck us most about the team was the immediate bond that we were able to form. We were heartened by their consistent, tireless will to always go the extra mile, above and beyond the call of duty for my aunt and family. The SCS Hospice Care team provided symptoms control, emotional, social and spiritual support. That level of dedication from them led us to better appreciate our extraordinary healthcare workers and the depth of work they do for our society," said Ms Eslinda.

The team was empathetic, assuring and showed encouragement for Ms Rohana and her family throughout. As a caregiver, Ms Eslinda's confidence level to take care of Ms Rohana increased with the support received. Simple acts such as sitting by Ms Rohana's side when she needed some personal time meant the world to her as she felt supported.

The team attended to all the family needs ensuring that Ms Rohana lived with dignity with the least suffering till the last day of her life. They also helped the family in accepting the reality giving closure.

"SCS Hospice Care team became an integral part of our lives as we experienced that journey with my aunt till she passed away earlier this year. We are eternally grateful to each one of them and everyone else who played a part in it", added Ms Eslinda.

HAVE YOU LOST SOMEONE TO CANCER OR KNOW ANYONE WHO DID?

Join the REMEMBER segment of the SCS-Talkmed Relay For Life (RFL) 2020 RFL is taking place on 15 Feb (6pm) – 16 Feb (9am) at the National Stadium Singapore Sports Hub. To register: https://scsrelayforlife.sg/

Support the Cancer Community. Download any of the apps and donate generously. All proceeds will be channeled to programmes and services managed by Singapore Cancer Society.

NO RECEIPTS WILL BE ISSUED DONATION IS NOT TAX DEDUCTIBLE SG CANCER SOCIETY-PUBLICATIONS







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