

SELF-CARE FOR CAREGIVERS

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Foreword

The presence of reliable, easily accessible and equal access to mental and physical healthcare facilities are the ingredients of a utopian society that in reality, is marred with severe lack of awareness, facilities and healthcare workers. The World Health Organisation (WHO) estimates that in the next fifteen years, the world would experience a shortage of nearly 13 million healthcare workers. ¹ These healthcare workers include those engaged in institutional healthcare and private healthcare practises for physical and mental illnesses and disabilities.

The #selfcare trend has seen a spike over the last few years across several social media platforms. While this has helped in increasing awareness and conversation about self-care, it has also brought to the surface a market for several self-care products. ² Each day we observe movements to bring sustainability and inclusion across all areas of our lives. Self-care, in a society that is reorganizing itself every day to new values, can be challenging and every bit confusing.

This manual recognises that self-care is not a solution to any mental or physical illnesses. It also recognises that self-care is a unique fit for every individual and culture: there is no set method of self-care. Keeping these in mind, the manual aims to provide a general guide to what self-care actually is and how one can personalise self-care to the best of their needs.

Keeping the increasing need for caregiver self-care, there is a section for caregiver self-care as well. At some point, each of us would be, are caregivers or have been caregivers to someone in our lives. The path to develop a self-care plan, although suggested from a caregiver's perspective, can be followed by everyone.

Self-care for Caregivers is an introductory manual and attempts to create awareness about the need for care for those caring for others and to provide the first step in their care journey.

We acknowledge that this manual doesn't cover all aspects of what selfcare for caregivers can look like, and doesn't deep dive into the need for community care for caregivers.

"I have come to believe that caring for myself is not selfindulgent. Caring for myself is an act of survival."

— Audre Lorde

About Us

One Future Collective (OFC) is a feminist youth-led non-profit that is harnessing the power of compassionate youth social leadership to undertake actionable change in their micro communities towards creating systemic transformation. Our work focuses on the thematic areas of youth leadership, gender justice, mental health, legal reform, and development policy: through knowledge, action, and consulting.

What is the problem? In India, and in the world, our society places great emphasis on caring for others—family, friends, those less privileged than us. Caregiving is work. Once we acknowledge this, we see a dangerous, less spoken of effect of caregiving: forgetting to take care of ourselves. Caregiving takes a physical, mental, and emotional toll on people. The health of caregivers is important, and should not be ignored. We want to fix this.

Self-care for Caregivers is as an introductory manual that we hope starts conversations around self-care for caregivers and gives them an active resource to commence their self-care journey.

Acknowledgments

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Errors, if any, are mine, alone.

To all the caregivers reading this—thank you for what you do.

Contents

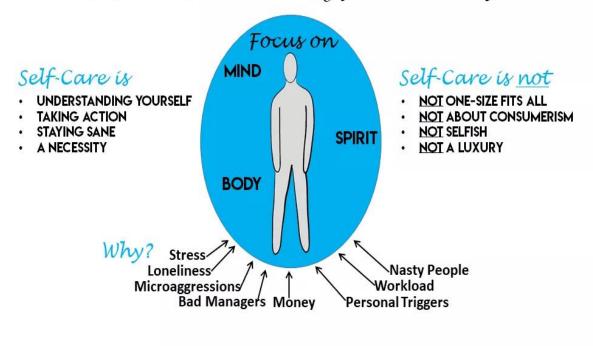
Fore	i	
Ack	ii	
Abo	About us	
1.	What is self-care?	1
2.	The process of self-care	2
3.	Why we need self-care	3
4.	Aspects of self-care	4
5.	Busting self-care myths	5
6.	Who is a caregiver?	8
7.	Do you identify as a caregiver?	9
8.	Why caregivers need to focus on their self-care urgently	11
9.	Developing a personalised self-care plan	13
10.	Communicating your need for self-care	16
11.	References	19

What is self-care?

SELF-CARE



Self-care is maintaining your immunity



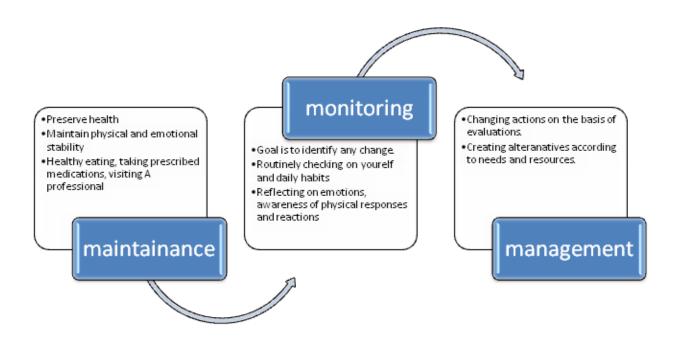
Source: Brilliant Idea Studio, 2019

Self-care involves taking care of one's physical, emotional and mental health. It also involves being aware of oneself and engaging in activities that gives oneself energy and taking responsibility for one's own needs. The primary focus being, to maintain your health.³ It is not limited to times of illness or stress, rather activities and behaviours that can be engaged in, even when feeling at ease and during perfect health.

Studies have shown that those who engage in self-care activities are better able to deal with stress and report a better quality of life.

The process of self-care

Self-care has no fixed process or fixed criteria. Rather, it is a process that can be tailor fit for each person according to their needs for the moment and the future.⁴



Why we need self-care

Better knowledge of the self

Self-care is about knowing what works for each of us personally. In the process, we are able to know and realise what we like, what our priorities are and what we are passionate about. It also helps to realise what we do not like. Better understanding of ourselves, can lead to healthier boundaries, increased self-esteem and better goal setting as well. This can help in maintaining our mental and physical wellbeing.

Better physical health

We are all affected by the various big and small5 quandaries that life presents us with. These events and situations can affect our physical health, making us more likely to fall ill. Engaging in self-care ensures that the likelihood of falling ill due to these factors are reduced.⁶

Better productivity⁷

More often than not, we tend to spread ourselves thin to perform various roles and duties, often not feeling satisfied with the results of our work. Self-care encourages that we engage in activities that matter more to us than others and learn to prioritise as well. This helps in bringing the goal into focus and increases productivity significantly in even the few tasks that we engage in.

Aspects of self-care

Physical

Being aware of one's own physical capabilities, limits and needs. Physical self-care not only involves indulging in expensive or luxurious activities such as a spa or massages. Taking care of everyday needs such as making sure to have 3 meals a day, or ensuring that you take a shower, or get enough sleep each day.

Emotional

Acknowledging, accepting and allowing oneself to express all the range of emotions one feels. This involves letting oneself cry when feeling overwhelmed without judging oneself. The key is allowing emotional expression without judging yourself.

Spiritual

Spirituality is irrespective of your religious beliefs or practises and rather involves getting in touch with the self. Trying to explore your own likes, values, strengths and hobbies and engaging in activities that gives you a sense of purpose.

Psychological

One of easily overlooked aspects of self-care, this involves drawing healthy boundaries to reduce engaging in activities or situations that induce stress. It also involves identifying and practising healthy coping mechanisms and yet being able to say "no". This also involves engaging yourself in cognitive activities that helps to oneself occupied and the mind running a focused. This also includes healthy time management.



Source: https://twitter.com/mhfaengland/status/1130106069160800257?lang=ca

Busting self-care myths

Self-care needs to be extensive to make a difference.

Self-care can be small, daily activities that help you take care of yourself. Taking care of yourself in the similar daily activities that you would take care for someone else. This may involve, making sure to have your meals on time, making sure you get enough sleep and rest or even engaging in an activity that you enjoy. The higher frequency of smaller acts of taking care of yourself can go a long way in ensuring your wellbeing.

Everyone does not need self-care.

A common myth is that self-care is only for those who are ill themselves or are taking care of terminally or chronically ill patients. The purpose of self-care is to equip oneself with better coping skills in order to deal with daily stress and challenges without reaching exhaustion. Self-care is not only for those who have reached exhaustion but for everyone to lead a better life and ensure personal wellbeing.

Practising self-care means ignoring or neglecting the needs of the patient or other family members.

You can pour from your cup only if your cup is full. An understandably common thought is "how can I take care of myself when he/she needs more care and support." when you are stressed or exhausted, you can get irritable, cranky or even lose focus in the daily tasks. This may in fact affect your ability to care for others. When you are well nourished and able to care for yourself, you can care better for others as well. Taking care of yourself does not mean not taking care of others.

Self-care is anything that helps you relax or soothe.

While relaxing and soothing are an aspect of self-care, they are not the only parts of it. Certain activities that may help to unwind may not support your health. Watching movies, TV or playing games on the phone may soothe and help to unwind but can be addictive and can be harmful for the body and/or mind.

Self-care is easy.

It is not always easy. However, accepting the hurdles that come in the way of taking care of oneself can help to make the process of self-care less difficult. Unlearning long term mindsets and replacing them with healthy but challenging mindsets and habits can be difficult to implement. Self-care involves changing expectations from the self and setting more realistic expectations from the self. Allowing oneself to express the emotions without judgements can be difficult and challenging. It can be difficult when taking on the role of a caregiver. As caregiver's we have to unlearn habits of taking care of others before ourselves.

Self-care is a replacement for therapy.

Therapeutic activities that make you feel at peace with yourself and that help to maintain your wellbeing are not remedies to any illness- physical or mental. Self-care activities are a part of the therapy process which requires one to take care of themselves so as to maintain the development of therapy and to not cause further damage.

Self-care is the same for everyone.

Like bathing, self-care depends on the needs of each person. Someone who has fallen in mud would prefer to take a longer bath than someone who has not. While the goal of self-care is the same for everyone (that is, maintaining mental and physical well-being), the way each of us achieves this goal is different. For every person, each day requires a different path to achieve the goal of self-care.

However, few activities that could help everyone maintain basic well-being could be the same, such as having at least one meal a day, getting at least a few hours of sleep every day, relaxation techniques for a few moments every day, reflecting on one's emotions.

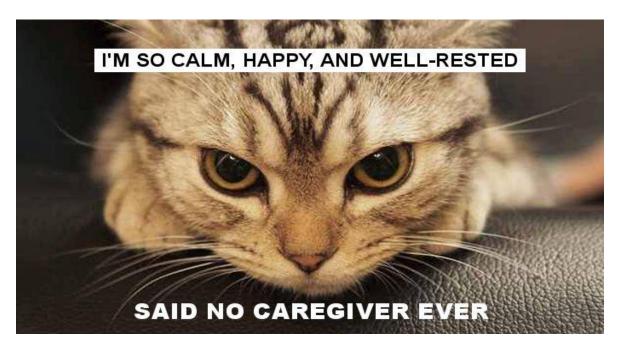
Caring for the caregiver

For those who take care of others.

Do we need this, really? YES, we do.

As a country we idolise those who put their heart and soul into taking care of others. The children who don't hesitate in prioritising their parents, the spouse who rushes home from work to take care of an unwell partner, the family that spends all their days with a critical senior member in the house or the nurse who spends more time with her patient than her own family.

Behind these heroic acts are moments—days and even months—of exhaustion, battling with finances, dealing with stigma or unsolicited advice from the society, visits to the hospital, sleepless nights of worry and fear and a countless list that caregivers could elaborate in relation to their own experiences.



Source: "Monday Mojo for Caregivers - Caregiver Memes for a Good Laugh", n.d.

Caregiving can vary depending on the needs of the recipient and does not come with a universal guide of what to do and how to deal with difficulties and challenges.

This manual acknowledges the varying and subjective needs of every caregiver and attempts to provide a universal framework on how to develop self-care for the caregiver.

Who is a caregiver?

The Cambridge English Dictionary defines a caregiver as, "Someone who provides for the needs of children or of people who are ill or cannot provide for their own needs."

Involved in treating or preventing an illness

Caregiving may often involve being a medical professional such as a doctor, nurse, para-medics.

Primary and secondary caregivers

Primary caregivers are those that are directly involved in the caretaking and have complete responsibility of the patient. Most usually the partner, family, close relatives or friends.

The care provided by those other than the primary caregivers, are secondary caregivers. The caregiving responsibilities are often shared between the two.

Caregiving involves attending to the needs of the recipient

The person in need of caretaking may be young, ill, disabled or elderly. One may attend to the emotional, physical, mental needs of the loved one or the patient.

Long term or short term care-giving

Caregiving may involve attending to the needs of the recipient either for long periods of time for chronic or terminal illnesses or disabilities such as cancer, dementia, Parkinson's disease, or it may involve taking care for short or intermittent periods of time for acute illnesses or disabilities such as asthma attacks, heart attacks, fractures, severe infections, head injuries.

Although the definition of a caregiver widely differs, an individual understanding of personal caregiver responsibilities is more important to understand your personal needs as a caregiver as well.

Do you identify as a caregiver?

You could be a caregiver. A simple way to check is if in the past one month, you have been involved in:

- > Assisting someone who is disabled or differently abled; a senior citizen or someone who is unwell.
- > Assisting in daily chores (laundry, grocery shopping, cleaning the house, cooking) for someone who is unable to do so.
- > Providing healthcare such us reminding to take medicines, taking care of wounds, checking up on vital signs etc.
- > Keeping someone physically or mentally engaged in order to keep them occupied or to provide social company.
- > Looking after someone who is suffering from a mental or physical illness.
- > Providing food or feeding someone and aiding in basic daily functioning (bathing, eating, dressing, moving around).
- > Providing immediate response to those who have faced any form of trauma.
- > Providing care for someone is chronically or terminally unwell.

You may also identify as a caregiver if you are:

- > A doctor, nurse, counsellor or any other form of medical practitioner.
- > A social worker or volunteer for causes which involves taking care of someone.
- > A family member, spouse, partner, close friend of someone who needs to be taken care of physically, mentally, emotionally or even spiritually.



Source: https://twitter.com/QualityNowCare1

Why caregivers need to focus urgently on self-care

Caregiver burnout is a state of physical, mental and emotional exhaustion as a result of long term or overwhelming stress of caregiving. Caregiver stress and burnout can be experienced by both, primary and secondary caregivers.

In the process of taking care of someone who is terminally or acutely ill or is unable to care for themselves, society often overlooks the efforts, energy and resources that a caregiver contributes towards taking care. Although looking after someone can be fulfilling, it can also be challenging.

Not being able to acknowledge the challenge and constantly pushing yourself to continue giving can lead to stress, fatigue and burnout.

Getting help in the form of additional help for the person you are taking care of, or by visiting a medical professional for your own health at the right time can reduce stress and help you deal better with it.

Expressing concerns over your own health while taking care of someone who is more seriously ill, brings in criticism or negative judgements from those around you. It may make you feel guilty and make you feel like your health concerns are not as serious or important as that of the person you're taking care of.

Caregivers who work full-time and are aged 45 years or less show the greatest emotional and physical health deficit¹⁰ in contrast to non-caregivers. Almost 50% of caregivers¹¹ of people with Alzheimer's have shown high anxiety and dementia scores. For every person who needs caregiving, there are at least 4 caregivers which includes the immediate family or partner, medical professionals and relatives.

Are you facing caregiver stress or burnout?

Experiencing caregiver stress may affect your physical, mental and emotional wellbeing.

Signs of stress or burnout could include:

A. Physical signs

- > Changes in sleep patterns
- > Loss of appetite
- > Feeling sick more often (increased headaches, fever, common cold and cough, gastrointestinal trouble, indigestion)
- > Feeling tired often
- > Unexplainable changes in weight

B. Emotional signs

- > Get irritable easily
- > Feeling low, sad often, or crying easily
- > Feeling hopeless or helpless
- > Getting angry easily
- > Not liking the previously fulfilling caregiver responsibilities

C. Psychological signs

- > Feeling lost in daily tasks
- > Unable to concentrate on tasks or conversations
- > Having no thoughts (blanking out) or having a rush of thoughts
- > Losing interest in activities that you previously enjoyed
 - Withdrawing from friends, family and relatives

Identifying with even one sign from the above list suggests that your health is in as much trouble as is anyone else's. Getting help for your own health would help you take better care of the recipient as well.

Here is a scale to help you understand what your levels of caregiver-stress are.

Developing a self-care plan

The self-care plan would differ from one caregiver to another, depending on the needs, available resources and needs of the care recipient.

Ask yourself these questions.

- > What aspects of your day are most stressful?
- > Have you been feeling down or blue lately?
- > Have you been feeling more anxious or irritable?
- > Do family and friends visit you?
- > How often do you interact with close friends or relatives in a week?
- > Do you ask for help from other family or friends to look after your relative OR do you have someone else to look after the care-recipient?

To create a personalised self-care plan, you can follow the steps below and use the resources at the end of this manual.

Remember—self-care isn't only for stressful situations but a way of healthy living.

STEP 1

List or identify from the list¹² below, what you do to currently take care of yourself. For every healthy action give yourself 1 point and for every unhealthy action, deduct 1 point. The higher your score, the healthier are your coping strategies.

Healthy	Unhealthy
Going for a walk	Withdrawing from friends and family – not socialising
Exercising	Smoking
Reading	Binge drinking or consuming alcohol beyond moderate levels
Watching a film or show you enjoy on TV	Taking illegal drugs or excessive legal drugs
Taking a bath / shower	Becoming frequently angry or aggressive
Using breathing or relaxation exercises	Overeating, skipping meals, or eating a lot of junk food or sugar
Meditation	Isolating yourself

Yoga	Not taking care of your personal hygiene because of how you are feeling
Talking with friends	Not sleeping or oversleeping
Socialising	Not delegating tasks among other family members/caregivers
Sitting with a warm drink	Being available at ALL times for taking care of someone (especially if you are a nurse, paid caregiver, volunteer, or a family/friend who doesn't live with the person).
Enjoying a hobby	
Saying no to more responsibilities when you feel overwhelmed/tired	

Keep using the healthy activities, we'll get to finding alternatives for the unhealthy activities!

STEP 2

Identify situations that make you stressed, overwhelmed, tired, or sad. If any of the areas below are affected at any time, they count as stressful situations.

Physical: sleep affected, food intake affected, amount of exercise reduced, feeling tired or restless. **Emotional**: crying easily, getting angry or irritable easily, feeling sad or low, feeling helpless, unable to express your emotions.

Mental: level of cognitive engagement, losing track of time, losing concentration in a conversation or blanking out.

STEP 3

Finding alternate self-care measures for the affected areas.

Here is a list of activities or actions that can be alternative selfcare measures:

- > Ask for help from other family/friends
- > Making sure you have at least 2 meals on time.
- > Being assertive and not taking up more responsibilities (from other areas of your life or even caregiving areas) when you feel overwhelmed.
- > Seek professional help for yourself from doctors, mental health professionals, financial advisors, NGOs that can help you in areas where you face issues.
- > Go for regular health checkups for yourself and take your medication on time as well.
- > Create a list of things that can help you relax.
- > Set a minimum amount of time each day to do one relaxing activity.
- > Let your family members know about your time so your "me-time" is respected and taken into consideration for making any other plans or appointments.
- > Practising relaxation or mindfulness activities.

Remember to include those activities that would support your health and wellbeing and would not affect it negatively in anyway.

Ask yourself—

- "Is this beneficial for my body, mind and soul?"
- "Is this flowing naturally for me?"
- "Am I comfortable doing this?"
- "Am I being harsh on myself if I am not able to perform certain activities?"

STEP 4

Share your alternate measures.

Sharing your list of self-care activities with family members can help them to remind you to take care of yourself as well. Make the list visible—keep it somewhere where everyone in the house and you can see easily.

STEP 5

Follow your plan.

Challenge yourself to follow the plan but don't be too hard on yourself if you aren't able to complete all activities in one day.

Acknowledging your lack of time and still making an effort to complete even one activity can help you take things one day at a time. This can help in dealing with anxious thoughts as well.

Acknowledging your lack of resources and not being harsh on yourself is also a part of self-care. Keep a track of what is and isn't working for you. Revamp your plan accordingly.

Communicating your need for self-care

Communicating your self-care needs is one of the most important aspects since it helps to create a support system for yourself as a caregiver. The support system can help you in following your self-care plan. Communicating your needs can be stress and anxiety inducing. You can follow the below strategies to communicate your self-care needs assertively and by dealing with your anxiety.

Creating healthy boundaries

Healthy boundaries are emotional or physical limits that we set for ourselves based on our present capacities. A common misconception about boundaries is that it involves pushing people away or shying away from challenges and responsibilities. However, a healthy boundary involves identifying your present capacities and working in those capacities which can later be expanded based on how you develop your physical or emotional skills and capacities further.

Healthy boundaries are seen to have a positive impact on mental and physical health since it reduces chances of burnout and helps in carrying out our responsibilities for longer. It also helps in decision making and time management since we can avoid taking on too many responsibilities and prioritise among those that are present.

An important step in creating boundaries is shifting the focus from others to yourself.

Instead of	Say
You need to let me sleep.	I need to sleep for a few hours.
Everyone expects me to do all the work	I need to take on less responsibilities OR I am feeling overwhelmed with all the pending work
The kids are making too much noise	I need some quiet time
You need to take care of your father too	It would help me if you could take on some responsibilities of taking care of our father.

Setting boundaries also involves delegating and having open conversations of your personal needs. It involves stating how you would like others to behave around you in a clear and precise manner. Boundaries need to be expressed in an assertive manner that lets the person know that you respect yourself.

Assertive Communication

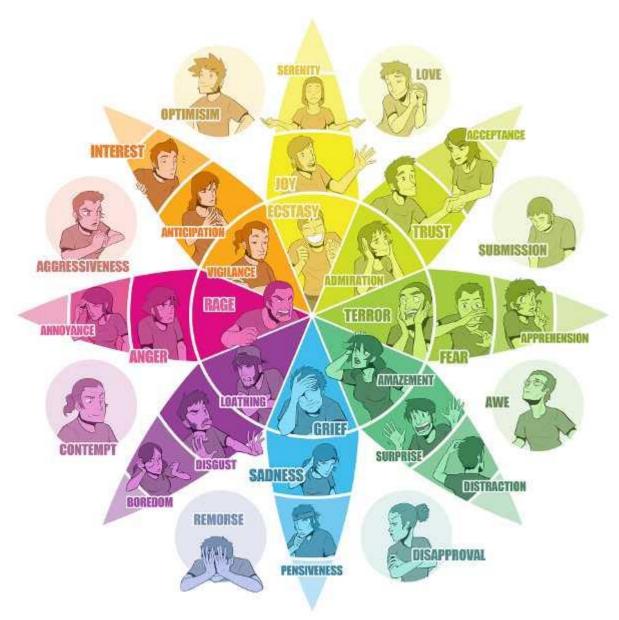
One way of communicating assertively, is by using "I-messages". I-messages helps to take responsibility for our own feelings and needs. Accepting and taking responsibility for our own needs is the first and major step in communicating assertively.

"I feel (state your feeling or emotion) when (state the situation) and would prefer/like (state what your need is)."

"You" message	"I" message
You never come on time and I have to do all the work	I feel burdened with additional responsibilities when you come late. I need the time in the afternoon to complete my school/college work.
You only care about yourself, even I am feeling unwell! How can you be so selfish!	I feel ignored when my health concerns are not taken care of. I need to visit the doctor as well.
You expect me to do ALL your work even though you can do some of it! It's not fair!	I feel burdened with doing all your work even when you can do some of it. I have some work of my own and need to attend to that as well. I'd like it if you could do XYZ tasks by yourself so I can get some time to myself.

Using precise words to express your feelings can make your statement shorter and more impactful.

You can use this Emotions Wheel to point out what exactly you may be feeling.



Source: Hogan, 2018

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