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Imagine you are on a plane. Suddenly, the plane starts to shake, and the captain announces you have to make an emergency landing. The oxygen masks pop out. What do you do? Read on to find out the answer and how this relates to being a caregiver.

THIS CHAPTER IS DEDICATED TO YOU, the most important person in the life of your loved one with schizophrenia. You are the one who **WORKS TIRELESSLY** for their everyday needs and keeps them from worsening symptoms, unemployment, and even homelessness. You should **TAKE PRIDE** in the work you are doing and acknowledge the magnitude of its importance. Never undervalue the change you make for that person and the extent to which your help has impacted their life.

However, being the caregiver of a person with schizophrenia can impose a **UNIQUE SET OF CHALLENGES** that can take control of your entire mind and your entire day, transforming your life for years or decades to come. Caregivers spend between **22** and **37 HOURS PER WEEK** providing direct care to their loved ones with schizophrenia. They are often "on call" for emergencies, many of them being on call constantly. In these circumstances, it can be very hard to think about something else. The only way you can rise to these challenges is to make sure you take care of yourself. Remember the question about the oxygen masks? Well, the answer is you need to put your own mask on first before you can help others. And the truth is, you have to do the same when you are a caregiver: **YOU NEED TO TAKE CARE OF YOURSELF FIRST TO MAKE SURE YOU PROVIDE YOUR LOVED ONE WITH WHAT THEY NEED AND EXPERIENCE THE REWARDING BENEFITS OF BEING A CARE-GIVER**.

By being attentive to your own physical and emotional health, you will find it easier to deal with the challenges of taking care of your loved one better. It will help you with adapting to changes, forming long-lasting connections, and recovering from complications. It will also prevent you from becoming increasingly impatient and irritable, angry, or unfair with the person you take care of. The challenges of caring for a person with schizophrenia, especially if that person is a family member, can have an enormous impact on you. Taking care of yourself will make you more resilient, **HELPING YOU TO GET THROUGH THE HARD TIMES AND ENJOY GOOD ONES**.

Diet, sleep, and exercise

One of the most extensive ways of supporting your mental health is by **WORKING ON MAKING YOUR PHYSICAL WELL-BEING BETTER**. You might find it less challenging to keep up good mental habits when you have a strong and resilient body as a foundation. To achieve that, it is essential that you take care of the fundamental health practices.

EAT WELL. Eating a healthy, balanced diet, which includes fresh fruits and vegetables, whole grains, a variety of lean proteins and a range of healthy fats is necessary to maintain a healthy body. Adopting a nutritious diet reduces the chance of getting chronic diseases, **HELPS STABILIZE ENERGY LEVELS**, and enhances mood. Avoid sugar and caffeine, as they only provide a quick boost and an even quicker crash. Alcohol

and drugs should be avoided as well, as they are not actually able to lower stress. In fact, it could even make it even worse.





GET ENOUGH SLEEP. Good sleep is crucial for your mental and physical health. Adults typically require around 7 to 9 HOURS of sleep. A short nap (up to half an hour) has the ability to make you feel more awake throughout the day. Even a guarter of an hour of sleep during the day can be beneficial. By practicing good "sleeping hygiene" you can increase the quality of your night sleep. This involves keeping a **CONSISTENT SLEEP** SCHEDULE (going to sleep and getting up at relatively similar times each day), abstaining from using computers, TV, and smartphones before bed, limiting caffeine intake, and exercising regularly. You can also create a relaxing bedtime routine that you start **30-60** MINUTES before you go to bed. This can include anything that helps you unwind, from

listening to soothing music or reading a book, to taking a warm bath or meditating for a few minutes. Cutting back on sleep can keep you back from accomplishing more, decreasing your mood, energy levels, and the extent to which you are able to deal with stress. **EXERCISE DAILY.** While experiencing stress and tiredness, exercise might be the last thing on your mind, however, it will actually leave you feeling better af-



ter it. Exercising is a stress-relieving and mood-enhancing activity. Strive for at least 30 minutes daily, which you can divide into 10-minute blocks throughout the day to make it more manageable. Small changes like choosing to take the stairs, walking up escalators, running and biking can be good starting points. If you struggle to stay committed to a schedule, you could try joining a class. Exercising every day is a natural way to release stress-reducing hormones, increase your energy levels and enhance your health in general.

PRACTICE A RELAXATION TECHNIQUE.

Practicing breathing exercises, progressing muscle relaxation and meditating are simple and fast methods for reducing stress. When you get into an argument with your loved one, such methods can help ameliorate the impact intensive feelings have on you and provide a space where you can peacefully contemplate your next actions. Some other ways to reduce stress and boost positive feelings can be practicing yoga or mindfulness meditation. As little as a few minutes during an intense day could benefit you by making you **FEEL MORE BALANCED**.



Taking care of these basic needs will help you a great deal in **OVERCOMING THE STRESS** of unexpected situations that can potentially last for a long time. The COVID-19 pandemic added another layer to the burden of caregivers all around the world, making it even more important to look after yourself in order to be able to take care of your loved one.

Reduce stress and avoid burnout

Taking care of a person with schizophrenia **CAN BE A STRESSFUL EXPERIENCE.** Because caregiving is usually a challenge of a long duration, the emotional hit can build up and form gradually. It can be especially disappointing when everything seems incomprehensible and hopeless, and even after putting in the best effort, your loved one's condition is slowly worsening. Additionally, believing that you are the only one responsible for doing everything will make your stress levels rise.

As a result, **STRESS CAN AF-FECT YOU BOTH PHYSICAL-LY AND MENTALLY**. Some of

the most frequent signs and symptoms of caregiver stress include:

- feeling anxious, depressed, and irritable;
- feeling fatigued and worn out;
- finding it difficult to fall asleep;
- having exaggerated reactions to insignificant annoyances;
- having new health problems or deteriorating present ones;



- finding it difficult to concentrate;
- experiencing more indignation;
- consuming a lot of alcohol, cigarettes, or overeating;
- avoiding responsibilities;
- reducing the time spent on recreational activities.

When a caregiver's stress is not inspected, it can negatively impact your mental health state and relationships. In due course, it can lead to **CAREGIVER BURNOUT,** a state of emotional, mental, and physical depletion that is harmful to both you and your loved one.



How to recognize caregiver burnout?

It is essential to be able to recognize the signs of **CAREGIVER BURNOUT** in order to act upon it right away and avoid its aggravation. This will **IMPROVE THE CIRCUM-STANCES** for you as well as the person you take care of. The following are an indication that you are experiencing caregiver burnout:

- you observe a drop in energy compared to before;
- you experience exhaustion consistently, even if you rest, sleep and take enough breaks;
- you fail to look after your own needs, either due to being too busy or simply not caring anymore;
- your life is oversaturated with your caregiving responsibilities; however, you get barely any satisfaction from them;

- you catch yourself reconceptualizing your values;
- you find it difficult to relax, even with help at hand;
- you get progressively more impatient and irritated with the person you care for;
- you feel an inner emptiness;
- you feel helpless and hopeless.

The signs and symptoms of burnout are very much **ALIKE TO THOSE OF DEPRESSION**. Burnout is considered a form of depression, and it should be taken **SERIOUSLY**. Inform your physician or a mental health professional once you observe the signs of burnout or you think you might be depressed.

How to avoid caregiver burnout?

There are many things that you can do to reduce stress and avoid caregiver burnout. The following steps can help you gain back the sense of balance, joy, and hope in your life.



PRACTICE ACCEPTANCE.

It can feel very natural to have the need for questioning and trying to make sense of a situation, especially at the encounter with this unfair burden of taking care of a loved one with a mental illness. This

way you are bound to spend an enormous amount of energy overthinking things that are not under your control and which have no definite answers. In the end, it will not make you feel much better. Aim at avoiding this emotional trap of self-pity or looking to put the blame on someone else.



EMBRACE YOUR CAREGIVING CHOICE.

Admit that, although you may experience resentment and a lot of pressure, providing care was a conscious decision that you yourself have made. Concentrate more on the positive intentions that led to this choice. The deep, meaningful motivations that keep you going every day could help you overcome challenging times.



LOOK FOR THE SILVER LINING.

Remind yourself of how being a caregiver has made

you more powerful and how it has helped you connect more with your loved one or the rest of your family.



DON'T LET CAREGIVING TAKE OVER YOUR LIFE.

Because it's fairly easy to come to terms with a difficult situation when your other life areas are rewarding, it is of high importance to not saturate your whole life. Invest in the things which provide you with meaning and purpose, regardless of whether it's your family, church, a favorite hobby, or your career.



FOCUS ON THE THINGS **YOU CAN CONTROL.**

It is not possible to make the days longer or insist that your sibling helps you out more often. Instead

of stressing about issues that are not under your control, try and direct your focus on the way you choose to react to them.



CELEBRATE THE SMALL VICTORIES. When you begin feeling downhearted, think back on all the

great efforts you have put in and how much they mean. You are not required to treat the illness your loved one has in order to have an impact. Give yourself credit for how important it is that you offer your loved one safety, comfort, and love!



IMAGINE HOW YOUR LOVED ONE WOULD RE-**SPOND IF THEY WERE HEALTHY.** Provided vour

loved one didn't suffer from schizophrenia; how would they make sense of the love and care you provide? Keep in mind that they would probably convey their appreciation more than they are currently able to.



APPLAUD YOUR OWN

EFFORTS. Seek ways to give vourself recognition and remuneration. Keep in mind the extent to which you are helping. In case you require something tangible, try to compile a list of all the ways in which you as a caregiver are impactful, and refer back to it when you catch yourself feeling low.



NOTICE THE POSITIVE.

When you devote time to acknowledging the positive instances in your life, the way you

experience that day can improve. Try to note down at least one thing, item, or event per day or week that you found good. Despite how big or small it is ("It was a sunny day."), it is real and it matters, and it can make a difference in the way you perceive life

MAINTAIN YOUR SENSE

OF HUMOR. Laughter is a great remedy for stress. Start reading a humorous book,

watch comedies, or reach peers that make you laugh. If possible, aim at finding humor in mundane situations.



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PRIORITIZE ACTIVITIES THAT BRING YOU ENJOYMENT. Make

sure you consistently devote time for hobbies that bring you joy,

regardless of whether it is reading a book, doing some gardening, crafting in your garage, knitting, or taking a dog for a walk.



FIND WAYS TO PAMPER

YOURSELF. Small rewards

can relieve stress and boost your spirits. Take a soothing bath and light

some candles. Get a relaxing massage. Decorate your house with fresh flowers. Anything that would make you feel special.



GET OUT OF THE HOUSE.

It is important to get out of the house for some time. If the person you care for

needs ongoing support, ask a friend or relative to step in for you for a couple of hours.



SHARE YOUR FEELINGS.

Communicating your experiences can be very relieving. Share how you

feel with friends or family members. It will make you feel better, and it will strengthen your bond. Also, talk to the doctor treating your loved one about what you are going through. The better they understand your burden, the more significant impact it could have on improving family intervention programs, the progress of your loved one's illness, and your own well-being.



JOIN A SUPPORT **GROUP.** Find out if there are care-

giver support groups in your area. Being part of a support group has many benefits that can improve your quality of life: they are a great source of useful information, they help you feel less lonely and isolated, and they help you regain a sense of control over your situation. Plus, you become part of a community that is always there for you. If there is no support group in your area that you can join in person, you can search for online groups which provide many of the same benefits.



STUDY RELENTLESSLY. One of the most important ways you can avoid burnout is by learning as much as you can about the disease and how a person with schizophrenia needs to be taken care of. In this regard, it is essential to read books, selfhelp materials, and other resources such as this guidebook. They will give you the confidence you need to tackle difficult situations and will prepare you to offer the greatest care possible for your loved one.

Make time for yourself

Being a caregiver to an individual with a mental illness can make it extremely difficult to make time for yourself, as you may spend a lot of time contemplating or being consumed by thoughts about what you "should" rather be doing. However, it is essential that you learn to TAKE TIME FOR YOURSELF

and not feel like you are being negligent of others (the individual you take care of and your family members too).

Every bit of time you dedicate to yourself is significant. Spending even just 5 minutes per day out of the "caregiver mode" when you are overloaded with responsibilities can act as a significant nudge to remind you of who you are in the grand scheme of things. It can prevent you from getting overwhelmed by all the responsibilities. **START SMALL:** remind yourself of the activities that brought you joy prior to assuming your role as a caregiver and try to introduce them back into your schedule.

It is not how frequently or what you do that is important, but the action of taking time for it itself. Unless you take good care of yourself in the first place, it is not possible to do that for someone else.

REMEMBER: being a caregiver is a major part of your life, however, it should not be the whole of it. Taking some time away will help you appreciate from a distance what you are doing.

It took me several years until I finally understood that I can only be a good help to my son, especially in the long run, if I take care of myself, too. For a long time, I felt guilty when I left him at home alone or with my husband. But at some point I learned that I can and should feel good, too - I can spend a nice evening with friends or go to the cinema, even when the times are a bit more challenging. I can give him so much more if I recharge my batteries every now and then.

> Mrs. H. P., mother of a young man with schizophrenia

Imagination exercise

Let's do a short exercise. Close your eyes and imagine you had one day without any duties, without any responsibilities, without anybody needing something from you. What would that day look like? How would you start it? How long would you sleep? What would you eat? What would you do all day? Would you spend it alone or with somebody? Imagine your entire day with as much detail as possible. Done? Great! Now take some of the nice things you imagined and try to make them true in the next few days. They will recharge you and help you get back on track.

7. Give yourself care, too

Know your limits and reach out for help

Assuming all caregiving responsibilities on yourself with no support is bound to burn you out. **DO NOT ATTEMPT TO MANAGE IT ALL BY YOURSELF.** Sharing the responsibilities will allow you to find time to recharge. are. Be straightforward about how you and the one you care for are doing. If you are concerned or are thinking of ways to make the situation better, make it known, even if you are not certain about their possible reaction. On the other hand, when someone offers assistance, do not be shy to **ACCEPT IT**. Accepting the help of your friends and family members will also make them feel



The biggest help you can get is from the people who are closest to you. Tell your family that you need help and try to involve as many family members as possible, from the earliest stages. **TELL THEM SPECIFI-CALLY** how you feel and what your needs good about supporting you. Organize a team, with well-defined duties and responsibilities. For example, someone could be in charge of medical responsibilities, someone else could take care of financial duties and pay the bills, and someone else could do the grocery shopping and run errands. This will provide you with more time for yourself, and involving family members will also strengthen family bonds. However, be ready to relinquish some control when you delegate certain tasks. People will not be as willing to help if you become authoritative, order others around, or are insistent about things being done a certain way.

Besides friends and family, you can also reach out for help in other places. Joining a **SUPPORT GROUP** ensures that you meet other people who are facing challenges like yours and are concerned about similar matters. Discussing your experiences and hearing how other caregivers solve their challenges can be of great help.

You may find that you have less time to stay connected with your friends or build new friendships. Put more emphasis on the longterm perspective. If you are able to see your friend once per month or attend local social events every couple of months, **IT AL-READY IS A WAY TO STAY IN TOUCH**. This also provides the opportunity to connect with others on different levels.





The benefits of being a caregiver

While we have mostly talked about the responsibility of taking care of a person with schizophrenia, caregiving also has **A SERIES OF BENEFITS** that become apparent only after a certain amount of time. These benefits are often elusive during hard times, for example during a crisis, having difficulties maintaining a job, being in a strained relationship with other family members, or when the disease takes its toll on health, relationships, jobs, and finances.

However, caregiving can provide you with countless moments that elicit joy or gratitude, like the reaction on your daughter's face when you hand her a piece of her favorite dessert or laugh together while watching a movie. There are also small achievements, such as getting your loved one to take their medicine, or large ones such as them being able to return to their job. These moments can **HELP YOU FO-CUS ON THE POSITIVE** instead of the frustrating and overwhelming. They can also **RECHARGE YOUR BATTERIES** and



GIVE YOU THE ENERGY you need to continue your tireless work as a caregiver.

Many of the benefits of caregiving are related to **SPIRITUAL GROWTH**, as the time spent taking care of a person with schizophrenia can change the way you see and appreciate life. It can make you become more responsible, appreciate the little things, or try to become a better human being.

"Caregiving has been one of the greatest challenges of my life. But I accepted it as my mission and it has made me stronger and more confident than ever. It taught me lessons that I will forever be grateful for: how to be more responsible, how to appreciate the little things in life, and how to value the time we spend together. Taking care of my daughter I learned the true meaning of selflessness. Being a caregiver also made me realize I have many flaws that I was not aware of. Because of caregiving, I strived every day to be a better person."

> – Mr. P. F., father of a young woman with schizophrenia

As you've seen throughout this guidebook, being a caregiver for a person with schizophrenia can be one of the most challenging life experiences you can go through. Sometimes you make mistakes, most days you do not have time for yourself, and the entire experience can take a toll on your private life and career. But **YOU CAN BE PROUD ABOUT CARING** for your child, parent, or another family member, proud to be doing your family duty, and proud to be doing the right thing. As Pablo Casals said,



"the capacity to care is the thing that gives life its deepest significance and meanings".

References

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