

A change of plans

Family plays a key role in dealing with schizophrenia. It provides long-term care and ongoing assistance, and most people who are afflicted stay with or return to their relatives. The primary caregivers in the vast majority of households are one's parents. In many cases, the responsibility of caregiving becomes theirs, before they even learn about the diagnosis.

The most significant impact of schizophrenia is that it permanently changes the everyday life of the entire family. As every decision and every action focuses on the person suffering from schizophrenia, caregivers aim to reduce the impact of the disease on their loved one's career, social life, physical health, and emotional well-being. They act as a benchmark

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to reality and serve as a source of support, encouragement, and drive. Schizophrenia also changes the plans the family had for the future of their loved one. These plans may have included finishing school, finding a reliable job, developing meaningful friendships, getting married, having children, altogether living a successful life. It is crucial to bear in mind, however, that schizophrenia does not necessarily cancel all these plans. With proper care and the concerted effort of the entire family,

MANY OF THESE PLANS MAY BECOME REALITY

Embracing emotions

After their first experienced shock caused by the schizophrenia diagnosis, many caregivers feel they have lost their plans, dreams, and expectations related to the person they love. They also fear that the situation may never return to the way it was before. This is a natural response, and recognizing these feelings and accepting them can actually facilitate a long-term successful confrontation with the disease. It is also an active process, one that requires work and uses up a significant amount of energy. Through this process, you may experience a wide range of emotions, such as anger, guilt, sadness, numbness, loneliness,

> but also irritability, sleeping difficulties, loss of appetite, and difficulty concentrating. A smooth way of getting to accept these emotions is allowing yourself to experience the complete emotional cycle.

Even though it might not seem easy at first, it is beneficial for you to go from emotional numbress to acceptance of the new circumstances and see your future from a new perspective. If you attempt to ignore or suppress your emotional discomfort, things will not soften. On the contrary, your attempt will only exacerbate them in the long run. You may find yourself stuck in a state of numbress, feeling anger, pain, and resentment. If these feelings are not resolved, they may get projected onto other relationships or situations, where they do not belong. It is very important to take into account that being diagnosed with schizophrenia does not mean that this situation is decisive. The person you care for is still there behind the symptoms, and many of the plans you had may still be achievable or just need to be slightly adjusted. The real purpose of going through all these emotions is to face them and approach the next stage of your life with curiosity. This will help you accept the disease and embrace your role as a caregiver, while also ensuring THE PERSON YOU CARE FOR CAN LIVE LIFE TO THE FULLEST

Coping strategies

Caring for someone with schizophrenia can take its toll on the entire family. Such an unfavorable situation is called a burden. This type of burden results from the collection of unpleasant experiences, challenges, events marked by stress, emotional issues, and substantial life changes that have a negative influence on the caregiver. In order to reduce their physical and mental burden, family members of people with schizophrenia develop so-called

COPING STRATEGIES

As a general rule, coping is the way people respond to tough conditions that may cause undue stress. Being a caregiver to a family member with schizophrenia can be a constant source of high levels of stress. As a caregiver, you have to cope with a wide range of issues including your caregiving responsibilities, your emotional distress, the symptoms of schizophrenia, the mental health system, and social stigma. Thus, coping with schizophrenia is a lifelong process. From the first episode of psychosis and seeing the diagnosis written on a medical chart, to the difficulties of everyday life with negative symptoms. There are three main methods of coping with stress in general:

EMOTION-FOCUSED, PROBLEM-FOCUSED, and MEANING-FOCUSED.

As its name suggests, we use emotion-focused coping to minimize the negative impact that stress has on our emotions. Problem-focused coping aims to directly solve stressful situations via problem-solving or eliminating the origin of stress. In meaning-focused coping, we use our beliefs, values, and purpose in life to find motivation and positivity during a difficult time.

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Due to the fact that every person, every family, and every case of schizophrenia is different, the emotional coping strategies that caregivers use can be laid out on a wide spectrum. On one end of this spectrum, there is complete **POSITIVITY**: the feeling of being in control, the belief that everything is the same as before, and hope for a cure in a not-so-distant future. On the other end of the spectrum, there is complete **NEGATIVITY**: the feeling of resignation, the belief that nothing will be the same as before, and hopelessness regarding the future.

NEGATIVE FEELINGS

THESE TWO EXTREMES ARE ALSO RE-FLECTED IN THE BEST AND WORST-CASE SCENARIOS THAT CAREGIVERS IMAGINE FOR THE FUTURE OF THEIR LOVED ONES:

"In my wishful thinking, my daughter will get back on her feet. She will catch up on her education, find a job that fulfills her, meet a great man and have a family. Then, my daughter would be able to take care of herself and her family independently. Even if there were occasional setbacks, I wouldn't have to worry about her anymore, and we could spend time together again without worries."

"My worst nightmare is that my son will never get back on his feet. That he is molding in his room without any drive, bound in his delusions, completely isolated and scruffy. What will become of him when I am no longer there? Certainly, I wouldn't have a restful night anymore, I would constantly try to get through to him. I don't know if I would ever be happy again." "My best case is that we find a medication to get rid of my daughter's voices. Or that she learns to deal with them. That she is no longer so affected and burdened every day. Then, I would know that she's feeling better, and I would feel better too. Maybe then I could go on a vacation again without a guilty conscience for having a good time."

"The worst thing that can happen is that my daughter has another relapse, then another and another, and eventually she loses her job. That she can no longer take care of her children, or even herself. That her children are taken away from her, and then she has nothing to live for anymore."

TAKE A MINUTE AND THINK ABOUT HOW YOU SEE YOURSELF, THE PERSON YOU CARE FOR, AND THE DISEASE. WHERE DO YOU FIND YOURSELF IN THIS SPE-CTRUM? WHAT KIND OF EXPECTATIONS DO YOU HAVE FOR THE FUTURE?

1. Emotion-focused coping

Studies indicate that the family members of individuals with schizophrenia use mostly emotion-focused coping strategies, and the most common strategy is to avoid dealing with the problem. This type of coping mechanism is not limited to the stress of having a sick family member; it can occur in all types of stressful situations. We tend to push away stressful thoughts instead of confronting them. By doing so, we fail to examine whether they were true in the first place because we try to shield them with a lot of energy. In time, the thoughts we pushed away start to intrude our consciousness, or they burst upon us unexpectedly. Thus, we have the feeling of not being able to control negative feelings and yet being at their mercy in



the long run. Hence, we try to suppress them even more, creating a vicious circle.

Emotion-focused coping is less useful at decreasing the caregiver's distress. As a consequence, **IT CAN HAVE A POWERFUL NEGATIVE IMPACT**

not only on the caregiver but also on the person with schizophrenia. Studies have revealed that using denial as a coping strategy can lead to substantial caregiver strain. In some cases, emotion-focused coping can start a chain of events that result in complete avoidance of the family member with mental illness, abandoning them to psychiatric services. The coping mechanisms of the caregivers can also affect the sick person's quality of life, including the frequency of relapses and hospitalizations.

2. Problem-focused coping

Conversely, those who resort to problem-focused coping strategies experience a much smaller burden. Some of these strategies include accepting responsibility, looking for information, assessing the positives and negatives and planful problem-solving, and seeking social support. In the case of schizophrenia, this means taking measures to make life easier for both you and your loved one, such as: joining support groups, securing medical care and financial resources, having a balanced diet, getting enough sleep, staying informed, and so on.

Finding the appropriate support group can aid belittle the original feelings of guilt, confusion, and anger, and build methods of handling the stress of having a loved one with schizophrenia. A notable method is shifting the responsibility from you to the rest of the family. It may help foster a sense of belonging and also a "we're all in this together" attitude that can actually strength-

en family ties. This approach allows both you and the person you care for to adopt a rather active attitude in regard to the illness. Instead of feeling overwhelmed by seemingly unsolvable problems, you can tackle the problems by splitting them into smaller, more approachable ones. Problem-focused coping requires a lot of mental and emotional energy, but it also provides the most benefits for both you and your loved one. Furthermore, there is evidence that problem-focused coping IMPROVES THE QUALITY OF LIFE. Make sure to involve your loved one in every decision regarding the management of their symptoms, their therapy, and even their everyday life. Making decisions together will not only

strengthen your bond but will also increase the chance for your decision to materialise.



3. Meaning-focused coping

As far as meaning-focused coping is concerned, its goal is to help us see stressful life events from a different perspective and to generate positive emotions. This type of coping includes strategies that allow to actively control the situation and fill daily routine with more meaning. One of these strategies is trying to find the benefits of the stressful event that has changed our



life. These benefits may include an expansion in wisdom, patience, and competence, pronounced cherishing of life, an improved sense of what is important, or more secure social relationships. In order for us to really value these benefits, we have to actively remind ourselves of their existence, often on a daily basis.

Another strategy is to adapt our goals based on the changed circumstances. This means abandoning goals that do not longer work and finding fresh ones that are valuable. By enhancing positive emotions, the stress of abandoning old goals can be alleviated. You may also need to reorder your priorities. While this process can be stress-inducing, it can bring about a revived sense of purpose and can help you focus on what matters most.

You can also infuse ordinary events with a positive meaning. For example, you can think of cleaning up after the person you care for as a way of expressing love. The wish to feel good has great significance for sustaining mental and physical well-being throughout difficult times. People frequently recall difficult times as critical moments that stimulated them in becoming more authentic versions of themselves. In these circumstances, positive emotions play a crucial role, leading people to see certain events in a more positive light, preserving energy for coping, as well as finding meaning in stress and suffering.

Building realistic expectations

As with everything that entails two extremes, the truth lies somewhere in the middle. There has been considerable progress in the treatment of schizophrenia, and many of the disease's manifestations that you are afraid of can be prevented or their impact lessened. At the same time, caring for someone with schizophrenia can be a challenging experience for the entire family. Having a plan and a sense of purpose, both for you and the person you care for can significantly improve the course of the disease. Learn about schizophrenia as

much as you can. Work together with the person you care for to find out what works best for you. Studies show that the lack of information about schizophrenia leads not only to negative attitudes towards mental illness but also to a higher rate of relapse.

The best way to provide the care your loved one needs is to develop a realistic, middle ground-type of expectation regarding your future together and the course of the disease. You can achieve this by learning as much as you can about schizophrenia and by being informed of all possible prevention measures and treatment options. Develop an action plan, with clear responsibilities, which will help you get over obstacles and gain greater control in the future. Focus on finding solutions for the problems you encounter. Address all measures that can avert a worst-case scenario and promote a best-case scenario. Make sure to establish not only your responsibilities but also those of the person you care for. This will boost their confidence and will significantly improve the quality of their life.

You also need to consider rehabilitation options, financial and legal aspects, and other practical measures that will enable you to have a clearer vision of the path ahead. You will find useful information on all of these topics in the next chapters of this guide.

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