Peter Falkai
János Kálmán
Fides Sophia Heimkes
Zoltán Sárkány

THE CANDID BOOK

FOR FAMILIES OF PEOPLE LIVING WITH SCHIZOPHRENIA

edited by
PETER FALKAI

The Candid Book – for families of people living with schizophrenia
by Peter Falkai, János Kálmán, Fides Sophia Heimkes, Zoltán Sárkány

Published by Inspira Research Ltd.
H-1132 Budapest, Váci Road 18.
https://inspira.hu/en/home/

First hardcover edition April 2022.

ISBN: 978-615-01-3795-7

Medical editing support by Diana Osadcii-Zaiat
Creative director Anna Csapó
Cover design by Mihai Croitoru

Supported by Gedeon Richter Plc.

The information contained in this book is not intended to diagnose, treat, cure, or prevent any condition or disease. Please consult with your physician or healthcare professional regarding the advice, suggestions, and recommendations made in this book.

The authors, publisher, contributors, and other representatives shall not assume responsibility or legal liability for any textual errors or damages occurring from or in connection with the use of this book.

You understand that this book is not intended to substitute consultation with a healthcare professional/licenced practitioner. Before you begin any healthcare program or change your lifestyle in any way, you will consult your physician or another licensed healthcare practitioner to ensure that you are in good health and that the examples contained in this book will not bring you any harm.

This book contains information related to physical and/or mental health conditions. As a result, the use of this book implies your agreement with this disclaimer.

Links to third-party websites are provided by the authors in good faith and for informational purposes only. The authors, contributors, and representatives disclaim any responsibility for the content of any third-party website referenced in this book.

All names that appear throughout this book are fictitious. Any resemblance to actual persons, living or dead, or actual events is purely coincidental.

Peter Falkai
János Kálmán
Fides Sophia Heimkes
Zoltán Sárkány

THE CANDID BOOK

FOR FAMILIES OF PEOPLE LIVING WITH SCHIZOPHRENIA

edited by
PETER FALKAI

supported by
Gedeon Richter

FOREWORD

Since I have dedicated more than 30 years of my life to this vast field of psychiatry, with no intention of stopping in the near future, it is my great pleasure to adjoin my name to this book as its editor. This book represents the common ground where its authors and I speak the same language with the purpose of helping families of people living with schizophrenia around the world.

"The family is the first essential cell of human society," said Pope John XXIII. Not only as a doctor but also as a human being, it is my firm belief that family generally plays one of the most important roles in the beautiful and harmonious upbringing of a person. When a person's life is influenced by various external factors, such as an illness, the family's role shifts from *one of the most important* to *the most important*. When a person is ill, in this context suffers from schizophrenia, they might feel incomplete, negatively different, or as if life itself let them down. This is the moment when family becomes indispensable. I cannot accentuate enough how vital family is to a person in this type of medical condition, how much stability and security family provides, how positively the family's regular support and presence influence the ill person's life, and how much the idea of togetherness in the ongoing conflict with the disease matters.

The book you are now holding in your hands is the product of similar ideas and ways of thinking of doctors from three different countries, who are willing to lend a helping hand to caregivers and dedicate an entire book to families that stick together and provide continuous help, support and care for their differently positioned members. It aims to help you help your loved one cope with the impact that such an illness might have on his or her life and to also remind you of how significant you are throughout this journey.

Although you might have quite a knowledge about schizophrenia so far, this book addresses schizophrenia and everything related to it from the very beginning. It will mainly answer questions that start with "what is". For example, *what* is schizophrenia and how does it manifest, *what* is stigma and its different perspectives, *what* is the outcome of positively or negatively looking at schizophrenia, *what* is the therapeutic amelioration, *what* is happening to your emotions as a caregiver, *what* is your role as a caregiver and *what* is the type of care you need to give yourself.

After having talked and listened to numerous families of patients throughout my activity of medical and treatment research in psychotic disorders as a psychiatrist, I came to the conclusion that the most effective way to answer these questions is to use a straightforward and candid approach. Even though you might have felt or still feel that life is not fair neither to your dear one nor to you for putting you through this, you do not need to be beautifully lied to. You need to know everything as it actually is in order for you to contribute to making your loved one's life good and worth living.

In addition to the trust you need to have in doctors and the medical team that takes care of your loved one, you also need to trust yourself that you are doing everything you can to the best of your ability. Know that your loved one is grateful, their doctor and medical team are grateful, the rest of the family members and friends are grateful, the world is grateful. And here I want to go back to the insightful words I quoted above and emphasize the importance of your responsibility as a caregiver in society. Thanks to you and the uninterrupted care and involvement you display, your loved one is able to be part of this society and lead what people call a normal life.

In my opinion, as you will learn from this book, what is also an extremely vivid idea that should remain with you for the rest of your life is that *you are not alone*. You will always be assisted and guided by doctors, but who could understand you better if not people who have a way of life similar to yours? People who are as strong as you are, as loving and caring as you are, people who shared their stories and want others like them to know that this journey is not a loss, but an opportunity to see, acknowledge and love your dear one as they truly are, without letting yourself misled by stigma, improper judgements, and false presumptions. If you ever need it, remind yourself that you are a pillar for your family structure and a bridge between that member of your family whose life has a different pattern and society.

The Candid Book – for families of people living with schizophrenia will help you shape and ground your role as a caregiver and will help you solve dilemmas and answer your questions through medical knowledge, practical insights, efficient remedies, and caregiver support. Besides being medical experts in their field, the authors of this book speak for all of us dealing with schizophrenia, no matter the roles we play.

Peter Falkai, MD, PhD

Chairman, Department of Psychiatry and Psychotherapy, Ludwig-Maximilians-University Munich, Germany

EPA (European Psychiatric Association) President

✋ IF SPECIALIZED WORDS GET HARD TO UNDERSTAND WITHIN THIS GUIDEBOOK…

The present guidebook contains medical terminology that might be difficult to understand for most readers. For this reason, we are offering you the proper solution in order for you to enjoy a smooth and relaxing reading altogether. Our solution consists of a brief glossary at the end of the guidebook that will come in very handy the moment you come by a specialized word you don't understand, haven't heard of before, or maybe you vaguely know the word, but not its literal meaning. The words in question will be marked with '✋' throughout the text and you will easily be able to find them explained in the handy glossary at the end of the guidebook in alphabetical order.

THE PURPOSE OF THIS BOOK

is to offer you guidance on how to help your loved one live a better life and navigate through the everyday challenges of schizophrenia. It also aims to provide useful information on how to accept and adapt to this new situation in your life, how to become a bridge between the person you care for and healthcare professionals, and last but not least, how to ***TAKE CARE OF YOURSELF THROUGHOUT THIS CHALLENGING BUT OFTEN REWARDING JOURNEY***.

CURRENT PROSPECT ON SCHIZOPHRENIA

Although the fact that a loved one has been diagnosed with schizophrenia may be hard to accept at first, there are many things to hope for. In recent decades substantial advancement has been made in how we understand and accept schizophrenia; also, effective treatments have been developed.

The general outlook of schizophrenia is favorable. Most patients who follow their treatment will improve, and many of them will be able to work and live independently.

While there is no cure for schizophrenia, ongoing research in genetics✋, behavioural science✋, and neuroimaging✋ holds the promise of new, innovative ways of treatment that will enable people living with schizophrenia to have an active, fulfilling life.

1. Schizophrenia in view

What is schizophrenia?

Schizophrenia is a chronic mental disorder that impacts the way a person **JUDGES, PERCEIVES, AND BEHAVES**. Individuals suffering from schizophrenia experience disruptions in how they perceive the world and express themselves. They often seem to have lost touch with reality and this would cause significant distress for them, their family members, and their friends.

People living with schizophrenia may have difficulties discerning reality from fantasy. They may worry that others are reading their mind, secretly planning to harm them. They may also hear, see, touch, or feel things that are not there. Other times, they may experience difficulties in feeling, reading, and expressing emotions. As their thinking process becomes affected, they may have trouble concentrating or making decisions. Also, activities that they used to enjoy may not bring them pleasure anymore.

These symptoms have a serious impact on their everyday activities and relationships.

Schizophrenia is less common than other mental disorders and affects an approximate number of

24 MILLION

people around the world or

0.32%

of the world population. Schizophrenia occurs at similar rates in all genders, races, ethnic groups, and economic backgrounds.

When do symptoms occur?

The first schizophrenia symptoms typically occur during the patient's late teenage years and early thirties. Men and women are equally likely to develop the disorder. In men, symptoms tend to appear earlier, from their late adolescence to emerging adulthood. Women are at higher risk of experiencing symptoms during their late **20s** to early **30s**. This disorder may also appear around the age of **45–50**.

Due to its wide range of manifestations, **SCHIZOPHRENIA IS ONE OF THE MOST COMPLEX MENTAL DISORDERS**.

Although schizophrenia is a chronic disorder, it can be treated with medication. In the long term, the lives of people with this condition may be substantially improved by psychotherapy and psychosocial treatments.

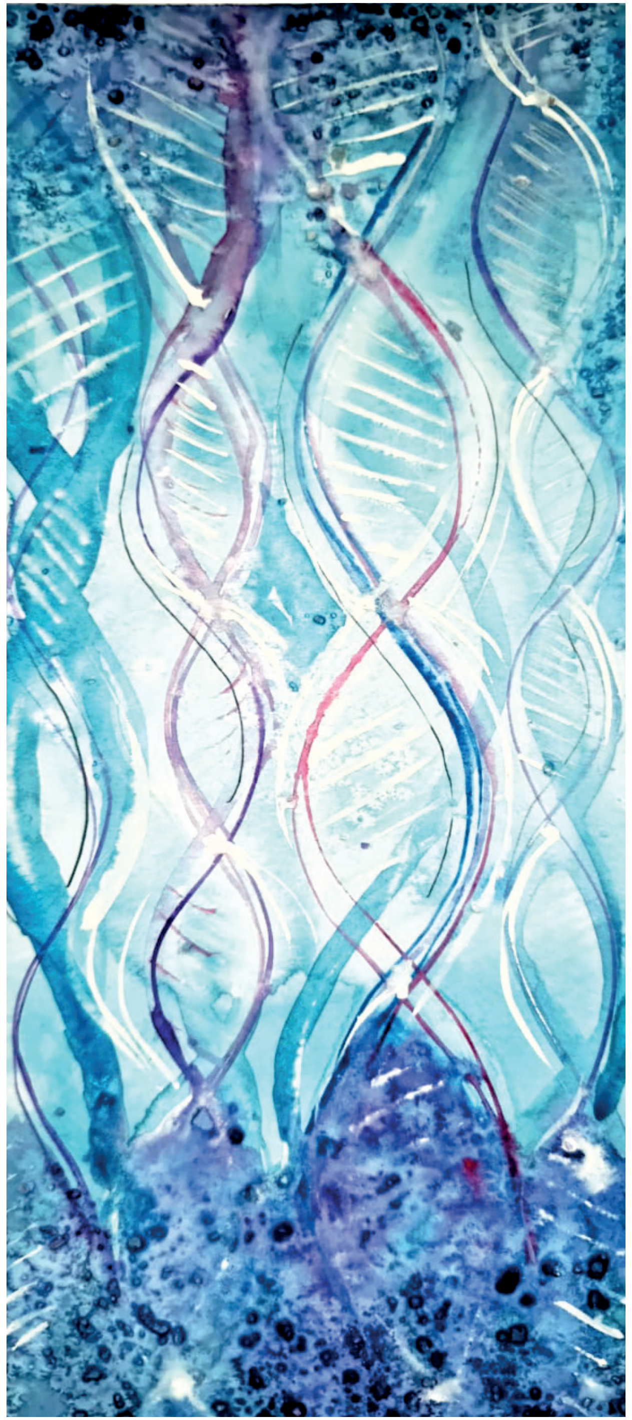
What are the risk factors for schizophrenia?

We've learned a great deal about schizophrenia in the last few decades. However, **THE PRECISE ORIGIN OF THE DISORDER IS UNKNOWN**.

Researchers believe that it could be caused by an interaction between **GENES AND ENVIRONMENTAL FACTORS**.

Genes play a very important role in schizophrenia. Studies suggest that many different genes may be involved. However, a single gene is not the cause of the disorder. It is also clear that genes are not the direct cause of schizophrenia. Rather, they foster individuals to be vulnerable to the development of this disease.

There is also evidence of a genetic predisposition. Sharing the same DNA as someone with schizophrenia increases the likelihood of developing it. If that relative is a close one, the risk becomes **15** times higher. But if that relative is an identical twin, the risk increases to around **50%**.



Developmental and environmental factors include poverty, stress, viruses, toxins, nutritional problems before birth, as well as pregnancy and birth complications. Living in an area with a dense population or having a familial background defined by abuse and trauma, high intelligence deficient, and distressing encounters with bullying may also represent risk factors.

Adolescence is considered a turning point in the development of schizophrenia. During this body development period, the brain goes through a series of changes as it matures. In the case of a vulnerable person, these changes may trigger psychotic episodes.

Drug abuse is also seen as a risk agent in the development of schizophrenia, especially in adolescence. Cannabis, for example, combined with other risk factors mentioned above, seems to be directly involved in the development of the disorder.

How does schizophrenia influence the brain?

Schizophrenia has a wide range of symptoms. In order to understand these symptoms, we first must take a look at what happens in the brain of a person with the disorder. Research has shown that in people with schizophrenia brain cells work and communicate with each other differently.

The role of neurotransmitters

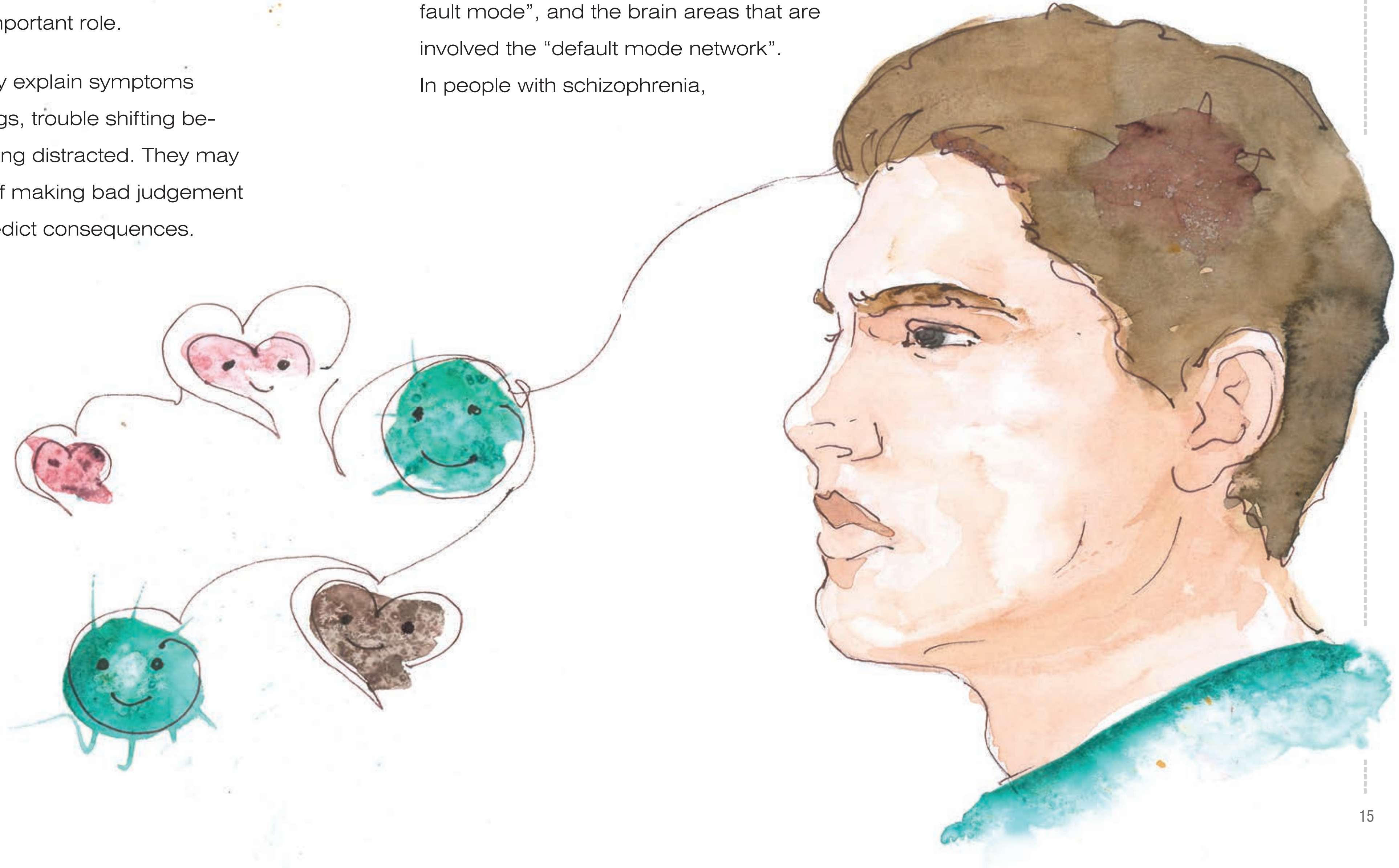
Neurotransmitters are chemical messengers that carry information between brain cells. Having too much or too little of these messengers has an impact on how the brain functions.

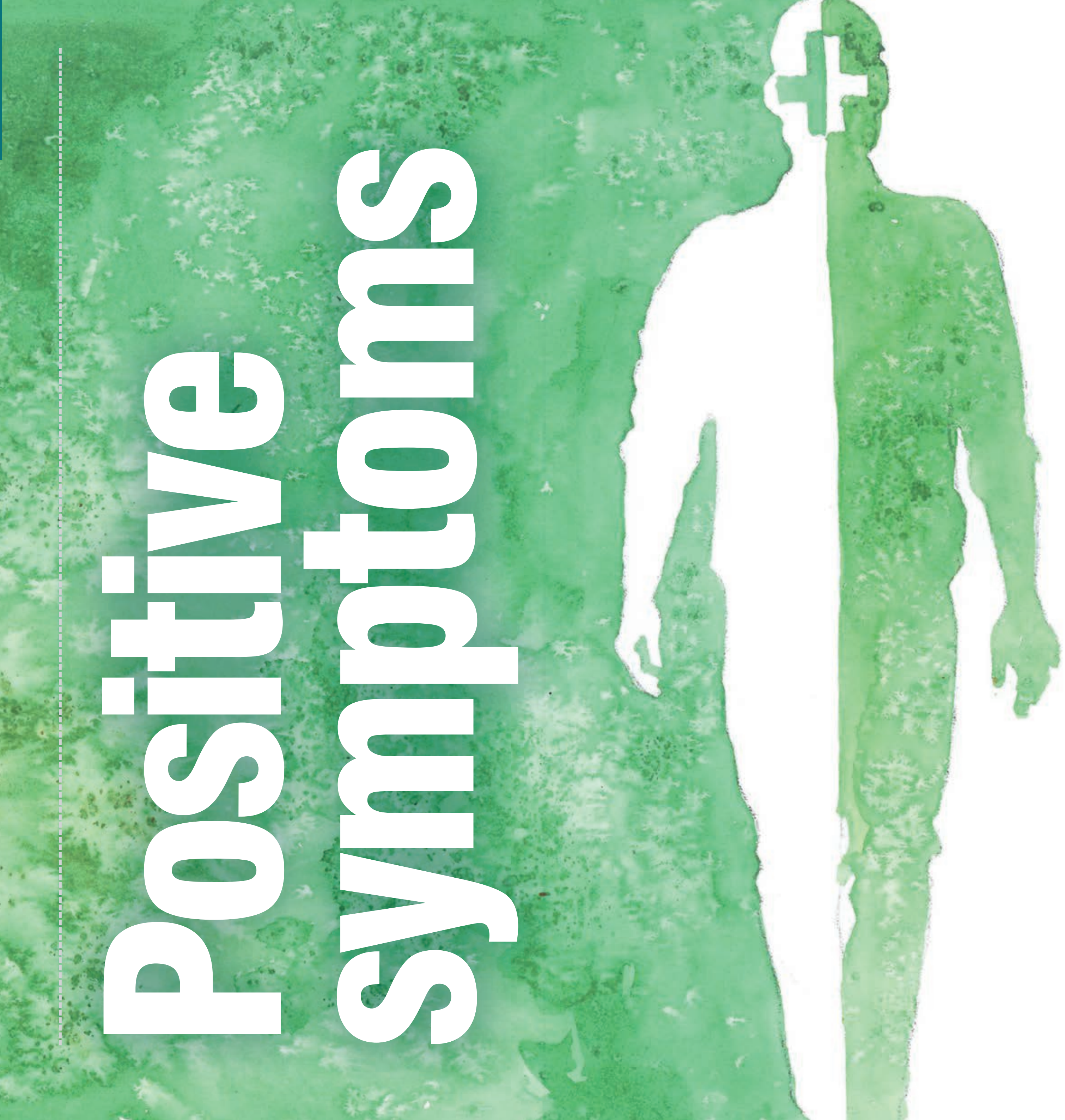
One of the most studied neurotransmitters in schizophrenia is **DOPAMINE**●. Also called the "feel good" neurotransmitter, **DOPAMINE** plays an important role in thinking, perception, and motivation. In schizophrenia, too much **DOPAMINE** in some parts of the brain may lead to hallucinations or delusions. On the other hand, too little **DOPAMINE** in other parts of the brain may explain the lack of motivation and energy that is typical in schizophrenia. Other neurotransmitters, such as GABA●, glutamate●, and serotonin● (also called "the happy chemical") may also play an important role.

These changes may explain symptoms such as memory lags, trouble shifting between tasks, or feeling distracted. They may also be the cause of making bad judgement calls or failing to predict consequences.

The default mode network

Some areas in our brain become active when we let our thoughts run free. This enables us to daydream and process thoughts and memories. Scientists call this the "default mode", and the brain areas that are involved the "default mode network". In people with schizophrenia, **THESE AREAS ARE ALMOST CONTINUOUSLY IN A STATE OF OVERDRIVE**. This makes it difficult for them to pay attention or remember information.





Positive symptoms

What are the symptoms of schizophrenia?

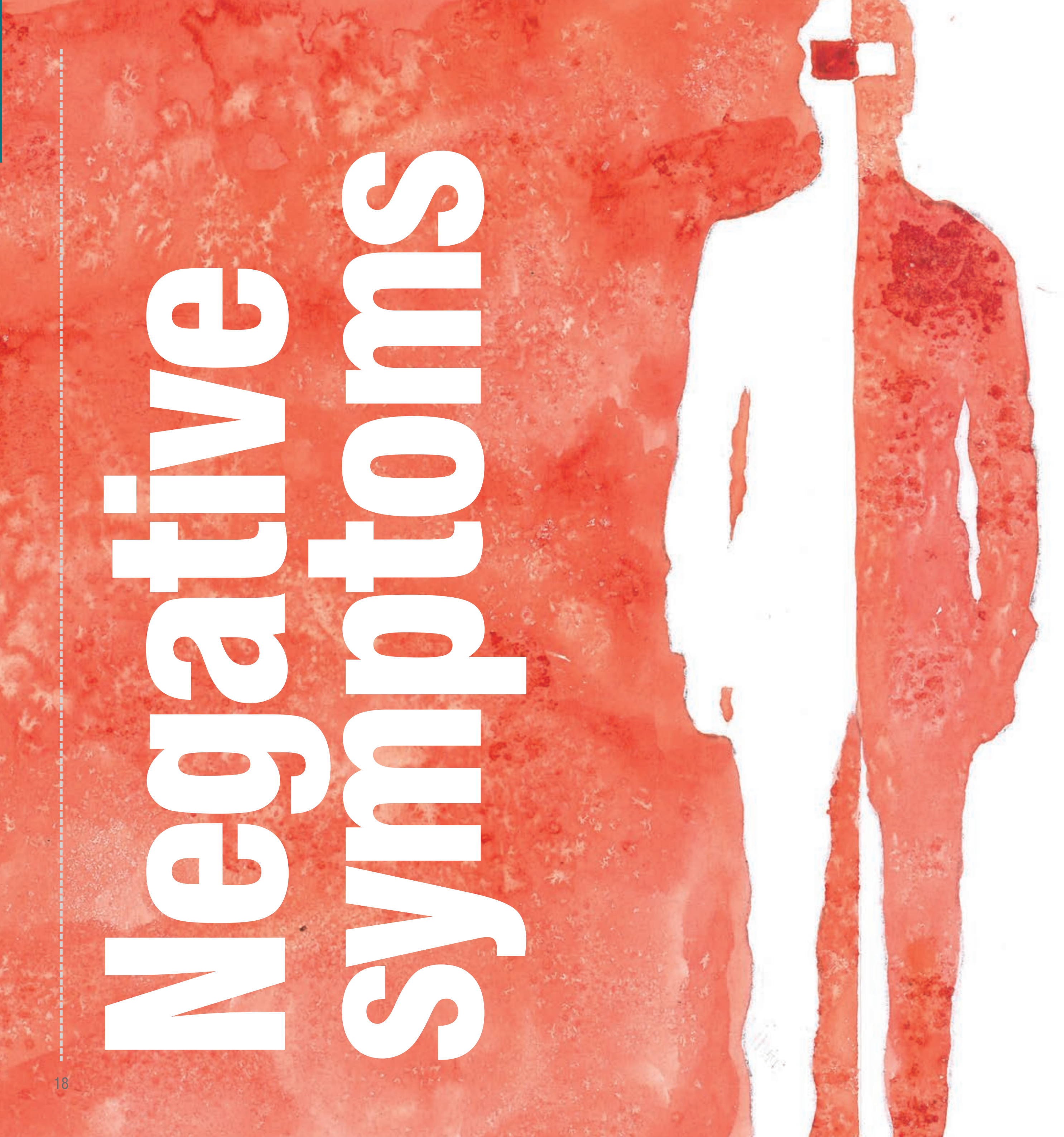
There are several main categories of symptoms: positive, negative, cognitive, and affective.

1. Positive symptoms

Positive symptoms (often called "psychotic symptoms") are thoughts and behaviours which are not present in healthy people. Several positive symptoms may be present at once. They include:

- **HALLUCINATIONS**: hearing, seeing, or feeling things that are not actually real and cannot be perceived by others. They can include hearing sounds, music, whispers or voices, seeing objects, flashes, or persons, sensing textures or objects, tasting or smelling things. The most common hallucinations involve hearing commenting voices, usually as a dialogue, which are often criticizing or threatening. These voices may also tell the patient to do things he/she otherwise wouldn't do.
- **DELUSIONS**: uncorrectable false beliefs that are not shared by others and may appear as bizarre. Individuals with schizophrenia frequently believe they are being persecuted or spied on. Other times they believe that others can read their thoughts, or that they have special powers or abilities. Several types of delusions can occur at once.
- **DISORGANIZED THOUGHT AND SPEECH**: involves confused and disordered speech and thinking. Patients often stop in the middle of a sentence. They may also put together words without any logical meaning, talk about things that are irrelevant to the topic, or jump from one idea to another. This way, their speech may become hard to understand.
- **BIZARRE BEHAVIOURS** could manifest in several forms, from childlike silliness to unexpected agitation. Other times, the patient may take a bizarre posture, or use excessive movement. He/She may also resist instructions, or show a complete lack of response.

Negative symptoms



2. Negative symptoms

Negative symptoms comprise thoughts and behaviours that schizophrenia reduces or makes absent, like motivation or the ability to express emotions. They are also inclined to be more difficult to treat compared to the positive ones.

Negative symptoms include:

- **REDUCED EXPRESSION OF EMOTIONS**

  (also called **“BLUNTED AFFECT”** or **“FLAT AFFECT”** ✋): this affects speech, facial expressions, and even movement. The person’s speech becomes flat, with a dull, monotone voice. Their face shows no emotion, and they may even avoid eye contact.

- **REDUCED ABILITY TO SPEAK**

  (also called **“ALOGIA”**): speech is reduced and becomes very poor. Replies may be delayed, using short or one-word sentences. This creates the impression of inner emptiness.

- **REDUCED ABILITY TO EXPERIENCE PLEASURE**

  (also called **“ANHEDONIA”**): little or no interest in activities that used to bring joy. These activities include listening to music, gardening, or even eating. Feelings towards loved ones can also be affected.

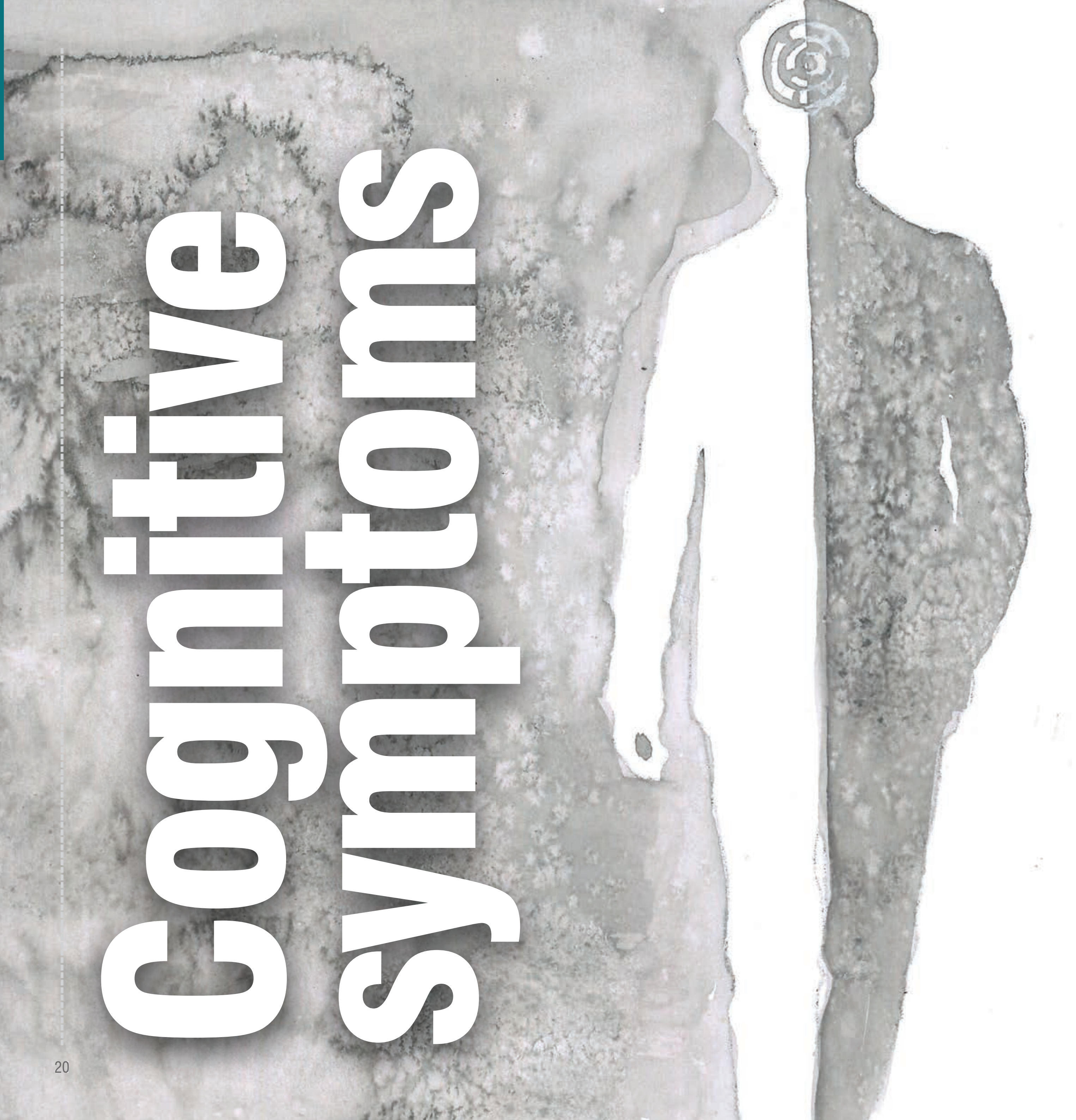
- **LACK OF MOTIVATION**

  (also called **“AVOLITION”**): a significantly diminished sense of drive and purpose. It also manifests as a lack of ability to follow through on plans. It is important to note that these manifestations are caused by the disease and not by a lack of willpower.

- **SOCIAL WITHDRAWAL**

  (or **“ASOCIALITY”**): a decreased interest in forming close relationships with others. This leads to a significant reduction in social interactions.

Cognitive symptoms



3. Cognitive symptoms

Cognitive symptoms affect thinking and mood and lead to worsening performance at school and work. They typically appear before the positive symptoms and are often still present after the positive ones have diminished.

Cognitive symptoms include problems with **ATTENTION**, **CONCENTRATION**, and **MEMORY**. People with schizophrenia have difficulties learning new things, or processing information to make decisions. They may also have trouble focusing and paying attention, often because of hallucinations. Because they are unable to respond properly to others, they often communicate as little as possible.

Cognitive symptoms make it more difficult to perform everyday activities. As a consequence, they can be one of the most debilitating aspects of schizophrenia.

Often, people with schizophrenia are not aware that they are suffering from the disorder. This lack of insight, also called "anosognosia", can make their treatment and care much more challenging.

4. Affective symptoms

Alongside the types of the aforementioned symptoms, people with schizophrenia frequently exhibit affective symptoms such as depression and anxiety. Depression can be present in up to **80%** of people with schizophrenia and can have a wide range of negative consequences: it increases the risk of a relapse, and it leads to worse social functioning as well as poorer life quality. Depression also increases suicide risk: almost two-thirds of people with schizophrenia who take their lives do so while having depressive symptoms. Around half of people with schizophrenia have suicidal thoughts and mood problems, either as a symptom of the illness or due to the stress and social issues caused by schizophrenia. Furthermore, around **30%** have obsessive-compulsive symptoms, manifested as recurrent, intrusive, and unwanted thoughts that cause significant distress and depression.

Schizophrenia reveals three phases

The schizophrenia course depends on several factors: when the symptoms begin, how severe they are, and how long they last. Early symptoms often appear progressively and become more severe and evident over time.

Individuals may experience periods of symptom worsening and symptom improvement. The periods of symptom worsening are known as flares or relapses. By using treatment, the majority of such symptoms can decline or disappear (particularly the positive ones). Remission relates to a period without symptoms or mild symptoms only.

Although the course of the illness varies from one person to another, it can be divided into three distinct phases:

PRODROMAL,
ACTIVE, and
RESIDUAL.

1. Prodromal phase

Prodromal means “before the disease”. In this phase, which may last **2–5 years**, individuals undergo changes that become noticeable to family and close friends. These changes include memory and concentration problems, or unusual behaviour and ideas. They may also exhibit disorganized communication and decreasing interest in daily activities. In adolescents, these changes are often overlooked because they are considered normal for this period. Looking back, these symptoms are easier to interpret as warning signs. However, at the time, it would have been extremely difficult to tell them apart from the usual signs of puberty.

2. Active phase

This phase is characterized by the appearance of psychotic symptoms such as hallucinations, delusions, and/or disorganized thinking and speaking, but also depression or flat affect. The presence of these symptoms is called “psychosis”, and its period of manifestation is called a “psychotic episode”. The symptoms may appear gradually or suddenly. In most cases, the cause remains unknown. Scientists think that the first appearance of psychotic symptoms (also called “the first break”) may be caused by stress. Patients and their family members usually seek professional help during this phase.

3. Residual phase

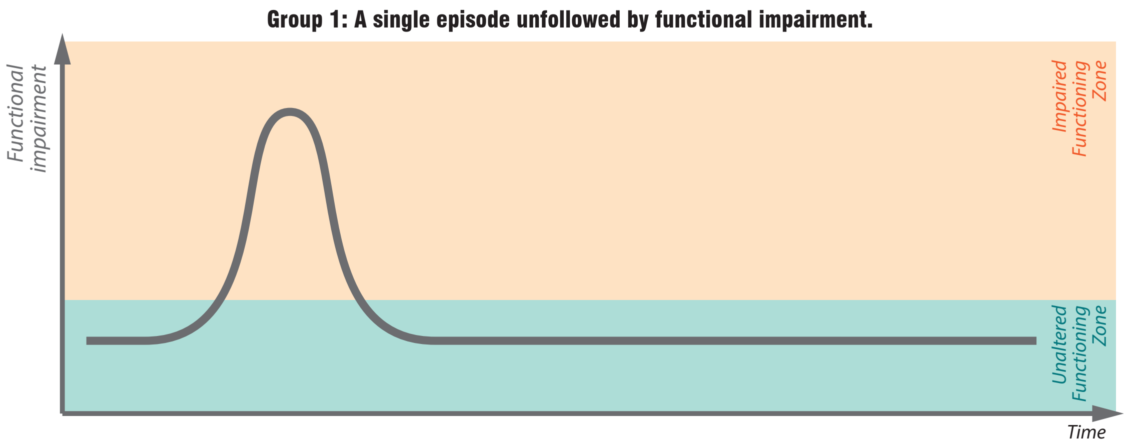
It depicts the period of **6–18 months** following the active phase. In this phase, many of the characteristic psychotic symptoms diminish. However, some residual symptoms, such as hallucinations or functional impairment, may remain. Positive symptoms may also be replaced by negative symptoms, for example, lack of energy and withdrawal from society. In many cases, patients begin to recognize their symptoms in this period and start to learn how to manage them.

How does schizophrenia progress?

Although the illness affects every patient differently, according to research in the field, the course of the illness usually follows one of the typical forms illustrated within the next four schematic representations of the possible course of schizophrenia and its impact on patients' normal functioning.

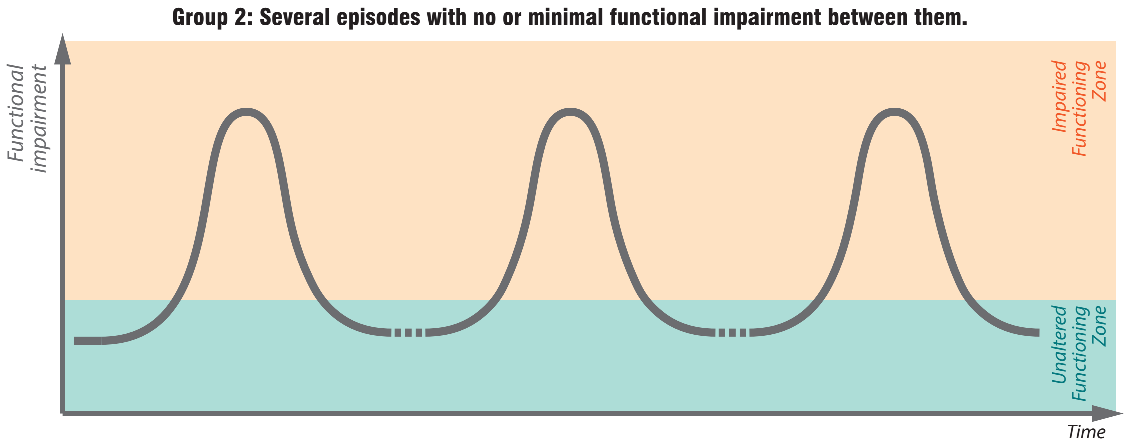
As Figure 1 below shows, after an acute first episode with psychotic symptoms, **22%** of those affected may experience remission, without recurrence or functional impairment in the future.

Figure 1.


Group 1: A single episode unfollowed by functional impairment.

Research reveals that in **35%** of the cases, the illness progresses in an episodic manner, with several psychotic episodes in the following years, as is shown in Figure 2 below. These episodes are often triggered by increased levels of stress. In some cases, there is a complete remission between individual episodes, with regained functionality.

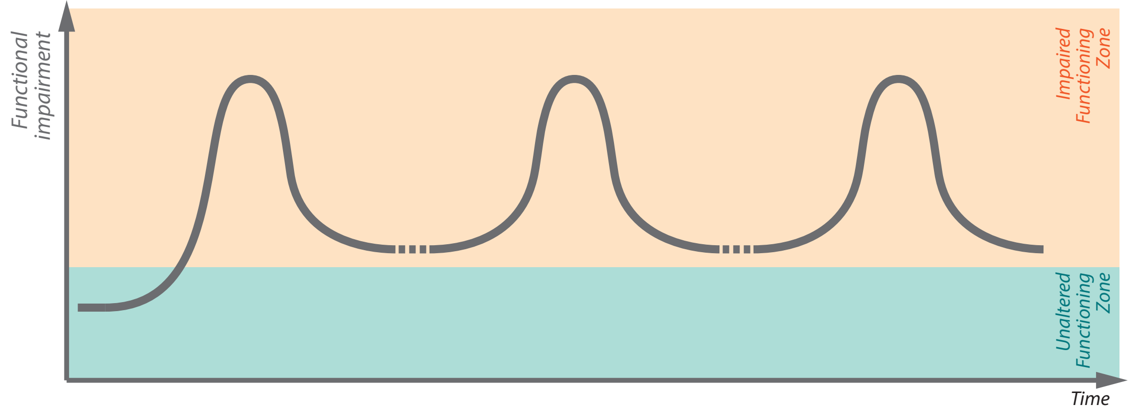
Figure 2.


Group 2: Several episodes with no or minimal functional impairment between them.

In about **8%** of those affected, there is partial remission, with diminished but persistent symptoms, as Figure 3 shows. These may include psychotic symptoms, negative symptoms, cognitive disturbances, and loss of normal functioning.

Figure 3.

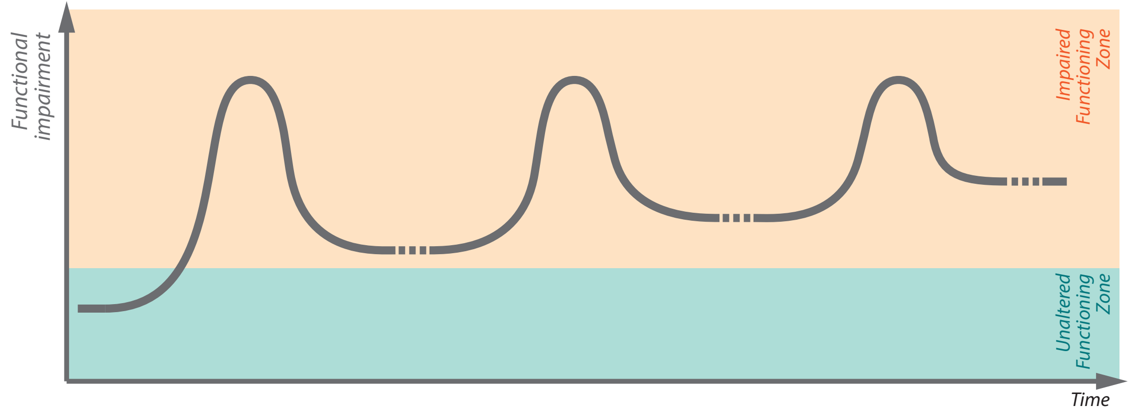
Group 3: Impairment appears after the first episode. No return to normal functioning.



In other approximatively **35%** of cases, the illness worsens progressively, and episodes cannot be identified separately. For a visual representation, please see Figure 4 below.

Figure 4.

Group 4: Impairment increases with each episode. No return to normal functioning.



Important note!

SCHIZOPHRENIA SYMPTOMS CAN BE WELL-CONTROLLED

by means of treatment and those affected can live a rich, meaningful life.

As a caregiver, your care and support can be essential in helping your loved one live life to the fullest.

References

1. World Health Organization. (www.who.int) Webpage: Schizophrenia. 2022.

2. Lewis SW, Buchanan RW. Fast Facts: Schizophrenia, Fourth Edition. Health Press; 2015.

3. James SL, Abate D, Abate KH, Abay SM, Abbafati C, Abbasi N, et al. Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. The Lancet. 2018 Nov 10;392(10159):1789–858.

4. Gaebel W, Wölwer W. Themenheft 50 “Schizophrenie.” Robert Koch-Institut; 2010.

5. Lindamer LA, Lohr JB, Harris MJ, McAdams LA, Jeste DV. Gender-related clinical differences in older patients with schizophrenia. J Clin Psychiatry. 1999 Jan;60(1):61–7; quiz 68–9.

6. Roberts LW, Hales RE, Yudofsky SC. The American Psychiatric Association Publishing Textbook of Psychiatry. Seventh Edition. American Psychiatric Association Publishing; 2019.

7. National Institute of Mental Health. Schizophrenia [Internet]. [cited 2020 Oct 4]. Available from: https://www.nimh.nih.gov/health/topics/schizophrenia/index.shtml#part_145430

8. Gaebel W, Hasan A, Falkai P. S3-Leitlinie Schizophrenie. Berlin: Springer-Verlag; 2019.

9. Cunningham T, Hoy K, Shannon C. Does childhood bullying lead to the development of psychotic symptoms? A meta-analysis and review of prospective studies. Psychosis. 2016 Jan 2;8(1):48–59.

10. Schizophrenia - Mental Health Disorders [Internet]. Merck Manuals Consumer Version. [cited 2020 Oct 4]. Available from: https://www.merckmanuals.com/home/mental-health-disorders/schizophrenia-and-related-disorders/schizophrenia

11. Ernest, D., Vuksic, O, Smith-Shepard, A., Webb, E. Schizophrenia. An information guide. Canada. Library and Archives Canada Cataloguing in Publication; 2017.

12. Conley RR, Ascher-Svanum H, Zhu B, Faries D, Kinon BJ. The Burden of Depressive Symptoms in the Long-Term Treatment of Patients With Schizophrenia. Schizophr Res. 2007 February; 90(1-3): 186–197

13. Harkavy-Friedman J. Risk Factors for Suicide in Patients With Schizophrenia [Internet]. Psychiatric Times. [cited 2021 Jun 16]. Available from: https://www.psychiatrictimes.com/view/risk-factors-suicide-patients-schizophrenia

14. Tezenas du Montcel C, Pelissolo A, Schürhoff F, Pignon B. Obsessive-Compulsive Symptoms in Schizophrenia: an Up-To-Date Review of Literature. Curr Psychiatry Rep. 2019 Jul 1;21(8):64.

15. Corcoran C, Walker E, Huot R, Mittal V, Tessner K, Kestler L, et al. The stress cascade and schizophrenia: etiology and onset. Schizophr Bull. 2003;29(4):671–92.

16. American Psychiatric Association. The American Psychiatric Association Practice Guideline for the Treatment of Patients With Schizophrenia. Third Edition. American Psychiatric Association Publishing; 2020.

17. Andresen R, Oades L, Caputi P. The experience of recovery from schizophrenia: towards an empirically validated stage model. Aust N Z J Psychiatry. 2003 Oct;37(5):586–94.

18. Andreasen NC, Carpenter WT, Kane JM, Lasser RA, Marder SR, Weinberger DR. Remission in schizophrenia: proposed criteria and rationale for consensus. Am J Psychiatry. 2005 Mar;162(3):441–9.

19. Bäuml J. Psychosen aus dem schizophrenen Formenkreis: Ein Ratgeber für Patienten und Angehörige. Berlin Heidelberg: Springer-Verlag; 2013.

20. Schizophrenia.com. Schizophrenia Facts and Statistics. (http://schizophrenia.com/szfacts.htm)

2. The 3 A's of stigma remedy: Acknowledge, Apprehend, Alleviate

You are not alone!

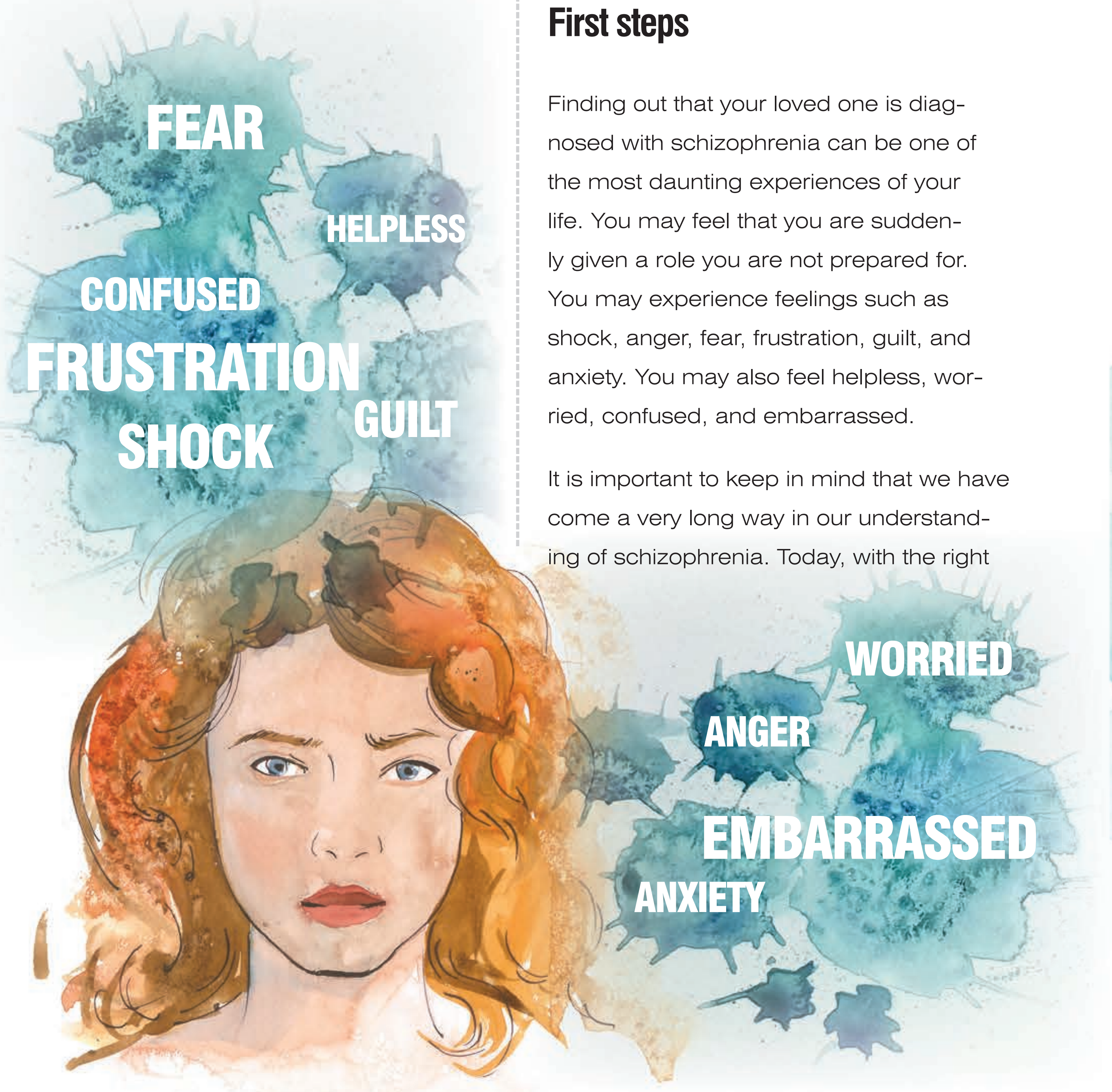
There are more than **20 MILLION** people living with schizophrenia around the world. By their side are the caregivers who face the same fears, difficulties, and challenges as you are right now. Get in touch with them. Join a support group or a caregivers association. There is a large network of caregivers in Europe who share the same goal: to positively impact the lives of those they care for.

This can also give you the opportunity to connect with other families affected by schizophrenia. People with schizophrenia and their families often feel isolated or misunderstood. You may find it helpful to connect with them and exchange experiences and advice.

Most importantly, talk to healthcare specialists. If there is a medical team taking care of your loved one, turn to them for advice. Become actively involved in the conversation. Remember: **YOU ARE NOT ALONE!**

"When I had the opportunity to talk to other caregivers, I suddenly realized that I was not alone. Hearing that so many families are struggling with their child's illness in a similar way as we are really helped me; that we share the same worries about our children, but also our sadness about the disease and all the restrictions that come along with it; that they are sometimes plagued by feelings of guilt and helplessness, too; that they are sometimes ashamed and insecure about how people around them react. And even if the exchanges with others did not solve all of my problems, I felt much lighter afterward, because I knew I was not alone and my feelings are valid."

– Mrs. A. J., mother of a young man with schizophrenia



First steps

Finding out that your loved one is diagnosed with schizophrenia can be one of the most daunting experiences of your life. You may feel that you are suddenly given a role you are not prepared for. You may experience feelings such as shock, anger, fear, frustration, guilt, and anxiety. You may also feel helpless, worried, confused, and embarrassed.

It is important to keep in mind that we have come a very long way in our understanding of schizophrenia. Today, with the right treatment and support, **WE ARE ABLE TO MANAGE THE DISEASE AND HELP PEOPLE WITH SCHIZOPHRENIA** take back their place in society and live a gratifying life.

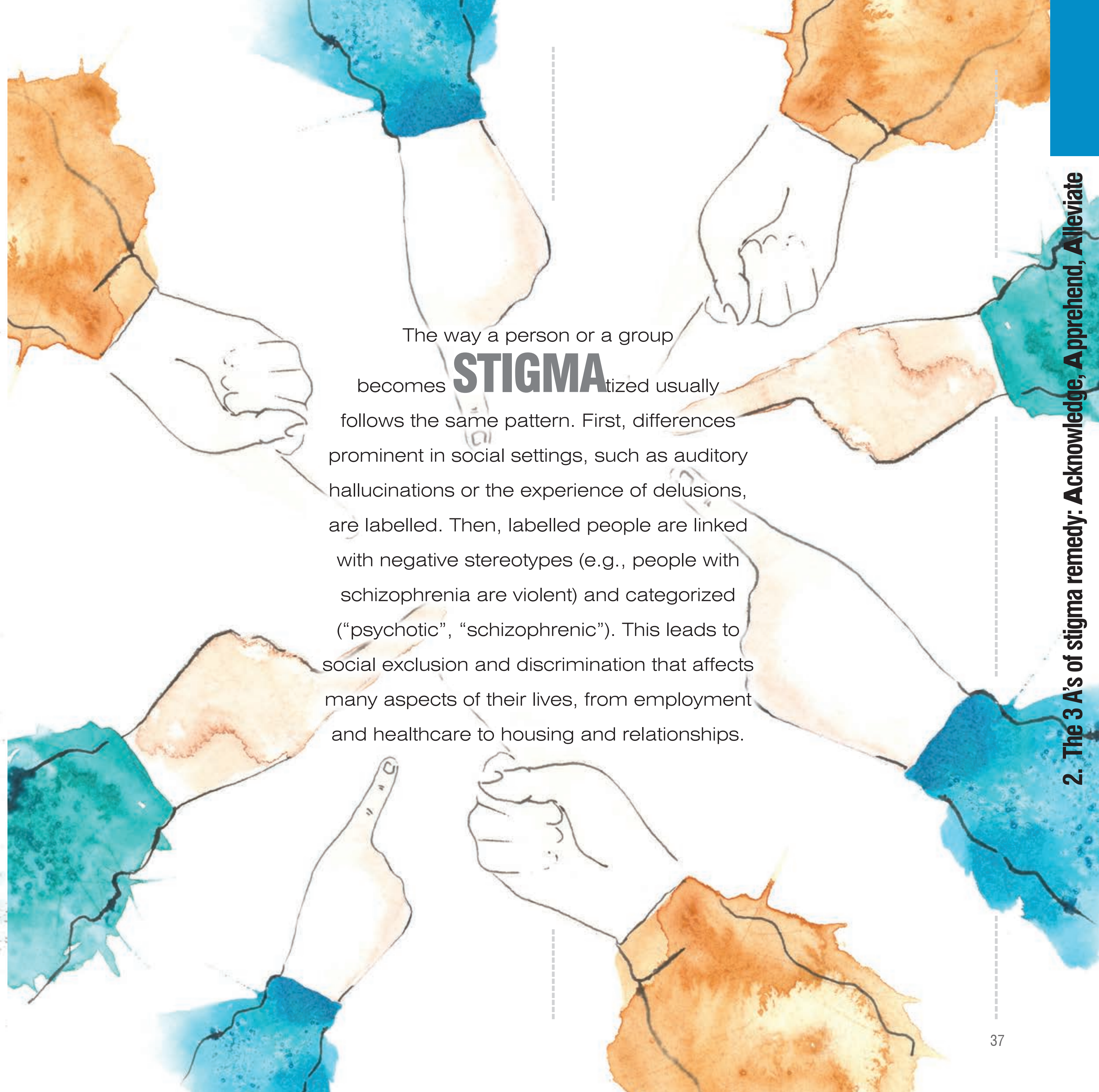
As a caregiver, you are very important in the life of the person with schizophrenia you care for. The first step in providing the support they need is accepting the diagnosis and understanding your own thoughts and emotions. In this process, it is very important to recognize that some of the negative thoughts you may have about schizophrenia are caused by the stigma associated with it.

> *“When I first heard the diagnosis, my world was shattered. Schizophrenia? My son? Immediately pictures of neglected and aggressive people shot into my head. It was a hard blow. I was so overwhelmed and confused by all of my thoughts, fears, and shame. What will happen to him? What if others find out? How will they react? Am I to blame? How should he live?*
>
> *After a while, my shock simmered down a little. The more I read about schizophrenia and talked to the doctors, the more I knew I would have to learn to accept this disease. It helped me a lot to be well-informed, and finally having a name for my son's behavior has also made things easier for me. Knowing that it is a well-known illness, that he is not the only one living with it, and that the illness can now be treated way better than before gave me hope. Nevertheless, it was not easy to see that my biggest worries were mainly based on the image of schizophrenia in our society and that I have to face and deal with my own prejudices.”*
>
> *–Mrs. A. J., mother of a young man*
> *with schizophrenia*

Stigma and its raison d'être

What is stigma?

In Ancient Greece, the term **"STIGMA"** was used for the marks pricked into the skin of slaves. These marks signaled that they are someone's property and have inferior social status. In our days, **STIGMA** represents something similar: we, as a society, mark a person for having a mental illness, a health condition, or a disability. We label them as inferior or threatening. As a result, they have to face negative attitudes in the form of prejudice, and negative behavior in the form of discrimination.



The way a person or a group becomes **STIGMA**tized usually follows the same pattern. First, differences prominent in social settings, such as auditory hallucinations or the experience of delusions, are labelled. Then, labelled people are linked with negative stereotypes (e.g., people with schizophrenia are violent) and categorized ("psychotic", "schizophrenic"). This leads to social exclusion and discrimination that affects many aspects of their lives, from employment and healthcare to housing and relationships.

There are three types of **STIGMA**:

INTERPERSONAL STIGMA or SOCIAL STIGMA

refers to the negative attitudes of society towards **STIGMA**tized individuals.

These attitudes are caused by feelings of anger, anxiety, pity, or fear and result in the social rejection and isolation of the **STIGMA**tized person.

Example: *"I'd like to invite everyone from the office to my party, but I'm afraid if poor George comes, he will make everyone feel awkward with his mental problem."*

INTERNALIZED STIGMA or SELF-STIGMA

develops when stigmatized individuals believe the negative assumptions that society has about them. They internalize negative stereotypes and view themselves as flawed compared to others, which leads to emotions of embarrassment, shame, fear, and alienation. These feelings act as a barrier, keeping them from seeking support, employment, or treatment.

Example: *"Someone like me, a mentally ill person, is dangerous for their family. I will not even try to have a family."*

INSTITUTIONAL or STRUCTURAL STIGMA

refers to situations where the policies established by institutions of either private or governmental nature limit, often invisibly, the opportunities of those experiencing mental illness (e.g., they have difficulties obtaining health insurance coverage, or they are unable to vote or hold political office). Although many health conditions are affected by **STIGMA**, mental illnesses seem to attract the most negative associations. People with schizophrenia are often targets of negative attitudes and social labels that lead to **STIGMA**. The reason is that there is still a lot of misunderstanding surrounding schizophrenia. Many people assume that it means having split personalities or being violent, neither of which is true.

Historically, there is a persistent case of stigmatization around mental illness in our society. There was a wide range of beliefs regarding the cause of mental illness, from being regarded as the devil's mark to being accounted as a divine punishment. The mentally ill were considered at best unable to pursue a life in society and at worst a menace to it. This belief has remained consistent over numerous centuries and it has only started to be disputed fairly recently. In the last decades, we've learned a great deal about how these conditions develop and how they can be treated. In spite of this, the **STIGMA** of mental illness is still widespread, and many people continue to negatively view individuals with mental health conditions.-

The stigma impact

STIGMA constitutes one of the major challenges that individuals experiencing mental illness have to face. In many cases, it is even worse than the symptoms of the illness itself.

> **"IN FACT, I SUFFER FROM TWO DISEASES, SCHIZOPHRENIA AND THE STIGMA OF SOCIETY."**

Regarding people with schizophrenia, stigma can affect not only their place in society but also their physical and emotional well-being. Thus, they have to endure not only the illness but also the negative attitudes that society attaches to them.

The social impact of **STIGMA** affects every life aspect of a person with schizophrenia. Prejudice and discrimination exclude them from activities that are open to other people. This limits their ability to get and keep a job or a safe place to live or get healthcare and support. It also limits their ability to make friends or have long-term relationships, or take part in social activities.

One important attribute of the social impact of **STIGMA** is that it is long-lasting. An episode of psychosis that is well treated may leave no trace and may never return. However, the **STIGMA** of the disease may last a lifetime. It may even have repercussions for the children of the person who experienced a stigmatizing illness.

STIGMA also has a direct impact on the health of people with schizophrenia. It causes them to question themselves and their capacity to achieve their life goals. Stigma increases feelings of isolation, resulting in decreased self-esteem as well as feelings of despair. These effects are vulnerable to the enhancement of the symptoms. After years of persecutory delusions and commenting voices, people with schizophrenia have little sense of their own worth or their capabilities.

SELF-STIGMA leads to isolation and a series of other negative effects: stigmatized persons tend to avoid or delay seeking treatment, perceive the need for treatment as a sign of weakness, and have trouble following the treatment. **STIGMA** can also influence how the illness progresses: it can precipitate initial episodes of psychosis, trigger relapses, and result in a more severe disease course.

> *"I withdrew more and more. Not to say I'd become really lonely. It became more and more difficult for me to meet with the people I knew because I was aware of their opinion about my disease. Before I got ill, I'd had prejudices about the disease myself. I still have some, occasionally. I question myself again and again and sometimes ask myself if I am actually just lazy and stupid. Sometimes I think I might be as unpredictable as they say in the media.*
>
> *I realize that I have become very insecure about what I can trust myself to do, that I often lack self-esteem, that I should apply for a job, or that I am more and more insecure in my interactions with others. I am afraid of coming across as strange, therefore I avoid other contacts and see only my family."*
>
> *–L. J., young man with schizophrenia*

What keeps stigma alive?

Although we know more about what stigma is than why it develops, studies suggest that one of its main driving forces is fear. Society perceives mental illnesses as a threat, both to its core values and material goods.

One of the most common stereotypes is that individuals living with a mental disease hold responsibility for their condition. As a result, their inability to secure or keep a job is seen as laziness, and society does not tolerate laziness. In this regard, mental illness is considered a symbolic threat to society's beliefs, values, and ideology. The other common stereotype is that those with a mental illness are erratic and dangerous. Thereby, they are seen as an actual, tangible threat to personal security. In this context, prejudices serve as a form of self-protection.

Another reason why mental health stigma exists is ignorance. Although we have an unprecedented volume of information at our disposal, our level of knowledge about mental illnesses is insufficient.
The most popular beliefs – people who suffer from mental illness are dangerous, their difficulties are self-inflicted, and they are difficult to communicate with – all come from a lack of knowledge.

Stigma is also deeply rooted in our inability to accept people who deviate from what we consider "normal". This can be related to their skin color, their cultural or religious beliefs, or even the way they dress. In the case of schizophrenia, it may be related to the way they see the world or how they act because of the disease. People who are different (i.e., are not part of the same social group as we are), are usually prejudiced. By definition, prejudice is a preconception that is not founded on reason or genuine experience. In some instances, prejudices are actually useful. For example, we are wired to rapidly appraise the surrounding environment and construct quick assumptions and generalizations. Such generalizations are vital as they enable us to foresee, simplify, and categorize our world. The problem occurs during the assumption of unfair negative beliefs on particular individuals or groups of them, and the categorization of "them" as possessing alike characteristics.

The media also has a significant role in mental health stigma. News reports often perpetuate harmful stereotypes by linking mental illness with violent behavior or depicting individuals with mental health issues as dangerous, criminal, vicious, or disabled.

Myths and misconceptions about schizophrenia

“PEOPLE WITH SCHIZOPHRENIA ARE VIOLENT OR DANGEROUS.”

Due to the way they are depicted in literature or media, people with schizophrenia are considered volatile or dangerous. However, the vast majority are not violent. On the contrary, they are often the victims of violence due to their strange behavior and the fear they elicit in others. There are exceptions, of course.

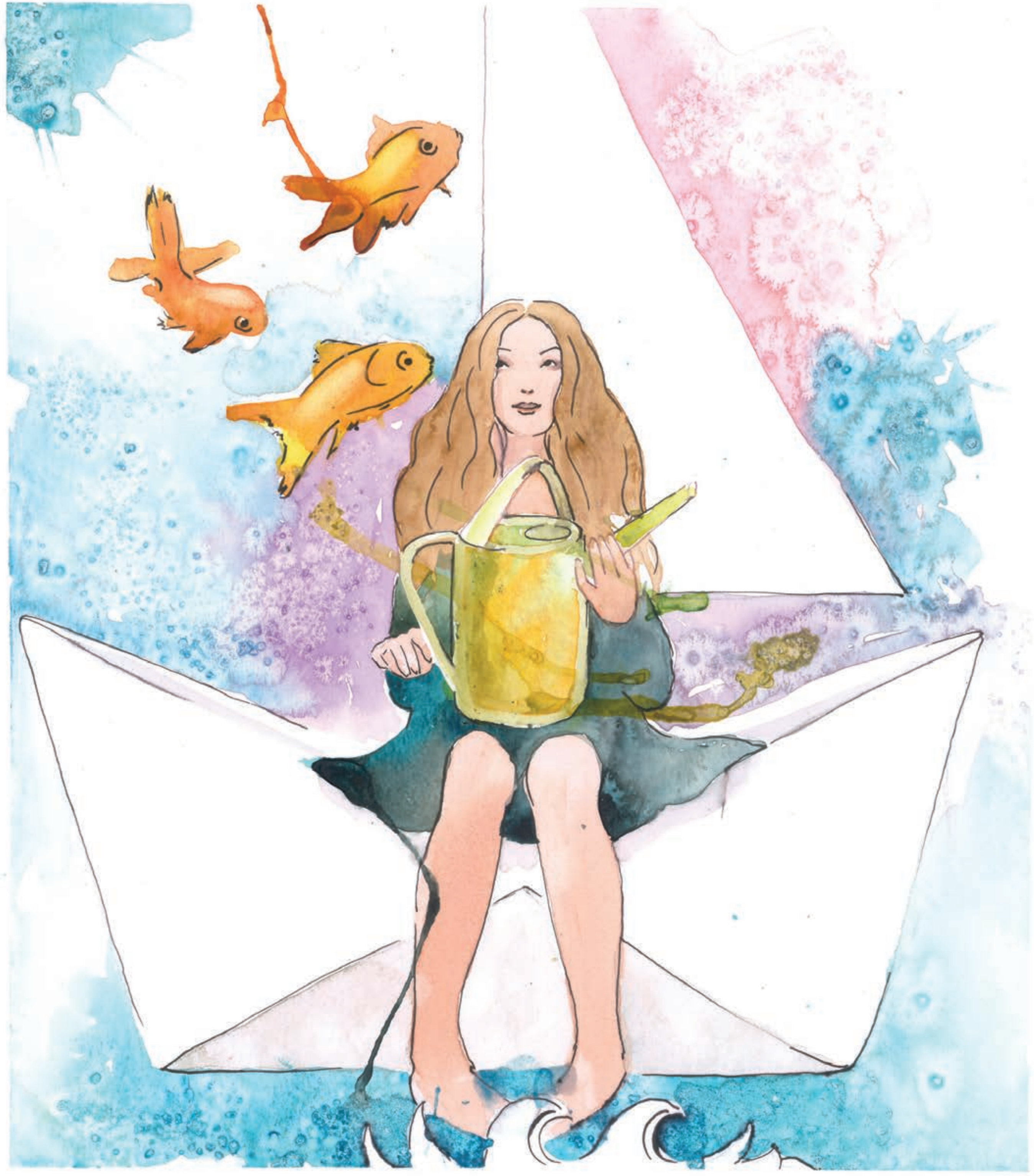
People who have untreated schizophrenia may become more violent over time, and alcohol and drug abuse may also lead to more aggressive behavior.

“SCHIZOPHRENIA IS PURELY GENETIC.”

There is a strong genetic component in schizophrenia, and the illness tends to run in families. However, genes are only a small part of the picture, as identical twin studies have shown. While we do not know exactly how schizophrenia develops, our current understanding is that it is caused by a complex interaction between genes and a series of other factors that include stress, hormonal changes, and drug abuse.

“SCHIZOPHRENIA IS THE RESULT OF BAD PARENTING.”

Bad parenting was believed to cause schizophrenia for a big part of the 20th century. It was thought that traumatic experiences in early childhood led to the occurrence of schizophrenia in teenagers. Mothers, in particular, were blamed. The theory was damaging for both the patients and their families, contributing to social stigma. It also induced feelings of guilt and did not help understand the disease. Although childhood abuse can be a risk factor, there is not any evidence that it causes schizophrenia directly.



“SCHIZOPHRENIA ONLY INVOLVES HALLUCINATIONS.”

People with schizophrenia often have hallucinations and delusions. However, they are not the only symptoms of the illness. Other symptoms include lack of motivation, disorganized speech, or reduced ability to express emotions. The misconception is probably explained by the fact that hallucinations are much more visible and can have a larger impact on people who are not familiar with them.

“MEDICATION FOR SCHIZOPHRENIA ARE JUST TRANQUILIZERS.”

Early antipsychotic medication had certain side effects that caused people to become sedated and more lethargic. These antipsychotics were misleadingly called “major tranquilizers”, and the term continues to be used, leading to confusion. With the development of modern treatments, these side effects have diminished greatly. Currently used antipsychotics are increasingly specific and selective.

“PEOPLE WITH SCHIZOPHRENIA MUST BE HOSPITALIZED.”

Owing mostly to media portrayals, it is a common misconception that people with schizophrenia need to be hospitalized for long periods of time. As a matter of fact, thanks to advancements in treatment possibilities, schizophrenia was de-institutionalized in the **1950s**.

As a result, increasing numbers of patients are treated at home. Although the disorder can be debilitating, and hospitalization may be needed for certain periods, with treatment, people with schizophrenia can function well in their daily activities and can live a rich, meaningful life.

“SCHIZOPHRENIA MEANS HAVING MULTIPLE PERSONALITIES.”

This is one of the most common schizophrenia-related myths. The confusion seems to originate from the Greek word schizophrenia, meaning “split mind”. However, the term actually refers to a split between thoughts, emotions, and behavior. There is also a misconception that the voices heard by people with schizophrenia are coming from other personalities within them. Although schizophrenia alters the way they think, it does not mean multiple personalities.

What can we do about stigma?

In a US study conducted on **200,000** people with mental illness, only **25%** considered that others were caring and sympathetic towards them, highlighting the lack of support they feel.

The first step in reducing stigma is to increase the self-esteem of individuals living with schizophrenia. Their capability to believe in themselves has been substantially damaged by the illness, but also by the stigma. Increasing their self-esteem will provide a foundation on which they can rebuild their lives. It will also provide an internal strength that will help individuals in the numerous challenges that await them.

People with schizophrenia need us to have more understanding, have more compassion, and be educated on the topic of mental health. They need others to acknowledge that their symptoms are not their fault. They need "others" to trust that recovery is realistic.

They need "others" to **UNDERSTAND** that having a mental illness does not imply that they are any less capable or intelligent. They need "others" to know that having a mental health condition does not necessarily mean they are violent.

Cure your own prejudice

Due to the inherent ways our society works in, we are all exposed in some form or other to prejudices towards people with mental illness. Starting from childhood, we see and hear almost exclusively the negative stereotypes that are associated with psychiatric conditions. Caring for someone with schizophrenia means that you may find yourself in situations that confirm some of these prejudices. However, prejudices are almost always wrong, because they generalize events that rarely occur or do not occur at all. You need to deal with your prejudices before you can take care of someone with schizophrenia and provide them with the support they need.

The power of knowledge

One of the most important ways you can get rid of your prejudices is by gaining knowledge. Educate yourself. Learn about schizophrenia. Find out as much as you can about its symptoms, its potential impact on the life of your loved one, and how you can make the best of it. This guide is a great start! The more you can learn about schizophrenia, the more you can do to help.

Talk to healthcare specialists. Read books and watch educational videos. Look up the websites of well-known health organizations and caregiver associations for valuable information. Although schizophrenia is still somewhat taboo, there are many great resources that you can use to learn more about the disease.

Learning about the disease will give you power. It will give you the confidence you need to navigate through the hardships of caring for someone with schizophrenia. Understanding the disease will also help you work out a strategy on how to deal with it.

Recommended reading

- **World Health Organization**
  https://www.who.int/news-room/fact-sheets/detail/schizophrenia
- **American Psychiatric Association**
  https://www.psychiatry.org/patients-families/schizophrenia
- **EUFAMI (European Federation of Associations of Families of People with Mental Illness)**
  http://eufami.org
- **Global Alliance of Mental Illness Advocacy Networks-Europe (GAMIAN-Europe)**
  https://www.gamian.eu

See the person and not the illness

Despite all the challenges that schizophrenia induces, it is essential not to dismiss the person behind the illness. Focus on the positive. Mental illness is only a part of someone's larger picture. Beyond the symptoms and daily struggles, the person you care for is still the person you know – your parent, sibling, or loved one, who is now battling an undermining illness.

It is also important not to confuse symptoms with personality traits, or the inability to act with the lack of willpower. As the illness changes the way they think and perceive the world, people with schizophrenia may not find certain aspects of life as important as before.

Withstand external prejudice

When faced with prejudices in your close environment – family members, friends, or colleagues – there are four strategies that you can use to deal with them. However, keep in mind that some of these strategies may not be beneficial in the long term.

SOCIAL WITHDRAWAL

Once the diagnosis of schizophrenia has been established, your first reaction may be to withdraw from all social activities and focus only on the person you care for. This can have many reasons, from feelings of shame and wishing to avoid stigmatizing people, to believing that you are able to do this alone. Whatever the reason, by choosing to do so, you reduce the very important social support of family and close friends. This will inevitably increase your burden.

CONCEALMENT

It is understandable that you may wish to keep the diagnosis a secret in particular social plights. However, this can lead to the fear of being discovered and feelings of shame when your secret is revealed. With that said, it is your right to decide who in your close environment should know or not about the illness, and how much information you want to share. Consider the advantages and disadvantages in each particular case.

ORGANIZING ENCOUNTERS

A significant barrier to eradicating social stigma is the fact that people rarely come into contact with stigmatized individuals, leading to a lack of empathy.
Even when contact does happen, it often involves stereotypical representations of people with mental illness – for example, interacting with a homeless person with a disorganized speech on the street –, which only reinforces the negative associations. However, things change when the contact occurs in conditions of relatively equal power and status. For example, imagine you invite a couple of close friends over for dinner, and they have the chance to talk to your loved one, who has schizophrenia.

This type of interaction is far more likely to generate positive attitudes and reduce stigma. The more frequent these interactions are, the more they are able to reduce the negative perceptions of stigmatized individuals. They are also an excellent opportunity to change the myths surrounding schizophrenia and mental illness in general.

EDUCATION

The most important measure in dealing with stigma is to educate people from your personal environment who express stigmatizing attitudes. Tell them what the disease entails, how it affects the person you care for, and what treatments are necessary. As stigma affects not only those with schizophrenia but also their families and caregivers, tell them what it means for you to take care of someone with schizophrenia. The more mental illness remains hidden, the more people think it must be something to be ashamed of. **Do not forget, however, to make sure your loved one is OK with you talking to others about their condition.**

Even in educational conversations, you can vary the depth of information depending on how much you want to share. Try to avoid overly technical terms and make sure to keep the conversation friendly. Also, try to be empathic and to understand their point of view. Remember, their prejudices may not be ill-conceived, but rather due to being uninformed.

For example, here is how a friend or a relative may approach you after hearing about the diagnosis:

> ***"Mrs. Johnson, our neighbor, told me that your husband is schizophrenic and that he was acting weird and is now locked away. How is he doing?"***

Your response can be something like this:

> ***"Yes, my husband has not been feeling well lately, and he is receiving treatment. But he is already on the road to recovery, and you can talk to him yourself when he gets home."***

Alternatively, you can start the conversation yourself:

"Hey Julia, I wanted to talk to you about my son. As you probably already know, he is in a psychiatric hospital. The doctors say he has a metabolic disorder in which certain nerve cells communicate much more strongly with each other. As a result, he perceives many more stimuli, and he sometimes hears things we don't or holds on to beliefs that we don't share. The good news is that this disorder can nowadays be controlled quite well with medication."

By educating others, you are able to positively impact not only the life of the person you care for but also those who have stigmatizing behavior. This positive impact can make a significant contribution to reducing stigma in society.

"When I finally found a good way for me to talk about the illness, I found it easier to bring it up with others. I still think carefully about who I talk to about it. But especially with people who are important to me, it is becoming easier and easier to share my knowledge, my thoughts, and my feelings. I noticed that education helps them to understand, too. Being in contact with my son they learn more and more that many of their prejudices are not true, they lose the fear of contact and show more understanding."

–Mrs. A. J., mother of a young man with schizophrenia

References

1. Economou M, Bechraki A, Charitsi M. The stigma of mental illness: A historical overview and conceptual approaches. Psychiatriki. 2020 Jan-Mar;31(1):36-46. Greek, Modern. doi: 10.22365/jpsych.2020.311.36. PMID: 32544075.
2. Hatzenbuehler, Mark L. Structural stigma: Research evidence and implications for psychological science. The American psychologist vol. 71,8 (2016): 742-751. doi:10.1037/amp0000068
3. Kobau R, Zack MM, et al. Attitudes toward mental illness: results from the Behavioral Risk Factor Surveillance System. Mental Health Program, United States. Substance Abuse and Mental Health Services Administration., editors. 2012; Available from: https://stacks.cdc.gov/view/cdc/22179
4. Maharjan S., Panthee, B. Prevalence of self-stigma and its association with self-esteem among psychiatric patients in a Nepalese teaching hospital: a cross-sectional study. BMC Psychiatry 19, 347 (2019). https://doi.org/10.1186/s12888-019-2344-8
5. Leamy M, Bird V, Le Boutillier C, Williams J, Slade M. Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. Br J Psychiatry. 2011 Dec;199(6):445-52. doi: 10.1192/bjp.bp.110.083733. PMID: 22130746.
6. Miller, Del D. Atypical antipsychotics: sleep, sedation, and efficacy. Primary care companion to the Journal of clinical psychiatry vol. 6,Suppl 2 (2004): 3-7.

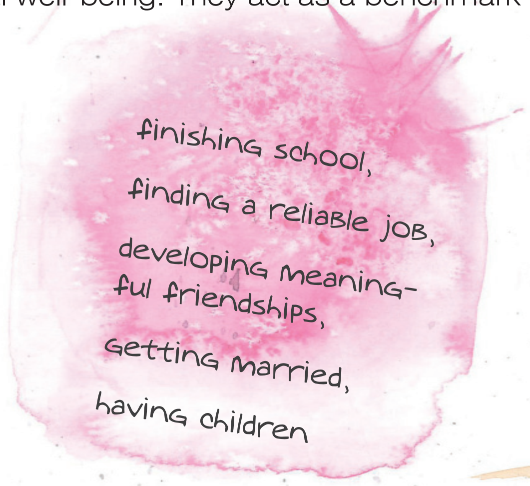
7 Harrow M. Do Patients with Schizophrenia Ever Show Periods of Recovery? A 15-Year Multi-Follow-up Study. Schizophrenia Bulletin vol. 31 no. 3 pp. 723–734, 2005 doi:10.1093/schbul/sbi026

3. Surmount vs. Surrender

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 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 numbness 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 numbness, 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.

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.

THESE TWO EXTREMES ARE ALSO REFLECTED 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 SPECTRUM? 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 strengthen 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.

References

1. Healthy grieving [Internet]. University of Washington. [cited 2020 Dec 23]. Available from: https://www.washington.edu/counseling/resources-for-students/healthy-grieving/
2. Dayton T. Why We Grieve: The Importance of Mourning Loss [Internet]. HuffPost. [cited 2020 Dec 23]. Available from: https://www.huffpost.com
3. Rahmani F, Ranjbar F, Hosseinzadeh M, Razavi SS, Dickens GL, Vahidi M. Coping strategies of family caregivers of patients with schizophrenia in Iran: A cross-sectional survey. Int J Nurs Sci. 2019 Apr 10;6(2):148–53.
4. Schizophrenia [Internet]. American Association for Marriage and Family Therapy. [cited 2020 Dec 23]. Available from: https://www.aamft.org/Consumer_Updates/Schizophrenia.aspx
5. Folkman S. The case for positive emotions in the stress process. Anxiety Stress Coping. 2008 Jan;21(1):3–14.
6. Vauth R, Bull N, Schneider G. Emotions- und stigmafokussierte Angehörigenarbeit bei psychotischen Störungen: Ein Behandlungsprogramm. Göttingen: Hogrefe; 2009.
7. Moslehi S, Atefimanesh P, Asgharnejad Farid A. The relationship between problem-focused coping strategies and quality of life in schizophrenic patients. Med J Islam Repub Iran. 2015 Nov 11; 29:288.

4. Therapeutic amends

Although at the present time schizophrenia does not have a known cure, the outlook for individuals living with this illness is in a **CONSTANT STATE OF IMPROVEMENT**. For most patients, the treatment of schizophrenia involves a combination of medication and talking therapy, accompanied by social training that helps them reintegrate into society. Throughout the crisis periods or intervals of time accompanied by severe symptoms, the need for hospitalization may occur in order to ensure safety, appropriate nutrition, sufficient sleep, and basic hygiene.

Schizophrenia calls for **LIFELONG TREATMENT**, despite the alleviation of symptoms. In many cases, the management of patients with schizophrenia is handled by a treatment team, led by an experienced psychiatrist. The team may also be comprised of a psychologist, a psychiatric nurse, a social worker as well as a case manager which would coordinate care.

Given the complexity of the disease and the fact that every person is different, there is **NO “ONE-SIZE-FITS-ALL” TREATMENT**. It is important to take the time to explore all options and develop an individually tailored treatment plan that works best for your loved one. The treatment objective is to reduce the symptoms, decrease the likelihood of a relapse, and increase the quality of life.

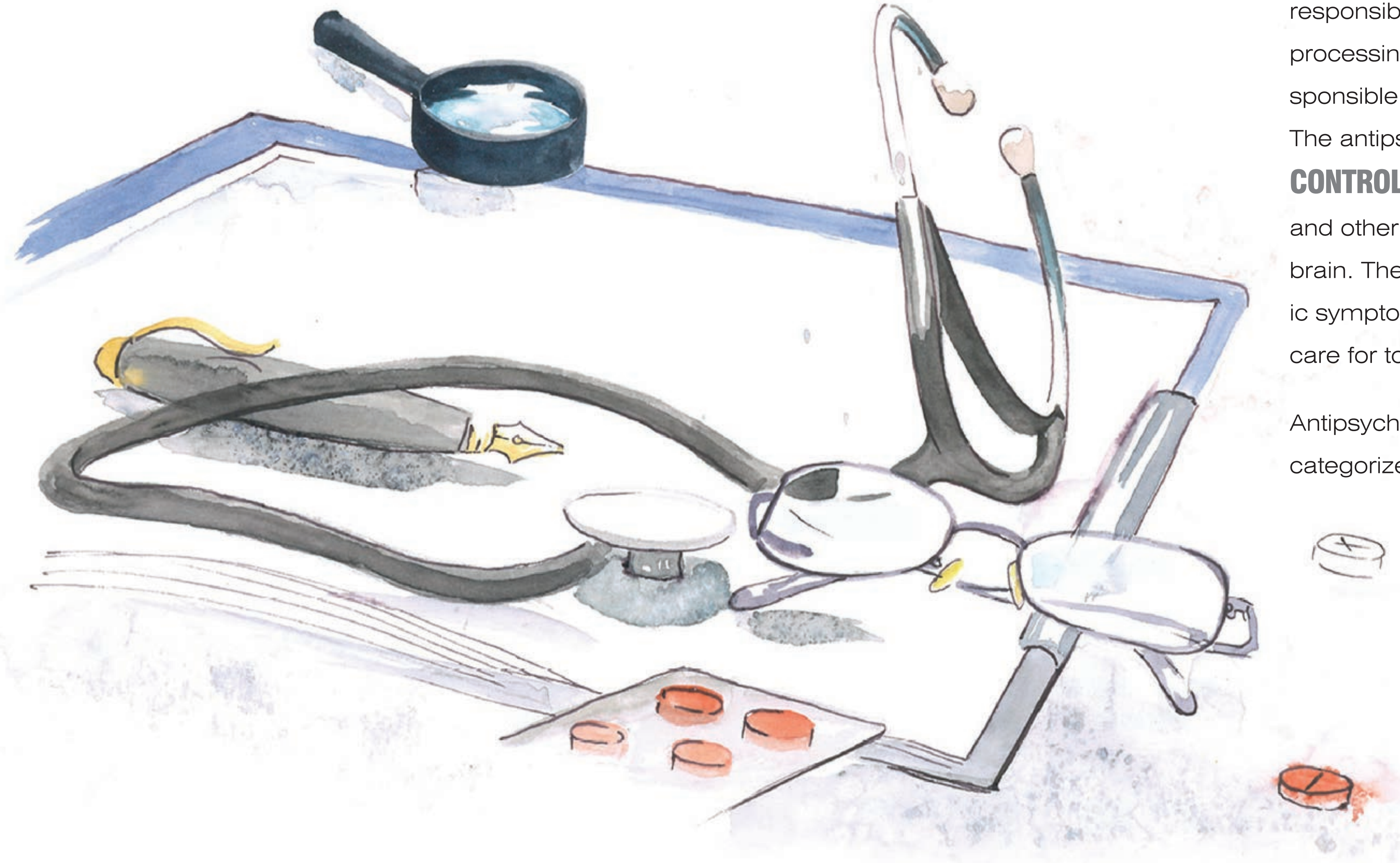
The importance of a healthy lifestyle

There are several reasons a healthy lifestyle is especially important for people with schizophrenia. Living a healthy, active life may be challenging for them because of their symptoms, such as lack of drive, or medication side effects. Also, they are more likely to suffer from an assortment of health problems, namely heart disease, stroke, cancer, and diabetes. In fact, over **75%** of people with schizophrenia will also have a chronic physical condition. This can be attributed to certain lifestyle choices, such as smoking or having a poor diet, but also to the side effects of antipsychotic medication.

Smoking is a major problem that affects around **60%** of people with schizophrenia, compared to **25%** of people without the illness. While people with schizophrenia often use smoking as a form of self-medication, there is no scientific evidence that smoking improves their symptoms. On the contrary, there is a wealth of evidence on the detrimental effects of smoking on general health. Thereby, it is critical for people with schizophrenia to give up smoking. Another major issue is weight gain. This can be caused by a sedentary lifestyle, enabled by not having a job and the tendency to live a life that is less engaging physically, but it can also be a side effect of antipsychotic medication.

Medication

Medications are the cornerstone of schizophrenia treatment. Although there are several different treatment options and approaches in schizophrenia, medication is an elementary part of all of them. There is practically no schizophrenia treatment without medication. The most commonly prescribed drugs in schizophrenia are **ANTIPSYCHOTIC MEDICATIONS**.



Types of medication

As you remember from the first chapter of this guidebook, the neurotransmitter dopamine plays an essential role in schizophrenia. It is believed that in persons with schizophrenia, the **AMOUNT OF DOPAMINE** is **TOO LOW** in areas of the brain that are responsible for attention and information processing, and **TOO HIGH** in areas responsible for imagination and emotions. The antipsychotic medication works by **CONTROLLING** the amount of dopamine and other messenger substances in the brain. These medicines reduce psychotic symptoms, allowing the person you care for to function and to adjust better.

Antipsychotic medications can be categorized into two groups:

TYPICAL ANTIPSYCHOTICS

(also called first-generation agents)
They were introduced in the **1950s** and made it possible for many people with schizophrenia to leave the hospital and return to their families and society. However, although these first-generation agents were able to control psychotic symptoms, they also caused unpleasant side effects that reduced adherence to treatment. This prompted the development of newer agents, with a lower risk of adverse events.

ATYPICAL ANTIPSYCHOTICS

(also called second-generation agents)
First introduced in the **1990s**, they have different mechanisms of action than first-generation agents, are better tolerated, and have the potential to lead to better long-term results. Atypical antipsychotics are more effective in preventing relapses, as well as in treating the negative and cognitive symptoms of schizophrenia. Some of the newer atypical antipsychotics discovered in the last few years have shown very promising results regarding the treatment of negative symptoms.

Both groups include many different agents with different potencies, meaning that a low-potency drug will require a higher dose to achieve the same effect as a high-potency drug with a lower dose.

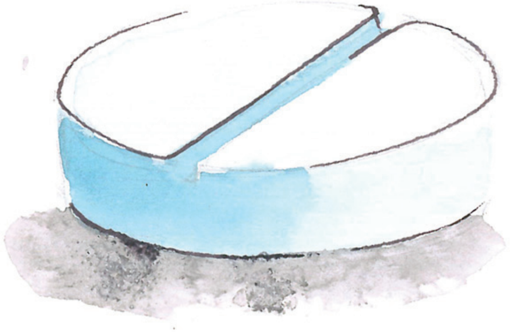
Antipsychotics are available in both **ORAL** and **INJECTABLE** forms.

Most frequently, long-term treatment is achieved with oral medication, taken **1–3 TIMES** a day. Some antipsychotics can be administered in the form of **QUICK-ACTING INJECTIONS**, which are especially useful in emergency situations. There are also **LONG-ACTING** (so-called depot) injectable antipsychotics that provide an effective alternative to persons who struggle with taking their oral medication regularly. These injections can be given **EVERY FEW WEEKS**, enabling a more consistent, long-term symptom relief, and are just as effective in controlling the symptoms as oral medication.

In the event of a **PSYCHOTIC EPISODE**, treatment with medication is started **IMMEDIATELY**. Most often, antipsychotics are administered in the form of injections, aiming to control the symptoms in a quick, safe, and effective manner. The goal of this treatment is to try to get the person back to normal functioning as soon as possible. This involves calming the agitated, violent, or disruptive patient, minimizing the danger to self and others, and achieving a smooth transition from injections to long-term oral treatment.

After the **FIRST PSYCHOTIC EPISODE**, antipsychotic medication is given as **MAINTENANCE THERAPY** for at least **12–18 MONTHS** in order to prevent further episodes. For people with **SCHIZOPHRENIA IN REMISSION**, **MAINTENANCE THERAPY** is given for at least **TWO YEARS**.

Within **CHRONIC SCHIZOPHRENIA**, when anxiety and depression are present and antipsychotics alone are not able to adequately reduce symptoms, they are sometimes combined with other types of medication such as **ANTI-ANXIETY DRUGS**, **ANTIDEPRESSANTS**, and **MOOD STABILIZERS**. In case of anxiety and insomnia, the most commonly used drugs are **BENZODIAZEPINES**✋, but most often they are recommended for a short period of time. In certain cases, different types of antipsychotics (for example a tablet and a depot injection) may be combined to keep the symptoms under control. Certain side effects of antipsychotics are also kept under control using other types of medication (see below).



When selecting a particular medication, the psychiatrist treating the person you care for must consider a multitude of factors. These include your loved one's symptoms, response to previous medication, and compliance; the pattern and severity of the illness; drug interactions, adverse reactions, dosage, and the presence of other diseases.

It is important to remember that every individual has a varied response to the medications administered for schizophrenia, and the time frames required to get different symptoms under control may be lengthy. While feelings of anxiety or aggression can be controlled in a matter of hours, other symptoms, such as hallucinations and delusions, may take several weeks to improve. In around **10–30%** of cases, there is little improvement in symptoms even after trying two or more different antipsychotics. These persons are said to have **TREATMENT-RESISTANT SCHIZOPHRENIA**.

The doctor treating your loved one may experiment with separate drugs and varying doses over time in order to reach the preferred result. The aim is to develop a personalized treatment that keeps the symptoms under control.

Side effects

Side effects can be a result of both typical and atypical antipsychotics, however, it may be that some individuals will not experience them at all, while their severity may also vary for each person.

Certain antipsychotics have a sedative effect, **SLOWING DOWN BRAIN ACTIVITY**. This effect is more frequent with first-generation antipsychotics and may be confused with negative symptoms such as avolition, withdrawal, and lack of motivation. Sedation can be troublesome for persons with schizophrenia who are trying to reintegrate into society and can also interfere with their treatment. They describe it as **LIVING IN A GLASS CASE**, not being able to actively participate in life. The doctor treating your loved one may be able to reduce the sedative effect of antipsychotics by lowering the dose, changing to a single bedtime dose, or switching to a less sedating medication.

A relatively common side effect of antipsychotics is a syndrome called akathisia, characterized by a state of **RESTLESSNESS** accompanied by an **URGENT CRAVING FOR MOVEMENT**.

In severe cases, persons exhibiting the syndrome feel an irresistible urge to move around and a mounting sense of tension when required to stand still. Akathisia causes severe distress, even leading to suicidal thoughts. The syndrome is caused mainly by first-generation antipsychotic drugs, but it can also be caused by newer ones. It occurs especially in the first few weeks of treatment but can become persistent if it is not addressed. Typical antipsychotics are known to aggravate the possibility of side effects that interfere with the ability to move and speak. These include **SHAKING**, **TREMBLING**, **MUSCLE TWITCHES**, and **MUSCLE SPASMS**. They can also cause intense muscle stiffness, called dystonia. Up to **40%** of the patients treated with typical antipsychotics can experience symptoms that are very similar to Parkinson's disease – tremor, rigidity, slow movement, and gait disturbance. The majority of such symptoms can be rectified by reducing the dose or they can be kept in check by additional medications such as anti-Parkinson agents.

One of the characteristic side effects of typical antipsychotics is a condition involving **INVOLUNTARY, JERKY MOVEMENTS OF THE LIMBS, TONGUE, AND LIPS** that cannot be controlled. The condition is called tardive dyskinesia and usually occurs after several years of treatment. Unlike other movement disorders caused by medication, tardive dyskinesia does not improve when lowering the dose or discontinuing treatment.

Atypical antipsychotics may also cause movement disorders, but the symptoms are usually much less severe. However, they are known to cause side effects interfering with one's metabolism for instance **WEIGHT GAIN, INCREASED BLOOD SUGAR AND CHOLESTEROL LEVELS**, and **OSTEOPOROSIS**. For this reason, regular blood testing is recommended. Adaptations in nutrition and exercise, and potentially medication intervention, can assist in tackling these side effects.

Both typical and atypical antipsychotics can cause drowsiness, an increase in body weight, blurred vision, constipation, absence of sex drive, and oral cavity dryness. Some of these side effects, blurred vision, for example, may improve in time with no intervention. Others are usually countered by reducing the dosage, changing to a different antipsychotic, or using a specific medication for that side effect.

As a caregiver, there are several things that you can do to reduce the negative impact of some of these side effects, especially in mild or moderate cases. You can help your loved one avoid gaining weight by ensuring they eat a healthy diet, avoid high-calorie foods and sweets, and work out. Muscle stiffness may be relieved by exercise, more specifically extensions and isometric exercises. Akathisia can also benefit from exercise and an active lifestyle.

The importance of compliance

Taking medication consistently is called medication compliance or adherence. Although taking medication on a consistent schedule may sound easy, complying with taking medication is usually one of the biggest challenges in the long-term treatment of schizophrenia. Studies have shown that **50–75%** of people with schizophrenia take their medication inconsistently, and more than **40%** stop completely during the first nine months of treatment.

Compliance is especially important because antipsychotic medications are **EFFECTIVE ONLY WHEN TAKEN REGULARLY AND CONSISTENTLY**. When not taken regularly, their blood levels fluctuate and their efficiency becomes worse. You can find more information about compliance and what you can do to make sure your loved one adheres to their treatment in Chapter 6 of this guidebook.

Concerns you may have about medication

Individuals living with schizophrenia, as well as their families, may often worry about the antipsychotic medications administered for the treatment against the disorder. Besides being concerned about the side effects, they may also worry about the potential risk of addiction. Antipsychotic medication does not get individuals “high” and does not facilitate the formation of habits. Additionally, **THEY DO NOT FOSTER THE DEVELOPMENT OF ADDICTIVE BEHAVIORS**. A further misconception regarding antipsychotic medication is that it controls one’s mind, acting like a “chemical straightjacket”. The appropriate use of antipsychotic drugs will not result in the lack of one’s free will or the “knocking out” of individuals who take them.

Taking into account their side effects, individuals with schizophrenia may be unwilling to adhere to their medication. Besides, some people believe antipsychotics to not be beneficial and may want to discontinue their usage after they experience initial improvement. Their **SUDDEN DISCONTINUATION SHOULD BE STRICTLY AVOIDED**, as it can lead to the return of psychotic symptoms. It is essential to reduce the dose slowly.

Always discuss with the medical team treating your loved one the benefits and side effects of the prescribed medication. It is **IMPORTANT TO WEIGH HOW MANY SIDE EFFECTS ARE ACCEPTABLE** in order to ensure that the person you care for is protected against a relapse, without jeopardizing their compliance.

Physical exercise

It is well known that physical exercise has a multitude of positive effects on the heart, lungs, muscles and joints, metabolism, and immune system. It also increases the production of “happy chemicals” in the brain, boosting our mood and overall sense of well-being.

Exercise has several **POSITIVE EFFECTS** on the physical health of people with schizophrenia. It can reduce weight gain and the risk of heart disease and diabetes. It can also reduce the risk of osteoporosis, another possible side effect of antipsychotic medication. Besides improving general levels of fitness, exercise helps keep blood pressure down as well. Furthermore, getting plenty of physical exercises, particularly in the open air, improves sleep. This is especially important, as schizophrenia is often associated with sleep issues.

But more importantly, exercise has significant benefits for the psychological well-being of people with schizophrenia. Studies have shown that exercise substantially alleviates negative symptoms, particularly social withdrawal, lethargy, apathy, and cognitive symptoms such as poor memory and thinking skills. Getting more exercise helps to reduce stress and improves mood, motivation, and self-esteem. It also reduces depression and anxiety, while increasing energy. Furthermore, it is an excellent way to socialize, both for you and your loved one.

There are many different types of exercise that your loved one can do including running, walking, swimming, weight training, etc. Each has different benefits: for instance, swimming will improve stamina, while weight training is better for bone strength. Sports that improve aerobic capacities, such as martial arts, yoga, or dancing, were also shown to improve the symptoms and comorbidities of schizophrenia. The recommended amount of exercise in severe mental illnesses is 90–150 minutes per week of physical activity at moderate to vigorous intensity. It is important to do types of physical exercise that bring joy to your loved ones, as they are more likely to keep it up. It is also important to have a custom-made exercise plan that takes into account your loved one's needs and is revised on a regular basis. Of all the treatment options listed in this chapter, exercise is the one in which you can get involved the most. Many exercises can be done at home, and you can contribute a great deal in finding the best workout routine for your loved ones and in helping them keep their motivation.

Psychotherapy✋

The goal of psychotherapy, or talking therapies in general, is to help persons with schizophrenia **UNDERSTAND THEIR SYMPTOMS AND LIVE THEIR LIVES WITH LESS DISTRESS**.

Psychological treatments can aid individuals with schizophrenia in dealing with positive symptoms, such as hallucination or delusions. On top of that, they can help relieve several negative ones, for instance, apathy✋ or anhedonia✋. Psychological treatments are most effective when used in combination with antipsychotic medication.

Cognitive-behavioral therapy (CBT)

CBT, or cognitive behavioral therapy, is the most frequently recommended form of talking therapy used for treating schizophrenia. Based on the idea that our emotions are produced by our thoughts, CBT is a problem-focused approach that teaches people with schizophrenia **HOW TO COPE WITH DIFFICULT SITUATIONS**. By helping to identify and change negative thoughts and behavior, CBT helps deal with symptoms like delusions or hearing voices, and with social anxiety and depression.

CBT works by teaching individuals how to reform the beliefs or behaviors they might have that could be causing the experience of negative emotions. The therapy consists of two major elements:

a **COGNITIVE COMPONENT** helping the individual to adjust their thought process when assessing a situation, and

a **BEHAVIORAL COMPONENT**, helping the individual regulate the way they react to it.

CBT sessions typically last **50 MINUTES** a week during the course of **3 TO 6 MONTHS**, sometimes **12 MONTHS** or more. During the sessions, the person you care for learns the effect their thoughts, feelings, and behaviors have on each other under the guidance of a therapist. With the end goal of eliminating undesired feelings, strategies for altering negative thoughts and improving one's reactions to them are also taught by the therapist. Furthermore, the individuals learn ways of assessing whether their thoughts and perceptions are based on reality, as well as how to manage the accompanying symptoms.

CBT helps people learn how their decision-making mechanism is influenced by thoughts they have about themselves and the world surrounding them. Since insights like this are not often present in those with schizophrenia, CBT can help them gain more control over their emotions and behaviors.

Another important component of CBT is psychoeducation. During these psychotherapeutic interventions, your loved one is informed about the disease and its treatment. The goal is to promote understanding of the disease and self-responsible coping. This is achieved by empathetic guidance through information and joint consideration. Your loved one can learn how to take control of their life, co-living with the illness. In order for them to be able to cope with the disease as well as possible, they must develop a basic understanding of the background of their disease and the treatment options currently available. They must also learn how to detect relapses at an early stage and be able to act against them.

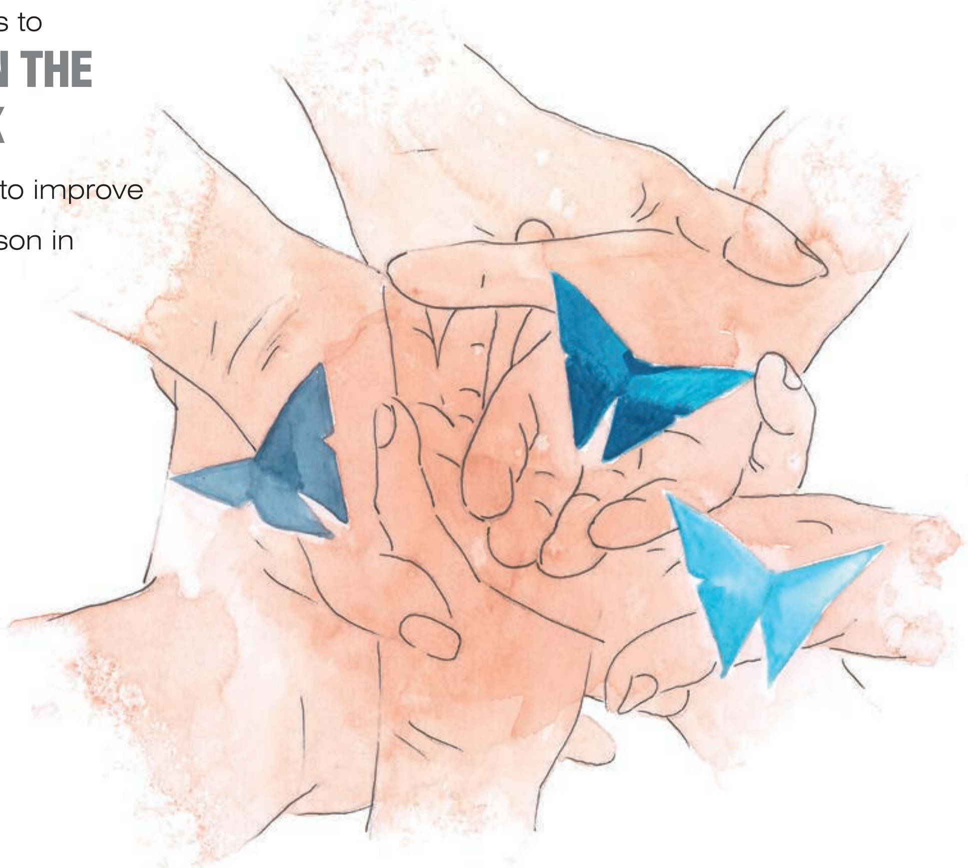
By combining CBT sessions and administered medications, persons with schizophrenia are ultimately able to identify the trigger factors leading to their psychotic episodes and how to reduce or stop them.

"Since my daughter has started psychotherapy, I've been feeling that she is no longer struggling with her symptoms so hard. On the one hand, it has helped her get an explanation for the voices she hears, and on the other hand, she is learning to deal with them better and to distance herself from them. It is such a relief to know there is someone other than me, someone professional, with whom she can talk about her issues on a regular basis. Someone who questions her beliefs without conflicts arising all the time. She is also learning to consider alternative explanations for her beliefs. I think she is learning not only to understand but also to manage her emotions better. Thanks to her crisis plan, she is well-positioned for further crises and knows early on what she can do."

–Mrs. B. K., mother of a young woman with schizophrenia

Family therapy

A large number of individuals are living with schizophrenia. Although the majority of family members are usually happy to provide help, taking care of someone with schizophrenia can be overwhelming for any given family. Family therapy is a means of supporting family members of a person with schizophrenia to cope better with the disease. It aims to **GET EVERYONE IN THE FAMILY TO WORK TOGETHER** in order to improve the situation for the person in question and the whole family.



Family therapy is comprised of a succession of meetings over the span of about **6 MONTHS**. The meetings have a clear structure and offer professional guidance. During these meetings, you may discuss information about schizophrenia, explore how you can support your loved one, and decide ways of working out practical problems brought about by the symptoms of schizophrenia.

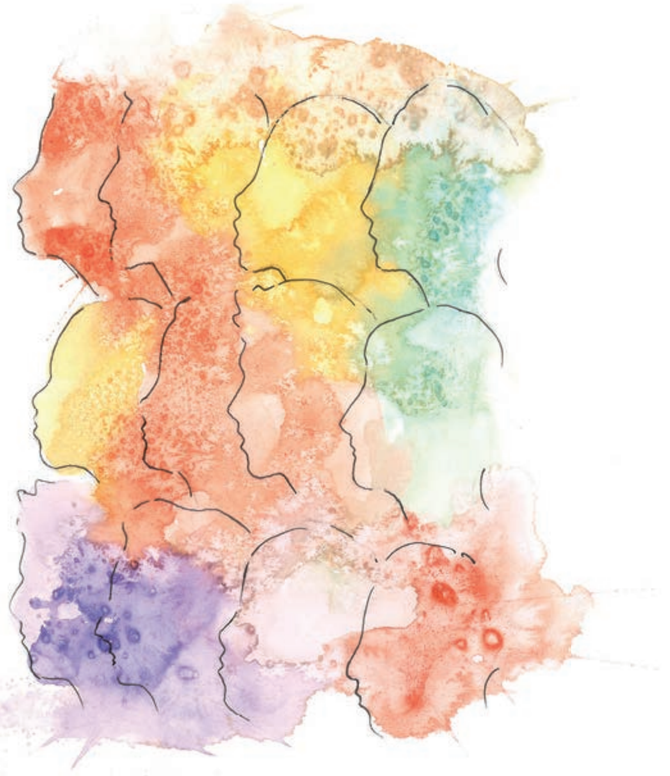
The main benefit of family therapy is that it offers a platform for the healing of family dynamics that could have arisen due to the illness. The sessions are also an opportunity for the collection of information regarding schizophrenia, cooperative navigation of challenges, as well as ways to enhance the expression and meeting of the needs of those involved. This type of psychoeducation has proved to be very effective in family therapy. Furthermore, family interventions for psychosis have been shown to reduce relapse rates, duration of hospitalization, and psychotic symptoms, as well as increase functionality.

> *“We were quite skeptical about family therapy at first... But the more we sat down together with the therapist, the more we were able to use these occasions to discuss our togetherness, how we feel, and what we need as a family. And of course, we talked about our son’s illness. We learned a lot about how we can speak well about it in the family, or what he wants us to do in case of a relapse.”*
>
> *–Mrs. F. M., mother of a young man with schizophrenia*

Social skills training

Social skills training employs behavioral therapy to teach people with schizophrenia **HOW TO COMMUNICATE THEIR EMOTIONS BETTER**. This is particularly important when they experience difficulties in expressing their emotions or a reduction in social interactions.

This type of training focuses on several aspects of a person's relationship to others, from using eye contact and gestures, to managing negative emotions. This enables them to navigate their relationships better, reducing the distress and difficulty they experience when relating to their friends, family members, or coworkers. Besides improving social skills, these programs also **IMPROVE THE QUALITY OF LIFE** of people with schizophrenia, reducing relapse rates.



> *"Due to the psychosis, our son has become more and more reserved and insecure at work and even with his old friends. In this social skills group, he not only has more contact with his peers, but he can also practice how to get in touch with others, how to express his needs adequately, and, most importantly for him, how to say 'no' when something becomes too much."*
>
> *–Mr. P. F., father of a young man with schizophrenia*

Electroconvulsive therapy

Although it has been around for a long time, electroconvulsive therapy (ECT) is still surrounded by several misunderstandings. It is often considered a method of “last resort” that causes a great deal of pain to the treated person. This can be attributed in part to the way it was incorrectly depicted in movies and TV shows.

ECT is actually a **SAFE AND EFFECTIVE METHOD** that involves sending a small electric shock to the brain. This is done by placing electrodes on the scalp and delivering electric current through them for a very short time, while the person is under general anesthesia. The current causes brief, controlled brain seizures. A course of ECT therapy generally entails **2–3** treatments per week over the course of several weeks. Gradually, **ECT RESULTS IN AN IMPROVEMENT OF ONE’S MOOD AND THOUGHTS**. The decision to use ECT is always based on ethical considerations and requires signed consent from the patient.

While ECT is traditionally used to treat severe depression or bipolar disorder, it is sometimes used to treat schizophrenia symptoms such as delusions, hallucinations, or disorganized thinking. It is usually employed in critical cases, when medications are no longer effective, or if the treatment of schizophrenia is impeded by severe depression. In this regard, ECT is many times a life-saving intervention.

Art therapy

Art therapy, a type of psychotherapy aimed at supporting people experiencing distress, uses art as its main method of expression and communication. Art therapy encompasses a variety of methods including music, visual art, movement and dance, drama and theater, and writing.

Frequently, more than one type of method is used in therapy. Art therapy is devised to FACILITATE CREATIVE EXPRESSION.

Working alongside an art therapist either as an individual or in small groups can offer a new-fashioned experience of schizophrenia as well as support in the development of alternative ways to relate to other individuals. As people with schizophrenia tend to withdraw socially, art therapy makes it easier for them to engage when direct verbal interaction becomes difficult.

Art therapy may help people with schizophrenia express how they feel, particularly in cases where they find it overwhelming to discuss things or experience alienation from their feelings. Additionally, they can help face up to traumatic events from their past which could have played a part in provoking their psychotic experiences. The aim of using art therapy is to elevate one’s level of creativity, ability to express emotions, communication skills, insight, and aptness at relating to their own self or others.

Art therapy empowers individuals to convey and project their experiences in their art, including the emotional, cognitive and psychotic ones and process them at a rate personally suitable to them. Even though it is not clear how and why art therapy works, there are studies suggesting that it helps people with schizophrenia control their psychosis. It also helps them to better understand symptoms such as hallucinations or delusions. Additionally, there is evidence that art therapy can facilitate recovery, particularly for individuals experiencing negative symptoms. Thus, art therapy is considered by both therapists and patients to be a beneficial and meaningful intervention.

Pets and animal-assisted therapy

Pets are known to have a positive effect on our lives. They can help ease the pain when we're facing chronic health issues, loneliness, or depression, giving us a reason to change our focus on a sense of purpose. As a result, they have been used in therapy for centuries. Animal-assisted therapy includes animals in the treatment plan, as emotional support, or as service animals trained to assist with daily activities. Although dogs are the primary animals used, animal-assisted therapy may also use horses, cats, birds, and other animals.

The positive effect of pets has also been studied in people with schizophrenia. One study found that the presence of a dog during therapy sessions improved anhedonia, motivation, and the way the participants used leisure time. The participants' ability to socialize and the way they viewed themselves have also shown improvements. Other studies reported improvements regarding three types of schizophrenia symptoms: positive, negative, and cognitive.

OWNING A PET HAS A SERIES OF BENEFITS on people with long-term mental health conditions: pets are often considered as important as family members, being capable of providing a secure and intimate relationship. They also have the ability to distract from distressing symptoms and upsetting experiences, and to encourage physical activity. Pets provide comfort in times when relationships with friends or family are limited or difficult.

Pets also help develop routines that provide emotional and social support.
By needing to be taken care of, they provide a sense of control that people with schizophrenia may not find in other relationships. Furthermore, pets can have a positive influence on the stigmatization related to mental illness, providing their owners with the feeling of being accepted.

As a result, pet ownership and animal-assisted therapy may contribute to the psychosocial rehabilitation and quality of life of people with schizophrenia.

Therapeutic communities

Therapeutic communities are small cohesive groups where people can practice the basic skills of living with other people and get help while helping others. Originally developed for the rehabilitation of psychologically traumatized soldiers, therapeutic communities have been successfully used in the treatment of severe mental illnesses such as schizophrenia. They are structured around responsibility, cooperation, and communication, and participants can live in the community as residents, or take part in group meetings several times a week. The goal is to provide low-stress family-like settings for people with a mental illness, where they receive continuous support and have the opportunity to improve their social relationships and sense of purpose. In this regard, the community itself works as an instrument of therapy.

Progressive muscle relaxation

Progressive muscle relaxation (PMR) is a technique for deep relaxation based on repeatedly tightening and relaxing one muscle group after the other, synchronized with breathing. PMR has been successfully applied to **KEEP STRESS AND ANXIETY UNDER CONTROL**, relieve insomnia, and minimize certain types of chronic pain. It can also be used to reduce stress and anxiety in patients with schizophrenia, leading to an increase in subjective well-being.

Video games

Video games are a relatively new method in the treatment of schizophrenia. Although they are often perceived to promote intellectual laziness or a sedentary lifestyle, video games actually allow players to **DEVELOP A WIDE RANGE OF COGNITIVE SKILLS**, and they **IMPROVE BRAIN PLASTICITY**. It has been shown that video games – especially those which involve movement and physical exercise (called exergames) – improve the cognitive abilities and motivation of young individuals with schizophrenia. They can also improve their emotional state, mood, and social skills, and can be an appealing alternative to physical activity. Furthermore, research suggests that by playing a video game, people with schizophrenia can be trained to **BETTER CONTROL VERBAL HALLUCINATIONS**.

Telehealth

During the pandemic, the possibility to see your doctor in person has reduced dramatically. At the same time, however, there has been a significant rise in the use of video chat applications that allowed people to see and talk to each other using their smartphones or computers. Besides enabling people to maintain contact as well as children to continue learning through online classes, these applications also allowed mildly ill patients to talk to their doctors and get the care they need while minimizing their exposure to the virus or other ill patients. Although there are some inherent limitations to this technology (mainly related to the quality of examination and the efficiency of health care delivery), we've witnessed the beginning of the digital transformation of the doctor-patient relationship, which provided patients essential health care access during a major public health crisis and on the long term it will probably change the way we communicate with our doctor.

Finding the right treatment

For a person with schizophrenia, finding the right treatment can often be quite a journey. A big part of this journey is **EXPLORING AND DISCOVERING THE METHODS** that work best for your loved one and their symptoms. It is important to be patient throughout this process. Despite the strong desire for the withdrawal of symptoms, each individual has their own path of finding what treatments are most suitable for them personally.

Although the process may feel overwhelming, there is a wide range of actions available to help ease this process. The most important is **TO SHARE YOUR EXPERIENCES** with your treatment team. It is important for the team to have a clear understanding of the symptoms to be able to generate a treatment plan that is personally effective for your loved one.

References

1. Altamura AC, Fagiolini A, Galderisi S, Rocca P, Rossi A. Integrated treatment of schizophrenia. Journal of Psychopathology 2015; 21:168-193
2. Uçok A, Gaebel W. Side effects of atypical antipsychotics: a brief overview. World psychiatry: official journal of the World Psychiatric Association (WPA) 2008. 7(1), 58–62. https://doi.org/10.1002/j.2051-5545.2008.tb00154.x
3. Caponnetto P, Polosa R, Robson D, Bauld L. Tobacco smoking, related harm and motivation to quit smoking in people with schizophrenia spectrum disorders. Health psychology research vol. 8,1 9042. 27 May. 2020, doi:10.4081/hpr.2020.9042
4. Haddad PM, Brain C, Scott J. Nonadherence with antipsychotic medication in schizophrenia: challenges and management strategies. Patient Relat Outcome Meas. 2014;5:43-62. Published 2014 Jun 23. doi:10.2147/PROM.S42735
5. Falkai P, Malchow B, Wobrock T. et al. The effect of aerobic exercise on cortical rchitecture in patients with chronic schizophrenia: a randomized controlled MRI study. Eur Arch Psychiatry Clin Neurosci 263, 469–473 (2013). https://doi.org/10.1007/s00406-012-0383-y
6. Farholm A, Sørensen M. Motivation for physical activity and exercise in severe mental illness: A systematic review of cross-sectional studies. Int J Ment Health Nurs. 2016 Apr;25(2):116-26. doi: 10.1111/inm.12217. Epub 2016 Feb 1. PMID: 26833453.
7. Jingxuan H. Art Therapy: A Complementary Treatment for Mental Disorders. Front. Psychol. 12 August 2021. https://doi.org/10.3389/fpsyg.2021.686005
8. Vancampfort D, De Hert M, Knapen J, Maurissen K, Raepsaet J, Deckx S, Remans S, Probst M. Effects of progressive muscle relaxation on state anxiety and subjective well-being in people with schizophrenia: a randomized controlled trial. Clin Rehabil. 2011 Jun;25(6):567-75. doi: 10.1177/0269215510395633. Epub 2011 Mar 14. PMID: 21402653.
9. Nathans-Barel I, Feldman P, Berger B, Modai I, Silver H. Animal-assisted therapy ameliorates anhedonia in schizophrenia patients. A controlled pilot study. Psychother Psychosom. 2005;74(1):31-5. doi: 10.1159/000082024. PMID: 15627854.
10. Hosak L. Electroconvulsive Therapy in Schizophrenia. World J Psychiatry Ment Health Res. 2018; 2(1): 1008
11. Almerie MQ, Okba Al Marhi M, Jawoosh M, Alsabbagh M, Matar HE, Maayan N, Bergman H. Social skills programmes for schizophrenia. Cochrane Database Syst Rev. 2015 Jun 9;2015(6):CD009006. doi: 10.1002/14651858.CD009006.pub2. PMID: 26059249; PMCID: PMC7033904.
12. Camacho-Gomez M, Castellvi P. Effectiveness of Family Intervention for Preventing Relapse in First-Episode Psychosis Until 24 Months of Follow-up: A Systematic Review With Meta-analysis of Randomized Controlled Trials. Schizophr Bull. 2020 Jan 4;46(1):98-109. doi: 10.1093/schbul/sbz038. PMID: 31050757; PMCID: PMC6942164.
13. Reeves JJ, Ayers JW, Longhurst CA. Telehealth in the COVID-19 Era: A Balancing Act to Avoid Harm. J Med Internet Res. 2021 Feb 1;23(2):e24785.

5. Coming to terms with your emotions

Providing care for a person with schizophrenia is a difficult job that requires a tremendous amount of time, energy, and dedication. Leaving aside daily struggles, caregiving can also bring to the surface **A WIDE VARIETY OF EMOTIONS**. Some of these emotions exist from the start, as many caregivers find themselves thrown into the role unexpectedly, and adjusting can be very stressful. Other emotions surface only after you have been caregiving for a while.

As a caregiver, you may experience both **POSITIVE AND NEGATIVE EMOTIONS**. Some days, caregiving may provide a deep sense of fulfillment and connection, along with feelings of respect, empathy, joy, and gratitude. Other days it may bring feelings of guilt, anger, shame, fear, anxiety, loneliness, or disappointment. You may also feel frustration, impatience, lack of appreciation, jealousy, irritability, and being overwhelmed. There may be a possibility for conflicting feelings to arise such as love and resentment being experienced simultaneously; these emotions may appear in various ways on a daily basis.

Experiencing all these emotions can become **GRUELING**, and if not closely monitored, they will wear you down. You may think that this will not happen to you because you love the person you take care of. But after some time, the negative emotions that we tend to bury come up. In the long term, they can take a toll on even the most dedicated caregivers, both physically and emotionally.

So how can you avoid burnout and feeling overwhelmed? It is essential for you to know that it is **COMMON** to experience a broad spectrum of emotions, including negative ones. Each and every one of your emotions about caregiving either positive or negative are perfectly reasonable and important, apart from being allowed and expected. Having all these emotions means that you are human. Do not try to avoid them. Ignoring your feelings and telling yourself that you must stay “strong” for your loved one or for the whole family is not the answer. Most psychologists agree that avoiding your feelings is not a sign of strength; actually, it takes more courage to face your emotions than to avoid them.

Coming to terms with your emotions is also **HEALTHIER**. Acknowledging and expressing your emotions can make you physically and mentally more resilient to stress and infections. In contrast, holding your emotions inside can weaken your immune system and expose you to a greater risk for conditions such as heart disease, cancer, or diabetes. Not paying attention to your feelings, and especially to expressing them, can lead to poor sleep, overeating, substance abuse, depression, and anxiety.

UNDERSTAND YOUR EMOTIONS AND POINT THEM TO YOUR ADVANTAGE. Rather than avoiding your emotions, you can use them to learn new things about yourself and your loved one. When you give yourself permission to have feelings and recognize that your feelings do not control your actions, your negative emotions will either subside or be easier to handle. In the long run, this will enable you to provide better care for your loved one, but it will also help you to take care of yourself.

As every caregiving experience is different, there are **NO “RIGHT” OR “WRONG” FEELINGS**. In order to provide the best care possible, it is helpful to be familiar with the type of feelings that could come about, ways of detecting them, and strategies of dealing with them. The following strategies are aimed at helping you cope with complex emotions that are experienced by numerous caregivers on a daily basis.

> “The unthankful heart discovers no mercies; but the thankful heart will find, in every hour, some heavenly blessings.”
>
> –Henry Ward Beecher

Although caregiving is most of the time challenging, it can also be a **REWARDING EXPERIENCE**. Allowing yourself to experience positive emotions is not about pretending that things aren’t difficult or that you are not stressed. It is also not about pretending you are not experiencing negative emotions, because that is normal and valid. However, you can experience positive emotions alongside negative ones, even in great stress. Positive emotions have unique benefits, independent of the effects of negative emotions. By giving yourself the permission to **FOCUS ON YOURSELF**, even if it’s just for a few minutes a day, you will be able to enjoy the positive moments and not let caregiving take over every aspect of your life.

Experiencing positive, rewarding feelings has multiple benefits, for both you and your loved one, as they reduce the physical effects of stress and can make both of you live longer. Moreover, we are “hardwired” in a way that tending to the needs of others helps reduce anxiety. Increasing the positive can help boost your reservoir of personal resources to cope better with your hardships and challenges. It can also make you a better caregiver and improve your relationship with the person you care for.

How to focus on the positive?

Learning positive emotion skills can help you experience more positive emotions and reduce anxiety. Practicing these skills every day will take you a long way ahead to a rewarding journey as a caregiver.

NOTICE THE POSITIVE. Be mindful of the positive things present in your life rather than reducing your focus to the negative ones.

CAPITALIZE ON POSITIVE EVENTS.
Savor your positive feelings by sharing them with others, making written notes of them, reminiscing on the event later.

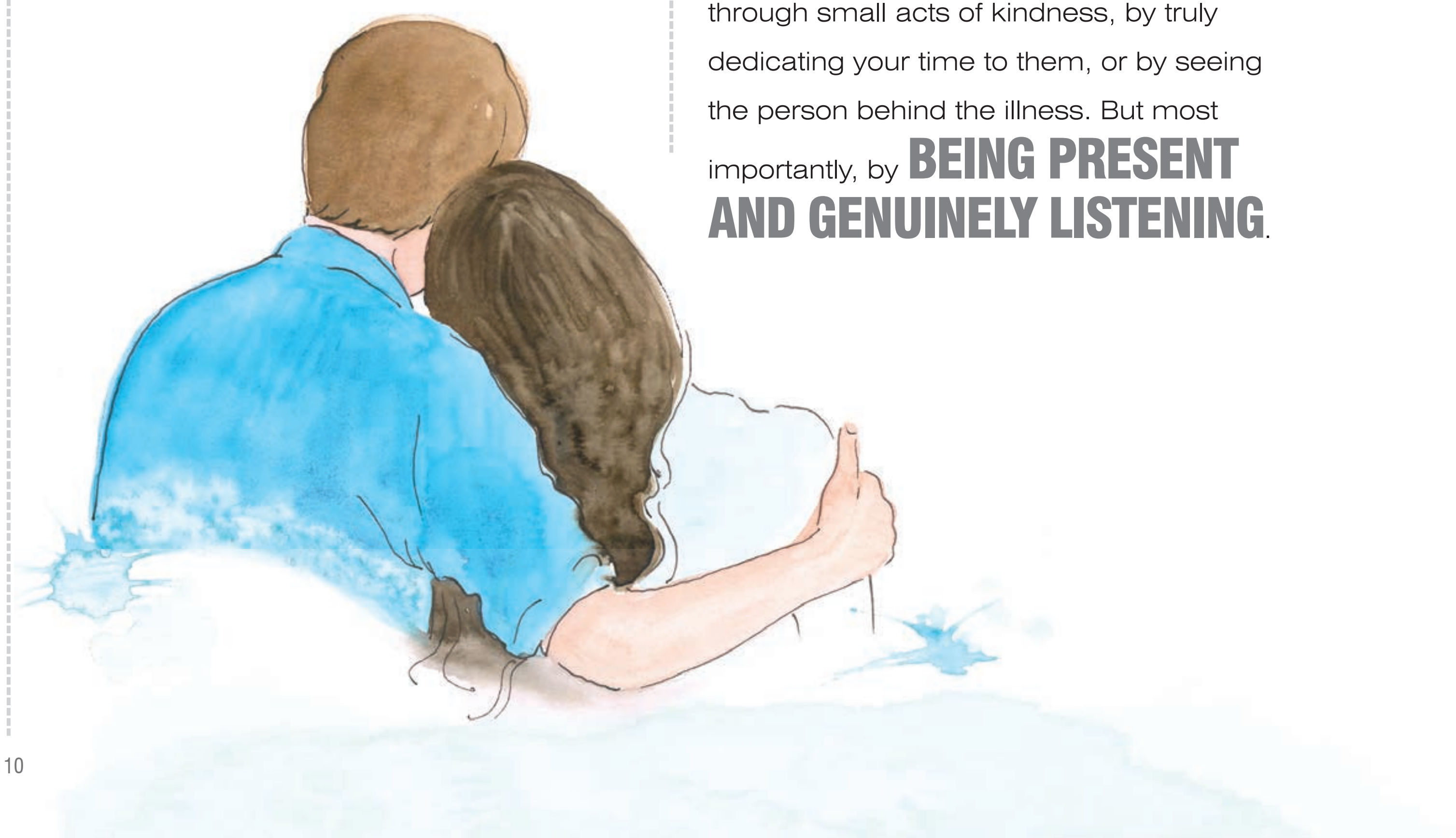
PRACTICE MINDFULNESS.
Be mindful of being present and disregard the judgement. You can incorporate mindfulness into the most basic daily activities like brushing teeth or washing dishes.

BE AWARE OF YOUR STRENGTHS.
Acknowledging the personal resources you hold and how to make use of them in your life will greatly reduce the feeling of helplessness.

SET ATTAINABLE GOALS. Choose challenging goals, but not overly, just enough to allow you to experience accomplishment and success without getting overwhelmed.

Compassion

Compassion is a person's ability to feel a sympathetic concern for another person's suffering, usually accompanied by a strong desire to ease that suffering. Of all the things you do as a caregiver, establishing a **COMPASSIONATE CONNECTION** with your loved one is probably the most important. It is the essence of being a caregiver.



Compassion enables individuals to soften their hearts towards others and engage in honest communication. When caregiving is done with compassion, you build trust and form a deeper, more meaningful relationship with your loved one. For you, this can change the entire caregiving experience from challenging to rewarding. For them, it has a significant positive impact on their life quality.

There are many ways in which you can show compassion towards your loved one: through small acts of kindness, by truly dedicating your time to them, or by seeing the person behind the illness. But most importantly, by **BEING PRESENT AND GENUINELY LISTENING**.

Respect

The desire for respect and dignity is among our most important human needs. Although offering a loved one help with maintaining a sense of dignity counts, there are many things you can do to make sure that they get well-deserved respect.

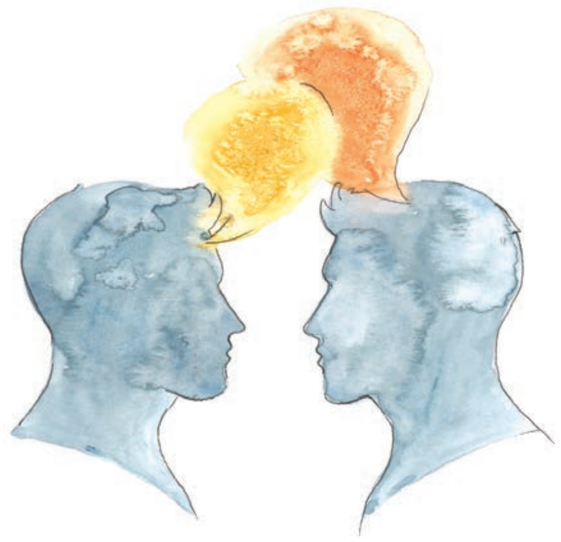
RESPECT THEIR PRIVACY.

Most of the time, people with schizophrenia live in the same household as their caregivers. This has many advantages, but it can also increase their stress if they feel you invade their private space, you are overprotective, or try to run every aspect of their lives. Besides their physical privacy, you should also respect their emotional privacy and not discuss confidential information with others without their permission.

RESPECT THEIR RIGHT TO MAKE CHOICES.

Let your loved one have a sense of control over their life by choosing what they wear or what they eat, for example. If you find it more helpful, try to offer several choices. If their choice is not important in your opinion, try to understand the reasons why it may be important to them. If you find their choice to be dangerous, try to encourage them by offering alternatives or negotiating possible solutions.

INVOLVE THEM IN DECISIONS RELATED TO THEIR CARE. Taking decisions without involving your loved one is possible to make them feel disconnected and undervalued. Make sure they are part of the discussions that affect their care. This will increase their feeling of being valued and in control, and therefore their adherence to treatment.



LISTEN TO THEM. Even if they have difficulties in expressing themselves, listen to their concerns, ask for their opinion, and try to include them in the conversation.

Making your loved one feel respected lowers their distress and increases their comfort. Moreover, respect provides you with mutual understanding, facilitates better communication, and builds a stronger connection.

Gratitude

It can be hard to be thankful when every day seems to hold a new challenge. And that's all right. Being grateful does not mean ignoring how hard caregiving can be. It is about finding something to be thankful for each and every day. When you are able to do that, you get a different perspective and the comforting thought that things are not bad all the time.

Gratitude can work wonders in restoring your well-being and has a multitude of benefits for your mental and physical health: it reduces stress, helps you sleep better, and boosts your immune system. Being grateful also helps you become more optimistic and focus on what you have instead of what you don't.

In time, being grateful becomes a habit that improves your overall attitude. The best way to develop this habit is to keep a gratitude journal. Each day, write down at least one thing that made you feel grateful that day. Be mindful of both the small and the big things. When you are down or feeling stressed, read from your journal to boost your mood and shift your perspective.

Challenging feelings

Guilt

Guilt is probably **THE MOST COMMON EMOTION** you may feel as a caregiver. We all experience guilt when we do something wrong. When taking care of a person with schizophrenia, guilt can come from a variety of sources. However, it is usually related to the fact that caregivers tend to blame themselves when something goes wrong.

The guilt that caregivers experience has a multitude of facets:

- guilt that they are not doing enough or they should be better at it;
- guilt that they are not spending enough time with the person they take care of;
- guilt that they are not spending enough time with their family;
- guilt that they are not taking care of themselves;
- guilt that they make their own well-being a priority;
- guilt that they are unfocused at work because of caregiving;
- guilt that they care about their career when they have others to care for;
- guilt for moving their loved one to an institution or assisted living;
- guilt over not taking enough action to prevent the illness to begin with;
- guilt over having the desire for this to disappear;
- guilt over all the negative emotions they experience.

The reason why guilt is so common among caregivers is that they often overwhelm themselves with a great deal of "oughts", "shoulds", and "musts" devised by their own self. They often have a pretty clear picture of how they should behave or act, and feel guilty when they do not succeed in acting accordingly. However, this picture is not always accurate. As a consequence, guilt often arises when there's a mismatch between their day-to-day choices and what they think the "ideal" choice would have been.

Whatever the source, guilt can be a particularly destructive emotion if you are blaming yourself due to mistakes that are most likely either presumed, exaggerated, or purely human.

How to cope with guilt

First of all, learn to forgive yourself. You cannot be perfect, and you cannot be in control all the time. Even with your best intentions, your time, skills, energy, and resources are limited. So go easy on yourself and provide the best care that you can while allowing yourself to be imperfect.

Second, lower your standards and set realistic limits to what you can accomplish. Instead of feeling guilty for not doing enough, look at the other way and appreciate the difference you are making every day in the life of the person you care for. Understand and accept your limits. Otherwise, you risk facing caregiver burnout.

Whenever you experience the feeling of guilt, it is worth asking yourself what might have triggered it. A firm "ought"? An exaggerated belief of your capabilities? Most importantly, you must recognize that guilt is unavoidable and get comfortable with not obtaining perfection.

Shame

Shame can be described as one's terrible feeling of embarrassment brought on by the realization of their own inappropriate behavior or actions. Shame is usually triggered by not aligning to social standards, and it is fueled by the fear of being socially excluded.

Although we often use the words "guilt" and "shame" interchangeably, there is a clear distinction between the two feelings. While guilt reflects how you feel about your actions, about what you did (or did not do) to another person, shame reflects how you feel about yourself. Shame is a painful feeling about how you appear to others, and it is not related to your actions.

As a caregiver, the guilt you may feel stems from the stigma connected with schizophrenia, which manifests itself as criticism or animosity from people who don't understand it. At the same time, your shame may be fueled by your own prejudices and lack of knowledge about the illness. The parents of young adults with schizophrenia often feel shame thinking that the illness could have been prevented had they been better parents.

Whatever the cause, shame leads to avoidance and isolation from friends, family, and society in general. But what is worse, shame also leads to avoidance of treatment: the families of people with schizophrenia are often reluctant to seek help to avoid feeling trapped and embarrassed.

In the long term, shame **HAS A NEGATIVE EFFECT ON THE QUALITY OF YOUR LIFE**, increasing the risk of depression and anxiety. Such an undesirable event can also have a negative impact on your relationship with the person you care for. In the worst case, it can lead to the development of an unpleasant environment for your relationship that will only worsen your loved one's symptoms.

How to cope with shame

The most important way you can deal with the shame caused by stigma is to educate yourself and others. Learning about the illness and spreading the knowledge will help reduce the stigma and will have a beneficial effect on you, the person you care for, and the people in your personal environment.

As for the shame you may feel as a parent, you need to stop blaming yourself. The theories that put the blame on the parents when a young adult was diagnosed with schizophrenia have crippled many families with feelings of guilt and shame, but time has proven that they were wrong. According to our current understanding of the illness, there is nothing you could have done as a parent to prevent it.

You must accept that no matter the connection or the relationship you share with the person you care for, you cannot control their behavior. What is in your power to do is to accept this reality and to be compassionate towards them. This way it is possible for you to cure yourself of the shame.

Anger

Anger is probably **THE SECOND MOST COMMON EMOTION** you experience as a caregiver. There are many situations that can lead to feelings of anger:

- seeing your loved one struggling;
- seeing that your loved one is irrational or combative;
- thinking about the future that both you and your loved one had to give up;
- feeling trapped in a situation you were thrown into unexpectedly;
- feeling that you are not appreciated enough for your everyday effort as a caregiver;
- feeling that the person you take care of does not accept your help.

In these circumstances, it is not always possible to keep your emotions under control. You might say things you don't mean or lose your temper. And while anger is a natural response given the hardships of being a caregiver, it can negatively impact both your relationship with the person you take care of and your health.

Chronic anger and hostility have been associated with high blood pressure, heart disease, digestive tract disorders, and headaches. Unexpressed anger that is built up over time can promote depression or anxiety, while explosive anger projected onto others may compromise relationships as well as cause them suffering. Managing anger does not only help with improving personal wellbeing, it also minimizes the likelihood of taking out the anger on a loved one.

How to cope with anger

Instead of avoiding anger, try to express it in healthier ways. Take the energy that comes with anger and try to channel it towards a positive experience. Ask yourself whether there may be a practical fix to the circumstances that anger you. Is a compromise possible? Would being more assertive (i.e., getting your point across firmly, fairly, and with empathy) help you feel a sense of control?

When you find yourself in a situation that angers you, try to remember the good times. Sometimes laughing at the absurdity of a situation can be a healthier way to let off steam than snapping. Another way to decrease anger, although a more difficult one, is to try to come to terms with the fact that your life has changed.

Most importantly, if you say or do something when you are angry, forgive yourself. Walk away and take a deep breath to regain your focus. Find constructive ways to express yourself, or talk to someone that you trust about what got you angry.

Resentment

Resentment is feeling bitter when you think you are being treated unfairly. In certain aspects, resentment is similar to anger. However, while anger is a sudden emotion, a reaction, resentment is a feeling of bitterness experienced when we let anger persist. Anger is natural; resentment is a choice. Thus, being resentful is choosing to keep the anger. It is reliving a hurtful experience over and over again. And while anger can sometimes be positive because it gives you the power to change things, resentment holds you back and can only hurt you and the person you care for.

Becoming the caregiver of a person with schizophrenia often means being suddenly placed in a situation that you didn't choose and taking on an enormous task that you were not prepared for. In these circumstances, it is quite common to feel pessimistic and resentful. Because of the extensive amount of time spent on taking care of your loved one, **IT IS REASONABLE TO FEEL RESENTMENT AS A CAREGIVER** – despite the amount of love or care you have for them. For instance, it may be that you experience resentment towards the overall situation, the illness, specific behaviors, uncooperative family members, or friends who don't offer much support. You may also resent your loved one, especially when their negative symptoms prevent them from showing compassion towards you.

How to cope with resentment

Being resentful actually requires a lot of energy, and you can redirect this energy in positive ways in order to find the silver lining. When you feel resentment towards your loved one, remember that many of your interactions are dictated by their disease. Their apparent lack of motivation and unwillingness to talk are symptoms of the illness that they cannot control.

Give your feelings some space by talking about your emotions with friends or family members. Be proactive in communicating with your loved one and everyone involved in their care; avoiding uncomfortable conversations will only add to your frustration and resentment. You can also use physical activity to move past the stuck emotional energy that usually accompanies resentment.

Most importantly, make the conscious decision to spend time on your own needs. If you don't take care of yourself, the resentment will not go away, but it will continue to build.

Fear and anxiety

Caregiving anxiety is often a result of facing the unknown, or feeling out of control and not knowing how to regain it. There are many aspects in the life of a person with schizophrenia that can cause fear and anxiety. You may feel frightened of making significant mistakes or being confronted with issues you are not aware of how to solve. You may be afraid that something happens to your loved one when you are not by their side. You may also be worried about your loved one losing their job, or about you losing yours. Also, seeing your loved one in an altered or uncomfortable state typically produces feelings of stress and confusion. As a caregiver, you may **EXPERIENCE ANXIETY IN MANY WAYS**, from having difficulty sleeping or feeling an impulse to run away, to having heart palpitations and feeling an urge to cry.

How to cope with fear and anxiety

The most effective way of dealing with fear when taking care of someone with schizophrenia is to educate yourself and try to plan in advance. Talk to the healthcare team treating your loved one and find out what to do in specific situations. Plan for every situation or crisis that may arise by finding the right balance between being prepared and being overprotective. Focus on the things you are able to have under control and make a contingency list of actions in case you are not nearby. Reaching out to others who are in a similar situation, for example through a support group, can also reduce stress-related anxiety.

It is important to be mindful of anxiety; it is your body's way of signaling a potential threat. In case of experiencing anxiety, pause for a moment, focus on your breathing and take some time off from what is happening at the moment.

Isolation and loneliness

Despite the fact that you spend a great amount of time with the person you care for, **YOU MIGHT FIND YOURSELF EXPERIENCING FEELINGS OF LONELINESS**. And the longer you are a caregiver, the higher the risk of becoming isolated. With no one to talk to all day except the person you take care of, it is easy to lose a sense of yourself.

Relationships with friends may suffer because of your intense schedule or because they feel less wanted. You may hesitate to reach out and spend time with them because you feel that your life is all about caregiving and you have nothing to talk about or they do not want to hear about your struggles anymore. When taking care of a person with schizophrenia, the feeling of having lost your loved one's companionship may also add to your isolation.

In the long run, the feeling of loneliness can have a negative impact on your health. It weakens your mental strength and makes you more prone to start having harmful habits like overeating, smoking, or abusing alcohol. Furthermore, social isolation is a risk factor for dementia.

How to cope with isolation and loneliness

The key to removing yourself from isolation is to sustain healthy relationships aside from your role as a caregiver. Find means of getting out of the house and engaging in other things besides caregiving. Find activities, such as sports or hobbies, that enable you to engage with individuals who can provide a feeling of belonging and support.

If getting out is troublesome, it might be worth reaching out to and inviting old friends over. Consider joining support groups concerned with your loved one's illness or caregiving in general. Alternatively, you can find kinship with individuals who share your experience in online support groups.

Helplessness

Being the caregiver of a person with schizophrenia provides **MANY OPPORTUNITIES FOR YOU TO FEEL HELPLESS**, especially at times when you do every single thing in your power in order to help the person you care for and they are not getting better. Beyond your caregiving challenges, the emotions we talked about in this chapter can also make you feel helpless and unable to continue to be a caregiver. The feeling of helplessness can negatively impact your emotional health, leading to irritation, guilt, and even depression if this feeling persists.

How to cope with helplessness

When you are feeling helpless, ask yourself the following questions:

- Am I having unreasonable expectations?
- Do I know enough about how to solve this problem?
- Am I getting enough sleep?
- Am I taking care of myself?

It is important for you to realize that by doing the best you can, you are of invaluable help to your loved one. You also need to remind yourself frequently that their health is often beyond your control. Acknowledging your limits will allow you to pinpoint what is it that you are able of controlling, as well as redirect your energy. Reach out to friends or family and delegate some of your caregiving tasks. Also, make sure to get enough sleep and have some time for yourself. Being constantly tired increases your stress and the feeling of helplessness.

When faced with a complex problem, breaking it down into smaller, more manageable tasks can help you find the solution and avoid the feeling of helplessness. You can also cope with this difficult feeling by learning as much as you can about the illness and communicating frequently with the medical team treating your loved one.

Depression

It frequently happens that the caregiver's attempt to offer their loved one the best possible care might be detrimental to their own physical and/or emotional needs. However, the stress of caregiving, the uncertainty of the future, as well as all **THE NEGATIVE EMOTIONS LISTED ABOVE CAN TAKE A TOLL ON THEIR WELL-BEING AND LEAD TO DEPRESSION AND MOOD PROBLEMS**. Studies show that as many as half of caregivers of people with schizophrenia have depression, particularly in cases where the illness is resistant to treatment.

People experience depression in different ways, as a change in symptoms can occur in time. If the occurrence of the following symptoms is persistent over the course of more than two consecutive weeks, it may be assumed that depression is present:

- a change in eating habits leading to undesired weight gain or loss;
- a change in the sleeping pattern (excessive or insufficient sleep);
- experiencing constant tiredness;
- a lack of interest in individuals and/or activities that were previously pleasurable;
- experiencing anger and agitation at a much faster rate;
- having the feeling of not being or doing good enough at anything;
- suicidal tendencies or thoughts of death, or attempting suicide;
- consistent physical symptoms which are unresponsive to treatment, for example, digestive issues, headaches, and chronic pain.

How to cope with depression

Depression is treatable and should be taken seriously. The attentiveness to symptoms in good time may help restrain the formation of a more severe depression case in the long term. Talk to your physician or a mental health professional if you suspect the presence of depression. Furthermore, physical activity and social interactions are excellent ways of dealing with sadness and depression as they create a way to alleviate tension, improve your mood, develop social relationships and boost your energy.

How to recognize emotional fatigue?

Emotional fatigue is a state of feeling emotionally worn out and drained as a result of the stress accumulated from caregiving. Emotional fatigue affects a large proportion of caregivers, and it is one of the signs of burnout.

Initially, the symptoms of emotional fatigue come and go; they may also be insidious or overlap with each other. They include:

- nervousness or tension;
- feelings of frustration, anger, or guilt;
- feelings of resentment, impatience, and/or irritability;
- feelings of sadness, hopelessness, and isolation;
- forgetfulness, inability to concentrate, and/or mental sluggishness;
- lack of motivation;
- change in appetite;
- poor or interrupted sleep;
- heart palpitations;
- increase in aches, pains, and blood pressure.

Your emotions in different stages of the disease

Your loved one's symptoms and the course of the illness may set the tone for the different types of feelings you are faced with in different stages of the disease.

The first psychotic episode (The prodromal phase)

The first episode of schizophrenia is a **CHALLENGING INTERVAL OF TIME THAT REQUIRES ACCEPTANCE AND ADJUSTMENT** by the patients, as well as their families. For people who were just diagnosed with schizophrenia, it is a personal crisis associated with fear, guilt, shame, and hopelessness. For their family members, who were suddenly placed in a situation that they did not choose, it is a period of **SHOCK, GUILT, SHAME, FEAR, ANXIETY, AND UNCERTAINTY**.

The active phase

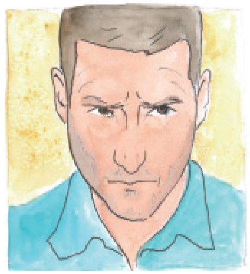
In the active phase of the illness, there is a predominance of positive symptoms such as hallucinations, delusions, and bizarre behavior. Almost all people with schizophrenia experience these symptoms at some point during the disease. In some cases, they appear only during the relapses. However, in almost half of cases, positive symptoms are present either most of the time or continuously.

Your loved one's positive symptoms **CAN HAVE A NEGATIVE IMPACT ON YOU**, especially when they are not aware of them. They may say things that don't make sense or accuse others of conspiring against them or stealing their thoughts. They may also see things or hear voices that frighten them. These symptoms may lead to verbal or bizarre behavior and put pressure on the entire family, leading to feelings of tension, frustration, and anxiety. The most common feelings and thoughts that caregivers experience in this period include the **FEAR THAT SOMETHING WILL HAPPEN TO THEIR LOVED ONE**, the fear of being subjected to violence, the idea that they may also have the illness, uncertainty, and hopelessness.

The residual phase

In the residual phase, when psychotic symptoms are subdued, there is a predominance of negative symptoms, such as avolition (the lack of drive or purpose), alogia (the reduced ability to speak), or blunted affect (the reduced ability to express emotions), and cognitive symptoms such as problems with attention, concentration, and memory.

In this period, for the family of a person with schizophrenia, **ONE OF THE MOST FRUSTRATING SYMPTOMS IS AVOLITION**. It is very difficult for them to see their loved one not having an interest in even the most basic daily activities. Many family members believe that the person they care for is able to influence their avolition. In this regard, they see their loved one's inability to get dressed or to go to an appointment as laziness. As we've talked about this in previous chapters, avolition is a symptom of the illness, and as such, your loved one cannot influence it directly.



The most common feelings that you may experience in the residual phase are **ANGER, FRUSTRATION, IRRITABILITY, IMPATIENCE, LONELINESS, LACK OF APPRECIATION, AND BEING OVERWHELMED**. And because people with schizophrenia often have difficulties finishing their studies or getting a job, it is also a period of intense worry about your loved one's future. In many regards, for you, the caregiver, the residual phase is even more challenging than the active phase. During the psychosis, even if the symptoms and events are frightening, you have some kind of interaction with your loved one. After the psychosis, families often expect things to return to normal and are waiting to get their loved one back. Instead, because of the negative symptoms, what follows is a period with fewer emotions and interaction from your loved one, which may lead to resentment and the feeling that your efforts as a caregiver are not appreciated.

Although we've talked mostly about challenging feelings related to the different phases of the disease, do not forget that in every phase of the disease, you can experience love, respect, and empathy, feelings that make your caregiving experience rewarding.

Emotionally-charged behaviors

In all phases of the illness, you may be faced with situations with a high emotional burden that **TESTS YOUR CAREGIVER ABILITIES AND YOUR RELATIONSHIP WITH YOUR LOVED ONE**.

HOSTILITY, VIOLENCE, AND AGGRESSION. People with schizophrenia are not usually aggressive or violent. However, in some cases, the severity of the illness, alcohol or drug abuse, or the stress and frustration caused by the disease may cause your loved one to become aggressive or even violent. Violence is also associated with more severe symptoms, lower family income, and unemployment. Other times, your loved one may exhibit hostility toward you, or blame you for everything from imposing limits on them to getting the disease in the first place. In these situations, **YOU NEED TO REMAIN CALM** and **REMEMBER THAT WHAT YOU SEE IS NOT THE PERSON YOU LOVE BUT THE ILLNESS**.

For them, schizophrenia is a painful journey riddled with fear, anxiety, crippling symptoms, stigma, and the sense of an ever-changing reality.

SUICIDAL THOUGHTS.

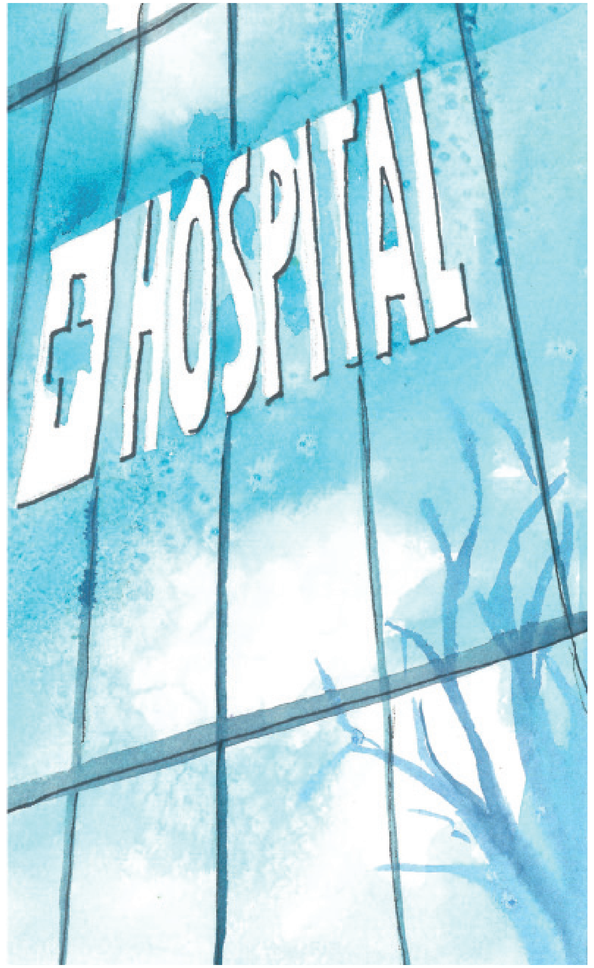
The symptoms of schizophrenia, stress, and depression may also lead to suicidal thoughts. These acute situations can be a deeply tense and emotional time for the entire family. You can **FIND MORE INFORMATION** on what to do if your loved one intends to hurt themselves in **CHAPTER 6 OF THIS GUIDEBOOK**.

REJECTION OF TREATMENT.

People with schizophrenia often reject medication or other treatment options. This can happen for a number of reasons: they are not aware of their illness (anosognosia), they are feeling better, or conversely, they are feeling worse because of medication side effects. Because of all these reasons, they may also reject hospital admission. Anosognosia can cause a great deal of frustration for the entire family, but most often it improves over time. The best solution in these situations is to **TRY TO UNDERSTAND THE CAUSE BY SEEING THE WORLD THROUGH YOUR LOVED ONE'S EYES**. Talk to the healthcare team to find solutions that will help your loved one stick to their treatment.

SPECIALIZED TREATMENT FACILITY. The severity of your loved one's illness may require long-term care that is only available in a specialized treatment facility. Dealing with the fact that your loved one can no longer be taken care of in the family can be particularly challenging emotionally. Make this decision together with everyone involved in their care, making sure to

ACT IN THE BEST POSSIBLE INTEREST OF YOUR LOVED ONE, BUT ALSO YOUR FAMILY.



Manage tough emotions healthily

As strange as it may sound, caregivers often **DO NOT REALIZE THAT THEY ARE CAREGIVERS**. When their child, parent, or other family member is diagnosed with schizophrenia, they help out, because it is the right thing to do. The sooner you self-identify as a caregiver, the sooner you will be able to recognize and deal with the emotional roller-coaster that is caregiving. You will also recognize the emotional weariness that you will inevitably experience and start looking for ways to manage it.

The emotions we talked about in this chapter are often warning signs from your body; little reminders for you to pay attention and remember that

YOU ARE IMPORTANT, TOO.

These emotions can be experienced by every caregiver. Admitting this will help you take care of yourself and not react to them in a negative way. You also need to understand that what causes your emotional fatigue the most is out of your control. Be aware of your limitations and let go or delegate some of the responsibilities.

The key to being a successful caregiver is **FLEXIBILITY AND ADAPTABILITY** on the journey.

Most importantly, remember that **NOBODY CAN DO THIS JOB ALONE**. Get help, even from the earliest stages of caregiving. It will significantly increase your well-being, and it will enable you to provide the best care you envision for your loved one.

References

1. How to Handle Guilt and Other Caregiving Emotions [Internet]. WebMD. [cited 2021 Mar 21]. Available from: https://www.webmd.com/healthy-aging/caregiver-overcome-guilt
2. Ong AD, Mroczek DK, Riffin C. The Health Significance of Positive Emotions in Adulthood and Later Life. Soc Personal Psychol Compass. 2011 Aug 1;5(8):538–51.
3. Mund M, Mitte K. The costs of repression: a meta-analysis on the relation between repressive coping and somatic diseases. Health Psychol Off J Div Health Psychol Am Psychol Assoc. 2012 Sep;31(5):640–9.
4. Kamil SH, Velligan DI. Caregivers of individuals with schizophrenia: who are they and what are their challenges? Curr Opin Psychiatry. 2019 May;32(3):157–63.
5. Newman KM. How Caregivers Can Cultivate Moments of Positivity [Internet]. Greater Good. [cited 2021 Apr 26]. Available from: https://greatergood.berkeley.edu/article/item/how_caregivers_can_cultivate_moments_of_positivity
6. Poulin MJ, Brown SL, Dillard AJ, Smith DM. Giving to Others and the Association Between Stress and Mortality. Am J Public Health. 2013 Jan 17;103(9):1649–55.
7. Tangney J, Tracy J. Self-conscious emotions. In: Leary M, Tangney J, editors. Handbook of self and identity. The Guilford Press; 2012.
8. Chan SW. Global perspective of burden of family caregivers for persons with schizophrenia. Arch Psychiatr Nurs. 2011 Oct;25(5):339–49.
9. Miller R, Mason SE. Shame and Guilt in First-Episode Schizophrenia and Schizoaffective Disorders. J Contemp Psychother. 2005 Jul 1;35(2):211–21.
10. De Rubeis S, Hollenstein T. Individual differences in shame and depressive symptoms during early adolescence. Personal Individ Differ. 2009 Mar 1;46(4):477–82.
11. Anger - how it affects people | betterhealth.vic.gov.au [Internet]. Better Health. [cited 2021 May 1]. Available from: http://www.betterhealth.vic.gov.au/health/healthyliving/anger-how-it-affects-people
12. Sundström A, Westerlund O, Kotyrlo E. Marital status and risk of dementia: a nationwide population-based prospective study from Sweden. BMJ Open. 2016 Jan 4;6(1):e008565.
13. Bademli K, Lök N. Feelings, thoughts and experiences of caregivers of patients with schizophrenia. Int J Soc Psychiatry. 2020 Aug;66(5):452–9.

6. Occupation? – Hero caregiver

Stay positive and come up with a plan

One of the most important ways to reduce stress, fear, and anxiety when taking care of a person with schizophrenia is to **MAKE A PLAN**. This plan should include your goals for recovery, daily activities for your loved one that keep them physically and mentally well, things to look out for such as relapse triggers or early warning signs, as well as how to deal with a crisis. Talk with the doctor in charge of treating your loved one about what kind of care and supervision they need, how frequently, and for how long. Make a list of all the friends and family members who can help you and be ready to adapt the plan as you go along.

Stay positive as you apply the plan on a daily basis. It will motivate you through your day-to-day challenges and will also give you hope regarding the development of new therapies that will take your loved one closer to recovery. **A POSITIVE MINDSET** will help you stay open to new possibilities, will increase your energy levels, and will help you prevent burnout. Having a positive attitude will also influence your loved one's mood, improving your relationship and making their journey towards recovery easier.

STAYING POSITIVE AND COMING UP WITH A PLAN will lead to one of the most important ingredients in providing the best possible care to your loved one: a **SENSE OF CONTROL**.

Create a predictable environment and routine

Creating a routine is immensely helpful to both you and the person you care for because it provides stability and reliability. With consistent support and predictable routines, you both know what to expect and how to seek additional help when necessary.

Following a routine basically means **PERFORMING CERTAIN TASKS REGULARLY**. For the person with schizophrenia that you take care of, a routine can encompass everything they do in a day or a week: when they get up in the morning, eat, take their medicine, go to an appointment, water the plants, or go to sleep.

Although it may appear monotonous, this type of routine **MAY PROVIDE ENORMOUS COMFORT** to your loved one by removing the possibility of the unexpected. When their minds are racing, they have a plan to fall back on, a pre-determined sequence of events that they can always rely on. A schedule can also help them remember to **TAKE THEIR PRESCRIPTION AND GET ENOUGH SLEEP**. But, more crucially, **IT CAN PROVIDE AN INTIMATE ENVIRONMENT**, which can help to establish a strong basis for recovery. And when they discover their own thinking to be unclear, this intimacy might be a blessing.

A routine can also **HELP YOUR LOVED ONE KEEP THINGS TOGETHER** when stressful life events bring chaos to their day-to-day life. At the time of this writing, the COVID-19 pandemic has been going on for more than **18 MONTHS,** causing distress not only to those with a mental illness but almost everyone. The unpredictability of these situations makes a routine that maintains your loved one's physical and mental health even more important.

To create a routine, **IDENTIFY WHICH TASKS YOU NEED TO COMPLETE** on a regular basis and figure out the frequency at which these would need to be done. Using daily, weekly, or monthly checklists can help you remember what needs should be done and when. When you've created the list of tasks, do not forget to prioritize, making sure to complete the most important tasks first.

You can **CREATE A PLAN TOGETHER** with your loved one, telling them about the benefits. However, keep in mind that they may be reluctant to get on board with the routine at first. That's OK. **GIVE THEM SOME SPACE** and let them know that they are welcome to join any time. You can repeat the invitation a few times over the course of several weeks, without pressure. Even if your loved one does not take part in the routine at first, **YOU SHOULD STICK TO IT** because it will make your job easier, and they will also find it easier to see the benefits and join at a later time.

How you can help as a caregiver

The following sections describe in detail how you can help your loved one navigate the everyday challenges of schizophrenia and ensure they are on the right path to recovery.

Provide support with basic daily needs

One of the features of schizophrenia is that the day-to-day life of those who suffer from schizophrenia can become disorganized. This means that basic tasks, for example taking care of personal hygiene or getting laundry done are either completely dismissed or become an obsession, taking over the individual's time.

This is particularly evident during the acute phase of a schizophrenic episode, as the persistent demands of the hallucinations and delusions require an overwhelming amount of energy to be satiated, diminishing one's ability to think about anything else. Later, in the residual phase, when they start to regain some normal functioning, daily tasks start to become important again. In this period, **THEIR BASIC LIFE SKILLS WILL NEED TO BE REFRESHED**. Tasks like taking medication accordingly, shopping, cooking, cleaning, and money management have been reported to represent a challenge for people with schizophrenia in this phase.

One of your duties **AS A CAREGIVER IS TO HELP THEM WITH THESE TASKS**.
As you will see, many of them require you to be organized. If you are not a naturally organized person, you can develop this skill through learning. **THINK ABOUT CAREGIVING AS A PROJECT**: the more organized you are, the easier it is to complete it. In fact, everything that can help you in a project – committing to deadlines, time management, breaking down large tasks into smaller ones, etc. – can also help you in caregiving.

The basic daily needs that your loved one may need your help with include:

- complying with the set time for taking medications on a daily basis;
- being consistent with regular body and hair washing, teeth brushing, and nail trimming;
- changing the bedding at appropriate times;
- cooking nutritious meals and eating them at appropriate time intervals;
- doing the laundry and housekeeping;
- grocery shopping and running errands;
- managing finances and respecting a budget;
- going on public transportation;
- scheduling appointments;
- transportation to appointments.

Some of these tasks need to be done on a daily basis, others once a week or even less frequently. Also, it is likely that you won't have to do them every single time instead of your loved one. The fact that they need help does not mean that they are invalid or incapable. It's just that the illness makes it much more difficult for them to be organized and to find basic tasks important. The main goal is to **DEVELOP A ROUTINE** and **SLOWLY TRAIN THEM TO DO THESE TASKS BY THEMSELVES**.

Create healthy habits:

EATING, SLEEPING, EXERCISING

PEOPLE WITH SCHIZOPHRENIA FACE A LOT OF CHALLENGES IN MAINTAINING A HEALTHY LIFESTYLE. THE SYMPTOMS OF THE DISEASE, PARTICULARLY NEGATIVE SYMPTOMS, MAKE BASIC NEEDS SUCH AS REGULAR EATING LOSE THEIR IMPORTANCE. CERTAIN ANTIPSYCHOTIC MEDICATIONS CAN RESULT IN WEIGHT GAIN AND INCREASE THE LIKELIHOOD OF CARDIOVASCULAR DISEASES AND DIABETES. HALLUCINATIONS, FEAR, AND PARANOIA CAN LEAD TO INSOMNIA, WHILE SOME MEDICATIONS MAY CAUSE EXCESSIVE SLEEPINESS DURING THE DAY. NEGATIVE SYMPTOMS SUCH AS APATHY OR ANHEDONIA ARE MAJOR IMPEDIMENTS TO GETTING ENOUGH EXERCISE, LEADING TO A SEDENTARY LIFESTYLE.

All these factors can have an **UNDESIRABLE EFFECT ON YOUR LOVED ONE'S PHYSICAL AND MENTAL HEALTH;** therefore, it is crucial to pay attention to them right from the beginning of treatment.

EATING BALANCED MEALS at regular intervals, with plenty of fruits and vegetables and proper quantities of proteins and fibers, will ensure healthy nutrition and will lower the risk of heart disease and diabetes.

A HEALTHY SLEEPING ROUTINE

WILL ENSURE YOUR LOVED ONE IS GETTING ENOUGH REST, MINIMIZING THEIR STRESS AND ANXIETY. IF THEIR MEDICATION IS MAKING THEM SLEEPY DURING THE DAY, TALK WITH YOUR DOCTOR ABOUT THE POSSIBILITY OF TAKING THEM IN THE EVENING. GETTING A MINIMUM OF **30 MINUTES** OF EXERCISE EACH DAY WILL HELP REDUCE THE RISK OF OBESITY AND WILL BOOST YOUR LOVED ONE'S ENERGY LEVELS.

AS WE'VE DISCUSSED IN CHAPTER 4,

INDIVIDUALS LIVING WITH SCHIZOPHRENIA ARE MORE LIKELY TO DEVELOP A RANGE OF HEALTH PROBLEMS. COUPLED WITH A SEDENTARY LIFESTYLE AND THE NEGATIVE IMPACT OF SMOKING, ALCOHOL, AND DRUGS, THESE HEALTH PROBLEMS COULD GREATLY HEIGHTEN THE CHANCES OF GETTING COVID-19 AND DEVELOPING A SEVERE FORM OF INFECTION. CREATING AND MAINTAINING HEALTHY HABITS CAN REDUCE THIS RISK IN SIMILAR SITUATIONS. PLEASE SEE CHAPTER 8 FOR FURTHER INFORMATION ON HOW PEOPLE WITH SCHIZOPHRENIA MIGHT HAVE BEEN AFFECTED BY COVID-19 AND HOW THE COVID-19 PANDEMIC HAS INFLUENCED SCHIZOPHRENIA MANAGEMENT.

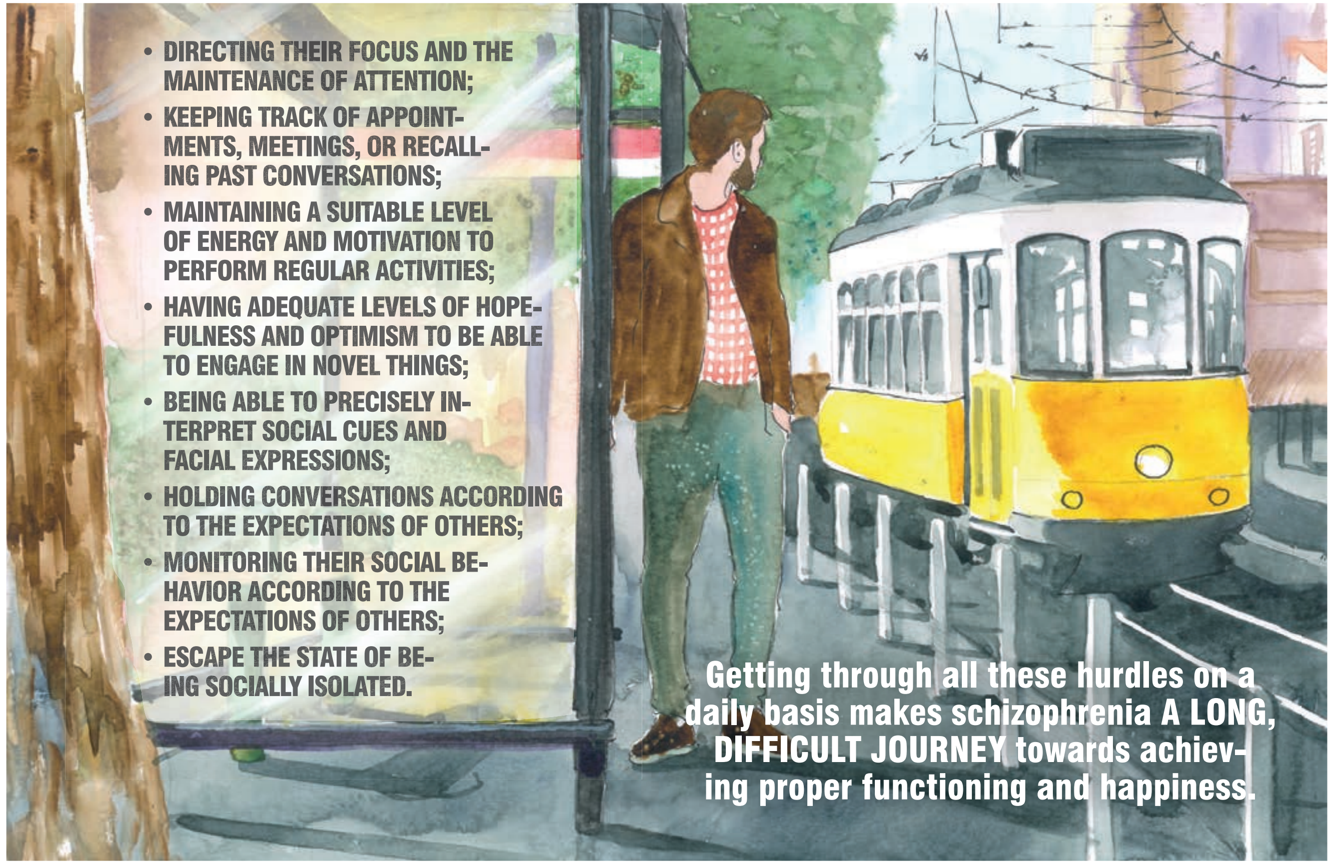
Creating a routine will be of immense help in forming certain habits and maintaining a healthy lifestyle. Having a specified time when to eat, when to go to bed, and when to exercise will provide structure for each day and a plan to follow.

Preserve your loved one's personal, social, and occupational functioning

Personal functioning

Schizophrenia is a disease that can cause your loved one to **QUESTION THE REALITY OF THINGS**. As a result, they may find it challenging to complete everyday tasks, have clear thought patterns, find solutions to problems, or make decisions. **THEY MAY FIND IT IMPOSSIBLE TO KEEP THEIR EMOTIONS UNDER CONTROL** and may find it **DIFFICULT TO INTERACT** with family, friends, or others, such as their healthcare team.

Based on how severely the illness manifests itself, your loved one may experience difficulties with skills such as:



- DIRECTING THEIR FOCUS AND THE MAINTENANCE OF ATTENTION;
- KEEPING TRACK OF APPOINTMENTS, MEETINGS, OR RECALLING PAST CONVERSATIONS;
- MAINTAINING A SUITABLE LEVEL OF ENERGY AND MOTIVATION TO PERFORM REGULAR ACTIVITIES;
- HAVING ADEQUATE LEVELS OF HOPEFULNESS AND OPTIMISM TO BE ABLE TO ENGAGE IN NOVEL THINGS;
- BEING ABLE TO PRECISELY INTERPRET SOCIAL CUES AND FACIAL EXPRESSIONS;
- HOLDING CONVERSATIONS ACCORDING TO THE EXPECTATIONS OF OTHERS;
- MONITORING THEIR SOCIAL BEHAVIOR ACCORDING TO THE EXPECTATIONS OF OTHERS;
- ESCAPE THE STATE OF BEING SOCIALLY ISOLATED.

Getting through all these hurdles on a daily basis makes schizophrenia A LONG, DIFFICULT JOURNEY towards achieving proper functioning and happiness.

Social functioning

One of the distinguishing aspects of schizophrenia is **SOCIAL DYSFUNCTION**, and many people living with the disorder find it difficult to interact with others, even when their psychotic symptoms are under control.

As a result, for people with schizophrenia, the illness can become a constant struggle to figure out **HOW TO FIT INTO SOCIETY**.

In this regard, the most debilitating symptoms are **PARANOIA AND DELUSIONS**. The belief that others are trying to hurt them or are thinking bad things about them makes it very difficult for people with schizophrenia to have a dialogue or keep their calm in any kind of social situation.

One of our most important social interactions is, of course, establishing a romantic relationship with another person. Generally, people aspire to form romantic relationships and start a family. However, a serious, long-term illness, like schizophrenia brings along a **SERIES OF PARTICULAR DRAWBACKS**, which makes it troublesome to form and maintain close relationships.

The most significant of these drawbacks is **THE NEED TO ADAPT TO THE ILLNESS**, which may cause alienation in the relationship due to the presence of stigmatization and self-stigmatization. The stigma of schizophrenia leads to a vicious **CYCLE OF SELF-STIGMATIZATION AND ISOLATION**, decreasing social functioning, which in turn amplifies the stigma. Self-stigmatization also leads to low self-esteem. As a result, the large majority of people with schizophrenia have the belief that others do not have the desire of being with a partner diagnosed with such illness. Hence, schizophrenia results in a reduced prospect of getting married, particularly for men, and an increased risk for broken marriages regarding women. Love relationships are also **COMPLICATED BY INTERNAL OBSTACLES**, described by people with schizophrenia as losing a part of themselves, modifications to the experience of emotions, and challenges with accepting alternative beliefs. They also report diminished trust towards others but also themselves, as well as towards their own memories, feelings, perceptions, and desires. There are also more practical challenges. Schizophrenia (and certain antipsychotic medications) may cause people to become less interested in sex. Some antipsychotics can cause weight gain, while the person taking them may **FEEL UNATTRACTIVE**. For people who have had schizophrenia for many years, poverty can also become a roadblock in creating and sustaining relationships.

All these difficulties might lead to the belief that love and schizophrenia are not compatible. However, regardless of the chaos in their minds and the lingering impact of psychotic experiences, most people with schizophrenia have the ability to communicate nuanced feelings and outlooks towards love.

THEY NEED TO LOVE AND TO BE LOVED. They have a strong desire for meaningful relationships, romance, and family. It's just that the illness does not allow their self to express the full extent of its potential.

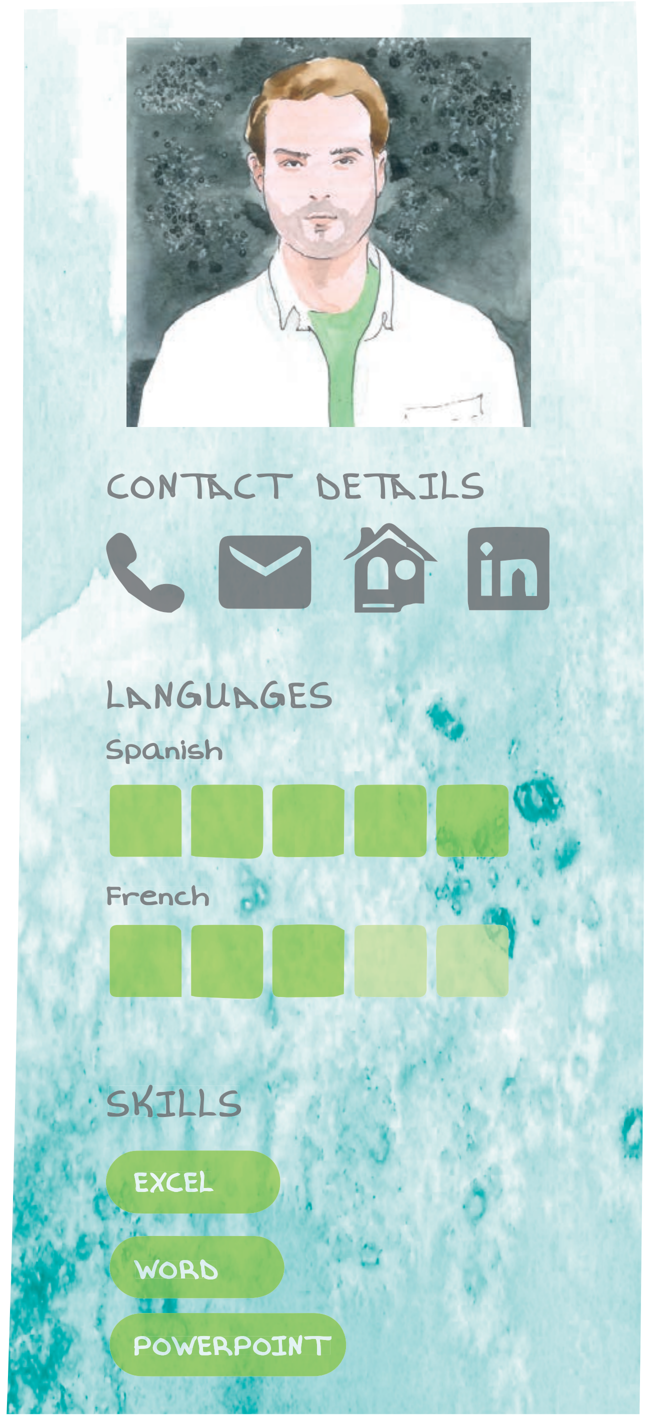
Although it means a lot of work, if the disease of your loved one is kept under control, establishing a romantic relationship with someone who accepts them as they are can have a huge positive impact on their life.

Occupational functioning

People with schizophrenia are known to have a **LOWER PERFORMANCE IN WORK-RELATED TASKS** as a result of their altered cognitive functioning and negative symptoms.

When the illness is not adequately controlled by medication, it can severely affect both their **PHYSICAL AND MENTAL WORK CAPACITY**. Hallucinations can make physical work impractical and can be dangerous for your loved one but also for others in the workplace. Most people with schizophrenia will also struggle with **DISORGANIZED THINKING, SPEECH, AND BEHAVIOUR**, symptoms that make it very difficult to function in a work environment.

The first symptoms of schizophrenia usually appear around the age when individuals are attending college. This period in their life can be marked by a psychotic episode, and it is natural for this event to be considered the end of what was supposed to be a successful life. But the reality is different and if symptoms are successfully controlled, enrolling back into education or getting a job may be **UTTERLY POSSIBLE**.



It is in our nature as humans to have a better feeling about ourselves when we are engaged in useful tasks. Your loved one is also able to pursue their life goals, a journey that has a significant impact on their recovery. **WORKING IMPROVES THEIR SELF-CONFIDENCE AND GIVES THEM A SENSE OF BELONGING, INCREASING AT THE SAME TIME THE QUALITY OF THEIR LIFE**.

When looking for a job, one of the major impediments in the case of people with schizophrenia is not having a clear idea of where to begin. Many of them possess minimal to no work experience at all and are not able to make out the nature of work they would be capable of pursuing. Therefore, it is very important to make sense of what they excel at by observing their **PERSONAL QUALITIES** and also to have a good understanding of the current job market prior to the job hunt.

However, most individuals with schizophrenia have the willingness and ability to flourish in their workplace if they find a job that matches their interests, acknowledges their strengths and skills, and is accommodating to them. **LIVING WITH SCHIZOPHRENIA DOES NOT IMPLY THE IMPOSSIBILITY OF HAVING A CAREER OR SUCCESSFUL LIFE.** As long as there is a positive treatment response, it is highly probable that people can accomplish whatever it is that they aspire to.

Assist with therapy and progress tracking

A person with schizophrenia will almost certainly be recommended prescription medication. As a caregiver, you may find yourself involved in tasks that include:

- picking up prescriptions;
- keeping a record of the use of medication;
- paying attention to side effects and reporting these to the doctor or psychiatrist;
- encouraging your loved one to take their medication at regular intervals;
- using a preplanned schedule to keep track of the medication use;
- encouraging the use of a pillbox or timer;
- assisting with long-acting injection type medication;
- consulting with the doctor regarding possible drug interactions;
- keeping a register of which medications and supplements are being taken;
- taking care that other substances, such as drugs or alcohol are not combined with the medication;
- keeping notes of medication to assess which one is personally more effective;
- keeping track of why some of the medications were changed.

TAKE SIDE EFFECTS SERIOUSLY. After noticing side effects, a vast number of individuals with schizophrenia quit taking their medication. A better alternative would be to bring up the undesired side effects to the doctor's attention, who can either reduce the dose, prescribe a different antipsychotic, or add another medication to combat specific side effects.

ENCOURAGE YOUR LOVED ONE TO TAKE MEDICATION REGULARLY. Even if the side effects are controlled, individuals with schizophrenia may reject their medication or simply find it difficult to remember when and how much of it to take. In such cases, they might find it helpful to install medication reminder apps, make use of weekly pillboxes and keep calendars on hand.

BE CAREFUL TO AVOID DRUG INTERACTIONS.

In order to prevent your loved one from any harmful drug interactions, present the doctor with a full list of drugs and supplements that they take. Combining schizophrenia medication with either alcohol or illegal drugs can cause serious harm.

In case the person you take care of has a problem with abusing substances, it is important to inform the doctor about it.

TRACK YOUR FAMILY MEMBER'S PROGRESS.

A good way to monitor the changes in behaviour and other symptoms your family member experiences as a result of taking medication are mood tracking apps, journal entries, and keeping a diary.

Your loved one may also attend cognitive behavioural therapy or social skills training. Your responsibility as the caregiver could be assisting them with their commute to therapy, ensuring they keep their therapy ongoing, or helping them with homework tasks. When **KEEPING TRACK** of your loved one's adherence to treatment and their overall progress, it is easy to become overprotective. Make sure you **RESPECT THEIR PRIVACY AND PERSONAL BOUNDARIES**. By giving them responsibilities (e.g., to take their medicine every day at the specified time), you are empowering and motivating them, providing a sense of purpose in their life.

MOOD TRACKER MOOD TRACKER

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
J																															
F																															
M																															
A																															
M																															
J																															
J																															
A																															
S																															
O																															
N																															
D																															

🟥 angry
🟨 happy
🟧 productive
🟦 sad
🟪 nervous
🟩 sick
⬜ tired

Staying on track with medication

Ensuring that an ill person takes their medication regularly and consistently is called **"COMPLIANCE"** or **"ADHERENCE"**.* Although it doesn't seem too difficult, compliance is actually one of the most challenging factors for long-term treatment in any type of illness.

In schizophrenia, the problem of non-compliance is significant: only **58%** of patients collect their medication in the first **30 DAYS** after hospital discharge, and only **46%** continue their initial treatment for **30 DAYS** or longer. This high rate of non-compliance can be explained by poor insight into the illness, cognitive problems, side effects, and substance abuse associated with schizophrenia. Stressful events that turn their lives upside down for long periods of time, such as the recent COVID pandemic and the restrictions that came with it, can also make it more difficult for them to take their medicine consistently or attend therapy appointments. Also, many people with schizophrenia do not recognize they are ill; hence they don't understand why they need medication. Figuring out the appropriate dose or combination is usually **TIME-CONSUMING**, and it's a difficult process that can lead persons with schizophrenia to abandon treatment altogether.

---

* You may hear both terms in conversations with the doctor treating your loved one. Although they mean roughly the same thing, "compliance" is a term associated more with following instructions, while "adherence" denotes a more active involvement, from both you and the person you care for.

Being compliant, not just with medication but the entire treatment plan is very important for overall success. As a caregiver, one of your **MAIN RESPONSIBILITIES IS MAKING SURE THAT THE PERSON YOU CARE FOR**:

- takes medication consistently;
- attends appointments on a regular basis;
- engages themselves in counseling and group therapy;
- informs the doctor about their experiences;
- asks for help from their support group if in need;
- has patience with themselves as well as their providers;
- reminds himself/herself that they are on a journey.

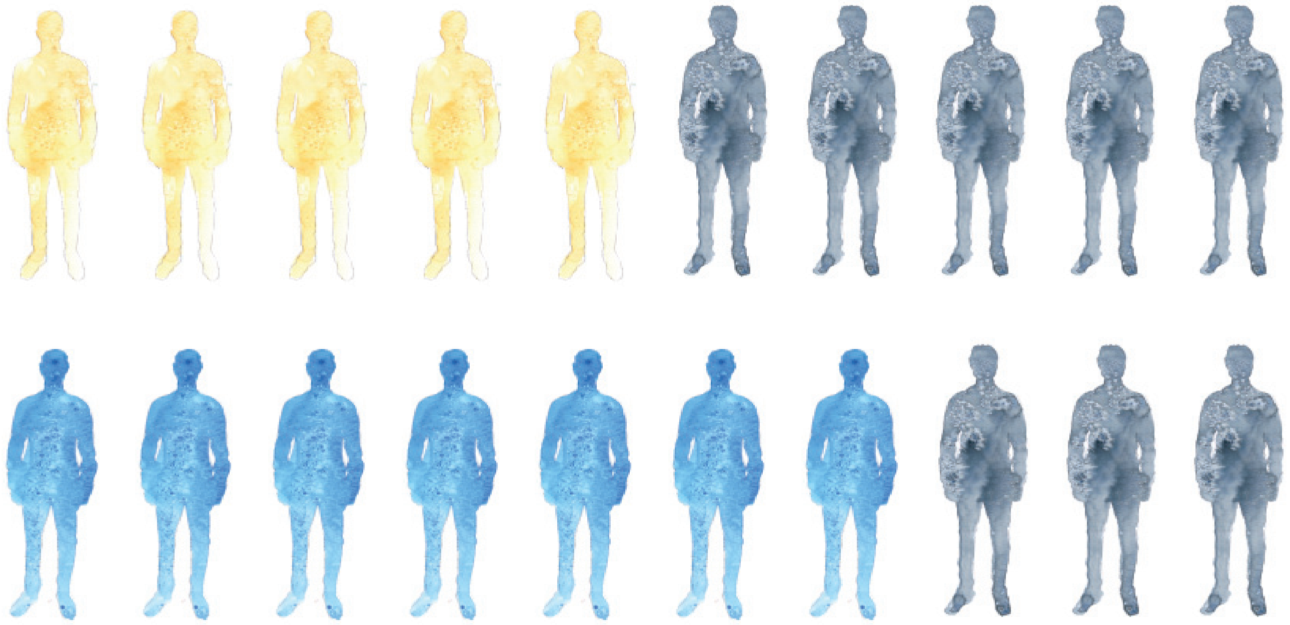
If you find out that your loved one has trouble keeping up with their medication, try to find the cause behind their non-compliance. Are they feeling better and think the treatment is not needed anymore? Do they think the treatment doesn't work? Are they concerned about the side effects? Or is it because of a lack of routine? Make medicine-related decisions with your relative's doctor or the care team that is caring for him or her. In this manner, you can all build a trusting environment in which your loved one feels comfortable sharing how and what they are feeling.

When a person with schizophrenia stops taking their medication, there is a **VERY HIGH RISK OF A RELAPSE**. This involves the return of psychotic symptoms, and the sudden interruption of treatment might cause significant adverse effects such as headaches, depression, anxiety, and suicidal thoughts. Talk to the doctor treating your loved one if you see they are thinking about or have already stopped taking their medication.

Tackle substance abuse and addiction

Individuals living with schizophrenia may experience a lot of **LONELINESS**, **DEPRESSION**, and **FRUSTRATION** due to the fact that their feelings and actions differ from those of others. Stress, anxiety, and prolonged isolation, characteristics of the recent coronavirus pandemic, may accentuate these feelings and their impact on your loved one's quality of life. In these circumstances, it is somewhat understandable that they try to find relief in substances that **CAN LEAD TO ADDICTION**. These can include anything from alcohol and nicotine to coffee, energy drinks, and drugs. Some of these substances, such as alcohol or marijuana, alleviate boredom and make it easier to forget about the illness for a short period of time, but cause hangovers or paranoid thoughts the following day. Others, such as coffee and energy drinks, are often used to overcome negative symptoms and sleepiness during the day, but **CAN ALSO CAUSE INSOMNIA**, leading to a vicious circle.

Statistical data suggest that around half of people with schizophrenia suffer from alcohol and drug dependency, while over **70%** of them have nicotine dependence.



An important thing to note is that there is a **DIFFERENCE BETWEEN ABUSE AND ADDICTION**. When the use of a substance interferes with work and social relations, affects the user's health, or causes danger, we are talking about substance abuse. When the substance causes physical dependency, and the user has difficulties controlling its use, we are talking about addiction.

The impact of substance abuse is substantial, both on the user and their family. Alcohol and drugs worsen the symptoms of schizophrenia and increase the risk of a relapse. The use of these substances also interferes with their daily activities, generates conflicts in their relationships, and can get them into trouble with the law. Family members usually find it very difficult to accept that their loved one does not have any control over alcohol or drugs, and they are faced with feelings of frustration, anger, helplessness, and despair. They may also feel increased fear and insecurity, as substance abuse can lead people with schizophrenia to become hostile, withdraw socially, or even attempt suicide.

It is essential that you try to **UNDERSTAND** the cause and approach them with deep understanding and compassion because substance abuse is usually a sign of suffering. They are not doing it because they are a bad person or because they are trying to hurt you or themselves. They are doing it because they are **TRYING TO FIND AN ESCAPE**, a way to alleviate their anxiety and depression. However, these substances provide only short-term relief, and the addiction adds to their stigma and suffering.

Overcoming addiction is a gradual, complex process that requires acknowledging the problem, motivation, behaviour changes, and help in achieving a healthier lifestyle. You can have a significant role in this process by empowering your loved one and providing them with a sense of purpose.

Talk to the doctor in charge of the treatment if you think your loved one is struggling with substance abuse or addiction. In severe cases, detoxification or hospital admission may be needed to get your loved one back on track.

What to do in different phases of the disease

The manifestations of schizophrenia can be markedly different in different phases of the disease and different approaches are required from you as well.

The active phase

The active phase, more specifically a psychotic episode, can cause a lot of stress and confusion for both you and your loved one. Due to the variety of symptoms, **THERE ARE NO GOLDEN RULES IN THIS PERIOD**. The most important thing you can do is try to **UNDERSTAND** what your loved one may be experiencing.

The hallucinations and delusions are very real to them. Do not get involved in long debates trying to convince them of the contrary, because this will make them feel like they cannot tell you what they are going through. **USE EMPATHY**, not arguments.

Show your concern while steering clear from confrontations and restraining from being critical of or putting the blame on them. Remember that most of what you see in this period is a **MANIFESTATION OF THE DISEASE**. Just listen and let them know that you understand that they must experience a lot of fear, frustration, and anger. Try to minimize their stress and provide a peaceful atmosphere that can help them recover.

When your loved one is experiencing hallucinations and delusions, they may need a lot of personal space and may feel uncomfortable being around other people. Usually, the positive symptoms do not stop suddenly, even with proper treatment. In this period, you may feel that you need to let them rest and do everything yourself. However, keep in mind that **REBUILDING THEIR CONFIDENCE** is very important for recovery. Encourage and support your loved one as they take on daily responsibilities, and let them know that you are there for them when they need help.

The residual phase

After a psychotic episode, your loved one may need a **QUIET PLACE AND A LOT OF REST**. The transition to a state where the symptoms are mostly subdued can be shorter or longer; some people can get back to their usual routine fairly quickly, others need considerable time and effort to do so. During this time, it may be difficult for the family to cope with negative symptoms such as avolition or anhedonia. As mentioned before, it is important to remember that **THEY ARE PART OF THE ILLNESS** and do not mean that the person you take care of is unwilling to get better.

With proper treatment, **YOUR LOVED ONE WILL BE ABLE TO START TO TAKE ON MORE RESPONSIBILITIES**. It is important to **START SLOW** and let them ease into them at their own pace. You can start with tasks related to personal hygiene, getting dressed, or doing household chores. With time, you can start to encourage social interactions, for example by inviting one or two friends over for dinner.
DO NOT FORCE your loved one to participate if they do not want to, and always make sure to provide a possibility to tone things down if they become anxious. You can also initiate going out for a walk in a quiet part of the city or spending some quality time listening to music or playing cards.

Remember that you are the person that your loved one spends most of their time with and their closest ally in their battle with schizophrenia. Respect, patience, and compassion will be remarkably valuable at helping both of you be in control of the illness and starting to live life to its full potential once again.

How to communicate with your loved one

Communication is an essential part of human relationships, especially when family is concerned. Schizophrenia can make it **DIFFICULT TO COMMUNICATE** with your loved one, posing a set of very specific challenges. These challenges **CAN BE OVERCOME**, however, by understanding how the illness impedes your loved one's ability to communicate. Basically, almost all manifestations of schizophrenia can lead to difficulties in communication: cognitive dysfunction can make it hard for them to focus or remember what you were talking about; hallucinations and delusions change their reality and can make any attempt of inserting logic into the conversation futile; negative symptoms, such as flat affect or apathy, can make it difficult for you to interpret their emotions.

Good communication is very important in a chronic mental illness where all family members must work together to minimize the symptoms. You can **IMPROVE COMMUNICATION** with your loved one by abiding by a few simple rules:

Really listen.
If your loved one opens up, listen actively, really paying attention to what they have to say. Give them time to finish their thoughts, even if it takes longer than usual. Do not force them to talk if they do not want to. It is important to respect their boundaries and let them come to you when they are ready.

Keep the conversation simple.
When talking with your loved one, keep it simple by speaking calmly and clearly. The illness can make it difficult for them to maintain focus during long, elaborate conversations.

Turn your emotions into words.
People with schizophrenia often have difficulties interpreting other people's emotions, not taking into consideration subtle variations in facial expressions or tone of voice. By turning your emotions, both positive and negative, into words, you can lower the risk of misunderstandings and unnecessary tension.

Give positive feedback.
People with schizophrenia often consider themselves worthless. It can be very helpful for them to know that they did something good or they made you proud. Positive feedback can strengthen their confidence and motivate them to be more independent.

Double-check whether you understood them correctly.
If your loved one has a reduced ability to express emotions and to speak, they may have difficulties expressing themselves. In these situations, it is better to pay attention, ask questions, and rephrase what your loved one has told you, asking them to confirm if you understood them correctly.

Good communication will **REDUCE YOUR LOVED ONE'S STRESS**, leading to better treatment outcomes and a lower risk of relapse. It will also lower the stress among the family members, will improve family relationships, and will reduce the risk of burnout.

Talking about your own emotions

As the caregiver of a person with schizophrenia, you may be burdened with feeling **UNCERTAIN**, **SHAMEFUL**, **GUILTY**, and **ANGRY**. Similarly to the person you are taking care of, you may feel stigmatized and socially isolated. Also, having the role of a caregiver on top of your existing roles in the family may provide additional stress, both psychologically and economically.

From your position, it is natural for stress to lead to negative attitudes and behaviours towards your loved one, such as aggression and cynical comments, and you may even get over-involved in their life. These attitudes and behaviours are collectively known as **EXPRESSED EMOTION** and **CAN HAVE A NEGATIVE IMPACT** on your loved one's illness. People with schizophrenia who live in family circles with high levels of expressed emotion have a higher risk of relapsing.

You can avoid letting your stress and tiredness take a toll on your relationship by **TALKING ABOUT YOUR FEELINGS** with the person you care for. As we've mentioned before, expressing your emotions is very important in coming to terms with the illness and can have significant benefits for both of you. Let them know that **YOU ALSO NEED SYMPATHY AND EMPATHY**. Rather than making accusations and leaving them with the feeling that they are a burden, talk about your emotional needs.

Ease the emotional impact of schizophrenia

Set goals and celebrate success

Creating a plan that will help your loved one on their journey to recovery also means holding on to some clear goals to **GUIDE** both of you along the way. Some of these goals **CAN BE SMALL**, like getting your loved one to take their medication each day. Other goals **CAN BE BIG**, like continuing school or getting a job. When setting these goals, it is very important to calibrate your expectations based on how severe the symptoms are and at what stage the disease is. You also have to be aware of your own limitations. **CAREGIVING IS LIKE RUNNING A MARATHON**: giving your all in the first few miles will quickly lead to exhaustion and will force you to give up the race.

Set these goals together with your loved one, and celebrate success each time you reach a goal. It will boost your motivation and will make it easier to keep the next goal in sight. **CELEBRATING SMALL WINS** will also help you achieve the bigger goals and will give you both energy to continue your journey.

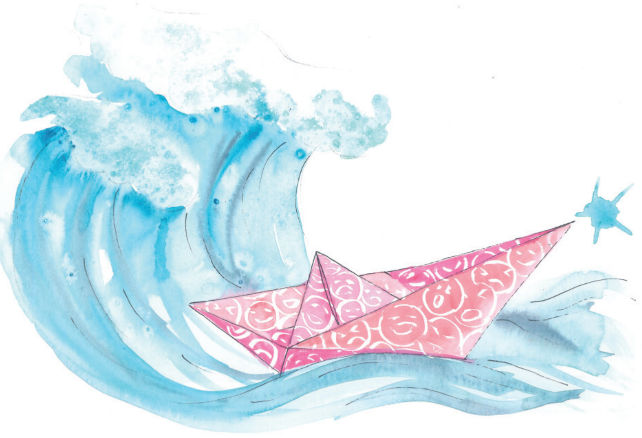
Make decisions together

Although the disease often causes chaos in their minds and interferes with their ability to make decisions, **PEOPLE WITH SCHIZOPHRENIA ARE NOT INCAPABLE**. However, they often have low self-esteem and do not consider themselves worthy of anyone's attention. Involving them in the decision-making process can **ENHANCE THEIR AUTONOMY AND EMPOWER THEM** to participate more actively in their treatment.

Make all kinds of decisions together, small and major, from what to eat or what movie to see, to developing a daily routine or discussing how their treatment is coming along. Making decisions together is a process of mutual acceptance and shared responsibility that places you and your loved one on the same level, making them feel **IMPORTANT AND RESPECTED**.

Deal with your loved one's emotions

For people with schizophrenia, the illness can be an **EMOTIONAL ROLLERCOASTER**. The abundance of negative emotions makes them feel less human, adds to their burden, and increases self-stigmatization. As the disease changes certain processes in the brain, they find their environment to be habitually **OVERWHELMING**, their thinking may be **OUT OF ORDER**, and they may have **DIFFICULTIES IN EXPRESSING THEIR EMOTIONS**. The latter is actually one of the most debilitating and treatment-resistant symptoms of schizophrenia. One of the most important ways you can cope is to continue to **GAIN KNOWLEDGE** regarding the condition, as well as what experiences your loved one will face.



Relapse and crisis

The course of schizophrenia is usually **EPISODIC**, with symptoms of varying severity. When your loved one's symptoms **WORSEN AFTER A PERIOD OF FEELING BETTER**, it is called a "relapse". The majority of people with schizophrenia experience multiple relapses during the course of the illness. As a caregiver, you have a very important role in **WATCHING FOR THE EARLY WARNING SIGNS**. This process is similar to setting up a light connected to a motion detector. If you set the detector's sensitivity too high, the light turns on even when you don't need it, wasting energy. If you set it too low, the light does not turn on when you need it, and you have to walk in the dark. Watching out for relapse is about calibrating your **"EMOTIONAL DETECTOR"** to find the right **BALANCE** between being overprotective and not paying enough attention to the warning signs.

A person with schizophrenia will usually show similar signs before each episode of psychosis. Thus, the symptoms and events that occur during the first episode can significantly help you in identifying specific signs in the days or weeks before the relapse. Knowing how to **IDENTIFY A RELAPSE** and what to do in a crisis will give you a **SENSE OF CONTROL** and will help you in overcoming this stressful period.

How to identify a relapse

The discontinuation of taking medication is the most common factor for relapses in schizophrenia, therefore, it is crucial that your loved one carries on with **TAKING THEIR MEDICATION AS INSTRUCTED**. Despite the fact that relapses may take place even in the event of compliance with prescribed medication, recognizing early warning signs and taking instant action may help you counteract a full-blown crisis.

Frequent warning signs of schizophrenia relapse include:

- irritability;
- nervousness;
- restlessness;
- sleep disturbances;

- loss of interests;
- narrowing of interests;
- loss of joy;
- sudden refusal to take medication;

- difficulty concentrating;
- loss of appetite;
- change in eating or drinking habits;
- social withdrawal;

- decreasing insight into illness;
- a sudden increase in religiosity;
- increasing conflicts with others;
- obsessive thoughts;

- neglection of physical appearance;
- changes in daily routine;
- decline in performance at work or in education;
- depressive moods;

- aggressiveness;
- auditory and other hallucinations of short duration;
- the feeling of being controlled;
- fear of going crazy.

IMPORTANT NOTE!

IT IS NOT NECESSARY FOR ANY OF THESE SIGNS TO INDICATE THE BEGINNING OF A PSYCHOTIC EPISODE, due to the fact that some may be associated with physical illness, work or school-related stress and pressure, or issues with important relationships. Moreover, these signs do not necessarily occur at once; they usually appear over a course of several days or weeks, or they are not present at all. **SMALL CHANGES IN THINKING, MOOD, OR BEHAVIOUR MAY OFTEN GO UNNOTICED** or seem insignificant, being recognized as warning signs only after the relapse had taken place. Also, you may notice other signs that are not on this list. In time, you will be able to compile **YOUR OWN LIST BASED ON THE SIGNS YOU OBSERVE** together with your loved one, and you can learn together how to recognize an impending relapse.

The main goal of looking for warning signs is to act quickly in order to **PREVENT RELAPSE AND AVOID HOSPITALIZATION**. If you observe several of the signs listed above, try to find the cause. Has your loved one been taking their medication regularly? Have they been recently using alcohol or drugs? Have they experienced high levels of stress lately? Are they eating, sleeping, and exercising properly? If none of these factors can be accounted for, consult with their doctor whether their medication dose should be increased. In any case, follow the warning signs closely, even after you have taken measures until you can see clear improvement.

If the warning signs do not regress shortly or if they get more prominent as time passes, call the doctor treating your loved one.

How to prepare for crises

Even when you do everything possible to avoid a relapse, there may be occasions where the condition of the person you care for declines quickly, and hospitalization is needed to ensure they are safe and treated optimally. A pre-arranged emergency plan may help with handling a crisis in a safe and swift manner in the case of an acute psychotic episode.

An adequate emergency plan for someone living with schizophrenia may involve several or all of the following items:

- phone numbers of the therapist, psychiatrist, and other healthcare providers treating your loved one;
- the phone number and address of the hospital mapped out for psychiatric admission;
- phone numbers of who would be helpful in a crisis, such as family members or friends;
- addresses of emergency rooms or walk-in crisis centers;
- your own contact details such as phone number and address;
- the diagnosis and medications of the person you care for;
- known triggers;
- known early warning signs;

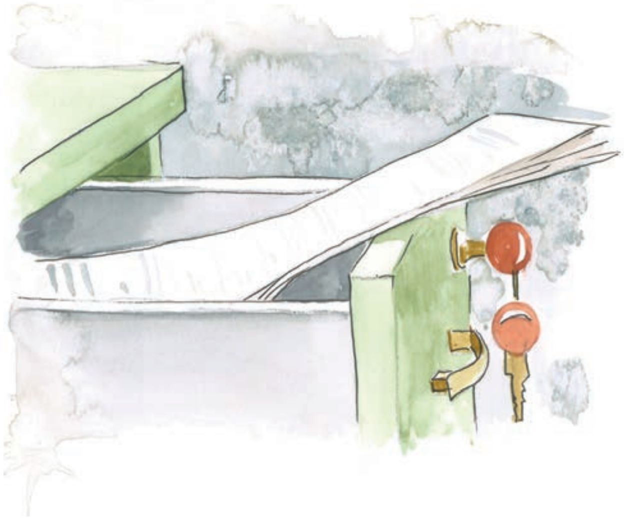
- history of drug use;
- previous psychoses or suicide attempts;
- things that have helped in the past;
- a plan on how to deal with acute psychosis;
- a plan to get them help.

You can add or remove items from this list based on your own experience.

Together with your family, you can also create a more specific plan based on your loved one's symptoms and disease course. This plan should be individualized as much as possible, and everyone involved should feel comfortable with it. In this plan, you can specify what kind of signs to watch out for, who will contact whom and when, and for what purpose.

DISCUSS THE EMERGENCY PLAN with the person you care for and the doctor involved in their treatment. It is very important to discuss the plan with your loved one at times **WHEN THEY ARE NOT IN A STATE OF CRISIS**. This would ameliorate the feeling of threat in case you do encounter such situations. Make sure to obtain their permission to call the doctor or do whatever is necessary to keep the crisis under control. Also, make sure you obtain a so-called **RELEASE FROM SECRECY** while their condition is stable. This document enables your loved one's doctor to share important information with you in case of an emergency. For more information, please see the **LEGAL ASPECTS SECTION** at the end of the chapter.

KEEP COPIES of the plan in multiple locations. Keep a print in a kitchen drawer, the glove compartment, your smartphone, your wallet, or on your bedside table. In the event of a psychotic episode, your loved one's symptoms may make it difficult for them to understand that you want to help, and they may feel threatened or even become violent. For these situations, keep a copy of the plan in a room that has a lock and a phone. This will enable you to contact your doctor in a safe environment.



How to handle a schizophrenia crisis

As a person taking care of someone with schizophrenia, it is essential to be aware of **WHAT YOU CAN DO IN CASE OF A CRISIS**. Below are several tips on what to do in this situation:

- Remain calm.
- Remember that what you see during a crisis is not your loved one, but the acute manifestation of a severe illness.
- Remember that you cannot reason with acute psychosis.
- Remember that your loved one may be frightened by the feelings they experience or by the inability to be in control.
- Reduce distractions by switching off the TV, PC, bright lights that might emit sounds, etc. Request that any casual visitors make their way out; the fewer people are present the better.
- Take a seat and ask them to do the same.
- Avoid direct, continuous eye contact.
- Avoid touching your loved one.
- Speak in a low voice and a calm manner, avoid shouting or threatening them.
- Validate their fears.
- Do not argue about their delusions.
- In case you feel irritated or angry, avoid making these feelings obvious.
- Abstain from sarcasm as a weapon.
- Gently redirect the conversation to safe topics.
- Contact the doctor treating your loved one.

What to do when your loved one intends to hurt themselves

Although it can be frightening to think about your loved one hurting themselves, you have to be aware that people with schizophrenia have an **INCREASED POTENTIAL** for depression and suicidal thoughts. As such, you need to take very seriously any gestures and threats that may appear related to self-harm. **SUICIDAL IDEATIONS**, also known as thoughts or comments about suicide, may appear minor initially, such as "I wish I was not here" or "Nothing matters". However, as time passes, they may progress and become evident and dangerous. There are several **SIGNS THAT MAY INDICATE THAT YOUR LOVED ONE HAS SUICIDAL THOUGHTS**: severe depression, the feeling that nothing has meaning or value anymore, or a bleak outlook into the future. Hallucinations are also often associated with suicidal thoughts, especially if there are voices telling your loved one to hurt themselves. **TAKE IT SERIOUSLY EVERY TIME** your loved one mentions death or suicide, even if it is only a passing reference or a joke. In case of a suicide-related crisis occurrence, family members and friends are frequently taken by surprise, being unprepared and not certain of what to do. Individuals experiencing a crisis may act unpredictably, with striking changes in their actions. The following tips can help you in handling a suicide crisis:

- Keep calm and practice patience.
- Communicate in an open and honest manner. Don't hesitate from asking direct questions like: "Do you have a plan for how you would kill yourself?"
- Remove any items from their environment that they would use to hurt themselves such as knives, guns, or pills.
- Ask short and direct questions in a peaceful manner, such as "Can I help you call your psychiatrist?"
- In the case of several people surrounding them, only let one of them speak at a time.
- Convey your concern and support.
- Don't argue, threaten them or speak in a different tone.
- Do not dispute the idea of the rectitude of suicide.

Let your loved one know that they are able to discuss what they are going through with you if they struggle with suicidal ideation. Ensure that they have an **OPEN AND COMPASSIONATE APPROACH** when they talk to you. Rather than proving their negative statements wrong, try to **ACTIVELY LISTEN TO THEM**, be reflective about their feelings and provide them with an overview of their thoughts. By doing this, you can help your loved one feel like they are listened to and validated.

Don't let fear prevent you from talking to them about how they feel, whether they feel safe or if they experience thoughts related to self-harm. **HAVING A CONVERSATION ABOUT SUICIDE DOES NOT MAKE IT MORE LIKELY TO HAPPEN**; it lets your loved one know that you care about them and makes prevention actions possible. Remind them that mental health professionals have training in how to provide help with understanding their feelings and improving their mental well-being. More importantly, let them know that suicidal thoughts are part of the disease; **THEY ARE A SYMPTOM**, and similarly to other symptoms, **THEY CAN GRADUALLY IMPROVE WITH TREATMENT**.

Address medical and/or healthcare professionals for assistance right away in case you think your loved one could harm themselves. Although you may feel that you are betraying their confidence by sharing their innermost thoughts, it is more important to **ACT IN THEIR BEST INTEREST** and **SHARE THE INFORMATION** with a healthcare professional.

If you are unsure about when to call the doctor, **DO IT SOONER RATHER THAN LATER**. Talk to a healthcare professional even when there is only ideation. Whenever there is a crisis, involve the doctor treating your loved one and discuss how to handle the situation. They will know how to assess the risk of your loved one hurting themselves. Similar to a psychotic episode, make sure to obtain a release from secrecy for the doctor before the actual crisis occurs.

At the doctor's office

Even if it appears uncomfortable from time to time, **EFFICIENT COMMUNICATION BETWEEN THE DOCTOR, THE PERSON WITH SCHIZOPHRENIA, AND YOU - THE CAREGIVER IS VERY IMPORTANT**. Accompany your loved one to their appointments. Receiving information directly and in-person is favorable as it lets you know what to expect and how to prepare for it.

Keep in mind, however, that there is a chance your loved one may prefer you not to come with them, particularly during the initial few visits. It is important to **RESPECT THEIR WISHES**, however, in case things change make sure to be there for them. It is essential to de-

velop **A TRUSTFUL ATMOSPHERE** that will make everyone's job much easier.

When face-to-face visits are not possible, you can use phone calls, emails, or video chat to discuss with the doctor treating your loved one. The COVID-19 pandemic has greatly increased the popularity of **TELEMEDICINE** because it allowed patients to consult their doctor without leaving their house and becoming exposed to the coronavirus. With the exception of acute or severe cases, telemedicine is invaluable in ensuring the continuity of care.

As the caregiver of your loved one, you have significant insight to share. **DO NOT BE AFRAID TO RAISE CONCERNS, ASK QUESTIONS**, and **BE OPEN** about discussing all the options out there.

How to prepare for an appointment

In preparation for the appointment, comprise a list of the following:

- the symptoms experienced by your loved one, even if seemingly unrelated to the appointment matter;
- essential personal information, taking into account considerable stresses and current life changes;
- the medications they are taking, as well as vitamins and supplements, including the dosages; also include information on which medication worked and which didn't. If a medication was changed recently, include the reason for changing it;
- information regarding substance abuse, addiction issues, or recent lifestyle changes;
- questions to ask the doctor.

Enter your and your loved one's ups and downs regularly in a diary. Based on the things you note in this diary, write down the answers to the following questions before your appointment:

- How do you feel about the overall management of their condition?
- Does your loved one achieve the expected results from the prescribed treatment?
- What is their opinion on their progress through this journey?
- What effects does their medication have on them, and do they experience any side effects?
- Do they take their medication as prescribed, and do you think they ever say they have taken it when they haven't?
- Do they ever stop taking their medication when they feel better/ill?

What to ask the doctor

Some basic questions to ask the doctor include:

- What treatment options are there?
- What can we anticipate short and long-term (symptoms as well as possible medication effects and related side effects)?
- What available support and services can we make use of?
- How can I make myself as supportive and helpful as possible?
- Have you got any leaflets or other printed resources you could give me?
- Are there any online resources that you would suggest?

DO NOT HOLD BACK FROM ASKING ANY OTHER QUESTIONS regarding your loved one's symptoms, treatment, challenges, or overall progress. **BE AS SPECIFIC AS POSSIBLE**. The doctor may also inquire information regarding the symptoms displayed by your loved one, daily functioning, and response to therapy. Getting involved in the conversation will make it much easier for both of you to ensure your loved one is on the right path to recovery.

Financial, legal, and housing-related aspects

Financial aspects

People with schizophrenia often have a reduced ability to function independently in the community. As a consequence, **THEIR FINANCIAL CAPACITY** – the ability to manage their own money and financial affairs – **CAN ALSO BE REDUCED**. The reasons are pretty straightforward: often, the onset of schizophrenia occurs at such an early stage in their life, that many of them simply do not have the chance to acquire basic financial skills and experiences. The unfavorable consequences of positive and negative symptoms, as well as the cognitive disturbances associated with the disease also hamper this process.

The reduced financial capacity of people with schizophrenia **CAN HAVE A NEGATIVE IMPACT** on their well-being, creating barriers to recovery, and also on their family relationships. The repercussions differ to a great extent depending on the person. It may include a decreased ability to earn an income, being incautious with their money, or being susceptible to being used for their funds by their own acquaintances or family members. In severe cases, the consequences can be devastating, leading to malnutrition, substance abuse, and even homelessness. People with schizophrenia can spend large amounts of money on addictive substances and many of them dissipate their monthly aids intended to support themselves. As a result, **MONEY MISMANAGEMENT IS A KEY CONCERN** for their family members.

When a person with a severe mental illness is deemed unable to be in financial control, they may be restricted from having access to their finances. For some, this may mean that a power of attorney is arranged. For more information on power of attorney, **PLEASE SEE THE LEGAL ASPECTS SECTION** below. It may be necessary to appoint someone else to **REPRESENT THE PAYEE** if the payee's income comes from disability benefits. Payees receive the disability benefits instead of the person with a mental illness and ensure that their needs are fulfilled, including those for nutrition, housing, and medication bills. In most cases, the payee of someone living with a severe mental illness is a family member.

Having a payee has **NUMEROUS BENEFITS** for people with schizophrenia, such as more stable circumstances, reduced or no consumption of alcohol, drugs, and other damaging substances, and even a constant pace with respect to therapy.

Payee arrangements are also **ASSOCIATED WITH REDUCED HOSPITALIZATION AND HOMELESSNESS**, as well as increased adherence to treatment. However, this kind of relationship has also **DRAWBACKS**. Since people with schizophrenia are usually less motivated to seek employment when receiving disability benefits, not having control over their own money can further increase their dependency. Having someone else control their money can also lead to **CONFLICTS**, money affairs being one of the main causes of disagreements within the family. People with severe mental illnesses are more inclined to display aggression towards their caregiver in cases where the latter is in control of their finances. Conflicts can also arise when the person with a mental illness feels that the payee has too much control or that spending decisions were forced on them.

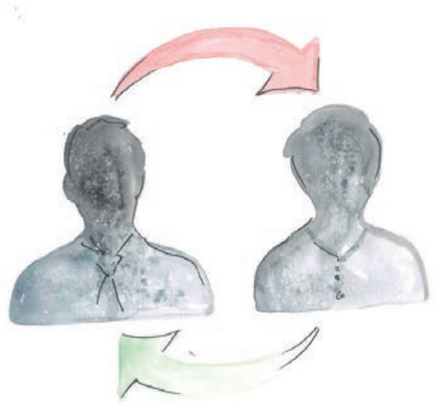
Even if you are not formally appointed as a payee, your responsibilities as a caregiver may include taking care of your loved one's finances.

Depending on their condition, you can **TEACH THEM SOME BASIC FINANCIAL SKILLS**, such as how to set up a budget or how to save money, which will help them become more independent in the long term.

Legal aspects

There are several different legal aspects that might come up in your relationship with the person you care for, depending on the severity of the disease and the extent to which it limits their capacities.

GUARDIANSHIP. Guardianship can be defined as the legal process used to certify that individuals incapable of making decisions by themselves have someone explicitly assigned to make these decisions in their name. The person who has an assigned guardian is called a **"WARD"**. A guardian has the responsibility of offering the ward care and comfort; **THE COURT IS LIABLE FOR ADJUSTING THE GUARDIAN'S POWERS BASED ON THE WARD'S DISPLAYED NEEDS**. Additionally, in order for the ward to revert to caring for themselves at the earliest opportunity, the guardian shall secure services in support of that. The ward is entitled to oppose the guardianship, the guardian's powers, and the appointment of a certain guardian.



ENSURING CONTINUITY OF CARE. Although it can be an awkward or uncomfortable subject, once you have become the caregiver of a person with a chronic mental illness, you should start thinking about **WHO WILL TAKE OVER YOUR CAREGIVER DUTIES WHEN YOU GET SICK, GROW OLD, OR DIE**. Consult with an attorney and make sure to prepare the legal documents in time. It is important to note that the decision regarding your replacement is yours only if you have guardianship over the person you take care of. Otherwise, you both have equal rights, and your loved one can also make this decision. Even if you are not a guardian, thinking about who can replace you should be a natural step in your relationship.

DECISION-MAKING CAPACITY. This capability may be characterized as one's ability to make reasonable judgments, which necessitates the acknowledgement, evaluation, and interpretation of data. Because of their impaired cognitive functioning, **PEOPLE WITH SCHIZOPHRENIA MAY BE LESS ABLE TO MAKE TREATMENT DECISIONS**.

RELEASE FROM SECRECY. In most countries, medical professionals are bound to secrecy. This means that they cannot share information about their patients or their condition with other individuals, not even to the family members of the patients. When you are the caregiver of a person with schizophrenia, **THE PERSON CAN SIGN A DOCUMENT THAT RELEASES THE DOCTOR FROM THE BOUNDS OF CONFIDENTIALITY AND ALLOWS THEM TO SHARE INFORMATION WITH YOU**, the caregiver, in the event of an emergency.

POWER OF ATTORNEY. A power of attorney is a legal instrument that authorizes another person (Attorney) whom the person with schizophrenia trusts to **MANAGE THEIR FINANCES WHEN THEY CANNOT DO IT INDEPENDENTLY**. This agreement might specify who will be in control of their money and how much power they will have (e.g., their personal bank accounts access or the ability to make payments on their debts).

Housing

Individuals with schizophrenia require a **RELIABLE LIVING SPACE**. The choice of place should depend on their ability to take care of themselves, as well as the necessary amount of supervision. Before taking a decision, try to answer the following questions:

- Is your loved one able to take care of themselves?
- How much support is needed to assist them with their daily activities?
- Does your loved one struggle with drug or alcohol dependence?
- How much supervision does your loved one need with their treatment?

Even when you can answer these questions clearly, making a decision about the living arrangements of your loved one **CAN BE A DAUNTING TASK**. It is normal to feel guilt when thinking about the possibility of placing them in an institution.

As we mentioned in the first chapters of this guidebook, the current trend in the treatment of persons with schizophrenia is to **KEEP THEM IN THE NURTURING ENVIRONMENT OF THEIR FAMILY AND TO REINTEGRATE THEM AS MUCH AS POSSIBLE INTO SOCIETY**. As such, the prospect of placing your loved one in an institution is rather the exception than the norm. However, in certain cases, there may be more benefits in treating them in a specialized facility.

Living with family is most successful in the following cases:

- The person with schizophrenia has high functionality levels, is able to sustain friendships, and engages in activities outside the home.
- The interaction between family members happens in a calm manner.
- Individuals with schizophrenia have the intent of using the available support services.
- There is not any negative impact on the life of young children living in the home.

Living with family is not recommended in the following cases:

- The main caregiver is themselves ill, single, or of old age.
- The individual's schizophrenia is critical and would impede an ordinary family life.
- The situation induces stress in the relationship or causes children to experience fear and resentfulness in their home.
- The majority of family events revolve around the member with schizophrenia.
- There are no support services available.

MAKE THE DECISION TOGETHER with your loved one and the medical team involved in their treatment. They can offer you advice regarding the specialized treatment facilities in your area.

References

1. Healthy Living: Organising Your Time [Internet]. Living With Schizophrenia. [cited 2021 May 8]. Available from: https://livingwithschizophreniauk.org/information-sheets/healthy-living-organising-your-time/

2. Clarke J. Living With Schizophrenia [Internet]. Verywell Mind. [cited 2021 Jun 16].

3. Budziszewska MD, Babiuch-Hall M, Wielebska K. Love and Romantic Relationships in the Voices of Patients Who Experience Psychosis: An Interpretive Phenomenological Analysis. Front Psychol [Internet]. 2020 [cited 2021 May 19];11. Available from: https://www.frontiersin.org/articles/10.3389/fpsyg.2020.570928/full

4. Hengeveld M. Job Hunting With Schizophrenia [Internet]. The Atlantic. 2015 [cited 2021 May 19]. Available from: https://www.theatlantic.com/business/archive/2015/07/job-hunting-with-schizophrenia/395936/

5. Rauh S. Working With Schizophrenia [Internet]. WebMD. [cited 2021 May 19]. Available from: https://www.webmd.com/schizophrenia/features/working-with-schizophrenia

6. Tiihonen J, Haukka J, Taylor M, Haddad PM, Patel MX, Korhonen P. A nationwide cohort study of oral and depot antipsychotics after first hospitalization for schizophrenia. Am J Psychiatry. 2011 Jun;168(6):603–9.

7. Brady KT, Sinha R. Co-occurring mental and substance use disorders: the neurobiological effects of chronic stress. Am J Psychiatry. 2005 Aug;162(8):1483–93.

8. Wright H. Caregiver and Schizophrenia: How to Handle the Psychosis [Internet]. Caregiver.com. 2017 [cited 2021 May 21]. Available from: https://caregiver.com/api/content/5f180622-35a6-11e7-8b89-0aea2a882f79/

9. Mueser KT, Gingerich S. The Complete Family Guide to Schizophrenia: Helping Your Loved One Get the Most Out of Life. New York: Guilford Press; 2006.

10. Birchwood M, Spencer E, McGovern D. Schizophrenia: early warning signs. Adv Psychiatr Treat. 2000 Mar;6(2):93–101.

11. Helping Someone with Schizophrenia - HelpGuide.org [Internet]. https://www.helpguide.org. [cited 2021 May 8]. Available from: https://www.helpguide.org/articles/mental-disorders/helping-someone-with-schizophrenia.htm

12. Risk of Suicide [Internet]. NAMI: National Alliance on Mental Illness. [cited 2021 May 17]. Available from: https://www.nami.org/About-Mental-Illness/Common-with-Mental-Illness/Risk-of-Suicide

13. Elbogen EB, Wilder C, Swartz MS, Swanson JW. Caregivers as Money Managers for Adults with Severe Mental Illness: How Treatment Providers Can Help. Acad Psychiatry. 2008 Mar 1;32(2):104–10.

7. Give yourself care, too

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 CAREGIVER**.

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 quarter 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 after 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 AFFECT YOU BOTH PHYSICALLY 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?

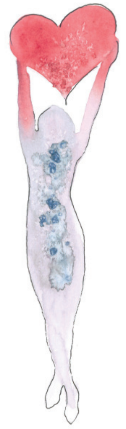
It is essential to be able to recognize the signs of **CAREGIVER BURNOUT** in order to act upon it right away and avoid its aggravation. This will **IMPROVE THE CIRCUMSTANCES** for you as well as the person you take care of. The following are an indication that you are experiencing caregiver burnout:

- 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.

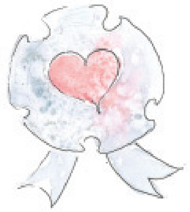
LOOK FOR THE SILVER LINING.

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.

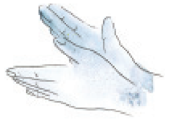
Because it's fairly easy to come to terms with a difficult situation when your other life areas are rewarding, it is of high importance to not saturate your whole life. Invest in the things which provide you with meaning and purpose, regardless of whether it's your family, church, a favorite hobby, or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

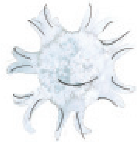


CELEBRATE THE SMALL VICTORIES. When you begin feeling downhearted, think back on all the great efforts you have put in and how much they mean. You are not required to treat the illness your loved one has in order to have an impact. Give yourself credit for how important it is that you offer your loved one safety, comfort, and love!

IMAGINE HOW YOUR LOVED ONE WOULD RESPOND IF THEY WERE HEALTHY. Provided your 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 yourself 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.

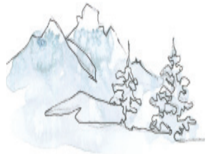


NOTICE THE POSITIVE. When you devote time to acknowledging the positive instances in your life, the way you experience that day can improve. Try to note down at least one thing, item, or event per day or week that you found good. Despite how big or small it is ("It was a sunny day."), it is real and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

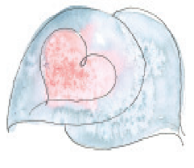
MAINTAIN YOUR SENSE OF HUMOR. Laughter is a great remedy for stress. Start reading a humorous book, watch comedies, or reach peers that make you laugh. If possible, aim at finding humor in mundane situations.

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.

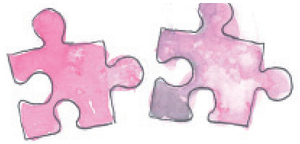
FIND WAYS TO PAMPER YOURSELF. Small rewards can relieve stress and boost your spirits. Take a soothing bath and light some candles. Get a relaxing massage. Decorate your house with fresh flowers. Anything that would make you feel special.



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 caregiver 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, self-help 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.

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.

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 SPECIFICALLY** how you feel and what your needs 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 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 long-term perspective. If you are able to see your friend once per month or attend local social events every couple of months, **IT ALREADY 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 FOCUS 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

1. Brain C, Kymes S, DiBenedetti DB, Brevig T, Velligan DI. Experiences, attitudes, and perceptions of caregivers of individuals with treatment-resistant schizophrenia: a qualitative study. BMC Psychiatry. 2018 Aug 13;18(1):253.

2. Smith M. Caregiver Stress and Burnout [Internet]. https://www.helpguide.org. [cited 2021 Apr 23]. Available from: https://www.helpguide.org/articles/stress/caregiver-stress-and-burnout.htm

8. Schizophrenia management in the aftermath of the COVID-19 pandemic

This chapter contains **USEFUL INFORMATION** regarding the COVID-19 pandemic, how it has affected people with schizophrenia, and what you can do as a caregiver to maintain your loved one's mental and physical health, alongside your own well-being given the recent pandemic we experienced, but also possible future pandemics, as well as in other similar situations.

A short history of the pandemic

At the end of **DECEMBER 2019**, the World Health Organization was alerted by Chinese authorities about a considerable amount of pneumonia cases with an undetermined cause in China's Wuhan city of Hubei province. On **JANUARY 5TH, 2020**, the cause of the mystery disease was identified as a new strain of coronavirus. In the following weeks, the virus spread to an increasing number of countries around the world. On **FEBRUARY 11TH, 2020**, the virus was named "severe acute respiratory syndrome coronavirus 2" (SARS-CoV-2), while the disease it produced was labelled as "coronavirus disease 2019" (COVID-19). On **MARCH 11TH, 2020**, the World Health Organization proclaimed the COVID-19 outbreak to be a global pandemic.

The most significant aspects of the current pandemic could be left behind in terms of affecting the health of the population and social constraints. The transition period could be a time of great challenges and difficulties for patients with pre-existing chronic diseases, including those suffering from mental illness.

The impact of COVID-19

The pandemic has **NEGATIVELY IMPACTED THE LIVES OF HUNDREDS OF MILLIONS OF PEOPLE** and has had a devastating effect on many aspects of our lives including the economy, employment, education, mobility, and family tradition. In most countries, it has stretched healthcare systems to their limit and has created long-lasting social, economic, and political crises. It has also changed the way we work and interact with other people.

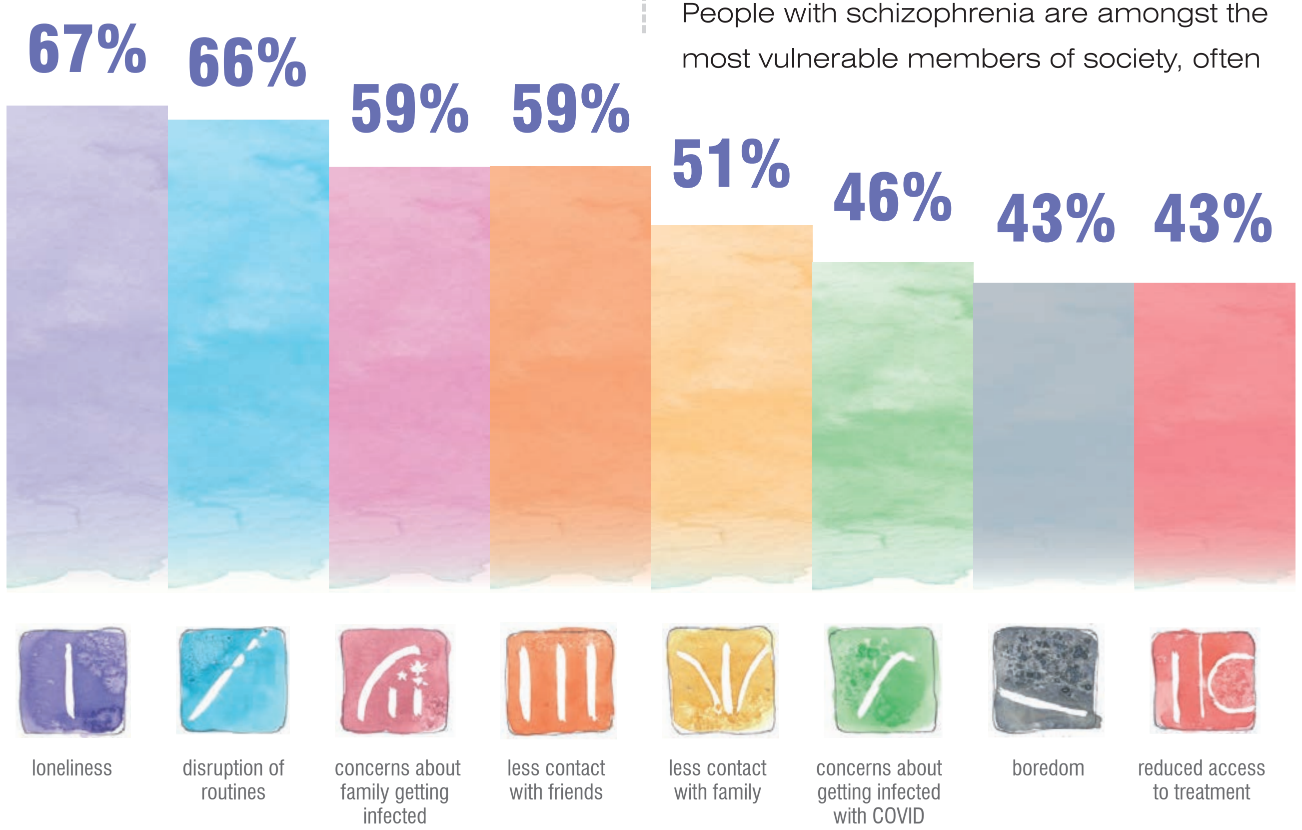
But more importantly, aspects like the chance of coming into contact and falling ill with COVID-19, the regulations aimed at reducing the spread of the virus, such as following lockdown rules, respecting social distancing, and self-isolating, have resulted in increased societal stress, affecting our mental health.

In the course of the pandemic, there was a significant increase in the number of adults reporting symptoms of anxiety and depression in the U.S., this figure jumping from **1** to **4** out of **10** adults compared to pre-outbreak. Also, many adults reported certain **ADVERSE EFFECTS THAT TOOK A TOLL ON THEIR MENTAL AND PHYSICAL WELL-BEING**, these including disrupted eating and sleeping patterns. They also reported engaging in the misuse of alcohol and drugs, alongside experiencing aggravated chronic conditions caused by coronavirus-induced stress and anxieties.

The coronavirus also had a major impact on family dynamics. Lockdowns and working from home resulted in more interpersonal tensions in crowded living conditions. Previous conflicts or difficult interactions intensified as there was less space for individual family members to retreat.

How has coronavirus affected people with schizophrenia?

The COVID-19 pandemic has rewritten the lives of people with schizophrenia and of those who take care of them. Additionally, it has generated **NEW CHALLENGES** for those already struggling with mental illnesses. In a study assessing the impact related to mental health that the pandemic has had on individuals with mental illnesses, over half of participants reported the pandemic lockdown has caused their mental health to worsen. The most frequently indicated factors to cause this deterioration were loneliness **(67%)**, disturbance of routines **(66%)**, concerns about family/friends getting infected with coronavirus **(59%)**, reduced contact with friends **(59%)**, reduced contact with family **(51%)**, concerns about contracting coronavirus **(46%)**, boredom **(43%)**, and the reduction in accessibility to psychiatric treatment **(43%)**.



People with schizophrenia are amongst the most vulnerable members of society, often being predisposed to homelessness, diseases, substance use, and lower socioeconomic status. As a result, they have several risk factors that **MAKE THEM MORE SUSCEPTIBLE TO COVID-19**.

The presence of other diseases (comorbidities) for example, is known to **RAISE THE RATES OF MORTALITY IN INDIVIDUALS ILL WITH COVID-19**. Over **70%** of people with schizophrenia suffer from one or multiple comorbidities, such as type 2 diabetes, respiratory diseases, and heart diseases. Because of this, the average lifespan of someone living with schizophrenia is **15 YEARS** shorter in comparison to a person without the disorder. Furthermore, in case of hospitalization with a respiratory condition, their admission rates to intensive care units are higher, as well as the need for mechanical ventilation. Also, the chance of respiratory failure and in-hospital death, as opposed to other patients, is higher, too. On the whole, the majority of people with schizophrenia belong to at least one known risk group and, if hospitalized, have an increased risk of worse clinical outcomes because of COVID-19. In fact, **INDIVIDUALS WITH SCHIZOPHRENIA HAVE DOUBLE THE SUSCEPTIBILITY OF BEING HOSPITALIZED WITH COVID-19** as those not ill with the disorder, and according to a new study, they are three times more likely to die from the virus. This higher risk cannot be explained by the presence of heart disease, diabetes, or smoking, factors that usually shorten the life of people with schizophrenia.

The findings from the study indicate that the vulnerability of those with schizophrenia to viral infections such as COVID-19 may be related to the disorder's own biology. A possible reason for that could be the derangement of the immune system, seemingly linked to the disorder's genetics.

The cognitive dysfunction associated with schizophrenia also increases the risk of infection. People with schizophrenia **MAY HAVE MORE DIFFICULTY FOLLOWING RESTRICTIONS, QUARANTINE PROCEDURES, AND ADEQUATE HYGIENE PRACTICES THAN THE GENERAL POPULATION**. Flawed judgement together with inadequate self-care, two frequent characteristics of schizophrenia, might also interfere with the conformity to health recommendations and lead to putting themselves, their family members, and health care professionals in danger.

Furthermore, the pandemic is likely to have had an indirect effect on people with schizophrenia by **INCREASING THE RISK OF A RELAPSE**. Generally, one of the most important measures in trying to limit the spread of the virus is social isolation, which can cause substantial emotional distress to people with schizophrenia, as well as to their caregivers. The stress caused by the outbreak, coupled with reduced accessibility to community-based care as well as the chance for impaired medication compliance, could increase the chance of a relapse. Alterations in the daily routine, anxieties from extensive confinement, the concern with coming into contact with the disease, or the loss of a family member due to COVID-19 could also act as **IMPORTANT TRIGGERS**.

We still do not know how the long-term effects of COVID-19 (the so-called "post-COVID syndrome") interfere with the natural course of schizophrenia. However, some of these effects, such as sleep disturbances, mood and anxiety problems, or symptoms similar to post-traumatic stress disorder (PTSD), could have major negative consequences and may affect your loved one's quality of life.

The pandemic has also changed the day-to-day lives of people with schizophrenia by providing "ammunition" for their delusions. One of the characteristics of schizophrenia is that it is always seeking new targets, new pieces of information that can become the subject of delusions. Usually, these can be anything, from current politics to UFO sightings. From the beginning of **2020**, the new coronavirus and the COVID-19 pandemic have become the most popular topic in the media and conversations around the world.

The many unknowns about the virus and the disease it causes have led to **A STATE OF UNCERTAINTY EVEN AMONG THE HEALTHY POPULATION**; people with schizophrenia are even more sensitive to these issues.

Thus, for people with schizophrenia, every COVID-related information, from restrictions to political issues, has the potential not only to **TRIGGER DELUSIONS**, but also to affect their **ATTITUDE TOWARDS SAFETY MEASURES**, **TREATMENT**, **AND VACCINATION**.

As a caregiver, you have an extremely important role in the management of these delicate situations because you are the only person who can handle the problems related to the misinterpretations of COVID-related news and your loved one's potential lack of insight regarding COVID-related health problems or prevention and treatment strategies. One of the most important issues in this regard is the widespread presence of **FALSE INFORMATION AND CONSPIRACY THEORIES** about almost every aspect of the pandemic, from the origin of the virus to the efficiency of face masks and the safety of vaccines. As the connection between your loved one and the outside world, you are the one who can protect them from the harmful effect of COVID-related misinformation, which can lead to symptoms worsening or even relapse. The most up-to-date information is usually found on the website of the European Centre for Disease Prevention and Control, as well as the websites of national health ministries, national departments of public health, and national coronavirus task forces.

European Centre for Disease Prevention and Control

National health ministries

National coronavirus task forces

The termination of Covid-19 preventive measures: a guide on how to take care of yourself and someone suffering from mental illness.

While the COVID-19 preventive measures were found to be difficult when first introduced, we might find their withdrawal just as challenging. Even if our society has gone back to how it was before the pandemic, you and the one you are taking care of **MIGHT NOT FEEL READY TO RECONVENE WITH THE ACTIVITIES** you partook in before, like watching movies at a cinema, having drinks in a pub, joining larger groups of people or commuting by public transport. With restrictions coming to an end, you and your loved one might experience the added pressure to join in, this fact potentially accompanied by the concern of others not having the legal requirement to enter self-isolation in case of being ill with COVID-19.

Similar to how finding ways to cope in the course of the pandemic took time, it is as likely that **IT WILL ALSO TAKE TIME** from now on to habituate and go back to our usual lifestyles. Try not to be too harsh on yourself if you notice this takes you a longer time than anticipated or if you find others to be more self-asserted and sociable. **PATIENTS WITH MENTAL ILLNESSES MAY BE MORE SENSITIVE DURING THIS DIFFICULT TIME**.

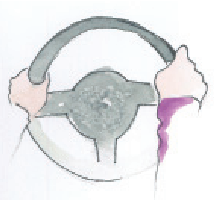
Some of the following mental health-related suggestions, such as introducing and upkeeping a routine, maintaining a socially active lifestyle, nourishing yourself with healthy food and exercising are just as relevant now as they were at the beginning of the lockdown. In fact, they might apply even more in the following period as we might face sizable changes.

Fear and anxiety

The termination of the COVID-19 preventive measures might result in some common emotional responses, such as **FEAR AND ANXIETY**. Both you and the ones close to you might feel unsafe or unprepared to break free from your coping ways with the COVID-19 regulations as you are moving from several lockdowns towards the progressive ease and the end of regulations.

Paying attention to and making room for your feelings is **HIGHLY IMPORTANT**, as opposed to overlooking or ignoring them. It is by gradually increasing our tolerance that we can overcome these fears.

Pointers on how to cope with fear and anxiety:



• CONTROL THE CONTROLLABLE.

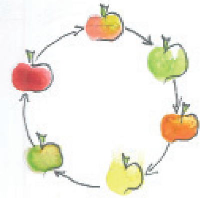
There are numerous fear and anxiety-inducing things that are out of your control and could negatively impact you, as well as your loved ones who struggle with mental illness. However, there are several things that can be managed and planned for. It might help be prepared and have a plan of action in order to manage complicated situations.

• TAKE THINGS ONE AT A TIME.

Be aware that you might be better off taking things slowly and adjusting the pace to suit your loved one struggling with mental health. Discuss concerning thoughts with someone close to you and trustworthy, while letting others adopt their own pace.

• WORK ON YOUR TOLERANCE.

Attempt to gently challenge yourself daily, or perhaps over the span of several days. Don't be too harsh if it does not go according to your initial plan. Note your achievements, things you enjoyed, or whose accomplishment brought you pleasure.



• MIX UP YOUR ROUTINE.

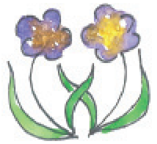
Introduce some form of variation in order to socialize with different people and face a range of situations. In case one grocery store is packed and fills you with worry, try a different one. If commuting at a certain point during the day is too busy, try alternating busier times with some more quiet ones.

• HOW TO COPE WITH UNCERTAINTY.

Switch your focus to the present. You are only able to make the most with what you have today. Considering the change in regulations and the influx of media controversies over what is right or wrong, try to maintain your focus on the present moment. One way of switching your focus to the present moment is mindfulness meditation.

• SPOTLIGHT WHAT IS CERTAIN.

With many things being uncertain at the present time, there are hopeful ones as well. Try taking into account and appreciating the positive things as they come your way, and use any opportunity to benefit from them, such as to relax and reset.



• TALK TO THOSE YOU TRUST.

Talking about how you feel and what is on your mind is essential. Avoid abandoning your worries and try not to be too judgemental towards yourself. You could find an online support system, however, it may be worth getting some outside prospects as well.

• RETURN TO A SOCIALLY ACTIVE LIFE.

While the regulations gradually reduce, you might begin to return to a more socially active life, whether it's because you feel it is less risky to do so, or you'll experience the pressure of joining those who cannot wait to start their normal lives again.

It could feel awkward at first to reconnect with people. Be it the uncomfortableness of being without a mask or feeling cautious about people being in big groups, it is essential that you do not rush the process and give yourself as much time as you feel necessary.

If you are self-isolating or part of a high-risk group, you might experience alienation due to seeing everyone else engage in the activities that you miss. There might be a high prospect that people closest to you, such as family and friends, might be less likely to relate to and support you. It might be worth trying to reach out to those who can relate to your situation, or - if you are comfortable with it - speak to someone trustworthy about how it makes you feel when you are left out. Maybe even suggest some possible ways of being included that do not necessarily involve being in physical proximity.

- Keep in touch with support groups and see what their experiences and recommendations are in this regard.
- Encourage your loved one to spend as much time outside as possible and to socialize with friends and family members as often as possible.
- Follow the health care professionals' advice and carefully monitor your loved one's symptoms in order to identify possible worsening.
- Do not forget to take care of yourself and your well-being and help the person you are caring for to get through this unusual period.

References

1. Zhand N, Joober R. Implications of the COVID-19 pandemic for patients with schizophrenia spectrum disorders: narrative review. BJPsych Open. 2021 Jan 12;7(1): e35.
2. Öngür D, Perlis R, Goff D. Psychiatry and COVID-19. JAMA. 2020 Sep 22;324(12):1159.
3. Panchal N, Kamal R, 2021. The Implications of COVID-19 for Mental Health and Substance Use [Internet]. KFF. 2021 [cited 2021 Jul 2].
4. Kølbæk P, Jefsen OH, Speed M, Østergaard SD. Mental health of patients with mental illness during the COVID-19 pandemic lockdown: A questionnaire-based survey weighted for attrition. medRxiv. 2021 Mar 20;2021.03.13.21253363.
5. Zhou F, Yu T, Du R, Fan G, Liu Y, Liu Z, et al. Clinical course and risk factors for mortality of adult inpatients with COVID-19 in Wuhan, China: a retrospective cohort study. The Lancet. 2020 Mar 28;395(10229):1054–62.
6. Mohan M, Perry BI, Saravanan P and Singh SP COVID-19 in People With Schizophrenia: Potential Mechanisms Linking Schizophrenia to Poor Prognosis. 2021. Front. Psychiatry 12:666067. doi: 10.3389/fpsyt.2021.666067
7. Manchia M, et. al. The impact of the prolonged COVID-19 pandemic on stress resilience and mental health: A critical review across waves. 2021. DOI: 10.1016/j.euroneuro.2021.10.864

HANDY GLOSSARY

WORD	EXPLANATION
Anhedonia	the impaired capacity of having an interest in and/or feeling pleasure from things or activities that used to be interesting and enjoyable, usually a symptom of mental health disorders
Apathy	the state of lacking interest, emotion, motivation, or concern towards the surrounding world
Behavioural science	the social science branch (included in disciplines like sociology, psychology, and anthropology) focused on the subject of human actions, aiming to generalise how humans behave and make decisions in the real-world society
Benzodiazepines	a type of medication that decreases brain activity and have a sedating effect; it is usually prescribed as a treatment for anxiety and insomnia
Dopamine	a neurotransmitter type produced and used by the body as a messenger substance, enabling communication between nerve cells; it has an important role in cells as it promotes interest, motivation, and focus; however, its excess or deficiency can produce various health issues
Flat affect	the lack of reaction to emotional stimuli and/or unexpressed emotions, usually as a symptom of a psychiatric disorder such as depression, autism, or schizophrenia, or other medical conditions such a traumatic brain injury; this does not mean a lack of emotions, but their absence expressed either vocally, facially, or through body language
GABA	the gamma-aminobutyric acid is an inhibitory neurotransmitter, which produces a calming effect by attaching itself to a receptor, this way reducing the nervous system activity and inhibiting neuron activity
Genetics	the biological study concerned with how living organisms pass down their characteristics to their offspring via their genes (chemically distinctive patterns)
Glutamate	a chemical, a levorotary glutamic acid salt or ester, used by nerve cells as a neurotransmitter in order to send each other signals by having an excitatory effect on neurons; in the vertebrate nervous system this is one of the most prevalent excitatory neurotransmitters
Neuroimaging	the non-invasive production of images representing brain function, structure, and activity, using several techniques, for example, computerized tomography or magnetic resonance imaging
Osteoporosis	a health condition meaning “porous bones”, characterized by reduced mass and strength in bones, leading to their weakness, brittleness, and increased risk for fractures, mostly in hips, wrists, and spine; it usually develops with no pain or symptoms, making it difficult to uncover until its effects lead to painful fractures
Prejudice	a preconceived attitude towards an individual put forward by their perceived association to a specific group, based on racial, religious, ethnic, sexual, and/or other categorization
Psychotherapy	a treatment for mental health problems and emotional struggles, usually involving “talk therapy” with a psychiatrist, psychologist, or other mental health professionals, where individuals learn about their condition and how to manage it in a healthy way, leading to increased well-being, healing, and optimal functioning
Serotonin	the essential mood-stabilizing hormone which is responsible for the optimal levels of someone’s well-being feelings and happiness, as well as digestion, sleeping, and eating, impacting the entire body by allowing the communication between the brain and nervous system cells
Stereotype	a conventionally accepted or fixed belief about a group of people who hold a common characteristic
UFO	or an ***Unidentified Flying Object***, is a moving aerial object or phenomenon that cannot be explained or identified, commonly believed to have extraterrestrial origins