RE THINKING SCHIZOPHRENIA

Phase I ,, Beyond the Voices

POLICY REPORT

EBC
European Brain Council

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For more information about Rethinking Schizophrenia, please visit: www.braincouncil.eu/projects/rethinking-schizophrenia/

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The policy report "Rethinking Schizophrenia: Beyond the Voices" was made by the European Brain Council (EBC), a network of key players in the "Brain Area", with a membership encompassing scientific societies, patient organisations, professional societies and industry partners.

Foreword

Schizophrenia is a complex psychiatric disorder with onset at a young age – most people are diagnosed between 20 and 30 years old. If early detection and intervention are not properly implemented, schizophrenia can turn into a chronic condition (Fusar-Poli et al., 2017). It has long been associated with the haunting echoes of voices, shaping public perceptions and treatment approaches alike. However, the essence of this condition extends far beyond the auditory hallucinations. It is a complex interplay of cognitive, emotional, and social dimensions that demands a holistic re-evaluation.

To better understand schizophrenia and provide optimal care, cognitive and emotional symptoms should not be neglected. Only by addressing those, we can ensure that every person with schizophrenia in Europe has their needs met for timely diagnosis and personalised treatment, interdisciplinary and coordinated care and human rights. To achieve this, we need to listen to the voices of people living with schizophrenia. We must better understand how the condition affects people and their families on a day-to-day basis and support them in a holistic way.

Rethinking Schizophrenia aims to offer tangible policy changes to improve the lives of people living with schizophrenia across Europe. It challenges the status quo and refreshes the European policy debate on people living with schizophrenia, recognises the presence of cognitive and emotional aspects in the condition as well as the essential role of social support and encourages multi-stakeholder-driven policy.

With this report, "Rethinking Schizophrenia: Beyond the Voices", we embark on a journey that transcends the traditional boundaries of how we conceptualise and approach schizophrenia. The report challenges prevailing stereotypes, and endeavours to illuminate the multifaceted nature of this condition. We delve into the experiences of individuals living with schizophrenia, listening to their stories with empathy and an open mind.

"Rethinking Schizophrenia: Beyond the Voices" is more than a report; it is a call to action. It beckons us to challenge preconceptions, embrace diversity, and work collectively towards a future where individuals with schizophrenia are not defined by their diagnosis but celebrated for their resilience, strength, and unique contributions.

May this report serve as a catalyst for dialogue, understanding, and progress. The journey to redefine our understanding of schizophrenia begins within these pages, and it is a journey we undertake with humility, curiosity, and a shared commitment to building a more compassionate and enlightened society.

Professor Suzanne Dickson
President, European Brain Council

Call to action

We call on EU and national policymakers and decision-makers across Europe to improve the lives of people living with schizophrenia through the optimisation of their care pathway. Investments in schizophrenia research and innovation are needed to better understand the pathophysiology, mechanisms, and risk factors of schizophrenia.

At national level, schizophrenia plans and strategies need to be developed and implemented that allow for:

- Prevention, early detection, and effective interventions in schizophrenia.
- A holistic and integrative approach to schizophrenia care and management.
- Human rights for people living with schizophrenia.

The following organisations endorse the "Rethinking Schizophrenia" report, including the call to action and policy recommendations, to help improve the care and life of people living with schizophrenia in Europe.

APICES Salud Mental Cartagena

European College of Neuropsychopharmacology (ECNP)

European Psychiatric Association (EPA)

European Federation of Associations of Families of People with Mental Illness (EUFAMI)

GAMIAN-Europe

National Institute of Health and Medical Research (INSERM)

Recovery Cat

Rethink Mental Illness

Schizo Oui

Policy recommendations and priorities

EARLY DETECTION/DIAGNOSIS AND EFFECTIVE TREATMENT

- Investment in research and innovation in the field of schizophrenia to enhance the understanding of its pathophysiology, mechanisms, and risk factors.
- Educate healthcare professionals, including general practitioners and nurses, throughout their career journey on the risk factors, early detection, and preventive interventions associated with schizophrenia.
- Empower individuals living with schizophrenia to engage in shared decision-making with healthcare professionals to effectively manage their symptoms.
- Ensure access to innovative and complementary interventions for individuals dealing with schizophrenia.

A HOLISTIC APPROACH TO SCHIZOPHRENIA CARE AND MANAGEMENT

- Assessment of people living with schizophrenia for the three components of schizophrenia, including positive, negative and cognitive symptoms.
- Advocate for comprehensive approaches encompassing pharmaceutical, psychosocial, lifestyle, and spiritual dimensions.
- Guarantee the continuity of care with dedicated healthcare professional teams, minimizing fragmentation in the care services.
- Prioritize physical health by incorporating general medical care into the overall management of people living with schizophrenia.
- The provision of support and development of trainings for family peer advocates.
- Provide support to families as caregivers involved in the care of individuals with schizophrenia.
- Encourage the adoption of a comprehensive approach as part of the European Mental Health Strategy.

HUMAN RIGHTS FOR PEOPLE LIVING WITH SCHIZOPHRENIA

- Confront and dispel stigma and misconceptions about schizophrenia by presenting accurate information.
- Cultivate an environment that is less discriminatory, more inclusive, and supportive.
- Address the fear of rejection and enhance confidence through the establishment of supportive networks for people living with schizophrenia and their families as caregivers.
- Increase awareness about the impact of schizophrenia on families as caregivers, social relationships, and work life.
- Advocate for the promotion of precision psychiatry approaches.

Executive Summary

Identified as a leading cause of disability worldwide with a peak age of 20.5 years and half the cases originating before age 25 (Solmi et al., 2022), schizophrenia is a complex psychiatric condition estimated to affect 24 million people globally and 0.3-1.5% of Europeans. Despite the substantial progress in treatment, schizophrenia has still a huge societal burden, largely because of the delayed recognition, prevention and intervention (Fusar-Poli et al., 2021) with an excessively long duration of untreated disorder – 43 weeks worldwide (Salazar de Pablo, 2023). It heavily impacts every aspect of life, including relationships, education, and employment. The needs of Europeans living with schizophrenia can be summarised in three broad themes:

PREVENTION, EARLY DETECTION, AND EFFECTIVE TREATMENT

To facilitate early detection and reduction of the duration of untreated psychosis, early recognition of subtle signs in schizophrenia is needed. This allows for maximising the associated preventive potentials (Fusar-Poli et al. 2020). Prevention is the most promising way to improve outcomes of this condition.

Education of healthcare professionals is essential to facilitate the recognition of subtle signs, early detection, and effective treatment of schizophrenia across Europe. During the interviews, people living with schizophrenia highlighted the sometimes long and winding road to diagnosis, and the related hardships of living with a condition that you cannot name, leading to a loss of self-recognition. General practitioners should be the first contact point to access a quality care pathway and work with colleagues to ensure an interdisciplinary, coordinated approach to schizophrenia.

Trust and communication are crucial to build a successful therapeutic alliance. People living with schizophrenia need their clinicians to be honest about the disorder, potential symptoms, and care options, and involve them in treatment decisions including innovative and complementary interventions combatting symptoms and limiting side effects.

A HOLISTIC APPROACH TO SCHIZOPHRENIA CARE AND MANAGEMENT

There is a need to rethink the current approach to schizophrenia care and management by integrating psychosocial and lifestyle solutions. People living with schizophrenia shared during the interviews that they can benefit from a number of psychosocial interventions, including wandering in nature, writing and painting. For people with schizophrenia to stay stable over time, it is crucial to accompany them through their care journey and thus ensure the continuity of care despite treatment changes and unexpected medication side effects.

Executive Summary

HUMAN RIGHTS FOR PEOPLE LIVING WITH SCHIZOPHRENIA

Schizophrenia is surrounded by stigma and false myths. This report challenges them with real facts: people with schizophrenia do not have a dual personality, rather than; they are generally not dangerous to themselves or others, and they can get better. They can work, function and live independently.

People fear what they do not know. By offering insight into the lives of individuals living with schizophrenia and the ripple effects on families, social dynamics, and work life, the report advocates for fostering less discriminatory and more inclusive environments, spanning schools and workplaces.

It is a historic moment for mental health in Europe and globally. The World Health Organisation (WHO)'s Comprehensive Mental Health Action Plan 2013-2030 puts emphasis on actions to promote mental health and well-being for all, to prevent mental health conditions for those at-risk and to achieve universal coverage for mental health services. The European Mental Health Strategy promotes a compressive approach to mental conditions, including schizophrenia. "Rethinking Schizophrenia: Beyond the Voices" sheds light on the disorder, raises awareness on its complexities and enhances a European discussion on new ways to build a mentally healthier Europe together.

Introduction

> **"How we label things is very important. If you change the name, you change the way in which people look at people living with schizophrenia."**
>
> *Matthieu de Vilmorin, Former President, Schizo Oui*

The term schizophrenia, which derives from the Greek and literally means "split mind", was coined in 1908 by Dr. Eugen Bleuler. Japan and Korea, which chose to change the name schizophrenia into "integration disorder" and "attunement disorder" respectively, register less stigma and more acceptance of the diagnosis. People living with schizophrenia we interviewed to create this report also proposed alternative terms such as "individuality trouble" or "psychosis spectrum".

Schizophrenia is a complex psychiatric disorder with a high prevalence, an enormous disease burden, multiple psychiatric and physical comorbidities, and high suicide rate. If early detection and intervention are not properly implemented, schizophrenia can turn into a chronic disorder (Fusar-Poli et al., 2017). It is characterised by significant impairments in perception and experience of the world. According to the Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5), six criteria must be met for schizophrenia (see Table 1).

Table 1. DSM-5 Diagnostic Criteria for Schizophrenia

A	Two or more symptoms lasting for at least one month (Should include at least one from 1-3) 1. Delusions 2. Hallucinations 3. Disorganised speech 4. Disorganised or catatonic behaviour 5. Negative symptoms such as diminished emotional expression and avolition
B	Level of functioning has to be significantly (and long term) lowered compared to previously achieved levels.
C	Continuous signs of disturbance persist for at least six months must include criterion A symptom(s) for at least one month.
D	Schizoaffective disorder and depressive or bipolar disorder with psychotic symtoms ruled out.
E	The disturbance is not caused by substance use or medical conditions.
F	If there is a history of autism spectrum disorder or communication disorder, the diagnosis of schizophrenia is only made if prominent delusions or hallucinations are present along with other symptoms for at least one month.

Because of its complexity, schizophrenia might be confused with other conditions (e.g., schizoaffective disorder, depressive or bipolar disorder with psychotic symptoms, substance abuse, autism spectrum disorder), go unnoticed or denied, which might result in delayed diagnosis and treatment. Additionally, people with schizophrenia have frequent physical comorbidities (Correll et al., 2017), unhealthy lifestyle (Firth et al., 2020), and cardiovascular risk factors (Vancampfort et al., 2015; Vancampfort et al., 2016) that, together with disparities in physical healthcare (Solmi et al., 2020; Solmi et al., 2021), and disease-related symptoms, lead to significant burden and premature mortality (Correll et al., 2022).

Schizophrenia usually develops at a young age and can have a devastating impact on people lives and the lives of their families as caregivers. Identified as a leading cause of disability worldwide with a peak age of 20.5 years and half the cases originating before age 25 (Solmi et al., 2022), schizophrenia is a complex psychiatric condition estimated to affect 24 million people globally and 0.3-1.5% of Europeans. People living with schizophrenia and their families as caregivers experience a decrease in functioning and quality of life in one or more major areas, such as school/work, interpersonal relations or self-care. Associated with unemployment and early retirement, psychiatric comorbidities, and premature death, schizophrenia has the highest median societal cost per person of all mental illnesses (Kotzeva et al., 2023).

Despite the substantial progress in treatment, schizophrenia still has a huge societal burden, largely due to the delayed recognition, prevention and intervention (Fusar-Poli et al., 2021) with an extensively long duration of untreated disorder — 43 weeks worldwide (Salazar de Pablo, 2023). The problem is that early detection is not fully implemented in Europe and therefore prevention is unexploited (McGorry, 2015).

Finally, schizophrenia requires a holistic re-evaluation. Researchers, healthcare professionals and policymakers need to consider the complex interplay between cognitive, emotional, and social dimensions to ensure individuals and their families, as caregivers, health and social needs, from early detection to accurate diagnosis to treatment and care.

The Rethinking Schizophrenia project aims to propose policy recommendations to improve the lives of people living with schizophrenia across Europe. It challenges the status quo and refreshes the European policy debate on people living with schizophrenia, recognises the presence of cognitive and emotional aspects in the condition as well as the essential role of social support and encourages multi-stakeholder-driven policy.

Society plays a crucial role at all levels of the care pathway, whose success depends on a cohesive network of people surrounding the person living with schizophrenia. Healthcare professionals (including general practitioners and social workers), families as caregivers, friends, colleagues, and all those with whom we interact on a regular basis in society: each of us has the potential to improve the lives of people living with schizophrenia.

The objective of this policy report is to listen to the testimonies of people living with schizophrenia, as well as their family members in the role of caregivers, who are best placed to respond to several pertinent questions (Fusar-Poli et al., 2022). Semi-structured qualitative interviews were performed with people living with schizophrenia and their caregivers. They were recruited from different European countries (including France, Germany, Hungary, Italy the United Kingdom) all with a diagnosis of schizophrenia for at least one year and all outpatients in a stable mental state. They shared with us the challenges they faced, how they dealt with them, and how love, acceptance, and inclusion are essential parts of the care they need in order to reach their full potential while living with schizophrenia. These interviews provided insight their world and a glimpse of their everyday experiences.

Interview questions:

- What challenges and obstacles do individuals living with schizophrenia encounter?
- What insights can be gained from the experiences of people living with schizophrenia?
- How can the retention and reintegration of individuals living with schizophrenia into occupational and social life be promoted?
- In what ways can society be rethought to contribute to the promotion and maintenance of citizens’ mental health?

This report is focused around three priority areas for policy action, as identified by people living with schizophrenia and their caregivers:

1. Prevention, early detection, and effective treatment
2. Holistic approach to schizophrenia care and management
3. Human rights for people living with schizophrenia.

Stories from people living with schizophrenia

Anastazia Benzahi,

Patient advocate, Positive Minders

I’ve been followed by a psychiatrist since I was 17. I was living in Russia at that time: after a very big incident in my life, I had post-traumatic stress disorder (PTSD), and since my childhood I had very big problems with my behaviour, my way of dealing with things. When I moved to France, my psychiatrist there just told me that this is how I am, that it was just my way of functioning: it was very hard to get a diagnosis from her. Then I moved to Prague, and that's where I got diagnosed. Furthermore, my psychiatrist called my mom to explain everything about the disease to her. I can now understand myself better and the people around me better understand me, too. My mother and stepfather were extremely supportive.

When I moved back to France, my new psychiatrist confirmed the diagnosis and since then, he’s following me: he’s very helpful. We are making a calendar with my different phases so that I can better deal with them in the future.

I just graduated from a Master’s in quantum physics, but it wasn’t easy at all. I failed my first attempt of my Master’s thesis because I just couldn’t work anymore. Recently, it has been very difficult to get out of my place to meet people or do groceries. It’s very hard for me to take public transportation — my friends are helping me a lot. The worst is going to the post office: there are people and waiting lines.

Sometimes I will have psychotic episodes, sometimes I will be extremely depressed, but I’m trying my best to be stable. My current treatment is helping me a lot to achieve my goals.

Stories from people living with schizophrenia

Matthieu de Vilmorin,

Former President, Schizo Oui

I did a lot of things before I got sick: I know how to drive, I was in the army as a trainee officer, I had friends and girlfriends. I was 23 when I had my first crisis of mystical delirium and ended up in a hospital in Rio de Janeiro, Brazil. They gave me an injection to put me to sleep, I don't remember anything. I had three other crises of that type: in 1985, 1988 and 2012, when I had to change medication – mine wasn't produced anymore. I didn't have to go from institution to institution or live alone knowing that I had an issue I was not able to label: I was diagnosed very early, and it really helped me. I was fighting also to be able to write again, I have always written.

I have a strong family and very good friends who support me, and I found very efficient doctors and carers. It's a long way since onset to my actual stage where I think I am completely reestablished, even if I still take my medicine and go to doctor appointments.

I worked as a handyman, a delivery guy, a limousine driver: they were the only jobs I could do in the state I was in. I never had voices or other positive symptoms. What I'm bad at is my relation to time. I was sleeping a lot, too much in a way. I also gained weight – because of medications, you eat but you're not hungry at all.

Schizophrenia is a combination of a lot of different things: DNA, environment, vulnerability for one aspect or another, your growth, your youth, your studies, people you meet; research is important, but I don't think medications will be the solution.

Schizophrenia: Defining the challenge

> **“Schizophrenia is as the world of deafness. There is a lot of unutterable pain and many things which are left unsaid.”**
> *Matthieu de Vilmorin, Former President, Schizo Oui, France*

Schizophrenia is a complex psychiatric disorder starting at young age that we still do not fully understand and for which diagnosis, treatment and care is not yet optimal.

> **“If someone has cancer, the teachers will understand that this person sometimes misses courses or is not feeling well enough to attend exams. But when it comes to mental disorders, it’s very difficult to make them understand that it is a disease.”**
> *Anastazia Benzahi, Patient Advocate, Positive Minders*

Policymakers need to address the challenges people living with schizophrenia and their families as caregivers are facing.

> **“Realising that she was living in a different reality than I was and that I couldn't get through to her — it was the worst.”**
> *Janine Berg-Peer, Author, Coach and Consultant for Carers*

Challenges:

- Lack of an accurate diagnosis
- Side effects of existing treatments
- Absence of effective treatments and interventions for cognitive and negative symptoms
- Employment-related struggles
- Insufficient support from family, friends, and the society
- Pertinent stigma and discrimination

Early symptoms

> **“I think my problem with schizophrenia already started when I was a kid. I didn’t want to be with other kids. Later, I started getting lower grades in discipline. All my life has basically been in isolation.”**
> *Anonymous*

More than two thirds of people living with schizophrenia display prodromal symptoms which often manifest as changes in behaviour, thoughts, or emotions, and/or social impairment several years before disorders onset. Sullivan et al. (2018) found that early symptoms were associated with a future diagnosis of psychosis.

Early Symptoms:
Attention deficit hyperactivity-disorder-like problems.
Bizarre behaviour.
Blunted affect.
Depressive-like problems.
Role functioning problems.
Social isolation.
Mania.
Obsessive–compulsive disorder-like problems.
Disordered personal hygiene.
Sleep disturbance.
Suicidal behaviour (including self-harm).
Cannabis use.
Cigarette smoking.
More frequent users of primary care services.

> **“When I was 23, I recognized some of the early warning signs myself and visited an early recognition center, but they only diagnosed a slight depression.”**
> *Cordt Winkler, Clinical Product Developer, Recovery Cat*

Because of the very subtle and gradual onset of early symptoms, it is challenging and difficult for individuals, their families, and even healthcare professionals to differentiate them from normal variations. They are often non-specific and overlap with other mental health conditions (e.g., depression and bipolar disorder), which makes an accurate diagnosis at an early stage very challenging.

In addition, societal stigma and discrimination associated with mental illness, including schizophrenia, can hinder early intervention, treatment adherence, and the overall well-being of affected individuals.

Societal stigma and discrimination surrounding mental health issues may also hinder individuals to seek help during early stages. Early intervention is crucial, but these challenges contribute to delays in diagnosis and treatment, impacting daily functioning, quality of life and overall wellbeing of people living with schizophrenia and their familes.

Symptoms

> **"Sometimes we think the symptom is what the person lives with, but that's not true. The symptom is what the family feels, the symptom is what the psychiatrist feels, the symptom is what the shopkeeper feels when a schizophrenic person goes into the shop. Schizophrenia is not an illness of a person but an illness on society."**
>
> *Péter Kéri, President, GAMIAN-Europe*

These are usually managed with antipsychotic medications but these drugs often Schizophrenia manifests differently in individuals, with a wide range of symptoms and severity levels. This heterogeneity makes diagnosis and treatment challenging, as there is no one-size-fits-all approach.

Symptoms of schizophrenia can be divided into three main categories: positive, negative, and cognitive symptoms (See Table 2).

Table 2. Schizophrenia symptoms

Positive symptoms	Negative symptoms - The 5 A's	Cognitive symptoms
Hallucinations *Hearing/seeing/smelling/feeling things that are not actually there*	**Blunted Affect** *Decreased ability to express emotion through facial expressions, tone of voice, and physical movements*	**Impaired attention** *Challenges in focusing and concentration, and being easily distracted*
Delusions *False/unusual persecutory, referential, somatic, erotomaniac, religious and/or grandiose beliefs*	**Alogia** *Lack of conversation or poverty of speech*	**Impaired memory** *Difficulties in remembering, retaining, or recalling information*
Disorganised speech/thinking *Unusual or illogical thinking; Trouble organizing thoughts; Not being able to follow a conversation; Zoning out or being distracted; Words do not make sense*	**Avolition** *Lack of motivation*	**Impaired reasoning** *Difficulties in thinking logically and making sound judgments*
Grossly disorganised or catatonic behaviour *Jumpy or repetitive movements as well as sitting still for hours*	**Asociality** *Lack of motivation to engage in social interaction, or a preference for solitary activities*	**Impaired problem solving** *Impaired problem solving Challenges in effectively analysing, evaluating, and resolving issues or obstacles*
	Anhedonia *Reduced ability to experience pleasure*	

Primary focus on positive symptoms

“Don’t listen to what you hear. Don’t watch what you see. Every time I start being uncomfortable, I think about what my psychiatrist once told me. There is a difference between listening and hearing and seeing and watching.”
Anonymous

Schizophrenia is associated with positive symptoms like hallucinations, delusions, thought disorders, and movement disorders.

“My son was at university. He was studying politics and wanted to become a political journalist. He’s so far away from anything like that now. His hallucinations do focus on his mental capacity. They use the word “inadequate” because he realizes that he can’t do what other people do.”
Philippa Lowe, Patient Advocate, Rethink Mental Illness

Positive symptoms can interfere with the ability to maintain employment or pursue educational goals.

“Schizophrenia is my unwanted travel companion for life.”
Cordt Winkler, Clinical Product Developer, Recovery Cat, Germany

The cumulative impact of positive symptoms, along with associated challenges, can significantly reduce an individual’s overall quality of life and has a profound impact on various aspects of their lives and those of their families.

“My daughter went to the hospital and gained 20 kg about the side effects in one month. We didn’t know why. Nobody told us anything about side effects of medications.”
Janine Berg-Peer, Author, Coach and Consultant for Carers

The use of antipsychotic medications, commonly prescribed for positive symptoms, can have side effects that impact physical health, contributing to challenges in overall wellbeing.

Insufficient focus on negative and cognitive symptoms

Historically, positive symptoms were the focus for diagnosis, treatment, and care.

Beyond the positive symptoms also stands a variety of negative and cognitive symptoms. Those symptoms still receive less attention than positive symptoms while their impact on daily lives of people living with schizophrenia and their families is huge.

“My son has never worked. He couldn’t do a job and be paid for it because he’s so disorganised. I think it’s actually the negative symptoms that are more preventative of a normal life than the positive ones.”
Philippa Lowe, Patient Advocate, Rethink Mental Illness

Negative and cognitive symptoms can occur early, persist over time, increase in severity, and remain between acute episodes of illness. Negative and cognitive symptoms of schizophrenia are often among the first signs of the disorder. Among persons living with schizophrenia who experience negative and cognitive symptoms, 73% had them before the onset of positive symptoms and negative and cognitive symptoms tend to be highly persistent during clinical stability as well.

Unfortunately, effective treatment of negative and cognitive symptoms remains an unmet medical need in schizophrenia. There are still no effective treatments and interventions to manage those ongoing negative and cognitive symptoms of schizophrenia. Secondary negative and cognitive symptoms (i.e., negative and cognitive symptoms to drug treatment of positive symptoms) can improve as a consequence of treatment to improve positive symptoms but primary negative and cognitive symptoms generally do not respond well to currently available antipsychotic treatments.

“I worked as a handyman, a delivery guy, a chauffeur. They were the only jobs I could do in the state I was in. I never had voices or other positive symptoms.”
Mattieu de Vilmorin, Former President, Schizo Oui

This lack of detection, diagnosis, treatment, and care of negative and cognitive symptoms can make it difficult to work and function in daily life. The degree of negative and cognitive symptoms interferes with social functioning and predicts future psychosocial functioning even better than positive symptoms (Kalisova et al., 2023).

Diminished motivation and a lack of interest in activities can hinder an individual’s ability to pursue and maintain employment or educational goals. This may contribute to financial difficulties and a sense of unfulfillment.

"Feeling depressed, not being able to clean my apartment or be motivated to do things, do sports. These symptoms are much more important than delusions, that's most of my life."

Cordt Winkler, Clinical Product Developer, Recovery Cat, Germany

Reduced motivation and apathy can impact the ability to perform daily tasks, such as personal hygiene, cooking, and managing household responsibilities.

"Recently, it has been very difficult for me to get out of my place to meet people or do groceries. It's very hard for me to take public transportation."

Anastazia Benzahi, Patient Advocate, Positive Minders

Individuals with pronounced negative and cognitive symptoms may become more dependent on others for support, including assistance with daily tasks and decision-making.

"Sometimes I just cannot get out of bed, but they just see it as a laziness or lack of hard work."

Anastazia Benzahi, Patient Advocate, Positive Minders

Negative and cognitive symptoms may lead to misunderstandings and stigmatisation, as others may misinterpret the individual's behaviour as disinterest or indifference.

"I lost a lot of friends. They were just tired of dealing with me because of my disease. That's a test for friendships. The friends that remain are really the real ones."

Anastazia Benzahi, Patient Advocate, Positive Minders

Communication difficulties and social withdrawal can strain relationships with family, friends, and colleagues, leading to social isolation.

"Carers want the truth, they want to receive information, they want to give information. I had to seek out information elsewhere and this was before the days of Google. Lots of people have to give up work to be a carer or perhaps reduce their hours to part time. The level of distress they were going through, the loneliness because it often cut them off from friends and relatives... it's an impoverishing thing, being a carer."

Philippa Lowe, Patient Advocate, Rethink Mental Illness

Families as caregivers may face increased challenges in providing support and understanding, as negative and cognitive symptoms can be less visible or apparent compared to positive symptoms. Families may experience stress, anxiety, and a range of emotions related to their role. They may encounter societal stigma associated with mental illness. This can lead to feelings of isolation.

Causes and risk factors

"How do you engage with these perceptions? Do you rely on them? Are they nice to you? Are they better company than your actual company? The voices are not accidentally there."

Péter Kéri, President, GAMIAN-Europe

Understanding the exact cause of schizophrenia is challenging due to its multifaceted nature but there is consistent evidence supporting risk factors (Radua et al., 2018). There seems to not be one single cause of schizophrenia, but genetic, neurodevelopmental, environmental and psychosocial factors would combine to increase a person's susceptibility to the condition and influence its onset and course.

Children of parents with schizophrenia are more at risk of experiencing it themselves (Uher et al, 2023).

Substance abuse, particularly cannabis and psychostimulant use during adolescence, is linked to an increased risk of schizophrenia. These substances may interact with genetic vulnerabilities. Heavy use of cannabis is associated with an elevated risk of the disorder (Kohn et al., 2004).

Facts and Figures

Worldwide, schizophrenia affects 1/300 (0.32%) or 24 million people (Institute for Health Metrics and Evaluation - IHME), while in Europe alone, this number is higher, around 0.3-1.5% of the population (Simeone et al., 2015). In high-income countries, people living with schizophrenia benefit from continuous treatment and care (Wittchen et al., 2011). Nevertheless, 15-50% of people living with schizophrenia do not receive adequate professional treatment (e.g., drug therapy, cognitive therapy, psychosocial rehabilitation), which contributes to poor prognosis.

Facts and Figure:

- The onset of schizophrenia is typically during adolescence or early adulthood, earlier in men (World Health Organization)
- Schizophrenia is a **leading cause of disability** worldwide in 25-49 year olds (Global Burden of Disease, 2019)
- Schizophrenia is estimated to affect **24 million people** globally (IHME)
- **50% of people in mental hospitals** have a schizophrenia diagnosis (World Health Organization)
- 15-50% of people living with schizophrenia do not receive adequate professional treatment (Kohn et al., 2004)
- People with schizophrenia are **two to three times more likely to die earlier** than the general population (Laursen et al., 2014)
- **Up to 60%** of people living with schizophrenia have prominent or predominant **negative and cognitive symptoms** that are clinically relevant and need treatment (Bobes et al., 2010; Rabinowitz et al., 2013)
- Negative and cognitive symptoms have been reported as among the **most common first symptoms of schizophreni**a (Van der Heiden et al., 2000)

Stories from people living with schizophrenia

Péter Kéri,

President, GAMIAN-Europe

I created huge travel groups for multinational companies all over the world; my task was to design once-in-a-lifetime tours. I created with my colleagues one of the most outstanding gastronomical and nightlife places in the middle of Budapest, I was very proud of it. After one year and a half, we didn't have guests, we weren't successful, and I had to say goodbye to all: that's when something changed in my life. You're known by everyone, you're on TV, you're in the centre of your social network and, suddenly, in a quick moment, you are nobody, without money, without a place to live. The friends who were close to you are not as close to you anymore. I felt very lonely.

When schizophrenia kicked in, I was absolutely lost. Voices hated me, they were awful: it was so big and painful that I could barely survive. I went to a normal clinical setting: there I had discussions with my doctor. I talked about my experience and how I felt about the voices, but he said it wasn't schizophrenia: "people living with schizophrenia are not like you". I received a little medication and a warning: "don't take these medications for more than two years, they will clear your mind".

I felt that the medication alone didn't help so I decided to look for something else. After approximately six years of very little medication, psychotherapy, and biomedical approach, today I'm without treatment. If we listen to the voices, we can understand something about their meaning, about the person: in Hungary we combine it with the biomedical aspect.

I truly believe that psychiatry, psychology, social work and sociology should work together. I think a nice initiative is community psychiatric care because it doesn't only treat you but also tyour family. In Hungary, we have a good one, but in many countries, people don't have this opportunity. Today, psychiatric care is wrong to think that only families are your true helpers; all the important people you have in your life play crucial roles.

Stories from people living with schizophrenia

Janine Berg-Peer,

Author, Coach and Consultant for Carers

I've been a carer for over 60 years, because my mother suffered from bipolar disorder. My youngest daughter got this diagnosis of schizophrenia 27 years ago, she was 17. The doctor said, "do not think that it's your fault," — I never thought it was my fault!. We had the same difficult journey together. At the beginning, she said, "I don't have this illness — so, if I don't have it, I don't need any medication". I'm not against medications but I do think they have her far too many, too potent medications.

Ten years later, she stopped taking medication due to the side effects. She had to go to the hospital and the doctor said: "I see that you're not feeling very well. If you stay here voluntarily, I guarantee you that in two or three weeks, you'll be fine again". It was the first time that any professional had given her a choice, some autonomy. From then on it really improved, and she still takes medications. She had an episode again two or three times, however, it wasn't as dramatic. Half of my friends didn't want to have anything to do with it, but she kept her friends from school.

Rethinking Schizophrenia: Addressing the challenges

Early detection/diagnosis and effective treatment

What we need:

- Increased investments in research and innovation in the field of schizophrenia to enhance the understanding of its pathophysiology, mechanisms, and risk factors.
- Education of healthcare professionals, including general practitioners and nurses, throughout their career journey on the risk factors, early detection, and preventive interventions associated with schizophrenia.
- Empowerment of individuals living with schizophrenia to engage in shared decision-making with healthcare professionals to effectively manage their symptoms.
- Ensured access to innovative and complementary interventions for individuals dealing with schizophrenia.

Schizophrenia is often diagnosed at a young age. In those years people make plans. They choose a profession, start new studies, set goals for the future, find partners and friends. Most of their time is spent in school, universities, and the workplace. Efforts therefore need to be made on prevention in pre-adolescents and adolescents in high schools.

A better understanding of the pathological processes and risk factors might help prevent schizophrenia in at-risk individuals and lead to more specific and effective detection, diagnosis and interventions giving them back the life they wish to live.

We need to be able to tell the difference between a teenage crisis, a refusal to go to school and the onset of illness. These three behaviours have similar symptoms, but only the onset of the disease can have irreversible consequences if it is not treated quickly. A diagnosis of schizophrenia might force them to question their choices: to suspend studies, change jobs, put their projects on hold to get better, impair their interpersonal relationships. They might feel rejected, withdraw, or drop out from school, lose autonomy and suffer.

To ensure mental health and counter school dropout, early retirement and unemployment, schools, universities, and workplaces should implement a series of preventive measures. This might include raising awareness on mental health conditions and the risks of cannabis use, identifying individuals at risk, offering psychological support and promoting a healthy lifestyle.

"To be in front of young medical students, who don't have a lot of psychiatry in their courses, to tell them how painful it was... I succeeded to do something with my pain. My cries and my shouts, in a way, were not in vain."

Matthieu de Vilmorin, Former President, Schizo Oui

People living with schizophrenia often access mental health services through a general practitioner: it is critical that primary care providers receive adequate and continuing education on mental illness during medical training and throughout their careers.

"I never looked at my files: I trusted doctors."

Matthieu de Vilmorin, Former President, Schizo Oui

People living with schizophrenia should be active players in their own treatment and care. To this end, it is necessary that a strong therapeutic alliance is established between the health care professional and the person living with schizophrenia. Based on such a mutual listening, understanding, transparency, respect and trust, better adherence to treatment can be ensured.

"Together with the psychiatrist, we decided to keep my son on a low dose of antipsychotics due to the side effects. His worst side effect has been a sharp increase in his weight. He weighs about twice as much as he should weigh, which, of course, is very dangerous."

Philippa Lowe, Patient Advocate, Rethink Mental Illness

Individuals with schizophrenia and their families as caregivers should actively participate in, and be consulted on, all decisions impacting their health, including medication type, formulation, and dosage. The psychiatrist should foster a collaborative relationship, emphasizing shared decision-making. Together, they can navigate diverse options, selecting an approach that minimizes symptoms and side effects concurrently.

"She had to go to the hospital and the doctor said: "I see that you're not feeling very well. If you stay here voluntarily, I guarantee you that in two or three weeks, you'll be fine again". It was the first time that any professional had given her a choice, some autonomy. From then on it really improved, and she still takes medications."

Janine Berg-Peer, Author, Coach and Consultant for Carers

It is important that families as caregivers become part of this therapeutic team. Their role is of utter importance in providing information to professionals. The choice of psychiatrist is a key moment in the treatment journey. A good psychiatrist ensures continuity of care and a positive treatment experience.

A holistic approach to schizophrenia care and management

What we need:

- Assessment of people living with schizophrenia for the three components of schizophrenia including positive, negative and cognitive symptoms.
- Advocating for comprehensive approaches encompassing pharmaceutical, psychosocial, lifestyle, and spiritual dimensions.
- Guaranteed continuity of care with dedicated healthcare professional teams, minimizing fragmentation in the care services.
- Prioritisation physical health by incorporating general medical care into the overall management of people living with schizophrenia.
- The provision of support and the development of trainings for family peer advocates.
- Encouragement to adopt a comprehensive approach as part of the European Mental Health Strategy.

"Pharmaceuticals help but the solution is everyday life. What we live every day, who we work with, the people we see, what we do. If love is missing, nothing works."

Anonymous

A holistic approach involves regular monitoring for medication effectiveness, potential side effects, and adjusting treatment and intervention plans as needed.

“Painting is my biggest ally. I would say it’s the thing that helps me most in life. Some people alleviate stress with sports, I do it with painting. It's my way of expression.”

“I see sounds in colours, so I can speak to my paintings.”

Anastazia Benzahi, Patient Advocate, Positive Minders

Incorporating psychosocial interventions can enhance coping skills, improve social functioning, and promote recovery.

“I have a summer cottage, as life in Berlin can be stressful and it is nice to spend weekends outside by the lake or in the forest. Being in the forest is really nice, calming; it gives me a different kind of stability.”

Cordt Winkler, Clinical Product Developer, Recovery Cat

Addressing physical health is vital, as individuals with schizophrenia may have a higher risk of certain health conditions. Encouraging regular medical check-ups, a healthy diet, exercise, and managing comorbidities contributes to overall well-being.

“Humour helps me tolerate the side effects of neuroleptics and ensures a better quality of life on this journey.”

Cordt Winkler, Clinical Product Developer, Recovery Cat, Germany

Also drug side effects, notably weight gain and sleep troubles, can be countered by adopting a healthy lifestyle, including a healthy diet and sport. Practicing physical activity also has the benefit of reducing stress levels and improving sleep quality.

“Tell what you hear and tell what you think about that. I asked the people in my life to share their ideas about me — that’s how my voices nearly disappeared.”

Péter Kéri, President, GAMIAN-Europe

Families as caregivers, friends, roommates, and colleagues are a fundamental part of social life and, consequently, of the treatment pathway. Ensuring a seamless transition between different levels of care, including inpatient and outpatient services, helps maintain continuity and prevents disruptions in treatment.

“We need other people around us. We need to talk, to do things together with other people, to listen to other people, to communicate, to spend time together. I always surround myself with people and that’s the solution, my small discovery.”

Anonymous

Families as caregivers need support and care for themselves. There is a need for training and development of family peer advocates. Enhancing training and support for family carers is a key strategy for mitigating the impacts and achieving substantial cost savings. Providing support for families as caregivers not only improves their well-being but also enhances their ability to provide effective and sustainable care to their loved ones with schizophrenia. Family carers must be seen beyond their role, deserving a life of fulfilment and joy.

“For 43 years, I thought mental illness was a concept I would never have to deal with. But you know what? I’m stronger and more solid than I’ve ever been, having dived to the very depths of it.”

Péter Kéri, President, GAMIAN-Europe

Through the European Mental Health Strategy, the European Union is promoting an integrated, multidisciplinary approach that engages all key players in the field around the treatment of mental disorders. By involving families, educators and healthcare professionals, such an approach might also benefit schizophrenia and those affected by it.

Human rights for people living with schizophrenia

What we need:

- Confront and dispel stigma and misconceptions about schizophrenia by presenting accurate information.
- Cultivate an environment that is less discriminatory, more inclusive, and supportive.
- Address the fear of rejection and enhance confidence through the establishment of supportive networks for people living with schizophrenia and their families as caregivers.
- Increase awareness about the impact of schizophrenia on families as caregivers, social relationships, and work life.
- Advocate for the promotion of precision psychiatry approaches.

"Last summer, there were some horrible murders and the person involved was sent to a hospital because he has paranoid schizophrenia. It's very much a hot topic at the moment. That sort of scenario feeds into stigma. People will feel differently about severe mental illness this week than they did last week, than they did the week before."

Philippa Lowe, Patient Advocate, Rethink Mental Illness

For years, the traditional media have fed a distorted narrative of schizophrenia. News stories involving people with schizophrenia ended up contributing to the growing public feeling of fear toward those who experience this condition.

"I talk about mental health on YouTube, I'm trying to raise awareness. I've already talked about my schizophrenia and received a lot of comments from people thanking me. Patients feel less alone in their disorder. More people should do it."

Anastazia Benzahi, Patient Advocate, Positive Minders

New social media has brought a paradigm shift. People with schizophrenia can tell their story and their voices can be heard. It turns out that schizophrenia is scarier to them than to the outside world. Everyone, at whatever level, can contribute to a mentally healthier society, and so much of what is heard is false or inaccurate.

"Mentally ill children need strong parents. Neither sacrificing yourself nor controlling your child is helpful. Support your child to become as self-reliant as possible. You don't live forever."

Janine Berg-Peer, Author, Coach and Consultant for Carers

People living with schizophrenia need all possible support to overcome the challenges that lie ahead. All these actors contribute, with the family as caregiver and healthcare professionals, to build a supportive environment for the person with schizophrenia, reduce social isolation, increase confidence and foster a sense of belonging. Nowadays, there are real or virtual support groups that help people living with schizophrenia feel less lonely and be part of a social network for a gradual return to social life.

"My son has always known he was ill, though he wasn't realising it was a mental illness. He thought there was something terribly wrong with him, he felt like the worst person in the world. But his paranoia isn't such that he would ever be angry with another person or violent with them. He's the gentlest person you can imagine; a very kind, sensitive sort of person. His paranoia is all about himself and his wickedness."

Philippa Lowe, Patient Advocate, Rethink Mental Illness

Accepting the condition, living with it, and standing by those who experience it, is a long and complicated journey. People living with schizophrenia, their loved ones, and society as a whole are often unprepared to meet the challenge. Information campaigns play a key role. To secure the help they need, people living with schizophrenia must be informed about their condition, feel accepted and understood in their social environment.

"I know what stigma is, people look at you as if you are an alien. The media makes people afraid of such problems, isolating families from society. Without society helping you, family cannot help you. My father was ashamed of me."

Anonymous

Increasing public awareness on schizophrenia will contribute to restore the truth, fight stigma, and dispel false myths surrounding this condition.

What people with schizophrenia say	Misconceptions vs reality
"In the old days they defined schizophrenia as a split personality."	People with schizophrenia do not have a double personality. They simply experience two realities at the same time.
"In people's minds, people with schizophrenia are dangerous."	People with schizophrenia are generally not dangerous to themselves or others. On the contrary, they are more likely to be subject to violence.
"The only way I found to be back on track is to work."	People with schizophrenia can get better. Not only people with schizophrenia can work, but it seems that work has a therapeutic effect on them.
"People with schizophrenia are incapable, permanently disabled."	People with schizophrenia can function well, live independently, ensure their self-care.

To respect the individual needs and characteristics of someone living with schizophrenia, precision psychiatry approaches should be promoted and implemented in the clinical practice. To make these approaches a reality, several ethical challenges should be taken into account (Fusar-Poli et al., 2022). For example, there is a high-risk of data leakage and privacy concerns, big data and actors from outside the healthcare system. Access to precision psychiatry is still limited in particular for vulnerable groups. Autonomy, beneficence, non-maleficence and justice criteria are imprecise. Precision psychiatry should be accurate, useful, transparent, secure, maintained, equitable, and empowering (Kéri et al., 2023).

Stories from people living with schizophrenia

Cordt Winkler,

Clinical Product Developer, Recovery Cat

My father was diagnosed with paranoid schizophrenia, so I knew the disease since I was a child and I was very afraid it could happen to me as well. When I was 23, I recognized some of the early warning signs myself and visited an early recognition center, but they only diagnosed a slight depression. I was diagnosed with psychosis after one year, and with schizophrenia one year later. It was dramatic: many things happened, and I completely lost control.

My first time in a clinic, I was very afraid. I had bad examples from my father in the 80s: he was treated with a lot of force and no communication at all, he was always traumatised by that. The second time, there were a lot of interns who took the time to see what was going on or just prepare a salad with you or play with a therapy dog – it was really helpful. But the third time, it wasn't: they just put me on a lot of medication and didn't want to hear anything from me. When the third episode happened, that was very dramatic. I got lost on a holiday in Italy, it was really dangerous. After the third episode and trying many kinds of neuroleptics, I switched to a new treatment, and I had the fourth and last crisis in 2013.

In the acute phase, there were delusions, loss of clear thinking and the ability to have a normal life. I tried a few times to get rid of the medication and I noticed I had the energy to eat better, to feel more joy, to be motivated and do more things. But as I want to be stable, it's always a balance between stability and quality of life: I feel that it's really hard to distinguish between the side effects of medications and negative symptoms. Feeling depressed, unable to clean my apartment, do things, be motivated, do sport: these symptoms are much more important than delusions, that's most of my life.

My friends were very helpful and supportive: they managed to keep me away from the hospital. I did cognitive behavioural therapy for a few years, and have been stable for 10 years now and I'm now doing depth psychology. I'm still on a very low dose of medication and I want to get rid of the medication completely in a few years.

Stories from people living with schizophrenia

Philippa Lowe,

Patient Advocate, Rethink Mental Illness

My name's Philippa Lowe and I spent my career as a psychologist in our prison service. My son developed the first symptoms of schizophrenia when he was 20 years old and in his third year at university. I've been looking after him since he was 20 and he's now 47.

He went into hospital then, apparently, recovered. Two years later, it happened again. Since then, he's been in the local hospital's psychiatric unit four times, between 1997 and 2008, and in another specialist hospital on two occasions between those dates - he was a bit obsessive, it was Obsessive Compulsive Disorder, Body Dysmorphic Disorder.

They were very unwilling to talk to us, as parents, about what was actually wrong. It was only after getting a second opinion that we discovered that when my son was first admitted to hospital in 1997, he was given the label "paranoid schizophrenia". Unfortunately, our psychiatrist has left the practice and there's no replacement, apparently. The state of our National Health Service is very bad for mental illness as well as physical.

My son doesn't live with me. He lives quite a long way from me, but he spends weekends with me, and in the week, he goes to various activities organised by a charity there. He has a personal assistant two afternoons a week, who helps him with housework, shopping, accompanies him on walks and weighs him weekly.

I won't last forever; I've just passed my 80th birthday. You always know that your child with mental illness will outlive you, but eventually it's not just philosophical, it becomes reality and there's things you have to do, like decide what happens to your money. So, you set up a trust, so the money goes somewhere else, but my son can have money from it whenever he needs it. But, you know, nothing can replace you: he won't be able to ring me up 10 times a day.

Conclusion

> “We have come a long way since diagnosis meant condemnation, but I'll continue to say it again and again: the sufferer is the actor in his or her own recovery. The sufferer is no longer alone in the face of the illness, but the sufferer is the one who takes the lead. To regain breath, you have to move forward. Life is movement.”

Matthieu de Vilmorin, Former President, Schizo Oui

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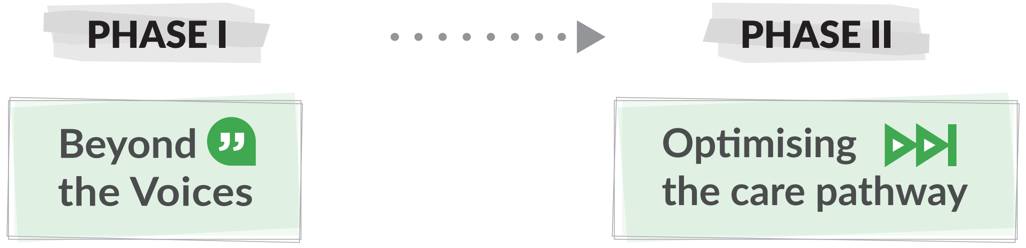
About Rethinking Schizophrenia

"Rethinking Schizophrenia: Beyond the Voices" is the first part of a research-driven project offering tangible policy and care pathway changes to improve the lives of people living with schizophrenia across Europe. It challenges the status quo and refreshes the European policy debate on people living with schizophrenia, recognises the essential role of social support and encourages multi-stakeholder-driven policy.



PHASE I

Beyond the Voices

PHASE II

Optimising the care pathway

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About the European Brain Council

The European Brain Council (EBC) is a network of key players in the "brain space", with a membership encompassing scientific and professional societies, patient organisations and industry partners. A non-profit organisation based in Brussels, its main mission is to promote brain research with the ultimate goal of improving the lives of those living with brain conditions, neurological and mental alike.

For more information about "Rethinking Schizophrenia: Beyond the voices", please visit: https://www.braincouncil.eu/projects/rethinking-schizophrenia/

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