

Healthcare  
professionals

**TIME TO  
COMMIT TO  
POLICY  
CHANGE**

# Schizophrenia

## Policy implications for healthcare professionals

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- European Federation of Psychiatric Trainees
- Global Alliance of Mental Illness Advocacy Networks-Europe
- National Alliance on Mental Illness
- National Council for Behavioral Health
- Royal College of Psychiatrists
- Schizophrenia International Research Society
- Vinfen
- World Federation for Mental Health



## Recommendations for policy change

**Schizophrenia has a profound personal, social and economic impact. Furthermore, public attitudes towards schizophrenia lead to prejudice and discrimination.**

**We therefore recommend the following policy actions to local, national and regional policy makers.**

1. Provide an evidence-based, integrated care package for people with schizophrenia that addresses their mental and physical health needs. This should be underpinned with an integrated approach by their healthcare professionals and supported by the national healthcare system and by educational and research facilities.
2. Provide support for people with schizophrenia to enter and to remain in their community, and develop mechanisms to help to guide them through the often complex benefit and employment systems to enhance recovery. Guidelines and educational programmes should be developed and implemented to support the inclusion of people with schizophrenia in their community, workplace or school.
3. Provide concrete support, information and educational programmes to families and carers on how to enhance care for an individual living with schizophrenia in a manner that entails minimal disruption to their own personal lives.
4. Consult with healthcare professionals and other stakeholders directly involved in the management of schizophrenia, including organizations that support people living with schizophrenia, their families and their carers, in order to regularly revise, update and improve policy on the management of schizophrenia.
5. Provide support, which is proportionate to the impact of the disease, for research and development of new treatments that improve the overall outlook for people with schizophrenia, including those that target negative symptoms and cognitive impairment.
6. Establish adequately funded, ongoing and regular awareness-raising campaigns to: increase the understanding of schizophrenia among the general public; emphasize the importance of positive societal attitudes towards mental illnesses; highlight available support for the management of schizophrenia; and deter discriminatory attitudes and actions. Such campaigns should form an integral part of routine plans of action.

**Our recommendations are based on research evidence, stakeholder consultation and examples of best practice, worldwide.**

## Executive summary

This report summarizes the evidence and consensus findings emerging from discussions among a group of international psychiatrists, researchers, advanced practice nurses, patients and carers with expertise and experience in the field of schizophrenia. The group met several times, bringing world-leading insight into the clinical and scientific evidence base for schizophrenia, combined with first-hand insight into the practical reality of living daily with the condition.

Excitingly, this diverse group was united in reaching three clear, evidence-based conclusions.

- The likelihood of a good outcome for people with schizophrenia has improved considerably in recent decades; with appropriate management, many people affected by the condition can now achieve an acceptable quality of life.
- A modern approach to schizophrenia management should aim to move patients along a pathway towards recovery of normal function, as well as to alleviate distressing symptoms.
- Driving further change towards a more positive outlook for schizophrenia requires fundamental policy change.

## Improving schizophrenia care – a priority in healthcare policy

### Protecting our human rights

The protection and treatment of people with mental disorders is recognized by the United Nations as a human right.<sup>1</sup> Freedom from prejudice, abuse, discrimination and hostility, and a right to the best available treatments are enshrined in the World Health Organization Global Mental Health Action Plan,<sup>2</sup> which emphasizes the use of evidence-based therapies and the empowerment of people with mental disorders. During the past 20 years schizophrenia care has improved, but many people with the condition still find it difficult to live a productive life in society. Improving the care of people with schizophrenia needs to be a priority in healthcare policy.

### Impact of schizophrenia

Schizophrenia affects a person's well-being, cuts life short and is among the top 10 causes of disability globally.<sup>3</sup> At least 26 million people are living with schizophrenia worldwide,<sup>4</sup> and twice as many are indirectly affected by it (e.g. as carers). Importantly, with appropriate care and support, people with schizophrenia can recover and live fulfilled lives in the community, with up to 50% of individuals potentially having a good outcome.<sup>5,6</sup> In 2012, the estimated total cost in Europe of psychotic disorders such as schizophrenia was €29 billion – equivalent to €5805 per patient per year.<sup>7</sup> Meanwhile, in the US, the total annual cost of schizophrenia has been estimated to be \$62 billion.<sup>8</sup>

### Social consequences for people living with schizophrenia

Despite improvements in societal attitudes, many people with schizophrenia still face social isolation, prejudice and discrimination, making it difficult for them to live a productive life in society. This discrimination can prevent them from seeking help

for their condition and can also disrupt their personal relationships and employment. Schizophrenia imposes a heavy toll on families and friends, who bear much of the day-to-day burden of care. Some carers may find the burden so excessive that they cannot continue in their role; better support is needed on all fronts. Improving the care of people with schizophrenia should thus be a priority in healthcare policy.

## Expanding the focus on recovery

The past four decades have seen a growing movement in schizophrenia that emphasizes the importance of recovery, in addition to symptomatic improvement, as the aim of treatment. This has led to widespread acceptance that some degree of recovery of normal function is possible, despite the presence of residual symptoms, and that some people with schizophrenia may achieve full recovery.<sup>9-11</sup>

### The concept of recovery

Recovery from schizophrenia is defined in various ways. It is often viewed clinically as the absence of symptoms and achievement of normal function. For a person with schizophrenia, the definition of recovery focuses on progression beyond the psychological effects of schizophrenia towards a meaningful life in the community.<sup>9</sup> From their perspective, recovery can

be viewed as a process of personal growth despite the presence of mental illness. Thus, the concept of recovery encompasses attainment of a fulfilled and valued life, rather than elimination of symptoms alone.<sup>12</sup>

### How can you help?

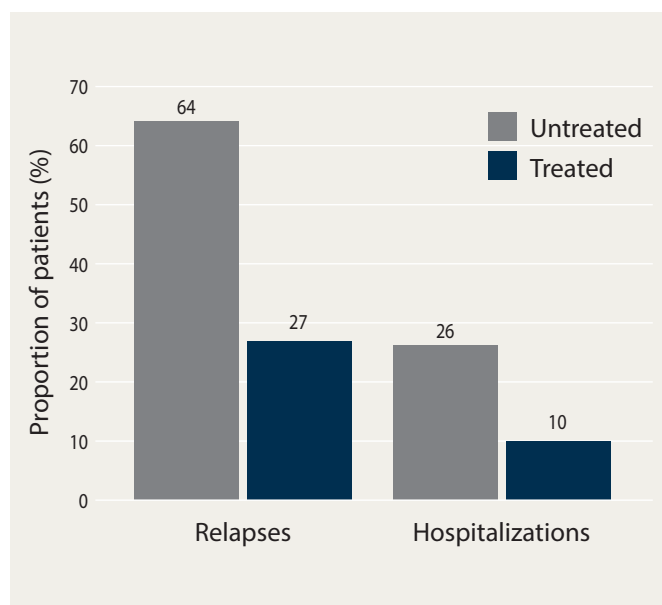
- Recognize and promote the fact that many people with schizophrenia can ultimately achieve a productive and fulfilled life in the community.
- Always aim for recovery as the first principle in treatment recommendations; such recommendations should be agreed jointly by healthcare providers and the person with schizophrenia (or their representative, if appropriate).

## Integrating current approaches to schizophrenia treatment

Adopting an integrated approach to the treatment of schizophrenia (i.e. combining medical and psychosocial therapies, while also paying attention to physical health) improves the outcome. Thus, clinicians should be part of a multidisciplinary team consisting of healthcare professionals, social service providers and other relevant agencies (e.g. housing authorities).

### The medical approach

Antipsychotic medication is effective in the treatment of acute psychotic episodes and first-episode or early schizophrenia.<sup>9,13</sup> Importantly, prompt treatment of psychosis in the early stages may avoid a long duration of untreated psychosis.<sup>14</sup> Long-term use of medication reduces the risk of both relapse and



**Figure 1.** Long-term antipsychotic medication significantly reduces the number of relapses (at 7–12 months) and the number of hospitalizations in patients with schizophrenia, compared with placebo (data from a combined analysis of 65 clinical trials).<sup>15</sup>

hospitalization in people with schizophrenia by about 60% (Figure 1).<sup>15</sup> By preventing relapses and restoring insight, antipsychotic medication can provide a period of stability, facilitating the introduction of and improved engagement with further treatments such as psychosocial therapies.<sup>16</sup>

Behavioural symptoms, such as hostility and aggression, are common in schizophrenia, and there is evidence that they are amenable to antipsychotic medication.<sup>13</sup> In general, good adherence to treatment appears to be associated with low levels of aggression,<sup>13,17</sup> and people with schizophrenia who adhere to treatment and are clinically stable appear to be no more violent than the general population.<sup>17</sup>

### Limitations of current antipsychotic medication

Antipsychotics are effective in reducing the positive symptoms of schizophrenia (e.g. delusions and hallucinations) and suicidal behaviour,<sup>9</sup> but they have limited effects on negative symptoms (e.g. apathy and lack of drive) and cognitive impairment.<sup>13,18,19</sup> This is a major concern, because negative symptoms and

cognitive impairment are associated with impaired occupational and social function, and constitute a significant barrier to independent living.<sup>13</sup> New therapeutic approaches, aimed at discovering novel drugs that are effective against negative symptoms and cognitive impairment, are under investigation.<sup>18,19</sup>

Antipsychotic medication is also associated with a number of side effects that can be severely troubling and may limit adherence to treatment, thereby reducing the potential for recovery. Individual antipsychotics differ in their side-effect profiles, but among the most common effects are motor symptoms and metabolic and hormonal disturbances.

### The challenge of adherence

Adherence to antipsychotic medication is often low in people with schizophrenia;<sup>20</sup> the principal reasons for this are shown in Table 1. Non-adherence is commonly associated with relapse,<sup>21</sup> often leading to hospitalization, although this association may reflect the possibility that non-adherence may be a symptom of worsening of the disorder. In addition, non-adherent individuals are more likely than adherent patients to have poor long-term function, to be violent,<sup>17</sup> to be arrested<sup>22</sup> or to attempt suicide.<sup>23</sup> Interestingly, being a member of a patient organization or self-help group can exert a positive influence on adherence.<sup>24</sup>

### Treatment-resistant schizophrenia

Many patients show only a partial response to treatment; even when remission is achieved, few people are completely symptom free.<sup>18,25</sup> In addition, up to one-third of people with schizophrenia show a poor response to antipsychotic medication, and some may develop treatment-resistant schizophrenia.<sup>13</sup> Symptoms can be improved in such cases, but they require specialist management and monitoring,<sup>26</sup> and timely intervention may help to avoid prolonged treatment with ineffective medications.



**Table 1. Principal reasons for low adherence to antipsychotic medication.**

- Insufficient information about the illness and its treatment
- Lack of improvement in psychotic symptoms
- Troublesome side effects (which may be relieved if the patient stops taking the medication)
- Lack of awareness of the need for treatment
- Financial difficulty (especially in countries facing economic crisis)
- Complexity of treatment schedules<sup>13</sup>
- Fear of discrimination
- Poor doctor–patient relationships
- Lack of support from carers

### How can you help?

- Encourage adherence by understanding a patient’s reasons for non-adherence and by involving them in treatment decisions.
- Commit to the principles of good prescribing practice, avoid polypharmacy and the use of excessive doses whenever possible, and consider appropriate alternative treatment measures at an early stage in patients who require it.
- Promote individualized therapy, basing treatment on the recipient’s choice and preferences.
- Carefully monitor patients for side effects and intervene if appropriate.
- Collaborate with carers and provide information and education to patients about self-help groups and patient organizations to help to achieve adherence and prevent relapses.

### Psychosocial therapies and schizophrenia

Psychosocial therapies are important in the treatment of schizophrenia (Table 2). They improve patients’ functioning in the community, which can lead to clinical improvements.<sup>27</sup> The evidence base for some psychotherapies is so strong that there is a good case for trying them before other potential treatments. Such therapies can substantially improve patients’ well-being and quality of life, and should be available to all people with schizophrenia. Importantly, people who are affected by schizophrenia, both the patients themselves and those who care for them, can offer powerful and eloquent insights into the condition.

As a result, peer-led interventions have an important place in schizophrenia care, and this approach has been actively promoted in both the US and the UK.<sup>6,28</sup>

### Limitations of psychosocial therapies

Psychosocial therapies may not be appropriate unless symptoms are well controlled and patients have insight into their condition and the need for treatment. Patient selection, for example, may be important for a successful outcome: highly motivated individuals generally respond to cognitive remediation better than those who are less

**Table 2. Potential benefits of psychosocial therapies.**<sup>12,29–37</sup>

Intervention	Potential benefits
Assertive community treatment	Reductions in rates of homelessness and lengths of hospital stays in high service users (but limited impact on social functioning and employment)
Cognitive behavioural therapy for psychosis	Decreases in both positive and negative symptoms and mood disturbances, and improved social functioning
First episode intervention for psychosis	Improvements in quality of life, social functioning and adherence
Cognitive remediation	Improvements in cognition and psychosocial functioning
Family psychoeducation	Some improvement in social functioning and empowerment; <sup>12,32</sup> family members also report reduced levels of distress and improved family relationships
Peer support and illness self-management training	Enhancement of empowerment and ability to cope with the illness Improved symptoms, hopefulness and quality of life
Social skills training	Improvements in social functioning and reduced relapse rates
Supported employment	Increased rates of competitive employment and fewer hospitalizations Increased hours worked and wages earned Gains in self-esteem and quality of life
Integrated treatment for coexisting substance abuse disorder	Reductions in substance use and arrests Improved functioning

motivated.<sup>38</sup> Moreover, some people, if not treated with antipsychotic medication, may worsen when stressed by psychosocial interventions.<sup>39</sup> The cost of

some therapies may also be prohibitive in countries where they are not available through public health services.

### How can you help?

- Establish a strong therapeutic alliance with patients and their families, and ensure that recommendations on treatment goals and strategies are followed as a result of such alliances.
- Encourage recovered patients to share their experiences with others and to act as role models for individuals undergoing treatment, and to provide such patients with appropriate support during this process.
- Consider using psychosocial therapies earlier in the course of the disorder.

### Management of coexisting physical illness

Schizophrenia is associated with a substantial burden of physical illness: on average, people with schizophrenia die 15–20 years earlier than the general population.<sup>40–42</sup> This burden is the result of a number of factors, including:

- a high frequency of poor health behaviours (e.g. smoking, alcohol, substance abuse)
- under-diagnosis of physical illness<sup>43</sup>
- decreased access to health care compared with the general population (furthermore, when care is provided it is often too late and of poor quality)<sup>41,44</sup>
- side effects of medication
- increased risk of cardiovascular disease
- suicide

- self-stigmatization (people with schizophrenia may be reluctant to seek health care because they fear prejudice and discrimination)
- self-neglect or inadequate self-care, as a consequence of schizophrenia.

Sometimes, too little attention is paid to treating physical illness in people with mental illness.<sup>41</sup> Recent years have seen improvements resulting in better coordination of healthcare services, with primary care physicians playing an increasing role. Carers, too, are becoming increasingly involved in monitoring the physical well-being of people with schizophrenia, forming a ‘therapeutic alliance’ with healthcare professionals.

### How can you help?

- Be attentive to the physical health needs of patients with schizophrenia. Actively monitor patients’ health and measure risk factors accordingly.
- Offer targeted interventions to stop smoking and alcohol or substance abuse to all people with schizophrenia who need them. Interventions aimed at alcohol or substance abuse should form an integral part of mental health care for people with schizophrenia.
- Ensure that people with schizophrenia are not prevented from seeking or receiving appropriate care for their physical health.

## Creating a supportive environment that promotes recovery

### Improving the environment results in better symptom control and function

The creation of a supportive environment in which people with schizophrenia can work towards recovery is central to schizophrenia care. Finding and keeping a job, being able to manage personal finances, and establishing and maintaining good interpersonal relationships are key needs for people with schizophrenia; social function often improves when these needs are addressed.<sup>45</sup> People with schizophrenia, however, often face prejudice and

discrimination when seeking employment or training, or when trying to form close relationships.<sup>46</sup> These negative attitudes towards schizophrenia can be effectively tackled by awareness campaigns aimed at the general public.<sup>47</sup> Importantly, educational campaigns should be a continuing process; single campaigns usually have a limited effect.<sup>48</sup>

### A poor social outlook

In today’s society it is unacceptable that patients with schizophrenia are 6–7 times more likely to be

unemployed than the general population, and only 10–20% are in competitive employment.<sup>12,49</sup> Supported employment approaches are effective and should be encouraged, and better mechanisms are needed to guide people through the benefit and employment systems. Furthermore, up to one-third of homeless people in the US have schizophrenia and 15% of people with schizophrenia in Europe have experienced homelessness,<sup>50</sup> which is a major barrier to recovery. Contact with the criminal justice system is also common, but this can be prevented by

### First-person account

"[My psychiatrist] listened to me patiently, got me on the right dose of medication, and after 6 months diagnosed me with schizophrenia. He described to me what the illness was and gave me literature references to read to help me understand the illness. I remember sitting in the family room with my mum and spending hours reading everything I could get my hands on."

From Scotti P. *Schizophr Bull* 2009;35:844–6.<sup>51</sup>

high-quality, early intervention services.<sup>35</sup> More therefore needs to be done to identify schizophrenia earlier and to initiate appropriate treatment as soon as possible to reduce these social consequences.

### Inform and inspire

Information for people with schizophrenia about the support available for employment, housing and other issues is often lacking. Advocacy groups, peer-led 'self-help' groups and volunteer groups that work with their peers who are mentally ill can offer valuable education and advice to address individual concerns. Groups such as the National Alliance on Mental Illness (NAMI), the European Federation of Associations of Families of People with Mental Illness (EUFAMI) and the Global Alliance of Mental Illness Advocacy Networks (GAMIAN) have an increasingly important influence on the care of people with schizophrenia. They speak out in support of those affected by mental illness, provide information and education, campaign against stigma and discrimination, and much more.

### How can you help?

- Intervene as early as possible when individuals show initial signs and symptoms of schizophrenia.
- Inform patients about advocacy and peer-led groups that can help the recovery process and offer valuable advice and support.
- Engage with policy makers and other relevant stakeholders and promote recognition that a supportive environment is essential for recovery in people with schizophrenia, as well as encouraging the use of cost-effective measures to achieve this.
- Engage with other stakeholders to ensure that effective psychoeducation and public education programmes are appropriately targeted and implemented, and that peer-led services are adequately supported and made available to all who could benefit from them.
- Ensure that the needs of people from ethnic minorities who have schizophrenia are identified and addressed in a culturally appropriate manner.

## Conclusions

- ***Better lives for people living with schizophrenia:*** this is a reachable goal! We have come a long way towards achieving this in recent years, but much can (and should) still be done. Successful care requires an **integrated team approach**, involving psychiatrists, a range of other healthcare professionals, social care providers and other external agencies. It also involves collaboration with people with schizophrenia, their families and other sources of support. For private healthcare systems, such a team approach will require careful alignment of reimbursement mechanisms to support high-quality care.
- A second prerequisite for successful care is **adequate funding** – at least equivalent to that for other medical conditions such as cancer and heart disease – for research, treatment, services and teaching of future mental healthcare professionals. At present, the extent to which effective psychosocial therapies are funded by public healthcare systems varies across countries; hence, many patients are denied treatment. More support is also needed for independent studies of potentially beneficial interventions.
- Implementation of the recommendations set out at the front of and within this report will require **engagement by every stakeholder**. With commitment from all, change can be achieved.

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