Patients and advocacy groups

TIME TO COMMIT TO POLICY CHANGE

Schizophrenia

A guide for patients and advocacy groups to support policy change

Wolfgang Fleischhacker
Celso Arango
Paul Arteel
Thomas R E Barnes
William Carpenter
Ken Duckworth
Silvana Galderisi
Martin Knapp
Stephen R Marder
Norman Sartorius

Publication of these recommendations has been funded by an educational grant from F. Hoffmann-La Roche, who had no editorial influence on the content

Authors

Professor Wolfgang Fleischhacker (Chair)
Innsbruck Medical University, Innsbruck, Austria

Professor Celso Arango
Hospital General Universitario Gregorio Marañón, CIBERSAM, Madrid, Spain

Mr Paul Arteel
GAMIAN-Europe, Brussels, Belgium

Professor Thomas R E Barnes
Imperial College London and West London Mental Health NHS Trust, London, UK

Professor William Carpenter
Maryland Psychiatric Research Center, University of Maryland School of Medicine, Baltimore, MD, US

Dr Ken Duckworth
National Alliance on Mental Illness, Arlington, VA, US

Professor Silvana Galderisi
Second University of Naples, Naples, Italy

Professor Martin Knapp
London School of Economics and the Institute of Psychiatry, King's College London, London, UK

Professor Stephen R Marder
Semel Institute, UCLA, and the VA Desert Pacific Mental Illness Research Education and Clinical Center, Los Angeles, CA, US

Professor Norman Sartorius
Association for the Improvement of Mental Health Programmes, Geneva, Switzerland

This publication highlights the key recommendations and actions for patients and advocacy groups contained in the full report, *Schizophrenia – Time to Commit to Policy Change*, which can be found here:

http://www.oxfordhealthpolicyforum.org/schizophrenia-time-to-commit-to-policy-change

The authors thank Professor Howard H Goldman for his support and consultation on the document. The full report was endorsed by the following organizations:

- American College of Neuropsychopharmacology
- American Psychiatric Nurses Association
- Brain & Behavior Research Foundation
- European Brain Council
- European College of Neuropsychopharmacology
- European Federation of Associations of Families of People with Mental Illness
- 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 and brought together 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 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 – delivering our fundamental human right

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.

What is schizophrenia?

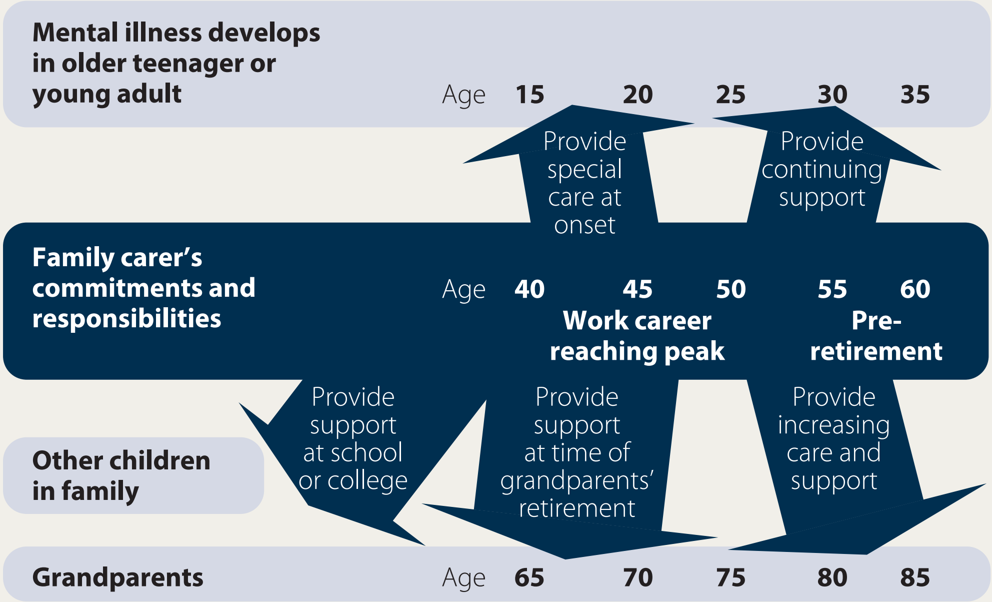
The term schizophrenia describes a mental disorder characterized by abnormal thinking, disturbances in perception, and decreased or increased emotional expression. It affects a person's well-being, cuts life short and is among the top 10 causes of disability globally.[1] At least 26 million people are living with schizophrenia worldwide,[2] 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.[3]

Social consequences for people living with schizophrenia

Despite improvements in societal attitudes, many people with schizophrenia still face social isolation, prejudice and discrimination. This can prevent them

Burden on family carers: what is the bigger picture?

- At the age of onset of a child's mental illness, the age of family carers (40–60 years) and the possibility of separation or divorce mean that they are at a time of great family stress and pressure.



Reproduced with permission from EUFAMI.

from seeking help for their condition and can also disrupt their personal relationships and employment. Furthermore, schizophrenia imposes a heavy toll on families and friends, who bear much of the day-to-day burden of care.

Making *best* practice *standard*: investment is needed

It is imperative that our existing tools are available to all those with schizophrenia who need them. More needs to be done to identify schizophrenia earlier and to start treatment as soon as possible. Improving the care of people with schizophrenia should be a priority in healthcare policy.

The concept of recovery

There is a growing emphasis on recovery, in addition to improvement of symptoms, as the aim of treatment. This development has led to widespread acceptance that some degree of recovery of normal function is possible, and that some people with schizophrenia may achieve full recovery.[4]

Importantly, the recovery movement has been led by people with schizophrenia. From their perspective, recovery can be viewed as a process of personal growth despite the presence of mental illness.[5] Their resilience and empowerment play an important role in recovery: each individual uses their strengths to develop strategies to cope with residual symptoms and to focus on where they want their life to go. For a person with schizophrenia, recovery focuses on progressing beyond the psychological effects of this condition towards a meaningful life in the community.[4] Studies show that many people with schizophrenia can achieve a good long-term outcome, and there is some evidence that not all people require long-term medication.[3,6]

What more can you do?

- Recognize that many people with schizophrenia can ultimately achieve a productive and fulfilled life in the community.
- Consider the potential for recovery as a first principle in treatment recommendations; such recommendations should be agreed jointly by healthcare providers and people with schizophrenia (or their representative if appropriate).
- Develop appropriate communication campaigns to present current views on recovery in schizophrenia to a wide audience.
- Empower patients to take action and use their inner strength to reach their full potential.

Current approaches to schizophrenia treatment

Combining medical and psychosocial therapies for schizophrenia and paying attention to physical health improve the outcome.

Medical treatment

Drugs used to manage schizophrenia symptoms (antipsychotics) are effective in reducing positive symptoms of schizophrenia (e.g. hallucinations and delusions), but they do not adequately treat negative symptoms (e.g. low motivation and restricted emotion) or cognitive impairment (e.g. problems with memory, decision-making and verbal skills). New treatments are under investigation, aimed at discovering drugs that are effective against negative symptoms and cognitive impairment.[7,8]

Negative symptoms and cognitive impairment may also contribute to failure to take medication as prescribed, which may result in relapse and hospitalization.[4] The very fact that a person is receiving antipsychotic medication may make them feel 'different',[9] which can further encourage them to neglect their drug treatment.[10]

Psychosocial treatment

Psychosocial or 'talking' therapies are important in the treatment of schizophrenia. They improve patients' functioning in the community, which in turn can help to improve symptoms and to reduce the number of relapses or hospitalizations.[11] Cognitive behavioural therapy (a talking therapy that aims to change thought patterns and resulting behaviours) and family therapy/psychoeducation are among the psychosocial treatments that can be helpful.

What more can you do?

- Encourage patients to work together with their families, carers and doctors to agree treatment goals; this should help them to take their treatment as prescribed.
- Remember that preferences about treatment vary among individuals; decision-making should be shared by the medical team and the person with schizophrenia.
- Make people with schizophrenia aware that a variety of treatment options are available.

Peer-support and self-help strategies play an important part in recovery-oriented care. People who are affected by schizophrenia can offer powerful insights into the condition, and peer-led groups can help both themselves and the people for whom they care in several areas (Table 1).[12] Such support can substantially improve patients' well-being and quality of life, and should be available to all people with schizophrenia. Some of the groups offering support for people affected by schizophrenia are listed on page 8.

Table 1. Areas in which peer-led and advocacy groups can provide support.[12]

- Feedback about current status and experiences in society
- Information about psychoeducation
- Updates on beliefs and attitudes that can lead to change, e.g. knowledge of the recovery model can change an individual's attitude to his/her illness
- Education for patients and their families

What more can you do?

- Promote membership of patient organizations and self-help groups.
- Encourage recovered patients to share their experiences with others and act as role models.
- Establish programmes to communicate the potential benefits of psychosocial interventions to payers and other healthcare policy makers, and ensure that the benefits of effective therapies are recognized and acknowledged.
- Join forces with other interested groups and individuals to ensure that effective psychoeducation and public education programmes are carried out and reach the right audiences.
- Ensure that peer-led services are made available to all who could benefit from them.

The added impact of physical illness

People with schizophrenia are highly likely also to have physical illness: their lives are cut short by 15–20 years compared with the life expectancy of the general population.[13,14] High rates of heart disease and smoking lead to early death and ill health;[15] alcohol and substance abuse (especially cannabis abuse) are also common and are linked with increased rates of relapses and hospitalizations, and physical illness.[10]

The physical health needs of people with mental illness are sometimes not identified or managed appropriately.[14] In recent years, however, attention to physical illness in people with schizophrenia has increased. This has led to 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; indeed, family members and physicians often recognize physical health problems more readily than people with schizophrenia themselves.[15]

What more can you do?

- Ensure that people with schizophrenia are not prevented from seeking or receiving appropriate care for their physical health because of prejudice or discrimination.
- Urge patients, family members and carers of people with schizophrenia to monitor physical health problems.
- Encourage patients to adopt healthy lifestyles and to take part in programmes to help them give up smoking and deal with alcohol or substance abuse.

A supportive environment promotes recovery

What are the barriers to recovery?

A supportive environment is vital if people with schizophrenia are to achieve their desired outcomes. For example, having a job, somewhere to live and meaningful personal relationships can all help to promote recovery. Unfortunately, prejudice and discrimination often hinder progress,[16] but with the continued efforts of patient-led and advocacy groups, these negative perceptions can be reduced.

Unemployment is high among people with schizophrenia, but schemes are in place to help them to find work; supported employment interventions can produce substantial savings and also reduce the risk of hospitalization.[17,18] Other barriers to recovery include **homelessness** and **contact with the criminal justice system**. It is estimated that, in Europe, 15% of individuals with schizophrenia have been homeless at some time during their illness,[19] and approximately 8% of the prison population have psychosis, with 2% qualifying for a formal diagnosis of schizophrenia, compared with 0.5% or less of the general population.[17]

Complicated benefit systems

While social security benefits are essential for people with schizophrenia who are unable to work, the benefit system can also make it difficult to find employment.[20] Information about the support available is often lacking (which can delay benefits being received) or may be difficult to access, especially if literacy is an issue.

Communication and education about schizophrenia

Psychoeducation campaigns aimed at the general public can be beneficial in increasing awareness of schizophrenia, decreasing negative attitudes towards mental illness and shortening the duration of untreated psychosis (Figure 1).[21,22] Importantly, they

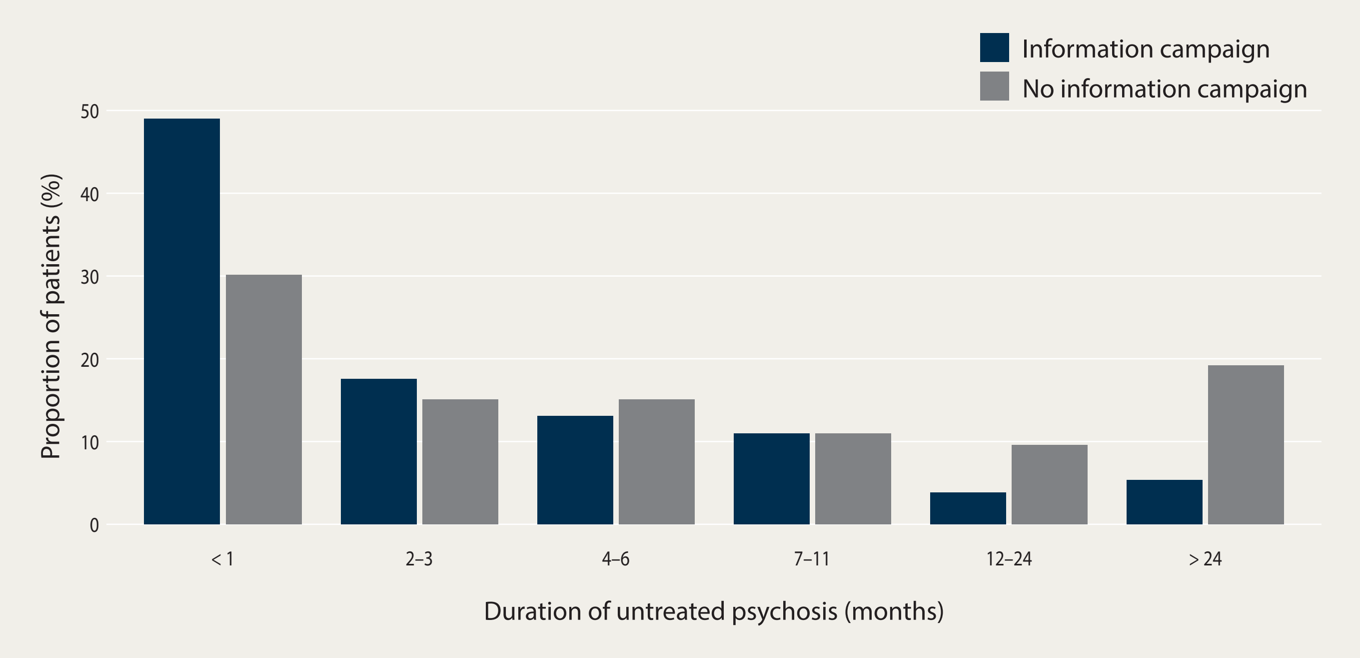


Figure 1. Information campaigns have been shown to have a beneficial effect on the duration of untreated psychosis.[22]

People are more likely to seek help when information campaigns are in progress, so the duration of untreated psychosis is shorter. Figure adapted from Joa *et al.* *Schizophr Bull* 2008;34:466–72.

should be a continuing process; single campaigns appear to have a limited effect.[23]

Schizophrenia services are often fragmented, and people with schizophrenia may find it difficult to navigate through the system. Peer-led interventions and advocacy groups can offer help to individuals to guide them through the complicated system and advise accordingly. In addition, advocacy groups, such as NAMI, GAMIAN, GAMIAN-Europe and EUFAMI, can speak out in support of those affected by mental disorders, provide information and education, and campaign against stigma and discrimination.

What more can you do?

- Offer guidance and advice to ensure that people with schizophrenia receive the benefits to which they are entitled.
- Participate in psychoeducation campaigns (preferably multimedia campaigns, including a social marketing approach) that are directed towards the general public to change attitudes to schizophrenia; highlight the need to end the discrimination faced by people with schizophrenia when seeking employment or training.
- Ensure that peer-led support and advice are readily accessible, particularly for young people with schizophrenia.

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 healthcare professionals, social care providers and other external agencies. It also involves collaboration with people with schizophrenia, their families and other sources of support.
- Successful care also needs **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 potentially 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 this report will require **engagement by every stakeholder**. With commitment from all, change can be achieved.

References

1. Murray CJL, Lopez AD. Burden of disease. A comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020. Cambridge, MA: Harvard School of Public Health, on behalf of the World Health Organization and the World Bank, 1996.
2. World Health Organization. Available from: http://www.who.int/healthinfo/global_burden_disease/2004_report_update/en/ (Accessed 30 August 2013).
3. Bellack AS. *Schizophr Bull* 2006;32:432–42.
4. Lieberman JA *et al. Psychiatr Serv* 2008;59:487–96.
5. Mueser KT *et al. Annu Rev Clin Psychol* 2013;9:465–97.
6. Harrow M, Jobe TH. *Schizophr Bull* 2013;39:962–5.
7. Miyamoto S *et al. Mol Psychiatry* 2012;17:1206–27.
8. Goff DC *et al. Pharmacol Biochem Behav* 2011;99:245–53.
9. Sajatovic M, Jenkins JH. *Int Rev Psychiatry* 2007;19:107–12.
10. Barnes TR. *J Psychopharmacol* 2011;25:567–620.
11. National Institute for Health and Clinical Excellence. Available from: http://www.nice.org.uk/nicemedia/live/11786/43607/43607.pdf (Accessed 30 August 2013).
12. Ahmed AO *et al. Psychiatric Clin North Am* 2012;35:699–715.
13. Chang CK *et al. PLoS One* 2011;6:e19590.
14. Thornicroft G. *Br J Psychiatry* 2011;199:441–2.
15. The Schizophrenia Commission. Available from: http://www.schizophreniacommission.org.uk/the-report/ (Accessed 30 August 2013).
16. Thornicroft G *et al. Lancet* 2009;373:408–15.
17. Andrew A *et al*. Available from: http://www2.lse.ac.uk/LSEHealthAndSocialCare/pdf/LSE-economic-report-FINAL-12-Nov.pdf (Accessed 30 August 2013).
18. Dixon LB *et al. Schizophr Bull* 2010;36:48–70.
19. Bebbington PE *et al. Soc Psychiatry Psychiatr Epidemiol* 2005;40:707–17.
20. Frey W *et al*. Available from: http://www.ssa.gov/disabilityresearch/documents/MHTS_Final_Report_508.pdf (Accessed 30 August 2013).
21. Leff JP, Warner R. Social inclusion of people with mental illness. Cambridge, UK; New York: Cambridge University Press, 2006.
22. Joa I *et al. Schizophr Bull* 2008;34:466–72.
23. Stuart HL, Arboleda-Flórez J, Sartorius N. Paradigms lost: fighting stigma and the lessons learned. Oxford: Oxford University Press, 2012.

Peer support and advocacy groups

Listed below are some of the groups that provide information and support for people affected by schizophrenia in Europe and the US.

European Federation of Associations of Families of People with Mental Illness
www.eufami.org

Global Alliance of Mental Illness Advocacy Networks-Europe
www.gamian.eu

National Alliance on Mental Illness
www.nami.org

Acknowledgements

Support for the writing and editing of this report was provided by Oxford PharmaGenesis™ Ltd, UK, and Oxford PharmaGenesis™ Inc, US.

Preparation and publication of these recommendations has been funded by an educational grant from F. Hoffmann-La Roche, who had no editorial influence on the content.

Revised edition: first published 2013

TIME TO COMMIT TO POLICY CHANGE

Schizophrenia – Time to Commit to Policy Change

A guide for patients and advocacy groups to support policy change