

a charter

FOR THE RIGHTS

to treatment

and care for people with

SCHIZOPHRENIA



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EXECUTIVE SUMMARY

The impact of a diagnosis of schizophrenia is often devastating; affecting relationships, the ability to work and much more. People living with a diagnosis of schizophrenia are often disadvantaged, vulnerable and experience high levels of stigma and discrimination. It can affect the way a person thinks, feels and perceives the world. It is important to ensure that the rights and expectations of people living with schizophrenia are maintained and upheld; now an urgent priority.

The purpose of this Charter is to define the rights, expectations and responsibilities for mental health care and treatment from the persons' perspective. We, members of organisations representing people diagnosed with schizophrenia, believe that it is essential that people with a diagnosis of schizophrenia are empowered to make informed choices about their care and treatment, and to be aware of their rights and what they can expect when they receive mental health services.

A consultation in 2019 with members of GAMIAN-Europe and other patient representative organisations across Europe highlighted key themes which form the back bone of this Patient Charter. Ten themes were highlighted by members as important areas to be included in this Charter. These include statements of rights of people living with schizophrenia and the responsibilities of mental health services and other relevant agencies:

Rights

Responsibilities and actions

1

The right of every person living with schizophrenia to advocacy and an advocate when requested.

The responsibility of mental health and other relevant services to provide access to advocacy and an advocate.

2

The right of every person living with schizophrenia to access mental health services treatment, which is affordable, up-to-date, evidenced-based and effective, and includes information about the treatment process.

The responsibility of mental health services to ensure patients diagnosed with schizophrenia are given access to affordable and effective treatment and care, together with information about the treatment process.

The responsibility of the Government to adequately fund and invest in mental health services, including quality control measures.

3

The right of every person living with schizophrenia to be involved in choosing/deciding their treatment (including any self-management tools), and personalising the care and services they receive.

The responsibility of mental health services to involve people living with schizophrenia in decisions about treatment and care and ensure this is personalised as much as possible. Mental health services and other relevant services should provide the information and advice needed to support this.

Rights

Responsibilities and actions

4

The right of every person living with schizophrenia to have timely access to a safe place during a crisis.

The responsibility of mental health and other relevant services to provide a safe place for a person living with schizophrenia experiencing a crisis and information on any available alternatives to psychiatric hospital admission.

5

The right of every person living with schizophrenia to legal protection and to appeal if receiving compulsory treatment and care.

The responsibility of mental health services and other relevant organisations to inform people living with schizophrenia their right to legal protection and the appeal process if receiving compulsory treatment and care.

6

The right of every person living with schizophrenia to wellbeing and prevention resources and interventions.

The responsibility relevant organisations working with people living with schizophrenia to promote well-being, physical health and to prevent relapse of their condition.

Rights

Responsibilities and actions

7

The right of every person living with schizophrenia access to physical health care, physical health screening and lifestyle interventions and advice.

The responsibility of healthcare services and professionals to provide routine physical healthcare to people living with schizophrenia.

8

The right of every person living with schizophrenia to be respected and to be treated with dignity.

The responsibility of everyone in society to respect and maintain the rights and expectations of people living with schizophrenia to an equitable life free of stigma and discrimination.

9

The right of every person living with schizophrenia to participate in society and access to adequate welfare benefits, recovery approaches and social inclusion opportunities.

The responsibility of relevant organisations and everyone in society to ensure that people living with schizophrenia are socially included and given access to housing, employment, welfare benefits and equal opportunities to employment.

Rights

Responsibilities and actions

10

The right of every person living with schizophrenia to access to non-pharmacological therapies and treatments, including effective e-health.

The responsibility of mental health services to inform and provide non-pharmacological therapies and e-health.



FIVE KEY RECOMMENDATIONS SUMMARISING THE 10 THEMES LISTED ABOVE ARE TO:

Maintain patient rights, entitlements and expectations for effective and safe treatment and care. [Read more.](#)

Create mental health services that are respectful and maintain patients' dignity and confidentiality. [Read more.](#)

Provide a safe space prior to and during a crisis episode, including alternatives to psychiatric hospital. [Read more.](#)

Ensure the provision of relapse prevention, early intervention, wellbeing interventions and physical health screening and care. [Read more.](#)

Provide recovery and beneficial social inclusion activities including employment, voluntary and other meaningful activities. [Read more.](#)



Stigma, discrimination, vulnerability and disadvantage remain a common experience for people with schizophrenia and this Patient Charter seeks to ensure that their rights of access to timely and safe treatment and care; and equal opportunities to meaningful social and employment activities are upheld.


INTRODUCTION

There is no Charter in existence yet, specifying the rights and expectations of people living with schizophrenia, and there is an urgent need for such a charter.

Schizophrenia is a mental health condition that affects the way a person thinks, feels and perceives reality. Around 1 in 200 (or 0.5% of) people in Europe is estimated to be diagnosed with schizophrenia¹ and its impact can be devastating; affecting relationships, the ability to work and much more. People living with schizophrenia are often disadvantaged and vulnerable. Schizophrenia is still often misconstrued as someone having a split personality or potentially being more violent. However, people diagnosed with schizophrenia are much more likely to be victims of violence in community settings than to be perpetrators of violence.² These continued misperceptions lead to fear and high levels of discrimination and stigma. This subsequently gives rise to frequent disadvantages, a lack of opportunities and access to general healthcare, education, housing and employment. People living with schizophrenia both within mental health institutions and their communities are susceptible to human rights violations.³

The purpose of this Charter is to define the rights to mental health care and treatment and responsibilities of governments and service providers. It is pivotal that people living with schizophrenia are and feel empowered to make informed choices about care and treatment, and are to be aware of their rights and what they can expect when receiving mental health services. Rights, in this context refer to broader human rights, for example the United Nations' Convention of the Rights of Persons with Disabilities (2006) and the Universal Declaration of Human Rights, adopted in 1948 which endorsed the right to the highest attainable standard of health.

Article 25 stated that



“Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing and medical care and necessary social services.”

Also, the International Covenant on Economic, Social and Cultural Rights (1966) which established the state's obligations to respect, protect, and fulfill “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health” (Article 12); and the endorsed World Health Organization's European Mental Health Action Plan 2013-2020 to strengthen mental health, well-being and quality of care for people with mental health problems.

¹ Simeone JC, Ward AJ, Rotella P et al. An evaluation of variation in published estimates of schizophrenia prevalence from 1990-2013: a systematic literature review. *BMC Psychiatry*, 2015, 15:193.

² Brekke JS, Prindle C, Bae SW, Long JD. Risks for individuals with schizophrenia who are living in the community, *Psychiatr Serv*, 2001, 52:1358-1366.

³ <https://www.who.int/news-room/fact-sheets/detail/schizophrenia>

A CHARTER OF RIGHTS AND RESPONSIBILITIES

A consultation in 2019 with members of GAMIAN-Europe and other patient representative organisations across Europe highlighted key themes which form the back bone of this Patient Charter.

Ten emerging themes were highlighted by members as areas important to them that needed to be included in this Charter. These are listed and explained in Table 1 as statements of rights of patients and actions/ responsibilities of service providers.

1

RIGHT

The right of every person living with schizophrenia to advocacy and an advocate when required.

ACTION

The responsibility of mental health and other relevant services to provide access to advocacy and an advocate.

We, persons living with a diagnosis of schizophrenia prefer to express our own wishes, concerns and treatment choices with or without the aid of an advocate to support our views or perspectives. There are times when an advocate who speaks on our behalf is helpful, particularly during a crisis. This can ensure our wishes in terms of treatment and care are heard. An advocate can also help provide information and advice about our rights as patients. Having an advocate should be something we choose to have or not to have and the decision should be reviewed on an ongoing basis.

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RIGHT

2

The right of every person living with schizophrenia to access mental health services treatment, which is affordable, up-to-date, evidenced-based and effective, and includes information about the treatment process.

ACTION

The responsibility of mental health services to ensure patients diagnosed with schizophrenia are given access to affordable and effective treatment and care, together with information about the treatment process.

Everyone has the right to the highest attainable standard of physical and mental health which includes access to treatment and healthcare services. Adequate and balanced information about what treatment is available and what is involved in the treatment process is equally important.

The treatment and services provided should be accessible and effective, available for all who require them. Mental health services require sufficient funds and investments to ensure they are up-to-date and evidenced-based and should include quality control. Variability in mental health services across geographical areas presents difficulties in the quality of services that can be received. This also needs to be addressed to ensure patients receive high quality care regardless of where they live.

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RIGHT

3

The right of every person living with schizophrenia to be involved in choosing/deciding their treatment (including any self-management tools), and personalising the care and services they receive.

ACTION

The responsibility of mental health services to involve people living with schizophrenia in decisions about treatment and care and ensure this is personalised as much as possible. Mental health services and other relevant services should provide the information and advice needed to support this.

Being involved in treatment and care decisions is critical to improving patient participation and the quality of the decisions made. Offering us choice in our treatment is important to maintaining dignity and respect. It also helps to improve adherence to treatment and reduce potential side effects. Alternative treatments, particularly psychological therapies must also be offered (see Theme 10 below) along with pharmacological options.

Good collaboration and building trust between a clinician and patient are essential elements to enhancing shared-decision making, personalised care, treatment choice and engagement with care and treatment.

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1 CHARTER FOR THE RIGHTS OF TREATMENT & CARE FOR PEOPLE WITH SCHIZOPHRENIA



¹ Around
1 in 200
people in Europe are
diagnosed with
schizophrenia

Schizophrenia has
devastating consequences

Many experiencing
stigma & discrimination

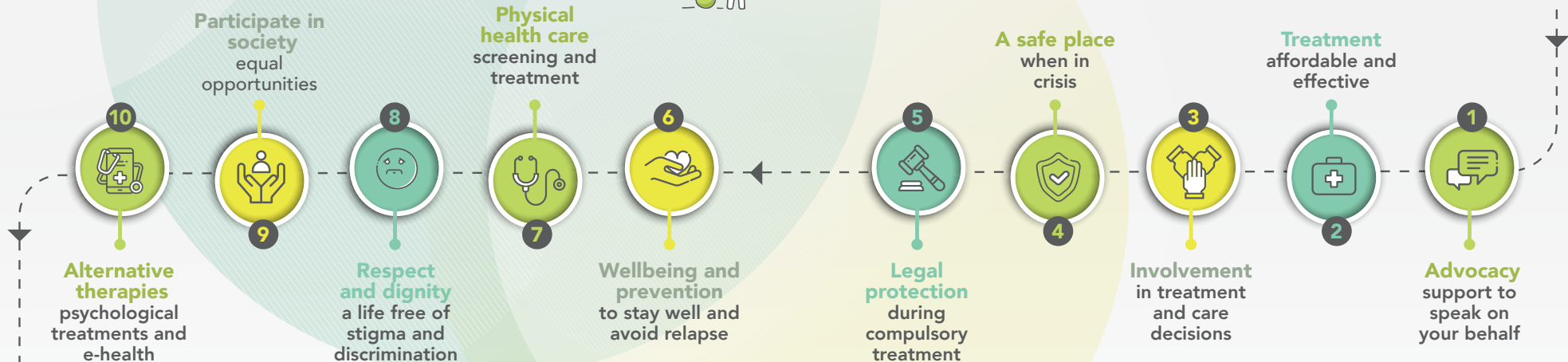


² The Universal Declaration
of Human Rights (1948)
endorsed the right to
the highest attainable
standard of health



Maintaining
THE RIGHTS
of people with
schizophrenia is
an urgent priority

10 THEMES IMPORTANT TO PEOPLE WITH SCHIZOPHRENIA



5 KEY RECOMMENDATIONS FOR TREATMENT & CARE OF PEOPLE WITH SCHIZOPHRENIA



¹ Simeone JC, Ward AJ, Rotella P et al. An evaluation of variation in published estimates of schizophrenia prevalence from 1990-2013: a systematic literature review. BMC Psychiatry. 2015; 15:193. ² Pillay N: Right to health and the Universal Declaration of Human Rights. Lancet 2008; 372: 2005-2006. Available online at DOI: 10.1016/S0140-6736(08)61783-3

The infographic was supported by Otsuka Pharmaceutical Europe and H.Lundbeck A/S. The opinions expressed in this infographic do not necessarily represent those of the supporters.

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CONTINUED

An appreciation of the knowledge that we have about our condition is important for clinicians to understand, and to utilise as much as possible in a personalised approach to our care and treatment.

Information about the side effects of medication is key to this process and for us to have the right to decide whether this is something to accept, manage or decline.

Care tailored to an individual's needs has become increasingly more important over the past decade, but is still to become a reality. Self-management of our condition is effective in improving quality of life outcomes, symptoms, self-efficacy, hope and empowerment.⁴ Schizophrenia and psychosis present themselves in many different ways. We will have different needs, wants and expectations and it is important to respect these. Stating preferences for treatment and care using a crisis card or advanced directive, for example, and the right to choose our doctor are other ways to ensure people's wishes can be expressed and adhered to as far as possible.

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⁴Lean M, Fornells-Ambrojo M, Milton A, et al. Self-management interventions for people with severe mental illness: systematic review and meta-analysis. *Br J Psychiatry*. 2019; 214(5):260-268.

⁵Johnson S, Gilbert H, Lloyd-Evans B, Osborn DPJ et al. In-patient and residential alternatives to standard acute psychiatric wards in England. *British Journal of Psychiatry* 2009, 194:456-463.

⁶Morant N, Lloyd-Evans B, Gilbert H, Slade M, et al. 2012 *Epidemiol Psychiatr Sci*. 21(2):175-85.

4

RIGHT

The right of every person living with schizophrenia to have timely access to a safe place during a crisis.

ACTION

The responsibility of mental health and other relevant services to provide a safe place for a person living with schizophrenia experiencing a crisis and information on any available alternatives to psychiatric hospital admission.

The right to a safe place for when we experience a crisis is hugely important. Ensuring the availability and timely access to a psychiatric bed when needed is critical in times of crisis. Recent reductions in psychiatric beds across Europe have become a concern in terms of timely access and availability of these.

Residential alternatives to psychiatric hospital can act as a place of safety and currently play an important part of managing mental health crises.^{5,6} There are many organisations that offer crisis or recovery houses as a safe space. A room in a hospital setting which is calming, safe and with well-trained staff can also work well.

We should be well informed by mental health professionals (and other relevant professionals) of any such safe places or alternatives and given access to this when required if it is their preferred option.

Adequate and appropriate support following discharge from hospital can still be lacking in many places, ensuring this can again prevent any further admissions or deterioration.

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5

RIGHT

The right of every person living with schizophrenia to legal protection and to appeal if receiving compulsory treatment and care.

ACTION

The responsibility of mental health services and other relevant organisations to inform people living with schizophrenia their right to legal protection and the appeal process if receiving compulsory treatment and care.

Legal protection and representation will be relevant where treatment is compulsory or involuntary, for example compulsory admission to a psychiatric hospital or a community treatment order. Accountability and a clear process of appeal should be available at all times. The right to legal protection and an appeals process are essential. Mental health services should be accountable for such decisions to ensure these processes are carried out in our best interest and with our involvement.

Again, ensuring we are fully informed of our rights and our right to appeal against a compulsory psychiatric admission are essential and should be offered at every opportunity by staff or an advocate. This is also part of maintaining dignity and respect for us. Where possible involuntary treatment should be avoided and alternatives to hospital should be considered where available and appropriate.

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RIGHT

The right of every person living with schizophrenia to wellbeing and prevention resources and interventions

ACTION

The responsibility relevant organisations working with people living with schizophrenia to promote well-being, physical health and to prevent relapse of their condition.

The importance of promoting wellbeing and prevention of mental illness cannot be overstated. For us achieving and maintaining wellbeing is just as relevant as treatment and care, especially given our much shorter life expectancy of between 15-30 years compared to the general population.⁷ ⁸Primary prevention, by identifying the things that lead to mental illness and intervening early can help reduce the risk of developing this condition or making it a long-term illness. Improving or maintaining quality of life (e.g. social contact, daily living skills, relationships) has been found to prevent relapse. Secondary prevention or relapse prevention and early intervention are especially important for us to avoid the difficulties associated with a crisis and further relapse.⁹

Avoiding any delays in responding to our needs, particularly during the early signs of relapse could help manage symptoms and avoid hospitalisation.

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CONTINUED

Avoiding any delays in responding to our needs, particularly during the early signs of relapse could help manage symptoms and avoid hospitalisation.

Education for patient, carers, friends and other social networks to identify early signs and symptoms can be helpful towards preventing admission.

Addressing any physical health problems and promoting healthy living and exercise can go a long way to improving our physical health and can help increase our life expectancy.

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⁷Hjorthøj C, Stürup AE, McGrath JJ et al. Years of potential life lost and life expectancy in schizophrenia: a systematic review and meta-analysis. *Lancet Psychiatry*. 2017 Apr;4(4):295-301.

⁸Laursen TM, Nordentoft M and Mortensen PB. Excess early mortality in schizophrenia. *Annual Review of Clinical Psychology*, 2013, 10:425-448.

⁹Boyer L, Millier A, Perthame E, Aballea S et al. Quality of life is predictive of relapse in schizophrenia. *BMC Psychiatry*, 2013, 13:15.

RIGHT

7

The right of every person living with schizophrenia access to physical health care, physical health screening and lifestyle interventions and advice.

ACTION

The responsibility of healthcare services and professionals to provide routine physical healthcare to people living with schizophrenia.

Access to physical health care can be overshadowed by a psychiatric diagnosis. Lifestyle factors (e.g. smoking, poor diet, lack of exercise) and side effects from psychotropic medication can also lead to physical health problems, such as heart disease, weight problems and diabetes. Regular physical health checkups can help identify problems early on and timely access to physical health care can address any physical health problems which can exacerbate symptoms of schizophrenia.

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RIGHT

8

The right of every person living with schizophrenia to be respected and to be treated with dignity.

ACTION

The responsibility of everyone in society to respect and maintain the rights and expectations of people living with schizophrenia to an equitable life free of stigma and discrimination.

We wish to be treated as a person and not as a mental disorder. However, stigma and discrimination present major challenges for us and are deeply ingrained in society at many levels. For example, many of us experience disadvantage in the labour market which is often based on employers' misperceptions and fear, making disclosure of their condition extremely difficult. Having respect for the person and offering them the opportunity to meet their expectations and life goals are hugely important to changing negative perceptions and making a difference. Empowering us is another important way for us to be able to create our own opportunities for meaningful activities which can be less stigmatising and helps promote a sense of achievement.

It is important to remember that we are not our condition or illness, but people first. We should not be stigmatised, for example with information, particularly when first admitted to hospital, that schizophrenia is incurable and a lifelong condition.

Media campaigns are also useful for educating the public about mental illness, helping people to better understand this, act accordingly and in turn reduce stigma and discrimination. [Back](#)

RIGHT

9

The right of every person living with schizophrenia to participate in society and access to adequate welfare benefits, recovery approaches and social inclusion opportunities

ACTION

The responsibility of relevant organisations and everyone in society to ensure that people living with schizophrenia are socially included and given access to housing, employment, welfare benefits and equal opportunities to employment.

The opportunity to participate in society, at local and community levels can be very fulfilling and is important to maintaining good health and wellbeing. Access to sufficient welfare benefits, good housing, education, employment and meaningful activities help achieve this. Access to recovery based approaches to assist with positive progress is another important addition to any mental health service. Recovery will involve different approaches depending on people's needs, goals and preferences. Recovery should be holistic; to include different outcomes and all aspect of the person's condition which all involved in the person's care and social networks should be aware of. Recovery also includes everyone involved with the person diagnosed with schizophrenia.

We are often at a disadvantage in terms of housing, employment and finances in particular. This in turn leads to social and economic exclusion which further adds to a difficult situation.

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The practice of assigning someone with a pension for the rest of their life because of their mental illness should change as it suggests their condition is incurable the person may not be able to secure employment. Instead an income during periods of illness should be guaranteed by other means such as sickness benefit or rehabilitation allowance.

Opportunities for voluntary work or other meaningful activities, and improved welfare benefits, together with employment opportunities and better housing will ensure better prevention and mental health promotion for us. The Finnish model of Housing First provides a good example of increasing the supply of affordable rental housing and prevention of homelessness in vulnerable people.¹⁰

Access to good social networks which go beyond the 'patient' group are also important. Social isolation is a particular challenge and improving access to social opportunities can help reduce the harmful effects of this, such as worsening physical and mental health.

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¹⁰<https://housingfirsteurope.eu/countries/finland/>

RIGHT

10

The right of every person living with schizophrenia to access to non-pharmacological therapies and treatments, including effective e-health.

ACTION

The responsibility of mental health services to inform and provide non-pharmacological therapies and e-health.

Psychotherapies and other effective non-pharmacological treatments (such as Mindfulness, Open Dialogue) should now become standard techniques and offered alongside with pharmacological treatments for people living with schizophrenia. Financial reimbursement via health insurance should be offered for using these options.

Digital technology is being developed to help support people with common mental disorders. It can provide timely access to online psychotherapy and support. It is still a relatively new area for people living with schizophrenia but could be a helpful way forward in promoting self-help and provide more rapid support for professional help, information and advice on treatment and symptoms. Digital technologies also offer opportunities for personalised treatments and self-management. It would be helpful to have the involvement of people with lived experience of schizophrenia or psychosis to aid our healing and recovery process. Some patient organisations offer support for this from their experts by experience.¹²

Access to effective e-health should be made free for us.

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It is important this technology should not become a cost saving substitute or replacement for face to face contact with mental health professionals which is valuable and important for us.



KEY RECOMMENDATIONS FOR MENTAL HEALTH SERVICES

To help focus the implementation of the Charter by mental health services, relevant organisations and Governments the following five key recommendations have been suggested which summarise the above ten themes. These are:

¹¹<http://open-dialogue.net/>

¹²<https://www.gamian.eu/wp-content/uploads/GAMIAN-Europe-Mental-Health-Support.pdf>

RECOMMENDATION

1

To maintain patient rights and entitlements to effective and safe treatment and care.

It is important mental health services are responsive and timely to meet our needs and that we are informed of our rights and able to actively participate in our treatment of choice. Mental health services also need to be comprehensive and work in collaboration with social care services to address both health and social needs and in keeping with the WHO European Mental Health Action Plan 2013-2020.

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RECOMMENDATION

2

To provide mental health services that are respectful and maintain patients' dignity and confidentiality.

Building trust and establishing a good rapport between patient and clinician is an important step to delivering respectful and effective care. Dignity and confidentiality are similarly important and will help promote better engagement with services. Confidentiality must be managed appropriately and sharing clinical information with close family and carers can only be done with consent from us. However, professionals should listen to carers, friends and family when they are concerned about us.

Support in the community with a sufficient range of community-based mental health and other supporting services (such as drop-in centres for mental health) are equally important. These can include access to group therapy and experts by experience for people diagnosed with schizophrenia and their carers or loved ones. This can also aid building social networks. Having services that are acceptable to us and are non-stigmatising adds a critical dimension to ensuring these services are responsive to our specific needs and vulnerabilities. Good quality mental healthcare is a must for us and high standards of care and treatment must be maintained as far as possible. This includes ensuring quality of life is preserved as part of building trust, dignity and respect for us.

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RECOMMENDATION

3

To provide a safe space prior to and during a crisis episode, including alternatives to psychiatric hospital.

It is essential that mental health services provide a safe space that is accessible in times of need, either during or just prior to a crisis, as part of an early intervention strategy to prevent relapse or simply to monitor a person's wellbeing. Alternatives to hospital admission should be offered, where available and appropriate. A safe space should not include police custody. Support in the community post-discharge should also be comprehensive. Prevention of relapse and early intervention are critical.

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RECOMMENDATION

4

To ensure the provision of relapse prevention, early intervention, wellbeing interventions and physical health screening and care.

Prevention of illness and relapse, well-being and physical health interventions and care have become important areas of attention in policy, but still lag behind in practice. There is an urgent need to address our significantly shorter life expectancy. Investment in prevention and mental health promotion can lead to future social and economic cost savings and importantly reduce the distress associated with schizophrenia.^{13 14} Digital technologies can be used to better engage us and help manage our condition, particularly in preventing relapse.

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¹³Campion J, Bhui K, Bhugra D and European Psychiatric Association. European Psychiatric Association (EPA) guidance on prevention of mental disorders. *Eur Psychiatry*, 2012, 27:68-80.

¹⁴Kalra G, Christodoulou G, Jenkins R et al. *Mental health promotion: Guidance and strategies*.

RECOMMENDATION

5

To provide recovery and beneficial social inclusion activities including employment, voluntary and other meaningful activities.

Because schizophrenia can have huge negative effects on our quality of life, including our social and economic opportunities it is important that mental health services and carers play a leading role in and underline recovery oriented approaches throughout the care process. Better information exchange, particularly at the beginning of a person's illness about their condition is crucial for the future. There are many psychosocial interventions, such as improving social networks, increasing social participation, securing employment and other meaningful activities which all have beneficial effects on mental health and recovery and in turn reduce the demand for continued mental health services.^{15 16}

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¹⁵Mazzi F, Baccari F, Mungai F et al. Effectiveness of a social inclusion program in people with non-affective psychosis. *BMC Psychiatry*, 2018, 18:179

¹⁶Drake RE. Employment and schizophrenia: Three innovative research approaches. *Schizophrenia Bulletin*, 2018, 44:20-21.



CONCLUSION

This Patient Charter draws on the experiences of people diagnosed with schizophrenia and key documents on patients' rights and expectations for healthcare. Stigma, discrimination, vulnerability and disadvantage remain a common experience for this group and this Patient Charter seeks to ensure that our rights of access to timely, effective and safe treatment and care and rights of equal opportunities to meaningful social and employment activities are upheld. With this focus and commitment from all relevant stakeholders in society we will have a better chance of leading an independent and decent quality of life regardless of this condition.

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