

# SCHIZOPHRENIA

## Companion Guide II:

Perspectives of people with schizophrenia and carers





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## ■ ACKNOWLEDGEMENTS

We are very grateful to and thank warmly the patients, carers, relatives and friends who took the time to respond to the survey for this guide. The experiences shared by everyone who responded to the survey provide a rich source of information about their journey and understanding of schizophrenia.

Development of this guide was supported by grants from Boehringer-Ingelheim and TEVA Pharmaceuticals who had no influence on the content.

Support for the independent writing and editing of this publication was provided by Chiara Samele, Informed Thinking Ltd, UK.

Coordination of this publication was provided by Nigel Olisa, Executive Director of GAMIAN-Europe with the support of Daphne Lamirel, Communications and Policy Assistant, GAMIAN-Europe.



## ■ INTRODUCTION AND HOW TO USE THIS GUIDE

This companion guide has been designed to provide practical advice to people with schizophrenia, and their caregivers, friends and family. It includes tips at the end of each section on how to manage a variety of situations that commonly arise. Some additional resources are listed in the appendix at the end of the guide.

The information used for this companion guide is based entirely on first hand experiences of people diagnosed with schizophrenia, along with carers, relatives and friends and it describes how they have learned to manage and live with this condition. These experiences were gathered through an online survey carried out in 2020.

This guide is a follow on from the first Schizophrenia Companion Guide produced by GAMIAN-Europe in 2016 which provides a comprehensive overview of schizophrenia, including symptoms and treatment.<sup>1</sup> Even though there is some overlap with the first guide, the current guide includes more personal experiences of people diagnosed with schizophrenia, carers, friends and family; their discoveries and the strategies they used as part of their journey.



The guide is divided into two parts. The first part is devoted to people diagnosed with schizophrenia and the second to those (carers, friends and family) who support people with this condition. Some of the experiences of people diagnosed with schizophrenia and carers can be very similar. The suggestions given here can be useful to both.

In the guide we use 'person' rather than patient to refer to someone diagnosed with schizophrenia. Carer is the term used to refer to relatives, friends and other people who offer practical and emotional support on a regular basis, but are not paid professionals.

**We hope you find this guide helpful and informative.**

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1. GAMIAN-Europe. 2016. Learning to live with schizophrenia. A companion guide. Accessed from: <https://www.gamian.eu/wp-content/uploads/Gamian-Schizophrenia-Guide-2016.pdf>

# Part One

for people with schizophrenia



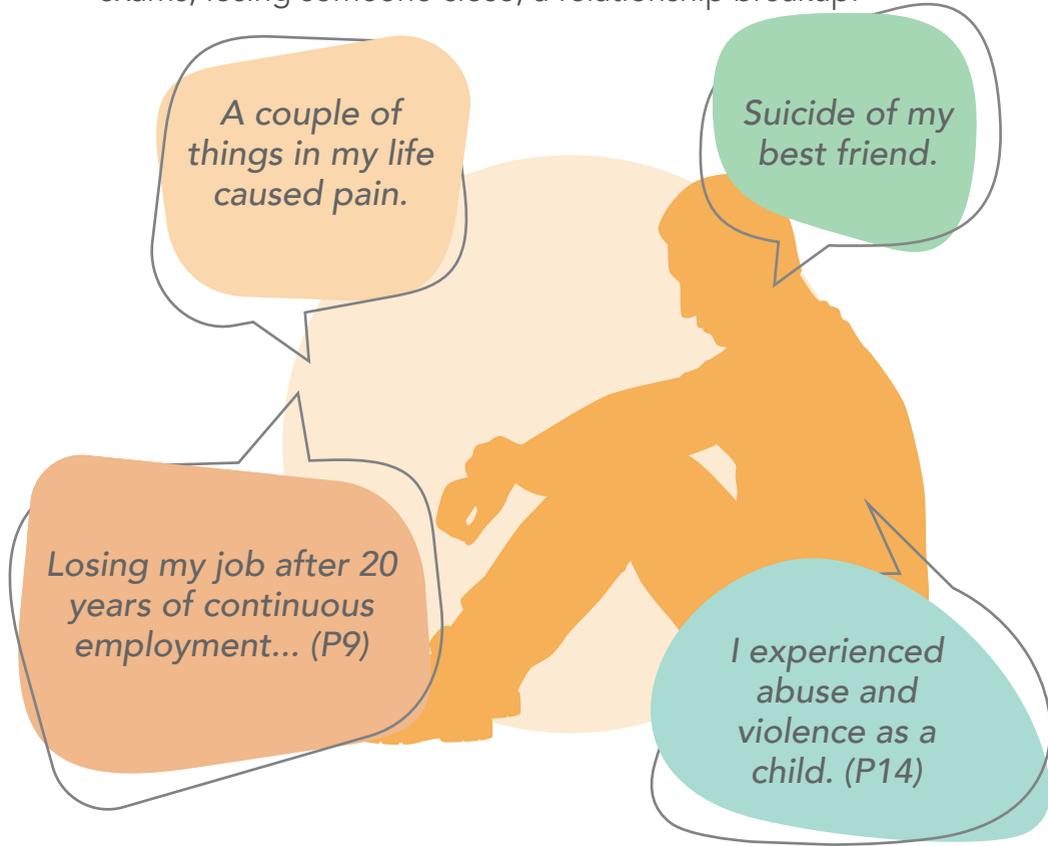
*Anybody can have schizophrenia  
if something goes wrong in life...*

*And there is recovery!' (P7)*



## EXPERIENCES BEFORE BEING DIAGNOSED

As people diagnosed with schizophrenia look back at their lives and what happened to them just before their diagnosis many point to very stressful events or situations; being bullied, trauma and abuse, difficult family relationships, the pressure of exams, losing someone close, a relationship breakup.



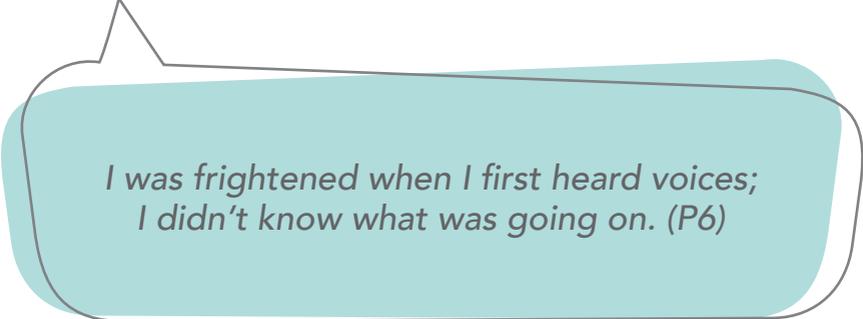
*A couple of things in my life caused pain.*

*Suicide of my best friend.*

*Losing my job after 20 years of continuous employment... (P9)*

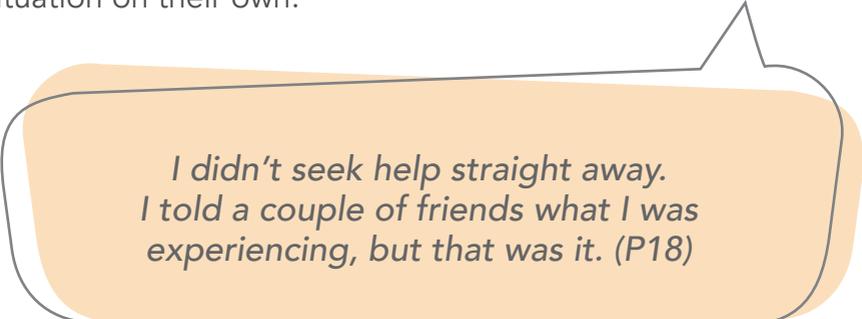
*I experienced abuse and violence as a child. (P14)*

The first symptoms of schizophrenia can be frightening. Many people don't know what is happening to them.



*I was frightened when I first heard voices; I didn't know what was going on. (P6)*

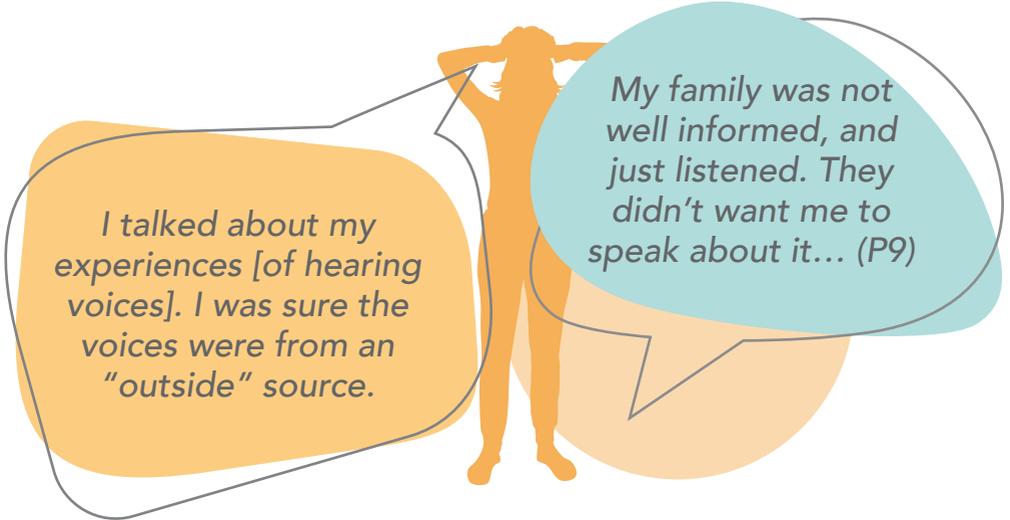
Often people don't know what to do when they get these first symptoms, especially if they don't know about schizophrenia. Some people speak to someone close - a relative or friend - but many don't speak with anyone and try to deal with the situation on their own.



*I didn't seek help straight away. I told a couple of friends what I was experiencing, but that was it. (P18)*

Friends and family react differently to hearing about a person's experiences of symptoms, most are shocked, become worried and find it strange. Family and friends may find it difficult to understand what a person with schizophrenia is experiencing.

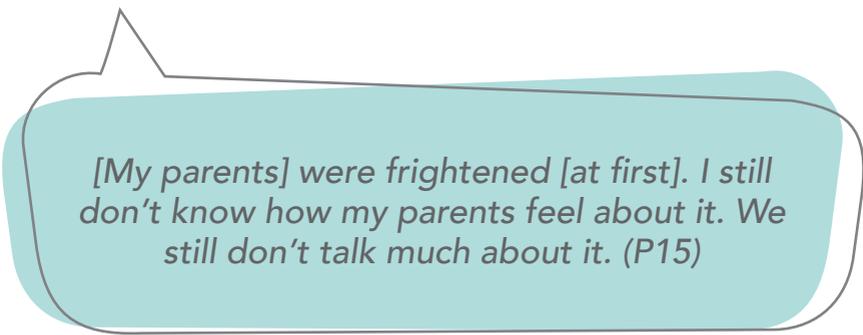
Because of the stigma surrounding this condition some people may prefer that this isn't talked about it.



*I talked about my experiences [of hearing voices]. I was sure the voices were from an "outside" source.*

*My family was not well informed, and just listened. They didn't want me to speak about it... (P9)*

This feeling of not wanting to talk about a person's symptoms of schizophrenia may continue.



*[My parents] were frightened [at first]. I still don't know how my parents feel about it. We still don't talk much about it. (P15)*

The person may not want to tell anyone about their symptoms at first, but with the right encouragement and support talking to a doctor is an important first step. As soon as a person notices their first symptoms speaking to a doctor as early as possible will help avoid these getting much worse.

*I didn't speak to anyone for several months about feeling down and lacking motivation to study, to socialise, and to keep up with my self-care and household chores. Then I spoke to my mum about it and she encouraged me to see my family doctor ... (P5)*

For some people the symptoms may become so serious they need to be admitted to hospital. This can happen quite suddenly or if a person has delayed seeing a doctor for whatever reason.

A silhouette of a person sitting on a hospital bed, facing right. The bed has a metal frame and a pillow. The person is wearing a long-sleeved shirt and trousers.

*My issues were acute, so my family called a doctor [and I was taken to hospital]... (P4)*

## Things people have found useful when symptoms of schizophrenia first happen:



**Avoid trying to deal with first symptoms alone**



**Speak to someone close to you, someone you trust**



**See a doctor as early as possible to get help straight away**

## GETTING HELP

It can be daunting to seek professional help for symptoms of schizophrenia, often people don't know what to expect. A family doctor can help with getting an appointment with a psychiatrist. Some people try to find a health professional by themselves.

*I decided to find a professional. I checked all the possibilities via the internet, and decided to accept a 2 week-long "initial" hospital screening. (P9)*

Some people may be taken to hospital by ambulance because of concerns for their safety.

*My GP (general practitioner) noticed that my behaviour had changed and asked me a few questions. They said my reality control doesn't work well and referred me to a hospital. I was taken to the hospital by ambulance. (P16)*

On rare occasions a person could be taken to hospital by the police, but this is not a good situation. It is very confusing and distressing for everyone involved, especially the person, and a sign that health services and the person have not been able to reach each other at this most important time.

What people need at this early stage is often quite simple; to be reassured and comforted, the space to talk about their issues and to be listened to. The most useful information needed at this time is to know what services are available to help people experiencing these symptoms.

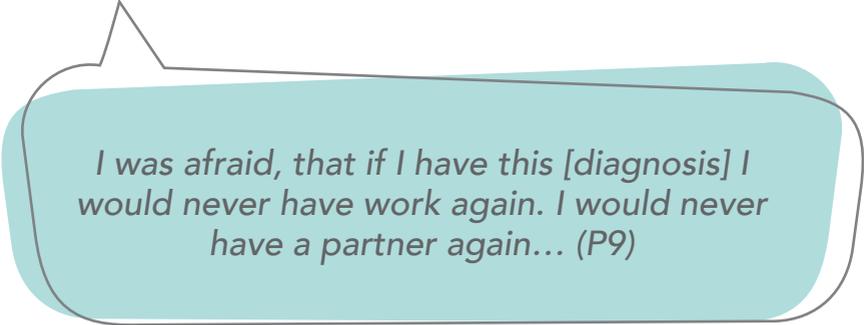
*I would have liked to know about community services, NGOs [Non-Governmental Organisations] and the like. And, I would have liked for people to tell me that I can talk about my issues and not to keep them all inside. (P14)*



## RECEIVING A DIAGNOSIS

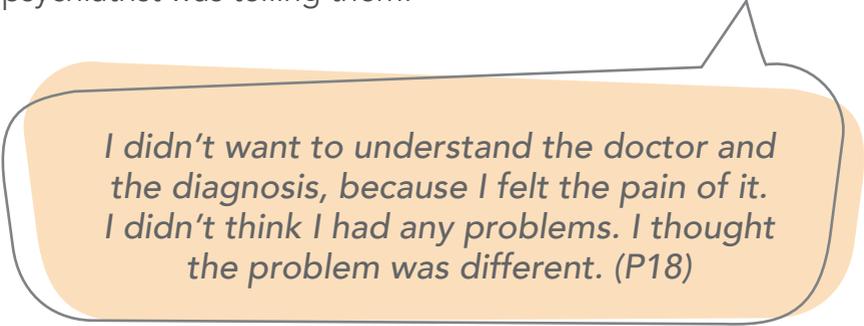
When people receive a diagnosis of schizophrenia it can be a shock, some people feel angry or scared and many will be concerned about what this means for them and their future. A diagnosis of schizophrenia is for many people a negative and stigmatising label.

*[I was] scared about my future and worried about the stigma, disbelieving that it [the diagnosis] was true. I was angry with the way the diagnosis was used to dismiss everything that I said... (P5)*



*I was afraid, that if I have this [diagnosis] I would never have work again. I would never have a partner again... (P9)*

Some people may go into denial and dismiss what their psychiatrist was telling them.



*I didn't want to understand the doctor and the diagnosis, because I felt the pain of it. I didn't think I had any problems. I thought the problem was different. (P18)*

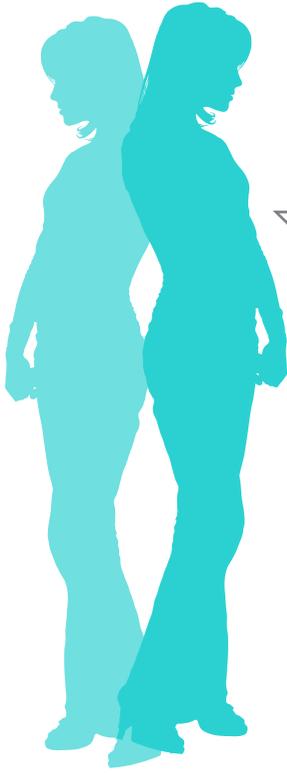
For others having a diagnosis of schizophrenia was even empowering because it helped them understand their symptoms and find a way to lead a fulfilling life regardless of them.

*I received [a diagnosis of schizophrenia] after eight manic episodes and in the middle of one. It makes me glad to have a name for my symptoms. I used [the diagnosis] to empower me. (P18)*

*It took me a long time to accept the diagnosis and I still have a hard time accepting it... I didn't know what the diagnosis meant. I have found a place where I can do things and feel I belong, so maybe I needed the diagnosis. I live a normal life; I am married with a child and I have a job... (P15)*

“  
**QUICK  
TIPS**  
”

**One of the most valuable lessons that many people diagnosed with schizophrenia talk about is the realisation that who they are as a person is not their diagnosis or their illness. This understanding is helpful in finding ways to move forward and to recognise the positives, like a person's strengths and good qualities.**



*I don't ascribe to the sick role of schizophrenia or make it my identity... I am a person with many, many facets and mental illness/schizophrenia is not who I am at all. (P5)*

## FINDING INFORMATION ABOUT SCHIZOPHRENIA

Often when a person receives their diagnosis they know very little about schizophrenia and how it might affect their future. It is helpful to take one step at a time, perhaps not to think too far into the future but to find out more; like what help is available and how best to manage the symptoms and the condition generally.

Speaking with a mental health professional is a good way to learn more about the illness, but some people have found this does not always give them enough of the information they would like, especially at the beginning of their illness.

*No one explained what this diagnosis meant. I was scared at first about the label. I wasn't able to Google search at the beginning, and I didn't know what exactly to search for. Later, I found information on the internet and I found a psychotherapist and a psychiatrist.  
(P21)*

*Nobody was interested in explaining to me the ins and outs of why they were diagnosing me with schizophrenia. Even four years later, I still don't know. (P5)*

Some people with schizophrenia will search the internet for more information, but not everyone has access to this. Published books by people with lived experience of schizophrenia can be helpful in understanding what they have gone through and how they have managed their symptoms.

It is important to be aware that some internet information can be misleading or unreliable, so it is best to find reputable websites produced by local or national health services or mental health non-governmental organisations.

*We got basic information from the hospital about symptoms, sleeping and other general information...I read books with personal stories of people with mental health issues. (P15)*

It can take some time to gain a full understanding of what schizophrenia is, how it affects a person and the impact it can have on their lives and the people close to them.

*After about 3 years, since receiving my diagnosis I have learned more about it and to find a way to heal. (P6)*

Information from mental health community groups and peer support organisations is another useful way to receive reliable advice. Advice from people with lived experience of schizophrenia is a great way to learn more about how to manage this condition and sharing personal experiences can be an important part of recovery.

When first diagnosed with schizophrenia some people say they would have liked the following advice and reassurance:



*[That] people with schizophrenia can live fruitful and successful lives. (P10)*

*You can live normally if you take your drugs. (P11)*

*[What to do] and how to function with schizophrenia and the medication... I got a lot of this information from a mental health non-governmental organisation. (P14)*



Things people have found useful when looking for information about schizophrenia:



Use information from reliable sources like health services or non-governmental organisations, either from their websites or published information



Read personal stories of other people who have been diagnosed with schizophrenia

## ■ TREATMENT

Antipsychotic medication is one of the main treatments for schizophrenia and managing symptoms, and usually prescribed by a psychiatrist or family doctor. Some people find taking this type of medication difficult because of the side effects it can give.

The Appendix below includes a brief description of what the side effects people can experience. Thinking and memory can be affected and some people put on weight.



It is important for a person to take the medication they have been prescribed but if the side effects are too difficult to tolerate then talking to a psychiatrist should be done as soon as possible. It may take a few attempts to find the right medication and at the right dose. Antipsychotic medication also takes time to work, sometimes a few weeks so it is worth persevering.

*I felt better after 2 weeks, I could sleep and I was merrier. (P8)*

*During my first hospitalisation I took some antipsychotics which made me very dizzy. After that I switched psychiatrist who changed my medication and I started to feel more active and present. (P21)*

Psychotherapy or talking therapy is another important treatment for schizophrenia and something people with schizophrenia find helpful.

*We [me and my psychotherapist] deal with past traumas. We use positive psychology. We use assertive problem-solving communication. (P9)*

There are many different types of talking therapy, including cognitive behaviour therapy which is commonly used. Sessions are usually given by a psychologist, but many psychiatrists are also trained to give psychotherapy.

*I have a therapist, an experiential expert and psychiatrist. I have been working with them for about six months and it works really well for me, [even though] at the beginning of my hospitalisation I wasn't too talkative. But now I can express my feelings more. (P21)*

Talking therapy might not always be offered by public mental health services to people diagnosed with schizophrenia, and some people may find a private therapist if they are able to afford one.



## “ QUICK TIPS ”

Things people have found useful regarding treatment for schizophrenia:



**Take medication regularly to help manage symptoms**



**Talk to a psychiatrist/doctor as early as possible if the side effects of medication become very difficult to tolerate**



**Consider having talking therapy, especially in combination with other treatments and support activities (like medication, cognitive and social skills training and physical exercise)**

## AVOIDING A CRISIS

If a person has experienced a crisis in the past it is also important to learn to recognise the early signs that may lead to this. With experience these signs can be recognised for most people.

The early signs of a crisis or relapse will vary from person to person. Just before a crisis starts some people with schizophrenia experience more negative thoughts, have more visual hallucinations (see things that may not be there) or hear voices more than usual. A person may not be sleeping properly.

*[For me the signs are] any excessive thinking, that I'm being watched and when my mind leads me to think that someone will talk about me or harm me. When this happens I know that I must go to the emergency service. (P3)*

*When I can't stop crying and I have suicidal thoughts, [then] I know I'm not okay. (P6)*

*First off, I get scared. Next, I head on to feeling depressed, then actually feeling psychotic<sup>2</sup>. Mostly, it is fear which takes over. (P22)*

For some people it may be more difficult to notice their signs of relapse and still something they have to learn.

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2. Where a person's thoughts and how they perceive things become disturbed, and they find it difficult to know what is real and what is not.

*I feel that it is a challenge to recognise [the first signs of a crisis]... I do not want a drop in my mood and that's why I work a lot to recognise [the early signs of] a crisis. (P15)*

Once a person or the people close to them can spot the first signs of a crisis, action can be taken to avoid this turning into an emergency situation. Usually this means seeking professional help as soon as possible for advice and what to do next.

If a crisis does happen a person can express their preferences for the care and treatment they wish to receive. These preferences can be written in a crisis plan, which also includes details of who to contact and other useful information (see the Appendix below for an example of a crisis card).





Things people have found useful to avoid a crisis:



**Take medication regularly**



**Learn to recognise the early signs of relapse**



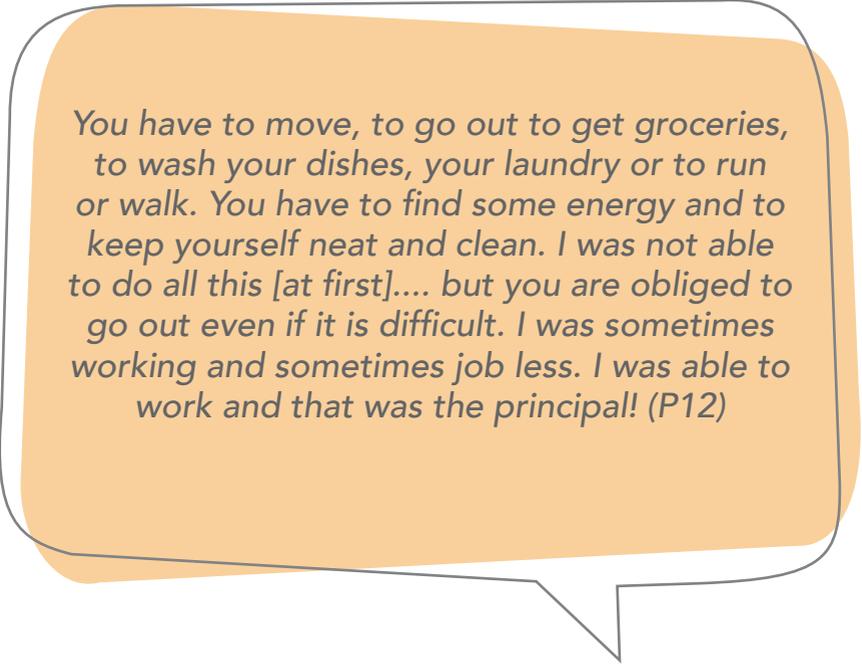
**Write a crisis plan in advance to express a preference for care and treatment should a crisis happen (see the Appendix)**

## ■ EVERYDAY ACTIVITIES

A person's daily routine can be disrupted by symptoms of schizophrenia and/or the side effects of the medication they may be taking. Things that a person use to do, such as getting up in the morning, washing and changing clothes, shopping, studying or going to work and meeting friends may become more difficult, slow down or stop altogether.

It is common for people to lose their jobs or stop studying if the symptoms become persistent and serious enough.

A person may become withdrawn and lack motivation to go about their usual daily routine. It is important that the person finds a way to establish a regular routine and times to do various things. Many people diagnosed with schizophrenia take part in different activities to get them moving and to provide some structure to their day.

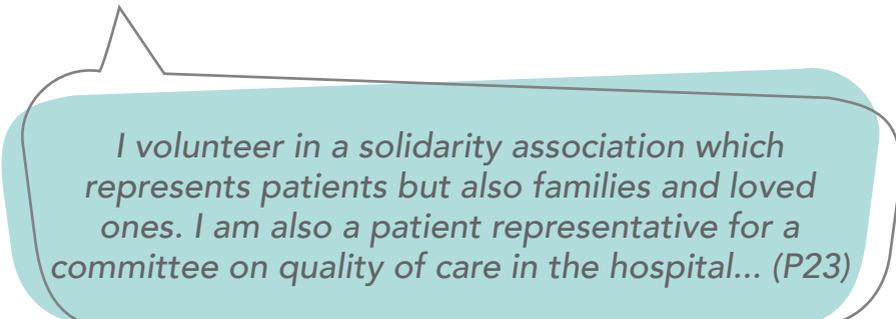


*You have to move, to go out to get groceries, to wash your dishes, your laundry or to run or walk. You have to find some energy and to keep yourself neat and clean. I was not able to do all this [at first].... but you are obliged to go out even if it is difficult. I was sometimes working and sometimes job less. I was able to work and that was the principal! (P12)*

Many people with schizophrenia benefit from keeping occupied with paid or voluntary work, hobbies and positive social contact. Help to find paid employment is becoming more available from health services and mental health organisations. Otherwise, taking up hobbies like photography, crafts, listening to music, reading and art can be rewarding.

People with schizophrenia often find activities outside the house also very beneficial. Outdoor activities like running, cycling, walking in nature or gardening can help improve a person's mood and well-being.

Becoming a member of a club, volunteering or joining a group are good ways to meet people and socialise. Many people with schizophrenia like to join groups with their peers or people like them with the same condition or experiences.



*I volunteer in a solidarity association which represents patients but also families and loved ones. I am also a patient representative for a committee on quality of care in the hospital... (P23)*

Part-time paid work may be another option if the person is willing. This has the added bonus of providing some income.

*My routine changed after losing my full-time job. I now work part-time and I earn a little money. (P9)*

It is also possible for a person with schizophrenia to work full-time if they wish to and find a job that is suitable for them.

*I work 5 days a week. I also do 10 hours of volunteer work in my church every week. (PA1)*



Things people have found useful for everyday activities and keeping occupied:



**Take up an interesting hobby or activity either inside or outside the home**



**Do some volunteer work for a local organisation**



**Find full or part-time work**

## ■ RELATIONSHIPS, SOCIAL ACTIVITIES AND PEER SUPPORT GROUPS

Positive friendships and close family and personal relationships are important for people with schizophrenia. The love and support from close family and friends are an essential part of helping a person with schizophrenia stay well. Having a good relationship with a relative, spouse or friend is fundamental to that supportive role.

*My husband helps me so I can do things on my own. And my daughter is also an important person who helps me maintain relationships with my neighbours or people from her daycare. (P15)*

When a person experiences many symptoms they may lose friendships and/or cut ties with the people close to them. Some people with schizophrenia might want to reestablish these relationships, and/or make new friends by taking part in social activities they have not tried before. Or, simply maintain existing friendships by meeting up regularly to socialise.

*I meet friends at the weekend and with coworkers some weekends. (P15)*

*I participate in social gatherings, events and concerts. I meet up with my friends and family. (P22)*



It is also helpful to have someone to talk to and confide in; to speak about feelings and to get help or support if needed.

Social media and online meeting platforms, like Zoom, Skype, Discord are another way to make new friends and maintain existing friendships. These have become an important way for people to keep in touch, especially with the current pandemic which has prevented people from seeing many friends and family. Many people use social media like Facebook, Instagram and/or messenger to communicate with friends and family. Some people don't use social media and prefer email or WhatsApp.

A speech bubble with a light orange background and a dark orange border. The bubble has a tail pointing towards the top right. Inside the bubble, there is a quote in a dark grey, italicized font.

*I only use Gmail. I used to use messenger but not anymore. I recently started using WhatsApp. I don't use Facebook because I don't trust it, but I have wished to use it for groups... I feel that a moderate use of social media is good. (P15)*

A person can join a group or become a member of a club.

*I belong to a nature/walking group and we go for walks together, which I enjoy. It helps me to socialise with others, as I have no friends. I also belong to a photography group and we meet to show our photos, go out and take photos together and to work on group projects, which I enjoy also. (P5)*

Peer support and self-help groups, (groups with people who are diagnosed with schizophrenia) offer another good opportunity to socialise, gain support and learn more about this condition and the positive ways to manage it.

*I get a lot out of peer support groups. Through them I learn information which isn't written in books and known by psychiatrists. I get a chance to listen and a chance to be heard. It is truly valuable. (P22)*

“**QUICK TIPS**”

Things people with schizophrenia have found useful for relationships and social activities:



To have positive friendships and close family relationships to help stay well and manage symptoms



Use social media, online meeting platforms and/or email to stay in touch with and make new friends



Become a member of a club, group or peer support group

## ■ IF A PERSON NEEDS A CARER

Not everyone diagnosed with schizophrenia will need an informal carer. Many people with schizophrenia are self-sufficient and can do things for themselves.

*I live with my parents. Fortunately I am able to do everything for myself. (P7)*

A carer is someone who provides support and help to a person who would not be able to manage without it. Informal carers can give the person emotional support and practical help with things like shopping, cooking, cleaning, managing finances, reminding the person to take their medication. A carer can be a parent, spouse, sibling, friend or other relative.

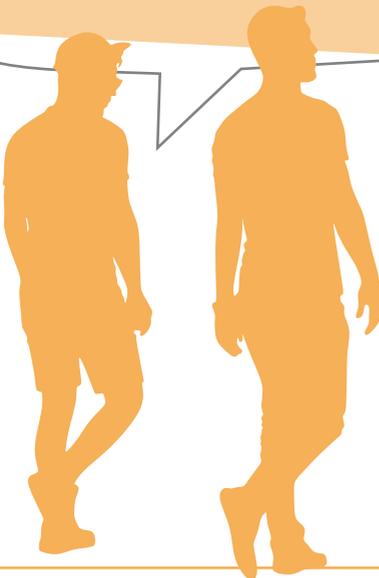
*I have a carer but his role is just to help me with my medication. (P23)*

Some people with schizophrenia do not like to see the person who supports them as their carer but see this as part of what families and friends should be doing to help each other.

*We support and help each other, like families should: they are not my carers! We offer each other emotional support, and practical support like doing favours and helping out with particular tasks; that is not caring, that is family life. (P5)*

From a carers' perspective providing emotional support, empathy and understanding are some of the best things to help a person manage their symptoms.

*My brother lacks insight into his own illness. He doesn't take his medication, doesn't engage and he withdraws from everyone. I get about 3 months a year with him when we go for walks and talk, and I let him talk and whatever is his reality is fine by me. I try to understand what he sees, feels and experiences. The 'normal' chat we used to have before he got ill doesn't happen. He doesn't live the way he used to and he is secretive about his current life. (C10)*



Some carers also like to help the person remain autonomous and independent. This is important for both the person and those close to them. It can help reduce a lot of potential stress and difficulties in the relationship, while at the same time keeping the person as active as possible.

*I don't actively help her [the person], as it invaded her privacy; it reduced her personal responsibility and autonomy. What we have now... is an openness. If she needs support she asks. 'Caring for' her, monitoring her, managing her medication and appointments caused her illness to remain active and my mental health to deteriorate. (C5)*

Sometimes a person does require support from an informal carer and this might well include support with taking medication.

*He [the person] needs constant reminders [about taking their medication]; due to forgetfulness and disorganization, rather than an unwillingness to take it. (C2)*

*Our son [the person] lives independently but we see him every weekend and twice in the week. I [the carer] follow very carefully his intake of medication, especially since he had a relapse due to refusing to take his medication. (C6)*

Carers can also help with attending appointments to see a health professional and act as advocates to help discuss the dose of medication and its effect on the person.

Some carers though do like to encourage the person to be autonomous and independent with regards to managing their medication.

*I write down which medication we buy and give her [the person] responsibility to count and put them in boxes, so that everything is scheduled, [which helps her] feel more free.' (C17)*

*'She [the person] takes her medication by herself. She does not require help in that regard. We always discuss the issue of medication sensibly and openly. She can decide if she wants medical treatment or not. (C11)*

Ideally, the decision whether a person needs support from an informal carer should be taken together by both the person and the potential carer, where any arrangements are mutually agreed and mutually beneficial.

## ■ STAYING FIT AND HEALTHY

Physical health for people with schizophrenia has become an important focus recently. This is because research has shown that people with schizophrenia live between 15-25 years less than people without this condition. The reasons for this are to do with the symptoms of schizophrenia, medication side effects (like weight gain) and the person becoming less active and not eating well. People diagnosed with schizophrenia are more likely to smoke tobacco which also has a negative effect on their health and how well the medication works.

Physical health problems for people with schizophrenia can include high blood pressure, diabetes, respiratory and heart problems. Regular physical health checks from a family doctor can help detect and treat any physical health problems early.

It can sometimes be difficult to get help for a physical health problem when a person is diagnosed with schizophrenia. This is because these symptoms are often interpreted by a doctor as part of their symptoms of schizophrenia rather than separate physical health problems. Not all generalist doctors understand schizophrenia.

*It's frequently suspected that I'm not experiencing actual physical symptoms, just my mental health condition. (P16)*

This might lead to delays in being seen and treated for a physical health problem, especially if a person has gone to an emergency department in a general hospital. To avoid this situation some emergency departments have a liaison psychiatrist who can help. A person (and someone close to them) can also insist on being taken seriously by doctors if they dismiss any physical health concerns.

Some people with schizophrenia look after their physical health by taking regular exercise and eating a balanced diet. Some reduce their sugar intake and try not to smoke and drink alcohol too much. For many others it is very difficult, but they are aware of what they need to do.



*It is my challenge to take better care of my health. I feel I eat too much, so I want to fix that. I have fluctuations in my weight which I also want to fix. (P15)*



*I do take exercise, walk and swim. I also watch my weight and I don't smoke. Unfortunately, it is difficult for me to maintain a healthy diet. (P10)*

Even gentle exercise like walking can be helpful but taking on more energetic exercise activities like going to the gym, running, cycling and swimming can be beneficial for improving well-being and managing symptoms.

*I usually eat healthily, do yoga, walk my dog, go jogging and swimming. I watch my weight and I don't smoke. (P21)*

**“  
QUICK  
TIPS  
”**

Things people with schizophrenia do to stay fit and healthy:



**Take regular exercise - walking, jogging, cycling and/or swimming**



**Have a physical health check once a year**



**Talk to a doctor about any physical health problems**

## ■ MAKING DECISIONS (MONEY, HOUSING, WORK)

Once people's symptoms of schizophrenia settle many are able to manage their domestic, work and financial responsibilities. But for others some support may be necessary to help with these responsibilities.

Sometimes people want someone who can help make decisions on their behalf, especially if it concerns family matters, relationships, accommodation or other legally binding arrangements or contracts. But many other people with schizophrenia prefer to make their own decisions.

*I try to make these decisions and arrangements by myself and I have so far been successful in doing that. (P10)*

If a person would like help with making decisions it is important that they are consulted and listened to rather than being told what to do.

*They [people who try to help] either tell me what to do, or make decisions for me. What would be helpful at times is if people can help me to figure out what I want to do... (P5)*

A positive way to help people make decisions about important matters is to involve other people in a discussion to explore the options available to them. If a person is not able to do this having an advocate, someone to speak to or help make decisions on their behalf, is another good option.

*My parents and my brother [the person] make the decisions when he is able to. (P7)*

**“  
QUICK  
TIPS  
”**

**Things people with schizophrenia do when making important decisions:**



**Try to do most of this by themselves if they can or with the support from someone close**



**Discuss any important decisions with people the person trusts**



**Seek more support if needed from a relative, friend or an advocate who can act on their behalf**

# Part Two

for carers, friends and family



*'There is nothing to fear, as recovery comes with love, creativity and availability.'* (C8)



## ■ BEING A CARER – WHAT TO DO

It can be can be daunting and overwhelming to hear that someone very close to you - a child, spouse, relative or friend – has been diagnosed with schizophrenia. The reaction many carers have when they first hear this is similar to the person themselves - a mix of emotions and concerns about the future. Some are shocked and/or confused as they may not know much about schizophrenia, and others are relieved, as it helps

*Relief. We were able to understand what our son was going through. We could educate ourselves to find out how to help him and also ourselves. We were fearful at first to think what sort of life [the person could] expect and would he ever have a happy, independent life.*  
(C7)

A close relative or friend who takes on the role of supporting the person may have to think about what this diagnosis means both for them and the person.

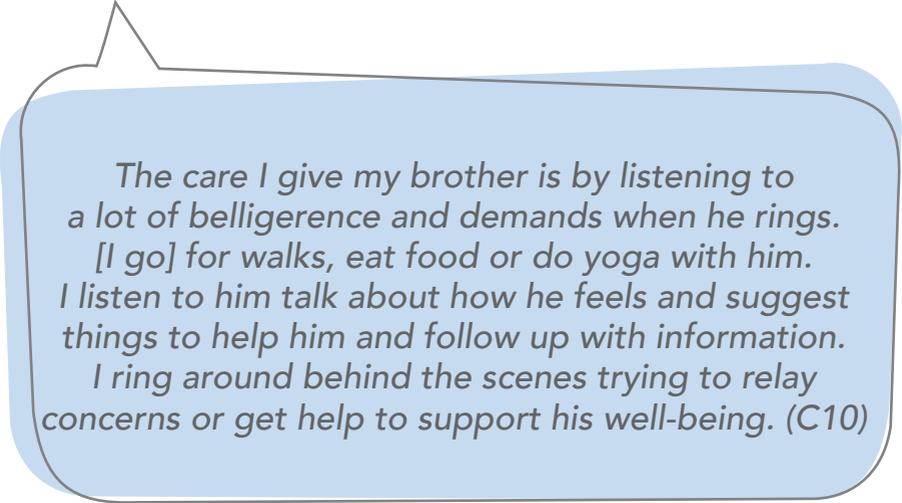
*I knew I would from that day on have to fight for him as I had seen my uncle overmedicated growing up and didn't want the same for my brother. I wanted to protect him, to keep him safe. (C10)*

Some people close to a person with schizophrenia don't wish to assume the role of carer because it can change the relationship and because they don't want to take away the person's independence and autonomy.

*I do not agree families should be assigned the title of carer. This is confusing. It affected my relative's self-esteem and made me feel guilty for wanting to live my own life. Also, it assumes that my relative is not capable of living her own life. (C5)*

These mixed feelings don't mean that a close relative or friend will not support the person in every way they can. It shows that they may find the situation difficult even when they want to be there for the person and to give support when needed.

A close relative or friend who gives support on a regular basis may find they do become a carer. As described in part one the practical support from a carer can include help with shopping, cooking, cleaning, reminders about taking medication and attending appointments. Sharing activities and giving emotional support through listening and talking are equally important and what many carers do. Listening and talking to a person may not always be easy; they may be finding things difficult and not know how to solve a particular problem or find the information and support they need.



*The care I give my brother is by listening to a lot of belligerence and demands when he rings. [I go] for walks, eat food or do yoga with him. I listen to him talk about how he feels and suggest things to help him and follow up with information. I ring around behind the scenes trying to relay concerns or get help to support his well-being. (C10)*

## ■ INFORMATION

Carers or close relatives/friends will need to think about the all information they need to understand; what the person is going through and how best they can support them when necessary. For many relatives/friends/carers this will include knowing about the symptoms the person experiences, how these are best managed, and the effects of medication and what to do if a crisis occurs.

*[For me, the relative/carer] it was how to understand the various symptoms, how to act during psychotic episodes and how best to support them [the person] when recovering. This information is the hardest to access or find and not always available from doctors or health professionals. (C7)*

Information, as explained in the section on 'Finding information about schizophrenia' should be from trusted sources like health service websites and mental health organisations.

## PHYSICAL HEALTH AND WELL-BEING SUPPORT

If a person has physical health problems these may also need to be given support by a carer or friend. Access to the right health services for these problems can be challenging if a person is known to be diagnosed with schizophrenia (see the section on 'Staying fit and healthy'). Carers might have to support the person access healthcare services for their physical health when necessary. Better communication between general and mental health services would be very beneficial, although can often be lacking. A good way for general healthcare services to support a person diagnosed with schizophrenia is:

*If physical and mental health care professionals liaised more often and acted as one whole unit, it would allow for better accessibility to clients and services which support their needs. (C16)*



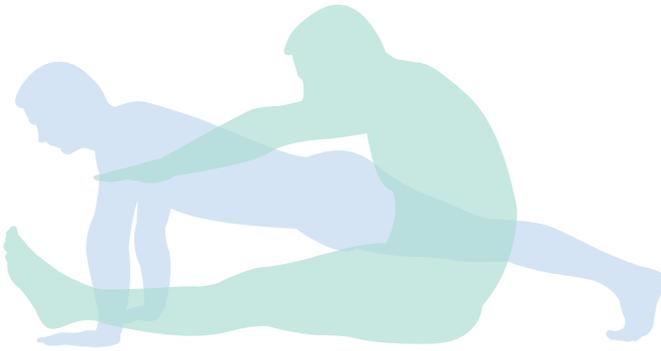
And to have:

*More understanding of how the suffering person feels, and a designated area in A&E for mental health patients. (C10)*

Carers might also give support and advice for the person to eat well and exercise regularly, especially if they have gained weight since taking antipsychotic medication.

*We try to walk, and be outside the house as much as possible, 3 or 4 times a day... Also we like to buy proper food and cook. My son has an interest in food... (C8)*

If the person smokes tobacco persuading them to cut down the number of cigarettes they smoke a day or to give up can be difficult, especially if they are heavy smokers.



*Personally, it is very difficult when you are alone with the person, to continuously address the problem of smoking. (C8)*

Smoking less or stopping altogether is particularly important for a person taking antipsychotic medication because tobacco smoking reduces the success of antipsychotic medication. Healthcare professionals can give advice on ways to stop tobacco smoking.

Some carers have learnt what works best in supporting the person to lead a healthy life.

*[It is] important not to 'nag'. [The person] has given up tobacco products and is using an electronic cigarette and vaping as a nicotine replacement...' (C7)*

Leading by example and doing activities together works well. This has the added benefit of helping carers to stay fit and healthy too.

*We do exercise together and it works fantastic. (C17)*

“**QUICK TIPS**”

### Things to do when supporting a person diagnosed with schizophrenia:



Give practical and emotional support as needed, but also help the person to maintain as much independence and autonomy as possible



Find out from trusted sources the information needed to help support someone diagnosed with schizophrenia



Support the person's physical health and well-being by doing activities together, encouraging them to eat well and find ways to smoke less tobacco or to give up smoking

## ■ EVERY DAY ROUTINES

Not everyone diagnosed with schizophrenia will need care on a daily basis. Many people with schizophrenia can and do lead an independent life. There are occasions when a person with schizophrenia requires more practical and emotional support because of their continuous symptoms and/or the side effects of medication. In these situations providing support can become a regular part of a carer's everyday routine, along with the other things they have to do.

*[I give] lifts to the supermarket, lifts to the local mental health clinic and make sure he [the person] is getting his medication and going to his doctor's appointments. [I] encourage him, when he is well to cook for himself. I cook at other times for all the family. I let him know what is going on in the local community and activities which may be of interest to him. I help with daily activities, like helping or reminding him to clean his room and to wash his clothes etc. (C7)*

*I am supporting her [the person] in her daily activities. I am motivating her. I try to give her enough space so she can become independent. (C11)*

## TAKING A BREAK

With such a busy everyday routine it is important carers find some time in the day for themselves, or to share the support they give with other people who are able to help.

*We try to take turns. We try to give each other free time so the other can regain some strength. Sometimes our children help too. We try shaping our programmes in a way so we can also relax.' (C11)*

It can be difficult for some carers to find time to relax, go on holiday or to do any leisure activities, but it is important to do so when possible, even for a short time period.

*[It is hard to do the things I would like to] as she [the person] requires someone to be close by in case she needs help. (C11)*

*Very rarely [do we get time to ourselves], only when [the person is] well. When unwell we do not go out except to get food etc. Even when well, we do not go abroad. Any break is for a couple of days and we have to make sure there is someone who knows him [the person] well to call or he can stay with a friend for a short time. (C7)*

## AN ALTERNATIVE WAY TO CARE

A few carers have discovered a different approach to caring called family recovery. This means carers take on helpful ways of living, thinking, feeling, behaving and generally being, which is not dependent on the recovery or well-being of the person with schizophrenia.

*Family recovery is taking personal responsibility for our own [the carer's] emotions, expectations, fears, behaviours and support in the process. It involves understanding the challenges we are facing within the family, including our own stress and how that impacts us as individuals. It means understanding how we communicate to have our needs met more effectively. Family recovery is respecting and accepting that while we all see things differently there are key skills we can draw on to live a life with hope, empathy, equality and autonomy. Learning to care about our relatives and feel supported is what family recovery is all about. (C5)*



## Things to think about if supporting a person diagnosed with schizophrenia everyday:



Find time in the day or week to take a break and plan ahead for leisure activities or vacations



Where possible share the support a person needs with another relative or close friend that the person trusts and knows well



See how family recovery might be included in the support given to a person

## ■ SUPPORT FOR CARERS

Carers often need their own support, especially as their situation can be emotionally challenging.

*I find it difficult to switch off. The situation with my brother is often traumatic and a crisis which stays in my head. (C10)*

Some carers find it useful to share experiences and learn more about managing their situation and emotions. It is helpful if they have someone to talk to. This can be done informally with close friends, relatives and in some instances with the person themselves.

*I can discuss everything with my son (the person). (C12)*

*I have my husband and my friends [to talk to]. (C4)*



Some carers find a therapist or counselor to talk about their situation.

*I've had a therapist with whom I could talk to about my difficulties. I would recommend it to all carers as the most valuable thing to do when caring for others. (C17)*

Community groups or carers organisations can be of great support to carers. This helps carers feel less alone, offers the chance for them to share their own experiences of supporting someone with schizophrenia, to hear the stories of other carers in a similar situation and to learn new strategies on how to manage.

*I go to a carers support group every other week. It makes it easier to know that you are not the only one with these problems. (C13)*

Some carers become a part of a carers' organisation by volunteering and educating others about the support they give which they find very rewarding.

*I am involved with the board of an Association for family members of people with mental illness and get support and a sense of value by doing this. (C6)*

Some countries in Europe don't always have a carers' group which makes it difficult to find this type of support, but some carers have found groups in other countries and attend these. Technology can be a helpful tool for support across countries.

*There is no such group in my country, but a wonderful support group exists in [my neighbouring country], at the Awakenings Foundation. We have been commuting there for a year, although currently we are taking part in Zoom meetings. This helps a lot.*

*(C11)*

Some carers attend more than one group, and some go with the person with schizophrenia.

*I receive help from two peer support groups. We have group conversations and they help. It is not easy to go to with the person I care for, but it still works and it helps a lot. (C17)*

**“ QUICK TIPS ”**

**What carers can do to find support:**



**Find someone to talk to who will understand the situation – a friend, relative or a therapist/counselor**



**Join a carers' group or organisation to share and to hear the experiences of other people in a similar situation**



**Become a volunteer at a carers' group or other organisation to support others, if time allows**

## ■ STAYING PSYCHOLOGICALLY AND PHYSICALLY HEALTHY

It is important for carers and the person with schizophrenia to keep psychologically and physically healthy. This will involve many things including getting enough sleep, taking time to relax, eating well, socialising and seeking help when needed.

*'I try as much as possible to stay healthy and to maintain contact with good friends. I very much like reading and going to the movies...'* (C6)

Eating well and taking exercise are also important for carers' physical health.

*We try to eat lots of vegetables every day. I do some training. If I can, I go for a walk every day.* (C13)

Carers can also experience mental health problems; depression and anxiety are common. Carers have found exercise and finding time to do something enjoyable helpful. Yoga, counseling and meditation are useful.

*I feel anxious about times to come and sometimes depressed. But I always overcome it by doing something that I like - shopping, walking and cycling... (C6)*

*[I have] anxiety. Counselling and meditation help me. (C18)*



*At times I feel like crying. I complain to my husband and to my friends and relatives. Then I say, 'OK, let's make some progress now. Let's not waste the day.' (C10)*

Some carers take medication for their mental health problems and make an effort to stay well.

*I have medication to suppress my mental health problems. It would be a nightmare if I become unwell. I do a lot to care for myself so this doesn't happen. (C17)*

## ■ SOCIALISING WITH OTHERS

Some carers have a busy daily routine and don't have the time to meet other people to socialise. Although some try as much as possible to make time to do this, others find it difficult as they may not feel motivated to socialise.

*The level of stress with caring is sometimes intense and I don't feel like meeting anyone to socialise, especially when my morale is low. With the stigma of mental health, people tend to shut off and not to open up, or meet up to share their day to day worries. It's a good day when someone rings or knocks at the door and listens. (C8)*

The stigma of mental illness can also affect carers and lead them to become isolated and/or feel alone. When making friends some carers prefer to find people who understand their situation, which is why joining a carers' group or similar organisation is beneficial.

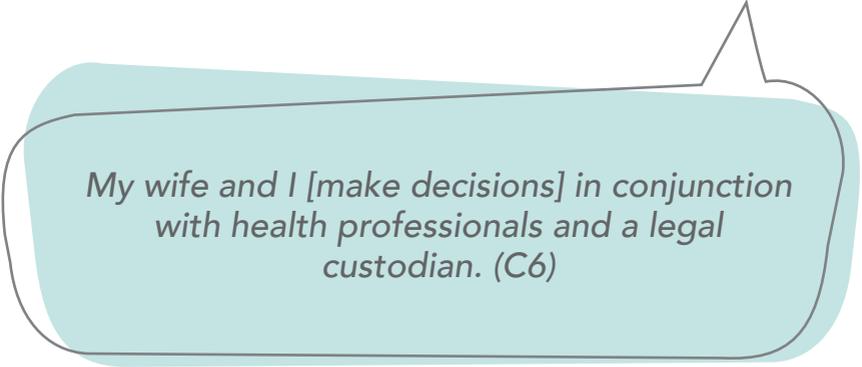
*It's an enormous help when you have a few friends who understand. It's not a help when you have to pretend that everything is alright! (C8)*

The time invested in meeting people and making new friends who understand a carer's situation is time well spent, as it can help with any difficulties when caring for a loved one.



## ■ MAKING DECISIONS WITH AND ON BEHALF OF THE PERSON

Apart from the practical and emotional support carers can often provide some also help with managing the person's accommodation and financial affairs, and with liaising with health professionals. Occasionally a person with schizophrenia may not be able to manage these things alone or their health may limit their ability to make important decisions regarding legally binding arrangements or contracts. A carer may then help with making decisions for the person.



*My wife and I [make decisions] in conjunction with health professionals and a legal custodian. (C6)*

Decisions on behalf of the person are usually made on an informal basis (without the involvement of a legal authority). Even if many of the decisions are made by a carer these can be legally and financially important.

*My dad oversees things but has no legal authority. My dad cancels my brother's bank card when he loses it and reorders him a new one. My dad tries to stop my brother doing big bank withdrawals. (C10)*

Carers may take on the responsibility for acting in the person's best interest, but they may not always talk with them about the day to day details if things become complicated.

*I make all the decisions, some of them I discuss [with the person], others I do not. It was not always like this, [only when the person's] health situation grew more complex. (C17)*

There are occasions when a carer and the rest of the family help with the person's affairs. This can sometimes become stressful for everyone involved.

*I [make the decisions on the person's behalf]. Siblings can be of help, but I found after a few years, their life is stopped by worrying about the person, their parents, especially their mother. The strain on a parent is enormous. So everything has to be organised and planned, and supported by the carer. (C8)*

Managing and dealing with the person's affairs can be time consuming, especially with regards to housing and financial issues.

*My parents were always at the citizens' advice bureau or in social housing offices or chasing social workers to try to get my brother somewhere safe to live... (C10)*

Many people with schizophrenia prefer to make their own decisions or make them jointly with the carer and any other people involved.

*Usually she [the person] is the one who makes the decisions about herself, and we support her. She cannot work enough to become fully independent, so we support her financially too. (C11)*

*All of us [make the decisions], [the person, me [the carer] and his dad. (C1)*

The person may need a great deal of support to live independently.

*Our son is happy living on his own, in his own house but the responsibility is totally on our shoulders and the burden is sometimes heavy, especially when we think about the future when we will no longer be able to take care of him. (C6)*

Making decisions on behalf of the person may involve some delicate diplomacy, sometimes this involves knowing when to and when not to get involved with their personal affairs.

*I have to be very careful. He [the person] will get angry if I take charge [of his personal affairs]. I have to back off. (C13)*



Decisions regarding health matters will involve healthcare professionals. Not all health professionals are willing to discuss a person's symptoms or medication with a carer, even if they are a close relative. The person with schizophrenia will need to give permission so that this is not considered a break in confidentiality. Carers can provide helpful information to health professionals about the person's progress or when they may be becoming unwell. Ideally, this too should be discussed and agreed with the person in advance.



## What carers can do to help make decisions on the person's behalf:



**Know when to help with managing the person's affairs and with their agreement**



**Help to maintain the person's independence as much as possible, and manage their affairs only when needed**



**Agree with the person how best to talk to healthcare professionals about their progress or when their symptoms are getting worse**

# Conclusion

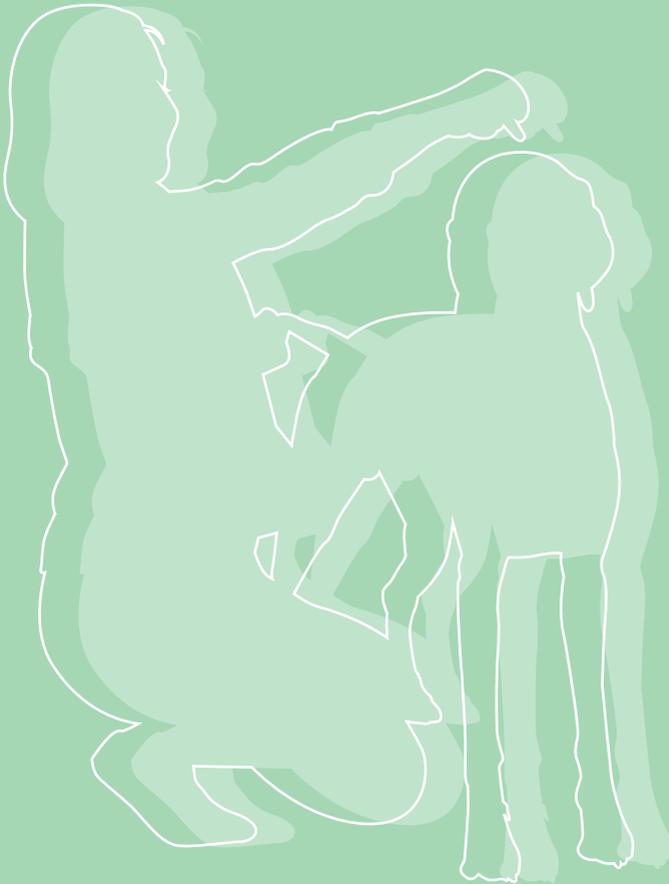


This guide has been developed by drawing on the experiences and histories of people diagnosed with schizophrenia and carers. When we listen to these we can see how it is very possible for them to live a good life and maintain their independence. All of the people consulted for this guide have become experts in their own right, knowing what the condition means for them and how to go beyond its boundaries to live well.

Some have found this more challenging to do, but they are still able to achieve independence with the support from the people close to them, along with their healthcare professionals.

There are many suggestions in this guide that can help with managing schizophrenia from the time it is first diagnosed and the journey thereafter, whether in terms of full recovery or continued symptoms. This includes an emphasis for both people diagnosed with schizophrenia and carers to maintain, as far as possible their social, psychological and physical well-being.

# Appendix



# SYMPTOMS OF SCHIZOPHRENIA SIDE EFFECTS OF ANTIPSYCHOTIC MEDICATION

- Symptoms of schizophrenia can be experienced in different ways and can include:
- hallucinations – hearing or seeing things that do not exist outside of the mind
- delusions – unusual beliefs not based on reality
- muddled thoughts based on hallucinations or delusions
- losing interest in everyday activities
- not caring about your personal hygiene
- wanting to avoid people, including friends



People diagnosed with schizophrenia are often treated with antipsychotics. It is important to know what side effects antipsychotic medication might give a person, as everyone will react differently to it. A patient information leaflet is usually provided with medication to explain what side effects can be experienced. Although not everyone will experience these, the side effects for antipsychotics can include:

- Stiffness and shakiness
- Uncomfortable restlessness (akathisia)
- Movements of the jaw, lips and tongue (tardive dyskinesia)
- Sexual problems due to hormonal changes
- Sleepiness and slowness
- Weight gain
- A higher risk of getting diabetes
- Constipation
- Dry mouth
- Blurred vision

# CRISIS CARD

This crisis card contains information about me and who to contact in the event of an emergency. I may be experiencing an episode of mental illness so please be patient when asking me questions and remain calm.

## My details

My name: .....

Medical condition/diagnosis: .....

Current medication:.....

If I need emergency treatment/care please take me to (hospital or an alternative place of safety). My preferred hospital is:

Name .....

Address .....

.....

Telephone.....

My preference for emergency drug treatment which has helped me in the past is:

.....

I have the following allergies:.....

.....

## Emergency contact details:

In the event of an emergency/crisis please contact my carer/relative/close friend:

1. Contact person's name (relationship to you): .....

Mobile number (or other contact number):.....

2.Contact person's name (relationship to you): .....

Mobile number (or other contact number):.....



# CRISIS CARD

**Please help me to contact the right services.**

My doctor's name and contact details are:

Name: .....

Telephone number (office hours): .....

Hospital or health center: .....

Out of hours telephone number: .....

**Other key contacts** In case of emergency, please contact:

**Key contact 1**

**Key contact 2**

Name .....

Name .....

Address .....

Address .....

.....

.....

.....

.....

Telephone.....

Telephone.....

Mobile .....

Mobile .....

**Other information:**

Blood group .....

Medication .....

.....

Health insurance.....

Other details.....

.....



## RESOURCES FOR FURTHER INFORMATION

Organisations for further information	What they do	Their website
EUFAMI - European Federation of Associations of Families of People with Mental Illness	The European representative organization for family support associations across Europe. EUFAMI promotes the interests and wellbeing of families and caregivers affected by severe mental illness	<a href="http://www.eufami.org/">http://www.eufami.org/</a>
GAMIAN-Europe - Global Alliance of Mental Illness Advocacy Networks-Europe	A patient-driven, pan-European organization that represents the interests of people affected by mental illness and advocates for their rights	<a href="http://www.gamian.eu/">http://www.gamian.eu/</a>
Intervoice - The International Hearing Voices Network	A network of people who hear voices, see visions or have other unusual perceptions	<a href="http://www.intervoiceonline.org/">http://www.intervoiceonline.org/</a>
Mind	A charity that provides advice and support to empower anyone experiencing a mental health problem	<a href="http://www.mind.org.uk/information-support/types-of-mentalhealth-problems/schizophrenia/">http://www.mind.org.uk/information-support/types-of-mentalhealth-problems/schizophrenia/</a>
Shine	A charity who provides information and support for carers	<a href="https://www.shinecharity.org.uk/information/support-for-carers">https://www.shinecharity.org.uk/information/support-for-carers</a>

<https://www.gamian.eu>

