



Schizophrenia Carer Playbook



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Schizophrenia

Carer Playbook


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Introduction

You are not alone!

The **Carer Playbook** exists to provide guidance and support to carers of those living with schizophrenia. Through patient and carer stories, a variety of topics are covered. These include ways to keep yourself as well as the person you care for healthy, how to prepare for an appointment and how to deal with stigma.

The playbook is an interactive document, and throughout it you will find clickable links to help you navigate, indicated by . You can also move between the sections using the arrows at the top of the page, and the contents bar.

Marie

Marie is 62 years old and is a long-term carer for her 34-year-old son **François**. Marie has been caring for **François** for 15 years

Anna

45-year-old Anna is a carer for **Leon** (43 years old), her partner for the past 7 years

Álvaro

Álvaro is 28 years old and has been caring for his 19-year-old brother **Théo** for the past 3 years

Klaus

Klaus, 52 years old, cares for his 15-year-old son **Peter**, who was diagnosed 18 months ago

We represent the **10 million family carers**, across the European Union, who are responsible for caring for and supporting their child, sibling or partner with a serious mental health condition on a daily basis¹

Some of us care for the **21 million people** worldwide who face schizophrenia²

You are not alone!

Marie's Story


“ My son, **François** has been living with schizophrenia for 15 years. We both struggled to come to terms with the diagnosis and even rejected it at first, although I knew deep down it was correct. After a few years we grew to accept the diagnosis and from there we've been able to build an environment that is supportive for both of us.

Over the years, **François** has often found it hard to keep a job and manage everyday tasks that most people take for granted, such as going shopping and cooking for himself. This means that he often relies on me for help.

Together we do our best to manage the everyday, whether that is helping him with his shopping, reminding him to take his medication or simply talking through the day's events.



Together, we can make a positive impact on the lives of the people we care for

- Nine out of ten of us play a key role in reminding the people we care for to take their medication³
- Half of us contribute to treatment decisions 
- Over half of us regularly manage finances⁴
- Half of us regularly help with transportation and meals⁴

Schizophrenia is a chronic and long-lasting illness but it is possible to live a good and fulfilling life with proper treatment



You are not alone!

Álvaro's Story

“ When we first learned of **Théo's** diagnosis, my initial reaction was one of shock, which later led to more distressing thoughts of what this would mean for me and my life. In the first year, a slight emotional rollercoaster ensued as I tried to learn more about the condition and work out what my brother needed.

I've had to learn how to balance my life between caring for **Théo**, and other activities such as my hobbies, to make sure that I remain well.

Being able to care for my brother fills me with a great sense of love and pride. I know we have a long road ahead of us, but having a strong relationship helps bring consistency to our lives, and I also believe it helps with the management of **Théo's** condition.

”

➔

The sections to the right will help you find information and advice so you can remain strong, look after yourself and provide the best support for the person you care for

Keep up the good work!

We all realise that mental health and wellness, for you and the person you care for, is as important as physical health. As a carer you care for the person, not their illness. What you do, each and every day, can have a positive and profound impact on their mental wellness and their general health and wellbeing

Providing care for someone can be both rewarding and challenging. It can impact your life in many ways so it's important to get the most out of your healthcare visits and to look after yourself

Anna's Story

When I heard the term 'schizophrenia', one of the first things I did when I got home was look it up on the internet – it told me it was 'a complex and chronic brain disorder, in which symptoms can be severe and disabling and can affect all aspects of a person's daily life'.⁵ That kind of made sense to me when I thought about **Leon** and how he had been behaving over the past few months.

Recently, **Leon** started to avoid using a debit card, he didn't trust it anymore and only 'real' money made sense to him – he was worried that everyone would be pointing, staring and laughing at him, that the walls would start to close in on him and that the 'voices', that frequently taunt him, would shout at him, causing him to panic and run away.



What does this mean for you?

- Caring for a person with schizophrenia can impact you emotionally, psychologically and financially⁶
- Therefore, seeking help and support not only for your caring role but also for your own wellbeing is extremely important

What are the symptoms?⁵

- Distortion of every day behaviour (positive symptoms)
- Decrease/loss of everyday functions (negative symptoms)



What are the causes of schizophrenia?

- The exact cause of schizophrenia is still unknown and is likely to be caused by a combination of factors that vary from person to person⁵

What impact/consequence can schizophrenia have on everyday life?

- Social withdrawal and less personal interaction
- Difficulty in finding/retaining employment
- Reduction in ability to develop and maintain meaningful relationships

Klaus's Story

When **Peter** was first diagnosed, we were so confused and believed that he would never be able to live a full life. Once the initial shock had worn off and we began to accept the news, we started to look at what this would mean for **Peter's** life.

I had googled to find out some information about what treatment options were available and to my surprise I came across stories of people who had been living with schizophrenia for over 20 years and were able to live a full life.

Establishing the correct treatment plan can still take some time to get it right but I have already seen some significant improvements in his behaviour.

Knowing that there are people out there who are living with this condition on a day-to-day basis and functioning well, has filled me with such hope for the future.

What treatments are available?

- While there is no cure for schizophrenia, it can be treatable and manageable, allowing for people to live a full life^{7,8}
- When the symptoms of schizophrenia are treated, most people will improve over time

Treatment options

- Talking therapies (psychoeducation)
 - Agreeing common goals between the healthcare professional (HCP), carer and patient is key in the management of schizophrenia
 - Cognitive behavioural therapy or supportive psychotherapy may help to reduce symptoms and enhance overall function⁷
- Medication
 - Medications can reduce symptoms and help to prevent any relapses⁷
 - Alongside the patient you care for, make sure that you have an open and honest discussion around all treatment options available
 - It's always important to discuss any potential side effects with a HCP, so you are equipped with the best way to recognise and deal with them. In addition, it is key to discuss any side-effects the person you care for may have previously experienced with medications
- Community Mental Health Team (CMHT)/Crisis team
 - For further support, the patient you care for may be referred to a CMHT, for secondary care



How can I identify a relapse?

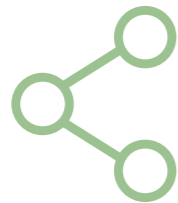
- There are multiple factors that can contribute to a relapse¹⁰
- Everyone will have their own individual warning signs of when a relapse may occur. Some of these may include:
 - Increased feelings of anxiety and/or worry
 - Feeling tense
 - Increased restlessness
 - Talking about hearing voices
 - Feeling paranoid

Trusted sources for information

Local support groups

Finding out more about schizophrenia

Anna's Story



Initially, we did not tell anyone about **Leon's** diagnosis. Once we had come to terms more with the news we had been given, we decided it was time to share it with our family



Through other family members, we learned that some people had grown uncomfortable around **Leon**, or even scared of him. They thought that his diagnosis meant that he was now a different person who they couldn't talk to in the same way, or was even dangerous

At first this was really hard to deal with, but we have learned to use this as an opportunity to educate people on the truth about schizophrenia and it being an illness like any other



When friends were given more time to come to terms with the reality of schizophrenia, we found that their relationships with **Leon** improved

Whilst some people were extremely supportive and loving, others did not respond in a very positive way

At first it was just small things that started happening, we were being invited less and less to family gatherings and people that we used to be close to, gradually stopped contacting us



How to deal with stigma

Negative attitudes, incorrect beliefs and fears about the diagnosis of schizophrenia can all result in stigmatisation⁹

To try and reduce the stigma of schizophrenia, it is important to:

- First accept that in the beginning some people may have certain misconceptions about the disease or even know nothing about it at all
- Understand that people's attitudes towards the disease may, in part, come from a fear of what they do not understand
- Where possible, try changing people's attitudes through educating them on what schizophrenia is

Let's talk!

▶ Let's talk

Álvaro's story

I'd often go with **Théo** to his appointments and not be at all prepared for what the doctor was going to ask me. "So, how has **Théo** been over the past month?", he'd say. And I would go blank. I would desperately try to remember what had happened and what I wanted to talk to the doctor about. In the end, since I kept a diary to organise myself at work, I decided it would be a good idea to keep one to better prepare me for the appointments.

I started to note down how **Théo** had been feeling, the difficulties he had been facing and whether he had taken his medication.

After keeping the diary for a while, I started to see a pattern. It started with a few missed pills here and there – I might not have noticed had I not kept a diary. So, I made an appointment to talk with his doctor.

We had a really good discussion and the doctor explained to us all of the available treatment options. **Théo** and I are going to talk it through, but I'm feeling very positive that we can find something that better suits him.



Who's in your corner?

- Doctors, nurses, members of the healthcare team and the mental health community are all in your corner. Although it can feel awkward at times, good communication between a doctor, members of the mental health team, a person with schizophrenia and you, the carer (all of whom make up the therapeutic alliance) is important
- If you feel that the person you care for isn't making progress or isn't satisfied with their HCP, it is okay to suggest to change or even look at alternatives
- To help prepare for times of emergency, it could be a good idea to discuss an emergency plan of action with the psychiatrist. This could involve requesting to have your psychiatrist's phone number and adding hospital and community service contact details into your speed dial

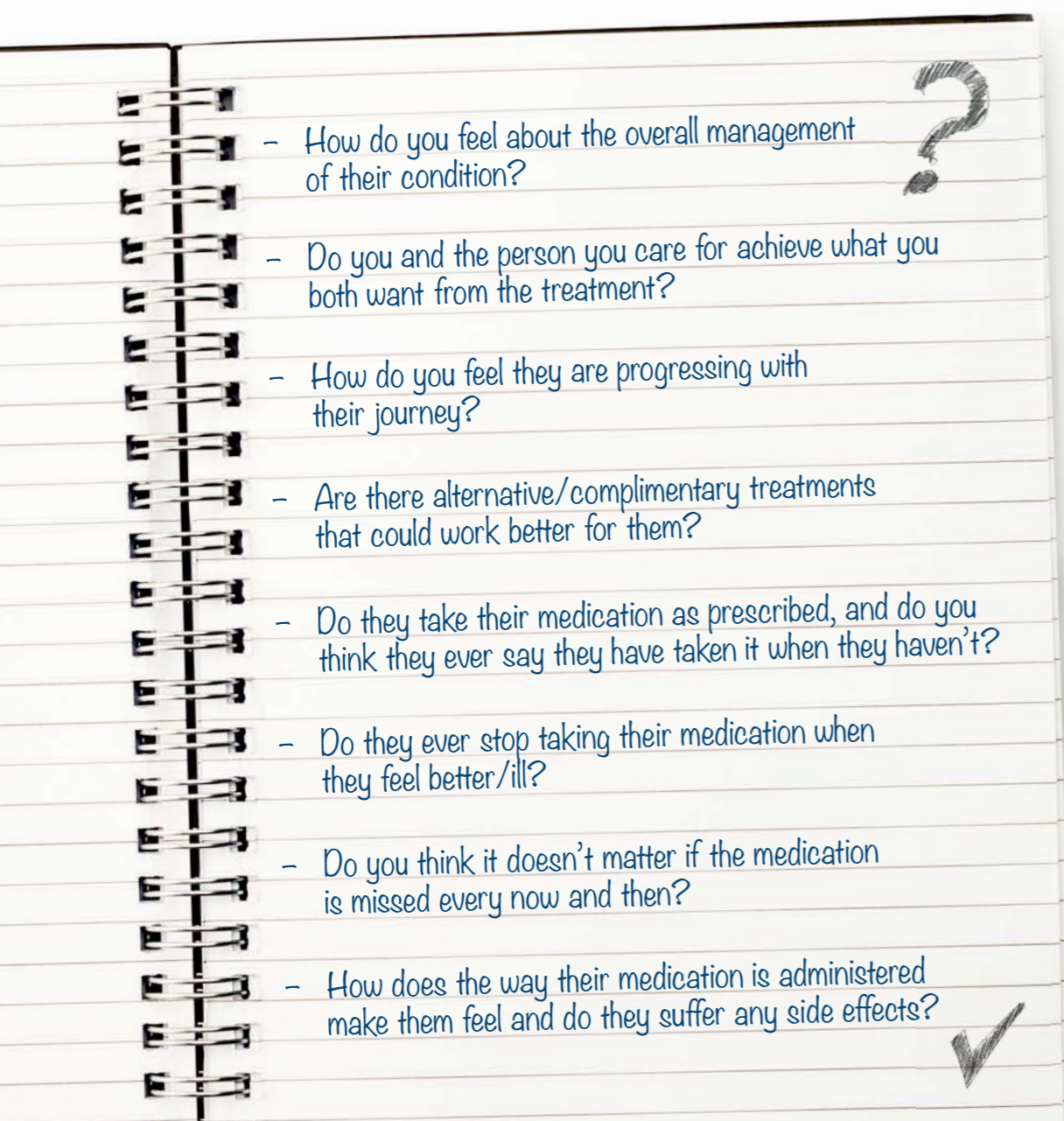


Let's talk!

How to prepare for an appointment



- Keep a diary of highs and lows for both you and the person you care for
- To help get the most from the appointment, try sitting down together and go through the questions below, noting the answers in your diary:



Let's talk!

Your input matters



- **Get involved in the conversations**

- You, the person you care for and the healthcare team can work together to make shared decisions
- Your input into the conversations around the management of schizophrenia is of great value – as you are a carer, you will have significant insights to share
- Don't be scared to ask and be open to talking about all available options – your healthcare team should be open to talking about different treatments and solutions
- Raise concerns and ask questions – use your diary to explain your reasons
- If you are still unsure, it's ok to ask for a second opinion
- Be prepared for the possibility that your loved one may not want you to accompany them, especially during the early visits. It is important to be respectful of their wishes, but be there for them should things change

- **Family therapy**

- Family therapy is based on the principle that having a stable family support structure can help the patient achieve their long-term treatment goals
- The person you care for may sometimes blame you/your family for their condition, taking part in family therapy sessions may help address some of these concerns in a protected environment

- **Questions to ask during a visit**

- What are our treatment options?
- What should we expect in the near future and over time (with regard to symptoms and also potential effects of medication)?
- What services/support is available to us?
- Are there other things we can do to help ourselves?



Marie's Story



It was about ten years ago, now, that I remember feeling overwhelmed. I felt like my life was on hold, and just dealing with the everyday reality of caring for my son was all encompassing. It wasn't until I met Julia, who was with her son, attending the clinic we visit for **François'** regular check-ups, that things started to change for the better. We started chatting and she told me about a day centre for those facing mental health issues



Julia and I both made new friends, ones close enough to help out. It's given me back some 'me time', allowing me to get back to gardening, which has always been a passion of mine

The centre opened up new avenues, and I finally had people to talk to. It gave me the mental strength to carry on



Key points and tips for mental wellness

Looking after yourself is as important as looking after the person you care for; know your limits and seek and accept help.

Develop a good personal support system:

Friends/family

Obtaining additional support within your circle of friends and family can be of significant help

In the initial stages, some friends and family members may struggle with the diagnosis, which can be due to misconceptions of the condition

In time, to help to try and reconnect the relationship, it may be useful to talk and provide factual information about schizophrenia and highlight this is an illness like any other

Self-help groups

Attending groups and sharing your experiences with other carers can offer an added layer of support⁶

Everyone within the circle of care may need different levels of input and outside help

It is important to establish if joining the group is just for yourself or if it is a family-based decision

Gaining external support can help with negative feelings,⁶ such as:

- Isolation
- Anger
- Fear
- Grief
- Distress
- Guilt

Professional support

Ask your treating psychiatrist or healthcare team for a recommendation or referral to psychotherapy if you feel professional guidance would be of help to you

Digital communities /e-therapy apps

Make use of online platforms and communities to gain additional outside support from people who know what you are going through

Key points and tips for mental wellness

Know your limits, avert a potential crisis^{11,12}

Set realistic goals/recognise your own boundaries

- Whilst caregiving for a loved one can be extremely rewarding, it can also be very demanding. Setting some specific boundaries and looking out for any warning signs of stress can help to protect your mental well-being
- Seek support/talk to your doctor – do not be afraid to ask and take help from those around you, you are not alone in this
- Take a break – know that it is ok to take and make time for your own well-being as well as the person you are caring for

How can I identify a relapse?

- Know what actions to take during a crisis – sometimes relapses can happen and it is important to be prepared for this should it happen



Reward yourself

- Make sure that you have some time within the week to reward yourself with an activity that makes you happy. This could be something as simple as going for a leisurely walk, having a hot bubble bath or sitting down to watch a movie
- Try and plan in small rewards every day, even for just 15 minutes

Get into healthy lifestyle habits

- Try and get into a routine of eating a healthy diet
- Exercise has been shown to help to improve mood¹³ – try and incorporate some form of exercise everyday such as a 30 minute walk or light yoga session
 - Make sure to get a good night's sleep and have a good sleeping routine
- Sleep should be viewed as just as important as eating well and exercising regularly¹⁴
 - Go to bed at the same time at night whenever possible and wake up at the same time of day
 - Try and get around 7–8 hours of sleep each night¹⁴
 - Feed your mind with positive thoughts

Top 10 take away points

- 1** Helping to manage the everyday tasks of people you care for is pivotal in making a positive impact on their lives

"Mum helps bring everything together"¹⁵

- 2** Providing care for someone can be challenging but it is also extremely rewarding

"There isn't a day that goes by without my son telling me that he loves me and thanks me for looking after him. That is enough to fill me with pride and love, bringing light to even the darkest of days"

- 3** Mental health and wellness, for you and the person you care for, is just as important as physical health

"We both made new friends, ones close enough to help out. It's given me back some time – some 'me time'"

- 4** Schizophrenia can affect both carers and patients in different ways

"I'm still learning about schizophrenia, about what it is, and how it affects both Leon and me"

- 5** When the symptoms of schizophrenia are treated, most people will generally improve over time

"At first I was a zombie, then little by little I could produce posters, today I tutor others"¹⁵



Top 10 take away points

6

Caring for schizophrenia can impact you emotionally, psychologically and financially and so seeking outside help is of great importance

"I now feel stronger and more positive than before. I have a network of people I can talk to and call upon if it gets too much"

7

Agreeing common goals between the HCP, carer and patient is key in the management of schizophrenia

"When we all agreed on the overall goals for going forward, it has meant that we are all striving for the same outcome"

8

Keeping a diary of highs and lows for both you and the person you care for can help you get the most from your appointments with your psychiatrist

"After keeping the diary for a while, I started to see a pattern. It started with a few missed pills here and there – I might not have noticed had I not kept a diary"

9

Don't be scared to ask and be open to talking about all available treatment options

"I quickly learned that no question was a silly question and being open with our HCP about what other treatment options were out there, led to us discovering the best treatment options for my son"

10

Looking after yourself is as important as looking after the person you care for

"I've learned now that I need to protect at least 30 minutes a day for myself so that I can be at my best to help care for my husband. In that time I either enjoy a good book or just go out for a 30-minute walk. Whatever it is I make sure it is just for me and use it to re-charge myself"



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