Beyond the diagnosis:

Understanding what matters most from people living with schizophrenia and their carers



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Executive summary

Introduction

Mental Health UK (MHUK) has co-produced an insights report with 12 people with lived experience of schizophrenia, including families and carers, to explore experiences of living with schizophrenia. The motivation behind this project was to better understand what it means to live with schizophrenia, or to care for someone who does, with a particular focus on the impact of medication and how side effects shape quality of life. These insights were gathered to ensure that decisions about treatment are informed by the real experiences of the people they affect most. This work builds upon existing evidence of experiences of people living with the condition and their carers, contributes to a broader evidence base about their challenges and priorities, and offers policy and practice considerations to drive improvement in care and support.

The project was initiated and funded by Bristol Myers Squibb (see page 51 for more information).

Our approach

The project followed a rigorous co-production model, placing lived experience at the heart of every stage. Participants were invited to take part from across the UK through MHUK's networks: six people with direct lived experience of schizophrenia and six family members, friends and carers. Group and one-to-one insight sessions were held separately for each group as well as preparation and debrief meetings to support accessibility and meaningful engagement, with safeguarding protocols followed throughout and informed consent provided by all participants. Full details of the methodology are provided in the appendix.

Key themes

Key themes from Experts by Experience (EbEs) with direct lived experience insight sessions

This report presents 12 key themes reflecting the voices of EbEs living with schizophrenia:

1. Living with schizophrenia is pervasive, exhausting and affects all aspects of daily life
2. Treatment is experienced as an ongoing trade-off between symptom control and quality of life
3. Stigma, social isolation and loss of identity are profound and enduring
4. Symptoms remain persistent, complex and difficult to manage despite treatment
5. Side effects are pervasive, multi-dimensional and highly impactful
6. Medication adherence is active, effortful and psychologically complex
7. Treatment pathways are variable, unpredictable and often reactive
8. Continuity of care and relationships with professionals are critical to positive experiences
9. Involvement in care is variable and often insufficient
10. Healthcare systems are fragmented, inconsistent and difficult to navigate
11. Peer support and lived experience connection are highly valued
12. Holistic needs are not fully addressed within current care models

Key themes from carer insight sessions

This report presents 7 key themes reflecting the voices of carers for those living with schizophrenia:

1. Caregiving is all-consuming, ongoing and impacts every aspect of life
2. Symptoms remain persistent, distressing and unpredictable despite treatment
3. Emotional, relational and social impact is profound and enduring
4. Carers play a critical but under-recognised and inconsistently supported role in care
5. Navigating services is complex, fragmented and problematic
6. Medication management is complex, unclear and difficult to evaluate
7. Information and support are insufficient, particularly outside of crisis



Considerations for policy and practice

Treatment and clinical practice

Optimise treatment and recognise unmet need

Current antipsychotics do not fully control cognitive and negative symptoms for many people.

Greater investment in mental health research and equitable funding are needed to expand the range of effective treatments available.

Acknowledge and address side effect burden

Side effects are pervasive and underacknowledged in clinical practice.

Patient-reported outcome measures and transparent prescribing conversations, including about weight, cognition and mood, are essential to building trust and supporting adherence.

Embed holistic, person-centred support

Care must extend beyond symptom management to address education, employment, finances, housing and wellbeing

The VCFSE sector and peer support networks have a vital role to play, supported by sustainable long-term funding.

Systems, support and society

Recognise and support carers as partners in care

Carers are consistently underrecognised and unsupported.

They should be treated as genuine partners in treatment decisions, with timely information, a named point of contact and access to carer-specific peer support.

Strengthen continuity of care

Consistent therapeutic relationships are fundamental in mental health.

Addressing the psychiatric workforce crisis, improving documentation and reducing caseloads are all needed to deliver more stable, person-centred care.

Tackle stigma at every level

Stigma affects both people living with schizophrenia and their carers.

Public awareness campaigns, professional training and co-produced mental health literacy efforts are needed, alongside action from the DHSC and DWP within their own systems.

Recent changes to the Mental Health Act signal a welcome shift towards greater patient choice and autonomy, but our findings demonstrate that care must evolve at every level of the system to match that ambition. Where shared decision making was present, even within an imperfect system, EbEs with direct and caring lived experience were clear that their experiences were significantly better.

Carers play a critical but consistently under-recognised role in the lives of people living with schizophrenia. They are frequently excluded from clinical conversations, left without adequate information and unsupported both during and outside of crisis. Services should treat carers as genuine partners in care, with meaningful involvement in treatment decisions, consistent access to information and support that does not depend on the person they care for being in crisis.

Stigma remains a profound barrier, both in society and within health and social care systems, and its reach extends to carers too. At a systemic level, schizophrenia has historically been deprioritised, with services underfunded and people living with schizophrenia too often placed in the ‘too difficult’ category by a system that has lacked both the resources and the cultural empathy to respond adequately.

This is reflected in wider society, where harmful media portrayals and deeply entrenched misconceptions mean that schizophrenia remains among the most misunderstood and stigmatised conditions of our time. Addressing this requires more than awareness campaigns; it requires a fundamental shift in how schizophrenia is perceived and prioritised at every level, from government and health systems to communities and the media.

Conclusion

For too long, people living with schizophrenia have been deprioritised by a system that has not always responded with the empathy, resources or urgency their needs demand. The experiences shared in this report are varied, but the message is consistent: schizophrenia affects far more than symptoms alone, and its impact extends to the carers who provide so much of the support that services do not. The experts by experience who contributed to this report, people with direct and caring lived experience of schizophrenia, did so with honesty, courage and generosity. Their voices deserve to shape the services, policies and treatments that affect them. We hope this report plays a small part in making that happen.

Living with schizophrenia:

In their own words

Introduction

In 2026, Mental Health UK co-produced a project alongside people with lived experience of schizophrenia, including families and carers. The project set out to explore experiences of living with schizophrenia, of accessing healthcare services and the impact of taking antipsychotic medication. The purpose of the project was to engage people living with schizophrenia, and those who care for them, to gather their views and experiences. As a leading charity for people severely affected by mental illness, including schizophrenia, we have built long-term relationships and networks with people living with severe mental illness and those who care for them, enabling us to reach and meaningfully engage people and communities.

This report describes how the project was conducted and presents key insights from the six Experts by Experience (EbEs) with direct lived experience and the six EbEs with caring lived experience who generously shared their experiences, views and opinions with us. Each theme is presented in people's own words, drawing on direct quotes and broader discussion, as the report is led by the voice of lived experience. The report concludes with Considerations for Policy and Practice, reflecting the insights and priorities from this project.

We hope this report will help drive that change.

Terminology

The language used to describe mental health carries different meanings for different people, shaped by personal experience, culture, and identity. This terminology continues to evolve over time as understanding shifts and preferred, more affirming language emerges. Wherever possible, the terms used throughout this report have attempted to reflect current, widely accepted language, though it is acknowledged that no single choice of words will resonate equally with everyone.

For more information about the work we do, please see page 48.



What is schizophrenia?

Schizophrenia is a severe mental health illness, affecting approximately 1% of the population (Rethink Advice and Information, 2023) and often commences during a person's late teens or twenties. In 2023, it was estimated that 177,979 people over the age of 14 in England have schizophrenia (GOV.UK, 2026).

The symptoms of schizophrenia vary between people but can affect thoughts, feelings and behaviour, with common symptoms including hallucinations, delusions and disorganised thinking and behaviour (Mayo Clinic, 2024). Symptoms can be categorised into three types: positive, negative and cognitive. Positive symptoms include delusions, hallucinations and disorganised speech; negative symptoms include social withdrawal, lack of motivation, decreased energy, loss of interest in usually enjoyable activities, a flattened mood and an inability to feel pleasure (called anhedonia); cognitive symptoms include impairments in memory, difficulty expressing thoughts and reduced processing speed. Together, these can have a broad effect on daily life and quality of life, and where symptoms persist despite treatment they are referred to as residual symptoms.

The existing evidence base on schizophrenia and its treatment is summarised in the appendix to this report (see pages 52-55). The insights that follow build on that evidence, bringing the voices of those with direct lived experience to bear on the gap between what current treatments offer and what people living with schizophrenia and their carers actually need.

Our approach

The project followed a rigorous co-production model, placing lived experience at the heart of every stage. It began with a co-design session involving four experts by experience (EbEs), who worked alongside members of staff to shape the questions, themes and approach before any insight sessions took place. Participants were invited to participate from across the UK through MHUK's networks. Six people with direct lived experience of schizophrenia and six family members, friends and carers who were either currently prescribed antipsychotic medication or actively caring for someone with schizophrenia.

Group insight sessions were held separately for EbEs with direct lived experience and caring/family lived experience, with additional individual sessions available to those who preferred that. Debrief sessions followed each insight session to support participant wellbeing and understand further reflections. Safeguarding protocols were followed throughout, all participants provided informed consent, and the draft report was reviewed by the co-design group prior to finalisation.

As with many insight projects, findings reflect the experiences of a small group and are not necessarily representative of the wider population. They are, however, rich, considered and consistent, and they are presented here in the words of the people who lived them.

For detailed information on how this project was conducted, please see pages 45-47.



Key themes

EbEs with direct lived experience of schizophrenia

The following 12 themes reflect what was heard across the EbE insight sessions for people with direct lived experience. They capture the breadth and complexity of living with schizophrenia, from the daily effort of managing symptoms and navigating treatment, to the profound impact on identity, relationships and quality of life. These themes are presented in the words of the people who lived them.

Theme 1:

Living with schizophrenia is pervasive, exhausting and affects all aspects of daily life

The emotional impact of living with schizophrenia was a recurring theme, in which people with direct lived experience highlighted the experience of daily life as effortful and cognitively demanding. This was often characterised as continuous, rather than episodic, with one stating, “it can be exhausting”. This exhaustion appeared to be a consequence of symptom management and effort to maintain daily functioning, “it’s like a constant battle”.

This shaped multiple aspects of daily life, especially planning, organisation and decision-making, “everything became chaotic and very disorganised and disjointed”, which can contribute to a loss of independence, “planning for the day-to-day activity went completely out”. One person extended this impact to hobbies, demonstrating that the daily impact can affect leisure activities that form part of a person’s identity, “I’ve always been really into video games, but at the moment I’m really struggling to even get the motivation up to start playing a game”.

This impact also spoke to wider unmet needs, such as financial stability, “I stopped paying all my bills, stopped paying off my credit cards and loans and everything”.

People with direct lived experience described a shift from acute disruption to partial adaptation, where increased effort is required to prioritise the most important aspects of their lives, “Going to the gym is really important to me and other people maybe see that I’m really well, but don’t notice that I’m having to invest a huge amount in doing that…but I need to do it because otherwise I would be really sedentary at home because I really struggle with things like the weight gain…I’ve had risk of type 2 diabetes… related to what I think is probably the medication that I’ve been on over the years.” This demonstrates how the burden of schizophrenia can persist despite tremendous effort. For many, a full return to previous levels of functioning currently remains out of reach, demonstrating the need for treatment and services to evolve.

Theme 2:

Symptoms remain persistent, complex and difficult to manage despite treatment

People with direct lived experience described their experiences of medication and how this shaped their symptoms. For some, medication was recognised as a key factor in keeping them well, “my medication helps me live the life I want” and another stated, “it’s played a big part in me feeling well. Probably, if I had to put a number on it, maybe 75%.” For some, the benefits were clear, with medication alleviating impact upon education or employment, “One of my meds, I was unable to do anything and then on this med, I’ve managed to complete a degree”.

For others, medication was associated with partial treatment of symptoms and these residual symptoms, either continuous or fluctuating, shaped daily life, “the voices aren’t as loud, they’re not as constant”. In some cases, medication was associated with a deteriorated mental state, “my medication often leaves me feeling drained and depressed and lonely, empty inside. This leads to me withdrawing until I feel better.”

> **“I was so flat and people wouldn’t know if I was happy or sad or what I was feeling and I didn’t really know either.”**

Certain positive residual symptoms including paranoia, voice hearing, intrusive thoughts and difficulty distinguishing reality, were common despite medication. People described the following: “I start to get a sense of paranoia”, “not quite knowing what’s real and what’s not”, “someone behind the window or someone behind the curtains”.

Residual cognitive and negative symptoms emerged as particularly impactful on daily life, “I was so flat and people wouldn’t know if I was happy or sad or what I was feeling and I didn’t really know either.” Another person reflected that residual cognitive and negative symptoms often go unrecognised by services, “I often have found that being on just an antipsychotic, means that aspect of living with schizophrenia is not well managed, like the motivation and that ability to concentrate and be cognitively well.” One person gave an account of how this affects their functioning and daily life, “I do think some of the negative symptoms, like lacking in motivation and not wanting to go out… is…almost as important to me as some of the unusual experiences because then I can take my daughter to the park or I can do things”.

This shows that cognitive and negative symptoms can respond poorly to treatment. It also highlights a potential conflict in priorities between people and clinicians when measuring treatment success, with EbEs focusing on the broader consequences of untreated symptoms for their daily functioning, relationships and quality of life. Collaboration between policy makers to ensure services have the resources to adequately assess and monitor people’s progress, as well as detect and treat residual symptoms, is crucial.

Theme 3:

Stigma, social isolation and loss of identity are profound and enduring

EbEs described stigma as a central and ongoing challenge that shapes how they live and interact with others. People shared that there was a reluctance to disclose their diagnosis due to fear of judgement and real experiences of being labelled, misunderstood or avoided, “you don’t want to share that you’ve got schizophrenia”, “they don’t want to come near you”. The media perpetuated this narrative, “I don’t ever remember seeing anything positive about the way people live their lives with it at all.”

EbEs highlighted the societal perception that people with schizophrenia are associated with being a danger to others, a narrative they strongly rejected, “people with schizophrenia are dangerous to other people. It’s not, that’s not how it is”.
Difficulty forming relationships, loss of friendships and reduced social networks, contributed to social isolation among the EbEs, “I lost all my friends, every one of them”. Internalised stigma played a role which led to shame and reduced self-confidence, “it’s actually made me not want to use the word schizophrenia sometimes. Often I tell people that I’ve had psychosis or I try and find softer ways to talk about things, because I think there’s so much self-stigma attached”.

Stigma was also felt from health professionals in other specialities as one person reflected upon in an A&E department, “I find that whenever I go to A&E for someone else, particularly having a child, they think about my mental health…. they almost get hooked onto the fact that I’m a parent with mental illness before thinking about the fact that I’m actually quite well and I’m here to support my child”. The impact of stigma was far reaching and observed in multiple settings, including the workplace; “when you’re at work, having discussions about mental health can be really hard and I’ve definitely been in workplaces before where I feel like I can’t use certain words or phrases about my mental health that I would like to because I fear about the stigma or the attitude change that might come with that.”

Likely in part due to the impact of stigma, EbEs demonstrated a preference to connect with others who share their lived experience, “The only person I could get close to is someone who’s got schizophrenia, who understands me. Yeah, yeah, otherwise I don’t think anyone could be friends with me.” This suggested social isolation may be externally imposed and driven by the individual’s fear of being judged or misunderstood; a fear which could encompass a person’s diagnosis or visible side effects of medication, such as movement disorders.



Theme 4:

Treatment is experienced as an ongoing trade-off between symptom control and quality of life

The insight sessions revealed that EbEs experience a dissonance towards medication, wishing to be free from it, “most time I wish I wasn’t on some medication…” whilst simultaneously fearing relapse if they stop it “…but then I’d be back to square one again”. The driver to continue treatment appeared to be risk of relapse, rather than perceived wellness, “will I return to being psychotic?”, “paranoia is worse than any side effect”. This reflected a continuous balancing act, with quality of life and the risk of relapse both being at stake, and a resultant resignation to continue treatment, “I just got to keep going”.

EbEs reflected on their experiences of stopping medication which informs these decisions, “for me, it’s the unusual experiences or perceptions. I’m lucky enough that my medication has totally stopped me hearing things that aren’t there, but as soon as I’m off it, they come back and it’s horrendous.”

Another person reflected on the personal nature of striking this balance, demonstrating that each person living with schizophrenia will have their own unique needs and priorities when it comes to medication, “living with schizophrenia, it comes with other things, like low mood. So if medications make that worse or my anxiety higher, that for me is intolerable because it stops me doing the things I want to be able to do. But also, if there was something that stopped me being able to drive, I would be furious because that’s been such an important part of like my recovery and ability to go to work, because I can’t get the tube, for example, during rush hour.” This highlights the compelling case for person-centred care, identifying medications that specifically meet their needs, to ensure clinicians support people to live the life they want.

Theme 5:

Side effects are pervasive, multi-dimensional and highly impactful

Side effects emerged as a significant and wide-ranging burden for people , affecting multiple body systems and areas of daily life. Among those reported were weight gain, cognitive difficulties including brain fog and poor concentration, sleep disruption, muscle stiffness, dizziness, constipation, loss of libido and raised prolactin levels. While the impact of individual side effects varied, together they touched on physical health, mental wellbeing, relationships and identity, often compounding one another and the difficulties of living with schizophrenia itself.

A broad range of side effects experienced by the EbEs emerged from the sessions:

"I definitely have...constipation"

"I get very vivid dreams and then I wake up suddenly when the dream become too vivid... very, very vivid, very graphic, very negative"

"sometimes I get dizziness and light-headedness"

"muscle stiffness"

"loss of libido"

"The brain fog makes it harder to think"

"it gives a feeling of being slowed down"

"I find myself really stiff in the mornings and going through life slower."

"One that was really a bit of a disaster for me was that you can get raised prolactin and it basically can stop your periods and then I had this horrible belief that I was pregnant and it was really unsettling and fed into lots of my symptoms of being unwell at the time."

These side effects showed the potential to compound existing cognitive difficulties and affect relationships and social engagement in particular.

Whilst some side effects could be managed by additional medication, there was resistance amongst some EbEs as this would result in polypharmacy:

"they put me on a medication that actually brings down prolactin, but it's also an antipsychotic."

"I dribble a lot and it's disgusting and there's not a lot I really can do about it because I don't particularly want to take any more medication than I'm already on."

> **"When it comes to concentration, I struggle a bit, to follow an entire movie for me now has become a very big challenge. In fact, I don't do [it] anymore. I just put it on in the background, watch for 10 minutes and then lose concentration."**

Amongst all the potential side effects, weight gain emerged as the most frequent and that exerted the greatest negative impact upon physical health, mental wellbeing, self-esteem and identity for EbEs:

"Weight gain has been a huge battle"

"the appetite and weight... if I came off treatment I know I would lose a lot of weight"

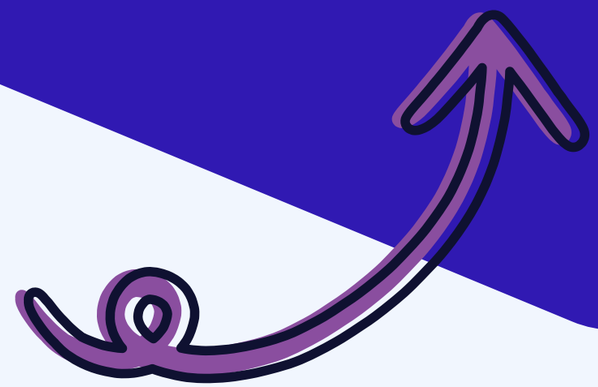
"I went from being actually quite underweight to being now very overweight and that's been bad for my self-confidence."

I really struggle with things like the weight gain and you know, I've had risk of type 2 diabetes and all sorts of things related to what I think is probably the medication that I've been on over the years.

"I just want to stress to the professionals just how significant the weight gain is on medication because it's enormous"

"The weight gain is always one that I kind of get frustrated with because people tell you that it's almost a choice, but it increases your appetite, it doesn't make you gain weight"

> **"It's just the extent of the weight gain and the impact it has on your self-confidence and stuff. It's just nothing can really prepare you for it."**



One person reflected on the interplay between side effects and that these can compound to exert a broad impact across multiple areas of daily life and a person's identity.

"even if they tell you it's...the best one for weight gain, it seems to be that it still has an impact. But also I used to play very high level sport, like for an international kind of level of sport. And I noticed when I got unwell, that has been the hardest thing to get back to is just being active."

EbEs reflected on the need for transparency around side effects as these drive treatment dissatisfaction and factor in when considering stopping medication.

"A doctor once sat down with me and did a side effects screen in a way that was really meaningful. And for me, if that had been done when I was younger...then maybe I could have had a bit more of a conversation about what was making me want to stop taking things."

This positive account demonstrates the benefit of using outcome measures recorded directly by people living with schizophrenia and how this can have enduring benefits for a person's journey through care.



Theme 6:

Medication adherence is active, effortful and psychologically complex

The insight sessions suggest that medication adherence is not passive but requires ongoing effort, routine, reminders and support systems to help facilitate, "I'm religious for my dossette box, but...I also always have an alarm on for the morning and an alarm on for the evening". Another EbE reflected, "my husband basically manages my meds, to be honest. He sorts it for me each week. He reminds me...so some of my medications you can take as required and he knows and helps me know if that's needed in the moment or to help me sleep because sleep is so important....I rely heavily on that structure around me to take it every day. My pharmacy will ring me to remind me that my prescription is due, which I think is quite rare".

Despite EbEs recognising the benefits of medication, there was often an ongoing internal tension, a wish to stop medication to feel more like themselves, "I want to sometime... stop the medication and try", offset by a fear of relapse, "I don't want to go back to that way". This suggests that medication adherence is a continuous, conscious process rather than a fixed behaviour, closely linked to perceptions of benefit, the burden of side effects and past experiences. This can have broad impacts upon a person's care journey, affecting their likelihood of remaining well and their potential need for intensive or inpatient services.

Theme 7:

Treatment pathways are variable, unpredictable and often reactive

EbEs clearly described "trial and error" with antipsychotic prescribing that had limited predictability and transparency, evoking uncertainty around their treatment journey. One person stated, "I went through a cycle of switching. I think I tried five other meds in that time and they just didn't work like the one that did work".

One person highlighted how this can delay optimisation of care, "I think there's this sort of trial and error thing...when treatment's less effective...it doesn't seem to be an algorithm which is followed particularly well. And that means that it's just shots in the dark, basically, with the vain hope that one will hit. It's a bit soul crushing really when you're being juggled on these medications, some with bad side [effects]".

In some cases, medication changes felt reactive, rather than planned, "they just did it... he suggested it". However, there were positive instances of structured and responsive care, "the best planning I've had was when I was referred to perinatal. They were just so on it and honest about what they could and couldn't do. And it was a totally different approach for me that I've actually taken...if there's a switch that's going to happen, what support I would like in place for my family...could home treatment team visit me?". This highlights that when communication between clinicians and those receiving care is clear and care is approached collaboratively, treatment experiences are more likely to be positive and care plans more comprehensive.

Theme 8:

Continuity of care and relationships with professionals are critical to positive experiences

Continuity of care strongly influenced how EbEs experience care. Seeing the same clinician builds trust and supports understanding, “it’s helpful having the same person”, “they know my pattern”. Conversely, frequent changes in clinician can disrupt care, leaving people frustrated and disempowered by having to explain their story again, “I don’t like to change because it’s starting from scratch again”.

Having consistent relationships improves communication and treatment experience and makes space for individualised appointments that go beyond purely clinical factors, “I feel that they treat me more like a human being”. Ensuring mental health services are able to deliver consistent continuity of care requires a multidisciplinary approach.

Theme 9:

Involvement in care is variable and often insufficient

EbEs value being involved in decisions about their care. Some reflected on positive experiences where they were involved in shared decision making, given clear explanations, time to ask questions, or felt heard and respected, “I was given the option to select”.

Unfortunately, many insights emerged where this was not the case, “I had no say at all”, where trust in clinicians leads to passive acceptance rather than active involvement, “I just trust him so he knows what he’s doing”.

One person reflected on their experience of a decision being made without their consultation, “I had a new psychiatrist once who, without meeting me, changed my medication. And that was pretty disastrous, to be honest”.

The inconsistency in involvement in care reflects the differences between individual clinicians, services, trusts and regions that can greatly influence a person’s experience of services.

EbEs were clear on what they would like from their interactions with services:

“there’s a lack of awareness of being transparent about what might work…I’m someone who would much rather have been told if something’s likely to work”

“Being listened to probably is definitely at the top for me. Time to process as well and the greater autonomy, but being asked what I thought or what’s worked before, that’s when I got to meds changes which have actually helped me.”

“information about what the meds do and side effects, also any research findings into who the meds work for best, being able to make an informed choice.”

“it would help to be involved, it would help to be explained…looking at giving us evidence”

Theme 10:

Healthcare systems are fragmented, inconsistent and difficult to navigate

EbEs described significant challenges interacting with services. Loss of continuity and poor communication when moving between services, “no communication between the two”, variability in quality of care depending on location or provider, “it’s a postcode lottery” or a lack of consistent clinician or relationship, “there’s no such thing as your GP… that relationship bond has disappeared” emerged as central themes. One person described this lack of individualised care, “it’s just basically in, bloods, and back out the door” and the disproportionate focus on clinical factors, “I have a monthly blood test where I check in with my team. But I also feel like without that support there, there wouldn’t be much support offered.” Over time, these challenges appeared to erode trust in services.

> **“it’s like the first thing that’s mentioned is hospital, when actually you might want more like a home treatment team type service, or you might just want a bit more wrap around support from your community team.”**

One person described difficulty accessing care, especially outside of a crisis situation, “there seem to be services that are also almost easier to access in a way if there’s something “crisis [sic]” going on”. They went on to describe the agenda of services, which may focus on risk management, which may not align with the person’s wishes, “it’s like the first thing that’s mentioned is hospital, when actually you might want more like a home treatment team type service, or you might just want a bit more wrap around support from your community team”. This may reflect a lack of resources for community services to manage high risk, crisis situations, resulting in an overreliance on costly inpatient care and out of area admissions that separate people from the support of their loved ones.

Inequalities in access to healthcare were readily identified by EbEs, “in some ways the most difficult to access is actually primary care…because GP waiting lists are also really, really long”, leading to delay in receiving appropriate support and a potential worsening of one’s mental health. Another person reflected on the barriers to accessing certain services, “for me, it’s about how services are accessible for all rather than just certain groups of people because the Recovery Cafe for me was absolutely brilliant and I often wished it was open during the day as well as the evenings.”

Theme 11:

Peer support and lived experience connection are highly valued

Peer support plays a unique and important role for EbEs in their lived experience of schizophrenia, not only providing emotional support, but offering practical coping strategies and reducing social isolation. Many felt understood by their peers in a way that was lacking by those without schizophrenia, or healthcare professionals, “the only person I could get close to is someone who’s got schizophrenia”.

Some reflected on specific services that had been helpful; “the hearing voices network… it’s been a big help”, but it was clear that access to peer support was inconsistent and varied by location.

One person also highlighted how service provision has changed in the wake of the Covid 19 pandemic, “I used to go twice a week to the day unit. And there were other people that went there as well, and there was help having other people there to speak to. But since the pandemic hit…there’s not that support anymore.” This points to a greater societal inequity between the value placed upon physical health versus mental health.

Theme 12:

Holistic needs are not fully addressed within current care models

For many EbEs, their interactions with healthcare providers focused largely on medication and more holistic needs were less consistently supported, for example, “support with your physical health”. Although one person reported having regular health checks, “physical check down twice a year”, scaling back of services was highlighted by another person, “I was referred to the losing weight programme and then I received a text message that the provider is not providing the service anymore and that was very upsetting.”, which can reduce trust and hope that services will deliver holistic healthcare.

EbEs were seeking meaningful activities to support their hobbies and interests, “I’d love to do something like that… pottery… but it’s very expensive”. One person reflected on how they used their lived experience to help the training of tomorrow’s doctors, allowing them to feel empowered in their identity; “the Academy of Lived Experience… helped me to take courage and tell my story to doctors, medical students, to the point that I now do, every Wednesday, simulation training”. These experiences reflected a desire for a greater recognition of the wider impact of schizophrenia, beyond symptoms experienced, focusing on holistic, person-centred care.





Looking into the future

What matters most to EbEs with direct lived experience?

When asked what matters most to them looking ahead, EbEs spoke with clarity and conviction. Their hopes were not abstract but grounded in the everyday realities of living with schizophrenia: wanting to be heard, to be treated as whole people, and to have access to care that is as responsive and evidence-based as that afforded to other long-term conditions.

> “The one thing I wish healthcare professionals understood is that it’s very confusing for living through this. And it would help to be involved, it would help to be explained…about looking at giving us evidence”
>
> “And for me, it’s remembering that my mental health and physical health are really closely linked…I think my hope for the future is that maybe living with schizophrenia is as researched and as specific when it comes to treatment as some of the other conditions that people are living with long-term.”
>
> “I hope in the future there’s an algorithm, it clearly explains and…gives people who live with schizophrenia the process…without random guesswork.”
>
> “Being respected as having insight into your own needs is always helpful.”
>
> “schizophrenia doesn’t define a human being. The courage does. The way you cope every day, fight back and then try to achieve and live a normal life. That’s what defines a human being, not the schizophrenia or psychosis.”

Across these reflections, several threads emerge: a desire for genuine involvement in care decisions, greater transparency from clinicians, and a treatment landscape that keeps pace with the complexity of living with schizophrenia. But perhaps most powerfully, EbEs spoke to something beyond the clinical: a wish to be seen not through the lens of their diagnosis, but for the resilience, courage and humanity they bring to each day.

Key themes

Carers of people living with schizophrenia

The following seven themes reflect what was heard across the carer insight sessions. Carers and family are too often the invisible backbone of mental health care, absorbing an enormous personal burden while remaining on the periphery of clinical decision making. Their experiences deserve to be heard not as a supplement to this report, but as central to it. These themes capture the reality of caring for someone with schizophrenia with honesty, clarity and an authority that comes only from living it every day.



Theme 1:

Caregiving is all-consuming, ongoing and impacts every aspect of life

Carers described a whole life impact from their caring responsibilities, “it just takes over the whole of your life when somebody is unwell… everything else is put on hold”. Effects were described as wide ranging, encompassing career and employment: “I lost my job when I was taking so much time off to care”, financial strain, “going down from two salaries to one was quite a knock on the household”, and daily tasks, “my husband does all the household tasks now, literally. I don’t have capacity to do anything like that and I’m very grateful that he does that”. The deprioritisation of carer needs, particularly sleep, was shared by many: “your sleep as a carer is definitely affected and that affects your whole day because you’re not getting your sleep” and “I don’t know how many sleepless nights I’ve had”.

The theme emerged that carers experience a journey from crisis, through adaptation, to ongoing management. While coping strategies improve, the underlying responsibilities, uncertainty and risk of relapse remain constant, “Self-care, mental and physical wellbeing took a massive hit…probably for the first five or six years and it took a while for me to get back to self-care and now I’m quite determined that there’s things that I will do. I will do various appointments and whatnot and look after myself and same with nutrition and exercise”. The same carer reflected that despite this adaptation over many years, a full return to normality is unlikely, “then saying that, if he became acutely unwell again tomorrow, that may change again. I’m talking now from a place where he’s very stable and I am able to look after myself better and work and whatnot, but it changes, and it may well change again if he has a relapse.”

Although times of relapse involved more intense support, “everything else is put on hold absolutely everything when you’re in a crisis”, a constant state of vigilance was acknowledged by carers, who knew that despite the course of illness being episodic at times, they remained ready for deterioration throughout periods of stability, “at any point… something could happen and then everything is cancelled and you’re a full-time carer”. The experience of constant vigilance and unpredictable course of illness links to carers’ ability to remain in the workplace, affecting not only their employment but their career progression and financial independence.

Theme 2:

Symptoms remain persistent, distressing and unpredictable despite treatment

Despite treatment, many carers described ongoing, severe symptoms, that are distressing for both the individual and carer alike. These continued to shape daily life and reflect prolonged periods of unwellness, “he feels there’s nothing in his head… he feels very vulnerable… he won’t move because he’s so scared”.

One carer shared that they have become the focus of the residual positive symptoms of the person they care for, “he is accusing you of all different things, you just have to let that go right over your head…and just concentrate on caring for your son… making sure he’s safe…making sure someone else can see to him that he’s not having these paranoid thoughts or delusions about”.

It emerged that carers found that the people they care for were not always able to articulate their symptoms, perhaps reflecting residual cognitive symptoms, “they are relying on the individual saying…what is it that’s making you feel possessed? How can you describe it? And my son would say, well, I don’t know. He can’t necessarily put it in words.” This also spoke to the advocacy role that carers embody, supporting the people they care for in many settings, including their medical appointments.

Theme 3:

Emotional, relational and social impact is profound and enduring

One theme that emerged strongly from the insight sessions was the significant psychological and social strain carers experienced, including the weight of stigma, which, as with people living with schizophrenia, proved both all-encompassing and enduring, though experienced through a distinct lens. This had a profound emotional impact including distress and tension when symptoms are directed at the person providing care, “it can be difficult to maintain that relationship, especially when the ideas and ideations in his head are negative towards yourself. But you just have to think…this is whatever his voices are telling them”. The long-term course of periods of unwellness could result in lasting anxiety and vigilance, “worrying about him all the time”.

There was an emotional dissonance created by hospitalisation which was often preceded by intensive carer input. Whilst the admission itself provided respite, this prompted guilt amongst carers, “when [they] were admitted or sectioned, it was actually a relief for the whole family, for me and my husband as caregivers.

And that’s quite a bad thing to admit that you are relieved. Your son’s in hospital, but he’s safe and you don’t need to do these practical things, you’re getting some actual respite”.

Carers found that their relationships with the person they cared for changed when they took on a caregiving role. This was particularly pronounced with children caring for their parents where role reversal took place, “I’m mothering her. She’s not mothering me.” Others felt their relationship had strengthened, “it brought me and my sister closer together, as I gave more and more informal care”.

> **“it can be difficult to maintain that relationship, especially when the ideas and ideations in his head are negative towards yourself. But you just have to think…this is whatever his voices are telling them.”**

Navigating this relationship was not without difficulties and carers reflected on the balance of providing support and encouraging independence. One carer spoke of the weight of this dependency, describing how the people they cared for relied on them for even small things, and the quiet worry of knowing that level of support could not continue indefinitely.

This was compounded by the social isolation observed by carers: “the isolation for your child is awful. You know, it’s the loneliness.” and “…he’s phoning and saying, I don’t have any friends”.

Carers likewise experienced a loss of friendships and social isolation, “I lost a lot of friends when my son was diagnosed”. This was often framed within wider societal stigma and a poor understanding of schizophrenia, “there is such a lot of judgement around…schizophrenia, psychosis, voices…negative images perpetuated by media, by films, that schizophrenic people are dangerous, they’re going to be carrying weapons, they’re going to hurt you, all this kinds of thing. You’re challenging that all the time…they’re more of a danger to themselves than anyone else and it’s always been that way.” This same carer went on to reflect on the partial normalisation of mental health difficulties in the context of the Covid 19 pandemic, but that this was often only afforded to certain conditions that are more palatable and less stigmatised; “I think we’ve, since COVID, normalised talking about maybe anxiety, depression, different OCD and I think that’s very normalised for us now and there’s lots of stuff on social media about helping yourself and calm apps and all that kind of things. But there’s still…not a lot of information there about schizophrenics or things that they think or how enduring it is…

I’m not saying there’s not a lot of sympathy, there’s not a lot of knowledge…they’re going with what the media says”.

One carer described their experiences of stigma and how this changed over the course of providing care, “I don’t have any concerns about what others may think now. But at the start, yes, very much so. We didn’t tell a lot of the family about everything. We kept a lot of things to ourselves. But we were very concerned about judgment but…it’s been many years and that’s completely changed now. Anyone else’s stigma is their problem, not mine. That’s how we look at it. But yeah, at the start, it was very worrying and embarrassing. I know it’s awful to say, but it did feel kind of embarrassing.”

Carers strongly rejected the more stigmatising narratives around people living with schizophrenia: ‘there certainly is a lot of public belief that somebody with schizophrenia is going to kill them…as has already been said, they are far more likely to hurt themselves than somebody else.’ For many, this rejection translated into a sense of personal responsibility to challenge misconceptions in their daily lives: ‘if somebody says something about schizophrenia to me, I think then that’s my cue to actually tell them a little bit about it, because there’s a lot of ignorance.’



Theme 4:

Carers play a critical but under-recognised and inconsistently supported role in care

Carers reflected on their experiences supporting someone with schizophrenia in their journey through care, “it’s frustrating for a carer because you see a psychiatrist for 15 minutes and then you say…we’ll just increase this…we’ll take this out. But they are relying on the individual saying…what is it that’s making you feel possessed? How can you describe it? And my son would say, well, I don’t know. He can’t necessarily put it in words.” These challenges were echoed by other carers who felt they were often acting as an advocate or coordinator, “often they’ll go in for an appointment and they’ll be asked, you know, how are you feeling? And both of my sons will say, I’m fine. And if it wasn’t for me sitting there saying, oh, but you were worried about that voice that you were hearing or whatever the clinician could easily just take that and have a completely wrong impression about what’s going on. So it actually takes over the whole of your life when somebody is unwell. Because you’ve got to advocate for them, you’ve got to think for them. When they’ve been ill…they’d be frightened of letting anybody know about their symptoms because they thought they’d be killed by the voices and so they would deny it”. This highlighted the potential barrier that positive symptoms could pose when eliciting an accurate clinical picture and therefore the unparalleled insight of someone living at home, observing the person for whom they care.

Carers’ experiences of services were inconsistent, “we had contrasting experiences in different parts of the country” and often insufficient, “we were hitting brick walls all the time”. Confidentiality emerged as a barrier that prevented involvement in care discussions, “I drafted a letter and went through it with them and they signed it that we gave…to the health authorities and it meant that we could talk to them because so often you get told, oh, sorry, we can’t talk to you, it’s patient confidentiality.” One carer remarked that they were more likely to be involved at times of crisis, “when she’s been in crisis…over the last decade, I’ve been involved with that decision-making process”.

> **“I drafted a letter and went through it with them and they signed it that we gave…to the health authorities and it meant that we could talk to them because so often you get told, oh, sorry, we can’t talk to you, it’s patient confidentiality.”**

Carers were clear they wished to have greater involvement in clinical discussions, “my hope for the future is that carers are given the status of being part of the health care team when it comes to making decisions”. They hoped for clearer, more detailed information, rather than simplified communication, “if we’d had more information….information around drooling or weight gain or just more knowledge from actual psychiatrists….[to] have more information, it would have been less distressing for [the person] and less distressing for us”. Above all else, carers wanted to be listened to and taken seriously as partners in care, “it’s absolutely essential that we are integral to the treatment of that…person. And if we can’t be, then they need an advocate that is actually seeing them daily”.

Theme 5:

Navigating services is complex, fragmented and problematic

Accessing and coordinating care emerged as a significant challenge. Although there was significant variability, some common challenges emerged among carers. Systems were often described as fragmented and difficult to navigate with a lack of clear pathways or guidance, “you’re thrown into it and you have to just sort of sink or swim at this point”.

Carers often experienced difficulty accessing clinicians, “contacting the trust only gets you access to the admin people, not the psychiatrists” and turnover of staff was a frequent setback, “there is no control over the psychiatrists, they sometimes disappear, a locum appears and then disappears”. Carers were aware this poor continuity of care often led to individuals needing to re-tell their story which could involve distressing trauma and ultimately reduces trust in the healthcare system, “the individuals have to go through all the trauma every single time they meet a new psychiatrist and that can be, we’ve had about 15 in about 3, 4 years. It’s just hopeless”.

In the context of these difficulties, carers felt they needed to educate themselves in order to navigate the system, but also to access the support that is available: “I had to learn the system, you know, no one’s going to teach you how to navigate the system” and “you have to know the system to get more support”.

One carer providing care for more than one person remarked on the difference between their experiences depending on region; “CPN put me in touch with Rethink. Rethink had a conference in Brighton for people affected by schizophrenia…which was so helpful and the booklets on site and the helpline, we used all of those and they were absolutely brilliant. We were also given a book by the psychiatrist about schizophrenia to help us understand it and actually because he was in a residential unit, they actually had a carer support meetings that we could go to. So it’s absolutely brilliant. There was nothing for my other son, unfortunately”.

> **“you’re thrown into it and you have to just sort of sink or swim at this point.”**

One carer also remarked on the complexity of the psychiatric system in general which provides additional opacity beyond other healthcare specialties, “We hadn’t dealt with tribunals, we hadn’t dealt with compulsory treatment orders…we were just thrown into, didn’t know what they were, you’d go to these meetings and you were like, well, what was that about?”

Theme 6:

Medication management is complex, unclear and difficult to evaluate

Medication is often a central component of a care plan in schizophrenia but at times is poorly understood by carers due to a lack of communication from services. One carer remarked in relation to response to medication, “it’s very difficult to measure what I call success” suggesting goals of treatment aren’t well communicated.

Some carers echoed the words of people living with schizophrenia, “it’s all trial and error” suggesting changes to medication feels reactive and without clear rationale.

Appointments often result in frustration due to limited proactive explanation of treatment rationale, side effects and monitoring, “I always leave meetings frustrated because, obviously, we can get the side effects papers which come with the drug. And you can read them and that’s absolutely fine, but it’s very restricted.” Time constraints were also highlighted, potentially limiting wider discussions around medication and the opportunities to ask questions, “it’s frustrating for a carer because you see a psychiatrist for 15 minutes” and to understand the nuances of treatment, “have an understanding of the limitations of psychiatry.”

Theme 7:

Information and support are insufficient, particularly outside of crisis

It emerged from the carers that the level of support varied by level of crisis, “Initially, we were dealing with early intervention services…which was very difficult for us and we didn’t feel that we were taken seriously. We had a lot of concerns that weren’t listened to and it got to a point when my son actually was arrested and had to go to prison…until he was finally transferred to hospital, which is what we had been begging for. And that’s when we got the care. So that we found it really difficult to access the services”. This suggests a gap exists within care systems for people not in acute crisis but experiencing a significant unmet burden from their condition.

Others remarked on the type of information given, this was either over simplified or limited, “we want to know about the jargon and the technical terms, you know… don’t speak to us like we’re in kindergarten”.

This appeared to prompt carers to take their education into their own hands, “obviously we’ve had to research all the different medications.”

Third-sector provision and community support were repeatedly identified as an area carers wish was more accessible, acknowledging its crucial role for emotional support and information sharing: “there should be more peer-to-peer support”, “I’d like the opportunity to have a support group locally” and “I wish there was more community support at the start. We felt very isolated. The community support would have helped me emotionally and would’ve also provided us with more helpful info”.



Looking into the future

What matters most to carers?

When asked what matters most to them looking ahead, carers spoke from a place of hard-won experience. Their hopes reflected years of navigating complex systems, advocating tirelessly for their loved ones, and absorbing an emotional burden that is rarely fully acknowledged. What they asked for was not radical, but it would be transformative.

> “One thing I wish that healthcare professionals understood is…to recognise the financial and personal cost of being a carer…it affects everything, it affects our relationships, health, work, finance, just understanding that all of that comes into being a carer, not just turning up for appointments.”
>
> “In order to make informed decisions about the treatment of our loved ones, it is absolutely imperative that we as carers are involved. Are part of the team. So, my hope for the future is that carers are given the status of being part of the health care team when it comes to making decisions.”
>
> “For the future, I hope for a sense of normality and balance, a life that isn’t defined entirely by illness”

Across these responses, a clear and consistent message emerges: carers want to be recognised as essential partners in care, not an afterthought. They are asking for the full nature of their role to be understood, not just the hours spent at appointments, but the financial strain, the effect on relationships, and the parts of their own lives that are quietly set aside. Above all, they are hoping for a future in which caring for someone with schizophrenia does not mean losing sight of themselves entirely.

Bringing it together

EbEs with direct and caring lived experience

Similar themes emerged across both the direct lived experience and family and carer insight sessions, reflecting a shared experience of inadequate symptom control despite treatment, a significant negative impact of side effects, and inconsistent, fragmented care. Where their perspectives differed, it was often in emphasis rather than substance, with carers frequently observing the consequences of these gaps from their perception.

Ongoing symptoms despite treatment

People with direct lived experience recognised the important role of medication in controlling symptoms, but acknowledged that treatment often did not result in complete symptom control, with cognitive and negative symptoms more likely to be residual, consistent with the existing literature (Bobes et al., 2010; Shen et al., 2023).

Carers more readily identified these shortcomings, their accounts of residual symptoms often reflecting the distress of witnessing the ongoing difficulties of the person they care for at close quarters.

Burden of side effects

People with direct lived experience provided a comprehensive account of the significant negative impact of side effects, with weight gain emerging as the most profound example. This is consistent with the wider literature, which reflects an extensive burden of side effects varying between antipsychotics (Stroup and Gray, 2018), with weight gain, movement-related side effects, QTc prolongation, prolactin elevation, sedation and anticholinergic effects widely reported (Huhn et al., 2019). Both people with direct lived experience and carers expressed concern about the impact on long-term physical health and the insufficiency of wider services in supporting and mitigating these effects.

Gaps in continuity and access to care

Both people with direct lived experience and carers were able to reflect on positive encounters with services, but inconsistency was the common theme, with disparate experiences evident by clinician, setting and geography eroding trust over time.

Notably, carers often navigated these gaps through self-education, highlighting the stark reality for the many people living with schizophrenia who do not have a carer to help them navigate a complex and unclear system.

Lack of holistic and person-centred support

From the insight sessions, although common themes emerged, it was clear that each person with direct lived experience had varying experiences of how their condition affects their daily life, their experiences of medication and the challenges they have faced accessing services. This highlights the underlying principle guiding person-centred care: that the needs, wants and priorities of each person will be different. Both the direct lived experience and carer sessions emphasised where needs were unmet and how services could be improved to provide holistic care.

Recognising the role and needs of carers support

The insights from this work support other findings about the often invisible and far-reaching impact of schizophrenia on carers and family.

Carers felt strongly about their role within a care journey. They experienced many barriers to being involved in care, including confidentiality, limited or over-simplified information sharing, limited contact with clinicians and the way mental health services work not being clear. Many felt the varied ways they supported the people they care for was under-recognised, with carers highlighting that this went far beyond participation in healthcare appointments. Alongside their caregiving responsibilities, carers' own needs were also deprioritised or unmet.
Across 38 papers and 543 participants, the needs of caregivers fell into five categories: rehabilitation and vocational support, information and education, self-help groups, enhanced healthcare services, and communication and collaboration.

To appropriately address these challenges, service improvements and a culture shift within services are required.

Considerations for policy and practice

Unmet needs

The unmet needs of people living with schizophrenia are multifaceted. Care and support need to move beyond managing symptoms and maintaining stability, towards a more ambitious, person-centred approach that places quality of life at its centre. Services have a responsibility to support individuals across their emotional and practical needs, including education, employment, finances and housing, not only symptom management. This same principle applies to carers, whose own wellbeing, financial security and sense of identity are profoundly affected by their caring role, yet who are too rarely offered support in their own right.

Grassroots and community initiatives have an important role to play in providing social opportunities for people living with schizophrenia. There is an interplay here with clinical care. Negative symptoms such as poor motivation can worsen social isolation and require active recognition and management by clinicians to support people to live as fully as possible. Peer support, both for people living with schizophrenia and for carers, was consistently identified as highly valued, offering understanding, practical coping strategies and a sense of connection that statutory services cannot always provide. Voluntary, community, faith and social enterprise (VCFSE) services, including charities, peer support groups, faith organisations and community enterprises, alongside the social care sector, have a vital role to play. However, long-term and sustainable funding for mental health social care is needed to ensure the stability of both sectors. Mechanisms such as the Better Care Fund, designed to integrate health and social care and avoid hospitalisation, represent a step in the right direction, but current provision remains insufficient to meet the breadth of need described by people with direct lived experience and carers in this report.

Antipsychotic medication

Findings from the insight sessions reflect that antipsychotic medications do not always fully control the symptoms of schizophrenia, particularly those of a cognitive and negative nature. Optimising treatment remains an important goal, both in terms of medication and non-pharmacological interventions such as psychological therapies. Mental health clinical research has a key role to play in expanding the range of effective treatments available, but this requires addressing the historical underinvestment in mental health research and overcoming practical barriers such as poor recruitment onto clinical trials and limited clinician capacity to engage in research. Many NHS services are already operating under significant pressure, with provision in some areas falling short of what people need.

> **“Alternative approaches, such as mixed contracting models that incorporate outcome-based or activity-based elements alongside block funding, could also be explored to see if they can support services to be more responsive.”**

Sustainable and equitable funding is therefore not simply about ambition, it is a prerequisite for ensuring that people living with schizophrenia can access consistent, high quality care.

Current commissioning environments can present additional barriers to adoption of innovation within mental health services. A common critique of block contracts is that they do not incentivise performance and/or innovation. However, this can be remedied through more innovative approaches to commissioning and contract management. Block contracts do offer stability in terms of funding, which can be invaluable for the sustainability of providers of smaller contracts (including VCFSE organisations), who would struggle to deliver essential community mental health support without this outlay.

Alternative approaches, such as mixed contracting models that incorporate outcome-based or activity-based elements alongside block funding, could also be explored to see if they can support services to be more responsive.

Even where the appetite for innovation exists, workforce pressures and budget constraints may mean that services are not in a position to adopt new approaches. The burden of side effects, as described powerfully by people with direct lived experience in this report, is too often insufficiently acknowledged in clinical practice. Greater integration of patient-reported experience and outcome measures, co-produced care plans and self-administered tools within routine appointments would give people the opportunity to describe the full impact of side effects in their own words, supporting more informed and collaborative treatment decisions.

Transparency around side effects from the point of prescribing, including honest discussion of likely impact on weight, cognition, mood and daily life, is essential to building trust and supporting adherence. Carers echoed this strongly, describing the distress of watching the struggle with side effects of those they care for while feeling unable to access clear information or have their observations taken seriously by clinicians.

The role of carers

Carers play a critical but consistently under-recognised role in the lives of people living with schizophrenia. They are often the most knowledgeable witnesses of the experiences and outcomes of the person they care for, the first to notice things getting worse and the most constant source of support across years and decades of care. Yet they frequently find themselves excluded from clinical conversations, left without adequate information and unsupported both during and outside of crisis.
Services should treat carers as genuine partners in care, involving them meaningfully in treatment decisions where the person they care for consents, providing them with timely and accessible information and ensuring that support for carers is available consistently, not only at times of acute crisis. A named point of contact within care teams, clear information about rights and entitlements and access to carer-specific peer support would make a meaningful difference to many of the carers who contributed to this report.



Continuity of care

Poor continuity of care is a widespread challenge across UK healthcare, but it is arguably more consequential in mental health than in any other specialty. Given the deeply personal nature of mental health, the trauma many patients have experienced, and the often lengthy journey through psychiatric services, a consistent therapeutic relationship is not a luxury but a cornerstone of good care. For carers, frequent changes in clinician mean repeatedly rebuilding relationships and re-establishing trust, often while simultaneously supporting the person they care for through the same process. Addressing the mental health workforce crisis will require action at a government level, including greater investment in recruitment and retention that goes beyond current commitments. In the shorter term, thorough clinical documentation and robust handover processes can help reduce the negative impact of staff change and use of agency staff on patients and carers alike. Similarly, reducing caseloads may allow for longer, more holistic appointments and more meaningful involvement of patients and carers in treatment decisions. Integration of different services and roles is also crucial, including neighbourhood health approaches, social care and VCFSE support.

Shared decision making

These findings reflect a broader need for culture change within mental health services, where treatment decisions are made fully in partnership with people living with schizophrenia and carers. Stretched services, an overly medicalised model of care and insufficient recognition of the expertise of people living with schizophrenia and their carers all present barriers to this. Many of these issues require structural solutions, but some can be addressed through education, training and a renewed commitment to shared decision making. This has been reflected in recent changes to the Mental Health Act, where greater patient choice and autonomy were cornerstone principles, but our findings demonstrate that care must evolve at every level of the system (Mental Health Law Online, 2026). Where a partnership was present, even within an imperfect system, people with direct lived experience and carers were clear that their experiences were significantly better.

The impact of stigma

Stigma can profoundly impact the lives of people living with schizophrenia and those who care for them. Carers described experiences of social isolation, judgment from friends and family and a sense that the stigma attached to schizophrenia extended to them too. Harmful media portrayals lead to widespread misconceptions, resulting in real and perceived discrimination across society. Reshaping these perceptions requires a multifaceted approach. Public awareness campaigns, educational interventions and efforts to improve mental health literacy, especially when co-produced with people with lived experience, all have a role to play in correcting misinformation, challenging negative attitudes and shining a light on the reality of living with and caring for someone with schizophrenia. The VCFSE sector is well placed to support this work, through peer support groups and non-judgemental community spaces that help combat self-stigma and build individual confidence.

Tackling stigma is a shared responsibility, from politicians and media commentators to public officials and the services that support people every day across health, social care and social security across the UK.

The consequences of stigma extend beyond the person. At a systemic level, schizophrenia has historically been deprioritised, with services chronically underfunded and people living with the condition too often placed in the ‘too difficult’ category by a system that lacks both the resources and the cultural empathy to respond adequately. This is reflected in wider society too, where harmful media portrayals and deeply entrenched misconceptions mean that schizophrenia remains a misunderstood and stigmatised condition. Addressing this requires more than awareness campaigns. It requires a fundamental shift in how schizophrenia is perceived and prioritised at every level, from government and health systems to communities and the media.

Conclusion

This project demonstrates that people living with schizophrenia and their family and carers have unique and invaluable insights into what it means to live with schizophrenia. While their experiences are varied, clear and consistent themes emerged. Antipsychotic medication plays a crucial role in the management of schizophrenia, but negative and cognitive symptoms frequently remain, exerting a real and lasting impact on daily life. The burden of side effects is significant, all-encompassing and shapes how people relate to and persist with their treatment over time. For carers, witnessing this impact whilst feeling excluded from clinical conversations and unsupported in their own right compounds an already considerable strain.

Navigating services was challenging for people with direct lived experience and carers alike, though where continuity of care was maintained, information was shared openly and carers were treated as partners in care, experiences were more likely to be positive. The contrast between these experiences, and the consistency with which both people with direct lived experience and carers described feeling unheard, points to a system that has not yet fully risen to meet the complexity of living with schizophrenia.

Above all, this report is a reminder that schizophrenia affects far more than symptoms alone. For too long, people living with schizophrenia have been deprioritised by a system that has not always responded with the empathy, resources or urgency people deserve. The people who contributed to this report, people with direct lived experience and carers alike, did so with honesty, courage, generosity and at times with anger. Their voices deserve to shape the services, policies and treatments that affect them.

We hope this report plays a small part in making that happen.



Appendices

Our approach

Here we describe how we carried out the project, which followed a staged process starting with planning and co-design, moving through recruitment and insight sessions, and then themes, priorities, recommendations, report writing and review. Throughout every stage, the wellbeing, safety and voices of people with direct lived experience and carers were placed at the centre of our approach.

Co-production

We began with a co-design session involving four people, two with direct lived experience of schizophrenia and two with experience of caring for someone with the condition. Participants were reached through our networks within Mental Health UK, through personalised email or face-to-face contact. The 90-minute session, held via Microsoft Teams, gave co-design partners the opportunity to review and shape the draft questions, themes, approach and framing before any insight sessions took place. We asked them whether the draft reflected their experiences and explored any gaps they identified.

We also discussed safeguarding, psychological safety and the practicalities of facilitation, including how to support participants before, during and after sessions. Debriefs were identified by the co-design group as an important feature, providing space for participants to ask questions, raise anything further and check in on their wellbeing given the sensitive nature of the topic. All materials were updated in response to the co-design partners' feedback before the insight sessions took place.

Recruitment and briefing

Participants were invited to participate from across the UK through MHUK's existing networks using a personalised and relational approach. Briefing calls were held with all prospective participants to assess their understanding of the project, their willingness and capacity to take part and any support they might need. Where someone was not able to participate in a group session, a one-to-one alternative was offered as a matter of course.

In total, 12 participants were invited to participate: six people with direct lived experience of schizophrenia and six family members, friends and carers. People with lived experience of schizophrenia met the inclusion criteria as being currently prescribed antipsychotic medication. Sessions were held via Microsoft Teams, with participants given the option to keep their camera off to support their comfort and sense of safety throughout.

Insight sessions

Two groups, one for people with direct lived experience and one for families and carers, had an insight session each, attended by three people with direct lived experience and five carers respectively. To promote accessibility and psychological safety, individual sessions were also offered to those who preferred that or were unable to attend on the day. Additional individual calls were available to people who wished to raise further topics outside of the group. In total, three people with direct lived experience and one carer took part in individual sessions. This flexibility was central to ensuring participants felt supported and able to share their experiences in a way that worked for them. At the start of each session, facilitators set out a clear group agreement to promote psychological safety, emphasising that there were no right or wrong answers, that participants were in control of what they chose to share, and that confidentiality within the group would be respected throughout.

Debrief sessions

Debrief sessions were offered to all participants following both the co-design and insight sessions. These served several purposes: giving participants space to share anything further they had not raised in the session, checking in on their wellbeing after discussing sensitive and personal topics, and providing signposting and resources as needed. No safeguarding concerns were raised across any session.

Note-taking and anonymisation

An independent note-taker was present during each session. An auto-generated transcript was also used with permission in Microsoft Teams. All identifying information was anonymised, and notes were cross-checked for anonymisation before being used in the report to ensure that no participant could be identified.

Feedback and review

Following the insight sessions, all participants were thanked for their contribution and given the opportunity to share anything further. The draft report was shared with the co-design group for review and comment prior to finalisation, ensuring that the people at the heart of this project had the opportunity to see and shape how their experiences were represented. Participants reported that their experience of taking part had been largely positive. They said they felt well-supported, heard, could recognise their voices and thought the work was comprehensive and meaningful. Many welcomed the opportunity to share their experiences openly and expressed hope that doing so would contribute to a wider conversation about schizophrenia and bring about meaningful change for people living with schizophrenia and those who care for them.

Limitations

As with all qualitative projects, this one gathered insights from a small group of people invited to participate through existing networks. The sample may not be fully representative of the wider population of people living with schizophrenia or their carers, and the findings should be understood in that context. They are, however, rich, considered and consistent, and reflect experiences that are widely echoed in the existing literature.



About us

Mental Health UK aims to tackle the barriers that hold people back and provide practical tools and support to help them thrive at home, at school, and at work. In a world that's changing fast, Mental Health UK combines the experience and expertise of four charities from across the UK (Rethink Mental Illness, England; Adferiad, Wales; Change Mental Health, Scotland; and MindWise, Northern Ireland), each with decades of supporting people's mental health, to create a stronger, more connected foundation for everyone.

Working across the UK, we provide services that empower people to understand and manage their mental health in a practical, person-centred way. By combining local delivery with national expertise, we reach communities where mental health challenges are most pressing, helping people regain stability and confidence in their daily lives.
We tackle some of the biggest pressures affecting mental wellbeing — from money worries and navigating support systems, to understanding mental health, combating loneliness, and building resilience in young people — giving people the tools and guidance they need to thrive at home, at school, and at work.

The Lived Experience Insights team sits within the wider Policy and Practice department and connects with wider teams via a matrix working approach. Our team develops new ways of working within mental health spaces by ensuring those with direct experience shape and direct progress. We connect commissioners, researchers, and professionals with people with lived experience, including families and carers, to unlock insights, challenge barriers, and drive meaningful change.

Co-production is central to our work. We collaborate with people with lived experience across planning, delivery and evaluation stages to create inclusive and accessible platforms that amplify often unheard voices, including underrepresented groups. By fostering meaningful engagement and creating safe, supportive spaces, we enable people to influence the services that affect them by sharing their stories.

Our mission is to bridge the gap between mental health systems and the people who use them, ensuring lived experience drives innovation, influence and impact.





Afterword

This report was initiated and funded by Bristol Myers Squibb, whose support made this work possible. Bristol Myers Squibb attended the co-design and group insight sessions in an observational capacity. Medical writing support was provided by Dr. Amber Barthorpe and Caroline Finn from Mednet Health and funded by Bristol Myers Squibb. Bristol Myers Squibb has reviewed the report for accuracy and ABPI Code compliance only.

The views and experiences expressed in this report are those of the people who generously contributed their time and insights. They do not necessarily reflect the views, policies or positions of Bristol Myers Squibb. The personal accounts included are shared solely to illustrate individual lived experience and should not be interpreted as official statements from Bristol Myers Squibb.

This report contains accounts of people's experiences with medication. Decisions about medication should always be made by a healthcare professional in partnership with the patient, with input from their carer wherever the individual consents to this.

The motivation behind this project was to better understand what it means to live with schizophrenia, or to care for someone who does, with a particular focus on the impact of medication and how side effects shape quality of life. These insights were gathered to ensure that decisions about treatment are informed by the real experiences of the people they affect most. This report exceeded that initial aim. What emerged was a nuanced, humane and often profound account of lives shaped by schizophrenia, told by the people living them.

We are grateful to every person who contributed.



Understanding the research so far

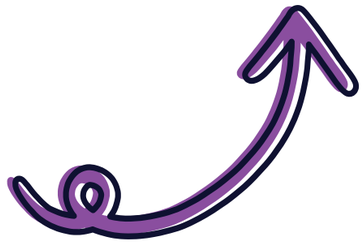
The following section provides a summary of the existing literature on schizophrenia and its treatment. It is intended to contextualise the lived experience findings presented in the main report and is written in language that reflects the scientific evidence.

Impact of schizophrenia and potential unmet needs

Current evidence reflects that living with schizophrenia can have a broad impact upon multiple facets of a person's life. Simmons et al. interviewed 41 patients diagnosed with schizophrenia who were involved in a clinical trial, to ascertain disease burden, symptoms, quality of life and experience of treatment. Their findings indicated that symptoms of schizophrenia had a negative impact upon multiple areas of their participants' lives, including their "work, relationships, self-esteem, emotional health, and daily activities". Better control of symptoms emerged as an area needing improvement from the participants, who felt this unmet need impacted them physically and socially.

A systematic review (Crespo-Facorro et al., 2021) encompassing 52 publications investigated disease burden in early schizophrenia. Unemployment and poor social functioning emerged as prominent burdens. Unemployment rates were drawn from 13 studies, varying between 10% and 88%, while employment levels were consistently below healthy controls ($p<0.01$). Social functioning was also consistently poorer. These findings emphasise the holistic needs of people living with schizophrenia and where current treatments may fall short. These conclusions are echoed by reports from caregivers in the international ADVANCE study (Franzenburg et al., 2025), in which carers focused more on the quality of life of the people they cared for, over simply treatment management. Together, the evidence demonstrates the unmet needs and holistic priorities of patients and carers, that go beyond symptom control.

A systematic review by Lyne et al. (2025) examined the role of negative symptoms in psychosis. A broad range were reported including poor motivation and energy, withdrawal and feeling numb. This review also highlighted the interplay between negative symptoms, unmet needs and cognitive effects of schizophrenia; difficulty concentrating was identified as a significant challenge in social settings and daily life, whilst impaired attention is a core cognitive feature of schizophrenia. These findings emphasise the importance of addressing management of negative symptoms, which can have wider implications upon people's unmet needs.



Experience of medication including side effects unmet needs

Many qualitative studies have identified medication as effective at reducing symptoms of schizophrenia. Amongst the 41 patients included in the study by Simmons et al.,:

78%

of patients had **positive experiences** with medication.

The benefits were further subdivided:

68.8% **Improvement in symptoms** including hallucinations, depression and anxiety

34.4% **Better sleep**

25% **Felt calmer**

An additional qualitative study conducted focus groups with 15 participants diagnosed with schizophrenia, with 14 (93%) describing their previous antipsychotic treatment as effective. However, the same study discovered that 87% of their participants had stopped their medication at one time and 53% gave side effects as the reason for switching medication. The most commonly reported side effects were "weight gain, drowsiness, sexual problems, and neurologic symptoms", affecting quality of life, health and self-esteem (Doane et al., 2023). Similarly, young adults (aged 18–30) prescribed antipsychotic medication viewed side effects as major obstacles despite recognising medication effectiveness in some domains (Grey et al., 2026).

Current evidence suggests that some side effects have a greater effect on people than others. Cognitive side effects emerge as particularly problematic. Arango et al. (2025) found in a mixed method study that "cognitive side effects such as 'feeling like a zombie' and 'memory/concentration issues' were the most frequently identified" amongst participants across qualitative and quantitative measures. These were identified as important factors leading to stopping taking medication and impacting daily life and employment. When participants were asked how they hoped schizophrenia treatments would change in future, cognitive side effects were cited. De et al. (2025) found that antipsychotics with greater weight gain liability were associated with an increased likelihood of nonadherence or treatment discontinuation, while Khandker et al. (2023) found that 7% weight gain within 90 days was sufficient to increase the likelihood of switching to a different medication, suggesting this is an especially intolerable side effect for people.

If a person has not responded to trials of two different antipsychotics, clozapine can be initiated. Due to its unique position in the treatment pathway, it is often investigated separately to other antipsychotic

medications. Findings from a mixed-methods design (questionnaires and semi-structured interviews) indicated that clozapine use was associated with substantially improved mood, sleep and overall quality of life but substantial side effects were identified, with hypersalivation, abdominal pain and unusual sensations exerting a negative impact (Khazaie et al., 2025). This is reinforced by a qualitative analysis conducted by Daniel et al. in which participants sought side effect burden to be balanced with control of their symptoms, recognising that higher medication doses may offer greater symptom control, but could also increase side effects. They highlighted the importance of "collaborative dose titration" to achieve this and emphasised the crucial role that family plays in providing support. This suggests that shared decision making between patients and clinicians, as well as involvement of a wider support network, can make a positive difference to people continuing their medication.

In addition to different efficacy and side effect profiles, clozapine has specific monitoring requirements due to the risk of serious blood disorders.

For these reasons, the decision to start clozapine, and how and where this takes place, requires careful clinical consideration on an individual basis.

A qualitative study (n=18) by Jakobsen et al. (2025) discovered that 50% of their participants (n=9) would not accept clozapine if offered to them. Its perception as "unmanageable or a last-resort option" compounded this reluctance and admission to hospital to start clozapine was the greatest barrier for participants. The study advises clinicians to follow guidelines by reducing the number of antipsychotic trials prior to clozapine, to alleviate "anti-psychotic-trial fatigue" and "last-resort treatment" stigma. However, real world data from Laforgue et al. (2023) including 287 patients demonstrated that in the 36 months before clozapine was commenced, the median number of antipsychotic trials was 3, suggesting that clinicians delay commencing clozapine, trialling more than the recommended two antipsychotics.

People stop taking their medication for reasons other than side effects. Aprile et al. (2025) reviewed 39 studies (1,477 patients) and identified lack of information and stigma as adherence barriers. These findings were echoed in a systematic review by Townsend et al. (2022) culminating in 40 unique studies. Their review found that "antipsychotic-related social and self-stigma" impacted participant's adherence to their antipsychotic medication.

Changes to medication

The complexities of antipsychotic treatment go beyond the considerations outlined above. Switching, stopping and managing changes all bring their own distinct challenges. Real-world data show that changes to antipsychotic medication and "suboptimal adherence" are common (Martin et al., 2022). In their systematic review of 81 studies, approximately half of patients had their antipsychotic treatment changed and nearly 30% received combination therapy. Antipsychotic switching can also be associated with additional effects; Gao et al. identified that switching during hospitalisation is associated with a higher rehospitalisation risk, demonstrating potential unintended effects of treatment changes.

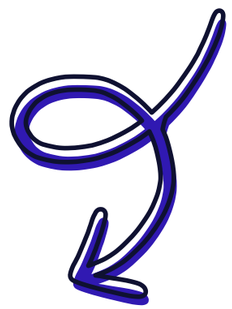
Summary of existing evidence

This predominantly qualitative review highlights that people living with schizophrenia recognise the benefits of antipsychotics in controlling their positive symptoms. However, negative and cognitive symptoms can remain despite treatment, with a broad impact upon daily life and highlighting unmet needs relating to antipsychotic medication. Side effects have been identified as burdensome, especially weight gain, and are often associated with stopping or switching to a different antipsychotic. Whole life, holistic, needs of people living with schizophrenia are under recognised, including unemployment, social relationships and activities and the impact of stigma. These holistic needs are often what matters most to people and their carers. The insight sessions build on this evidence base, bringing the voices of those with direct lived experience to bear on the gap between what current treatments offer and what people living with schizophrenia and their carers actually need.



Abbreviations

A&E	Accident and Emergency
ABPI	Association of the British Pharmaceutical Industry
BMS	Bristol Myers Squibb
CPN	Community Psychiatric Nurse
EbE(s)	Expert(s) by Experience
GP	General Practitioner
MHUK	Mental Health UK
NHS	National Health Service
OCD	Obsessive-compulsive disorder
QTc	Corrected QT interval (a measure of the heart's electrical activity)
VCFSE	Voluntary, Community, Faith and Social Enterprise



Glossary

Adherence: Taking medication as prescribed, at the right dose and the right times.
Anhedonia: Losing the ability to feel pleasure or enjoyment from things that used to be enjoyed.
Antipsychotic medication: Medicines used to treat the symptoms of schizophrenia and other mental health conditions.
Better Care Fund: A government scheme that brings NHS and social care funding together, so that health and care services can work more closely and help people stay out of hospital.
Block contract: A way of funding services where a fixed amount is agreed in advance, rather than paying only for the exact activity delivered.
Co-production: Working alongside people with lived experience, as equal partners, to design and shape a project, service or piece of work, rather than doing something "to" or "for" them.
Cognitive symptoms: Difficulties with memory, concentration, processing speed or putting thoughts into words.
Commissioning: The process by which local health and care organisations decide what services are needed and arrange funding for them.
Compulsory Treatment Order: A legal order that allows someone to be treated for a mental illness without their consent in the community, under certain conditions set out in law.
Expert by experience (EbE): People who live with illnesses or conditions over time, and their carers/family, who gain expertise in what it's like to live with the illness/condition and/or to care for someone.
Hallucinations: Perceiving something, without an external stimuli, that feels real to the person experiencing it. An example of this would be hearing voices.
Holistic care: Care that looks at a person's whole life, not just their symptoms, including things like work, relationships, physical health and finances.
Home Treatment Team: A team that supports someone in crisis at home, as an alternative to a hospital stay.
Negative symptoms: Symptoms such as low motivation, low energy, withdrawing from others, and a flattened mood.
Polypharmacy: Taking multiple medications at the same time, sometimes to manage the side effects of another medication.
Positive symptoms: Symptoms that are not usually part of a person's experience, such as hallucinations, delusions or disorganised speech.
Prolactin: A hormone that can rise as a side effect of some antipsychotic medications, sometimes affecting periods, fertility or causing other physical symptoms.
Psychosis: A state in which a person loses some contact with reality, which can include hallucinations or delusions.
Real world (evidence/data): Information gathered from everyday clinical practice, rather than from controlled research studies.
Relapse: A return or worsening of symptoms after a period of being more stable or well.
Residual symptoms: Symptoms that remain, even when someone is taking medication as prescribed.
Sectioned/section: Being admitted to hospital under the Mental Health Act, without needing to give consent.
Shared decision making: Clinicians and patients (and, where appropriate, carers) working together as partners to make decisions about treatment and care.
Stigma: Negative attitudes, judgement or discrimination that someone can face because of a health condition, and which can lead a person to feel shame about their own condition (self-stigma).
Tribunal: A legal hearing that reviews whether someone should continue to be detained under the Mental Health Act.

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