

The Carer series

UNUSUAL EXPERIENCES

Caring for someone with unusual experiences, day by day

A warm, plain guide for families: what helps at home, your rights, and when to act.

Who this is for: the parent, spouse, or family member caring day to day for someone with long-term unusual experiences.

Cited: NICE, Cochrane, the Mental Healthcare Act 2017, and peer-reviewed research.

Languages: English, Hindi, Marathi, and Kannada.

Read it free at weave.clinic/family

1

WHAT IS REALLY HAPPENING

Real to them, and not your fault

IN SHORT

Someone you love may hear things others do not, or hold beliefs no one else shares. It may have gone on for years. This is a health condition, not something anyone chose. You did not cause it, and you cannot cure it. But you can help, and your help matters.

Meena's son Arjun is 28. Six years ago he began to hear voices. He became sure the neighbours were watching him. Today he takes his medicines, but he sleeps late and rarely leaves his room. Meena's sister-in-law says he was spoilt. A neighbour hints at black magic. Meena lies awake, wondering what she did wrong.

If your home looks anything like this, start here. These experiences are part of a health condition, and they can feel very real to the person. Doctors look for health causes, such as a mental health condition or a physical illness. You did not cause it, you cannot cure it, but you can help.

Many families live with this quietly, out of fear of "log kya kahenge". You are far from alone, and treatment can help.

More, if you want it

Doctors may use a clinical name for this pattern. The one you may hear is psychosis, or sometimes schizophrenia. Only a doctor can say whether any name applies, and no name describes the whole person. In this booklet we simply say "unusual experiences", and we talk about what helps.

TRY THIS

Say this to yourself once, slowly: this is an illness, not something I did, and not something they chose. Notice whether your shoulders drop a little. You can hold this truth and still be firm about everyday life at home.

2

THE LONGER ROAD

When they seem to have stopped trying

IN SHORT

After the frightening phase settles, some difficulties can stay. The person may seem to have little drive and keep away from people. Before you push, ask the team what lies behind it. Small steps, a calm home, and patience are a kinder place to start.



Slow days have reasons, and the team can help find them.

Farida's husband Imran used to run a busy shop. Now he sits for hours. He does not start the things he says he will. Relatives tell her he needs to be pushed. Pushing only ends in silence or a fight.

What Farida sees can have more than one cause. Some symptoms can carry on for a long time, even with treatment, and there is help for them, such as talking therapy and arts therapies. Feeling sleepy or slow can also be a side effect of medicine. Low mood can sit alongside the illness too. The team can help tell these apart, so ask them.

Try a steady rhythm and very small, shared steps. A regular time to wake. One chore done together. A short walk to the market, the temple, or a friend's house. Praise the effort, not the result. Expect slow progress, and count small steps as real steps.

Ask the team about family sessions. They teach everyone about the illness and help the family solve problems together. Studies suggest they may also help the family talk with less heat, and lower the chance of relapse and of hospital stays.

3

MEDICINES AND SIDE EFFECTS

What medicines do, and what to watch

IN SHORT

Medicines a psychiatrist may suggest are one part of care. Staying on them, as agreed with the doctor, makes a return of the experiences much less likely. They can have side effects. Tell the team about any problem, rather than stopping or hiding the medicine.



Talking side effects through together, before the next visit.

For these experiences, a psychiatrist may suggest a group of medicines that calm them and help keep them away. Some come as tablets. Some come as a slow-release injection every one to four weeks, which some people prefer. Staying on the medicine as agreed lowers the chance of a relapse.

Medicines can also bring side effects. They can include weight gain, feeling sleepy or slow, shaking, restlessness, and muscle spasms. The team should check weight and some blood tests from time to time. If a side effect becomes hard to live with, tell the team. There may be another medicine that suits the person better.

1 in 4 vs 2 in 3

chance of the experiences returning within a year

In research trials, about 1 in 4 people who stayed on this kind of medicine had a return, against about 2 in 3 who were taken off it. Your doctor can explain what this means for your family member.

More, if you want it

Many families are tempted to stop the medicine once the person seems well. Some slip it secretly into food. Both come from love. Stopping can bring the experiences back, so any change should be planned with the doctor. Rather than hiding medicine, bring the worry to the team. A slow-release injection or a different medicine may solve the problem openly.

4

THE TEAM AND THEIR RIGHTS

Working with the team, and respecting their choices

IN SHORT

You know the person best, and the treating team needs what you see. Your family member also has rights under Indian law. These include a say in their own treatment, choosing a trusted supporter, and planning ahead. Knowing these rights helps you work with the team, not around it.

You see the daily picture that a doctor sees only at short visits. Note changes in sleep, mood, and routine, and bring the notes to visits. Ask for a family meeting if you need one. Your family member has a right to confidentiality, so the team may not share everything with you. If you are their nominated representative, the team can share what you need to know to help. You can still tell the team what you notice. Guidelines ask teams to agree early on how information is shared, and to stress sharing anything about risk.

India's Mental Healthcare Act 2017 gives people with mental health conditions clear rights. Respecting their rights is part of good care, not an obstacle to it. This can feel hard when you are frightened for them. The law tries to balance their choices with their safety, and the team can explain how.

A say in treatment.

Treatment usually needs their informed agreement. If they are very unwell and cannot decide, the law allows short, supervised care with extra safeguards. They, or the person they named, can ask the Mental Health Review Board to look at it again.

Dignity and information.

They have a right to live with dignity, to confidentiality, and to be told about their treatment in simple words they understand.

A nominated representative.

They can name a trusted adult, in writing, to support their care decisions, and change this later. If they have named no one, the law follows an order: the person in their advance directive, then a relative, then a carer who lives with them, then someone the Review Board appoints.

An advance directive.

While well, they can write down how they do and do not want to be cared for, and who should support them. It is used only when they cannot decide for themselves, and they can change it any time they are well.

TRY THIS

On a calm day, ask your family member: if things got hard again, what would you want, and who would you want beside you? Write their answers down. Then ask the team about making an advance directive or naming a representative. This is a plain summary, not legal advice. The team or a lawyer can explain the details.

5

LOOKING AFTER YOURSELF

Your own oxygen mask

IN SHORT

Caring for someone over many years can wear you down. Tiredness, worry, anger, guilt, and grief are all common. This is the weight of a long load, not a weakness. Looking after yourself is part of the care plan, and you deserve support of your own.

Here is something families rarely say aloud. Caring for someone with long-term unusual experiences is heavy. The stress of caring can strain any family. You may also meet whispers from relatives, or worry about marriages in the family. Watch your own signs of strain: broken sleep, a short temper, dread, or feeling numb.



You can care for someone through a long illness and still keep a life, a name, and a future of your own.

Your rest, your friends, your faith, and your health are not extras for later. Looking after yourself is part of the care plan, not a reward for finishing it. Share the load across the family, including in-laws who keep their distance. Ask the team about education and support for carers like you. Set limits that keep you steady. A limit is not abandonment. It is what lets you keep showing up.

You do not have to do this alone. Ask the treating team whether there is a carer group near you, in person or online. In a group you may meet people who understand without needing an explanation.

For years I thought I had to carry my son alone. In the carers' group I cried in front of others for the first time. Nobody asked me what I had done wrong.

Sunita, mother, 56

REMEMBER

You did not cause this, you cannot cure it, and you can help. Helping includes looking after yourself. Rest is what lets you keep going for years, not weeks. Share the load, keep your own life, and take the long view.

6

WHEN TO ACT

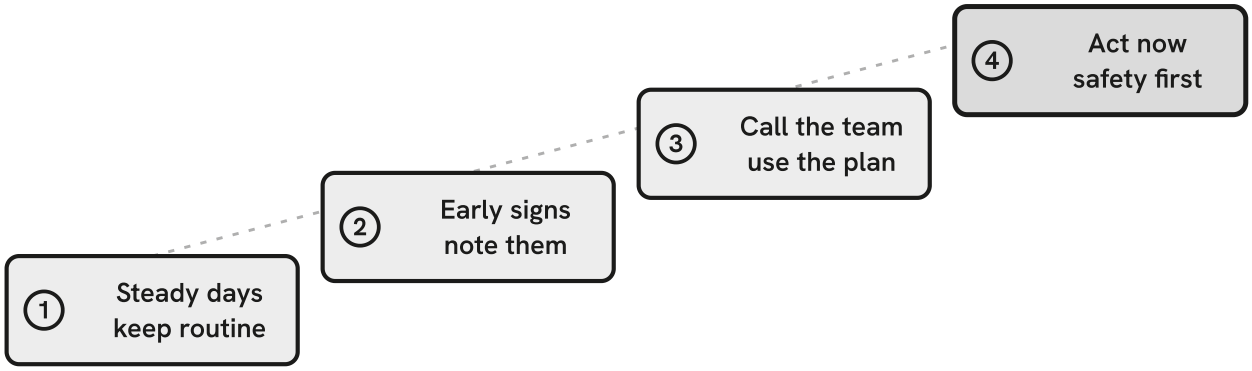
A relapse plan, and safety first

IN SHORT

Setbacks can show small signs before a crisis. Make a simple plan together on a calm day, so you know what to do. If you ever fear for their safety, or anyone's, get help straight away. Tele-MANAS, the free government helpline, is there any time. In an emergency, call 112.

A relapse can show itself through signs such as the old experiences returning, or a sharp rise in drinking or drug use. Lack of sleep and severe stress can also set off an episode in some people. Each person has their own early signs. You may both already know them from last time.

Make a short plan together while things are calm. Write down the early signs, what helps, who to call in the team, and what your family member wants if things get worse. In guidelines, a crisis plan names a key person in the team to contact. Keep a copy at home and on your phone. Any talk of ending their life needs help now, not at the next visit.



agreed together, on a calm day

A relapse plan in four steps. The higher the step, the sooner you act, and the more help you bring in.

Steady days: keep the routine, sleep, and medicines as agreed.

Early signs: old experiences returning, poor sleep, rising stress.

Call the team early, and use the plan you made together.

Act now: any talk of ending life, or anyone feeling unsafe.

IF YOU ARE WORRIED ABOUT SAFETY RIGHT NOW

If your family member talks about ending their life, take it seriously. Research suggests that asking them directly about suicide does not put the idea in their head. Stay with them, reduce access to things they could use to hurt themselves, and get help straight away. You can call Tele-MANAS, a free government mental-health helpline, on 14416, any time, day or night. If anyone is in immediate danger, step back, keep calm, and call 112. The crisis card linked below has more people you can reach.

TRY THIS

Today, write down one early sign you have seen before, one person in the team you would call, and the number 14416. Keep it where you will find it. Deciding the plan in the calm is far easier than deciding it in the storm.

WHERE THIS COMES FROM

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FURTHER READING

- NHS: Psychosis
- Royal College of Psychiatrists: Antipsychotic medication

This guide helps you recognise and understand. It is not a diagnosis. For that, see a professional.

- Feeling like it is all too much? **Read the crisis card.** Help is one page away.
- Tele-MANAS, the free national helpline: **14416**. Any time, day or night. From the Government of India.