

LIKEMIND

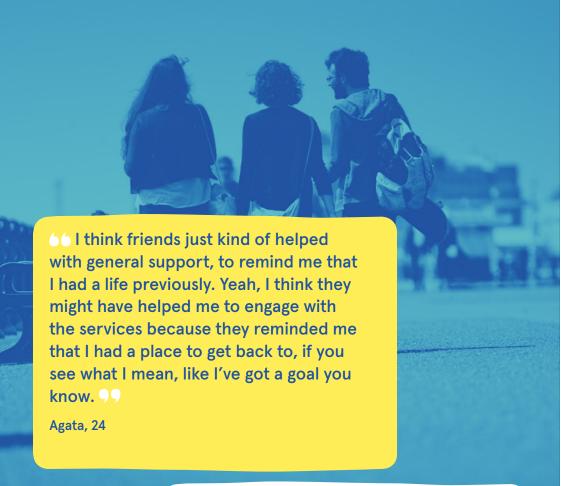
A mental health companion for young people

MYTH-BUSTING INFORMATION

For friends and family of people with psychosis







66 I think if you include the family as much as you can, obviously respecting like you said, confidentiality, I think they're more likely to engage with the service if it's more of a whole family-type approach. I can then see that her care coordinator is doing a lot of good work for her and then I'll encourage it more, if you see what I mean.

Lauren's mum

So, why would you want to read this booklet?

Do you have a friend or relative and are worried about their mental health?

Has your relative or friend already been referred to mental health or early intervention in psychosis services?

Do you want to know more about what's going on for your friend or relative, how mental health services can help and how you can help?

Are you finding it difficult to cope with everything that's going on?

If your answer to any of these questions is yes, then this booklet and our website likemind.nhs.uk may be helpful for you.

You can use the website to read friends and families' stories, share your own story, ask for advice and give advice from your own experience.



See also our booklets on 'Mental health and getting help', 'Early intervention in psychosis services', 'Treatment choices', and 'Getting the most out of hospital'. You can download these from our website likemind.nhs.uk



Why isn't there a separate booklet for family and friends? Aren't the issues different?

This booklet is for friends and family of people who are experiencing mental health problems, like psychosis. Although some of the issues that you might face as a family member will be different from those as a friend and vice versa, many of the issues may be the same for each of you.

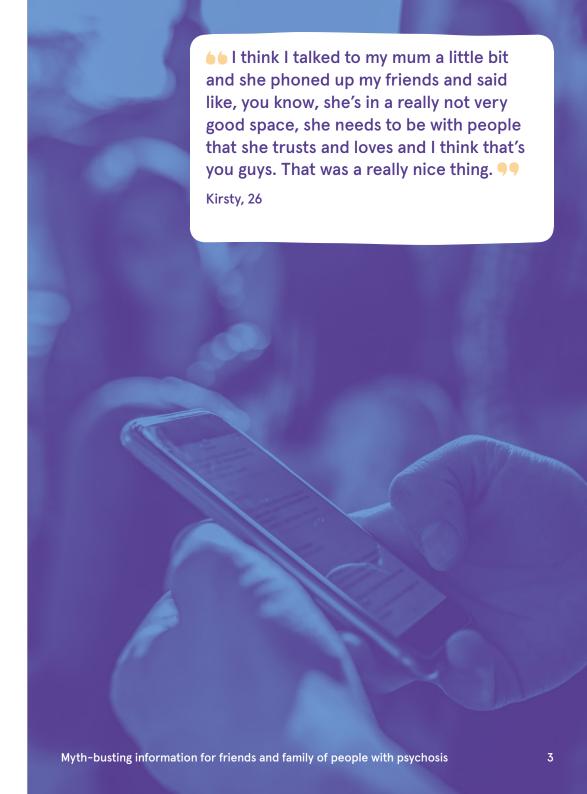
The best way to help your friend or relative is by being part of a supportive social group, who understand what's happening, talk to each other, have a clear sense of what services can offer that would be helpful, and have a clear sense of what you can do to help too.

When people have mental health problems, like psychosis, having really good social support from family and friends, makes a big difference. Research has already shown us that having this social support helps people to recover more quickly and completely. It's also helpful if friends and family are in general agreement about what will help their friend or relative.

This is why we've put information for family and friends together, because understanding how you can each help, and understanding each other's views, will be helpful.

You can share your experiences and hear other people's stories on our website and forum likemind.nhs.uk







This booklet is here to give you some ideas for how to help your friend or relative, and yourself.

Myth busting information about mental health and psychosis

What is psychosis?

You might think the word psychosis is a bit unsettling. You might think your friend or relative can't have psychosis because they aren't 'mad' or 'dangerous'... or you might be scared or worried about what psychosis means. Some of this is the result of stigma!

We can blame some of that on the media but we can feed into it too. What do you imagine when you think of psychosis? Would you be surprised to know that half of the people pictured in this booklet have psychosis? You may have heard about people with psychosis on TV, in newspapers or in books. Some of this will be true (although it may show the most severe problems) but a lot of it isn't!

TVs and newspapers like to tell a good story, but in reality everybody's experience is different. Psychosis is quite common. People can experience psychosis symptoms for lots of different reasons, like when you don't get sleep for a long time, take drugs, have epilepsy, or have a lot of stress or trauma. Some people think that psychosis is just an extension of anxieties that we all have.

Psychosis is a word that describes a set of experiences. It's not a diagnosis. Specific diagnoses like Schizophrenia, Schizo-affective disorder, Bipolar disorder, Delusional Disorder, or Drug-Induced Psychosis, all include unusual distressing (psychosis) experiences.

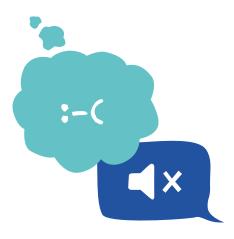
They just describe slightly different problems, like how much your experiences affect your emotions (happiness and sadness), the types of unusual experiences you have, how long they last and how much they affect your life overall.

What is psychosis?

There are two main phases of psychosis. In the acute phase, your friend or relative might experience paranoia, hearing and seeing things and having jumbled thoughts, but then they begin to recover. In the recovery phase, your friend or relative might have similar beliefs and experiences but they may be less upsetting and affect them less.

Psychosis includes things like:

• Paranoia, thinking someone's laughing at you, talking about you, following you or out to get you, thinking that things on the TV, radio or in newspapers relate to you, believing you or others are famous people or imposters, having other strange upsetting thoughts.



- Having what seem like real experiences of hearing, seeing, feeling, smelling, and tasting things that other people don't.
- Having confused thinking and sometimes jumbled speech too, so that what you say goes off topic, includes odd words and is hard for other people to understand.

It can be scary at the time, but your friend or relative can recover, have a life, a good job, a relationship and a family.

As psychosis symptoms lessen, your friend or relative may also:

- Lose motivation, energy and interest in things. They may spend a lot of time sleeping or not really doing anything. They may lose interest in their appearance, stop washing, cooking or looking after themselves. They may struggle or not want to do things that they used to do like working, going to college, seeing friends or family and they may seem withdrawn or quiet.
- Feel flat, depressed, empty or just not like they used to be. They may be worried about things getting worse again and feel trapped, embarrassed or a failure because of psychosis.

• They may have ongoing problems with thinking, planning, organising and remembering things.

What you do as a friend or relative is really important here.

See the section on what you can do to help for more advice and guidance. You can also get advice from other friends and relatives, read their stories or provide your own on our website likemind.nhs.uk





What might you notice if your friend or relative is becoming unwell? Where should you go for help?

Some people will have a second episode at some point, but recognising the early signs can reduce the impact of this or even avoid it altogether and needn't stop your friend or relative from getting on with their life.

Things you might notice include a re-emergence of unusual experiences in a mild form, increased suspiciousness or any changes in how your friend or relative feels, how they look after themselves or how they get on at college or work.

Generally, a re-emergence of psychosis symptoms is a late sign. Earlier signs may be harder to separate from ordinary variation in life. It's easy to get worried unnecessarily. After all, we all go through periods where we feel fed up, tired or when we struggle at school or work, but if problems last longer than a week or two they may be early warning signs.

If you're worried about an early change in your friend or relative's mental health, try talking to them. You can also talk to your friend or relative's mental health or EIP team. It is likely that your friend or relative and their team, will do some work around triggers and early warning signs for becoming unwell.

Ask if you can input to, and have feedback on what the team is doing. Your view is important as your relative or friend might not recognise early signs for themselves. If you have more of an understanding about triggers and early warning signs you will be less worried and better able to support your friend or relative.

● I could explain what Alex had been like and, um, again they'd obviously seen it before and could reassure me that he would get better, which was so good to hear because he'd been getting worse and worse over a period of months. To hear someone say, 'we can help and he will get better' was really reassuring. 99 Alex's dad





Who's to blame for psychosis? It's no-one's fault!

It's tempting to look for someone to blame for mental health problems and it's quite common to blame yourself. It's not uncommon to look back for things that might have 'caused' the problem, such as a stressful time, a relationship break up, a house or school move, or simply your genes and to think 'If only I'd been a better mum, dad, brother, sister, relative or friend'.

Or, you might blame someone else or even the person themselves, and think 'if only this hadn't happened, everything would be alright' or 'if only they'd stuck up for themselves at school and not let people get at them' or 'if only they hadn't taken drugs or fallen in with the wrong crowd'.

Life stresses, trauma, bereavement, sleep deprivation, drugs, epilepsy, general sensitivities that you are born with (your genes) all influence whether you develop one mental health problem or another.

Mental health problems aren't caused by one gene or one stressful event or action, they're the result of a combination of things acting together. Mental health is just like physical health. Heart disease isn't down to one thing, it's a combination of our genes, personality, diet, exercise, life choices (e.g. smoking) and life stresses. Some people are more prone to psychosis, others to depression, others to heart disease and others to asthma.

Medication

My friend or relative doesn't want to take medication or I'm not sure if it's a good idea.

This is quite a common problem. Medications do help with psychosis symptoms but they have side effects too. On top of that, your friend or relative may not want to take medication because the experiences they have are real to them and they won't necessarily view them all as part of psychosis.

It is worth encouraging your friend or relative to try medication. You might want to encourage them to try it for at least a few months (as it can take this long to work) and possibly to try a second medication if the first doesn't work (as it may take a little while to get the right medication) or try taking it at a different time of day, e.g. at night rather than in the morning, if it makes them feel tired.

Once they have given medication a good try, they can think, with you, and their clinical team, about which medications and treatments are right for them. Generally, the final decision about medications or treatments is for your friend or relative and their mental health team.



Stigma

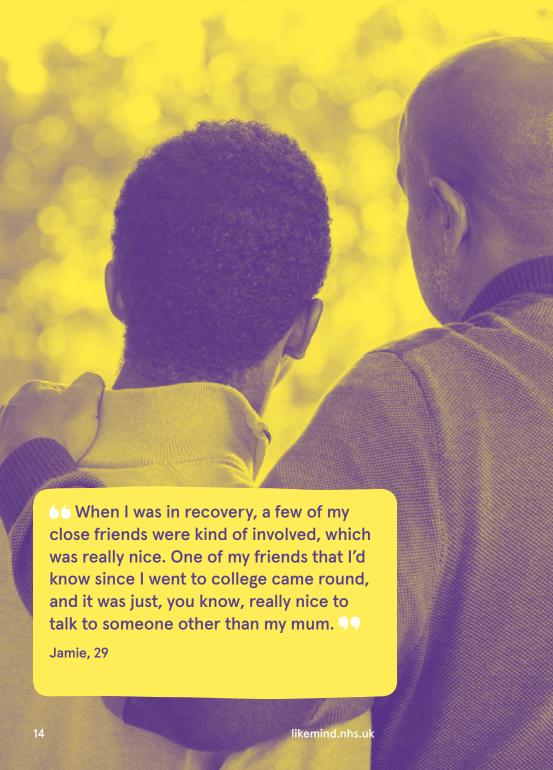
I'm worried about telling people about my friend or relative's problems. What if they judge me?

Stigma or fear that you will be rejected or judged because of a mental health problem, can be a problem. This is often because people don't know enough about mental health and psychosis. It may also be because of cultural beliefs.

You may want to discuss this with your friend or relative and with their team, so that you can weigh up the pros and cons of talking to people you know about what's happening.

Talking to friends and family members who are supportive can really help you and your friend or relative to have the support you need.

Talking to your relative or friend's work, university, school or college may also be helpful, but this will be up to your friend or relative to decide. Their team may be able to help with this too. You (and your friend or relative) may want to start by telling someone who you trust. You may want to give them a copy of this 'friends and family' booklet too.



Hospital

Hospital has been suggested but my friend or relative doesn't want to go, or I don't know if I want them to go.

If your friend or relative is having a difficult time with their mental health, and there is talk of them going into hospital, do talk to their team about this. Early intervention in psychosis (EIP) services aim to stop people from going into hospital.

Only if you, your friend/relative or the EIP team really think there is a need for assessment in hospital or things are unsafe will hospital be considered.

If you are their 'nearest relative' you may be informed or in some cases asked to agree to your relative/friend being taken to hospital when they don't want to go. This might happen if your relative is being 'sectioned' under certain sections of the mental health act.

'Sectioning' means that a section of legal power is applied to the situation, to allow the mental health service to place someone in hospital for assessment or treatment. The person will then have a right to appeal this section, and an independent group of people (tribunal) will hear from all sides, and will decide whether the person should stay in hospital, or should go home.

If your relative or friend doesn't want to go into hospital, do take some time to think very carefully about what you think is right for them.

You know your friend or relative better than most, so you are in a good position to share your thoughts.

Do listen to other people's views but try not to get caught up in defending one side or the other. Instead decide what you think is the best option and then explain this to your friend or relative and their service.

Sometimes, this might mean saying that you think they should be in hospital. This may be difficult, but it's the right thing to say if you think it's right. Remember that sometimes people with psychosis don't believe their experiences are related to mental health problems, and this may impact on their judgement in the short term.

If you decide you don't think your friend or relative should go to hospital, then tell the service what you think and why you think it.

Sometimes it can help to write this down in a letter as it can help you to think clearly about your reasons and it will help the team to understand your view too. Listen to the views of the team as well and try to find a workable solution.

Being consistent will be helpful for your friend or relative. If you don't agree, then in some cases this will stop your relative going into hospital, especially if there is an alternative, workable plan in place. However sometimes the team may still feel an admission is necessary, and will seek legally to take your relative to hospital without needing your permission.

If your friend or relative does go into hospital there's a booklet to help you with that too. It's called 'Getting the most out of hospital'.

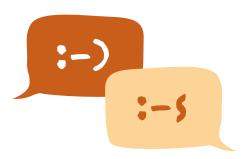


Conflicting information

People have different opinions about my friend or relative's experiences

You may find that different people have different opinions about where your friend or relative's experiences have come from and the best ways to deal with them.

For example, you, your relative or a religious leader may view the experiences as spiritual, and may think that prayer, or family support is the best way to cope, whereas a psychiatrist may be recommending medication.



You may also find that sometimes the advice given conflicts with your own personal values. For example, at times you might feel it is best to be with your friend or relative at all times to keep an eye on them and make sure they are safe, however the NHS team might suggest your relative can be more independent.

Do speak to your friend or relative's care coordinator if you are confused about any information you have been given, or if you or your friend or relative has cultural or religious concerns.

likemind.nhs.uk

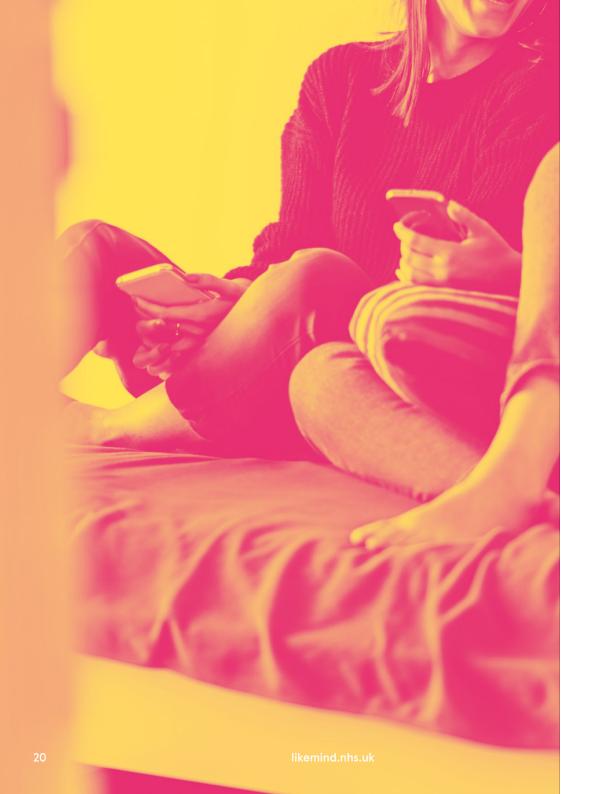
The NHS team will try to work with language barriers, and may involve an interpreter, if you think this would help. They will also respect your families' or friends' confidentiality.

Everyone is different in terms of culture, gender, religion, ethnicity, sexuality and many other ways. Your friend or relative's care coordinator may not know everything about your particular cultural or spiritual background or that of your friend or relative, but they will aim to listen, understand and respect your views, and those of your friend or relative.

Where family, friends, religious leaders, the NHS or your friend or relative have different views about what will be most helpful, your friend or relative's care coordinator will aim to listen to everyone. They will help your friend or relative to find the most helpful treatments, and can adapt their approach for your friend or relative's particular situation.

66 My parents, they kind of have mixed views really 'cause in some ways they view it as like a clinical disorder but then sometimes they say something like it's spiritual and maybe there are some kind of spirits that have gone into your body and possessed you. 99

Taylor, 20



How to help your friend or relative to recover, and reduce the risk of a relapse of psychosis

Here are some suggestions for things that might be helpful for you to do, or not do, to help your friend or relative to feel better.
Listening and trying to understand is especially important when someone is experiencing psychosis, and promoting independence is more important when someone is recovering.

Other things like keeping calm and taking time out for yourself, are important all the time, and whilst conflict and stress is sometimes unavoidable it can often make things worse.

66 He did have the support of one or two of his housemates, one in particular, who tried to help him along, and he was, you know, encouraging him to do the right things, like not smoke dope.

Jon's mum

66 I dunno, I kind of would just, wanna be there to like, help her through it because I know it's not going to be easy for her. I'd just wanna kind of, show that I'm there to support her, I'm not gonna go round telling everyone about it. **99**

Aliyah's friend, 19



How to help - do:

Listen and try to understand what your friend or relative is trying to tell you and why they think the way they do.

This may be hard as they may be telling you some things that sound quite unusual, unbelievable or distressing but the more you listen the more you will understand. Having someone who they can talk to, will help your friend or relative to make sense of what's going on, and may even make them start to question it.

Encourage your friend or relative to get back to the things that they have previously enjoyed in life, or to take up new hobbies, social activities, college courses or job opportunities.

You might remind your friend or relative of their skills and strengths, and the things they're good at, but then let them decide how much they are able to do and how quickly.

Tell them how well they're doing when they make even small steps to recovery. This will encourage them to keep going.

Think positively and be optimistic about the things that your friend or relative might want to do in life.

Help them to think about the future and the things that they may want to get back to. Psychosis often begins when people are younger, so it's easy for it to interrupt college, university, work and friendship groups.

Low mood, lack of energy and negative thinking about psychosis (self-stigma) can make it harder to get back to these things, but the more hopeful you are for your friend or family member, the more you think with them about their goals and how to get there, the more likely they will achieve things, in their own time.





How to help - do:

Promote your friend or relative's independence.

It might be tempting to 'look after' or 'protect' your friend or relative. This may especially be true if they have lost their confidence and you, or they, are worried about the psychosis coming back. Worrying about psychosis coming back is normal but it can stop people from getting where they want to be.

It's important that they rebuild their hope, confidence, independence and social life, but perhaps just being a little bit aware of 'triggers' or 'signs of relapse'. If you are worried, it might help to discuss a 'wellness or relapse plan' in general or in relation to your friend or relative, with their local EIP service.

Have realistic expectations.

It can be tempting to push your friend or relative to get back to their old life as soon as possible after psychosis. This may be because you want to be reassured that they're better again, because you think it will help, or because you miss the old them or need them to do the things they used to do. Your friend or relative may find it hard to get back to things they used to do or start new things (see the section about the recovery phase).

Pushing people to do too much at this stage can cause more stress and if your friend or relative can't do things, can make them feel even more of a failure. Do encourage your friend or relative, but do let them recover at their own pace. Remember, small steps will build confidence and will reassure your friend or relative (and you) that these small steps will lead to bigger gains in the future.

Keep calm and make time for yourself.

Having a relative or friend with psychosis can be upsetting and stressful for you too. You may find it hard to understand what they're going through, how to talk to them and how to help them. You may miss your friend or relative's input or company, their help around the house, their contribution to money.

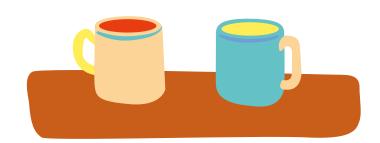
There may be mental health professionals, other friends and family and the person themselves telling you different things or saying things that you don't agree with. It's important that you keep calm, take time for yourself, and get the support that you need. That way you will have the strength and energy to help your friend or relative. See the section below on how to help yourself.

Remember you have lots of experience to draw on from other difficult situations in the past.

Mental health is no different from other problems like relationship break-ups and problems at school, work and home. Use your experience from dealing with problems in the past, to help you approach the new situations that you face together, as a result of mental health problems. Keep trying different approaches to solving problems until you find the things that work best.

Be flexible and open minded about what might be helpful for your friend or relative. Talk to other people and get more information.

Having more information and a range of perspectives can help you to think, with your relative or friend, about what might be helpful.





How to help - do:

Support your friend or relative to choose and use the interventions that are on offer.

You could talk to them about their options, linking this to what's important to them and what they want to achieve. You could even come with them to a session where they discuss treatments and goals. There are a number of recommended interventions for psychosis. These include:

- Medications that help with unusual and distressing experiences, moods like depression and anxiety, and with keeping your mood stable.
- Talking therapies such as cognitive behaviour therapy (CBT) which can help people to understand their experiences, thoughts and behaviours so that they can improve things for themselves.

Have a crisis plan in place

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When your friend or relative is well, you can discuss with them, the sorts of things that may be helpful for them if they become less well again. This can include things that they, you and mental health services can do to support them in a way that works best for them.

Ask if you can input to and have information about your friend or relative's care plan.

You may have useful information which will help other people to understand your friend or relative's difficulties, how they cope and early signs that they are struggling. Your friend or relative may not be very good at recognising their problems themselves. Also, if you have more information, you will be better able to support your friend or relative.

- which help the whole family to understand what's been happening, to solve problems, deal with difficult emotions and reduce stress and tension which will also reduce the risk of relapse.
- Vocational or occupational support which can help people to get back to work or education.
- Physical health interventions
 which provide support for general
 health such as diet, exercise, smoking
 and substance use.

Lots of other therapies and approaches may also be helpful with stress, thinking problems, well-being and health, like yoga, art, drama, music, relaxation and cognitive remediation.

You can find out more about treatments in our 'Treatment choices' information booklet, and on our website likemind.nhs.uk



How to help – do not:

Don't keep telling your friend or relative that they've got it wrong and that what they're concerned about isn't happening.

Very occasionally, if your friend or relative is already questioning things then telling them you don't think they're quite right can be helpful and reassuring. Often though, when people are experiencing psychosis they are completely certain that they're right.

They may be absolutely sure that they are hearing someone talking to them, that someone is out to get them, or that another unusual experience is entirely true. Telling them they're wrong can alienate them and make them even more defensive, angry or upset. People with psychosis have often said that the worst thing is people telling them they're wrong and that what they're experiencing isn't happening.

Don't force or pressurise your friend or relative to do things that they don't want or aren't ready to do.

When people are experiencing psychosis, they can feel very scared or anxious, they may struggle to concentrate, and it can be extremely difficult to do the things they used to do. Even when the psychosis experiences have gone, people may have lost a lot of confidence and may continue to feel anxious, depressed or lacking in energy and motivation.

Different people recover at different speeds. For some, it may take a long time, and involve very small and gradual steps.

Pushing your friend or relative too much when they're not ready can make them feel like a failure, which will make them feel even less able to do things.

Don't devalue or ignore your friend or relative's progress and try to have realistic expectations.

It can be hard to understand why it takes so long for your friend or relative to recover, and it can seem like they're being lazy, not trying or not getting anywhere. Remember, your friend or relative will take time to recover. Your support and encouragement for their efforts, however small, will be really helpful to them.

Don't try to protect your friend or relative.

It's tempting, especially if you're worried, to keep a close eye on your friend or relative, to go with them when they go out, to check up on them, or to discourage them from doing anything that might cause stress, like living alone, getting a new job or starting a new relationship.

But, taking risks and experiencing stress is a part of life.

A better approach would be to encourage your friend or relative to find better ways of coping with stress.

Don't be critical, blaming, pessimistic, angry or upset with your friend or relative.

It's hard to be positive all the time but negative and critical comments will undermine your friend or relative's efforts to change. Remember, psychosis is no-one's fault. If you're feeling negative, and are tempted to criticise or blame your friend or relative, try doing something for yourself instead to help you to relax and to feel more positive.

66 In our country when somebody is mentally ill, they normally hide them away and keep it at home so they don't go out and disturb other people. It's quite shameful to the family, the society and the community 99

Lakshmi's mum

What might be helpful for you to do for yourself? Where can you go for help?

Keeping calm and making time for yourself

Different people find different things help them to relax and switch off. You could try having a relaxing bath, watching a good film, going for a walk, run or swim, going to the gym, playing sport, reading a book, meditating, praying, relaxation, going out with friends, going shopping, listening to music, listening to the radio.

Whatever works best for you, make sure that you have time for yourself to relax and do the things that you enjoy. This will benefit your friend or relative. You won't be able to support them if you're struggling yourself.



Practical support

Supporting a young person with mental health problems such as psychosis, can have quite an impact on practical things like money, housing and work. You can get advice on practical issues from the early intervention service, but also from other places too like Citizens Advice. You can also ask for a carers' assessment through the NHS or EIP service to support your own needs.

Family work

If there are tensions and stress within the family, or the place where you live, that are linked to your relative or friend's mental health problem, you may be able get a specific family intervention to help reduce this pressure. This will help the whole family or household, and can also reduce the risk that your relative (or friend) becomes less well again.

66 The support groups are good, very good. We started going with other parents. There was a lot of informative things, so it was very useful. I think that helped. It helped us certainly, to feel confident that on the whole, the way we were approaching this was ok. ■●

Stuart's mum

66 In fact you know I was probably ill a bit myself with the worry of everything. 99

Adah's mum

Managing the impact on your own stress and mental health

It's not uncommon for the stress of mental health problems and psychosis to impact on relatives and friends. Do make sure you get the support you need for yourself. This might be informal support from your own friends and family, from a religious or spiritual leader or from local carers' support groups.

You can find out about carers' support through the NHS, the EIP service or through other organisations such as Rethink and Mind. You can also find out about additional support from our website at likemind.nhs.uk

If you are worried about your own mental health you might find some of the self-help materials on the website useful, for things like managing sleep, low mood, worry and anxiety. You can also access support for your own mental health by visiting your GP.

What should I expect from an EIP service for myself and my relative or friend. What are my rights?

Early intervention in psychosis services are specially designed to help people who experience psychosis, to recover and get on with their lives. They do this by working in an all-round way and this should normally include working with family and friends. This is because people are more likely to recover from psychosis more quickly if they have supportive family and friends around them.

The EIP service will be focused on supporting the person with psychosis. They have to respect a person's views and keep things confidential when they are asked to by the person. Sometimes, they are asked to keep things from friends and family that the person doesn't want to share, or occasionally they are asked not to speak to family and friends at all, but early intervention services will normally ask how, rather than whether to include friends and relatives in the person's support.

You should expect an EIP service to:

Talk to you in general about mental health, psychosis, the role of the EIP service, the people who work in the service and the treatments for psychosis that are on offer.

Listen to your concerns and talk to you in general about things that you can do that may be helpful.

Support you in your role as a relative or friend. This might include speaking to you on the phone, meeting with you, inviting you to a carers' group or offering you a carers' assessment to support you with your own needs.

66 I typed up a consent thing and Rachel signed it all. And she verbally told everybody that I was to be fully involved. She was able to do that. ■●

Rachel's mum

If your friend or relative is happy for information to be shared with you, the EIP service can also:

- Talk to you about the specific problems that your friend or relative is experiencing and the specific supports and treatments that they are putting in place to help
- Invite you to care plan and review meetings
- Offer a family intervention where this is available and may be helpful.

Places to go for support

rethink.org
0300 5000 927 (9.30am-1pm, Monday-Friday)
Information and support for people affected by severe mental illness

rethink.org/carers-family-friends/ caring-for-yourself-guides An eight-part guide for people who care for someone who experiences mental health problems

youngminds.org.uk
0808 802 5544 (9.30am-4.00pm, Monday-Friday)
Free information and support for parents on child and adolescent mental health

mind.org.uk
0300 123 3393 (9.00am-6.00pm, Monday-Friday)
or text 86463
National helpline providing information on mental
distress, where to get help, interventions and advocacy

Mind legal line 0300 466 6463

For advice on the mental health act, mental capacity act, community care, human rights and equality in relation to mental health

samaritans.org.uk 116 123 (24 hours) Helpline for anyone needing emotional support

carersuk.org
0808 808 7777 (10.00am-4.00pm, Monday-Tuesday)
Independent information and support for carers

If you want some advice from other people, want to see what other people found helpful, or have any advice that you could share yourself, take a look at our website likemind.nhs.uk





Your friend or relative's care coordinator or lead practitioner is:

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(Professor Kathryn Greenwood, Dr Kirsty Labuschagne, Dr Clio Berry,

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INSTITUTE OF PSYCHIATRY, PSYCHOLOGY & NEUROSCIENCE





















