MYTH-BUSTING INFORMATION

Treatment choices for unusual distressing experiences and psychosis

A mental health companion for young people



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Why bother reading this? Why do treatments or choice about treatments matter?

Are you someone who is struggling with unusual distressing beliefs or experiences and wondering what might help you?

Are you getting some support from a mental health or early intervention in psychosis (EIP) service, and want to know more about which treatments might be best for you?

Are you unhappy with the treatments on offer and want to know about alternatives?

Are you a friend or relative of someone struggling with these issues and want to know what might be helpful?

If your answer to any of these questions is 'yes' then this booklet is for you. Lots of people who have unusual distressing experiences, or who use early intervention in psychosis services have told us that they want a booklet like this. They want easy to read, accurate and honest information about treatments for these experiences so that they have choices, and can make their own decisions about the right treatments for them. So, this is what we've tried to do!

Even if these experiences have got better or stopped, sometimes unusual distressing beliefs and experiences come back again, particularly at times of stress, so getting treatments that suit you and work over a period of time may be important.

This booklet will tell you about treatments that might be helpful, so that you can discuss them with your team or clinician and make decisions about what may work best for you.

This booklet has been written with and for people who've experienced unusual distressing experiences, or who use early intervention in psychosis services.

See also our booklets on 'Mental health and getting help', 'Early intervention in psychosis services', advice 'For friends and family of people with psychosis' and 'Getting the most out of hospital'.

You can find out even more information and updates about treatment choices on our website likemind.nhs.uk

66 Many people are seeking to take control of their mental health using self-help, and to find approaches they can use alongside medication.

Jim, Care Coordinator

Well there's a lot of people who are against CBT you see, a lot of people in mental health say it's not helpful, but then, my sister thinks it is.

Jack, 22

66 The main qualm I have with my treatment is that it's mostly been based on medication. I was on antipsychotics which were helpful for me, but there was quite a lot of resistance to me coming off them. **99**

Ahmed, 19

has been really helpful. She was really good at identifying where my thinking is going astray and helping it come back to where it should be.

Jenny, 32

them, you know, plugging the medication a lot. They never said to me 'you have to take it'. They said, 'obviously it's your choice but I do recommend that you stay on it for as long as we say'. They didn't even say anything to me about the other things that could make me better.

Simon, 17

More information about this booklet

How we describe experiences

This booklet is about the types of help that may be offered for unusual beliefs and distressing experiences, such as:

- 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 are about you, believing you or others are famous people or imposters, or 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.

Alongside these experiences, some people will also struggle with motivation, energy and interest, feeling low and having problems with memory and thinking.

Sometimes people call these experiences psychosis but not all people agree with this description. So, in this booklet we will refer to these experiences as unusual, distressing experiences.

Why we've chosen the treatments we have

This booklet includes a selection of treatments such as medicines, psychological therapies, general health, occupational, service-based and peer (support from other service users) treatments.

We have tried to include the main treatments that are commonly offered but also some that are newer or less common that you may want to know more about.

Some of these are core EIP treatments, but others may not be available in your local EIP service or the NHS. We've added information in the relevant sections of the booklet on where else you might be able to get these treatments.

How long do the treatments last?

The direct effect of medicines will usually only last for as long as you take them, although if you stop taking medicines it can sometimes take several weeks before all of the medicine has gone from your body and sometimes months before the effect of stopping it on your mental health is known.

The effect of talking therapies may reduce over time after you stop, but keeping practicing what you've learnt and having booster meetings may be helpful. Similarly, general health interventions, like exercise, will also gradually lose their effect if you stop doing them.

After all, you wouldn't expect that doing lots of sport in one year, will mean that you are healthier the next year, if you've spent all the time in between watching TV and eating pizza! We need to keep going with things to keep seeing the benefits.

Where can you get more information?

We haven't been able to include everything. There are other types of medicines and treatments that we didn't have room to include in this booklet. Also, treatments change and new treatments are developed all the time.

We will keep adding more information on our website likemind.nhs.uk

We will also try to include videos of people talking about different treatments and you can use our discussion forum on the website to get advice.

You can also speak to your family, friends, doctor, care coordinator or someone else who you trust in your local EIP or mental health service about treatment choices.

HOW TO USE THIS BOOKLET

The 'thumbs up' symbol tells us whether the treatment works

The green thumbs up means that the treatment works (the more thumbs up signs, the more evidence there is that the treatment works). So three thumbs up signs means there's lots of good evidence, two thumbs up signs means that there's an encouraging/reasonable amount of evidence, and one thumbs up sign means there's only limited or poor quality evidence.



The sideways thumb means that it's not clear yet whether the treatment works, because there's not enough evidence.



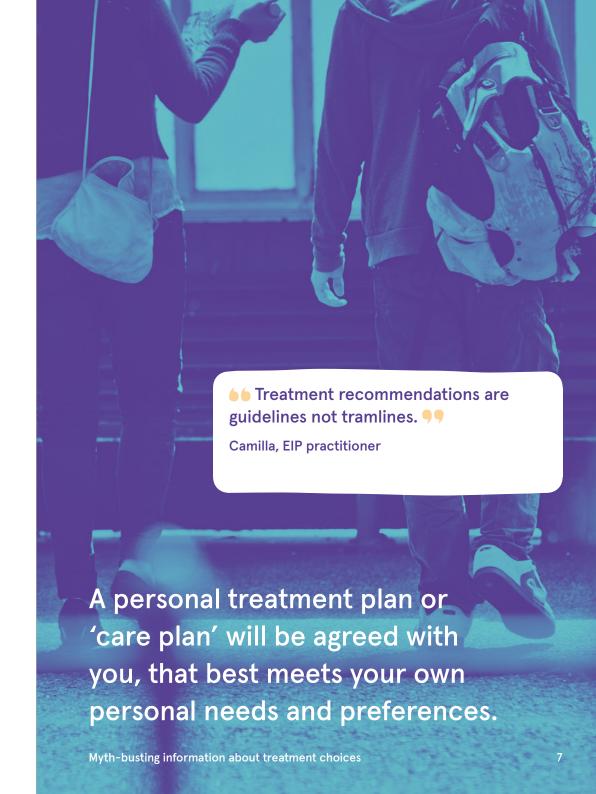
The red thumbs down sign means that there's enough evidence to suggest that this treatment doesn't work.



The yellow star means that this treatment is a main treatment that is offered in EIP services.

There may still be a waiting list though if the treatment takes time.





What is good evidence that a treatment works?

All the information we've put in this booklet is based on the most up to date evidence we've got for the treatment.

We may get evidence from a natural study, for example, in a clinic, or a group of people where the treatment seemed to work, and we may get evidence from a report on one person where the treatment was carefully tested.

The best quality evidence is the evidence that we get from a randomised controlled trial or RCT.

An RCT is a special type of test of a treatment. In an RCT, people who might be helped by the treatment, are randomly offered either the new treatment, or a comparison or 'control' type of treatment. The comparison treatment might be no treatment at all, the usual standard treatment or another type of treatment. That way we can see whether the new treatment is better than doing nothing, better than what we usually do or better than other treatments.

Imagine for example, that you want to see whether a special type of vitamin reduces depression.

Imagine also that in reality the vitamin will only reduce depression in people who don't have enough of this vitamin in their body.

If you test this vitamin in one person, two people, or even a big group of people, the result (whether the vitamin works) will always depend on how many of the people who you gave the vitamin tablet to, were lacking in it.

If you tested the tablet in a group of people who mostly all had the vitamin already in their body, you might assume that the vitamin tablet didn't work for anyone, whereas if you tested this in a group of people who mostly lacked the vitamin, you might assume the tablet worked for everyone.

Both of these conclusions would be wrong – and it would be hard to be confident in the result!

What a randomised controlled trial does, is to randomly (like flipping a coin) put people into groups; for example, you might randomly put each person into either the group that will be given the vitamin tablets or the group that will have a neutral sugar tablet.

Because people are randomly put into groups, people lacking in the vitamin will be just as likely to be in the vitamin tablet group, as in the sugar tablet group.

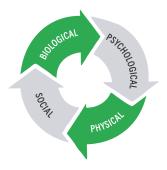
Equally, any other differences between individual people, will be just as likely in each group. This means that if depression reduces more in the group who were given the vitamin tablet than in the group who got the sugar tablet, you can be pretty confident that this was because of the vitamin tablet itself, and not because of something else that differed between the groups. So, a randomised controlled trial is really good evidence, because the more people there are who randomly get the treatment and have good outcomes, the more confident you can be that the treatment works.

It's quite hard though to do very big trials, so sometimes the results of lots of smaller randomised controlled trials are all combined together into a big test called a 'meta-analysis' so that we can compare whether a treatment works or not in a very big number of people. A meta-analysis of lots of good randomised controlled trials is the best possible evidence.

This example with the depression, also highlights another important point which is that we are all different. What works for one person won't necessarily work for another. Sometimes you might need to try a few different types of treatments to find the ones that work best for you.

HOW TO USE THIS BOOKLET

The 'circle' symbol tells us how the treatment works



The treatments that we've included in this booklet work in different ways but they all have the same aim, to help you to feel good mentally and physically. Importantly, whatever way a treatment works, it still affects the whole of you.

For example, medicines mostly work biologically and physically, affecting the brain and body.

Medicines are produced now by big companies, but they aren't just 'factory-made' chemicals, some have come from natural ingredients and traditional remedies.

Did you know, for example, that the common pain killer, aspirin, was originally made from the bark of a willow tree? Anti-malaria tablets also traditionally came from the bark of a tree (the Cinchona tree which grows in South America) and a medicine called Digoxin, which is used to slow down a fast heart rate, was first found in foxgloves!

Medicines made by medical companies are sometimes better than natural remedies because they make drugs that are easier to take and work better with as few side-effects as possible.

The medicines we've described in this booklet act biologically and physically at first, but should then help you to feel and think more positively and get on with your life (psychological and social responses).

Psychological (talking) therapies, general health treatments (like exercise), occupational therapies, services and peer support work the other way round by addressing thoughts and what we do (our activities and social life), but as we start to feel happier and more active, this can actually change our brain chemistry (biology) and our physical health too.

On each treatment page you will see a circle shape. Each part of the circle represents a different way in which a treatment might work to improve your health and wellbeing: a biological (brain) way, a psychological (thinking) way; a social (people) way; or a physical (body) route.

The part that is highlighted in green will show you the main way that the treatment works, but remember everything affects us as a whole person!

The example above shows a treatment that would work through a biological (brain) and physical (body) route.

Anyway, that's the introduction out of the way!

We hope this booklet is helpful to you. It's part of a series. You might also find the following booklets helpful:

- Myth busting information booklet about mental health and getting help
- Myth busting information booklet about early intervention in psychosis services
- Myth busting information booklet for family and friends
- Myth busting information booklet for getting the most out of hospital

Remember, you can find them on our website likemind.nhs.uk

1. Mental health service support



Early intervention services



A good early intervention service focuses on all aspects of your physical health and mental health.



Remember, more thumbs ups just means that more people have done research that shows that this approach works.

What is it?

Unusual and distressing experiences (e.g. paranoia, fear that people are out to get you, hearing or seeing things that other people don't) tend to start when you're in your teens or early 20s, although for some people it can be later... in your 30s or older.

Evidence suggests that what you do and the support you receive in the critical first months and years with these experiences is especially important.

The sooner you get support for unusual and distressing experiences the more likely you are to recover and get on with your life.

Early intervention services are made up of mental health workers from a range of different backgrounds, who work with you when you first have unusual and distressing experiences, to try to reduce the impact of these experiences, and help you get back to the things that are important to you.

What does it aim to do?

An early intervention service aims to do two main things. Firstly, it aims to work closely with schools, colleges, young people's services, GPs and other services to help you to get help and support as quickly as possible. Secondly, it aims to provide useful treatments and broad all-round support when you first develop unusual and distressing experiences, to help you to keep up with work, school, college, your social life and friends, and to help you get back to normal life as quickly as possible.

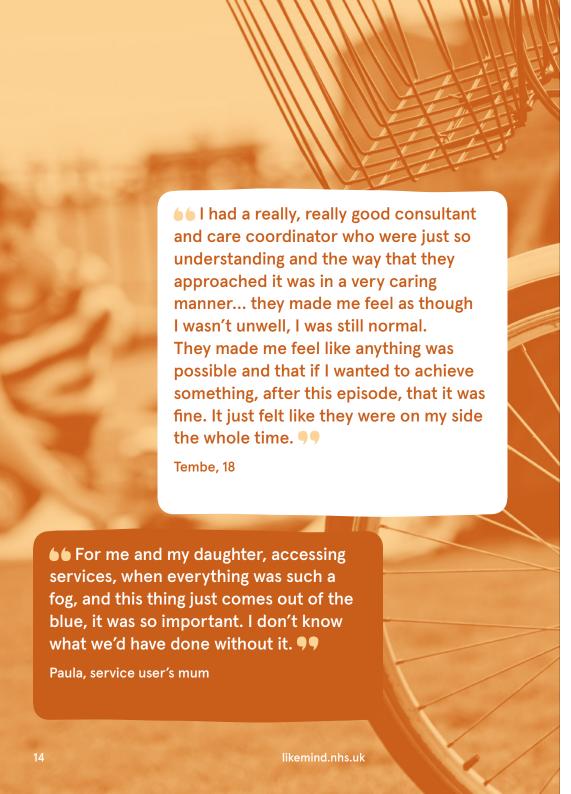
If unusual and distressing experiences are recognised early, then useful treatments and support can reduce the impact of them on your life, allowing you to recover as quickly as possible.

Do they work?

A number of studies have found that early intervention services are better able to reduce unusual and distressing experiences and are better at preventing these experiences from returning, compared to standard community services.

•• The key to early intervention is the way services can convey real hope for recovery, and help people to achieve their goals. It is providing intervention early at the time users and their families most need it, helping them through the crisis in the least stigmatising way and helping people see the light at the end of the tunnel. ●●

Professor David Fowler,
Professor in Clinical Psychology



People using these services also tend to be more engaged and satisfied and have a better quality of life than people using more traditional community services. EIP services lead to better outcomes as they offer a broad set of support including medicine, psychological and vocational support (see the next section for more information on all of these treatment options).

The National Institute for Health and Care Excellence (NICE)

NICE backs this evidence and also shows that early intervention services offer more talking therapies than standard services.

A lot of evidence is based on the work of the Early Psychosis Prevention and Intervention Centre (EPPIC) in Australia, but there is also growing evidence from the UK and other countries, such as Norway.

These have found fewer relapses, fewer associated problems, better wellbeing, work and education outcomes for people receiving early intervention services compared to standard care.

How can I get this treatment?

EIP services should be available in all local areas and if you have unusual and distressing experiences your GP should be able to refer you to your local service.

You could also look up your local service on the 'help and support' page of our website likemind.nhs.uk

In some areas, clinicians with lots of EIP experience are working in general mental health teams instead of EIP teams. If you don't have a local EIP service, you could ask instead to speak to someone in your local mental health service who has EIP experience!

✓ Main pro

Early intervention services help you to recover better than other mental health services.

Main con

There is not yet enough evidence to show whether this better recovery carries on in the long term.

2. Support from other people with similar experiences and understanding

Hearing Voices Network groups



The main focus of this treatment is on social factors.



Remember, a sideways thumb just means not enough people have done research yet that shows that this approach works. This might be really helpful (and some people say it is), we just don't know for sure!

What is it?

The Hearing Voices Network is run by and for people who hear voices, noises, or have other unusual experiences of people speaking to them when no-one seems to be there. If you have these experiences, then the Hearing Voices Network is about 'peer' support – that's support from other people like yourself.

The Hearing Voices Network has peer support groups all over the country; these are based both within, and independent from, services. It is not a treatment but a source of support which may help you on your journey to recovery.

What does it aim to do?

The key idea behind the Hearing Voices Network is that unusual experiences are a reaction to trauma or other difficulties in life. You are supported to talk about your experiences in a way that makes sense to you, using the explanation that you find most helpful.

Through peer support, the groups aim to help you to find your explanation, and provide choices in how you might understand your experiences. Additionally you are encouraged to discuss ways of coping with these distressing experiences.

All hearing voices groups operate in slightly different ways, as the way they work and what they talk about is shaped by you and the others in the group.

Some groups let you just turn up on the day, and some ask that you contact the group first, to arrange to come. A hearing voice group is at its root, a peer support group. Most groups will have someone in an organising and helping role whose job is to take care of arranging and helping the group to run smoothly.

The group doesn't see a difference between mental health staff and service-users, anyone who goes to the group or helps to run it is an equal member, whatever their background.

66 The Hearing Voices Network provides a safe space where people can receive peer support and make sense of their experiences in a way that is meaningful to them. **9 9**

Cassie, hearing voices group member

Anyone can attend a hearing voices group and most groups are happy for you to bring someone along for support if you want to. All members of the group are expected to 'join in'. There is no pressure to talk or share anything personal though – 'joining in' just means listening.

Hearing voices groups are confidential – so what you say in the group is private and no-one will talk about it outside the group, or tell anyone else what you say – and what you talk about is varied to best support you and the others in the group. Many hearing voices groups also run a social programme i.e. social get togethers and events, that you can go to, or even organise if you want to.

Does it work?

The Hearing Voices Network was started by a psychiatrist called Marius Romme. Marius began to question whether unusual experiences, like hearing voices, were a symptom of an illness.

He realised he had not been listening to other people's views, and that it might be better to let people decide for themselves what was or wasn't real.

He brought people together who heard voices and gave them a space to talk about this experience. Those who heard voices felt more free and more in control because they could talk about their voices, without being diagnosed or judged.

♦ Hearing people speak in the group and attending events has given me the courage to find an understanding of mental health issues in a way that I feel comfortable with. ¶¶

Jack, hearing voices group member

18

Quite a few people who go to hearing voices groups go on to run and set up their own groups, and the whole Hearing Voices Network is run by people who hear voices and have been to these groups.

Because all the groups are different, and members run the groups themselves, no-one has 'tested' whether hearing voices groups 'work'; but there is some early support for the benefits of peer support (see below) which is a key part of hearing voices groups.

The National Institute for Health and Care Excellence (NICE)

NICE does recommend peer support as part of a package of support and as one way to help with recovery.

How can I get this treatment?

Hearing voices groups are not a treatment, and instead offer a space to talk and an offer of support.

There are hundreds of hearing voices groups across the country.

To find a group go to the Hearing Voices Network website – hearing-voices.org – and look for the group nearest to you.

Many groups also have social networking sites you can access. Those working within NHS services may also know of local hearing voices groups that are available to attend.

Main pro

Hearing voices groups are an opportunity to meet other people with similar experiences to you and to talk without being judged, in complete confidence and in a way that you find most helpful.

Main con

Attending a group can be a bit scary at first. To help with this, you can bring someone along for support, or get in touch with the group before you come, to ask any questions or discuss anything that's worrying you.

2. Support from other people with similar experiences and understanding

Peer support



The main focus of this treatment is social.



Remember, a sideways thumb just means not enough people have done research yet that shows that this approach works. This might be really helpful (and some people say it is), we just don't know for sure!

What is it?

Very often when you have unusual upsetting experiences for the first time, you can think that you're the only one who's gone through strange and sometimes frightening experiences. Peer support is when somebody who's also had these experiences – and often also used mental health services – draws on their experience of personal and social recovery to support you.

A peer support worker will be hopeful for you and for your recovery, helping you to make sense of the future, holding hope for the future, helping you to build your own recovery pathway. Peer support can involve lots of different things, from one-to-one sessions, to groups and drop-ins, depending on your preference and what the service you are in can offer.

What does it aim to do?

Peer support workers aim to support you to make sense of what's happened and to help you to set goals for yourself, to help you get on with your life. They are not there to give clinical advice or to tell you what to do.

They can help you to think about what kind of goals support your personal and social recovery, like making new friends or getting in touch with old ones or something more practical, like travelling to new places or to the places you used to go to.

They can also talk about how they got through difficulties with these kinds of things, for example being anxious, being worried about being judged by other people because of your experiences, or other difficulties.

Because peer support workers have gone through it themselves, they can often talk about things with you that are not so easy for staff from mental health services to understand.

They can use their experience to help you make best use of the other supports on offer to you.

•• I feel better supported meeting someone else with this experience, thinking about self help options. Peer support workers are able to give hope and I feel more confident about recovery.

David, 32

♦ Although there are over seven billion people on the planet, the idea that 'you aren't alone' is not always obvious. It can be enormously helpful to connect with someone with similar experiences. Simply hearing someone else's thoughts about these experiences, can offer valuable views on feelings you thought you were alone with.

Increasing hope, being empowered, and feeling like you belong are some of the main things that peer support offers. Providing a non-judgemental place to reflect and talk openly, without any sense of 'us and them', may provide a start for further understanding yourself.

Support from a peer (someone else who's been through things like you), balances power evenly compared to more traditional therapy relationships. It can be helpful, for example, by sharing coping strategies with each other. Of course it's important to remember nobody's path is the same, but it may surprise you how often they cross or run parallel.

John, Peer Support Worker

Does it work?

It's too early to tell yet whether peer support works. There are a lot of first-hand accounts from people who've been supported by a peer support worker, saying that it's helped them personally and socially, as well as being rewarding for the peer support workers themselves. There is limited evidence for peer support, and only one large RCT so far.

The evidence that does exist has often used clinical and service measures (like whether it stops experiences coming back and whether it stops you going into hospital) to see whether peer support works or not. A very recent study in 2018 did show that peer supported self-management slightly reduced readmission rates in the following year. There haven't been any big studies looking at whether peer support helps with social and personal outcomes for people receiving a peer support service.

The National Institute for Health and Care Excellence (NICE)

NICE does recommend peer support as part of a package of support and as one way to help with recovery.

✓ Main pro

Peer support workers can be hope inspiring, just by being there, as they are living proof that you are not the only one and that it's possible to get beyond difficult and scary times.

Main con

We don't yet know how peer support works and what it does that's different to a support worker who doesn't have unusual upsetting experiences. Some people just want to forget about their experiences as quickly as possible and would not want to be reminded by a peer support worker.

2. Support from other people with similar experiences and understanding

Spiritual and faith-based support



The main focus of this approach is social, psychological and spiritual.



Remember, a sideways thumb just means not enough people have done research yet that shows that this approach works. This might be really helpful (and some people say it is), we just don't know for sure!

What is it?

Faith or religion involves beliefs, practices and rituals related to a higher power (in western countries we usually call this higher power a god).

Every faith has its own god or spiritual lead (such as Allah for Islam, and Buddha for Buddhism). Different faiths usually have different beliefs about life after death, as well as rules about how to behave in life and socially.

Spirituality and religion are linked. But spirituality can be more general and include many other things. It can mean different things to different people. Or you can follow a common spiritual belief. You can be spiritual without being religious.

Religion and spirituality can help you to develop inner strength, peace, hope and optimism. Many people within the UK have a religious or spiritual belief. There are some religions that are more common in the UK than others such as Christianity, Islam, Hinduism, Sikhism, Judaism and Buddhism.

What does it aim to do?

Religious beliefs and spirituality tend to be experienced positively. For example, people often find that having a religion or spiritual belief helps them to cope with a variety of life events such as illness, loss and general stress.

In addition, religion and spirituality might help to improve your wellbeing, hope, optimism, meaning and purpose, and inner peace. This may be because religious and spiritual beliefs provide tools to help you to cope with stress. These coping tools include faith and beliefs that give meaning to difficult life circumstances.

Religious and spiritual beliefs might provide answers to big questions in life such as 'where did we come from?', 'why are we here?', and 'where are we going?'. But asking yourself 'big questions' can sometimes make you feel worse.

Religions might also provide a positive worldview that may involve the existence of a caring god.

Additionally, within many religions prayer is common and this can provide a sense that you have control over some of your life events by communicating with a higher power that you trust.

You may practice meditation as part of spirituality or religion, and this may bring a sense of control, understanding and connectedness.

In addition, most religions emphasize love, compassion and being kind to others, as well as meeting together during faith-based social events. These behaviours may give you a sense of belonging as well as making you feel good about yourself.



Lots of people who use mental health services have said they find religion or spirituality helpful for managing their mental health issues. But often they find it difficult to speak about with their health care professionals.

If you want to begin thinking or talking about your religious or spiritual needs, you could think about the following questions.

- What keeps you going in times of difficulty?
- What is important to you?
- Are you being listened to as you would wish?
- What makes you feel supported?
- What makes you feel happy?

Talking about how you feel you fit into the world and your personal values may be useful for your health and recovery. It may help you figure out your feelings, beliefs and attitude towards religion and spirituality. Try talking to someone who you trust and who respects you. This could be a friend, chaplain or faith leader as well as your mental health professional.

Does it work?

Overall, there is not enough evidence to draw any firm conclusions about whether having religious or spiritual beliefs can help with unusual distressing beliefs and experiences such as psychosis.

Some small studies have found that positive religious and spiritual coping, such as turning to god or a spiritual leader during difficult times, can help improve your quality of life.

Although some religious and spiritual beliefs may be empowering, some beliefs may be unhelpful. They may lead you to feel guilty or in need of forgiveness. This may have an adverse effect on your mental health.

Some religious groups may believe you are possessed by demons or spirits if you have a mental illness. Others may say that mental illness is a punishment for something you have done wrong. These beliefs are unhelpful and might stop you from getting professional help when you need it.

Certain groups may suggest different things to help you such as exorcisms and herbal remedies. They are sometimes more harmful than helpful.

Recently, researchers have developed a new treatment called religiously integrated cognitive behavioural therapy (RCBT), which is similar to CBT (see page 70), but also includes a person's religion to help identify and replace unhelpful thoughts and behaviours.

6 • Even at the church I was going to, I was still torn because they were convinced that healing came from Jesus and that medication, you shouldn't need it, and, you know, I disagree − I disagree completely • •

Lucia, 35

Several small studies have found that RCBT can help with anxiety and depression, but these are small studies with poor quality, meaning there is still not enough evidence for us to make a conclusion about whether it works or not.

With regards to psychosis, the majority of the research found that adding a religion aspect to CBT did not improve people's outcomes, or only improved them in the short term. More research is needed before we can make strong conclusions about the effectiveness of this treatment.

The National Institute for Health and Care Excellence (NICE)

NICE do not mention the influence of religion or spirituality in their guidelines. RCBT has not been reviewed or recommended by NICE. This is likely because there are still very few studies that look at the effectiveness of this treatment for psychosis. More research needs to be done before NICE will review this treatment.

How can I find out more?

Speak to your religious or spiritual leader about what support they can offer you if you are struggling. Also, you can ask your care coordinator how they might include aspects of your spiritual beliefs or people from your religious/spiritual circle in supporting you.

Main pro

Lots of people find having a religious or spiritual belief helpful during difficult times as you have a god, spiritual leader or community to turn to for help or direction if you wish.

Main con

Sometimes people say that there are conflicts in the information they receive from health care professionals and religious/spiritual leaders – speak to your care coordinator if you are confused about any information you have been given and they can help you to get the best support from everyone.

Self-management



The main focus of this approach is psychological.



Remember, one thumbs up means that enough people have done research to show that this approach does work.

What is it?

Self-management means your ability to manage the symptoms, treatments, physical, psychological, social and life style effects of living with unusual distressing experiences such as psychosis.

The main way of training in selfmanagement skills is through teaching, learning, and actively doing things.

What does it aim to do?

Central to this approach is the development of your own personal ways of doing things. Self-management activities are rooted in your own personal experiences of what works for you, and you take your own approach to each topic.



The main topics that selfmanagement works on include:

- Having information about mental health difficulties, treatments and services.
- Developing ways to notice early warning signs that things are going less well so that you can reduce the chances of your problems coming back or getting worse (relapse prevention).
- Managing your experiences of medication, so that you can tell your psychiatrist, pharmacist or care coordinator about side-effects and can agree a medication plan that is best for you.
- Having ways to manage your unusual distressing experiences, anxiety or low mood.
- Setting individual recovery goals and developing ways to achieve them.
- Developing life skills important for wellbeing, self-care, productivity and leisure. For example, a healthy diet, exercise, smoking cessation, finance management, positive relationships, organisation, home making and communication.

Does it work?

A number of studies (25 randomised controlled trials) have been run across the world for adults with unusual distressing experiences like psychosis, to find out what the benefits or potential harms are of self-management approaches compared with other treatments.

These studies found that selfmanagement can help to reduce unusual distressing experiences such as psychosis. It was less clear whether it reduced the chances of hospitalisation.

Self-management helped to improve quality of life immediately after using the approach, but the long-term benefit was less clear. Self-management was also found to aid recovery, and this effect continued in the longer term.

There was no definite evidence that self-management helps day-to-day function.

The National Institute for Health and Care Excellence (NICE)

NICE said that overall, selfmanagement and peer support are likely to be helpful for people with psychosis, but they should not be provided as treatments on their own because they were not designed as sole treatments.

Self-management should be provided as additional support for people at all stages to instill hope; improve self-management of distressing experiences; provide information about the nature of experiences and treatments; develop self-monitoring skills; improve coping; and develop skills to manage life changes.

How do I get this treatment?

Training in self-management may come from mental health professionals, peer support workers, through a local recovery college, or it may be provided partly or completely through a computer package.

It is important that whoever you are working with believes that you can contribute to your own health management, and that you can work together to strengthen your own personal skills.

It may be harder to actively form your own self-management approaches and keep these going when you're working with a mental health professional who might be seen as the 'expert'.

So, a recent UK trend is the setting up of peer support groups and recovery colleges, where other people with experiences like your own, carers and mental health professionals work together to support you to learn about mental health and recovery.

Recovery colleges provide a chance to learn more about your experiences, as well as learning life skills and abilities. The way recovery colleges are set up and run encourages you to take responsibility and gives you confidence to go on to further education and employment.

Main pro

Overall, the evidence suggests that self-management can help to reduce unusual upsetting experiences like psychosis and can improve your quality of life at the end of training, and can aid recovery over the longer term.

Main con

Self-management approaches rely on you taking responsibility for managing your mental health and some people find this difficult. It is unclear whether these approaches help with day to day function or stop you from going to hospital, and they are best done in combination with other treatments.

in mental health. It puts a person's recovery back in the service user's control. Recovery College can offer a new strand to what is available on mental health to assist people with hope, choice and learning opportunities to develop self-help and self-management skills and explore vocational and personal development.

Hastings Peer Trainer

4. Support and therapies for work, education and things that you do



Individual placement (vocational) support (support to get and keep a job)



The main focus of this approach is on social and occupational factors.



Remember, more thumbs ups just means that more people have done research that shows that this approach works.

What is it?

Individual placement support (IPS) is a type of vocational support which aims to help you to get and keep a paid job.

There are eight principles of IPS:

1. An employment specialist (ES) works as part of the clinical team, so that there can be a team approach to supporting you to achieve your work related goals.

- 2. Normal paid work is the main goal you are not asked to take part in lengthy pre-work training or 'sheltered' work that is separate from normal work.
- 3. Job searching begins quickly, usually within 1 month, after you start with the Employment Specialist. Supporting you to develop work skills on the job is more effective than other types of pre-work training or sheltered work.

- 4. You decide when you are ready to start the job search process. As long as you are interested in getting a job, Individual Placement Support may be helpful your own motivation to work is an important part of successfully getting a job.
- 5. The aim is to match the job to your choices and preferences about types of work, place, hours, etc.
 Unsurprisingly people tend to stay employed longer at jobs that meet their preferences.
- 6. In-work, support is provided for you and your employer over a number of months, and help is provided if you want to change jobs.
- 7. Benefits advice is given during the change into a job. This is so that you can understand how part- or full-time work will affect the money that you have each week. You can then make choices about the right work for you.
- 8. Working with the person or company that gives you the job is a key part of the employment specialist's role.

What does it aim to do?

There is strong evidence that work is good for health:

- it promotes recovery
- leads to better health outcomes
- reduces poverty and social exclusion
- improves quality of life and wellbeing.

There is a lot of evidence that people with unusual distressing experiences can do normal paid work or education, with the right support.

Does it work?

There have been at least 16 good quality research trials nationally and internationally which show clearly that IPS supports more people into work than any other approach.

One of the main things that makes IPS successful is that the employment service is part of the early intervention or mental health service. Eight randomised trials compared IPS services in mental health teams with IPS services on their own. These studies showed that people getting help from IPS services that were part of the mental health team were more likely to get a job, for more hours and with higher wages than people who were getting help from a separate IPS service.

National Institute of Health and Care Excellence (NICE)

Individual placement support (IPS) is described in NICE guidance as the best way to support people with unusual distressing experiences who want to work, to be able to get a job.

How can I get this treatment?

Employment support should be available either within the early intervention or mental health service, or from another agency working closely with the mental health team.

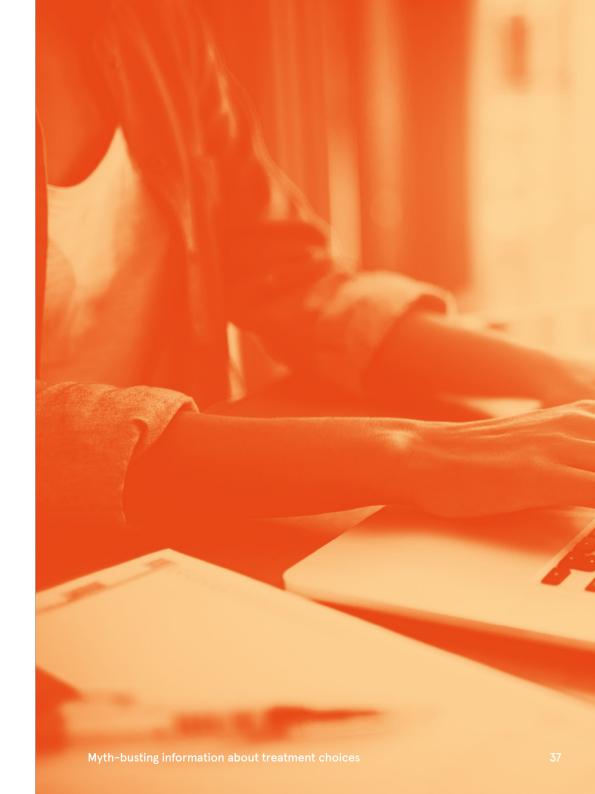


Lots of research shows that this approach really works and that people do get and keep a job, which can have an enormous positive effect on their life. The whole approach is positive and encouraging; as long as you want to work the support is available.

Main con

Not all mental health services have employment support, so sometimes availability can be patchy.

Employment support is sometimes offered alongside voluntary work and support for other leisure activities. This can mean that there is not enough focus on work related issues, so the chances of getting and keeping paid work are not as good as they could be.



Support for meaningful activities (occupations)



The main focus of this approach is on social and occupational factors.



Remember, a sideways thumb just means not enough people have done research yet to show whether this works. This might be really helpful (and some people say it is), we just haven't tested this.

What is it?

Support for what you do. Meaningful activities that are important to you, allow you to carry out practical, purposeful tasks (sometimes referred to as 'occupations'). This could be the day-to-day tasks we all have to do: dressing, cooking and going shopping; as well as the things that make you who you are: your job, interests, hobbies and relationships. Occupational support focuses on the things that are important to you and have meaning in your life.





What does it aim to do?

A balance of activities is important, we all need to look after our basic needs, engage with others, find some kind of purpose in our days and take part in activities which fulfil us, as well as have fun and relax.

When you have been feeling highly distressed or unwell it is easy to stop doing things, including normal healthy habits and become isolated. Restarting a healthy balance of activities that are important to you leads to an increased belief that you can do things, as well as giving you more confidence and better selfesteem.

Does it work?

Rethink Mental Illness published a report in 2015 which outlined key interventions for people with unusual distressing experiences such as psychosis which they felt should be provided, and had good evidence. These included early intervention (including support with daily occupations).

The National Institute for Health and Care Excellence (NICE)

NICE guidance recommends that occupational support is offered to support people with unusual distressing experiences, to keep or get back to a balanced daily routine, with work, leisure and education.

How can I get this treatment?

Occupational support is offered as part of a general mental health or early intervention service. Elements may also be offered by other agencies such as community and voluntary services and charities. You can ask for occupational support if you would like to work on this area of your life in more depth.

Main pro

Occupational support is focused on the area which is most important to you, it can support you to make a real difference to everyday life very quickly.

🔀 Main con

The formal evidence base is limited.

4. Support and therapies for work, education and things that you do

Using green spaces like parks, gardens and woodlands



The main focus of this approach is physical and psychological.





for general wellbeing

A sideways thumb means that not enough people have done research yet to show whether this works for unusual distressing experiences, but there is a good amount of evidence that it is helpful for your mood and wellbeing in general.

What is it?

Green spaces are natural spaces like parks, gardens, woodlands, heaths and wetlands.

What does it aim to do?

Green spaces are part of the natural countryside that are available for public use. Using green spaces like parks and countryside may improve your mental well-being.

How does it work?

In general, green space may be linked to better air quality, and using green spaces may encourage physical activity, as well as reducing stress. Being outside also boosts your vitamin D levels!

Does it work?

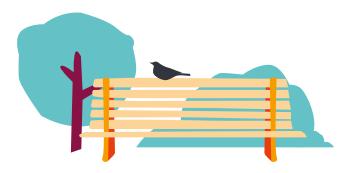
Four reviews of published studies have found evidence that access to green space is associated with a range of better health and mental health outcomes.

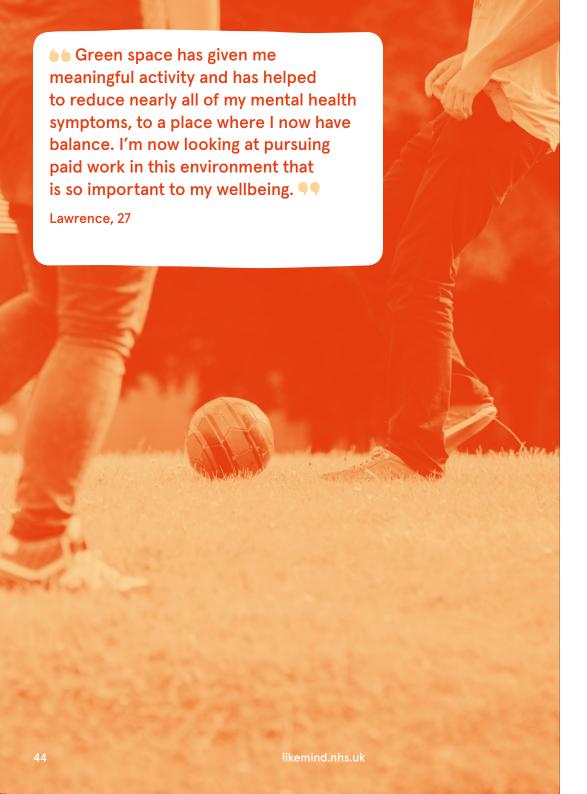
For example, studies have suggested that the more access you have to green spaces like countryside, parks and gardens the less likely you are to feel anxious or depressed, and the better your self-esteem and mood.

In addition, some studies suggest that if you use green spaces you are less likely to have cardiovascular problems, type 2 diabetes and are more likely to live longer. And studies that looked at people's mental health over several years, found that moving to an area with easier access to green space can help to improve your mental health.

There isn't much evidence that green spaces can help with unusual distressing experiences specifically. A new study that was published in 2018 found that Danish children who lived in areas with less green space were more likely to develop psychosis as adults, but, this is the only study so far.

As using green spaces are free, it seems worth a trip outdoors to try to improve your general wellbeing!





The National Institute for Health and Care Excellence (NICE)

There is currently no specific guidance from NICE about using green spaces to improve unusual distressing experiences (e.g. psychosis). This is probably because there is not enough evidence specifically for these experiences. However, there is a lot of evidence for general wellbeing, and stress reduction.

In fact, research suggests green spaces are so beneficial for general wellbeing that Public Health England (a government department) put together a document to show the government that they need to spend more money on creating more green spaces across the most built up locations in the UK.

How can I get this treatment?

The good news is that most green spaces are free to visit. Use this link to help you to find your local green spaces:
getoutside.ordnancesurvey.co.uk/greenspaces/



Using green spaces is free, there are no waiting times, they are easy to access, and there's good evidence that accessing green spaces can help with general wellbeing and stress reduction.

Main con

It is not clear whether green spaces can reduce unusual distressing experiences (e.g. psychosis). More research needs to be done.



4. Support and therapies for work, education and things that you do

Cognitive remediation



The main focus of this treatment is on psychological and social factors.



Remember one thumbs up sign means that enough people have done research to show that this approach does work.

What is it?

Cognitive remediation therapy is not routinely available in the NHS. Cognitive remediation therapy (CRT) is a psychological therapy which uses talking and activities (e.g. puzzles) to try to improve your concentration, memory, planning and thinking skills so that you can do better in education, work and daily life.

In CRT, you would normally have an assessment first, to find out about the things that you're good at and the things that you're less good at. You would then have one-to-one meetings with a therapist, who would help you to use your strengths, and to practice things that you're not so good at, by doing puzzles, games and other activities and talking about how you're doing them.

It's often offered quite intensively, two-three times a week for three months or more. Sometimes CRT is offered on its own, but often it's offered alongside vocational support like individual placement and support (IPS), which gives practical, social and emotional support to help you get and then stay in education or work. This could be weekly support, or less often, depending on your needs.



What does it aim to do?

CRT aims to help you to build on your strengths, to help you to improve your concentration, memory, planning and thinking skills, so that you are able to get on better in day-to-day life, school, college, university, work or living independently.

CRT involves lots of practice, talking and learning about how to improve your skills, so that you can meet the goals that are important to you. It helps you to better understand your strongest thinking skills and where you may have difficulty, so you can find the best strategies that work for you, to make improvements.

66 I suppose I walked away [from CRT sessions] feeling quite challenged and refreshed. It was intellectually stimulating and I felt in sort of... let me see... a contemplative mood, I think. **9 9**

Jayden, 26

•• It can be really frustrating if you are not able to concentrate for long enough to read a book or watch TV, or you struggle to remember things that are important to you. It can also make it hard to do well at college or in a job. CRT can help you to improve these sorts of thinking skills.

You and your therapist will try to work out what sorts of improvements in thinking skills help you to achieve the goals that are important to you. Then you will use games and puzzles, (sometimes on a computer), to practice things and to find the right approaches for you to help you to improve.

Dr Clare Reeder, Clinical Psychologist and CRT Therapist Vocational support helps you to put your skills into practice in real life, and provides advice and other support to deal with any problems as you get back into work, school or college.

Does it work?

There have been a lot of trials conducted in America and some in Europe too, that have shown that CRT alongside standard care is better than standard care on its own.

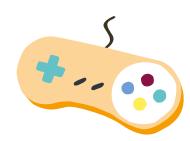
It has been shown to improve your skills in attention, memory, thinking and planning that are taught and practiced in the sessions. Some studies have also shown that it can lead to better social function, self-esteem and work outcomes.

There is evidence to suggest that CRT works best when combined with a vocational support element, and that vocational support works best when it involves actually doing a job and getting support at the same time, rather than doing a pre-work training programme.

Vocational support, on top of normal early intervention support, seems to lead to better work outcomes. So, having CRT and vocational support in school, college or work is likely to give you the best chance of success.

The National Institute for Health and Care Excellence (NICE)

NICE found that in adults, CRT seems to help you to be better at reasoning and problem solving. There isn't a lot of evidence that CRT alone helps with unusual upsetting experiences, hospital admissions, education or employment, but some studies do suggest that CRT with vocational support, is better than just having vocational support for your work and social life.



In young people, there's some evidence that CRT is better than an educational programme for reducing upsetting experiences and improving day-to-day function and work outcomes, but the quality of the research is low. There is a large study that is testing CRT in people who use early intervention services, but we don't know the results of this yet.

How can I get this treatment?

There are very few people in the UK who are qualified to provide cognitive remediation therapy for unusual distressing experiences at the moment. You can ask your care coordinator for advice about whether anything is available locally.

There are UK-based researchers in CRT, so there may be a research project offering CRT that you may be able to get involved in.

There is more opportunity to receive individual placement and vocational support with an employment specialist often as part of an early intervention service, and you can ask your care coordinator about this too.



CRT and vocational support are the only therapies specifically designed to help you to get a job, get back to college and do well in education and work.

Main con

Although CRT helps with memory planning and thinking tasks, it's not entirely clear how well CRT helps you with real life things like doing well in a job or at college, and it doesn't reduce distressing unusual experiences. Also it's not readily available at the moment, and because it's quite intensive it's quite a commitment.



5. Physical health support and therapies



Physical health checks

What are they for?

If you have don't eat very well, don't do much exercise, or are a bit overweight you are more likely to have problems with your health in the future, like heart problems, strokes and diabetes. Unfortunately, all of these physical health problems are a lot more common if you also have unusual distressing experiences. This can affect how long you live.

NICE recommends that if you have unusual distressing experiences, especially if you're taking medication you should have regular check ups on your physical health and any medication side-effects too. You could have these check ups with your early intervention or mental health team, or your GP. Typical physical health checks include; response to medications, including symptoms and side-effects; weight, waist circumference, pulse, blood pressure, blood tests to check hormones, glucose and lipid (fat) levels, general physical health and day-to-day function.

Your team should be able to provide advice about healthy eating and exercise. You can also discuss any non-prescribed therapies you may wish to use (including any complementary medications) and the safety and effects of these therapies in combination with other medication you might be taking.

A note on alcohol and drug use

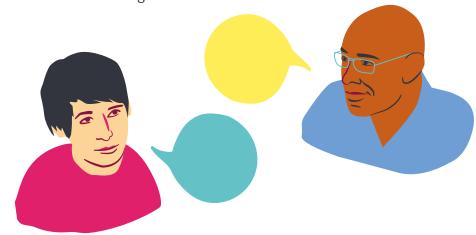
Sometimes people use alcohol or drugs as a way to cope with difficult experiences, but it can be difficult to tell the difference between the effects of alcohol and drugs, hangovers and come downs, and mental health problems.

After all, alcohol and drugs can make you feel great but they can also make you feel depressed, anxious, suspicious, paranoid and panicky.

Your care coordinator or lead practitioner can talk to you in a helpful and non-judgmental way about the use of tobacco, alcohol, prescription and non-prescription medication and drugs.

They can discuss how substances might impact on the effects of prescribed medication and psychological therapies you might be receiving, as well as considering the long term impact on your health and mental health. Did you know, for example, that smoking tobacco can affect how medications work?

If you want, your care coordinator can refer you to someone who may be able to offer additional support with substance use reduction, harm reduction or stopping all together.



5. Physical health support and therapies

Diet



The main focus of this treatment is on biological and physical factors.



Remember, a sideways thumb just means not enough people have done research yet to show whether this works. More thumbs ups means that more people have done research that shows that this approach does work.

What is it?

There has been some interest in the role of diet and food supplements to help when people are having distressing and unusual experiences. Two food supplements that have been considered are fish oils (unsaturated fatty acids) and vitamin D.

What does it aim to do?

There is a little bit of evidence to suggest that unusual distressing experiences may be linked to changes in the way our nerve cells are built and how they work. The way these cells are built and work is linked to the 'building blocks' (essential fatty acids) that they're made from, and possibly to one particular 'building block' – the essential fatty acid in fish oils.

It is thought that by having a much higher level of these fish oils in the body, nerve cells might work and function better, leading to fewer unusual distressing experiences. It is unclear at the moment how vitamin D might have an impact on unusual and distressing experiences.

Does it work?

There are a few small studies suggesting that fish oils (if you take the right amount) may possibly help to reduce unusual, distressing experiences and make it easier to do things like work and socialise, when taken alongside usual medicines.

It has been suggested that taking fish oil, alongside usual medicines may improve the effect of the medicine, so that lower doses are needed.

One study with fish oils has shown significant drops in mild, unusual distressing experiences, in people at risk of developing psychosis, but a more recent study in Australia has shown that taking 1.4g of fish oils daily alongside good quality psychological and social support, is not better at stopping unusual distressing experiences from getting worse than good support alone. The suggested dose of fish oil can range from 700mg to 4g a day which is a very large dose!

People with unusual distressing experiences appear to have lower levels of vitamin D than the general population, but there is no evidence to date that taking a vitamin D supplement is helpful.

6 Eating healthily keeps you happy and fit. I have also found, since changing my diet, that I have more motivation, which has improved my overall lifestyle. I would encourage people to eat healthier. ■●

Max, 27



But wait – remember, a good diet helps you with your weight, health and wellbeing

There's not a lot of evidence currently for the impact of diet on unusual and distressing experiences, BUT there's absolutely loads of evidence that eating a balanced and healthy diet is really good for your weight, health and wellbeing in general.

Also, if you're taking medicines that have weight-gain as a side-effect (especially Olanzapine but some of the others too), you might put on weight very quickly, within a few weeks.

Eating healthily, right from the start, may prevent you putting on weight while you're taking these medicines. A good diet is one that includes lots of vegetables and fruit, protein (e.g. fish, meat, beans and nuts), fibre and carbohydrates (e.g. rice, pasta, brown bread, potatoes) and not too much fat, sugar or take-aways!

The National Institute for Health and Care Excellence (NICE)

NICE has not yet examined fish oil or vitamin D for unusual and distressing experiences, but it does recommend that you have a good diet if you're taking some of the medicines we've talked about, so that you're less likely to put on weight.

NICE reviewed 24 randomised trials of either exercise and healthy eating or just exercise in people who experience unusual distressing experiences.

They found that interventions that included exercise and healthy eating together reduced weight gain and improved wellbeing in people with unusual, distressing experiences. Healthy eating alone wasn't looked at, and exercise alone wasn't better than usual care at reducing weight.

So, just like it's better to have medicine and talking therapy together for unusual distressing experiences, it's better to have exercise and healthy eating together for weight and physical health.

How can I get this treatment?

Vitamins are available over the counter in your local pharmacy, but you should seek medical advice from your doctor, pharmacist or care coordinator to make sure you take the right dose, as taking too much of some vitamins is dangerous.

The doses for fish oils can be high so it may be worth checking whether this is likely to be helpful, and whether you can get fish oils on prescription.



A healthy diet is a cheap and easy way to help you feel better. You can get advice about healthy eating from your local GP surgery.

If fish oils do help, then they have fewer side-effects than standard medicines and are easier to use than lengthy Talking Therapies.



There really isn't enough evidence that fish oils or other vitamins work at the moment for unusual distressing experiences, and if you can't get a doctor to prescribe them, then they're expensive. To get the right dose, you have to take either big tablets, or lots of smaller tablets.





5. Physical health support and therapies

Exercise



The main focus of exercise is on physical factors, although it may help with your social life if you take up a sport or group exercise!



Remember, a sideways thumb just means not enough people have done research yet to show whether this works. More thumbs ups means more people have done research that shows that this approach does work.

What is it?

Exercise might be any type of physical activity or movement, like walking, running, yoga or football. Exercise groups and treatments offered through the NHS for unusual, distressing experiences are usually offered alongside medicines and other standard care.

What does it aim to do?

Exercise may stop you from putting on weight when you're taking some of the medicines in this booklet. It's also been suggested that exercise may help if you feel sad or anxious too, so a possibility might be that exercise reduces how upsetting your unusual experiences are or how much they affect your daily life.

Exercise also aims to improve physical health by helping you to have a healthy weight and a healthy heart. It aims to help your general health and wellbeing. If you are physically fit and healthy, you may find you've got more energy for the things you want to do in the day and you may find it easier to keep a healthy body weight. Also, when you exercise your body produces special chemicals called endorphins that are known to help reduce stress, ward off anxiety and depression, and aid good sleep.

Does it work?

The effects of exercise (e.g. yoga) on unusual distressing experiences have only recently been looked at, so there are only a few studies that have looked at how helpful exercise is for unusual, distressing experiences alongside medicine and other usual care.

Only the studies with a good design – remember these are randomised controlled trials – were considered. These have shown that exercise helps when people feel down, flat, or de-motivated and one study showed that yoga (alongside usual care such as medicines) was helpful for reducing unusual, distressing experiences and that it also improves your general quality of life.

Results do show that regular exercise can help you to be more healthy generally, with a healthier weight and better mental wellbeing.

A recent big review (meta-analysis) of exercise interventions has shown that exercise alone, can make you more physically fit, which protects against heart disease. It also showed that moderate-vigorous exercise (90 minutes a week or more) can reduce unusual upsetting experiences and give you more energy and motivation. It may also improve your day to day function, quality of life, depression, anxiety and memory.

The National Institute for Health and Care Excellence (NICE)

NICE reviewed 24 randomised trials of either: exercise and healthy eating, or just exercise, in people with unusual, distressing experiences. They found that interventions that included exercise and healthy eating together reduced weight gain and improved wellbeing in people who experienced unusual distressing experiences.

Exercise alone wasn't better than usual care at reducing weight and there weren't any studies that looked at healthy eating alone. So, just like it's better to have medicine and talking therapy together for unusual distressing experiences, it's better to have exercise and healthy eating together for weight and physical health.

See if you can build up to exercising for one and a half to three hours a week for the best results, but remember exercise means lots of different things: walking to a friend's, to work, or to the shops all count. And it helps to watch what you're eating a bit too!

How can I get this treatment?

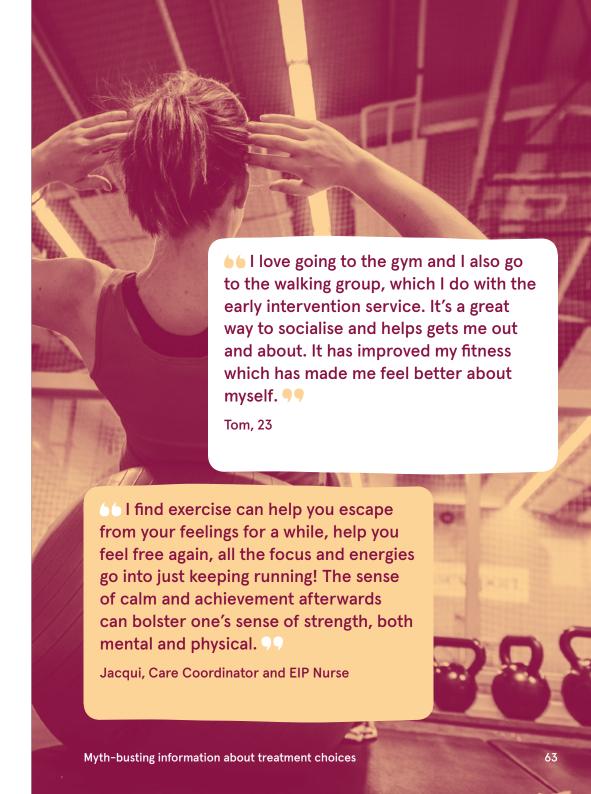
There are lots of exercise things that you can do for free, like walking, cycling, running, playing football etc. You can also ask your care coordinator, GP or mental health worker about any free passes for local classes, gyms or leisure centres that you might be able to get, as well as any classes that they might be running.

Main pro

Exercise is easy and free to do. It helps you to keep fit, improve your physical health and wellbeing.

Main con

There is not enough evidence yet to show whether exercise interventions also help with unusual and distressing experiences.



Introduction to psychological therapies

The psychological treatment you are offered will depend in part on the difficulties that you want help with, like voice hearing, upsetting thoughts (paranoia), low mood or anxiety.

The aim in a psychological approach is to work together with you to help with particular difficulties as well as improving how you feel, your wellbeing and your recovery.

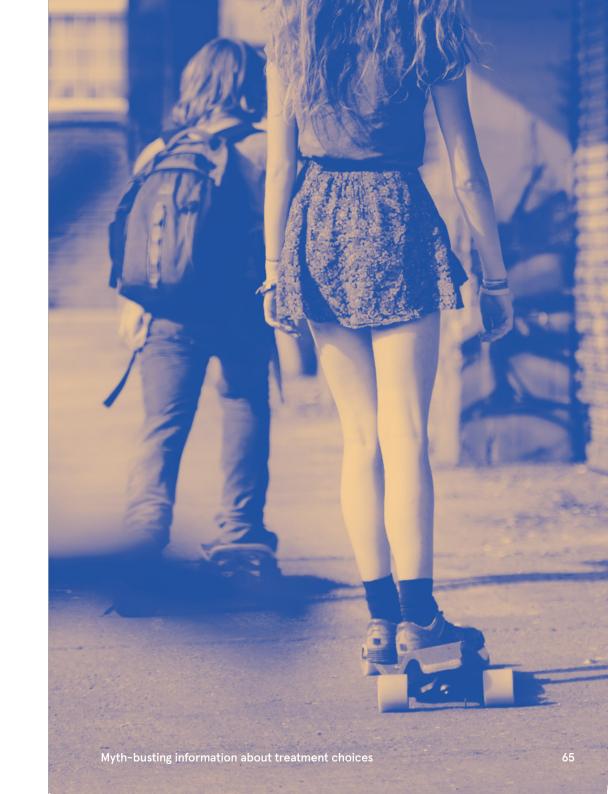
Before you start any psychological work and often when you are first referred to an early intervention or mental health service, your team will work with you to agree your needs and make a plan for supporting you. Part of this plan will involve agreeing a shared understanding of your strengths and difficulties.

How do you get to a shared understanding of psychological difficulties?

A shared understanding of your strengths and difficulties is sometimes called a formulation. It is a way of making sense of your experiences, by looking at how they have come about in your life and the meaning they have for you.

It is a bit like a personal story that a psychologist or other mental health professional draws up with you. It tries to understand what may be keeping your difficulties going, and helps you to break out of unhelpful ways of doing things and find the best path towards recovery.

It draws attention to your talents and strengths in surviving what might be very challenging life situations.



Art therapies



The main focus of this treatment is on psychological factors, as well as social factors when it's offered in a group.



Remember one thumbs up means that enough people have done research to show that this approach does work.

What is it?

Art therapy uses a mix of art, making and talking; so it's different from other talking therapies because you do art and have the option of talking with the therapist at the same time.

Art therapy is often offered in a group setting. The British Association of Art Therapists says that art therapy is "the use of art materials for self-expression and reflection in the presence of a trained art therapist".

What does it aim to do?

You don't have to be good at art to use art therapy! The art therapist will tell you about paint, oil pastels, pencils, different types of paper, materials, clay, glue etc. and help you get started, as art therapy uses lots of different art materials.



You can choose whatever you want to do, for example drawing, painting and making things. Art and drawing might help you to talk and think about things that are happening for you and to understand difficult thoughts, feelings and experiences.

Creating pictures or objects within the therapy may help you to talk with the therapist and others, tell them who you are and how you feel. Art therapy can be helpful if you tend to be withdrawn, don't feel like doing things or find it hard to talk about things. It can help you to feel more confident, interested and better able to do stuff socially with other people

Does it work?

Several studies have looked at whether art therapy helps with unusual and distressing experiences for people who are already taking medicine and having other mental health support.

Some studies found that art therapy improved the way people thought about themselves and how they related to other people and one study found that people had more motivation and felt less down and flat after art therapy – but one study found that art therapy didn't improve psychological health and none of the studies found effects on unusual distressing experiences themselves.

when I felt very vulnerable. It felt hard at first, learning to be creative again, but then it became a useful outlet to channel what I find difficult to express. It's not so difficult once I have done some artwork because it makes it easier to relax and talk about things.

Sharpey, 24

The National Institute for Health and Care Excellence (NICE)

NICE found six good quality studies and recommended that art therapies (including art, music, drama and dance movement therapies) be considered for those experiencing unusual, distressing symptoms to help with things like motivation, withdrawal, lack of interest and lack of activity.

They also highlighted the need for more high quality research as the current evidence is limited – especially in young people – where there's only been one small study.

One large study that happened more recently, has shown that for people with longer term problems, group art therapy didn't improve mental health, health or day-to-day life more than another activity group.

How can I get this treatment?

Art therapy is something that may be offered by a local mental health service, but it's not readily available. Ask your doctor, care coordinator or GP if you're interested and they will be able to tell you about local options.

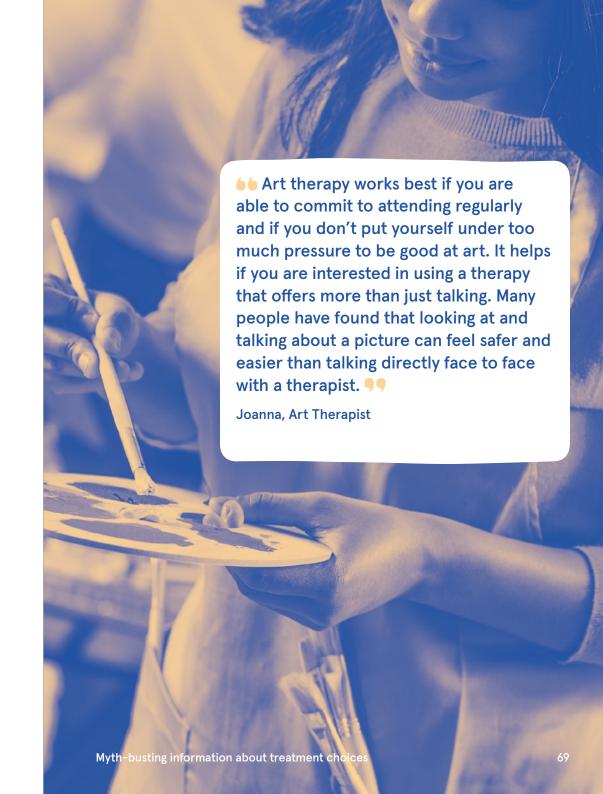
You may also be able to pay privately for art therapy. Try looking on the British Association of Art Therapists' website baat.org where there's a section on finding a private art therapist.

Main pro

Art Therapy offers a different way to show your feelings and talk about thoughts than other therapies.

🔀 Main con

There's not a lot of good quality evidence, so it's hard to know whether it's helpful or not. It may feel hard to start with, to do art with a group of people you don't know.



6. Psychological therapies



Cognitive behavioural therapy



The main focus of this treatment is on psychological factors.



Remember, more thumbs ups just means that more people have done research that shows that this approach does work.

What is it?

Cognitive behavioural therapy (CBT) is one of the 'talking therapies'. Cognitive relates to what you think, and behaviour relates to what you do.

By meeting on your own with a CBT therapist to talk about things that are bothering you, you will learn about the links between your thoughts and your behaviours, how you came to think and do things the way you do, and how that affects how you feel.

The amount of therapy meetings you have will depend on what is helpful to you, but a guide would be around 16 weekly or fortnightly meetings of about an hour. Some newer CBT approaches are shorter and focus on specific issues like sleep, worry, self-confidence, thinking, drug and alcohol use, or trauma (see below).

CBT doesn't involve lying down on a couch, it isn't about telling you your thoughts are wrong, and it won't make you do anything you don't want to do; it will always respect your view on things and works with you to achieve your goals.

Often you will meet at an NHS base but sometimes you can also meet somewhere that suits you, like your house, a café or even in a park if it's nearby.

What does it aim to do?

CBT deals with thoughts, feelings and behaviour. CBT tries to support you to feel less upset, afraid or bothered by your thoughts and experiences and more able to get on and do the things you want to in life.

It does this by helping you to understand how you came to have these thoughts, experiences or things that bother you and possibly to change how you think about and deal with things.

Sometimes, you can think about things in ways that end up making you more upset, worried or frightened, so that you end up doing things (or avoid doing things) that make the situation worse. CBT helps you to see that there are different ways of thinking about the same situation and that having a new perspective may be helpful.

66 CBT can help people recover, overcome their problems and become less distressed, by looking at the way they think and feel and how their actions and thoughts affect each other. However, CBT does not help everybody. Generally, only people who want therapy and engage fully are likely to benefit.

Professor Philippa Garety, Professor in Clinical Psychology Thinking and doing things differently can help you break out of vicious cycles that may be maintaining your problems and make you feel better. CBT tries to give you more helpful ways of thinking about things and reacting to them so that you're less bothered, upset, worried or frightened. The idea is that then you practice thinking or doing things differently in your day-to-day life.

CBT involves working together with your therapist. You decide what main problems you want to work on and discuss them in meetings.

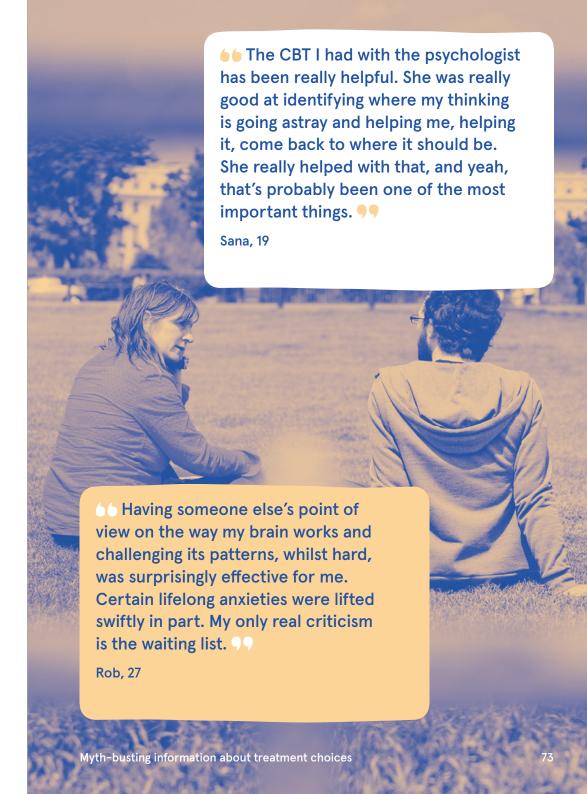
Does it work?

There has been a lot of good quality research about how helpful CBT is for unusual, distressing experiences. All of the research, apart from one study, looks at whether CBT is helpful for people who are already taking medicines.

There is clear evidence from lots of different groups of studies (meta-analyses) that CBT helps with unusual distressing experiences. The effect of CBT overall is small-medium. This might be because in most studies people are already taking medicines, and also because lots of different types of CBT for lots of different problems are all being compared together.

It also seems to make a difference how experienced and well-trained your therapist is and whether you are joining in with the therapy.
CBT works best of all when a well-trained, experienced therapist works with someone who's really engaged in trying to use the therapy to make a difference.

The research suggests that CBT does work, in that it can reduce unusual upsetting experiences, and help with mood, recovery and having a social life.



When CBT was compared to other talking therapies, it came out as the best one to help with dealing with emotions (like sadness, anxiety or fear), and helped about as much as other talking therapies for unusual upsetting experiences, motivation, social life, or stopping experiences from coming back.

All the talking therapies, when people had these and medicine together, were better than medicine alone. This means that it is better to combine medicine with CBT or another talking therapy. The evidence is better for longer therapies (i.e. 16–20 meetings).

Only one small study has looked at whether CBT helps with unusual distressing thoughts when people are not taking medicine, and it showed that CBT does help even when people have chosen not to take any medicine.

There's very little research on CBT in young people (under 18) and what's there suggests it's not necessarily better than really good early intervention services (see earlier for more on these services), but then good EIP services all offer psychological therapies (including CBT), vocational services and medicine as part of the service.

So the key message is that the best treatments involve CBT and medicine together.

6.6 The CBT enabled me to get in control of what was in my head. Everything is less chaotic and my mind is now freed up to do other things. Now I have the illness – the illness doesn't have me. ■■

Tanya, 36

The National Institute for Health and Care Excellence (NICE)

NICE recommends CBT along with antipsychotic medication for adults and young people with unusual distressing experiences for symptom reduction and relapse prevention.

NICE also recommends that CBT should be delivered on a one-to-one basis over at least 16 meetings. NICE recommends that young people receive family intervention with individual CBT, especially if the young person doesn't want medication.

NICE recommends that CBT with young people should focus on helping people to understand how common their experiences are and helping them to accept them.

How can I get this treatment?

CBT should be available through your EIP service or through local psychological therapies services within the NHS. However, it isn't always readily available. Ask your doctor, care coordinator or GP if you're interested and they will be able to tell you about local options.

You may also be able to pay privately for CBT. Try looking on the register for the British Association of Behavioural and Cognitive Psychotherapists at cbtregisteruk.com where there's a section on finding a private CBT therapist in your local area.

⊘ Main pro

Learning how to relate differently to distressing experiences has been shown to be helpful for dealing with emotions and reducing distressing experiences.

Main con

There can be a long waiting list (6 months or more) to start CBT, because it is a lengthy therapy. It can be difficult to talk about personal things. It requires quite a bit of commitment to go to meetings and practice things outside of meeting. It can take a long time (six months or more) and it doesn't work for everyone.

Brief CBT-based interventions



The main focus of this treatment is on psychological factors.



Remember, more thumbs ups just means that more people have done research that shows that this approach does work.

What is it?

Newer short forms of CBT have also been developed that focus on more specific problems associated with unusual distressing experiences, such as worry and anxiety, low mood, sleep, reasoning, self-confidence, paranoia and voice-hearing.

They are all CBT-based talking therapies, where you meet individually with a therapist but they are much shorter than traditional CBT for unusual distressing experiences, generally involving about 4–8 meetings focused on one problem.

What does it aim to do?

These interventions all aim to improve how you feel and what you do day-to-day, by focusing on your thinking and behaviour, just like the CBT interventions described above.

They are different to general CBT for unusual distressing experiences, because they focus on one specific problem, (e.g. worry, anxiety, mood, sleep, reasoning, self-confidence and thinking patterns) that can make unusual, distressing experiences worse.

By improving this one specific problem, they reduce the distress and impact of your experiences on your life. For example, you may worry a lot about things that might happen in the future or struggle to go out, or to do new things because of anxiety. CBT might help you to understand why you worry or feel anxious, and help you to break out of worry cycles, and gradually work through the things that make you anxious by practicing facing these things, bit-by-bit.

You may feel down and lacking in energy and enthusiasm, sleep too much or too little. CBT can help you to gradually build up the things that you used to do and even add new things, so that you gradually regain your energy and your sense of pleasure, enjoyment and success.

A detailed focus on sleep in CBT can help you to understand why your sleep is poor and can suggest good sleeping habits to help you to sleep better. Paranoia and other experiences can get worse when your thinking spirals out of control, so that you see danger everywhere. CBT can help you to understand and get control over your thinking.

All of these things, if they're a problem for you, can make experiences worse, so dealing with them can make life better. After all, we all know how much harder everything is, if you've not had enough sleep, or feel sad or anxious all the time.





What's the evidence base?

There are now several trials and a growing evidence that these short interventions work when delivered by well-trained and expert therapists.

Most of them have at least one good randomised controlled trial so far, but early results from these new studies do suggest that focusing on individual difficulties with CBT can work really well on their own.

They have not yet been reviewed by NICE.

How can I get this treatment?

These Brief Interventions are starting to become available in the NHS, as more therapists are getting the training. A standard CBT therapist should be able to offer sessions to help with these issues.

Ask your doctor or care coordinator for more information about seeing a CBT therapist, or refer to the website cbtregisteruk.com to find a private therapist.

Main pro

These are short interventions with a limited time commitment. Sometimes they include interactive computer exercises and early evidence is promising.

Main con

The interventions are quite set and they focus help on a specific problem area only.

66 We know that sleeping badly, worrying a lot, and feeling low in confidence can be exhausting. Getting anxious, stopping activities, and becoming isolated can all too easily follow. We've found that it can be really valuable to spend time sorting out − one by one − these problems. After one goal is achieved, we move on to the next. **99**

Professor Daniel Freeman

6. Psychological therapies



Family interventions



The main focus of this treatment is on psychological and social factors.



Remember, more thumbs ups just means that more people have done research that shows that this approach does work.

What is it?

Being offered family intervention doesn't mean that you are a 'problem' family, nor that your family is to blame in any way! A family intervention is a talking therapy that focuses on difficulties that the family is facing, and that plans ways of solving them as a family.

It usually includes you, your family (or others who are close to you), and two therapists. It is normally offered to you if you're living with or in close contact with your family. You might expect to meet all together, about 10 times over 3–12 months or more. The therapy may focus on support, education, or treatment, and may include managing crises, solving problems and stopping problems from coming back.

What does it aim to do?

Experiencing unusual and distressing symptoms can be difficult not only for you, but also for the people close to you.

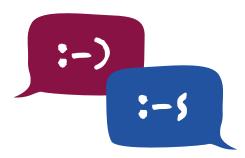
If you have close family or friends, they can play an important part in helping you to manage your experiences and stay well. Family interventions focus on encouraging understanding, communication and independence within the family, and working through problems and emotions.

These interventions aim to encourage everyone in the family to talk to one another about things that they are finding difficult and to think of more helpful ways of supporting each other.

Through this process, family interventions help you and your family to better manage the effect of stress and other unusual and distressing experiences on everyone's lives, leading to better health and wellbeing and reducing the chances that problems return.

Unusual upsetting experiences in one person, can affect the whole family, so family interventions are there to help the whole family to cope, to support each other as best they can through a difficult time, and to help you to stay well.

As understanding, communication and coping get easier, everyone should start to feel less emotional, less stressed, and better able to get on with the things that are important to them in their own lives. Less family stress also means you are less likely to have another episode of unusual experiences!





Does it work?

There are a large number of good quality trials (involving over 2,500 people) that show that family intervention, when delivered by expert therapists, is helpful for families with a person who has unusual and distressing experiences.

They generally compare what happens when you have family intervention and usual care (including medicine) together, with what happens if you only have usual care (including medicine).

One big review (meta-analysis) that looked at results from lots of smaller studies found that including the family in therapy could reduce the chances of a relapse – that's when the unusual distressing experiences come back – by 20%. The longer the family intervention went on for, the less likely the experiences were to come back.

Family intervention reduces the likelihood that you will need to go to hospital too. So family intervention is a useful part of helping you to stay well. It also helps you to make the most of the treatments on offer – maybe because your family are on board with and help you get what you need.

There's very little research on family interventions in young people (under 18) but what's there suggests that family therapy helps to stop experiences coming back in younger people too.

For young people under aged 18, family intervention isn't necessarily better than really good early intervention services, but then good EIP services all offer psychological therapies (including family intervention), vocational services and medicine as part of the service.

The National Institute for Health and Care Excellence (NICE)

NICE recommends family interventions (alongside medicines) for both adults and young people, to help reduce unusual and distressing experiences, and stop them from coming back. They also recommend that young people receive family intervention with individual CBT, especially if the person doesn't want medicine. NICE found that more research is needed on family intervention with younger people.

How can I get this treatment?

Family intervention should be available through your EIP service or through local psychological therapies services within the NHS.

However, it isn't always readily available, especially because it needs two trained therapists. Ask your doctor, care coordinator or GP if you're interested and they will be able to tell you about local options. You may also be able to pay privately for family therapy in your local area.



Family intervention can result in a more supportive family environment, which can mean that your family feel less stressed and more positive and you find it easier to stay well.

🔀 Main con

Family intervention is not always available because it depends on having enough trained staff to offer it. You need to be in contact with your family and happy to involve them. It can be practically difficult to get everyone in the family together at the same time.



Mindfulness-based interventions



The main focus of this treatment is on psychological and social factors, as it's offered in a group.



Remember, a sideways thumb just means not enough people have done research yet to show whether this works. More thumbs ups means that more people have done research that shows that this approach does work.

What is it?

The word 'mindfulness' comes from eastern spiritual and religious traditions like Zen Buddhism. It's about being in touch with and aware of the present moment, and taking a non-judgmental approach to your thoughts and things that happen in your life – this is sometimes called being 'mindful'.

People who work in the NHS and in mental health services have started to see that mindfulness can have lots of benefits for people suffering from anxiety and depression, and more recently perhaps also for unusual and distressing experiences. Mindfulness-based therapy usually takes place in a group and involves a mixture of talking and short practices at trying to be 'mindful'. The number of meetings has varied between 6–12.

If you're having unusual distressing experiences, mindfulness is often offered in combination with CBT type therapy.

What does it aim to do?

Mindfulness encourages you to become more aware of unusual and distressing thoughts and feelings. It supports you to accept your thoughts and feelings and notice your experiences without judging them (for example as being negative experiences), or responding to them, (for example by being upset or anxious).

Mindfulness also encourages you to go easy on yourself and be less self-critical. By learning to react and think differently about everyday things that happen, mindfulness is thought to help you gain a greater sense of control and wellbeing.

Does it work?

Mindfulness-based therapies are a relatively new type of psychological treatment. There have been a number of small RCTs and a bigger 'meta' analysis, that includes mindfulness.

Early results suggest that mindfulness-based therapies may help with distress and general wellbeing, and may increase your ability to have control over your experiences. There is not much good evidence yet on whether it really helps with unusual distressing experiences, but there is lots of good evidence that mindfulness is helpful for depression.

The National Institute for Health and Care Excellence (NICE)

NICE does not yet recommend mindfulness-based therapies for unusual upsetting experiences.



How can I get this treatment?

Mindfulness is a very new treatment for unusual upsetting experiences. It is unlikely to be available through your local NHS service as it isn't yet clear whether it works. If you suffer with depression or anxiety, it is possible that your local NHS service may offer mindfulness for these difficulties.

Some NHS services also do research on Mindfulness so you may be able to take part in some research and get the therapy this way.

If you're willing to pay privately, some private services and CBT therapists specialise in mindfulness approaches.

You can find out more about this by looking on the register for the British Association of Behavioural and Cognitive Psychotherapists at cbtregisteruk.com where there's a section on finding a private CBT therapist in your local area.

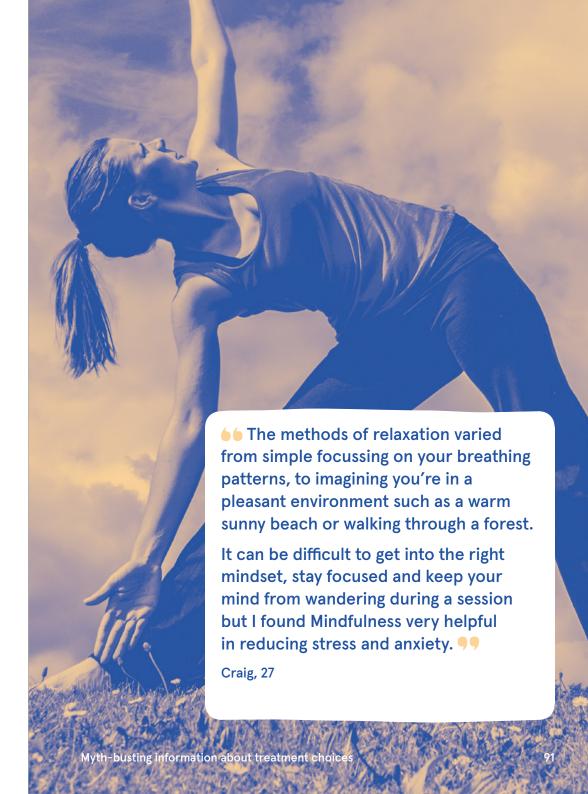
Finally, there are some good online materials and resources, like those published by the Oxford Mindfulness Centre at mbct.co.uk and Sussex Mindfulness Centre at sussexpartnership.nhs.uk/mindfulness

Main pro

Mindfulness-Based Therapies originate from meditation and spiritual approaches, and so might appeal to you if you're more of a spiritual person. They may possibly help if you're feeling upset, bothered, worried or frightened and they may help you with the things you want to do in daily life.

🔀 Main con

Mindfulness-Based Therapies have limited availability and at this stage it's not clear whether they work for people with unusual upsetting experiences. They also involve a lot of work on the part of participants, because it's important to practice at least short mindfulness exercises daily.



6. Psychological therapies

Acceptance and commitment therapy



The main focus of this treatment is on psychological factors.



Remember one thumbs up means that enough people have done research to show that this approach does work.

What is it?

Acceptance and Commitment
Therapy (ACT, which is pronounced
as the word 'act') is aimed at helping
you to take active steps towards
building a rich, full and meaningful
life, and at the same time, helping
you to develop psychological skills
to be able to deal with painful
thoughts and feelings, in better
ways so that they have much less
impact and influence on your life.

What does it aim to do?

The core skills that ACT focuses on include:

1. Defusion: which means distancing yourself from, and letting go of, unhelpful thoughts, beliefs and memories.

- 2. Acceptance: which means making room for painful feelings, urges and sensations, and allowing them to come and go without a struggle.
- 3. Mindfulness: which kind of means being in the moment (the 'here-and-now'), and being open to and interested in your experiences.

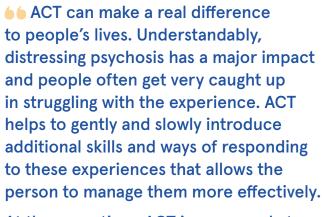
At the same time, ACT will help you to clarify what is truly important and meaningful to you – i.e. your values – then use that knowledge to guide, inspire and encourage you to change your life for the better.

Unlike CBT approaches it doesn't focus on the content of distressing thoughts, but just on accepting them and not letting them get in the way of your goals

Does it work?

There are now at least four RCT studies that have looked at ACT for unusual distressing experiences and psychosis. These studies have shown that ACT is helpful for reducing the distress that comes with the experience of psychosis.

6.6 ACT helped to focus on what's important to me rather than all the other stuff that goes on in my head. It gave me that time and space to say 'hang on a minute' and let it go by, rather than getting carried away with thoughts. It gave me a breather where I was able to pause. This really helped me to get my life back on track again. **9.9** Louis, 29



At the same time, ACT is very good at helping people to reactivate their lives by developing goals that are clearly linked to what is important to the individual. In this way, recovery becomes not just about escaping distress, but about rebuilding a purposeful life.

Dr Joe Oliver, Clinical Psychologist

In a US-based study, ACT has also been shown to help people keep out of hospital for longer. Although still early, ACT appears to be useful in helping people develop better psychological health and wellbeing by using the core skills (the defusion, acceptance and mindfulness ones we mentioned above) which help with recovery.

Additionally, there are several studies underway that are looking at the effectiveness of ACT in groups. Early evidence suggests that ACT groups may be both helpful and useful.

The National Institute for Health and Care Excellence (NICE)

NICE does not yet recommend ACT for unusual upsetting experiences.

How can I get this treatment?

ACT is a newer treatment for unusual upsetting experiences. Although some NHS services do offer ACT, it is not yet common place. It is possible to get ACT from an independent therapist, who specialises in ACT.

You can check the main international ACT website which has a list of ACT therapists in the UK – contextualscience.org – or the register for the British Association of Behavioural and Cognitive Psychotherapists at cbtregisteruk.com

Main pro

ACT can help you to think more about actively building a meaningful life, and also learning skills to help lessen the impact of your distressing experiences.

Main con

ACT is not yet commonly available in the NHS. The evidence, whilst promising, is still in the early stages so it is not yet possible to say who may benefit more from ACT treatments.



Medicine



The main way these treatments work is biological (brain) and physical (body) factors.

There is a lot of money available for research on medications, some of it from pharmaceutical companies and some from



independent researchers who are not sponsored by pharmaceutical companies, so there is a lot of research into medications. Remember, more thumbs ups just means that more people have done research that shows that this approach does work.

What are they?

The medicines in this booklet are all part of a group of medicines that help to reduce or stop unusual and distressing thoughts and experiences.

What do they aim to do?

All these medicines work in a similar way by trying to reduce unusual and distressing thoughts and experiences such as hearing and seeing things, or having strong upsetting beliefs.

They try to do this by changing the way that messages are transferred by the chemical messengers in our brain.

There are lots of natural chemical messengers (neurotransmitters) in the brain. The main chemical that these medicines work on is called dopamine. Others include serotonin, glutamate, acetylcholine and noradrenaline.

Dopamine affects our 'reward' system, for example by influencing what we notice and pay attention to. In this way it affects your thinking, emotions, and behaviour. Too much dopamine in some parts of the brain means that there are too many confusing messages flying around or messages that make you notice and pay attention to unusual things. This can then be distressing and make you feel bad.

The medicines block some of the effects of dopamine, so that these chemical messages are gradually dampened down or even stopped.

The medicine doesn't necessarily change what you think, but sometimes people do find they have a different perspective on their experiences after they've been taking a medicine for a few weeks or months, as well as feeling less worried or scared and better able to do the things they want to do.



Do they work?

Lots of studies have looked at whether these medicines work better than a sugar pill that doesn't do anything (a placebo), and which of these medicines work better than the others.

People tend to drop out of medicine trials, making it hard to draw firm conclusions about how helpful the medicines are in real life.

Nevertheless, there is lots of good quality evidence from randomised controlled trials (RCTs) and meta-analyses (remember, meta-analyses are lots of RCTs all put together) that these medicines reduce unusual and distressing experiences and particularly prevent them from coming back again (a relapse).

There are lots of different medications. The main ones that you may be offered include Amisulpride, Aripiprazole, Olanzapine, Paliperidone, Quetiapine, Lurasidone or Risperidone.

The National Institute for Health and Care Excellence (NICE)

NICE reviewed randomised controlled trials of these medications in 1,800 people with a first episode of psychosis, 16,500 people with acute upsetting experiences and 3,500 people who were recovering.

NICE has recommended all these medications for unusual and distressing experiences.

The research evidence shows that they are all equal in how much they help with acute episodes of upsetting experiences, with recovery and with stopping the experiences coming back (relapse). Some of them also help with depression and anxiety.

The main reason for choosing one medication over another is because of the different side-effects, and which would bother you least.



In the next few pages we will give you some more information on side-effects, to help you to discuss this with your care coordinator, doctor or pharmacist and choose a medication that is best for you.

Clozapine is different from the other medications and is the best one when other medications haven't worked.

How do I take them and how long for?

These medicines come in tablet, syrup, and long-acting injection form, though not all of them come as injections. They are different from some of the common medicines that you may have taken before like pain killers, because they don't work immediately to affect your experiences.

In fact, they generally take at least a few weeks and even a few months before you might notice any change at all in your unusual distressing experiences. For some people, the medicines will stop your unusual experiences and for other people they will only reduce them.

The sooner you take medicine after you develop unusual experiences the more likely the experiences are to go away completely, and the lower dose you will need – which is great as lower doses mean fewer side-effects.

Some medicines will work for some people but not for others (a bit like in the vitamin example that we talked about earlier! see p.8), and sometimes even when a medicine works, the experiences may come back occasionally, especially in times of stress.

This is because they have to work quite hard to gradually, rebalance the chemical messages that lead to upsetting experiences. After all, our brains are pretty complex and powerful things! You may need to try a few medicines before you find the best one for you.

Again, unlike some common medicines, these medicines carry on working to rebalance or stop experiences all the time that you are taking them.

This means that if you stop taking them, sometimes upsetting experiences come back again, gradually over a few weeks or months but other times the experiences may have truly gone away.

It's hard to know when is the best time to reduce, or stop the medicine. Some doctors suggest that you should take it for at least a year after any upsetting experiences have gone away, and some suggest even longer. This gives the medicine time to work, and you time to get back to things you enjoyed doing before the experiences started.

NICE guidelines suggest that there is a high risk of your experiences coming back if you stop taking medicines in the first one or two years and any discontinuation should be gradual and monitored for at least two years.

At least half of people who stop taking the medicines will get the upsetting experiences back again (a relapse). However, some people (one in every five) can stop medicines sooner without the experiences coming back, and some people (also one in every five) will have a relapse anyway, even though they're taking the medicines.

Everybody is different so it's worth discussing this with your care coordinator, doctor or pharmacist.

Even though the medicine may take a while to affect your unusual or upsetting experiences, you may notice some physical effects of the medicine immediately. This is because anything we do or take affects us as a whole person, so although the medicines are designed to do one thing, they also affect other things as well.

These other things are often called side-effects because they aren't the main effect of the medication. Some side-effects are there immediately but gradually go away, some appear over time and some will stay there unless you change the amount of the medicine that you take (the dose).

The dose of medicine is important, as with any medicines, they only work properly at certain doses: too little might not work at all, and too much might be bad for your health.

The dose usually also affects which side-effects you might get, so again, it's worth discussing this with your care coordinator, doctor or pharmacist so that you get the best effects with the least side-effects.

Working together you can work out the best dose and medicine to suit you. After all we're all different and it can be really helpful to take time to personalise medicine use to best suit you.

Other medicines you might be offered

Alongside the main medications above, you might also be offered additional medications for mood and anxiety. These might include antidepressants for low mood and depression, anxiety medications to help you to relax if you feel more anxious or worried, or mood stabilisers if your mood goes up and down a lot.

What are the main types of sideeffects?

The main types of side-effects are described below. Very common side-effects in this booklet are those that affect at least one out of every ten people (10%) and common side-effects are ones that affect at least one out of every 100 people (1%). Remember, different medicines have different chances of causing these side-effects and some have a lot fewer side-effects than others.

If you notice any of the following side-effects then you should discuss them with your care coordinator, pharmacist or doctor.

Weight gain

What does it mean?

Feeling more hungry and eating more so that you put on weight. This can happen quickly in even a few weeks, and can put you at risk of diabetes in the longer term.

What can you do?

Eat lots of healthy food like fruit, vegetables and fibre. Avoid sugar, fat, take-away food etc. You could also do some extra exercise.

Metabolism changes

What does it mean?

Changes in how your body deals with sugars and fats, so that you might have higher types of (unsaturated) fats (e.g. cholesterol). These changes can also put you at a risk of diabetes.

What can you do?

A blood test will tell you if this is a problem. Again, a good diet and exercise might help. Try eating lots of healthy food like fruit, vegetables and fibre. Avoid sugar, fat, take-away food etc.

Cardio-vascular problems

What does it mean?

Heart and circulation problems and changes in how your heart works, including odd or fast heart beats or chest pains.

What can you do?

Tell your doctor straight away especially if you're taking Clozapine. They can check your heart and give you good advice.

Hormone changes

What does it mean?

Changes in your hormones which can lead to problems with your sex drive, your periods (women only), breast growth, and very occasionally to milk production (men and women). The changes are reversible with changes in dose or medicine.

What can you do?

If you have any concerns please speak to a member of the early intervention team so we can work together to make changes. Tell your doctor if you notice any of these problems and they can arrange a blood test to check your hormones and give you good advice.

Movement changes

What does it mean?

Changes in your movement so that you may be more stiff, shaky or restless and feel on edge and like you have to keep moving.

What can you do?

Tell your doctor if you notice any of these problems and they can give you good advice. If you're feeling restless try wearing comfy clothes, and doing things that help you relax. Sometimes tablets are given to counteract these effects.

Stomach upset

What does it mean?

This might include feeling sick, vomiting and diarrhoea.

What can you do?

This could be a tummy bug but if it lasts more than a day or two, tell your care coordinator or doctor.

Dizziness

What does it mean?

Feeling dizzy when you stand up.

What can you do?

Don't drive or cycle! Try lying down for a minute or two and then standing up slowly. Talk to your doctor and they can give you some advice.

Blurred vision

What does it mean?

Not being able to see properly because things are blurred and fuzzy.

What can you do?

Don't drive or cycle! This could just be because you need glasses. You could get an eye test, but if it continues and you're worried do talk to your doctor.

Headaches

What does it mean?

When your head hurts.

What can you do?

This could be just a headache but could be a side-effect. Pain killers can help.

Anxiety/agitation

What does it mean?

When you keep worrying about things.

What can you do?

If you're worrying a lot, you may be tempted to avoid doing things. If this starts to happen you may want to change your medication dose, but you may also want some psychological therapy to help with anxiety.

Tiredness (or not being able to sleep)

What does it mean?

Feeling really tired and like you haven't got the energy to do anything, or – the opposite – not being able to sleep!

What can you do?

Don't drive or cycle if you're tired! The same things will help whether you're too tired or not able to sleep. Try to get a good sleep habit, including a regular bed time, and getting up time.

A brief psychological therapy for sleep might help. You could try gradually doing some exercise to give you more energy in the day and a better sleep at night, and change the time you take any medicines so you're tired at night.

Hypersalivation or dry mouth

What does it mean?

Hypersalivation is when you have too much saliva in your mouth. If it's very bad it may be difficult to talk, you may dribble and your pillow may be wet when you wake up.

A dry mouth is the opposite, when you don't have enough saliva and your mouth is dry and sticky.

What can you do?

If you have too much saliva at night, you could add an extra pillow so you're propped up a bit. There is also a medicine that can help with this, if you tell your doctor.

Aripiprazole





There is a lot of money available for research on medications, some of it from pharmaceutical companies and some from independent researchers who are not sponsored by pharmaceutical companies, so there is a lot of research into medications. Remember, more thumbs ups just means that more people have done research that shows that this approach does work.

What is it?

Aripiprazole is a medicine that's licensed for adults. It's also licensed for young people aged 15 years or older, and for 13–14 years old if you're experiencing a manic episode (extremely excited). It's available in a tablet, a melt-in-themouth tablet, syrup or an injection. The normal amount that you take is 10–15mg, although the maximum amount is up to 30mg.

What does it aim to do?

Aripiprazole can reduce unusual and distressing thoughts and experiences (hearing and seeing things or having strong upsetting beliefs). It also tries to help you if you have slowed movements, slowed thinking or you've lost interest in life.

The National Institute for Health and Care Excellence (NICE)

NICE recommends Aripiprazole for adults. It didn't report on the effects of Aripiprazole for young people who were experiencing symptoms for the first time and were under 18 because there hasn't yet been very much high quality evidence on this medicine in under-18s.

What are the side-effects of Aripiprazole?

There are no very common sideeffects in over-18s, unlike all the other similar medicines.

Aripiprazole has fewer side-effects than all the other medicines but still has more side-effects than if you didn't take anything at all. In under-18s, tiredness, movement and hormone problems are very common.

Less common side-effects (between 1 in 10 and 1 in 100 people) include movement problems, feeling restless and agitated, feeling sick, feeling tired (or having problems sleeping), feeling anxious, dizzy or shaky, having headaches, blurred vision, indigestion, not being able to poo or having too much saliva (spit). Less common side-effects in under-18s also include a drop in blood pressure, being more hungry and having a dry mouth.

Many side-effects are related to the amount of Aripiprazole you take, so they are less likely with low doses, and stop if Aripiprazole is stopped.

66 At the moment I take Aripiprazole which I tolerate well. **99**

Katie, 27

How can I get this treatment?

Aripiprazole can only be prescribed by your GP or mental health team. You can't buy it over the counter.

Main pro

People tend to find Aripiprazole easy to take because it has fewer side-effects than other medicines, and people usually feel less tired and flat than on other medicines. Aripiprazole is least likely to make you put on weight or have metabolism changes out of all these medicines.

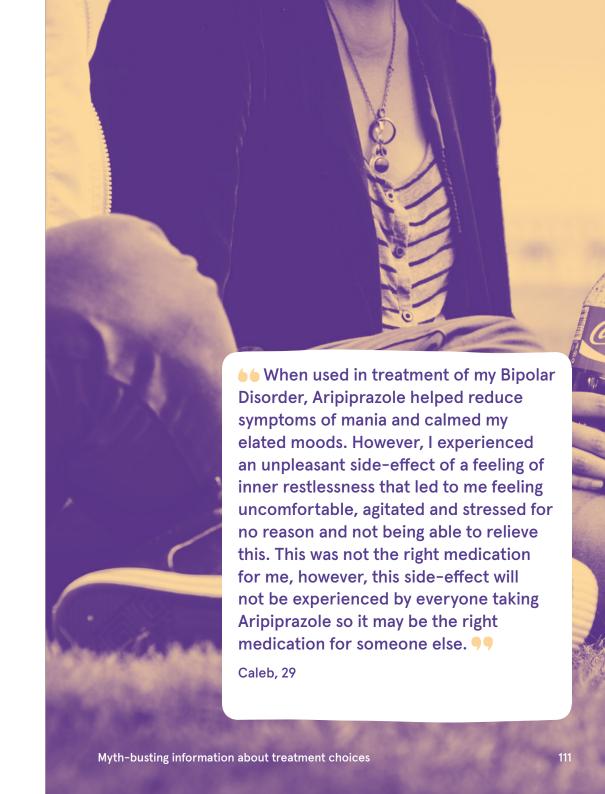


Sometimes people say they feel restless and find it hard to sit still when they're taking higher amounts of Aripiprazole.

Aripiprazole has proven beneficial for psychotic symptoms. Aripiprazole is the least sedative and least associated with weight gain, out of all antipsychotics in comparison studies.

Aripiprazole injection is one of the newer antipsychotics available and particularly useful for those who would rather have a monthly injection than take tablets every day.

Dr Richard Whale, EIP Consultant Psychiatrist



Amisulpride









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What is it?

Amisulpride is a medicine that's licensed for over-18s. It's available as a syrup and as tablets. The normal amount you might take is between 400-800mg but the maximum amount is up to 1200mg. Lower amounts of 50-350mg may help improve your motivation, interest and enjoyment of life.

What does it aim to do?

Amisulpride can reduce unusual and distressing thoughts and experiences (hearing and seeing things or having strong upsetting beliefs), as well as improving motivation, interest and enjoyment.

What are the side-effects of Amisulpride?

In adults very common side-effects are movement problems (shakiness, muscle stiffness or spasms, rigid, reduced and uncontrolled movements, and restlessness) and having too much saliva.

Less common side-effects (between 1 in 10 and 1 in 100 people) include putting on weight, hormone and metabolism changes, not being able to poo, sleep problems, dry mouth, feeling sick, low blood pressure, anxiety or agitation and neck or eye muscle spasms. These problems are related to the amount of Amisulpride you take, so they are very mild with low doses, and stop if Amisulpride is stopped.

How can I get this treatment?

Amisulpride can only be prescribed by your GP or mental health team. You can't buy it over the counter!

Main pro

Some studies say Amisulpride is one of the medicines that works best for unusual upsetting experiences.

Main con

The main side-effect is movement problems, which very occasionally become semi-permanent if you keep taking this medicine for a long time (years) after the movement problems have started.



Clozapine





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What is it?

Clozapine is a medicine that's licensed for people who are 16 years and older. It isn't offered the first time someone has unusual distressing experiences, because it's for people who've tried at least two other medicines and found that they don't work. It is available in syrup and tablets. The normal daily amount is 200–400mg a day up to a maximum of 900mg a day.

What does it aim to do?

Clozapine can reduce unusual and distressing thoughts and experiences (hearing and seeing things or having strong upsetting beliefs). It is usually only offered to people when they've already had two other medicines that haven't worked. This is because it needs regular monitoring with blood tests.

Does it work?

Clozapine is a bit different from the other medicines described in this booklet. Studies have found that Clozapine is better at reducing unusual distressing experiences and the risk of becoming unwell again, than other medicines, for people who found that the other medicines don't work.

At least one out of every three people who didn't find other medicines helpful will find that Clozapine does help with their unusual distressing experiences.

What are the side-effects of Clozapine?

Clozapine is also different from the other medicines in this booklet in it's side-effects. Like most medicines, Clozapine has sideeffects. An important common (1 in 100 people) side-effect of Clozapine is that it can sometimes reduce your white blood cells (the ones that fight disease!). If your white blood cells get too low this can be life-threatening, so if you take Clozapine you need to have your blood checked regularly at a doctor's surgery or clinic, to make sure everything is OK. Any change in your white blood cells happens really slowly, so if you start taking Clozapine you will have blood tests first weekly, then fortnightly, then monthly.

The blood tests check for changes in your blood cells. A green result means everything's fine, an amber result means you'll need extra blood tests to check on things and a red result means there are signs that your white blood cells have got too low for the time being and you need to stop taking Clozapine.

The longer you are taking Clozapine the less often you will have blood tests because most problems with your blood happen in the first 18 weeks.

If you start or stop smoking, you may need more or less Clozapine, so do let your doctor know. You also need to let your doctor, pharmacist or care coordinator know if you stop taking Clozapine, because stopping for more than two days and then starting again on the same amount can be dangerous.

Very common side-effects of Clozapine include tiredness and too much saliva (spit in the mouth), dizziness, a fast heart rate and not being able to poo, especially when first taking it, but fewer movement related side-effects, than with other medicines.

Less common side-effects (between 1 in 10 and 1 in 100 people) include feeling more hungry and putting on weight, movement problems, blurred vision, dry mouth, low blood pressure, fainting, headaches, slurred speech, fits, heart and liver changes (experienced as sickness, appetite loss and jaundice) and problems with controlling your body temperature and with needing the toilet a lot.

How can I get this treatment?

Clozapine can only be prescribed by your mental health team. You can't buy it over the counter or get it from your GP.

Main pro

When people have found two or more other medicines haven't been helpful for them, Clozapine may well be helpful. This can be lifechanging!

Main con

Clozapine can reduce white blood cells (about 1 in 100 people may get this), which can have serious health consequences. People who take Clozapine need to have their white blood cell count checked regularly. By having regular blood tests Clozapine is made safe to use.



Lurasidone





There is a lot of money available for research on medications, some of it from pharmaceutical companies and some from independent researchers who are not sponsored by pharmaceutical companies, so there is a lot of research into medications. Remember, more thumbs ups just means that more people have done research that shows that this approach does work.

What is it?

Lurasidone is a new medicine that's licensed for people aged 18 years or older. It's available in tablet form. The normal dose is between 37-74mg daily.

What does it aim to do?

Lurasidone can reduce symptoms such as unusual and distressing thoughts and experiences (hearing and seeing things or having strong upsetting beliefs) as well as helping with depression if you have problems with your mood.

The National Institute for Health and Care Excellence (NICE)

NICE have recently reviewed and recommended this medication. It's very new and has only recently got a license in the UK. It's in the same class as the other medicines described in this booklet.

What are the side-effects of Lurasidone?

In adults, very common side-effects are movement problems such as restlessness, and feeling tired and sleepy (this can be worse if you drink alcohol). Less common sideeffects (between 1 in 10 and 1 in 100 people) include not being able to get to sleep, feeling sick, having headaches and having hormone changes.

Many side-effects are related to the amount of Lurasidone you take, so they are very mild with low doses, and stop if Lurasidone is stopped.

How can I get this treatment?

Lurasidone can only be prescribed by your GP or mental health team. You can't buy it over the counter.



Main pros and cons

Lurasidone is a very new medication so we haven't listed any main pros or cons for it yet. We'll add more information about Lurasidone to our website as we get it. The same goes for quotes from NHS staff and service users. It's too new so we don't have any yet!

Olanzapine





There is a lot of money available for research on medications, some of it from pharmaceutical companies and some from independent researchers who are not sponsored by pharmaceutical companies, so there is a lot of research into medications. Remember, more thumbs ups just means that more people have done research that shows that this approach does work.

What is it?

Olanzapine is a medicine that's licensed for people aged 18 years or older. It's available in syrup, tablets, melt-in-the mouth tablets and injection form. The normal dose is between 5–20mg daily.

What does it aim to do?

Olanzapine can reduce symptoms such as unusual and distressing thoughts and experiences (hearing and seeing things or having strong upsetting beliefs) as well as reversing slowed movement and slowed thoughts.

The National Institute for Health and Care Excellence (NICE)

NICE recommends that people should be offered counselling about their diet and lifestyle (i.e. exercise and activity) when they start taking Olanzapine to help reduce the chances of putting on weight and the problems that come with weight gain.

What are the side-effects of Olanzapine?

In adults, very common side-effects are weight gain, tiredness and metabolism changes, as well as a drop in blood pressure, and risk of falling over.

In young people, there is a particularly high risk of weight gain, as well as hormone and metabolism changes if you take Olanzapine. It's more likely to cause weight gain than all the other medicines in this booklet but not everyone will put on weight when they take it.

Less common side-effects (between 1 in 10 and 1 in 100 people) of Olanzapine include not being able to poo, or weeing when you don't mean to, feeling weak, dizzy or restless, having a fast heart rate, dry mouth, fever, joint pain, skin rashes, swollen hands or feet, speech problems or problems controlling movement, having pneumonia.

66 Olanzapine has proven benefit for psychotic symptoms. Olanzapine is especially associated with feeling tired and putting on weight but some people find the calming effect of Olanzapine helpful. **99**

Dr Richard Whale, EIP Consultant Psychiatrist

How can I get this treatment?

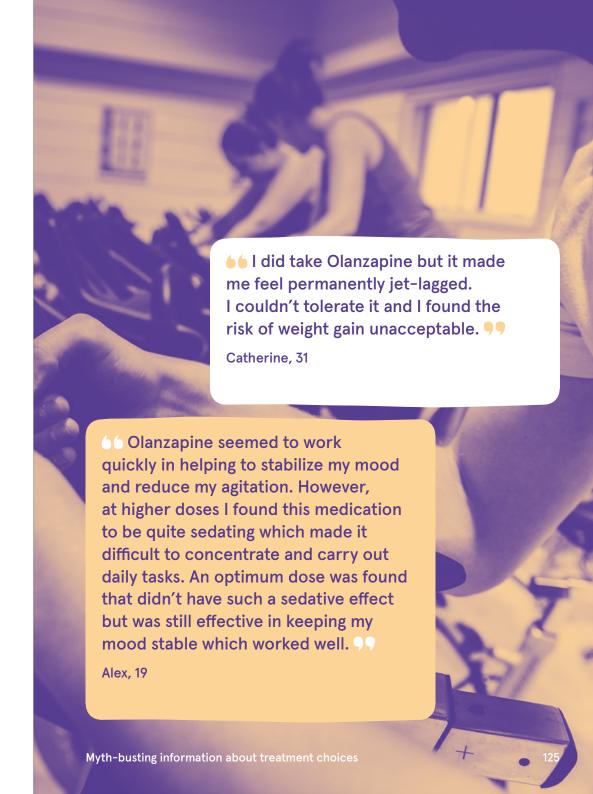
Olanzapine can only be prescribed by your GP or mental health team. You can't buy it over the counter.

Main pro

Olanzapine is good at reducing unusual and distressing thoughts and experiences. It also helps people to feel calm and has fewer movement-related side-effects (like shakiness and stiffness) than some medicines.

Main con

Olanzapine has a major side-effect of weight gain which happens more than with most other medicines. In tests of Olanzapine, over half of people dropped out of the studies because of weight gain. As with all studies of these medicines, it's hard to find out exactly how many people will have these side-effects as people often drop out of trials.



Paliperidone





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What is it?

Paliperidone is a medicine that is very similar to Risperidone (see the section on Risperidone in this booklet). It's licensed for over-18s and it's available in tablets, and injection although it's usually only prescribed as an injection. The normal daily amount is 6mg but the range is from 3mg up to 12mg.

What does it aim to do?

Paliperidone can reduce symptoms such as unusual and distressing thoughts and experiences (hearing and seeing things or having strong upsetting beliefs).

What are the side-effects of Paliperidone?

In adults very common side-effects include sleep problems (tiredness/sedation or not sleeping) and headaches. It also causes movement problems (shakiness, muscle stiffness, rigid, reduced movements, and restlessness) and more hormonal problems than some other medications.

Less common side-effects (between 1 in 10 and 1 in 100 people) include metabolism problems, infections, cold and flu symptoms including having a fever, joint, back and tooth pain, having high blood pressure and a faster or slower heart rate, having an upset stomach, indigestion or not being able to poo, feeling anxious, dizzy, depressed, agitated or tired.

Sometimes the site where you have the injection can become itchy, sore or hard. Many sideeffects are related to the amount of Paliperidone you take, so they are very mild with low doses, and stop if Paliperdone is stopped.

How can I get this treatment?

Paliperidone can only be prescribed by your GP or mental health team. You can't buy it over the counter.



• Paliperidone injection is one of the newer antipsychotics available and particularly useful for those who would rather have a monthly injection than take tablets every day.

Dr Richard Whale, EIP Consultant Psychiatrist

66 I did find it hard to think when I took Paliperidone, but I spoke to the doctor and he changed it to the injection rather than tablets and this has really helped. **9 9**

Tara, 23

• It's really good not to have to remember to take tablets every day, although I don't like having to go for injections once a month as I don't like needles. I had some side-effects, so I spoke to the doctor and I've changed medication.

James, 24

Quetiapine





There is a lot of money available for research on medications, some of it from pharmaceutical companies and some from independent researchers who are not sponsored by pharmaceutical companies, so there is a lot of research into medications. Remember, more thumbs ups just means that more people have done research that shows that this approach does work.

What is it?

Quetiapine is a medicine that's licensed for over-18s. It's available in tablets. The normal daily dose is between 300–450mg but the maximum dose is up to 750–800mg.

What does it aim to do?

Quetiapine can reduce symptoms such as unusual and distressing thoughts and experiences (hearing and seeing things or having strong upsetting beliefs). It may also treat depression symptoms.

What are the side-effects of Quetiapine?

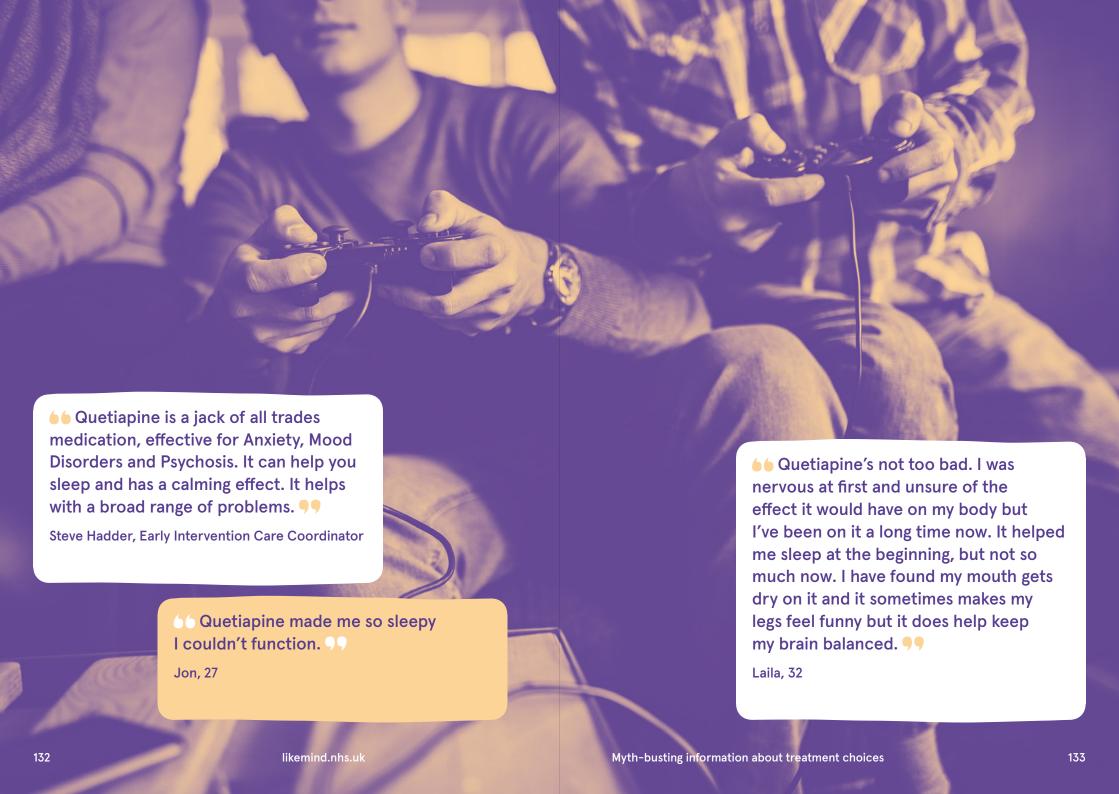
In adults, very common sideeffects are tiredness, dizziness and headaches, having a dry mouth, weight gain and changes in metabolism (cholesterol and fat). It is less likely to cause weight problems than Olanzapine. High blood pressure is also common in younger people. Muscle weakness, constipation, indigestion, and having a fast heartbeat are also common.

Less common side-effects (between 1 in 10 and 1 in 100 people) include low blood pressure and fainting, feeling sick, blurred vision, shortness of breath, swollen hands and feet, movement changes, strange dreams and nightmares, fever, speech difficulties, and very occasionally increased suicidal thoughts.

Young people unusually, may get annoyed easily. Many side-effects are related to the amount of Quetiapine you take, so they are very mild with low doses, and stop if Quetiapine is stopped.

How can I get this treatment?

Quetiapine can only be prescribed by your GP or mental health team. You can't buy it over the counter.



Risperidone





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What is it?

Risperidone is a medicine that's licensed for over-18s but it can also be used in under-18s. It's available in syrup, tablets, melt-in-the mouth tablets and in injection form.

The normal daily dose is between 4–6mg per day but the maximum dose is up to 10mg for tablets.

What does it aim to do?

Risperidone can reduce symptoms such as unusual and distressing thoughts and experiences (hearing and seeing things or having strong upsetting beliefs).

What are the side-effects of Risperidone?

In adults, very common side-effects are movement problems (including shakiness, spasms, and problems controlling movements, muscle stiffness and tension, slowness and restlessness), too much saliva (spit), headaches and problems with sleepiness.

As with Paliperidone it can cause hormonal changes more than some other medicines. Less common side-effects (between 1 in 10 and 1 in 100 people) include cold and flu like symptoms, fever, feeling sick and having stomach ache, breathing difficulties, pneumonia, faster heart rate, joint, back and chest pain, toothache, speech and eye/ eyesight problems or facial numbness (tell your doctor if this happens!), feeling depressed, anxious, agitated, weak, dizzy, having changes in appetite and putting on weight, having skin rashes, not being able to poo or having runny poo, weeing when you don't mean to, having a dry mouth, ear infection, nose bleed, swollen hands or feet, indigestion, high blood pressure and problems with metabolism.

Many side-effects are related to the amount of Risperidone you take, so they are very mild with low doses, and stop if Risperidone is stopped.

How can I get this treatment?

Risperidone can only be prescribed by your GP or mental health team. You can't buy it over the counter.

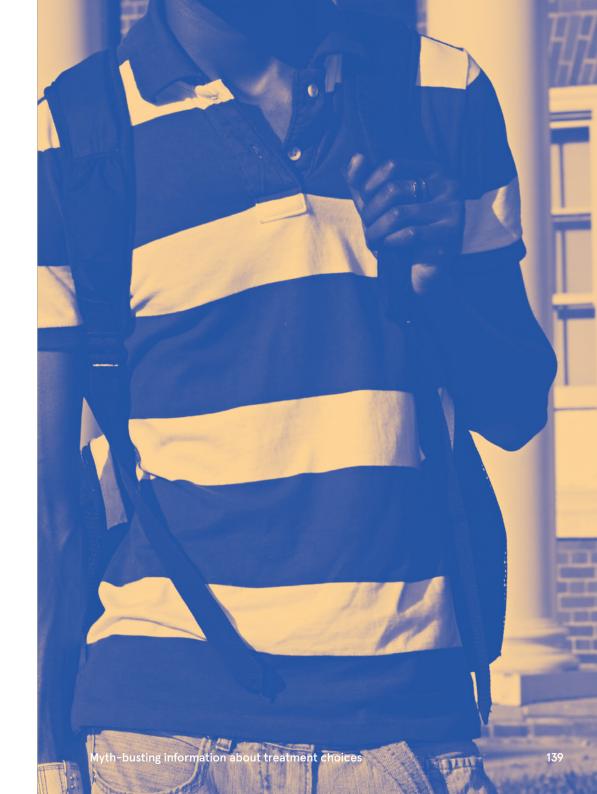


What does recovery mean?

All of these treatments are aimed at helping you to recover after you've had unusual upsetting experiences.

Recovery means different things to different people. Some people will stop having these experiences and will never have them again, others will stop having them, but they may come back again and others will still continue to have these experiences at a low level.

Most people think that recovery following these experiences involves rebuilding your relationships, rebuilding your life, increasing self-confidence and self-reliance and developing hope for the future. Working towards these things can help you to get on with your life, and the treatments in this booklet can support you with this.



Want more information?

There's lots more information about treatments for unusual and distressing experiences on our website likemind.nhs.uk

Including some of the ones that don't seem to work for these types of experiences, like:



Adherence Therapy (talking therapy to encourage you to take medication) but NICE does support discussing medicine options with you, which is helpful!



Social Skills Training (training to help you to learn social skills).



Psychodynamic and Psychoanalytic Therapy (talking therapy that focuses on 'unconscious' experiences).



Supportive Counselling (a very general type of talking therapy support).

Different things work for different people though so it's possible they may still work for you. There's lots of information on our website about lots of things to do with mental health, dealing with unusual distressing experiences, and staying well.

Your care coordinator or lead practitioner is:

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(Professor Kathryn Greenwood, Dr Fran Meeten, Dr Kirsty Labuschagne, Dr Sam Fraser, Dr Clio Berry, Katie Alford, Luke Slater, Dr Rebecca Webb, Dr Emmanuelle Peters, Dr Richard de Visser, Professor Philippa Garety, Professor Andy Field, Ruth Chandler, Ritka Kochhar, and the Service User Research Forum).

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