



LIKEMIND

A mental health companion
for young people

MYTH-BUSTING INFORMATION

Early intervention
in psychosis services



Myth-busting information about early intervention in psychosis services

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“ I was very obsessed with the idea I might be psychic ‘cos I’d had a lot of experiences that I couldn’t really rationalise or explain. I still get days when I think I am and I still have doubts that it’s just an illness. ”

Jenny, 24

Why bother reading this?

Are you someone who is worried about whether you have psychosis? Have you already been referred to or seen someone from an early intervention in psychosis (EIP) service? This booklet and the website likemind.nhs.uk can tell you more about these services, what they can offer, how they might help and how you might benefit.

This booklet doesn’t make assumptions about your experiences, where they’ve come from or what’s caused them. Everybody’s experiences and understanding is different.

This booklet aims to tell you more about the services that might be useful for you, and how you can get the best out of them.

It has been produced with and for young people aged 14–35.

You might also find our **‘Mental health and getting help’, ‘For friends and family’ and ‘Treatment choices’** booklets helpful. You can download these from our website likemind.nhs.uk



COMMON MYTHS

MYTHBUSTER 1

“ Young people don't have mental health problems! ”

False! Young people have mental health problems too.

Did you know that one in ten young people will have some sort of early mental health problem and as many as two to three people in 100 will develop psychosis? This is normal!

You can share your experiences and hear other people's stories on the 'your stories' page and forum at likemind.nhs.uk



“ I think knowing that other young people have it as well, really helps, because a lot of people think 'oh I'm really unusual' and kind of shy away from it. But I think when you do realise how many other people can have the same problem it helps. ”

Sabah, 19

“ I was hearing voices. I thought there was someone trying to get me out of the house. I thought I heard my neighbours walking past and I thought they were talking about me. Then they went round the corner and I could still hear them. I looked out and I thought I saw some guy in like a van trying to contact me and I thought 'well that's my next door neighbour' or whatever cos I've seen him going in the house once. I went outside, just to check, and like a leaf fell from the tree and I thought I heard the leaf like saying something. ”

Tom, 20



Getting the right amount of support and advice at the right time can make a big difference to your life in the long term.

This booklet is here to give you some advice on how to find someone you can talk to.

What are EIP services?

‘It’s what you do next that counts’

EIP stands for Early Intervention in Psychosis.

You might think the word psychosis is a bit unsettling and maybe it’s putting you off reading any more?

Unfortunately, this may well be because of stigma! We can blame some of that on the media but we can feed into it too. What do you imagine when you think of psychosis? Would you be surprised to know that half of the people pictured in this booklet have psychosis? Psychosis is not being dangerous and violent, and it’s not being a psychopath or having a split-personality.

Psychosis is not a diagnosis, it’s just a description of a set of experiences. They include things like being paranoid, thinking someone’s following you or out to get you, having other strange or upsetting thoughts or indeed real experiences of hearing, seeing, feeling, smelling, and tasting things that other people don’t.

It can be scary at the time, but you can recover, have a life, a good job, a relationship and a family – psychosis is quite common. Some people think that psychosis is just an extension of anxieties that we all have.

Different people respond to it differently and some people struggle more and have a harder time and more long term problems.

It’s what you do next that counts!

If you think you have psychosis, or someone has suggested this to you, choosing to work with early intervention services is a first step to doing the best you can for yourself. EIP services try to meet and support people with psychosis as quickly as possible so that they have the best and fastest recovery that they can. Your decisions are important here and they matter.

COMMON MYTHS

MYTHBUSTER 2

“ They put everyone on medicines! ”

Not true! Early intervention services don't want to put everyone on medicines.

Certainly one of the main treatments for psychosis is medication, but over half the people who are seen in EIP services don't end up having psychosis.

If you don't have psychosis, you might just have a few meetings to reassure you, you might still be seen for a longer period to offer support or you might be recommended to a different service that will suit you better. If you do have some of the unusual distressing experiences we've been talking about (psychosis), remember it's quite common, and doesn't mean you're 'weird'!

Someone will probably talk to you about medication because some people do find it really helpful to deal with stuff that's happening and to stop it coming back again!

Generally speaking you don't absolutely have to take medication, and someone will also talk to you about other things that might help, like talking therapies, support for getting back to school, college or work, help with money and housing, and help with diet and exercise.

Our 'Treatments choices' booklet tells you more about all sorts of things that might be helpful.





COMMON MYTHS

MYTHBUSTER 3

“ They put you in hospital! ”

False! Early intervention services for psychosis definitely don't want to put you in hospital.

EIP services definitely don't want to put you in hospital. In fact, EIP services were specially set up to do the opposite!

They try to make sure that things never get that difficult. They try to help you recognise ups and downs so that you can deal with issues early.

Only if things are impossible to manage, very distressing and you or the EIP team really think things are unsafe will you end up going to hospital... and that doesn't happen often because it also costs the NHS lots of money (e.g. about £2,700 per week in 2017)!

If you do end up going into hospital, there's a booklet to help you with that too. It's called 'Getting the most out of hospital'. You can get this from our website at likemind.nhs.uk



COMMON MYTHS

MYTHBUSTER 4

“ They judge everyone and give them a diagnosis! ”

Untrue! More people don't have psychosis than do. An assessment doesn't mean a diagnosis.

More people who are seen by EIP don't have psychosis than do. But if you're told you have psychosis, don't panic!

You may have heard about people with psychosis on TV, in newspapers or in books. Some of what you read is true but a lot of it isn't! TV and newspapers like to tell a good story, but in reality everybody's experience is different.

People can experience psychosis symptoms for lots of different reasons, like when you don't get sleep for a long time, take drugs, have epilepsy, or have a lot of stress or trauma.

Psychosis is a word that describes your experiences. It's not a diagnosis. It doesn't mean that you are dangerous or a psychopath.

Sometimes a diagnosis is helpful, as it can help you and others understand more about what's going on. It can also help to get benefits and support so that you can do what you want to do in life, in your own time.

Specific diagnoses like Schizophrenia, Schizo-affective disorder, Bipolar disorder, Delusional Disorder, or Drug-Induced Psychosis, all include unusual distressing (psychosis) experiences.

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

Sometimes a diagnosis is not helpful. Often this is linked to stigma again! You can discuss with your EIP team whether a diagnosis will be helpful for you or not.



“ Now I have the language to describe it in a way that, not many people necessarily get, but at least it sounds sane you know. At least it doesn't make me sound like a mad man. ”

Ali, 29

COMMON MYTHS

MYTHBUSTER 5

“They will expect me to fit into a ‘psychosis patient’ box!”

False! EIP services aim to be tailored to your needs.

You may be worried that you will be pushed to do things that don't suit you as a person or don't respect your values. You may be worried that your religious or spiritual beliefs won't be taken into account, or that important aspects of your culture, such as meeting someone of the same gender, will be ignored. You may have specific immigration, religion or other concerns.

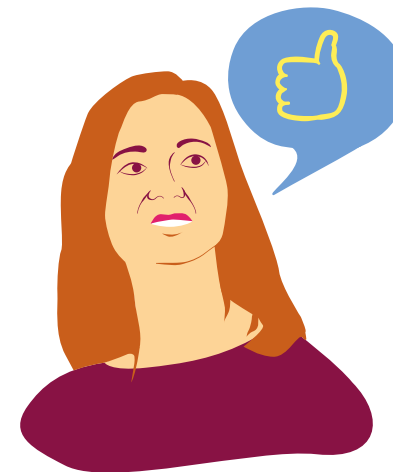
EIP services, and your care coordinator, aim to work with you as an individual.

Your care coordinator will ask you about the things that are important to you. You can tell your care coordinator about your beliefs, your values, your culture, and anything else that matters to you. They will aim to tailor the service to meet your individual needs.

This can be also be a confusing time if you and your family members have different cultural, religious or spiritual backgrounds.

It can feel like everyone has a different perspective on what you should do. You may worry that your own or other important family members views may get lost. You or your family may have concerns about the NHS, and be more comfortable using traditional or spiritual healers. You may worry that having a different background may make it even harder to recover from your experiences, and get on with life.

Your care coordinator will understand that everyone is different, and that what works for one person may differ from what works for another. Indeed, cultural, religious and spiritual support can be really valuable.



Your care coordinator will aim to understand and respect your individual gender, sexuality, ethnic, cultural and spiritual views and values, and those of your family, without making assumptions.

They will respect your own and your families' confidentiality. They will try to work with language barriers, and may involve an interpreter, if you think this would help. They can offer you a space to make sense of your cultural background and how it relates to your mental health and your future plans.

Where family, friends, religious leaders and the NHS have different thoughts about what will be most helpful, your care coordinator will aim to listen, and help you to find the right path for you.

OK, so we know what EIP services don't do, but what does the service do?

EIP services work to support you with whatever you hope to do. They also support you to manage and recover from your unusual distressing experiences, to feel more positive, and to reduce the chances of this happening again.

They work in lots of different ways: medical, psychological, social and physical, helping you with work, college, family and friends, relationships, where you live, money, drugs, alcohol and health.

EIP will advise and support families and close friends but you can tell them if there are people you don't want them to talk to. They know it is important to respect your wishes.

EIP services offer support for two or three years, even if things get better in a matter of weeks. This is because quite a few people will have other episodes of these unusual distressing experiences. Getting the right support in the following three years is really important to give you the best chance of recovery.

“ My care coordinator is really good at communicating and has patience and has the skills, is probably better equipped than, like a GP. She encounters psychosis on a day to day basis and she's like, so brilliant at it and like, you know, anticipating how you're gonna respond. ”

Jia, 26

“ The support is really important for me in terms of getting better and feeling normal because it is such a strange thing to happen, it's not something people talk about, or what you hear in everyday life. ”

Emily, 21

Who is part of an EIP service?

What do the people do?

Because EIP works in an all-round way, there are lots of different types of people who work in the service. They're all used to working with young people. This is because unusual distressing experiences often start in young people in their teens, and early 20s, although you may be in your 30s or older.

When you begin working with an EIP service you will be provided with a 'care coordinator' or 'lead practitioner', they are the person who you will generally have the most contact with. They are most likely to be a nurse, OT or social worker but they will also each have a broader EIP experience to help you with the things that are important to you.

They provide emotional and mental health support, and support to get back to your family, friends, work, college and the things you enjoy in life.

Staff may also have had some extra training to prescribe medication or offer talking therapies. They will support you to get the things you want sorted.

Psychiatrists are doctors like your GP, who are specialists in mental health. They can prescribe medications and can discuss diagnoses with you. They can also advise on practical things like whether it's OK to drive when you're taking medicines.

Psychologists offer talking therapies that help you (and your family) to make sense of what's been happening for you and how to deal with it. They can also help with memory and thinking problems.

Pharmacists advise on medicines, drugs and side effects.

Nurses advise you (and your family) on medicines, health and mental health.

Occupational therapists (OT) can support all the things that you do (occupations) at home, in work, in relationships and in communities.

Social workers can support you to get access to services, social activities, education and work, especially if you feel that you don't have many options.

Support time and recovery (STR) workers can come with you to help sort things out like shopping, money, social things, appointments or even exercise. A few services also employ peer workers who have had psychosis in the past and can talk with you about psychosis and getting over it.

You can find out more about the individual backgrounds and training of particular professions and what they can offer, as well as hearing from EIP workers in our services, on the 'meet the team' section of our website likemind.nhs.uk



“ I had a really, really good consultant and care coordinator who were just so understanding and the way that they approached it was in a very caring manner. They made me feel as though I wasn't unwell, I was still normal. They made me feel like, anything was possible and that if I wanted to achieve something, after this episode, that it was fine. It just felt like they were on my side the whole time. ”

Tembe, 18

Specific treatment options and advice

The most common specific treatment options are medicines and talking therapies.

In EIP, some of the most common medicines are Aripiprazole, Olanzapine, Quetiapine and Risperidone, but there are others. They all work in similar ways in the brain but can feel different to take.

Some may suit one person better than others and so discussing the options with a doctor, nurse or pharmacist is important.

There are also different types of psychological or talking therapies.

Cognitive behaviour therapy aims to reduce distress and help you get on with your life by looking at thinking and behaviour patterns.

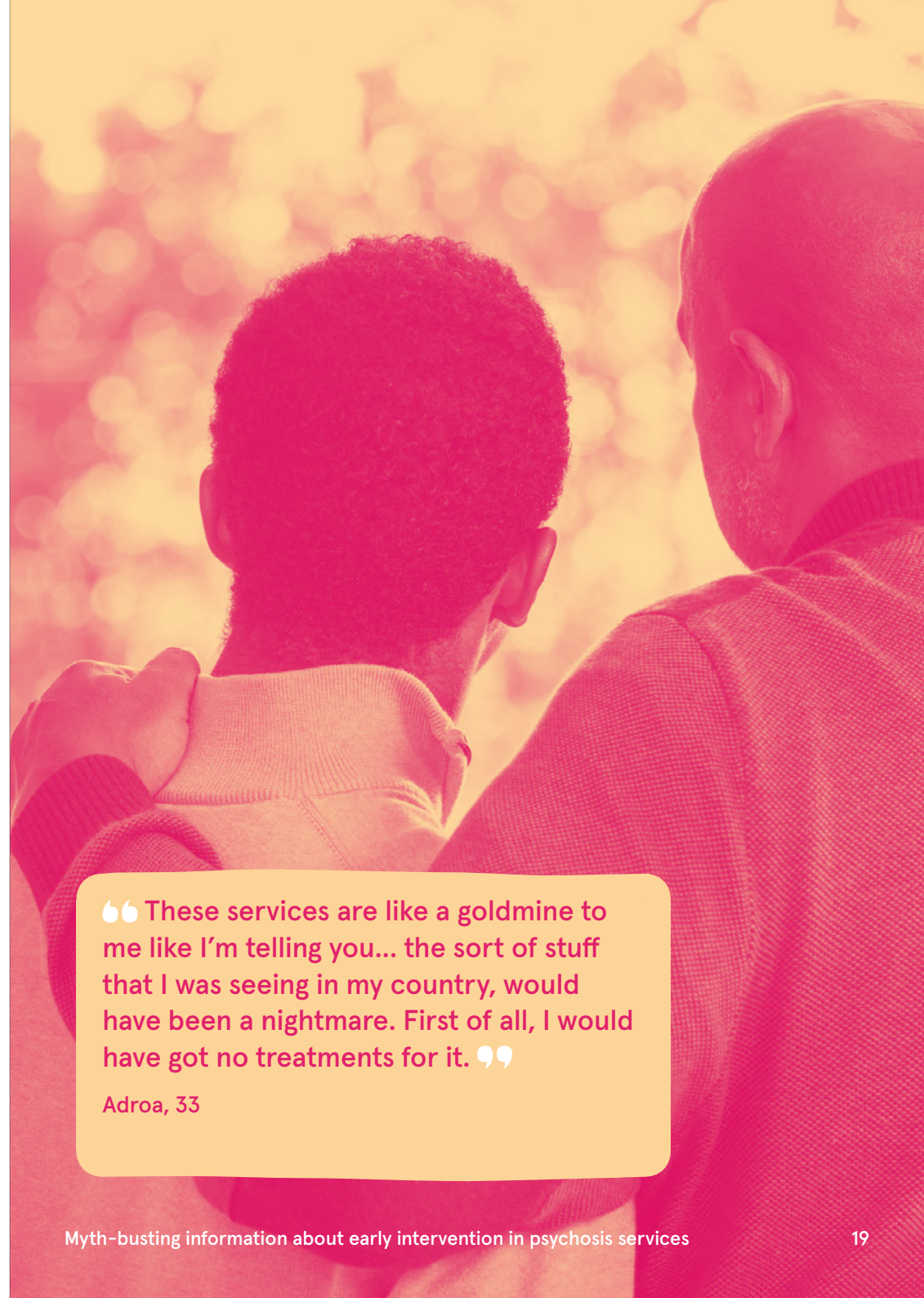
Family intervention aims to reduce stress and tension within families after psychosis. Family Intervention also reduces the chances of getting another episode of psychosis.

All of these treatment options are recommended by the National Institute for Health and Care Excellence (NICE) because they are helpful for young people with unusual distressing experiences. Arts therapies might also be helpful especially if you've stopped doing a lot of things recently and are finding it really hard to feel motivated.

You can decide what treatment is best for you and you can get advice in our 'Treatment choices booklet'. You can get a copy on our website at [likemind.nhs.uk](https://www.likemind.nhs.uk)



Your care coordinator can help you to choose and adapt treatments to fit with your (and your families) cultural, religious or spiritual beliefs and practices.



“ These services are like a goldmine to me like I’m telling you... the sort of stuff that I was seeing in my country, would have been a nightmare. First of all, I would have got no treatments for it. ”

Adroa, 33



How to get help

People are most likely to start having unusual and distressing experiences in their late teens or early 20s but this can start in your 30s or later. EIP services work closely with GP surgeries, schools, colleges, universities, drug and alcohol services and other local young people's health and mental health services. So you can start to get help from any of these.

If you or the person you talk to think you may be having some unusual distressing experience like psychosis: try to talk to someone you trust, they can contact a local EIP service. There are EIP services all over the country, aiming to meet you as quickly as possible, often within a few days, to try to help. If you don't have anyone you feel safe enough to talk to, or you are worried about telling your friends and family then you can contact the service yourself to talk to someone if you want to!

What happens when the service ends

EIP services normally offer a service for two to three years. This doesn't mean your problems are really severe, it's just what's offered to everyone. Research says that young people do best after these experiences if they get support for this long. You can use EIP services during this time to help get any part of your life where you want it to be.

At the end of two to three years, most young people don't need support from anyone and just carry on with their life. This is what the EIP service aims for as it tries to make sure people feel independent and confident. At the end of two to three years, some people do need a bit more on-going support either from their GP or from standard adult mental health services. The EIP service can help you to decide what's going to be the best thing for you.



Do tell your care coordinator what's important to you, including things you want to do in the next few months or years. If there are things you especially like or don't like about life or about the service, or you have important cultural or spiritual practices to consider, do tell them. That way they can do things that are right for you!

Things to expect, things to ask

You should be invited to meet someone from EIP within a week or two of contacting them.

You can ask about who you're going to meet and where you're going to meet. If you don't like the arrangement you can ask to meet someone different or somewhere different and the service will try to help if it can. If someone else contacted EIP for you, you may be visited at home. Hopefully someone will give you this booklet which tells you more about the service.

An EIP assessment may take a little while. Someone will try to give you advice and support as fast as they can, but sometimes it will take weeks or months to get to know you and understand what the difficulties are.

You might need to explain things a few times before somebody gets to understand you properly, so you might need to be patient at the start.

Most people find that they get on well with their care coordinator, but if there's a problem with them you can ask for a change.

Your care coordinator and team aim to listen, to hear you and to treat you with respect. So, if you don't feel listened to and supported do say so, either to your care coordinator or to someone else in the team.

The team will try to be open and honest with you, but if there's anything you want to know or are concerned about don't be afraid to ask, the service is there for you.

Want more information?

This booklet has been developed based on feedback from young people (aged 14–35) who use early intervention in psychosis services (EIP). It has been written with their help. You can get copies of this and other booklets on our website likemind.nhs.uk

There's also lots more information on the website about places to go to get help. You can reach your local EIP service through the person and phone number on page 29.

Where to get help

If you are already in contact with an EIP service the most obvious place to get help is your care coordinator or someone you trust in the team. Alternatively, you could go to your GP, school or college counsellor, religious or spiritual leader or your local youth service, as a start.

Here are some more ideas. There are also some good websites and a lot of them have helplines too, where you can speak to someone, (e.g. Talk to Frank).

Some of them also have self-help stuff on there, so you can start to do something yourself or with a friend. It doesn't really matter where you start. As soon as you start talking, someone can help.

If you want some advice from other people who've had similar experiences, want to see what other people found helpful, or have any advice that you could share yourself, you could have a look on the forum at [likemind.nhs.uk](https://www.likemind.nhs.uk)



“ I think if you were to see the information online of what the service offered, that it was all confidential, here to help not to judge, just to make people feel a bit more reassured and just make it as easy as possible to get in touch. ”

Navya, 31

Help lines

Talk to Frank	0300 123 6600 or text 82111
Samaritans	116 123
Childline	0800 1111
Saneline	0300 304 7000
The Mix	0808 808 4884 or text THEMIX to 85258

Self-help resources

talktofrank.com

youngminds.org.uk

samaritans.org

sane.org.uk

childline.org.uk

themix.org.uk

moodgym.com.au

Web-based self-help courses for low mood and depression

littf.com

Free web based self-help course based on cognitive behavioural therapy principles

[likemind.nhs.uk](https://www.likemind.nhs.uk)

This is our website; we're gradually adding self-help stuff all the time



...and remember:

“ One must still have chaos in oneself to be able to give birth to a dancing star. ”

Nietzsche

Your care coordinator or lead practitioner is:

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