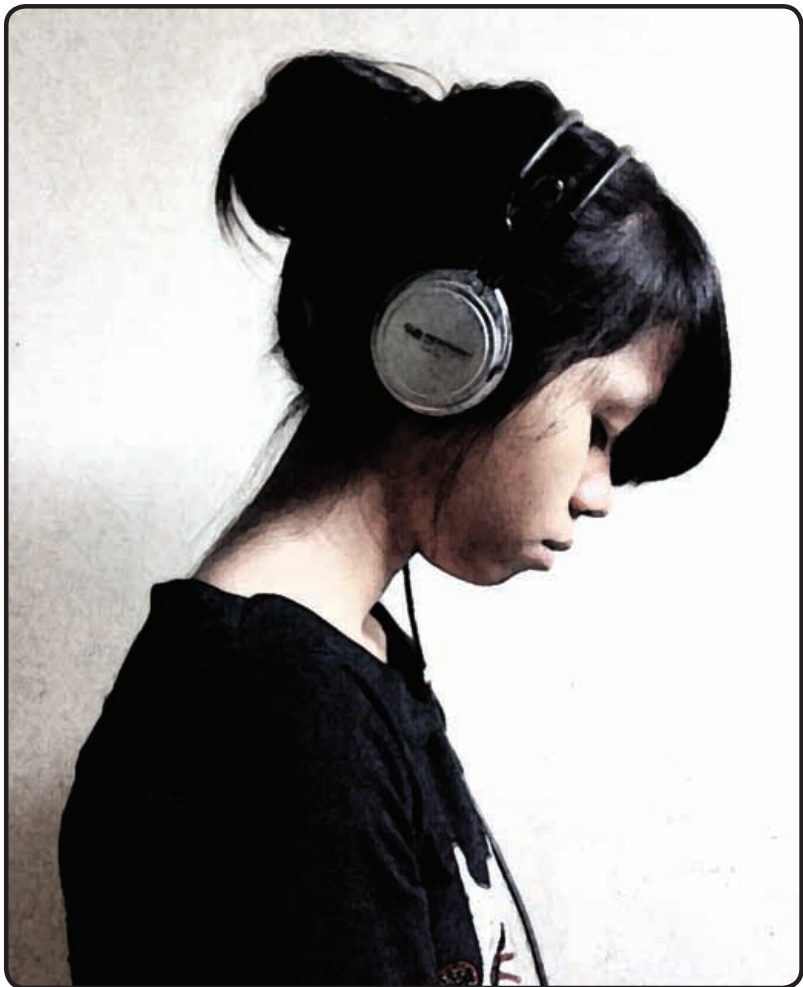


1

VOICES & VISIONS



A straight talking introduction:
for parents, carers and family members of
young people who hear voices or see visions



ABOUT

This booklet has been put together by Mind in Camden's London-wide Voice Collective project. Voice Collective works with children, young people, families and youth agencies across Greater London to help improve the support available to young people who hear voices, see visions or have other unusual experiences.

The information in this booklet has been created by project staff, some of whom have personal experience of living with voices and visions. Whilst developing the booklet we were also guided by parents and carers, and have used some of their quotes throughout.

If you, or someone you know, would like to find out more about our services, please contact:

Voice Collective
Mind in Camden, 8 Fairhazel Gardens
London, NW6 3SG

T: 020 7625 9042

E: info@voicecollective.co.uk, **W:** www.voicecollective.co.uk

Twitter: www.twitter.com/voicecollective

Facebook: www.facebook.com/voicecollective

WITH THANKS TO:

Funders:

BBC Children In Need
City Bridge Trust
Comic Relief

Front Page Reference Image:

sweetcaffeine-stocks
(<http://fav.me/d37ua2j>)

*The information in this booklet is not a substitute for professional advice. If you are concerned about your child - please speak to your GP.

INTRODUCTION

Dealing with a child who hears voices is like going through a process in which the voices are accepted and the child will be supported based on the acceptance. It is a 'searching together'

Dr Sandra Escher, Children Hearing Voices (p1)

So your child hears voices or has other unusual experiences? Don't panic! You are not alone and neither is your child.

Many of the parents we work with tell us that they feel overwhelmed. Understandably, they often search for answers on the internet - but sometimes find the information they receive both confused and confusing.

Did you know that around 8% of children and young people hear voices that others don't? Many more (up to 75%) have one off, or transient, experiences in their childhood. Most aren't bothered by these experiences, and they don't need extra support from mental health services.

However, even when the voices and visions cause a problem - **there is hope**. Research shows that 3 out of 5 young people may stop hearing voices within three years. Even those who continue to hear voices can learn to cope with these, going on to live a full and happy life.

This booklet is intended to give you some sensible and honest information about voices and visions to help you better understand what your child is experiencing.

It is the first of a series of four; each tackling issues parents/carers have told us are important to them.

THE EXPERIENCE

Always be there for your child, however tough it becomes. You are the one they most rely on and trust. Follow your instincts and remember you know your child better than anyone else

Anne*, Parent of a child supported by Voice Collective

WHAT ARE VOICES AND VISIONS?

When we talk about voices and visions, we mean any experience a young person has when they hear, see or sense something someone around them doesn't. These experiences can include all five senses, hearing, sight, smell, taste and touch.

For some, this experience can be reassuring. For example, a young person who has recently moved house and feels isolated at school might value a voice that is there for them when they're feeling down. For others, it can be confusing or frightening and cause distress.

WHAT'S IT LIKE?

We are all unique. The way young people experience, and react to, voices and visions is individual. The following is an overview of the kinds of experiences young people often tell us about.

If you want to find out more about your child's experiences, it can be helpful to ask them if they want to talk about it. Some young people will feel uncomfortable or embarrassed talking about voices and visions - but many are happy to open up once they know you're ok to listen to them.

Hearing Voices

I hear a little girl who's scared. She cries sometimes, and I feel sorry for her. I also hear a man's voice who tells me I'm no good. He's worse when I'm struggling at school.

Some people hear voices talking when no-one is around. These could be like the voices of people they know, or complete strangers. They might hear many voices, or just one. Voices can shout, whisper, be clear or muffled. They can speak in sentences or say single words. These voices can be male, female, old or young. Sometimes they have names, but not always. People can hear other types of sounds too, including knocking, crying or music.

Some voices can be positive - encouraging or supporting you. Others may say things that are confusing or distracting, perhaps echoing thoughts or repeating strange phrases. Some voices can be very frightening, saying things that are critical, threatening or commanding. Others are funny, saying things that make you laugh.

Seeing Visions

I sometimes see people's faces change. One minute they look normal and the next they look like stone statues. It freaks me out.

Some people see things that others don't. These visions can be very clear and realistic, but they can also include fuzzy shapes, shadows and beams of light. Sometimes, it can seem as if people or objects around you are changing shape. As with voices, these visions can be reassuring, funny, frightening or distracting.

Smell

Once, when I was travelling home on the tube, I started to smell something horrible. I thought we were being gassed

Some people smell things that remind them of their past. This could be something nice, like a favourite food or their mum's perfume. Sometimes, when a child has been through a difficult or traumatic experience, they may smell things related to this experience. For example, a child whose house burned down may smell smoke when they are anxious. This can be very frightening, especially if the child doesn't realise that this sensory experience belongs in the past.

Sometimes the smell isn't linked to a particular memory, but can still be very worrying. For example, some young people smell gas, burning or rotting food. These smells can feel very real and leave them fearing for their safety.

Taste

There are times when my tastebuds go a bit strange. I try and eat things, but everything tastes like it's gone off.

It can be difficult to know if you're tasting something that others can't - unless you taste something in your food and get someone else to try it too. This can make taste experiences particularly difficult to deal with.

Some young people get a strong bitter taste in their food or drink and, understandably, start to worry that there is something wrong with it. Others may taste things when they are not eating or drinking. They may taste

something pleasant (like chocolate or a favourite food) or something they dislike (perhaps something bitter or metallic).

Feeling (touch)

I get worried that there's something in the back of my neck. The more I think about it, the more I can feel it

Some people can feel things on their skin when there doesn't seem to be anything there. They might feel something crawling over their skin, tickling them or pushing them. Sometimes people feel something underneath their skin, and this can lead them to feel really worried about what is happening to their body.

Understandably these experiences can be very confusing and frightening. It's not as simple as this, though. For others, these experiences can be reassuring. For example, a young person who feels upset and lonely may feel reassured by a gentle hand on their shoulder. They might interpret it as a sign that someone is there to support them.

Or any combination of the above

Whilst some young people experience these things in only one of their senses, many have a combination. For example, they may both hear and see someone speaking to them. They might have a strange taste in their mouth just before they see a vision. They may both see, and feel, something on their skin.

The above is only a sample of the range of experiences young people can have. If you're unsure what your child is experiencing, the best thing to do is ask if they feel OK talking to you about them. Show them that you're interested in what they have to say, and stay calm even if their experiences sound very unusual. Remember that lots of young people have experiences like these. Your child is not alone.

HOW CAN IT AFFECT YOUNG PEOPLE?

We are all unique, so voices and visions affect each of us differently.

The negatives

For some, hearing voices or seeing visions can be a scary and overwhelming experience. If the voices or visions are distracting, or the young person copes by going inside themselves, they might get into trouble at school for not paying attention. They might find themselves getting frustrated easily, getting in to arguments or lashing out when it gets too much.

Others react to the voices by withdrawing and spending lots of time alone. Some develop ways of coping with their distress that can seem odd or unusual to others (counting, checking and completing rituals, for example).

If they are confused about the things they are thinking, feeling and experiencing, a young person may develop unusual beliefs. Whilst these can be helpful, providing a narrative or story to explain their situation, they can also result in more distress. Beliefs that leave the child powerless (e.g. government conspiracies) can cause a lot of fear and paranoia.

Negative voices can chip away at a young person's self esteem and confidence. Attempts to manage feelings of hopelessness and powerlessness can include self harm, eating distress and substance misuse. Some young people hear very scary voices that threaten the people they care about, or tell them to hurt themselves.

Most of the young people we meet at Voice Collective tell us that they feel weird, freakish or wrong. In our society, hearing voices is associated with so many negative media stereotypes that many feel unable to talk with their closest friends or family about what's going on for them. Others have already been bullied for being different or struggling with mental health problems.

The positives

For some people, hearing voices or seeing visions can be a positive or helpful experience. Imagine being alone in your room at night, feeling worried about an exam at school when a familiar voice tells you that it's going to be ok, or makes you laugh. Some young people hear voices that give good advice, or keep them company when they're lonely.

Voices can be creative, helping give the young person ideas for poetry or artwork. Some writers, for example, say how the characters in their story speak to them and tell them what to write. A skill like that can be a wonderful asset.

Even distressing voices can have positive effects. A young person who can stand up to commanding or nasty voices is someone who can use those skills to assert themselves with bullies. Whilst critical voices can devastate a child's self esteem, learning to deal with these can help a child become more sure of their identity and strengths.

Rather than seeing difficult voices as a purely negative experience, it's helpful to remember that they are there for a reason. Difficult voices are usually linked to things that the young person is struggling to cope with. The positive impact of negative voices can, with the right support, be the young person and their supporters dealing with that problem.

The middle ground

For many young people, the voices are neither wholly positive or negative - they are somewhere in the middle.

Young people can, and do, find ways of coping with any negative or difficult effects of their voices or visions. With the right support, we've seen young people grow and take control of their own experiences and get on with their lives. That members of the Voice Collective project team have their own experience of hearing voices is proof that negatives can be turned to positives. **See our recovery booklet for more information.**

MAKING SENSE OF VOICES AND VISIONS

You know your son/daughter better than anyone. You should never doubt your judgement, or be afraid to ask for advice, support and help

Anne*, Parent of a child supported by Voice Collective

WHY DOES IT HAPPEN?

As frustrating as this may be, there is no single answer to why children and young people hear voices or see visions. There are lots of different ideas about this, so the important thing is to find an explanation that makes sense to you and your child.

Some possible explanations:

Trauma / difficult life events: This can include being bullied, changing schools, problems at home (divorce or arguing), abuse, bereavement, physical illness, being the victim of, or witnessing, a crime - anything that makes a child feel overwhelmed or powerless. These events can leave a child with powerful thoughts and feelings that can be linked to the voice or vision in some way.

Spiritual experiences: Some people hear the voice of God or other beings. For some, this can be life-affirming, but for others it can be very scary. Different religions and belief systems have their own ways of responding to these experiences, but it is good to remember that a voice claiming to be God or a demon isn't necessarily telling the truth. If you, or your child, believe that they are having a spiritual experience it can be helpful to consult with a reputable spiritual advisor for guidance.

Individual difference: For some people, hearing voices or seeing things is just part of who they are. It's like having green eyes or being left

handed. However, when young people are under stress these experiences can change and become difficult to cope with. This is a sign that they need extra support.

Special gift or sensitivity: Many cultures believe spirits can talk to humans. Some people believe they have a gift that helps them talk to ghosts and spirits. It can however be very confusing to develop this gift and your child may need support in doing this.

Emotional health problems: For some people their voices and visions can be triggered by how they're feeling. For example, someone who feels really anxious may hear voices telling them they're in danger. A young person who is struggling with feeling low, perhaps diagnosed with depression, may hear voices that tell them that they're a bad person and should be punished. Someone who is struggling with an eating disorder may hear a voice telling them not to eat, or to binge and purge.

Physical health problems: Our state of mind is related to the state of our body. Not sleeping, being isolated, having a fever, epilepsy, severe infections and head injuries can all cause voices and visions in some people. See your GP if you think there may be a physical cause to your child's experiences - they will be able to advise you.

Legal and illegal drugs: The substances we put in our body can affect our state of mind. Cannabis has been linked to the onset of voices and visions in some people. Others may feel their experiences are linked to heavy use of amphetamines or cocaine (drug induced psychosis). These experiences can be very intense, but are often short-lived.

In some cases, voices and visions can arise as rare side effects from prescription or over the counter medication. This includes some strong pain medication, antibiotics, antidepressants and antimalarials. If you want to find out more, please speak to your GP or a pharmacist.

What about psychosis and schizophrenia?

Psychosis is just a word. It has no power to change the future or the past. See your child, not the label

Desmond*, Parent of a child supported by Voice Collective

Psychosis is simply an umbrella term that is used when young people are struggling with voices, visions or unusual beliefs and seem to be out of touch with reality. This term is also used when people seem to have very muddled or confused thinking, which can make it difficult for the people around them to understand what they are saying.

Whilst this term may sound very frightening, it can be helpful to see it as a description of a state of mind rather than a predictor of future problems. Stress, trauma, drug use, overwhelming spiritual experiences and physical health problems can also cause periods of psychosis. With support, the young person can deal with the underlying issues and recover.

Some parents worry about whether their child has schizophrenia. With so much negative media coverage, this diagnosis carries a lot of fear and stigma. Doctors may use this diagnosis when someone has more long term difficulties with voices, visions, beliefs and muddled thinking - but it is rarely used for children and young people in the UK. When a child has severe problems it's much more common for professionals to speak in terms of psychosis, anxiety, depression, PTSD or emotional problems.

Many young people who hear voices are not diagnosed with psychosis or another mental health problem. However, if your child is given a diagnosis - try to remember that these are merely labels and cannot predict the future. At Voice Collective, our manager was diagnosed with schizophrenia as a young adult. She now works full time, is no longer unwell and lives a life she loves. No matter what the problem is - recovery IS possible.

A MORE HELPFUL QUESTION

The range of potential causes can feel quite confusing. Some parents find that they tie themselves in knots trying to understand why this is happening to their child. The problem is, no-one can give you a definitive answer to why your child is hearing voices (the root cause). Different people, different doctors and different researchers will have different ideas.



Given that many young people don't have problems with hearing voices or visions, a more helpful question is: **Why do some young people hear voices that they struggle to cope with?**

VOICES, VISIONS AND EMOTIONS

Whatever their root cause, difficult or distressing voices tend to be related to difficult or distressing feelings (including fear, guilt, anxiety, powerlessness, insecurity and anger). These feelings can stem from life experiences that the young person has not been able to deal with.

If your child is struggling with voices and visions it is helpful to think about what may have happened, in their past or present, that could be troubling them. Sometimes this is obvious, for example, you may know that your child has been bullied at school or has lost someone close to them. They may have experienced some form of abuse, or be struggling with their schoolwork. Other times, it is less clear and needs some investigation. In this case, it is worth seeing the voices as messengers. The things they say, and their underlying themes, often point to difficulty itself.

Escher describes hearing voices as 'mostly a reaction to a situation or a problem the child or young person cannot cope with. It is a signal.' So, if your child is struggling with voices it is important to help them to find someone to talk to about their feelings - so that they can deal with any underlying problems.

SUPPORTING YOUR CHILD

Listen to your child and take them seriously but don't forget to look after yourself too

Jo*, Parent of a child supported by Voice Collective

Once the problems underneath difficult voices are addressed, many young people find that the voices they hear either disappear completely or become more helpful. Others find that the voices stay the same, but they themselves have become more confident and feel able to cope with experiences that previously overwhelmed them.

TOP TIPS

Don't Panic: The most important thing you can do is to stay calm. Although this may seem difficult, it is vital you show your child that you are not afraid of the voices they hear and don't see them as 'mad' or 'crazy'.

Believe Them: Hearing voices and seeing visions is a really common experience in childhood - so, if your child says they're hearing voices it's likely that they are. Young people can be very sensitive to the reactions of the people closest to them, so show them as clearly as you can that you're taking what they say seriously, even if it sounds unusual.

Space To Talk: It's hard to make sense of experiences if you keep them inside. So, if your child would like to talk about their voices, visions or feelings - encourage them to do so. Ask them whether they would like to tell you more about what's going on for them, and show that you're interested. Really try to listen to what they are describing, asking them questions if they find it helpful.

If your child's beliefs or experiences sound strange, try and listen without judgement. Remember that they're trying to describe, and make sense

of, experiences that are quite extraordinary. Under the circumstances, unusual beliefs are quite understandable. Try not to get caught up in arguments about logic and reality - if you're unsure how to respond just focus on how they are feeling.

If your child finds talking difficult, then explore other ways of helping them to open up. Some young people find it easier to talk whilst they're walking or doing an activity. Others prefer to write or draw about how they are feeling, and then show it a parent afterwards. There is no right way to communicate - find a method that works for you and your child.

Avoid Assumptions: If your child is distressed and tells you they hear voices it's easy to jump to the conclusion that the voices are causing the problem. This is understandable, but it can mean that the real problem your child is worrying about can go unaddressed (e.g. bullying or problems at school). Try and be open to whatever your child wants to say to you, and check things out if you're unsure what they mean.

Hold The Hope: Struggling with voices can make your child feel isolated and different from the people around them. They may worry that they're going 'crazy', so it can really help to know that these experiences are relatively common (1 in 12 young people hear voices) and that they do not always lead to mental health problems. Even those who are overwhelmed by voices and experience psychosis can, and do, recover and live the life they want to live.

Coping Strategies: If your child is struggling, there are lots of simple ways that they can begin to deal with difficult experiences. In general, strategies that promote feelings of safety and deal with the underlying difficult emotions are most helpful. As a parent you will already have ideas about how your child copes with stress; your child will have some good ideas too. These strategies can help with voices and visions. **See our website or 'Guide To Coping & Recovery' booklet for more ideas.**



our services



Around 8% of children and young people hear voices or see things that other people don't. It's much more common than many people think.

Voice Collective is a Mind in Camden project that works in partnership with youth services across London to help ensure that these children, young people and families get the best support possible.

W: www.voicecollective.co.uk, E: info@voicecollective.co.uk, T: 020 7625 9042

FOR YOUNG PEOPLE

If you hear, see or sense things that others don't and are 18 or under, we can offer:

- Peer support groups, so you can meet with other young people
- Creative workshops, where you can learn new skills and have some fun
- 1-2-1 support around making sense of voices and finding coping strategies (email, phone and in person)
- Information & signposting, to help you find the right services and support for you
- Online support forum
- Website, including lots of information and ideas to help you understand your experiences and find ways of dealing with them
- Support for your family, school or youth workers

"Without the group I would be isolated. I used to think I was the only person this is happening to, that I was freakish or wrong. It helped me realise that there are other people. It normalised it and made it less inhuman"

- Andy*, Aged 16

FOR WORKERS

A large part of our service involves supporting schools, social services, CAMHS & other youth agencies to work with children & young people who have these experiences.

We are flexible in what we offer, so do get in touch to explore how we might work together.

- Coaching and training for staff to support staff already working with a young person who hears voices
- Awareness raising (including PSHE lessons and workshops for staff)
- Help developing written information, policies and guidance around supporting young people who hear voices

FOR PARENTS / CARERS

If your child hears voices, we can offer:

- Support workshops, so you can meet with other parents, share experiences & get new tips
- 1-2-1 support to help you make sense of your child's experiences and think of ways of helping them cope (email, phone & in person)
- Information & signposting
- Website & online support forum

You have brought us 'normality' within these experiences. You have taught us that with the appropriate support young people can lead happy and successful lives. You recognise the love we have for our children and have taught us how to support them"

- Sue*, Mother of a 12 year old