

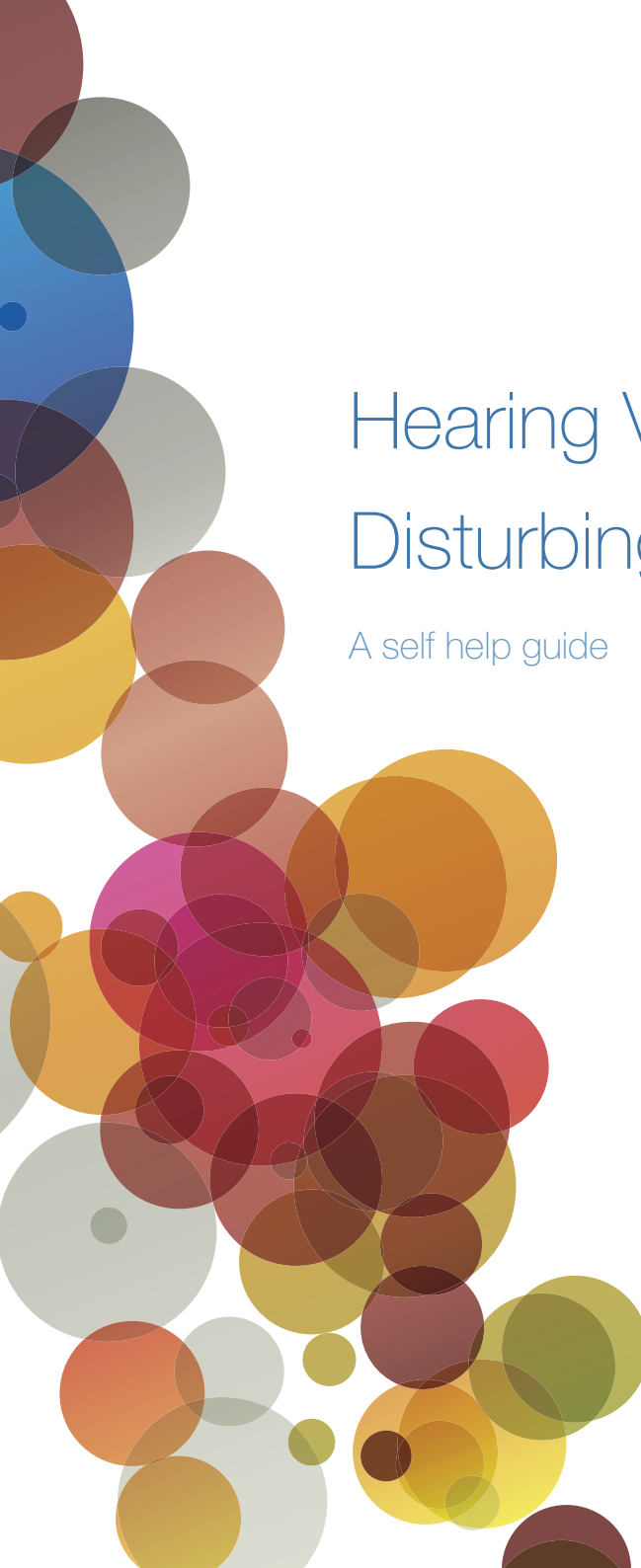


Camden

Clinical Commissioning Group

Hearing Voices and Disturbing Beliefs

A self help guide



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Who is this guide for?

This guide is for people who experience voices or disturbing beliefs. But you may not be sure whether you need to read this. Some people hear voices and are quite happy with the experience – if you are one of these the booklet may not be particularly relevant to you. If, on the other hand, you feel confused, reading it may be a start to making sense of what is happening to you.

It is important to remember you are not on your own: there are people who have been through this before you. Perhaps up to 15 percent of people will hear voices at some time in their life, many of whom will not need help.

In order to offer some help, a group made up of people who have personal experience of hearing voices and experiencing disturbing beliefs, and caring relatives, got together to produce this guide to inform other people who hear voices, their caring relatives, friends and anyone else who may be interested. As well as giving you information we have given you space to write in your own experiences.

What causes voice hearing and disturbing thoughts?

For most people there is no simple cause and usually lots of issues and problems continue to make the person struggle. Some things have been shown to increase the risk of hearing voices. These include having close family members who have had the same experiences, having traumatic experiences when young, and using street drugs. Often once difficulties start they become a vicious circle with people sometimes feeling unsafe and avoiding things they normally enjoy. Seeking help early can help break this vicious circle.

What are the early days like?

In the early days you might be very frightened by what is happening to you. These experiences can come on slowly or quickly and this can affect how you react to them. If they come on slowly they tend to be wearing, if they come on quickly they can be a shock. Both can be exhausting.

The voice hearers who seek help usually are distressed by the voices and find it reduces their ability to continue with their routine tasks. If this is the case for you, the sooner you seek help the easier it will be to reduce your distress. You may have to deal with your own misconceptions, as well as those of people around you.

Here are some of the experiences of people who wrote this booklet. You might have some, or all of these experiences, or different ones:

- You may feel tired and lack motivation.
- You may suffer from depression.
- You may experience panic.
- You may experience anxiety.
- You may be in a world of your own.
- You may be staring without blinking.
- You may feel social isolation.

My experiences have been:

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What might the voices be like?

These are sometimes described as hallucinations but the writers of the booklet found the term hearing voices most useful.

- They may be coming out of the air.
- They may be in your head.
- They may be in your body.
- It may be your own voice.
- It may be the voice of someone else.
- There may be more than one voice.
- It may seem like a cross between a voice and a thought.
- The voice you hear may have a specific identity you can recognise.
- Voices can be loud or quiet.
- Voices can communicate many different emotions.
- They may be critical.
- They may be friendly.
- You may hear sounds that are not like ordinary speech, like whistling, whining, singing, humming and murmuring.
- You may have other sensations alongside, like seeing things that aren't there, sensations in your body, or the feeling of a presence.
- You may be able to influence your voices, or anticipate when they are going to occur.
- They may vary in strength and frequency from day to day and over longer time periods.

My voices are:

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What might it feel like to experience them?

Some people find voices are helpful, some do not.

Some positives

- They can provide company.
- They may cheer you up and make you laugh.
- A “good voice” can help against a “bad” one.
- They can help you to cope with bad things that happen in your life.
- They can give sexual enjoyment.
- They can make you feel special.

Some negatives

- They can be very repetitive, particularly if linked to past experiences.
- They can cause paranoia.
- They can be upsetting.
- They may say frightening things about harming yourself or others.

What about disturbing beliefs?

Different people call this experience by different names. Doctors might call it "having delusions". Some people describe it as having “false beliefs” but we have chosen the term “disturbing beliefs” because this experience can disrupt and disturb your life. At the same time for some people these beliefs can be a comfort.

What they may be like:

- You may feel everyone else is out of step - not you.
- You may feel statements on TV or radio refer to yourself.
- You may feel that everyone is against you (sometimes called a persecution complex).
- If you hear voices, you may feel that your beliefs offer an explanation for them.

As a result you may not be able to enjoy things like you used to.

My experiences are:

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All this can back up feelings of paranoia that can develop into a vicious circle, each experience firing off the other.

What do caring relatives and friends need to know?

The caring relatives within the group identified the following as important issues in the early days:

- You may know something is not quite right.
- You may feel in an awful position and not know who to turn to.
- You may feel helpless and not know how to offer help.
- You may find yourself looking at your loved one and thinking “they have changed, they are lost”.

Worries about what people might think – stigma

- You may not want your relative or friend to be labelled.
- You could describe it as having had a psychotic episode.
- You may find people think that the person's parents are responsible or to blame.
- The stigma can be hard on the relative: you may find you can't talk to anyone in case they find out.
- You may or may not find a diagnosis helpful - some people don't want the label whilst some do.

My issues and worries as a caring relative or friend have been:

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Where can you look for help if you experience voices or disturbing beliefs?

You, or people around you, may see a difference in your behaviour. You, or they, may suspect that something is not quite right, but you might not think there is anything the matter.

You might not know what to do, who to see or who could help. There may be a local voluntary group, sometimes called 'hearing voices groups' (see links at end), who you could contact to talk things through. Usually the first contact for help is your family doctor or GP, who would be interested in looking thoroughly at your physical and mental health. Usually it is a good idea to discuss the problem with your GP, who may reassure you or suggest seeing someone with more experience with these problems. If you can get the right help quickly, then difficulties are easier to overcome.

In the experience of the writers of this guide some people find it helpful to make a list of what they want to talk about, before seeing their GP; others don't feel able to do this or prefer not to. Some people find it helpful to take along a relative or friend they feel comfortable with when they go to see the GP; others find it more helpful to go by themselves.

This may lead to you seeing any of the following people (but you can continue to be seen by your own GP throughout):

- Mental Health Nurse
- Mental Health Social Worker
- Psychiatrist
- Psychologist
- Early Intervention Team

Any of the above may be a care co-ordinator. If you have complex needs, this is the person who will be your main contact and who will ensure you receive the care you need and take the lead in your care. Some people may need to come into hospital and for some people, in a crisis, the police may be involved.

Some people will be prescribed medication to reduce the distressing effect of voices and disturbing beliefs. Alternatively, a psychologist may work with the individual using techniques such as Cognitive Behavioural Therapy (changing the way you react to your voices and beliefs) and working with your family.

What if you are concerned about what is going to happen?

You might be worried what will happen to you and about the treatments you may receive.

It may be helpful to know that:

- Treatment methods have improved.
- These days people are offered more choice.
- There is more flexibility and services try and meet your individual needs.
- Not everyone has to go to hospital. This can usually be avoided if you work closely with the help offered in the community.

You may be worried about going into hospital, but remember that:

- This will be for as short a period as possible.
- You may be offered a range of alternatives, for example aromatherapy, art therapy, occupational therapy and psychotherapy as well as the opportunity to join in discussion groups, breakfast clubs, relaxation sessions and more. You will probably also be offered some medication.

You may feel you don't know who to trust

- It may take time to build relationships with the professionals who are helping you.
- It is important to give yourself time to get to know them.

What questions will you be asked?

Different people may ask you the same questions again (i.e. nurse, consultant psychiatrist, other doctors). Here are some examples:

- What has been happening in the last few weeks?
- When did you start to notice that things were changing? What is your general health like, sleeping pattern etc?

They may also carry out some tests. All this could feel a little overwhelming in the first few hours. Don't worry, things do calm down!

What questions would it be helpful to ask?

Our suggestions are:

- Will I need to go into hospital?
- Who can I talk to when I need to talk to someone?
- If I do have to go into hospital, when can my family/friends visit?

My questions are:

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What do caring relatives and friends need to know?

Once the person you care for is starting to get support from professionals you may experience the following:

- If the person you care for is over 18 you can't be told anything without their consent. However services do have an obligation to you, to help support you as a carer. Also they should be prepared to listen to your concerns.
- You may feel that you are being left in the dark.
- You may want to find an answer to why it happened.
- You may find yourself looking back and asking "Why did it happen, what did I do wrong"?
- You may wish "to wrap them up in cotton wool" though you know it is important to support them to be independent.
- You may wonder whether to go with them to the GP or not – we suggest you give them a choice and support them in the way they feel is most useful.
- Some people find that having a carer there is really helpful when taking part in a hearing voices group or other local voluntary group.

- During this time it is really helpful if you can stay calm while you are with your relative or friend even if you don't always feel calm yourself.
- Some people find it useful to be put in contact with others in the same position.
- Many people find it useful to read more about the experience.

My experience has been:

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So how do you keep going?

Different people have different ways of understanding what is happening - it may link to things that have happened to you in the past. It is often helpful to develop a shared understanding of what has happened with the mental health professionals you are working with (they will call this a formulation). It is usually best to avoid rushing to an explanation when you are feeling stressed.

My understanding is:

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What can help you cope with the voices or disturbing beliefs?

These are some suggestions from the writers of this guide. In the early days you won't know what suits you, but after a time you may find out what works for you.

Managing voices

- Headphones and music may help with voices.
- You could talk into a mobile phone if you need to respond to voices.
- Pick and choose a voice to deal with at any point in time (be selective about time and situation).
- Send the voices away on a mission.
- If voices are oppressive, coach them to tone them down.
- Fall back onto your basic beliefs - don't let the voices detract from your basic personality.
- Sometimes you can ignore the voices - sometimes you can take notice of them.
- Keeping busy and distracting yourself can often make the voices more manageable.

This has worked for me:

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Managing disturbing beliefs

We suggest you:

- Take things easy and try to relax.
- If you feel tired, sleep.
- Try deep breathing exercises.
- Go walking.
- Have some trips out (this may be difficult if you are on benefits).
- Take up a hobby.
- Keep your mind occupied.
- Don't be frightened to try something new.
- You may have to look at ways of relieving pressure on your life.
- Yoga and alternative therapies might help.
- It helps to talk to people with a similar experience.
- Eat well.
- If you have spiritual beliefs you may be able to use them to support you.
- Give yourself time to take care of your appearance.
- Give some thought to where you live, the quality of your surroundings - both buildings and people can affect how you feel.
- Work or study as much as you feel able to.
- Many disturbing beliefs make people feel unsafe or threatened. Trying to feel safe and discussing concerns with others can help.

I find it useful to:

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Try and remember you are not the only person with these experiences. As time goes by it becomes easier to cope. You will find ways of dealing with your experiences that suit you. When you are feeling better it can help to talk to people around you about your experience - this will help them cope if you become unwell again.

How can caring relatives or friends help?

The people who are writing this guide think that carers need a lot of patience and tolerance. They can help their relative or friend by:

1. Understanding the experience, as each person's experience is different.

- Watching a video about someone like your relative. In the views of one of the writers of this guide it helps to do this as early as possible and it also helped that the whole family saw it. (see video link)
- Know what it is you are dealing with – know what you can do.
- Get information about where you can go for support and what information you can get.
- Being told what is going on can be helpful.

2. We also suggest you can help by:

- Doing practical things together with your relative or friend.
- Finding people to listen to you and your relative or friend.
- Finding someone you can phone to check questions out with.
- Learning how not to be negative and how to encourage your relative/friend to take their days one bit at a time.
- Recognising that your relative needs independence. You need to know where to draw the line – how much control/help you should give. You can be too kind.
- Trying to be there and being prepared to be flexible about time.
- Knowing you need a break at times.

In the early days it is difficult to see warning signs – it can take a few crises for you and your relative or friend to recognise them. With time you learn to ask for what you want.

3. Remembering

- Professionals should listen to carers.
- Professionals see carers as a useful part of the healing process.
- User groups can be helpful (see list at back) - they are open and listen to each person's experience.
- It can be very frustrating – you know what is happening but others don't listen.
- The trouble is you can't see what is wrong – it is not like a broken leg.
- You don't need to know what is wrong, you just need to hold onto hope.
- It would have helped if someone would say "It is not the end of the world, you will get her back".

I have found this helpful:

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Will I learn to recognise early signs and patterns?

After a while you and your caring relatives and friends and professionals working with you may start to see early signs when you aren't feeling so good and recognise them. The writers of this booklet found it very useful to learn to recognise early signs. Each person's early signs will differ. Some examples of early signs experienced by the writers of this booklet have been:

- Being introverted and lacking in conversation.
- Staring into space.
- Sleeping more or less.
- Talking more or less.
- Avoiding activities that you usually like.

My early signs are:

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How can people go on to achieve personal growth and recovery?

The understanding you gain of what has happened to you can help you in moving on in your life. It is helpful if you believe in yourself and remain hopeful – this may help you to look ahead to the future.

How can I learn more about voices and beliefs?

Some people find it helpful to read and talk to other people to help understand their experience. Here are some suggestions that you may find useful. You may wish to add to it.

Further information

- **Hearing the Voice** – an interdisciplinary study of voice-hearing based at Durham University and funded by the Wellcome Trust. The project website contains useful information about hearing voices, as well as answers to frequently asked questions about voice-hearing and sources of support for people who find their voices distressing.
www.hearingthevoice.org
www.hearingthevoice.org/frequently-asked-questions/
www.hearingthevoice.org/looking-for-support/
- **The Hearing Voices Network** – the leading peer support and advocacy group for people who hear voices in the UK.
www.hearing-voices.org
Email: nhvn@hotmail.co.uk
Tel: 0114 271 8210
c/o Sheffield Hearing Voices Network, Limbrick Day Service,
Limbrick Road, Sheffield, S6 2PE
- **Voice Collective** – a London based organisation that provides information, advice and support specifically for young people who hear voices, their families and carers.
www.voicecollective.co.uk
Tel: 020 7911 0822
- **Intervoice – the international Hearing Voices Movement**
www.intervoiceonline.org
- **Useful videos**
Eleanor Longden's TED talk: 'The Voices in My Head'
www.ted.com/talks/eleanor_longden_the_voices_in_my_head?language=en

Useful organisations

- **British Association for Counselling and Psychotherapy**
Tel: 01455 883 300
www.bacp.co.uk
Offers an information service providing contacts for counselling in England and Wales.

- **Carers UK**
 Tel: 0808 808 7777
www.carersuk.org
 Email: advice@carersuk.org
 Provides information, advice, and support to carers and their families, with useful information for carers who have suffered a bereavement.
- **Healthwatch**
www.healthwatch.co.uk
 Healthwatch England is the independent consumer champion for health and social care in England. Working with local Healthwatch networks, we ensure that the voices of consumers and those who use services reach the ears of the decision makers.
- **Mental Health Matters**
 Tel: 0191 516 3500
www.mentalhealthmatters.com
 A national organisation which provides support and information on employment, housing, community support and psychological services.
- **Mind Infoline**
 Tel: 0300 123 3393
 Text: 86463
www.mind.org.uk
 Provides information on a range of topics including types of mental distress, where to get help, drug and alternative treatments and advocacy. Also provides details of help and support for people in their own area.
 Helpline available Mon - Fri, 9am - 5pm.
- **NHS Choices – Your health, your choices**
www.nhs.uk
 Information about conditions, treatments, local services and healthy lives.
- **Rethink**
 Advice Line: 0300 500 0927
www.rethink.org
 Provides information and a helpline for anyone affected by mental health problems.

- **Samaritans**

Tel: 116 123

www.samaritans.org

Email: jo@samaritans.org

Freepost RSRB-KKBY-CYJK, PO Box 9090, Stirling, FK8 2SA

Provides confidential support for anyone in a crisis.

- **SANELine**

Tel: 0300 304 7000

www.sane.org.uk

Offers practical information, crisis care and emotional support.

Helpline available 6pm - 11pm.

Useful books

- **Recovery: an alien concept (3rd revised edition)**

Ron Coleman

P&P 2011

An exploration of the concept of recovery. Attempts to reflect on the past and learn the lessons of history in the psychiatric system, by exploring recovery and encouraging professionals, clients and carers to begin their own personal journeys towards recovery.

- **Making sense of voices**

Marius Romme and Sandra Escher

MIND

Making sense of voices is a method to explore the problems in the life of the voice hearer that lie at the roots of the hearing voices experience.

References

A full list of references is available on request by emailing pic@ntw.nhs.uk

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- Members of Northumberland's Hearing Voices Groups, their caring families and friends

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Northumberland, Tyne and Wear

NHS Foundation Trust

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