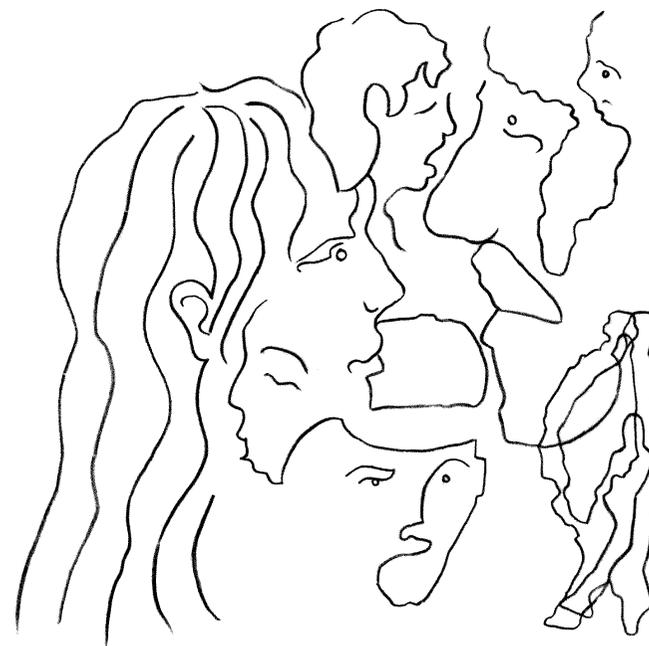


Understanding Voices and Disturbing Beliefs



Newcastle, North Tyneside 
and Northumberland

Mental Health NHS Trust

Designed by the Department of Design and Communication

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Mental Health NHS Trust

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A self-help guide

Who is this Leaflet for?

This leaflet 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 leaflet 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.

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 booklet to inform other people who hear voices, their caring relatives, friends and anyone else who may be interested. This drew on the experiences of the writers of the booklet information gathered that seemed useful. As well as giving you information we have given you space to put in your own experiences.



- "Understanding Schizophrenia" (1997) by the Mental Health Foundation. This a booklet for those wanting to know more about schizophrenia. If you telephone 020 78020300 you can order a copy.
- "Hearing Voices" and "Recovery an Alien Concept" by Ron Coleman. Published by Handsell 01452 380319
- "Making Sense of Voices" by Prof. Marius Romme and Sandra Escher. Published by MIND.

Further booklets developed in Northumberland on topics such as stress, anxiety and depression can be obtained from the Department of Psychological Services and Research, St George's Hospital, Morpeth, NE61 2NU. Telephone: 01670-512121. All booklets can also be obtained from the HAZ website: WWW.northumberland-haz.org.uk



Samaritans. The national number is 08457-909090 or consult the inside cover of a telephone directory. 24-hour service. www.samaritans.org.uk

- Mental Health Matters www.mentalhealthmatters.com

Other websites

- Members: aol.com/DGKingdon/private/voices
The information on this website has been useful in leaflet form to a number of people who are troubled by hearing voices.
- www.mindout.net
This is a government website providing links to other key mental health sites.
- Mad Pride. This is an organisation committed to ending discrimination and promoting survivor equality. www.ctono.freereserve.co.uk

Booklets

- "On learning from the patient: hearing voices" (1996). This is a summary of the coping strategies developed by one woman who has experienced 18 years of managing voices.
- "Hearing Voices" by Pathfinder Hearing Voices Group. (1997). This is a summary of the experiences and coping strategies developed by a group of people from London who hear voices.
- "Hearing Voices" by CONTACT Northumberland and Hearing Voices Group. (1998). This is a summary of the experiences of three Northumberland people.

You can get a copy of these three from Northumberland User Voice. Tel 01670 512121 ext.3698

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.

You might not know this is a mental health problem. 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 leaflet. You might experience some, or all of these, 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.



My experiences have been:

What might the voices be like?

These are sometimes described as hallucinations but the writers of the leaflet 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 be a cross between a male and a female.
- They may be critical.
- They may be friendly.
- You may hear whistling or whining.

They may vary in strength and frequency from day to day and over longer time periods

My voices are:

- Carers UK
Tel. 020 79408818
Helpline No: 0808 8087777. www.carers.gov.uk
This association has a telephone helpline for carers. It works to improve recognition and services for them.
- Young Minds
102 - 108 Clerkenwell Road
London EC1 M5SA Tel: 0800 0182138
- Rethink (National Schizophrenia Fellowship)
Helpline: 0181 547 3937
Advice Service: 0181 9746814 (Mon-Fri, 10am-3pm)
www.nsf.org.uk
This organisation provides support groups, publications and a range of services.
- SANE - This is a confidential helpline offering practical information, crisis care and emotional support 12noon - 2am on Tel. 0845 767 8000 (local rate). www.sane.org.uk
- Rural Minds
Resource Centre
Arthur Bank Centre
National Agricultural Centre
Stoneleigh Park
Warwickshire CL8 2LZ
- Hearing Voices Network. www.hearing-voices.org.uk
Telephone: 0161-228386
This network has set up self-help groups to allow people to explore their experiences of hearing voices.
- NHS Direct. Telephone help line/Health Information Service. Talk confidentially to a nurse or information officer. Calls charged at local rate. Tel: 0845 4647.

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.



Organisations that can support you

- MIND (National Association for Mental Health)
Tel: 020 85192122
Advice helpline: 020 77353505 (London)
0345-660163 (outside London)
www.mind.org.uk
Provides information; local groups offering a range of community supports; legal advice. "Mindlink" is the part of the organisation specifically set up to help mental health service users.

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 "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.
- They can cause paranoia.
- They can be upsetting.

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).

My experiences are:

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, are lost".*

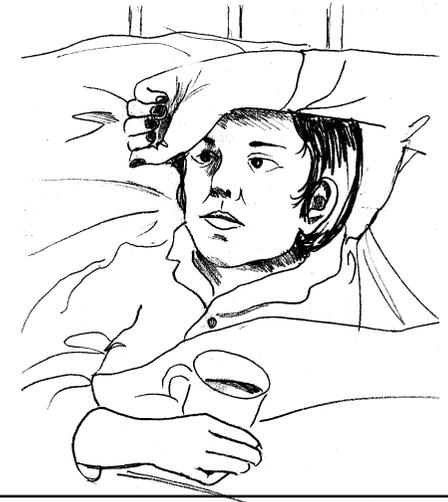
Worries about what people might think – stigma

- *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.*

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 leaflet 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 leaflet have been.

- Being introverted and lacking in conversation.
- Staring into space.
- Sleeping more or less.
- Talking more or less.



My early signs are:

- *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 are just starting to 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:

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

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. The first contact for help is usually 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 booklet 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 coordinator and take the lead in your care. Some people may come into hospital and for some people, in a crisis, the police may be involved.

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.

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.

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 booklet 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 booklet it helps to do this as early as possible and it also helped that the whole family saw it.*
 - *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.*

Managing disturbing beliefs:

We suggest you:

- Take things easy and try to relax.
- If you feel tired, sleep.
- Try deep breathing exercises.
- Have a couple of drinks (but don't over do it and please talk to your doctor about whether alcohol might disagree with your medication).
- 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.

I find it useful to:

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 (ie nurse, consultant psychiatrist, other doctors). Here are some examples:

- What's been happening in the last few weeks?
- What happened to bring you into hospital?
- 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:

- How long will I be there?
- Who can I talk to when I need to talk to someone?
- When can my family/friends visit?

My questions are:

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, Further details can be found in the Northumberland Carers' Guide.*
- *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.*
- *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:

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. If you have an explanation that you feel comfortable with, it is more likely to be helpful to you and you are more likely to be able to keep going.

My understanding is:

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

These are some suggestions from the writers of this booklet. 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.

This has worked for me: