Participant FAQ V2 15.05.23 IRAS: 322330



Frequently Asked Questions for Participants and Their Voices

If you decide to take part in the study, there is a 50% chance you will be offered the Talking With Voices therapy. This information sheet is to try and help answer some of the queries which you or your voices might have about that if it happens. Please take as much time as you need to read it, and feel free to contact us if you would like to ask anything further.

How common is voice hearing?

Hearing voices can feel like a very lonely experience, but it is actually rather common. For example, it is thought

that approximately 10% of the population hear voices at some point in their lives, which is about as likely as being left-handed. Not everyone is troubled by their voices, but we know that some people (especially those who have experienced difficult life events) can find hearing voices to be a distressing and overwhelming experience. However, we also know that in some cases even people who hear very negative voices can develop more respectful relationships with them and live peaceful, fulfilling lives as voice-hearers. This is one of the things which we hope Talking With Voices might be able to help you and your voices to do.



What happens during therapy?

The start of therapy involves time for you and your therapist to get to know one another. They will discuss different ways of understanding voice hearing and suggest strategies that can be helpful for coping with it. Once you are ready, you will then be asked more detailed questions about your voices, such as what they say and what was happening in your life when each one first started. This will include being asked about painful life events and how the voices might relate to them. This is a process which you may find upsetting, although the therapist will never force you to share any information you don't want to. When you and your voices feel ready, the therapist will then 'talk' with the voices. They will ask questions then ask you to listen to what the voices are saying and repeat their



responses aloud. The aim of this is to understand more about how you and your voices feel about things and to use this information to help you work together to develop a more peaceful relationship. It is very important that both you and your voices feel safe and comfortable with this process, and the therapist will spend time in advance to help make this happen. However, it is still possible that you may find aspects of TwV to be distressing or difficult, and you are free to stop the sessions at any time if you feel it is not right for you.

What 'types' of voices can talk with a therapist?

Many people hear voices which repeat the same words or phrases over again (a bit like a tape recorder) without ever saying anything new. If this is similar to your experience, then Talking With Voices won't be a useful approach for you as it is intended for working with voices that are able to hold conversations, share their opinions, and respond to things the therapist says to them. In this case, you might like to ask your GP, care-coordinator, or psychiatrist about other therapies you could try instead which would be more helpful and suitable for you.

My voices don't want me to talk about them

It is very understandable that your voices may feel this way at the moment. Anything new can seem difficult at the start. However, once you meet the therapist, then he or she will spend time getting to know you and your voices to try and help all of you feel safe and comfortable. Once again, it is very important to know that you are in control of the process; you are free to wait weeks or months before trying to dialogue, and if you decide to go ahead then the therapist will make sure to get everyone's permission in advance. Neither you nor your voices will ever be put under pressure to do something you're unhappy with.



I already tried having a conversation with my voices - and we didn't like it

You are the expert of you and your voices, and we fully respect your decision about what is best for you all. However, for some people it may be the case that speaking with the voices on their own is a very different experience from having a therapist speak to them. This is because the therapist can act as a go-between; someone who works with both you and your voices to try and resolve conflicts and find some common ground. It's a bit like the difference between a couple trying to improve their relationship by themselves, or by working with a marriage counsellor instead.



I want my voices to go away. Will Talking With Voices be able to do that?

We understand that many people want their voices to go away because they are so upsetting. In turn, many voices want the opposite – they would much prefer to stay where they are. In our experience this can create a conflict where neither the voices or the person is particularly happy, and this is something we hope Talking With Voices can help with. As with any therapy we cannot guarantee a particular outcome, including making the voices stop entirely. However, an important goal is to help you to understand the voices better and hopefully live more comfortably with them. For many people this can be an achievable outcome, whether the voices stop or not.

The voices might embarrass me in front of my therapist



Your conversations with your therapist will remain private and he or she will not think any less of you for sharing what your voices say. All the Talking With Voices therapists have been trained to support people who hear voices and three members of the study team, including the joint Chief Investigator, also hear voices themselves. We have a lot of respect for voice-hearers and understand that there is usually a reason for why voices say the things they do. For some people that reason can be linked to negative emotions and life events, and finding out more about these links can sometimes be helpful for both voices and voice-hearer to learn to relate to each other in a different way.

The therapist is the 'enemy' of the voices. He or she will want to get rid of them

It's possible that your voices don't want you to take part in this study because they're concerned that the therapist wants to make them go away. If this is the case, it may be reassuring for them to know that the therapist's goal is to try and engage with both you and your voices. The therapist will spend time trying to understand why your voices are there and what their reasons might be for saying the things they do. Although we cannot guarantee it, we hope that this information can then be used to develop a more peaceful, positive relationship. Ideally, this is something that the voices can benefit from too, as well as you as the voice-hearer.



Isn't talking to my voices a bad thing? What if it gives them power over me?

Many people want to resist their voices and not 'give in' to them, usually either by ignoring them or not doing what they say. On one hand, we think it is very important not to obey your voices unless you made an independent choice to do so. However, even if their content is distressing, it may still be productive to listen and try to understand what their meaning is in order to move towards a more equal relationship. We have discovered that even very negative voices can sometimes have an underlying message or function that can be used to make positive changes in the hearer's life – and one way of doing this is to try and make sense of their messages through speaking with them. Your therapist will be on hand to support you and your voices with this process and will always be happy to answer any questions you might have.

My voices might be aggressive to my therapist

We know that some voices can hold a lot of anger and (just like angry people) can express this in quite a hostile



way. Your therapist will be prepared in advance for this; he or she knows that you listen to similar content for perhaps hours a day and will feel honoured to have a chance to support you in dealing with it. As such, the therapist will not be shocked or offended by voices which (for example) swear, say rude things, or are very argumentative. An exception to this is threats of violence or physical aggression, which will not be accepted. However, you, your therapist and your voices will have as much time as you need to plan the dialogue to ensure it feels safe for everyone involved. This will include planning how to end it early if needed, choosing which voices to speak with, and developing strategies to make sure you feel fully in control.

The therapy focuses on discussing events from my past. I'm not comfortable with that – and neither are my voices

It's true that Talking With Voices involves asking you about negative events in your life, and we understand that this can feel very stressful. You may have things you prefer to keep private, or it might be that certain events feel

too upsetting to discuss. The reason we have these conversations is because we have found it can sometimes be helpful for people to have the support of a therapist to work through the emotions/memories linked with these events. However, you will never be forced to share something you don't want to, and no one will be angry with you if there are certain things you prefer not to talk about. During the dialogue, the therapist will also check that the voices are comfortable with what is being disclosed. For example, it may be that one voice wants to talk about a negative life event while another voice would prefer the information to be kept private. In this case, the therapist would work with you and the voices to try to find a compromise that everyone feels safe with.



What if my voices won't speak during the session?

We sometimes find voices refuse to talk to the therapist at first, or simply don't 'turn up' during the session. If this happens it is nothing to worry about. Over time, the voices may grow more comfortable with having a conversation (for example, they might have concerns or questions that the therapist can help with in advance), or they and/or yourself might arrange for the therapist to leave written questions. One of the therapist's jobs is to support you and your voices to be in a position where you both want to have a dialogue, and they will spend as much time as is needed for everyone to work together to try to make this happen.

What if I agree to take part in the trial and don't get offered therapy?

While we have reason to believe Talking With Voices may be a useful form of support, this has not yet been assessed on a large-scale. This means the involvement of all participants and their voices is equally valuable in the trial as it is very important to compare the experiences of those who have therapy with those who don't. Whether or not you receive therapy, the information shared by both groups will help us in the future to learn more about how to support people who hear distressing voices. If you don't have therapy, you will also still have a chance to meet with a research assistant. You will be paid £20 at each meeting (up to a total of £60) and we hope that you might find these meetings a helpful opportunity to discuss your experiences and how things have been going for you.

I still don't think the Talking With Voices trial is right for me



That's absolutely fine, and it doesn't mean that there is anything 'wrong' with you or your voices. The most important thing is that you feel safe and comfortable with the idea of therapy, and if that's not the case there are other coping strategies and therapies you could try instead. If you're interested, then your GP, care-coordinator or psychiatrist will be able to speak more to you about these. Alternatively, you could ask the person who gave you this letter to put you in contact with someone who can tell you more about other therapy trials which may be taking place locally.

Do you or your voices have any other questions for us? If so, please ask the researcher who gave you this sheet to arrange a time to speak with one of the Talking With Voices therapists.

If you'd like to find out more about support for people who hear voices, please visit:

Intervoice: www.intervoiceonline.org
Hearing Voices Network: www.hearing-voices.org

Hearing the Voice Project: www.dur.ac.uk/hearingthevoice

Mind - Hearing Voices: www.mind.org.uk/information-support/types-of-mental-health-problems/

hearing-voices

Dr Eleanor Longden is the joint Chief Investigator of the Talking With Voices trial and has heard voices for many years. If you would like to find out more about her experiences, then a short video is available to view here: https://www.ted.com/talks/eleanor_longden_the_voices_in_my_head