UNDERSTANDING AND SUPPORTING PEOPLE WHO EXPERIENCE HALLUCINATIONS

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Understanding and supporting people who experience hallucinations

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Executive Summary

This report and related recommendations should be considered vital to any organisation seeking to engage victims, survivors and people with experience of all different types of abuse, oppression, health and illness, loss, distress, and trauma.

With many organisations now moving towards, or aspiring to trauma informed approaches and philosophies, now is the time to explore what we really know about hallucinations, hearing voices, seeing things and experiencing sensations.

For centuries, these experiences have been framed as 'madness', or seen as the 'red flag' for mental illnesses, disorders, and insanity. Despite this, there remains much contradiction in the experiences of hallucinations. For example, why can one person report seeing and speaking to God, and be revered and respected, whilst another can be sectioned and pathologised? Why are some hallucinations accepted, and others penalised?

For this reason, we decided to invite neuroscientist Dr Rachel Marchant to write this resource for us, to explain what she has learned about hallucinations in people who are considered to have 'disorders', and those without. Interestingly, she argues that hallucinations are common, normal, and some studies have found that they occur more frequently in the general public than they do in people who are diagnosed with psychiatric disorders.

This important finding therefore suggests that hallucinations should not be considered the 'red flag' symptom of a mental illness or disorder, but instead, should be explored for meaning, purpose, patterns and causes. Whilst Dr Marchant considers many different neurological, psychological and genetic theories of hallucinations in this resource, she is clear in her anti-pathologising approach. Indeed, as her work progressed, she moved more and more towards a critical position, and she adopted trauma-informed approaches in all her work and lecturing in neuroscience.

In this resource, we consider that children and adults experiencing hallucinations should be supported in trauma-informed approaches that seek to help the person explore, understand and learn about their hallucinations, and what could be causing them to happen. We have developed a set of interactive flashcards to accompany this report, too.

I would like to thank Dr Rachel Marchant for her extensive work on this topic, and for developing something accessible for professionals and individuals as they learn more about hallucinations from a critical, trauma-informed perspective.

Dr Jessica Taylor

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About the authors

Dr Jessica Taylor is the Director of VictimFocus, author, academic researcher, and chartered psychologist from Birmingham, UK. Jessica completed her PhD at the University of Birmingham. Her research explored the measurement and conceptualisation of victim blaming of women and girls subjected to male violence and abuse.

Dr Rachel Marchant is an academic researcher and lecturer from London, UK. Rachel completed her PhD at the University of Birmingham. Her research explored the neurocognitive mechanisms of hallucinations and other anomalous experiences in the non-clinical population.

Introduction to this guide

Who is this guide for?

This guide provides a straightforward and accessible introduction to hallucinations, based in current academic theory and scientific research. It is aimed at anyone who is interested in learning more about hallucinations, whether you have experienced them yourself, you have a friend or family member who has experienced them, or if you're a professional who might encounter or work with people experiencing hallucinations, in any capacity. This guide provides a comprehensive introduction to hallucinations based in current theory and research, covering the "what, who, when, how, and why" of hallucinations:

- What are hallucinations?
- Who can have hallucinations?
- When can hallucinations happen?
- How do hallucinations happen?
- Why do hallucinations happen?

This guide also includes a discussion on medicalisation and stigma, and practical guidance on interacting with and resources for people experiencing hallucinations. After reading this guide, you will have a better understanding of hallucinations, and feel better equipped to discuss them.

This guide is not intended to replace input or guidance from health professionals, or provide a detailed discussion of every topic included. Instead, it aims to provide an accessible introduction that is not overly complex or written in academic or medical jargon.

Why should I read this guide?

Hallucinations are fascinating, but are also very misunderstood. Many commonly-held ideas about hallucinations are not very accurate. In the modern Western world, hallucinations are often viewed as indicators of mental health problems by many people. When we hear the word "hallucination", we might think of something frightening or strange. We might view them as decidedly "abnormal". These ideas come from many places, but a lot of misinformation about hallucinations and mental health comes from popular media.[1,2]

However, although hallucinations can be very unusual, they are not only had by people who have experienced severe mental and emotional distress; they can be experienced by almost anyone, and even by "healthy" people (see Chapter, "Who can have hallucinations?")
Some hallucinations are scary and negative, but people can also have positive, helpful hallucinations. Some people who might have been labelled as seriously unwell due to having hallucinations and other experiences, have found alternative ways of understanding their experiences, outside of traditional medical frameworks.[73] Therefore, there is not an automatic line from hallucinations to being unwell. The reality is much more complicated.

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[1] https://doi.org/10.1007/s10597-010-9309-1

[2] https://doi.org/10.1007/s10597-009-9229-0
[3] National Hearing Voices Network, 2021 - https://www.hearing-voices.org/voices-visions/

Further, hallucinations tell us a lot about how the brain and mind work. For example, they have allowed us to understand much more about how our conscious experiences are "generated" by the brain. With newer models of how the brain processes information, we have come to understand that what we experience is not a simple reflection of what's "out there" in the world, as if our eyes and other senses were like windows. Instead, our minds and expectations significantly influence what we experience. Hallucinations just reflect a different way of processing what is going on for an individual, in their world, at that time. They are just a different version or output of a normal process. If you find this interesting and want to learn the real story of hallucinations, please read on.

It is very common for people who don't regularly interact or work with people experiencing hallucinations to feel uncertain about how to approach them. This might be because of feeling uncertain or uncomfortable, pre-existing biases (compounded by society), or for any number of other reasons. This can result in some misguided reactions[4], which may have good intentions but can be unhelpful. These include:

- **Amusement** – Hallucinations may be viewed as only a "quirk", or people may "humour" individuals without taking their experiences seriously;

- **Uncertainty** – A lack of knowledge or experience may make people feel uncomfortable, or unsure of how best to respond to reports of hallucinations;

- **Disregard** – Hallucinations can be viewed as "just a symptom" of "mental illness", occurring just because someone is "crazy", and so people and appropriate professionals may not take the time to support the individual and investigate the causes and content of hallucinations as important in their own right;

- **Avoidance** – Uncertainty and disregard may lead people to avoid talking about or engaging with hallucinations altogether;

- **Stigmatisation** – Existing stigmas and biases about hallucinations may lead people to negatively judge or label people (e.g., calling them "mad" or "crazy"), which will likely prevent effective communication, support, and intervention where needed.

If you have experienced any of the above, or have had other difficulties in responding to or engaging with hallucinations, read on to discover more about them and what you can do to support individuals who experience hallucinations.

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[4] https://www.health.qld.gov.au/__data/assets/pdf_file/0021/444630/hallucinations.pdf

Important terminology

Several important terms and phrases will be used throughout this guide:

- "**Hallucination**" – this term is explained in detail in the section "**What are hallucinations?**"

- "**Experiencer**" – this is the person who is experiencing the hallucinations. This word is used as shorthand for "a person experiencing hallucinations" throughout this guide. This avoids using words such as "patients" to describe experiencers, which can have clinical connotations (which some people dislike, or which might be inaccurate), imply that someone's identity is defined by their hallucinations, or can be stigmatising. This will be explained and discussed further in the Language section.

  - You can use the word "experiencer" if you want to, or you can use another word or phrase that you are comfortable with (if you are the experiencer), or that the person who is experiencing the hallucinations is comfortable with (if you are not the experiencer). Try to avoid clinical language (unless this is preferred by the experiencer) and stigmatising language.

- "**Clinical**" – This term traditionally refers to anything that is formally part of a clinical or medical model, interpretation, or label. For example, "clinical groups" can refer to groups of people who are receiving support from a medical service or have been given medical diagnoses. An example of a clinical group would be individuals who have been diagnosed with high blood pressure. In research, clinical groups are sometimes referred to as "patients". "Clinical treatment" usually refers to treatment based in the bio-medical model (see below), received from formal health services (such as the NHS). An example of clinical treatment would be medication prescribed by a health professional.

- "**Non-clinical**" – This term usually refers to anything that is *not* formally part of a clinical or medical model, interpretation, or label. For example, "non-clinical groups" can refer to groups of people who are not receiving support from a medical service or who have not been given a specific medical diagnosis. In research, this group can also be referred to as "psychologically-healthy" or "control" groups. However, the distinction between clinical and non-clinical groups of people is often not very clear; see the section "Stigma and medicalisation" for more detail.

- "**Bio-medical model**" – This is the dominant model used in Western medicine to explain disease or health conditions. The bio-medical model proposes that all disease is caused by deviations from "normal" or "ideal" values of different biological measures.[5] Biological factors could include the nervous system, tissues, cells, chemicals such as hormones, and genetics. Taking the example of blood pressure, the NHS in the UK defines normal blood pressure as 90-120/60-80mmHg, and so deviations away from these ideal numbers are labelled as "low" or "high" blood pressure[6]. So, the health condition of high blood pressure has a clearly defined biological measure and cut-off (140/90mmHg or higher). Although modern medicine often incorporates psychological and social considerations to a point[7], at its roots, the bio-medical model "leaves no room within its framework for the social, psychological, or behavioural dimensions of illness".[5]

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[5] Farre & Rapley (2017)
[6] NHS (2019)
[7] Johnstone, L. (2014). *A straight-talking introduction to psychiatric diagnosis.* PCCS Books.

- "**Bio-psycho-social model**" – This model takes into account biological, psychological, and social factors. It is often seen as an alternative or complement to the bio-medical model. The bio-psycho-social model was developed because of the limits of the purely bio-medical model, and includes biological factors as well as psychological ones (such as experiences, thoughts, and behaviours) and social ones (such as family, friends, community, and culture). This model was proposed by George Engel, an American psychiatrist. Engel emphasised that, to understand something, it is important to acknowledge the influences of and connections between all the different levels in a system, and how they interact with one another.[5]

- **Medicalisation** – This term refers to the process of turning "normal reactions and problems… into "illnesses" to be treated by medication", or some other medical intervention.[7] For example, critics of psychiatry might argue that grief has become medicalised in recent decades.[8] Many people would understand grief as a normal and expected process. In the early versions of the manuals used for the diagnosis of mental health problems by psychiatrists, "depression-like" experiences related to grief that were "unduly severe or prolonged" (with no specific time frame) could contribute to a diagnosis of major depression. Later, the time frame was specified as 2-3 months. With the current criteria, the time frame is just 2 weeks.[8,9] The criteria for major depression also previously had a "bereavement exclusion"; if you had recently experienced a loss, your grieving would not necessarily contribute towards a diagnosis. However, in the most recent version of one of these manuals, the bereavement exclusion was removed. For some, this suggests the medicalisation of normal human reactions and behaviours.

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[8] Pies R. W. (2014). The Bereavement Exclusion and DSM-5: An Update and Commentary. *Innovations in clinical neuroscience*, *11*(7-8), 19–22.
[9] Iglewicz, A., Seay, K., Zetumer, S. D., & Zisook, S. (2013). The removal of the bereavement exclusion in the DSM-5: exploring the evidence. *Current psychiatry reports*, *15*(11), 413.

Guide outline

Here is a brief overview of the contents of this guide:

BACKGROUND – A concise but comprehensive overview of the concept of hallucinations, answering the questions: What are hallucinations? Who can experience hallucinations? When and how can hallucinations happen? Why do they happen? This brief introduction is sourced from up-to-date academic literature and scientific research.

STIGMA & MEDICALISATION – This section will cover the medicalisation of hallucinations, with a historical perspective from the origins of psychiatry, as well as the stigma attached to hallucinations and how this influences practice.

WORKING WITH PEOPLE – This section will give practical pointers on how to engage and work with people experiencing hallucinations. It will cover general communication, how to avoid stigmatising language, questions that your clients might ask you (and how to respond), and questions that you might like to ask your clients.

SUPPORTIVE APPROACHES – This section will provide a brief overview of the various options for supporting someone experiencing hallucinations. These can include focusing on lifestyle changes, social networks, psychological therapies, and medication.

RESOURCES – This section will provide some links to various resources that may assist you in engaging and working with people experiencing hallucinations, and that you can visit for more information about hallucinations.

Background

What are hallucinations?

Definition

To properly define hallucinations, we need to first consider how perception (seeing, hearing, etc.) works.

We perceive the world using our senses. These senses detect "stimuli"; sensations, objects, or events in the external world that "stimulate" our senses. Our brain interprets these stimuli so that we can make sense of what is happening, and react appropriately. For example, if we see a tiger running towards us, we can run away from it and survive! However, sometimes the processes that allow us to accurately perceive the world do not work properly, and this can cause hallucinations. Hallucinations are experiences of things that seem to exist in or come from the external world, that do not actually exist in that world. So, **hallucinations are experiences that are not caused by exactly corresponding external stimuli, but that feel just as real as any other conscious experience[10].**

If we are hallucinating, we may think we see a tiger running towards us, even though no tiger exists in the external world. Importantly, though, it is very real to us, and so we may still respond to this experience in a way we think is appropriate – such as by running away! **The image below** shows an example of a visual hallucinatory experience, and how it compares with the external world and someone else's experience.
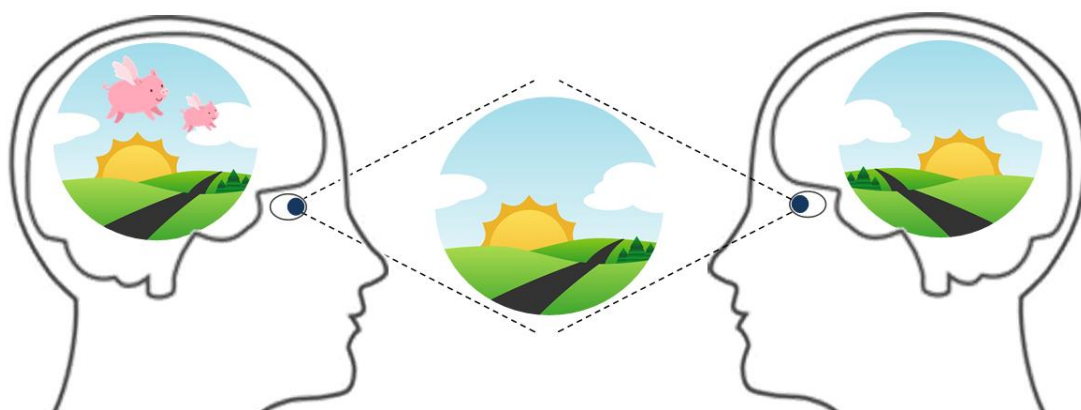
© Rachel Marchant

An illustration of a hallucination (left), where someone's *inner experience* of the world differs from what is *actually present* externally and from other people's non-hallucinatory experience (right). Our brains actively construct our reality, and so two people looking at the same scene can have vastly different experiences – including a hallucinated one.

As we can also see from the image above, **hallucinations are also partly defined as something that is experienced in isolation by one person, with no one else being able to have or access this**

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[10] David (2004)

personal experience. For example, if we can clearly hear a voice talking to us that is not sourced in our external environment, and no one else around us can hear it either, it could be a hallucination.[11]

Hallucinations can happen because our conscious experiences are actually models of the world that are *actively constructed* **by our brains**[12]. When we see an apple, for example, it is not like simply looking through a window (our eyes) at the object. Instead, our brains combine information from the external world (the stimuli), what we expect, *and* our prior experiences, to create our experience of the apple.

From the time we are born, our brains learn the rules of our world and use these to figure out what we are experiencing. This is a very complex process, and so sometimes, it can lead to inaccurate experiences. For example, have you ever thought that you saw a face in a pattern, for example? This is a phenomenon known as "**pareidolia**" – seeing a pattern where no such pattern exists. Our brains do this because, from an evolutionary perspective, it is extremely important for humans as a species to recognise faces or other patterns that have meaning to us[13].

So, humans tend to see faces where there are none – because faces are important information. This is just one way that our brain "fools" us into thinking it is experiencing something, that does not actually exist in the external world. But, we have a very strong experience of the face anyway! See the image below for an example! Can you see the face?
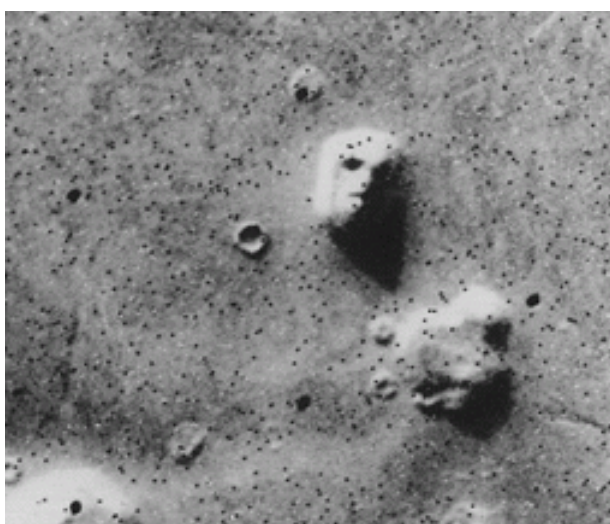
The image on the last page is the "*Face on Mars*". In 1976, NASA's Viking 1 spacecraft took a picture of this part of Mars' surface. One rock looks remarkably like a face. The image has become a popular example of pareidolia. (Source: NASA, 2018).

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[11] The exception to this would be your inner voice. Inner voices can be thought of as representing someone's inner thoughts, or their conscience. These are not thought of a hallucinations because they are generally recognised as generated by the individual (you cause your inner voice), and as being under the individual's control. This is why a "lack of control" can sometimes be a part of the definition of hallucination. However, some people have experiences that for all intents and purposes are hallucinations, but they feel that they do have control over them (Swyer & Powers, 2020, NPJ Schizophrenia). Further, it is not true that we have complete control over our "true" perceptual experiences – for example, when we get a song stuck in our heads, can we always stop our inner voice from playing it? Therefore, a lack of perceived control has not been included here as a part of the definition of hallucinations, because the role of control in hallucinations is not clear.

[12] Panichello et al. (2013)

[13] Palmer & Clifford (2020)

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Of course, the "Face on Mars" turned out not to be a face at all, but a two-mile long rock formation (NASA, 2018). This example shows how **our internal models of the world, and our expectations, strongly influence what we see**. Another good example of this is the "checker shadow illusion" – see the image below. Are the squares marked A and B the same, or different, shades of grey?
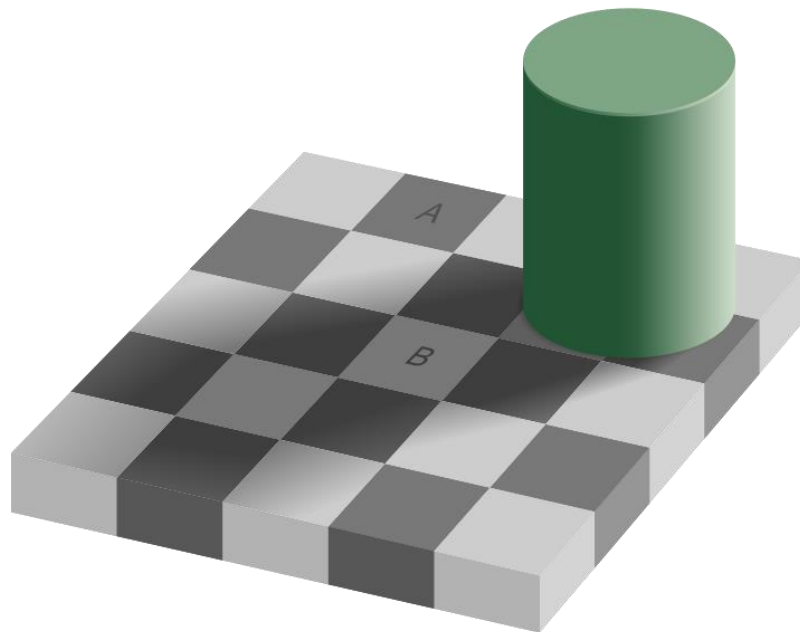
The "checker shadow illusion", created by Edward Adelson. In this illusion, the squares marked A and B appear as different shades of grey, with A being darker than B (Source: The Illusions Index, 2018).

You might be surprised to learn that squares A and B are in fact the <u>same</u> shade of grey! (You can test this by covering up all the parts of the image that surround squares A and B, just leaving these squares visible.) So, why do we see two different shades? Again, our brain combines the actual sensory input (the image) with the brain's own very strong expectations about light, colour, and shadow (which are based on rules we have learned from our physical world). The result is that we do not see the true shades when looking at the full picture.

From these examples, we can see how **the brain creates an imperfect interpretation of the world based on information from our senses, *and* our expectations and past learning**. Our brains are constantly working hard to create an accurate experience of the world, so that we can act accordingly. This model of conscious experience is known as "predictive coding"[14]. Because there are so many complex processes going on to give us a stable and accurate experience of the world, it is easy to see how these processes can sometimes make a mistake, and this could potentially cause hallucinations.

Some important concepts to consider here, related to the above ideas, are "bottom-up" and "top-down" processing in the brain. The brain is a highly complex network, and most of the brain is

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[14] Aru et al. (2016)

actively involved in processing what is going on at any given time. Different parts of the brain talk to each other constantly to support appropriate functioning.

Scientists often classify different types of this chatter, or processing, as "bottom-up" and "top-down". **Bottom-up processing refers to receiving and processing all the incoming information from our senses**. This information is received by our "sensory organs" (such as the eyes and ears) and sent to the brain through nerves. In contrast, **top-down processing refers to the "control" mechanisms of the brain, which influence how we process sensory information and so what we experience.**

Examples of top-down influences are attention, previous experience, learning, and contextual information.[15] Let's take the example of attention. At any one moment, we are receiving a significant amount of information from our bodies and environments – in this moment, you might be able to feel the contact between your body and the surface you are sitting or standing on, you might have an itch or ache somewhere, you might be able to hear several different noises in you environment, you might be able to smell something distinctive, and you may be able to see a lot of different things across your field of vision. However, you cannot pay attention to all of these experiences, all the time! This would be overwhelming, and would not allow you to concentrate on reading these words, or any other task that required your focus. This is just one way that top-down processing influences our experience.

Another good example of how top-down processing influences what we experience can be seen in the illusion example above. There, contextual information and our learned models of the world do not allow us to experience squares A and B as the same colour.

We will come back to bottom-up and top-down processing later in this section. You can read more about how the brain works in the "Brain basics" section of "How do hallucinations happen?".

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[15] Aleman & Vercammen, 2013

Hallucination categories

If you choose to read more about hallucinations beyond this guide, it may help you to know some of the technical terms used to describe hallucinations. Hallucinations are often categorised into "**simple**" and "**complex**" types:

- **Simple hallucinations** are experiences such as flashes of light and colour, spots, or geometric shapes. They do not have a clear, concrete form[16] (see image below);

- **Complex hallucinations** are clearly defined and have a specific form, such as people, animals, or objects[17].

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Example of a "scintillation", a type of simple hallucination commonly experienced during "migraine aura" (a collection of hallucinations associated with migraines). Scintillations are usually seen to shimmer and move across the visual field.

You may also come across some other names for different types of altered perception, such as "**illusions**" and "**distortions**". These are often defined as cases of *misperception* of a stimulus that does exist in the external world. However, although some people use these different categories to define different experiences, they are only a rule of thumb.

There is no clear line between hallucinations and misperceptions, and we still do not have an exact definition of hallucinations that can be consistently applied[10]. The complexity of human

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[16] Barnes & David, 2001 - https://jnnp.bmj.com/content/jnnp/70/6/727.full.pdf

[17] *ibid*

experience does not usually fit into neat boxes or categories. Experience can be thought of as a **spectrum**, running from clear, accurate perception to highly complex hallucination. **The diagram below** illustrates the "fuzzy boundaries" between different experiences.[18] In practice, it can be very difficult to draw clear lines between these. Because incoming sensory information ("bottom-up" processing) is always combined with expectations, previous learning, and other "top-down" processing to create our experiences, different combinations of these inputs will produce different but related experiences.

To further understand why it can be so difficult to make clear distinctions between hallucinations and misperceptions, please see **Activity 1**.

Rachel   ©
                                                                                                                        Marchant
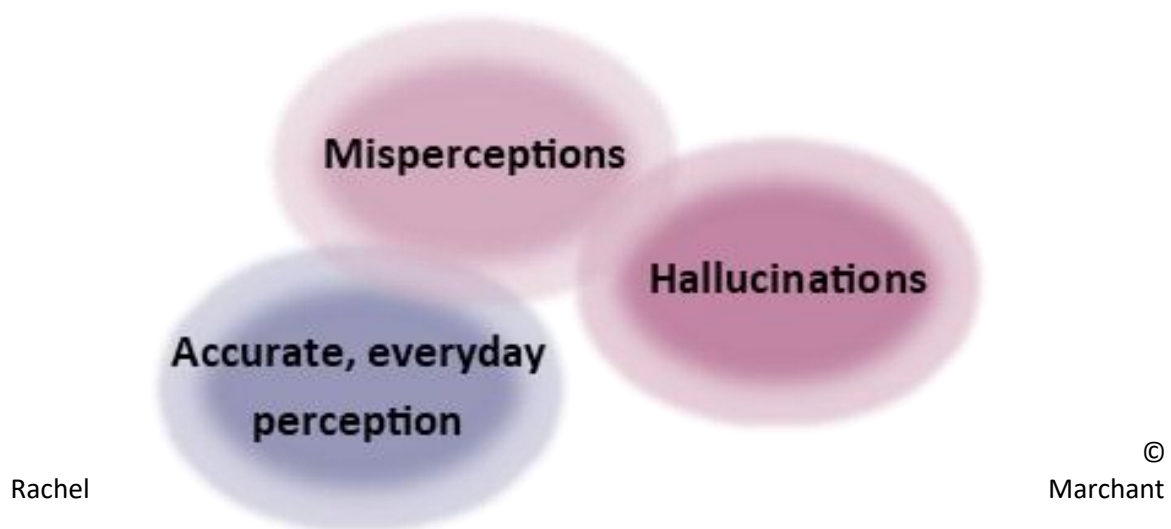
There are no clear boundaries between different experiences. There is some overlap between accurate, everyday perception, misperceptions (distortions and illusions), simple and complex hallucinations, and even dreams[18]. (Diagram inspired by Waters et al., 2016.)

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[18] Waters et al., 2016.

"Balance" between processes

"Bottom-up" processes (e.g. incoming sensory information)

"Top-down" processes (e.g. attention control, expectations)

Sensory overload, Hallucinations

Accurate, everyday perception

Misperceptions, Hallucinations
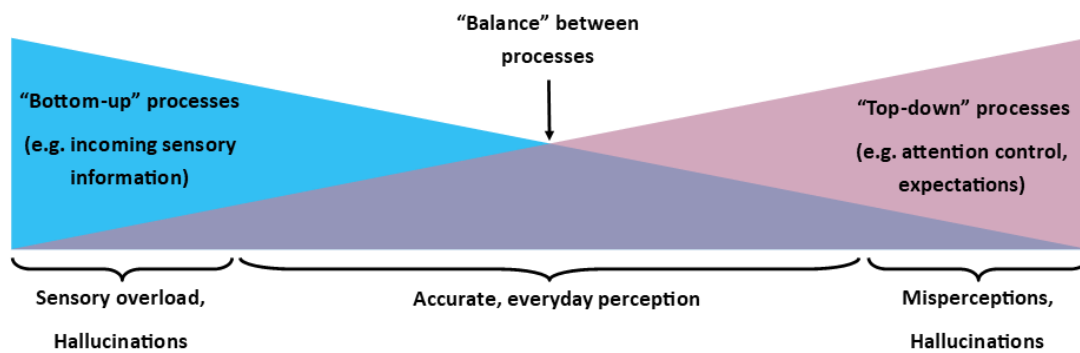
© Rachel Marchant

This is a simplified diagram of the possible influences of "top-down" (purple) and "bottom-up" (blue) processing on our experience. On the far left, too much or inaccurate processing of sensory information alone, without any "control" from top-down processes, might lead to sensory overload or hallucinations. Around the centre, we can see that accurate, everyday perception is facilitated when there is more of a balance between the processes.

Here, the brain processes sensory information correctly. This balance also stops sensory overload and helps us to pay attention to the important incoming information. On the far right, an increased influence from top-down processes and decreased influence of actual sensory information may lead to misperceptions and hallucinations. As above, there are no clear "cut-offs" or divisions between these different types of experience – changes in these balances likely affect everyone differently.

Based on these models, some scientists have taken the idea that human experience exists along a spectrum or continuum even further. One expert on the cognitive neuroscience of hallucinations, Dr Anil Seth, famously suggested that if hallucinations are a kind of "uncontrolled" perception, then normal perception is a type of controlled hallucination[19]. This means that we are actually "hallucinating" all the time, but it's just that when we agree about our hallucinations, we call this "reality"!

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[19] Seth, A. (2017). Your brain hallucinates your reality. TED Talk.

ACTIVITY 1: To illustrate the difficulties in making distinctions between different types of experience, image that someone tells you that they have had the following strange experience. They were looking in the mirror, when all of a sudden they noticed that their features seemed distorted and as if they were moving. Their mouth appeared much bigger than usual, and their eyes were slowly moving down their face. The experience lasted for around a minute or so before their reflection went back to normal. What type of experience would you class this as?

On the one hand, we could say that the person was experiencing a *distortion* of an existing stimulus; their face was already present, but it seemed to change in strange ways (similar to common visual illusions). However, we would not predict that most people, when looking at their reflection, would experience this type of distortion. In another sense, we could say that the person was experiencing a *hallucination*, because they were definitely experiencing something that did not actually exist in external reality. Their mouth had not actually changed size, and their eyes were not actually moving downward. So how would we classify this experience – as a *distortion*, or a *hallucination*? Discuss this idea with someone.

Types of hallucinations

Hallucinations can occur in any of our senses. This includes the senses we usually think of – vision, hearing, taste, touch, and smell – but also many other senses that are less commonly considered. Examples of the senses we can hallucinate in include[20]:

- **Visual** – our vision;

- **Auditory** – our sense of hearing;

- **Olfactory** – our sense of smell;

- **Gustatory** – our sense of taste;

- **Tactile** – our sense of touch;

- **Proprioception** – our sense of our body's movement and position in space, relative to other parts of our body. (To test your proprioception, close your eyes and touch the tip of your nose with your index finger. If you can do this easily, you have good proprioception!)

- **Balance and acceleration** – our sense of our body's balance, direction, and speed;

- **Thermoception** – our sense of temperature, both internally and externally;

- **Nociception** – our sense of pain;

- **Mechanoception** – our sense of the mechanical manipulation of our body, or pressure, such as when part of us is being pushed, pulled, or stretched;

- **Interoception** – our sense of the internal happenings of our body, such as our heartbeat;

- **Chronoception** – our sense of the passage of time.

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[20] Laroi, 2006

Here are some examples of hallucinations that could occur in each sense. Can you think of any other examples?

Sense	Hallucination
Visual	Seeing
Auditory	Hearing someone calling to you from another room, but there is actually no one there calling to you
Olfactory	Smelling something unpleasant, when there is nothing around causing the smell
Gustatory	Tasting something very sweet, when there is nothing in your mouth causing the taste
Tactile	Feeling someone touch your shoulder, when there is no one there
Proprioception	Feeling yourself rising up or floating, when you are actually sitting down and stationary
Thermoception	Feeling that your limbs are very hot, when they are actually a normal temperature
Nociception	Feeling an intense pricking sensation on your body, when there is nothing there to cause that pain
Chronoception	Feeling as if time is moving very fast, or as if you are moving through time very fast

Hallucinations can occur in one sense only – e.g. be purely visual – but can also be **multi-modal** or **multi-sensory**; occurring in multiple senses at once[21]. This is why hallucinations can be so complex, and feel very real.

People can also have hallucinations that are specifically associated with sleep. **Hypnogogic hallucinations** are experienced when falling asleep, and **hypnopompic hallucinations** are experienced when waking up[22]. **Bereavement hallucinations** are types of experiences associated specifically with the death of someone, and can include seeing, hearing, and feeling the presence of someone who has passed away (such as a friend, family member, or partner)[23]. Both sleep and bereavement hallucinations are very common in the healthy general population.[23,24]

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[21] Laroi, 2006
[22] Laroi, 2006
[23] https://doi.org/10.1016/j.jad.2015.07.032
[24] https://doi.org/10.1016/S0165-1781(00)00227-4

Another type of hallucination that is fairly common is the "**out-of-body experience**" (OBE). OBEs are experiences where an individual feels a disconnection between their physical body and their conscious awareness, and can view the world from a vantage point outside of their physical body. This happens when awake. For example, a person may feel that they are drifting away from their physical body, leaving it behind, and floating up towards the ceiling. From the ceiling they may be able to look down and see their physical body. OBEs can sometimes be multi-modal; someone can feel they are in a different position as compared to their physical body, and also perhaps see, hear, or feel their environment from a different perspective.

Limited research on OBEs in the general population exists, but a recent study of over 550 healthy people found that 24% had experienced at least one OBE in their lifetime, unrelated to any health issues or substance use[25]. OBEs are commonly experienced during or after traumatic experiences (e.g. as part of a "near death experience") but can also occur without a clear cause or during non-traumatic experiences, such as during meditation[26].

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[25] Milne et al., 2019 - https://www.sciencedirect.com/science/article/pii/S001094521830354X
[26] De Foe et al., 2017 - https://www.researchgate.net/profile/Elena_Prati/publication/317994201_Out-of-Body-Experiences_A_Phenomenological_Comparison_of_Different_Causes/links/59ecb6c7a6fdccef8b0dbd85/Out-of-Body-Experiences-A-Phenomenological-Comparison-of-Different-Causes.pdf

Who can have hallucinations?

Contrary to popular opinion, research suggests that **practically anyone can experience hallucinations**. Although it is commonly thought that hallucinations are symptoms of severe mental and emotional distress (or mental health "disorders"), **hallucinations are actually experienced by a wide range of people and groups**[27,28]. Hallucinations can occur:

- As "symptoms" classed under various **psychiatric diagnoses**, such as 'schizophrenia' and 'bipolar';

- In various **neurological conditions**, such as migraine aura, epilepsy (seizure disorder), narcolepsy (sleep disorder), and macular degeneration (age-related vision loss / blindness);

- In **neurodegenerative conditions**, such as Parkinson's and Alzheimer's disease;

- Due to **substance use**, such as intoxication with psilocybin (a hallucinogen)[29];

- Due to **fever and delirium** (e.g. when ill with an infection);

- Due to **sensory deprivation** (e.g. when blindfolded);

- Due to **trauma and stress**; and

- Spontaneously in the **general healthy population**, not necessarily caused by any of the above[30,31,32].

Below are some brief summaries of the types of hallucinations experienced by a few example groups. However, **it is important to remember that the types (and contents) of hallucinations vary hugely from person to person**, and so the information below offers only a basic overview.

Psychosis and schizophrenia

As hallucinations are considered to be important "symptoms" of, and are included in the formal diagnostic criteria for, psychosis and schizophrenia, it is unsurprising that many people who have been given these diagnoses experience a wide variety of hallucinations. They are most commonly auditory-verbal (hearing voices) (Nayani & David, 1996). These voices can range in volume from whispering to shouting, though are commonly at a normal conversational volume. Voices can be singular or as if a crowd of people were present, all talking together. The frequency and duration of these voices ranges widely; from a few times a day to constantly, and from seconds to minutes to hours (Nayani & David, 1996). Like most hallucinations, voices are typically experienced as being external, as if they are coming from another person, but can also seem to be internal or "inside the head" (Nayani & David, 1996). Explanations for these voices can be generally categorised into: (1) forces of good or evil, (2) conspiracy or plot (such as being monitored by the FBI), and (3) ghosts, spirits, or aliens (Nayani & David, 1996).

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[27] Laroi, 2006
[28] Waters & Fernyhough, 2017
[29] Frederick et al., 2018
[30] Bauermeister et al., 2017
[31] Preti et al., 2014
[32] van Os & Reninghaus, 2016

Visual hallucinations are estimated to be experienced by 27% of people diagnosed with 'schizophrenia'[33]. These experiences are often highly realistic, being "life-sized, detailed, and solid", with depth, shadows, and distinct edges[34]. Examples of content include people, faces, animals, and spiritual beings such as God, angels, devils, saints, and fairies (Waters et al., 2014).

These visual hallucinations are often frightening, can be very frequent or rare, and generally last seconds to minutes (Waters et al., 2014). Although visual hallucinations in schizophrenia are thought to be less common than auditory ones in Western populations[35], the rate actually varies by country.

For example, one study found that visual hallucinations were very common in a group from Saudi Arabia (Zarroug, 2018). "Perceptual fragmentation" can also be experienced, where the organisation of sensory information becomes confused, fragmented, or distorted, so that people can have problems experiencing their world as an organised whole (Pienkos et al., 2019). For example, someone might look in the mirror and see parts of their face changing shape or becoming distorted, while the rest of the scene remains the same.

Generally, hallucinations within 'psychosis' or 'schizophrenia' are experienced as negative and frightening, and so may be interpreted as threatening or harmful.[36] For example, people can experience abusive voices or those that command them to do degrading things. However, not all hallucinations within these diagnoses are experienced this way and some are very positive, particularly in non-Western cultures. For example, they can be experienced as the divine voices of gods, guidance from family members, and helping people to "do the right thing".[36] There are strong cultural influences on hallucinations, which we will explore in the section "Cultural perceptions of hallucinations".

Migraine

Some people who have **migraines** will also experience "**migraine aura**" – unusual visual and sensory experiences that precede the start of migraines (Chen et al., 2011). There are many different types of aura experiences. Visual disturbances are common, usually consisting of simple hallucinations, such as seeing fortifications (black and white linear, angular, or zigzag patterns), scintillations (flashes or sparkles of light), and scotoma (dark or blind spots) (Panayiotopolous, 1994). However, hallucinations in other senses are also frequently experienced during migraine: olfactory hallucinations, commonly including experiencing unpleasant smells (such as cigarette smoke); auditory hallucinations, such as ringing, buzzing, or music; and gustatory hallucinations, again usually unpleasant (such as the taste of blood) (Armand et al., 2016).

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[33] Waters et al., 2014

[34] Waters et al., 2014

[35] Waters et al., 2014

[36] Luhrmann, T., Padmavati, R., Tharoor, H., & Osei, A. (2015). Differences in voice-hearing experiences of people with psychosis in the USA, India and Ghana: Interview-based study. *British Journal of Psychiatry, 206*(1), 41-44. doi:10.1192/bjp.bp.113.139048

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Epilepsy

Simple hallucinations are also common in **occipital lobe epilepsy** – seizures in the visual part of the brain (Panayiotopolous, 1994). In contrast to migraine aura, hallucinations in epilepsy tend to be visions of many vivid, multi-coloured circular or spherical (and sometimes triangular or square) patterns, which sometimes flicker or flash, and "balls of light" moving across the visual field (Panayiotopolous, 1994).

Eye disease

Hallucinations due to eye disease (such as macular degeneration) are called "**Charles Bonnet Syndrome**" (CBS), a very common condition in people who are older or have diabetes. About 40% of people with eye disease will develop CBS[37].

Although many more healthcare professionals are aware of CBS now as compared to 20 years ago, a recent survey found that 39% of patients with CBS reported that their general practitioner was "not at all well informed" about CBS[38]. CBS hallucinations can range from very simple to highly complex (e.g. detailed scenes, including people, animals, and landscapes)[10].

Hallucinations are a completely normal part of CBS, but can be mistaken as symptoms of other conditions. For example, in one case an elderly man was misdiagnosed with dementia with psychosis due to his visual hallucinations, before being correctly diagnosed with CBS (Liantonio & Hersh, 2017). Cataract removal resolved his visual problems and hallucinations (Liantonio & Hersh, 2017).

Many people who experience hallucinations as part of CBS do not immediately realise that the things they are experiencing are not real, and so may become engaged with or confused by their experiences. However, many people with CBS come to realise that their experiences are hallucinations relatively quickly (Liantonio & Hersh, 2017). Although CBS hallucinations are mostly fleeting, they can sometimes persist for years (Liantonio & Hersh, 2017). Many people experiencing CBS hallucinations do not report them for fear of being diagnosed with a mental illness (Liantonio & Hersh, 2017).

Neurodegenerative conditions

Neurodegenerative diseases are conditions that involve the progressive deterioration and/or death of nerve cells in the brain (JPND, 2017). Unlike some other tissues in the body (such as skin), nerve cells in the brain cannot be reproduced or replaced, and so when they are damaged or die this can cause problems for normal brain function (JPND, 2017).

This is what causes the signs and symptoms usually associated with neurodegenerative disease, such as cognitive and functional decline. Hallucinations occur in approximately 22-75% of people with Parkinson's disease (PD), and the prevalence increases over time (Burghaus et al., 2011). This estimate is so broad because different studies use different standards for what is considered a hallucination.

Visual hallucinations and distortions are more common than auditory, olfactory, and tactile hallucinations in PD (Burghaus et al., 2011). PD hallucinations often vary in their intensity but are quite short in duration, and frequently occur in the evening or nighttime (Burghaus et al., 2011). Visual hallucinations in PD often involve misperceptions of objects as people or animals (such as seeing a tree branch as a cat); auditory hallucinations can be simple sounds (knocking or ringing) ranging to more complex experiences; and many people often sense the presence of an unseen animal, person, or supernatural being ("I see someone arriving; I turn back but nobody is there") (Burghaus et al., 2011; Fénelon et al., 2000). In Alzheimer's disease (AD), approximately 10-73% of people experience

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[37] Coltheart, 2018
[38] Boxell et al., 2017

hallucinations (Burghaus et al., 2011). The most common type of hallucination is visual, with auditory, somatic, olfactory, and tactile hallucinations also experienced by a small number (Burghaus et al., 2011).

Substance use

Hallucinations can also occur due to: **intoxication** from alcohol, stimulants, hallucinogens, and cannabis; **withdrawal** from substances such as alcohol; and **prescribed medication**, such as drugs intended to help with Attention Deficit Hyperactivity Disorder (ADHD) or Parkinson's, or malaria medication[39]. For example, hallucinations experienced during alcohol withdrawal are very vivid and real, and can include hearing voices commenting on the experiencer or talking to each other (tending to be negative, accusatory, or derogatory) or seeing supernatural beings (Waters & Fernyhough, 2017).

People in major alcohol withdrawal can also hallucinate music, or see normal shadows and shapes as animals or disastrous events (such as floods, erupting volcanoes, and violence) (Platz et al., 1995). Tactile and olfactory hallucinations can also be experienced (Platz et al., 1995). For another example, use of the drug MDMA (ecstasy) is associated with hallucinations in vision (such as vision becoming more intense and clear, or seeing patterns dots, and colours, and walls seeming to move), and hallucinations in time perception (such as time being "compressed, dilated, expanded, slowed down, and sped up") (Liester et al., 1992). The types and contents of hallucinations associated with substance use vary hugely, and will be specific to the individual and type of substance.

Delirium

Hallucinations also commonly occur in **delirium**, a condition that involves global cognitive dysfunction in the form of "clouded consciousness" – feeling foggy, and being unable to focus attention consistently or respond properly to changes in surroundings, leading to "incoherent thinking and speech" (Ross et al., 1991). Delirium is often accompanied by visual hallucinations (in approximately 50-63% of cases) and, less commonly, tactile hallucinations (Gupta et al., 2008; Ross et al., 1991). In children, visual distortions and hallucinations in delirium are more intense as compared to adult and elderly groups (Leentjens et al., 2008).

General population

One study that used a large sample of the general, healthy population (N=13,057) aged 15 years and over from the UK, Germany, and Italy, found that 40% of the people surveyed had experienced some type of hallucination (such as visual, auditory, and out-of-body experiences) (Ohayon et al., 1991).

A more recent study reviewing over 31,000 healthy people from 18 different countries suggested that 5.2% of healthy people experience visual or auditory hallucinations unrelated to sleep problems or drug and alcohol use (McGrath et al., 2016). By comparison, only 0.4% of the general population sample from this study experienced hallucinations as part of a psychiatric diagnosis!

So, because hallucinations are now understood to be fairly common in the general population, some researchers have proposed the idea of a "**psychosis continuum**". This is the idea that "psychotic-type" experiences (such as hallucinations) lie along a spectrum, with non-clinical experiences at one end and clinical psychosis at the other (Guloksuz & van Os, 2017; Shelvin et al., 2017; van Os, 2016; van Os & Reninghaus, 2016). The phenomenon of "schizotypy" – schizophrenia-like traits occurring in

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[39] Waters & Fernyhough, 2017

the general population – also supports the view that experiences and behaviours often ascribed clinical relevance can and do occur in the general population, with no apparent negative effects (van de Ven & Merckelbach, 2003).

So, **hallucinations are widespread throughout the general population and across different groups**.

This has led some researchers to conclude that **hallucinations are not condition-specific** (Goodwin & Rosenthal, 1971; Guloksuz & van Os, 2017; Stip & Letourneau, 2009; Waters & Fernyhough, 2017; van Os & Reninghaus, 2016), and so they are not very useful on their own for differentiating between conditions or groups of people.

One review stated that "hallucinations are a feature of human experience that crosses diagnostic boundaries" (Waters & Fernyhough, 2017). Each hallucination must be viewed in its own unique context, with its qualities carefully considered to decide its clinical relevance (if any). Despite this evidence, the presence of frequent auditory hallucinations that are distressing or interfere with someone's daily functioning is sufficient for a diagnosis of "Other Specified Schizophrenia Spectrum" or "Other Psychotic Disorder" using current psychiatric diagnostic manuals, despite the fact that such hallucinations can also occur as part of epilepsy, due to brain tumours or trauma, and in the healthy population (Waters & Fernyhough, 2017).

Therefore, some current research is questioning the usefulness of our current methods of psychiatric diagnosis, with one large study concluding that strictly categorical models of disease (which categorise certain symptoms under specific diagnoses) are not supported by the evidence[40].

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[40] Bauermeister et al., 2017 - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5240854/

When can hallucinations happen?

Research suggests that hallucinations can occur at any time of life. However, different studies have reached different conclusions about how age, significant life events, and traumatic experiences are related to hallucinations.

Age

Overall, the general rate of hallucinations seems to decrease with age. One study found that around 2 in 100 people aged 15+ experienced daytime hallucinations more than once per week, and that 6 in 100 people aged 15+ experienced daytime hallucinations at least once per month (Ohayon et al., 1991).

This study also found that the occurrence of hallucinations overall, across different types, was not different across different age groups. However, 15-44 year olds were more likely to experience hypnogogic and hypnopompic hallucinations than adults aged 45 and over. So, the likelihood of experiencing these types of hallucinations seems to decrease with age.

Also, for all reported hypnogogic and hypnopompic hallucinations, over half were *not* related to the use of psychoactive substances or existing medical problems / disorders. This study found that some people experiencing hypnogogic and hypnopompic hallucinations were misdiagnosed with psychosis, when in fact these hallucinations were related to narcolepsy (a sleep disorder) instead.

A review of different types of hallucinations (visual, auditory, olfactory, tactile) in a healthy Norwegian population of 2461 people found that experiences of hallucinations tend to significantly decrease with age (Larøi et al., 2019). Interestingly, the hallucinations reported by this healthy group were found to be more varied then those reported by clinical populations. However, sensed presence hallucinations were the most common experiences.

Another piece of research that reviewed auditory hallucinations in 84,711 people from the general population suggested that 1 in 10 people will have hallucinations in their lifetime, and also found that children and adolescents reported more frequent auditory hallucinations than adults and the elderly (Maijer et al., 2018). Experiences of auditory hallucinations were estimated to be 13 in 100 for children, 12 in 100 for adolescents, 6 in 100 for adults, and 5 in 100 for the elderly (Maijer et al., 2018).

Hallucinations associated with Charles Bonnet Syndrome (CBS) are more likely as age increases, because the risk and incidence of macular degeneration increases with age.

Life events

Life conditions such as stress can also trigger hallucinations (Ohayon et al., 1991). For example, **bereavement hallucinations** are very common in those who have lost a loved one, such as a spouse. These hallucinations typically involve feeling the presence of, and hearing, seeing, or talking to, the deceased (Grimby, 1993). These hallucinations can be experienced at any time of life, but seem more common in older people due to this group's increased risk of encountering death.

For example, Larøi et al. (2019) found that sensed presence hallucinations increase with age, being experienced by 12 in 100 young people (19-30 years) versus 30 in 100 older people (61+ years). One study found that 82% of a bereaved group aged 70+ experienced post-bereavement hallucinations, and importantly, perceived these experiences as pleasant and helpful (Grimby, 1993).

Another study that reviewed many different pieces of research suggested that in bereaved people generally, 57 out of 100 will experience at least one bereavement hallucination (Kamp & Due, 2019). Bereavement hallucinations occurred across a wide range of ages (38 to 80 years) and types of

loss (spouse, child, relation, friend). The types and contents of bereavement hallucinations can vary hugely between people, with no two individuals having the same experience. Greater grief and distress over a loss seem to increase the likelihood of experiencing bereavement hallucinations (Kamp et al., 2018).

Other stressful life or traumatic events can also trigger hallucinations. Stress sensitivity have been linked to experiences of hallucinations associated with adverse life events (Laloyoux et al., 2016). Traumatic life events that are associated with a direct intention to harm (actively meaning to cause harm) to the victim are associated with hallucinations in children aged 6-14 years (Moriyama et al., 2018).

Stressful life events are also associated with hallucinations in adolescents aged 16, and there is also some evidence of a genetic predisposition towards experiencing hallucinations due to stressful events (Shakoor et al., 2018). Auditory hallucinations have also been specifically linked to traumatic experiences, as many people who are diagnosed with Post-Traumatic Stress Disorder (PTSD) also experience auditory hallucinations. PTSD can be diagnosed after someone experiences highly traumatic events, and is characterised by distressing or intrusive memories, nightmares, and hypervigilance (heightened state of threat sensitivity)[41].

Some research suggests that hallucinations are trauma-based memories "reactivating"[42][43]. Because of this, research recommends using trauma-informed interventions for hallucinations that are related to traumatic events, as opposed to the commonly used anti-psychotic medication (which treats symptoms but not their cause)[14].

Hallucinations are also related to how people psychologically process trauma. Laloyoux and colleagues (2016) explored the experiences of victims of physical assault at 4 weeks and 6 months post-event, and found that lack of self-referential processing, dissociation, beliefs about permanent negative change, self-vulnerability, and self-blame and related cognitive response styles (such as thought suppression) were all related to increased experiences of hallucinations. Therefore there is a close relationship between experiences of hallucinations and the psychological processing of trauma.

Similarly, there are many potential psychological triggers for hallucinations that are not directly linked to an intensely stressful or traumatic event. General stress, tiredness, loneliness, and negative emotions have all been linked to hallucinations in clinical groups, and this likely co-varies with anxiety levels (Waters et al., 2014). See section "General Lifestyle – Stress and Anxiety" for more detail.

However, a lot of evidence also supports the idea that hallucinations can occur at random, without a clear cause, in the healthy general population (Bauermeister et al., 2017; Preti et al., 2014; van Os & Reninghaus, 2016).

Hallucinations experienced by "healthy" people share a lot of characteristics with those experienced by "clinical" groups. For example, vivid and frequent voice hallucinations are common in the general population (Waters & Fernyhough, 2017). In fact, *only age of onset and negative interpretations of hallucinations can be used to reliably differentiate between the hallucinations of clinical and non-clinical groups* (with hallucinations beginning in the late teens to early 20s, and more negatively interpreted, being associated with clinical diagnoses) (Waters & Fernyhough, 2017). Even risk factors such as familial and childhood trauma, which are often stressed as important in the aetiology of

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[41] Yehuda et al., 2015 – PTSD, a primer - https://www.researchgate.net/profile/Stevan_Hobfoll/publication/282796995_Post-traumatic_stress_disorder/links/5624f03408aea35f2687158a.pdf

[42] McCarthy-Jones & Longden, 2015 - https://www.frontiersin.org/articles/10.3389/fpsyg.2015.01071/full

[43] Steel, 2015 - https://www.frontiersin.org/articles/10.3389/fpsyg.2015.01262/full

psychiatric conditions such as psychosis, do not help us to reliably differentiate between hallucinations experienced by clinical and non-clinical groups (Baumeister et al., 2017; Read et al., 2005).

Summary

There is limited research available that explores whether hallucinations happen at particular times, or in response to particular situations. At the moment, research suggests that children and adolescents are more likely to experience hallucinations than older people, and that stressful life events (such as bereavement and traumatic experiences) are also associated with hallucinations. Hallucinations can also occur randomly in healthy people. However, only age of onset and a negative interpretation can reliably indicate membership of a clinical group (but this does not mean that these traits *predict* future clinical diagnosis).

How do hallucinations happen?

Scientists are not certain about the brain mechanisms that produce hallucinations, but there are several theories supported by good evidence. Each of these can apply differently to different types of hallucinations. To understand these theories, we first need to understand how the brain works.

Brain basics

Our brains have three main parts: the "cerebrum", "cerebellum", and "brain stem" (see diagram below). The **cerebrum** is the largest part of the brain and has two "hemispheres" (halves); the right and left hemispheres. These two halves are joined by a bundle of nerves called the "corpus callosum", which allows the two halves to communicate. The **cerebellum** controls functions such as muscle movements and balance. The **brain stem** connects the cerebrum and cerebellum to the spinal cord and controls basic processes that are not under our conscious control, such as breathing, heart rate, and digestion.
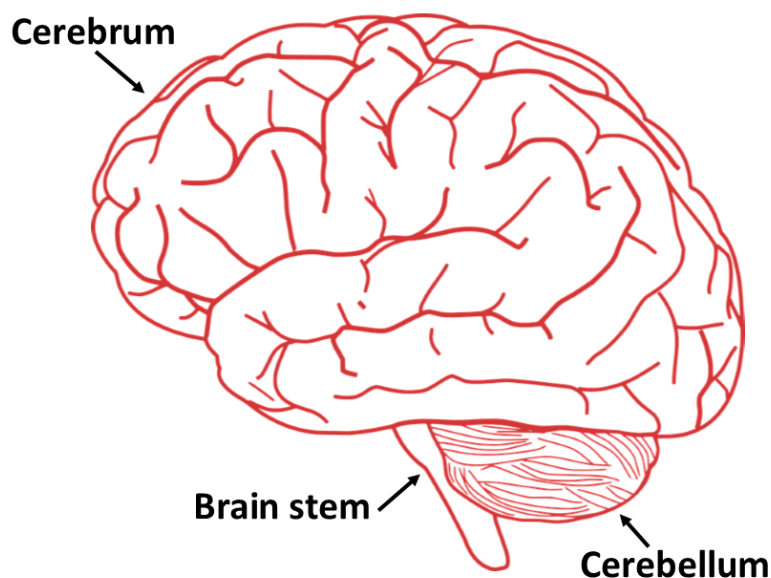
The three basic areas of the brain.

The outer layer of the cerebrum is called the "**cortex**". The cortex is made up of "**neurons**"; the cells in our brain that process information and communicate with each other, to allow us to think and function. These cells are arranged in a specific pattern which means that the cortex is grey-coloured (and so is called "**grey matter**"), and the layer underneath is white (called "**white matter**"). The white matter consists of long nerve fibres that connect the different neurons and brain areas to each other.
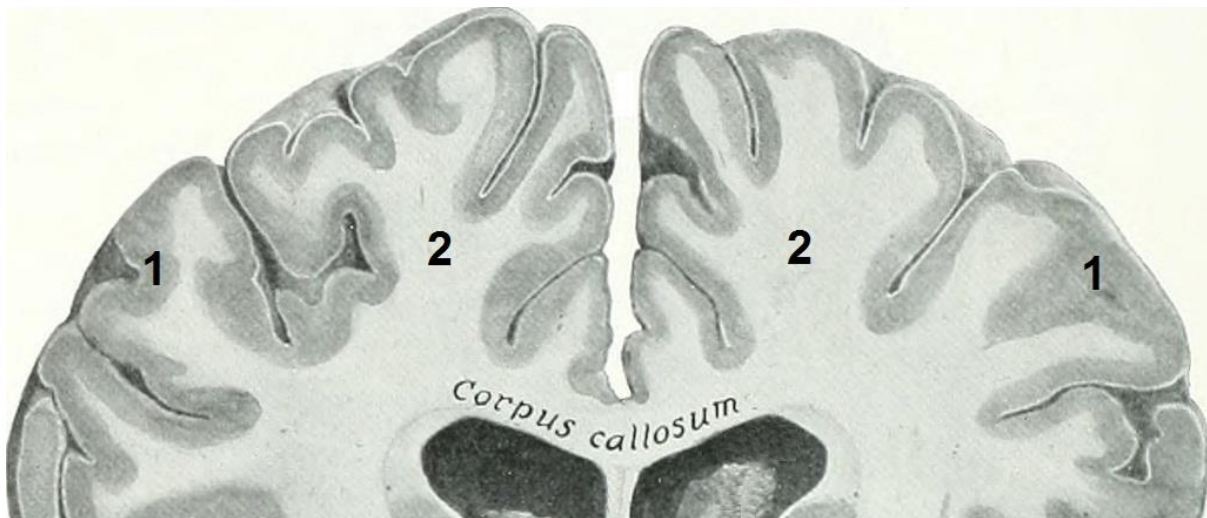
1 = cortex / grey matter; 2 = white matter.

Each part of the brain generally processes a different type of information. This is known as "functional specialisation". See the diagram on the next page for a basic map of the brain's functions.

However, the brain's structure is not fixed and unchangeable. If someone loses a part of their brain (such as through surgery or an accident), the brain can change and adapt quickly to recover from this. This can lead to a different part of the brain adapting to process a type of information that it would not normally process.

For example, someone who has the parts of their brain removed that control small, precise finger movements (such as writing) can recover this ability rather quickly, and this is because other parts of their motor cortex (that would not normally process this information) adapt and "take over" control of this function (Darling et al., 2011).

There is lots of evidence for similar adaptive changes across many different brain functions and areas. This ability of the brain to change and adapt is called "**plasticity**".

Frontal lobe
Parietal lobe
Temporal lobe
Occipital lobe

Speech · Movement · Touch · Taste · Hearing · Vision

Attention, Planning, Decision-making

Smell · Memory processing · Heart rate, Breathing · Movement coordination
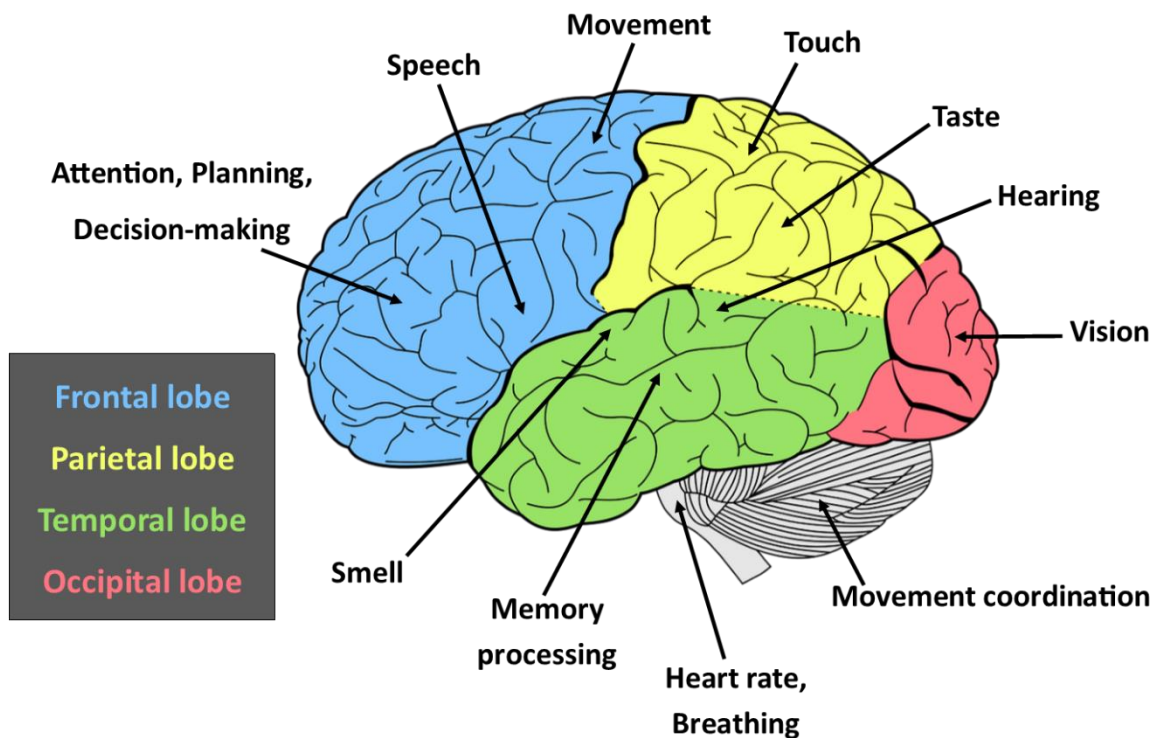
© Rachel Marchant

Basic functions of the cortex. The cortex is divided into four different "lobes": the frontal lobe (involved in advanced functions such as planning, organising, controlling emotions and behaviour, problem solving, and personality expression), parietal lobe (sensation, spatial awareness, integrating sensory information), temporal lobe (memory, sound processing, language, recognising faces, emotions), and occipital lobe (vision). This image shows some examples of where different types of information are primarily processed in the brain.

Neurons communicate using electric and chemical messages. These messages are sent across the chains and networks of neurons, so that they can reach different parts of the brain. Neurons can send messages that either "**excite**" (activate) or "**inhibit**" (suppresses) the next neuron in the chain. When we sense something, this information excites neurons in the parts of the brain that process that specific sense.

For example, for you to hear someone speaking to you, the signal is sent from your inner ear along your auditory nerve, to the brain stem (which processes basic features like sound duration and intensity), to the thalamus (which integrates the signal with signals from other senses), and finally to your auditory cortex (to allow us to become conscious of the sound and respond). At the same time, the brain also inhibits some messages about irrelevant sounds, such as a clock ticking in the background, so that it does not interfere with our processing of the important information that we want to pay attention to.

This method of balancing excitation and inhibition allows the brain to carefully control how it processes all the information we receive, and what we become conscious of and respond to. We have a limited attention span, and so the brain needs to inhibit some information and only make us aware of the important bits. Otherwise, we would be overwhelmed by all the information we are constantly receiving. For example, think about how much background noise and information your brain filters

out all the time, every day. You might regularly filter out, for example, noises like the tapping of keyboards, other people's conversations, or your dishwasher, when you are busy focusing on working, talking on the phone, or reading a book. Your brain is processing all of these noises in the background, but they are not always sent to the "higher" (more advanced) brain areas that allow us to become conscious of them. Only important sounds – such as the podcast we are concentrating on, or our baby crying – will be made conscious, so that we can respond to them. (Note: we can react to some information unconsciously. This is known as a **reflex,** such as automatically pulling our hand way from a very hot surface. In these situations, our brain skips the time-consuming process of making information conscious to make us act quickly and protect us from threats).

The first brain-based account of hallucinations was proposed by the French psychiatrist Jean-Etienne-Dominique Esquirol in 1838, who thought that hallucinations were caused by abnormal brain functioning (Weiss & Heckers, 1999). This theory "remains the backbone of modern psychiatric theory on this subject", but even over 180 years later we are still not sure how exactly hallucinations are caused (Weiss & Heckers, 1999).

However, the central and overarching idea in modern consciousness science is that "for every mental state… there is an associated neural state; it is impossible for there to be a change of mental state without a corresponding change in neural state" (Frith et al., 1999, as quoted in Weiss & Heckers, 1999). Currently, there are many different theories and models based on this idea, which are summarised below. These theories are not completely separate from each other, and so any overall theory developed in the future will probably contain ideas from several or all of these.

Cortical hyperexcitability

The careful balance between excitation and inhibition in the brain can sometimes go wrong. For example, parts of the cortex may sometimes become over-excited in the *absence* of any sensory information. This is a phenomenon known as "**cortical hyperexcitability**" – increased activity in the cortex over and above what we would expect during normal functioning. Cortical hyperexcitability can be caused by increased excitation and/or decreased inhibition. This increased activity may cause us to experience things that don't actually exist in the outside world – a hallucination (Allen et al., 2008; Kumar et al., 2009). This idea is also known as "disinhibition". The idea that a lack of inhibition may cause hallucinations was first proposed in 1932 by Jackson, and in 1950 Penfield and colleagues suggested the idea of hyperexcitability (Kumar et al., 2009).

There is substantial evidence that cortical hyperexcitability may be one cause of hallucinations across many different groups, including in healthy people (Braithwaite et al., 2011, 2013ab), epilepsy (Badawy et al., 2009), migraine aura (Lauritzen et al., 2011; Wolmarans et al., 2018), neurodegenerative conditions (Burghaus et al., 2012), Charles Bonnet syndrome (CBS) (Painter et al., 2018), psychosis, substance use (Baggott et al., 2010; Iaria et al., 2010; Oliveri & Calvo, 2003), sensory deprivation (Daniel, 2017), and fever and delirium (Gupta et al., 2008).

As we saw above, different types of sensory information are (initially) processed in specific parts of the brain. In line with this, research shows that increased activation in the visual cortex is associated with visual hallucinations, increased activation of the auditory cortex is associated with auditory hallucinations, and so on (Weiss & Heckers, 1999).

For example, one study found that people with CBS who hallucinated in colour had increased brain activity in the colour area of the visual cortex. In contrast, one person who hallucinated in black and white had increased brain activity in other visual regions, but not the colour area (Allen et al., 2008). There is also now evidence that hyper-activity of other, non-sensory brain areas can also

contribute to hallucinations (Allen et al., 2008). This hyper-activity can make hallucinations very vivid, so that they feel "realer than real".

Cognitive-perceptual processing

Some models suggest that hallucinations occur because of abnormalities in "bottom-up" processing. To review, this is the processing of incoming, basic sensory data (Kumar et al., 2009). For example, **sensory impairment** (problems in detecting or interpreting sensory information) may lead to inaccurate perception and experiences of things that do not exist in external reality. A good example of this is Charles Bonnet Syndrome, where visual impairment leads to vivid visual hallucinations (see "Who can have hallucinations?") (Aleman & Vercammen, 2012). Similarly, acquired deafness in old age is also associated with auditory hallucinations (Aleman & Vercammen, 2012). Sensory impairments or damage to sensory networks are often part of explanations for hallucinations in many different conditions such as migraine, epilepsy, stroke, and brain tumours (Aleman & Vercammen, 2012).

However, bottom-up processing alone cannot account for the complexity of hallucinations (Hugdahl, 2009). Therefore, **models of hallucinations also emphasise abnormalities in "top-down" processing**. To review, this is where the brain of the experiencer (unconsciously) imposes expectations on incoming sensory information, to influence what is experienced (Kumar et al., 2009). As we have seen above, expectations play very important role in what we perceive (see "Definition of hallucinations"). Expectations can come from previous experiences, existing knowledge, and attention, for example (Kumar et al., 2009). A good example of top-down expectations influencing hallucinatory experiences is the "White Christmas" experiment. In one version of this experiment, a group of healthy undergraduate students were asked to listen to white noise and press a button when they heard Bing Crosby's "White Christmas" (when in fact the song was never played). Nearly a third of the students indicated that they heard the song, and these students also scored highly on measures of fantasy proneness and predisposition to hallucinations (Merckelbach & van de Ven, 2001). This shows how our expectations can strongly influence what we experience.

Interestingly, the influence of expectations on what we experience is thought to depend on a balance between inhibition and excitation (Aleman & Vercammen, 2012), which links this theory to cortical hyperexcitability. Overall, we can see that accurate perception relies on having the right "balance" in many different types of brain processes.

Source monitoring

Another theory suggests that hallucinations may be caused by flawed "**source monitoring**" (Weiss & Heckers, 1999). Source monitoring is a type of **top-down process**. To decide what is part of external reality, as compared to our internal realities, we need a way of distinguishing between these sources (e.g. sounds that come from the "outside", as compared to sounds generated inside our minds, such as our inner voice). If this process goes wrong, we may make a mistake and not recognise a sound that was generated by our own mind, and so it appears to be external. This is called "**misattribution**", because we misattribute the source of the sound. This experience will also violate our *expectations*. Expectations play a very important role in what we experience (see "Definition" of hallucinations), and so if we do not expect an inner thought, we may not label it as our own and so mistake it for an external voice (Brookwell et al., 2013). This produces a feeling of not having *control* over the experience (i.e. not having freely willed it) (Allen et al., 2008). People who have hallucinations may also have an unconscious bias towards labelling internally-generated events as external ones (Brookwell et al., 2013).

So, this idea suggests that if we mislabel or do not recognise our own inner speech or speech memories, we might hear these as an external voice. For example, the voices heard during voice hallucinations are often known to the individual, suggesting that hallucinations are based or modelled on memories of real voices (El Haj at al., 2016). This is a well-evidenced explanation for voice hallucinations particularly, but can easily be applied to hallucinations in other senses. It is also applicable to hallucinations across different groups (Brookwell et al., 2013).

Release theory

Finally, "release theory" combines the sensory impairment and top-down approaches (Kumar et al., 2009). This theory suggests that normal experience depends on constant sensory input that "controls" background noise in the brain (Aleman & Vercammen, 2012). That is, the sensory information we receive from our senses (such as what we see) competes with our internal experiences (such as visual imagination) to be processed in the brain (e.g. visual cortex).

However, when we lose some sensory input, or experience complete sensory deprivation, the lack of incoming sensory information (bottom-up) means there is no competition with our inner experiences. This could lead to our attention (top-down) becoming highly focused on our inner experiences, so that they are "released" into our conscious experience. These are known as "unconstrained perceptions" or "memory/thought intrusion" (Aleman & Vercammen, 2012; Zmigrod et al., 2016), and is where actual sensory experience is overridden by thoughts or memories. It is suggested that this could lead to hallucinations (e.g. we experience imagined or remembered images as real). There are many documented cases of spontaneous hallucinations caused by sensory deprivation (Manford & Andermann, 1998), such as those experienced by prisoners who are isolated in darkness for long periods (known as "prisoner's cinema") (Aleman & Vercammen, 2012).

Integration and Summary

Few models have been proposed that integrate evidence from many different groups and pieces of research. One model suggests that several thought processes and related brain regions are involved in producing hallucinations, involving interactions between emotional attention and regulation, sensory perception, and experience of free will / source monitoring (Allen et al., 2008).

The "perception and attention deficit" model suggests that impairments in both sensory processing and attention are needed for hallucinations to occur (Aleman & Vercammen, 2012). This would require imbalances in both bottom-up and top-down processing, where sensory information (bottom-up) is not properly combined with expectations (top-down) (Aleman & Vercammen, 2012). This model is similar to the "integrative model" of visual hallucinations in Parkinson's disease, which suggests that an imbalance between internal imagination and external sensory information might lead to hallucinations (Aleman & Vercammen, 2012).

Another model from Alemon & Laroi (2008) suggests that any of the following may produce hallucinations: (i) damage or hyperactivity, leading to "released" perceptions; (ii) cortical hyperexcitability in specific sensory areas; (iii) abnormal processing, leading the brain to focus its attention on thoughts or memories in the absence of sensory input; and (iv) top-down processes negatively affecting source monitoring, leading to mistaken expectations and misattributions (Kumar et al., 2009).

The theories described above clearly overlap with one another, with many highlighting imbalances in bottom-up and top-down processes. It is also likely that each aspect of a hallucination is "correlated with a unique pattern of neural activity" (Weiss & Heckers, 1999). However, it is important to note here that the brain changes suggested by these theories are mostly only *correlates*

of hallucinations. This means that we have good evidence that these changes in brain activity or processing are strongly *associated* with the occurrence of hallucinations. But, we do not always know for sure that these changes *caused* the hallucinations. So, although we have many possible, brain-based theories for how hallucinations happen, we have little *direct* evidence for these at the moment. This is because most research on hallucinations uses *non-invasive* techniques; the studies do not require anything to be inserted or implanted into the persons brain for us to gather the data, for safety and ethical reasons. Future brain imaging research and new techniques will hopefully allow scientists to create more exact models of hallucinations.

Why do hallucinations happen?

Why do hallucinations happen? The bottom line is, we don't know. Hallucinations can occur for many reasons; randomly, as part of certain medical conditions, alongside certain diagnoses, as a response to stress and trauma, or maybe even for reasons we aren't yet aware of. **There is no existing model that accounts for all the known biological, psychological, and social factors that contribute to hallucination proneness, across all the different groups that experience them**. So-called "bio-psycho-social" models of hallucinations are currently rare, even though these models have been recommended by healthcare professionals since the late 1970s (Santos et al., 2018).

These models are important in healthcare, as interactions between biological, psychological, and social factors "determine the cause, manifestation, and outcome" of all health problems, including initial susceptibility (Santos et al., 2018). Biological approaches alone are certainly not sufficient to explain mental health, as "psychological (human perspective, experience, and behaviour) and social or environmental (relationships, family context, community, society) also need to be considered" (Santos et al., 2018). However, as we will see below, there is some reason to doubt that hallucinations are a purely "medical symptom".

As we have seen, hallucinations are usually thought of as a *clinical* symptom, and so models that try to explain why hallucinations happen tend to be restricted to specific groups (e.g. people with migraine, people diagnosed with schizophrenia). This means that these models might not be applicable to other groups. The hallucinatory experiences of non-clinical groups, and the mechanisms behind these, have also largely been ignored until recent years.

Overall, there is currently very little integration of relevant theory across groups (i.e. clinical and non-clinical) and disciplines (such as psychiatry and sociology). However, from the previous chapters, we can see that there are many similarities in the types of hallucinations, and the possible brain-based causes of hallucinations, across groups. We have also seen that hallucinations are not unique to one diagnosis or condition, but are experienced by people in many different groups.

Interestingly, there is also no good evidence for the idea that all hallucinations are caused by biological disease processes.

The medical model characterises experiences such as hallucinations as "symptoms" of bodily disease, which means that (according to this theory) we should be able to find reliable biological tests, determinants, or indicators for psychiatric conditions and associated "symptoms". For example, in medicine, detecting "rheumatoid factors" (specific proteins) in the blood is one of the best and most widely-used indicators of the presence of autoimmune conditions, such as rheumatoid arthritis.[44] So, given recent rapid developments in medical sciences and neuroscience, and the (inaccurate) reporting of dazzling new findings by the media, the general public should be forgiven for believing that we are also edging closer to uncovering reliable biological determinants or indicators of psychiatric diagnoses and their specific "symptoms" (such as hallucinations).

However, although many studies have claimed to find initial evidence for some determinants or indicators, none have been verified, and none are routinely used to diagnose psychiatric conditions as standard. This is in stark contrast to standardised biological markers that are used to diagnose medical conditions across the world. On this subject, in 2013 the chair of the committee responsible for putting together the Diagnostic and Statistical Manual of Mental Disorders (DSM), one of the most widely used manuals for psychiatric diagnosis, commented that:

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[44] https://doi.org/10.1093/rheumatology/kei228

"In the future, we hope to be able to identify disorders using biological and genetic markers that provide precise diagnoses that can be delivered with complete reliability and validity. Yet this promise, which we have anticipated since the 1970s, remains disappointingly distant. We've been telling patients for several decades that we are waiting for biomarkers... We're still waiting."[45]

As we saw in the previous section ("How do hallucinations happen?"), there is a lot of research suggesting possible neurobiological causes or "correlates" of hallucinations. This is not surprising, because everything we do and experience changes our brain's function (and sometimes structure)! However, a definitive neurobiological model that can explain all the different types of hallucinations that occur across all the different groups of people who experience them, has not yet been developed. Therefore, at the time of writing, biological tests, indicators, and explanations have not provided any definitive answers as to why hallucinations occur.

Some research has attempted to address the psychological and social factors that contribute to specific types of hallucinations. A recent study concluded that "hallucinations are often meaningful and relate to one's psychological and sociocultural context, particular the experiencer's negative life experiences and related distress".[46] This research suggested that hallucinations may help people to cope with negative life experiences, so that these experiences both contribute to and perpetuate hallucinations. Hallucinations may be the brain's way of coping with traumatising experiences and restoring emotional balance. Psychologically, stress, trauma, loss and unmet needs are all related to the onset of hallucinations, with these emotions and experiences leading to "guilt, loneliness, feeling unloved, creating an inability to cope".[47] Hallucinations can sometimes take on the personality of a saviour or protector, seemingly in response to negative emotions and experiences. Socially, factors such as norms or customs likely contribute to the content of hallucinations. For example, many voice hallucinations berate experiencers for deviating from social conventions or expectations, and so may be a manifestation of inner discomfort or guilt.[48]

Because of this uncertainty about the "why" of hallucinations, it is crucial that we approach every experience of hallucinations as unique, and respect the person's individuality. Even people with the same condition (such as epilepsy) will experience hallucinations differently and for different reasons. We can't know for sure why someone is experiencing hallucinations based on a label or diagnosis they have been given. To understand why hallucinations happen, we need to explore their **context** and **content**. We need to try and understand the relationship between the individual's hallucinations and their personal history, current situation, lifestyle, personality, experiences, and relationships, for example. New therapies are now promoting the effectiveness of understanding the *meaning* of hallucinations in the context of the experiencer's life, which can facilitate psychological growth (Lonergan, 2017). This is in line with recent recommendations made by some clinical psychologists that we must move away from a "disease" model of mental distress, towards an understanding that centres people's personal stories, and helps them to create a meaningful narrative of their experiences and distress.[7] We will explore this idea further in the section "Supportive approaches to hallucinations".

So, encouraging people to reflect on their hallucinations can help them to better understand the hallucinations and themselves (if they are psychologically ready to do this). This can be done either

[45] Kupfer, D. (2013), as quoted in: Johnstone, L. (2014). *A straight-talking introduction to psychiatric diagnosis.* PCCS Books.

[46] Vallath et al., 2018, p7

[47] Vallath et al., 2018, p9

[48] Vallath et al., 2018

on their own or (preferably) with the support of others (see the "Supportive approaches to hallucinations"). One such approach is known as "collaborative formulation" – where the experiencer and professional/s work together to develop an understanding of the experiences and how they affect the individual (Lonergan, 2017). To think about this further, see the Case Study activity box below.

CASE STUDY

Louise is a 21-year-old student who has moved away from her hometown for the first time, to study at university. Louise's parents have always been very concerned with safety and security, which has made Louise an anxious person. Louise's parents have always emphasised not to trust strangers, and to always make sure her front door and windows are properly locked. Louise does not feel comfortable in her new student accommodation, which is not as secure as she or her parents would like (it doesn't have a house alarm, and some of the windows can't be locked). Louise also does not feel very safe being surrounded by people she does not know or trust. Louise is feeling very stressed due to this and her large university workload, and is not sleeping well. Mid-way through her first term, Louise begins to hear voices talking to or shouting at her, saying things like "Someone's going to break in and kill you" and "You're not safe here!". These voices are frightening, and make Louise feel ever more stressed and unwell.

ACTIVITY: What could be the cause of Louise's hallucinations? What do they reflect? What could help Louise to cope with her hallucinations and general situation (stress, anxiety, feeling unsafe, getting behind with university work)? Discuss.

Hallucination myths

Table 1 – Many commonly held ideas about hallucinations are inaccurate (see left column). The right column shows more accurate, research-based views.

Myth	Fact
Hallucinations are only experienced by people with mental health problems.	Unusual experiences are not necessarily associated with mental or physical health problems. They can be had by healthy people in the complete absence of any health problems.
Hallucinations are only experienced by people at certain times of life.	Unusual experiences can be had by anyone at any time in their lives. (see, "Who" section)
The general population do not experience hallucinations.	Unusual experiences are relatively common in the general population (~5.4%)
Hallucinations must be treated with anti-psychotic medication.	There are plenty of alternative treatments or interventions available for hallucinations, if desired. Some people with hallucinations do not need or want any treatment at all.
People cannot experience hallucinations and also live a normal life.	Many people experience hallucinations in their day-to-day lives and are also able to have normal and fulfilling lives.
Hallucinations will never go away.	Sometimes hallucinations are fleeting, and sometimes they become a permanent part of someone's life. Both are normal and manageable.

Medicalisation & stigma

The **medicalisation** of hallucinations

Many vivid descriptions of hallucinations can be found in Greek and Roman texts from the 8th century BC. For example, the philosopher Socrates is thought to have hallucinated a "divine" inner voice, which gave him advice (Robb, 2014). Hallucinations were sometimes given medical causes, or attributed to divine or demonic powers, but some groups took a more philosophical, naturalistic view on them (i.e. that hallucinations happen when the mind makes a mistake, and so are a natural part of human experience) (Robb, 2014; Weiss & Heckesr, 1999). Although we have historical evidence of hallucinations occurring for different reasons since these ancient times, they have only become medicalised in the Western world over the past few centuries (Weiss & Heckesr, 1999).

Fast forward to modern times, where during the 19th century Western scientists began to define hallucinations and identified the occurrence of hallucinations in many different medical conditions (Britannica, 2019). In 1959, the German psychiatrist Kurt Schneider's textbook called "*Clinical Psychopathology*" was translated into English. In this book, Schneider defined what he called the "first rank" symptoms of schizophrenia, which included auditory and somatic (bodily) hallucinations. Schneider suggested that these were "strongly suggestive" of schizophrenia (Soares-Weiser et al., 2015). Schneider focused on the *form* that experiences took (such as a hallucination, or a delusion) and not the specific *content* of that experience (such as whether it included people or religious symbols) (Bentall, 2003, p31). Schneider hypothesised that the *content* of hallucinations was subjective, biographical, and open to interpretation, and so any "meaning" was irrelevant, whereas the *form* of hallucinations was more important and relevant to diagnosis (Bentall, 2003, p31). Unfortunately, this view still persists today (Lonergan, 2017).

However, Schneider made it clear that hallucinations were not critically important features of schizophrenia – rather, they were chosen for convenience because they are easy to recognise (Bentall, 2003, p31). Unfortunately, the first rank symptoms became very popular and influential in English-speaking countries, and it became the norm amongst psychiatrists and researchers for anyone showing these symptoms to be diagnosed with schizophrenia (Bentall, 2003, p34). This began the process of making "hallucinations" synonymous with "madness" in Western psychiatry.

Because of this, schizophrenia diagnoses are often still based on these "first rank" symptoms, using hallucinations as a key diagnostic measure when in fact they were initially intended to be used as a guide and not a definitive indicator (Bentall, 2003, p31). Much research in psychiatry has shown that hallucinations are not a reliable way to recognise schizophrenia. In 1924, in his "*Textbook of Psychiatry*", Bleuler explored the relationship between the diagnoses of schizophrenia and manic depression, and concluded that these diagnoses were not separate but were two points along a "continuum", with no clear line between them (as cited in Bentall, 2003, p24). The diagnoses of schizophrenia and manic depression overlap considerably and are likely not distinct conditions (Bentall, 2003, p71). Bleuler also concluded that there was "no precise dividing line between normality and illness".

In support of this idea, the "inter-rater reliability" of psychiatric diagnoses is also consistently low (Bentall, 2003, p64). Inter-rater reliability refers to how consistently the same diagnosis is given to the same person by different professionals. Unfortunately, there is often little agreement between different professionals on the diagnosis to give the same individual (see Bentall, 2003, p64 onwards for a detailed analysis). Therefore, Bentall suggests that the "apparent consensus created by [psychiatric handbooks of diagnosis] is illusory" (Bentall, 2003, p64) and that the "boundaries between sanity and madness are indistinct and permeable" (Bentall, 2003, p115).

Because of this history, hallucinations are still commonly thought of as "hallmarks of mental illness", despite the fact that they are not always associated with illness[49,50]. In fact, more and more research shows that hallucinations are experienced by mentally-healthy people who do not feel the need to seek treatment (Bentall, 2003, p97). Despite this, because of the psychiatric focus on hallucinations as a key part of psychosis, research into hallucinations has largely been restricted to people given this diagnosis.

A classic study on the medicalisation of hallucinations was conducted in 1979 by David Rosenhan, and this study became famously known as the "Rosenhan experiment". This study, called "On Being Sane in Insane Places"[51], illustrates how a medicalised view of hallucinations can lead to healthcare professionals coming to mistaken conclusions about the patients in their care (a finding that was replicated by Scribner in 2001[52]).

For this study, eight sane participants ("pseudo-patients") admitted themselves to various psychiatric hospitals, stating that they were hearing voices. The pseudo-patients disclosed nothing about themselves other than a false name and the hallucinations. When asked, the pseudo-patients' described any significant life events exactly as they had occurred – and nothing in their histories or current behaviours was pathological. Upon admission to the psychiatric hospitals, pseudo-patients stopped simulating any symptoms, and behaved normally.

Despite this, none of the pseudo-patients were ever identified as such by staff. In fact, most staff assumed that the pseudo-patients had schizophrenia. The pseudo-patients were hospitalised for an average of 19 days, with the maximum being 52 days. Staff perceptions of the pseudo-patients' characters and experiences were demonstrably tainted by the assumed diagnosis of schizophrenia. For example, the facts of pseudo-patients' histories were "unintentionally distorted by staff to achieve consistency with [schizophrenia]"[53]. Here is an example in an excerpt from the original paper:

"A clear example of such translation is found in the case of a pseudopatient who had a close relationship with his mother but was rather remote from his father during his early childhood. During adolescence and beyond, however, his father became a close friend, while his relationship with his mother cooled. His present relationship with his wife was characteristically close and warm. Apart from occasional angry exchanges, friction was minimal. The children had rarely been spanked… Observe, however, how such a history was translated in the psychopathological context, this from the case summary… "This [patient] manifests a long history of considerable ambivalence in close relationships, which begins in early childhood… Affective stability is absent… His attempts to control emotionality with his wife and children are punctuated by angry outbursts and, in the case of the children, spankings. And while he says that he has good friends, one senses considerable ambivalence embedded in those relationships also." Clearly, [this interpretation] was determined by the diagnosis: schizophrenia." (Rosenhan, 1979, p253)

[49] Chaudhury, 2010 - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3105559/
[50] Lonergan, 2017 - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5450989/
[51] Rosenhan, D. (1979). On being sane in insane places. http://emilkirkegaard.dk/en/wp-content/uploads/On-being-sane-in-insane-places.pdf
[52] https://psycnet.apa.org/doi/10.1037/0735-7028.32.2.215
[53] *ibid*

Unfortunately, this overly simplistic view of hallucinations still persists today. Consequently, many people who experience hallucinations are reluctant to admit their experiences due to worries about seeming "mad" – and when they do disclose these experiences, they are often misdiagnosed[54]. Disclosure of auditory hallucinations is most commonly linked to (mis)diagnosis of psychosis or manic depression[55]. Oliver Sacks, a neurologist renowned for his work on hallucinations, has said that "[through his experiments], Rosenhan demonstrated convincingly that auditory hallucinations and schizophrenia [are] synonymous in the medical mind"[56]. The strong (but mistaken) association between hallucinations and "madness" is now also prevalent in the general public[57].

For a modern perspective on psychiatric diagnosis, we will look at a program televised by the BBC: the poorly entitled "*How Mad are You?*" (2008). This program was inspired by Rosenhan's original experiment. In the show, a panel of experts (including a psychiatrist, a professor of clinical psychiatry, and a psychiatric nurse) remotely observed ten people for a week and tried to pick out the five volunteers who had been diagnosed with some form of mental health difficulty (such as depression, bulimia, and schizophrenia). The experts felt that this was insufficient time to make these decisions – even though most psychiatric assessments take only 1-2 hours (Royal College of Psychiatrists, 2018). The volunteers completed some basic tasks that were designed to help inform the diagnoses, but these actually created a lot of confusion and contradictions in the experts' attempts at diagnosis. Overall, the panel only correctly identified the diagnoses of *two out of ten* volunteers. They incorrectly identified one volunteer as a healthy control, when in fact she had a history of mental health problems; misdiagnosed two people with bipolar disorder and mood disorder (when in fact these volunteers had previously experienced depression); and diagnosed three healthy volunteers with mental health problems – one with schizophrenia[58]. This programme further illustrated the problems with current psychiatric systems of diagnosis, and how symptoms and behaviour can be misinterpreted even by a group of trained professionals.

As a consequence of all this confusion, Bentall (2003, p141) suggests that, contrary to what was recommended by Schneider, we should try to understand and explain the experiences and behaviours of people who are suffering. This will contribute far more to recovery than if we try to identify a supposed illness "category" and attempt to treat this illness in the same way across all the different individuals in this category. Further, paying attention to and interpreting people's experiences allows us to appreciate and understand individuals across many contexts – biological, psychological, social, and environmental – and more fully understand their unique story. Biological approaches alone assume that any brain "abnormalities reflect processes that are unconnected to the social environment… [we need] a better understanding of the relationships between the brain, mental events such as thoughts and feelings, and the social and physical environment" (Bentall, 2003, p174).

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[54] Sacks, 2012, https://www.nytimes.com/2012/11/04/opinion/sunday/seeing-things-hearing-things-many-of-us-do.html
[55] *ibid*
[56] *ibid*
[57] Moskowitz et al. (2011), p22
[58] Progler, Y. (2009). Mental illness and social stigma: Notes on "How Mad Are You?".

Stigma and hallucinations

Many people are afraid to disclose their hallucinations for fear of being negatively judged. This is called "**stigma**", which comes from the Greek for "mark or brand" and originally referred to something odd or bad about a person (Joachim & Acorn, 2000). **Stigma is a disgrace or shame that is wrongly associated with a particular characteristic, quality, or person**. Stigmas are a type of **"cognitive bias"** – a quick thinking or shortcut strategy used by our brains to evaluate situations and come to a rapid conclusion or decision[59]. Cognitive biases can be beneficial; our unconscious tendency to see faces everywhere (**pareidolia**, as discussed earlier) is highly useful for our survival, as we need to know when another, potentially-threatening human is close to us. But, these biases can also cause faulty thinking and mistaken conclusions. According to the socio-cognitive model, stigmas are formed from **stereotypes**, **prejudices**, and **discrimination**:

- Stereotypes are <u>attitudes</u> about the self or others

- Prejudices are "the <u>emotional reactions</u> resulting from <u>agreement with attitudes</u>"

- Discrimination is "the <u>behaviour</u> that results from stereotypes and prejudices"[60,61]

All of these can be expressed towards others and towards the self. See Table below for an example (adapted from Corrigan et al., 2002 & Sheehan et al., 2016).

Stereotype: attitudes about others or the self	**Public: "Most people think people with mental health problems are violent."** **Self: "I am incompetent"**
Prejudice: agreement with stereotypes and/or an emotional reaction	**Public**: "Yes, people with mental health problems are very dangerous; I'm frightened of them." **Self**: "I can't handle a regular job"
Discrimination: action	**Public:** Avoiding engaging with people perceived to have mental health problems, including choosing not to help them and avoiding / ostracising them **Self**: Not pursuing a career

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[59] If you are interested in reading more about different types of cognitive bias, visit: https://betterhumans.coach.me/cognitive-bias-cheat-sheet-55a472476b18
[60] Sheehan et al., 2016 – Structures and types of stigma
[61] Corrigan et al., 2002 - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1489832/

Stigmas can be due to physical differences (such as missing limbs), character "blemishes" (such as having been in prison), or "tribal stigma" (e.g. because of race or religion) (Joachim & Acorn, 2000). Stigmatizing someone involves attaching a social meaning to these or other qualities, behaviours, or individuals (Joachim & Acorn, 2000). Some psychologists have suggested that people who hold stigmatised views construct a belief system that leads them to identify people who are different as dangerous, and so may act according to this belief (Joachim & Acorn, 2000). For example, before epilepsy was understood as a neurological condition, it was historically associated with demonic possession (due to seizures) (Joachim & Acorn, 2000). People may also use cruel, dismissive, or offensive language (e.g. "cripple", "loony", "moron") (Joachim & Acorn, 2000).

Stigma also leads people to discriminate against others by identifying individuals as members of a supposed "group", so that any stereotypes associated with that group are also associated with those individuals (e.g. "He's got schizophrenia, he's probably dangerous")[62].

Some different **types** of stigma are shown in the table below. Try **Activities 2 and 3** to think more about how stigma might impact people experiencing hallucinations.

Stigma type	Description
Felt stigma **(also known as internal stigma or self-stigma)**	When someone holds stigmatised views about themselves, and this leads to a feeling of shame and the expectation of discrimination. This can stop people from talking about their experiences and seeking help when needed[63]
Enacted stigma **(also known as external stigma or discrimination)**	The experience of unfair or prejudiced treatment from others (because of a perceived characteristic or condition)
Discrediting stigma	When someone shows visible signs of being different (including them directly communicating this difference), they can potentially be **discredited** – doubted, questioned, or disparaged

Unsurprisingly, self-stigma can promote a negative self-opinion and low self-esteem, and lead to poorer outcomes (Corrigan et al., 2002). Therefore, the individual should be empowered to recognise their experiences as valid and supported to see themselves more positively (and not through a stigmatised lens). In schizophrenia and other mental health problems, experiences are often labelled

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[62] Sheenan et al., 2016

[63] Gray, 2002 - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1279314/

as simply being the result of a "brain disease" – this view takes control away from the experiencer, which can increase distress and low mood, and prevent recovery (Harrow et al., 2009).

> **ACTIVITY 2**: Charnjit has been experiencing auditory verbal hallucinations for the past month. During these experiences, she can hear two people talking to each other about her every day activities, in a neutral, non-threatening way. The hallucinations happen once or twice a day. Although the experiences are not frightening, Charnjit feels that they are unusual and wants to talk to a family member or friend about them. What types of stigma might Charnjit experience due to her hallucinations? How might this change her behaviour, or influence her decision to speak to someone about her experiences? Would this stigma affect her relationships, social interactions, or other parts of her life (such as work)? Discuss.

There are also different **dimensions** of stigma, related to the types above[64]:

- **Concealability** – the degree to which the stigmatised quality or condition can be hidden. This is key to stigma, as visibility or disclosure are central in "producing negative social reactions"[65];

- **Course** – the degree to which the quality or condition changes over time;

- **Strain** – how much strain does the stigma place on relationships?

- **Aesthetic qualities** – how much does the quality or condition affect someone's physical appearance?

- **Cause** – what is the cause of the quality or condition? Is it acquired, inherited, controllable or uncontrollable?

- **Peril** – are there any dangers associated with the stigmatised quality or person? (Note: this means <u>unevidenced, stereotyped</u> dangers)

> **ACTIVITY 3**: Robert has been experiencing visual hallucinations of birds and other flying creatures for the past three years. Sometimes they are benign and easy to ignore, but sometimes they are very vivid and fly straight at Robert, causing him distress and to react by swatting them away. The hallucinations often happen when Robert is stressed, and his wife feels upset and uncomfortable when Robert's hallucinations cause him distress and worsen his negative mood. Robert often blames his high stress on work and his long commute. Robert has never hurt anyone as a result of his hallucinations. Discuss the different dimensions of stigma that apply in Robert's case. How might these affect his life – e.g. his opinions of himself, his relationships, work, and free time? What could be done to improve Robert's quality of life?

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[64] Joachim & Acorn, 2000
[65] Joachim & Acorn, 2000

Misconceptions about certain health conditions or groups can lead to stigma. For example, many people hold negative stereotypes about people with certain health problems, such as the common (mistaken) idea that people with mental health problems are violent (Gray, 2002). In fact, there is no evidence that common mental health problems are linked to violent behaviour (Mind, 2013). Similarly, people can have more negative views of mental health problems as compared to other health conditions. For example, one study found that children viewed their peers with mental health problems as "more likely to get into trouble" than peers with asthma, and peers with depression "more likely to get into trouble" than peers with Attention Deficit Hyperactive Disorder (ADHD) (Parcesepe & Cabassa, 2012).

Accordingly, research has shown that stigmatising beliefs are directly associated with stigmatising attitudes (prejudice) and actions (discrimination) towards mental health problems and treatment[66]. To look into this, some studies have explored "social distance"; a measure of exclusion, such as being unwilling to work closely with someone or to have them as a neighbour (Parcesepe & Cabassa, 2012). The general adult population show a widespread preference for social distance from people with mental health or drug abuse problems, as compared to people with health problems such as asthma (Parcesepe & Cabassa, 2012). For people diagnosed with schizophrenia, the desire for social distance has significantly increased since 1996 (Parcesepe & Cabassa, 2012).

People with mental health problems are also commonly stereotyped as being incompetent and unable to make their own decisions (Sheenan et al., 2016). All of these stigmatising or stereotyped attitudes towards a person can therefore lead to that individual being subjected to coercion or control by a "guardian" (due to perceived incompetence), withdrawing from society, having reduced independence, and having restricted social support. Some mental health problems are also perceived as being permanent and unchangeable, which can lead to less support for interventions, support, or rehabilitation, and independence, and increased stigmatisation[67].

Related to the above, some research has also shown that biological explanations for mental health problems can actually increase stigma. For example, recent research suggests that "biogenic" explanations for mental health problems – those that cite a biological cause – are not associated with more tolerant attitudes. In fact, they lead to stronger rejection of diagnosed individuals.[68] Despite generally increasing public awareness of supposed biological causes and mental health literacy, and acceptance of seeking professional help for mental and emotional distress, people's general attitudes towards and acceptance of those struggling with their mental health have not improved (and have in fact worsened for some diagnoses).[69,70]

Research suggests that biological explanations for mental health diagnoses (such as genetic causes or ideas of "brain disease") imply that these are a permanent, unchangeable part of who someone person is.[68] It suggests an inescapable fate, determined by biological factors that are not under the individual's control. Not only can this increase stigma against and a desire for distance from the person experiencing mental distress, but it can also lead to lower expectations for their recovery or good outcomes.[68] Therefore, there is no strong evidence that approaching mental health problems as "diseases like any other" effectively reduces stigma.[71]

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[66] Parcesepe & Cabassa, 2013 - https://link.springer.com/article/10.1007/s10488-012-0430-z
[67] Sheehan et al., 2016 – Structures and types of stigma
[68] Angermeyer, M., Holzinger, A., Carta, M., & Schomerus, G. (2011). Biogenetic explanations and public acceptance of mental illness: Systematic review of population studies. *British Journal of Psychiatry, 199*(5), 367-372. doi:10.1192/bjp.bp.110.085563

[69] https://doi.org/10.1111/j.1600-0447.2012.01826.x
[70] https://doi.org/10.1016/j.eurpsy.2008.06.010
[71] https://doi.org/10.1177%2F1355819613485853

Even though the public's attitudes towards seeking professional help for mental health problems have become more positive over time, there have not been any changes in the public's perception of the actual *effectiveness* of any treatments or interventions (Parcesepe & Cabassa, 2012). One study found that the public estimated that only half of people who seek help will get better (Mojtabai, 2007). "Informal" sources of help or non-biological treatments – such as talking to friends or family, seeing a therapist – were more commonly endorsed options for depression, compared to more "formal" sources or biological treatments, such as seeing a psychiatrist or taking medication (Parcesepe & Cabassa, 2012). People with mental health problems can be stereotyped as incompetent, weak, and violent, which then leads to attempts at justifying coercive treatment. In line with this stigmatised viewpoint, the public are likely to endorse coercive treatment that does not require an individual's consent (such as forced hospitalisation) for schizophrenia and drug addiction, as people experiencing these are (mistakenly) viewed as less competent to make decisions and more likely to be a danger to self or others (Parcesepe & Cabassa, 2012).

There is very little research that specifically explores personal experiences of stigma associated with hallucinations, and how these affect individuals' quality of life and mental health. One study that explored experiences of stigma in people diagnosed with schizophrenia found that they experienced judgement from many sources, and were very aware that their quality of life was negatively affected by their diagnosis (Knight et al., 2003). These judgements included examples of stereotypical attitudes, prejudice, and discrimination:

"People don't understand… they'll say, is it split personality or something basic like that"

"Part of society sees schizophrenics as dangerous and unacceptable. I have had it from my parents, my family and my friends, my close encounters"

"[I experience stigma] even by doctors. They don't see you as a person"

"Mainly like it was the psychiatrist versus us lot"

"We're not accepted when we go back to work, no matter that you do the job. They don't treat you as an equal, they're always a bit wary of you… from my experience"

Individuals felt labelled as "'dirty, unacceptable", with "such a bad, bad image"

"I don't know that you have much of a future with this illness… they say it gets better as you get older but I'm not finding that"; "I don't have a future"

Quotes from Knight et al., 2003

There were also reflections on the individuals' personal understanding of the issue, about their health, and how they cope:

"I don't go out my house… I stay in my house"

"Sometimes I break off… don't bother to contact them"

"I don't tell members of the public. I mean people I don't know, not any more… They think you're a f**king nutter"

"I wouldn't tell other friends… Because they would judge me"; "I especially try to keep it a secret about my mental illness when I'm in the normal outside world"

Quotes from Knight et al., 2003

Here, we can see how people cope with stigma using the defence mechanisms of withdrawal and secrecy, to protect themselves from further judgement. They feel socially-excluded and alienated. All of these factors come together to create what can seem "an almost insurmountable barrier to recovery" (Knight et al., 2003).

Comparatively, a study on healthy people in the general population who experienced many different kinds of hallucinations also found that people were afraid to discuss their experiences with anyone other than friends and family, and only in spaces such as meditation centres or paranormal societies (Faccio et al., 2013). Interestingly, not one of the people in this study coped with their experiences by speaking to a psychologist or psychiatrist about them (Faccio et al., 2013). There is also very little research into experiences of stigma in such non-clinical groups, and more work is needed in this area.

Research into stigma has shown that education about mental health problems, and increased contact with people with mental health problems, are the most effective ways of reducing stigma (Corrigan et al., 2012). Contact is most effective in adults, whereas education is most effective in adolescents (Corrigan et al., 2012).

Stigmatising language

Because of the numerous stigmas associated with mental health diagnoses, stigma can be inadvertently introduced when discussing hallucinations is by using clinical language. We will discuss below that it is important to allow the experiencer to choose what language they use to describe their experiences, and this may include clinical language if this is their choice (see section "General communication with experiencers"). However, there seems to be a particularly clear relationship between psychiatric language and stigma.

For example, words such as "patient" or any descriptor that centres a diagnosis (such as "schizophrenic") can be very stigmatising because they define the whole person by their experiences, the labels that others have given them (which they may not agree with), or use of health services (which is sometimes forced). This is why it is so important to carefully consider the language we use to describe people and their experiences. Think critically and reflectively on why you might use certain terms, and what language might be preferred. We will explore this in more detail in the chapter "General communication with experiencers".

Cultural perceptions of hallucinations

Culture – "shared patterns of meaning that are learned in a particular social world" – can have significant influence on definitions, experiences, and interpretations of hallucinations[72]. Culture can influence "the way that people pay attention to their sensory experience", and how people interpret this experience[24]. Because of this, definitions of hallucinations vary by culture. For example, how reality is defined, and what sensory experiences are deemed "normal" or "appropriate", will influence what is labelled a "hallucination" (Larøi et al., 2014). As Larøi and colleagues point out, "this is important because research on hallucinations usually involves asking people about experiences that are not explainable, have no obvious source, or are not shared by others" (Larøi et al., 2014).

The types of hallucinations experienced by people vary widely across cultures. Auditory hallucinations, for example, are the most common in clinical groups in the West, whereas visual hallucinations are more common in these groups in African and Asian countries (Laroi, 2006). For example, in people diagnosed with schizophrenia, auditory hallucinations that were frightening, commanding, or abusive were found to be much less frequent in Nigerian people as compared to people from the UK (Laroi, 2006).

One study compared the prevalence of auditory and visual hallucinations in people diagnosed with schizophrenia across different countries, and found that auditory hallucinations varied from 67% in Austria to 91% in Ghana, and visual hallucinations from 4% in Pakistan to 54% in Ghana (Larøi et al., 2014). Bereavement hallucinations are common in Western and Japanese cultures, and are usually seen as positive or helpful experiences, whereas the Achuar people of Ecuador consider visions or dreams of the deceased "as a threat to the soul of the experiencer" (Larøi et al., 2014).

It is important to be aware that the negative, medicalised view of hallucinations that is conventionally held in the West is culturally-specific, and by no means applies to other places or cultures. **In many cultures, hallucinations are viewed as positive, beneficial, and culturally-meaningful.** Hallucinations can play key roles in many religions and are often seen as spiritual, supernatural, or divine. For example, the Sinoa and Schuar peoples of the Upper Amazon both use hallucinogenic plants for spiritual guidance, and these groups each have a different view of what hallucinations actually are (Larøi et al., 2014). The Sinoa people believe that the hallucinations are part of an alternate reality, whereas the Schuar people believe that the hallucinations allow access to part of everyday reality that they don't usually see (Larøi et al., 2014).

One study found that hallucinations played a role in ordinary rituals in 62% of the 488 cultures explored[73], and that these hallucinations were positively-valued and not usually associated with substance use. For example, one study that interviewed Pentecostal Christians from a church in London, UK found that 25 of the 40 people interviewed believed they had heard the voice of God answering their prayers, with 15 of these people hearing God's voice aloud[26]. These individuals described God's voice as being practical and directed at solving problems, sometimes giving commands but not compelling individuals to follow these without question. This contrasts with some experiences of hallucinations that are often categorised under schizophrenia, which tend to involve the individual feeling that their thoughts, emotions, and actions are "taken over" or replaced by another power[26]. Despite the negative stigma that is commonly attached to hallucinations, spiritual events that are clearly recognisable as hallucinations are often positively reported as "religious experiences" in Western media, which contrasts with the conventionally negative reporting on hallucinations[24].

One difficulty with Western hallucination research, like much experimental work in psychology and neuroscience, is that the majority of participants (and researchers) are "WEIRD"; Westernised, Educated, Industrialised, Rich, and Democratic. This limits how generalisable the

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[72] Laroi et al., 2014 - https://academic.oup.com/schizophreniabulletin/article/40/Suppl_4/S213/1874317
[73] Bourguignon, E. (1970). Hallucinations and trance: An anthropologist's perspective.

findings are to other countries and cultures, and how much is known about hallucinations. Therefore, much more diverse research is still needed to fully understand cultural and societal differences in hallucinations[24]. Consider the below case studies to further explore the influence of culture on understanding hallucinations.

CASE STUDY – One piece of research interviewed a Pentecostal Christian from a church in London, UK, who had been diagnosed with bipolar disorder. This man described the differences between his experiences of hearing God speak to him and hearing his "psychotic" voices speak to him. He said: "God says something and doesn't force you, so you can do what you like with it… [the psychotic voices] you can't refuse to do something when you hear them. They are very pushy… [The voice of God is] very calm and peaceful… He tells you what you should do but basically it is up to you."[1]

What can we understand about this man's experiences from this quote? What are the qualities of his "God" hallucinations versus his "psychotic" hallucinations? How might he interpret and react to each experience, and how might this influence his quality of life? Discuss.

CASE STUDY – Akhona is a man from the Xhosa culture of South Africa, who recently moved to the UK to study at university. Akhona has begun to experience auditory hallucinations. He hears a voice speaking in the Zulu tongue, and this voice seems to be coming from his stomach. This has been going on for around a month and is starting to affect his studies and personal life. The voices have become steadily more aggressive and negative. Akhona has stopped seeing his friends, and is struggling to keep up with his university work. When he decides to see a local therapist, Akhona tells her that he thinks he is a victim of "*amafufunyana*"; possession by spirits due to black magic. However, the therapist labelled Akhona's belief in spirits and black magic as a delusion associated with his hallucinations, and suggested traditional Western solutions (medication or cognitive behavioural therapy) to help alleviate the hallucinations. However, because this clashed with Akhona's own interpretation of the source of his experiences, the therapists' treatment recommendations resulted in Akhona no longer wanting to see the therapist, and refusing further help. Akhona felt undermined and misunderstood. He also felt that he has not been helped to gain control over the spirits or reverse the black magic, and because of this stress his hallucinations might get more frequent or distressing in future. He might have preferred that the therapist discuss other options, such as seeking help from a spiritual leader or traditional healer, who could perform a traditional ritual to rid him of the spirits. It is very important to ask about and respect the cultural beliefs of experiencers, as this may have a huge impact on the type of help they want, whether they continue to engage with any sources of support, and their overall health outcomes.

What do you think about this case study? How might Akhona's therapist have approached this situation differently? Can you think of other situations in which culture may have an important influence on someone's interpretations of their own experiences?

Summary

Hallucinations are defined differently, and have different meanings, across cultures. In many groups and cultures, hallucinations are viewed and interpreted in a positive way. A culturally-sensitive approach to hallucinations is recommended wherever possible, as approaching hallucinations in a way that potentially clashes with the experiencer's viewpoint can have negative consequences (such as discouraging further discussion or treatment).

Supporting people who experience hallucinations

This section contains information on factors that can discourage and prompt help-seeking, practical tips on general communication with experiencers, and a list of questions experiencers might ask you or that you might like to ask experiencers (in the appropriate setting). If you find the term "experiencers" too clunky, you could use the phrase "people who experience hallucinations". If you are an experiencer yourself and you feel psychologically ready and safe, you could consider how these different factors influence your own disclosure, discussions, and experiences of hallucinations. (This section is not intended to provide clinical guidance or replace support from a qualified health professional.)

Psychological barriers to help-seeking

Disclosure

Because hallucinations cannot be experienced by anyone else, someone who is experiencing hallucinations must often choose to actively disclose them before anyone else is aware of them (with the exception of situations in which an observer might guess that someone is hallucinating from their behaviour). Information management is therefore critical, as people choose whether to disclose their experiences, who to tell them to, and how much information they give (Joachim & Acorn, 2000). Reluctance to talk about and get help for distressing hallucinations is understandable, as it can be uncomfortable and risky for people to disclose their experiences (due to potential stigma or forced treatment, for example). Several factors decrease the likelihood of people disclose any mental and emotional distress, including[74]:

Factor	Illustrative quotes from interviews
Fear of consequences (e.g. confronting oneself, the unknown, judgement, possibly unwanted treatment, losing children, being institutionalised, losing control)	"You give people power over you by opening yourself up too much… people don't want to admit that they've got a problem… because it puts things out of your control… I want to be in control of me" "I think perhaps women who are bringing up kids on their own, you don't want to tell your doctor because you think you've failed… But I thought if I, if I tell him, if I tell him he'll think I can't cope or I can't do it"
Lack of trust (see "Trust" under "What prompts health-seeking") **Stigma of mental health (see "Stigma" section below)**	"I think also the reality is that they have the power to make a judgement on your state of health and can have you sectioned or, you know, there is that element … of being careful about what to say because it could be misjudged as, you know, you might have a severe mental illness… I don't think they can be objective… mentally there's that examination feel and feeling judged"

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[74] Dew et al., 2007 - https://doi.org/10.1111/j.1467-9566.2007.01022.x

Doctors are not able to help / can only help with physical problems	"'We spend too much time thinking "why", wondering why something is happening instead of trying to fix it… when you're going to a psychologist or psychotherapist or something like that you can get too side-tracked and you can go for too long. And in the end, you end up worse"
Being resilient or self-reliant	"I am my own health professional"
"Bottling it up" (suppressing problems)	"I think it'd open up a lot of, a lot of things that I'd have to deal with, and because… I don't know actually how I'd deal with them, so that's probably why I don't or why I never did pursue it. Yeah, 'cos I wasn't, probably wasn't too sure how I'd be able to cope with what came out."
Sex (men suppress their emotions and don't seek help, women are expected to endure them)	"Having to go to a psychologist … was just very frightening and … it was threatening… One of the motivators behind that feeling I think that, you know, you're definitely less of man…"
Other factors identified	
Limited appointment time; Lack of awareness or denial; Culture (see "Beliefs" section below); Being a burden / "whingeing"; Lack of encouragement from health professionals	

(summarised from Dew et al., 2007)

Stigma

Stigma (see section "Stigma and hallucinations") is a serious barrier to disclosure and help-seeking, as well as continued participation in support when it is sought or offered. Self- and public-stereotypes, prejudice, and discrimination can all influence behaviour around help-seeking. For example, someone who starts experiencing hallucinations for the first time may be aware of some stereotyped and negative views of people who hallucinate ("they're crazy"). They might agree with these stereotypes and therefore feel an emotional aversion to being associated with the stereotype or associated group/s. They will want to avoid any labels or discrimination that might affect them if they are identified as part of a stereotyped group. All of these thought processes may prevent someone from seeking help, because by doing so they will inadvertently identify as part of a stigmatised group. Negative labels (such as being "nuts", "mentally ill", or "schizophrenic") have been identified as the "single greatest cue that yields public stigma" (Corrigan et al., 2002, p319), and therefore people may avoid seeking help because they want to avoid being labelled.

As might be expected, **research has shown that people avoid help services if they encounter negative attitudes about mental health problems** (e.g. from service providers or family members), but that **positive attitudes from family members increase service use** (Corrigan et al., 2002). Moreover, increased perception of or exposure to stigmatising attitudes leads to reduced engagement with suggested support options (Corrigan et al., 2002, 2014).

Therefore, it is vital that steps are taken to reduce stigmatising attitudes and behaviours as much as possible. This could be achieved through, for example, programs and training on cognitive biases and stigma. These can be tailored to the public through general campaigns and advertising, or

to specific groups of people or contexts (such as your own workplace, organisation, or speciality). Campaigns aimed at the public generally try to change attitudes through objecting to stigma, education, and promoting contact between people and stigmatised groups (Corrigan et al., 2002). Due to "psychological reactance", however, objections to stigma that attempt to suppress certain attitudes and stop people thinking certain ways – e.g. by calling them disrespectful or ignorant – can often lead to those attitudes staying the same or even becoming worse (Corrigan et al., 2002). Generally, people do not like to be told what to think and do. Education and contact are much more effective approaches. Education aims to replace emotionally-charged prejudices with facts that counter stereotypes, and contact aims to practically negate stigma by familiarising people with mental health problems and those experiencing them (Corrigan et al., 2002).

As self-stigma can lead to decreased self-esteem and low mood, it should also be empathetically challenged (Young, 2018). This can be done through any number of supportive techniques, such as **cognitive behavioural therapy** (CBT). CBT is a talking therapy that tries to change people's patterns of thinking about and responding to different thoughts and events, by teaching people to notice and change thinking styles and behaviours (BABCP, 2019). CBT can therefore be used to change negative, self-stigmatising thoughts and beliefs by encouraging more rational and positive ones. One study tested CBT in a group of Chinese people who had received a diagnosis of any type of mental health problem and who felt self-stigma (Young, 2018). CBT was very effective in reducing self-stigma and improving mood (Young, 2018). Another study in Japanese people with anxiety and depression who experienced self-stigma also benefited from a CBT program, with significant improvements in mood, self-esteem, anxiety, and reductions in self-stigma (Shimotsu et al., 2014).

(For more information, see Corrigan et al. (2014) for an excellent review on this topic.)

However, it is important to note here that techniques like CBT are focused on the individual, and do nothing to address external factors that might be contributing to self-stigma or other mental and emotional distress. It is always important to recognise the influence and power of external factors, such as social and environmental contexts, when supporting any individual. Individually-based support options will often only address a small part of a wider issue, and this is particularly true for a socially-based phenomenon like stigma.

Beliefs about the ineffectiveness or irrelevance of support

A lack of trust or belief in available treatments and services will inevitably lead to reduced help-seeking. Psychiatric medication, for example, is often recommended in clinical practice but is generally viewed very negatively by the general public, who see such medication as potentially doing more harm than good (Jorm, 2012). So, an individual with this view who is recommended medication by a healthcare provider is not likely to continue with the treatment. Further, biologically-based ideas about and treatments for mental and emotional distress can actually promote stigma, because they suggest that mental distress or mental health diagnoses are biologically pre-determined for that individual[68]. This contributes to the idea of mental distress being caused by unavoidable "brain diseases" or genetic predispositions that are out of the individual's control (even though there is no strong evidence for this[7,75,76,77,78,79,80]). Psychological approaches, such as cognitive behavioural

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[75] CEP, 2021 - http://cepuk.org/unrecognised-facts/no-biological-causes/

[76] CEP, 2021 - http://cepuk.org/unrecognised-facts/myth-of-the-chemical-imbalance/

[77] Zipursky et al., 2012 - https://doi.org/10.1093/schbul/sbs135

[78] Szasz, 2018 - https://doi.org/10.1192/pb.bp.110.031310

[79] https://doi.org/10.3389/fgene.2019.00985

[80] Moncrieff, 2020 – A straight talking introduction to psychiatric drugs.

therapy, are often viewed more positively by the public (Jorm, 2012). These perceptions should be considered when support is offered, as beliefs and opinions about the effectiveness and limitations of support will strongly influence whether someone continues to seek and engage with help.

Research also consistently shows that people rate informal sources of help, such as friends and family, very positively – and more so than professional sources of help (Jorm, 2012). This is a concern, because the average member of the general public has fairly low mental health literacy (Jorm, 2012) and may therefore inadvertently share inaccurate or stigmatising ideas (see next section).

Cultural beliefs will also play a role in how effective people perceive help-seeking or treatment to be. Stigma is socially-constructed, and is therefore influenced by social categories such as cultural norms and ethnicity (Corrigan et al., 2014). As discussed in the "Culture" section, culture determines how people think about mental health and experiences such as hallucinations, and what attitudes and behaviours are normal or acceptable. For example, some Asian groups may perceive any mental health problems to "reflect flaws in the family" due to collectivist ideals, whereas individualist cultures such as many Western societies tend to see mental health problems as the responsibility or fault of the individual (Corrigan et al., 2014)[81]. So, help or treatments that focus on the individual may not be seen as appropriate or effective by someone from a collectivist culture. Additionally, a focus or preference for Western methods may alienate people from different cultures that have alternative explanations for their experiences. Culturally-diverse ideas about mental health, stigma, and symptom expression across involved parties may clash during help-seeking, which can lead to distrust in the effectiveness or relevance of support (Corrigan et al., 2014). Therefore, cultural perspectives should be discussed, addressed, and respected wherever possible.

Mental health literacy

Limited or inaccurate knowledge and beliefs about mental health can lead to stereotyping, prejudice, and discrimination (Corrigan et al., 2014), which (as we have seen above) are likely to discourage help-seeking. Further, knowledge and beliefs about mental health predict help-seeking and participation in care (Corrigan et al., 2014), partly because improved mental health knowledge allows people to recognise when they might need help and support (Jorm, 2012). Cross-cultural studies across many different countries have shown that many people are unable to correctly identify common signs of mental and emotional distress (Jorm, 2012). Further, limited knowledge about the types of support and treatments available may make people hesitant to seek help or believe that the support will actually be effective (see above) (Jorm, 2012). Although some types of treatment often endorsed or used by the general public are likely to be effective for mental health problems (such as increased exercise and meditation), others may worsen them (such as alcohol or pain-reliever use) (Jorm, 2012). Therefore, improving mental health literacy can potentially increase help-seeking. There are a variety of methods for improving mental health literacy, such as community-wide campaigns, interventions in educational settings, web-based interventions, and "mental health first aid" (which began in Australia and has been adapted in 15 other countries, including the UK). Further, these campaigns will be strengthened if they are culturally- informed and -sensitive.

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[81] It is important to remember that groupings such as "Asian", "African", or "European" are too broad to assume that everyone from these groups will behave in the same manner (as this would be stereotypical!). Rather, culture is just one factor in many that can influence attitudes and help-seeking.

What promotes help-seeking?

Need to disclose

There are various psychological and emotional reasons for disclosing experiences, and it is important to understand someone's motivations for doing so. Someone may choose to talk about their experiences with the aim of protecting themselves or people they know. **Protective disclosures** are planned and allow the individual to control the "how, what, when, and who" of talking about their experiences (Jaochim & Acorn, 2000). This is similar to **preventative disclosure**, which allows someone to have control over when to talk about their experiences and so potentially prevent negative reactions (Jaochim & Acorn, 2000). For example, someone who has started experiencing vivid hallucinations that they actively react to (e.g. by hiding) may disclose their experiences to a friend who has come to stay with them, for example, so that the friend is prepared for the hallucinations. This is a method of managing judgment or stigma, and of testing relationships and the reactions of others (Jaochim & Acorn, 2000). Individuals may also **spontaneously disclose** their hallucinations if they are in a state of emotional shock or disbelief (Jaochim & Acorn, 2000). For example, a highly stressed individual may experience a spontaneous, threatening hallucination at work and spontaneously blurt out her experience to a co-worker in her state of distress. This type of disclosure can lead to stigma, rejection, isolation, stress, and attempts to hide future experiences.

Reducing stigma

Reducing stigma is clearly important for promoting help-seeking. As discussed in the "culture" section, some cultures view hallucinations as positive and a central part of their spirituality, meaning that those who experience them may be seen as being special or chosen by God (Corrigan et al., 2014). This protects these individuals from stigma within their culture. Accordingly, individuals from these cultures are less likely to seek help if stigmatising views are endorsed (Corrigan et al., 2014). Reducing stigma also reduces fear of negative consequences from disclosing hallucinations. Stigma leads many people fear being judged as mentally "unstable", or unable to be independent and care for dependents such as children. Because stigma is a cognitive bias, it can override rational thinking and lead to snap judgements. Therefore it can have severe consequences for stigmatised individuals, including discrimination, violence, and forced restraint, sectioning, and treatment[82,83]. The potential for very negative consequences can be an intense fear for stigmatised individuals. Therefore, less stigma people encounter (e.g. from society at large, the media, friends, and family), the more likely they are to feel safer and perceive fewer negative consequences from disclosing.

Trust

As we can see from the above examples, **trust** is key in prompting help-seeking. Trust is "overcoming the problem of vulnerability in the face of uncertainty" (Brown et al., 2009). Disclosing hallucinations is likely to be perceived as risky by the experiencer, as hallucinations are traditionally associated with mental ill-health in Western cultures. By disclosing these experiences, the individual is *vulnerable*, and risks being stigmatised, rejected, isolated, and mis-treated. The process of disclosing will likely be emotionally difficult, and stressful. So, the individual must be able to trust the people

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[82] Pandarakalam, J. P. (2015). Formal Psychiatric Treatment: advantages and disadvantages. *British Journal of Medical Practitioners*, *8*(4).

[83] McWade, B. (2019). 10 Madness, Violence, and Media. *Madness, violence, and power: A critical collection*, 150, p157

they tell about their experiences, and the systems they engage with – otherwise, they will avoid or abandon ideas of help-seeking.

Some individuals will have preconceived ideas about hallucinations or mental health in general, the risk of being stigmatised, usefulness of support and treatment (see "Psychological barriers to help-seeking", above), and the system of support that they need to access. All of these factors will influence the amount of trust that individuals have in people and support services. Some people you speak to will have existing opinions on and experiences of mental health services, treatment, and other sources of support. Some individuals may have had very positive experiences of previous help-seeking, which will increase their trust and willingness to seek help again. However, some individuals may have had to endure ineffective, intrusive, unwanted, or forced treatments, such as forced "detention" (being forcibly sectioned / hospitalised) (Brown et al., 2009). In the UK, the Mental Health Act (1983) can be used to forcibly section someone if they are viewed as a threat to themselves or others[84]. In the UK in 2016/17, 45,864 forced mental health detentions were made (NHS, 2017). However, this number may be considerably higher, as this data is incomplete; in this period, 33% of organisations (both NHS and independent) didn't submit their data about use of the Mental Health Act to the Governmental Statistical Service (NHS, 2017). It is understandable, then, that people who have been detained against their will and/or treated without their consent before may be highly reluctant to engage with support, due to a deep distrust of staff, services, or a whole system.

Therefore, trust impacts initial help-seeking, disclosure of relevant information, and an ongoing relationship between the help-seeker and supporters/professionals (Brown et al., 2009). Trustworthiness is determined by the perceived approachability of services, the effectiveness of support or treatment, and willingness of care providers to co-operate with the help-seeker rather than control them (Brown et al., 2009). Approachability and treatment / support effectiveness can be judged by several factors or sources of information, such as previous experience with support services or other institutions that fall under the same umbrella (e.g. NHS-based mental health services and other government-run systems), the media, social networks, and general cultural and socio-economic background (Brown et al., 2009). Co-operation may also be judged based on previous experience. It is common practice in psychiatry to talk of "compliance" or "concordance" with suggested treatment (such as medication) (Brown et al., 2009) – however, these words suggest control and pose the psychiatrist or care professional as a dominant authority, with the patient in a passive or compliant position. Understandably, this may undermine trust. Humans generally wish to be treated as equal, autonomous, and with respect.

Trust is "a communicative, relational process" (Brown et al., 2009) – and so good communication and an empathetic approach are essential in conversations about hallucinations. People seeking support must feel centred and attended to, and treated in a professional manner by someone with enough expertise (Brown et al., 2009). Trust is also developed when the help-seeker believes that the professional they are talking to has good motives and will act in their best interest (Brown et al., 2009). Active listening and the ability to encourage communication from the help-seeker are key. So, developing a relationship with the experiencer that is grounded in mutual respect, trust, and empathy will facilitate conversations about hallucinations, encourage a continued relationship, and allow you to explore support options that take into account the individual's history and personal needs.

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[84] https://www.legislation.gov.uk/ukpga/1983/20/contents

General communication with people who experience hallucinations

Language

Language for describing hallucinations

Ask the person what words or phrases they would like to use to describe their experiences. Don't assume that they will want to use the term "hallucinations" – this can feel intimidating, stigmatising, or too clinical. More neutral terms can put people at ease when discussing experiences that are highly personal. Labelling an individual's experiences as "hallucinations" may also frighten or confuse them, particularly if they have not realised that they are experiencing hallucinations. The individual may not be psychologically prepared or ready to identify their experiences as "hallucinations". Work with the individual to agree on words to use that they feel comfortable with. Let them arrive at their own decision. Increasing perceived control over any aspect of hallucinations is very important for reducing distress.[85,86]

It is also worth noting is that experiences should not be automatically described as "hallucinations" just because they seem to match common ideas about what a hallucination is, when this has not been verified by a health professional. Immediately labelling an experience as a hallucination risks inaccuracy, and can also be possibly damaging to the individual for the reasons described above. Remember that "hallucination" is a culturally- and socially- loaded word that should be used with caution. Even if a health professional has labelled an individual's experiences as "hallucinations", the experiencer might have their own preferred language for describing and discussing their experiences. Support them in exploring this.

Language for referring to the experiencer

Similarly, people experiencing hallucinations will likely have preferences about the language they use for themselves. This guide uses the word "experiencer" as shorthand for "person experiencing hallucinations" and in place of clinical language such as "hallucinator", "patient", or similar. It is important to discuss preferred language with each individual. People may prefer "**person-first**" language, such as "person experiencing hallucinations", or they may prefer experience- or "**identity-first**" language.

Person-first language puts emphasis on the person, putting them before any experiences or labels they may have (such as "person on the autistic spectrum"[87]). There is considerable research demonstrating the positive impacts of person-first language in mental health settings[88,89]. This is because this phrasing emphasises the individual and personhood, does not define the individual by only one of their many experiences, and combats the idea that every individual with the same diagnosis or label is part of a homogeneous group[88]. This helps to reduce stigma and negative attitudes[88].

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[85] Hill et al., 2012 - https://doi.org/10.1111/j.2044-8260.2012.02039.x
[86] Singh et al., 2003 - https://onlinelibrary.wiley.com/doi/full/10.1046/j.1440-1819.2003.01157.x
[87] Botha et al., 2021 - https://doi.org/10.1007/s10803-020-04858-w
[88] Jensen et al., 2013 - https://doi.org/10.1177%2F1078390313489729
[89] Shakes & Cashin, 2019 - https://doi.org/10.1080/01612840.2018.1522400

Identity-first language puts emphasis on one part of the individual's identity that they feel is important (such as "autistic person"). Some research suggests that this phrasing can increase negative attitudes and stigma towards the individual[88]. However, other studies have suggested that identify-first language can empower people who may feel stigmatised or marginalised, by allowing them to re-claim what might be perceived as negative words or labels[87]. Further, some identity-first colloquial terms can also feel less stigmatising, often because they are created by communities of people with shared experiences, and so can be strongly preferred (such as "aspie" for those on the autistic spectrum[89]).

Further, some individuals who have experience with accessing formal mental health services (who might traditionally be described as "patients") prefer the terms "**service user**" or even "**service survivor**".[90] Many organisations now exist that provide support for service users and survivors who have been significantly harmed by their experiences of and treatment from formal mental health services.

There is no consensus on which of these terms are generally preferred by relevant groups, even for those communities where a lot of research has been done[87]. Further, to the best of the authors' knowledge at the time of writing, no research exists on what type of language people experiencing hallucinations generally prefer. As there is no research to guide practice at this point, it is important to ask each individual what they prefer. This supports self-determination.

Communication techniques

You can use **"mirroring"** to make people feel more at ease. Mirroring is a communication technique that involves imitating the body language, physical position, mannerisms, and verbal tone, style, or approach of the person you are communicating with. Verbally, this can mean imitating the word use of the other person. Word use is particularly important in the context of talking about hallucinations, as the person you are talking to may have a preferred way to refer to their experiences. Unless it is negative, try to mirror the way the other person talks about their experiences. For example, if they call them their "visions", you should also use this word. Mirroring someone's vocabulary and verbal style makes the conversation feel less intimidating and more natural. The person you are talking to might not be psychologically ready to use a word like "hallucinations", or recognise their experiences as being hallucinations. They may also not want to refer to their experiences as "hallucinations" at all. It is important to match the individual's psychological approach, to avoid causing them any stress or anxiety and encourage them to feel at ease in the conversation.

Avoid using "clinical" words. This includes, for example: hallucinations, delusions, schizophrenia or schizophrenic, psychosis or psychotic, and bipolar. There are many others. Use terms that the individual has expressly stated that they would like to use for their experiences. **Avoid negative, stigmatising words and phrases**, including colloquialisms, such as: weird, crazy, mental, mad, insane, loopy, barmy, loony, "a button short of a cardigan", etc. Anything that "others" people and makes them feel different will make them feel negatively about themselves, defensive, reluctant to talk, and potentially stigmatised. It is important to continue to use less clinical and more neutral language even when you are not interacting with the experiencer directly, as this will contribute to positive changes in attitudes and practise over time. For example, avoid using the word "mad" in conversations with clients as well as with colleagues.

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[90] Wallcraft et al., 2003

Paraphrasing is a good way of communicating to the other person that you are actively listening to what they are saying and trying to understand it. Try to re-phrase what the person has told you in a different way, without introducing your own ideas or undermining the thoughts, feelings, or actions of the other person. Try to do this in a non-judgmental or un-biased way. It's fine to ask the other person to feed back on whether your paraphrasing is accurate, and whether you have understood what they have said (e.g. "Let me know if I haven't got this right...", or "My understanding of what you've just said is…").

Attitudes

Be aware that, due to stigma, personal significance, and other factors, hallucinations are often highly private experiences. Treat both the experiencer and experiences with respect. Remember, it is not helpful to discuss or analyse hallucinations without the permission and input of the experiencer. Hallucinations are very personal, and the same experience can mean different things to different people. As with any personal experiences, disclosure and discussion requires trust and compassion.

Approach conversations with a positive attitude – don't assume hallucinations are a negative thing and therefore that you should respond negatively. There is no need to pass judgement on someone's experiences. You should not let your personal views of hallucinations influence your conversations with experiencers – just listen to them. See **Table 2** for some examples of stigmatising comments and responses. For example, don't respond with "That sounds really distressing" unless the person has explicitly told you they found it distressing. This approach uses the concept of **mirroring** that was introduced earlier. Don't interrupt to make comments until the person is finished speaking.

Be sympathetic – don't assume you understand what it was like to have that experience, or assume the reasons behind it. Just make the person feel that you are there to support them, and create a safe environment to discuss their experience/s.

Don't assume anything from a label or diagnosis, if you know this information. Diagnostic categories are guides only, and everyone with the same diagnosis will experience things differently. Don't insert any assumed experiences or knowledge of what's it like to be that person, or have specific experiences, into conversations. It can feel invasive for someone to assume they know about your experiences just because you have been assigned a label. People's experiences are very diverse; people do not appreciate being treated like a specimen. Sensitivity and nuance are needed when discussing people's experiences; do not undermine or shown scepticism about someone's diagnosis or self-ascribed label if they choose to tell you this. It may be an important identifier to them, and it is their choice as to how they define themselves and their experiences.

Similarly, NEVER impose a label on someone they have not chosen or are not comfortable with. People have many different reasons for wanting or not wanting to label themselves certain ways. Although some people may find comfort or utility in labels, others may actively reject labels that have been given to them by others, such as mental health professionals, for many reasons. It is not your place to question or debate suitable labels or descriptors for an individual's experiences or mental health, unless this has topic has been opened for discussion by the experiencer.

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Table 2 – Some phrases or responses relating to hallucinations can be very stigmatising (see left-hand column). We have provided some examples of alternative, non-stigmatising phrases in the right-hand column. Please note that these are flexible, e.g. if someone feels more comfortable describing their experiences as "weird" or "odd", engage with this language. You can later explore it for any possible negative connotations (such as self-stigma) when the individual feels comfortable doing so.

Potentially stigmatising phrases	Alternatives
"Hallucinations" **"Weird experiences"**	"Unusual experiences" However, there is potential to reduce the stigma of the word "hallucinations" if we use it more frequently in a normalising, non-stigmatising way. The terms used should be decided by the experiencer.
"You may have had some of these weird experiences…"	"You may have had some of these [insert preferred term] experiences…"
[In response to someone's experiences] "That sounds really weird!"	"That's interesting", or just nod!
[In response to someone's experiences] "That sounds really distressing!"	[You should not assume someone's experience is negative or distressing.] "How did you feel about that?" or "What was your emotional reaction to your experience?"
[In response to someone's experiences] "I would freak out if that happened to me!"	[In response to someone's story] Just listen. Try not to put your own personal angle on the experience, and instead listen to the personal experience of the individual. You could ask "How did that feel?" or "How did you interpret that experience?"

Questions the experiencer might ask, and how you might respond

Q) Are hallucinations normal?

A) Around 5% of the general population experience hallucinations! More people from the general population have them than people with mental health problems (see Chapter, "Who can have hallucinations?"). Hallucinations are not necessarily a problem.

Q) Are hallucinations always related to mental illness?

A) No! We know that many people without formal health or psychiatric diagnoses traditionally linked to hallucinations can also have these experiences. We also know that hallucinations can happen across many different mental and physical health categories, such as fever, delirium,

migraine aura, and epilepsy, and in healthy people too. Therefore, at the moment, these experiences are not necessarily related to mental and emotional distress. An individual's interpretation of their experiences is generally more important.

Q) Am I crazy/unwell/mental/insane/etc. because I have hallucinations?

A) No! Hallucinations are not necessarily associated with mental health problems. Hallucinations are part of the normal spectrum of human experience. It is more important to focus on how the hallucinations make you feel. What kind of impact do they have on your life? Do they interfere with your day-to-day activities? If they do have a negative impact on your life or are distressing for you, you can choose to seek help and support for this if you want to.

Q) Will my hallucinations stop?

A) Some people only experience hallucinations briefly – others experience them occasionally, throughout life – and some people experience them frequently, for a long time. It is difficult to predict how long someone will experience hallucinations for. But, I will help to give you the support you need.

Q) What can I do to regulate, reduce, or prevent hallucinations?

A) There are many available options to support those experiencing hallucinations. Sometimes, hallucinations will decrease over time – sometimes, they will remain at the same level of frequency for someone. There are lots of options that could help to reduce the hallucinations' negative impact or interference with daily life. Please see the section "Supportive approaches" for more information.

Q) What do my hallucinations mean?

A) They are unique to you, and so we cannot say what they mean without considering your individual thoughts, feelings, attitudes, personality, history, and experiences, as well as considering wider influences such as social and environmental factors. If you want to, we can explore their meanings together.

Q) Will I be able to lead a normal life?

A) Yes! People can lead normal and fulfilling lives and also experience hallucinations. Many people live with them day-to-day and continue to be functioning members of society. Although your own journey to understanding and coping with your experiences might take time, there are many other people who have also been through this process. Please see the "Supportive approaches" and "Resources" sections for more information.

You can also refer the experiencer to this guide, if you think they would find it helpful.

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Questions you might like to ask

Q) How do you feel about your experience/s? How do they make you feel?

>   **Pause for thought**: If someone doesn't find their hallucinations distressing, are they a problem? Discuss both negative and positive evaluations of the hallucinations with the experiencer, if they want to. What specific help and support do they need, if any?

Q) Do your experiences interfere with your daily life in any way? If so, how? What could we do to help this?

Q) Do your experiences help you in any way? If so, how?

Q) Do you view your experiences as positive or negative? Why?
-    If they cause distress, why is this?

Q) What story do you tell about or with your experiences? What is your explanation for them?

Q) What do your experiences mean to you?

Q) Do you feel that you have enough resources to manage your experiences?
-    If not, what do you feel would help?

Q) Do you think there is a pattern to your experiences? When are you more likely to have them?

Q) Are there any external factors that might be contributing to your experiences? What can we do to mitigate or change these?

Q) Do you feel that your experiences are influenced by sources or structures of power in your life?

Q) Do you feel that your experiences are influenced by sources or structures of threat in your life?

Q) Is there someone you trust that you can talk to about your experiences, if you want to? (such as friends, family, etc.)

Spread the knowledge!

As well as using the above approaches when interacting with people who experience hallucinations, it is also important to communicate these ideas to other people, professionals, and service providers. Moving towards a more holistic understanding of and approach to hallucinations can only be achieved if more people increase their understanding and change their behaviours and methods. If you feel that this knowledge and these tips on changes to practice have helped you, please be an advocate for the approach outlined in this guide. Spread the knowledge by discussing it with your colleagues, or by purchasing additional copies of this resource and others from website.com!

Supportive approaches for experiencers and hallucinations

This section gives an overview of some approaches that could help to support experiencers. There are lots of treatment options beyond the conventional option of medication, which treats hallucinations as a medical symptom to be cured rather than experiences with wider meaning and implications. Medication can certainly help some people, but others will want to explore alternative options. Due to the dominance of the bio-medical view of hallucinations as a symptom of illness in Western medicine, it is important to be aware that, as compared to the evidence based on medication, there is much less research available on other supportive approaches. For example, there are several general lifestyle changes and habits that could potentially help experiencers to improve general mental wellbeing and better cope with hallucinations, and perhaps even help to regulate hallucinations. However, as much more research is needed on the role of these factors in hallucinations, the below sections on these summarise preliminary findings only. This chapter is not intended to provide clinical guidance, replace support from a qualified health professional, or give an exhaustive guide to all available therapeutic options. It aims to provide an accessible overview, for your information.

General lifestyle

Stress and anxiety

There is a range of evidence suggesting that stress and anxiety are related to hallucinations [see "When do hallucinations happen?" section]. "Stress" refers to "the body's physiologic response to real or perceived threats"[91], with psychological stress occurring when someone perceives these threats as being beyond their ability to cope or adapt as needed[92]. "Anxiety" means a state of apprehension, tension, or worry[93]. Both stress and anxiety can be accompanied by physical sensations such as increased heart rate, sweating, and problems sleeping, and have effects on the mind, such as feeling unable to relax, having a sense of dread, and not being able to stop worrying[94].

General stress, tiredness, loneliness, and negative emotions have all been linked to hallucinations in both clinical and non-clinical groups, and this likely co-varies with anxiety levels (Waters et al., 2014; Waters & Fernyhough, 2017). Some evidence suggests that anxiety directly influences the occurrence of hallucinations, with higher anxiety linked to increased likelihood of experiencing hallucinations[95][96]. Anxiety tends to increase just before a hallucination, and decrease afterwards, suggesting that anxiety may be involved in the development or onset of hallucinations[27]. It is thought that anxiety might exacerbate deficits in the cognitive control mechanisms that usually inhibit intrusive memories, so that during anxiety, thoughts are not as well "controlled", and this can lead to thoughts being experienced as hallucinations[27]. Because of this, many studies have used interventions that aim to reduce stress and anxiety in people who are experiencing distressing hallucinations. Decreasing negative emotions and anxiety may help to reduce the number of hallucinations experienced, or the distress associated with them[27].

"Mindfulness" – being aware of your current state of mind and thoughts, or environment, without judging them – is becoming a popular mental health intervention. One small study used

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[91] Kondo et al., 2018 - https://www.sciencedirect.com/science/article/pii/S1353829217307633

[92] Snast et al., 2018 - https://onlinelibrary.wiley.com/doi/pdf/10.1111/bjd.16116

[93] https://www.psychologytoday.com/gb/basics/anxiety

[94] https://www.mind.org.uk/information-support/types-of-mental-health-problems/anxiety-and-panic-attacks/anxiety-symptoms/#.XFHsUGlpHIU

[95] Larøi et al., 2019 - https://www.sciencedirect.com/science/article/pii/S0165178118319000

[96] Paulik et al., 2006 - https://www.sciencedirect.com/science/article/pii/S0191886906001589

mindfulness to reduce worry and stress in people diagnosed with schizophrenia[97]. These mindfulness classes successfully reduced stress, increased self-compassion, and helped participants to calm themselves and have better reactions to stressful situations. Participants also reported that mindfulness helped them to be less overwhelmed and stimulated by their hallucinations. Similarly, another study used cognitive therapy to reduce the negative emotional impact of auditory hallucinations in people diagnosed with schizophrenia, by "weakening the associations between auditory verbal hallucinations and negative self-evaluations, through strengthening access to memories of positive self-esteem"[98]. This did not reduce the number of hallucinations, but did reduce depressive emotions by promoting self-esteem and voice acceptance.

A systematic review of several studies exploring the usefulness of mindfulness for schizophrenia also found that mindfulness can reduce the distress association with hallucinations[99]. However, this review also concluded that there are very few good studies that effectively explore this topic. Therefore, the evidence base for the effectiveness of mindfulness is not strong at the moment. Although a lot of research remains to be done before we know more about the exact relationship between hallucinations and stress or anxiety, strategies and interventions to reduce these are highly beneficial for people's general physical and psychological health, and so there is little risk associated with these supportive options.

Sleep

The "circadian rhythm" is the automatic synchronisation of bodily functions to the light-dark cycle (Reeve et al., 2015). This rhythm leads to the body continuously balancing wakefulness with the need for sleep (Reeve et al., 2015). There is a large amount of evidence suggesting that the circadian rhythm is linked to hallucinations (which may be because the circadian rhythm regulates the balance of excitation and inhibition in the brain; see "How do hallucinations happen?"). So, it follows that regulating sleep patterns can potentially reduce the frequency or intensity of hallucinations (Freeman et al., 2013, 2015). There is a known relationship between "sleep disturbances" (irregularities in or dissatisfaction with sleep quality, timing, or amount) and hallucinations across several different groups (clinical and non-clinical). For example, people diagnosed with psychosis often report disturbed sleep, experiencing difficulties in falling or staying asleep (insomnia) (Freeman et al., 2013). Sleep deprivation (e.g. due to insomnia) can lead to hallucinations or aggravate hallucinations in those already experiencing them (Freeman et al., 2013). One study that assessed ~262,000 people across 56 countries found a global association between sleep problems and hallucinations (Koyanagi et al., 2015). Another review of all relevant scientific research on the relationship between sleep dysfunction and hallucinations evidenced a clear co-occurrence of these, and suggested that sleep dysfunction could predict later hallucinations (Reeve et al., 2015). One study that followed people with Parkinson's disease for 10 years found that severe sleep fragmentation (sleep broken by awakening) was associated with hallucinations (Goetz et al., 2010). Sleep deprivation in the general population is associated with experiencing hallucinations, with the intensity of hallucinations increasing with time spent awake (Reeve et al., 2015). Sleep deprivation can reliably produce hallucinations in healthy people (Reeve et al., 2018).

One large study found that cognitive behavioural therapy (alongside standard treatment) was highly effective in improving sleep quality in people diagnosed with psychosis, however the results concerning the impact of this on hallucination intensity and frequency were inconclusive (Freeman et al., 2015). As this was the first large-scale study of this relationship, more research is

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[97] Davis et al., 2007
[98] Van der Gaag et al., 2012 -
[99] Lam & Chien, 2016

needed to better explore the effects of sleep quality on hallucinations. However, due to the well-evidenced relationship between sleep problems and hallucinations, any method that promotes better sleep quality may be helpful for those experiencing hallucinations, and will also be beneficial for general mental and physical wellbeing. This is also a low-risk intervention.

Exercise

A lot of research suggests that exercise can be very effective in improving general mental health (Acil et al., 2008; Ekkekakis et al., 2013; Morgan et al., 2013; Pedersen & Saltin, 2015). For example, one Dutch study of over 7000 people found that mood and anxiety problems were lower in people who did regular physical exercise, even after taking people's socio-economic status and physical illnesses into account (ten Have et al., 2011, as cited in Morgan et al., 2013). Further, people who exercised were more likely to recover from a mental health problem that people who did not exercise (ten Have et al., 2011). Out of the most common mental health diagnoses, exercise seems to be most effective for mild to moderate depressive feelings, but can also help improve mental wellbeing in people who have been diagnosed with psychosis and who have chronic physical illnesses (such as chronic pain) (Morgan et al., 2013). There is also evidence that physical exercise can improve wellbeing in people who have been given anxiety, bipolar, obsessive compulsive, and psychotic diagnoses, as well as alcohol and drug addiction (Bernard & Ninot, 2012). For example, a combined exercise and "brain-training" intervention of 75 minutes, 3 times a week for a month, significantly improved perceived quality of life, decreased anxiety, and increased visual learning, working memory, and thinking speed in people diagnosed with major depression or schizophrenia (Oertel-Knöchel et al., 2013).

Physical exercise may help to improve mental wellbeing by decreasing stress and anxiety, low levels of which are strongly associated with mental wellbeing (see "Stress and Anxiety" section above) (Morgan et al., 2013; Oertel-Knöchel et al., 2013). Both exercise and relaxation training are beneficial for anxiety (Morgan et al., 2013). Exercise has been shown to improve psychological wellbeing through increasing social competence and self-esteem, for example (Morgan et al., 2013). Importantly, exercise can help to reduce medication-induced disability and early mortality, by helping people to reduce the weight gain that is a common side-effect of anti-psychotic medication, and improving overall health (Morgan et al., 2013).

However, there is not a lot of evidence that the benefits of exercise are long-lasting once it is stopped. Studies that have followed people up after exercise interventions have been completed have not shown any differences in mental wellbeing between exercise and control groups (Morgan et al., 2013). Therefore, it is essential to promote increased physical activity as a long-term lifestyle change, so that any benefits are maintained. Although there is limited evidence that supports exercise as a treatment for hallucinations specifically, this is not surprising given that the benefits of exercise on mental health have only recently become recognised, and so there is limited scientific research. One small study suggested that three exercise sessions a week over 10 weeks decreased the number of hallucinations experienced by people diagnosed with schizophrenia (Acil et al., 2008), which supports the findings of previous work (Chamove, 1986; Faulkner & Sparkles, 1999). Exercise may provide a safer alternative to treatments such as medication (which can have severe side effects), and so more research is needed in this area. However, the general benefits of exercise for mental wellbeing (such as reduced anxiety, and increased self-confidence and -respect (Acil et al., 2008)) should not be ignored.

The type of physical exercise generally recommended by research is aerobic exercise (anything that gets you short or out of breath; e.g. walking, cycling, swimming, and running), but resistance exercise (such as lifting weights) may also be beneficial (Morgan et al., 2013). The recommended duration for this exercise is 30 minutes, 3 times per week for at least 8 weeks, in

accordance with national UK guidelines (Morgan et al., 2013). This exercise should be moderate (you can talk but not sing during exercise) to vigorous (you can only speak in short phrases during exercise).

However, there are multiple potential barriers to exercise that must be considered here. The recommended activity must be easily within the reach and means of the individual and suit their preferences and individual circumstances – otherwise, it is unlikely that the individual will continue to exercise (Morgan et al., 2013). Low accessibility, pre-existing poor motivation due to low mood or existing illness, social anxiety, tiredness (e.g. due to medication), lack of social support, and co-morbid health issues that reduce mobility, must all be considered (Pedersen & Saltin, 2015; Yung & Firth, 2016). It is also important to note that exercise is not necessarily a low-risk intervention, due to possibilities of injury. Increasing general physical activity may be as beneficial as, and may suit some people better than, a specific exercise plan or program. It is important to start with easily attainable goals that people feel comfortable with, as achieving these will promote increased self-confidence and perceived ability, and make people more likely to continue. Establishing a routine is also helpful in integrating new habits into people's lives (Morgan et al., 2013). To encourage increased physical activity, brainstorm the costs and benefits associated with exercise, address any barriers or resistance, promote problem solving skills for when things don't go to plan, tailor the changes to the individual (e.g. accounting for their means, preferences, previous hobbies or experience), ensure the individual has the needed resources, and encourage them to keep a record of how they feel before, during, and after exercise so that they can see the benefits (Bernard & Ninot, 2012; Morgan et al., 2013).

For more information, see the Routledge Handbook of Physical Activity and Mental Health (2013).

Social support

There is a lot of evidence to suggest that social deprivation, isolation, and loneliness significantly decrease mental wellbeing (El Haj et al., 2015). Loneliness is "distress caused by lack of social support", and isolation is a "lack of social contact and support (i.e. being alone)" (El Haj et al., 2015). Loneliness and isolation may particularly affect people with mental health problems, as stigma can lead to rejection and shunning. One study found that a lack of social support and trust significantly influenced the relationship between diagnoses of psychosis or depression and increased "multiple deprivation" (social and economic deprivation across income, employment, health, education, skills, housing, living environment, and crime) (Wickham et al., 2014). Social isolation also predicts more frequent hallucinations in both healthy people and people with Alzheimer's disease – perhaps because hallucinations "fill a gap" in social stimulation (El Haj et al., 2015). Hallucinations may come about because a brain deprived of information will begin to produce information by itself, and so hallucinations that are emotionally compelling may replace the social exchange of thoughts and feelings with other people (El Haj et al., 2015; Selten et al., 2013). In support of this idea, many people who experience voice hallucinations say that they have an "intimate and intensely personal relationship with their voices" (El Haj et al., 2015). There is strong evidence that long-term "social defeat" – being excluded from the majority social group – is related to the diagnosis of schizophrenia, and so increased social support can protect against this (Selten et al., 2013). There is also some evidence that social anxiety is linked to increased rumination (continuously thinking about the same thing), which could influence hallucination-proneness (Jones & Fernyhough, 2009).

Therefore, increasing social contact, support, and engagement has the potential to improve general wellbeing and reduce hallucinations. Increased social support and networks also increase the likelihood that people will maintain changes in physical activity (Morgan et al., 2013). However, it is important to note here that even though there are numerous benefits to enhancing social

contact and support for most people, stigma and discrimination from others are significant concerns for those experiencing hallucinations. People who have avoided social contact for a significant period of time due to stigma and feeling isolated may also feel intimated by social spaces, and feel that they lack the social skills to interact with people. Therefore, this may be considered a medium-risk intervention if appropriate and dedicated supportive, non-stigmatising spaces are not available.

There are a number of networks in the UK and beyond that aim to reduce mental health stigma and so may be social options for experiencers – please see the "Resources" section for more information.

Medication

"Anti-psychotic" medications (drugs that are thought to reduce delusions, hallucinations, anxiety, paranoia, and mood fluctuations) are "the only type of medication known to effectively reduce… hallucinations" (Mind, 2013; Sommer et al., 2012). Anti-psychotics are generally effective in reducing both the frequency and severity of hallucinations from severe to mild or minimal, particularly in the first month of treatment (Sommer et al., 2012). However, "anti-psychotics" do not in fact "target" psychosis, as they have a range of effects and are also prescribed to people diagnosed with bipolar, anxiety, depression, ADHD, and Tourette's.[7,100] Therefore, the name "anti-psychotics" is a misnomer.[7] A more accurate term is "neuroleptics"; drugs that cause sedation, decreased sensation, and muscle rigidity.[101]

Neuroleptics are a high-risk intervention. Some neuroleptics (olanzapine and clozapine) that are the most effective are also associated with severe weight gain (Sommer et al., 2012) and the development of type 2 diabetes.[102] These drugs and quetiapine are also associated with sedation (Sommer). All other neuroleptic drugs frequently cause several other well-known negative side effects, such as "extrapyramidal symptoms"; dystonia (abnormal, repetitive movements, abnormal postures, or tremors), parkinsonism (slow movements and problems moving the body accurately, tremors, rigidity, postural instability), and akathisia (severe restlessness) (Sommer et al., 2012). They can also cause changes to hormones and different parts of the blood, bone marrow, and lymph tissues.[103] It is also important to consider that stopping neuroleptics without appropriate gradual reduction of the dose can cause serious withdrawal effects, such as nausea, vomiting, diarrhoea, anxiety, insomnia, pain, and tremors.[80]

Neuroleptics do not work for everyone. Medication may sometimes be only slightly effective, or completely ineffective, in reducing the frequency of hallucinations. Sometimes, attempts are made to "augment" (increase the effectiveness of) neuroleptic medication by also prescribing other drugs at the same time, such as lithium or benzodiazepines – however, there is not much evidence that this works (Sommer et al., 2012).

Therefore, neuroleptic medication is a high-risk intervention and should be carefully considered. It is very important that experiencers are given the opportunity to fully discuss any treatment they are offered with a qualified health professional, and have any questions answered, so that they can make an informed decision.

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[100] https://www.ncbi.nlm.nih.gov/books/NBK459150/
[101] https://doi.org/10.1007/978-1-4757-6740-7_13
[102] https://doi.org/10.1007/s40264-017-0543-0
[103] https://doi.org/10.1517/14656566.2012.656590

Psychological therapies

Because auditory hallucinations (usually of voices) came to be thought of as key "symptoms" of "psychosis", most research into therapeutic approaches for hallucinations focuses on these. Although the principles of this research can partly be applied to other types of experiences, it is worth keeping in mind that much more research is needed to help us understand what the best psychological therapies are for supporting experiencers, to inform best practice. Some research has now also been done into supportive approaches for visual hallucinations.

In general, voice hallucinations tend to: (i) be personally meaningful, (ii) have relatively fixed identities, (iii) have an intimate relationship to the experiencer, (iv) have significant impact on the experiencer's life, and (v) seem very real (Sommer et al., 2012). All of these aspects can be approached using psychological therapies.

One such therapy is called "**cognitive behavioural therapy**" (CBT). CBT for hallucinations aims to change the way people relate to their experiences. Often, hallucinations are seen as having great power and malicious intent, and being all-knowing and sourced in the external world, and this can increase the severity of and distress from hallucinations (Sommer et al., 2012). CBT tries to change these opinions, considering "other possible explanations for the origin and meaning of voices" (Sommer et al., 2012). For example, CBT for voice hallucinations encourages the experiencer to evaluate the beliefs they hold about the "identity, power, and intent of voices, and degree of control over the experience".[104] This helps the experiencer to explore their relationship with their voices, and make sense of them within their own context. Overall, CBT is very effective in reducing the severity of hallucinations (Sommer et al., 2012).[105]

There are also specialised types of CBT available, such as Compassionate Mind Training (CMT) and Competitive Memory Training (COMET). CMT teaches people to reflect on how criticising voices (or "inner bullies") reflect their own "personal needs and distresses", so that people can are warm and compassionate towards themselves rather than being critical (Sommer et al., 2012). COMET teaches people to consistently counteract negative or humiliating voices with positive personal memories, which reduces depressive feelings and improves self-esteem (Sommer et al., 2012). Although CBT does not generally reduce the frequency of hallucinations, it can significantly reduce the anxiety and distress associated with them (Sommer et al., 2012).

A psychological therapy that has promise for supporting those experiencing hallucinations, and that is sometimes used as part of CBT, is known as "**formulation**". In this approach, a professional (usually a clinical psychologist) will work together with the individual to create an explanation or theory for their experiences and difficulties, to help make sense of them. The individual's unique personal history, experiences, and context are central to creating a formulation.[7] In this way, an individual's experiences can be understood as normal reactions to abnormal circumstances, and even as necessary survival strategies. Recent research has shown that formulation-driven CBT is very effective for reducing scores on a hallucinations measure (as rated by clinicians).[106] This suggests reduced experiences of, for example, hallucination frequency, duration, and intensity, and associated distress. Research has also shown that enabling individuals to create a meaningful story about their hallucinations can help them to "reclaim [their] life and identity".[107]

Although most current psychological therapies for hallucinations have a CBT focus, these are just some examples of the many types available that can support experiencers. Because psychological therapies focus on individualised support, and some types are best suited to particular experiences, different therapies may work better for different experiencers who are seeking

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[104] https://doi.org/10.1093/schbul/sbu037
[105] https://doi.org/10.1016/j.schres.2014.03.016
[106] https://doi.org/10.1093/schbul/sbaa045
[107] Johnstone, L. (2014). *A straight-talking introduction to psychiatric diagnosis.* PCCS Books. p77

support. It is worth exploring several different options in order to find the approach that works best. Please also see the "Resources" section for more information.

Self-guided therapies

- **Conference therapy** – People experiencing hallucinations are often advised not to engage with them. For example, people hearing voices are often told not to answer or converse with the voices. Clinicians are unlikely to pay attention to the content of people's hallucinations, partly for fear that this will reinforce them (Jarosinski, 2008). This is unhelpful, as it does not help the experiencer to understand the sources or causes of their hallucinations. It can also be very difficult or impossible to ignore hallucinations, and so trying to do so may promote feelings of stress, frustration, guilt, and being out of control. Engaging with hallucinations may improve the individual's relationship with the hallucinations, and help the individual to cope with or accept them. Creating an open conversation about the content of hallucinations can enhance our understanding of them (Jarosinski, 2008). One new way this is being done is through "AVATAR" therapy; a type of therapy where someone who is experiencing voice hallucinations can create a digital representation (avatar) of their voice/s (Craig et al. 2018). The person speaks to their avatar, who is voiced by a therapist, and the avatar gradually becomes "less hostile and concedes power over the course of therapy" (Craig et al. 2018). For example, the therapist may say something that the individual's voices commonly do, such as "You're worthless", and the experiencer can respond with strong statements such as "I don't have to listen to you" or "You don't have power over me". AVATAR therapy can significantly reduce the frequency *and* severity of hallucinations, appears more effective than CBT, and in one study the effects of a 12-week course of AVATAR therapy were sustained 12 weeks after the course had finished (Craig et al. 2018).

- **Journaling** – This can be especially helpful for recording the details of experiences, including the content, duration, perceived cause or trigger, vividness or intensity, level of distress caused, perceived control, emotional reaction, and anything else the individual wants to record. These records can be used when working with the individual, to notice patterns in experiences. For example, someone might notice that their most distressing hallucinations tend to occur when they are very stressed. It is important that individuals seek any support needed when engaging with their experiences in this way, as it can be difficult, distressing, and frightening. Please see an example on the next page.

When? Date & time	What? General content Write about your experience here	Valence Overall, was this a positive or negative experience?	Vividness How vivid or intense was the experience?	Why? What do you think caused or triggered this experience?	Length How long did the experience last for? (Short or long? Seconds, minutes?)	Control Did you feel a low or high level of control over your experience?	Emotions What was your emotional reaction to this experience? Write your emotions and thoughts here	Extras Is there anything else you want to write about? Write it here

VictimFocus
CHALLENGE | CHANGE | INFLUENCE

Resources

Hallucination flash cards resource

Use hallucinations flash cards by VictimFocus can be used in a trauma-informed, anti-pathologising way to prompt conversations with children and adults who tell us that they hear voices, see hallucinations or experiences sensations. The cards contain sensations, experiences, feelings, responses and actions that can be discussed openly and without medicalising terminology.

Our flashcards are built from the perspective that hallucinations often have a root or purpose, and understanding them can help children and adults to become less frightened of them. They can be used by professionals, or by the individual themselves, to explore what their hallucinations make them feel, what they might mean and when they happen.

Supportive groups

Hearing Voices Network
https://www.hearing-voices.org/

A supportive network for people who hear voices, see visions, or have other unusual experiences. The network includes people who do and do not have clinical diagnoses. Their resources page can be found here: https://www.hearing-voices.org/resources/ . A collection of personal experiences can be found here: https://www.hearing-voices.org/voices-visions/personal-experiences/

Coping strategies

This document from the Hearing Voices Network lists some strategies that can be helpful for people experiencing voice hallucinations that they might find distressing (but these strategies can be applied for other types of hallucinations too): http://www.hearing-voices.org/wp-content/uploads/2012/05/Hearing_Voices_Coping_Strategies_web.pdf

Mad in the UK and Mad in America
MITUK's mission is to serve as a catalyst for fundamentally re-thinking theory and practice in the field of mental health in the UK, and promoting positive change. We believe that the current diagnostically-based paradigm of care has comprehensively failed, and that the future lies in non-medical alternatives which explicitly acknowledge the causal role of social and relational conflicts, abuses, adversities and injustices. We campaign for a change in the professional and public discourse about emotional distress and unusual experiences; for support, both within and beyond services, which meets people's real needs; and for social policy which addresses the causes of distress at its roots.

https://www.madintheuk.com/

Drop the Disorder
Drop the Disorder (Facebook) – A group for anyone who is interested in challenging traditional approaches to emotional distress.

A Disorder 4 Everyone – Exploring the culture of psychiatric diagnosis – creating change. Provides events, blogs and other resources.

https://adisorder4everyone.com/

Intervoice
https://www.intervoiceonline.org/

"A supportive network that works across the world to spread positive and hopeful messages about the experience of hearing voices." The network includes people who do and do not have clinical diagnoses. Their "recovery and support" page can be found here:
https://www.intervoiceonline.org/publications/more-books/recovery-and-support

Helpful websites
Here are some websites that discuss some of the topics covered in this resource in more detail.

Council for Evidence Based Psychiatry
http://cepuk.org/

The "CEP exists to communicate evidence of the potentially harmful effects of psychiatric drugs to the people and institutions in the UK that can make a difference. The scientific record clearly shows that psychiatric medications, portrayed as safe and effective by areas of the medical profession, often lead to worse outcomes for many patients, particularly when taken long term."

Asylum Magazine
https://asylummagazine.org/

A radical mental health magazine that includes articles from experiencers, service or ex-service users, and professionals.

Behind the Label
https://www.behindthelabel.co.uk/

Independent mental health trainer, writer, and former service user Rachel Waddingham discusses her experiences with a diagnosis of psychosis. The website has a host of information and resources on mental health. Read her story here: https://www.behindthelabel.co.uk/about/

Jacqui Dillon's website
http://www.jacquidillon.org/

"Jacqui Dillon is a writer, campaigner, international speaker and trainer. She has personal and professional experience, awareness and skills in working with trauma and abuse, dissociation, 'psychosis', hearing voices, healing and recovery." Her website includes lots of information around these topics.

Rufus May's website

http://rufusmay.com/

Rufus May is a clinical psychologist who has personal experience of psychosis. His website explores a holistic approach to mental health and has a host of useful resources and links.

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