Family Matters: Strategies for Families Supporting People Who Have Experiences Labeled as Psychosis

Cindy Hadge





What is "The Wildflower Alliance"??



The Wildflower Alliance supports healing and empowerment for our broader communities and people who have been impacted by psychiatric diagnosis, trauma, extreme states, homelessness, problems with substances and other life-interrupting challenges.

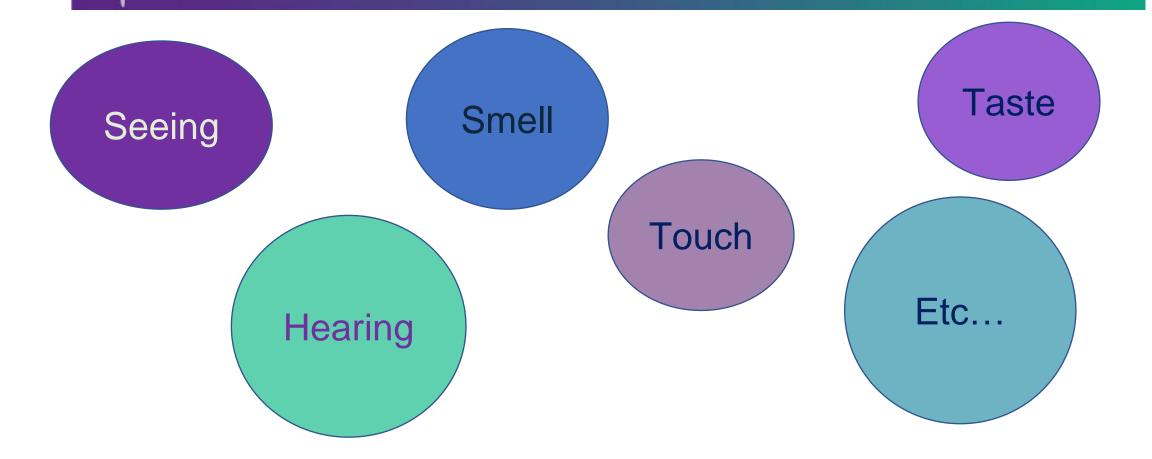
We do this through:

- Peer-to-peer support & genuine human relationships
- Alternative healing practices
- Learning opportunities
- Advocacy

Essential to our work is recognizing and undoing systemic injustices such as racism, sexism, ableism, transphobia, transmisogyny, and psychiatric oppression.

Hearing Voices Network

for people who hear voices, see visions or have other unusual perceptions



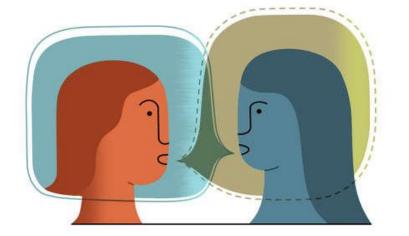


Hearing voices is **not** necessarily a sign of illness.

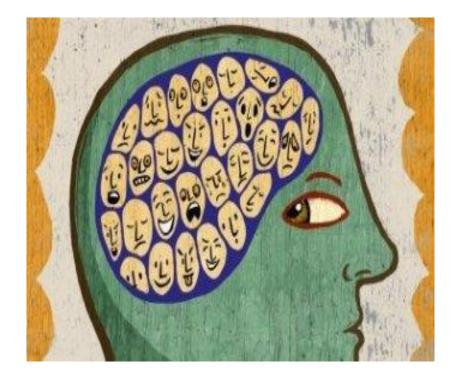
Hearing voices is a normal, though deeply personal, variation of human experience.

About 1 in 10 people hear voices at some point in life.

Over one third of voice hearers **never** seek psychiatric services.



Hearing voices makes sense in relation to our personal life experiences...



...the problem is not hearing voices itself, but the difficulty with navigating the experience. People who hear voices can cope with their experiences by owning and making meaning of their voices, dialogue with our voices is encouraged...



...And can change the relationship we have with our voices.

HVN Family & Friends Groups

• Family and friends are uniquely positioned to validate the experiences of those who hear voices or otherwise perceive things not perceived by others.

• At the same time, the experience of family members and friends also benefit from validation and a sense of community as they learn to resist oppressive conventions and develop alternative frameworks for understanding their own and their loved ones' experiences.

Started in 2019

Respect	Respect their loved one's experiences;
Examine	Examine their beliefs and feelings as a gateway to changing their relationship with their loved one;
Ownership	Take ownership of their fears and examine where the fears come from and how to manage them;
Share	Share experiences of what has been helpful and in that context share resources;
Explore	Explore the family member's experience including the language used when talking about their loved ones;
Validate	Validate friends' and family members' experiences while at the same time helping them to develop empathy and undo stereotypes and discrimination against voice hearers, and;
Create	Create a safer place for family members to talk about their experiences without judgement, ridicule or unsolicited advice.

Common Challenges Within Families

The focus is on the identified patient versus a focus on relationships and the needs of all the family members.

Parents feeling judged, guilty, shamed, and isolated. Their loved one feeling judged, shamed, and isolated. Parents feeling a responsibility **for** instead of **to** their loved one

Power struggles, between family members and between family members and providers.

Fear and fear-based responses instead of curiosity and negotiation.

Grief and loss

Concern being perceived as aggression

Secrets (wrapped up in shame and guilt and fault finding)

Competing Needs and narratives

Exhaustion

One in Ten People Hear Voices at some point in their lives...Research shows "good copers":

Feel themselves to be stronger than their voices.

Communicate more often about and to their voices.

Set limits and listen selectively to their voices.

Use fewer distraction techniques.

Many frameworks work equally well (with one exception...)



General Strategies

•Acknowledging that the experience is REAL and meaningful.

•Not feeling obligated to do what voices tell you to do, but to look for the metaphor/meaning and or feeling.

- •Talking with people:
 - Particularly those who have similar experiences and who have learned to manage and integrate it
 - Particularly in a safe (judgement free, non fear based, non pathologizing) place.





Examples of the Context of Voices

- A voice that serves of a reminder unresolved issues, on the anniversary of event.
- Voices starting with in a year of major life events.
- A voice of a lost loved one or a person that has been harmed.
- A voice that serves as a spiritual guide.
- A voice that repeats negative messages that the person has received in life.
- Ages of voices can be linked to events that happened when the person was that age.



A "Greatest Hits List" of Problematic Trauma Related Beliefs

Responsibility	
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I should have known better I did something wrong I can not be trusted Safety I can not trust myself I can not trust anyone I am in danger I am not safe I can not show my emotions

Choice

I am not in control I have to be perfect/please everyone I am weak I am trapped I have no options

Power

I can not get what I want I can not succeed I can not stand up for myself I am powerless/helpless

Addressing shame and guilt.

Being seen, heard, and validated.

Playing a role in one's own healing/rescue.

Human connection (reducing isolation).

Sharing power (information is empowering).

Factors that Mitigate Trauma



In Supporting others, I learned to:

- Take care of myself what is my support system? What are my limits?
- Start with basic needs food, water, sleep, shelter.
- "Help isn't help if it isn't helpful"- Ask what the person you are supporting is looking for in terms of help. What is it that <u>they</u> want to work on? What do <u>they</u> want to achieve in life? What do <u>they</u> perceive is getting in the way? And to question - is what I am doing is actually helpful?
- Be transparent- Own your own needs, concerns, feelings. "I" statements work great! Modeling vulnerability creates connection and new ways forward.

Partnering versus Power Over

- Honor Multiple Truths- How does the person you are supporting understand their experiences? What are their fears, identifying emotions and beliefs Nothing ends a conversation quicker than "You're wrong!"
- **Build connection** Instead of arguing the "facts", relate to the feelings.
- Build on Strengths Instead of being deficit based.
- Curiosity Asking open-ended questions keeps the lines of communication open – judgment or agenda-driven questioning can shut it down. Where do those beliefs, feelings and messages come from. When are things more difficult and when are they less difficult.
- **Support Meaning-Making** Be willing to explore the metaphor and context of voices.
- Transparency and choice

Looking for Meaning in Metaphors

The Doctor on this unit is an agent

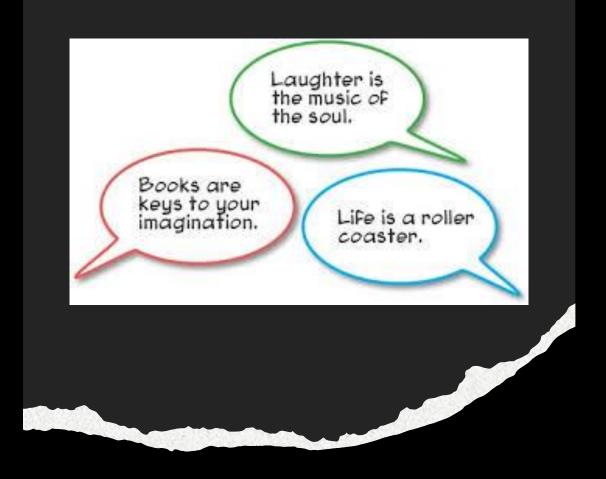
My parents are vampires, but not the evil kind

I hear voice from the upstairs neighbors

This is war

It is a bee

I have a voice telling me to kill myself



Is this disruptive? Is this destructive? Is this dangerous?

Vermont Soteria House Family Support





PARTNERING TO MOVE THROUGH FEAR

- If this is dangerous what will help to decrease the danger, what will increase the danger?
- Turning "f" you into "f" this.
- Addressing the feeling instead of arguing this facts.
- Fear is contagious and so is calm.
- Modeling calming techniques, modeling expressing feelings.
- Moving from fear based responses to hope and possibility.
- And consider the impact to the Relationship.
- Build trust and be flexible about forms of communication



The Model	The Goal
Validation	I see you. I accept you as you are. I am here to partner with you.
Curiosity	I value your individual story. I see you as whole human being (not a number or a diagnostic label). I care about the context of your life and this moment.
Vulnerability	I am also a whole human being with my own strengths and limits, including the scope of my role.
Community	We are not alone. Our connection exists in wider community. Share resources, encourage and help identify a broader network of support.

PROTECTIVE FACTORS MEANING, PURPOSE AND CONNECTION

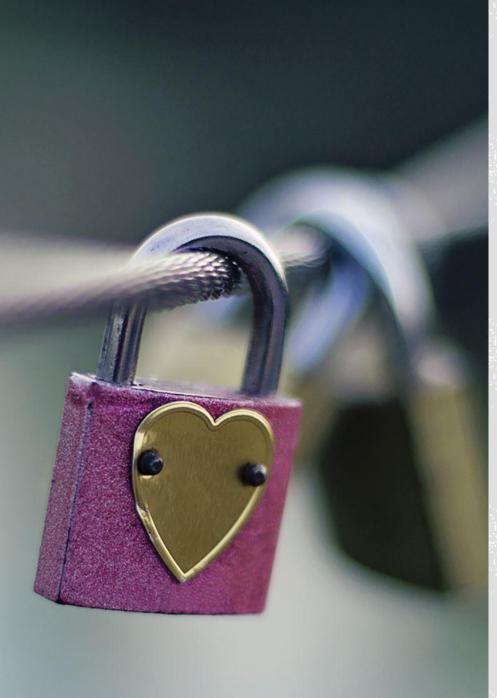
- Future plans something to look forward to, to work towards
- Accepting relationships
- Opportunities for belonging
- Opportunities to practice naming and expressing feelings
- Calming, soothing strategies



MORE PROTECTIVE FACTORS MEANING, **PURPOSE AND CONNECTION**

- Choice/power Addressing feelings of shame and guilt Opportunities and support to "tell" addressing secrecy and shame.
- Redefining success
- Mirroring back strength





THE POSITIVE POTENTIAL POWER OF FAMILY

Connection Time line Awareness of the here and now Positive messages Calm

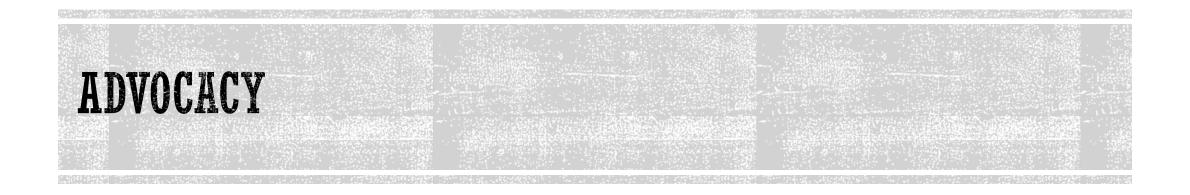
Context

Model being aware of emotions and expressing them

To hold a vision of possibility

To be an advocate





- Promoting Informed Consent
- Sharing rights and information with the person receiving services.
- Amplifying Voice of the person receiving services
- Being a witness
- Making sure the whole person is seen and is not reduced to a diagnosis
- Gathering information
- Documenting services
- Can include advocating for different options/services.





- <u>cindy@wildfloweralliance.org</u>
- families@wildfloweralliance.org
- info@wildfloweralliance.org
- info@hearingvoicesusa.org
- cthvn@advocacyunlimited.org

https://wildfloweralliance.org/ https://www.hearingvoicesusa.org/ https://www.intervoiceonline.org/#content https://www.cthvn.org/

