

## FINDING A PLACE AMONGST THE THEORIES?

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## HOW IT IS FOR ME TO BE HERE ...

Many responses ...

**Testing** ideas and theories  
against my own experiences (as  
a person with lived experience  
and as a worker)

**Engaging** with a search for  
structure to tame the messiness  
of experience

**BUT** ... growing unease at some  
things we seem to take for  
granted



## IMPLICIT ASSUMPTIONS I HEAR

1. Psychosis, Schizophrenia, Dissociation and DID are 'real' and meaningful
2. The experiences people have that lead to these labels are indicative of a deeper psychopathology
3. We need to know what someone 'has' so we know how to treat it
4. Our (many) theories are useful and help us see more clearly (we need better theories and greater understanding to be more helpful)
5. It is desirable to be 'normal'

**These are (some of the) assumptions I hope to question during this presentation**

## MY PSYCHOSIS STORY

Teenager: An alien inside me that could affect my body and, eventually, my reality. Hair pulling and cutting, in secret, to regain control.

University: Being watched by cameras – alien experiment, controlled by government. Friends/students as stooges. The voices describing my actions and writing it down for the experiment.

People trying to poison me.

Hospitalisation – didn't trust the staff.

Meds worked, but I kept stopping them. More hospital

No motivation or spark, lost myself. So called cognitive problems and 'negative symptoms'

Diagnosed with schizophrenia (sometimes schizoaffective)



## A TURNING POINT

What almost killed me was the lack of hope, disconnection and dehumanization. Initiated by my childhood trauma, but reinforced by my time in hospital.

What helped me find a foothold was connection – connection with peers through a Hearing Voices Group. Here, slowly and in my own time, I found interest in others ... and allowed them to become interested in me.

This formed a foundation that helped me begin to grow.

hearing  
voices  
network

## CHANGING MY RELATIONSHIP WITH 'PSYCHOSIS'

### Recognising I could make voices/beliefs worse

- Putting myself under pressure, success, busy environments

### Possible to do things to help make things better

- Finding ways of calming voices & beliefs – inc grounding
- Reclaiming power within beliefs (without changing them)

### Learning more strategies

- Expressing content in creative ways, becoming less afraid
- Empowering – working to develop an 'I' to have an opinion on what voices say (and an entitlement to choose what I do)

### Understanding experiences in context

- Listening to content & emotional tone
- Becoming curious about metaphors and meaning
- Exploring context of experiences (past and present), inc trauma

## GETTING A LIFE

Through the HVN group, I found friends. They inspired me to get back in to music. I went to college to study popular music and graduated my first mainstream course. I went to London to study as a session musician, met my husband and eventually got a job as London Hearing Voices Project Manager – developing Hearing Voices Groups. I developed projects for children, young people, people in prison and those in secure forensic units. I began to travel, asked to share my work.

All the time I was on medication and felt I always would be – but had to mess around with my dose to help get to work. But over time I began to see medication was making it hard to live my life as I wanted. It became a block.



## WITHDRAWING FROM MEDICATION — AND SURVIVING THE AFTERSHOCK

I slowly began to reduce the medication. But, 1 month after my final pill I was hit with extra voices and the belief that someone was doing surgery in my brain. I could feel my thoughts falling out of the gaps they left ... going into the people around me.

I was lost. My husband didn't recognize me. Thankfully he'd listened to my workshops and been to Hearing Voices Networks events and he helped me find a way forward. Slowly I began to re-engage the strategies I'd used before.

I got into private therapy, knowing I had more to work out/heal from ... and my psychiatrist wasn't happy for me to do anything except CBT.

## MY DISSOCIATION STORY

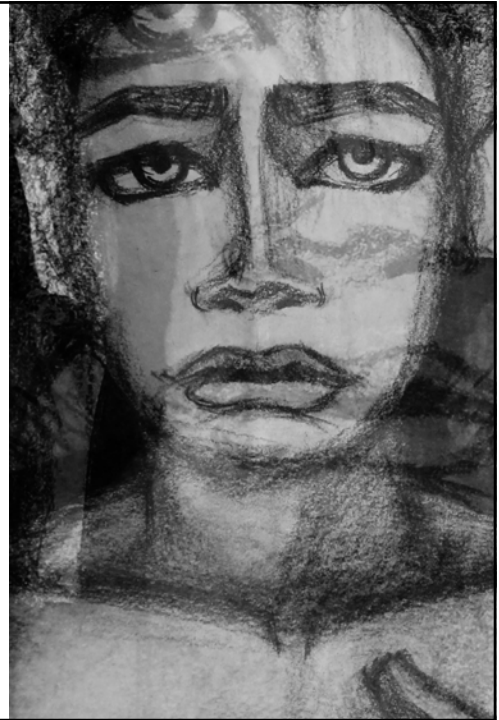
After 1 year of going round in circles, I tried hard to focus on something painful in a therapy session and dissociated – freaking out both me and my therapist.

Years of assessments and attempts at connecting with therapists followed.

High point was filling in the Somataform questionnaire (SDQ-20). I cried as it worded some things I'd experienced but didn't know how to explain.

I was diagnosed with DDNOS and then, at a subsequent assessment, DID with CPTSD & psychosis.

These diagnoses shocked me ... I felt like something massive had changed. That everyone who knew my diagnosis knew everything about me. I felt exposed.



## MAKING SENSE OF MY DISSOCIATION ...

With the new diagnoses and more awareness of dissociation, I began to notice things I'd not thought to question before:

- Huge gaps in childhood memories (and a well worn limited collection of memories I used time and time again)
- Body experiences (including paralysis of my arm when I was a child) with no physical cause
- Times at university people called me by others names
- Mental health workers talking about previous sessions I had no recollection of
- Times Joel had witnessed begin repeating words and rocking like a child
- The echo chamber experience, where I could hear but not hear so much in my head it felt like my mind was expanding and I was losing control (this became conversations between parts)
- Some memories that felt like someone else's – a dream, but not a dream



## THE CHAOS YEAR

Unfortunately my first DID-specialist therapist was well known and respected, yet wasn't the right person for me.

Her approach made things worse for me - suggesting details to fill in my memory gaps, frameworks (mostly ritual abuse & giving presents to some young parts, saying others were 'irritating' and asking if I could lock up the most difficult ones so we could get on with the session.

But she was kind. I de-stabilized. I was easily triggered ... re-experienced a lot (according to my husband), lost a lot of time (which became an issue at work) and was extremely suicidal.

Eventually I realized it wasn't me, it was her. I moved on from the therapy and found someone who could work with me where I was at and not push or shape things as much.

This relationship had a huge impact on me – I still don't know what of my trauma memories are mine and which are my parts trying to please her (or having gotten confused).



## FINDING SOME NEW WAYS OF BEING:

### Acknowledging my parts and how dissociation impacts on my life

- and helping my husband to feel OK to acknowledge them too

### Being OK with not being OK with having parts and dissociation

- and really wanting it all to go away

### Finding a sense of compassion for my parts and myself

- even if it was fleeting – it helped to imagine parts as outer people first, and consider their story as separate to mine

### Showing willingness to reach out to my parts

- Inc: supporting Blue to choose a fluffy; letting Bunny and Elfie help choose socks; getting puzzles for Tommy

### Discovering ways of staying present

- engaging some parts in helping me ... helping parts develop additional roles ... developing co-consciousness for 'fun' reasons (e.g. showing parts aspects of nature, as if walking with an outer child; introducing Blue to a Wombat)

### Listening to, and processing, difficult content

- learning that Elfie was trying to protect me when she sent me stabbing visions and burned my skin (I wasn't listening to her)
- drawing 'the door' and using creativity to help some of the terrified parts feel safer – not dismissing fears

## SLOWLY, PARTS BEGAN TO INTEGRATE INTO MY LIFE

Like any team or network, we took time to find out 'groove'.

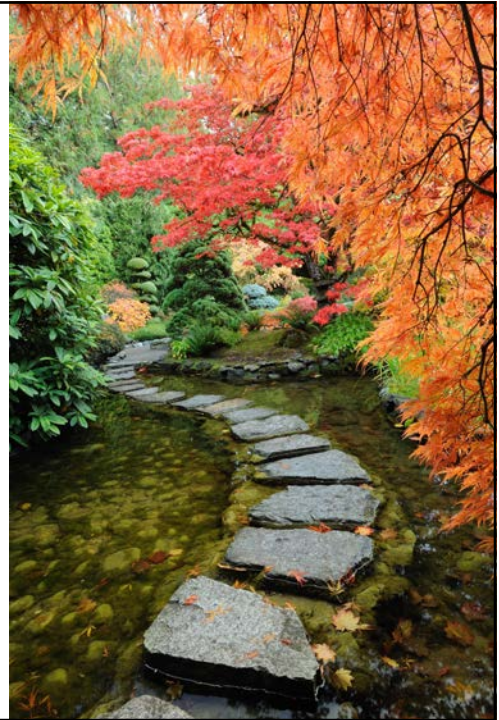
The more I learned about my parts, the more I was able to understand what was triggering the times they stepped up to take control.

The more I understood, the more I could find ways of reducing the need for them to steal time from me. E.g. instead of overworking (and then losing big chunks of time) I began to schedule breaks where parts could choose something fun to do.

I recognized that trying to blocking them out doesn't help, and accepted them as part of my daily life.

I began to use some of the HVN wisdom/strategies.

I slowly started to feel less ashamed of this way of being in the world. I stopped trying to be unitary & accepted my diversity.



## MY LIFE AS IT IS NOW



## RELATIVE HARMONY

For years I lived, free of medication, in relative harmony with my parts, voices & other experiences.

I had times of being an android (similar to a nexus 7 with implanted memories), but it didn't bother me. I've always had a loose relationship with reality anyway.

Some of the most violent and challenging voices caused me some pain as I found ways of relating to them ... but as I was less afraid I was able to find space for them too.

I had stopped wanting ways of stopping any of my experiences, but sought understanding instead.

It wasn't always easy – but I figured that life wasn't always easy. Like nature and the power of the elements – their impact on my life wasn't always benign ... but I kept learning and growing.



## OVERWHELM (RE-ENTERING PSYCHIATRY)

Before giving birth I was coerced into re-entering mental health services 'just in case'.

After the birth, I coped amazingly well. People were surprised how grounded and natural I was with my child. I didn't have the usual new-mum anxieties.

Yet, 3 months later I was overwhelmed with the belief I was an android and confused about my programming. Was I there to protect or harm my child? If I was to protect her, who was trying to harm her?

I was OK with my voices and parts etc, but this belief crushed me. I found it hard to think and got lost. The 'crisis team' support made things worse. They tried to rationalize with me ... which led me further into my overwhelming beliefs.

I agreed to take medication (antipsychotic & antidepressant) eventually. It was the only option available and I needed to sleep. 1 year later, I'm still on them – but have tardive dyskinesia and plenty of adverse effects. I'm slowly withdrawing once more and reconnecting with my previous strategies. I was given the diagnosis of 'schizophrenia' yet again, though \*sigh\*.



## THINGS I'VE NOTICED ...

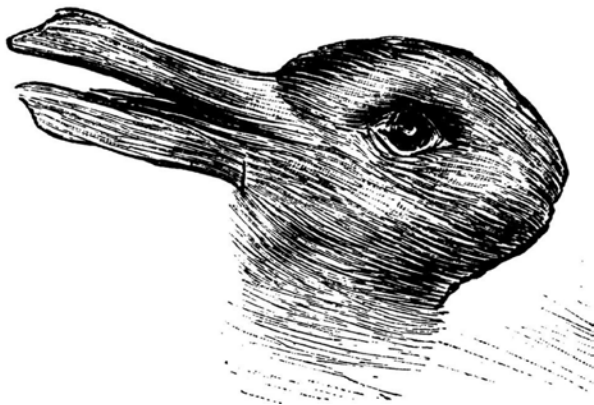
Before becoming a practitioner, my training was through reflecting on my lived experience (and in being with others in distress – my peers).

I attended, and then facilitated, Hearing Voices Groups (peer support groups for people who hear voices, see visions or have other similar sensory experiences).

I became part of the Hearing Voices Movement and set up projects in a range of contexts (prisons, youth etc).

Later, I trained – and began to practice – as an Open Dialogue therapist.

**These are some of the things I've noticed in my life and in my work.**



**PSYCHOSIS & DISSOCIATION ARE  
STRUCTURES WE CREATE TO  
ORGANISE EXPERIENCES**

Whilst my dissociation and psychosis stories occupy the same time period, it's hard to integrate them and tell them as one narrative.

Each has its own use of words, assumptions & concepts. My experiences are organized differently in both of them.

I can only see the whole if I stand back and loosen my gaze.

It's like this optical illusion. Is it a duck? Is it a rabbit? No .. Yet we use the structures we have to impose meaning and sense on something we struggle to see as it is. This can be useful, or not.

They are an artefact. Not reality.

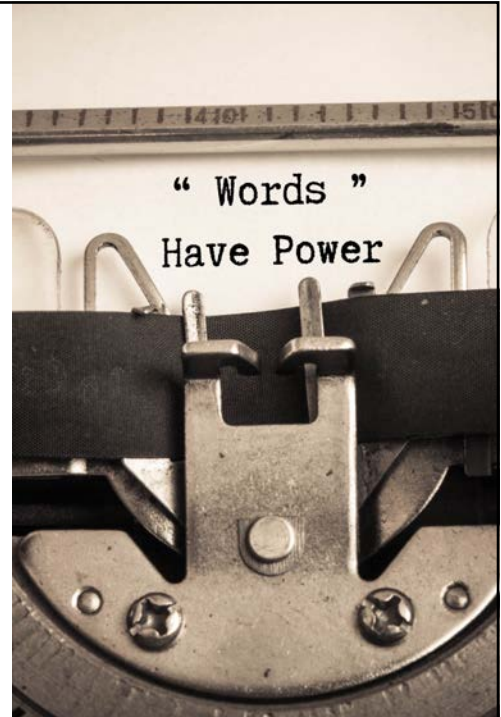
## LANGUAGE HIGHLIGHTS SOME EXPERIENCES & HIDES OTHERS

Both the traditional psychosis and dissociation frameworks come with very different words and ways of speaking about experiences – based on different assumptions.

A therapist that sees complex dissociation/DID will ask different things and speak in different ways to one that sees psychosis.

What is said, and what is responded to, can shape how the person thinks about – and speaks about - their own experience. It might even affect the experience itself.

If we shape the way people talk about their experiences, how do we know if there's more left unsaid by the particular framework.



## STOP LOOKING FOR WHAT IS 'WRONG' WITH ME

The focus on 'what's wrong with me' or what I illness I 'have' has brought me more harm than good. It has crowded the space I need to discover and heal.

It's possible to engage with the different aspects/facets of my experience without first identifying an over-arching pattern and theory.

I prefer approaches that emphasise 'not knowing' as a valid and valued position ... Open Dialogue and some approaches within the Hearing Voices Movement. Process-based approaches.

These approaches often prioritise creating space, 'being with', diversity and mutual learning.



## LIFE IS MESSY ... DIAGNOSES CAN'T TAME IT

Diagnoses were originally a way of grouping together or categorizing messy and overwhelming human experiences.

Over time we have begun to reify diagnoses and they have begun to take on a life of their own.

Whilst they can sometimes shape what a practitioner is able to see (and what is able to be articulated or expressed) – lived experience has always been far messier than we admit.

Diagnoses, and the theories that can accompany them, seem like a way of easing (practitioner) anxiety .... Imposing enough order to be useful.

That doesn't make them universally useful, necessary or benign. They can cloud our thinking and obscure our sight.



## WHAT MAKES 'NORMAL' SO DESIRABLE?

Throughout this conference I have felt the assumption that the experiences labelled as 'psychosis' or 'complex dissociation' are inherently pathological – and that the goal of therapy is to help people return to a more normal way of being.

As we often meet people in incredible distress within mental health services, this is an understandable assumption.

Yet it's limited. More than that, it's disrespectful.

I expect that I'll always hear voices, navigate unusual realities and be building my relationship with parts. This is not pathological. It's just a different way of being.

**What makes not hearing voices or having parts so good? Why is your way of being better than mine?**





## EMBRACING DIVERSITY — LOOK OUTSIDE THE BOX

In the Hearing Voices Movement we recognize that voices, visions and related experiences are not pathological ... even though some of us can be extremely confused, distressed and overwhelmed.

In the Multiplicity Movement, having dissociated identities or selves is not pathological. There are those who live as multiples, don't (necessarily) identify with trauma and have found ways of navigating their experience.

In both movements there are examples of people who live without illness frameworks — or who have found a way out of them. Embracing and connecting with these ideas helps us to challenge our assumptions and biases.



## EVERYTHING IS FULL OF MEANING

One of the assumptions people sometimes make is that 'psychosis' is 'un-understandable' and deep exploration of meaning is unlikely to be fruitful. Yet dissociative experiences contain memories and information essential to healing.

To me — and to many others — this is an unhelpful and inaccurate distinction.

Everything we experience is full of meaning.

More than this, the ways I explore experiences with people does not depend on their diagnosis ... it's more about where they are at and what journey we feel equipped to embark on.





## CREATING SPACE FOR NEW DESCRIPTORS/WORDS

Language is loaded with associations.

If I say 'anxiety', 'depression', 'sadness', 'tired', 'angry' or 'empty' you will bring your own associations to the table and – possibly – believe you understand what I mean.

In my journey I have often found it useful to create new words to describe how I am. Words that prompt dialogue as we struggle together to find a shared meaning.

E.g. If I tell my husband that I feel kitten-like today, he needs to ask what kind of kitten. We bring in rich descriptions that help pad out experiences that we might otherwise – falsely – assume we understood.



## RELATIONSHIPS ARE FLUID ... THEY CAN CHANGE

Whether I'm dealing with my parts, my voices or my beliefs (or anything else, for that matter) - taking a relational approach has been a life-saver.

We can have a relationship to anything ... and, with the right conditions, that relationship can change.

Exploring my relationships with different experiences has helped me both accept things as they are, and be open to them changing.

This enables me to have similar experiences but no longer feel 'ill'.



## EMBRACE THE SKILLED WORK OF SURVIVOR PRACTITIONERS & PEER SUPPORT

It's easy at these conferences to get sucked in to the belief that only highly qualified professionals are suited to working with such 'complex clients'.

This is an attractive idea, but it's born out of a lack of experience.

Peer Support stands on a rich and deep history of survivors finding ways of being with and supporting each other, without recourse to medication or coercion. It flourishes in a sense of equality and co-creation. Lived experience practitioners – those of us whose reflection on lived experience forms a big part of their training for in depth support (that isn't 'peer', but does have some power differentials) - is a growing field.

I was working with psychosis, trauma and dissociation long before I trained as a therapist.

I hope you become curious about wider approaches to these issues and are willing to learn and share with those who have alternative backgrounds. We have insights and ideas to share that go beyond our own personal experience.

## THANK YOU FOR LISTENING



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