

"Respond to Passages from "The Invisible Kingdom" by Meghan O'Rourke"

Alice Krueger

Virtual Ability, Inc.

Mental Health Symposium 2022

Friday, May 13

[2022/05/13 08:37] LV (LoriVonne Lustre): Hello everyone.

Today's presentation is being transcribed so those without audio or who require text only can participate in real time.

The speakers may be using a text teleprompter tool for some or all of their presentation.

Transcriptionists will fill in any gaps and support the Question & Answer section at the end.

A little explanation about this service.

Voice-to-text transcriptionists provide a translation of the key ideas discussed, NOT a word for word transcription.

Voice-to-text services provide an in-the-moment snapshot of ideas and concepts, so that those who are unable to hear or to understand the audio program are able to participate in real-time.

You will see the transcription in local chat.

Transcription is provided by Virtual Ability, Inc.

The transcriptionists are:

Lorivonne Lustre

Carolyn Carillon

The speakers will be identified by initials as they speak.

The following initials in the transcription record will identify the speakers:

GH: Gentle Heron

[2022/05/13 08:38] LV (LoriVonne Lustre): <<transcription begins>>

[2022/05/13 08:38] Pecos Kidd: Alice Krueger, known inworld as Gentle Heron, needs no introduction. If you are here today, you probably know her.

Most of you are here at this event because she inspired you, networked with you, asked you, or cajoled you to attend – or most likely all of the above.

Alice is a former education researcher and professional development provider.

Fifteen years ago, when her multiple sclerosis made it impossible to continue her previous career, she and a few friends purposefully decided to create a community in a virtual world.

The result is the Virtual Ability community within Second Life, and the corresponding Virtual Ability, Inc. non-profit corporation, of which Alice is the President.

In Virtual Ability's founding documentation, Alice defined the essential aspect of community as offering its members:

- information
- encouragement
- training
- companionship
- referrals to other online resources and groups

- ways to contribute back to the community
- ways to have fun

This conference, now in its eleventh annual iteration, expressly provides *all* of these facets to its attendees.

I am honored and inspired to work with Alice. Please join me in welcoming her to this presentation.

[2022/05/13 08:40] Gentle Heron: Thank you for that introduction, Pecos. I really don't know EVERYONE in Second Life!

[2022/05/13 08:40] Mook Wheeler: 🎵:***♥**:*🎵 APPLAUSE 🎵:***♥**:*🎵

[2022/05/13 08:40] Valibrarian Gregg: applause!!

[2022/05/13 08:40] Elektra Panthar: 🎵🎵🎵🎵 Applauds🎵🎵🎵🎵

[2022/05/13 08:40] Shyla the Super Gecko (KriJon Resident): applause!!

[2022/05/13 08:40] Zzri Avian (Zri Portal): /me claps talons!

[2022/05/13 08:40] Buffy Beale: cheering loudly!!

[2022/05/13 08:40] Lyr Lobo: /me claps

[2022/05/13 08:40] Gentle Heron: Hi everyone and welcome to this book discussion.

Has anyone else besides me read "The Invisible Kingdom: Reimagining Chronic Illness" by Meghan O'Rourke?

(pause for audience response)

[2022/05/13 08:41] Carolyn Carillon: GH: I want this to be an interactive session

[2022/05/13 08:40] Sitearm (Sitearm Madonna): n

[2022/05/13 08:40] Marli Hax: no

[2022/05/13 08:40] LV (LoriVonne Lustre): LV: Not yet. But I have ordered it!

[2022/05/13 08:40] Buffy Beale: no

[2022/05/13 08:41] Sarvana Haalan: n

[2022/05/13 08:41] Suellen Heartsong: n

[2022/05/13 08:41] iSkye Silvercloud (iSkye Silverweb): I'm ordering it!

[2022/05/13 08:41] Gentle Heron: Meghan O'Rourke is an American author who for most of her adult life has been dealing with mysterious, changing, and frustrating symptoms. She has been eventually diagnosed with chronic Lyme disease, autoimmune thyroiditis, hypermobile Ehlers-Danlos syndrome, and postural orthostatic tachycardia syndrome (POTS).

She will probably live the rest of her life dealing with neurological and connective tissue problems, fatigue, and brain fog.

After years of infertility, she now has two young sons.

Her book, "The Invisible Kingdom" is a New York Times Bestseller work of nonfiction.

It is both scholarly and intimate.

I'm going to read some selections from the middle of the book.

When I have had to change the author's wording for grammatical or clarification purposes, my words will be enclosed in square brackets like this: [my wording]

To indicate the beginning and end of each selection, I will use two sets of double colons, like this

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After each selection I will ask for your response to it.

Let's begin. I'm going to start with a short quote from the book.

O'Rourke reminds us (page 237-238) that

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"The World Health Organization's definition of healing goes beyond the mere curing of disease.

It defines health as 'a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.'

[O'Rourke goes on to ask Anne Berger, chief of the Pain and Palliative Care Service at the NIH Clinical Center, for her definition of healing.

Berger says,] "In palliative care, healing is thought of as a sense of wholeness. It is not being cured necessarily, but feeling whole."

[O'Rourke concludes that,] "A patient is healed, that is, not solely by steroids or antibiotics, but also by nature, thrilling conversation, touch, empathy—being made to feel whole rather than distraught, as she exits doctors' appointments."

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I hope you could tell which words were O'Rourke's and which were mine. I know it can be complicated in unformatted text chat.

Here's my first discussion question for the audience.

How do you feel about that definition of healing? Should health be thought of as including physical mental and social well-being?

If you agree, why? If you disagree, what other definition would you propose?

[2022/05/13 08:45] iSkye Silvercloud (iSkye Silverweb): Yes! I agree because of two things:

Validation - it helps to walk out of an appointment feeling validated by my doctor, that what I am reporting is not "all in my head" but a real thing that I am experiencing.

Second, isolation is a serious problem, feeling like I am alone or not feeling supported or knowing that there are others like me.

It's a huge help to be validated and also to know that I am not alone in what I am living with.

[2022/05/13 08:45] Shaerken Changeheart (ChangeheartShaerken Resident): Yes. Unequivocally.

Why: because it's what I've felt and it's being voiced by another person -- so it's not just me. And it's a power trip people use to make "others" feel broken or that we need to be fixed.

[2022/05/13 08:47] Myrica Jenkins: health benefits from lifelong good habits

[2022/05/13 08:48] Senn Maximus: attitude

[2022/05/13 08:46] Shyla the Super Gecko (KriJon Resident): Can we define social well-being?

[2022/05/13 08:48] Carolyn Carillon: GH: Shyla asked if we can define social well-being and we would definitely want to do that

Any other comments about the definition of wellness?

Health is not just curing

[2022/05/13 08:49] Namaara MacMoragh: Excellent point Gentle about not [just] curing.

[2022/05/13 08:49] Carolyn Carillon: GH: yes, Namaara, for my MS, there is no cure

[2022/05/13 08:48] Sitearm (Sitearm Madonna): wellness is a moving target

For me :)

[2022/05/13 08:49] LV (LoriVonne Lustre): LV: Amen Site!

[2022/05/13 08:49] Marly (Marly Milena): Wellness and a feeling of well-being are related

[2022/05/13 08:49] RoXkSie (Roxksie Logan): /me nods

[2022/05/13 08:49] Elli Pinion: So love this definition.

[2022/05/13 08:49] Carolyn Carillon: GH: I like that definition, too [O'Rourke's]

[2022/05/13 08:49] iSkye Silvercloud (iSkye Silverweb): it's also helping us arrive at a knowledge of "I am not my illness"

[2022/05/13 08:49] Megs (megscandles Resident): wellness is the goal; to be able to respond to whatever the environment gives you and remain resilient.

[2022/05/13 08:49] James Heartsong (PeacefulJames Heartsong): Wellness is a targeted way of life, not a cure

[2022/05/13 08:50] Sitearm (Sitearm Madonna): /me dittoes James

[2022/05/13 09:43] Gentle Heron: For our next passage to discuss today, O'Rourke begins by talking about some famous lines from a poem by John Donne:

"No man is an island,

Entire of itself.

Each is a piece of the continent,

A part of the main.

If a clod be washed away by the sea,

Europe is the less. ...

Each man's death diminishes me,

For I am involved in mankind.

Therefore, send not to know

For whom the bell tolls,

It tolls for thee."

Is anyone else here familiar with that poem?

(pause for audience response)

[2022/05/13 09:44] Rhiannon Chatnoir: yes

[2022/05/13 09:44] iSkye Silvercloud (iSkye Silverweb): OH yes

[2022/05/13 09:44] Shyla the Super Gecko (KriJon Resident): yes

[2022/05/13 09:44] LV (LoriVonne Lustre): yes

[2022/05/13 09:44] Sheila Yoshikawa: yes

[2022/05/13 09:44] Lyr Lobo: yes

[2022/05/13 09:44] Wisdomseeker (Lissena Resident): y

[2022/05/13 09:44] ♡ Anya ♡ (Anya Ibor): yes

[2022/05/13 09:44] Namaara MacMoragh: yes :-)

[2022/05/13 09:44] Polaris Grayson: yes

[2022/05/13 09:44] Eme Capalini: yes

[2022/05/13 09:44] Ava Dougall: y. love it

[2022/05/13 09:44] Hope PAŞŞİFLØRÅ (LPEaceAndLove Resident): y

[2022/05/13 09:44] Stranger Nightfire: very much so

[2022/05/13 09:44] James Heartsong (PeacefulJames Heartsong): nods

[2022/05/13 09:44] Marly (Marly Milena): It's a classic quote

[2022/05/13 09:44] Lizard of ARS (Marylou Goldrosen): YEs!

[2022/05/13 09:44] Elektra Panthar: GH: Quite a few people heard it, good

[2022/05/13 09:44] Gentle Heron: You should know that John Donne was 51 when he wrote that poem. He was at the time Dean of St. Paul's Cathedral in London. He was near death in the hospital of "spotted fever" (probably typhus) which was rampant among the population then.

Church bells were ringing for funerals regularly.

O'Rourke tell us (pages 238-239) that

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"Physically, Donne felt alone, as he writes in Devotions Upon Emergent Occasions, a twenty-three-part prose work about his illness.

"Variable, and therefore miserable condition of man! This minute I was well, and am ill, this minute," he reflects, meditating on the uncertain night land of illness.

"I am surprised with a sudden change, and alteration to worse, and can impute it to no cause, nor call it by any name."

This uncertainty brings with it an almost unbearable sense of isolation: "As sickness is the greatest misery, so the greatest misery of sickness is solitude."

And yet from the loneliness of his hospital bed, as he listened to funeral and wedding bells ring around him, he came to his famous insight about the spiritual connectedness of human experience: "No man is an island, entire of itself; every man is a piece of the continent, a part of the main. ..."

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On pages 264-265, O'Rourke states

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"Being ill is a social experience, as John Donne realized.

It is what [Arthur] Frank calls "dyadic": impossible to understand without thinking about the self in relation to others.

Yet Western medical culture insists on the solitariness of illness:

everything about it intensifies the monadic aspect, confining patients to hospitals where anonymity differentiates and isolates

rather than enhances and unifies us in our interconnected humanity.

The patient's identity is thwarted, silenced, distorted in a culture that does not recognize itself in its sick members.

One of the most important discoveries I made in the process of being ill is that solitary striving, my American habit of self-focus, was in some fundamental way a degradation of the most powerful aspects of our lives, which now seem to me to be our interconnectedness and need of others.

I look at my small sons, and I see that they need me, and in that I see what is most meaningful in the end—

not children, specifically, but the bonds among us."

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Do you see disability and/or illness as a social experience? If you do, in what ways? If you don't, why not?
(pause for audience response)

[2022/05/13 09:49] Rhiannon Chatnoir: yes

[2022/05/13 09:49] Elektra Panthar: Rhiannon Chatnoir: definitely speaks to that interconnected nature of humanity and how we all experience the same things and sometimes together and sometimes alone, but on well tread steps of others somewhere.

[2022/05/13 09:49] LV (LoriVonne Lustre): Yes, the interconnectedness of being with Virtual Ability!

[2022/05/13 09:50] Rhiannon Chatnoir: Yes, finding your peers / community connect us

[2022/05/13 09:49] James Heartsong (PeacefulJames Heartsong): Well said... and now I read your questions

[2022/05/13 09:49] Namaara MacMoragh: It is a social experience imo

[2022/05/13 09:49] Polaris Grayson: everything is an experience when you learn

[2022/05/13 09:49] iSkye Silvercloud (iSkye Silverweb): Being Deaf I am a member of a community that lives in a world that has varying amounts of sound. For me the world is entirely silent except for the 24/7/365 tinnitus in my head that is in the form of music. I am connected by the common language of Deaf people, sign language, which is crucial for me.

[2022/05/13 09:50] Mook Wheeler: Much depends on *what* disability or illness, what your family/social circle is like, your financial situation, your living conditions, etc. The 'social aspect' of any disability/illness must necessarily be a continually changing experience made up of variables. What cannot be disputed is that being 'undiagnosed and dismissed' adds a plethora of NEGATIVE social experiences to the situation, impacting your mental health and perception of self-worth.

[2022/05/13 09:50] RoXkSie (Roxksie Logan): I think it's situational and environmental also to who we're around.

[2022/05/13 09:51] Namaara MacMoragh: There are many communities that do not isolate an individual, especially with mental health challenges, but instead, surrounds them and supports them. And I agree with what Mook just shared.

[2022/05/13 09:51] iSkye Silvercloud (iSkye Silverweb): I am the only Deaf person in my family so I am surrounded by family and family friends but isolated because of an invisible barrier

I am more connected with people outside my family but the pandemic provide video chat opportunities with my mother and sister and they have actually gotten to know me, and discovered a whole different me than they thought I was.

[2022/05/13 09:52] Mook Wheeler: @iSkye :))))))

[2022/05/13 09:51] James Heartsong (PeacefulJames Heartsong): I grew up as a "lone wolf", but that was due to constantly moving to new homes.
I got used to it

[2022/05/13 09:52] Shaerken Changeheart (ChangeheartShaerken Resident): Yes. Being disabled is unintelligible to others who have no conscious awareness of what is going on in their own bodies (proprioception and enteroception). Sensory perception is a major factor (among its numerous spectrums) is regarded as "not real". Real and not real are inimitably tied to sociability.

[2022/05/13 09:52] Carla Heartsong: Being isolated at home after brain surgery was very socially impacting, but SL and Virtual Ability have been a major positive

[2022/05/13 09:53] Elektra Panthar: GH: Thank you all for your comments

[2022/05/13 09:53] Gentle Heron: Thank you all for discussing this thought-provoking book with me today.

If I have interested you in purchasing The Invisible Kingdom so you can read more of O'Rourke's story and suggestions for improving the medical system to benefit people who are dealing with conditions for which there is no easy cure, here is the Amazon link:

<https://www.amazon.com/Invisible-Kingdom-Reimagining-Chronic-Illness-ebook/dp/B097XDLS7F>

And please, if you shop on Amazon, consider adding Virtual Ability, Inc. as your chosen charity for the Amazon Smile program.

You would be making a donation to support our work in Second Life at no cost to yourself. Information on how to use the Amazon Smile program is on a notecard in the blue poster to the left of the stage.

Thank you again, and please enjoy the remainder of the conference.

[2022/05/13 09:54] RoXkSie (Roxksie Logan): /me .:{APPLAUSE}:

[2022/05/13 09:54] Tori Herbit Landau (Tori Landau): Applauds

[2022/05/13 09:54] Hope PAŞŞÎFLØRÅ (LPEaceAndLove Resident): ty

[2022/05/13 09:54] Sheila Yoshikawa: thank you!

[2022/05/13 09:54] Lizard of ARS (Marylou Goldrosen): So Special!

[2022/05/13 09:54] Eme Capalini: Great job, Gentle

[2022/05/13 09:55] Marly (Marly Milena): Hamlet - "the heartache and the thousand natural shocks

That flesh is heir to" unites us

[2022/05/13 09:58] Lyr Lobo: powerful thought, Marly

[2022/05/13 09:54] LV (LoriVonne Lustre): <<transcription ends>>