

"Panel Discussion: Fear within specific disabilities"

Cicero Kit (moderator), Kathryn Post, Leigh Brosos, Gloria Kraegel

Mental Health Symposium 2025

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[2025/05/15 13:32] Elektra Panthar: Hello everyone.

A little explanation about this service:

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

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Transcription is provided by Virtual Ability, Inc.

The transcriptionists today are

Elektra Panthar,

Shaerken Changeheart.

The speakers will be identified by initials as they speak:

CK: Cicero Kit / Stealth

KP: Kathryn Post,

LB: Leigh Brosos

NM: Namaara MacMoragh (Gloria Kraegel)

[2025/05/15 13:32] Cicero Kit: Hello everyone. For those who do not know me, I am Cicero Kit or Stealth in Second Life; Jen Dolan in real life.

I am a member of Virtual Ability and the moderator for today's panel discussion. I have worked as a journalist in both real life and Second Life, and worked in higher education and the non-profit sector before going on disability in 2017.

Fear and anxiety affect so many lives, in so many situations.

Today's panel includes a cancer doctor, a clinical psychologist, and a traumatic brain injury survivor who helps other neurodivergent individuals.

I will have each person introduce themselves to you, starting with Dr. Post.

[2025/05/15 13:34] Elektra Panthar: KP: Hi, thank you so much. I have been taking care of patients with breast cancer as a nurse practitioner for about 18 years now at the Massachusetts General Hospital Cancer Center. I am also a nurse scientist in the MGH Cancer Outcomes Research and Education Program and am part of the Harvard Medical School faculty.

I spend most of my time conducting research to improve the quality of life and outcomes for patients with cancer and their families. My work is funded by both the American Cancer Society and the National Cancer Institute of the NIH.

I am so pleased to be here today speaking with you all about this important topic.

[2025/05/15 13:34] Namaara MacMoragh: Thank you for inviting me. I'm glad to see everyone today.

My name is Namaara MacMoragh; Gloria Kraegel in that other life. I'm with the Brain Energy Support Team (BEST) which is a US based nonprofit organization. I'm also the chief grounds keeper at Etopia Sustainable Communities (<http://maps.secondlife.com/secondlife/Etopia%20Island/194/56/22>) where we create supportive and engaging opportunities for neurodivergent persons and their loved ones to build skills and systems for success in a space that reflects our passion for regenerative living in social, community, business, and environmental contexts. I want to clarify that while the Brain Energy Support Team works with a variety of individuals, families, and groups we do not provide medical or psychological services. You can find out more about us and what we offer from our website, <https://brainenergysupportteam.org>.

[2025/05/15 13:36] Shaerken Changeheart (ChangeheartShaerken Resident): LB: Hi everyone. Dr. Leigh Brosf
Licensed psychologist
Making treatment for folks is one of my specialties
As well as suicidal thoughts.

[2025/05/15 13:36] Cicero Kit: The topic for today's conference deals with fear.
As you all know, fear can sometimes be productive.
For example, I have multiple sclerosis and am afraid of how further progression of my MS could impact my life, so I have regular MRIs, take medication and engage in physical therapy to help mitigate that.
What are some ways in which fear may be productive for the people you work with?

[2025/05/15 13:37] Elektra Panthar: KP: Fear can absolutely be productive. The way I see this manifest in my patients is that it can drive them to obtain the appropriate cancer screenings (such as mammogram, colonoscopy), and take medication they may be prescribed to reduce their risk of recurrence. It can also drive patients to modify their lifestyle behaviors as we know that a healthy lifestyle can decrease the risk of a cancer recurrence.

[2025/05/15 13:38] Namaara MacMoragh: Fear is designed to help us deal with threatening or unexpected situations in the moment. Anxiety, which is what I understand your example to be referring to, is more of a steady sense of uneasiness, that sense of "dread", that helps us manage how we prevent, respond to, or address specific circumstances that may not be manifest in this moment.
In terms of making anxiety productive, our goal, at BEST, is to help our program participants acknowledge the emotion, identify the trigger, and create the steps or address the process to resolve the situation, and then work through how to best respond and navigate it.

[2025/05/15 13:39] Shaerken Changeheart (ChangeheartShaerken Resident): LB: Fear can be adaptative.
We differentiate fear as a stimulus or from anxiety. We tell our clients fear and anxiety are there to tell us something
People I work with have an overactive response to weight gain
What is the fear trying to tell us?
It's the fear of the consequence that they'll be judged, abandoned.
The function of the fear is important.
Anxiety and fear can be adaptive telling us what's going on inside.

[2025/05/15 13:41] Cicero Kit: Anxiety arises from our fears and is largely seen as unproductive or even counterproductive.
What are some anxiety management techniques that you recommend?

[2025/05/15 13:42] Elektra Panthar: KP: There are some easy strategies that people can incorporate into their daily lives to help manage fear and decrease anxiety.
I am a big proponent of mindfulness techniques, as there is evidence to support that regular practice can reduce stress and anxiety. This does not have to be intense meditation; we teach our patients simple, quick exercises like belly breathing, body scans, and present moment awareness that can all help manage the stress and uncertainty they experience after a cancer diagnosis.
For some patients, anxiety can more severe and impact their daily lives and functioning. For these patients, I recommend connecting with a mental health expert for counseling (such as a social worker) and occasionally refer them to onco-psychiatry for more in depth anxiety management.

[2025/05/15 13:43] Namaara MacMoragh: I agree, there are times when anxiety can result from our fears. We encourage our program participants to create action plans, create steps cards for tasks and routines, maintain a schedule, how to best use reminders, create habits, and establish a circle of support. These help things can lessen the impact of anxiety.
Peer support, whether it is one-to-one or in a group, is a safe space and excellent way to help someone articulate what they are anxious about. Having a way to articulate or express what's going on is often difficult and particularly important for neurodivergent individuals, especially those with word finding issues or expressive aphasia, for example. This gives them the opportunity to wrestle a potential monster in their head and make it more manageable.
We also provide mindfulness activities, guided meditations, and self-care resources which are also helpful in minimizing anxiety.

[2025/05/15 13:46] Shaerken Changeheart (ChangeheartShaerken Resident): LB: As a psychologist ...
When we see it problematic..
catastrophizing..
We find it really paralyzing.
That's when it's counterproductive
Echoing Dr. Post -- 1st thing we recommend is deep breathing and muscle relaxation.
There are lots of great videos on line.
When we find ourselves confronted with anxiety our fight-flight takes over.
When we feel really anxious we can't rely on rational thought to get us out of these situations.
We slow our breathing ..
Relax our muscles ...
Lower our heart rate ...
We bring the anxiety down a couple of notches
Tried once and it didn't work? Try it again.
When faced with a lot of anxiety you can use these techniques effectively
A worry journal or worry time can also be effective
You're not ignoring the issues, you're giving permission to worry for a set time.
I'm happy to go into more detail on these if you want to contact me.

[2025/05/15 13:49] Cicero Kit: In addition to working with patients, do you also work with the loved ones of patients to help them cope?

[2025/05/15 13:50] Elektra Panthar: KP: We do work with caregivers, but there is currently not as much support for them as I would like there to be.

For example, if caregivers are experiencing significant anxiety or fear surrounding their loved ones diagnosis, I can't refer them directly to a mental health provider as they are not officially my patient. However, as oncology clinicians we are providing support to caregivers during appointments, and over the phone or the patient portal.

My research lab also has a body of work dedicated to supporting caregivers and we are able to offer support and mental health resources to caregivers that enroll in these programs.

[2025/05/15 13:51] Namaara MacMoragh: We strive to include loved ones in the process to increase their understanding of what's happening to the person they love and how to navigate a significantly changed life. So, in addition to providing peer support and education for individuals we offer discussion groups, resources, and training for caregivers and family. Often things need new words and we know that's very true for managing anxiety.

Second Life is an excellent platform for the work we do. In Second Life we host guided meditations, mindfulness activities, and we also engage caregivers and family in respite gatherings. As part of the gathering the group chooses a particular activity or discussion topic for the next time we meet.

[2025/05/15 13:54] Shaerken Changeheart (ChangeheartShaerken Resident): LB: We often involve loved ones in the treatment for eating disorders.

Eating disorders are really tough to deal with.

We bring in parents, siblings and others.

Our job is to understand what is going on.

Family members often don't know how to help their loved ones.

Education on eating disorders is what we provide.

For client and family

Opening that line of communication provides relief for family members.

We do recommend that loved ones get their own individual therapy

[2025/05/15 13:55] Cicero Kit: When I think about anxiety, I often think of how one's perception of self becomes threatened.

For example, people often identify heavily with their career, but when they retire or become disabled, there is then this need to identify one's self in other ways.

How do you think perception of self factors into the anxiety that the people each of you work with face?

[2025/05/15 13:56] Elektra Panthar: KP: That is an excellent question. The perception of self is often threatened with a cancer diagnosis and treatment. Many patients struggle with their new identity as a patient with cancer, or as a "sick person".

I think this does get better over time for patients that are treated and then can return to their "normal lives" and reclaim their previous identity. I think its more challenging for patients who live with advanced cancer, where the disease is no longer curable, and their lives are forever changed. For these patients, it can be challenging to incorporate this new identity and reality, and I see a lot of grief and feelings of loss that patients experience.

In the best-case scenario, patients are able to integrate this as part of the “new normal”, although it is not a road they would have ever chosen for themselves. For some patients, this is an ongoing struggle. Mindfulness is a great strategy here, too, and we often refer our patients to mental health providers to help them work through their understandable feelings of frustration, grief and sometimes anger.

[2025/05/15 13:58] Namaara MacMoragh: Our identity, as an individual, as a spouse or parent, as part of a social group, etc is core to who we are and how we engage with the world around us. It's natural that following such a significant change either from the examples you gave or because of a TBI a person will feel anxious about what comes next. Values, beliefs, family & community support are important to our perception of self. The BEST Empowered Self program is designed to rebuild identity and identify challenges & build on strengths. As participants work through the steps and exercises they are able to redefine who they are which, in turn, lessens the anxiety they may be feeling.

[2025/05/15 14:01] Shaerken Changeheart (ChangeheartShaerken Resident): LB: This is an excellent question

It's very central to people with eating disorders.

Eating disorders are unique in that they often convince the individual that they need their disorder

To function in general and other specifics

The eating disorder becomes essential to sense of self

Change includes how they view themselves as people

We work to build a life worth living

What creates a full life for the individual?

We usually see recovery when we build this up

[2025/05/15 14:03] Cicero Kit: Often with anxiety or fear, one may also experience grief, whether that be grieving a loss of ability to do things one might enjoy, the potential of missing moments with loved ones, or even a sense of loss due to something such as body dysmorphia.

Could each of you speak to how grief affects the communities you work with.

[2025/05/15 14:04] Elektra Panthar: KP: Grief is absolutely a huge part of caring for patients with cancer. Patients grieve for what they have lost and can potentially lose in the future. Many patients grieve about the physical limitations and changes a cancer diagnosis and treatment can bring and as you mentioned, missing important events with family and friends.

There is a lot of anticipatory grief on the part of the patient as well as their caregivers when they worry about not being present in the future for major milestones like children's birthdays and graduations and also for life goals they worry they will not be able to reach.

[2025/05/15 14:06] Namaara MacMoragh: The majority of people we work with are navigating life after brain trauma; TBI, Stroke, Brain Aneurysm, etc. We commonly hear how after such a trauma they aren't the same person. Memory issues, physical challenges, behavioral changes, an inability to work any longer because of seizures, persistent and consistent headaches, and more not only impact daily living, but how we see ourselves as well as how we are seen by others.

Who am I now that everything I knew about me is gone? What am I supposed to do now? Where do I go from here? Why did this happen to me?

Grief is, yes, a big part of what we deal with.

We know that grief, if left unresolved, fuels depression, suicidal ideation, and, not least, anxiety. It's been our experience that when offered appropriate peer support and the tools to succeed people can define a new life that can be brilliant, exciting, and full of love. That's why we focus on brain energy and not brain injury.

[2025/05/15 14:08] Shaerken Changeheart (ChangeheartShaerken Resident): LB: Grief looks a little bit different in my work than it does in Nam's and Dr. Posts's work.

Losing the eating disorder usually produces a large amount of grief

We talk a lot of what that is like

Loss of identity ...

Moving to recovery, there is often grief about what the eating disorder made them miss out on.

Work opportunities ...

Living opportunities ..

Grieve the time away from their life that they lost

We hold space for that grief

It comes up in different ways for people

We are open to that

[2025/05/15 14:10] Mook Wheeler: COMMENT: I want to say this as someone living with clinical depression and anxiety. You all agreed that anxiety is paralysing. I also want to say that anxiety lies. Anxiety tells us lies. It distorts and warps what we see or think, and (always) affects every decision and action in a *negative* manner. It can make you think in a 'wrong' or 'untruthful' manner. It can taint perspective. Reminding yourself constantly that anxiety lies is very necessary if you are caught up in a journey with it. And your loved ones need to know this, too.

[2025/05/15 14:12] Shaerken Changeheart (ChangeheartShaerken Resident): LB: It's so important for people to share their own experiences.

It gives others a lot of hope

That they aren't alone

That others are dealing with similar challenges

Anxiety is "that is what you're doing" it's telling you "this is reality"

It's hard to fight that.

Thank you for sharing that Mook.

[2025/05/15 14:13] Elektra Panthar: NM: this ties into the idea of negativity bias

I think those are difficult to navigate through, being aware that it lies to us, and makes us unable to make rational decisions in the moment - that's why support is important

[2025/05/15 14:13] Gentle Heron: Thank you panelists for many wise insights. QUESTION - I suspect much of what you said about the population you work with applies to many other groups. Are there some people who should not follow your suggestions? And why[?]

[2025/05/15 14:15] Elektra Panthar: NM: what we do at BEST can be adapted to other groups

In terms of navigating fear and anxiety

KP: I agree

It can also be adapted to other groups

Mindfulness techniques are appropriate for most people to de-escalate stress

In my case cancer patients have anxieties about day to day life on top of their diagnosis so the techniques help

[2025/05/15 14:17] NSTAG8R Resident: QQQ - in April 2021, I moved to a new state. No friends, family, just myself. 2 months later I spent 11 days in Coma, Renal and respiratory Failure, Sepsis, MRSA, and necrosis of the small intestine. For the first 17 days, staff had little hope for my survival. April 2023, Sepsis arthritis, caused me to become a Below the Knee Amputee (BKA). I'm finally living on my own, using a K3 prosthetic now and trying to get work. My goal everyday is to make one stranger smile.

[2025/05/15 14:18] Elektra Panthar: NM: I'll respond

I love that idea, great energizer to refocus

I think it's beautiful, Thank you for sharing

[2025/05/15 14:19] NSTAG8R Resident: yw.

[2025/05/15 14:19] Elektra Panthar: KP: I agree

Finding a way to live a full life and find purpose and joy again, it's great

Great way to face your challenges

[2025/05/15 14:20] NSTAG8R Resident: everyday I wake up, is a GREAT DAY. Much better than the alternative and that's how I set my positive goal every morning

[2025/05/15 14:20] Itico (Itico Spectre): C[omment]: Learning to live no matter your situation is very important and healthy to our own mental health.

[2025/05/15 14:20] Shaerken Changeheart (ChangeheartShaerken Resident): LB: All of the panelists today work in very different areas. The themes among people we work with are similar.

Shared humanity is important. Everyone is going through different struggles.

Coming together in communities like this is powerful.

Thank you for having me on the panel today

[2025/05/15 14:21] Elektra Panthar: KP: I agree, I appreciate everyone having me here
Dealing with fear and anxiety is also knowing it's something everyone experiences, it's common

So many patients struggle with fear of cancer resurfacing and that stress impacts the outcome - knowing it's a shared experience can help them diminish that fear and [stress]

[2025/05/15 14:20] Pecos Kidd: I think this was a brilliant panel and discussion. Thank you all so much!

[2025/05/15 14:20] Elektra Panthar: CK: all great suggestions and comments!

[2025/05/15 14:23] Lorin Tone: Yet another great panel discussion, bravo!!!

[2025/05/15 14:23] Tricia Funizza: Everyone...thank you so much

[2025/05/15 14:23] Itico (Itico Spectre): C: Thanks panelists!

[2025/05/15 14:23] Dr. Kathryn Post (VAIPresenter7 Resident): Thank you so much for having me!

[2025/05/15 14:23] Dr. Leigh Brosos (VAIPresenter4 Resident): Thank you everyone!

[2025/05/15 14:23] Elektra Panthar: <<transcription ends>>