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Johns Hopkins Schizophrenia Symposium – August 2025

Good afternoon. My name is Michael Uram. I am a retired educator and 20+ year caregiver for two adults who have SMIs. I run a private Facebook Caregiver Group with 5,600 families and recently formed a non-profit foundation focused on helping SMI caregivers become more effective: SMI Caregiver Academy (SMICA). I'd like to share the story of "**My Caregiver Journey and the Heart of Hopkins.**

My home was filled with **conflict** – as are many homes which have a Loved One with an SMI. It was awful. I owe a **huge** amount of gratitude to my Loved Ones for their resilience and patience while "Dad**"** learned about SMIs **- and himself.**

My Caregiver Journey got stuck in a ditch where so many do – at the intersection of **Frustration** and **Anosognosia.** We are often stymied trying to **CONVINCE** our Loved Ones that they need help. Attempts to **CONVINCE** our Loved Ones that they are "sick" is where **caregiving and recovery run into a ditch. Eight Guiding Principles** helped keep me on a positive, effective path. I'd like to share four of them:

1. **Our life experiences are different than our Loved Ones'.** Their brain neurochemistry is different than ours – affecting cognition, emotion, perception, memory, judgment, and behavior. This means that **they** don't experience life the way **we do.**

2. **We cannot "fix" our Loved Ones.** These are medical illnesses. Contrary to romantic notions, no amount of "**love**" can "**fix**" them.

3. **We must first "fix" ourselves.** Author David Foster Wallace observed that the default human setting is "me" (egocentrism). To be **EFFECTIVE** caregivers we must learn about the brain and SMIs, **develop empathy**, and treat our Loved Ones with **respect** and **dignity.**

4. **We are either making things better or making things worse. There are no in-betweens and no other options.** When we **REACT** emotionally with our **amygdala – the emotion processing part of our brain** - we make things worse for them, for us, for everyone. When we **RESPOND** with our **prefrontal cortex** (the thinking, reasoning, figuring-out-stuff part of our brain**) things get better.**

Research focused on caregiving for Schizophrenia and then BiPolar, conducted by Dr. David Miklowitz of UCLA showed that Loved Ones who have Caregivers who react **emotionally** - **blaming, criticizing, castigating** - have a **94% probability of returning to the hospital** in the 12 months after being released from a hospital stay - **94% probability**. Miklowitz refers to this blaming, criticizing, castigating as **High Expressed Emotion**.

Conversely, Loved Ones who have Caregivers who have **Low Expressed Emotion** (responding with their **prefrontal cortex** instead of their **amygdala) have only a 17% probability** of returning to the hospital in the 12 months following hospital release. **94% … and 17% ….**

In full transparency, my Loved Ones had **multiple crisis hospitalizations** but **none since I learned, developed, and interact:**

- the basics of brain neurochemistry
- how SMIs affect cognition, memory, perception, judgment, and behavior
- developed and used high emotional intelligence
- and interact with my LOs with empathy, always protecting their dignity.

I knew -I- had to change or lose my Loved Ones. I discovered that my new approach closely aligned with Miklowitz's **Family Focused Therapy**. Both have four elements in common:

1. **Education**: brain neurochemistry basics and how these illnesses affect – well, everything
2. **Communication** – how we communicate with our Loved Ones
3. **Tools** – to use to avoid escalation .. being more empathetic, understanding, and supportive
4. **Family Dynamics** – how we relate to and interact with our LOs.

I started with **Education** – reading, taking CME classes, learning all I could about brain neurochemistry.

I learned:

- That SMIs rob the **prefrontal cortex** of the needed neurochemical activation to function properly. As a result, **abstract "conceptual" thinking** can degrade to **concrete thinking** – that of a 3rd of 4th grader.
- The prefrontal cortex is ALSO where **emotions are regulated AND** where our **sense of "right" vs. "wrong"** resides. In psychosis, moral and ethical judgment can be reduced **from** "what's good for **us**" to "what's good for **me**". Research shows that this aligns with the theories of Cognitive and Moral Development by psychologists Jean Piaget and Lawrence Kohlberg.
- when the prefrontal cortex is **deprived** of the needed neurochemical activation to work properly, the **amygdala** is left **un-regulated** and their **amygdala is now driving their bus.**
- The **hippocampus**, involved in memory formation and emotion is where so-called false memories" form. Before my LOs were stable, there were allegations of sexual abuse which never happened. Their hippocampi neurologically linked the internal agony of their illnesses to memories from TV and movies.
- And finally, SMIs **GRIND** a person's self-worth **to dust. THAT's** why the **suicide rate is so high**.

These basic understandings were what I needed to learn to **STOP** blaming and criticizing my Loved Ones and instead accept that their perceptions, judgments, and behaviors were not **THEM** but rather **off-kilter brain neurochemistry**.

Next COMMUNICATION - verbal and non-verbal.

- A BIG part of non-verbal communication is our **behavior**. Parents of infants understand that behavior is "**Communication**" **not** "**Character**". We SMI Caregivers need to realize this as well.

  Modeling with our own behavior is critically important. We must model **self-awareness** of our own **faults, vulnerabilities, and uncertainties** to demonstrate that these are not "**defects**" but are just part of **being human**. Many parents have the fantasy of **raising "perfect" children** and most of us are a "bit less than forthcoming" about our own imperfections and weaknesses. If we teach our Loved Ones to **compare** themselves to **perfection, we only** magnify and compound their **agony, self-criticism,** and sense of **worthlessness.**

- Lastly, **everyone deserves RESPECT and DIGNITY,** no matter what. As awful as these illnesses are, they are in the realm of **legitimate human experience.** In other words, our Loved Ones are not **less than human**. They are not **"defective",** have "poor character**", nor** are they evil or immoral.

Confusingly, the signs on every hospital and clinic in America say **"Behavioral Health"** – as if the problem to be "fixed" is ***behavior.*** As a result, relationship with our LOs can be **toxic** – destroying **CONNECTION –** the most basic and universal of human needs. To **re-connect** with my Loved Ones, I needed to use a four-step method I call: **"Relationship Rescue":**

Step 1: no matter how egregious the behavior or disrespect towards me, the **ONLY life-saving response** is "I love you. I love you. I love you. I love you. I love you. I love you. I love you. I love you. I love you."

Those "**I LOVE YOU's"** repeated **ten times in a calm, sincere voice** are magical. They are a fire extinguisher cooling the raging fires of angry emotion. But the magic fire-extinguisher has two nozzles – **one pointed at our Loved One's amygdala,** and one pointed **at ours**. Repeated "**I Love You's**" calm both CG and LO .

Step 2: Apologize … for two of my assumptions which were **profoundly wrong:**

(a) that I knew what my Loved Ones were feeling and experiencing inside (because none of us can really know that about another person) and **(b)** that approaches and solutions that I use in **my** life to help **me** navigate my own difficulties and challenges would work for **them** – or **FOR ANYBODY ELSE** .. because each life is unique as is the sum of each person's experiences.

Step 3: **Do Kindnesses -** to assure them that they **matter** and are **cherished**. I learned to thank them when they were considerate of others – even if it was as simple as putting dirty dishes in the dishwasher. How many kindnesses and how often? **5 KT's**: **Do 5 kindnesses** a week and **5 Thank You's** each week.

Step 4: **Congratulate them for their resilience.**
When a person has an SMI, it can take an **enormous** amount of resilience just to get out of bed each morning. And that resilience requires **courage**. And that **courage** requires **inner strength**. Our LOs are not **defective.** Rather, they are struggling to survive **every day.**

Next: Tools - My extended family has lost 3 members to suicide. It became horrifyingly clear, that to keep suicide from claiming yet another family member – this time under my own roof – I had to learn how to better regulate **my OWN emotions.** I needed to learn a host of caregiver tools like:

- **de-escalation** – keep emotional dysregulation from turning into conflict
- **translating** 2nd-person **YOU-stmts** into 1st person "**I stmts**" and then **neutral 3rd person** stmts
- **expressing my personal boundaries** calmly and non-judgmentally, without blaming
- **strengthening the five elements of Emotional Intelligence** (Self-awareness, Self-regulation, Motivation, Social Skills, and Empathy) so that **my** amygdala would not be driving my Bus

As caregivers, we are either **making things better** or **making things worse** – and there are **NO in-betweens** and **NO Other options** because EACH additional manic or psychotic episode damages brain grey matter, imperiling better outcomes for our LOs.

This meant … I had to SEARCH inside myself …

- to dig deep and bring into my own conscious awareness .. what made -me- tick: my **core values**, my **hot buttons**, my **strengths**, **weaknesses** and **vulnerabilities**.
- to **whack myself up-side-of-duh-head (Doh!)** that my Loved Ones' struggles were **NOT about me** … because behaviors resulting from serious mental illnesses are about **communication, not character.**
- And that the parental focus on **"achievement"** had to give way to **focusing on "being"**

Lastly, Family Dynamics:

I had to reflect on and analyze my interactions my Loved Ones through the lens of **EIGHT caregiver archetypes:**

1. **Expert** – "playing a doctor on TV" – which only injured my credibility and encouraged them to ignore me
2. **Authority** – treating my **adult** kids as **kids**, denying their "agency"
3. **Hero –** trying to "**fix**" everything
4. **Martyr** – I'll just suffer the **disrespect and indignities** instead of calmly and lovingly **insisting on respect**
5. **Supplicant** – **please - please - please** just … take your meds …
6. **Friend** – ignoring my life experience by pretending we were "equals"
7. **Victim** – WHY are you making things so difficult for our family?
8. **Advocate** – the ONLY role which works.

But advocate for whom?

- **For our LOs:** with doctors, nurses, teachers, schools, police, courts, neighbors, therapists, and family
- **For ourselves:** for what we need to be comfortable in a relationship with them.

I realized that:

- as a caregiver, I must **ASK and never TELL**
- **the primary job** of a Caregiver is to help our Loved Ones feel **respected, safe, and comfortable enough** to be open to medical help

- I had to make my home a **SANCTUARY** for my LOs - where they would feel safe - with **minimal stress** and **maximum support** **and** **acceptance** so that, when they were ready, they would have the confidence to again venture out into the world.
- and the importance of Caregivers meeting each other, **learning with and from each other** in conferences, Facebook support groups, webinars, Caregiver Education Classes and …. yes, thank you Dr. Sawa and researchers …… **academic symposia.**

It's a tremendous amount of learning … taught to me by those the world dismisses as "crazy".

I believe we have an **ENORMOUS** opportunity to **educate** ourselves, minimize **conflict,** restore **mutual respect and dignity** and **collaborate** with our Loved Ones to:

- Achieve better outcomes
- reduce family stress and conflict
- strengthen relationships
- have fewer hospitalizations and more loving and supportive family
- and, oh by the way, **help psychiatrists feel more comfortable and willing** to interact with caregivers. Very few psychiatrists are trained therapists. With the shortage of psychiatrists, they are under pressure to serve as many families as possible – **and** repay **HUGE** medical school expenses. Also, **let's be honest,** it can be very difficult to deal with caregivers when **our hair is on fire**.

So .. how to do this? Here are two proposals:

- **Caregiver Training** in hospital **IOP and PHP** programs. Our LO attend classes. So should we.
- **Caregiver Seminars** through psychiatric practices and schools of Public Health, Medicine, Psychology, Counseling, and Social Work.

Understanding, Empathy, and Dignity - All critically important in becoming more supportive, more effective caregivers, spouses, parents, … and **humans**. And THIS is what is so **incredibly AWESOME** about Johns Hopkins researchers **and this symposium**:

- **Understanding, Empathy, and Dignity** – what I received from Dr. Sawa - which led to his incredibly-gracious invitation to share my story here at Symposium.
- **Understanding, Empathy, and Dignity** – what my family received from Dr. Nucifora, Arlene Cuerdo, Dr. Bodnar, and Claire McCaulley when we ran into some roadblocks during one of my Loved One's participation as a Hopkins research volunteer. Home is his "safe place" and travel is anxiety-producing and he didn't know what to expect.

  Because **CHANGE** for our Loved Ones is **difficult** beyond Caregiver understanding. "I'm sorry for **ASSUMING** that I know what you are feeling and experiencing inside. I apologize.

  Please forgive me".

As we gather at this Symposium, world-class researchers and families … consider this:

- These Hopkins neuroscientists and researchers dedicate their careers **to research** … **PRECISELY** because their empathy **precedes** and drives their curiosity and passion for **learning and understanding**.
- But for us CGs – **it's just the opposite** - we must **UNDERSTAND** before we can develop the **EMPATHY** that our Loved Ones **so desperately crave,** helping them protect and maintain **the DIGNITY** they so deserve

So .. I envision a partnership – between the American Psychiatry Association, psychiatrists, hospitals, NIMH, SAMHSA, insurance companies, **and trained peer caregivers** … teaching Caregivers how to make things better and not worse for our Loved Ones and our families.

Thank you Dr. Sawa, Hopkins researchers and practitioners for inviting families and caregivers - like all of us here this afternoon - to observe and participate.

It's a brilliant example of what such a partnership can be and it is proof of the "Heart of Hopkins

Thank **you all** for listening **kindly** to my **Caregiver Journey of Learning, Understanding, Empathy, and Dignity.** I will be here for the duration of the symposium and would be honored to meet each of you.

Those interested can subscribe to my Caregiver Blog Site: **Patreon.com/SMICaregiver**.
Subscriptions are free or voluntary donations.

Lastly, two important announcements, please.

First, a friend of mine is here - Katrin Kutlucinar. Katrin studied under Dr. Miklowitz and is a trained Family Focused Therapist. Katrin – please stand up and say hello.

Second, a new friend .. who is responsible for getting clozapine approved by the FDA in the US. Dr. Gil Honigfeld please stand. Your work has saved hundreds of thousands of lives – including the lives of my own my Loved Ones.

Please give a standing ovation for Dr. Honigfeld.

Thank you all.

SMI Caregiver Academy