



Mental Health and Neurofibromatosis

September 21, 2024
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Outline

- Confidentiality
- Poll
- Teen Mental Health
- Teen Mental Health and Neurofibromatosis (NF)
- What Does this Mean for Me?
- Prevention and Resources
- Questions and Discussion

Confidentiality

- Anything shared or discussed in this room by attendees will remain confidential, and not be repeated outside of this room.



What Does Having NF Mean to Me? (polleverywhere.com)

Join by Web

PolleEv.com/jenniferdorr244

Join by QR code

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What is Mental Health?

- "Mental health is a state of mental well-being that enables people to cope with the stresses of life, realize their abilities, learn well and work well, and contribute to their community. It is an integral component of health and well-being that underpins our individual and collective abilities to make decisions, build relationships and shape the world we live in. Mental health is a basic human right. And it is crucial to personal, community and socio-economic development."
- "Mental health is more than the absence of mental disorders. It exists on a complex continuum, which is experienced differently from one person to the next, with varying degrees of difficulty and distress and potentially very different social and clinical outcomes."
(1)

[A Deeper Look Into The Teen Mental Health Crisis In The U.S. - YouTube](#)

(2)



NF and Mental Health

- Differences in social skills
- Theory of mind deficits
- Hyperactivity and ADHD
- Parasomnias
- Anxiety
- Depression (3, 15)

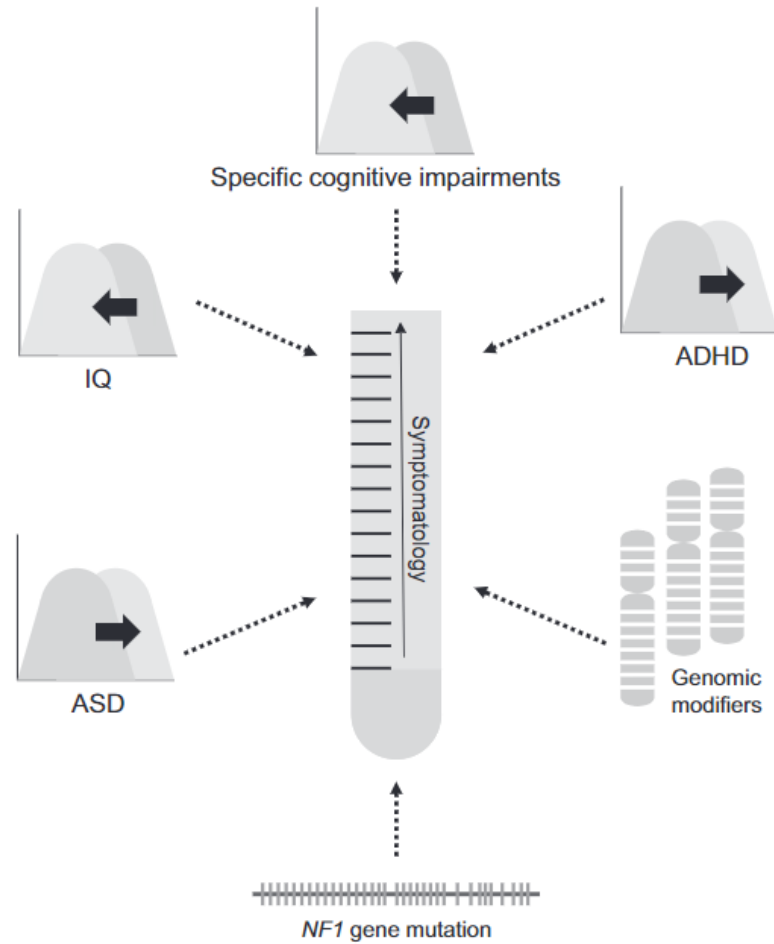


Figure 1: The spectrum and severity of neuropsychiatric symptomatology reflects the contributions of individual variations in IQ, autism spectrum disorder (ASD), attention-deficit-hyperactivity disorder (ADHD), and specific cognitive impairments, coupled with genomic modifiers and the impact of the germline neurofibromatosis type 1 (*NF1*) gene mutation. The dark grey colour denotes the schematic representation of the population distribution, while the light grey colour denotes that for children with *NF1*.



Differences in Social Skills

- Internalizing behaviors
- Externalizing behaviors
- Behavioral difficulties
- Loneliness
- Lack of social support
- Disempowerment
- Uncertainty about the future
- Feelings of blame or loss
- Co-occurring Autism Spectrum Disorder (3, 8, 14)

Theory of Mind Deficits

- The ability to understand that others have a mind inhabited by various mental states
- May differ from own mental state (3)





Hyperactivity and ADHD

- Executive function deficits
- Not associated with cognitive deficits (3, 4, 5, 6, 7, 8)



Parasomnias

- Undesirable experiences that occur falling asleep, sleeping, or waking from sleep
- Sleep walking
- Sleep talking
- Night terrors
- Nightmares (3, 10)



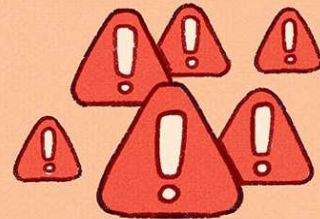
Depression

- Perceived lower quality of life
- Increased loneliness
- Pain interference (5, 9, 10, 12, 13, 14, 15, 16, 17)



Anxiety

Signs of an Anxiety Disorder



Frequent worry that interferes with daily life



Withdrawal from social life



Fixation on fear of next panic attack



Irrational fear and avoidance of a harmless object, place, or situation



Out-of-the-blue panic attacks



Recurring nightmares, flashbacks, or numbing of past trauma

- (5, 9, 15)



Suicidal Ideation

- Increased 4x (3, 13)
- What are your thoughts?

[Neurofibromatosis and Mental Health \(youtube.com\)](#)

(19)

What Does This Mean for Me?

- May be at a higher risk to develop mental health concerns
- Is this bad?
- What can I do?





Prevention and Supports

- Support system
- Positive habits
- Being honest
- Obtaining help
 - Individual therapy
 - Support groups
 - Support in school
 - Medications
 - Dr. Dorr at Children's! (3, 5, 14)

STRONG START TO THE SCHOOL YEAR!

LOCK IN HEALTHY HABITS

Get enough sleep. Aim for 8-10 hours per night.

Move more and sit less. Try to be physically active each day.

Take breaks from electronics and social media. Try to turn off screens while doing homework or with friends and family.

SLEEP SUCCESS STRATEGIES

- Set an early bedtime.
- Exercise at least 30 min each day.
- Put your phone out of reach when you get into bed.

PRACTICE POSITIVE SELF-TALK

Say “I’ll try it!” instead of “I can’t do it.”

CONNECT WITH OTHERS

Get involved. Join a club, try out for a team, and attend school and neighborhood events to meet new friends!

Talk with family and friends. It can be normal to feel nervous. Talking about how you feel can help.

(20)

MANAGE STRESS

Make time to unwind. Balance schoolwork with activities you enjoy and time with friends.

Talk to your teachers. If you need extra help, reach out to your teachers, they're there to support you.

Healthy ways to handle conflict: Communicate clearly and calmly, find compromises, and seek advice.

TRY DEEP BREATHING TO HELP YOU RELAX:

Place a hand on your belly to feel it moving when you are breathing. Take a slow breath in through your nose, hold your breath while counting to 5, and then breathe out slowly.

HOW TO ASK FOR HELP:

"I have been feeling ____, and it's starting to affect my grades. I really need to talk to someone."

NEED MORE SUPPORT?

Reasons you may want to ask for help: If you have trouble sleeping, concentrating in class, or don't enjoy things you used to.

Ask for help by reaching out to friends and trusted adults – like a family member, teacher, school counselor, doctor, faith leader – for support.

If things feel overwhelming, you can call, chat, or text 988, the Suicide & Crisis Lifeline any time – calls are confidential.



SCAN THE QR CODE
for more information.






988

SUICIDE & CRISIS
LIFELINE



About 988

People can call or text [988](tel:988) or chat 988lifeline.org  for themselves or if they are worried about a loved one who may need crisis support.

988 serves as a universal entry point so that no matter where you live in the United States, you can reach a caring, trained counselor who can help.

988 offers 24/7 access to trained crisis counselors who can help people experiencing mental health-related distress. That could be:

- Thoughts of suicide
- Mental health or substance use crises
- Emotional distress

"I am not my NF."

*"There is nothing wrong with
me."*

"I am not alone."

“There is help available.”



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Images:

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Questions/Discussion

