

*Educational Webinar Series for
Adults with Spina Bifida*



**Take care of your
mental health**

April 10, 2019

What is SB-YOU?

- Conversational presentations by subject-matter experts
 - Adults with Spina Bifida who are “life experts” on the subject
 - Health care professionals
- Practical information
- Tips and suggestions that are attainable and within reach

Why “SB-YOU?”

- Content is driven by YOU
 - Topics resulted from 2016 survey of adults with Spina Bifida
 - For, about, and by adults with Spina Bifida
 - Everyday concerns regarding living with Spina Bifida

Today's session will cover:

- Why it's important for adults with Spina Bifida to care for their mental health and well-being
- What the latest research tells us about mental health diagnoses among adults with Spina Bifida
- What are ways to address your mental health needs
- Our panelist's favorite materials/resources for and about mental health

Today's presenters

- **Karlin Bruegel, PhD, Clinical Psychology, CO**
- **Sarah Haywood, SBA Adult Advisory Council, ME**
- **Kristin Lovering-Marquis, SBA Adult Advisory Council, NH**

What I've learned about mental health – Karlin Bruegel, PhD

- Managing Spina Bifida is a daily challenge requiring the person with SB to keep multiple “plates” in the air at all times, so don't feel ashamed if you sometimes feel overwhelmed or demoralized!
- You do not have to apologize for having SB and needing to manage it in order to survive and thrive. You have as much of a right to survival, respect, happiness, and health as *anyone else*.



What I've learned about mental health – Sarah Haywood

- It is deeply connected to my physical health.
- I cannot do it on my own. I need a network of resources in order to properly take care of my mental health, and that is okay.
- Mental health needs are not always addressed within my team of doctors that are taking care of my physical health. I had to reach out on my own when I felt like I needed help.

What I've learned about mental health – Kristin Lovering-Marquis

- Even when you think your life is going according to plan, you can always be working on your mental health.
- Regularly working on your mental health gives you a unique set of skills to cope with whatever may come your way!

Why it's important for adults with Spina Bifida to care for their mental health and well-being. – Dr. Bruegel

- If you don't, who will?
- Mental health and physical health are deeply intertwined.
 - Depression, anxiety, and chronic stress can exacerbate or create physical problems and pain.
 - Stress and depression can deplete your energy and drain your motivation to take care of yourself.

Why it's important for adults with Spina Bifida to care for their mental health and well-being. – Sarah

- If we don't take care of our minds, our bodies are far less likely to heal.
- Our mental health influences our relationships with others.
- It is important to have a clear mind to be able to advocate for yourself.

Why it's important for adults with Spina Bifida to care for their mental health and well-being. – Kristin

- Working on your mental health and well-being helps you live your life to the fullest and love yourself the way you should.
- Our mental health impacts how we handle stress and make choices.
- Working on your mental health helps you live a more balanced life.

Primary mental health diagnoses among adults with Spina Bifida

– Dr. Bruegel

- Studies show an increased incidence of symptoms of depression, but insufficient/mixed data on anxiety.
- People with Spina Bifida may not demonstrate the “standard,” stereotypical, or expected signs and symptoms of depression.
- Executive dysfunction (troubles with organization, prioritization, initiation, etc.) can potentially mimic *or* compound symptoms of depression.

Signs and symptoms of depression

– Dr. Bruegel

- Prolonged sadness
- Hopelessness
- Emotional numbness and/or flat affect
- Poor self-worth/self-esteem.
- Lack of motivation and interest, especially in previously-enjoyed activities.
- Decreased interest in self-care/health management; chronic fatigue
- Frequent negative and/or self-critical thoughts
- Self-harm
- Suicidal thoughts or actions
- Frequent crying *or* inability to cry
- Frequent anger or irritation; outbursts
- Increased or decreased appetite
- Increased or decreased sleep
- Increased aches and pains

Signs and symptoms of anxiety

– Dr. Bruegel

- Rumination/worrying
 - Replaying past mistakes and upsetting events
 - Imagining future negative outcomes
- ‘Rituals’ to avoid triggers/bad outcomes
- Avoidance of ‘triggers’ (including social isolation/avoidance)
- Nightmares and/or ‘flashbacks’
- Chronic agitation
- Frequent irritation or anger
- Panic attacks
 - Racing heart
 - Dizziness
 - Shortness of breath
 - Nausea
 - Fainting or feeling like you’re about to faint
 - Fear of death/dying
 - Urge to fight, flee, freeze, or flop

Physical causes of anxiety and depression in people with Spina Bifida

– Dr. Bruegel

- Hydrocephalus/shunt failure
- Traumatic brain injury
- Neurochemical imbalances
- Other organic neurological ‘quirks’ or abnormalities
- Other physical health problems (e.g., adrenal issues)

Social-emotional causes of anxiety and depression in people with Spina Bifida

– Dr. Bruegel

- Academic or career struggles
- Financial stress
- Health problems/health management
- Frustration at not being 'normal' or meeting 'normal' milestones
- Barriers due to mobility/incontinence issues
- Socio-political turmoil or injustice
- Prejudice/discrimination
- Interpersonal problems (conflict, loneliness)
 - Feeling dependent on/enmeshed with family
- Stress/struggle navigating bureaucracies
- Lack of access to medical care and/or professionals
- Lack of access to accommodations and supports
- Lack of access to transportation

Ways to address your mental health needs

– Kristin

- Combination of group and traditional therapy
- Meditation
- Journaling
- Exercise
- Started my own, closed Facebook group

Ways to address your mental health needs

– Sarah

- Talk therapy with a psychologist
- Art therapy on my own
- Go outside
- Exercise
- Guided meditation
- Medications are an option – discuss it with your therapist
- Horseback riding therapy

Ways to address your mental health needs: Self care basics – Dr. Bruegel

- Adequate sleep
- Proper nutrition
- Enjoyable exercise
- Mindfulness exercises
- Self-expression: art, singing, journaling
- Spend time with friends/family
- Make friends online
- Join Meetup or other special-interest/hobbyist group
- Join emotional support group
- Take up a hobby (old or new)!
- Ask trustworthy, supportive ones for help
- Volunteering
- Break stressful/daunting tasks into smaller pieces, delegate to trustworthy loved ones/ supportive people
- Spend time in solitude

Types of counselors and therapists

– Dr. Bruegel

- Counseling Psychologist (Ph.D.)
- Clinical Psychologist (Ph.D.)
- Psychologist (Psy.D.)
- Psychiatrist (M.D.)
- Social Worker (M.A., D.S.W., Ph.D.)
- Therapist/Counselor (M.A. or M.S.)
- Licensed Clinical Social Worker (LCSW)
- Licensed Professional Counselor (LPC)
- Nursing assistant (CAN)
- Licensed practical nurse (LPN)
- Registered nurse (RN)
- Advanced practice registered nurses (APRN)
- Life coach (Credentials may vary)
- Marriage and Family Therapist (MFT)
- Advanced Psychiatric Nurse (APN)

Popular types of therapies

– Dr. Bruegel

- Cognitive Behavioral Therapy (CBT)
- Eye-Movement Desensitization and Reprocessing (EMDR)
- Internal Family Systems (IFS)
- Emotion-Focused Therapy (EFT)
- Existential Therapy
- Relational Therapy
- Narrative Therapy
- Psychoanalytic/Psychodynamic Therapy.
- Adlerian Therapy
- Art Therapy
- Marriage and Family Therapy
- Play Therapy (for children)

Main factors to consider when choosing therapy / a therapist

– Dr. Bruegel

- What your insurance will approve and pay for (unfortunately).
- The therapist's experience and specialty areas.
- Rapport/ "fit"— do you like and respect one another?

What are your go-to resources?

– Dr. Bruegel

- <https://www.kbruegelpsych.com/>
- *Mind Over Mood* by Dennis Greenberger
- *Freedom from Your Inner Critic* by Jay Earley and Bonnie J. Weiss
- The Bloggess <https://thebloggess.com/>
- Captain Awkward Advice Blog <http://www.captainawkward.com>
- Andrea Lausell: Latina Youtuber with SB <http://www.andrealausell.com/>
- Shine: Hydrocephalus and SB <https://www.shinecharity.org.uk/>
- NAMI <https://www.nami.org/find-support/nami-helpline/top-25-helpline-resources>

What are your go-to resources?

– Kristin

- Closed (private) Facebook groups
- Your local hospital's weekly/monthly support groups
- Your local SBA Chapter
- Phone apps (Virtual Hope Box, Headspace, Calm, Insight Timer)
- Journaling

What are your go-to resources?

– Kristin

- Books
 - *The Universe Has Your Back: Transform Fear to Faith*, Gabrielle Bernstein
 - *Girl, Wash Your Face*, Rachel Hollis
 - *You are a Badass*, Jen Sincero
 - *Unf*ck Yourself: Get Out of Your Head and Into Your Life*, Gary John Bishop
 - *Born to Break the Boundaries*, Stacey Santonastasso

What are your go-to resources?

– Sarah

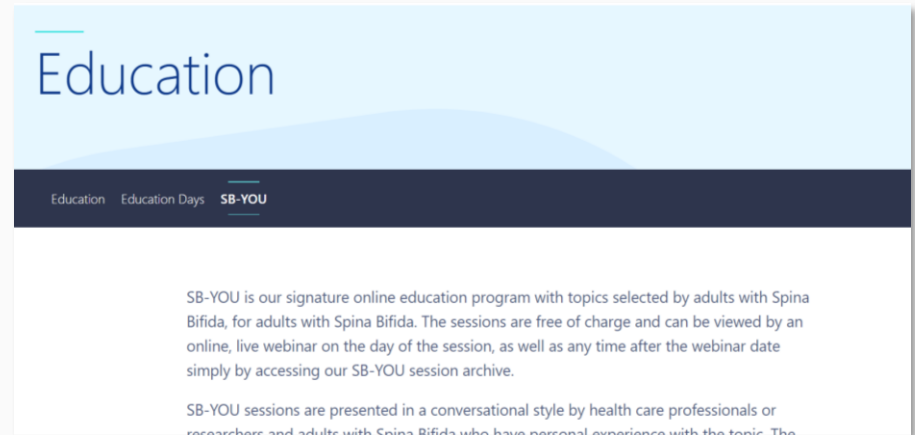
- Kristin's blog - <https://spina-beautiful.com/blog/> !
 - Features profiles of others living with Spina Bifida
 - Can be a great way to connect with people
- Guided meditations on YouTube
 - Search for the type of healing you want (sleep, anxiety, depression, etc.)
- Journaling: Helps me sort everything out when things feel overwhelming
 - Make lists. Every time I cross something out, it's a weight off my shoulders

Questions?

Resources and Archived Recording

See the full list of resources and an archived recording of this session:

<https://www.spinabifidaassociation.org/education/sb-you/>



Thank you!

Questions?

- Judy Thibadeau, jthibadeau@sbaa.org
- Juanita Panlener, jpanlener@sbaa.org