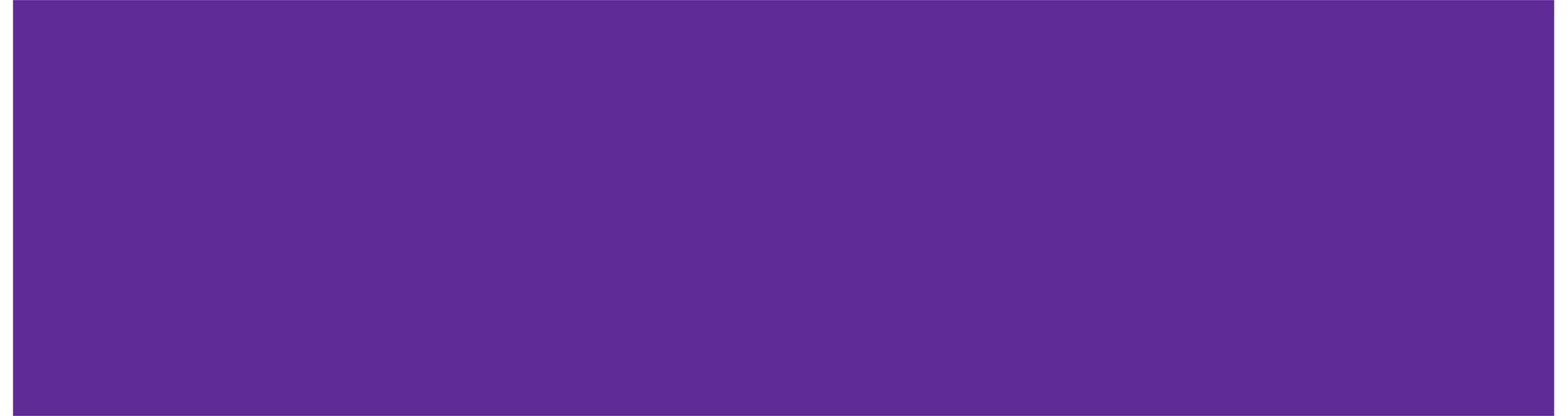


Mental Health for FASD Caregivers

What does it look like?



It is different

Mental health for caregivers of those with FASD is - unique -
difficult if not impossible at times.

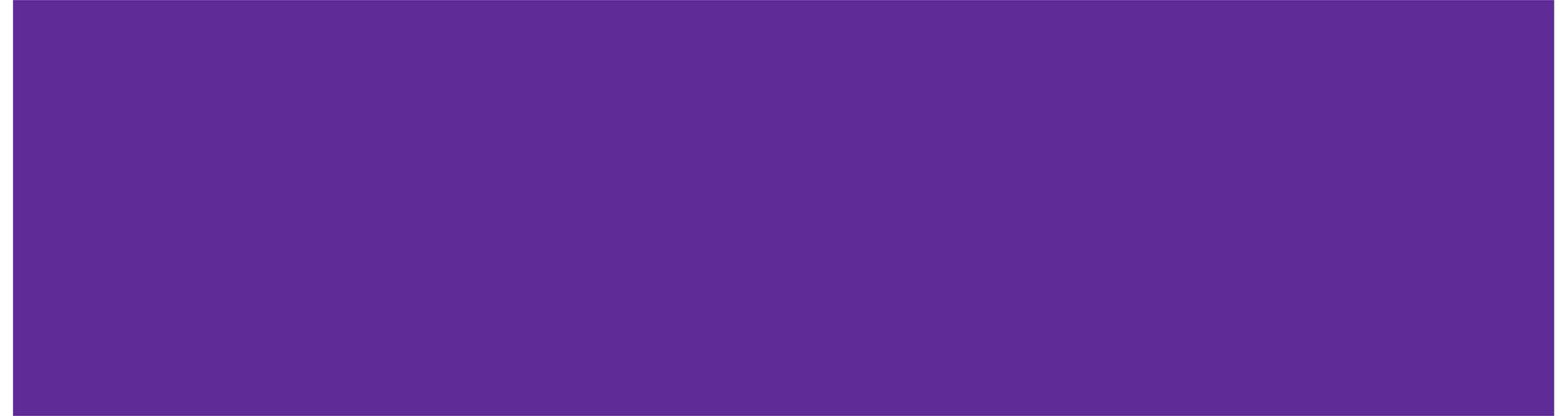
Different standard than most caregivers and people

It always comes last because we are managing others

I hate the part of me that is present right now. The angry part, that one that judges, assumes, explodes, implodes, cuts with words and hurts others. It feels scary and horrible to be on the edge, the edge of losing it, saying things that will hurt and then when I do say or do things that hurt him I hate myself even more.

Everything is just so close to the surface...I want to scream, cry, yell, throw things, hide, sleep, run away..shut out everyone and everything. My stomach is churning, my hands keep going numb and my chest feels compacted and squeezed. Trying to do deep breaths...not really working. I am so tired. Tired of feeling like this, tired of everything.

How do you think about your mental health?



“I have a friend with a daughter who is non-verbal and quadriplegic. I was expressing how exhausting it must be to be constantly providing to the physical needs of her daughter including rising in her sleep twice per night to roll her. She disagreed. She said that my role is much more difficult as it is inconsistent, and is emergency response based. The needs her daughter are the same all day every day and therefore she can book support workers and plan a schedule. Her point about predictability versus urgent response was eye opening for me.”

Caregiver

“I'm very lucky to have a partner who can take over when I'm in a bad place, to be able to walk away and calm myself down when behaviours get bad. On the other hand it's great to have people you can celebrate the good things. Even the smallest step ahead is huge for us and it's important to have people around you who can help celebrate.”

Caregiver

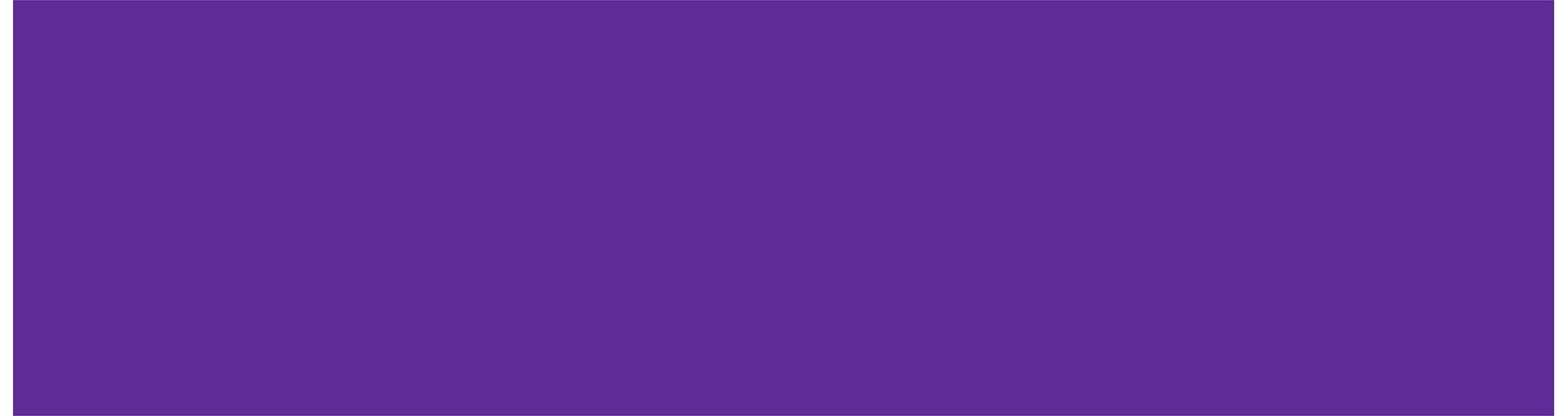
*“My first indication of being overstretched is resentment. That twinge of “Go *&#;\$ yourself” when my kids need something. Chronic resentment is physically and emotionally toxic. So when I feel that I need to find ways to pull back - which of course is more easily said than done.”*

Caregiver

“I often empathize with an analogy I saw once saying our kids can be “joy vampires”. They can suck any and all joy right out of you some days. We also can never plan something “fun” or joyous” as a family because it could go terribly wrong. Then there are the quick snapshots of the funny, creative kiddo that make our heart melt and just like that....back to vampire mode.”

Caregiver

Shame and Vulnerability



To ask for help caregivers feel...



*Shame is believing that
we are flawed and
therefore unworthy of love
or connection.*

*Shame is never known to
lead toward positive
change.*

Brene Brown

*Vulnerability is having
the courage to show up
when you can't control
the outcome.*

*To show up and be seen.
To ask for what you need.*

Brene Brown

Factors That Affect Mental Health



Mental health is influenced by

- Life experiences, such as:
 - Family situation, financial and employment status
- Relationships with others, such as your:
 - Friends, family members, co-workers
- Work or school environment
- Physical health, such as problems caused by:
 - Long-term illness, problematic substance use
- Type of community you live in
 - Is it a supportive and trusting community?

Life experiences

- Infertility
- Trauma
- Financial
- Life plan

THERAPY - ACKNOWLEDGE

“Resentment towards the systems, medical, educational etc for constantly letting our kids down. Feelings of being overwhelmed for long periods. Loneliness and sadness - it is lifelong struggles for the person affected by FASD and us as caregivers.”

Caregiver

Relationships with others

- Judgement
- Loss of friends and family
- Isolation

Vulnerability - Shame

SUPPORT GROUP! Find your peeps!!

I don't want to be alone with this. It scares me, scares me how I am thinking and feeling, what the outcome will be. But I am alone – I can't let myself be with this with anyone so it stays trapped, eating me from the inside out. Leaving me feeling like I am screaming, screaming inside for anyone to see me, for anyone to help get the feelings out.

Journal Laurie

Work and school environment

- Flexible working environment
- Forced to quit due to needs
- School - constant advocacy and education of others

Vulnerability - Shame

Be honest - Look outside the box

Physical Health

- Long terms stress cause physical illness
- Injuries
- PTSD
- Medications
- Pre - existing conditions

**Small things add up
Both positive and negative**

“One study found that our trauma levels are equivalent to soldiers in combat. And that trauma doesn’t go away, even as our kids grow up and sometimes do better. So PTSD - like cringing every time the telephone rings. Also the good times are haunted by the next potential crisis.”

Caregiver

Type of community you live in

- Constantly educating and fighting
- Agencies and schools supportive?
- Seen and not judged?

Vulnerability - Shame

Support Groups/1:1 connections - Laughter

Support and Respite



Support

Trained support workers in home and community

Case management

Respite

A period of rest or relief from a situation that is difficult or unpleasant.

A chance to breathe

Barriers

Ignorance

Bad
Experiences

Financial

Trained
Workers

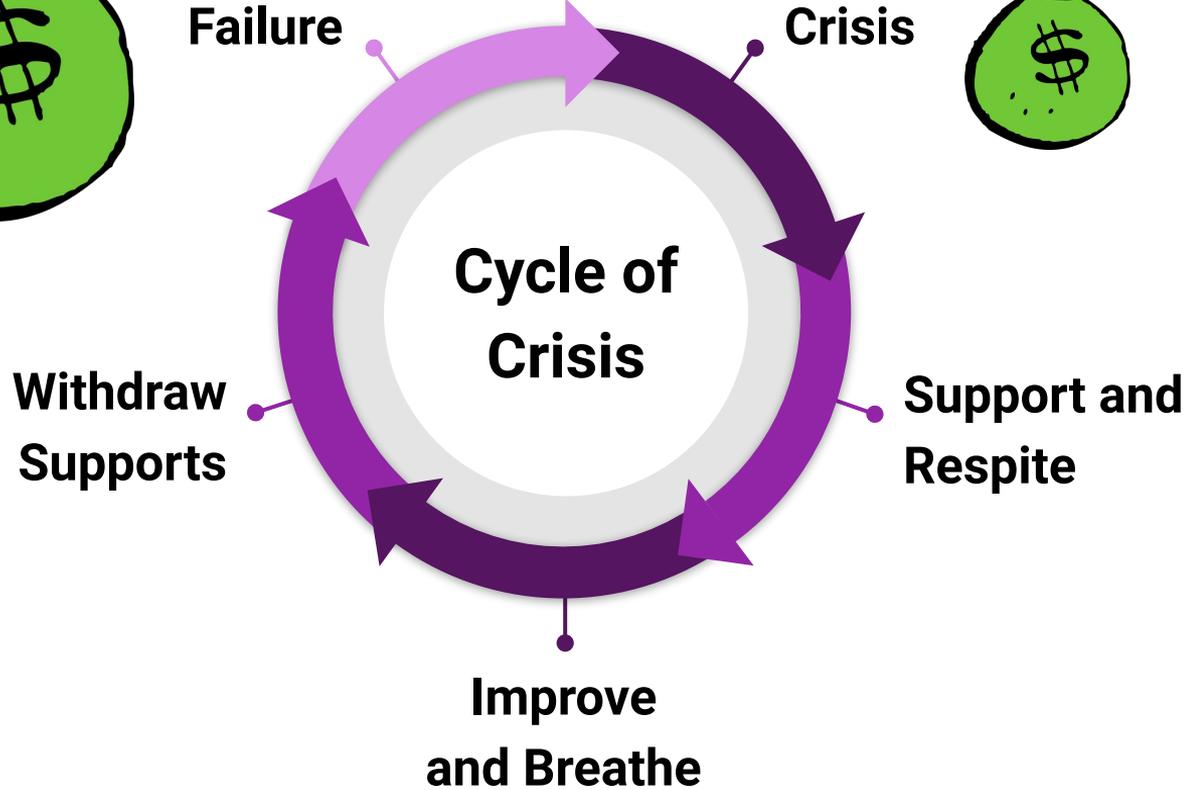
Process

Time

Benefits of Respite

- Self Care
- Primary Relationship
- Social Relationships
- 1:1 time with other children
- Continuing education and support (support groups, trainings)
- Household tasks - element of choice

Permanency



Financial Perspective

	Per Week	Per year	For 4 years
7 yr old (4 hrs - \$40/hr)	\$160	\$8 320	\$33 280
11 yr old (7 hrs - \$40/hr)	\$280	\$14 560	\$58 240
15 yr old (30 hrs - \$40/hr)	\$1200	\$62 400	\$249 600
Total (7 - 18 yrs old)			\$341 120
Child goes to group home 14 yrs old 1:1 support for wake hours (13 per day)			\$328 500/yr
Total (14-18 yrs old - 5 years)			\$1 642 500

Hardest decision

- Crisis cycle
- Early intervention - minimize the times that cycle happens
- Safety - child, other children, caregivers, community
- Sustainability
- Intentional and purposeful
- Be parents - emotionally available, advocate, joy
- Grief and loss for all

Final Thoughts on Support and Respite

- Don't wait - start respite NOW - create pattern
- Start it and keep it when you "don't need it" - attachment and loss
- Normalize the emotions that can arise from respite (guilt, shame, anxiety, etc)

SAVES MONEY!

Strategies for Mental Health



General

- Acknowledge your feelings
- Mindfulness
- Therapeutic support
- Reach out to community supports - school, community, support groups
- Pursue further learning opportunities

Strategies to use when you can...

- Get a drink of water - forces you to breathe
- Step outside for 30 sec and breathe
- Take a few extra minutes in the bathroom to wash your face
- Watch them while they sleep
- Stop following people on social media - or don't look at it
- Be vulnerable
- Ask for help - groceries, walk dog, cut grass
- Support group - online options
- Text others for support
- Don't just track the "bad behaviour"
- Find the joy - even if it is only a few minutes

She is holding on, but barely. Gripping whatever she can to keep it together for another day. She doesn't think about next week or next month, just today. That's what she tells herself. That's how she's gone this long. Just keep it together, today.

JM Storm