



HEALTH OUTCOMES OF PARENTS WITH CHRONICALLY ILL CHILDREN

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**THOMPSON
RIVERS
UNIVERSITY**

LAND ACKNOWLEDGEMENT

We want to acknowledge that we are on the traditional lands of the Tk'emlúps te Secwépemc (Kamloops campus) and the T'exelc (Williams Lake campus) within Secwepemcúl'ecw, the traditional and unceded territory of the Secwépemc.

AGENDA



01

**The What &
Why**

02

The Impact

03

**Environmental
Scan**

04

**Solutions &
Priority
Solution**

WHAT'S THE PROBLEM?

The nurse is caring for a 13-year-old child named Harry, who has been diagnosed with short gut syndrome, resulting in frequent hospital and clinic appointments. Harry was brought into the hospital for a procedure.

During the assessment, the nurse noticed Harry's parents appeared disengaged, tearful, and exhausted. When asked, Harry's parents stated, "Oh, nothing is wrong; we are here to help our child. We are fine."





UNSEEN



How We're Failing
Parent Caregivers
& Why It Matters

ANXIOUS
STRESSED
EXHAUSTED
ISOLATED
LONELY
DEPRESSED
FRUSTRATED
UNCERTAIN
WORRIED
OVERWHELMED

WHY IS THIS A PROBLEM?

Caring for a chronically ill child is associated with poorer mental health outcomes for the parents (Cohn et al., 2020).

- A 2023 study showed a 49.3% rate of severe burnout among caregivers whose children suffer with chronic disease (Shattnawi).
- Preventing parental fatigue is imperative to decreasing the probability of parental harm, child neglect and child violence (Smith et al., 2022).



Effects on Harry

- Feel less supported and find it difficult to ask parents for help
- Insufficient social support resulting in poor parent-child relationships
- Ineffective coping styles and emotional regulation methods





ENVIRONMENTAL SCAN: CANADA WIDE

CONNECTED CARE PROGRAM AT SICKKIDS IN TORONTO

Education for Families program offers classes to support family caregivers preparing to go home.

They also offer a Bridged Transitions program that offer training for families, and home care providers, a review of childcare plan, and additional education and support via virtual visits within one week of discharge (Connected Care @ Sickkids, 2022)

SLOCAN CENTRE IN VANCOUVER

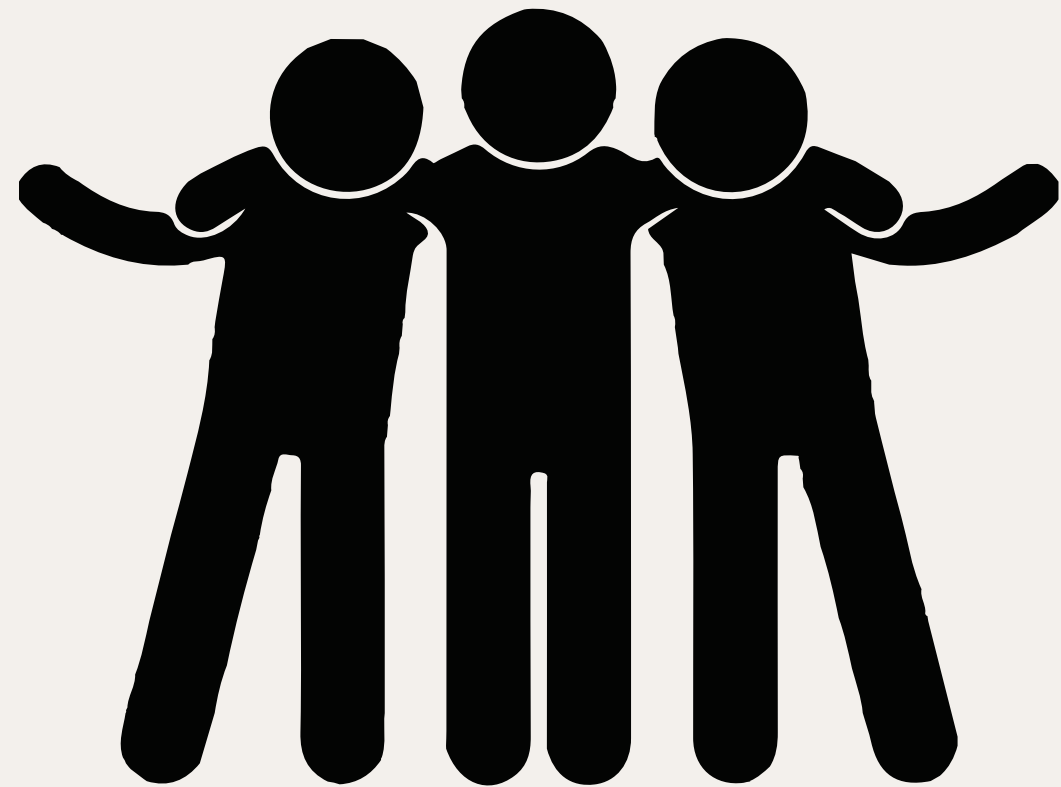
BC Children's is developing a center for children and youth living with health complexities that is set to open in 2028.

They will offer a variety of services for families with children living with health complexity. Care coordination, training and support and family and child suites are some of the proposed services (Chan, 2022).

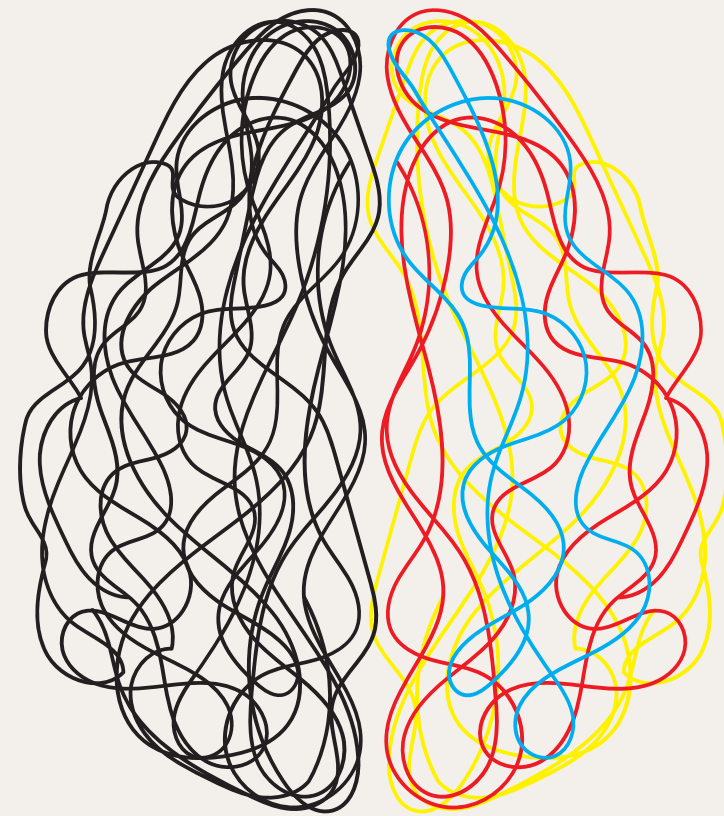
FAMILY CONNECTIONS CENTRES IN BC

Piloting four new family connections centers in Kelowna, Prince Rupert, Terrace, and Smithers. These centres will help to offer services delivered by multidisciplinary teams and a variety of services that can be accessed by children youth and their families without the involvement of the Ministry of Children and Family Development (Emmerik, 2023).

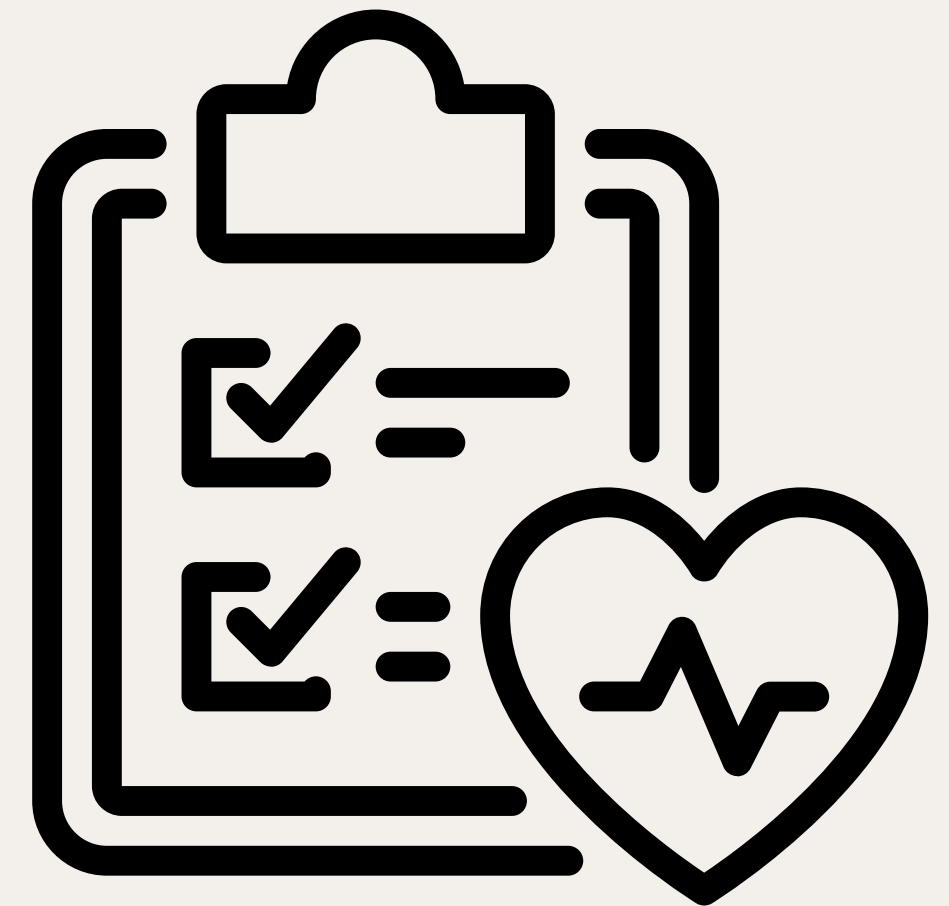
SOLUTIONS



PEER MENTORSHIP



ACT & MINDFULNESS



SCREENING



PEER MENTORSHIP



Description

Connection with peers from the same population

- Phone
- Email
- In person visits
- Video calls

Rationale

- Better understands the role of the parent
- Peers can connect parents with resources that worked for them
- A mutually beneficial system where parents are also able to give back and support someone in a similar situation

Strengths

- Available from home
- Multiple points of access
- Mentors can relate to experiences

Challenges

- Requires community participation
- Time of mentors

Is this a priority solution?



No!

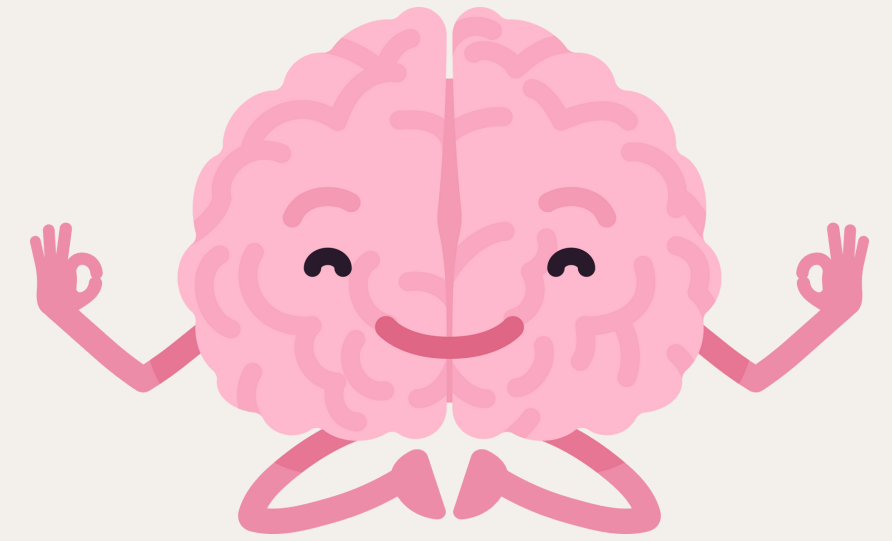


Due to the outlined challenges and our other needs for this issue we have not made peer mentorship our priority solution!





ACT & MINDFULNESS



Description

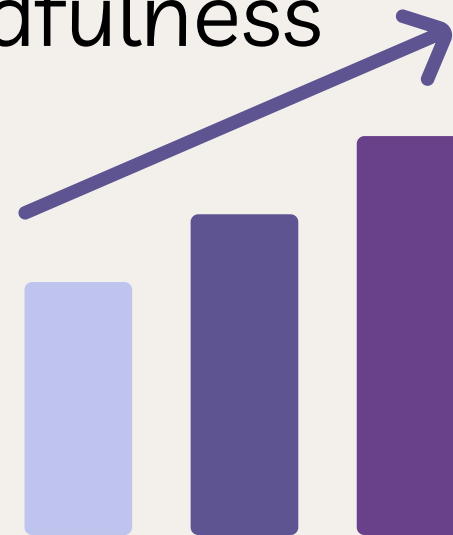
Supported web-based
Acceptance and Commitment
Therapy (ACT) intervention

1. Online website
2. Three psychologist
video conferences
3. Five module workshop

Rationale

Proven to be effective in the
improvement of:

- Physical fatigue
- Emotional exhaustion
- Depressive symptoms
- Quality of life
- Mindfulness



Strengths

- Easily transferable
- Not tied to time and
place

Challenges

- Requires access and
digital literacy
- Participation
- Loss of in person
component

Is this a priority solution?



No!



Due to the outlined challenges and our other needs for this issue we have not made ACT interventions our priority solution!



SCREENING



Description

- A tool that can be utilized by nurses to quantify parental distress and burn out.

Rationale

- Parents experiencing burnout endure both physical and mental exhaustion, exhibit physical symptoms such as reduced sleep quality, worsening somatic complaints, emotional distancing from their children, and a sense of incompetence in their parental role (Griffith, 2020).
- Parental burnout is not widely known or understood. Parents are likely to not know what the condition is or what their risk level may be. Practitioners may also not be aware. (Griffith, 2020)
- There is similarity in patterns of parental struggles and adjustments across different chronic illnesses (Thomas et al, 2023).
- Similar unmet needs were identified among various chronic illness groups, implying the potential for shared support programs or services across different chronic health conditions (Thomas et al, 2023).

Strengths

- Standardized care: parents get the same quality of care regarding assessment.
- Helps to identify interventions, and resources to connect parents to
- Easy to implement screening

Challenges

- Doesn't provide direct care
- Timely and tedious to develop a screening tool



SCREENING IS PRIORITY!

Assessment identifies current and future care needs of the client (Toney-Butler & Unison-Pace, 2022).

Quantifying the risk level of parents ensures the provision of suitable social support and the allocation of resources to families facing heightened risks (Verma et al., 2020).



Caregiver Screening Tools

1. Modified Caregiver Strain Index^{1,2} (To be completed by the caregiver)

Directions: Here is a list of things that other caregivers have found to be difficult. Please put a checkmark in the columns that apply to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	Yes, On a Regular Basis=2	Yes, Sometimes=1	No=0
My sleep is disturbed (For example: the person I care for is in and out of bed or wanders around at night)			
Caregiving is inconvenient (For example: helping takes so much time, or it is a long drive over to help)			
Caregiving is a physical strain (For example: lifting in or out of a chair; effort or concentration is required)			
Caregiving is confining (For example: helping restricts free time or I cannot go visiting)			
There have been family adjustments (For example: helping has disrupted my routine; there is no privacy)			
There have been changes in personal plans (For example: I had to turn down a job; I could not go on vacation)			
There have been other demands on my time (For example: Other family members need me)			
There have been emotional adjustments (For example: Severe arguments about caregiving)			
Some behaviour is upsetting (For example: incontinence; the person cared for has trouble remembering things, or the person I care for accuses people of taking things.)			
It is upsetting to find the person I care for has changed so much from his/her former self. (For example: he/she is a different person than he/she used to be)			
There have been work adjustments (For example: I have to take time off for caregiving duties)			
Caregiving is a financial strain			
I feel completely overwhelmed (For example: I worry about the person I care for; I have concerns about how I will manage)			

Sum responses for "Yes, on a regular basis" (2 points each) and "Yes, sometimes" (1 point each)
Total Score =

¹ Thornton, M. & Travis, S.S. (2003). Analysis of the reliability of the Modified Caregiver Strain Index. *The Journal of Gerontology, Series B, Psychological Sciences and Social Sciences*, 58(2), S129.
² The Hartford Institute for Geriatric Nursing (2007). Try This: Best Practices in Nursing Care in Older Adults: The Modified Caregiver Strain Index. Issue #14, available online at: <http://www.hartfordign.org/publications/trythis/issue14.pdf> Please note this adaptation is for clinical practice purposes only.



Interior Health

2. Caregiver Risk Factors Screen (to be completed by (referring) Health Provider)

Directions: Please consider each caregiver risk factor that may be present.

- Self-identifies as stressed
- Exhibits signs of stress/strain
- Long-term care-giving role³
- Loss or decline in social supports (isolated)
- Behavioural responses of care recipient present
- Emotional lability of care recipient present
- Increasing functional dependence of care recipient on caregiver
- Historically poor relationship between caregiver and care recipient
- Poor self-efficacy ("I can do") beliefs as caregiver
- Lack of knowledge⁴ (Example: knowledge of caregiving role, self-care, dementia, etc.)
- Health issues for caregiver (Example: frailty or poor physical or mental health)
- Other: (Describe: _____)

Total # of known caregiver risk factors: _____

Provider Notes Relevant to Referral:

Summary:	Modified Caregiver Strain Index Score _____		
	Risk Factor Score _____		
Decision-making Criterion:		<u>Yes</u>	<u>No</u>
or	1. Modified Caregiver Strain Index > 12 and Risk Factor Score >4	<input type="checkbox"/>	<input type="checkbox"/>
or	2. Modified Caregiver Strain Index > 16, regardless of Risk Factor Score	<input type="checkbox"/>	<input type="checkbox"/>
or	3. Risk Factor Score > 8, regardless of Modified Caregiver Strain Index	<input type="checkbox"/>	<input type="checkbox"/>
Outcomes:	Admit to Program (specify: _____)		
Notes:	Follow-up/Referral(s) to: _____		

³ In a significant care-giving role for greater than one year

⁴ Evidence that caregiver has not sought knowledge of dementia, caregiving, or self-care information or that caregiver demonstrates or identifies a deficit of knowledge about the caregiving that is required.

**THANK YOU
SO MUCH!**

Raise your hand if you
have any questions for us

REFERENCES

- Chan, K. (2022, March 9). BC Children’s Hospital planning first-of-its-kind care facility in East Vancouver. Urbanized. <https://dailyhive.com/vancouver/3580-3644-slocan-street-vancouver-bc-childrens-hospital>
- Cohn, L. N., Pechlivanoglou, P., Lee, Y., Mahant, S., Orkin, J., Marson, A., & Cohen, E. (2020). Health outcomes of parents of children with chronic illness: A systematic review and meta-analysis. *The Journal of Pediatrics*, 218. <https://doi.org/10.1016/j.jpeds.2019.10.068>
- Connected care @ sickkids. Connected
- kolajczak, M., Brianda, M. E., Avalosse, H., & Roskam, I. (2018). Consequences of parental burnout: Its specific effect on child neglect and violence. *Child Abuse & Neglect*, 80, 134–145. <https://doi.org/10.1016/j.chiabu.2018.03.025>
- Shattnawi, K. K., Al Ali, N., Almanasreh, A. A., & Al-Motlaq, M. A. (2023). Caregiver burden among parents of children with chronic diseases: A cross-sectional study. *Journal of Clinical Nursing*, 32(17–18), 6485–6493. <https://doi.org/10.1111/jocn.16672>
- Smith, S., Tallon, M., Clark, C., Jones, L., & Mörelius, E. (2022). “You never exhale fully because you’re not sure what’s next”: Parents’ experiences of stress caring for children with chronic conditions. *Frontiers in Pediatrics*, 10. <https://doi.org/10.3389/fped.2022.902655>
- Thomas, S., Byrne, L. K., Ryan, N. P., Hendrieckx, C., & White, V. (2023). Unmet supportive care needs in families of children with chronic health conditions: An Australian cross-sectional study. *World Journal of Pediatrics*, 19(12), 1181-1191. <https://doi.org/10.1007/s12519-023-00730-w>
- Toney-Butler, T. J., & Unison-Pace, W. J. (2022). Nursing admission assessment and examination. In StatPearls. StatPearls Publishing. <https://www.ncbi.nlm.nih.gov/books/NBK493211/>
- Verma, R., Mehdian, Y., Sheth, N., Netten, K., Vinette, J., Edwards, A., Polyviou, J., Orkin, J., & Amin, R. (2020). Screening for caregiver psychosocial risk in children with medical complexity: A cross-sectional study. *BMJ Paediatrics Open*, 4(1), e000671. <https://doi.org/10.1136/bmjpo-2020-000671>
- Wang, W., Chen, S., Wang, S., Shan, G., & Li, Y. (2023). Parental Burnout and adolescents’ development: Family Environment, academic performance, and social adaptation. *International Journal of Environmental Research and Public Health*, 20(4), 2774. <https://doi.org/10.3390/ijerph20042774>
- Yamaguchi, S., Costello, C., Lalonde, C., McCarry, S., Majnemer, A., Shikako, K. (2023). Supporting families and caregivers of children with disabilities through a parent peer mentor (PPM): Experiences from a patient-oriented research network. *Research Involvement and Engagement*, 9(1), 1-11. <https://doi.org/10.1186/s40900-023-00481-y>