CAREGIVER BURNOUT: TANGIBLE & REALISTIC STEPS TOWARDS IMPROVING FAMILY QUALITY OF LIFE

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Noonan Syndrome Foundation Conference

7/30/2026

INTRODUCTION TO DR. ELLISON

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SESSION GOALS

01 NORMALIZE BURNOUT AMONG PARENTS CAREGIVING FOR KIDDOS WITH EXTRA NEEDS

02 REVIEW RESEARCH ON CAREGIVER BURNOUT

03 DISCUSS SPECIFIC TIPS, TOOLS, AND STRATEGIES FOR MINIMIZING BURNOUT

LITERATURE ON CAREGIVER BURNOUT

- Across studies, caregiver burnout is best understood as occurring across five interconnected domains:
  - **Emotional:** chronic stress, grief, uncertainty, hypervigilance, anxiety
  - **Physical:** fatigue, sleep loss, pain, impact on personal health
  - **Financial:** lost wages, healthcare costs, insurance challenges, increased caregiver support costs, cost of specialized products/clothes, etc.
  - **Social:** isolation, disrupted relationships, reduced leisure
  - **Systemic:** fragmented care, bureaucracy, care coordination, difficulty accessing services

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EMOTIONAL ASPECTS OF CAREGIVER BURNOUT: NOONAN SYNDROME

- Stress of unknowns (e.g., waiting for periods of elevated risk to pass)
- Unknown of medical or academic/cognitive functioning for kiddo in the future
- Exhausting having to stay on top of so many different medical specialties in addition to behavioral and/or academic concerns
- Vigilance staying on top of safety concerns:
  - Continuous concern about preventing medical crises, medication errors, equipment failures, or providers/sitters/other caregivers unfamiliar with kiddo's condition
  - Emotional toll of managing self-harm type behaviors during periods of emotional dysregulation

Image generated with GhatGPT

EMOTIONAL ASPECTS OF CAREGIVER BURNOUT, CONT.

- Possibly experiencing stages of grief at initial diagnosis of with subsequent medical diagnoses/changes – and navigating caregivers' timing of different stages

PHYSICAL ASPECTS OF CAREGIVER BURNOUT

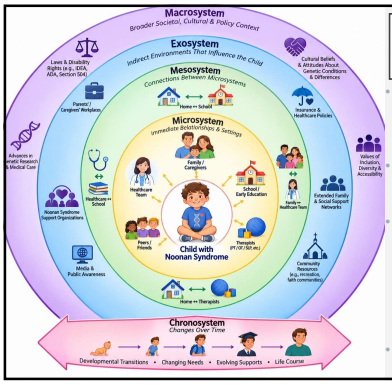
Image sourced from: https://www.akc.org/expert-advice/health/how-much-do-puppies-sleep/

- Accumulated dysregulated/disrupted sleep
  - chronic sleep deprivation, which can worsens mood, cognition, and physical health
- Fatigue associated both with disrupted sleep, as well as general stress
- Potentially reduced time/opportunities for self-care (e.g., meal prep; slowing being able to sit and eat; consistent physical activity)

FINANCIAL ASPECTS OF CAREGIVER BURNOUT

- Additional costs for childcare (e.g., injection coverage + babysitter; caregivers/sitters with increased qualifications)
- Impact of interventions/appointments/caregiving responsibilities on ability to work (at full capacity, or at all)
- Cost of interventions not covered by insurance, or when maxing out benefits for the year
- Financial cost of specialized products/clothes, etc. (e.g., $15 unfavored toothpaste; specialized interests; accommodating sensory needs, etc.)

Image generated with GhatGPT



SOCIAL ASPECTS OF CAREGIVER BURNOUT

- Impact to siblings
  - Increased stress, increased feelings of responsibility, their own emotional reactions
  - Reduced attention from parents/caregivers
- Friends "that understand"
  - Balancing optimism and positive outlook with not minimizing your experience
- Caregiver reduced availability for social plans
  - Coordinating around endocrine injection timing
  - Childcare coverage
  - Not wanting to stay out late because exhausted, or expectations of disrupted sleep
  - Scheduling around kiddo appointments
- Marital strain

Image generated with GhatGPT

WHERE WE CAN INTERVENE FOR REDUCED IMPACT OF CAREGIVER BURDEN

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REDUCING SOCIAL ISOLATION AND INCREASING SOCIAL SUPPORT

- Intentionality in calendar planning (e.g., trying to organize a monthly dinner, or bi-monthly calendar reminders to organize XYZ).
- Sometimes partner may be in different place/space in processing everything is going on- reflect if you need additional supports?
- Consider using Noonan Syndrome groups to facilitate/organize meet-ups
- Using tools like FB groups (e.g., even neighborhood parent groups) to see if you can organize a quarterly dinner for parents with kiddos with extra needs
- Kiddos' pediatric or hospital system may have opportunities for parent groups, or formal therapeutic parent support groups
- Coming to conferences like this!

Image obtained from: https://www.verywellmind.com/social-support-for-psychological-health-4119970

WORKING WITH YOUR INTERNAL SELF-TALK: DIALECTICS AND **SELF-COMPASSION**

- Working with a kiddo with extra needs, especially if there are behavioral/ sensory/ neuropsychiatric needs, can be exhausting- and you are not a robot!
  - Sometimes we are not fully present.
  - Sometimes we may not give 100%.
  - Sometimes we may lose our temper, or not be our best self.
- **Practicing dialectic thoughts-** holding space for two contradictory/opposing thoughts

*"I'm **doing the best that I can in this moment***

AND

maybe I could have handled that better"

CALENDAR PLANNING FOR ROUTINE, SCHEDULED TIME AWAY

- Working with partner/family in weekly or monthly calendar planning to schedule in protected time for you (bonus points if you can care out some activities you enjoy or that recharge you)
- Avoid the 'all or nothing' trap
  - E.g.: Can you get a walk around the block by yourself?
  - 20 minutes away vs. an afternoon or full day?
  - Can someone else help do bedtime and you just get ready for bed early and start an audiobook or show but you're still at home? *(my favorite)*
- Intentionally planning and scheduling (or pre-discussing intentionally) can also help to reduce the guilt of not helping the other parent/caregiver

COMMUNICATION AROUND TASK BURDEN WITH JOINT CAREGIVER

- **Self reflection**, and then **communication** with joint caregiver:
  - Are there *certain tasks* that drain you more or stress you out more?
  - *Certain times of day* where caregiving is more burdensome for you?
- Can you **reallocate tasks** (even if not all the time, part of the time) *to reduce tasks that are more emotionally draining*?
  - E.g., If we're both home, husband does bedtime with my kiddo with Noonan Syndrome most nights, I do at least 2 nights per week
  - E.g., I handle early morning with both kiddos, but husband almost exclusively does brushing of teeth *(I don't know why but I absolutely hate doing this)*
- Having **choice** and **autonomy** of tasks can help, at times, to reduce the emotional burden of overall task/responsibility load

IMPROVING COMMUNICATION BETWEEN CAREGIVERS

- Chosen word between adults for being able to communicating discretely that need to "tap out and need support to step in"
- Explicit communication of needs in stressful conversations
  - Do you want to just **vent**? Do you want **advice**? Do you want **validation**?
  - Do you NOT want your concerns to be minimized?
- Self-reflection- do you know which fits for you? Which fits for your partner?
  - Are you someone who needs the repetition of content in a discussion for closure?
  - Frustration when mismatch between communication needs (e.g., someone for who it's cathartic to re-communicate or discuss vs. someone who that is frustrating to hear it again)

RECOGNIZING UNSEEN EFFORT

- For some, there may be the experience of an unseen lift or invisible labor, especially if it ends up not being equitably distributed among caregivers
  - E.g., one person managing more of the medical appointment, or more of the communication with providers
  - Or one person who is stepping in more to assist with childcare, or whose work day is more interrupted
- It may not be realistic or practical to make the mental and time burden equitable- but what are ways that the person doing this aspect of heavy lifting can be 'seen'?
  - If you are that person with unseen effort/labor- self-reflection on your own needs and communicate with your partner
    - Do you want time/space to be able to vent or go through in your day all those little things that you did or managed?
    - Do you want verbal validation (e.g., thank you for… XYZ)?

SUMMARY & TAKE HOME MESSAGE

- It is normal to experience periods of increased caregiver burnout
- Caregiver burnout is serious and can have significant impact on yourself and your family system
- There are steps that you can take individually as well as within your family system to help reduce the impact of caregiver burnout
- Being connected with larger communities such as this and coming to events like the Family Conference can help to reduce overall caregiver burnout – we're glad you're here!

NOONAN SYNDROME FOUNDATION

THANK YOU!

Any questions?

Feel free to approach me during the rest of the conference, or email me at rachael.ellison@rosalindfranklin.edu