Self-Care for Caregivers of Individuals with CdLS

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Caring for those who care for the rest of the world ~



~As the pillars of the family, your needs must also be at the forefront.



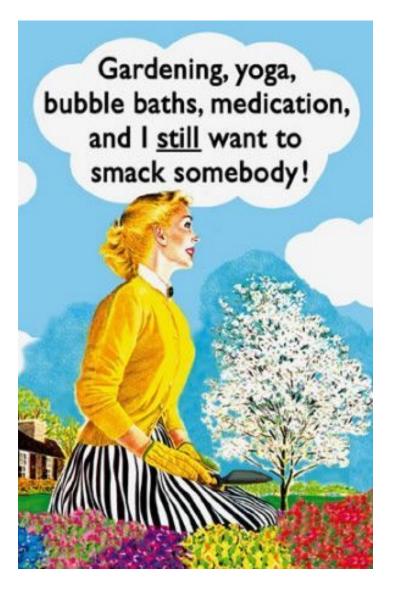


Taking Care of the Basics

- Listen to your body
- Increase movement
- Address sleep disturbances
- Coping skills-can you list at least 10?
- * Are you making and keeping your own doctor appointments?
- Have something to look forward to each day
- Self soothing activities
- Exit strategies
- Don't lose yourself











Confront Emotions

- Grief
- Anger
- * Guilt
- * Sadness
- Fear (of the present and future)
- Resentment
- Envy



- * Evaluate your thought processes
 - * Thoughts often dictate our emotions





Ask for Help...Just Do it!

"It takes the strength and courage of a warrior to ask for help."

- Reframe your beliefs about asking for help
- Make the decision to begin asking for help
- ❖ Determine what feels comfortable and doable
- Go to those safe and dependable
- * Reevaluate your emotions and comfort level after asking for help
- * Take it to the next step





Protect Your Time

- Get creative
- Don't replace newly created time with new activities
- ❖ Learn to say <u>no</u>
 - * "If you never say no, how much is your yes worth?"
- Create more time for just you
- Selfishness vs. Self-preservation





Create a Village

- * Take a critical look at your current support system
- * Find a meaningful group of friends that can support you where you are at now
- * Connect with other parents raising children with special needs
- Emotional safety
- * Judgment free
- Stay connected







Boundaries

"A lack of boundaries invites a lack of respect."





Steps to Setting Boundaries

- 1. Clearly identify your boundary
- 2. Understand the need for the boundary
- 3. Be straightforward
- 4. Do no apologize or provide lengthy explanations
- 5. Communicate in a calm and polite way
- 6. Start with tighter boundaries and loosen as needed
- 7. Address violations of boundaries early
- 8. Do not make it personal
- 9. Utilize your support system
- 10. Trust your intuition







- Remaining a Team- How are you doing it?
- Protecting your marriage
- Nurturing your marriage
- Being intentional
- * Making Decisions- are they helpful to your marriage?
- Do you have each other's back?







CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

- * How do you feel after being around certain people?
- Have your phrases prepared
- Use limited self disclosure at times
- * Be aware of the intentions of others

Make sure
EVERYBODY
in your boat is
rowing, and not
drilling holes
when you're
not looking.
KNOW YOUR
CIRCLE.





Handling Unsupportive People

What do you do when people are unsupportive?

- Educate and raise awareness
- Provide helpful and scholarly information
- Maintain your boundaries
- Know when to ignore
- Know when to stop
- Know when to let go





Remove What is Toxic







Modify Expectations

* Reevaluate your expectations and know how to modify accordingly







Respite Care

- * Know your available resources
- * Address guilt
- Identify smaller forms of respite
- * Utilize it...it is there for a reason







Seek Professional Help

- Therapy
 - Individual
 - Marital
 - Family

Medication

Support groups

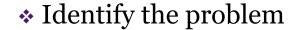






Develop Solutions





List possible solutions

Select one solution from your list and try it

Evaluate the results

* Use other resources

* If nothing seems to help, the problem may not be solvable right now. Revisit it at another time.

* Be patient. Do not give up too quickly.



Invite Joy Into Your Life

- Practice daily gratitude
- Self-compassion
- Celebrate the little things
- Build in room for error- you won't always get it right!
- Self-forgiveness
- Trust yourself







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