

PROTECTING YOUR HEALTH, IDENTITY AND SANITY AS THE PARENT OF A CHILD WITH SPECIAL NEEDS

THE MOTHER SHIP, INC.

THE-MOTHER-SHIP.ORG



WHAT WE'LL COVER

1. Introductions & Ground Rules
2. Caregiver Wellness - Why It Matters
3. Planning For Your Needs Generally
4. Caregiving in Crisis
5. Discussion & "Life Hack" Sharing



The **MOTHER SHIP** *Inc.*

ABOUT US

The Mother Ship is a 501(c)(3) nonprofit organization and our mission is to provide social, educational, emotional, physical and mental health, and community supports to caregivers of special needs children in the Central Ohio area. We aim to change society's understanding around caregiver self-care, wellness, self-empowerment, and self-advocacy.

Offerings include caregiver health and wellness education, events, and funding to help parents achieve the personal care and life goals they may have put on hold while caring for their children's needs. We are here for everything from spa days, to group grief recovery sessions, to parent scholarships.



WHO'S TALKING TODAY?

I'm the founder of The Mother Ship and serve on its board to this day. I am an attorney, an author, and a soon-to-be student (yikes!), but my real fulltime job is being a spouse and a parent to my three boys, the oldest of which is significantly impacted by autism, and the rest of which are significantly impacted by the impact.

ELIZABETH "EMY" TRENDE



WHO'S TALKING TODAY?

Kathryn is the board president of The Mother Ship and has served on the board since 2018. She lives in Central Ohio with her husband and their three children, one who is impacted by Autism, another with severe Dyslexia and Anorexia, and one neurotypical. In addition to being a full-time caregiver, she is a two-time cancer survivor and works full-time in nonprofit communications.

KATHRYN CLAUSEN





A FEW GROUND RULES

- The Mother Ship is a parent -to -parent organization. Nothing you hear today constitutes medical or legal advice. We are just sharing what has worked for us and the parents we serve.
- This is a SAFE SPACE, where all feelings are inherently valid. We want those who attend to be able to share stresses and challenges of caregiving and autism freely and without retaliation. If attacks occur, the chat will be closed.

LET'S GET STARTED!

CAREGIVER WELLNESS - WHY IT MATTERS

FIRST, LET'S ASK THE
AUDIENCE



POLL:
HOW HAS
YOUR CHILD'S
NEEDS
IMPACTED
YOUR
PERSONAL
LIFE?

(CHECK ALL
IMPACTED
AREAS)

- 1 physical health
- 2 mental health
- 3 sense of personal identity
- 4 romantic relationships
- 5 career goals
- 6 life goals
- 7 friendships
- 8 finances

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IF YOU ARE THE PARENT OF A CHILD WITH DEVELOPMENTAL DISABILITY, YOU HAVE BEEN A FRONT-LINE HEALTH CARE WORKER, ON-SHIFT EVERY DAY, 24/7, WITHOUT PAY SINCE THAT CHILD WAS BORN. TAKE A MOMENT TO TAKE THAT IN AND APPRECIATE YOUR WORTH.

EMY TRENDE, FOUNDER,
THE MOTHER SHIP, INC.

POLL: IF YOU
THINK YOUR
HEALTH HAS
DECLINED
DURING THE
TIME YOU HAVE
BEEN A
CAREGIVER,
WHAT IS THE
PRIMARY
REASON?

(CHECK ALL
THAT APPLY)

- 1 overall stress increase
- 2 chronic illness (cancer, diabetes, etc)
- 3 no assistance to help with my child while I receive care
- 4 too expensive/lack of insurance
- 5 my work schedule
- 6 I feel guilty about seeking care for myself
- 7 no good reason, just have not made myself a priority
- 8 other



AT THE MOTHER SHIP, WE'VE OBSERVED AN ADDITIONAL REASON THAT MAY SURPRISE YOU...

- Everyone agrees that more public and community resources are needed to assist caregivers. That reality needs to change, and will take time to change.
- BUT...often, caregivers are too overwhelmed to identify and specify, and to receive, the type of help they really need.
- When open -ended assistance is offered, they demur, delay, "let me think about it" or default to "NEVERMIND, I'M FINE."



OR, WHEN PRESSED, THEY DEFAULT TO REQUESTING AN "ESCAPE" SOLUTION IN LIEU OF FUNDING THE HARDER WORK.

- What we have offered:
 - Funding to support caregiver therapy, recovery programs, gym memberships, education, career tools.
- What people default to requesting FAR more often: massage, social activities, weekend away, vacation.
- This often goes by the more socially acceptable term - "respite" - but let's call it what it is: getting out rather than getting through.

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DO WE PARENTS HEAR OURSELVES ON THAT? WE EXPOSE OUR KIDS TO HOURS OF EXHAUSTIVE THERAPIES BECAUSE THEY NEED TO LEARN TO ADAPT AND COPE AND SUCCEED. BUT WHEN ASKED TO DO THE SAME FOR OURSELVES, WE RUN.

WHEN
SOMEONE
OFFERS TO
HELP YOU, IF
YOU USUALLY
DECLINE THE
HELP (“I’M
FINE”), WHY?

- I honestly don’t need any help
- I know they probably won’t be able to handle what I need
- I don’t want to be a burden to others
- I don’t like the idea of charity/“handouts”
- I feel guilty/others probably need the help more
- Other

WHY THE "I'M FINE" HABIT HAS TO CHANGE

Trigger warning -- we're about to get tough here!

- 1 • AS A PARENT, WE ARE ALL RESPONSIBLE FOR MODELING BEHAVIOR FOR OUR KIDS.
Many of our children will have to request and receive help from other all their lives. How does it look to them when mom and dad continually reject help? Will they think - is being helped something to be ashamed of? Do "the strong" always say no to help?
- 2 • THE HARD TRUTH IS YOU CANNOT DO THIS ALONE. "TYPICAL" PARENTS DO NOT DO THIS ALONE.
Part of learning independence and learning to feel secure in this world is learning to build trust relationships with people other than you parents. Keeping your family members insulated from the outreach of others deprives them of a life skill.

- IDENTIFYING THE HELP YOU REALLY NEED IS HARD.
- SEARCHING FOR IT IS HARD.
- SAYING "YES" WHEN IT IS OFFERED IS HARD.
- TRAINING THE HELP OFFEROR IS HARD.



...BUT YOU'VE BEEN DOING IT FOR YOUR KID FOR YEARS. NOW IT'S YOUR TURN.

MYEP (MY EMOTIONAL STATE IMPROVEMENT PLAN)



WHAT IS MY
GOAL?

Be specific and concrete.

WHY AM I NOT
THERE NOW?

Do not say "my kid has autism." Your child is not responsible for your feelings, reactions and decisions.

WHAT NEEDS TO
CHANGE IN ORDER
TO GET ME
THERE?

WHAT DO I NEED
AND WHO CAN
GIVE IT TO ME?

EXAMPLE: DON'T SAY "NO" JUST BECAUSE THE HELP CAN'T MEET YOUR EXACT NEED.



PROBLEM: LORI NEEDS HOUSEKEEPING HELP.

Her blood pressure (already high) rises every time she opens the door to see clothes and toys everywhere, every day.



WHAT IS HER IDEAL HELP?

A live-in maid.
Or, someone to take her child out of the house for a couple of hours so that she can get ahead on cleaning.



CHALLENGES

Lori is afraid to leave her child with anyone because of behaviors. It just wouldn't work out. Past sitters have been a disaster.

EXAMPLE: DON'T SAY "NO" JUST BECAUSE THE HELP CAN'T MEET YOUR EXACT NEED.



OFFERS OF HELP

Neighbors have offered generically to help here and there, but again, Lori can't leave these people with her child. A teen down the street babysits for extra cash, but has no ASD experience.



CAN WE WORK WITH THIS?

She is uncomfortable leaving her son with a neighbor, but Lori agrees to let the neighbor come in while Lori is still present, as a "mother's helper."



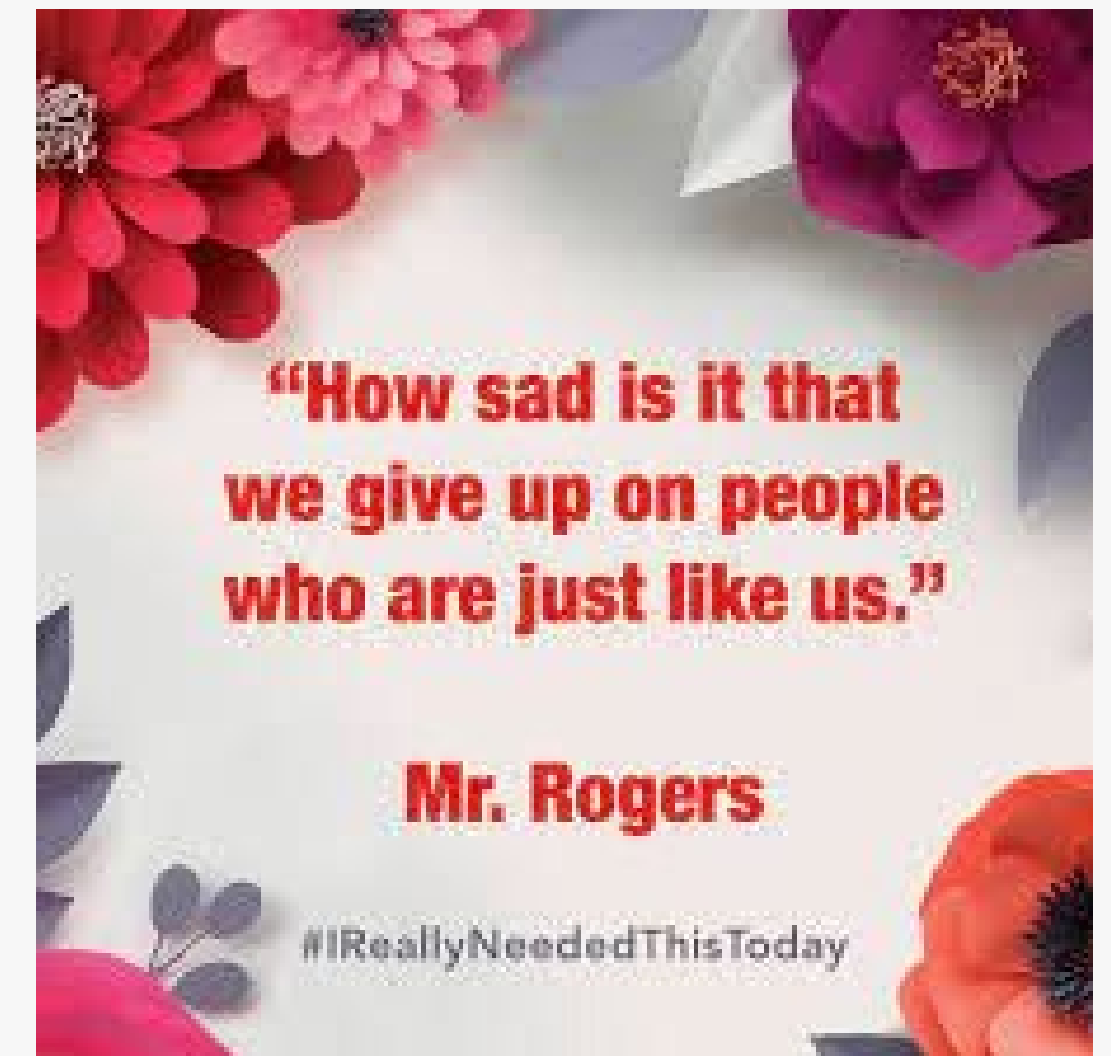
For two hours a week, the neighbor watches TV with Lori's son, while Lori folds laundry (and watches a Hallmark movie) in the bedroom upstairs. If there's a meltdown, she's literally feet away, and she still gets tasks down and a moment (relatiely) to herself.

TAKEAWAY: WE ALWAYS ASK TEACHERS AND OTHERS TO MEET OUR CHILD WHERE THEY ARE. WE NEED TO EXTEND THE SAME GRACE TO OFFERORS OF ASSISTANCE. DON'T ASSUME THEY CAN OFFER NOTHING JUST BECAUSE THEY CANNOT OFFER EVERYTHING. WORK TOGETHER TO GET THE NEED MET.

*THIS ALSO GOES BACK TO IDENTIFYING THE NEED - LORI THOUGHT SHE NEEDED A LIVE-IN MAID OR A SPECIALLY TRAINED AIDE, REALLY, SHE JUST NEEDED A LITTLE EXTRA TIME AND SPACE, AND THERE WAS MORE THAN ONE WAY TO MEET THAT NEED.

TAKEAWAY:
RESIST THE URGE TO REJECT THE ENTRY
OF A POTENTIAL RESOURCE INTO YOUR
LIFE BECAUSE THEY SAID/DID THE
WRONG THING ONCE.

WE CONTINUALLY ASK PEOPLE
TO GIVE OUR CHILD GRACE WHILE
THEY LEARN. WE CAN GIVE IT, TOO.



OTHER WAYS TO CREATE TIME AND SPACE FOR CARE

DON'T GET TRAPPED BY "NO SITTER = NO HELP"

Instead of saying "I can't leave the house because I don't have a trained aide", say "I can be in the house, upstairs, and a mother's helper can assist downstairs."

IF YOU HAVE A PARTNER (OR TRUSTED FRIEND), SWAP A "VACATION DAY" EACH MONTH

One person watches the kids all day one Saturday, the next weekend, switch.

MAKE YOUR PERSONAL PCP A PARTNER

If your personal physician does not know about your challenges with your child, and if they are not prepared to write you an excuse note for work if you have not slept for several nights, or if you are having a mental health crisis and need the day to yourself, get a new PCP.

If you are a PCP and you are not making caregiver health a topic of discussion, whether your patient is the parent or the child, please change your approach. Autism is a whole family diagnosis.

THINK "ALTERNATIVELY" IN TERMS OF THERAPIES

IT'S NOT ALL DEPRESSION AND ANXIETY

- Many of the parents we serve report success with therapies designed for PTSD and other trauma-informed approaches.
- Many caregivers - especially those who observe autistic tendencies in themselves - do not like the idea of face-to-face "talk" therapy. There's more out there!
- Consider:
 - Art/craft therapy
 - Grief therapy
 - Group therapy
 - Telehealth services, some of which will work with you via text.

WATCH OUT FOR "SUPPORT" GROUPS (INCLUDING SOCIAL MEDIA GROUPS AND PAGES) THAT...WELL...AREN'T.

- Watch for "circles of validation." Online bullying is unfortunately common in environments where participants have experienced trauma, and are protective and defensive about the choices they have made regarding their child's care.
- There is some value to "venting", but if you leave the group feeling more angry than when you arrived, reconsider.

OTHER WAYS TO CREATE TIME AND SPACE FOR CARE

MAKE SCHOOL A PARTNER

It's okay to tell your child's teachers and therapists how what they do impacts your well-being. If you do not want a laundry list of negatives at the beginning of every IEP meeting, say so. If you want them to identify one positive item every day on your child's data sheet, you can and should ask for that.

IF YOU HAVE TO BE PHYSICALLY WITH OR NEAR YOUR CHILD AT ALL TIMES

They probably have a tablet, you might want to get one too. Load it up with favorite tv shows, games, or other items for you. Get some earbuds. You can sit with them and still have a separate activity.

Take a ride. Many people with autism enjoy the motion of rides in the car. While they are safely seat-belted in the back, turn on some favorite music or an audiobook for you in the front (don't drive distracted), pick up a favorite treat at a drive-through.

HOW PROVIDERS CAN HELP

BE CREATIVE WITH THE WAITING ROOM

If you are a therapy provider for individuals with special needs, consider making a treadmill available in the waiting area, or a tablet with self-help and training resources for parents, while they wait. If anyone in your practice can provide services to adults, see if you can offer co-scheduling with the child's appointment. But be cognizant of legal restrictions on offerings to Medicaid beneficiaries.

PROVIDE YOUR PATIENT'S CAREGIVER WITH A LIST OF ACCESSIBLE LOCAL RESOURCES FOR THEIR OWN NEEDS

Pro-bono mental health resources may be available or referred through NAMI, Mental Health America, or your county's local mental health services board.

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CAREGIVING IN CRISIS

With Kathryn Clausen



POLL

Have you ever overlooked your need for therapy, surgery, or general self-care because you are a caregiver?

- Yes
- No
- Maybe





STORY TIME

WHAT IS A CRISIS?

MEDICAL EMERGENCY

Whether the medical emergency is for yourself, your family, or your child(ren).

AN ACCIDENT

A fall, slip, car accident, fire, car repair emergency, or other unplanned event causing short- or long-term harm to your routines and care plan.

MENTAL HEALTH CRISIS

Again, yourself, your family, or your child(ren). Mental health matters.

RELATIONSHIP STRAINS

Stress can bleed into relationships. Partners, spouses, friends, and family all feel the impacts and want to help. Prioritize self-care to help reduce the bleed effect.

CONTINUALLY FEELING OVERWHELMED

Continual stress has harmful medical impacts. Self-care activities can help to reduce your overwhelming thoughts and feelings before they become a crisis.

WHAT CAN I DO TO HELP?

1 • SHARE TIPS FROM REAL-LIFE EXPERIENCES TO HELP YOU PLAN AHEAD

I will share some of the things I've learned along the way to add to your tool belt, help you plan ahead, and allow yourself some grace.

2 • FOLLOW YOUR GUT AND YOUR OWN ADVICE

You know that you need care and I bet you would all tell your best friend to prioritize themselves, too. Listen to yourself and follow your own advice.

A VILLAGE IN A HURRY

How to be prepared when your own health needs must take precedence:

- Have an emergency and safety plan in place before an emergency or safety risk occurs.
- Talk to your friends and family about how they can help. Create a list of go-to people you trust.
- Be specific.



EMERGENCY PLANNING

Have a written plan and make it available:

- Including emergency care contacts including doctors and others
- Daily routines, medications, and safety concerns
- HIPAA authorization, power of attorney, wills, and other documents
- Trusted contacts professionals can reach out to if you are unable to speak for yourself or your child(ren)



BE SPECIFIC

Seek help with:

- Meal planning
- Transportation
- Pharmacy delivery
- HELP-ME contacts!



PRIORITIZE YOU

Plan ahead for:

- Date nights
- Girl's Night Out
- Seek grant opportunities



EXAMPLE: A SINGLE CAREGIVER IN CRISIS

01

Barbara had been putting off a needed surgery because she was the only caretaker for her disabled adult daughter.

02

She felt absolutely uncomfortable with anyone else taking over care tasks while she recovered.

03

She identified her real fear as not being present for the daughter (so the daughter would not be fearful).

04

The Mother Ship was able to get her a recliner so she could recover in her living room and still serve/direct and be available.

CONTACT US

1. Visit our website
www.the-mother-ship.org
2. Connect on Facebook, Instagram,
Twitter, and LinkedIn
3. Email us at info@themothership.com



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