

Medically Complex Program



One year old.

We're One Year's Old! It's been one year of the Medically Complex Program at The Nemasket Group! Thank you so much for welcoming us into you and your family's lives. We are privileged to work with you and can't wait to see where the next year takes us!

On the back pages of this newsletter is a short survey for you. You can mail the completed survey to 109 Fairhaven Road, Mattapoisett, MA 02739. You may also email or send a photo of your completed survey to your advisor. You may also call us to ask you the survey questions at 508-999-4436. We appreciate you taking the time out of your busy day to let us know how we are doing and what needs you may have.

We have had several requests to host a support group. Would you be interested in attending a support group on Zoom? What day and time work best for you? Please contact your advisor for more information.

Is the content of our monthly newsletter valuable to you? Are there other topics you would like us to cover? Please let us know by contacting Shanell Stewart at 508-999-4436 x 161 or email ShanellStewart@nemasketgroup.org

Do you have new or gently used items you'd like to donate to another individual or family? Please contact your advisor for more information.

Medically Complex Program at The Nemasket Group

109 Fairhaven Road, Mattapoisett, MA 02739

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Analysis: As a Parent of a Medically Fragile Child, How I've Learned to Stay Calm in a Crisis

<https://www.calhealthreport.org/2021/05/12/analysis-as-a-parent-of-a-medically-fragile-child-how-ive-learned-to-stay-calm-in-a-crisis/>

I am a parent of a 10-year-old child who has complex and medically intensive disabilities. The disability community has been incredibly welcoming, and I've been fortunate to learn more about how adults with disabilities fit into the world and how I can raise my son to accept his body and how it works. My goal as a parent is to raise a child who is comfortable with himself and can live independently.

For that to happen, I have to be able to maintain his unstable airway and breathing. My son has a tracheostomy — a surgically created artificial airway that is held open by a plastic tube. He also uses a ventilator — a machine that breathes for him overnight, because his body doesn't always initiate breathing.

Parents of children with fragile, medically complex disabilities are expected to provide the same level of care that intensive care units provide, but they're expected to do it in the home environment. When a child stops breathing in the hospital, staff calls a "code blue" and experts from all over the hospital come running to help. When a child stops breathing at home, seconds count and help is minutes away. We, parents of children with breathing disabilities, are obligated to provide the same level of care that the hospital provides — but without backup. The stakes are high: If you make a mistake, your child could die. That's not a comforting thing to tell a new parent of a fragile baby.

Prior to my life as a mom and health care and disability rights advocate, I worked as a police officer. In law enforcement, I was expected to remain calm in emergencies to do my job. Exposed to extreme stress, I specifically received training on how to keep my composure and perform critical tasks in emergency situations.

One key thing I learned as a cop is that people don't rise to the occasion in an emergency, they default to their level of training. Medical professionals also know this, so they drill tasks like CPR over and over again. That way, when an emergency happens, they can shift into autopilot to complete procedures, such as intubation and pulmonary resuscitation that engage their fine motor skills.

The human body responds to extreme stress by releasing cortisol. This hormone kick starts a cascade of physical reactions that prepares the body for the fight-or-flight response. Your heart rate increases, and your body shifts its energy toward the major muscle groups and away from fine motor skills. Have you ever been so angry or frightened that you couldn't do a simple task like turning your keys in the door? That's cortisol at work. The cortisol response is useful when you're dealing with a dog who's trying to bite you. In such a situation, you need to fight or run away rather than reason with the dog. But the fight-or-flight response isn't useful when you're trying to figure out why a ventilator alarm is sounding or when you need to push a three-millimeter tube into a four-millimeter hole in your child's neck while he's blue and limp. This terrifying situation is all too common for parents of children with tracheostomies.

As a police officer, I was trained to perform breathing exercises to keep my cool during an emergency. These exercises consist of inhaling through the nose for four seconds, holding your breath for four seconds, exhaling through the mouth for four seconds, and then holding your breath again for four seconds. This works to counteract the cortisol cascade and trick the heart into slowing down. Once you bring your pulse rate down, you can control the way your body responds to the emergency and perform the complex fine-motor and cognitive tasks needed to save your child's life.

Hospitals give parents of medically fragile kids a list of things to do in an emergency. But this training doesn't actually explain how a real emergency could affect their functioning and what to do about it. Being able to remain calm, make complex decisions, and perform complex fine motor skills during an emergency isn't a trait people have from birth; it's a learned skill. Hospitals can do a better job of teaching it, and parents can do a better job of acquiring those skills outside the hospital once the need becomes apparent.

I see it over and over again in my online support groups. Parents leave the hospital thinking they know what to do in a crisis, only to freeze up when an emergency occurs. Freezing up in a critical situation is a common reaction, especially for people who aren't trained first responders and have never been confronted with a true life-or-death emergency. It's incredibly traumatic to practice a skill and then watch your hands fail at the task you expect them to do. We can set parents up for success in critical situations by giving them the tools to manage their own emotional and physical responses while they provide care for their children.

I was fortunate to have a background as a first responder. When the hospital started the training process for my son's tracheostomy care, I remember thinking that the wound was so much smaller and cleaner than a bullet hole. In a way, managing his airway seemed easy compared to the things I had done in the past. But most parents of medically fragile children don't share my first responder background.

I wanted to tell my story to help other caregivers of medically fragile children. I'm passionate about helping these families who are often overlooked by the wider community. I'm excited to be a regular columnist for the California Health Report, where I will write about the challenges families of children with medically intensive disabilities face as well as larger disability rights topics. We'd love to hear any ideas or thoughts you have — send them to info@calhealthreport.org.

Thanks for joining in this conversation. If you're a parent of a medically fragile child, I see you. If you're a broader community member, thank you for listening. I look forward to helping other families work together to make the programs we depend on run more smoothly.

Online American Sign Language (ASL) Classes



Online

January 11th – March 16th, 2022, with DEAF, Inc., of Massachusetts.

Fees apply, registration is required by January 3rd, 2022 to www.deafinonline.org/asl/classes or contact asl@deafinonline.org

The curriculum has been adapted to be taught in a Zoom presented format.

- A strict cap of 15 students per class ensures that each student still receives individual attention.
- These voice-off online classes provide a fun, relaxed, and interactive learning environment.
- Get support and feedback from their instructors, who are Deaf and native ASL users.
- DEAF, Inc. Uses the TRUE+WAY ASL Curriculum, which is a technology-driven curriculum that provides online videos and interactive activities. TWA's main objective is to promote real-world conversations related to student's daily lives with the goal of students being able to converse with Deaf people in the community.

Virtual Drums Alive® for Attleboro Area



Online

January 6th – April 28th, 2021 with the Arc of Bristol County's Family Support Center.

For families with special needs of all ages. Drums Alive® is a movement-based fitness program that allows all participants to engage at their level: from novice to expert drummer.

About Drums Alive: Drums Alive® is a research based, unique fitness/wellness program that captures the essence of movement and rhythm and combines it with fun. Ability Beats is full of powerful and motivating music and drumming rhythms that get feet stomping and bodies moving. The original whole brain and whole body program that allows individuals of all ages and all abilities to participate without ever having picked up drum sticks before Drums Alive® Ability Beats also:

- Strives to unlock limitations and empowers participants with "abilities" to achieve a healthy, happy lifestyle
- Fosters creativity through a brain/body workout that integrates kinesthetic awareness, neuromuscular skills, cardiovascular conditioning, flexibility, and strength.
- Provides opportunities to build on social skills and cognitive learning.
- Offers sensory stimulation while keeping participants engaged in the activity for extended periods of time.

For more information visit the Arc of Bristol County's calendar www.arcnbc.org/get-involved/event-calendar.html/calendar/2022/1, or contact Kristin Bosclair, kbosclair@arcnbc.org, 508-226-1445.

Sleep & Sensory Processing: Understanding the Link



Webinar

January 11th, 2022, with Therapro of Framingham

Sleep health is often overlooked in current care for children with sensory processing concerns.

- In this short course, explore the neurological and clinical relationships between sleep and sensory processing, and build a tool kit of assessment and intervention techniques specific to children with sensory processing difficulties.
- Explore the neurological components of sleep, arousal, and sensory processing using a novel theoretical model grounded in current literature.
- At the conclusion of this session, attendees will be able to identify neurological components of sleep that may be impacted for people with sensory processing dysfunction, and apply this knowledge to develop assessment and intervention plans for people with sensory processing difficulties.

About the Presenter: Amy Hartman is an occupational therapist and doctoral candidate currently researching sleep health in children with sensory processing difficulties at the University of Pittsburgh. She has over 10 years of experience working in pediatrics across the USA, and has raised two poor sleeping children that has informed her approach to sleep, occupational therapy research and dissemination.

For more information visit www.therapro.com/Information-Items/Webinars/ or contact (800) 257-5376 or info@therapro.com

Meet Department of Mental Health Commissioners



Virtual Town Hall

January 11th, 2022 with The Parent/Professional Advocacy League of Massachusetts.

PPAL Statewide Meetings are only for people with lived experience, including Family Members, Family Partners, Family Support Specialists, Parent/Caregivers, Others in Family Support Roles.

If you want to attend and are NEW to the PPAL/DMH family support network, you will be contacted by a PPAL staff member to confirm that you have lived experience with raising a child with mental health needs or as a peer mentor/specialist.

MEET the guest presenters:

- Department of Mental Health Commissioner Brooke Doyle
- Department of Mental Health & Deputy Commissioner Kelly English

The meeting will be a "Town Hall" style meeting where everyone can voice their thoughts and ask their questions with a focus on special topics pertaining to mental health.

Free, but you **MUST pre-register to be guaranteed** a seat and lunch to

<https://events.r20.constantcontact.com/register/eventReg?oeidk=a07e1w2cb4za0b1b00d&oseq=&c=59514330-4233-11e3-9b3c-782bcb740129&ch=73a0fda0-61a8-11e7-bc35-d4ae52754db0> or contact statewide@ppal.net 508-767-9725



**Plymouth County
Family Support Inc.**



**Bay State
Community
Services**

Helping Families. Saving Lives.
Empowering Communities.



PLYMOUTH FAMILY RESOURCE CENTER
CONNECTING FAMILIES
TO THEIR COMMUNITIES

January 12th, 2022 from 4 – 5:30 p.m.

Parents of School Aged Children are welcome to join Plymouth County Family Support, Community Autism Resources, and Plymouth Family Resource Center for a virtual learning opportunity about the signs of Autism in school aged children as well as the next steps to take.

Presented by Jan Randall, who uses her own experiences with her son, Andrew to support parents and families in the Autism Community. As the Autism Resource Specialist at Community Autism Resources (CAR) for the last 27 years, Jan brings personal and professional experiences and knowledge to this workshop with the goal of providing information, support and resources that parents are seeking.

Please sign up by calling Shannon at 774-283-6531 or emailing signham@baystatecs.org by Monday, January 10th.

SELF-DIRECTION PROGRAMS



SUPPORT



EMPOWERMENT



CHOICE

DDS SELF-DIRECTED SERVICES

Please join us for an interactive discussion about expanding choices and control in your life through Self-Directed Supports. This is an opportunity to hear how participants and their families can design individualized services to meet their needs through the

Participant Directed Program

or

Agency with Choice

WHEN:

1/12/22 10:00am to 11:30am

1/26/22 4:00pm to 5:30pm

2/9/22 10:00am to 11:30am

2/23/22 4:00pm to 5:30pm

3/9/22 10:00am to 11:30am

3/23/22 4:00pm to 5:30pm

Offered via **WEBEX**

To register please contact: jennifer.r.benoit@mass.gov

TNG MCP Family Questionnaire

Name: _____

DOB: _____ Tel: _____

Email: _____

Street Address: _____

City: _____ Zip Code: _____

School _____ Day Hab _____ Work _____

Parent/Guardian Names: _____

Relationship (Over 65?): _____

Adult Eligible Done (17 years old & older): YES NO

Current Diagnoses: _____

Family Strengths & Interests: _____

Needs assistance with:

- Housing/Home Mod Van Nursing PCA SSI DME
 Support Group Premium Assistance Guardianship/SDM Energy Assistance

Are you involved in : Sport: _____ Club: _____

Do you get PCA hours__ How many _____ what agency _____ PCA name _____

Do you have nursing hours? __ How many _____ what agency _____

Are you involved with Fragile Footprints/Hope Health? YES NO

Person working with you _____

Are you involved with DMH? YES NO Person working with you _____

Are you involved with MCB? YES NO Person working with you _____

Are you involved with DPH? YES NO Person working with you _____

Are you involved with MRC? YES NO Person working with you _____

Are you involved with MCDHH? YES NO Person working with you _____

Are you involved with any other agencies? YES NO

Agency: _____ Person working with you _____

Agency: _____ Person working with you _____

Do you have an IEP Plan? YES NO

Do you want a Medically Complex Advisor to attend an IEP meeting with you? YES NO

Do you have an Emergency Plan? YES NO

EP Details: _____

Have you started guardianship or SDM (17 years old & older)? YES NO _____

Are you planning to do AWC or a DayHab? _____

Do you need a vehicle? YES NO _____

Do you need help with the Catastrophic Illness in Children Relief Fund? YES NO

Have you heard of the Family Leadership Series? YES NO

Do you want more information on the Family Leadership Series? YES NO

Do you know your Family Support Center? YES NO

Please let us know how we are doing. Is there an area where we can better serve you?
