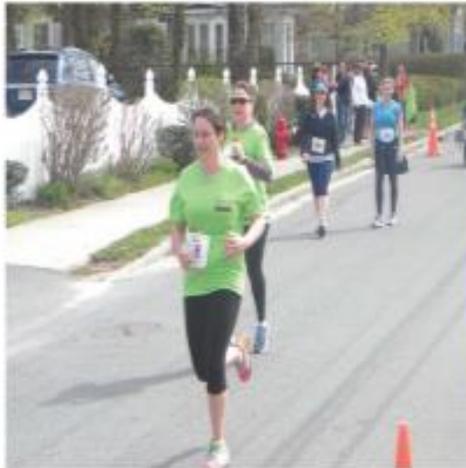


Medically Complex Program



**5K
Walk/Run**



Saturday, May 7, 2022

**Fort Phoenix State
Reservation Fairhaven, MA**

Registration Begins 8:00 am

Race Begins 9:00 am

\$15 Registration fee
includes event T-shirt
T-shirts are limited, register early
For more information and to
register, visit our website at
www.NemasketGroup.org

PROUDLY SPONSORED BY:



Prizes will be given to:
1st, 2nd & 3rd Male
1st, 2nd & 3rd Female
Largest Team
Largest Fundraiser

Refreshments will be on
site and police detail will
be present to ensure the
safety of our participants.

Medically Complex Program at The Nemasket Group

109 Fairhaven Road, Mattapoisett, MA 02739

Tel: (508)999-4436 Emergency Tel: 508-207-2538 Fax: (508)997-9239



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Climbing the Emotional Caregiving Mountain

<https://complexchild.org/articles/2020-articles/fall/climbing-caregiving-mountain/>

BY JENNIFER KING

You keep putting one foot in front of the other, and then one day you look back and you've climbed a mountain. – Tom Hiddleston

One day, several years ago now, I was in the grocery store feeling totally overwhelmed and exhausted. I had just picked up some medicine from the pharmacy for my son, and I was sort of walking aimlessly with a long list of grocery items we needed. Then suddenly I came to a complete stop in the middle of an aisle.



I just felt I could not go on anymore. I stood there for a few moments. My head hanging down, my eyes closed. I slowly opened my eyes and I saw my feet and I thought, just keep putting one foot in front of the other. That's all I need to do. Those words helped me get through that grocery visit and so much more throughout the years since.

I recently ran across the above quote by Tom Hiddleston and I realized I've been climbing a mountain all these years and didn't even know it. It gave me a sense of accomplishment and a moment to pause and reflect on how far we have come.

CIRCULAR EMOTIONS

I have been caregiving for 13 years now. My son is severely disabled and medically complex with an unknown type of mitochondrial disease. As hard as things have been, and as hard as they are now, they will only continue to get harder because this disease will continue to progress. I remember when he was a year old rocking him to sleep for his nap. He was so tiny, and I just wanted to wrap my arms around him and protect him from all that was to come. Telling myself, "as hard as this is now, it will only get harder."

And it has.

I have been through many emotional ups and downs these past 13 years. Periods of relative stability, periods of complete chaos. Periods of grief, pain, anger, fear, joy, love, happiness, contentment. Periods of acceptance. Periods of rebellion. From appreciating how lucky I am to experience this incredible journey we are on, to wondering when I will get my life back.

And what does "my life" even look like now? Would I even know what to do with myself after being totally devoted and self-sacrificing to my son for so long?

What I have realized though is that the emotional journey of caregiving is circular, and seemingly, at least for me, the circles extend out wider with each passing year. This journey is not linear. We do not pass through one stage, enter the next and leave the previous one completely behind. We circle through all stages, all emotions, again and again.

Some stages I recognize and have become very familiar. Other stages are new and alien, knocking me down and taking my breath away. I have much longer periods of acceptance and contentment than I used to have. I think, "okay, I've got this, I know how to handle this." Then out of nowhere, rebellion sneaks back in and I lose myself in the grief and pain all over again. And unfortunately, while there are longer periods of contentment and acceptance as the years pass, when the rebellion stage hits, it seems to hit harder and deeper than before.

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Caregiving is a complex emotional journey that can only be truly understood by experiencing it. Outsiders would be shocked by the thoughts and feelings caregivers have. We wonder how much longer we can keep doing this, then feel guilty because the only way "this" comes to an end is through the demise of our child. And how terrible that makes us feel, as it is the absolute last thing we want to happen. And yet, we can't help but feel we want our life back. We are only human, after all.

We are running a marathon intermixed with sprints with no end in sight. We are exhausted in our bones, our souls, to the very essence of our being.

The love, though. The love is amazing. So is the joy and happiness. I have come to the realization that there are no words, nor is there any form of measurement that can accurately describe the love I have for my son. It is a love beyond words and measure. I do feel incredibly lucky to be living this life. To experience this amazing journey. When my son smiles, we say "all is right in the world." And he smiles a lot. We are lucky with that. He's never said a word, but he has a beautiful smile and an infectious laugh. It makes my heart sing. There is nothing else like it.

MINDFULNESS

One way I have chosen to manage the emotional journey of caregiving is to practice mindfulness. I meditate very early every morning before anyone else is awake and attempt to be in the present moment throughout the day, particularly when I am providing direct hands-on care to my son. This helps me better deal with the wide-ranging emotions that pop up. It helps slow things down and makes me more patient while I provide care. It gives me a stronger source of resilience and helps me to be better able to respond to situations instead of reacting to them. It has been a lifesaver for me.

Part of this journey includes getting knocked down by our emotions. A lot. I have found that through the years when I have gotten knocked down, I quickly get up, dust myself off, and resume my normal activities as soon as possible. And most of the time there is no choice. My child's needs still need to be met.

What I am finding now is that I think too many times I have picked myself up too quickly and not let myself really feel the emotions involved. Once I get knocked down now, I try to let myself stay there for a few moments. I take a look around and really feel what I am feeling and how it feels in my body and get a better understanding of it before picking myself up, dusting myself off, and going on as before.

I think this is a healthier way of dealing with emotions than rushing through them hurriedly, thinking we will deal with them later, or that they don't matter. Otherwise, when all those stuffed up emotions do catch up with us, we will be knocked down all the harder the next time. Being able to recognize what we are feeling and observe it and really let ourselves feel it helps to move on from it quicker and in a healthier way. It is not an easy thing to do, and sometimes we literally do not have the time, but bringing awareness to our emotions at any level is helpful.

Caregiving is one of the hardest jobs there is. It is relentless and difficult and rewarding, all at the same time. Emotions range from the highest of highs, to the lowest of lows, and everywhere in between, often just within moments of each other.

But no matter how hard this journey is, we keep doing it. We keep going. When it is our child, we have no choice. We will go to the ends of the earth and the outer reaches of the universe to take care of our child. And along the way we will experience every emotion imaginable and some unimaginable. It's all part of the journey. Embrace it.

MA Adult Literacy Hotline

800-447-8844

Mass.gov/edu/literacyhotline

What is literacy?

Literacy is more than reading and writing. Literacy includes computing, solving problems, using technology, evaluating and using information, and participating fully at home, at work, and in the community. Literacy helps people develop their knowledge and potential. It also helps people to set and achieve their personal, educational, and career goals.

What is the Massachusetts Adult Literacy Hotline?

The Massachusetts Adult Literacy Hotline is a statewide information and referral service that connects adult learners and volunteers to local programs. These programs provide:

- Basic reading, writing, and math instruction.
- Preparation for the GED or HISET high school equivalency tests.
- English classes (ESOL)
- Preparation for the U.S. Citizenship test.
- Transitions to college.

In addition, the Hotline can help adult learners and workers find:

- Vocational/job training.
- Career centers.
- State-licensed childcare providers.

How does the Hotline work?

First, call the free Massachusetts Adult Literacy Hotline at 1-800-447-8844. Our operators speak English and Spanish, and have access to interpreters for many other languages.

The Hotline operator will provide you with the names and phone numbers of several programs in your area that might be appropriate for you. Next, call the local programs for more detailed information about their services.

Or, go to the free website at www.mass.gov/edu/literacyhotline to search for a program, career center, or state-licensed childcare provider.

Where are services provided?

The Hotline includes more than 300 programs around the state – community based organizations, public schools, libraries, churches, and community colleges – each with its own philosophy, program design and methodology.

Who should access the Massachusetts Adult Literacy Hotline?

- Adults who want to improve their math, reading and writing skills, learn English, prepare for the GED or HISET high school equivalency test, transition to college or job training, find a career center, or find childcare for times when they are in class.
- Volunteers who are interested in giving their time and skills to adult literacy programs and students.
- Allies such as employers, health care providers, social service case-workers, and counselors who want to obtain referrals for their clients.

Digale que contacte a la Línea de Información de Educación de Adultos de Massachusetts
1-800-447-8844

FEDERATION FOR CHILDREN WITH SPECIAL NEEDS

INFORMING, EDUCATING, EMPOWERING FAMILIES

FEDERATION PROGRAMS AND SERVICES

Special Education Center

Provides support, information, training and workshops statewide related to special education to families of children with special needs. Projects include:

- Parent Training and Information Center (PTIC)
- LINK Center/Transition
- Community Outreach and Empowerment Project
- Parent Consultant Training Institute

Family Support Center

Provides parent to parent support for families who have children with a wide variety of special health care needs and/or disabilities. Projects include:

- Family TIES of Massachusetts
- MassCARE
- Project Launch/My Child
- Pathways for Parents

Health Advocacy Center

Provides healthcare information and support to families of children with special needs, and programming that helps build capacity for family partnerships between managed care organization and parents. Projects include:

- Mass Family Voices
- Family-to-Family Health Information Center
- Mass Family Voices collaborates with Massachusetts' Children's Health Insurance Program Reauthorization Act (CHIPRA)

Family and Community Engagement Center

Offers education improvement services to districts and schools in Massachusetts, and trains community volunteers to act as educational decision-makers for students whose parents are not available. Projects include:

- Family and Community Engagement Team
- Recruitment Training and Support Center for Special Education Surrogate Parents
- The Family and Community Engagement Center

Parent-Professional Leadership Center

Focuses on activities that help build collaborative relationships among key education stakeholders. Projects include:

- Massachusetts Association of Special Education Parent Advisory Councils
- Advancing Parent-Professional Leadership in Education
- Massachusetts FOCUS Academy – Graduate level professional development courses for school personnel
- The Partnership Project

How to Contact the Federation for Children with Special Needs

Toll Free: 800-331-0688

info@fcsn.org



For children, schools, and parents

- **Child-centered**
- **Appropriate program**
- **Trust-based**

SpedEx Consultation is a dispute resolution option available in certain cases after an IEP has been rejected, or if a mediation or hearing request has been filed. We help families and schools resolve disputes concerning free and appropriate public education (FAPE) or the least restrictive environment (LRE).

SpedEx Consultation is an on-going experimental project, funded through the 2020-2021 school year. Requests for this option may be made after an IEP has been rejected, or if mediation or a hearing request has been filed. Requests will be accepted on a first-come, first-served basis. SpedEx is funded by the Massachusetts Department of Elementary and Secondary Education (DESE). However, SpedEx operates independent of the DESE.

SpedEx Consultation is...

- designed to assure that a child receives a free appropriate public education (**FAPE**) in the least restrictive environment (**LRE**);
- voluntary and will build trust between parents and schools;
- expedient

SpedEx provides a jointly agreed-upon independent SpedEx Consultant to review evidence and advise the parties on a program to provide FAPE and LRE **so they may resolve their own dispute.**

Key Features

- Use of an independent, neutral SpedEx Consultant jointly agreed-upon by **parent and school, whose fee will be paid by the DESE**
- Decision made through joint school-family knowledge and cooperation
- Placement of student, by agreement within 30 days, with optional post-placement observation by Consultant

Is SpedEx Consultation appropriate for my situation?

Are the school district and the parent...

1. Disputing whether the district's proposed IEP offers a FAPE in the LRE?
2. Disputing what services the child needs in order to receive a FAPE in the LRE?

If you answer "Yes" to either of these questions, your case is likely eligible. There must be a rejected IEP, or mediation or a hearing must be scheduled.

You may consult the SpedEx Consultation Administrator at any time.

SpedEx Consultation Timeline

Please read "SpedEx During Covid" on the Policies page.

SpedEx is Fast!

Gratis para las escuelas, familias

SpedEx is financiado por el Departamento de Educación Primaria y Secundaria de Massachusetts (Massachusetts Department of Elementary and Secondary Education DESE)

Para más información

o

Para preguntar sobre cómo comenzar SpedEx:

Por favor mande un email ad administrador del programa David Scalon en Boston College

David.scalon@bc.edu



También, visite a
<http://spedexconsultation.com>

Project RIDE “Tune Up” Day



Springfield

April 24th & 25th, 2022

In-person at the JCC Springfield.

Fees apply, registration is required to www.kehillah-sjcc.org/project-ride/ or contact (413) 739-4715 (ask for Project RIDE) or email tedwards@springfieldjcc.org

- Project RIDE stands for Recreation, Independence, Development and Equipment.
- **Tune Up Day** – The JCC will offer a tune-up day for those trikes that are in need of repair, to fit riders who might have grown out of their current trike, and to offer trikes to new riders. Call or email to reserve your spot.

COVID-19 Protocols (these protocols are form 2021. Please check with the JCC for the updated 2022 protocols). This is NOT a mandatory event and due to the safety protocols that are in place at the J.

*There will be an option for the rider and family member or caregiver to take a ride around the J campus once the tune-up is complete. Signs will be posted.

- Only 1 family member/care giver can attend the tune-up with the rider
- Masks must be worn at all times
- Complete the Springfield JCC COVID screening form prior to arrival (1 for the rider and 1 for the caregiver in attendance)
- Agree to non-contact temperature check upon arrival
- Please follow the signs in the Converse St. parking lot at the J
- Stay in your car until the COVID screening form is complete and collected and the temperatures are recorded
- Maintain 6 feet social distancing at all times

Sensory-Sensitivity Museum Event: Providence



Spring & Summer of 2022

With the Rhode Island Museum of Arts & Science

Fees apply

Registration is required <https://form.jotform.com/213146351363045> or contact gshneider@rimosa.org

- Sensory Sensitive Saturdays occur on the first Saturday of each month.
- Make reservations for 10 AM to 12 PM
- These visit times are two hours prior to opening to the general public.
- Accommodations are set up to support welcoming environment and experience for individuals affected by various degrees of sensory sensitivities.
- The host is currently admitting one group per time slot, so your group will have a private visit with the museum all to yourselves.

ABLE Accounts Workshop



Webinar

April 12th, 2022

With the Special Needs Transition Group of Wakefield, MA.

RSVPs are required to SPEDHousing.Transition@gmail.com

Topics may include:

- ABLA Accounts and Qualified Disability Expenses
- Expenses That Do or Do Not Meet QDE Criteria
- The Impact of an ABLA Account on Social Security and SSI Disability Benefits
- Maximizing the Use of an ABLA Account Without Jeopardizing a Range of Other Benefits
- A Range of Strategies for Funding an ABLA Account
- Using ABLA Accounts to Support the Transition from School to Adult Training, Higher Education
- Work, and Independent Living

About the speaker: Michael Weiner is Financial Advisor specializing in Special Needs. Michael has gained a wealth of experience navigating through available programs and resources for his own son with Special Needs. He says he was fortunate because he had the time and ability, but he has met many families who have no idea how or where to start.

Working Memory



Webinar

April 30th, 2022

With Mass Down Syndrome Congress and the 3-21 Foundation of Burlington, MA.

The 3-21 Foundation's mission is to promote advances in education and cognition for people with Down syndrome so they can be empowered to pursue their dreams.

Registration is required to education@mdsc.org or the Massachusetts Down Syndrome Congress at 781-221-0024