



LETTER TO CAREGIVERS

2 COMMUNITY RESOURCES FOR FAMILIES

MEDICAL SUPPORT
RESOURCES FOR
CHILDREN

8 - S EMOTIONAL SUPPORT RESOURCES FOR CAREGIVERS

NOTE: IN THE DIGITAL VERSION OF THIS BOOKLET, ALL LINKS ARE EMBEDDED, THEREFORE YOU ARE ABLE TO SIMPLY CLICK ON THE HEADINGS - TAKING YOU TO THE RESOURCES WEBSITE PAGE

A Lefter to Caregivers

I need to be listened to without feeling judged.

I sometimes just need to vent.

I need to be understood when I say that I'm physically and emotionally exhausted.

I need a hug.

I often need a nap.

I need a shower without company or screaming.

I need a time-out.

I need to laugh.

I often feel guilty for having these needs.

Most importantly, I need you to know that with all of these "Needs" I never stopped loving my child and feeling very blessed that she / he's mine.

A Plea from A Parent with A Child Who Has Special Needs

Have you ever felt or shall we ask, when was the last time you felt like the parent above?

We at North River Collaborative want you to know that we see and hear you! We applaud your tireless efforts to care for your child. We know it is not easy. Yes, it is tiring, exhausting, and sometimes you may even feel alone. We want to let you know that we are here for you, and want to continue to help you and your child.

We love caring for your child! It is truly a privilege to work with each and everyone of you. We take time to learn about your child's interests and needs so that we can provide the best possible care. Seeing their smiles and laughs on a daily basis warms our hearts and brings us great joy.

Therefore, we have created this brochure to direct you to helpful support and resources for you and your child. We hope these resources will help you keep up the great work you are doing! We know it is not easy, and YOU are doing an amazing job! We truly appreciate your tireless efforts and more importantly your child appreciates and loves you!

Sincerely,
North River Collaborative Staff

Community Resources for Families

Federation for Children with Special Needs

The Federation for Children with Special Needs focuses on community participation for all individuals including those with disabilities. It provides support, information and assistance to parents of children with disabilities, their professional partners, and their communities. What makes them unique is The Federation staff members who are parents or family members of children with disabilities and people with disabilities, knowing first hand what goes on and coming up with creative ways to help all in the community with special needs.



BAMSI Kids



Provides support for children from birth through adulthood via an integrated array of services, addressing physical, emotional, intellectual, and social development, even providing physical therapy, occupational therapy, or behavioral health. They are aware that no two families are alike, therefore each family is catered to, with individualized care and helps with everything from accessing nutritional assistance to parent support groups.

Community Resources for Families



MASS 211

Mass 211 is similar to the 9-1-1 system, available 24 hours a day, 7 days a week. Instead of emergencies it helps individuals find health and human services available in their individual community. Providing a list of resources and services in their area. It is free and open to the public, calls are always kept confidential.

FindHelp.org

Insert your zip code, and it provides areas and centers for financial assistance, food pantries, medical care, and other free or reduced-cost help

Greater Massachutestes Special Needs Events

Provides a variety of events for special needs children across the commonwealth.

Medical Support Resources for Children

COMPLEX CARS

Having multiple doctors, therapists, outpatient resources, school and sometimes home nursing, it can be difficult and messy to juggle everything. Complex care services specifically specializes in children with medical complexity and becomes the central personnel to do all the juggling between providers. They coordinate the care between all providers, look at the holistic child, going system by system, school, home life, medical equipment and much more. They are a valuable resource to help you and your child and take some of the stress and burden off of yourself



Complex Care
Services
Boston Children's
Hospital



Pediatric
Coordinated Care
Clinic
Massachusetts
General Hospital



Pediatric
Comprehensive
Care Program
Boston Medical
Center

Medical Support Resources for Children

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Rainbow Team Boston Children's Hospital

The Rainbow Team includes the primary care physician along with a nurse practitioner, nurses, and social workers. They can assist in medical advice, home and school nursing, getting and maintaining medical supplies and medications, and be able to connect you and your child to community resources.



<u>Autism Spectrum Center</u> <u>Family Education & Support</u>

Provides parent/caregiver support resources, insurance resources, bullying prevention, and sibling support resources



Pediatric Palliative Care Network (PPCN)

The Pediatric Palliative Care Network (PPCN) serves the unmet physical, emotional, social and spiritual needs of eligible children in Massachusetts and their families. Services are provided at no cost to children 18 years old and younger who have a life-limiting illness.



<u>Health Transition for Youth & Young Adults</u> <u>with Special Health Needs</u>

The transition from pediatric to adult care can be difficult. This resource helps to provide valuable tips, support and advocacy, and simple wording of the law and legality all to help bridge the gap.

Emotional Support Resources for Caregivers



SWOTIONAL SUPPORT

<u>Family TIES of Massachusetts</u>

A statewide, local support network center for families of children with special needs. They specialize in emotional support for families, providing parent-parent support groups, workshops, training, referrals and community resources.

Courageous Parents Network

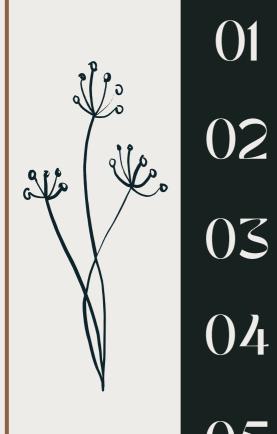
Courageous Parents Network is a non-profit organization and educational platform that orients, empowers and accompanies families and providers caring for children with serious illness. Their vision is to bring out the confidence and best ability each family has to be the best caregivers they can possibly be, resulting in minimal regret and maximal healing.

Emotional Support Resources for Caregivers

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FACEBOOK SUPPORT GROUPS

Each of the groups listed below are different examples of support groups designed to exchange stories, words of comfort, successes of the day to inspire, motivate and encourage one another.



<u>A Very Special Needs</u> <u>Resource Page</u>

Raising Children with Cerebral Palsy

<u>Parents of Children with</u> <u>Down Syndrome</u>

Massachusetts Parents of Autism

<u>Parents of Special Needs</u> <u>Kids South Shore MA</u>

** CAUTION** One must be careful about receiving advice on the social media page, as there is an influx of ideas, not all ideas are relevant or safe for your particular child. Always consult medical advice first.

REMEMBER

job!

