

# Medically Complex Program

## Emergency/Important info Binder Workshop

Do you have too much paperwork for your child/family member? Have you forgotten a doctor's name and/or their telephone number? Have you ever found yourself at a new doctor's office but forgot to bring the medication list with you? Let us help you organize your information and keep it all in one spot! We recommend an Information Binder where you can place any important documents or information you may need to bring in case of an emergency. POA, insurance cards, various records, IEP's, progress reports, a doctor/specialist information list and any results.

Empty your unorganized file cabinet onto your dining room table (or maybe your paperwork is already in piles on your table, no judgment) and set up your phone and let us help you get Organized.

\*Binders and Blank Forms can be provided \*

RSVP required. Email [Shanellstewart@nemasketgroup.org](mailto:Shanellstewart@nemasketgroup.org) or call Shanell at 508-562-7265

## What do you do for self-care? How can we help you with it?

Would starting a monthly self-care day help? Maybe we can go as a group to dinner. We can even set up a wine night. If leaving the house is an issue maybe we can set up a Zoom paint night. We can even set up a make a recipe day where we all make a meal together and talk while eating it. Really we can do anything that will help you with doing something that helps you relax. Let me know what you would like to do and what day works best for you.

Email me at [Shanellstewart@nemasketgroup.org](mailto:Shanellstewart@nemasketgroup.org) or call/text me at 508-562-7265.

### 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



**Sandra Heller**  
Associate Executive Director  
Medically Complex Program Director  
Ext. 128  
[SandyKinney@NemasketGroup.org](mailto:SandyKinney@NemasketGroup.org)



**Shanell Stewart**  
Medically Complex Program Assistant Director  
Ext. 161  
[ShanellStewart@NemasketGroup.org](mailto:ShanellStewart@NemasketGroup.org)



**Patrick Russell**  
Medically Complex Program Advisor  
Ext. 106  
[PatrickRussell@NemasketGroup.org](mailto:PatrickRussell@NemasketGroup.org)



**Ana Colon**  
Medically Complex Program Advisor  
Ext. 118  
[AnaColon@NemasketGroup.org](mailto:AnaColon@NemasketGroup.org)

DDS, Southeast Region, Learning and Staff Development  
&  
Widening the Circle Pathways to Friendship & The Arc of Massachusetts  
Is Pleased to Announce a **VIRTUAL** Workshop

## The Ask: Invitation to Engagement

**Part 1: Tuesday, May 4th, 2021: 9:00 AM to 12:00 PM**

**Part 2: Thursday, May 6th, 2021: 9:00 AM to 12:00 PM**

**(Part 1 Participation Required for Entry into Part 2)**

**Workshop description:** This workshop engages participants with our fundamental, shared need for freely-given friendships. People with disabilities usually have most of their relationships through human service programs and with their families. While such relationships are important, the hard reality is that most disabled people have few, or even no, freely-given friendships outside of those circles. For such relationships to begin and grow, someone needs to take the initiative to issue an invitation. For several reasons, neither disabled people themselves nor community members who are not involved in service provision rarely make this invitation. To address this reality, others need to become the “askers”—the inviters—into relationship. This workshop will provide potential inviters with a deeper understanding the opportunities and challenges in the current situation—especially in this time of pandemic. It will also provide guidance and practice on effectively fulfilling the role of inviter.

**About the Presenters:** Tom Doody has been actively involved with Social Role Valorization training. He has promoted friendships involving disabled people through a variety of training and consultation roles. For many years, his primary direct service role was as coordinator of North Quabbin Citizen Advocacy, an organization exclusively focused on recruiting and supporting freely-given relationships between disabled people and their non-disabled neighbors.

Tom will be joined in presentation by Katie Driscoll, Pathways to Friendship Facilitator and DDS Regional Staff Trainers, Becky Morrissey and Christine Sheedy.

To register, please type this link into your browser: <https://conta.cc/3czkDiV>

Once you have registered, you will receive a confirmation email with a link to join the Zoom meeting. Handouts will be electronically mailed just before each of the sessions.



**See, Touch and Try.** Assistive Technology Regional Centers are operating in western, central and eastern Massachusetts; visit them to learn about, try out or borrow assistive technology.

**Website Massachusetts Assistive Technology Loan Program (MATLP)** is an alternative financing program funded through state and federal resources to give people with disabilities and their family's access to low-interest cash loans to buy the assistive technology devices they need.

**Equipment:** Choose to reuse your D M EDMequipment.org offers free gently-used, refurbished wheelchairs and other DME to people who need it. Delivery is available. Search for available items here.

**Go To Get AT Stuff.** MassMATCH is happy to announce the establishment of Get AT Stuff Massachusetts, a new Assistive Technology Exchange website. Here visitors can shop for used equipment or advertise what they are no longer using.

## 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

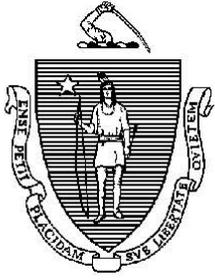
**Agency with Choice**

### WHEN:

4/6/21 10:00am to 11:30am  
4/28/21 4:00pm to 5:30pm  
5/11/21 10:00am to 11:30am  
5/26/21 4:00pm to 5:30pm  
6/8/21 10:00am to 11:30am  
6/30/21 4:00pm to 5:30pm

Offered via **WEBEX**

To register please contact: [jennifer.r.benoit@mass.gov](mailto:jennifer.r.benoit@mass.gov)



The Commonwealth of Massachusetts  
Executive Office of Health & Human Services  
Department of Developmental Services  
1000 Washington Street, Suite 401  
Boston, MA 02118

Charles D. Baker  
Governor

Karyn E. Polito  
Lieutenant Governor

Marylou Sudders  
Secretary

Jane F. Ryder  
Commissioner

Area Code (617) 727-5608  
TTY: (617) 624-7590

March 24, 2021

Dear DDS Community:

Just over a year ago, I sent my first “Coronavirus update” to the DDS community. We shared the Governor’s declaration of a State of Emergency, and the steps we were taking within DDS to protect your loved ones. We declared that health and safety of your loved ones is our top priority. No one could have predicted the ways the pandemic would impact all our lives.

Soon after, with guidance from our partners at the Massachusetts Department of Public Health and the Command Center, we made some of the hardest decisions I hope this organization ever has to make, including suspending in-person visitation and closing day programs to in-person services. Like the rest of the world, when the virus first hit, our programs didn’t have a reliable supply of PPE or the capacity to conduct testing at scale. That quickly changed.

With a strategy focused on testing, infection control, and PPE, we flattened the curve by summer 2020. We re-opened our day programs to in-person services with precautions and guidance to keep participants and staff safe. And we resumed in-person visitation, with outdoor and off-site visits starting 4th of July weekend, and indoor visits starting October 1, before the cold weather set in. When the second surge hit our programs as predicted in the fall, we were better prepared.

**Your voice was instrumental in driving and shaping these developments.** You let us know when our policies and protocols went too far – or not far enough. You shared your stories, ideas, frustrations, and hopes. Your thoughtful suggestions help us provide our programs the flexibility and guidance to meet the unique needs of each individual we serve.



Thank you to all who are active in your local Citizen's Advisory Board, our Statewide Advisory Council, and advocacy organizations like The Arc of Massachusetts and Massachusetts Advocates Standing Strong.

DDS remains committed to hearing your voice, and keeping you informed and engaged as we go. On the pages that follow, please find important updates including Phase 4 reopening and vaccinations.

As always, please stay in contact with your Service Coordinator and Area Office and follow the Department on our website ([mass.gov/dds](http://mass.gov/dds)) and social media.

Take good care,

Jane



### **Massachusetts Homebound Vaccination Program**

**In-home vaccinations are now available to individuals who are not able to leave their home to get to a vaccination site, even with assistance. These homebound individuals either:**

- Require ambulance or two-person assistance to leave the home, or
- Are not able to leave the home for medical appointments under normal circumstances, or
- Have considerable difficulty and/or require significant support to leave the home for medical appointments (including behavioral challenges)

Call the State Homebound Vaccination Central Intake Line (1-833-983-0485) to be screened for appropriateness for an in-home vaccination.

### **Travel Advisory**

On March 22, the Governor updated the [COVID-19 travel advisory](#) in Massachusetts. Visitors entering Massachusetts, including returning residents, are advised to quarantine for 10 days upon their arrival. However, **travelers who are fully vaccinated and who do not have symptoms are exempt from this quarantine advisory.** Please keep this advisory in mind as you make summer vacation and travel plans.

## **Phase 4 Reopening**

On March 22, the Commonwealth entered Phase 4 of the reopening process. To bring our programs and policies up-to-date with the latest guidance from DPH and the CDC, updated COVID-19 guidance has been issued for DDS programs around visitation, residential congregate care programs, day programs, and transportation. For example, fully vaccinated individuals (who have received two doses of either the Moderna or Pfizer COVID-19 vaccines OR who have received a single dose of the Johnson & Johnson vaccine, 14 days or more ago) are now exempt from quarantine. Please know that important COVID-19 protocols on surveillance testing, PPE, and infection control will remain in place for our programs as we transition to this new normal.

## **Vaccination Update**

With the start of the new year came an all-out effort to vaccinate our congregate care residents and staff. I'm proud to report that every resident living and staff working in DDS residential congregate care programs has had access to the COVID-19 vaccine. Nearly all the individuals we serve and many staff in congregate residential settings are now fully vaccinated.

Recently, Governor Baker made important announcements about the timeline, process, and eligibility for COVID-19 vaccinations that may impact individuals and families served by DDS.

- March 22: all individuals **age 60+** and **certain workers** are now eligible.
- April 5: all individuals **age 55+** and individuals with **1 certain medical condition** are eligible.
  - **Certain medical conditions** include down syndrome, asthma (severe to moderate), chronic kidney disease, obesity, heart conditions, COPD (chronic obstructive pulmonary disease), cancer, immunocompromised state, pregnancy, sickle cell disease, and smoking.
- April 19: all individuals **age 16+** in the Commonwealth are eligible.

There are new ways to access COVID-19 vaccination appointments:

- **Preregister online** for an appointment at a Mass Vaccination site **now**:  
**[vaccinesignup.mass.gov](https://vaccinesignup.mass.gov)**
  - Tip: Answer yes to the first question to preregister on behalf of someone else.
  - All seven Mass Vaccination sites are accessible, with wheelchairs provided on site, staff designated to assist with mobility issues, accessible entrances, and accessible drop-off and pick-up. Learn more about each site **here**.
- **Call 2-1-1** or (877) 211-6277 to schedule an appointment over the phone.
- Use the **[VaxFinder.mass.gov](https://vaxfinder.mass.gov)** website to search for appointments at pharmacies, health care providers, and other community locations.

**If you need help planning a COVID-19 vaccination for an individual served by DDS, please contact your DDS Service Coordinator.**

# Life With Three Medically Complex Kids

It's complicated. And hard. And worth it.

By Sigourney Humus



I have three medically complex kids. Twin three-year-old boys and a seven-year-old daughter. They are wonderful and amazing humans. Each an absolute individual with enough attitude and strength to put me to shame. Honestly, I want to be as cool as them someday.

But, I'm their parent and my view is probably biased. I have been constantly in their lives since birth and I can't imagine my world without them. Their health issues are multifaceted and unique to each of them, making the complexities of our life more severe.

**Side note:** My kid's names have been changed to protect them and to have some fun. Besides, my wife would never go for these names in real life and I can't imagine why. Don't judge my choices ;)

## It's Complicated

### Leia

My daughter, Leia, has JIA (Juvenile Idiopathic Arthritis). JIA is a debilitating autoimmune condition where inflammation begins to affect areas of the body. In her case, this means her eyes and joints. She is at constant risk of developing glaucoma that can lead to blindness. Her joints have not been heavily affected yet, however, it is likely to develop significantly in the next few months.

*Continued...*

*Continued...*

## **Finn and Han**

The twins were born at twenty-four weeks, leading to unique developmental issues. If you have had a baby that is premature you understand. If not, let me put it this way, while they are three years old in age, they are almost identical to your average two-year-old in both physical and mental development. And on top of that, they have their own issues from their traumatic world entering experiences.

One of my twins, Han, had such a hard time breathing on his own that he almost died immediately after birth. Respiratory issues are common in premature babies, but his inability to function was much worse than average. He now suffers from CLD(Chronic Lung Disease).

This has led to him being extremely susceptible to the flu and other common viruses. But the difference is that anything he contracts puts him right back in the hospital, where he spent the first four months of his life. He pretty much quits breathing anytime he catches anything.

It may be hard to imagine, but my other twin, Finn, is much worse off. After their birth, he developed NEC(Necrotizing Enterocolitis). NEC is an intestinal disease that causes tissues death and perforation in the intestines. Long story short, he has lost over two-thirds of his small intestine and is likely to lose more in the coming years.

This means that he is unable to support himself nutritionally. Eating is not enough, he has to be supplemented with intravenous nutrition in order to grow and thrive. You know those people in hospitals that walk around with the IV pole? That is my son 24/7.

Perhaps you didn't intend to go to medical school when reading this post? Too bad. I didn't intend to be teaching people about unusual medical conditions that plague my children for the rest of my life either.

So now you know. This is my family and I love the f\*cking hell out of them.

## **It's Hard**

Having three medically complex kids changes the way you live life. We do things that other parents laugh at. We wipe down everything. We carry hand sanitizer in our pockets and dispense it to our kids every few minutes. We Lysol wipe everything before we touch it.

We sound and look paranoid and often insane, but it keeps our kids out of the hospital.

We look strange when we go to the park. Finn is attached to a backpack with fluid running into a port on his chest. We carry large industrial cans of emergency oxygen with us, in case Han has trouble breathing. Leia can't play on some things at the park, because the impact can further damage her joints. This means that my wife and I are running around more than the kids, chasing them to ensure their safety.

During the winter, Finn and Han hardly ever leave the house because the chance of catching a disease or virus is so high. We live for the summer. We can't wait until it warms up and most infectious bugs go on vacation. But during the winter we have to find ways for our kids to enjoy being trapped in a house for months at a time. It's like we are in a doomsday bunker and need a new game to play because we are all sick of checkers by now.

*Continued...*

*Continued...*

*Side note again: My kids are highly susceptible to diseases and viruses. And they cause long-term damage to their health. Vaccinate yourself and your kids. Its called herd immunity. Come on, people!*

My wife and I have had to sacrifice our dreams and ambitions beyond our kids. Dream jobs, destination vacations, our dating life, our sex life. Even five minutes alone is hard to find because Finn's IV pump goes off and then Leia's eyes start getting blurry and Han starts turning blue.

And none of this includes normal kid stuff, because they have that too. Throwing fits, screaming, crying, not wanting what's for dinner, not wanting to go to bed, etc. I'm sorry if I have convinced you to never have kids, that was never my point. However, I can see how you got there.

Things like this, and more, is why life is hard with medically complex kids. But they are still so f\*cking amazing.

### **It's Worth It**

Yeah, it is hard. And it is absolutely insanely complicated. But that doesn't stop any of it from being worth it.

Kids are amazing. If I was diagnosed with half of what they had I would crumble and fall apart. Kids have a way of stepping out of their issues and just being small humans that enjoy life.

Finn has endured more abdominal pain than most people will ever know, but nobody can smile like him. Nobody is going to take away his happiness and love for life.

Leia is relentless in her love for people and has little time to slow down and consider her health issues. She wants to eliminate inequalities for women and girls globally and she is obsessed with climate reform. She is more in tune with the needs of the world than I will ever be.

Han is running and playing and embracing life even when it is hard to breathe. Nothing is going to slow him down. I spend much of my day chasing him and watching him explore his curiosity for the things of life.

They are living life in the best way they know how. Their fragile health doesn't slow them down from being themselves. It should be the same for the rest of us. And for my wife and I, we can keep going through it all knowing that it is worth it for them.

### **Your life is worth it too**

The issues of my daily life may seem extreme and honestly, they kind of are. But you can relate. No matter what your hard situations are, they are just as valid as mine.

Sometimes people apologize to me for sharing their hardship, because they think that their issues must be less than what my family goes through. I tell them that, pain and hardship is relative to your situation. It is no less valid than mine.

**Nothing can minimize your life circumstances. I didn't tell you this story to prove to you how much harder my life is, I told you so that you could see the good in our lives despite all the hardship. Embrace the good in your life. It makes it worth it.**



MassFamilies

In partnership with the MAICEI program at Bristol Community College

# Implementing The Vision

*What to Keep In Mind While Navigating a Service System*

Thursday, May 6<sup>th</sup>, 2021

6:00 pm-7:00 pm via Zoom

**Registration Required**

Listen and learn about strategies that can help negotiate large human service bureaucracies. Guest Speaker, Ed Wilson has worked for over thirty years in Human Services. He shares what is necessary for families to know, and what they can do to help support their son or daughter to achieve their vision.

This workshop is geared toward families within the Southeast Region of Massachusetts. However, the MAICEI program at BCC currently contracts with the Old Rochester, Somerset Berkley, Fall River, Dighton Rehoboth and Swansea school districts.

## Questions?

Kathleen Amaral [Kathleen@massfamilies.org](mailto:Kathleen@massfamilies.org)

Ross Hooley [MAICEI@bristolcc.edu](mailto:MAICEI@bristolcc.edu)

## Registration Required:

<https://massfamilies-org.zoom.us/meeting/register/tZYIcuqrqjloHtz4ok7wFemixnE7QOkI5PPN>



# Home Healthcare Services

## MASSACHUSETTS

We have been making a difference in patients' lives across the nation for more than 30 years. Our team of nurses, therapists, and home health aides help patients of all ages maintain the highest quality of life in the comforts of the home. We offer skilled nursing, physical rehabilitation, companion care, respite care, and behavioral care for individuals with chronic and acute illnesses and disabilities. Our commitment to compassionate care and excellent service makes us an established provider wherever healthcare is needed.

### Some of our areas of expertise include\*

- Skilled medical care
- Private duty nursing
- Personal caregiving services
- Case coordination services

### 2020 Snapshot Massachusetts Patients

Total Patients: **387**  
 Adult Patients: **197**  
 Pediatric Patients: **190**

### Massachusetts Employees

Caregivers: **928**

### Maxim Healthcare Services Contracted Payors\*\*

Aetna (Commercial/Medicare/Medicaid/Exchange)  
 All Long Term Care Insurances  
 American Veterans Care Connection  
 Amerigroup Health Plans  
 Anthem Blues Plans  
 BeechStreet  
 Blue Cross Blue Shield Plans  
 Bright Horizon's Back-Up Care Advantage  
 Cigna/CareCentrix  
 CareScout  
 Centene Health Plans  
 CHAMPVA  
 Companion Property and Casualty

Dept. of Labor OWCP Programs (DFEC, DEEOIC, DCMWC, FECA)  
 Dept. of Veterans Affairs (Spina Bifida, Camp Lejeune, CWVV)  
 Evolutions Healthcare Systems  
 Fed Med PPO  
 First Choice Health Network  
 First Health Network  
 Foreign Embassies  
 GEHA  
 Health Net Federal Services  
 HealthSmart  
 Homecare Connect  
 Humana (Commercial/Medicare/Medicaid Exchange)

Long Term Solutions  
 Molina Health Plans  
 Multiplan  
 Neuro Rehab Management  
 NPPN/Plan Care America  
 Orchid Medical  
 Paradigm Health Corporation  
 PHCS  
 Prime Health Network  
 Procura Management  
 Rockport Health Network  
 SHIP LTC Plans  
 TRICARE East - Humana Military  
 TRICARE East Prime Pilot Demonstration - Kaiser Permanente  
 TRICARE West - Health Net Federal Services

TRICARE for Life - Wisconsin Physician Services (WPS)  
 TriWest VA Choice and PC3 Programs  
 United Healthcare (Commercial/Medicare/Medicaid/Exchange)  
 USA MCO  
 U.S. Department of Veterans Affairs  
 US Family Health Plan (TRICARE) - Johns Hopkins  
 US Family Health Plan (TRICARE) - Martin's Point  
 US Family Health Plan (TRICARE) - Pacific Medical Center (PacMed)

Veterans Health Administration - Community Care Network (OPTUM)  
 Veterans Health Administration - Community Care Network (TriWest)  
 Veterans Health Administration - Patient Centered Community Care (PC3) (TriWest)  
 Veterans Health Administration - Veterans Care Agreements  
 Veterans Home Care  
 Wellcare Health Plans  
 Workers Compensation

### Massachusetts Specific Contracts:

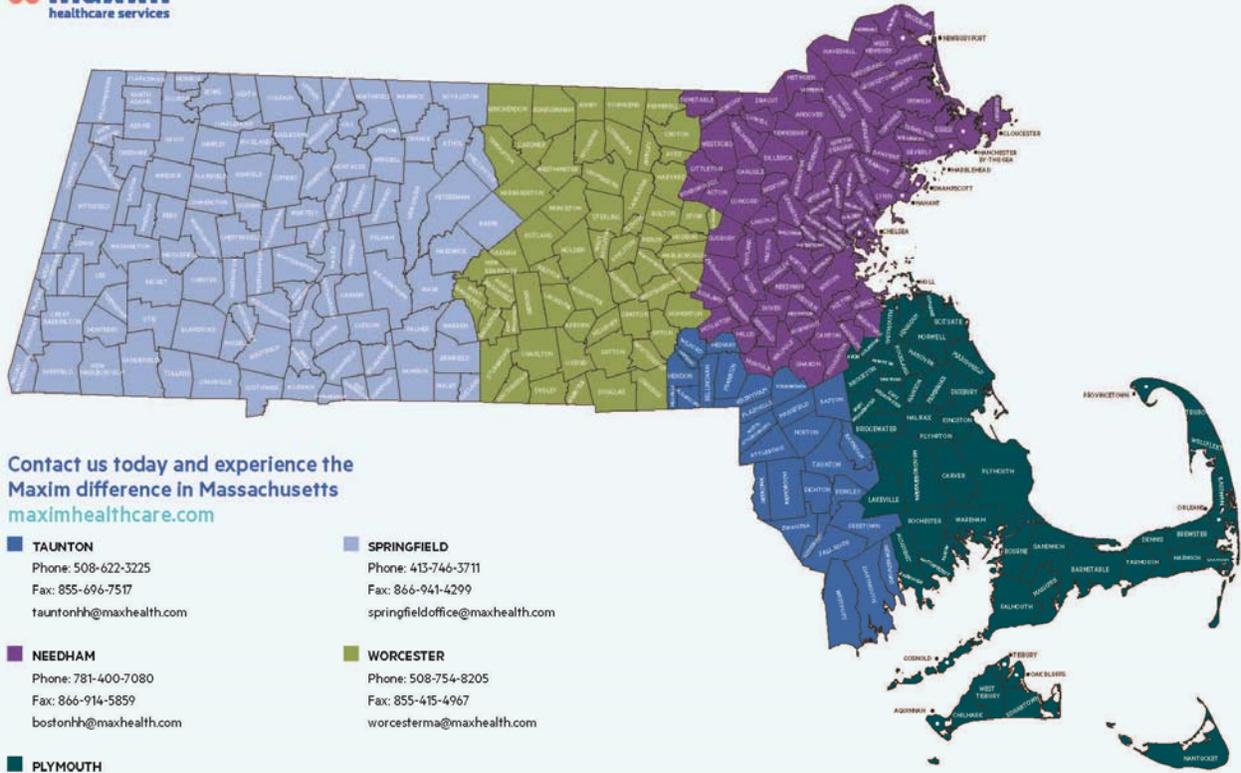
Allways Health Partners  
 Blue Cross Blue Shield of Massachusetts  
 BMC HealthNet Plan  
 CareLink  
 Caremark  
 Commonwealth Care Alliance  
 Fallon Community Health Plan  
 Harvard Pilgrim Health Care  
 Health New England (HNE)  
 Health Plans  
 Healthy Start  
 MassHealth  
 Medicare  
 Senior Whole Health  
 Tufts Health Public Plan  
 Unicare

\* Actual services provided vary by office. Please contact your local office to determine the services provided.

\*\* As applicable per local office.

Contract updates: Maxim is a national company and is constantly expanding our Managed Care Contracts. Please feel free to call the office should you need help with an insurance that is not listed above.

Out-of-network: Maxim is familiar with the process of working with out-of-network insurance companies. Should you need help with a referral that is not in-network, please feel free to call us.



Contact us today and experience the Maxim difference in Massachusetts  
[maximhealthcare.com](http://maximhealthcare.com)

- **TAUNTON**  
 Phone: 508-622-3225  
 Fax: 855-696-7517  
[tauntonhh@maxhealth.com](mailto:tauntonhh@maxhealth.com)
- **SPRINGFIELD**  
 Phone: 413-746-3711  
 Fax: 866-941-4299  
[springfieldoffice@maxhealth.com](mailto:springfieldoffice@maxhealth.com)
- **NEEDHAM**  
 Phone: 781-400-7080  
 Fax: 866-914-5859  
[bostonhh@maxhealth.com](mailto:bostonhh@maxhealth.com)
- **WORCESTER**  
 Phone: 508-754-8205  
 Fax: 855-415-4967  
[worcesterma@maxhealth.com](mailto:worcesterma@maxhealth.com)
- **PLYMOUTH**  
 Phone: 508-747-3521  
 Fax: 877-394-4763  
[plymouthhh@maxhealth.com](mailto:plymouthhh@maxhealth.com)



### The Maxim Advantage

- 24-hour services, including all holidays and weekends
- Trained, screened and certified healthcare professionals
- Certified by The Accreditation Commission for Health Care (ACHC)
- Matching patients with ideally-suited caregivers
- Award-winning compliance and ethics program
- Thorough, routine assessments by licensed clinical supervisors for delivery of quality patient care
- Flexible payment options, including the acceptance of most insurances
- National footprint, local presence
- FREE in-home consultation

### About Us

As a national provider of a comprehensive suite of services, we have been making a difference in the lives of our employees, caregivers and patients for 30 years. We offer services including home healthcare, behavioral care, healthcare staffing, personal caregiving, and population health and wellness. Our commitment to customer service, compassionate patient care, and staffing experienced healthcare professionals has made us an established resource in the healthcare industry.

