

After the ICU

Resources and information to help you and your family thrive after a critical illness



thrive



Atlantic
Health System

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About This Booklet

This After the ICU booklet is intended to be used by former ICU patients and their family/caregiver to help find the health care services and community resources that may be helpful during recovery from critical illness. Specifically, this booklet was created to provide information and resources related to Post-Intensive Care Syndrome (PICS). While PICS and PICS-F can be common after a critical illness, you may not experience all or any of these symptoms. PICS is defined as new or worsening physical, cognitive and emotional health problems that remain after a critical illness. Family members and caregivers of former ICU patients can also experience emotional and psychological health problems such as anxiety, depression and post-traumatic stress disorder. This is referred to as PICS-F. Our hope is to raise awareness about PICS and PICS-F and provide resources for those who are experiencing these symptoms. If you or your family/caregiver are having difficulty, we want you to know that you are not alone and that help is available.

Atlantic Health System does not endorse or recommend any particular service listed in this booklet and resources are referenced for informational purposes only. The information in this booklet is the most current available at the time of publication, however, some programs/services/contact information may change or become outdated. Please check with individual organizations to verify accuracy and availability of programs and services.

Resources listed include those associated with government, non-profit organizations, for-profit organizations and private businesses. This booklet is not intended to be a comprehensive list of services, but rather a starting place for information.

A Note About Your Needs After Discharge

Each unit within the hospital has staff dedicated to assisting with your plan for needs after discharge.

The unit social worker helps with resources and referrals to physical rehabilitation facilities and other facilities. The unit nurse care manager helps with resources and referrals to community-based services should you be going directly home after the hospital. This process is often started within the ICU; however if you have not yet met with a social worker or nurse care manager, please ask to speak with them. This booklet is not intended to be a guide for discharge planning.

How Critical Illness May Affect Your Body

- › You may have dry or itchy skin. Moisturizing can help.
- › Your hair texture may change or it may fall out. It typically will grow back but may be a different texture or color than how it was before your critical illness.
- › Your skin may be bruised from tubes, IVs or injections given during your time in the ICU.
- › Your voice may be different if you needed help breathing while in the ICU. Your throat may be sore and your mouth may feel dry.
- › Your muscles may feel weak and you may feel very tired. If you were on a breathing machine while in the ICU your muscle loss will be greater. You may weigh less now because of muscle loss. Physical therapy and exercise can help get you stronger and help with weight gain.
- › If you were on a ventilator during your time in the ICU, keep doing the breathing exercises recommended by the physical and respiratory therapist. This will help get your muscles stronger and reduce the risk of chest infection.
- › If you had a tracheostomy (a procedure to make a small hole in your throat and insert a tube that is connected to a breathing machine) you will have a scar on your neck where the tube was inserted. The scar will gradually fade and be less noticeable.
- › Sensory changes to your hearing, taste, touch and smell can be common after critical illness. The effects usually don't last long.
 - **Taste & Smell:** If you were fed through a tube or IV, when you begin to eat or drink normally food may taste different. Your sense of smell may also be affected.
 - **Eyes:** If you were sedated, your eyes may feel dry and sore. Your eyes may be puffy or swollen if you were given fluids to keep you hydrated.
 - **Touch:** Your sense of touch may feel different, this may be caused by medications you were given or by your body's reaction to your illness.
 - **Taste:** Some medication can leave a metallic taste in your mouth.
 - **Hearing:** Some medications can affect your hearing.
- › If you had a urinary catheter your muscles may be weak, which can make it hard to control urination. This usually returns to normal. If you have difficulty passing urine, have blood in your urine or have pain or burning, talk to your nurse or doctor as soon as possible as you may have an infection.
Bowel Movements: some medications can affect your bowel movements. Please talk to your doctor or nurse if you have difficulty.

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Post-Intensive Care Syndrome (PICS)

Recovery from critical illness is often a long road. While leaving the ICU is an important milestone, it is often the first of many steps on the journey to recovery. ICU survivors can experience new or worsening physical, cognitive (difficulty with word recall, memory, thinking) and emotional health problems that remain after a critical illness. These problems are known as Post-Intensive Care Syndrome, or PICS. Family members and caregivers of former ICU patients can also experience emotional and psychological health problems such as anxiety, depression and post-traumatic stress disorder. This is referred to as PICS-F. While PICS and PICS-F can be common after a critical illness you may not experience all or any of these symptoms.

What is Post-Intensive Care Syndrome (PICS)?

- › **ICU-Acquired Weakness** includes physical limitations, muscle weakness or problems with balance. Patients with ICU-acquired weakness can also have trouble with activities of daily living such as bathing, dressing, walking and grooming.
- › **Cognitive or brain dysfunction** includes difficulty with thinking, remembering, problem solving, paying attention, word finding, organizing your thoughts and concentrating on a difficult task.
- › **Emotional and psychological health** problems can arise after critical illness. Common struggles include depression, anxiety and post-traumatic stress disorder (PTSD). Critically ill patients may develop sleep problems including difficulty falling and staying asleep, nightmares and may confuse sleeping and waking times. Family members are also at risk of developing the above emotional struggles.

How common are the different parts of PICS?

- › **ICU-Acquired Weakness occurs in:**
 - 33% of all patients on ventilators
 - 50% of all patients with sepsis
 - Up to 50% of patients who stay in the ICU for at least one week.

- **Cognitive difficulties:**
 - 40% have cognitive difficulties similar to patients with moderate traumatic brain injury
 - 26% have cognitive difficulties similar to patients with mild dementia
- *Statistics are from the study, Long-Term Cognitive Impairment after Critical Illness where medical and surgical ICU patients with respiratory failure, cardiogenic shock or septic shock were assessed for cognitive difficulties at 3 months post ICU discharge.
- › **Emotional and psychological struggles:**
 - 25%-44% of ICU survivors experience symptoms of post-traumatic stress disorder
 - 33% of ICU survivors experience symptoms of depression
 - 33% of ICU survivors experience symptoms of anxiety
 - 30% of family or caregivers experience stress, anxiety, depression or post-traumatic stress disorder.

What Can Family Do to Help Reduce PICS?

While your loved one was in the ICU, the team worked to help reduce PICS. However, not all problems related to PICS can be completely prevented.

As your loved one transfers out of the ICU continue to help them stay "oriented".

- › Talk about familiar things, people and events.
- › Tell your family member the day, date and time and remind them where they are.
- › Bring in pictures and favorite items from home.
- › Read aloud or play music at the bedside.
- › Keep and continue to write in the ICU Diary. Once your loved one is ready you can share the diary to help them understand their illness, fill in the gaps and reduce their sense of lost time.
- › Ask the nurse or physical therapist how you can help with bedside exercises. Continue to do these exercises after the ICU.

- › Ways to meet your own needs while caring for your loved one. Self-care is not selfish, it is essential to your loved one's recovery that you find balance between their needs and your own.
- › As your loved one prepares to leave the ICU take time to review and make sense of what has happened. Review the ICU Diary or journal you have been keeping and use this time to ask any additional questions.
- › Practice self-care by getting enough rest, remember to eat and drink throughout the day, take breaks and be open to support.
- › When a loved one is in the ICU, family members tend to get less sleep than normal or they suffer from poor sleep quality. Getting enough rest is essential to your physical and emotional health. Lack of sleep can put you at higher risk for physical illness, depression and memory issues. Practice good sleep habits such as, avoiding caffeine and nicotine close to bedtime, exercise to promote good quality sleep, go to bed and wake up at the same time each day, establish a regular relaxing bedtime routine.
- › Find small ways to recharge your batteries such as taking a short walk, going for a massage, listening to music, praying and seeking support from friends and family.
- › If your loved one cannot be left alone when they return home, ask friends and family to set up schedule of visitation. This will allow you to take breaks and time to get out of the house. Organizations such as CaringBridge and Supportful allow you to set up a private care page to help organize help from family, friends and your community. You can use these sites to share updates, organize visits, errands and other assistance. Consider hiring help for a few hours each day if family and friends are unable to assist.

What Have Others Found to Be Helpful During Recovery?

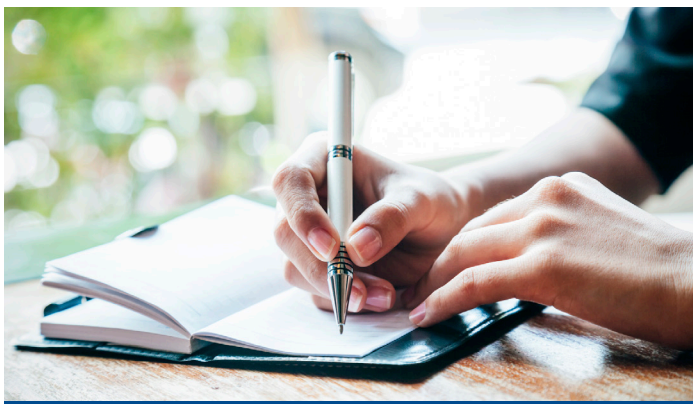
Challenges and difficulties can be common after surviving a traumatic event, such as an accident or serious illness. It can be valuable to learn the tools others have found to be helpful during their own recovery. These practices have been shown to provide

hope and can lead to healing and personal growth.

- › Practice self-compassion. Be as kind to yourself as you are to your best friend. Be mindful of any harsh or negative "self-talk".
- › Be open to support from others. Allow yourself to rely on trusted family and friends for help.
- › Express yourself and the experience you are going through. You can do this through writing, talking, art, music or other creative outlets.
- › Seek meaning in your faith, spirituality or belief system.
- › Allow yourself to feel all your feelings but make an effort to focus on the positive. Highlight the things going well with your recovery and practice gratitude.
- › Consider and be open to new experiences, interests or hobbies.
- › Find a support group where you can share your experience with people that get it.

The following is a reading list if you are interested in learning more about ways to foster healing and growth. Some of the books listed below include accounts of other people's serious, traumatic and critical illness. These stories may remind you of your accident, illness or time in the ICU. Learning about other people's experience may be helpful as it can make you feel less alone in your recovery and provide hope. However, please consider your own readiness and go at a pace that feels right for you.

- › *Upside: The New Science of Post-Traumatic Growth* by Jim Rendon
- › *When Walls Become Doorways: Creativity and the Transforming Illness* by Tobi Zausner
- › *Writing to Heal: A Guided Journal for Recovering from Trauma and Emotional Upheaval* by James W. Pennebaker
- › *In Shock: My Journey from Death to Recovery and the Redemptive Power of Hope* by Rana Awdish
- › *Self-Compassion and The Mindful Self-Compassion Workbook* by Kristin Neff
- › *The Post-Traumatic Growth Workbook* by Richard G. Tedeschi and Bret A. Moore



ICU Diary

ICU Diary

If you have been keeping an ICU Diary for your loved one during their time in the ICU it may be helpful to continue updating the diary during their recovery. It is especially important to continue updating the diary if your loved one is still experiencing confusion or trouble with their memory and thinking.

If you have not been keeping a diary, it is not too late to start. You can go back and summarize your loved one's time in the ICU. Follow your loved one's lead in terms of sharing information from the diary. You can let them know that you have been keeping a diary and ask if they are ready to hear more about their time in the ICU and in recovery. Some people may be ready to hear this information earlier in their recovery while others may need months before they feel ready. A person must be emotionally ready and cognitively able to process the information.

What should I write in the ICU Diary?

- › A good starting point can be what brought your loved one to the ICU.
- › A general idea of the care they received and how they progressed while in the ICU.
- › Personal messages and news from home can decrease their sense of the loss of time.

Why do we recommend keeping an ICU Diary?

Decreases false memories

- › Keeping an ICU diary has been shown to reduce the onset of post-traumatic stress disorder in patients and families following critical illness.

Stress reduction

Some patients' memories can be affected by the use of sedative drugs or by the illness itself. Often patients have little to no factual memory of their stay and instead develop false memories of their time in the ICU. Though false, the memories can feel real. The ICU diary can help patients understand some of the general and factual things related to their care.

Decreases sense of time loss

- › As ICU patients recover many feel a sense of the loss of time during their stay. Keeping a record of their time in the ICU can help orient and ground patients during recovery by filling in the gaps.

Relatives/Caregivers experience

- › Former ICU patients report a greater ability to empathize with the experience and feelings that their family member/caregiver endured while they were in the ICU. The diary promotes understanding and increases patient and family member/caregiver connection.
- › Writing and journaling about difficult experiences provides an outlet, helps create new meaning and fosters growth. Writing can also highlight questions you may have or alert you to information you need clarified.

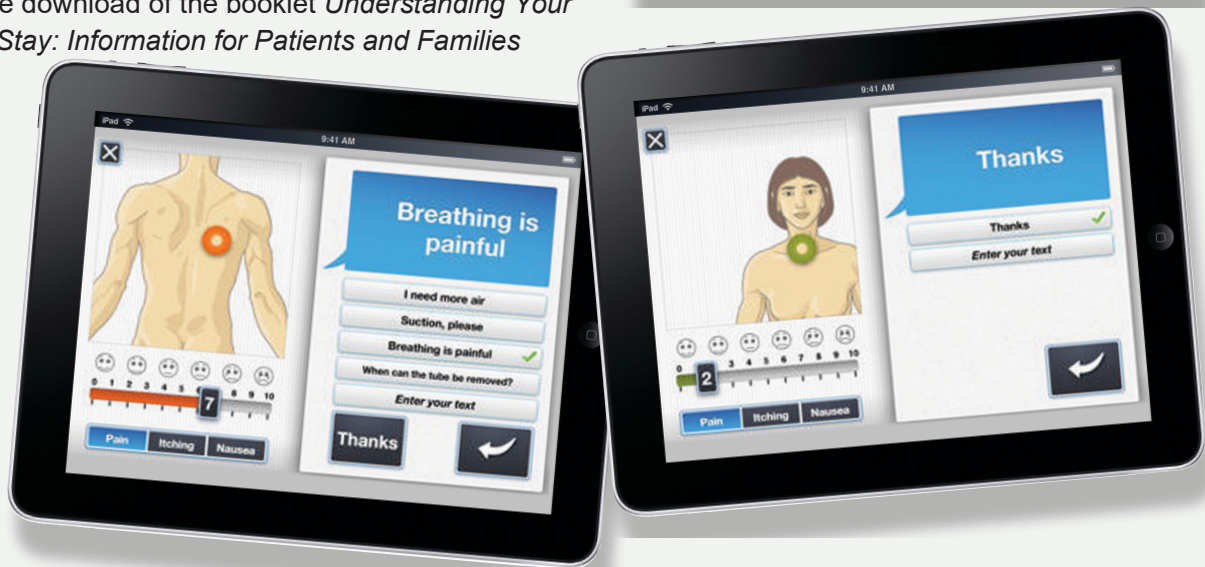
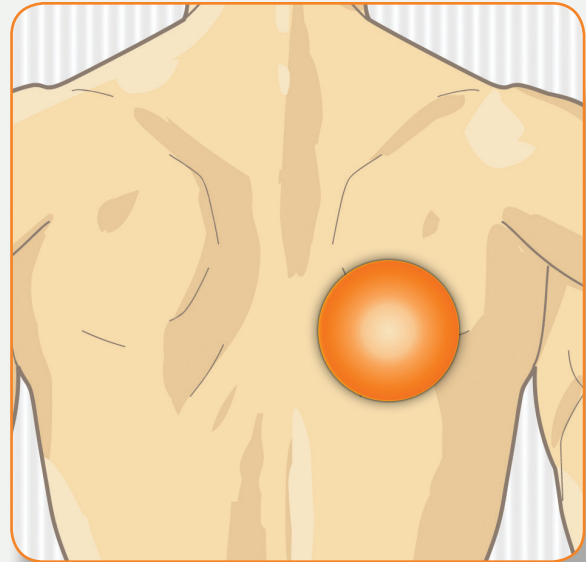
Patient Communicator

Free App!

The Patient Communicator app by the Society of Critical Care Medicine is designed to improve communication among patients, families, and caregivers. The app can help ease the stress of a hospital stay.

Features include:

- A new diary function that allows patients, or their family members, to track daily progress during and after a hospital stay
- Translation capabilities that allow for two-way communication in 18 languages on a variety of topics, such as pain, basic needs, and moods
- A scale that allows patients to identify where on the body they feel sensations of pain, itching, and nausea and express the intensity of these sensations
- More than 30 translatable phrases that allow patients to express various needs related to their care and well-being
- A glossary of terms to help educate patients and families about the intensive care unit
- A free download of the booklet *Understanding Your ICU Stay: Information for Patients and Families*



Download the app or recommend it to patients and families in your ICU. The app is available for iPhone and Android. For more information and to download the app, visit scm.org/PatientCommunicator

Society of
Critical Care Medicine
The Intensive Care Professionals



Helpful Providers During Recovery

Please consult your primary care doctor if you are unsure what provider you need.

- › **Occupational therapist:** A caregiver who helps those who are recovering from injury or illness regain activities of daily living such as grooming, bathing and dressing. An occupational therapist can also assist with cognitive rehabilitation and memory.
- › **Physiatrist:** A medical doctor who specializes in treating injuries or illnesses that affect functional abilities such as athletic injuries, neurological disorders, strokes and concussions, as well as injury to the brain, spinal cord, nerves, muscles, tendons and ligaments. They can prescribe medicine for pain and teach exercises to restore functionality.
- › **Physical Therapist:** A caregiver who helps improve mobility and strength. The goal of physical therapy is to restore independence, relieve pain and ensure safe return to daily activities.
- › **Speech-Language Therapist:** A caregiver who helps with speech, cognitive -communication and swallowing difficulty. Speech therapists can also help with cognitive rehabilitation.
- › **Neuropsychologist:** A specialized provider who can do testing to determine diagnosis and treatment for patients who have difficulty with memory, thinking and brain dysfunction.
- › **Behavioral Health Counselor:** A therapist or counselor who can help treat depression, anxiety and PTSD. Counseling can help relieve symptoms, identify solutions and increase coping skills. Counseling can also help family members and caregivers reduce stress, increase coping and self-care. Counselors are advanced degree professionals and may be licensed clinical social workers (LCSW), licensed professional counselors (LPC), licensed marriage and family therapists (LMFT) or psychologists.

- › **Social Worker and Care Manager:** Each unit of the hospital is staffed with a social worker and nurse care manager to assist with information on helpful services, resources and referrals for your needs after the hospital. The social worker will help with referrals to facilities such as physical rehabilitation centers and the nurse care manager will provide information and resources if you are going directly home after the hospital. Social workers and case managers are also part of the team at rehabilitation facilities and home care agencies.
- › **Psychiatrist:** A mental health doctor who specializes in diagnosing and treating mental health conditions. Psychiatrists can prescribe medication, if needed.
- › **Post-ICU Clinic:** A comprehensive outpatient clinic that specializes in providing care and coordination for ICU survivors and their families. These clinics are made up of an interdisciplinary team of critical care doctors, mental health professionals, nurses, physical and occupational therapists and care managers.

Atlantic COVID Recovery & Post ICU Care Center.

Call our designated care coordinator who will speak with you about your symptoms and schedule an appointment for you to meet with one of our specialists. Please see page 11 of this booklet for more information, call 908-522-3361, or visit atlantichealth.org/ICU or atlantichealth.org/covidrecovery.

If you live outside of the Morristown, NJ, area visit MyICUCare.org for a directory of clinics in the United States and internationally, or you can contact your local hospital system and inquire about the availability of Post ICU Care and or COVID Recovery programs.



Post ICU Care Center

Recovery challenges can be common after critical illness. Post Intensive Care Syndrome includes new or worsening physical, cognitive (difficulty with word recall, memory, thinking) and behavioral health problems, such as anxiety, depression and posttraumatic stress symptoms that remain after a critical illness. Whether your time in the ICU was a result of COVID-19 or another illness, the Post ICU Care Center can help.

"The goal of this new program is to identify a core team for coordinated care to streamline the referral process with timely scheduling, testing and communication among our physicians."

-Scott Lauter, MD, Chief Medical Officer, Atlantic Medical Group

Our providers will make a plan specific to your needs, working closely with specialists such as:

- › Primary Care
- › Behavioral Health
- › Pulmonology
- › Neurology and Neuropsychology
- › Rehabilitation Medicine

Peer Support for former ICU patients and their family members is available through our Thrive: Post ICU Recovery Group.

The First Step to Make You Well Again

The first step in post ICU recovery is contacting our designated care coordinator who will speak with you about your symptoms and schedule an appointment with one of our specialists. To schedule an appointment or for more information call 908-522-3361 or visit atlantichhealth.org/ICU.



Atlantic Covid Recovery Center

If you or your loved one have persistent COVID-19 symptoms, you're not alone. Shortness of breath, extreme fatigue, anxiety or depression, tachycardia (racing heart), joint pain, chest pain, cough, memory loss and brain fog are common and can persist for weeks, sometimes months. Whether you are experiencing mild symptoms or need more specialized care — the medical team at the Atlantic COVID Recovery Center are with you every step of the way.

Many patients diagnosed with COVID-19 continue to experience symptoms that require aftercare. The Atlantic COVID Recovery Center addresses the needs of patients who have symptoms that persist 30 days after having the virus.

Specialty care and peer support groups for COVID-19 recovery and post ICU recovery are also available.

"The goal of this new program is to identify a core team for coordinated care to streamline the referral process with timely scheduling, testing and communication among our physicians."

-Scott Lauter, MD, Chief Medical Officer, Atlantic Medical Group

COVID-19 can affect many different systems within the body. At Atlantic COVID Recovery Center, we have a team of experts for treating medical conditions related to the lung, heart, brain, or many behavioral health complications, depending on the severity of your conditions:

- › Cardiologists
- › Pulmonologists
- › Behavior health specialists
- › Neurologists
- › Rehabilitation and physical therapists
- › Primary care physicians

The First Step to Make You Well Again

The first step in post COVID-19 recovery is contacting our designated care coordinator who will speak with you about your symptoms and schedule an appointment with one of our specialists. Our care coordinator helps guide each patient through the process — from arranging appointments and test authorizations to acting as a patient liaison. You can schedule an appointment by calling the number below or by visiting atlantichealth.org/covidrecovery.

Contact the Atlantic COVID Recovery Center today at 908-522-3361.



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Emotional and Psychological Health Problems After Critical Illness

If you or your loved one experience depression, anxiety or post-traumatic stress after the ICU, a behavioral health counselor or therapist can help. If you are transferring to another unit within the hospital, you may want to speak with a social worker or counselor. You may also benefit from speaking with the hospital psychiatrist. If you are transferring to a rehabilitation facility, ask about services available. Facilities may have a psychologist, social worker, psychiatrist or support group that can help.

Signs of Depression

- › Symptoms of depression can include feeling sad, empty, worthless or hopeless. Loss of motivation, loss of interest in things that you used to find joy in, difficulty sleeping, and loss of appetite are some signs of depression.

Signs of Anxiety

- › Symptoms of anxiety can include feeling panic, fear, being unable to stay calm, shortness of breath, tense muscles, dizziness, and persistent worrying are some signs of anxiety.

Signs of Post-Traumatic Stress Disorder (PTSD)

- › After witnessing or experiencing a traumatic event you are at risk for developing PTSD. Serious illness such as critical illness can result in PTSD for both patients and their family members. Some symptoms of PTSD include unwanted memories of the trauma, flashbacks that feel as though you are reliving the trauma, avoiding thinking or talking about the trauma, avoiding places and people related to the trauma, feeling on edge or easily frightened, feeling numb or detached.
- › If you are experiencing PTSD, make sure you find a therapist or counselor who has special training and expertise in treating trauma. Below are examples of trauma-focused treatments.
 - Trauma-Focused Cognitive Behavioral Therapy
 - Prolonged Exposure

- Cognitive Processing Therapy
- Eye Movement Desensitization and Reprocessing (EMDR)
- › The online PTSD Treatment Decision Aid <https://www.ptsd.va.gov/apps/decisionaid> is a helpful tool to learn about your treatment options and to find the one that is best for you.

Remember it is never too late to get help. It is normal to feel worried about starting treatment. You are not alone and help is available.

Outpatient Behavioral Health Counseling

- › Atlantic Behavioral Health's Behavioral Medicine Program can help treat anxiety and depression related to physical illness. Please call their main access line at 1-888-247-1400 or visit atlantichealth.org.
- › Online Directories such as psychologytoday.com have features where you can locate therapists and psychiatrists by zip code, insurance accepted and specialty. You can also search therapists that provide video counseling if you are unable to leave your home.
- › Community Mental Health agencies also have therapists that can help, some agencies will offer home visits to clients with health and physical disabilities.
 - Jewish Family Services of MetroWest NJ provides in-home and office-based counseling. In home counseling is determined on a case-by-case basis. Counseling services are not religious-based and you do not have to be Jewish to receive services. They are located at 256 Columbia Turnpike, Suite 105, Florham Park, NJ 07932; 973-765-9050.
 - Mental Health Association of Morris & Essex County MHA Morris 973-334-3496, MHA Essex 973-509-9777 Behavioral health counseling services as well as medication management services available with a psychiatrist mhaessexmorris.org
- › Lastly, you can contact your insurance company and ask for an in-network list of providers in your area.

Other Resources for Emotional Help

- › The Trauma Survivors Network’s mission is to provide, “a community of patients and survivors looking to connect with one another and rebuild their lives after a serious injury. The underlying goal of our resources and programs is to ensure the survivors of trauma a stable recovery and to connect those who share similar stories.” Please visit traumasurvivorsnetwork.org for helpful resources, online programs and more.
- › The National Center for PTSD has information, education and resources for the public about PTSD. The website also features a “Treatment Decision Aid” this online tool helps you learn about and compare effective treatments for PTSD including cognitive behavioral therapy, cognitive processing therapy, prolonged exposure, EMDR and other effective treatments. Most treatments for PTSD average 10 to 12 sessions. Visit ptsd.va.gov.
- › Peer Support Groups can be another resource as you recover. Peer support is not treatment but rather helps reduce feelings of loneliness by connecting you and your family to others in the “same boat”. Peer support groups foster hope and increase connection. Members share knowledge, tips and experiences related to their recovery.
 - NJ Self-Help Group Clearinghouse lists support groups for stroke, caregiver, amputee, etc. Contact 1-800-367-6274 or njgroups.org.
 - Thrive: Post-ICU Recovery Peer Support Group in this booklet.

Morristown Medical Center’s Post-ICU Recovery Support Group

For former adult ICU patients and their families

Meetings are held on the fourth Monday of the month from 6:30 to 8:00pm and are being held virtually during the pandemic.

Many people face challenges after critical illness and enduring long ICU stays, including: cognitive and memory issues, muscle weakness, emotional stress/PTSD-like symptoms.

Family members/caregivers can also experience these emotional symptoms. This is called post-ICU Syndrome (PICS).

To help patients and their families identify and support PICS, Morristown Medical Center has begun the state’s first support group for PICS.

The group, part of the Society of Critical Care Medicine’s Thrive collaborative, is a safe space to give and receive support and connect survivors and their caregivers to others facing similar challenges and situations.

Thrive is a peer support group, facilitated by a social worker.

Registration is required before each member’s first meeting. For more information, please contact Heather Imperato-Shedden, LCSW, or Amy Hendricks, LSW at 973-971-5699 or Heather.Imperato-Shedden@atlanticealth.org, Amy.Hendricks@atlanticealth.org.



Hopeful Encounters



Through the Eyes of an ICU Trauma Survivor's Lived Experience

My name is Pedro "Pete" Martins, a former Intensive Care Unit (ICU) patient. I'm a current volunteer in the ICU where my spiritual awakening, transformation and Post-Traumatic Growth (PTG) began. In 2017, I was involved in a serious motorcycle accident in which I sustained a vast number of life-threatening injuries causing me to be on life support for 10 days. Having 18 surgeries completed as of today, I'm blessed and grateful to be alive.

As a volunteer in ICU, I work closely with nursing, social work and other support staff members to help patients and their families. I also represent patients' and family members' feedback and perspective on the ICU Patient Family Centered Care Committee.

My purpose is to:

- › Help patients and families navigate the ICU through support and lived experience.
- › I can also provide insight on the path of recovery and what may lie ahead.
- › I often talk to patients and families about challenges, ups and downs, fears, uncertainties, and the ongoing journey of recovery.
- › I also share and celebrate the milestones, progress, and transforming experience that can happen after critical illness.
- › I am here to listen and provide comfort and hope so that no patient or family must go through this experience alone.
- › Despite the challenges I have been through, I have experienced significant growth as a result of my own injuries. I have found that the practices of gratitude, spirituality, meditation and sharing my own story have put me on the path of positive transformation.

My goal is to partner with the ICU staff as they support the patient, family and loved ones on their path of recovery. I hope to empower, inspire, and motivate people during their trials and tribulations.

***"We Can, We Will, We Must" (Eric Thomas).
We rise by lifting others.***

Pete Martins

Morristown Medical Center - ICU
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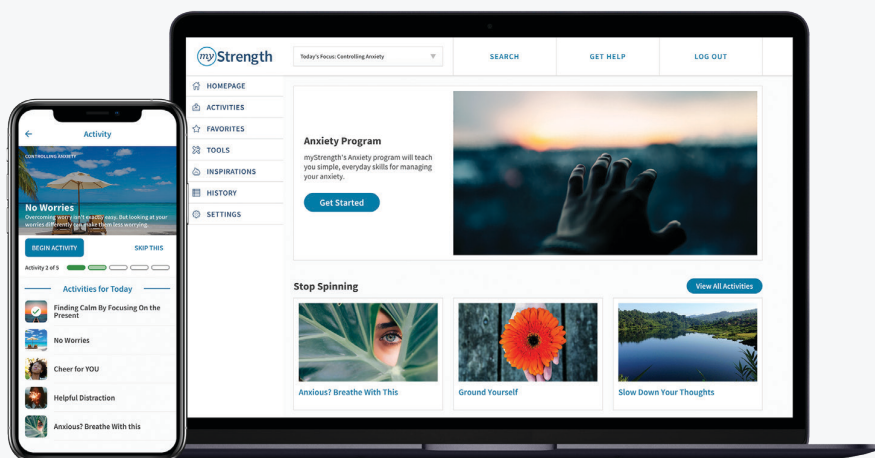
Schedule:

Tuesday, Wednesday and every other Saturday

PERSONAL SUPPORT FOR YOU

Recharge, Refresh and Improve Your Mood with myStrength

Now you can use myStrength's web and mobile tools to support your goals and well-being. Learning to use myStrength's tools can help you overcome the challenges you face and stay mentally strong. And it's all safe, secure and personalized – just for you.



**What myStrength
users are saying:**

“It’s nice to have self-guided help that is so accessible.”

“myStrength gives me back some of the ‘light’ I had lost.”

SIGN UP TODAY

Visit www.mystrength.com and click on “Sign Up.”

- If you or your loved one's time in the ICU and recovery is a result of COVID please use the access code: **CovidICUSupport**
- If it is NOT a result of COVID please use the access code: **ICUSupport**

Go Mobile! Download the **myStrength** mobile app, log in, and get started today.

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Substance Use Disorders and Trauma

If you or your loved one have a history of substance use, are currently using or were using prior to critical illness be mindful of your recovery needs. Experiencing a trauma like serious illness can trigger relapse. If you are looking for treatment and support for substance use, the following resources may be helpful:

› **U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration**

Treatment locator to find services in your area. For tips on locating quality treatment view, Publications tab, search “Finding Quality Treatment for Substance Use Disorders”.
samhsa.gov

› **NJ Addiction Hotline**

State-funded hotline staffed by Rutgers Behavioral Health professionals
844-276-2777

› **National Institute on Alcohol Abuse and Alcoholism**

Resources and treatment navigator
alcoholtreatment.niaaa.nih.gov

› **American Board of Addiction Medicine**

If you are looking for a physician to provide medication-assisted treatment you can search the directory
abam.net

› **New Jersey Coalition for Addiction Recovery Support (NJ CARS)**

A coalition of compassionate caregivers and providers who offer recovery support services to individuals with substance use disorders and their families.
nj-cars.org

› **The New Jersey Alliance of Recovery Residences**

A non-profit agency that maintains high quality standards for recovery residences in the state of New Jersey

njarr.org to find a list of certified residences

- Members

- Certified Residences

Self-Help and Peer Support Groups

› **Alcoholics Anonymous**

12-step program with other peers who are in recovery

njaa.org/

› **Al-Anon**

A 12-step program to provide help and hope for families and friends of a person with an alcohol problem. While the primary focus is to help solve problems experienced by family and friends of a person with alcoholism, groups may also be helpful if you are the family or friend of a person with a drug addiction problem. Adult and teen groups offered.

nj-al-anon.org/

› **Narcotics Anonymous**

12-step program with other peers who are in recovery for drug addiction.

nanj.org/

› **Smart Recovery**

Mutual support meetings are free and open to the public. Meetings are for anyone seeking science-based, self-empowered addiction recovery (alcohol, drugs, or activities such as gambling or overeating). Family and Friends meetings also available as well as online meetings.

smartrecovery.org

THREE STEPS TO ACCESSING CARE

1. If you have insurance: Contact your insurer. Ask about your coverage and whether they have a network of preferred providers for you to use.

If you don't have insurance: Each state has funding to provide treatment for people without insurance coverage. Find where to call for information about payment for services at: [samhsa.gov/sites/default/files/ssa-directory.pdf](https://www.samhsa.gov/sites/default/files/ssa-directory.pdf)

2 Review the websites of the providers and see if they have the [five signs of quality treatment](#) detailed below.

3 Call for an appointment. If they can't see you or your family member [within 48 hours](#), find another provider. One indicator of quality is the ability to get an appointment quickly. Many programs offer walk-in services. Look for programs that can get you or a family member into treatment quickly.

FIVE SIGNS OF QUALITY TREATMENT

You can use these questions to help decide about the quality of a treatment provider and the types of services offered. Quality programs should offer a full range of services accepted as effective in treatment and recovery from substance use disorders and should be matched to a person's needs.

1. Accreditation: Has the program been licensed or certified by the state? Is the program currently in good standing in the state? Are the staff qualified? Good quality programs will have a good inspection record and both the program and the staff should have received training in treatment of substance use and mental disorders and be licensed or registered in the state. Does the program conduct satisfaction surveys? Can they show you how people using their services have rated them?

2. Medication: Does the program offer FDA approved medication for recovery from alcohol and opioid use disorders? At this point in time, there are no FDA approved medications to help to prevent relapse from other problem substances.

3. Evidence-Based Practices: Does the program offer treatments that have been proven to be effective in treating substance use disorders including medication management therapies, such as motivational therapy, cognitive behavioral therapy, drug and alcohol counseling, education about the risks of drug and alcohol use, and peer support? Does the program either provide or help to obtain medical care for physical health issues?

4. Families: Does the program include family members in the treatment process? Family members have an important role in understanding the impact of addiction on families and providing support.

5. Supports: Does the program provide ongoing treatment and supports beyond just treating the substance issues? For many people addiction is a chronic condition and requires ongoing medication and supports. Quality programs provide treatment for the long term which may include ongoing counseling or recovery coaching and support, and helps in meeting other basic needs like sober housing, employment supports, and continued family involvement.

TREATMENT LOCATORS

Substance Use and Mental Health Treatment Locator:

findtreatment.samhsa.gov/
1-800-662-HELP (4357)
1-800-487-4899 (TTY)

Alcohol Treatment Navigator:

alcoholtreatment.niaaa.nih.gov/

FOR A DRUG OR ALCOHOL USE EMERGENCY, CALL 911 OR GO TO THE NEAREST EMERGENCY ROOM

PICS Groups in Other Locations & Online Support

The Society of Critical Care Medicine's THRIVE peer support initiative believes strongly in the unique power of ICU survivors supporting one another. If you live out of the Morristown, NJ, area please visit the below website to find a group near you:

› **MyICUCare.org**

As part of this initiative, SCCM THRIVE hosts an online Facebook Group: Post-Intensive Care Syndrome Support Group. The group is a closed, private group started by ICU survivors. To join please visit **facebook.com** and enter: "Post-Intensive Care Syndrome Support Group" in the search. Once you are on the Support Group page, click on join. Your request will be sent to the group's administrator and you will receive an alert once you are added to the group. Or you can visit **MyICUCare.org** and click on Join the Facebook Group.

› Mayo Clinic Connect **connect.mayoclinic.org**

An online community where you can share your experience and find support from people like you.
- Join a Discussion Group
- Search "Intensive Care"

Additional Support Groups

If you are looking for a group specifically for issues related to Post-ICU Syndrome then please see page 11 for information about Morristown Medical Center's Thrive: Post-ICU Recovery group.

There are many other support groups geared towards specific illnesses such as, stroke survivors, caregivers of stroke survivors, cancer support groups, traumatic brain injury, amputee support groups, etc. For a complete directory of support groups in NJ, please visit the NJ Self Help Clearinghouse where you can search by zip code and group topic at **njgroups.org**, or call 1- 866-367-6274.

Stroke Support Groups

- › Atlantic Rehabilitation - 6 Saddle Road, Cedar Knolls: 973-971-4412
- › Atlantic Neurosurgery Partnership for Strength: 862-345-7392
- › Kessler Institute for Rehabilitation. Groups are held at the following locations:
 - Saddle Brook, NJ: 201-368-6012
 - Chester, NJ: 973-252-6316
 - West Orange, NJ: 973-731-3600, ext. 2276

Amputee Support Groups

- › Atlantic Rehabilitation - Amputee Walking School: Cedar Knolls, New Providence, Newton Medical Center, Pompton Plains, Hackettstown Medical Center: 973-971-4659
- › Kessler Institute for Rehabilitation. Groups are held at the following locations:
 - Saddle Brook, NJ: 201-368-6087
 - West Orange, NJ: 973-414-4755

Brain Injury

- › Atlantic Rehabilitation, New Providence, NJ: 908-522-2885
- › Kessler Institute for Rehabilitation. Groups are held at the following locations:
 - Chester, NJ: 973-252-6375
 - West Orange, NJ: 973-677-4260
 - Saddle Brook, NJ: 201-368-6194

Brain Tumor

- › Atlantic Neurosurgery Center for Hope, Brain Tumor Support Group: 862-345-7392

Spinal Injury

- › Kessler Institute for Rehabilitation, West Orange, NJ: 973-731-3600, ext. 4725

Cancer Support

atlantichealth.org

See: Conditions & Treatments, Cancer, Cancer Support Groups

Chronic Pain

- › Overlook Medical Center, Summit, NJ:
908-665-1988

COVID Recovery Group

- › Atlantic COVID Recovery group is made up of peers and clinicians who provide support on how to manage the various psychological challenges that accompany this novel virus. The group is ongoing and individuals can choose to attend regularly or as needed. Meetings are on Wednesday from 6:00 to 7:00pm. Please call 862-217-3491 for more information.

Cognitive, Thinking and Memory Problems After Critical Illness

If you experience difficulty with:

- › Thinking, remembering, problem solving, paying attention, word finding, organizing your thoughts and concentrating on tasks, you may be suffering from the cognitive effects of critical illness.
- › If you are transferring to an inpatient rehabilitation facility, ask if they have inpatient cognitive rehabilitation services. The below resources are for outpatient services. You may need a prescription from your primary care doctor.
- › If you are interested in beginning outpatient cognitive rehabilitation, ask your physician for a prescription that states, "neuropsychological evaluation." The Cognitive Rehabilitation program will require this to schedule an appointment.
- › If you have a traumatic brain injury and are uninsured or do not have insurance coverage for outpatient cognitive rehabilitation, the New Jersey Division of Human Services has a traumatic brain injury fund that covers services and support including neuropsychological and cognitive therapy. Please call 1-888-285-3036 or visit state.nj.us/humanservices/ and search TBI fund for an application.

Outpatient Cognitive Rehabilitation Resources

Atlantic Health System has several locations for outpatient cognitive rehabilitation.

This service is provided by a speech pathologist and occupational therapist that will conduct a cognitive-linguistic evaluation and will develop an ongoing plan to meet your needs.

- › Atlantic Rehabilitation – Brain Works,
6 Saddle Road, Cedar Knolls, NJ
973-971-4451
- › Atlantic Rehabilitation- New Providence
550 Central Avenue, New Providence, NJ
908-522-2215
- › Atlantic Rehabilitation- Pompton Plains
242 West Parkway, Pompton Plains, NJ
973-831-0717
- › Hackettstown Medical Center
651 Willow Grove Street, Hackettstown , NJ
908-850-6925
- › Newton Medical Center
175 High Street, Newton, NJ
973-579-8600

Private Practice Neuropsychologists

- › American Academy of Clinical Neuropsychology has a provider directory at theaacn.org
- › New Jersey Psychological Association has a provider search, enter neuropsychology in the practice area and search by county at psychologynj.org

Atlantic Health System Neuroscience – Memory and Cognitive Disorders Program

The program treats conditions such as dementia, Alzheimer's disease and mild cognitive impairment. Our highly specialized team will work with patients, families and referring physicals to coordinate treatment, follow-up care and education, and make referrals to other services, when necessary.

Locations

- › Atlantic Neuroscience Institute
99 Beauvoir Avenue, Summit, NJ 07901
908-522-2829
- › Atlantic Neuroscience Institute
741 Northfield Avenue, Suite 210
West Orange, NJ 07052
908-522-2829

ICU-Acquired Weakness

If you experience difficulty with:

- › Strength, mobility, pain or endurance you may be suffering from ICU-acquired weakness.
- › If you are transferring to an inpatient rehabilitation facility, they will provide physical and occupational therapy. When you are ready to leave rehab, the case manager can provide referrals and resources for home based or outpatient care, such as physical and occupational therapy.
- › If you continue to experience weakness after rehab, you may find a post-rehab exercise program helpful.

Outpatient Physical Therapy Resources

A physical therapist is a caregiver who helps restore a patient's ability to function and be independent after injuries to the muscles, bones, tissues and nervous system.

The goal of physical therapy is to improve mobility and strength, restore independence, relieve pain and ensure a safe return to daily activities. Physical therapists will work with the individual in a one-on-one environment throughout their course of treatment, gauging their progress and making adjustments as needed to meet individual goals. Any accompanying pain is closely managed to ensure the greatest possible benefit from therapy.

- › Physical therapy is provided at a variety of Atlantic Health System locations, including Cedar Knolls, Morristown, New Providence, Byram, Summit, Chatham, Hackettstown, Rockaway, Mountain Lakes, Newton, Pompton Plains, Randolph, Union and Warren, NJ. Please call 1-855-862-2778 to schedule an appointment or to verify availability of services.
- › You can also call your insurance provider for a list of physical therapy centers covered by your plan.

Outpatient Occupational Therapy Resources

An occupational therapist is a caregiver who helps patients relearn life skills, such as the activities of daily living and the use of memory (for example, grooming, feeding, dressing, balancing a checkbook). Occupational therapy is used to help those who are recovering from injury or illness regain the functional abilities necessary for daily life and independence, such as grooming and dressing.

- › Occupational therapy is provided at a variety of Atlantic Rehabilitation locations, including Atlantic Rehabilitation – Morristown, Newton Medical Center, Hackettstown Medical Center, Cedar Knolls, New Providence, Rockaway and Pompton Plains. Please call 1-855-862-2778 to schedule an appointment or to verify availability of services.
- › You can also call your insurance provider for a list of occupational therapy centers.

Post-Rehab Exercise Programs

Atlantic Rehabilitation's post-rehabilitation exercise and maintenance programs are ideal for post-stroke patients and those with neurological disorders who may not feel comfortable in a common health club setting. Patients with pulmonary conditions and orthopedic injuries may also benefit from training in our non-threatening atmosphere supervised by a team of exercise physiologists.

Our group programs help patients build endurance and strength while improving their productivity, quality of life and social skills. We offer a wide variety of exercise options both on land and in water.

For more information visit atlantichealth.org

Look under Conditions and Treatments, then tab to Rehabilitation and Physical Therapy, Post-Rehab Exercise Programs.

- › Atlantic Health has three locations for post-rehab exercise. This program is not covered by insurance and typical monthly membership is approximately \$65.
 - Atlantic Rehabilitation – Morristown
111 Madison Avenue, Morristown, NJ 07960
973-683-2360
 - Atlantic Rehabilitation- New Providence
550 Central Avenue, New Providence, NJ 07974
908-522-2215
 - Atlantic Rehabilitation- Pompton Plains
242 West Parkway, Pompton Plains, NJ 07444
973-831-0717

Speech-Language Therapy

If you experience difficulty with speaking or swallowing a speech-language therapist can help. In addition, speech therapists are typically part of cognitive rehabilitation and can help with memory, thinking and attention problems.

If you are transferring to an inpatient rehabilitation facility, they will have speech therapists available to assist you. When you are ready to leave rehab, the case manager can provide referrals and resources for outpatient speech therapy.

Outpatient Speech-Language Therapy Resources

A speech therapist is a caregiver who helps patients with problems related to memory, attention and swallowing. Speech therapists help patients that have trouble with their thinking and their memory and are usually part of cognitive rehabilitation programs. Speech therapists also help patients learn to speak again, if necessary.

Patients recovering from stroke, neuromuscular disease, critical illness, traumatic brain injury or vocal cord impairments can turn to a speech-language pathologist for help. Programs can provide children and adults with a wide variety of diagnostic and treatment services.

- › Ask your primary doctor for a referral to a speech-language therapist.
- › Speech therapy is provided at a variety of Atlantic Rehabilitation locations, including Atlantic Rehabilitation – Cedar Knolls, New Providence, Newton Medical Center, Chilton Medical Center and Hackettstown Medical Center. Please call 1-855-862-2778 to schedule an appointment or to verify availability of services.
- › You can also call your insurance provider for a list of speech-language therapy providers.

Home Care Agencies and Private Home Health Aide Agencies

Home Care

Home care is supportive health care provided in an individual's home by health care professionals. These professionals may include Certified Home Health Aides (CHHA), Certified Nursing Assistants (CNA), Nurses (RN or LPN), Rehabilitation Therapists (Physical/Occupational/Speech), or Case Managers/Social Workers. Home care is often needed for those recovering from surgery or hospitalization, home care may also be provided after a rehabilitation stay. Home care is for skilled care and treatment or rehabilitation services to homebound patients. It is usually for short-term support and requires individuals to meet specific criteria to continue to medically qualify for home care services through insurance.

- › If you are going home after the hospital talk with the nurse care manager about home care services.
- › If you are going to a rehabilitation facility after the hospital, once you complete inpatient rehabilitation the social worker or case manager can help with a referral to a home care agency.
- › Atlantic Visiting Nurse, 465 South Street, Suite 100A, Morristown, NJ 07960, 973-379-8400: atlanticehealth.org
- › Medicare Home Health Compare: medicare.gov
- › National Association of Home Care and Hospice: nahc.org

Home Health Aide and Non-Medical Companion Agencies

While Medicare and private insurance may cover some home care services, such as help after surgery, hospitalization or rehab, it is usually short-term and an individual must meet medical criteria. Medicare and private insurance do not cover ongoing home care to assist with personal care and supervision, often called "custodial care," and therefore this is often an out-of-pocket expense. Medicaid and Long-Term Care Insurance do cover custodial care. If you are a Veteran or spouse/widow(er) of a Veteran, consider applying for the Veterans Aid & Attendance pension benefit. Home health aides and non-medical companion agencies can provide light housekeeping, meal preparation, laundry assistance and activities of daily living such as bathing, dressing, and using the bathroom. Average hourly cost in Northern NJ is \$24-\$26 per hour.

- › Atlantic Private Care, 465 South St., Morristown, NJ 07960, 973-540-9000: atlanticprivatecare.com
- › Home Care Association of NJ: homecarenj.org
- › Veteran's Administration: benefits.va.gov/pension
- › NJ Medicaid: state.nj.us/humanservices

Helpful Websites

Post-ICU Syndrome Information

atlanticealth.org/icu	What to Expect in the ICU Meet the Team
myicucare.org	Patients & Families tab
icusteps.org	Patients & Relatives tab
sepsis.org	Resources tab, Patients & Family
icudelirium.org	For Patients & Families
aftertheicu.org	What is PICS What is PICS-F Patients & Family ICU Discussion
healthtalk.org	People's Experiences, Categories, Browse All, Intensive Care Patients' Experiences
ptsd.va.gov	For the Public

Disability and Family Leave

- › **Federal Family and Medical Leave Act** allows eligible employees of covered employers to take unpaid, job-protected leave.
dol.gov/whd/fmla
- › **NJ Family Leave Act** allows eligible employees of covered employers to take unpaid, job-protected leave.
njoag.gov, **Divisions, Division on Civil Rights, Resources, NJ Family Leave Act**
- › **NJ Family Leave Insurance** allows eligible employees to receive paid leave to care for a family member with a serious health condition. The definition of "family member" has been expanded to cover more people including domestic partners, any blood relative and any individual whom you consider to be family.
myleavebenefits.nj.gov
- › **NJ Temporary Disability** allows eligible employees to receive a portion of their pay if their illness prevents them from working and was not caused by their work. Ask your employer if their coverage is through a private plan or through the State plan. If through the State plan, visit:
myleavebenefits.nj.gov
- › **Social Security Disability** provides eligible employees with a qualifying medical condition monetary benefits. This program is generally for people who are unable to work for a year or more. You can apply as soon as you are disabled, you do not have to wait until a year has passed.
ssa.gov/disability/

Medical Records and MyChart

Medical Records

Medical Records Department – Morristown Medical Center

The Medical Records office is located on Level B
Hours: Monday to Friday, 8:00am to 6:00pm
Saturday, 8:00am to Noon, Sunday, Closed
Phone: 973-971-5183; Fax: 973-290-7999

To request a copy of a medical record from Morristown Medical Center's Medical Records Department, begin by printing a HIPAA-compliant authorization form – available in English or Spanish. You can download the form at the Morristown Medical Center Medical Records website: atlantichealth.org/morristown/the-patient-experience/after-your-stay/medical-records.html

Mail or fax the completed form to:

Morristown Medical Center
Attention: Medical Records, Box #22
100 Madison Avenue, Morristown, NJ 07960

Once the form is received, an invoice for the associated fee or a status letter will be sent to the requestor's address. There is no charge for your record if it is faxed or mailed to a physician's office or health care facility. If your request requires a fee, please send payment as soon as possible to the department. Upon receipt, the medical record copy will be available for pick up or mailed within 30 days.

MyChart — Patient Portal

Patient portals offer our patients the convenience of managing their Atlantic Health System medical information from anywhere at any time using your computer, smartphone or tablet.

MyChart is a feature of our new, fully-connected electronic medical records system, Epic. It currently supports patients of Atlantic Medical Group physician practices and all Atlantic Health System hospitals.

Download the MyChart app from the Apple Store or Google Play or go to mychart.atlantichealth.org

Supporting Children and Teenagers – When a Loved One Is Recovering from Serious Illness

Critical illness affects the whole family. It is important to find ways to support, include and encourage children and teenagers to share their experience throughout their loved one's illness and recovery.

Visitation

The ICU allows visitors age 12 years and older. During flu season, further age restrictions apply. Depending on circumstance, exceptions may be granted. Other units of the hospital and rehab facilities are likely to allow for visitors under age 12 years old, but check with the unit or facility first. Please visit atlantichealth.org to review if any visitor restrictions are in effect. If your child or teen did not visit their loved one in the ICU, they may be eager to see them. Research has shown that children over the age of four typically find visiting a sick family member helpful.

A visit can help children and teens understand and participate in caring for their loved one and often lessens feelings of separation and fear. You should not force your child or teen to visit, but, if your child or teen is asking to visit, it is important to explore their need.

Prepare them for what they will see; does their loved one look different? If so, explain this before a visit, such as "Daddy's body was working very hard in the ICU, so he looks thinner than when you last saw him".

Some families find it helpful to take a picture of their loved one to show children and teens before a visit to help prepare them for any physical changes.

If your child or teen does not visit, find ways to include them by giving them age-appropriate updates, have them draw pictures, make cards and care packages or record video messages for their loved one. Allow and give permission for them to ask questions. Teens who are reluctant to talk about their feelings and experience may find it helpful to write in a journal or diary.

Helpful Websites for Children and Teens

sesamestreetincommunities.org	Topics section
kidshealth.org	Videos explaining how the body works and illness
artwithheart.org	Shop section has therapeutic books for kids and teens
ELunaNetwork.org	Resource Center, Explore topics such as “resiliency”
TeenHealthFX.com	Online resource for teenage health

Support Groups for Children and Teens

Imagine – Coping with Illness: Support Groups for Caregivers and Children

244 Sheffield Street
Mountainside, NJ 07092
908-264-3100;

imaginej.org

Imagine provides free year-round peer support groups for adult caregivers and children who are living with a family member’s chronic or terminal illness. Groups are safe spaces for people to express feelings and gain support. Newark, NJ, location opening in 2019.

The David and Joan Powell Center for Healthy Aging

The David and Joan Powell Center for Healthy Aging

also has a geriatric assessment center.

973-971-7022

435 South Street, Suite 390,

Morristown, NJ 07960

The center is an interdisciplinary approach to identifying the medical, functional and psychosocial challenges faced by many adults age 65 and older. It focuses on older individuals with complex problems and the goal is to improve functional status and quality of life. Below are some of their services:

- › Consultative geriatric assessment for adults 65 and older with complex medical issues and/or memory changes
- › Social work consultation and referrals to community services
- › Primary care services for ongoing care for those age 60 and older
- › Caregiver guidance, education and support
- › Help if you are facing challenges as a caregiver
- › For a free resource directory with services in surrounding counties that are relevant to older adults or adults with a disability, please call the center.

Morristown Medical Center

100 Madison Avenue
Morristown, NJ 07960

atlanticealth.org/ICU

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Atlantic
Health System
