



Beth Israel Lahey Health

Post-ICU Care for Survivors of COVID-19

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BILH Interim Handbook to Address Post-Intensive Care Unit (ICU) Care for ICU Survivors with Coronavirus Disease-2019 (COVID-19)

RATIONALE

The care of ICU survivors with COVID-19 will pose unique challenges for in-hospital care by medical and surgical floor teams. First, these patients will require relatively intense and sophisticated acute management in the hospital related to issues such as delirium, acute physical impairments, acute social needs, residual pulmonary disease and residual effects of investigational COVID-19 medications. Second, due to their prolonged critical illness, these patients will be at risk for the Post-Intensive Care Syndrome (PICS), in which patients experience impairments in the domains of mental health, physical function, or cognition.^{1,2} These new impairments may be severe and enduring, impacting quality of life months to years after critical illness. Additionally, the health system will face unique challenges due to sheer number of patients as well as unprecedented strain on the health system's resources (including both staff and available personal protective equipment (PPE)).

These guidelines seek to empower all care providers to optimize patient care and recovery of ICU survivors with COVID-19. Specifically, it will assist providers in (a) applying best practices and expert recommendations to the acute in-hospital management of ICU survivors with COVID-19, (b) recognizing patients at risk for PICS, and (c) participating in a tiered approach to PICS patient/family education and early management, with the overall goal of optimizing patient recovery after critical illness.

SCOPE

This interim guideline applies to the medical/surgical wards. It will not cover issues covered in-depth in existing institutional guidelines, such as empiric anticoagulation for patients with COVID-19 or speech and swallow issues after prolonged intubation.

TARGET PATIENT POPULATION

This interim guideline seeks to identify patients transferred from an ICU to the floor who:

- Received mechanical ventilation for ≥ 2 days, +/- sedation or paralysis, AND/OR
- Received vasopressors ≥ 2 days while in shock, AND/OR
- Were documented to have episodes of delirium in any setting during this hospitalization

COMMON POST-ICU COMPLICATIONS AND INTERVENTIONS

Delirium

Acknowledgements: Sharon K. Inouye, MD, MPH; Joshua Leo, MD, MPH; Lew Lipsitz, MD; Edward Marcantonio, MD, SM

The circumstances surrounding critical illness from COVID-19 (prolonged mechanical ventilation with often deep levels of sedation, potentially from multiple pharmacologic classes, in an isolated environment) place patients at high risk for delirium. Moreover, isolation precautions required for COVID-19 patients place unique challenges on delirium management (e.g. limited use of 1:1 sitters, inability of staff to rapidly enter rooms to intervene).

1. Promote **mobilization**; see Physical Limitations section, below.
2. Ensuring **adequate fluid intake** can be challenging in absence of frequent in-person contact. Consider leaving a water jug in the room with a reminder note to drink (when volume overload is not a concern).
3. ICU survivors with COVID-19 are at **high risk for constipation and urinary retention** given prolonged bed rest and sedating medications, especially opiates. Monitor bowel/bladder output; consider prophylactic use of gentle bowel stimulants, if needed.
4. Because in-person contact is limited, **frequent reorientation** is important. Put a clock and calendar in each room, and ensure it is kept up to date. Orient also to the presence and use of telephone or any other communication devices.
5. Encourage **virtual contact from family**. Ensure patients have access to bedside phones, charged cell phones or tablets. Provide advice to family on conversations to manage delirium

virtually. (See Additional Resources below). Social Work (SW) can also help families engage in interventions that will help ground and orient patients virtually.

6. **Communication in PPE can be disorienting** to patients and adapt communication approach accordingly. (See Additional Resources below).
7. Antipsychotics do not treat delirium but rather provide chemical sedation. Antipsychotics contribute to QTc prolongation. Monitor EKGs and potassium/magnesium levels; **avoid/wean antipsychotics as able**. Antipsychotics also increase risk of aspiration pneumonia.³
8. Encourage **families to keep an ICU diary** after receiving updates from medical staff. This may help patients to reflect upon events of their hospital stay after they are discharged.

Consult triggers:

- Obtain a **Geriatrics** consult for any older adult with a) agitated delirium in whom providers are considering pharmacotherapy or b) multimorbidity whose delirium could be due to underlying diseases/dementia/medications.
- Consider **Psychiatric** consultation especially for patients with delirium on multiple psychiatric medications that may need adjustment in the acute setting.
- Consider **Occupational Therapy (OT)** consult for patients with new cognitive deficits/delirium

Additional resources:

1. How to prevent and support delirium in an older adult in hospital or a care home, when you can't visit in person (*A resource for families*):

<https://www.rgptoronto.ca/wp-content/uploads/2020/04/How-to-prevent-and-support-delirium-in-an-older-adult-when-you-can%E2%80%99t-visit-in-person.pdf>

2. Communication tips for clinicians caring for older adults experiencing delirium during the COVID-19 pandemic:

<https://www.rgptoronto.ca/wp-content/uploads/2020/04/COVID-19-Communication-tips-for-clinicians-caring-for-older-adults-experiencing-delirium.pdf>

3. Considerations for preventing and managing delirium in older adults during the COVID-19 pandemic, across the care continuum:

<https://www.rgptoronto.ca/wp-content/uploads/2020/04/COVID-19-Prevention-and-management-of-delirium-in-older-adults.pdf>

4. COVID-19 Resources from the Hospital Elder Life Program (HELP)

<https://www.hospitalelderlifeprogram.org/for-clinicians/covid19-resources>

Physical Limitations

Acknowledgements: Brian McDonnell PT, DPT, GCS; Shannon Stillwell PT, DPT, GCS

ICU survivors with COVID-19 will also face immediate limitations on their mobility and functional status as well as longer-term effects of PICS (see below). Besides being personally challenging, these limitations may constrain discharge options; delaying discharge further challenges limited resources in the hospital. As such, maximizing mobility for a prompt and safe discharge is not only a patient and provider priority but also a health system priority. Physical therapy (PT) consultation for patients diagnosed with COVID-19 will occur once patient is medically appropriate for mobility assessment. Due to PPE limitations and transmission risk, PT and/or OT will not be able to provide every patient with a high frequency of PT and/or OT treatment sessions.

1. Patients should be **screened for mobility impairment by nursing**. If a patient is **limited by fatigue** but is physically able to perform basic functional mobility (transfer out of bed, stand, walk) then encouragement/education regarding the role of strengthening exercises and the importance of graded return to mobility/activities of daily living (ADLs) should be provided by the nursing staff and medical team. Refer to **Appendix A** for a higher-level exercise handout that teams can provide to such patients. (See below regarding lower-level activity handout for less active patients.)

2. **Be aware of patients' level of activity.** Reference the Activity section of nursing notes. Medical teams should communicate with nursing staff to **assess barriers to mobility** if entries indicate that the patient is spending an excessive amount of time in bed.
3. **De-escalate precautions** as soon as is safe (see ['BILH Guidance for Discontinuing Precautions for Hospitalized Patients with Suspected COVID-19'](#)) and coordinate with Infection Control as needed) in order to allow for increased frequency of OT and PT visits as well as increased options for rehab placement.

Consult triggers:

- Consult PT and/or OT if **physical assist is required for basic functional activities**. PT may ask team members to provide **Appendix B**, a lower-level exercise handout, to such patients.
- Consult PT/OT if there are concerns for **"Intensive care unit-acquired weakness" (ICUAW)**, which includes critical illness myopathy (CIM) and critical illness polyneuropathy (CIP). **CIM** presents primarily as quadriparesis that may affect proximal more than distal muscle (resolves in weeks to months). **CIP** may include reduced or absent deep tendon reflexes, or loss of peripheral sensation to light touch and pinprick (may take longer to resolve).
- Consider consulting **neurology** for weakness noted in extraocular muscles or other cranial nerve impairment; these are NOT typically seen with ICUAW. Significant, asymmetric upper extremity weakness may warrant further work up for potential brachial plexus injury related to prolonged prone positioning.

Acute Social Needs

Acknowledgements: Jaclyn French MSW, LICSW; Katherin Hudkins MSW, LCSW; Kayley Walsh MSW, LICSW

ICU survivors with COVID-19 may face a unique set of social challenges related to feelings of trauma, isolation, personal and family finances, and family support. While Social Work will be following from the ICU, they will be constrained in terms of their ability to visit and support these patients.

1. Ensure any necessary **Family and Medical Leave Act (FMLA)** paperwork is completed for patients and family.
2. Inquire with patients/families about any **specific resource concerns**, as well as **coping and mental health**.

Consult triggers:

- Patient endorsing/demonstrating high anxiety/panic attacks, feelings of depression, or appear very withdrawn from team/family: SW can offer psychoeducation on medical and other trauma symptoms, brief interventions to reduce anxiety and other symptoms, provide resources on mental health, and also aid in referral/counseling depending on patient's cognitive status and ability to engage. In some cases, this allows SW to develop relationships that can be followed-up on discharge and to assess PTSD, anxiety, depression, resource needs.
- Family manifesting anxiety, e.g. by calling team multiple (e.g. >3) times per day: SW can help counsel family members and provide some psychological first aid and psychoeducation on trauma reactions for families while loved ones are still admitted, provide some information on PICS-Family variant.
- Patient/family endorsing resource concerns: SW can provide information on food pantries, unemployment and benefits, legal aid, housing assistance and rights.
- Disposition unclear due to home situation: SW can help navigate resources for patients with COVID-19 in need of quarantine.
- Poor prognosis requiring multidisciplinary GOC conversation.

Toxicities of Investigational Pharmacotherapies for Management of COVID-19:

Acknowledgements: Mehrnaz Sadrolashrafi Pharm D, BCCCP

Patients receiving investigational therapies for COVID-19 should be monitored for the following side effects,^{4,5} in some cases beyond the duration of therapy (e.g. hydroxychloroquine):

Medication	Mechanism of action	Side effects
Azithromycin	Macrolide antimicrobial, possible immunomodulating properties	<ul style="list-style-type: none"> • QTc prolonging, especially in combination with other QTc prolonging agents. Maintain serum magnesium >2 and potassium ~4 • N/V/D
Hydroxychloroquine	Alteration of membrane pH preventing viral fusion, inhibits binding to ACE2, blocks viral protein transport to nucleus	<ul style="list-style-type: none"> • QTc prolonging, especially in combination with other QTc prolonging agents. If QTc>500 or ΔQTc >60 ms, consider discontinuation. Maintain serum magnesium >2 and potassium ~4. • Note prolonged half-life (~40-50 days); cardiac abnormalities may persist beyond duration of therapy • N/V/D, abdominal cramps • Hypoglycemia from possible inhibition of insulin degradation • Metallic taste
Remdesivir	Inhibition of viral RNA-dependent RNA polymerases in the viral infectious cycle	<ul style="list-style-type: none"> • Data limited, reports of ↑ LFTs and kidney injury (can also accumulate in renal failure due to drug formulation and further worsen renal injury)
Sarilumab & Tocilizumab	Monoclonal antibody IL-6 receptor antagonist; may potentially combat cytokine release syndrome (CRS) and pulmonary symptoms in severely ill patients diagnosed with SARS-CoV-2	<ul style="list-style-type: none"> • Neutropenia • Thrombocytopenia • ↑ LFTs • Hyperlipidemia • ↑ risk of diverticulitis and bowel perforation (rare) • Infectious complications (reactivation of TB/Hepatitis, and other opportunistic infections) • Note: Majority of the safety data is extrapolated from RCTs studying tocilizumab in rheumatoid arthritis.

Post-Intensive Care Syndrome (PICS): Mental Health, Cognitive, and Physical Domains

Patients with prolonged ICU stays, especially those on mechanical ventilation with sedation/paralysis, will be at risk for the Post-Intensive Care Syndrome (PICS), in which patients experience impairments in the domains of mental health, physical function, or cognition (see box). In many cases, SW, OT, and PT will have become involved while the patient is still in the ICU; see notes in OMR for plan of care and recommendations.

1. Ensure the action items in the above sections, Delirium, Physical Limitations, and Acute Social Needs are all met.

Domains of impairment following critical illness:

- **Mental health:** anxiety, depression, and post-traumatic stress symptoms such as nightmares, flashbacks, touchiness
- **Cognitive:** memory loss, “foggy” thinking, difficulty making decisions
- **Physical:** weakness, falls, inability to perform activities of daily living

2. Discuss with patients and families the potential for PICS, distribute **Appendix C**.

Consult triggers:

- Follow above consult triggers for further involvement of SW, PT, or OT. Note that OT can provide initial cognitive testing, like a mini-MOCA.

Resources:

1. Patient-facing video discussing PICS:

<https://www.youtube.com/watch?v=T03palv4mYU&feature=youtu.be> (English version)

<https://www.youtube.com/watch?v=IFHAqf0p7JY&feature=youtu.be> (Spanish version)

2. Patient and family resources for PICS:

<https://www.sccm.org/MyICUCare/THRIVE/Patient-and-Family-Resources>

<https://www.sccm.org/MyICUCare/THRIVE/Post-intensive-Care-Syndrome>

Post-ARDS Pulmonary Management

Patients recovering from ARDS, especially those with underlying chronic lung disease (e.g. COPD or interstitial lung disease) may experience prolonged recovery courses, where hypoxemia may take longer to resolve. Mitigate readmission by recognizing and treating common complications.

1. Be vigilant about **aspiration**. Patients can be screened informally by nursing at the bedside; if concern persists, involve Speech and Swallow for formal evaluation.
2. Patients recovering from concomitant acute renal failure or heart failure may be susceptible to **volume overload**. In such patients, monitor ins and outs carefully and be judicious about oral intake.
3. Patients with viral upper respiratory infection are susceptible to **bacterial superinfection**. Monitor for new signs of infection (WBC, fever curve, new sputum production). Initiate basic workup with sputum and blood cultures and CXR before initiating empiric coverage.
4. Consider **DVT/PE** in patients who have been weak/bedbound for many days.
5. Recognize risk factors for significant **atelectasis**, including pain (causing splinting), obesity (causing abdomen to reduce total lung volume), and weakness/supine position. Ensure underlying pain is treated adequately and encourage patients to be out of bed and upright during the day. Provide patients with an incentive spirometer to reduce atelectasis (and supply encouragement).

Consult triggers:

- Consult Pulmonary for refractory hypoxemia unexplained by aspiration, volume overload, or atelectasis, or in patients with complicated underlying chronic pulmonary conditions.

Basic Tracheostomy Care

Acknowledgements: Mihir Parikh, MD

Some patients will be transferred to the floor receiving oxygen through a new tracheostomy tube.

1. An HME filter and/or surgical mask should cover the tracheostomy at all times. This can be discussed with Respiratory Therapy.
2. If the tracheostomy tube is dislodged within the first few 1-2 weeks of placement, **do not attempt to replace**. Consult anesthesia for intubation from above if a new artificial airway is urgently needed.
3. Tracheostomy suctioning and tube exchange are aerosol generating procedures and proper PPE and safety practices should be followed.
4. Getting patients **on the road to speaking** can be very helpful for the patient psyche. When patient is awake and interactive, consult speech and swallow (if not already involved) and encourage patient to begin using a Passy-Muir speaking valve when safe. This is a one-way valve that allows air to enter the trachea via the tracheostomy tube, but air must exit via the patient's vocal cord. **ENSURE PILOT BALLOON is down** when valve is in place.

Consult triggers:

- Consult the service that performed the tracheostomy for hemoptysis or bleeding at the tracheostomy site, difficulty suctioning or clearing respiratory secretions, and inability to tolerate speaking valve trials.

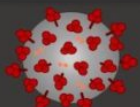

Pre-Discharge Checklist

Acknowledgements: T. Jack Iwashyna MD, PhD (University of Michigan): <https://litfl.com/the-dirty-dozen-common-errors-on-discharging-patients-recovering-from-critical-illness/>⁶

- **Reconcile home medications:** Many medications (antihypertensives, statins, inhalers, Synthroid) are transiently held in the ICU and often need to be restarted. Consider starting at a lower dose if blood pressure, blood sugars, weight, or creatinine have not returned to baseline, and ensure a realistic plan for outpatient follow-up to continue titration is in place.
- **Stop new ICU medications:** Many medications (anti-psychotics, PPI, H2 blocker, sleep aids, or opiates) are transiently started in the ICU.
 - Antipsychotics from ICU stay should be discontinued without taper if there is no strong indication to continue
 - Opioids (PO, IV, or patch) used during ventilation in ICU should be discontinued if no strong indication: can initially change to PRN and discontinue after 24-48 hrs. if no ongoing needs
 - Benzodiazepines: discuss with a pharmacist to guide rapid taper, dependent on duration and half-life
 - Discontinue PPI/H2 blocker unless patient has a baseline indication.
- **Discuss anticoagulation plan:** Many patients with COVID-19 receive empiric anticoagulation. Determine if anticoagulation was based on known clot or simply empiric (e.g. based on elevated d-dimer). If no signs/symptoms/past known clot, consider discontinuation
- Ensure patient has a **point person to field follow-up questions** prior to first primary care provider visit.
- **Provide exercise handouts** with sufficient education and encouragement (see above Physical Limitations section and Appendix A and B).
- **Ensure “temporary devices” are all out**, including temporary IVC filters.
- Provide a **list of lines/tubes/drains** placed during the hospitalization. Knowing what their “bumps/bruises/holes” are from can help patients re-orient/cope, and also help patients be aware of healing/infection risks.
- Determine **essential follow-ups:** given difficulties with follow-up in the current environment, prioritize 1-3 areas of follow-up (consider nutritional support among these three).
- Educate patients on **signs and symptoms of common reasons for readmission**, including: infection, heart failure, aspiration, acute kidney injury, and COPD exacerbation.
- Ensure **PT/OT has signed off** on the patient, and/or provided necessary resources.
- Ensure patient has the **resources to pay** for follow-up; involve SW as necessary.
- Ensure patient has the **handout on Post-Intensive Care Syndrome (Appendix C)**.

The Dirty Dozen: 12 Points to Cover Prior to COVID Dispo

Home Meds Restarted?	Should new ICU meds be stopped?	What is the anticoag plan?	Who fields q's prior to 1 st follow up?	Exercise Plan to recondition	What follow up is most key?
Removal Plan for tubes/lines/filters	Written tubes/lines recap	Teach common readmit issues	Have PT/OT evaluated?	Can they pay for what they need?	Expect post-ICU syndrome

 **#CoVisuals** Source: Dr. TJ Iwashyna @iwashyna
 @CAHarrisMD

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Appendices

Appendix A: Higher-level Exercise Handout

Appendix B: Lower-level Exercise Handout

**Appendix C: Patient Education on Post-
Intensive Care Handout, ATS**



Exercise program for: _____

It is important that you keep active while you are hospitalized. The transition from hospital to home will be easier if you maintain your strength as much as possible. Stay active in the hospital by participating in general daily tasks such as washing up and brushing your teeth. Perform the exercises below to help to maintain your strength.

Many people also experience continued difficulty breathing while recovering from COVID-19. It is common to experience fatigue and frustration upon return home from the hospital. Activities that used to be easy may be difficult or may cause shortness of breath. A general rule is that you should be able to maintain a light conversation while walking or performing daily tasks.

Focusing only on rest during your recovery may contribute to even more weakness. Learning how to conserve energy is all about finding a good balance between work and rest so that you can be more independent in getting back to activities that you enjoy. Here are some strategies that can be useful in conserving your energy:

- **Pace yourself.**
 - Take breaks during tasks
 - Avoid activities that cannot be stopped.
 - Avoid rushing. Use a slow, steady pace.
 - Remember to stop tasks before you feel tired.
- **Think ahead.**
 - Plan out activities to be done during the day so you're not doing too much at once or planning for too many activities in one day.
 - Prioritize activities so the most important tasks get done first.
 - Delegate tasks to others as needed.
 - Gather the tools you need prior to starting a task to avoid extra trips.
- **Sit down when possible.**
 - It may be helpful to use a shower chair or sit to prepare meals.
- **Avoid holding your breath during activities.**
- **Avoid excessive bending and reaching.**
 - You may find it easier to bring to leg up to rest on your opposite knee when dressing your lower body.



Exercises:

Below are some examples of seated exercises. You should try and perform 10 repetitions of these exercises three times per day, whenever you are seated in a chair. Perform each exercise slowly.

Sitting



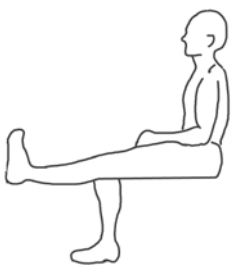
Raise toes, then heels.



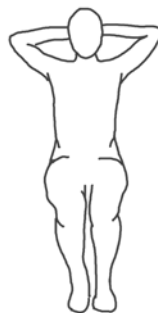
Raise your arms up straight in front of you toward your ears, then lower.



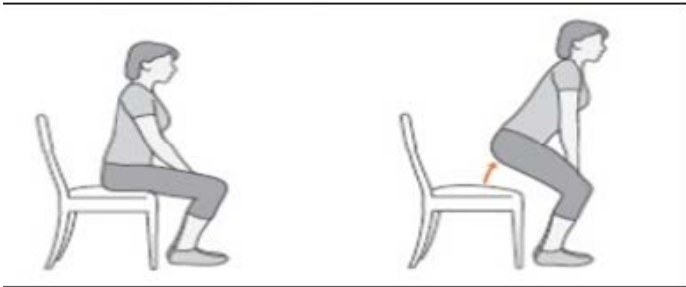
While sitting, march one leg at a time.



Raise one foot to straighten knee, then lower, one leg at a time.



Breathe in, and then slowly exhale as you bring elbows together in front of your face. Breathe in again while moving elbows back out to the side, squeezing your shoulder blades together.



Sitting in your chair, lean forward and stand up, using your arms, if necessary, to support you. Return slowly to sitting. Repeat this exercise 10 times in a row, if possible.

Standing

Below are some examples of standing exercises. You should try and perform these exercises three times per day, whenever your nurse or doctor is in the room to assist you. You should perform these exercises while holding onto the back of a chair for extra support.



Lift one knee, then the other, marching in place.



Raise heels and toes up and down.



Bring one leg out to the side while standing tall. Repeat with your other leg.



Walking Log:

Each day, you should try and walk around your room several times. The goal is to build up to walking a total of 30 minutes daily. Check in with your nurse before walking to ensure you don't have any lines or tubes in your way. Below, you can track your activity:

<u>DATE</u>	Walk #1 Time	Walk #2 Time	Walk #3 Time	Walk #4 Time	Walk #5 Time



Exercise program for: _____

It is important that you keep active while you are hospitalized. Your recovery will be easier if you maintain your strength as much as possible. Stay active in the hospital by participating in general daily tasks such as washing up and brushing your teeth. Perform the exercises below to help to maintain your strength.

Many people also experience continued difficulty breathing while recovering from COVID-19. It is common to experience fatigue and frustration during the recovery process. Activities that used to be easy may be difficult or may cause shortness of breath. A general rule is that you should be able to maintain a light conversation while performing exercises or mobility.

Focusing only on rest during your recovery may contribute to even more weakness. Learning how to conserve energy is all about finding a good balance between work and rest so that you can be more independent in getting back to activities that you enjoy. Here are some strategies that can be useful in conserving your energy:

- **Pace yourself.**
 - Take breaks during tasks
 - Avoid activities that cannot be stopped.
 - Avoid rushing. Use a slow, steady pace.
 - Remember to stop tasks before you feel tired.
- **Think ahead.**
 - Plan out activities to be done during the day so you're not doing too much at once or planning for too many activities in one day.
 - Prioritize activities so the most important tasks get done first.
 - Delegate tasks to others as needed.
 - Gather the tools you need prior to starting a task to avoid extra trips.
- **Sit down when possible.**
 - It may be helpful to use a shower chair or sit to prepare meals.
- **Avoid holding your breath during activities.**
- **Avoid excessive bending and reaching.**
 - You may find it easier to bring to leg up to rest on your opposite knee when dressing your lower body.



Exercises:

Below are some examples of exercises. You should try and perform 10 repetitions of these exercises three times per day, when you are in bed or seated in a chair. Perform each exercise slowly.



Slowly pump your ankles up and down. You may feel a stretch in the back of your leg.



Lie on your back with one leg straight and the other bent. Lift your leg straight off of the bed and hold for 5 seconds.



Bend and straighten your leg by sliding your heel up toward your buttocks.



Tighten your buttocks and lift it up off of the bed. Hold for 5 seconds.



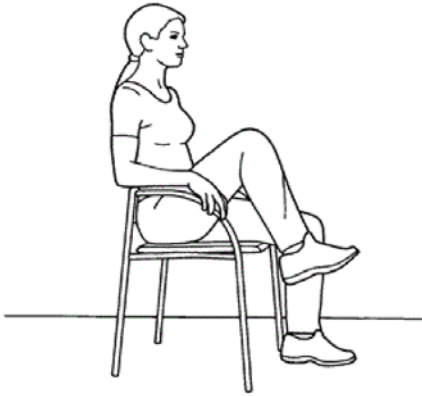
With your thumb pointing toward the ceiling, slowly raise your arm. Keep your arm as close to your ear as possible.



Slowly bend your elbow, bringing your hand toward your face. Now straighten.



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While sitting, march one leg at a time.



Raise one foot to straighten knee, then lower, one leg at a time.



Roll your shoulders back, bringing your shoulder blades down and together. Hold for 5 seconds.



Activity Log:

Each day, you should try and increase your mobility and how much activity you can tolerate. In addition to the exercises listed above, you can also work on progressing your mobility both in bed and out of bed. You may need help to perform these tasks from the hospital staff, and to ensure you don't have any lines or tubes in your way. Below, you can track your activity:

	Sit at edge of bed	Sit in chair	Stand	Walk to bathroom	Walk around room	Exercises	How I felt
Sunday							
Monday							
Tuesday							
Wednesday							
Thursday							
Friday							
Saturday							

What Is Post–Intensive Care Syndrome (PICS)?

Post-intensive care syndrome (PICS) is a group of problems that people can experience after surviving a life-threatening illness. More than half (50 percent) of all people who survive a hospital stay in the intensive care unit (ICU) will have at least one of the problems seen with PICS. These problems can greatly affect the lives of survivors of critical illness. Problems can be physical or mental and may affect one's ability to think or function in daily life. Many patients are unable to return work and do not have the same energy level that they had before their illness. This fact sheet will review common problems seen with PICS as well as ways to try to prevent and treat these problems.



"I have had problems associated with PICS since 2008. I have had issues in all areas: physical, mental and cognitive in one way or another. I have always found it striking when talking to my fellow survivors how much variability there is in how people cope with the problems associated with PICS. One person can still function and work, while another patient who was only hospitalized

for three days in the intensive care unit (ICU) will not leave her home. Some people's entire life may be destroyed by fear. Based upon my own and others' experiences, I advocate for early physical therapy and humanizing the ICU as much as possible.

I was fortunate that my family, and even my hairdresser and massage therapist were able to visit often, which helped me to feel less anxious and feel better emotionally and physically. We stopped the sedation while I was still on the ventilator, so I was able to think more clearly, communicate, start PT, and even use my cell phone and laptop once I had regained some strength. It is also very helpful to work with your healthcare team to create a schedule so that you can do all of the "work" during the daytime, and sleep at night without interruptions. We need to help patients and families have a menu of strategies to manage stressors during and after the ICU and hospital stay. The sooner a patient starts to think, communicate, and be more physically active, the sooner he or she will start to feel like him or herself again."

Susan East, ARDS Survivor and Patient Advocate.

For more about Susan's story, see: <https://www.thoracic.org/patients/par/par-publications/patient-voices6/resources/11-east.pdf>

What kinds of problems are seen with PICS?

There are three main kinds of problems:

- physical function
- mental health
- cognitive function

Physical symptoms include weakness, pain, shortness of breath, and difficulty with movement or exercise.

Mental health symptoms range from mild anxiety or irritability to severe depression, sleep disturbances, and post-traumatic stress disorder.

Cognitive changes include difficulty thinking, remembering, or concentrating.

People who develop PICS can experience any combination of these physical, emotional, and cognitive symptoms. They may be entirely new problems, or worsening of problems that were present before the critical illness.

How can you tell if a person is having problems from PICS?

PICS is likely when a person is having new or worsening physical, mental health, or cognitive symptoms following

a critical illness. A healthcare provider may notice these symptoms by asking a person or his or her caregiver specific questions about how he or she is doing. There are also formal tests that may provide more information about the severity of symptoms. Walking tests or other measures of strength and endurance can check for physical problems. Lung function testing checks for breathing problems. Healthcare providers often use questionnaires to ask about anxiety, depression symptoms, breathlessness, the ability to complete daily tasks (such as bathing), and a person's overall quality of life. There are no specific blood or radiology tests to diagnose PICS. Your healthcare provider may advise some tests to check for other health conditions needing to be treated.

Who gets PICS?

PICS can affect any person who survives a critical illness, even people who were healthy prior to their severe illness and hospital stay. PICS is most common among people who were admitted to an ICU, but many people treated outside of the ICU can develop this condition. People who had existing health problems, such as lung disease or muscle disorders, prior to a hospitalization are at higher risk of developing PICS. People with psychiatric illness or cognitive impairment (dementia) are also more likely to have worsening of their



symptoms after an ICU stay. Some types of illnesses and events that may occur in the hospital may also increase a person's risk of developing PICS. For example, people who have severe infections, acute respiratory distress syndrome, delirium, low oxygen levels, and/or low blood pressure during their illness are more likely to have PICS.

Can PICS be prevented?

Several things can be done during a hospitalization that may reduce the risk of developing PICS. If a person needs breathing support, the healthcare team will try to minimize time on the mechanical ventilator and use as little sedating medication as is safe. Physical therapy can be started early during an illness even while other intensive medical therapy is going on. Family members and healthcare providers can keep a diary of events that happen in the hospital to help patients link memories they have to the care they received. Having family and friends talking with the patient, bringing in music and pictures from home, and being with the patient may also help the healthcare team's efforts.

How is PICS treated?

Treatment for PICS depends on the specific symptoms. Weakness and deconditioning can be treated with physical therapy and exercise programs. Mental health symptoms such as depression or anxiety can be treated with a combination of therapy and medications. If cognitive impairment results in difficulty thinking, remembering, or concentrating, a formal evaluation by a neurocognitive specialist may help. Occupational therapy may help ICU survivors manage these new difficulties and improve symptoms. Several multidisciplinary clinics now exist to provide support for patients after critical illness, and primary care physicians should be educated about and involved in this complex care. Treatment plans may involve several professionals working as a team. Social workers, pharmacists, physical therapists, occupational therapists, nurses, and physicians may each contribute to the recovery process. Clinicians do not have all the answers for helping patients recover from PICS and adapt to new problems. Sometimes patients and their caregivers may find it helpful to share stories with each other—both to get advice, and for the benefits of being able to help others with the things they have figured out.

Does PICS resolve?

PICS symptoms are often present six months to one year after a hospitalization. Every person will have a different recovery process. Some symptoms may improve or resolve completely within weeks, while other symptoms may improve slowly or persist for years. Even if symptoms do not improve, healthcare providers are able to support people as they adjust to a new level of functioning after critical illness. PICS may greatly alter the quality of life for people and their caregivers. Some people are not able to return

to work or the same type of work after critical illness. They may have financial challenges including difficulty paying for medications.

Does PICS affect caregivers?

Yes. Critical illness can be difficult for family members and other caregivers. This difficulty can extend after the loved one is discharged from the hospital. Caregivers can develop depression, anxiety, or post-traumatic stress disorder. It is important that caregivers find time to take care of themselves, ask for support when they need help, and work with their own healthcare providers to manage any symptoms they may have.

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Rx Key Points

- ✓ PICS can cause physical, emotional, and cognitive symptoms after a severe illness.
- ✓ Your healthcare provider may diagnose PICS based on the symptoms you have after leaving the hospital.
- ✓ The symptoms of PICS can last months to years.
- ✓ PICS can also affect family members and other caregivers.
- ✓ Work with your healthcare team and your caregivers to develop a treatment plan.

Healthcare Provider's Contact Number:

Resources

THRIVE Initiative: Redefining Recovery

- <https://www.sccm.org/MyICUCare/THRIVE/Post-intensive-Care-Syndrome>

After the ICU: PICS Online Library

- <https://www.aftertheicu.org/what-is-pics>

American Thoracic Society

- <https://www.thoracic.org/patients>
 - ARDS
 - Mechanical Ventilation

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