ICU Family Workbook
Working Draft

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Table of Contents

Introduction

It takes a village to care for someone after experiencing a critical illness because many aspects of daily life become disrupted, the recovery process can last for a long time, and it is normal to have a lot of questions. Also, the patient and you may have different types of needs during the post-ICU adaptation process. For example, some patients have physical needs (i.e., require assistance walking or going to appointments), need to make emotional adjustments (i.e., support to work through the changes experienced during this time), as well as cognitive needs (i.e., help managing finances or managing medications). The goal of this workbook is to provide guidance for patients, as well as their friends and family members, to navigate those stages of adaptation after an ICU stay. Here's how to use it:

- Review the topics in the contents.
- Focus on the areas that are currently important.
- Write down your questions, concerns and plans to address them.
- Access the resources offered at www.picturethis.pitt.edu
- Discuss your questions and needs with someone you trust on your relative's care team.
    - Doctors, social workers, and nurses can help with questions about the health condition, medications, discharge plans, and follow-up
    - Physical, occupational, and speech therapists can help you understand how to help your relative get stronger, move around safely, complete daily activities (such as bathing and dressing), eat safely, and explain

    equipment and changes you may need for your relative to return home.
    - Social workers can help you with questions about insurance, leave from work, caregiver support resources, discharge planning and financial assistance related to your relative's condition. They also can help you understand the role of other team members.
- Put sticky note tabs on the pages you're using the most, so you can find them easily.
- After discharge, take this workbook with you to any healthcare appointments. Review it with the provider, and take new notes.
- Feel free to reprint pages as needed. This resource is for your benefit so use it in the best way that fits for you.

Just like it takes a village to navigate critical illness, it took a village to design this workbook. We want to thank everyone who contributed. Since it's supposed to be a "living document," we welcome ongoing contributions. If you have a suggestion to make it better, please email it to picturethis@pitt.edu.

The ICU Stay

Personalizing the ICU/hospital room from Day 1

Having familiar things to look at, listen to, and touch can be comforting. It also helps the care team get to know you and make their conversations with your relative more personal. Even more importantly, it helps them personalize care for your family in a variety of ways; including understanding your relative’s likes and dislikes and helping find motivation for rehabilitation activities (ex: working towards the goal of returning home to be with pets, family, friends, etc.).

You can ask the ICU team for a whiteboard or paper on which you can share information you’d like them to know about your relative, like:

- Important people in their lives
- Music preferences
- Pets
- TV show preferences
- Things that cheer them up
- Things that help them relax
- How they spend their free time (i.e., hobbies, work)

Include photos of them before their illness and photos of important people or pets.

You can work with the ICU team about helping your relative:

- **Balance between pain and pain medications, and anxiety and sedative medications.** People in ICUs experience lots of symptoms. Medications to treat them come with side effects. Ask the nurse how they’re assessing symptoms, and look for signs that help you understand how your relative is feeling - and how they respond to different treatments. Often pain is better when anxiety and sleep are better - so use music, conversation, rest, and other tools to help.
- **Get protected sleep at night.** It is very hard to get high quality sleep in ICUs, but we should try.
    - Could music help?
    - Do they need ear plugs or an eye mask to help with the noise and light in the hospital? How else can we reduce disruptions from the ICU?
- **Safely move as much as possible.**
    - Bed and chair exercises can be done even when the person isn’t upright. Help set the expectation that everybody moves!
    - Ask about equipment in the hospital (e.g., recumbent bike) or ask the nurses/rehabilitation specialists for recommendations about equipment you can bring (e.g., resistance bands, stress balls).
    - Log activity and celebrate movement.
- **Connect as much as possible.**
    - If your relative has an electronic device (e.g., phone, tablet), consider queuing channels of their favorite calming music to play. Make sure headphones are available.

- You may not want to bring cherished or valuable items to the hospital for fear of them getting lost or ruined, but consider bringing something less precious that is still familiar and comforting (e.g., blanket).
- There is a lot of waiting time at the hospital - bring simple things to do (e.g., cards, simple crafts, knitting). If your relative is awake or alert, they may want to do some of these things with you, or have them available to do themselves.
- If your relative has a pet, ask if the visiting policies permit a visit - or if the hospital has a pet therapy program.
- Ask your relative’s nurse or doctor about any diet restrictions your relative may have. When you relative is able to eat/swallow, consider bringing comfort foods, as permitted by the healthcare team.

ICU Team Members

A lot of people work in ICUs. They are all there to care for your relative and your family. The Society of Critical Care Medicine's detailed descriptions are here. Atlantic Health also includes some here. This section gives a briefer description of common roles.

First, a few notes:

- Your relative's ability to recognize and remember people may be impaired. It's okay to remind the staff to introduce themselves each time they come into the room.
- Different roles have different work schedules. You can ask how long each person will be working with you and your relative. Some examples:
    - Attending physicians often work about a week at a time (although they go home to sleep)! The work is intense, and they rotate so that your relative and your family can receive care from fresh hearts and minds.
    - Nurses typically work 12 hour shifts. Some nurses will work a few days or nights in a row and others work less or more frequently. Nurses also rotate which patients they work with within a given unit. You may not have the same nurse each day or night.
    - Ancillary services (occupational therapists, physical therapists, speech therapists) typically work daylight hours (ex: 7-3:30 or 8-4:30). You can ask your nurse to ask if these individuals will be working with your relative.

Physicians

- There are a variety of terms used to describe the physician or doctor. You may hear the terms attending, resident, or fellow. These refer to the level of training the doctor has completed. You may also hear a doctor referred to by their specialty area (ex: intensivist (a doctor specializing in ICU care), pulmonologist (a lung doctor), cardiologist (a heart doctor), etc.). If you are uncertain about the role of the doctor, it's okay to ask.

Nurses

- Most of your contact will be with the bedside ICU nurse. There is also a "Charge Nurse" orchestrating nursing tasks across the ICU. Some ICUs have nurses who specialize in family support.

Respiratory Therapists

- Respiratory therapists treat breathing problems. In the ICU, they help with suctioning, breathing treatments, and running the breathing machines.

Technicians

- **Radiology technicians** frequently come to the ICU to take portable x-rays.
- **Personal care technicians** support personal care tasks like moving around with equipment, bathing, and feeding.

Social Worker

- Social workers have a wide range of practice for meeting the needs of individuals, families, groups, communities, and society.
- Across the post-ICU spectrum, they often:
  - Provide counseling
  - Facilitate peer support groups
  - Facilitate referrals to community-based resources
  - Help coordinate care that is aligned with the values and goals of patients and families

Case Manager

- Case managers help people navigate the health and social services systems. Their backgrounds are often in nursing or social work.
- Across the post-ICU spectrum, they often:
  - Facilitate discharge planning, including referrals for equipment, services, and community-based resources
  - Facilitate care coordination among complex care teams

Occupational Therapist

- You may hear the term “OT” or “therapy”
- Occupational therapists are involved in beginning the physical and cognitive rehabilitation for your relative.
- Occupational therapists are experts in assisting individuals in becoming as independent with daily living activities as possible. For your relative, this may look like working on getting out of bed, brushing teeth, getting dressed, or improving their strength to be able to get to the bathroom.
- Occupational therapists also help to determine what supports your relative may need for successful living

arrangements after they are discharged (ex: whether they will need durable medical equipment, like a bedside commode or shower chair, or whether they would benefit from additional therapy prior to returning home).

- They can help adapt habits and routines to emphasize what matters most to your relative and you - conserving energy and building up over time.

Physical Therapist

- You may hear the term “PT” or “therapy”
- Physical therapists specialize in activities and mobility.
- They help patients/clients improve strength, balance, gait, stamina, and mobility.
- They also help train families to support safe mobility.

Speech Language Pathologist

- You may hear the term “Speech” or “SLP”
- Speech language pathologists specialize in swallowing, talking, and cognition.
- They are often involved after critical illness to:
    - Help people who have been intubated or experienced delirium practice safe swallowing.
    - Address language impairments after stroke.
    - Provide cognitive rehabilitation to people with changes in their memory, organization/planning, and other cognitive functions after delirium.

Communicating with the ICU Team

There are lots of different ways to communicate with the ICU team depending on your availability and what you need to communicate about.

- Questions:
    - It’s important to know who your point person is. The ICU workflow makes continuity a challenge. Ask the care team members if there is someone who usually acts as a point person for families. It may be a case manager, social worker, or bedside nurse. Once you've identified someone you think would be a good point person, confirm with them that they can fill that role and ask how and when you may contact them. Keep in mind that you may need to update this for shift changes and there may be more than one individual in this role. Some people find that having a daytime point person and a nighttime point person works well.
    - Name of point person:________________________
    - How to contact:_________________________
- Daily updates:
    - If you are present in the hospital, the team should welcome you to listen in on their daily rounds. Daily rounds are usually in the morning. They are when the team reviews your relative’s progress and plans care for the next day. Ask the nurse about what time the team should get to your relative’s room, and if they can help make sure you are there to participate during rounds.

  - If you aren't present in the hospital, ask the team to identify a 2-hour time window when you're available for a physician or nurse to call you with a daily update.
- Family meetings:
  - Family meetings are opportunities to look at the "big picture." They help the ICU team get to know you, your relative, and understand what is important to you. They are typically longer than daily updates, include as many family members as wish to participate, and include key members of the clinical team (you can ask anyone you want to participate). The ICU team often offers information about how things are going, what to expect (including the prognosis), and potential treatment options. You work together on treatment decision-making and planning next steps. If you have a long ICU stay, it is valuable to have family meetings about once a week. This gives you a reliable way to be able to talk about issues that may otherwise get missed in the daily momentum of the ICU. If the ICU team has not offered to schedule a family meeting and you would like time to talk about things that are not discussed during rounds, it is okay to ask for one.

Questions you want to ask:

____

____

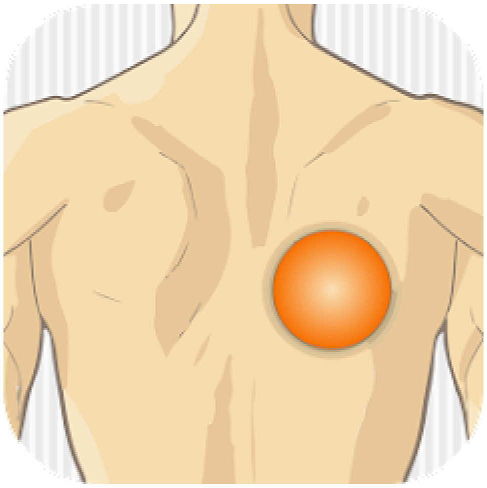
____

Notes on updates and family meetings:

Communicating with your Relative

Communicating with critically ill people can be difficult because of the equipment (e.g., ventilator), symptoms (e.g., weakness, shortness of breath, anxiety), sedation, and confusion. That makes maintaining connection all the more important.

The Society of Critical Care Medicine has made an App, available in the App Store and Google Play, to ease many aspects of communication: Patient Communicator App . The icon looks like this:



Many of the staff in the ICU can coach you about how to communicate with your relative. They may also have equipment that can help, including:

- Amplifiers for people with hearing loss
- White boards/pads for your relative to write
- Communication boards, which have pictures of common feelings and needs as well as an alphabet to allow your relative to point to or spell what they want to say

It is often surprising what people remember hearing during their ICU stays. Even if your relative does not appear to be able to hear, tell them anything you want to say. It may be comforting to them to hear normal chit chat. On the other hand, it is okay to ask to step out of the room for potentially sensitive conversations in which your relative cannot participate.

Activity Therapy in the Hospital

The ICU Journal: A diary of daily life in the ICU

The purpose of an ICU journal is to provide you and your relative with messages of hope, encouragement, and support while in the ICU -- and to help you and your family recall and process what happened afterward. The journal is not part of the medical record. If you keep a journal, we encourage you to review it with the care team every day. Anyone can make entries describing what is happening, what is making noise around your relative, and how your relative is interacting with everyone. Take this journal with you when you leave the hospital. When you are ready to review the contents of the journal - or share them with your relative - consider involving a counselor, support group, pastor, or someone else with experience helping people process major life events.

Other notes:

- Since others may read the entries in this journal, please do not write confidential messages.
- Write about:
    - Daily events, such as what is happening at home or outside the hospital.
    - The plan of care and progress that is occurring (What are the doctors and nurses doing? Are there other healthcare professionals involved? Who? What are they doing? Were there procedures or tests done?)
    - The physical surroundings, including sounds in the room and equipment you see.
    - Who has visited
    - How you feel
    - Messages of encouragement for your relative

    - Your hopes for the future
- Post pictures, drawings, or place cards into the pages.
- Sign and date each entry

____________________Family’s ICU Journal

Date Admitted to the Hospital: ________________

Today’s date:________________

What brought the patient to the Hospital and to the ICU:

The ICU Stay: Diary (print daily as needed)

Date:________________

(Name) has been in the ICU for ______(number) of days.

General condition: (How is (name) doing today? Are they awake? Peaceful? Agitated? Comfortable?)

Doctors that (name) saw today:

Doctor Name	**Specialty** **(i.e., ICU doctor; cardiologist, etc)**	**Notes:** **(include any relevant information or things they said)**

Plan of care - What does the medical team have planned for today? Will (name) be having any tests or procedures done?

Personal messages and updates from home: (What is the weather outside today? What is happening at home with the people/pets in my life? Are there important world or community events happening that I would want to know about?)

How would you like to be involved in your relative's hospital care?

What's your general availability during the patient's hospital stay?

- ☐ Morning
- ☐ Afternoon
- ☐ Evening

How do you like to learn new information? Select all that apply:

- ☐ Visually (Pictures, diagrams, charts)
- ☐ Auditory (Listen)
- ☐ Reading (Written notes)
- ☐ Hands-on (practice doing something)
- ☐ Other: ________________________________

Do you currently have access to the patient's electronic health record (e.g., MyChart)?

- ☐ Yes
- ☐ No/Unsure → Consider asking a medical receptionist for help accessing it

Transferring out of the ICU: Ongoing Hospital Stay

The Team

Communicating with the Team

- Questions:
    - Identify new point people. The step-down or floor have more dispersed team structures. You may need more people to answer questions about how your relative is doing, and to help you prepare for discharge. Again, if you identify someone you think would be a good point person, ask them if they can fill that role. You may need to update this as staff turn over - or for day shifts and night shifts.
    - Point person for clinical information:____
    - How to contact:____________________________________
    - Point person for discharge planning:____
    - How to contact:____________________________________

What to expect after transfer from the ICU

Transfer from the ICU to the hospital floors is often anxiety-provoking. The monitoring equipment and contact with nurses in the ICU helps patients and families feel safe. At the same time, going to the floor is a sign - and also a test - of getting better. If you really don't feel your relative is ready, explain the reasons why to the care team. Otherwise, ask them what signs would indicate a setback.

When you get to the floor, review the signs of a setback with the new team - and ask who to tell if you see those signs.

On the floor, the focus often shifts to identifying changes in functioning that developed during the critical illness, while also addressing ongoing medical needs. Work with the team about helping your relative:

- **Get protected sleep at night.**
    - Can lab draws and routine vital sign checks wait until morning?
    - Can medications be given before they go to sleep or after they wake up?
    - Do they need ear plugs or an eye mask to help with the noise and light in the hospital?
- **Safely move as much as possible.**
    - Does the patient have a chair to sit up during the day?
    - Can the physical therapist and occupational therapist leave exercises to do between rehabilitation sessions?
- **Begin reconnecting with the world.**

    - What activities bring your relative pleasure without exhausting them? (e.g., listening to music, playing cards, crafting, journaling, visiting with friends) Can you build them into a daily routine?

It is common for people to have difficulty thinking like themselves after being critically ill. If that is the case for your relative, ask the doctors, nurses, and therapists:

- What's causing it?
- What can we do to help them function better?
- Who can we follow-up with if it's not better in a few months?

Planning for Discharge

(These tools are adapted from the United Hospital Fund screener and D-CHAT tool developed by researchers at the University of Wisconsin)

Identifying needs before discharge

In order to identify what additional supports you may need for discharge, it's important to take a look at what supports are currently in place. Sharing this information with your care team will help them ensure you have the supports you need when you leave the hospital.

What is your relationship to the patient?

☐ Spouse/partner
☐ Son/daughter
☐ Parent
☐ Sibling
☐ Friend
☐ Other: ____________________________

How long have you been involved in the patient's care?

☐ I haven't, this is a new situation (patient was fully independent or arranged own care)
☐ I haven't, someone else has been the caregiver
☐ I've been doing this a while (how long? _______)

How convenient is the patient's home for you to reach?

- ☐ Easy to - Same home
- ☐ Not hard - Close by
- ☐ Not easy - A long trip
- ☐ I really can't - Out of state/county/another reason

Do you work or have other responsibilities that will take you away from caregiving?

- ☐ No
- ☐ Yes. If yes:
  - ☐ What work/other responsibilities?
  - ☐ Does your employer have >= 50 employees?

    Do you work:
  - ☐ Full-time
  - ☐ Part-time

Are you raising children?

- ☐ No
- ☐ Yes. If yes:
  - ☐ Under the age of 18?

Are you also a caregiver for someone else with medical problems or disabilities?

- ☐ No
- ☐ Yes.

Do you have health problems that affect you as a caregiver?

- ☐ No
- ☐ Yes. If yes, are these problems due to (check all that apply):
  - ☐ Arthritis
  - ☐ Asthma
  - ☐ Back problems
  - ☐ Diabetes
  - ☐ Other:______________________________

Will other people (such as family members or friends) help care for your family member?

- ☐ No
- ☐ Yes. If yes,
  - ☐ Who will be helping?

What other professionals are involved (check all that apply)?

- ☐ Home care
- ☐ Adult day care
- ☐ Home companion
- ☐ Transportation
- ☐ Meals on Wheels
- ☐ Personal emergency response system
- ☐ Senior Center
- ☐ Other:______________________________

What training do you need to help the patient?

Tasks **(Your care team can help figure out which of these apply to your situation)**	**I am able to help WITHOUT training**	**I am able to help WITH training**	**I am unable to help**
Bathing (washing in the shower, bath, or sink)			
Dressing (getting dressed and undressed)			
Eating			
Personal hygiene (such as brushing teeth)			
Grooming (such as washing hair and cutting nails)			
Toileting (going to the bathroom or changing protective undergarments)			
Transfer (such as moving from the bed to a chair)			
Mobility (includes walking)			
Medication (ordering medications, organizing them, and giving all medications as prescribed)			

(Continued)	**I am able to help WITHOUT training**	**I am able to help WITH training**	**I am unable to help**
Managing symptoms (such as pain or nausea)			
Equipment (such as oxygen, IV, or infusion)			
Coordinating the patient’s care (includes talking with doctors, nurses, and other health care workers)			
Making and keeping appointments			
Driving or helping with transportation (such as car, bus, or taxi)			
Household chores (such as shopping, cooking, and doing laundry)			
Taking care of finances (includes banking, paying bills, forms and applications)			

If you need TRAINING to help your relative:

- Do self-paced learning using training videos at **UHF Next Step in Care | Videos**
- Ask for hands-on training from the physical therapist, occupational therapist, speech therapist, or nurses
- Practice before discharge. It lets you learn if you need additional equipment or help to get home safely.

Bring other needs to the case manager or social worker. Often they will be able to help directly. Otherwise, they can coordinate with other team members to get the help you need.

Making home safer and easier to manage

Consider taking pictures of the living space your relative plans to go to after discharge to share with the care team. They will help them set rehabilitation goals with your relative, recommend safety measures (including a home safety assessment), and identify other equipment or services to make the transition home.

Is your relative going back to the place they lived before the ICU?

- ☐ No
- ☐ Yes. If yes:
  Had they previously fallen or had other challenges navigating their living space?
  - ☐ No
  - ☐ Yes

After discharge, how many stairs will your relative have to navigate to get:

- Into their living space?________________
- To a toilet?_________________________
- To a bathtub or shower?______________

Is your relative going home with equipment (check all that apply):

- ☐ Cane
- ☐ Walker
- ☐ Wheelchair
- ☐ Bedside commode

☐ Shower chair
☐ Bathroom grab bars
☐ Pill box
☐ Hospital bed
☐ Oxygen tank
☐ IV/PICC
☐ Feeding tube
☐ Nebulizer
☐ CPAP machine
☐ Home ventilator
☐ Chair lift
☐ Hoyer lift
☐ Other_____________________________

Put a star next to the equipment on the list that is new for your relative.

What worries do you have?

Being a family caregiver is a big responsibility. Do you sometimes worry about: (check all that apply)

- ☐ Your level of stress and how to cope with it
- ☐ How to balance work and caregiving
- ☐ How to get time off (respite from being a family caregiver)
- ☐ What your family member’s condition means to you and others who care about him or her
- ☐ How to manage medications and care for your family member
- ☐ How to deal with your family member’s behavior (such as refusing to eat or take a bath) and feelings (such as anger, resistance, and resentment)
- ☐ Whether your family member is safe at home, or what to do if he or she wanders
- ☐ Where your family member lives, and if this needs to change (such as moving to a nursing home or assisted living)
- ☐ Making health care decisions on behalf of your family member (being the health care proxy)
- ☐ How to talk about what is going on with other family or friends
- ☐ Legal issues (such as Living Will, Power of Attorney, and other paperwork)
- ☐ How to pay for care
- ☐ What to do if your family member needs end-of-life care
- ☐ Taking care of your own needs (such as eating and sleeping)
- ☐ Other worries

  ____

  ____

Developing a caregiving village

Again, it takes a village to care for someone after experiencing a critical illness. There may be physical needs (i.e., getting help walking or going to appointments), emotional needs (i.e., support to help you work through the changes you've experienced during this time), and/or cognitive needs (i.e., helping with managing finances or taking medications at the correct times). The earlier you can start to identify who will be part of your village, the better. These can be people who are close to you or your relative; who are part of your neighborhood, faith, work, or other community; who your healthcare team recommends; or who you hire. It depends on your personalized needs and the needs of your family.

Review all the needs and worries you have identified in the needs assessments in the preceding sections. Use it to strategize about the kinds of help that matter the most.

- **Family, friends and volunteers** can often help:
    - Motivate participation in rehabilitation
    - Encourage home exercises to continue getting stronger after formal rehabilitation sessions are over;
    - Deliver meals;
    - Do laundry;
    - Keep your relative company while you do errands or work;
    - Recommend people you can hire to help with other needs

- **Personal care assistants** can help people:

  - Prepare meals;
  - Toilet;
  - Bathe;
  - Keep your relative company while you do errands or work;
  - Do tasks like light cleaning and laundry

- **Community organizations** like senior centers, faith centers, the Area Agency on Aging, and others, often have connections to:
  - Transportation services;
  - People who can help build a ramp or modify a bathroom;
  - Programs that keep people connected and moving (e.g., Silver Sneakers);
  - Support groups or contacts of people who have been through similar experiences;
  - Getting durable medical equipment (canes, walkers, tub seats, potty chairs, etc) at low cost or free;
  - Recommendations for finding reliable personal care assistants and or respite care organizations

If you don’t know where to start thinking about these issues, set up a meeting with the team social worker or case manager to help you. Make notes with questions, needs, and ideas as they come to you.

My Village

Person/organization	Contact information (phone/email)	Have you asked for their help? (Y/N)	If yes: what kind of help have they committed to? If no: what kind of help do you want to ask for? (**tasks/dates/times**)

Main needs without an identified helper:

Respite

Even when people are really close, it’s healthy to have time apart. And, everyone deserves time to themselves - even you. Use your caregiving village to make sure you have time for your own needs every week.

Area Agencies on Aging typically have some kind of respite services, including Senior Centers with day programs and transportation. Ask the social worker to get you information on respite services in your area. Make notes or paste the information you receive here:

Contact information about respite services:

Other notable information (for example, advice on how to use respite services to make caregiving sustainable):

Self-Care Plan

Caring for yourself is essential - for your own sake, for the ICU survivor in your life, and for all the other people who care about you. Consider what routines provide you necessary structure, what makes you feel healthy, and what makes you feel grounded, and what gives you a break.

Start thinking about whether you can make some tasks more automatic. Any little bit helps. For example, can you set up automatic bill pay (for your relative and/or for yourself)? Have your kids/spouse commit to weekly chores? Schedule someone to clean every 2 weeks? Schedule friends to bring a meal 3 days a week for the next 2 months? Have groceries delivered?

List your ideas here:

Consider what routines provide you with necessary structure. What makes you feel healthy, what makes you feel grounded, and what gives you a break? For example, are you eating and sleeping regularly? Could you schedule an hour a week for a walk/meditation/coffee with a friend? Do you you have a faith community where you can get support?

List your ideas here:

____

____

____

____

____

____

If you would like a referral for psychological support services to help you through all of this, please talk with the social worker. The social worker can also help you organize resources to support yourself. If you are reaching a crisis, call or text 988 for immediate help.

Weekly Planner Page

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning 8AM-12PM							
Afternoon 12PM-4PM							
Evening 4PM-8PM							

Monthly Planner Page (include personally meaningful dates)

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
☐	☐	☐	☐	☐	☐	☐
☐	☐	☐	☐	☐	☐	☐
☐	☐	☐	☐	☐	☐	☐
☐	☐	☐	☐	☐	☐	☐

Discharge preparation checklist

You should get discharge instructions and paperwork from the hospital team. Here are questions to make sure you have the answer to before leaving the hospital:

- ☐ What brought us to the hospital?
- ☐ What medications is my relative supposed to take after discharge and why?
  - ☐ Have all the prescriptions been sent to the right pharmacy?
- ☐ Do we have all the equipment we need?
- ☐ What tests do we need after discharge?
- ☐ What follow-up appointments do we need and why?
- ☐ Do we have transportation to get to those appointments?
- ☐ What kinds of problems should we be looking for?
- ☐ If we have questions after discharge, who is our point person?

The worksheet on the next page can be printed to keep a record of the answers.

Discharge Notes

(Name)________________________ was in the hospital because ______________________

Diet recommendations:

Activity and exercise recommendations:

What new equipment are we getting?

Equipment	Who is getting it to us?	When will we get it?

Medication List:

Medication & dose	Route	# of times a day	Do we have this at home or has a new script been sent to the pharmacy?	Reason for taking

What follow-up tests should we expect? (Put on calendar when scheduled)

Test	Timing (how many weeks?)	Who will order?

What appointments will we have?

Who to follow-up with	When (if scheduled, place on calendar)	What is the transportation plan for the visit?

What should we be watching for?

Common signs/symptoms	What to do in case it occurs

- Point person after discharge::____

- How to contact:____

Notes (include reminders about training that would be helpful from the home health team)

After Discharge

What to expect after discharge from the hospital

Leaving the hospital is an important step - and many people are surprised by difficulties during the transition home. The hospital has all kinds of equipment and people that provide support in subtle ways.

Here are some common challenges that you or your relative may face. Pick any of the tips about how to cope with them that fits your situation:

- **Changes in appearance**. Hair loss is common. The good news is, it typically grows back. Many people have dramatic changes in weight. Scars are often tight and uncomfortable.
    - **Tip #1**: Ask for a referral to a nutritionist to help make sure your diet is providing the nutrition you need to heal.
    - **Tip #2**: Ask for a referral to a nurse, massage therapist, or lymphedema clinic to release tight scar tissue or swelling.
- **Changes in thinking**. Many people have challenges with short-term memory loss, keeping track of lists, and keeping track of time. Motivation may also be more difficult.
    - **Tip #3**: Use phone apps designed for people with executive dysfunction/ADHD to address organization challenges.
    - **Tip #4**: Build supportive structures over time. For example, could a friend help you review your calendar

    or to-do lists for the week or month? Or could you put together your to-do lists with the home health team and make them your accountability partners for your goals over the next week?
  - **Tip #5**: Ask for a referral to an Occupational Therapist or Speech Language Pathologist for activity-based rehabilitation around the cognitive tasks that are causing the most challenges.
- **Changes in mood, motivation, or spirits.** Many people feel alone or like people do not know what they have gone through after critical illness. Those feelings are often worse when they get tired easily and are a little bit bored because they don’t have the energy for the activities that would engage them the most.
  - **Tip #6**: Ask for help! Some people are helped by medications, counseling, peer support, or even just building in activities that are really engaging. Think about what feels accessible for you, and talk with the team about how to try it out. Make a plan for checking in about how it’s working. This is an absolutely critical part of healing.
- **Weakness and exhaustion**. Critical illness is draining, and few people move as much in the hospital as at home. Resuming the pace of daily activities can be hard. This is especially true if your relative is wiped out by one trip to the kitchen or bathroom.
  - **Tip #7: Make sleep rituals**. Getting a good night’s rest is important to have energy for the day. Here are some behaviors that can help people get to sleep and stay asleep:

    - Exercise during the day - but not within 2 hours of bedtime.
    - If napping during the day, play with the time of day and duration so it doesn't disrupt sleep at night.
    - Avoid alcohol or benzodiazepine medications (e.g., lorazepam, clonazepam, alprazolam, diazepam) within 2 hours of bedtime.
    - Turn off electronic devices 30 minutes before bed.
    - Drink herbal tea or warm milk to relax.
    - Read a book or listen to calming music to help your mind wind down.
    - Toilet just before bed. If you often need to get up in the middle of the night, have everything in place to get there safely (e.g., night lights on, obstacles out of the way, walker handy)
    - Consider using eye masks, ear plugs, or white/brown noise to reduce sleep interference from light or noise. Many streaming music services have brown and white noise tracks.
  - **Tip #8: Set realistic goals to build healthy habits over time.** It's not realistic to go back to life as usual all at once - but you can build up to it. Physical therapists and occupational therapists can help set goals that balance making progress with taking time for recovery.
  - **Tip #9: Conserve the energy you have for activities that inspire you to keep on keeping on**. Occupational therapists can teach energy conservation strategies. Just make sure there is space for joy as you adapt and heal.

- **Tip #10: Track and celebrate your progress**. Progress is typically slower than anyone imagines - at least 1 week for every day in the hospital, and even more if the hospital stay was long. That means progress is like marathon training: impossible to see on a day-to-day basis. Set goals. Find an accountability partner to tell about how close you are to meeting your goals. And if you’re not making the progress you wish, set a smaller short-term goal that can remind you that you are making progress - and keep you motivated to keep going.

Problem	Current Status	Treatment Plan & Goals (Recommended: highlight medications in one color and other therapies in another)	Follow-up	Responsible Healthcare Team Member	Notes

Problem	Current Assessment	Treatment Plan & Goals (Recommended: highlight medications in one color and other therapies in another)	Follow-up	Responsible Healthcare Team Member	Notes

Problem	Current Assessment	Treatment Plan & Goals (Recommended: highlight medications in one color and other therapies in another)	Follow-up	Responsible Healthcare Team Member	Notes

Problem	Current Assessment	Treatment Plan & Goals (Recommended: highlight medications in one color and other therapies in another)	Follow-up	Responsible Healthcare Team Member	Notes

Post-Intensive Care Syndrome - See p. 63 for associated resources

- Includes new or worsened physical, cognitive, or mental health impairments after critical illness.
- It is often underrecognized by hospital- and community-based providers. Families can be very helpful identifying changes from baseline.

Post-Intensive Care Syndrome-Family - See p.63 for associated resources

- Includes new mental health symptoms and financial toxicity for families of people who have been critically ill
- Mental health support alone may not be enough to address it
  - Consider also asking for education and training to support your relative
  - Consider also asking for education and training to take care of yourself while providing support for your relative
  - The resources in this workbook are designed to help

Transition To Short-Term Rehabilitation/Skilled Nursing Facility

- What is a Skilled Nursing Facility (SNF)? Skilled nursing facilities provide a mixture of short-term rehabilitation and long-term care.
  - Insurance typically pays for short-term stays as long as a person is making progress towards rehabilitation goals. They provide up to 2 hours a day of rehabilitation. It is important to make the most of all that rehabilitation time.
  - Nursing staff and nurses aides do medication management, wound care, and personal care

    assistance as needed.
  - Doctors see patients within 72 hours of admission and then on a regular basis until discharge.
- Coordinating care with the team.
  - Understaffing is a major challenge in many SNFs. While the amount of personal attention is likely less than what you would give at home, time in a skilled nursing facility may help your relative get back enough functional independence to come home safely - while giving your whole family time to prepare for a safer transition.
  - If toileting is a challenge for your relative, ask the SNF team if they can do timed toileting (scheduled ~every 4-5 hours while awake) to minimize rushing or accidents, and allow the staff to plan ahead.
  - Consider providing photos of your relative’s home environment so that the SNF team can help practice walking/stairs/etc., and access equipment to help with safe mobility at home.
  - The team has care planning meetings at least weekly. Ask if they can schedule when you’re available on site or by phone so you can participate.
  - Ask the SNF social worker about community resources that might help with a safe transition from the SNF to home for your relative.

Getting back to your PCP

PCPs often do not have access to hospital records to easily get up to speed on details of the critical illness. Clinic visits are short and make it challenging for them to assess functional changes from the hospitalization. The worksheet on the following page was developed based on research about what PCPs want to know. Ask the clinicians in the hospital or SNF to help complete it along the way - or keep your own notes.

Feel free to share any other aspects of this workbook with the PCP. Ask about the best ways to communicate with the clinic, and community resources to address challenges you are facing.

If you want to use the handoff sheets on the following pages, ask the hospital team to help you complete them.

Primary Care Handoff Worksheet

Patient Name: Date:

Family Support System: Contact Info:

Life Support Interventions Received (Days)

Mechanical ventilation:

Non-invasive ventilation:

Pressors: None

Dialysis: None

Central lines/chest tubes/drains:

Transfusion or fluid resuscitation:

CPR or rapid response:

Reasons for Treatment Decisions

Goals of Care:

Medication Changes:

Other:

Significant Tests

Cardiac catheterization:

Scopes:

Thoracentesis:

Lumbar puncture:

Other:

Potential Complications

Infections:

Delirium:

Wounds:

Dysphagia:

Post-Intensive Care Syndrome:

Other:

Follow-up Needs

Incidental Findings:

Care Coordination:

Function:

Family Support:

Other:

Additional resources

❖ Family Training

UHF Next Step in Care | Videos

Includes English- and Spanish-language training videos for:

- Skin Care
    - Skin tears
    - Prevention of pressure ulcers
    - Management of ostomy bags
    - Diabetic foot ulcers
    - Lower extremity wounds and cellulitis
    - General principles of wound care
- Safe Mobility
    - Preparing your home for safe mobility
    - Getting from a car to a wheelchair
    - What to do if someone falls
    - Using a walker or cane and navigating stairs
    - Moving from a walker to a shower or bed

Project RED (Re-Engineered Discharge) Toolkit

Consider asking your healthcare team if they can use these tools to help your family with:

- A Post-Discharge Follow-up Phone Call
- A “Warm Hand-off” to help your relative’s primary care provider and home health team know what happened during the hospitalization
- Culturally humble education and training related to managing chronic health conditions after discharge

❖ Family Support After Critical Illness

Most of these organizations have ICU survivors and family caregivers in leadership positions. They are always evolving to build better communities and meet more needs.

- CAIRO Peer Support Collaborative **(international)**
- ICUSteps **(based in the United Kingdom)**
- Critical Care Support Network **(based in the United Kingdom) - includes long-standing peer support**
- Ptsd.va.gov **(mental health support for the public)**
- Home | NAMI: National Alliance on Mental Illness **(mental health support for the public)**
- **Facebook and other social media have different support pages - use the search terms that speak to you to find one**

More General Caregiving Resources

- Caregiver Action Network: Resources for Family Caregivers
- Caring Bridge
    - **Offers tips for developing a caregiving calendar here.**
- Conversation - Caring Across Generations

Map and Contact Information for Post-ICU Clinics

Eldercare Locator is sponsored by the Federal Government of the United States. It integrates a huge number of resources and may be the place to start even if your relative is younger, because you can access information about everything from respite care to legal services to working with your employer about caregiving.

- Ursuline Support Services - provides independent support, guardianship, grief support, and other help for life transitions for people in southwestern Pennsylvania

❖ Financial, Legal, Employment, and Insurance Issues

Financial

- **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/**
- **Short-Term Disability** requires a Disability Determination (PA's policy is located here) based on inability to work for a year or more when not receiving Social Security Disability. Instructions on filing for Short-Term Disability in Pennsylvania are located here: https://www.dli.pa.gov/Individuals/Disability-Services/bdd/Pages/How-Do-I-File-Short-Term-Disability-in-PA.aspx
- User guide to understand your medical bills and dispute unnecessary or erroneous ones: pennpirgedfund.org

Legal

- **National Academy of Elder Law Attorneys (NAELA)** is dedicated to improving the quality of legal services provided to older adults and people with disabilities. You can search for a lawyer here. **https://www.naela.org/**
- **A Better Balance** is a nonprofit dedicated to advancing justice for workers, so that they can care for themselves and their families without jeopardizing their economic security. They have a helpline in English and Spanish: 1-833-NEED-ABB or 1-833-633-3222 **https://www.abetterbalance.org/**

Employment

- **Federal Family and Medical Leave Act** allows eligible employees of covered employers to take unpaid, job-protected leave. **dol.gov/whd/fmla**
- **Vocational Rehabilitation Services** are offered to eligible people with disabilities to help them gain employment in their state of residence. You can find them via google. Pennsylvania's is here: **https://www.dli.pa.gov/Individuals/Disability-Services/ovr/Pages/default.aspx**
- **Job Accommodation Network** provides free, expert, and confidential guidance on job accommodations and disability employment issues: https://askjan.org/

Insurance and other kinds of assistance

- **Medical Assistance (Medicaid)** is provided to eligible people by the state government. Instructions on applying in Pennsylvania are located here:

https://www.dhs.pa.gov/services/assistance/pages/medical-assistance.aspx

- **Other services (for example, housing, heating, food, employment, mental health, cash assistance)** are also offered to eligible people by state governments. A list of assistance an instructions to apply in Pennsylvania are located here: https://www.dhs.pa.gov/Services/Assistance/Pages/default.aspx
- Ask for a consultation with a social worker.
- Also, consider calling your congressperson. Many have staff with expertise related to Social Security, Medicare, Medicaid, and other federal benefits.

Food Services

- AngelFood Medically tailored meals

Disability Services

- **Disability Services** are also available in each state. Pennsylvania's are located here**:** **https://www.dli.pa.gov/Individuals/Disability-Services/bdd/Pages/How-Do-I-File-Short-Term-Disability-in-PA.aspx**

Disability Peer Advocacy

- Pennsylvania's Peer Advocacy groups focus on mental health and recovery from substance use disorders. Consider writing your representatives to ask to expand programs for a wider array of disability
- Other networks include:
    - Health Justice Commons

  - disABILITY LINK
  - TDN: The Disability Network
  - The Administration for Community Living

Respite Services

- **ARCH National Respite Network and Resource Center** offers a range of resources for people to get paid for caregiving, to planning for respite, paying for respite, and identifying respite providers: https://archrespite.org/caregiver-resources/

Community Integration/Wellbeing

- **BRaIn Training and Exercise Program (BRITE Program)** aims to promote the overall health and wellness of people with mild cognitive impairment who want to optimize their physical, cognitive, and social functioning https://www.britewellness.org/

❖ Information on PICS and PICS-F

Aftertheicu.org
Icudelirium.org - For patients and families
Myicucare.org
sepsis.org

❖ Testimonials from ICU survivors and families

Healthtalk.org
Icudelirium.org

Glossary

References

A living bank of resources including references is located at www.picturethis.pitt.edu
We adapted materials developed by the United Hospital Fund at the Next Step in Care website as follows:

- Caregiver Needs Assessment

The Society of Critical Care Medicine has developed educational materials for ICU patients and families.
Chest has published an ICU Guide.

Lara Goitein, MD wrote a book called The ICU Guide for Families: Understanding Intensive Care and How You Can Support Your Loved One. It provides rich detail about the equipment, personnel, and procedures of the ICU as well as what comes next.

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