A family handbook for specialty hospital care

A loved one can be stable enough to move out of the ICU and still need daily medical care. Work through the sections that fit your situation and bring the notes to your next conversation with the team.

When your loved one needs more time

A move to another hospital can be exhausting for patients and families. You may have spent days watching breathing equipment, waiting for test results or hearing about one setback after another. Tell the team what is hardest to understand and ask who will set aside time to explain it.

A person with breathing support, wounds, infections or several organ problems may need more hospital care even when the first hospital has treated the immediate crisis. An LTACH review asks what treatment must continue, how much nursing or respiratory support is needed and what the patient can safely do today.

Six questions about your experience

The historical family booklet used a four-point survey. The same six questions can help you bring a specific concern to the bedside team. For each, write one example and what you would like to happen next.

- Did the doctors treat you with courtesy and respect?
- Did the doctors explain things in words you could understand?
- Did the team clearly explain the goals of your treatment?
- Did staff listen and respond to your concerns about pain?
- Were your room and bathroom kept clean?
- Based on your experience, would you recommend the hospital to friends or family? What most influenced your answer?

A partner in care

Tell the team what matters to your family, what you are worried about and how the patient prefers decisions to be discussed. Ask for an explanation in familiar words. If different teams seem to be giving different messages, request a shared update. You can ask what has improved, what has become harder and what choice you face next.

Who does what?

- The attending clinician reviews medical stability, orders, new symptoms and the treatment plan. Ask who covers the patient when the usual clinician is away.
- Nurses monitor changes, give medicines, protect skin, manage lines and coordinate care throughout the day. They are a good first contact for a new concern during the stay.
- Respiratory therapists assess breathing support, airway clearance, oxygen and readiness for ordered trials. Ask how they coordinate with speech and mobility staff.

- Physical therapists help with bed mobility, balance, transfers, walking and endurance. Occupational therapists work on everyday activities such as dressing, bathing and safely using equipment.
- Speech-language pathologists assess communication, thinking and swallowing. Dietitians review nutrition needs, food textures and nutrition delivered through a tube or IV.
- Pharmacists review medication doses, combinations and transitions. Case managers work with the patient, family, payer and next provider on coverage, equipment, transportation and discharge.
- Tell the team about spiritual, language, hearing or other communication needs. Ask about interpreter services or how to contact a spiritual adviser the person knows.

Breathing with less support

A ventilator gives breathing support while clinicians treat an illness or injury. Some people still need it after the ICU. The team looks at the underlying illness, the need for oxygen, strength, airway secretions and ability to protect the airway. A spontaneous breathing trial lets clinicians observe what happens with less machine support when it is safe to try.

A person who needs a tracheostomy may need humidification, suctioning, skin care, communication support and a plan for secretions. Ask whether the next goal is a longer breathing trial, a change in the type of support or time to recover before trying again. Progress can vary from one day to the next.

The clinician directing breathing care, respiratory therapist, nurse, pharmacist, dietitian and rehabilitation staff bring different information to rounds. Breathing and mobility sessions must fit around rest, procedures and nutrition. Ask what happened during the last trial, what led the team to stop, and what they are watching before the next trial.

Wounds and infection

A wound that is deep, slow to heal or repeatedly infected may affect the entire plan of care. The team assesses the wound, surrounding skin, pressure, circulation, pain, nutrition and other illnesses. A serious pressure injury, nonhealing surgical wound, fistula or amputation site may need frequent care and careful positioning during therapy.

Vascular and arterial ulcers, burns, infected wounds and bone infection can require different approaches. The clinician selects dressings, assesses the need for negative-pressure therapy or debridement, and considers measures to improve blood flow or relieve pressure. Some procedures, including operative or ultrasonic cleaning or specialized lymphedema care, require separate expertise. Confirm where any proposed procedure will occur.

Bacterial, fungal and viral infections need different treatment. Bring recent culture results, antimicrobial medicines, the date of the next review, precautions and signs of worsening. Sepsis, an infected surgical site or pressure injury, osteomyelitis and severe soft-tissue infections may require urgent hospital assessment. Report a new concern to staff immediately.

Brain injury, stroke and post-trauma care

After a stroke, brain injury, spinal cord injury or severe trauma, breathing, circulation, nutrition and infection control can remain urgent while rehabilitation starts. A stroke interrupts blood flow or involves bleeding in the brain. A traumatic brain injury is caused by an external force. Either may affect movement, thinking, speech and swallowing.

Describe airway support, breathing trials, surgical wounds or pressure injuries, renal treatment, infection or isolation needs, infusions, nutrition and feeding tubes. A person who cannot yet sustain intensive therapy may still take short, supervised steps toward communication, comfort and movement as medically appropriate.

Rehabilitation assessment can include aphasia (trouble using or understanding language), dysphagia (trouble swallowing), and changes in attention, judgment or memory. A clinician may recommend a swallowing study when it would change care. Ask how balance, coordination, joint movement and strength affect getting out of bed, using a wheelchair, walking, bathing, eating and dressing.

Family members can help identify the person's usual communication and what would matter most to recover. Ask the team to demonstrate transfers or communication strategies before you try them. If longer therapy sessions become possible, ask when an inpatient rehabilitation assessment would be appropriate.

Cardiac, kidney and other complex conditions

A person recovering from heart failure, heart attack, valve disease, peripheral vascular disease, endocarditis or cardiac surgery can have several needs at once. Describe blood pressure, rhythm monitoring, fluid changes, breathing and the current response to activity. Ask which change needs urgent reassessment.

Diabetes, kidney failure, malnutrition, cancer, severe infection or a complicated recovery after abdominal, cardiac or chest surgery may affect the pace of care. Treatment may involve IV medicines, antibiotics, dialysis, bowel rest or tube or IV nutrition. Include recent results, current orders and pending procedures when requesting a review.

If the person uses a specialized support device such as a ventricular assist device or needs an infusion, extracorporeal support or a procedure, explain this at the first call. The sending and receiving clinicians should agree on who can provide and monitor that specific treatment before the transfer is arranged.

Five individual recovery accounts

These historical accounts came from an earlier care setting. They illustrate the range of care a person may need. Individual timelines and outcomes vary.

Breathing after a cardiac arrest. A person who collapsed after chest discomfort required intensive care and ventilation for nearly a month. At transfer the family was concerned about the effects of lack of oxygen on the brain. In the following weeks the person regained awareness, came off the ventilator and went home. The account describes a later return to work and walking for exercise.

Wound and kidney recovery after a burn. An adult sustained burns over about one quarter of the body and developed serious infections. At transfer the person was being treated for pneumonia, needed ventilation and dialysis and remained critically ill. As the burns healed, breathing and kidney function improved and dialysis was discontinued. The next step was a rehabilitation facility, followed by a return home several months after the accident.

Infection after an implanted device. An adult with a previously implanted stimulator developed a spinal abscess and septic shock after a device replacement. Surgery removed the infected device. The subsequent plan included several weeks of IV antibiotics and physical therapy. During recovery the patient continued coursework and later resumed teaching dance.

Brain injury with multiple fractures. A young adult with a severe head injury, respiratory failure and fractures underwent surgery and treatment for infections and other setbacks. After moving from acute trauma care, the family saw progress in walking, eating and speaking. Family involvement and communication goals were important parts of that individual's recovery.

Heart failure with respiratory failure. A person had swelling and shortness of breath severe enough to make lying down difficult. Acute treatment included ventilation. Medical care addressed heart failure, blood pressure and diabetes while therapy helped the person begin moving again. After coming off ventilation and regaining walking ability, the person went home.

Understanding numbers in an older brochure

The earlier family guide reported historical network figures for ventilator liberation, pressure-injury frequency, infection volume, satisfaction and discharge to a lower level of care. For example, it described a 70% ventilator-liberation result in 2011 and more than 70% moving to less intensive care in 2009–2013. Its pressure-injury measure was reported as fewer than one event per 1,000 patient-days in 2011. It also reported more than 23,000 complex patients treated for infections in a typical year across that network. These measures came from different populations and years. Ask for Waterford-specific figures and definitions if comparing hospitals.

The measures behind the archived family survey

In the archived 2011 network survey, conducted on a four-point scale, the six reported scores were 3.8 for courtesy and respect, 3.9 for understandable explanations, 3.8 for clearly explained treatment goals, 3.9 for pain management, 3.7 for a clean room and bathroom, and 3.6 for likelihood of recommending the hospital. The reported overall grade was 3.8. These were self-reported experiences across the historical network. Ask Lakeview for any current Waterford survey result you want to compare.

Other treatment needs to raise during the review

Breathing problems may follow chronic lung disease such as COPD or emphysema, a neuromuscular disorder, pneumonia, surgery, stroke, brain injury or a spinal cord injury. Ask whether the team is treating the underlying condition, supporting breathing or preparing for another trial with less support.

For wound treatment, describe surgical incisions that have not healed, pressure injuries, arterial or venous ulcers, burns, amputations and affected bone or soft tissue. Ask what will protect the area from pressure, what nutrition support is needed, which dressing is prescribed and what changes the staff will watch for.

Infection review can include a wound or pressure injury, cellulitis, bone infection, an infection involving the heart, tuberculosis or an infection related to a weakened immune system. A bacterial, viral or fungal cause can require different medicines or precautions. Confirm whether the proposed setting can provide each treatment and precaution.

For recovery after heart attack or surgery, ask how valve disease, blood-vessel disease, fluid retention or infection affects the plan. Which symptoms or changes in weight, swelling or breathing should be reported, and to whom? Confirm the instructions for this person before going home.

From bedside rounds to the next care setting

At the bedside, ask staff to introduce their role, explain the next activity, leave room for questions and make sure the patient can reach the call light or communication aid. Small steps like these make it easier to report a change early.

At a care conference, ask the team to explain the medical goal and the function the person is working toward. Agree on how progress will be described, which barriers remain, what the patient can practice and when the plan will be reviewed. Ask which disciplines need to hear new information from home.

At the team review, bring medical treatment, nursing, respiratory care, rehabilitation, nutrition, equipment and coverage into the same plan. Identify the task, the person responsible and when an answer is expected. Discuss what would make the current setting unsafe or a lower level of care appropriate.

Before discharge, ask for an updated medicine list, instructions for equipment and wound or airway care, arrangements for supplies, follow-up appointments and a written plan for changes in symptoms. Ask a clinician to watch the caregiver practice any new task and confirm who will take the first call after the move.

Notes for the next conversation

My loved one wants to be able to _____

The change we have noticed since the last update is _____

The medical support they still need is _____

The next goal, and how we will know they have reached it _____

The question we still have _____

The person following up and how we can reach them _____

Questions for a tour or admissions conversation

- Which clinician directs medical care? Who is available on the unit overnight and how does the team respond to a sudden change?
- How are family visiting and overnight stays handled? Ask about private rooms, Wi-Fi, a quiet place to meet, visitor age rules and pet visits if these affect your decision.
- When is skin checked, how does wound prevention start and how do the team and caregiver continue the plan after discharge?
- What are the arrangements for emergency response or transfer to a higher level of care? What advanced life support training do staff have and when is a respiratory therapist available?
- How does the team help a person begin moving safely, including someone with breathing equipment or someone who cannot yet stand?
- Who handles a concern that the bedside team cannot resolve? How can you reach a patient advocate, unit leader or hospital leader?
- Which patient outcomes does the hospital track? Ask for definitions, the period covered and which patients are included. Ask how often you will receive updates about your own loved one.

Arrange the visit and verify the transfer

Ask Lakeview Admissions about visiting or tour arrangements. Have the referring case manager share the current clinical summary and ask who can tell you when a decision has been made. Confirm financial coverage, any authorization requirement, transport and the planned time of arrival. Keep the name or department for the next call.

Request a Lakeview review

Ask the referring physician or case manager to discuss whether Lakeview Specialty Hospital and Rehab in Waterford can meet the person's current needs. A diagnosis or day count alone does not settle that question. Clinical review, insurance coverage, availability and transport need to fit together.

Lakeview Admissions • (262) 534-8509. Referral fax • (262) 534-8507. Lakeview Specialty Hospital and Rehab • 1701 Sharp Road, Waterford, Wisconsin 53185. Main hospital • (262) 534-7297.

https://www.lakeviewsystem.com/long-term-acute-care

https://www.lakeviewsystem.com/brain-injury

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