

WELCOME TO THE INPATIENT REHABILITATION PROGRAM

We are pleased that you will continue in your child's rehabilitation process with us and we look forward to partnering with you in your child's healing process. The information in this packet is designed to help you understand how to best support your child's rehabilitation in order to maximize his or her recovery.

Why is my child participating in rehabilitation?

If your child is being admitted to the Inpatient Rehabilitation Program (sometimes called "Rehab"), he or she has experienced an injury or illness that has led to a significant change in functioning. Your child may have trouble performing day-to-day activities, for example. Rehabilitation therapies are designed to help your child to regain skills and to teach family members how to care for your child with his or her new health condition. We know that the more intensive and skilled therapy that people receive after significant injuries or illnesses (such as brain injuries, spinal cord injuries, strokes, etc.) the better their long-term outcome. Our goal is to help your child be as independent as possible for his or her age and functional level.

Who qualifies for Rehab?

A rehabilitation medicine physician will help determine if your child would benefit from participating in Rehab.

Your child may qualify if:

- Age 6 months – 21 years
- Has impairments in movement, performing daily tasks, speaking, or thinking
- Has specific rehabilitation goals that can be achieved within the program
- Is medically stable (not requiring frequent labs, tests, or other procedures/interventions) but still needs to be in the hospital
- Can participate in 3 hours of therapy per day

Your child may not (yet) qualify if:

- Behavior or level of alertness limits participation
- Weight-bearing or movement restrictions limit participation
- Needs breathing support from ventilator or CPAP/BiPAP machine
- Has planned procedures or tests that will limit therapies
- Already safe to discharge home with outpatient or in-home therapies
- No caregivers or home have been identified for discharge

We do not discriminate based on race, color, religion, national origin, creed, genetic information, sexual orientation, gender identity or expression, or ancestry. We work with nearly all insurance companies; our Financial Services Team will help guide this process.

How is a Rehab admission different than a general medical hospitalization?

Rehab days are different than general hospital days for several reasons. Rehab is billed through your insurance differently, so authorization is required before starting. If your child qualifies, the Rehab team will work with your insurance company to obtain authorization. This can take up to 5 days, but will not impact the care your child receives.

Our focus is on recovery. Your child will have a daily schedule of activities to support recovery and establish a routine as similar to home as possible. Visitors may be limited during these activities and therapy sessions to maximize recovery. The Rehab team will guide you on when to have visitors.

While your child is still in the hospital, our goal is to prepare him or her and families for discharge and life at home. To do this, the care of your child is transitioned from nursing to family members. A significant part of Rehab is teaching family members how to safely care for their child, so practicing these skills and getting comfortable with new skills before going home is very important. Also, your child may be asked to do more and more for him or herself as they gain these skills. The Rehab team will guide you on how to best help and how to keep your child safe while letting them be as independent as able.

In order to continue in the program, your child must show progress from week to week. This is measured by WeeFim scores (see below). There may be short periods of time during which your child's scores do not change. However, a longer period of time without improvement means a different type of program may be better for your child at that time (for example, in-home therapies).

How is Rehab different?

- ❖ There is a schedule of activities throughout the day
- ❖ Every effort is made to establish a home routine, including getting out of bed, sleep schedules, school activities, and nutrition
- ❖ Visitors should come only at times when your child is not in therapy
- ❖ Cares transition from the nurses to the family
- ❖ Your child does more for him or herself to be as independent as is safe and practice new skills
- ❖ Progress is tracked by function

What should I expect when my child transfers to Rehab?

Your child will likely move to a room on 5 Sutherland, where our team members and therapy gym are located. Rooms are similar to general hospital rooms, but may have extra equipment to support your child (ex. a ceiling lift). The same general hospital rules apply (ex. who can stay overnight). Your child will be seen regularly by members of the Rehab team (see below) and will participate in at least 3 hours of therapy daily, including Occupational Therapy (OT), Physical Therapy (PT), and Speech/ Language Therapy (ST). Physicians from other specialties will continue to be see your child as needed. Your child will continue to have access to all services in the hospital.

Who will be working with my child?

Rehab Attending Physician:

The pediatric rehabilitation doctor has special training in caring for children who have physical disabilities. This doctor is the leader of the rehabilitation team and will be working with your child and family to help your child regain as much previous function as possible.

Rehab Fellow:

Fellows are rehabilitation physicians who have completed their residency and are continuing their education to specialize in Pediatric Rehabilitation.

Rehab Resident:

Rehab residents are physicians-in-training who will assist the attending in evaluation and treatment of your child's needs. The Resident and Fellow will organize the plan and the Attending will approve of what is done.

Nurse Practitioner:

The rehabilitation nurse practitioner (NP) is an advanced practice nurse with specialized training in working with rehabilitation patients. The NP will work with the doctors, nurses, and other members of the rehabilitation team to assist in the care of your child.

Neuropsychologist:

Neuropsychologists are clinicians who specialize in how the brain works and how we think. They evaluate cognition (thinking), emotions and behaviors. They also assist with developing plans for managing behaviors that are either dangerous or limit the patient's ability to participate in therapies. The neuropsychologist will also provide ongoing education about your child's injury and recovery process.

Physical Therapist:

A Physical Therapist (PT) helps individuals of all ages affected by illness, injury, or congenital conditions to achieve or regain movement skills. PT focuses on gross motor skills such as crawling, walking, transfers, and balance activities. PT's provide exercises for stretching, strengthening, and balance. PT's will also make recommendations for transfers and mobility including equipment such as crutches, walkers, and wheelchairs.

Occupational Therapist:

An Occupational Therapist (OT) helps individuals of all ages affected by illness, injury, or congenital conditions to achieve or regain independence in daily activities. OT focuses on fine motor skills such as grasping and writing as well as daily activities such as dressing, bathing, and feeding. Our OTs also provide sensory integration and vision therapy.

Speech Therapist:

The Speech and Language Pathologist (SLP) works with individuals to evaluate and treat communication, cognitive disorders, and oral motor/swallowing problems.

Rehab Team Nurse Care Manager:

The Nurse Care Manager will assist your bedside nurse in teaching any new cares you may need to learn. She will assist with discharge planning and will communicate between all members of the team and help prepare you and the child for transition home.

Social Worker:

The social worker provides supportive services to patients and their families. As families adjust to changes associated with their child's injuries/illness, the social worker can assist with tasks such as finding resources, providing emotional support and coordinating with outside agencies.

Dietitian:

The dietitian ensures the nutritional needs of the patient are met by monitoring the patient's weight, intake, and tolerance of intake. The dietitian promotes adequate food and fluid intake to promote healing and provide energy for growth.

Music Therapist:

The music therapist will plan music tasks that are based on the needs and age of your child, and that support the work of OT, PT and/or ST. Because music is generally familiar and fun for children, it can provide motivation for your child as he/she works on needs such as movement, problem-solving, and choice-making.

Massage Therapist:

The massage therapist may work with your child at different times during their hospitalization, depending on his/her needs. Massage therapy is beneficial for pain and muscle tone management, can improve efforts in therapy, and assists with recovery from intensive therapy sessions. Massage may also assist with sleep and relaxation in general.

Child Life Specialist:

The Child Life Specialist strives to promote a positive hospital environment for patients and their families. Child Life Specialists offer opportunities for developmentally appropriate play, preparation for medical experiences, self expression and socialization with peers. The Child Life Specialist can also assist with adjustment for siblings of the patient.

Hospital Based School Teacher:

The Hospital Based School Teacher works with patients and their families to promote the patient's growth in academic and cognitive skills. They can also assist with contacting the home school and adapting a school program as needed. The Hospital Based School Teacher can also assist with school work for siblings of the patient.

Chaplain:

The chaplain works with the family throughout their child's hospital stay by offering spiritual and emotional support to both the family and the child. Chaplaincy will honor the beliefs and traditions of your family.

Therapy Dog:

Therapy dogs are trained to work with children in the hospital setting. Therapy dogs are utilized to promote healing and recovery by helping during therapy sessions and providing comfort in the hospital.

What does a typical day look like?

We encourage families to help their children to begin to normalize their schedules. This includes having them dressed, showered, and out of bed (including for meals) for the majority of their day. Your child's schedule will vary based on his or her medical needs.

Child Life will post your child's schedule in the room for each weekday.

Below is an example of what a typical Rehab day will look like on Monday-Friday:

8:00: Breakfast, get dressed and ready*	1:00: PT
9:00: OT	2:00: School, Child Life, or Music Therapy
10:00: PT	3:00: OT
11:00: Speech Therapy	4:00: Rest and dinner
12:00: Lunch and Rest	6:00: Evening Child Life activity

Saturday and Sunday: Your child will receive OT and PT services 1x each (both Saturday or one each day).

*If OT is working on ADLs (dressing, grooming, showering, eating) they will post this on the schedule, otherwise, nursing will help you to have your child ready by 9:00.

What should I expect from therapy?

Your child will be evaluated for appropriate therapy goals and these will be advanced as your child makes progress. We will work with you and your child to meet all needs from admit through discharge. Outings during therapy may be done to address community reintegration skills. These outings are usually with the therapist(s) only to promote increased independence in directing needs, wheelchair propulsion, social interaction, etc. For therapy, your child may be seen in his or her room, in the 5 Sutherland gym, or in the 1st floor gym.

Caregivers are welcome to attend therapy sessions. We know that some children do better with caregivers present and others do not. We can work together to determine what works best for your child. We also realize families need breaks and therapy can be a time for that. If you are needed in a session for teaching, your therapist will let you know.

What clothes should I bring for my child?

Please provide comfortable clothes for your child to dress in each day. This includes shorts or sweats, t-shirts, zip-up jacket, shoes that tie and socks. If your child is appropriate for aquatic therapy they will also need a swimsuit.

How is my child's progress tracked and communicated?

WeeFIM® Scores: WeeFIM® is a set of scores that measure performance in daily functional skills in self-care, mobility, and cognition. It helps to identify strengths and weaknesses your child may have in order to adjust treatment plans and goals. As a team, we assess each patient at admission, weekly, and at discharge. This allows the team to evaluate your child's progress and the effectiveness of his or her therapy program, and also helps to determine when your child is ready for discharge.

Morning Rounds: The physicians, nurse practitioner, and bedside nurse will see your child daily during rounds; this is a good time to ask any questions you may have. Rounds are usually between 8:30 am to 10:30 am. The doctors may see your child in your room, or in the therapy gym. You can write additional questions on the dry erase board in your room to remember to ask when the doctors come to see your child. These boards will have goals for your child, and they will be updated frequently. For therapeutic questions, therapists are available daily. We will make sure your question is directed to the appropriate person.

Team Staffing: Along with daily communication, the Rehab Team meets as a group each Tuesday to review the progress your child has made. Team discussion includes goals, discharge planning, equipment needs for home, plan of care and estimated length of stay. WeeFIM® scores are documented and placed in the chart. A copy of WeeFIM scores will be provided to your family after each staffing. Family will be updated on any changes to the plan after staffing.

Family Conference: Your family is an important member of the Rehab program. We may arrange formal times to meet with your family and any caregivers to discuss the plan of care.

Orientation: A medical provider (physician or nurse practitioner) and social worker will meet with your family before or at the time of admission to Rehab to review goals and expectations and answer questions about the transition.

Family Meeting: Approximately 1-2 weeks after admission to the program, your child's team (Physician, OT, PT, SLP, Social Worker, Nurse Practitioner, Nutrition, Care Manager and Psychologist) will meet with your family and caregivers. The team will discuss your child's medical condition, progress he or she has made, and goals for discharge. We will also discuss discharge planning and how long we expect your child to be in the hospital. You are encouraged to ask questions in this conference so you have a good understanding of your child and his or her condition. Notes will be taken during the meeting and you will be given a copy of the notes once they have been signed by the attending physician.

Discharge Meeting: Closer to the time of discharge, the team may meet with family and caregivers to review current status, equipment, safety at home, outpatient plans, and education needed prior to going home. This is to provide any additional education and answer questions prior to leaving the hospital.

Other: Interpreter services are available if needed. Efforts will be made to communicate with a family member daily if not present for rounds or meetings. We encourage your child to participate in as much communication as he or she is able to understand based on age and ability.

Some tasks are very hard for my child and he/she gets frustrated with having to do them. Why shouldn't I help him or her do these tasks so there is less frustration?

We know that many things that used to be easy for your child are challenging now. It is natural as a parent to want to help your child through difficult times. However, by doing tasks for your child, it decreases the opportunities for your child to learn and master skills and potentially lengthens the time your child is in the hospital. It may also negatively affect his or her long-term outcome. Frustration, unfortunately, is a natural part of the rehabilitation process. Letting your child work through difficult tasks will allow for him/her to master those tasks sooner.

If you want my child to master skills, is it still okay for me to help sometimes, instead of letting him do a task on his own?

While we want to promote as much function and independence in your child, he or she might not be able to do some things independently right now, or might not be able to do them safely. At these times, it is appropriate to help your child. The therapists and nurses will help you to decide which tasks to help with and how to help to support your child's best recovery.

Why am I given different instructions with regard to taking care of my child?

If your child is on the Rehab service, it is likely that he or she has had a significant loss of skills. With the goal of Rehab being to increase your child's ability to function independently, you will be given different instructions on how to best care for your child as he or she makes changes during hospitalization. Thus, while you might need to help a lot with some tasks at first, we will want you to help less as your child is capable of doing tasks more independently. This is also true with regards to your child's room environment, especially if your child has had a brain injury. The stages of recovery will determine how the room should be with regards to light and noise. The team will give you information on this as your child recovers. We want to match the type of support we are giving with your child's current functioning and since your child is changing, so will how we support your child.

What is available for my child to do when not in therapy?

See the Bear notebook in your child's room for information about available activities for your child during their hospitalization. There are activities offered for patients and families most evenings. Ask your nurse or Child Life Specialist for a schedule of the activities. Your child's therapists may also give you exercises to work on outside of therapy hours.

What about visitors? What do I tell people who want to come to visit my child?

Patients often love to have visitors while they are in the hospital. Having visitors often keep spirits up and let patients know that their friends and family love them and are thinking about them. We would encourage visitors to support your child's recovery. Here are the best ways to balance having visitors and maximizing your child's recovery:

- Have visitors come after the therapy day (After 4:00 Monday–Friday; after 12:00, Saturday). Visitors during therapy times have the potential to lessen the gains made during therapy sessions.
- Sometimes visitors can be motivating for patients as well. Please check with your child's therapists to determine if visitors will help or hinder your child's progress in therapy.
- For most patients, it works best to have visitors come in the evenings and on the weekends when they are not busy with therapies and they can enjoy their visitors.
- If your child has a brain injury or other neurologic disorder, visitors during certain stages of recovery may be more detrimental to their rehabilitation. The Rehab team will provide you with guidance in these situations and let you know when your child will be able to benefit from having visitors. Typically, if your child is very agitated, we would recommend limiting visitors.
- Visitors should leave at 9 PM. Those staying overnight should help to promote your child's sleep by being quiet with lights off from 9 PM to 7 AM.

What can friends or family do if they cannot visit?

Send cards, post messages on social media, send pictures or videos so your child can look at them at a time that works best for him or her. Many families keep family and friends updated on their child's progress via social media such as Facebook or Caring Bridge. This allows for those not at the hospital to keep up-to-date and share their concerns and words of encouragement for your child.

Sleep and rest are important for recovery. How can I help my child and how does the team help?

Appropriate sleep is essential for your child to get the most out of his or her rehabilitation. How is this best achieved?

- Establishing a good sleep/wake cycle is a priority for your child.
- The goal is for your child to get most of his or her sleep overnight. We know that consolidated sleep (sleeping for many hours at a time rather than napping on and off throughout the day) helps to promote healing and restfulness. They do their greatest healing during periods of consolidated sleep.
- In order to promote good sleep, your child should remain awake during the day and, aside from scheduled times, should not nap throughout the day.
- If your child has a break during the therapy day, allow for him or her to rest, but not sleep, unless it is a designated nap time.
- Many families want for their children to continue to do exercises in between therapies. Unless directed otherwise by your child's therapists, your child should rest in between therapies. If he/she is not given rest breaks, your child will become more fatigued and will not be able to benefit as much from the skilled therapy times.
- Completing additional exercises in the evenings and on weekends however is encouraged. You should monitor your child's level of fatigue and endurance so as to not "overwork" him or her. Your child's therapist will give you tasks/exercises to complete outside of therapy.
- Other ways to promote good sleep schedule:
 - Maintain the same schedule as much as possible from day to day
 - Dim the lights at night and have lights on during the day, unless directed otherwise.
 - Electronic use at bedtime tends to interfere with sleep onset, so turn off electronics at least one hour before bedtime.
 - Keep room quiet so your child can sleep at night.
- Since your child needs to be in the hospital, nurses **must** come in throughout the night to complete cares. Nursing cares will be minimized throughout the night as much as possible, but if the nurses are coming in, it is because your child needs these cares to keep him or her healthy.

How is family teaching completed?

In preparation for your child's discharge, the responsibility of care is shifted from the hospital staff to parents/caregivers. At this time of the rehabilitation process we encourage more active participation by family members so they can develop the skills needed to provide necessary care and supervision to their child. Teaching sheets, therapeutic family passes and Patient Care Status may be implemented.

Teaching Sheet: A teaching sheet will be posted in your child's room to be completed prior to discharge. Listed are skills for family members to be taught for independent care of your child at home. A staff member will initial each task as it is completed. This helps the family and team know the areas that still need to be addressed prior to discharge.

Therapeutic Family Pass: As your child gets closer to discharge, and your child is medically appropriate, a pass may be given for you and your child to leave the hospital grounds for a short time. This allows you to be in the community or home environment to practice newly learned skills and identify any needs prior to discharge. Therapeutic passes are given for 6 hours or less, and passes are not permitted to interfere with scheduled therapy sessions or nursing cares. You will receive a checklist of tasks to attempt while on pass so that any issues needing attention can be addressed prior to discharge home.

Parent Care Status: This is a period of 24 to 48 hours in which the parents/caregivers are expected to provide **complete** care for the child once the teaching sheet is completed. This allows you to practice the skills that have been taught for tasks such as g-tube care, feedings, medication administration, positioning, etc. A parent care status helps to identify if any further education or training is needed prior to the child being discharged. This is seen as a transitional step between the inpatient stay and returning home.

How do we get everything ready for going home?

Discharge planning begins for your child on day one of their inpatient stay. It is individualized for each patient. The Rehabilitation Team will evaluate what goals your child needs to achieve before discharge and what family education will be necessary. We will work together with you to identify equipment needs for home. This may include feeding pumps, feeding supplies, a wheelchair, or bath equipment. We will also assist you with home accessibility and transitioning back to school as needed. Outpatient rehabilitation services are also typically needed and the team will make recommendations regarding which types of services will be best for your child's recovery.

Although we start talking about discharge on day one, your child will not be discharged until he or she is ready for the transition to home. Oftentimes, it is difficult to determine the exact date that your child will be ready for discharge. The discharge date is determined by many factors that can change during the course of the hospitalization. We strive to alert you to the date of discharge at least one week in advance.

Why is my child being discharged when he or she still has limitations in functioning?

We always strive to achieve the best possible outcomes for your child. Inpatient rehabilitation is just the first phase of your child's rehabilitation course. The goal of the inpatient program is to get your child to a point that he or she can be safely cared for at home. Your child's rehabilitation will continue as an outpatient to work on skills that they have yet to regain. Your child will likely go on to receive outpatient rehabilitation therapies. These may be at an intensive day treatment program, traditional outpatient therapies or in-home therapy. Most individual's rehabilitation process takes months to years. The inpatient rehabilitation is just the first step in that process.

What happens at discharge?

When the day of discharge is close, your child's medications will be sent to the pharmacy and should be ready to pick up before you leave the hospital. A pharmacist will review all of the medications to ensure you know what each medication is used for, when to give the medication, and how to give the medication. You can even request that the medications are delivered to your child's room through the Meds to Beds program.

The Rehab physician or nurse practitioner will call your primary care provider (PCP) to give them an update. Your child's PCP receives weekly updates from the team and this final update will include important information on what needs to be followed after you leave the hospital. You should make an appointment with your PCP within 2 weeks of discharge so he or she can assess your child. Appointments with specialists at Children's Mercy will be made prior to discharge and will be included on your discharge paperwork.

Therapy referrals are faxed prior to discharge and typically, your child's first therapy appointments are scheduled within a week of getting home. Our team will send your new team information on your child's progress so that they can continue this progress as an outpatient or in the home.

Any equipment needed should be delivered to your child's room or your home before discharge. Occasionally, we may ask you to provide some equipment if it is not covered by insurance. Equipment may be long-term or rented. Our Care Manager will help arrange this with your input.

On the day of discharge, your child's therapists will review any last safety concerns, techniques, or exercises and answer any last-minute questions. Your child will be ready to discharge around lunchtime. Contact information for different team members will be on the discharge paperwork so you know who to call if anything comes up before your first appointment.