Chronic Illness Management Program

RWJBarnabas HEALTH

Children's Specialized Hospital

Our Mission

To provide the children we serve the best tools to effectively manage their illness, maximize their quality of life, and achieve their family-centered goals of care.

Children Served

The Chronic Illness Management Program focuses on treating children (up to age 21) with chronic, life-altering conditions including diabetes, cystic fibrosis, sickle cell, heart disease, autoimmune disorders, metabolic disorders, organ transplants, chronic respiratory disease and other conditions that require strict adherence to prescribed treatment regimens.

Services Provided

Initial Enhanced Evaluation: All participants in the Chronic Illness Management Program undergo an enhanced evaluation which is completed by the team medical provider and a mental health professional to assess the patient's physical, emotional, mental, and psychological status. The team will then make recommendations for ongoing treatment; this may include ongoing outpatient services, referral for a follow-up with specialty providers, referral for mental health services, and/or admission to the four-week inpatient Chronic Illness Management Program located in New Brunswick, NJ.

Outpatient Program: Our Outpatient Program is offered at CSH sites throughout NJ and consists of individual or group mental health support, nutrition support, and physical and/or occupational therapy evaluations and treatment.

Inpatient Program: The Inpatient Program is typically for children, adolescents, and young adults with chronic, life-altering conditions who have demonstrated the need for additional support to better manage their condition. The comprehensive four-week inpatient program provides the child and family with a structured, comprehensive service plan to address their medical nutritional, psychological, and communication needs to enhance the child's total health and well-being.

Follow Ups: All patients who participate in the inpatient program attend follow up appointments at three, six, and 12 months post hospitalization. These follow up appointments are with a medical provider, mental health clinician, and a nutritionist/diabetes care & education specialist to promote continued success in managing the chronic condition.

Arranging Services

Patients, caregivers, and referral sources seeking an evaluation to develop a treatment plan and determine needs may contact:

Ayana Hamilton, Programmatic Lead
Phone: 732-258-7411
Email: AHamilton@childrens-specialized.org

Children's Specialized Hospital
200 Somerset Street
New Brunswick, NJ 08901

**Families seeking outpatient physical or occupational therapy evaluation and treatment may contact our scheduling department at 888-244-5373, option #2. Please mention if the child has recently had a PT or OT evaluation and is now seeking treatment.

**Families seeking outpatient mental health services may call our mental health access coordinator at 888-244-5373 ext. 55851 or 55131.

Details of Inpatient Chronic Illness Management Program

Rationale for inpatient approach to treatment of chronic conditions: Inpatient treatment in a medical-based facility provides goal directed care, significantly helping the patient to be more independent at managing their chronic medical condition, to become more involved in collaborative decision-making with medical and health professionals, more adherent of their medical plan, and adept at making choices for a healthier lifestyle and improved quality of life.

Program goal: To aid in a healthy transition back into the home and community and to help the patient and the family work with medical personnel, health professionals, and community-based agencies to ensure long term success.

At admission, a full evaluation will be completed by the Physical Therapist, Occupational Therapist, Psychologist, Child Life Specialist, Recreational Therapist, Nutritionist, Diabetes Care and Education Specialist, and Physician/ Advanced Practice Nurse. At the evaluation, the team develops initial treatment goals with the patient/family and establishes a plan of care including frequency of therapies.

Interventions that patients can receive in an individual, group or family format include:

Diabetes Education with Certified Diabetes Care and Education Specialist (CDCES):

- Works with patients with diabetes and their caregivers/families to learn basic skills needed for diabetes management such as:
  - ** Taking diabetes medications
  - ** Monitoring blood glucose
  - ** Using diabetes technology
  - ** Healthy activities and eating
  - ** Problem solving and coping strategies for diabetes management
  - ** Safety issues and risks for developing medical complications

Other disease specific education with a Clinical Nurse Educator:

- Provides disease specific education to both the patient and caregiver

Nutrition/Dietitian support:

- Focuses on the prevention and management of chronic disease by providing individualized nutrition education, counseling, diet and lifestyle modification, and meal planning
- Works toward accepting a balanced diet by gaining exposure to new foods and cooking techniques
- Incorporates innovative approaches like gardening and experiential learning to practice a healthy lifestyle

Physical Therapy:

- Education and hands-on experience on ways to safely manage a chronic condition during physical activity
- Focuses on building the patient's confidence and knowledge of their chronic illness while educating them on the importance of physical activity and ways to incorporate exercise safely and realistically into their daily lives

Occupational Therapy:

- Supports the patient in following a daily schedule while hospitalized and building positive health habits and routines necessary for chronic illness management
- Individual and group-based sessions focusing on activities that incorporate mindfulness, cooking, communication skills, and self-reflection skills

Recreational Therapy:

- Utilizes games, sports, aquatics and physical based leisure activities to address physical health and well-being
- Provides opportunities to learn and support how to manage one's chronic illness in the community
- Helps to plan and provide community recreation resources near home

Psychological Therapy:

- Explores factors contributing to the patient's difficulties with adherence to chronic illness management including family dynamics, intellectual functioning/ learning difficulties, mental health diagnoses, and peer/social conflicts
- Provides individual group or family support to help develop strategies to overcome barriers and improve family communication/overall adherence

Community Out Trips:
- When appropriate, therapy-based community outings are scheduled to practice and reinforce generalization of chronic illness management skills

Recreation Room:
- Patients are encouraged to attend daily and evening recreation programs to promote socialization, normal routines, and age-appropriate activities. The Recreation Room provides an environment to practice leisure activities and carryover therapeutic recommendation including coping skills.

Child Life Support:
- Promotes self-expression, use of coping skills, and offer diversional activities to supplement their physical program

Patient Care Coordination:
- Assists with discharge planning including coordination of school services and community supports

At Discharge: patients will work with their primary therapists to develop a home exercise/activity program. Their participation in development of the program assists in carryover and transition to independent management. Each program is individualized to the patient's needs, goals, and interests. The anticipated goal is sustainable improvement, including a significant decrease in future chronic illness-related medical complications, hospitalizations and improved lab markers/scores following discharge from the inpatient program.

Program Outcomes

- Over 100+ patients and families served!
- 91% of patients with diabetes
- 57% of patients successfully used CGMs* or insulin pumps
- 1.9% average reduction seen in A1C* from 11.2% at admission to 9.3% at discharge
- 10% average increase in disease-specific knowledge scores* seen from 70% on admission to 80% at discharge

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**Outcomes represent data from 2020-2023 admissions to the inpatient 4-week CIMP*

**CGM – continuous glucose monitors are wearable devices which track interstitial glucose concentrations*

**A1C – blood test measuring average blood glucose levels over the past 3 months. It is used to help patients and health care teams manage diabetes care.*

**Validated assessments such as the Michigan Diabetes Knowledge Test, are used to measure disease-specific knowledge*

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