

## Pediatric Complex Care Program

### What is the pediatric complex care program?

We are a team at American Family Children's Hospital (AFCH) who manage and coordinate care for children with complex health needs. Our team includes doctors, nurse practitioners, nurses, care coordinators, dietitians and social workers. We help care for our patients in the hospital, clinic, or at home.

### Who can be in the program?

Our mission is to serve patients and families who have needs that cannot be met by other programs and we have the expertise and resources to meet.

Children can be enrolled if they:

- Have problems in three or more body systems.
- Get care from three or more specialists.
- Had a hospital stay lasting at least 5 days **or** had at least 10 specialty clinic visits in the past year, and have unmet care coordination needs.
- Are enrolled in the WI Medicaid program/have a Forward Health card.

Many of our patients:

- Use a feeding tube.
- Have seizures or other neurologic problems.
- Have breathing issues.
- Take many medicines.

### How can my child become a part of the program?

A health care provider who knows your child can ask for a referral, or you can refer your child yourself. After we get the

referral, we will place your child on the waiting list and send you a letter. When we have space to enroll a new patient, your child will be screened to see if they qualify. If your child qualifies, we will call you to explain the program and set up a clinic visit. The program starts at the time of the first clinic visit.

Sometimes, for certain health problems there are other doctors or teams that are a better match to manage and coordinate care. Some examples include cystic fibrosis, pediatric cancer, and transplants.

There are other health conditions that we do not have the expertise and resources to manage. These includes mental health disorders, chronic pain and "diagnostic dilemmas."

Sometimes, insurance issues or other issues prevent us from being part of a child's care.

If your child doesn't qualify, we will send a letter to your child's primary care doctor and the person who requested the referral.

### What happens once my child is enrolled in the program?

At the first visit, we will talk about your child's history and current problems. This visit takes up to two hours. We will have at least 3 members of our team at this visit. We then create a care plan for your child. We will send a copy of the care plan to you.

After your child is enrolled, we provide:

- **Clinic visits** with us at least every 6 months to update the care plan. We try to schedule these visits on days when your child has other visits scheduled at AFCH.

- **Phone advice and/or clinic visits when your child is ill.** We may give advice on how to manage issues at home, see your child for an urgent care visit, or contact the emergency department to give some background on your child.
- **Consults when your child is in the hospital.** We talk with the team caring for your child in the hospital. We try to be a part of daily rounds with the team. We help with transition back to home.
- **Monthly phone or MyChart contact.** We check in each month to see how things are going.
- **Ongoing program support.** Between visits call us if you have questions and don't know who to ask.
- **Assistance** with making appointments, talking to insurance providers, arranging home health and medical equipment, and finding community resources.
- **Join you at your child's visits with other specialists.** This is an option that we try to do for you if you would find it helpful.
- **Ongoing program support.** You can call us if you have questions and don't know who to ask.

### **How long can my child be part of the program?**

Your child will graduate from the program:

- When care transitions from pediatric to adult providers around ages 18-20. We help you with this process.
- When your child's medical issues become less complex.
- If you find our services are no longer needed or helpful or you don't want to participate anymore.

Sometimes we find it is no longer working:

- If your child misses 3 or more scheduled Pediatric Complex Care clinic visits.
- If we cannot reach you by phone or electronic contact after many attempts.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 8/2020 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#7966.