

Building Clinician-Parent Partnerships to Improve Care for Chronically Critically Ill Children (CCI)

Tips for Families

Getting ready for your new role

- Inform your child's pediatrician of the hospital stay and any changes in your child's medical care
- Make a binder detailing your child's medical needs and care
- Have a plan for health emergencies
- Consider working with a case manager

Our whole family

- Take care of your own health care needs.
- Your family, friends and community may be able to help: make a list of your needs and schedule to help people pitch in

Preparing for home

- Nursing care will be different at home than in the hospital
- Make space for your new equipment and supplies
- Write all your questions down

Preparing to leave the hospital:

- Prepare a document with your child's medical history and medications
- Ask for written instructions for all equipment and medical devices
- Families of children with similar medical needs can be a great resource and support