


How to get the most out of your CF Center

Mary Helmers, R.N., B.S.N.
Pediatric CF Nurse Coordinator
CF Care Center
Lucile Packard Children's
Hospital



Who Does What

- Check in
 - Front desk staff
 - Insurance information/HIPAA
- Vital signs
 - Including height, weight, review meds
- Care team

Your Team

- Nurse coordinator
- Dietician
- Respiratory coordinator
- Social worker
- Patient service coordinator
- Research staff
- Your doctor

Mary Helmers

- Nurse coordinator
 - Ties your child's care together
 - Education
 - Prescriptions
 - Running CF clinic
 - Phone advice
 - ***NO live person***
 - Calls returned within 24 hours
 - Transition coordination
 - Monitor all test results
 - Labs, cultures, spirometry, x-rays....
 - Parent advisory board member

Contact Information: mhelmers@lpch.org

Phone: 650 736-1359

Julie Matel

- Dietician
 - Growth curve
 - Nutritional status
 - Diabetes education
 - Recommendation on enzyme dosing
 - Supplements
 - Tube feedings

Contact Information: jmatel@lpch.org

Phone: 650 736-0248

Kristin Shelton

- Respiratory coordinator
 - Therapy review
 - Spirometry
 - Sputum induction, sputum collection
 - Teaching new modalities
 - Equipment acquisition

Contact Information: kshelton@lpch.org

Phone: 650 724-0206

Lindsey Martins

- Social worker
 - Assess social situations
 - Coordinate assistance:
 - Financial
 - Counseling
 - Disability information
 - State assistance program
 - Mentoring

Contact Information: lmartins@lpch.org

Phone: 650 736-1905

Zoë Davies, Colleen Dunn, Cathy Hernandez, Angie Leung, Cassie Everson

- Research staff

- Meet all newly diagnosed
- Consent for the CFF registry
- Identify eligibility for new studies
- Coordinate lab samples
- Continuity between both adult and pedi programs
- Plan education days

Contact Information: cedunn@stanford.edu

Phone: 650 736-0388

Miguel Huerta

- Patient Services Coordinator
 - Initial contact for all new patients
 - Schedules all new patients
 - Authorization for testing, visits, prescriptions
 - **Contact him with insurance changes, ASAP**
 - Mails out sputum and lab results
 - Assists the nurse coordinator

Contact Information: mhuerta@lpch.org

Phone: 650 498-2655

FAX: 650 724-6400

Your CF Doctor

- The CF expert
 - Additionally you may see...
 - Medical student
 - Resident
 - Fellow
 - Contacting your doctor:
Please call Mary at 650 736-1359

Goal of Care Coordination

Proactive prevention of CF symptoms through...

Your Child's Care

- Quarterly clinic visits
- Sick visits
- In-depth yearly visit
 - Done on birth date
- Transition
 - Booklets handed out at age 8

Quarterly Visits

- Proactive Prevention
- Watching for early CF related symptoms
- Medications & refills
- Flu & other vaccines as needed
- Education as needed

Sick calls – What we need to know

The Cystic Fibrosis Center at Stanford



CHECK FIRST

- Feeling sick?
- Concerned about your child?
- Have a question for the nurse?
- Need prescription refills?

Things to **check** before you call the CF Center

Please leave the answers to this simple checklist on our voicemail when you call.

Include the questions on allergies, treatments, pharmacy, meds, and how to reach you.

TEMPERATURE

- ✓ Current temperature
- ✓ Medications taken
- ✓ Time meds taken

SPUTUM

- ✓ Color
- ✓ Consistency
- ✓ Amount

COUGH

- ✓ Frequency
- ✓ Productive
- ✓ Non-productive

ABDOMINAL PAIN

- ✓ Taking enzymes
- ✓ Stools float or sink
- ✓ Last bowel movement

HEADACHE

- ✓ Sinus pain
- ✓ Nasal congestion
- ✓ Nasal discharge: color

APPETITE

- ✓ Good
- ✓ Fair
- ✓ Poor

WEIGHT LOSS

- ✓ Yes
- ✓ No

ENERGY LEVEL

- ✓ Normal
- ✓ Low

In-Depth Yearly Clinic Visit:

- Review medications & refills
- Annual Labs
- Chest X ray
- CF-related diabetes (OGTT)
 - Age 6
- Bone disease (DEXA scan)
 - Age 16
- PFT's
 - Age 6
- Education review

Additional Needs, PRN

- Phone Advice
- Follow-up
- Medications refills
- Home care management
- Labs & tests results
- Hospital & clinic communication
- Collaborates with adult coordinators

Transition

- Ongoing process
- Booklets
- Individual plan
 - 18-21years
- Hospital transition
 - Team role
- Quarterly transition meetings

