CLINICAL CARE SCHEDULE

FOR NEWBORNS TO 5 YEAR OLDS WITH CYSTIC FIBROSIS

Clinical care guidelines for the management of both infants and preschoolers with cystic fibrosis have been published.[1, 2] This table combines the recommended care management schedules from those publications. Please note while this schedule is intended as a guide, individual circumstances will dictate the timing and care provided.

[1] *Infant Care Guidelines:* Cystic Fibrosis F, Borowitz D, Robinson KA, et al. Cystic Fibrosis Foundation evidence-based guidelines for management of infants with cystic fibrosis. The Journal of pediatrics. 2009;155(6 Suppl):S73-93.

[2] *Preschool Guidelines:* Lahiri T, Hempstead SE, Brady C, et al. Clinical Practice Guidelines From the Cystic Fibrosis Foundation for Preschoolers With Cystic Fibrosis. Pediatrics. 2016;137(4).

KEY ● Do ○ Consider ◆ Attempt ■ Perform Quarterly — Perform at one of these visits

DATE DONE →

INTERVENTION ↓

AGE AT VISIT	DAY OF SWEAT TEST	24-48 HOURS OF DX	1WK LATER OR AGE 1 MO	2 MO	3 MO	4 MO	5 MO	6 MO	8 MO	10 MO	1 YR	EVERY 2-3 MO. IN THE 2ND YR OF LIFE	2 YR	3 YR	4 YR	5 YR
CARE ISSUES																
Discuss diagnosis			●	○	○	○					●	●	●	●	●	●
NUTRITION																
Assess weight gain, caloric intake, and PERT dosing and CF specific vitamin use	Start PERT and CF specific vitamins		●	●	●	●	●	●	●	●	●	●	■	■	■	■
Encourage human milk feeding			●	●	●	●					●					
Salt supplementation	1/8 tsp salt							● Increase to 1/4 tsp salt					● Continue supplement			
History and physical with weight, length, OFC			●	●	●	●	●	●	●	●	●	●	■	■	■	■
PULMONARY																
Airway clearance, review airway clearance techniques			● Teach & initiate airway clearance								○		● Assess annually and review technique			
Introduce chronic Dornase Alfa and/or Hypertonic Saline													○	○	○	○
Seasonal influenza vaccination								●	●	●	●	●	●	●	●	●

*Annual labs include: Vitamin levels A,D, E, prothrombin time, serum electroytes BUN creatine glucose, complete blood count, AST/ALT/GGT/ Bili, albumin, ALP

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TESTING AND ASSESSMENTS																
Sweat test and genotyping confirmed documentation	●	○	All 1st ° siblings										●	○	○	○
Annual labs*											●		●	●	●	●
NUTRITION/GI																
Pancreatic functional status testing				○	○	○	○	○	○	○	○	○	○	○	○	○
Abdominal pain assessment													■	■	■	■
Set energy and caloric goals and assess progress													●	●	●	●
PULMONARY																
Respiratory culture			●		●			●			●	●	■	■	■	■
Chest radiograph or CT											●		●	○	●	○
Spirometry														◆	◆	■
BEHAVIOR																
Assess ability to sustain daily care				○	○	○	○	○	○	○	○	○	○	○	○	○
Assess for presence of mealtime behavior challenges and provide proactive behavioral assistance						Anticipatory guidance			Anticipatory guidance			Anticipatory guidance	●	●	●	●
EDUCATION																
Teach and assess infection control			●	●	●			●			●		●	●	●	●
Fill out "who to call-where to go" sheet																
Consent and document CFF patient registry				●	●	●	●	●	●	●	●	●	●	●	●	●
Discuss clinical research			○	○	○	○					○		○	○	○	○
Tobacco smoke exposure avoidance education		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Genetic counseling								○			○			●	●	●

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