CYSTIC FIBROSIS(CF) IN CHILDREN

Cystic fibrosis is a congenital, chronic, and progressive life-threatening pulmonary disorder that causes the production of thick mucus. Children with CF also experience gastrointestinal symptoms and can also develop CF-related diabetes and liver disease. The necessary routine care for CF can take 2-4 hours each day.

MAINTENANCE CARE FOR CHILDREN WITH CF

Cystic fibrosis requires routine at-home maintenance in order to avoid serious exacerbations and delay progression of the disease.

Some of this maintenance includes:

- Air-way clearance
- Maintenance medications
- Taking enzymes with meals
- Increased nutritional and caloric needs
- Regular attendance at doctor's appointments
- Occasional hospitalization for tune-ups

WITHOUT ROUTINE CARE

Some potential outcomes if recommendations are not followed include:

- Increased risk of hospitalization
- Worsening of symptoms
- Faster progression of the disease
- Frequent exacerbations
- Decreased life-expectancy

Healthcare providers are concerned about potential medical neglect if the following scenarios arise: At-home treatments are not being completed, the patient's health status is deteriorating more than one would expect, there is a lack of pharmacy refill history, the patient has poor PFTs (breathing tests), there is a history of frequent hospitalizations or ER visits, there are frequent appointment cancellations and no shows, or a significant drop in weight or BMI.

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