

Home Care

Most children and adolescents with CF can be managed at home. The goals of care include normalization and daily activities, including school and peer involvement. The care plan should be flexible so that family activities are disrupted as little as possible. Parents may initially require assistance finding and contacting durable medical equipment companies that will provide home care equipment. They also need opportunities to learn how to use the equipment and to solve problems that they may encounter while delivering therapy at home (see [Chapter 19](#)).

Patients and family members need education about the preferred diet of nutritious meals with tolerated fat, increased protein and carbohydrate, and the administration of pancreatic enzymes and nutritional supplements. It is important to stress to parents that the enzymes, in the amount regulated to the child's needs, should be administered at the beginning of all meals and snacks. For enteral feeds administered overnight, enzymes are generally administered at the start and finish of the feeds.

One of the most important aspects of educating parents for home care is teaching techniques for the removal of mucus (ACT, vest, forced expiration) and breathing exercises. The success of a therapy program depends on conscientious performance of these treatments regularly as prescribed. The number of times these therapies are performed each day is determined on an individual basis, and often parents readily learn to adjust the number and intensity of the treatments to the child's needs. For pulmonary infection, home IV antibiotics may be prescribed pending verification of insurance coverage and availability of an agency with adequate staff to perform multiple daily home antibiotic infusions. With use of the venous access devices (such as PICC lines and implanted ports), the parents and child can be taught the technique of direct administration into the IV line.

Families also need information about medications and possible side effects. Children receiving multiple antibiotics may require serum drug levels to ensure therapeutic dosing as well as other laboratory testing.

If the child has CFRD, education on self-blood glucose monitoring, insulin therapy, diet control, and possible complications related to these may be needed. Follow up with a