

How CF Affects Daily Life

For New Parents of a Child with Cystic Fibrosis



This information sheet is intended to empower and encourage parents with the confidence to care for a child diagnosed with Cystic Fibrosis. It outlines the importance of normality in the home environment, contains handy tips for parents and provides you with an idea of the daily routine for a child with CF.

Importance of Normality at Home

At first it may be difficult to come to terms with your child's diagnosis of cystic fibrosis (CF), and everyone worries that they will be unable to manage the medications and treatments needed by their child with CF. You will be the loving parent who becomes very capable at understanding medical terms and your child's nutritional requirements, administering medications and carrying out physiotherapy. You will surpass yourself with skills and abilities you never knew existed.

However, it is important to bear in mind that CF is only part of a person's life/family life and does not represent the complete package; medications and physiotherapy will have to be done just the same as other daily routines such as brushing teeth and eating meals.

Daily fun activities must not be missed due to CF; everything in life has a time and a place.

Each family will fall into a routine that suits their particular lifestyle needs depending on the age of the person with cystic fibrosis (PWCF), their medications and treatment program.

Good habits and routine are important from the start. All PWCF need prescribed medications, physiotherapy, exercise (cardio and strength training), good eating habits and diet, and good hygiene (especially hand washing).



Parent Empowerment (words of Wisdom)

As with all newborn babies we do our best to protect them in every way possible. Our precious CF babies are no different; we feed them, we clothe them, we keep them warm, we love and cuddle them in the very same way as other children, but unfortunately we also have to administer medicines and do physiotherapy to keep our children with CF as healthy as possible.

It can be very daunting at the beginning learning how to administer medications, remembering what each medication is for, the correct dosage and recalling all of the above at hospital visits. However, it will soon become second nature to you as you become an expert on all of the medications your child with CF has to consume.



At first, doing physiotherapy on a newborn who looks perfectly normal will feel awkward and you may even feel like you are punishing your child for no reason. Physiotherapy is extremely important even if you think your child has no mucus plugs in his/her lungs. As your child with CF grows, physiotherapy techniques will change and you can incorporate exercise and fun breathing games into your physiotherapy routine.

You will learn to read the signs of congestion and when to do an extra set of physiotherapy to aid chest clearance (Ref: Physiotherapy Treatment for babies and toddlers with Cystic Fibrosis (CF Trust, UK).

Listening to your child cough will be difficult; you will want to run to the doctor at every cough or running nose, but with experience you will quickly learn to identify the

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difference between a tickle cough and a chest infection. You will be able to describe your child's cough to the CF nurse or doctor and they will be able to decide more accurately what medications if any your child with CF needs.

Remember your child with CF knows no different, and all of the above will become normality in your family lives. CF will have an effect on the whole family, but with your guidance and support your child will learn to take ownership and make good decisions, and create good habits about their treatments and life choices.



Daily Routine for Children with CF

All children with CF will have an individualised plan according to the degree of progression or condition of the disease. All babies will require physiotherapy and good nutritional guidance from their CF multidisciplinary team. Hospital appointments will primarily be about monitoring your child's growth projectile, however it is also the time for parents/guardians to ask questions and further educate themselves and gain valuable understanding of CF. Your CF Team will guide you through this early stage and explain your child's medical needs as they arise.

If your child with CF gets a chest infection they will be given antibiotics, and sometimes a maintenance antibiotic is given for a longer period of time depending on the infection.

Toilet habits of a child with CF can be very different and vary from other children. This can be quite a shock for parents but you will learn to read your child's toilet habits and regulate enzymes accordingly.

The daily routine will change as your child grows older leading eventually to your child developing their own unique daily routine around medications, meals, school, play, homework and family life; this may sound overwhelming now but it will all fall into place with time.

Further Information:

- A Guide for Parents of Newly Diagnosed Children with Cystic Fibrosis (CFAI)
- Cystic Fibrosis Care – Information Sheet for New Parents (CFAI)
- Entitlements For Parents of Children with Cystic Fibrosis (CFAI)
- CF Advocate Service – For People with Cystic Fibrosis & their Families (CFAI)
- Paediatric Nutrition and Cystic Fibrosis (CFAI)
- Genetics Factsheet (CFAI)
- CFAI Grants and Support Services Information Sheet (CFAI)
- Physiotherapy Treatment for babies and toddlers with Cystic Fibrosis (CF Trust, UK)