



Educating your child about Cystic Fibrosis



Around the age of 3 to 4, children become curious, aware of differences and tend to ask a lot of questions. Educating your child around CF can help prepare them for starting school and interactions with their peers.

Educating your child about CF early can:

- Help them learn about their body
- Help them start to develop an understanding of why their treatments are important
- Answer questions they may have about being different
- Teach them how to answer questions and explain CF to their peers

Educating your child

Parents often start by teaching their child about basic body parts and systems. You can read your child books about the body and use pictures to help them understand.

- When we teach children about the lungs we often have them blow up a balloon to understand how the lungs fill and empty with air as we breathe.
- We also teach children about the tummy and how it collects all the good stuff out of the food to give us energy, be strong and help us grow.

Next, you may teach your child about CF and its effect on those body parts. A good explanation to use would be to discuss that you are born with CF and it cannot be caught from others. It affects your lungs and stomach. Everyone's lungs make mucus, but people with CF have extra sticky mucus that germs can get stuck in and make them sick.

Some resources you may use to teach your child through could include:

- Reading them children's books about the body and CF. There are many helpful books available
- Watching videos together (see resources below)
- Playing games around CF and the body. For example, playing doctors with dolls and stuffed animals, drawing pictures, using playdoh and creating artwork, making up silly songs about CF care, etc.



- Asking questions to check what your child understands to help you know what they may need further education about.

Resources:

- Books about the body:
 - Look Inside: Your Body by Louie Stowell (2011)
 - Books about CF:
 - *Monty: A story about Cystic Fibrosis* by Meredith Bubb (2014)
 - *Mallory's 65 Roses* by Diane Shader Smith (1997)
 - *Cadberry's Letters* by Jennifer Racek (2008)
 - *Who I Am! A children's guide to cystic fibrosis* by Brent Gairy (2012)
- https://issuu.com/brentrg/docs/pulmozyme_story_book

To keep your child from getting sick there are a number of jobs they need to undertake to stay strong. Teaching your child basic words for CF care can help them name what they are doing. At the same time, beginning to teach your child why each treatment is important. For example:

- *"You take your Creon so you don't get smelly poos."*
- *"Doing your pats/chest physio will help to keep your lungs nice and strong so you can run fast."*

Once your child is school-aged it may be a good time to educate them on common health conditions that other children at school also have (e.g. nut allergies, diabetes, asthma) and be able to answer questions they could be asked related to their condition.

Talking about the ways your child is similar and different to other children their age, may help them understand that CF is just one difference that they were born with. You might say something like:

- *"CF is something you were born with. It means you have to take tablets to help you eat food, and take care of your lungs so you don't get sick. But you can still do all the fun things that your friends do!"*

Some common examples of questions and some responses could be:

- Why do you cough?

"My lungs are a bit different to yours and this means I have to cough more to keep them clean."

- What are those tablets (Creon) for?

"I have to take tablets before I eat because my tummy doesn't digest some things properly. If I don't take them I will get a sore tummy"

2. Educating siblings

Siblings often also benefit from education about CF. Many siblings may notice differences between themselves and their sibling with CF, and may not understand CF or the treatments involved. This can lead to feeling jealous, worried or left out. It may be helpful to:

- Be honest with them.
- Plan to spend individual time with them.



- Explore their understanding of the human body, their sibling's CF, and health care – including jobs they have to do to care for their own health and body (e.g. brush their teeth). Older children may benefit from learning about genetics.
- Involve them in their sibling's daily CF treatment routines where possible and praise them when they do. Some ideas may include:
 - Picking out foods from two choices
 - Helping to hold the mask during treatments
 - Sprinkling opened up enzymes on applesauce

Additional resources: Educating your child about CF

- Video: Getting Nosey about CF with Oli and Nush | Children and cystic fibrosis:
 - <https://www.youtube.com/watch?v=Wul72eMrIQI&t=3s>
- Video: What is cystic fibrosis
 - <https://www.youtube.com/watch?v=DtL-3VIBHTs>
- Teaching your child about CF and suggested language:
 - http://www.happyheartfamilies.com/teaching_child_about_cf.html
 - http://www.happyheartfamilies.citymax.com/f/4b.Suggested_Language.pdf
- Website about CF for family and friends
 - <http://www.cysticfibrosis.org.au/all/learn/>
- Online community for families and siblings affected by health conditions to connect:
 - <https://www.livewire.org.au/>