# Living with cystic fibrosis

Reviewed by SickKids Staff Last updated: January 25, 2023

You should live a normal active life when you have CF, though you will likely need to do some extra therapies to stay healthy.

### **Key points**

- Find a sample schedule of a day in the life of a teenager with cystic fibrosis (CF).
- Remember that healthy sleeping patterns are important.
- Remember to bring your medications with you to school and when you travel.

Some examples of extra therapies include airway clearance, inhalations and medications. Continue to live an active lifestyle and include exercise and good sleeping patterns.

#### Sample day in the life of a teen with CF

7:00 am	<ul> <li>Wake-up</li> <li>Inhaled therapies - puffer and hypertonic saline (7%)</li> <li>Physiotherapy/PEP treatment - PEP 5 sets of 15 with huff/coughs in between</li> <li>Clean nebulizers and PEP device</li> </ul>
7:45 am	Morning routine and get ready for school Eat breakfast- enzymes and vitamins, medications
8:15 am	Leave for school
12:00 pm	Lunch and enzymes at school
3:15 pm	Walk/bike/bus home
4:00 pm	Pulmozyme mask, snack

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4:30 pm	Extracurriculars – hockey, skating, swimming, dance, music lesson
6:30 pm	Dinner and enzymes, medications
7:00 pm	Homework
9:00 pm	<ul> <li>Inhaled therapies- puffer and hypertonic saline (7%)</li> <li>Physiotherapy/PEP treatment</li> <li>Clean and sterilize nebulizers and PEP</li> </ul>
9:30 pm	Bedtime routine

### Sleep hygiene

It is important to make sure that you get enough sleep. Your body needs time to rest and recover from your daily activities in addition to the time and energy it takes for you to do your treatments. Sometimes, excessive coughing can be exhausting or coughing at night can interfere with the quantity or quality of your sleep. Some people with CF may have abdominal or chest discomfort, reflux, stuffy noses or nasal blockages – all of which can influence your sleep.

#### School and medications

When you go to school, these are the things you should try to remember to bring:

- enzymes packed in your lunch in a separate container
- puffers (with aerochamber)
- other medications
- tissues

## **Travel and medications**

When you go on a trip or go travelling, remember to make a list of things to pack:

- medications
- compressor (portable if available)

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- nebulizer cups
- aerochamber for puffer
- cleaning supplies
- PEP device
- tissue paper

You can ask your clinic nurse for a travel letter so that you can keep your medical equipment with you when you travel on an airplane.

#### Milestones

CF R.I.S.E. (Responsibility.Independence.Self-care.Education) provides a transition toolset so that you can work with your parents, caregivers and health-care team to become more independent.

Download their <u>milestones at a glance</u> document to learn about health-related milestones and how responsibilities evolve as a person with CF moves from one life stage to the next. The milestones document focuses on four areas:

- understanding CF
- managing CF care
- taking CF treatments and therapies
- living with CF

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