

CYSTIC FIBROSIS

INCLUSIVENESS

“ Hardship invokes awareness, which in turn generates opportunity for enhanced living.”

-Scottie Somers

The Aim of Scouting is to promote the development of individuals, enabling them to grow and take their place in society as active citizens. As we move forward with the Canadian Path we are much more aware of each individual's personal progression, inclusive of their varying abilities. This inclusiveness within Scouting uniquely positions us to play an important role in modifying community attitudes and behaviour towards individuals with identified needs; it starts with Scouts.

Please use this guide for a better understanding of youth with Cystic Fibrosis; how as Scouters, we can make a difference through simple interventions, program modifications and knowing where to get help when needed.

DESCRIPTION

Cystic Fibrosis (CF) is a genetic disorder that affects the lungs and digestive system. The CF gene disrupts the essential balance of salt and water needed to maintain a normal thin coating of fluid and mucus inside the lungs, pancreas, and other organs. The mucus becomes thick, sticky, and hard to move. Normally, mucus in the lungs traps germs, which are then cleared out of the lungs. But in CF, the thick, sticky mucus and the germs it traps remain in the lungs, which can become infected. In the pancreas, thick mucus may block enzymes from reaching the intestines to digest nutrients properly, especially fats. That's why some youth with CF have problems gaining weight, and have to eat more. There currently is no cure for CF.

CHARACTERISTICS/BEHAVIOURS

- Youth with CF may have problems with weight gain, and may have to eat more
- CF does not affect cognitive or learning abilities
- Youth with CF take oral or inhaled medication

Youth with CF may:

- Need to go to the restroom often (digestive problems from CF can cause diarrhea and flatulence)
- Need to eat at times that are not scheduled for such as camps, meetings, etc.
- Cough frequently to clear mucus from the lungs (CF is not contagious)
- Tire during activities due to early-morning breathing therapy or staying awake from coughing at night
- Miss scheduled activity times or be absent entirely due to breathing therapy at home, lung infections, doctor visits, and hospital stays

IN A SCOUTING SITUATION

- Scouters should educate themselves about the youth's condition and prepare for the future by asking the right questions to both the youth and parents
- It is important for Scouters to be educated by the parents on the youth's condition so that they understand the youth's unique abilities and challenges
- To support both skill and social development on the part of the youth, an attitude of inclusion must be adopted by both the Scouters and the other youth in the group
- If you, as the Scouter, don't understand something, ask for it to be explained
- Establish an on-going rapport with all the support people involved in the youth's life
- All Scouts must be encouraged to use sanitizer or soap and water to wash their hands after bathroom times, after playing games, after coughing and/or sneezing to assist with the prevention of lung infections
- Ensure that the youth has access to a bathroom facility at their discretion, without having to obtain consent to go, and that the youth can remove themselves to a quiet area to cough when required



PROGRAM MODIFICATION SUGGESTIONS

- Scouters must fully consult with the youth, parents and perhaps specialists to ascertain how to best engage the youth to successfully experience the most out of their Scouting adventure
- With the approval of the youth and the parents, it may be advisable to have a professional Personal Support Worker (PSW) accompany the youth to camp outings
- Youth with CF may need special considerations regarding missed instruction and activity program projects
- Youth with CF may need encouragement to take part in games and physical activities - being physically active will help loosen mucus in their lungs
- Again, the youth will need to be able to eat at their discretion, as needed

FURTHER ASSISTANCE

This Info Sheet is a resource guide only and is not intended to be therapeutic, diagnostic, medical, or legal advice. Our best source of assistance for youth with identified needs is the youth's parents or caregivers; the information provided is designed to support the relationship that exists between a youth and his/her parents or healthcare providers and the Scouters involved with the youth.

SOURCES

www.webmd.com/children/tc/cystic-fibrosis-topic-overview, <http://kidshealth.org/parent/classroom/factsheet/cf-factsheet.html>, www.cysticfibrosis.ca, and material adapted and used by permission of The Scout Association (UK), Scouts Australia, and Scouting Ireland

