



INCLUSIVE 4-H:

LESS PREVALENT MEDICAL CONDITIONS: CEREBRAL PALSY, CYSTIC FIBROSIS, EPILEPSY, MUSCULAR DYSTROPHY, SPINA BIFIDA, SPINAL CORD INJURIES

These medical conditions are not as commonly seen in children, but you may still have children with at least one of these medical conditions in your 4-H program. These medical conditions could also be present in conjunction with other disabilities. These medical conditions may require extra intervention and accommodations from 4-H Extension Educators and 4-H volunteers. It is important to keep in mind that each of these conditions affect the body in different ways. Read each description below for more details.

CEREBRAL PALSY

Cerebral palsy (CP) is a group of disorders that affect a person's ability to move and maintain balance and posture. It also affects muscle tone, gross and fine motor functions, and reflexes. CP is caused by abnormal brain development or damage to the developing brain that affects a person's ability to control his or her muscles.

All people with CP have problems with movement and posture. Someone with CP may also have intellectual impairment; seizures; vision, speech, or hearing impairments; and/or joint problems. Most people with CP have trouble controlling facial muscles, resulting in trouble breathing, swallowing, or communicating. The symptoms of CP will present differently from person to person. Some people with CP may need special equipment to walk or might not be able to walk at all. Others with CP may only need minimal assistance or no assistance at all.

There is no cure for CP, but symptoms can be controlled and improved through various therapies.

SPINA BIFIDA

Spina bifida is a condition that affects the spine and is usually apparent at birth. It occurs when a neural tube does not close all the way resulting in damage to the spinal cord and nerves. Spina bifida might cause physical and intellectual disabilities that range from mild to severe. Because spina bifida affects people in many ways, their needs will vary tremendously from person to person. People with spina bifida may have different levels of mobility. Regular physical activity can be beneficial for children with spina bifida.

Some common symptoms of spina bifida include:

- Incontinence (inability to control bladder and bowels)
- Learning disabilities
- Possible paralysis
- Memory problems
- Impulsivity
- Average IQ but low math skills
- Poor hand-eye coordination

CYSTIC FIBROSIS

Cystic Fibrosis (CF) is a progressive, genetic disease that causes persistent lung infections and limits the ability to breathe over time. CF causes mucus to clog the airways and trap germs in the lungs leading to infections, inflammation, respiratory failure, and other complications. This mucus build-up affects multiple organs including the lungs, pancreas, liver, and intestines. There are a variety of symptoms including:

- Persistent coughing, at times with phlegm
- Frequent lung infections
- Wheezing or shortness of breath
- Poor growth or weight gain
- Difficulty with bowel movements

These symptoms will vary with age and disease severity. Medication, respiratory therapy, and exercise can help improve symptoms, but there is no cure. Someone with CF will also likely work with a dietitian to follow a high calorie, nutrient dense diet, because their body does not absorb nutrients as well as it should.

People with CF **must stay at least 6 feet away** from people who are sick and other people with CF due to the risk of spreading bacteria and causing infection. Children with CF can and should live relatively average lives. Some things that people with Cystic Fibrosis need to be mindful of are listed below.

- *Good Hygiene*- frequent hand washing is important, because exposure to germs can easily lead to lung infections in people with CF.
- *Avoiding air irritants*- another cause of lung infection can include exposure to people who are sick with a contagious disease (such as a cold or flu) and cigarette smoke.
- *More doctor visits*- Cystic Fibrosis treatment will require children with the disease to have more frequent doctor visits to receive specialized care.
- *Respiratory Therapy*- CF treatment may require a significant amount of time (up to 2 hours) everyday doing respiratory therapy.
- *Nutrition*- due to specific dietary needs, people with CF must also be mindful of their nutrition.
- *Exercise*- getting the heartrate up for at least 30 minutes per day can help improve lung capacity and breathing.

EPILEPSY

Epilepsy is a brain disorder in which electrical and chemical signals are disrupted. Epilepsy is characterized by having a predisposition to generate unprovoked epileptic seizures. Seizures take many different forms and affect people in different ways. Some people may be able to tell when they are going to have a seizure, but others may have no warning signs.

There are many different symptoms of epileptic seizures. A person may become confused and unable to focus at the beginning of a seizure. They may even lose awareness. During a seizure, a person may have difficulty talking, tremors, convulsions, repeated blinking, among other symptoms. (A full list of symptoms can be found at www.epilepsy.com) Seizures may or may not be caused by triggers. Some common triggers of epileptic seizures include:

- Specific time of day
- Sleep deprivation
- Illness
- Flashing lights
- Stress
- Specific foods (e.g., caffeine)

Remember **Stay, Safe, Side** for seizure first aid. **Stay** with the person and start timing the seizure. Remain calm while interacting with someone having a seizure. Check their medical ID. Keep the person **safe**. Make the person as comfortable as possible and loosen any clothes around the neck. If they are able to, have them sit down in a safe place. If they are at risk for falling or convulsing, lay them on the floor, put something soft under their head, and turn them on their **side** with their mouth pointing toward the ground. Do not put anything in the person's mouth during a seizure. Rescue breathing is not typically needed for someone having a seizure. Stay with them until they are awake and aware, continue to remain calm and keep others around you calm.

Always call 911 if an individual has a seizure during a 4-H event. Purdue University policy mandates that an ambulance must be called if an individual has a seizure during a Purdue sanctioned event and the same protocol should be followed during Purdue Extension activities.

MUSCULAR DYSTROPHY

Muscular dystrophy is a group of diseases that cause progressive weakness and loss of muscle mass. There are many kinds of muscular dystrophy. The most common variety begins in childhood, mostly in boys. Medications and therapy can help manage symptoms of muscular dystrophy. The main symptom is progressive muscle weakness. Muscular dystrophy can lead to trouble walking, trouble using arms, breathing problems, curved spine, heart problems, and swallowing problems.

SPINAL CORD INJURIES

A spinal cord injury occurs when the spinal cord is cut, damaged, or pinched. In most spinal cord injuries, the spinal cord remains intact but is damaged. Spinal cord injuries usually result in permanent changes in strength, sensation, and other body functions below the site of the injury. The place of the injury along the spinal cord and the severity of the injury are both factors in the amount of mobility and function that is lost. Spinal cord injuries may also result in incontinence, spasms, chronic pain, and difficulty breathing. Spinal cord injuries are usually caused by trauma (e.g., car accidents, sports injuries, etc.)

IMPORTANT CONSIDERATIONS

- Have contact information for parents or guardians and the member's doctor in an accessible place. An example of this would be behind the child's nametag and in the medical forms box at the location of 4-H events. This form should include information such as what kinds of medications the child is taking, allergies, if any adaptive devices are used, and other health conditions.
- No two people with any type of medical condition are the same, and each person will have unique needs that need to be met. It is a good idea to meet with the child and his or her family to discuss appropriate accommodations during all 4-H events and activities. Questions to ask could be:
 - a. What do I need to know to keep you safe?
 - b. How can we make 4-H accessible for you?
 - c. What are you looking forward to in 4-H?
 - d. When thinking about the 4-H program, what do you see as challenges?
- Understand that some people may not feel comfortable talking about certain aspects of their condition or disability. Do not force someone to answer questions that make them uncomfortable. Remind them that any information they share is voluntary, confidential, and not required.
- During events that last a day or longer (such as 4-H camp), the child with a medical condition may need a nurse, personal care attendant (PCA) or family member present to help with specialized care.
- Consider offering training to 4-H volunteers about interacting with 4-H members who have disabilities.

CEREBRAL PALSY TIPS

- Keep in mind that not every child with CP will have delays in mental development. Many children with CP have average or above average IQs.
- Some examples of accommodations for a member with cerebral palsy may include:
 - a. An adaptive apparatus to help show a livestock animal.
 - b. An assistant, such as a family member or other 4-H member, who can assist with communication and/or movement when presenting a project or activity.
 - c. Have a caretaker nearby or easy to contact in case of safety issues or if personal care needs arise.
 - d. Provide the member with extra time to complete a task.
 - e. Remember that not all people with Cerebral Palsy will need major accommodations, and it is always best to develop a plan with the member and his or her family.

SPINA BIFIDA TIPS

- Latex allergies are common in children with spina bifida. Make sure you know if the child is allergic to latex and avoid using products like latex bandages and gloves when working with a member with a latex allergy.
- If the member has learning disabilities due to his or her spina bifida, make sure to take this into account when planning activities, giving feedback, and judging record books and projects.
- A parent or caregiver may need to stay near the member with spina bifida to help with personal care needs such as bathroom trips.

CYSIC FIBROSIS TIPS

- You likely will not be able to tell if a child has Cystic Fibrosis just from looking at or even interacting with them. Family members may choose not to inform you about the disease, because they do not want their child to be treated differently than his or her peers. Unless the child will be spending more than a few hours at a 4-H event, their CF can be managed without intervention from 4-H leaders.
- If the family does choose to disclose that their child has Cystic Fibrosis, visit with the child and their guardians to discuss their needs. Questions to be asked may include:
 - a. What information is helpful for us to understand your disability?
 - b. Do you have a special diet we need to be aware of?
 - c. What do you need access to for an accessible and safe 4-H experience?
- While not common, if there are multiple 4-H'ers with CF in the same program/workshop/etc, they MUST be kept away from each other.
- Emphasize the importance of good hygiene practices and staying home if you are sick to all 4-H members. Do not single out the child with CF and instead make it a fun learning activity for all. Knowing that the 4-H leaders are concerned about healthy habits may help the child with CF and his or her parents feel at ease in the new environment.
- Some situations during 4-H events that may trigger problems for children with CF include exposure to animal dander, dirt, dust from barns, and other people with contagious illnesses such as colds. Help the member avoid these situations to your best abilities without making them feel excluded.

MUSCULAR DYSTROPHY TIPS

- Questions that can be asked include:
 - a. What information is helpful for us to understand your disability?
 - b. What do you need access to for an accessible and safe 4-H experience?
- Learning the type of muscular dystrophy the child has can help better understand how their symptoms affect their life and how you can best accommodate their needs.
- Activities that require a full range of motion may be difficult for individuals with muscular dystrophy. Take this into consideration when planning activities and try to find activities that are inclusive for all.
- Allow an assistant to help the child during 4-H activities if needed.

EPILEPSY TIPS

- Questions that can be asked include:
 - a. What does a typical seizure look like?
 - b. Do you experience any signals or signs before you have a seizure?
 - c. What are some things that can trigger your seizures?
- In the event of a seizure, always call 911. You can develop a plan with a family that once the ambulance arrives to deny care, but that decision should be made once a medical provider reviews the situation.
- People with epilepsy can usually participate in all activities. However, some activities may require extra caution. For example, swimming must be closely monitored because the person could easily drown if they have a seizure in water. Lifeguards should always be on duty.
- Do not activate strobe lights or other bright flashing patterns which could trigger seizures.
- It may be helpful to participate in seizure first aid training, especially if you know of a member with epilepsy in your 4-H program.

SPINAL CORD INJURY TIPS

- Many spinal cord injuries occur in the teenage years. Leaders may have worked with the member before he or she sustained the spinal cord injury. After the injury, the member may be discouraged to continue participation. It is important to make sure he or she still feels welcome in the 4-H program. Consider what the member's interests were before the injury, and work with the member to find ways to modify projects so the member can still complete them.
- When choosing event spaces consider handicap accessibility. Make sure doorways, stages, and seating areas are equipped for those with mobility challenges.

ADDITIONAL RESOURCES

- General: www.CDC.gov and www.mayoclinic.org are reliable sources for information regarding most medical conditions and disabilities.
- Cerebral Palsy: www.Cerebralpalsy.org.
- Cystic Fibrosis: www.cff.org
- Epilepsy: www.epilepsy.com
- Muscular Dystrophy: www.mda.org/disease/list
- Spina Bifida: www.spinabifidaassociation.org

Visit us at purdue.ag/inclusive4h for more information!



An Equal Access/Equal Opportunity Institution

Updated March 2021 by Molly Bull Childers. Reviewed by Mandie Waling, Purdue Disability Resource Center. Adapted from original resources developed by: Patricia Tatman, Department of Family and Consumer Sciences, University of Wyoming.