

## WHAT IS CYSTIC FIBROSIS?



Cystic fibrosis (CF) is the most common fatal genetic disease affecting Canadian children and young adults. At present, there is no cure.

CF causes various effects on the body, but mainly affects the digestive system and lungs. The degree of cystic fibrosis severity differs from person to person, however, the persistence and ongoing infection in the lungs, with destruction of lungs and loss of lung function, will eventually lead to death in the majority of people with CF.

Typical complications caused by cystic fibrosis are:

- Difficulty digesting fats and proteins
- Malnutrition and vitamin deficiencies because of inability to absorb nutrients
- Progressive lung damage from chronic infections and aberrant inflammation
- CF related diabetes
- Sinus infections

It is estimated that one in every 3,600 children born in Canada has CF. More than 4,300 Canadian children, adolescents, and adults with cystic fibrosis attend specialized CF clinics.

### **SYMPTOMS OF CYSTIC FIBROSIS**

Cystic fibrosis is a multi-system disorder that produces a variety of symptoms including:

- Persistent cough with productive thick mucus
- Wheezing and shortness of breath
- Frequent chest infections, which may include pneumonia
- Bowel disturbances, such as intestinal obstruction or frequent, oily stools
- Weight loss or failure to gain weight despite possible increased appetite
- Salty tasting sweat
- Infertility (men) and decreased fertility (women)

For information on Cystic Fibrosis Screen Positive Incon-

clusive Diagnosis (CFSPID), please see link: <https://www.cysticfibrosis.ca/about-cf/living-with-cystic-fibrosis/newly-diagnosed>

## WHAT IS HUNTINGTON DISEASE?

Huntington disease (HD) is a hereditary, neurodegenerative illness with physical, cognitive and emotional symptoms. Huntington disease is caused by a mutation in the gene that makes the protein called huntingtin. In people with HD, the CAG sequence is repeated too many times at the beginning of the gene. That causes cells to manufacture a harmful protein called mutant huntingtin. The mutant huntingtin protein causes certain parts of the brain to die – specifically the caudate, the putamen and, as the disease progresses, the cerebral cortex. As the brain cells die, symptoms will appear in each of the three components (physical, cognitive and emotional).



To date, there are no drugs to slow or stop the progression of Huntington disease; however, there are specific drugs available to reduce some of the symptoms. Research is being conducted in Canada and globally to find promising treatments and approaches to treating HD.

### **WHO GETS HD?**

Huntington disease is a genetic disorder. The HD gene is dominant, which means that each child of a parent with HD has a 50% chance of inheriting the disease and is said to be at-risk. Males and females have the same risk of inheriting the disease. HD occurs in all races. Symptoms usually appear between the ages of 35 and 55, but the disease can appear in youth (under 20 years – Juvenile HD) or older adults (Late Onset HD).

### **WHAT ARE THE SYMPTOMS?**

Symptoms vary from person to person and at different stages of the disease.

- Physical symptoms: weight loss, involuntary move-



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ments (chorea), diminished coordination, difficulty walking, talking and swallowing

- Cognitive symptoms: difficulty with focus, planning, recall of information and making decisions; impaired insight
- Emotional symptoms: depression, apathy, irritability, anxiety, obsessive behaviour

### Early Stages of HD

At this stage, people with HD can function quite well at work and at home. Early symptoms of the disease may include the following:

- Difficulty organizing routine matters or coping effectively with new situations
- Decreased ability to recall information and make decisions
- Increased difficulty with work activities
- Decreased attention to details
- Mood changes and irritability
- Minor involuntary movements (e.g. “nervous” activity, fidgeting, a twitching of the limbs or excessive restlessness)
- Changes in handwriting or difficulty with daily tasks such as driving

### INTERMEDIATE STAGES OF HD

People with HD in the intermediate stage may have increasing difficulty working or managing a household but can still deal with most activities of daily living. Symptoms progress over time and may include the following:

- More obvious involuntary movements (chorea)
- Increased difficulty with walking, coordination and balance
- Challenges with speaking (speech may become slurred) and delays in thinking process
- Solving problems becomes more difficult
- Difficulties with swallowing
- Weight loss

### ADVANCED STAGES OF HD

People in the advanced stages of HD can no longer manage the activities of daily living and usually require professional care. Symptoms will include the following:

- Decrease in involuntary movements and increase in

rigidity

- Increased difficulties with swallowing
- The ability to communicate diminishes, but understanding what is being said remains possible
- Significant weight loss

<https://hdsa.org/what-is-hd/overview-of-huntingtons-disease/>

## What is Multiple Sclerosis (MS)



MULTIPLE SCLEROSIS  
AWARENESS

Canada has one of the highest rates of multiple sclerosis (MS) in the world, with an estimated 90,000 Canadians living with the disease. On average, 12 Canadians are diagnosed with MS everyday. Most people are diagnosed with MS between the ages of 20 and 49 and the unpredictable effects of the disease will last for the rest of their lives.

MS is a chronic autoimmune disease of the central nervous system. Since that includes the brain, spinal cord and optic nerve, MS can affect vision, memory, balance and mobility. It is considered an episodic disability meaning that the severity and duration of illness and disability can vary and are often followed by periods of wellness. It can also be progressive.

The disease attacks myelin, the protective covering of the nerves, causing inflammation and often damaging the myelin. Myelin is necessary for the transmission of nerve impulses through nerve fibres. If damage to myelin is slight, nerve impulses travel with minor inter-



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ruptions; however, if damage is substantial and if scar tissue replaces the myelin, nerve impulses may be completely disrupted, and the nerve fibres themselves can be damaged.

MS is unpredictable and may cause symptoms such as extreme fatigue, lack of coordination, weakness, tingling, impaired sensation, vision problems, bladder problems, cognitive impairment and mood changes. Its effects can be physical, emotional and financial. Currently there is no cure, but each day researchers are learning more about what causes MS and are zeroing in on ways to prevent it.

We are here to help. No one needs to face MS alone. In communities across Canada, the MS Society provides information, support, educational events and other resources for people living with MS and their families. Learn more about the programs and services we offer. Have questions about MS? We're here to help. Contact an MS Navigator: 1-844-859-6789, [msnavigators@mssociety.ca](mailto:msnavigators@mssociety.ca)



**SKIP THE DEPOT**

Join VAD in our fundraising by donating your bottles and cans to Skip the Depot.

<https://app.skip-the-depot.com/vad-society>

Our ID number is: 6K9E



[www.huntingtonsociety.ca](http://www.huntingtonsociety.ca)

[www.cysticfibrosis.ca](http://www.cysticfibrosis.ca)



MULTIPLE SCLEROSIS AWARENESS

[www.mssociety.ca](http://www.mssociety.ca)

**Voice of Albertans with Disabilities is raising awareness during May.**



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## National AccessAbility Week – NAAW: May 30 to June 5, 2021

### **Disability Inclusion 2021: Leaving no one behind**

National AccessAbility Week (NAAW) is an opportunity:

- to celebrate the valuable contributions of Canadians with disabilities
- to recognize the efforts of individuals, communities and workplaces that are actively working to remove barriers to accessibility and inclusion

We all benefit from a society and an economy without barriers to inclusion. When persons with disabilities can participate in all aspects of society, including accessing employment, resources and services, it enriches Canada's economy.

Throughout the ongoing COVID-19 pandemic, the Government of Canada has been helping Canadians with disabilities maintain their health, safety and dignity. This year celebration activities for NAAW will be virtual, respecting current public health instructions.

### **Suggested tweets:**

- Highlight National #AccessAbility Week, from May 30 to June 5. Let's dedicate this week to accessibility and inclusion in Canada. Find out more: [Canada.ca/accessibility-week](http://Canada.ca/accessibility-week) #AccessibleCanada
- Hey Canada! #DYK this week is National #AccessAbility Week? #AccessibleCanada [Canada.ca/accessibility-week](http://Canada.ca/accessibility-week)
- This National #AccessAbility Week, let's highlight & promote accessibility and inclusion in Canada. #AccessibleCanada [Canada.ca/accessibility-week](http://Canada.ca/accessibility-week)
- Join us in recognizing National #AccessAbility Week! #AccessibleCanada [Canada.ca/accessibility-week](http://Canada.ca/accessibility-week)

- Share a picture or video of how you are marking National #AccessAbility Week! #AccessibleCanada
- During National #AccessAbility Week, highlight an individual or an organization that makes accessibility a reality in your community! #AccessibleCanada

### **Suggested Facebook posts:**

- From May 30 to June 5, we're highlighting National #AccessAbility Week, a week dedicated to inclusion and accessibility in Canada. Let's work together for a more #AccessibleCanada! [Canada.ca/accessibility-week](http://Canada.ca/accessibility-week)
- National #AccessAbility Week in Canada is here! Share a photo or a video of how you are marking this important week! [Canada.ca/accessibility-week](http://Canada.ca/accessibility-week) #AccessibleCanada
- During National #AccessAbility Week, let's:
- highlight all the work individuals and organizations are doing for accessibility and inclusion contribute to building a more #AccessibleCanada [Canada.ca/accessibility-week](http://Canada.ca/accessibility-week)
- During National #AccessAbility Week, recognize an individual or an organization that improves accessibility in your community. #AccessibleCanada [Canada.ca/accessibility-week](http://Canada.ca/accessibility-week)





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# Watch For Access: A NAAW Virtual Film Festival

Presented by Voice of Albertans with  
Disabilities (VAD)

2021 marks the 5th annual National Access Ability Week in Canada. We are excited to host a “Virtual Film Festival” this year to highlight some of the incredible films that showcase the realities of living with disability.

Each night we will post on our Facebook what movie we’re watching and encourage everyone to watch with us. Comment on the post to tell us what you think about the movie and if you learned something new about disability. Everyone who comments something about the movie will be eligible to win a gift with a value of up to \$100! We will begin watching the movie at 6:00 pm MST each day but you can comment up until the next day at 3:00 pm MST to be eligible for the prize.

We will wrap up the week with a Watch Party of “The Upside” (2017) a dramatic comedy based on a true story.

Registration for that can be found at <https://www.generoussolutions.com/e/watch-for-access-naaw-virtual-film-festival-618>

A Note: We did our best to showcase a variety of disabilities across many genres and over the various streaming options to try and represent and accommodate the most people we could. We understand that some of these movies aren’t perfect and that there will be criticisms of the portrayal and content and we welcome those discussions as they are important. However, everyone in the comments is expected to be respectful of others opinions- comments that insult or attack another’s character will be removed.

Date and Time	Movie	Genres and Rating	Streaming Service
Sunday May 30 6:00 pm	No Ordinary Hero: The SuperDeafy Movie	Childrens, Comedy, Drama (7+)	Amazon Prime, Rent from YouTube (\$3.99)
Monday May 31 6:00 pm	Penguin Bloom	Drama (14+)	Netflix
Tuesday June 1 6:00 pm	My Beautiful Broken Brain	Documentary (14+)	Netflix
Wednesday June 2 6:00 pm	My Blind Brother	Comedy, Romance, Drama (14+)	Amazon Prime, Crave, Rent from YouTube (\$3.99)
Thursday June 3 6:00 pm	Finding Dory	Childrens, Comedy (7+)	Disney+, Amazon Prime, Rent from YouTube (\$3.99)
Friday June 4 6:00 pm	Crip Camp	Documentary, (18+)	Netflix
<b>Saturday June 5 4:00 pm - LIVE WATCH PARTY must register for link</b>	<b>The Upside</b>	<b>Comedy, Drama, (16+)</b>	<b>We will be streaming on Zoom</b>

We will also do our best to provide content warnings so everyone can prepare beforehand.



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**Watch For Access**  
**NAAW Virtual Film Festival**  
JUNE 5  
4PM-7PM MST

**The Voice of Albertans with  
Disabilities Proudly Presents:**

A VIRTUAL SHOWING OF  
"THE UPSIDE"  
VIA ZOOM

<https://www.generoussolutions.com/e/watch-for-access-naaw-virtual-film-festival-618>

SCAN BELOW



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