

***Clostridium difficile* Survey**

Preamble

The Gastrointestinal Society represents patients with gastrointestinal diseases and disorders on a variety of health care fronts. We have designed this survey to help us understand your opinions and outlook regarding the effects that infection with the *C. difficile* bacterium has on the lives of patients. We will use this information anonymously and in aggregate to shape future programming and to inform community members, health care professionals, and health policy decision-makers.

Clostridium difficile (*C. difficile*) is a virulent, toxin- and spore-producing pathogen that causes inflammation of the inner lining of the colon, incapacitating diarrhea that frequently requires hospitalization and, in the most serious cases, death. The spore form of the pathogen is resistant to gastric acid, antibacterial soaps, and alcohol-based hand sanitizers, and can survive for months on surfaces. *C. diff* has been associated with numerous outbreaks across Canada.

1. To complete this survey, you must meet one of the following criteria:

- person who has been infected with the *C. difficile* bacterium
- caregiver/loved one of a person who has been infected with the *C. difficile* bacterium, but not in a health care provider capacity

[Can't continue if one of these categories is not selected]

The following questions are asking for the patient experience, so please answer as the patient, or on behalf of the patient for whom you are responding.

Personal Information

Please note: we will keep all personal information strictly confidential and use it only for the purposes of facilitating this survey.

2. Age [CHECK ONE]

- <19
- 19-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- >89

3. Gender [CHECK ONE]

- female
- male
- other
- prefer not to say

4. In which Canadian province or territory do you live? [DROP-DOWN BOX]

- Alberta
- British Columbia
- Manitoba
- New Brunswick
- Newfoundland and Labrador
- Northwest Territories
- Nova Scotia

- Nunavut
 - Ontario
 - Prince Edward Island
 - Quebec
 - Saskatchewan
 - Yukon
 - I do not live in Canada (please specify country)
5. Are you a health care professional? [CHECK ONE]
- yes
 - no
6. If yes, do/did you work in a: [MULTICHECK]
- long-term care facility
 - hospital
 - clinic/physician's office
 - dental office
 - other health care setting (please specify)
 - none of the above
 - not a health care professional

C. difficile Questions

7. What symptoms or complications have you experienced at any time while infected with *C. difficile*? [MULTICHECK]
- diarrhea
 - watery, severe diarrhea
 - fecal incontinence
 - fever
 - loss of appetite
 - weight loss
 - nausea
 - abdominal pain/tenderness
 - fatigue
 - pseudomembranous colitis
 - bowel perforation
 - bowel surgery
 - sepsis
 - *C. difficile* infection recurrence
 - resulted in the death of the person you were caring for
 - other (please specify)
8. How many times have you had *C. difficile* infection? [CHECK ONE]
- 1
 - 2
 - 3
 - 4
 - 5+ (please specify)
 - I don't remember/know

For the remaining questions on this page, answer based on your experience with your **FIRST** *C. difficile* infection only.

9. How long was it from onset of diarrhea until you received a diagnosis? [CHECK ONE]
- <48 hours
 - 2-5 days
 - 6-10 days
 - 11-30 days
 - >30 days
 - I don't remember/know
10. Had you been taking antibiotics in the three months preceding diagnosis? [CHECK ONE]
- yes
 - no
 - I don't remember/know
11. Who prescribed you the antibiotics in the three months preceding diagnosis? [CHECK ONE]
- physician in clinic or office
 - physician in hospital
 - naturopath
 - dentist
 - pharmacist
 - other (specify)
 - I wasn't taking antibiotics in the three months preceding diagnosis
12. Did your first experience with *C. difficile* infection begin following any of these situations: [MULTICHECK]
- an existing severe illness
 - an abdominal surgical procedure
 - having another gastrointestinal infection
 - childbirth
 - a flare of Crohn's disease or ulcerative colitis
 - bone marrow/stem cell transplant
 - undergoing cancer chemotherapy
 - taking antibiotics for a chronic condition unrelated to *C. difficile* infection (especially over a prolonged period of time)
 - taking medication to reduce stomach acid
 - taking medication to suppress your immune system, e.g., for an autoimmune disease or due to an organ transplant
 - in hospital for some other reason
 - none of the above
13. Which treatment(s) did you use to combat your first *C. difficile* infection? [MULTICHECK]
- antibiotics: (e.g., metronidazole, vancomycin, fidaxomicin)
 - fecal transplant from a relative
 - fecal transplant from a non-relative
 - probiotics
 - other (please specify)
 - I don't remember/know
14. How many days after starting treatment did your symptoms completely resolve (even if you relapsed later, answer with how long it took to resolve initially)?
- <4
 - 4-7
 - 8-14

- >14
 - did not resolve
 - did not treat
15. Did your symptoms begin while: [MULTICHECK]
- in a hospital
 - in a long-term care home
 - living at home
 - travelling
 - other (please specify)
16. If your symptoms began while in a hospital, did your first experience with *C. difficile* infection prolong your stay? [CHECK ONE]
- yes
 - no
 - not applicable
17. Did your first experience with *C. difficile* infection require hospitalization? [CHECK ONE]
- yes
 - no
 - I was already in the hospital
18. How long was your hospital stay? [CHECK ONE]
- 1-3 days
 - 4-6 days
 - 1-2 weeks
 - 3-4 weeks
 - other (please specify)
 - I was never hospitalized

***C. difficile* Questions Continued**

19. Do you have any of these gastrointestinal conditions? [MULTICHECK]
- diverticular disease
 - irritable bowel syndrome
 - gastroesophageal reflux disease (GERD)
 - inflammatory bowel disease (e.g., Crohn's disease, ulcerative colitis)
 - celiac disease
 - none of the above
20. How would you rate your quality of life **before your first *C. difficile* infection**? [CHECK ONE]
- able to carry on normal activity including work; no special care needed, social activities not restricted
 - able to carry on with most normal activities and able to work, but social activities restricted
 - able to carry on with most activities but unable to work
 - some assistance needed with normal activities
 - unable to care for self but able to stay at home
 - unable to care for self and requiring institutional or hospital care
21. How would you rate your quality of life **at your worst with *C. difficile* infection**? [CHECK ONE]
- able to carry on normal activity including work; no special care needed, social activities not restricted
 - able to carry on with most normal activities and able to work, but social activities restricted

- able to carry on with most activities but unable to work
 - some assistance needed with normal activities
 - unable to care for self but able to stay at home
 - unable to care for self and requiring institutional or hospital care
22. How would you rate your quality of life **currently**? [CHECK ONE]
- able to carry on normal activity including work; no special care needed, social activities not restricted
 - able to carry on with most normal activities and able to work, but social activities restricted
 - able to carry on with most activities but unable to work
 - some assistance needed with normal activities
 - unable to care for self but able to stay at home
 - unable to care for self and requiring institutional or hospital care
23. Thinking of any or all **subsequent** experience(s), which treatments have you used to combat *C. difficile* infection? [MULTICHECK]
- antibiotics: (e.g., metronidazole, vancomycin, fidaxomicin)
 - fecal transplant from a relative
 - fecal transplant from a non-relative
 - probiotics
 - other (please specify)
 - I don't remember/know
 - I only had *C. difficile* infection one time
24. In your opinion, what is the most important priority regarding improving your experience with *C. difficile* infection?
[BOX]

Finish

Thank you for taking part in this survey!

If you would like to be entered into a draw to win an iPad mini, please provide the information requested below. *We will keep all of your information confidential and will never share it or sell it to any outside party. Your name and address will be detached from your answers before we conduct the survey analysis.*

To accept, please complete this section. If you are not interested, please leave this section blank.

[TEXT BOXES]

Salutation

First Name

Last Name

Address Line 1

Address Line 2

City

Province

Postal Code

Email

Phone

25. If you have any additional comments, you can enter them here:
[BOX]

Thank you for completing our survey!

Appendix 2 - Final Codebook

Themes	Codes		Inclusion	Exclusion	Examples	
Concerns about healthcare system	Time to diagnosis	T	Comments regarding time to initial diagnosis	Comments on time between first diagnosis and subsequent diagnosis of CDI or other illnesses	Much quicker diagnosis	
	Wrong initial diagnosis	W	Comments regarding quality of diagnosis or specific statement of wrong diagnosis		Better faster diagnosis	Cdiff was misdiagnosed for an anxiety attack
	Speed and selection of treatment	S	Comments referring to correct treatment choice (or mentioning of wrong treatment). Comments on the importance of short time between diagnosis and treatment	Comments on medication for pain or other conditions	Having a Doctor with knowledge of the right antibiotic for this condition	Identifying the possible infection and expediting lab work to confirm a diagnosis and move to treating sooner
	Faster referral to specialist	F	Comments indicating experience with slow referral to a specialist. Comments indicating necessity for fast referral to specialist	Comments on seeing a specialist without mentioning time of referral	being referred to an internal disease specialist immediately	
	Poor attitudes towards patient	P	Comments on patients being mistreated or not cared for appropriately by a healthcare provider		Attitudes of nurses at hospital. They acted almost repulsed	I was treated awfully because I had c-diff, even had a nurse berate me in emerge because I "contaminated" the bathroom
	Insufficient prevention protocols	I	Comments regarding the lack of proper prevention protocols in the Canadian healthcare setting	Comments regarding the lack of prevention outside the healthcare setting or in healthcare settings outside of Canada	Hospital staff have to be more pro active in making sure extra care is given to stop any out breaks	Prevention is key
Concerns about antibiotics	Clindamycin	C	Comments linking clindamycin to perceived reason for CDI		Was prescribed clindamycin by a dentist.	
	Antibiotics in general	A	Comments linking antibiotics as reason for having contracted CDI or recurrent flare off CDI	Comments on antibiotic use as therapy for CDI. Specific comments on clindamycin.	c diff outbreak occurred after being prescribed a second-round antibiotics for a severe hand injury	

Themes	Codes		Inclusion	Exclusion	Examples	
Needs from healthcare providers	Patient education	E	Comments on patient or family education, for example on on CDI, long term consequences, or suggested changes of life habits	Comments on educating healthcare providers or the public	Education of families and caregivers of risks to vulnerable people in hospital setting	Education about potential long-term effects after clearing the infection
	Pro/Prebiotics	PR	Comments on probiotics either during CDI therapy or post CDI		Dad should have been given a prescription for Probiotics immediately	Take probiotics
	Fecal transplant	FT	Comments mentioning fecal transplants a cure		Identifying it and having the transplant. That stopped it	
	Alternative providers	ALT	Comments and recommendations on seeing alternative healthcare providers		See a naturopath immediately	
	Importance of cure	CU	Comments highlighting the importance of being cured or stopping recurrence	Comments coded as "severity of symptoms" such as diarrhea	Getting rid of it	Finding a permanent solution to be free of potential re-occurrence
	Ongoing bowel concern and recurrence	O	Comments on long-term consequences either directly related to CDI or related symptoms such as fatigue	Any comment on recurrence	my grandma had it she died due to the long-term effects of c diff	However, not sure that my energy level has ever been the same since
Impact on life	Severity of symptoms	SY	Comments on CDI symptoms such as diarrhea	Comments on the emotional impact of CDI	The most important thing is to be able to control the Doreatha and stomach pain	she had lost 10% of her body weight and had severe and constant diarrhea
	Complaints about treatments	CT	Comments on side effects or low efficiency of treatments		The medication made me really sick	The side effects of medication basically wiped out my white blood cell count
	Change in daily habits	D	Comments on change, delay and return to daily activities due to CDI	Comments referring to CDI symptoms such as fatigue, ongoing bowel issues	Ensure you always wash hands and clean areas you touch	Having to extend hospital stay delayed return to life
	Emotional impact	EI	Comments interpreted as emotional impact on the patient	Comments on emotional impact on anyone else than the patient	She did not need c diff to complicate things	once she contracted the disease and became so depressed
		EF	Comments interpreted as emotional impact on relatives of the patient	Comments interpreted as emotional impact on the patient	It has affected our social life, ..., worry	c diff had a devastating effect on the family