



PROJECT ZEBRA

Real-World Insights from the Carcinoid and
Neuroendocrine Tumor Patient Community

A report by Self Care Catalysts Inc. in partnership with the Carcinoid Cancer Foundation



Self Care Catalysts Inc.



FOREWORD

The Carcinoid Cancer Foundation and Self Care Catalysts Inc. are honored to partner together on the first ever *Project Zebra: Real-World Insights from the Carcinoid and Neuroendocrine Tumor Patient Community*, to help increase awareness and knowledge about what it is like to live with these diseases.

Approximately 125,000 people in the United States are diagnosed with carcinoid and other neuroendocrine tumors (NETs). As one of the rarer types of cancers, the day-to-day experience of people living with these rare diseases has not been understood widely. Project Zebra aims to put together a cohesive report that demystifies the experiences of individuals living with carcinoid and NET cancer, especially those with functional NETs (neuroendocrine tumors that produce distinct hormonal syndromes such as carcinoid syndrome).

For the carcinoid and NETs community, this is a tribute to your experience. There is much more to your journey as a person living with carcinoid and NET cancer, than what is commonly understood through medical literature and research about what it means to be a patient. The daily challenges—both physical and psychological—that you live with might often go unnoticed and misunderstood, so this is a testament to your ongoing perseverance beyond what is visible on the surface.

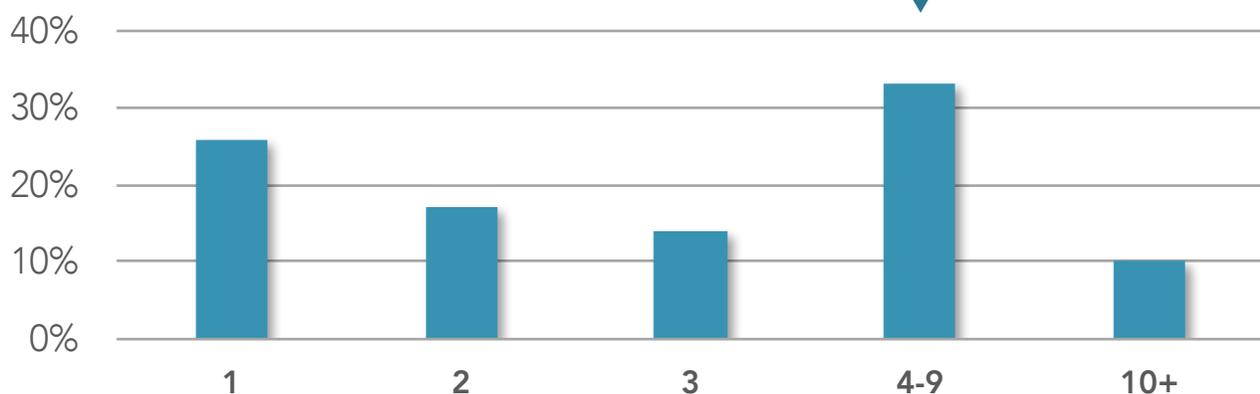
For the family, friends, and caregivers, who tirelessly support those living with carcinoid and NET cancer, this report will help you better understand the innermost struggles of the individuals that you care for—put into words what is often difficult for them to verbalize because they perceive this burden to be theirs alone. As you read this report, you may begin to empathize with your loved ones with a deeper appreciation of their most intimate day-to-day struggles.

For healthcare organizations and companies that provide treatment and services for the carcinoid and NET community, this report provides you with real world insights that contextualize a patient's life beyond physiological metrics. By having an in-depth understanding of the psychosocial impact of carcinoid and NET cancer on patients, you can develop more effective and informed patient support programs, messaging, and campaigns that address the true reality and aspirations of these patients.

Project Zebra would not have been possible without the support from over 200 individuals who participated in sharing their stories and experiences with carcinoid and NET cancer. Thank you for giving us the opportunity to amplify your voice so that others can understand your extraordinary journey.

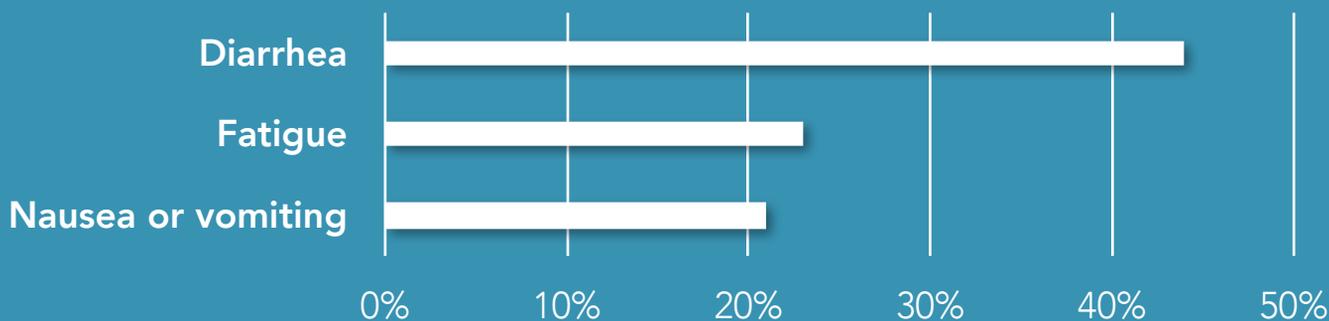
Patients with functional NETs (neuroendocrine tumors that produce distinct hormonal syndromes such as carcinoid syndrome) display incredible resilience in the face of the symptoms they experience on a daily basis, which may be unpredictable in nature. The top symptoms reported by patients that impact their quality of life are gastrointestinal issues such as diarrhea, as well as fatigue.

33% of patients with carcinoid or NET cancer report between 4-9 symptoms.



44%

of patients have diarrhea, making it one of the top symptoms reported.



With their physical well-being in a constant state of flux, it becomes challenging for patients to make plans with others, or have a long term view of their future.



Having NETs makes the lives of patients uncertain due to the unpredictability of their symptoms. With their physical well-being in a constant state of flux, it becomes challenging for them to make plans with others, or have a long term view of their future.

Patients see a need to plan each day in anticipation of sudden symptom onset, so they are not caught unawares. For instance, there is a need to schedule activities around symptoms, and a need for nutritional planning. There is a desire to regain control.

“

I am reluctant to commit to invitations or requests for help too far in the future. I never know what my day will be like until I get up and assess my condition. I've made promises to others but couldn't fulfill [them]."

“

It is difficult with so many interruptions and disconnection between my brain and body. I can think of and plan activities, but my body often has its own agenda."

“

Very rigorous to stay one step ahead with all these eating restrictions and bathroom needs. I have to stay positive to stay on top of all my needs."

There is a worry of disease progression among patients.

Even with treatment, the uncertainty of the illness and its ongoing symptoms mean that patients are made to be fully aware of their disease on a daily basis, resulting in worry about the outcome of this constant struggle.

“

Just waiting for the other shoe to drop sucks. I worry about my kids if something happens to me.”

“

I feel as if carcinoid is looked down upon because it's not quite [deadly], but in fact we die slower because we are left untreated for so long. This makes my life a strange, unwanted, rude way to live.”

“

Because I still have my primary tumor I fear that eventually it will secrete a metastasis beyond my liver. Each time I have a new pain or a new symptom I wonder if it is due to the NET.”





Having a circle of support that is truly present is one of the most important aspects of coping with carcinoid and NET cancer.

Immediate family members have proven to be essential partners on the patient journey—by not only taking on tasks to help relieve some of the stress that patients face, but also to provide a source of distraction by keeping things light and instilling a sense of “normalcy.”

“

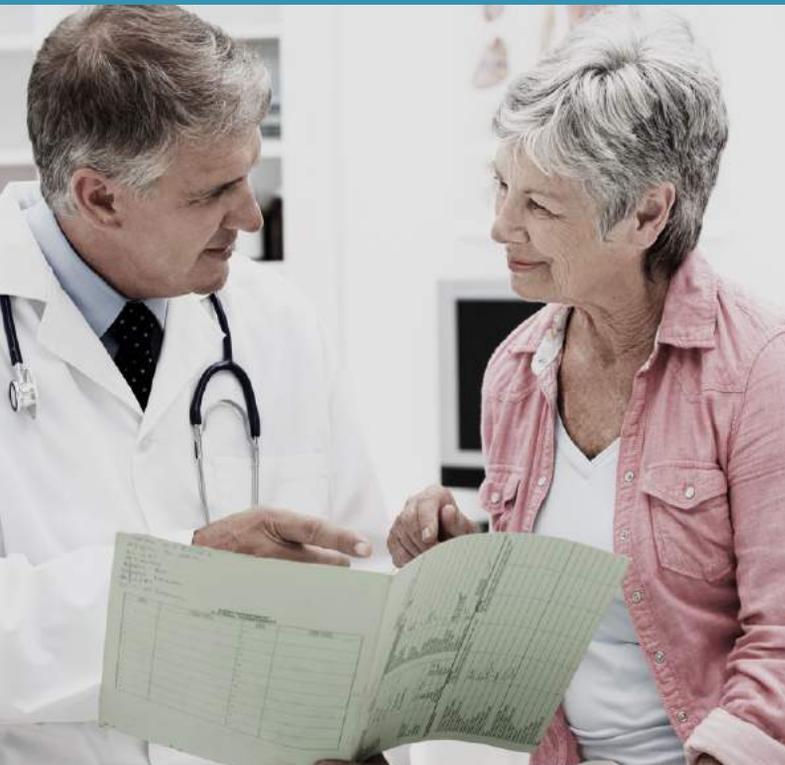
So thankful for my three beautiful grandchildren who bring me so much joy and happiness. They are a good distraction and keep me from dwelling too much.”

“

I am thankful for my husband and my sisters and my kids and grandkids. They give me hope. They show me so much love which motivates me to keep fighting.”

“

I am so thankful for my husband's support and caring. He really is so patient with me and my mood swings! Cooks dinner every night, walks the dog and just loves me! It's wonderful to be cared for.”



Medical and informational support from a NET specialist is significant for patients, who value expert advice on this little-known disease.

The support from healthcare providers, especially carcinoid and NET cancer specialists is highly valued by patients. Patients who had the chance to work with expert healthcare providers who provide them attentive care are thankful for the support they receive from the medical community.

Apart from medical information and support, 15% of patients surveyed reported a desire for more support on different aspects of self-care – which refers to actions that they take to maintain their overall physical, mental and emotional health. This presents an opportunity to support patients in their self-management.

“

I'm thankful for my carcinoid specialist in New Jersey, if I didn't have him I wouldn't be here.”

“

Thankful for my oncologist and the ARNP who helped me with a problem yesterday. They are wonderful people and I'm so fortunate to have them caring for me.”

“

I'm thankful for having a kind and patient doctor, and his nurse who listens patiently to everything that I need to get feeling better, hopefully healed once and for all.”

Being diagnosed with carcinoid or NET cancer can be an isolating experience.

Many symptoms do not manifest themselves externally, leaving the patient to experience them with little empathy from others, including family members. As a result of this, some patients feel compelled to reach out to their peers as they can relate to what they have gone through.

“

No one knows anything about it. Some don't even think it's a real cancer. And because I have good days and bad days I get: 'Gee you look fine to me.'”

“

I am a carcinoid cancer support group leader, and when I hear what others have had to endure, I want to reach out to anyone facing carcinoid cancer challenges and be of help to them.”

The experience of NETs sometimes makes patients feel guilty, due to the perceived burden they have on others. As a result, they may keep their symptoms to themselves and pretend that everything is okay.



While patients may be emotionally affected by symptoms, the power of positive thinking helps them to cope.

Sometimes these mood fluctuations are referenced as “carcinoid rage,” and patients explain that they have no control over these negative emotions.

The power of positive thinking helps patients to cope. Some patients see their NET cancer experience as a journey of gratitude, showing greater appreciation for the people around them.

“

I'm thankful for my 7+ years of survival. When I was first diagnosed I read that I would only last 4-5 years after diagnosis.”

“

It does help to keep my mind busy, then I don't dwell on my pain.”

“

I find that if I spend some time in meditation [and] having a positive outlook on life really changes [my] mood.”



Faith and religion are sources of support for some patients with carcinoid and NET cancer.



After a diagnosis of carcinoid or NET cancer, some patients feel that they lose part of their identity because they fail to continue with their planned career path, or continue to pursue their life goals.

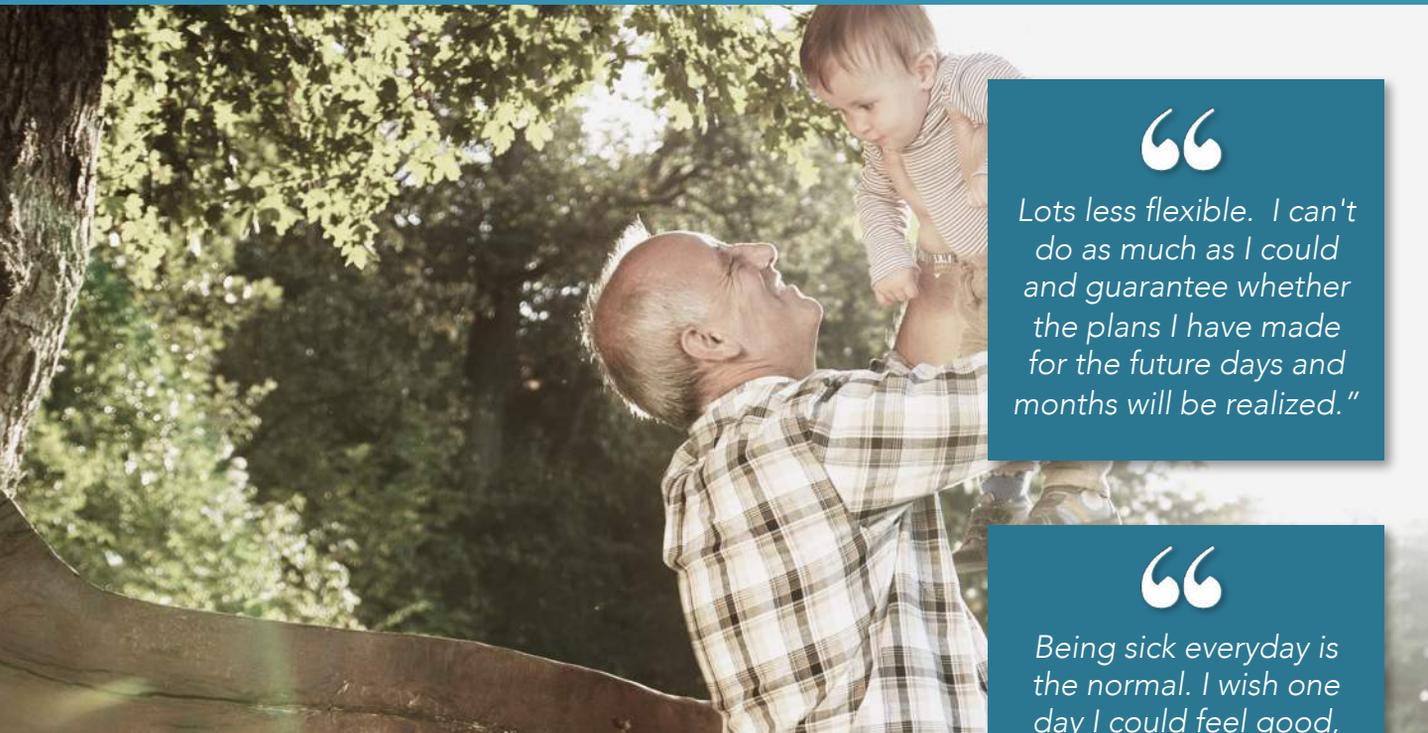
Patients cite the limit on one's independence, and the disruption of one's "former" lifestyle, as one of the biggest challenges of living with carcinoid and NET cancer. They mention having to give up their long term plans and the things that they love doing as a result of the disease.

“

I've lost my job I've worked so hard for. I'm now on full disability because now I can't work. Just like every single illness it has taken over my whole life. I will never become better, but [I'm] not at all complaining because I am being treated that keeps me at least living with this.”

“

I went from active military, with an active life, a side business, and part time student working towards my PhD, to a world that is foreign. I had to contact senators, congressmen to be properly diagnosed, fight for treatment, close my business, and put school on hold to put my health as my focus.”



Life with NET cancer can sometimes mean missing out.

With the impact of the illness constraining their ability to do the things that they used to – their “new normal” is one that is greatly limiting.

Pain is one of the top symptoms that affect patients’ quality of life. Many patients journal about their experience with pain and how it impacts their daily activities and emotional health.

Furthermore, gastrointestinal symptoms also disrupt quality of life – they affect patients’ physical well-being, limit their social activity, and are a source of psychological upset.

“

Lots less flexible. I can't do as much as I could and guarantee whether the plans I have made for the future days and months will be realized.”

“

Being sick everyday is the normal. I wish one day I could feel good, like a healthy person feels like. Just one day even 1 hour. I wonder what that is like.

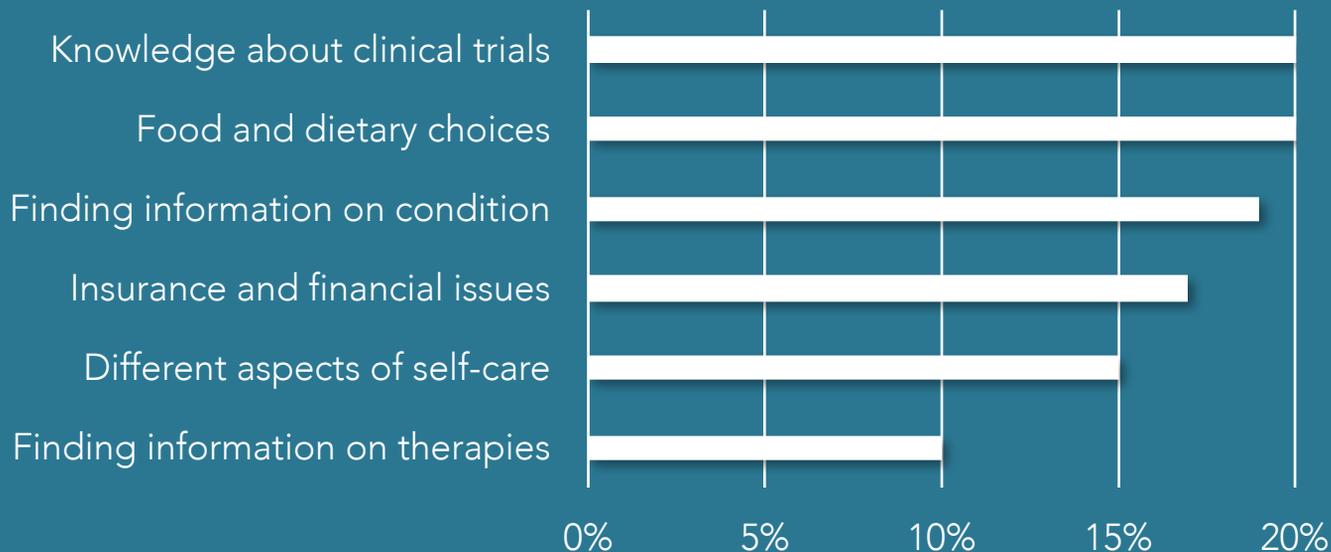
“

[Life with NETs is] harder and has changed the way I live my life and not be able to be independent like I used to be. Very hard and sad.”

“

I wish I can be with my family the way I used to be with them.”

What information do patients seek?



20% want to know more about clinical trials.

Based on qualitative journal entries, it appears that some patients derive their optimism from the hope that there might be new treatments being developed.



20% want more information on food and dietary choices.

The inability to eat as freely as before is more than just an inconvenience. Meal planning can be challenging for patients, but may be necessary for coping with gastrointestinal symptoms.

Patients feel a lack of validation for their illness experience.

Due to the lack of awareness around NETs and the experience that patients go through, one of the challenges faced by patients is the need to fight the public perception that their experience is as painless and uncomplicated as it looks on the outside.

“

I'm living with an oddity. Between explaining to people who honestly want to understand, and those who are supposed to know and provide care, the constant explaining gets aggravating. It creates a discomfort, and a situation where honesty when describing how I feel, and just saying I'm fine becomes blurred.”

“

Looking "better" than I should. People constantly tell me that I "don't look like I have cancer," but the truth is that inside I'm littered with tumors.”

“

I am not good at articulating how I feel, in terms of the pain I feel in my abdomen and back. I find myself feeling very angry at the medical community.”



A black and white photograph of two women laughing together outdoors. The woman on the left is older with short, curly hair, wearing a light-colored cardigan over a dark top and a patterned scarf. The woman on the right is younger with short dark hair, wearing a light-colored button-down shirt over a t-shirt. They are both smiling broadly and looking at each other. The background is a soft-focus outdoor setting.

SELF-CARE INSIGHT

Through a combination of self-care enablement and engaging their circle of support, we can provide hope, and empower the carcinoid and NET community to gain control over these rare diseases.

Despite the fact that carcinoid and NET cancer do not make patients appear “sick” on the outside, they experience a range of symptoms that impact their quality of life both physically and psychologically. Disease progression and the unpredictability of daily symptoms leads to the uncertainty that patients face, and the lack of control over their illness—even if they are receiving treatment.

Knowledge gaps in optimal self-management present an opportunity to support the carcinoid and NET cancer community, to help them achieve a better sense of control, improve quality of life and health outcomes. Particularly, nutrition and the need to adjust to different foods are among the top concerns of patients with carcinoid and gastrointestinal NET tumors, therefore leaving patients to seek more information and self-care support in this area to complement medical treatment.

Aside from providing physical support, caregivers, family members and friends of those living with carcinoid and NET cancer can provide comfort and reassurance by validating their illness experience.

METHODOLOGY

Project Zebra combines both qualitative and quantitative data collection using a mobile self-care application, Carcinoid NETs Health Storylines™. Over 200 participants were recruited from an existing user base, as well from new acquisitions as a result of outreach by the Carcinoid Cancer Foundation. The criteria for inclusion is a positive diagnosis of carcinoid or NET cancer, and residence in the United States.

Participant self-reported data was collected electronically in real time over a two-month period on the mobile application—utilized by participants on their personal iOS or Android mobile device. Types of data captured includes daily moods, symptom severity, and journaling eliciting qualitative data on their carcinoid or NET experience.

Apart from using the technology for data collection, regular engagement was a key component of Project Zebra. Interested participants were encouraged to fill out an online enrolment form, after which they would be contacted by Self Care Catalysts' community support coordinator. The community support coordinator provided guidance over the phone to help participants complete the required demographic data, and a detailed tutorial of how to use specific health tools within the app. Daily notifications on the mobile application, and the ongoing support and follow-up from the community support coordinator helped to ensure optimal participant compliance and engagement throughout the project. Furthermore, to recognize the value in sharing one's story and health data, all participants were given an incentive for contributing their experience.

The aggregated data collected from participants was analyzed using Self Care Catalysts' analytics platform, Patient Storylines™, and by a trained team of health researchers. Self Care Catalysts' proprietary Patient Decision Making Framework™, was used to analyze the qualitative data that was captured—to uncover relevant insights based on the following five dimensions: 1) patient experience, 2) influencers and supporters, 3) psychosocial impact of illness, 4) quality of life, and 5) knowledge.



CARCINOID NETS HEALTH STORYLINES™



CARCINOID NETS HEALTH STORYLINES™



Developed in partnership with the Carcinoid Cancer Foundation, this app makes it easy to record your symptoms, nutritional concerns, moods, set up medication reminders, and more. Choose what you want to track to build your own summary “My Storylines” to learn more about your health, and to share more—safely and securely—with your doctor about what happened between visits.

Choose from a customizable range of health tools to help you better manage and monitor carcinoid cancer and neuroendocrine tumors (NETs), including pancreatic NETs—whether you are just diagnosed, on active treatment, or on surveillance.

By using Carcinoid NETs Health Storylines, you have the opportunity to anonymously contribute learning from your story to a vital data resource that the healthcare industry can use to improve care in the future, for people like you.



I'm not giving up on controlling this disease. Even though it was hard keeping connection with the doctors that have the expertise on this disease being so far away, this app will help me keep my thoughts organized so that I can remember what I need to ask the doctors.”

Project Zebra participant and Carcinoid NETs Health Storylines user



PROJECT ZEBRA



Self Care Catalysts is a cloud-based patient solutions, intelligence and analytics company. They leverage the patient clout to map human health behavior through self-care data science to deliver better care, health outcomes and drive health care innovation.



The Carcinoid Cancer Foundation is the oldest nonprofit carcinoid and related neuroendocrine tumor organization in the United States, founded in 1968. The mission of the foundation is to raise awareness and educate the general public, patients, and the healthcare community about these rare diseases; to support NET cancer patients and their loved ones; and to serve as patient advocates.

© Self Care Catalysts Inc. 2016

Canada: 101 College Street, South Tower, Suite 200, Toronto, ON M5G1L7
United States: 123 10th Street, San Francisco CA 94103
Website: selfcarecatalysts.com
Toll-free number: 1844.475.4637