

CANADIAN CIDP PATIENT JOURNEY

Is something wrong?

- Onset of symptoms
- Unconcerned

Patients begin to notice symptoms; however, they are fairly innocuous and have a minimal impact on daily life. They are not a cause for concern and can often be attributed to other factors.

Something is wrong

- Continuation of symptoms
- Concern

Most patients experience a slow worsening of symptoms, however for a proportion they rapidly deteriorate which can be frightening.

Am I crazy?

- Initial contact with HCPs
- Confused, isolated
- Lack of awareness of CIDP

Patients will go either to their GP or the ER. These HCPs often lack relevant disease experience and can often discharge patients without follow-up. This leads to patients doubting their symptoms and feeling as if it's all in their head.

Prodded and poked

- Testing
- Exhausted, frustrated
- Lack of experience with CIDP; Poor communication

Patients will undergo a myriad of tests, the reasons for which are not always clearly communicated. Testing is often repeated by each physician as past results and interpretations are not always trusted. Patients feel left in the dark and frustrated that there are no answers.

This is forever

- CIDP diagnosis
- Relief, devastated and confused (following GBS diagnosis)
- Access to information; Poor communication

Diagnosis is often given by an experienced neurologist or neuromuscular specialist. For HCPs this is a positive diagnosis as there are treatment options available. However, this positivity is confusing for patients who may be experiencing disability at the time.

Patients can be devastated by the chronic nature of the diagnosis. This is especially the case for patients who have relapsed after a GBS diagnosis.

The constant fear

- Relapse
- Fearful, uncertain
- Poor communication; Access to information

Patients are fearful of relapse and returning to the same way they were toward the beginning of their journey (often experiencing significant disability). This affects how they live their lives, for example: not having any more children; never going too far from home; and being extremely grateful for their treatment.

Bittersweet gratitude

- Treatment
- Grateful, restricted
- Logistical issues with treatment; Access issues; Access to information

Patients typically receive IVIG soon after diagnosis and are grateful for the quick symptom relief. This gratitude is measured by the restrictive treatment regime, yet patients remain mostly positive. Patients that have transitioned onto SCIG are highly positive due to regaining a degree of freedom.

Road to recovery

- Rehabilitation
- Isolated, hopeful
- Poor communication; Access issues; Access to information

Patients still face many daily challenges and focus on regaining strength and lost mobility. Many feel isolated as if no one really understands their illness, particularly if they don't appear disabled. Even if responding positively toward treatment, a cloud of uncertainty hangs over their lives.

Barriers

- Lack of awareness of CIDP**
 - CIDP is not always immediately suspected
 - Referral may not be seen as a priority in triage
- Lack of experience with CIDP**
 - Repetitive testing and a delayed diagnosis
 - Unlikely to be seen by a specialist
- Poor communication**
 - Unaware why each test is being carried out
 - Expectations around prognosis and effort for rehab are off
- Access to information**
 - Limited information and resources at diagnosis
 - No RN to answer questions between appointments
- Logistical issues with treatment**
 - Planning life around IVIG treatment regime and symptoms
 - Infusion suites are often over capacity and; therefore, difficult to schedule IVIG infusion appointments
- Access issues**
 - SCIG may not be available at certain centers
 - Access to quality wraparound care is inconsistent