

# UNDERSTANDING ICANS

## WHAT PATIENTS & CAREGIVERS NEED TO KNOW



### WHAT IS ICANS?

**Immune Effector Cell-Associated Neurotoxicity Syndrome (ICANS)**, also known as neurotoxicity, is a potential side effect of immunotherapy treatments. The specific cause of ICANS is still under research.

Immunotherapy treatments, such as CAR T-cell therapy and bispecific antibodies, target T-cell activation in the immune system to recognize and damage lymphoma cells. The thymus gland plays a key role in producing T-cells, which are crucial for fighting infected or abnormal cells.

ICANS can range in severity from mild to severe, with symptoms affecting brain function. These range from headaches and attention loss to life-threatening issues, like brain swelling. See below for a more detailed list of symptoms.

ICANS often develops a few days after Cytokine Release Syndrome (CRS), another side effect of immunotherapy. It is common for both syndromes to occur after receiving immunotherapy. Visit our website for more information about CRS.

Symptoms of ICANS typically resolve within 2-3 weeks after treatment. Healthcare teams will monitor for clinical signs of ICANS, as symptoms can appear from a few days to 3 weeks after immunotherapy.

### WHO IS AT RISK FOR ICANS?

ICANS is most common in patients undergoing T-cell immunotherapy. CRS can predict the likelihood and severity of ICANS, meaning patients who experience CRS after immunotherapy may be more susceptible. Patients with a higher disease burden and younger patients are also at greater risk.

While higher doses of immunotherapy are necessary for treating advanced stages of cancer, they also increase the risk of ICANS. Reducing the cancer burden before immunotherapy, such as through chemotherapy, can help minimize the risk of ICANS and its severity. Adjusting immunotherapy dosage and using preventive measures may also reduce the likelihood of ICANS, and treating CRS may further help prevent it.

### TREATMENT OPTIONS FOR ICANS

Due to the varying severity of ICANS, different treatment approaches will be recommended by your healthcare team. Doctors use a grading system to assess the severity of ICANS, along with your neurological status, to determine the appropriate treatment.

Grading helps differentiate the syndrome based on the number and severity of symptoms, allowing your healthcare team to understand the extent of the disease and monitor its progression.

ICANS is categorized into two grades:

**Low Grade:** Mild symptoms (e.g., confusion, difficulty concentrating)

**High Grade:** Severe symptoms (e.g., brain swelling, loss of consciousness)

- For **low-grade ICANS**, patients typically receive supportive care to manage symptoms such as inattentiveness, language deficits, and disorientation. Levetiracetam is often prescribed as a preventive measure for seizures, a common symptom of ICANS.
- For **high-grade ICANS**, patients may be treated with corticosteroids, an immunosuppressive medication. Corticosteroids reduce immune activity but are reserved for severe cases as they can counteract the beneficial effects of immunotherapy. Due to their broad immune suppression, corticosteroids should not be used for prolonged periods, as they may negatively impact survival.

## WHAT YOU CAN DO FOR YOURSELF

### SIGNS AND SYMPTOMS OF INFECTION

If you experience any of the following symptoms after receiving immunotherapy treatment, contact your doctor or visit the emergency room immediately. While many cases of ICANS are mild, some can be severe and life-threatening:

- Confusion
- Headache
- Decreased consciousness
- Inattention
- Language dysfunction or speech difficulties (dysphasia)
- Seizures
- Tremors
- Disorientation
- Difficulty with coordination (ataxia)
- Dizziness or vertigo
- Memory impairment
- Visual disturbances

Most side effects are short-lived, but some may persist for weeks or months after treatment. Occasionally, side effects may be permanent or emerge long after treatment has finished (known as late side effects). Your doctor will discuss potential side effects before you begin treatment.

It's important to take any symptoms seriously and seek immediate medical attention, as untreated ICANS can lead to life-threatening complications.

### QUESTIONS TO ASK YOUR DOCTOR

Consider taking notes on any side effects during or after treatment. This can help you communicate your symptoms and concerns with your doctor, improving understanding and reducing stress. Here are some questions you may also want to ask your doctor before treatment:

- What are the potential risks or side effects of this treatment, and how serious are they?
- How will my symptoms be monitored during and after treatment?
- What symptoms should I report immediately, and who should I contact if they occur?
- How long should I monitor for side effects, and when will they subside?
- Are there any foods or activities I should avoid during and after treatment?