

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 like CAR T-cell therapy, bispecific antibodies, and monoclonal antibodies. The specific cause of ICANS is still under research.

ICANS can range in severity from mild to severe, with symptoms affecting brain function. These range from headaches, inability to speak, loss of attention, decreased consciousness, and other 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 resolve quickly in a few day with minor cases but can take 2-3 weeks after treatment in severe cases. Your healthcare teams will monitor for clinical signs of ICANS, as symptoms can appear from a few days to 3-8 weeks after immunotherapy. Note: this is the reason patients are told not to drive 8 weeks after CAR T-cell therapy.

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.

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 four grades, with grade one having mild symptoms (e.g., confusion, difficulty concentrating) and grade four having severe symptoms (e.g., brain swelling, loss of consciousness).

All patients are treated with corticosteroids, which are immunosuppressive medications. Additionally, patients require supportive care to manage symptoms such as inattentiveness, language deficits, and disorientation. Levetiracetam, a medication that helps reduce the risk of seizures, is often prescribed as a preventive measure, even though seizures are a rare symptom of ICANS. Severe cases may require management in the Intensive Care Unit (ICU).

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?
- Will I need special support at home (like help with mobility, memory, eating)?
- 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?
- Will I need follow up appointments or tests after treatment, and how often?
- Is it safe to take over-the-counter medications, supplements, or herbal products during treatment?
- Are there any foods or activities I should avoid during and after treatment?

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 and reversible (even severe cases), 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.