

# Emergency Situation Tips & Checklist for People with Dravet Syndrome

## About This Guide

This checklist has been created by parents, carers, and the team at Dravet Syndrome UK. It brings together lived experience and expert advice to help you feel more prepared in emergency situations. Every tip and tool included has been shaped by real-life challenges faced by families living with Dravet Syndrome with the goal of reducing stress, saving time, and helping emergency responders provide the best possible care.

## Essential Equipment at Home

### Pulse Oximeter (Fingertip Monitor)

**Why it's important:** Measures oxygen levels and heartrate. Will help assess breathing and need for ambulance.

**When to use:** During and after seizures.

**Tip:** Share the oxygen/heartrate reading with 999 call handlers if you're concerned, this can highlight to the call handler the severity of the emergency.

**PLEASE NOTE:** DSUK fund 1 battery fingertip oximeter per family suitable from age 2 years and this can be applied for via our website. This is handy to have in your bag when out for an on-the-spot reading in an emergency.

## Calling 999: What to Say

### Key Phrases for Priority Response

If asked: **"Is the patient breathing?"** — say: **"Intermittently, because they're having a seizure"** (this triggers a high-priority response)

Mention you have a **Red Flag/CMC plan** and give the person's **full name and date of birth**.

Clearly say if the **seizure is ongoing** (as stopped seizures may be downgraded)

Make them aware the person has **Dravet Syndrome and is at high risk of prolonged seizures and Status Epilepticus**.

### Information to Have Ready

- Full name, date of birth, and address
- Seizure start time and duration
- Medication already given (what and when)
- How the current seizure differs from their usual pattern.

## Priority Systems to Set Up

### Red Flag System

A system that alerts ambulance services to your complex medical needs, helping prioritise emergency response.

**How to set it up:** Contact your local ambulance service (non-emergency line), your community nurse, or ask your neurologist to send your care plan directly to the ambulance service.

**Also called:** CMC Plan (Coordinate My Care), High Priority Marker, Patient-Specific Instructions.

**Why it matters:** It ensures crews see your details and medication protocols before arriving even when you're away from home.

**PLEASE NOTE:** The red flag will be on your primary address so if you are at another location (e.g. on holiday) the red flag will not be active. you can tell the call handler your normal address does have red flag but it may not be visible on an out of area call system.

### What3Words App

A location tool that gives emergency services your **precise** 3-word location - especially helpful when you're in an unfamiliar place (e.g. motorway, park or on holiday in the UK).

🦋 **Download:** Free on iOS and Android.

🦋 **When to use:** If you don't know your exact location during an emergency.

🦋 **Benefit:** Prevents delays when calling 999 from unfamiliar areas.

## Contact Us

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# Hospital Bag (Always Packed)

## For Person with Dravet Syndrome

- ☐ **Emergency medications** - Clearly labelled with expiry dates
- ☐ **Clean clothes and underwear** - 2 days worth
- ☐ **Comfort item** - e.g. blanket, toy
- ☐ **Special dietary items** - e.g. keto meals
- ☐ **Toothbrush and toiletries**
- ☐ **Wipes or plastic bag** - For soiled clothes

## Essential Medical Documents

- ☐ **Laminated emergency care plan (min. 3 copies)** - These can be handed out without you worrying it may go missing and one always in the bag until you can next restock. Includes medication protocols, emergency contact numbers, known hospital preferences.
- ☐ **Hospital passport** - Brief summary of condition, communication needs, need for a single room (if applicable), key medical contacts.
- ☐ **Up-to-date medication list** - All current medications with doses and times, emergency meds, expiry dates, and clearly marked maximum safe doses.

## Practical Emergency Tools

### Portable Moving Aid

- ☐ **Rug/blanket with corner handles** - To help lift the person safely if they have a seizure in an awkward location (e.g. park, car park)

### Communication Aids

- ☐ **Laminated 999 call instruction card** - This can be given to someone helping at the scene as you may be solely focused on helping your child as others may be doing the phone call. With this, they will have all the answers the call handler may need without distracting you. Or you can quickly relay all medication lists and important information without having to think when you are on your own and helping your child at same time. You can then read off quickly knowing you did not forget anything.
- ☐ **Medical alert bracelet or wallet card**
- ☐ **Emergency contact card**
- ☐ **Lifesaver Pod Keyring** - Small waterproof keyring where you can add your child's/adult's important information. Simply fill it in, pop it on your keyring, in your bag or on your belt. These are available on our website shop: [www.dravet.org.uk/shop/](http://www.dravet.org.uk/shop/)

### Medical Supplies

- ☐ **Spare syringes/dosing tools** - For emergency meds
- ☐ **Measuring tools** - If needed for less common meds
- ☐ **Oxygen equipment** - If prescribed
- ☐ **Other essential medical devices** - E.g. valve mask

## For Parent/Carer

- ☐ **Change of clothes and underwear**
- ☐ **Phone chargers**
- ☐ **Small cash** - For parking and vending machines
- ☐ **Toothbrush and basic toiletries**
- ☐ **Glasses or contact lenses**
- ☐ **Snacks** - Whilst there are vending machines, but for if you don't feel you can leave your child.
- ☐ **Parent/carers medications** - Don't forget your own medications and paracetamol/ibuprofen just in case.
- ☐ **Sibling emergency bag** - Have a bag ready for anyone that may have to go with you to hospital or to a family members house.
- ☐ **Mobile phone power bank charger** - Not all hospitals have accessible sockets or charging points and some NHS hospitals get hot under the collar if they see you using sockets to charge a phone. A power bank can be discreetly placed in a bag and phone charged out of sight. It also facilitates use of the phone while charging in a mobile/active situation.

## Emergency Grab List

**TIP:** Attach this laminated list to the outside of the hospital bag.

- ☐ **Keys**
- ☐ **Wallet/purse**
- ☐ **Phone & charger**
- ☐ **Any medication not already packed**
- ☐ **Child's comfort item**

## Important Reminders

-  **Trust your instincts**  
You know their seizure patterns better than anyone else.
-  **Be clear and assertive**  
Explain what's normal vs. unusual, even if call handlers don't understand the condition.
-  **Expect delays**  
Some NHS calls are now taking longer. Category 3 calls may take 2+ hours.
-  **Stay calm with dispatchers**  
They must follow a script. Your clear, calm communication makes a difference.
-  **Keep records**  
Log seizures, meds used, and ambulance response times.