# Seizure diary

To record every seizure and take with you to every neurology appointment.

Name _____ Started on _____

## WHAT IT IS FOR

It helps their neurology team know how many seizures there are, what they are like and what triggers them, and assess changes in treatment. Write things down as soon as it is all over: details are quickly forgotten.

## HOW TO USE IT

1. **Name their seizures.** With their neurology team, give each type of seizure a letter in the table below.
2. **Mark each day on the calendar:** seizures of each type, and any fever, rescue medication or emergency.
3. **Record each seizure in the log:** date, time, type, duration, possible trigger and what happened afterwards.
4. **Fill in the major seizure form** if a seizure is long, needs rescue medication or ends in hospital.
5. **Video it if you can,** only if someone else keeps them safe: it helps to identify the type of seizure.
6. **Take it to every appointment,** with the videos and the list of their medicines.

## THEIR SEIZURE TYPES

| Letter | Name given by their neurology team | What it looks like<br>What you see and how long it usually lasts |
|---|---|---|
| A | | |
| B | | |
| C | | |
| D | | |

## POSSIBLE TRIGGERS · CODES FOR THE LOG

- **F** Fever
- **H** Heat or a sudden change in temperature (hot bath, hot day, exercise)
- **M** Strong emotion or excitement
- **L** Flashing lights, or striped or checked patterns
- **S** Too little or poor sleep
- **D** Missed or vomited dose
- **N** None known
- **O** Other: write it in the notes

Everyone has their own. Write down what you suspect, even if you are not sure.

**Safety first.** During a seizure, follow their emergency protocol: the diary is filled in afterwards. Call 112 (or the local emergency number outside the EU) when their protocol says so, or if they do not respond and are not breathing normally. This diary does not replace the advice of their neurology team. Emergency protocol template, in English and Spanish, at dravetfoundation.eu/protocolo-de-emergencia.

# Monthly calendar

**Name** _____ **Month and year** _____

Write the date of each day in its small box. On days with seizures, write how many of each type there were (for example, “2A 1C”) and circle **F** if they had a fever, **R** if they needed rescue medication and **E** if you went to the emergency department or called 112.

| Mon | Tue | Wed | Thu | Fri | Sat | Sun |
|---|---|---|---|---|---|---|
| ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE |
| ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE |
| ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE |
| ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE |
| ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE |
| ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE | ☐ FRE |

## MONTH SUMMARY

| Total seizures | Days with seizures | Times rescue medication was given | Emergency visits or 112 calls |
|---|---|---|---|
| | | | |

## CHANGES IN MEDICINES OR DOSES

Date and what changed.

_____

_____

_____

## OTHER CHANGES

Illnesses, vaccinations, travel, changes in routine.

_____

_____

_____

# Seizure log

Name _____ Sheet no. _____

**Type:** the letter for their seizures (page 1). **Trigger:** F fever · H heat · M emotion · L lights · S sleep · D dose · N none · O other. Tick the boxes that apply.

| **Date** | **Time** | **Type** A to D | **Duration** min or sec | **Asleep** | **Trigger** Code | **Rescue** Time and whether it stopped | **112 or hospital** | **Recovery** How long it took | **Video** | **Notes** |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | ☐ | | | ☐ | | ☐ | |
| | | | | ☐ | | | ☐ | | ☐ | |
| | | | | ☐ | | | ☐ | | ☐ | |
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| | | | | ☐ | | | ☐ | | ☐ | |

More seizures than usual within a few hours, or several in a row without recovering in between? Write it in the notes and fill in the major seizure form.

# Major seizure form

For a long seizure, one that needed rescue medication or one that ended in the emergency department. Fill it in as soon as you can and take it to their next appointment.

Name _____

## WHEN AND HOW LONG

Date _____ Start time _____

End time _____ Duration _____ minutes

- [ ] Several seizures in a row without recovering in between
- [ ] More seizures than usual within a few hours

## WHAT THEY WERE DOING

- [ ] Asleep
- [ ] Had just woken up
- [ ] Resting
- [ ] Playing or exercising
- [ ] In the bath or shower
- [ ] Other: _____

## WHAT YOU SAW

- [ ] Stiffness
- [ ] Jerking
- [ ] Staring or blank look
- [ ] On the right side
- [ ] On the left side
- [ ] On both sides
- [ ] Started on one side and spread
- [ ] Eyes or head turned to one side
- [ ] Did not respond
- [ ] Fell
- [ ] Blue lips or pale skin
- [ ] Drooling
- [ ] Noisy breathing
- [ ] Wet themselves

Type (letter from page 1): _____

## POSSIBLE TRIGGERS

- [ ] Fever: _____ °C
- [ ] Heat or a sudden change in temperature
- [ ] Strong emotion or excitement
- [ ] Flashing lights, stripes or checks
- [ ] Too little or poor sleep
- [ ] Missed or vomited dose
- [ ] None known
- [ ] Other: _____

## RESCUE MEDICATION

- [ ] Not given
- [ ] Given at _____

Did it stop? [ ] Yes, after _____ minutes [ ] No

Second dose, only if their protocol says so:

- [ ] No
- [ ] Yes, at _____

## 112 AND HOSPITAL

- [ ] We called 112 at _____
- [ ] Emergency department
- [ ] Admitted to hospital

Hospital _____

Treatment given there _____

## AFTER THE SEIZURE

It took _____ to be back to how they were before. [ ] Slept afterwards [ ] Confusion

- [ ] Weakness on one side
- [ ] Vomiting
- [ ] We recorded a video
- [ ] Got hurt: _____

## WHAT HAPPENED, IN YOUR OWN WORDS · NOTES FOR THEIR NEUROLOGY TEAM