

# Streamlining the Process of Caregiving for a Loved One With Dravet or Lennox-Gastaut Syndrome

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\*During the present work.

## OVERVIEW

### QUESTION

How can we reduce the emotional and logistical burden on caregivers of loved ones living with Dravet syndrome (DS) or Lennox-Gastaut syndrome (LGS)?

### INVESTIGATION

- A human-centred design approach was used to co-develop a digital solution with caregivers.
- Insights were gathered through focus groups and interviews to identify unmet needs and inform the design of a prototype.
- The resulting tool, CareCompass™, a secure, free-to-use, and mobile-friendly online platform that helps caregivers organise care information, track well-being, and create personalised care guides, is currently available for US residents.
- A 2- to 4-week pilot study with 23 caregivers was conducted to evaluate usability, acceptability, and early impact, using weekly surveys and regular check-ins.
  - To accommodate demanding schedules, caregivers could choose to participate for either 2 or 4 weeks; 21 chose the 4-week option, while 2 caregivers participated for 2 weeks.

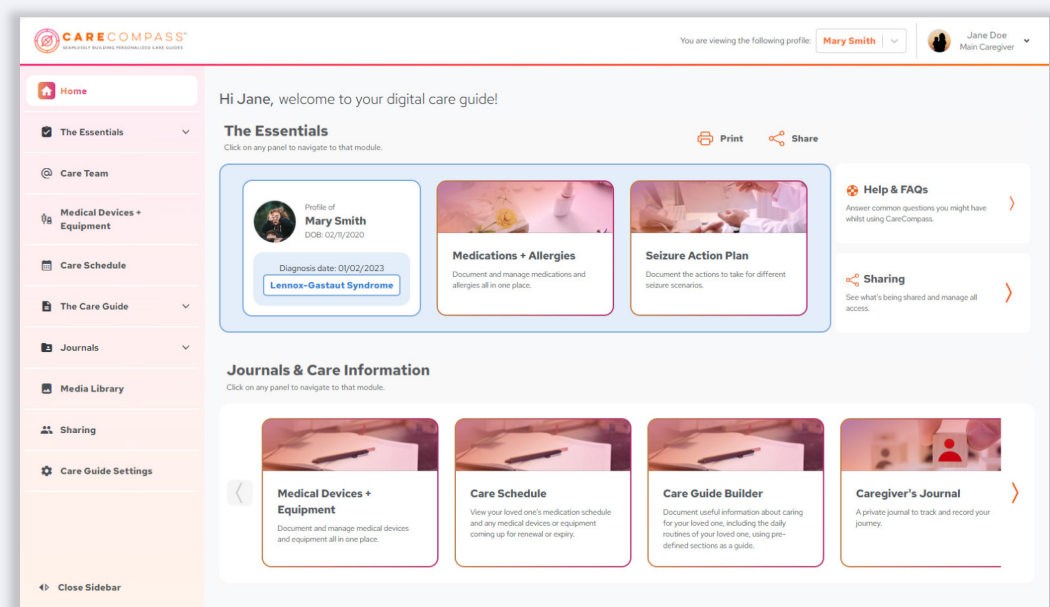
### CONCLUSIONS

- The CareCompass™ platform shows strong potential as a digital support tool for caregivers of individuals with rare epilepsies (DS and LGS). It simplifies care coordination, addresses emotional and informational gaps, and may improve quality of life for both caregivers and their loved ones. A dedicated mobile app could further enhance caregiver satisfaction and accessibility.

### RESULTS

- Net Promoter Score of 62 during the pilot phase.
- Caregivers suggested that a **dedicated mobile app** could further enhance their experience.
- Reported benefits: centralised care information, peace of mind, improved communication, and valued journaling feature.

### Overview of the essentials of CareCompass™



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## Background

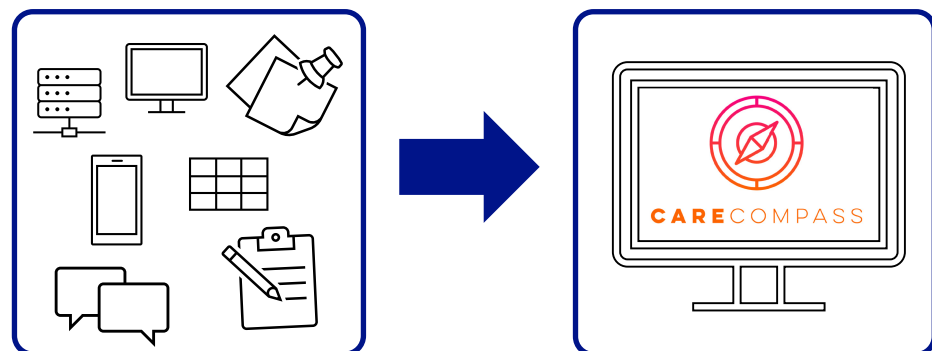
- Caregiving for people living with Dravet syndrome (DS) or Lennox-Gastaut syndrome (LGS) is often complex and emotionally demanding.
- Caregivers are responsible for coordinating multiple aspects of care, including medical treatments, daily routines, and communication with healthcare teams.
- Many caregivers rely on fragmented systems—such as handwritten notes, phone reminders, or spreadsheets—to manage care-related information.
- This lack of centralisation creates significant challenges, particularly when onboarding new care team members, introducing a new treatment, or ensuring continuity of care if the primary caregiver is unavailable.
- Maintaining these disparate sources adds an additional burden to caregivers who are already managing high-stress responsibilities.
- This fragmentation can compromise clarity, consistency, and confidence in care delivery, ultimately impacting both caregivers and the individuals they support.
- The CareCompass™ platform<sup>1</sup> was designed to address these challenges by providing a secure, centralised digital platform that organises essential caregiving resources in one place.
- The goal is to simplify daily tasks, improve communication, and reduce stress for caregivers navigating complex care needs.

## Objective

- This poster presents findings from a pilot study conducted among caregivers of individuals living with DS and LGS.
- We aimed to assess the usability, acceptability, and early impact of CareCompass™, a digital platform designed to support daily caregiving:
  - Demonstrate practical application  
Show how the platform can be used as a real-life tool to support caregivers of individuals with DS and LGS managing daily care responsibilities.
  - Present pilot phase insights  
Share data and observations from the pilot phase to illustrate initial caregiver engagement, usability, and perceived value of the platform.
  - Highlight key features and benefits  
Explain the core functionalities and how these features aim to simplify caregiving tasks.

## Methods

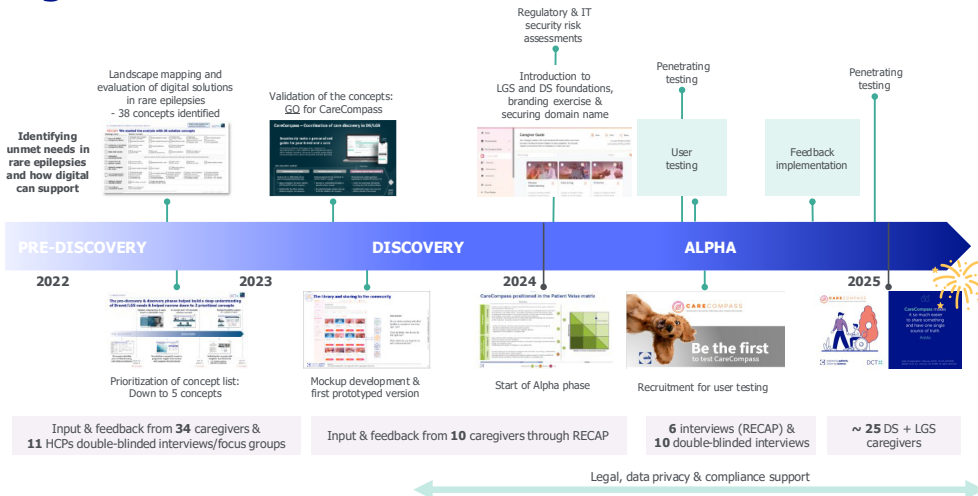
**Figure 1. From a fragmented to a centralised caregiver experience**



- The **CareCompass™** platform was developed in collaboration with caregivers to provide practical support for those managing the daily responsibilities of caring for individuals with DS and LGS (**Figure 1, Figure 2**).
- The platform includes practical templates that assist with organising and completing routine caregiving tasks.
- It also offers resources aimed at providing emotional support to caregivers.

- In addition, it provides essential tools designed to help simplify daily activities and reduce stress (**Figure 1**).
- All caregiving resources are stored in one centralised location, making them easy to access and securely share.
- This structure is intended to help caregivers feel supported, maintain confidence, and stay connected throughout their care journey.

**Figure 2. Human-centred method and timeline**



DS, Dravet syndrome; HCP, healthcare professional; IT, Information Technology; LGS, Lennox-Gastaut syndrome; RECAP, Rare Epilepsy Caregiver Advisory Panel.

## Results

### CONSISTENT USE

- Overall, 21 out of 23 caregivers (91%) actively used the CareCompass™ platform throughout a 4-week pilot.

### USER SATISFACTION

These caregivers responded to the question:

**'After another week of usage, how likely are you to recommend CareCompass™ to a friend or colleague who also cares for someone with DS/LGS?'**

**NET PROMOTER SCORE (NPS): 62**

- 14 Promoters (67%) 6 Passives (28%) 1 Detractor (5%)
- This score suggests **strong satisfaction** and enthusiasm for the solution (**Figure 3**).

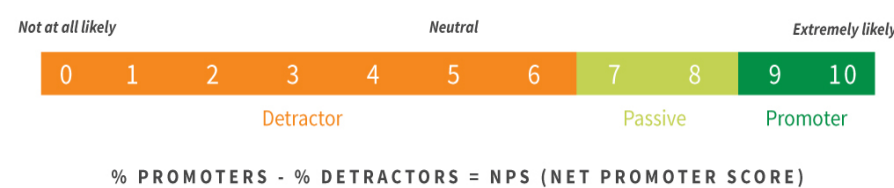
### FEATURE FEEDBACK

- Caregivers suggested that a **dedicated mobile app** could further enhance their experience.

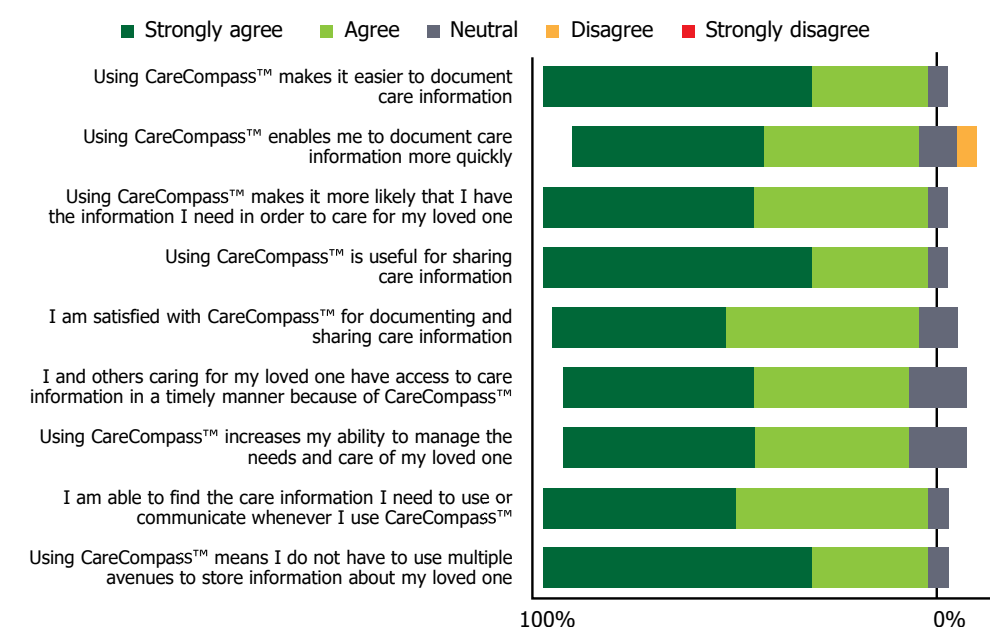
### PERCEIVED USEFULNESS

- At the end of the pilot, caregivers rated several statements about the usefulness of the CareCompass™ platform; results were **encouragingly positive** (**Figure 4**).

**Figure 3. Definition of Net Promoter Score<sup>2</sup>**



**Figure 4. What 4 weeks revealed about the CareCompass™ platform value for 21 caregivers**



**Figure 5. Voices from the pilot: what caregivers shared**

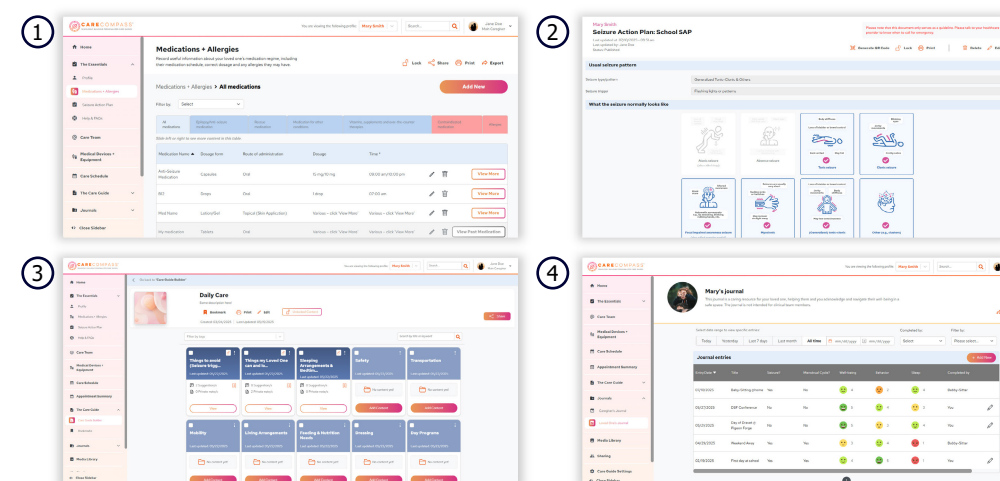


**'You don't want to think about getting sick and not being able to take care of your child (...), but if you have a tool like CareCompass™ you are going to be ok.'** (Melanie, caregiver of a loved one living with DS)



**'Our focus should be on our loved ones and what's best for them.'** (Kurt, caregiver of a loved one living with LGS)

**Figure 6. Popular features: 1) medication and allergies; 2) seizure action plan; 3) daily care templates; 4) loved one's journal**



## CONCLUSIONS

- This pilot study suggests that the CareCompass™ platform may have strong satisfaction from the NPS and **potential as a supportive digital tool** for caregivers of individuals with rare epilepsies, particularly DS and LGS.
- Co-designed** features were shown to directly address emotional and informational gaps experienced by caregivers.
- Key benefits of the CareCompass™ platform were shown to include:**
  - Centralised care information to simplify communication and coordination.
  - Increased peace of mind and confidence in care continuity.
  - Enhanced quality of life for both caregivers and their loved ones.
- Native mobile app was preferred by caregivers over a mobile-friendly web for stronger adoption and usability.
- Future research** should assess long-term impact on:
  - Caregiver burden.
  - Confidence in caregiving.
  - Engagement with the healthcare system.
- Scalable impact:** The CareCompass™ platform is currently available for US residents; however, there is potential to expand the platform to support caregivers across other rare epilepsies, broader epilepsy populations, and diverse global regions worldwide.

## References

- CareCompass™. <https://care-compass.io/>. Accessed 29 July 2026.
- Net Promoter System®. <https://www.netpromotersystem.com/about/measuring-your-net-promoter-score/>. Accessed 29 July 2026.

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