



# My Care Guide

Use this guide to help me get the most out of my treatment journey with DAYBUE®

Learn more about me, Rett syndrome, and the valued role you play as a member of my Care Team.

<b>Name:</b>	<b>Age:</b>
<hr/>	
<b>Fun facts about me:</b>	
<hr/>	
<b>My caregiver's contact information:</b>	

## Indication

### What is DAYBUE or DAYBUE STIX?

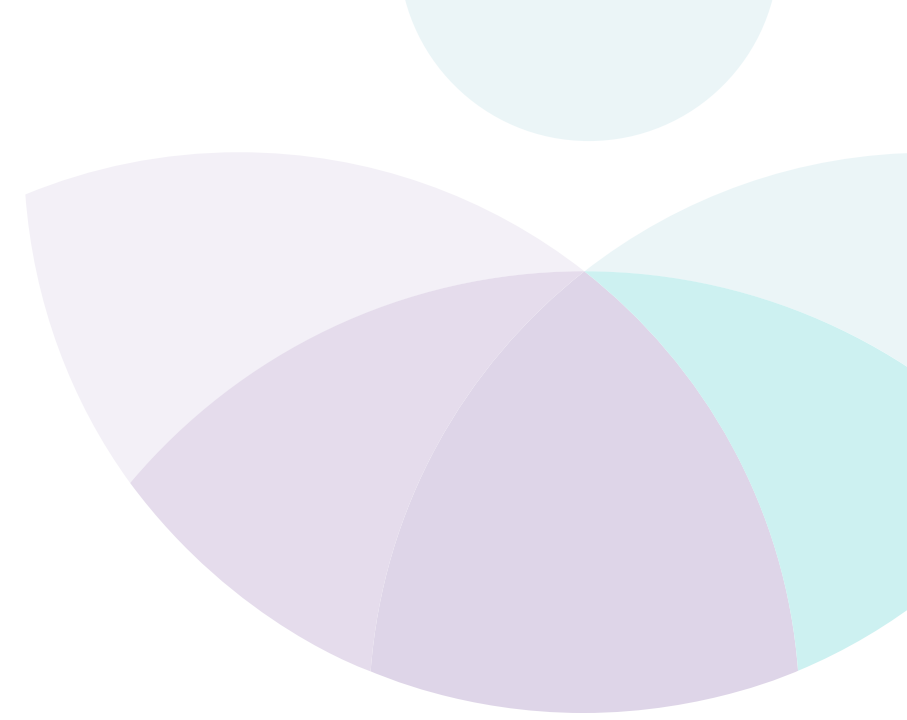
DAYBUE or DAYBUE STIX are prescription medicines used to treat Rett syndrome in adults and children 2 years of age and older. It is not known if DAYBUE or DAYBUE STIX is safe and effective in children under 2 years of age.

## Important Safety Information

### What are the possible side effects of DAYBUE or DAYBUE STIX?

- **Diarrhea:** Diarrhea is a common side effect of DAYBUE or DAYBUE STIX that can sometimes be severe. Diarrhea may cause you to lose too much water from your body (dehydration). Before starting treatment with DAYBUE or DAYBUE STIX, stop taking laxatives. Tell your healthcare provider if you have diarrhea while taking DAYBUE or DAYBUE STIX. Your healthcare provider may ask you to increase the amount you drink or take antidiarrheal medicine as needed.

See additional Important Safety Information throughout. Please read the full [Prescribing Information](#), including [Patient Information](#).



## What is Rett syndrome?

A rare condition that impacts about

**6000 to 9000** people in the United States



**A complex genetic disorder that requires lifelong care**

**Rett syndrome is a rare neurodevelopmental condition**, meaning it affects how the brain functions and develops.

**It is not neurodegenerative**, meaning brain cells will not become damaged or die and changes in symptoms may be possible at any age.

**Rett syndrome is most common in girls**, but it can affect boys too.

**Rett syndrome is unique to each person living with it.** The symptoms can affect each individual in different ways, at different times, and at different stages of the disorder.

## Typical signs and symptoms for a Rett syndrome diagnosis



Partial or complete loss of ability to verbally communicate



Trouble walking or loss of ability to walk



Repetitive hand movements like washing, balled up hands, hands in mouth, clapping, or pulling hair



Partial or complete loss of ability to use hands for daily activities

Additional challenges associated with Rett syndrome include irregular breathing patterns, epileptic seizures, movement disorders, behavioral disturbances, gastrointestinal disorders, heart issues, curvature of the spine, hip displacement, and bone fractures.

## Communication and Rett syndrome

Many individuals with Rett syndrome are cognitively aware but are unable to effectively act on their desire to verbally communicate. They may have trouble using words, making sounds, or controlling hand movements. This can leave them feeling frustrated and misunderstood.

Due to these challenges, their abilities are often underestimated. However, with support from their care team, adaptive tools and communication strategies provide new ways to express themselves.

## What you should know about DAYBUE

DAYBUE is the first and only FDA-approved treatment shown to improve Rett syndrome in adults and children 2 years of age and older



### DAYBUE can help provide meaningful improvements in the signs and symptoms of Rett syndrome

In a clinical trial, DAYBUE was shown to significantly reduce the severity in signs and symptoms of Rett syndrome at 12 weeks as measured by the Rett Syndrome Behaviour Questionnaire (RSBQ) when compared to placebo.

#### The RSBQ assessed the following signs and symptoms:



Breathing



Hand movements or stereotypies



Repetitive behaviors



Nighttime behaviors



Vocalizations



Facial expressions



Eye gaze



Mood

#### At 12 weeks, doctors also observed:

Significant improvements in the signs and symptoms of Rett syndrome in patients taking DAYBUE vs placebo.

The CGI-I (Clinical Global Impression-Improvement) scale was used by doctors to evaluate improvement or worsening of Rett symptoms.

- 38% of patients (n=77) had improvement in symptoms with DAYBUE vs 15% of patients (n=86) on placebo

**Important note:** Because everyone with Rett syndrome is unique—with a unique set of symptoms—the response to DAYBUE may be different for each individual. Not all patients in the clinical trial responded to treatment with DAYBUE.

## Help track my progress

You are a valued member of my Care Team. If you notice any changes in my signs and symptoms of Rett syndrome, please write them down and let my caregiver know. Even small details can provide my doctor with helpful insights.

### Notes

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### Important Safety Information (continued)

#### What are the possible side effects of DAYBUE or DAYBUE STIX? (continued)

- **Vomiting:** Vomiting is a common side effect of DAYBUE or DAYBUE STIX. Sometimes vomit can get into your lungs (aspiration), which could cause an infection (aspiration pneumonia). Tell your healthcare provider if you have severe vomiting or if vomiting happens often.

See additional Important Safety Information throughout. Please read the full [Prescribing Information](#), including [Patient Information](#).



## Things I may experience

I may have some side effects while at school. The most common of them are diarrhea and vomiting, which are unintentional and not contagious.

I may feel embarrassed, so please help me take care of this private matter quickly and discreetly. Not every person will have the same experience as me. To learn more about managing side effects, read below.



### Helpful tips to consider for managing diarrhea

- ✓ Tell the school nurse right away and notify my caregiver if I have diarrhea
- ✓ Keep an eye on my fluid intake, watch for signs of dehydration, and increase my oral fluids if needed. My doctor may have also suggested a fiber supplement—ask my caregiver about it
- ✓ It is recommended that I have antidiarrheal medications at school to help me manage my diarrhea. Please ask my caregiver about the plan we set up with my doctor



### Helpful tips to consider for managing vomiting

- ✓ It helps me to have meals somewhere calm. My stomach can be sensitive to stress, so finding somewhere relaxed to eat can reduce the likelihood of vomiting. If I start vomiting after receiving my dose of DAYBUE or DAYBUE STIX, please help me sit forward to prevent choking and don't give me an additional dose of DAYBUE or DAYBUE STIX
- ✓ It's helpful to avoid meals before nap time

## Notes



### Want to know more about Rett syndrome?

Click [HERE](#) to check out other resources to help you better understand me and my condition.

### Important Safety Information (continued)

#### What are the possible side effects of DAYBUE or DAYBUE STIX? (continued)

- **Weight loss:** DAYBUE or DAYBUE STIX can cause weight loss. Tell your healthcare provider if you notice you are losing weight at any time during treatment with DAYBUE or DAYBUE STIX.

See additional Important Safety Information throughout. Please read the full [Prescribing Information](#), including [Patient Information](#).



## Indication and Important Safety Information

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- **Vomiting:** Vomiting is a common side effect of DAYBUE or DAYBUE STIX. Sometimes vomit can get into your lungs (aspiration), which could cause an infection (aspiration pneumonia). Tell your healthcare provider if you have severe vomiting or if vomiting happens often.
- **Weight loss:** DAYBUE or DAYBUE STIX can cause weight loss. Tell your healthcare provider if you notice you are losing weight at any time during treatment with DAYBUE or DAYBUE STIX.
- **The most common side effects of DAYBUE or DAYBUE STIX include diarrhea and vomiting.** Other side effects include fever, seizure, anxiety, decreased appetite, tiredness, and the common cold. These are not all the possible side effects of DAYBUE or DAYBUE STIX. Tell your healthcare provider if you have any side effects that bother you or do not go away.

### What should I tell my healthcare provider before taking DAYBUE or DAYBUE STIX?

**Before taking DAYBUE or DAYBUE STIX, tell your healthcare provider about all of your medical conditions, including if you:**

- have kidney problems.
- are pregnant or plan to become pregnant. It is not known if DAYBUE or DAYBUE STIX will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if DAYBUE or DAYBUE STIX passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby while taking DAYBUE or DAYBUE STIX.

**Tell your healthcare provider about all of the medicines you take**, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Taking DAYBUE or DAYBUE STIX with certain medicines may affect how the other medicines work and can cause serious side effects.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch) or call **1-800-FDA-1088**. You can also call Acadia Pharmaceuticals Inc. at **1-844-4ACADIA (1-844-422-2342)**.

DAYBUE is available as an oral solution (200 mg/mL).

DAYBUE STIX for oral solution powder is available in 5,000 mg, 6,000 mg, and 8,000 mg packets.

**The risk information provided here is not comprehensive. To learn more, talk with your healthcare provider and read the full [Prescribing Information](#), including [Patient Information](#), also available at [DAYBUE.com](http://DAYBUE.com).**



