



Revestive® ▼ (teduglutide) Patient diary

For children and carers of children receiving Revestive®



This patient booklet is provided by



▼ This medicine is subject to additional monitoring. This will allow quick identification of new safety information. You can help by reporting any side effects you may get.

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at www.mhra.gov.uk/yellowcard. By reporting side effects you can help provide more information on the safety of this medicine.

Contents

Appointment planner

About this diary	3
How to use the diary	4
What you can record in this diary	5
How to track your child's digestive health	6
Before your child starts Revestive treatment	8
Getting started	9
Keeping track of your child's health status	11
Your child's appointment planner	12
Weekly status tracker	13
Stool/ostomy output tracker	14
Your child's health tracker	15
Summary status sheets	18
Notes: changes in your child's health and questions for your next appointment	19

About this diary...

This diary is an interactive PDF which will help you to take an active role in your child's treatment by recording and sharing information that will help you, your child and your doctor make important treatment decisions.

This diary will help you and your child get the most from your treatment with Revestive (teduglutide) for injection.

This diary belongs to:

Contact details:

Carer contact details:





How to use the diary:

In the next few pages you will see examples of how to record important information regarding your child's Revestive treatment. This diary is an interactive PDF, but you can print these pages at home to help you to record this information.

First of all, it is important to write down your child's scheduled appointments in the appointment planner (see example below).

You can also write down any questions you want to ask your child's healthcare team and doctor in the notes section.

Appointment		Reason	Notes
Dr. Smith Smith Imaging Labs Colonoscopy	02/07/24	Colonoscopy	Ask about dry mouth





In this diary, you can record:



Your child's nutrition and fluid intake



Your child's sleep



Your child's stool/ ostomy output



How your child feels



Your child's urine output



Your child's appointments with your healthcare team



Your child's weight



Other treatment information and any concerns you want to record and report to your child's healthcare team



Oral fluids/ intravenous fluids



Stoma



Vomit

To learn more about why this diary is important, please see the brochure 'Starting on Revestive'.



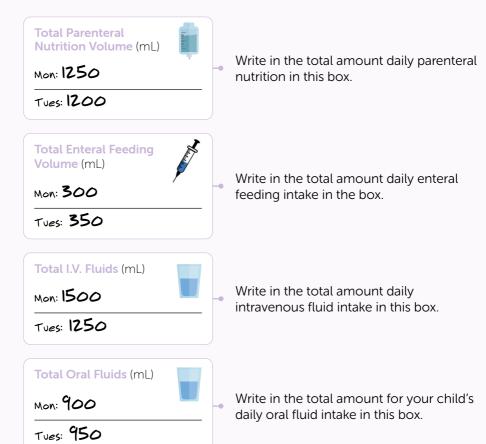
How to track your child's digestive health

These examples show you how to track your child's health status for sharing with their healthcare team.

This diary will help you remember important information to discuss with their doctor. See below for instructions and helpful tips on filling in some of the sections relating to your child's health status.

You will be asked to add details of how much parenteral nutrition your child has had, their urine output, their total oral/I.V. fluids, their weight, their stool/ostomy output and also how they are sleeping.

You will be asked to complete tables with this information. The following are examples on how to record the information for each status item.









Keep track of the urine output as instructed by the healthcare team and fill in the total amount here. This information will help your child's healthcare team know how the treatment is working.



Your child should wear the same type of clothing and use the same scales.

You may weigh your child in the morning after finishing their nightly parenteral infusions, after your child's morning toilet visit, after emptying their stoma bag and before eating breakfast.

per day changes in colour, consistency, etc?	Stool/Ostomy Output							
Monday 4 No 09/07/24	Date/Day		changes in colour, consistency,					
	Monday 09/07/24	4	No					

Make a note of the number of times each day that your child passes a stool or the stoma bag needs to be changed.

Please also note if there has been a change in colour, consistency etc.



Before your child starts Revestive treatment

Your child will soon start therapy with Revestive but before they do, it is important to know their health status today.

By entering your child's current health status information into this diary now, and during their on-going treatment, you will help your child's doctor and healthcare team in monitoring your child's response to Revestive.

Filling in the diary will also help ensure you are fully involved in your child's treatment



Read the Package Leaflet that comes with the Revestive therapy – this will help you learn more about your child's treatment.



Knowing what to expect from your child's treatment will help you see if they are doing better and will help your child's doctor make the best decisions about their care.



It is important to discuss your child's treatment with their healthcare team and to ask any questions you may have about your child's health or about Revestive.



Inform your doctor about any prescription or non-prescription medicines that your child currently takes.

See the examples on pages 6-7 and the templates on pages 9-16 for the information you will need to complete about your child's current status and on-going treatment.

Remember to bring the pages you have completed with you when you visit your child's doctor/nurse or other members of your child's healthcare team.



Let's get started:

Starting point (Your child's current health status – before starting treatment)

You should complete your child's current status before they start treatment with Revestive. Then you should complete the diary for each week of treatment for the first month of therapy.

After that it is important that you continue to track your child's progress in this diary since your child's healthcare team will make decisions on any reduction of your child's parenteral support based on your child's fluid status as well as your child's general health.

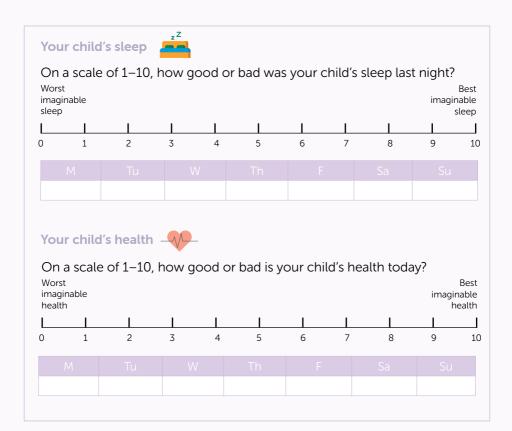
Before your child starts taking Revestive, please fill in this table with your child's healthcare provider.

- Together, you should decide what information to track and if you should set specific goals for your child's treatment
- By entering summary information on the update sheet at the end of this diary, you will then be able to track the changes in your child's health status
- This information can help you and your child's healthcare provider see how your child's treatment is going, and make decisions about your child's treatment

oday's date:
Veekly volume (mL) Parenteral nutrition: Interal feeding: Oral fluids: Intravenous fluids:
Days per week Parenteral nutrition: Interal feeding: Dral fluids: Intravenous fluids:
Veight (kg):
Other:







Keeping track of your child's weekly health status over the first month of treatment

Continue to complete the status weekly or as agreed with your child's healthcare team using the tables on pages 13-16.

- Note any changes in your child's condition.
- Tell your doctor about possible side effects and ask for advice on how to manage them.
- Contact your child's doctor if you have questions about perceived side effects.
- As Revestive begins to work, your child's nutritional support may be reduced by the healthcare team slowly but steadily for your child's safety, under your child's healthcare team's supervision. By filling in your child's weekly status you may help your child's doctor know when to reduce the parenteral support.
- Your child's diet and medicines may be adjusted by your child's healthcare provider depending on how they respond to Revestive.

To be able to follow your child's progress with their healthcare provider, you should enter your child's pre-treatment status from page 9 into the overall summary chart at the end of this diary.

Remember to have the pages you have completed available when calling or visiting your child's healthcare provider.



My Appointments

Your child's appointment planner

Appointment	Date	Reason	Notes



Weekly status







Revestive Week

Date

Volume parenteral nutrition (mL)				
Volume I.V. fluids (mL)				
Volume enteral nutrition (mL)				
Volume oral fluids (mL)				

Compare your child's parenteral/enteral and/or I.V. / oral fluids to last week did your child consume more or less or the same? Record in terms of volume and days

Your child's Urine Output (mL per day)				
Your child's Total Oral Fluids (mL per day)				
Your child's Weight				



Your child's Stool/Ostomy Output



Your child's Stool				
Your child's Ostomy				

Your child's Sleep



On a scale of 1–10, how good or bad was your child's sleep last night?

	orst aginable ep								imag	Best inable sleep
L										
0	1	2	3	4	5	6	7	8	9	10

Your child's Health



On a scale of 1–10, how good or bad is your child's health today?

Wors imag heal	ginable								imagi ł	Best nable nealth
0	1	2	3	4	5	6	7	8	9	10



Your child's health



Are there symptoms/problems that have started or worsened since your child has started treatment with Revestive? Yes **Remember**: Report any side effects your child may experience to their doctor, pharmacist or nurse. If yes please describe: Have you noticed any changes to your child's symptoms in the past month? Yes No. If yes please describe: Stoma (mL): Please detail the volume of stoma output and when Vomit: Please circle the best description for any vomiting episodes that have occurred and when > < > < > < > < > < 23 23 25 2 23 25 23 2 2



Pain: How is your child feeling?

General Instructions

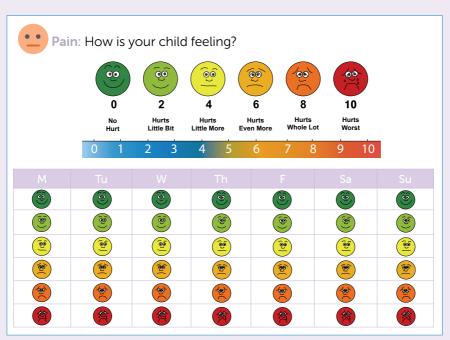
Faces Pain Scale: Suitable for children >3 years:

• Get child to point to the face that shows how much they hurt.

Visual/Verbal Analogue Scale: Suitable for children >5 years: (check that they know their numbers)

• Get child to say how much they hurt on a scale 0-10, with '0' being no pain and '10' being the worst pain imaginable.





DATE/TIME (24 hour clock)	PAIN SCORE (0-10)	ACTION TAKEN i.e. analgesia, changing position, drink, distraction etc.	REVIEW (30-60 min) 1. Effective 2. Some change 3. No change/Worse

Summary status sheets

You can use these sheets to create a summary of your child's data to help you track progress and discuss with your child's healthcare team



Summary status sheet

Example:

Days = days on supplementary nutrition/fluids Days / Week = number of days on supplementary nutrition/fluids divided by 7 f you receive parenteral nutrition 3 days in a week, you would go to the two rows in dark purple. The top row would be filled in as 3/7 and the bottom row would be filled in with the total volume of parenteral nutrition eceived during the week.

	Week Commencing										
Weight	Weight kgs / stones /lbs										
Oral Fluids	Days/Week										
	Weekly Volume (mL)										
Enteral Feeding	Days/Week										
	Weekly Volume (mL)										
I.V. Fluids	Days/Week										
I.V.F	Weekly Volume (mL)										
Parenteral Nutrition	Days/Week										
	Weekly Volume (mL)										



Record any changes in your child's health and any questions you may have for your child's next appointment with your child's healthcare team





