



EDUCATING THE INTESTINAL TRANSPLANT PATIENT

A Guide for Teachers and
Other School Members



Transplant
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The purpose of this material is to inform educators about the unique circumstances of an intestinal transplant patient and help guide them in creating a supportive educational environment.

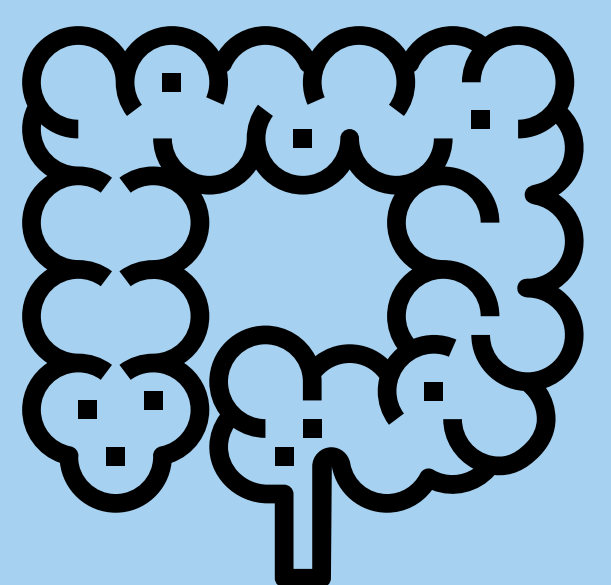
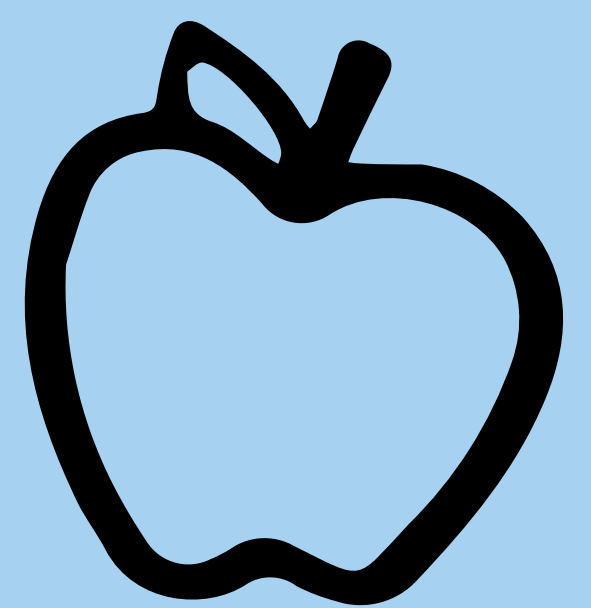
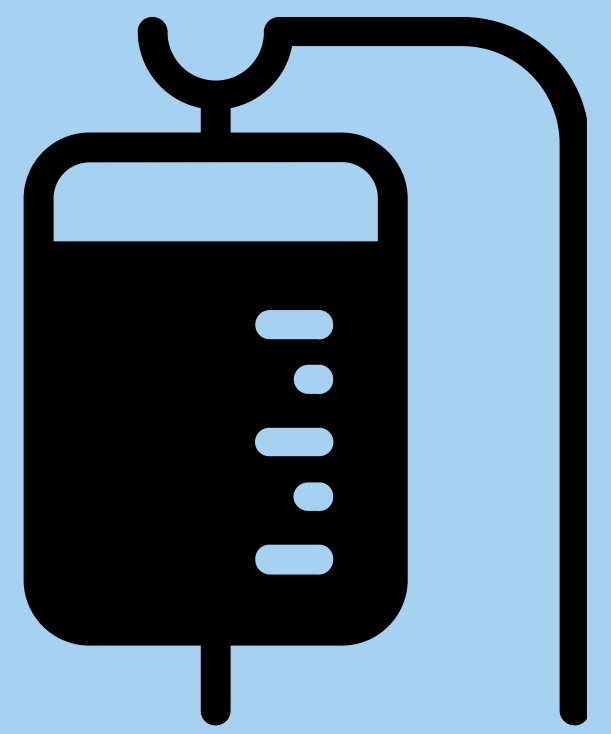
The material covered is not all-inclusive and is simplified for ease of reading. Further information about intestinal transplant can be found on our website.

What is an Intestinal Transplant?

An intestinal transplant is an operation to replace a diseased or shortened small intestine with a healthy intestine from a donor. It is a highly specialized and complicated operation that has only been performed since 1987.

When is an Intestinal Transplant Required?

- An intestinal transplant may be considered in patients with intestinal failure who have developed complications from parenteral nutrition, or PN.
- PN is when a person requires all their nutrition to be given through a line into a vein because their intestine is unable to absorb nutrients from the food they eat.
- Intestinal or bowel failure means a person's intestine can no longer absorb enough nutrients from food. It is usually caused by short bowel syndrome or a non-functioning bowel.



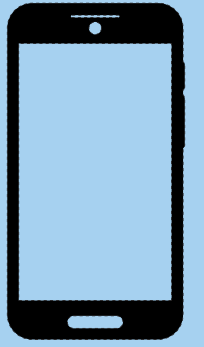
How Can this Affect a Child in School Pre-Transplant?

Before transplant, the child will still be afflicted with their underlying disease process that is leading to his or her intestinal transplant, so accommodations for the student may be necessary.

Things to take into consideration for the pre-intestinal transplant patient include:

- The patient may be on 24 hour PN (IV nutrition), so accommodations to allow for help carting around supplies or homeschooling may be required.
- Many patients experience symptoms such as abdominal pain and nausea/vomiting that can be life-limiting.
 - If this is the case, school accommodations, such as homebound services or a 504 plan, should be considered.
- Pre-transplant patients will have frequent doctor appointments, especially during the transplant evaluation, which sometimes can be two weeks of back-to-back appointments.
- Absences from school and make-up work should be coordinated accordingly, and a reduced load may be necessary.

- Older children may feel the need to carry a cell phone with them at all times when on the waiting list as they are waiting for 'the call.'



- Providing accommodation for this can help relieve anxiety and stress for the adolescent patient.



- Dehydration is a concern for many intestinal transplant patients.

- Allowing accommodations such as permitting water bottles and rehydration solutions are recommended.



"Courage is not having the strength to go on; it is going on when you don't have the strength."

THEODORE ROOSEVELT



School and the Post-Transplant Patient

The risk of infection due to the student's weakened immune system is the biggest concern after transplant. In the beginning, it is best to keep the child away from large groups and refrain from returning to a school environment. The transplant team may recommend homebound services until it is safe for the child to return to school.

Even with an all-clear from the transplant team, extra vigilance on the teacher and school is needed to help keep the child infection-free. The promotion of handwashing and disinfecting of surfaces in the classroom is a must.

Some accommodations may still be necessary, such as hydration allowances or frequent snack breaks, as the child adjusts to having a new intestine.



Keeping Transplant Patients Involved

It is essential to recognize that the child may become socially isolated from their peers because of his or her illness and intestinal transplant. The school system needs to take the initiative to keep the child involved with their classmates and the school system's happenings.

Sending newsletters, pictures from events, announcements, staying in touch virtually through social media or other online modalities will help keep the child engaged and feel less isolated throughout the process.

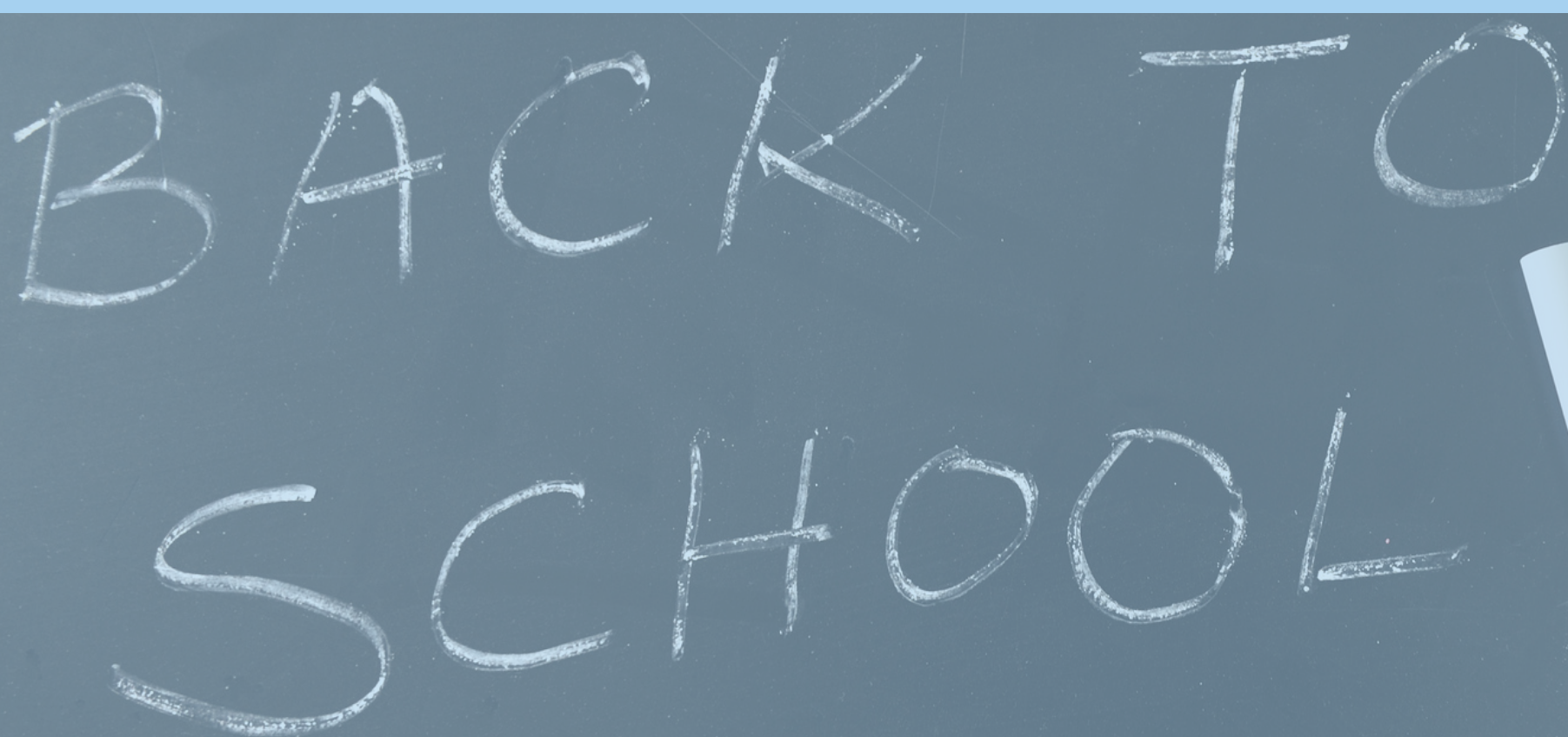


Instructional Options to Consider for the Intestinal Transplant Patient

The following schooling options may be suggested for a pre- or post-transplant patient. Each case should be considered on an individual basis to determine which type of instruction is the safest and most beneficial for the child.

- Full homebound instruction
- Partial school days and partial homebound
- Full school days with accommodations
- Full school days with no accommodations

Accommodations may change often depending on the condition of the child. Communication between the school and the child's caregiver is critical to allow for the best outcome.



BACK TO
SCHOOL

Important School Considerations

- Remember that a child with an intestinal transplant is still an average child. He or she comes from ordinary families and can grow up to live normal lives. The child is just dealing with abnormal and unique medical challenges.
- It is important to offer flexibility to the child and the caregiver. A transplant patient's life can change at a moment's notice, and it is essential to recognize this.
- Many on immunosuppression medications often feel that they experience "prograf brain" or akin to a "brain fog."
 - If a child seems not to comprehend a particular topic or explanation, understand that the child is on many medications that may interfere with his or her abilities.
- Before and after transplant, absences will be frequent- planning, communication, and understanding are necessary.



Important School Considerations

- While intestinal transplant patients should avoid large crowds and classrooms initially, they do not have to remain in a bubble for the rest of their lives.
 - Participation in normal 'kid' activities and sports is encouraged once they are healed and feeling well.
- Water and hydration are essential and should be allowed at all times.
- Frequent snacks may be required to help achieve appropriate nutritional status.
- Bathroom breaks may be frequent and prolonged.
- During times of outbreaks of viruses or infections at school, the child may consider staying home to avoid exposure.
- Frequent hand washing and sanitizing is critical.
- Helping to educate the child's peers about intestinal transplant can help reduce any stigma others may place on the child about his or her illness and squash any rumors that may form.

Communication is Key

In the end, educating an intestinal transplant patient boils down to communication between the child's caregiver, the child, and the school system. Having a general understanding of intestinal transplant and the individual needs of the child will aid in a better educational experience for the child.

More Info?



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Citations:

1. Kosmach-Park B, Dennison J, Hiller J. Maintaining a Healthy Lifestyle After Transplantation. Maintaining a Healthy Lifestyle After Transplantation.
2. Health Resources and Services Administration. Partnering With Your Transplant Team. Rockville, MD: Healthcare Systems Bureau; 2008.

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