



# Students Living With a Genetic Condition: A Guide for Parents

How-to Guides



## Introduction

As parents of a child living with a genetic condition, you may feel apprehensive about sending your child to school. You know how to identify and manage symptoms at home, and it may be scary to have someone else manage your child's medical care in your absence. Before your child begins school, it may be important to explain your child's condition and how it may impact your student's school experience to certain members of the school staff. You may do this by sending a letter or by going to the school for a meeting.

This Guide provides information that may be helpful when writing a letter or when preparing to meet with your student's teacher, school nurse, and physical education teacher or coach. This may also be a useful resource for bus drivers, babysitters, church leaders, or any other potential caregiver. This packet includes general template letters that can be adapted to fit your personal needs. Once you develop your personal resource, it may be useful to laminate your resource and give it to your student to keep in his or her backpack. In addition, this resource includes ideas for how your child can talk to classmates or peers about his or her genetic condition.

Developing a plan for your student's school year and meeting with relevant staff at the school may help you feel more confident as you send your child to school. Teachers and other staff members also feel more comfortable about their ability to manage your child's care and to provide the necessary support and encouragement for a positive school experience when they possess the information they need.



**In this Guide, you will find** how to prepare letters to your student's:



Teacher



School Nurse



Physical Education Teacher or Coach

In addition, this Guide provides your child with information about how to talk to friends and classmates about his or her genetic condition.





## How To Prepare a Letter to Your Student's Teacher

Dear \_\_\_\_\_

### **Introduction:**

Hello, we are \_\_\_\_\_'s parents. \_\_\_\_\_ has been diagnosed with a genetic condition called \_\_\_\_\_, which causes (provide a simple and basic medical description and/or attach a simple fact sheet provided by the support organization for this condition).

Individuals with (name of condition) often (or sometimes) experience the following symptoms: \_\_\_\_\_ . We wanted to take the time to discuss \_\_\_\_\_'s condition with you so that you are prepared to provide the encouragement and support \_\_\_\_\_ will need to have a positive and successful school year.

**The following topics can be addressed in the body of your letter. Be succinct in your explanation.**

- Description of times the condition may be worse
  - Certain foods, eating schedules
  - Stimuli: loud noises, lights, textures
  - Deviating from routine: fieldtrips, holiday parties
  - Unstructured times: lunchtime, recess, breaks
  - Physical activity
  - Having restricted bathroom or water access
  - Time of day
  - Certain circumstances: when tired, hungry, has full bladder/bowels
- What you have found to be effective management/treatment/prevention
  - Give child adequate time to eat
  - During times when there is a lot of noise or chaos, provide a quiet spot for the child to go to if needed
  - Provide additional guidance and support during unstructured times
  - Allow student to determine extent of involvement in physical activity and allow access to water during this time
  - Special diets
  - Make sure a bathroom is accessible at any time it is needed
  - Do/do not administer certain drugs
- Accommodations that may be needed during the school day
  - Access to private bathrooms, possibly in the nurse's office
  - Permanent hall pass for bathroom, water fountain, nurse's office
  - Access to food and drink throughout the day, outside of scheduled lunch period
  - Air conditioning or heating needs
  - Visual cues--picture schedules, hand signals
  - Considerations for orthotics and/or prostheses and open areas: medical ports, feeding tubes
- How the child's learning may be affected and how the teacher can help



- When in pain, the child may be easily frustrated. During times like this, our child reacts positively to a patient and encouraging approach of teaching.
- Child may have difficulty concentrating. Repeating instructions more than once may be helpful. Eye contact may or may not be helpful, depending on the child.
- Child may experience inconsistent school performance or excessive school absences. Help arrange for the student to receive additional help or tutoring. Have a pre-arranged agreement on how this situation will be handled.

**Conclusion:**

We would like to thank you for taking the time to understand \_\_\_\_\_'s situation and how you can help him/her. We know that as \_\_\_\_\_'s teacher you will get to know him/her very well. Therefore, if you recognize that \_\_\_\_\_ is having any difficulties—problems with school performance, behavior, withdrawing from the social group, or difficulty coping—please let us know! We respect the role you will be playing in the care of \_\_\_\_\_ and communication is the key to a successful school year. Please contact us at any time if you have any questions or concerns, or if you want additional information about \_\_\_\_\_'s condition. We look forward to working with you this school year.

Sincerely,

Name  
 Address  
 Home phone  
 Work phone  
 Cell phone  
 Email addresses (home and work)



## How to Prepare a Letter to Your Student's School Nurse

Dear \_\_\_\_\_,

**Introduction:**

Hello, we are \_\_\_\_\_'s parents. \_\_\_\_\_ has been diagnosed with a genetic condition called \_\_\_\_\_, which causes (provide a simple and basic medical description and/or attach a simple fact sheet provided by the support organization for this condition). Individuals with (name of condition) often (or sometimes) experience the following symptoms: \_\_\_\_\_ . We wanted to take the time to discuss \_\_\_\_\_'s medical needs throughout the school day so that you will feel adequately prepared to help.

**The following topics can be addressed in the body of your letter. Be succinct in your explanation.**

- Required medication during the school day
  - Name of medication
  - Dosage
  - Dosing instructions
  - Name of prescribing doctor
  - Written permission for administering medication
  - Permission for older students to carry medicine themselves to help alleviate symptoms (such as Tums)
  - Address when and how the child will get the medicine
- Special care needed during the school day
  - Access to private bathroom in the nurse's office
  - Specific exercises (such as airway clearance for children with cystic fibrosis)
  - Special diet supervision
  - Any other special instructions
  - Identify who is responsible for the child's care each day and in case of the caregiver's absence
- Emergency protocol
  - Emergency contact information for parents, relatives, friends
  - Provide statements from doctor or specialist regarding treatment and emergency protocols, if necessary
  - Name of doctor or specialist who coordinates care
  - Name of hospital or medical center where the child is treated
  - Current list of medications
  - Allergies
  - Current weight, height, other baseline information

**Make sure all of this information is updated on a regular basis**

**Conclusion:**

We would like to thank you for taking the time to understand \_\_\_\_\_'s situation and how you can help. We respect the role you will be playing in the care of \_\_\_\_\_ and communication is the key to a successful school year. Please contact us at any time if you have any questions or concerns, or if you need additional information about \_\_\_\_\_'s condition. We look forward to working with you this school year.

Sincerely,

Name  
Address  
Home phone  
Work phone  
Cell phone  
Email addresses (home and work)





## How to Prepare a Letter to Your Student's Physical Education Teacher or Coach

Dear \_\_\_\_\_

### Introduction:

Hello, we are \_\_\_\_\_'s parents. \_\_\_\_\_ has been diagnosed with a genetic condition called \_\_\_\_\_, which causes (provide a simple and basic medical description and / or attach a simple fact sheet provided by the support organization for this condition). Individuals with (name of condition) often (or sometimes) experience the following symptoms: \_\_\_\_\_. We wanted to take the time to discuss how \_\_\_\_\_'s condition may be affected by physical activity so that you will feel adequately prepared to help.

**The following topics can be addressed in the body of your letter. Be succinct in your explanation, and mention only what is necessary for the physical education teacher or coach to know.**

- How physical activity may affect the condition
  - Strenuous physical activity may cause ill effects such as overheating, difficulty breathing, dehydration, or need to use the restroom
- Special Accommodations
  - Allow student to determine extent of involvement in physical activity
  - Provide less strenuous activities for the student if he or she is unable to participate in the scheduled class activity
  - Allow water, bathroom, or snack breaks whenever needed
  - Develop a signal that the student can use to indicate if he or she needs to come out of a game or take a break from an activity
- Emergency protocol
  - Emergency contact information for parents, relatives, friends
  - Provide statements from doctor or specialist regarding treatment and emergency protocols, if necessary

### Conclusion:

We would like to thank you for taking the time to understand \_\_\_\_\_'s situation and how you can help. The value of sports and physical activity is very important, so we encourage you to work with \_\_\_\_\_ to find a way to enable participation while accommodating \_\_\_\_\_'s condition. We respect the role you will be playing in the care of \_\_\_\_\_ and recognize that communication is the key to a successful school year. Please contact us at any time if you have any questions or concerns, or if you need additional information about \_\_\_\_\_'s condition. We look forward to working with you this school year.

Sincerely,



Name  
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Home phone  
Work phone  
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## Ideas About How to Talk to Your Friends and Classmates

Most students are uncertain about what to say to their peers and are nervous about how their friendships and relationships with classmates may be impacted. If you are worried, therefore, you are not alone. The following ideas may help you develop a plan for how to talk to your friends and classmates. Remember, this is just advice, and you are in control of what you say and when you say it.

- Use simple language to explain your condition.
  - Use your own words.
  - You don't have to explain everything at once. If people want more specific details, they can ask you.
  - If there are certain questions you do not want to answer or topics you do not want to discuss, tell your peers.
- Let your friends and classmates know how they can help.
  - Clearly state what you want from your peers. This could include helping you catch up with any missed schoolwork or asking your friend to bring homework home from school for you.
    - "It would be nice if you could help me by \_\_\_\_\_."
    - Develop code words to communicate the type of help you may need in a certain situation.
  - If someone offers help, take him or her up on the offer if you feel up to it. If not, that's okay too.
    - "I appreciate you offering your help, but I want to do this on my own today."
- Initiate the conversation if you feel someone is curious or uneasy about your situation.
  - If you are open to talking and can explain some of your hassles in a lighthearted way, others may feel more comfortable and may have a better understanding.
    - "Do you have any questions about my condition or how it affects me doing \_\_\_\_\_?"
    - Use humor to break the ice.



- Being open to conversation will let others know that you are not defined by your condition. You have interests, feelings, strengths, and weaknesses just like everybody else.
  - “I may miss school sometimes or have to take medicine, but I still am capable of/enjoy doing \_\_\_\_\_.”

Remember that you are in control over what and how you share information with others. Some people prefer to be honest and straightforward, while others prefer to joke and be funny. Regardless of your approach, it is helpful to be prepared with answers to comments or questions that may come up in conversation so that you will not have to worry about being caught off guard.



## Acknowledgments

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*Pediatric/Adolescent Gastroesophageal Reflux Association*  
“Going to School with Acid Reflux: A Guide for Parents”  
Written by Jan Burns, M.Ed. and Beth Anderson  
[www.reflux.org](http://www.reflux.org)

*Crohn’s & Colitis Foundation of America*  
“Guide for Teachers” and “How to Deal: Friends & Foes Tips”  
[www.ucandcrohns.org](http://www.ucandcrohns.org)

*National Foundation for Ectodermal Dysplasias*  
School Packet 2005  
[www.nfed.org](http://www.nfed.org)

*Online Asperger Syndrome Information and Support*  
“Asperger’s Syndrome Guide for Teachers”  
Written by parents of OASIS Asperger Syndrome Forum  
Compiled and Edited by Elly Tucker  
[www.udel.edu/bkirby/asperger/](http://www.udel.edu/bkirby/asperger/)

