

# Potentially Life-Limiting Conditions

## Take-Home Message

It is increasingly common for children with serious and potentially life-limiting medical conditions to attend school in regular classes. School staff can take important steps that provide support to both the ill student and to classmates who are likely to have questions and concerns.

## Children With Life-Limiting Conditions in the Classroom

Children with serious and potentially life-limiting conditions are frequently enrolled and active in regular educational settings. This is the result of:

- advances in medical treatments and assistive technologies
- a trend toward brief hospitalizations
- policies that aim to maintain children with disabilities in regular education settings whenever possible

Such children may continue in school until very close to the time of their death. Some children also take advantage of technologies that allow them to participate remotely in classroom activities. They can stay in touch with teachers and classmates even while they are in the hospital undergoing treatment, or very ill at home.

Teachers are often in a situation where they need to consider how to both support a seriously ill student and help classmates understand and cope with the illness of a peer.

## Help Students Understand

Help students understand what is happening with their ill classmate. The focus should be on providing relevant information about the illness. Ideally, this will cover information about the underlying condition and its treatment. Emphasize that the condition is not contagious; otherwise the student would not be permitted to return to class.

Include discussions of side effects—both those that are visible, such as weight gain or acne caused by steroid use, and those that are less apparent. These might involve such things as learning difficulties, pain, or fatigue.

Obtain permission from the ill student's parents or guardians about what information may be shared with the class. The student should also be asked what information is to be shared and how he or she would like this done.

For example, ask if the student would like to be present for this discussion. Students sometimes ask that a parent, a member of the medical team, or the school nurse speak to the

class. Some prefer to have the classroom teacher speak to the students after being briefed by a professional. Some students elect to speak on their own behalf. They may wish to be present to answer questions after someone else has presented background information.

## Classmates' Reactions

Children who witness the physical deterioration of a peer or are aware of the seriousness of the condition may become worried about their own health. Sometimes they become overly concerned about common illnesses such as when they, their family, or friends get sick with a cold or the flu.

This underscores the need for students to understand the cause of their peer's illness. With appropriate understanding, they will be able to differentiate mild illness from more serious conditions. These discussions can also help create an atmosphere where students can express their concerns openly and receive appropriate information and reassurance.

## Keep Parents Informed

It's important to inform parents about what their children are learning in class. Provide additional information that will prepare them to answer their children's questions and respond to their concerns.

Most parents appreciate this guidance. They will respect the ill student's desire to remain in school. They will see this as an opportunity for their own children to learn tolerance for differences and empathy for others.

Some parents, however, may feel protective of their children. They may advocate for the ill child to be educated



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outside the regular classroom. In these instances, it will be useful to arrange a parent meeting involving medical professionals such as the school nurse, along with the school mental health and support personnel. This discussion can address the parents' concerns and questions while clarifying that the child who is ill has a right to attend the school.

### Other Seriously Ill Students

There may be other seriously ill students in the classroom, or students who have a seriously ill family member. These children may be more sensitive to their classmate's condition and the progression of his or her illness. Often, teachers are not aware of these concerns or experiences.

It is helpful to conduct all discussions of the ill child's circumstances with the presumption that other students in the class may also have these vulnerabilities.

### Help Peers Be Helpful

If students are unable to understand what is happening to a seriously ill peer, or why their classmate looks or acts different, they are more likely to isolate or even tease the child. Part of the ongoing discussion about the child's condition can include suggestions about what peers might do to be helpful to the ill student.

These are steps that will be different for every ill student, and that are likely to change over time as the condition progresses. They might include such things as inviting the student to join them at lunchtime, coming up with a sit-down activity they can share at recess, or offering to carry books when walking between classes. Classmates might share notes for lessons missed or offer peer tutoring for concepts the ill child has difficulty understanding (perhaps because of side effects from treatment).

Students might come up with ideas for group projects where the group collaborates to complete a project or assignment, thereby engaging the ill student in a more dynamic and active way.

### Focus on the Present and Near-Term

The aim of these interventions is not to anticipate or prepare the class for the student's death. Rather, it is to help everyone understand the student's current condition and level of functioning.

It is sometimes helpful to prepare students for likely

near-term changes, such as fatigue or the need for extra infection-control measures due to a weakened immune system. This might be appropriate, for example, in the week following a course of chemotherapy.

In situations where a student is known to be critically ill and likely to die soon—for example, the student is in a coma and expected to die in the coming week—classmates can be told that the student is seriously ill and the family is concerned that the child may not recover.

### Support the Ill Student

Ultimately, the goal is to maximize the ill student's current quality of life. Sometimes the greatest gift teachers can provide such students is the opportunity to feel normal. School and learning are the primary work in children's lives. Students' ability to attend school, actively learn, and contribute in class allows them to feel a continued purpose in life.

Children who are seriously ill with a potentially life-limiting condition tend to have a precocious understanding of the concepts of death—even young children. They are usually aware of the seriousness of their condition even if they haven't been explicitly told.

Parents often prefer to think their children are unaware. Children tend to comply by entering into a mutual pretense where they don't share their awareness with family members. Unfortunately, this leaves children emotionally isolated. They are unable to seek information or reassurance about concerns they may have from their own family and may turn to their teacher, or other adult in the school such as the school nurse, for advice.

Staff should seek advice from a school mental health or support professional about how to help a student in this situation.



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## When a Teacher or Other Staff Member is Ill

When the person with the serious illness is a teacher or other school staff member, similar steps can be taken to support and prepare students. For example, while respecting the individual's privacy, explain to students why the person will not be in school for a prolonged period of time. Describe the nature of the illness and explain any major changes in appearance that are likely.

Work with students to identify ways to offer support and assistance. They might want to make cards, draw pictures, create a video, or record messages to send. These activities will help students feel less anxious about the situation or what to expect upon the staff member's return.

## Seek Support Yourself

It is challenging to meet the diverse needs of a large group of students, even when they are all healthy. Trying to

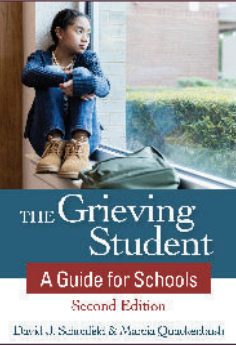
accommodate the additional needs of a seriously ill student, while also considering how to support other students, is likely to be difficult for any teacher.

Teachers care about their students. Watching a student deteriorate physically and eventually die can be particularly difficult.

Seek assistance from support staff at school. It is helpful to have colleagues and friends to talk to. It may be useful to engage in specific activities for stress management or seek out an employee assistance program. The advice in the module on Professional Self-Care is particularly relevant in this context.

## Use Guidance From Other Modules

Professional Self-Care offers suggestions for recognizing the challenges of this work and obtaining appropriate and helpful support.



For more information on supporting grieving students, refer to *The Grieving Student: A Guide for Schools* by David Schonfeld and Marcia Quackenbush.

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