Chronic illness - coping at school

Summary

- A ‘whole school’ approach to support a student with a chronic illness is important.
- Relevant information about the student’s condition should be shared with appropriate school staff.
- Maintain regular communication between the school and family regarding how the student is coping at school and at home.
- Explore possible sources of additional support.

Beginning primary school, or moving to secondary school, can be a challenging time for any student and family. This can be even harder when the student has a chronic (ongoing) health condition. To get the most out of their schooling, students with a chronic illness need ongoing and coordinated support from their families, schools and medical carers.

Chronic illness affecting children

Chronic illnesses are usually associated with older people and not with children. However, a small but significant number of children in Australia suffer from chronic illnesses – mainly asthma, but also diabetes and cancer. Cerebral palsy, epilepsy and cystic fibrosis, along with musculoskeletal disorders and illnesses affecting sight, hearing and allergic reaction affect smaller numbers of children.

Effects of chronic illness on schooling

Students with a chronic illness may miss a lot of school. This might be because they need to go to hospital, recover at home or attend regular medical appointments. This can lead to:

- Difficulty completing work on time or taking part in exams
- Decreased academic performance
- Difficulty keeping up relationships with school friends
- Difficulty getting around the school environment
- Difficulty participating in some school activities (for example, physical education or excursions)
- Feeling less confident and less motivated, also possibly affecting self-esteem and body image.

Supporting students with chronic illness

The family and the school need to work together to establish and maintain good communication and cooperation. Everyone needs to understand what is needed and expected to support your child. The family and the school also need to be clear about what can, and cannot, be done so that everyone’s expectations are achievable and realistic.

The important things to remember are that you:

- Share information
- Develop a care plan
- Keep up good communication
- Make changes where necessary
- Seek extra support.

Sharing information about chronic illness

You and your child should decide what information about your child’s condition should be shared with appropriate
school staff. Remember to:

- Decide how much information should be shared with school staff, classmates and the wider school community.
- Try to find a balance between the need to give adequate care and support for your child, and their right to confidentiality and privacy.
- Work out who will be responsible for passing on the information, who it will be given to, how and when. This could be your child, a family member, a friend, another parent chosen by the family, a staff member who works closely with the family or a support group or association.

**Develop a chronic illness care plan**
In consultation with your child’s doctor, family and school principal, a school-based care or management plan should be developed. This plan should be accessible to relevant staff and reviewed every year, or whenever there is any significant change to your child’s condition or treatment.

Make sure that relevant information is communicated to casual teachers and other staff who have occasional care of your child. The plan should also indicate which school staff will be responsible for carrying out certain tasks and what to do in case of emergency.

The Victorian Government School Policy and Advisory Guide offers help for schools in developing a health support plan for students with a chronic illness.

**Keep up good communication**
Regular communication between the school and the family is the best way to monitor how your child is coping at school and at home (academically, socially, physically and emotionally). For younger children, writing daily messages in a home-school communications book may help. Teachers and parents can then describe changes in energy levels, whether your child is keeping up with schoolwork, taking part in everyday activities or how they are feeling generally.

When a student misses a lot of school because of their health condition, both the parents and the school should try to reduce how much this affects their schoolwork and social life. For example, it might help to:

- Send home schoolwork
- Establish email contact
- Refer to the Visiting Teacher Service
- Organise a Program Support Group.

The school should also immediately let you know if your child has received any additional medical care.

**Making changes for students with chronic illness**
The physical environment may need to be modified to allow full access to school facilities and activities for children with chronic illness. For example, ramps, rails, adaptive equipment or disabled toilets may be needed.

The academic environment may also need some changes. For example, adapting the curriculum, work requirements, timetable or subject choices might be necessary for your child. For VCE students, you should work out whether the school will need to apply for special provision on behalf of your child.

**Extra funding support for students with a chronic illness**
Your school may be eligible to apply for extra funding or support for a student with a chronic illness. Staff may also need education or information about the specific condition or chronic illness in general. Discuss this with your child’s school principal.

**Special services for students with chronic illness**
A variety of specialist staff may be available or may be called in to assist your child. These include visiting teachers, education support officers, psychologists, guidance officers, speech pathologists, social workers and other allied health professionals. Talk to your principal about whether any of these services may be available.

**Visiting teacher service**
In Victoria, the Department of Education and Early Childhood Development and the Catholic Education Office provide a Visiting Teacher Service. Your child’s school is responsible for applying to the Visiting Teacher service. If your child attends an independent school, please contact your child’s school principal to discuss additional support.

Visiting teachers may work with visually, hearing and physically impaired students, as well as students with a chronic health condition. They provide additional educational assistance, advice and support to school-aged children and young people, their parents, schools and school communities.

**Student welfare coordinators**
Schools have dedicated staff members called student welfare coordinators who help develop programs to meet the individual needs, interests and abilities of those students who may find education challenging. They may also be called pastoral care coordinators or primary welfare officers.

**Royal Children’s Hospital Education Institute**
The Royal Children’s Hospital Education Institute brings together and passes on education and health knowledge for students, schools and the community by:

- Partnering with school systems, individual schools, teachers and families
- Providing support, information and advice to schools
- Conducting research and distributing knowledge to inform decision-makers
- Delivering training and professional development for people working with students who have a health condition.

**Special programs for students with chronic illness**
In addition to specialist professionals to assist your child, the Victorian Government and the Catholic and independent school systems offer programs to meet the needs of children with a chronic illness.

**Program for Students with Disabilities**
The Program for Students with Disabilities (PSD) provides additional resources for the education of students with disabilities and additional learning needs in Victorian government schools.

Your child’s school can apply for the PSD by completing an educational needs questionnaire that will determine if your child meets eligibility criteria under one of seven categories, including:

- Physical disability
- Visual impairment
- Severe behaviour disorder
- Hearing impairment
- Intellectual disability
- Autism spectrum disorder
- Severe language disorder with critical educational needs.

If your child is eligible for the program, the school is then responsible for organising a program support group (PSG) to monitor your child’s progress. The PSG can include a parent, advocate, teacher, principal and, if appropriate, the child.

There is a similar program within the Catholic and independent school systems called the Literacy, Numeracy and Special Learning Needs Program.

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Ronald McDonald Learning Program
The Ronald McDonald Learning Program is a unique educational ‘catch-up’ program that tailors tuition for children who have missed school due to serious illness. Parents must apply for this service. It is recommended that you apply for this program as soon as possible, as the processing of applications and the allocation of a suitable tutor may take some time.

Where to get help
- Your doctor
- School principal
- Royal Children’s Hospital Education Institute Tel. (03) 9322 5100
- Chronic Illness Peer Support, Centre for Adolescent Health, Royal Children’s Hospital Tel. (03) 9345 6616
- Yooralla Independent Living Centre Tel. (03) 9362 6111

Things to remember
- A ‘whole school’ approach to support a student with a chronic illness is important.
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- Maintain regular communication between the school and family regarding how the student is coping at school and at home.
- Explore possible sources of additional support.

This page has been produced in consultation with and approved by:
Royal Children's Hospital - Clinical support services
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