

Invisible Illmess

—an online resource about children and young people with chronic conditions for school communities





Student Health Support Plans

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In preparing this resource on Student Health Support Plans, the Chronic Illness Alliance would like to thank and acknowledge the important contribution made by each of the following organisations:

The Royal Children's Hospital Education Institute;

The Chronic Illness Peer Support program, Centre for Adolescent Health, RCH;

the Department of Education and Early Childhood Development;

the Catholic Education Commission of Victoria;

and Independent Schools Victoria.

We are particularly grateful to Eliza, James, Jemma, Sarah, Tamara and Vassie for giving us the opportunity to learn from their many experiences at school.

Chronic Illness Alliance www.chronicillness.org.au

WHY SHOULD A STUDENT HAVE A HEALTH SUPPORT PLAN?

About 15% of school-aged children and young people experience chronic illness. Examples of chronic illnesses are Asthma, Cancer, Cystic Fibrosis, Diabetes, Epilepsy and Haemophilia.

A chronic illness is any long-lasting health condition that requires regular, but not necessarily constant, monitoring and treatment. It is often 'invisible' without any outward signs of physical limitation or disability.

The illness may affect the student's diet, learning style and capacity to exercise. It will certainly affect their quality of life and capacity to participate in activities. It may even be life threatening.

In most cases, how the illness is managed on a day-to-day basis will affect the student's health and general well-being. The most effective way to support the individual needs of a student with a chronic illness is to work in partnership with them and their family or carer to devise a Student Health Support Plan.

To help all parties involved we have developed a step-by-step guide to preparing a Student Health Support Plan. We have also created six very short video clips of students giving practical examples of how their schools helped them to overcome their individual challenges.

WEBSITE RESOURCES:

Specific information about a range of chronic illnesses can be found on the Chronic Illness Alliance's Invisible Illness website http://www.chronicillness.org.au/invisible. This online resource aims to assist teachers, students and their families learn about these illnesses and how they affect students.

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Step-by-Step Guides to Preparing a Student Health Support Plan

Department of Education and Early Childhood Development policy

The Schools Reference Guide states that 'Victorian Government schools have a responsibility to provide equitable access to education and respond to diverse student needs, including health care needs. Schools need to make local decisions and create innovative solutions to meet the needs of all students.'

(Schools Reference Guide 4.5.1, Planning for and supporting students' health care needs at school-www.education.vic.gov.au/edulibrary/public/schadmin/environment/4-5.pdf)

A Student Health Support Plan should focus on two key areas

- what the school can do to help the student best manage their health
- what the school can do to ensure that the student's school life is not disadvantaged in any way compared with other students in their year.

To help schools, students and their families achieve positive outcomes when developing a Student Health Support Plan, we have prepared a 'Recommended Approach' guide for each of the parties involved. The guides outline the recommended approach for working together and negotiating an effective Student Health Support Plan for the student. Each guide is designed to be quick and easy to use.

These guides, for schools, families and students, appear later in this document.

We have also developed a list of helpful strategies, many of which were taken from the six student video clips (view these videos at http://www.chronicillness.org.au/invisible/healthplan3.htm).

The Strategies for Helping Students guide appears later in this document.

Practical Examples of Schools Supporting Students

Each of the short videos tells one student's story about the practical ways their school has helped them.

- Vassie's story tells how a teaching aide and adjusting teaching styles were crucial to her succeeding beyond expectations at school.
- Tamara's story tells how, on returning to school, she was able to manage her health care needs at school through a 'pink' card.
- Sarah's story tells how she was able to manage her condition through peer and teacher support.
- Jemma's story tells how she used public speaking opportunities at school to explain her illness and her needs to staff and students.
- James's story tells how his school helped him to improve his general well-being and expand his social networks by developing his interest in sport.
- Eliza's story tells how modifying the curriculum helped her to continue at school.

We gratefully acknowledge the support of the Chronic Illness Peer Support program (ChIPS) in the making of these videos. For more information about this program for adolescents living with chronic health conditions go to www.rch.org.au/chips.

Strategies for Helping Students

Don't be afraid to ask

Don't be afraid to ask questions about what the student is physically capable of doing. Some students can participate in all activities, some need a slightly modified approach, and others are greatly limited in what they can do.

Most students are willing to talk about their needs and limitations. Communicating directly with the student and their family will help you to work out where they fit in the continuum, and help you to decide what you can reasonably expect of them.

James's story (see http://www.chronicillness.org.au/invisible/healthplan3.htm) tells how his school encouraged him to step outside his comfort zone, which led to great benefits for his social and physical well-being.

Who should be told

Students are often very self-conscious about having a health condition. Involve the student and family in any discussions about

- who is to be told about the student's illness
- what is to be told
- how they are to be told
- when they are to be told.

Tamara and Jemma (see http://www.chronicillness.org.au/invisible/healthplan3.htm) have quite different stories about how their schools told their fellow students and teachers.

Student and family are experts

The student and their family are usually the experts on managing the student's condition, and the amount and type of support likely to be needed - after all, they've often been living with the condition for some years. Discuss with them how the school could best accommodate the student's needs.

Listen to Jemma's, Sarah's and Tamara's stories to find out about the strategies that were adopted to allow them to manage their health condition at school and to take part in normal school life.

Modifications can make a big difference

Modifying the curriculum or adjusting a teaching style to accommodate a student with a learning difficulty can make a dramatic difference to their academic outcomes and self-esteem.

Vassie's story (see http://www.chronicillness.org.au/invisible/healthplan3.htm) tells how she exceeded initial academic expectations, and successfully progressed to university with the help of a teaching aide. Eliza's story tells how frequent illness-related absences warranted reductions to her workload and leniency at exam time.

Vassie's and Eliza's stories illustrate the benefits that can result when schools are flexible and responsive to individual needs. Not all students need such modifications, which is why flexibility is important.

Symptoms vary

The symptoms of an illness often vary from person to person. Also, the symptoms experienced by an individual may vary with different episodes of an illness. Stereotyping an illness and its symptoms can disadvantage the student. It is important to speak to the student and their family about the nature of their illness and how it affects them.

Support is important

Support is important in managing any serious health condition. Older students can often manage their own health care needs. However, all students need support from those around them. Understanding their condition, dealing with their individual needs, and giving them emotional and physical support are all vital in maintaining the student's health and well-being, and ensuring that they function at their best.

Recommended Approach for Schools in Supporting Students with Health Conditions

Department of Education and Early Childhood Development policy:

'The Department acknowledges that early intervention is critical, especially in relation to a student with an identified healthcare need. It is essential that upon enrolment or when a health care need is identified, the school has clear plans and processes in place to support the student's health care need.'

(Schools Reference Guide 4.5 The Department's policy on student health support: http://www.eduweb.vic.gov.au/edulibrary/public/schadmin/environment/4-5.pdf)

Step-by-step guide to preparing a Student Health Support Plan

- 1. Prior to enrolling the student or following their medical diagnosis, tell the student and their parents/carer about the school's policy for supporting students with health care needs.
- 2. Ask the student and their family to provide accurate information about the student's routine health and personal care support needs, including emergency care if needed.
- 3. Arrange a student support group meeting with the student, their family, and any relevant support people in the school that the student feels comfortable having present. Ensure that the student and their family participate in the discussion and contribute to all decisions made.
- 4. Encourage young students, including primary-aged students, to engage in the meeting process. It is important that they have the opportunity to speak, and to learn about the process in preparation for future years when they will play a more active role.
- 5. At the meeting
- Complete a Student Health Support Plan (refer to 4.5.3.1 of the Schools Reference Guide). When completing the form, ask how the student's illness might limit their participation in the everyday school environment. In consultation with the student and their family, plan strategies to overcome these limitations.
- Modify the student's learning programs to allow for absences due to medical appointments, illness, hospital stays, etc.
- Discuss any upcoming events and excursions. Anticipate what additional preparations will be needed, and plan accordingly.
- Find out if the student is unable to comply with any existing school rules or procedures, and devise strategies to compensate.
- Establish an agreed communication strategy that specifies who in the school will be told about the student's illness, what they should be told, and how they should be told.
- Arrange for regular reviews of the Student Health Support Plan, and ensure that a strategy is in place for ongoing open communication between the student, the family and the school.
- 6. If the school has several students with chronic illnesses, ask them if they would like to be part of a chronic illness peer support group.
- 7. Work with the student to identify a person within the school who will be their key support person that they can approach any time for support.

This Recommended Approach for Schools guide is intentionally brief. It highlights only the key elements of the Department of Education and Early Childhood Development's policy on students with health care needs. It does not attempt to replace or replicate the policy. To read the full policy, use the link in the shaded box above.

Generally speaking, students with chronic illnesses should be treated in the same way as other students in the school. However, their illness may mean that they have to do some things differently from their classmates.

Finding a happy balance for the student is important, as is asking the student how their illness affects their participation and enjoyment in school life.

Being creative in finding solutions to problems is also important - small changes can make a big difference. If you haven't done so already, listen to Sarah's, James', Vassie's, Eliza's, Jemma's and Tamara's stories about how their schools supported them.

[by going to www.chronicillness.org.au/invisible/healthplan3.htm]

Specific information about Acquired Brain Injury, Asthma, Cancer, Chronic Fatigue Syndrome, Cystic Fibrosis, Diabetes, Epilepsy, Haemophilia, Hepatitis C, Slow Transit Constipation and Thyroid conditions can be found on the Chronic Illness Alliance's Invisible Illness website www.chronicillness.org.au/invisible.

Recommended Approach for Students with a Chronic Illness

This guide is intended to help you talk to your school about how to overcome any problems you might experience as a result of your illness.

If you haven't done so already, listen to Sarah's, James', Vassie's, Eliza's, Jemma's and Tamara's stories about how their schools supported them.

[by going to www.chronicillness.org.au/invisible/healthplan3.htm]

If you have a chronic illness, it is really important that you:

Manage your health as best you can, so you can participate in all aspects of school life as much as possible.

Tell the school that you have an illness, and tell them about it and how it affects you. If your health changes, tell them about the change, and how it may affect you. The school may ask you to get a letter from your doctor that explains some or all of this information. Your parents/carer can also help you with this information.

Some of the things the school may need to know include

- what medication you take, and when you take it
- any special dietary requirements you have
- what they and you should to do in a medical emergency.

If you haven't done so already, ask your principal to arrange a meeting with you and your family to talk about a Student Health Support Plan. The aim of a Health Support Plan is to make sure that the school understands your special health and learning needs, so it can help you in a way that you feel comfortable with. It's a really good process for you to be involved in, so don't be shy: speak up and tell the school how they can make life easier for you.

When the meeting is being arranged, tell the school if there is anybody from the school that you would like to be involved. For example, you might have a specific teacher or counsellor that you would like to be present. It's also important that your parents or a trusted adult from outside the school be involved, so they can support you and help you negotiate a Health Support Plan that works for you.

At the meeting

Help the school complete the Student Health Support Plan. Speak up if you have any suggestions about how the school could help you. Don't forget they have called this meeting because they want to help you.

Tell them about any things you can't do, and tell them what sort of things you're likely to need help with. This is your chance to explain why you need to do some things differently from other students, and what changes would enable you do them.

Tell the school what they can do to help you keep up with your class work or homework when you're away from school.

Tell the school about any events, subjects or rules that you may find difficult as a result of your illness, and how they could be modified.

You might want other teachers and students to know about your illness, or you might not. The school might want to tell certain staff members, usually for your health and safety. Tell the school who you want to be told about your illness, what they should be told, and how they should be told. Getting this right can make a big difference to how you feel at school.

Before you leave the meeting, make sure you, your family and the school arrange to meet again regularly to discuss how your Student Health Support Plan is going.

Victorian Government schools are required to meet with students and their families to complete a Health Plan. Non-government and independent schools have similar policies. If your school is unsure about Student Health Support Plans, tell them about the Chronic Illness Alliance's Invisible Illness website (www.chronicillness.org.au/invisible).

Recommended Approach for Parents and Carers of a Student with a Chronic Health Condition

As a parent or carer, it is important that you work in partnership with your child's school to optimise your child's wellbeing, health, learning and enjoyment of school.

If you haven't done so already, listen to Sarah's, James', Vassie's, Eliza's, Jemma's and Tamara's stories about how their schools supported them.

[by going to www.chronicillness.org.au/invisible/healthplan3.htm]

Your level of involvement will depend on your child's age, maturity and level of independence. Young primary-aged children should be encouraged to engage in the meeting process. It is important that they are given the opportunity to speak about their needs, and to learn about the process in preparation for future years when they will play a more active role. As students move into more senior years, they may assume more responsibility for discussing their needs. However, parents/carers will still have a vital role to play.

You can best support your child by:

- Providing the school with accurate and up-to-date information about your child, including
 - what medication they take, and when they take it
 - what dietary requirements they have
 - •what the school and your child should do in a medical emergency.

The school may ask you to provide some or all of this information in the form of a letter from your doctor.

- If not already arranged by the school, you or your child should ask for a meeting with the school to devise a Student Health Support Plan. The Plan is a form that outlines how the school will support the student's health care needs. It focuses on the medical management of their illness. However, you will also have the opportunity to discuss your child's learning needs and any problems that your child may have as a result of their illness, and to work out a plan to overcome or minimise the impact of these problems while your child is at school.
- If your child is in primary school, keep in regular contact with the school to ensure that your child's needs are being met, and to ensure that the school is aware of any changes in their health.

At the meeting:

- Discuss any strategies that you think will ensure that your child keeps up with their schoolwork, and ensure that their special needs are met.
- Tell the school about any events, subjects, rules or procedures that your child may have difficulty participating in or complying with due to their illness. Also, tell the school how they might be modified to allow your child to participate or comply.
- Before the meeting, encourage your child to talk to you about which staff and students they want to be told about their illness, what they should be told, and how they should be told. At the meeting, ensure that a plan for this is discussed, because some students find disclosure a very distressing aspect of their illness.
- Before leaving the meeting, make arrangements to meet regularly with the school to review your child's Student Health Support Plan. This may require updated medical advice each time, at least annually.

Victorian Government schools are required by the Department of Education and Early Childhood Development to meet with students and their families to complete a Health Plan. Non-government and independent schools have similar policies. If your school is unsure about Student Health Support Plans, tell them about the Chronic Illness Alliance's Invisible Illness website (www.chronicillness.org.au/invisible).