

Supporting a student with congenital adrenal hyperplasia (CAH)

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Contacts: RCH Education Institute and Department of Endocrinology and Diabetes
RCH

What is congenital adrenal hyperplasia (CAH)

Congenital adrenal hyperplasia (CAH) is a disorder present at birth (that is, congenital) involving the hormones of the adrenal glands. The adrenal glands are located above the kidneys. Children with CAH are born with overgrown adrenal glands (hyperplasia) leading to insufficient production of essential hormones. Treatment for CAH is lifelong and aims to provide the body with the necessary hormones to maintain normal sugar levels and blood pressure, allowing normal development. Typically, the medications are hydrocortisone and Florinef taken in tablet form, usually two or three times every day. Treatment is conducted under close medical supervision with regular evaluations and dosage adjustments. Failure to maintain these levels can lead to a life-threatening situation such as 'adrenal crisis'. With the correct treatment and medical care, children with CAH should expect a completely normal quality of life.

What is an 'adrenal crisis'?

When students with adrenal insufficiency/CAH become unwell, sick or injured, they will need extra doses of medication. Each student should have a treatment protocol or 'Action Plan' for staff to follow, and in most instances it will be enough for the student to take extra hydrocortisone tablets (extra Florinef is not needed). However, in some situations an urgent injection of hydrocortisone may be required. If the medication is not administered correctly, the student may develop an 'adrenal crisis'. This is a life-threatening condition that requires immediate medical attention.

Support mechanisms

Schools are encouraged to explore support mechanisms available to students with CAH. There are a range of resources and community groups available to assist schools, such as the CAH Support Group Australia (www.cahsga.org.au) contactable on (03) 9513 9255, and CLAN (CAH Living As Neighbours) (www.cahclan.org) contactable on (02) 9874 1276. Please contact the Royal Children's Hospital (RCH)

Education Institute or the Department of Endocrinology and Diabetes RCH for further information.

Strategies for schools supporting students with CAH

The implementation of the whole-school and classroom strategies listed below will assist and support students with CAH. While the supports and initiatives aim to build the capacity of schools in recognising the general needs of these students, we also acknowledge that individual needs may vary depending on the severity of the condition.

Whole-school approach

- The school, health professionals, family and student should work in collaboration to best support the student at school.
- Discuss care management plans and emergency protocols with the student/family in a Student Support Group (SSG) meeting to develop clear procedures. These plans and protocols need to be updated regularly as dosages will change as the student grows.
- Keep up-to-date files with the student's emergency contact details, medical history and action plans, ensuring that these are located in an accessible location.
- Consult with the student/family about what information is disclosed to the school and individual parties.
- Provide information and education about CAH to staff and students via communication with the student/family.
- Establish a key contact person with whom the family and student can liaise with regard to CAH and school issues.
- Assign a key contact person who can monitor, explore and assist with stress-related issues.
- Discuss all treatment needs with the student's parent/guardian and offer as directed.
- Involve the student in extracurricular activities.
- **Communicate with parent/guardian and doctors immediately if the student:**
 - Is ill or suffers an injury. His/her hydrocortisone dose will require immediate adjustment.
 - Has a high fever (that is, over 38 degrees centigrade) or stomach upset, severe enough to prevent normal activities at school
 - Has diarrhoea and vomiting. Hydrocortisone (injection) will need to be administered as soon as possible (preferably in less than one hour). It is important to note that students with CAH can become critically unwell very quickly. An unnecessary dose of hydrocortisone is not dangerous, but delaying the dose in a sick student can have serious consequences.
 - Appears shocked (pale, clammy, drowsy or unconscious). This may be a sign that the student is developing an adrenal crisis. Give the student his/her hydrocortisone injection immediately and call an ambulance.

Classroom approach

- Keep an emergency supply of hydrocortisone at school (either in the classroom or in the sick bay/office). Talk to the family regularly about dosage requirements and check that the medicine has not expired.
- Educate the class about CAH in consultation with the student and parents/guardians. This may assist with possible adverse reactions from peers and in building social connections in later school years.
- Ensure that the student receives relevant educational support for any missed work. Attendance should not be an issue other than regular visits to the paediatric endocrinologist or clinic three to four times a year.
- Include the student in special events and activities such as class parties or school productions.
- In consultation with parent/guardian, students with CAH can receive all recommended vaccinations for school-aged students.
- Administer hydrocortisone at times specified by the parent/guardian. This is usually given two to three times a day. Empower students with CAH to foster positive, responsible attitudes to remembering daily doses (for example, going to the office for a hydrocortisone dose when the final lunch bell rings), as they will ultimately be responsible for taking medication throughout their lives.
- Ensure that the student wears his/her medical alert bracelet stating their condition *at all times* so appropriate treatment can be given in an emergency.
- Encourage the student to carry a letter from their specialist, particularly if travelling overseas.

Contacts: RCH Education Institute and Department of Endocrinology and Diabetes RCH

The RCH Education Institute and Department of Endocrinology and Diabetes RCH encourage schools to contact us should they require further information.

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