

Your child is ready for their new school. How to help school get ready for your child.

Things to consider in developing a health care plan to support a child with a disability or chronic disease.

When starting at a new school, many families will organise ways to support their child with all the expected changes in life; managing their new school bag, making friends, opening lunch boxes, how to tie shoe laces, and the ins and outs of playground politics.

But what if your child needs more than that? Managing a child with a disability or a chronic disease requires so much more; communication books, medications, alterations to mobility or different seating plans. For some children, such as those with the rare disease Epidermolysis Bullosa, even the different weather patterns need management strategies put in place, as hot weather can cause spontaneous blistering, or old wounds to become worse.

What do these parents and care givers need to consider when getting their child ready for school?

1. Care plans

Many state/territories in Australia will have a Department of Education 'Health Care Plan' for public schools. This plan is filled out by the school and the family, and may or may not have enough room to outline your child's needs. Extra documentation from your primary treating team is always a good idea as supporting documentation to the main plan.

Topics to cover in this plan could include alterations to any of the following topics:

- Mobility
- Medication
- Excursions
- Alterations to motor skills for learning
- Eating and drinking
- Emergency management
- Contact list
- Attendance Toileting
- Sport
- Wound care
- Medical surveillance and expectations through the year

2. School structure, classes and support already in place

Some schools already have learning support classes, or support classes in place for children with special needs to progress through mainstream classes. Occasionally families choose a school outside of their area as the structures in place may support their child more effectively. Strict school boundaries can be discussed with the principal, as attending a different school may be easier and more cost effective than altering classrooms, walkways, and bathrooms in your local school.

Sometimes these schools also have more funding and ability to have support staff assisting in classrooms as they pool funding from different students for resources.

3. Funding

There are many options to explore when looking for funding to enable your child to participate in school. Options may vary depending on whether your family is accessing a Public/State, Catholic, Independent, or private school. The first place to start would be to ask your school what options of funding they often utilise and what supporting documentation they would like from your care team to support the application they will make.

Each state/territory also has their own funding opportunities that schools and health care workers would be familiar with accessing. Options that the family can explore outside of the school system include seeking support from diagnosis specific, needs specific or community run charities.

Two examples of families that worked with their schools with positive outcomes:

Case 1

Starting a new school

John (name changed) has a rare disease called Epidermolysis Bullosa and is moving from his preschool to his local primary school. The local preschool staff have already worked together with the primary school to let them know about how to cater for John's health condition.

Strategies that John's family have utilised are:

- Additional documentation to support the school health care plan
- Linked other educators to the school for practical advice on ways to support John in the playground and classroom
- Set up an education session at school for staff so that everyone can learn about EB and why John needs the support that he needs
- Creation of an "Introduction letter" for parents and students in John's class so that everyone understands why John wears bandages and does not play the same way as other children
- An Occupational Therapist's assessment of the school, so that a report could be used for funding applications
- Funding application submitted to the Department of Education for classroom support
- Funding application submitted to charities for a wheelchair to enhance John's mobility more effectively around the playground and on excursions

Case 2

Updating education of staff for ongoing support

Josie (name changed) has been at the same preschool for the last 2 years. Initially Josie and her family had put in place a lot of the same strategies that John's family has utilised.

The family were settled and happy at the preschool however, as time passed, they noticed that more incidences relating to her wounds and overall care kept popping up.

After enquiring at the centre, Josie's family learnt that all the staff in Josie's room had been educated on how to support Josie, however, none of the original staff that received the training from the Educator/hospital staff, still worked in the room.

Ongoing education of staff had been passed down from other staff and appears to have diluted over time.

Strategies put in place by Josie's family to support her at preschool are:

- Update the health care plan written for the centre, and the addition of a 'Date of next review' and 'date of next education session by health professional'
- Inclusion of the communication book where Josie's parents could communicate with staff about any changes to health or wound care overnight, and staff could communicate with Josie's parents about health changes during the day

Communication books are common practice in the younger years at day-care but are often phased out in the older years.

Personalise your child's plan

Contact your local lead treating professional or care coordinator when your child is starting or changing schools, or if their care needs change. Many health professionals working with children with chronic illnesses have experience supporting families through these life stages. They will be able to help create a healthcare plan and education strategies specific to your child!

An example of a Health Care Plan that has been designed for children with Epidermolysis Bullosa (EB) is accessible online via the National Epidermolysis Bullosa (EB) Dressing Scheme website www.ebdressings.com.au

The National EB Dressing Scheme is funded by the Australian Government and administered by Independence Australia. The scheme supports people with EB who are most in need by improving access to appropriate dressings and bandages.

For a copy of the EB Day Care and Pre-School Healthcare Plan or EB School Healthcare Plan visit www.ebdressings.com.au/downloads