

# At school with a chronic condition



A study is looking at how families deal with teachers when a student is diagnosed with a serious illness. By Evelyn Bowtell.

Students with chronic health conditions are appearing in our classrooms at all levels with increasing frequency, yet can receive less support than those with disabilities.

In 2002 it was estimated that about 8.3 per cent of Australian adolescents were attending school with some type of health condition that would have an impact on their well being.

The Chronic Illness Alliance defines chronic conditions as: "... illness that is permanent or lasts a long time. It may get slowly worse over time. It may lead to death, or it may finally go away. It may cause permanent changes to the body. It will certainly affect the person's quality of life."

A chronic condition could be life-threatening such as cancer, life-limiting but temporary like a badly smashed knee requiring treatment over months, or it may be a life-long invisible condition such as diabetes or cystic fibrosis. The ongoing management of chronic health conditions in young people needs to include the management of what can be seen as normal life goals such as education participation. Such management needs to be shared by doctors, educators and parents.

The Royal Children's Hospital (RCH), Centre for Adolescent Health is conducting a qualitative study exploring the interface between the health and education sectors and focused on young people with chronic illness in the final years of secondary education.

In this PhD study parents who have a young person living with a chronic condition in the final years of secondary education were invited to participate via in depth interview. The conditions included in the study were: cystic fibrosis (CF) an invisible condition that is life-long and usually diagnosed within the first year of life, cancer (CAN) a condition well-recognised by the community, and anorexia nervosa (AN) a mental health condition with clear physical impact.

Staff members in both the education and health sectors were also invited to share their perceptions and experiences of seeking or providing support for these young people. Of interest has been the comparative information across the three conditions and what this means for provision of support for students with chronic health conditions. Preliminary analysis is raising some key themes that are discussed below; two aspects of the

preliminary findings that potentially affect the support of young people with chronic conditions in education. First, we examine the pathway that parents undertake when deciding whether to tell their child's school of a diagnosis; secondly, we explore the communication pathways that parents find either useful or detrimental to achieving appropriate support for their child.

## To tell, or not to tell?

Preliminary results indicate that parents engage in ongoing decision-making about whether to tell schools of a diagnosis, what to say and who to engage in this dialogue. Parents whose child has been ill for a length of time have become experts at this decision-making and are admirable advocates for their child across both sectors. These parents have developed a system of telling school staff and of co-ordinating care for their child across the interface.

Significantly, parents whose child's diagnosis of AN was recent (within 12 months of the interview) were less likely to inform the school of this diagnosis – even when a staff member asked directly. Parents' reasons for not telling schools of a diagnosis included: the belief that schools are not confidential places; the child asked parents not to tell ("She was absolutely mortified to involve [the] school"); feelings of shame and the fear of being blamed for their child's diagnosis; and not believing that the school had a useful role in providing support for their child.

However, some families of young people with AN felt the school "needed to know" and sometimes elected to inform the school secretly asking that the staff collude in the secrecy, therefore making school-based supports difficult to enact. Parents of young people with CF noted a change in their child's desire for privacy once high school had begun ("She didn't want to be known as the CF kid"). These parents respected their child's view but still openly informed the school.

Parents whose child had a diagnosis of cancer described a very different experience with their child's educators.

These parents did not question the need to inform the school and did so almost immediately after diagnosis. These families reported a wealth of different supports provided by school communities that included academic, social and proactive planning over the Victorian Certificate of Education years ("The school, they just couldn't do enough for us"). Families who had a child diagnosed with cancer found that the wider community, including the school recognised that support in a variety of areas would be needed, and acted upon this immediately.

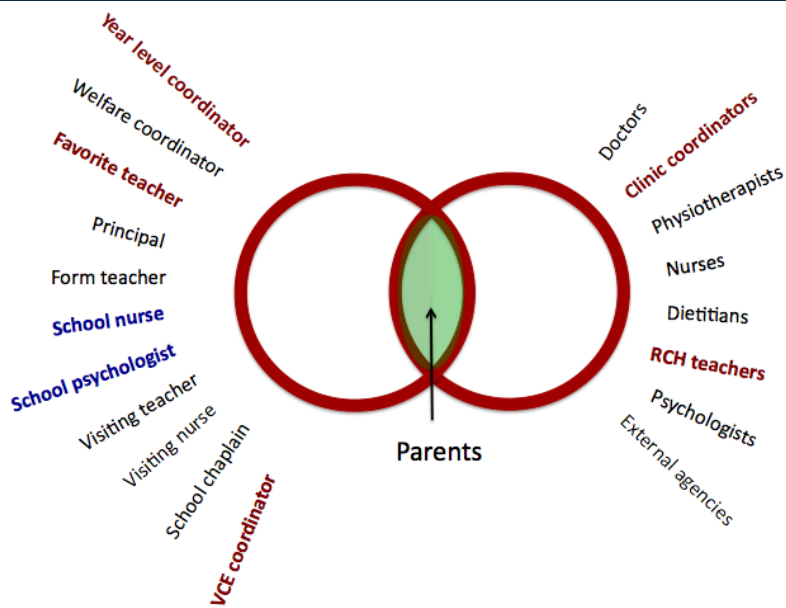
The tension between a perception of a lack of privacy and of requiring staff to pass on information is of interest as it directly affects how we handle documentation and word-of-mouth communication in schools.

## Communication pathways, conduits and processes

If we use the term "interface" and apply the dictionary definition of an interface (to meet or communicate directly; interact, co-ordinate, synchronise, or harmonise), we could suggest that the two communications systems, health and education, are able to interface with each other. However, parents seem to be the conduits between the two sectors when a child with a chronic health condition is involved.

In figure one, the parent is positioned between the two sectors operating as the "link in the chain". The red coloured titles are those referred to most often by participant parents as staff members that were contacted by the parents in seeking support for their young person.

The blue coloured roles, school nurse and school psychologist were rarely mentioned by parents or by health professionals in our study, despite the fact that these roles are filled by staff who have health training and must follow legal guidelines in managing health information, therefore fulfilling the often cited concern of young people in schools about confidentiality. Of course not all schools have registered nurses or the use of



Above: The interface between the education and health sectors in Victoria, 2011.

a psychologist on staff.

Parents' who indicated that they were happy with their school contact system had often created their own procedure, by finding a staff member who they could trust with their child's information. It was apparent that it was the staff member's personal qualities that appealed to the parent and usually the student as well. These were: taking an interest in the child, the family and the disease; being available; following through; and proactively seeking to know

how the treatment or situation was progressing.

This staff member then became a conduit for information and communication between the parent and the school. "There are those teachers who have a nurture factor and the understanding and then there are those that are just strictly business."

Key informants in the education sector described in interviews the expected pathways of communication for parents to pass information to

teachers. Yet, parents found these pathways difficult to navigate alone, complicated and less than helpful when they attempted to use them regularly.

Figure one also illustrates the multi-disciplinary nature of health teams who work with young people who have a chronic health condition, as well as the multi-disciplinary nature of education teams operating in high schools. Some staff members in the health sector were regularly mentioned by parents as being able to cross the interface and assist them in obtaining supports in school or academic work or even in advocating for the student who is also a patient. These staff members were clinic co-ordinators ("those people are gold") and the RCH education team was particularly helpful in acquiring academic work from patients' schools and supporting documentation such as student health plans.

### Next steps

This study is due for completion in mid-2012. In coming months, attention will be focused on how the interface between the education and health sectors operates and the roles

of parents and key staff members at the intersect.

The preliminary findings reported here suggest that to usefully support students with chronic health conditions the following is important: communication between the health and education sectors, the confidentiality of student health information and clear pathways that respect this but simultaneously enable teachers, including emergency teachers, to understand individual students' needs.

The importance of the student health plan and why these plans are not more widely used should be explored. It is important that we consider a process that can be engaged in by all schools so that children and young people can be assured that they receive a level playing field in their care and education. ▢

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