

SUPPORTING CHRONICALLY ILL CHILDREN IN SCHOOLS

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Around two per cent of the childhood population endure repeated and chronic bouts of illness (Ashton & Bailey 2004). This includes conditions such as severe allergies, asthma, epilepsy, arthritis, diabetes, meningitis, kidney, liver or heart disease, illnesses such as AIDS and cancer (Shiu 2001, 2004) and, increasingly, health complaints associated with obesity, which will disproportionately affect economically disadvantaged students.

Chronic illness has a well-documented effect on young people's school performance (Boyle et al. 2007), increasing the risk of grade retention or dropping out of school (Cunningham & Wodrich 2006). In contrast, returning to school after a relapse or prolonged illness symbolises normality and hope for the future (Worchel-Prevatt et al. 1998). Achieving this transition can entail:

- collaborating with the convalescing student and his or her parents to organise a schedule for the student's return;
- gaining the information you need to manage the illness and to understand the student's emotional reactions to it;
- establishing ongoing liaison with the parents and medical personnel;
- assessing the school environment ahead of time to assess architectural or other constraints to mobility so these can be attended to before the student returns to school;
- arranging for a tutor or other means to assist the student to catch up academically;
- preparing peers for changes in their classmate (Worchel-Prevatt et al. 1998).

Illness management

Teachers' own self-efficacy and duty of care to chronically ill children require that you understand the nature of individual students' illness and its implications for their education (Ashton & Bailey 2004). Incomplete information can result in unrealistic expectations for students, inadequate educational adjustments, or over- or under-protectiveness by educators (Ashton & Bailey 2004; Cunningham & Wodrich 2006). Therefore, your first task will be to learn from parents and, with their consent, medical personnel about individual students' condition and its ramifications for their learning. You will also need to gain an understanding of the expected course of the illness over time.

In terms of their health care, you will need to know what monitoring ill students may require, how to deal with any medical emergencies, what

restrictions the illness may place on their activities, what medication or dietary regimes they need to observe, and which educational tasks will need adjusting to accommodate their condition. Any medication and dietary regimes will need to be integrated unobtrusively into the children's daily routines, ensuring that these are followed strictly without making a spectacle of the students in front of their peers. So that the adults know which procedures to follow, it will be important to prepare all staff and classmates for the possibility of a health crisis in an ill student, to have at least one staff member with specialised first aid training, and to have on file the contact details for emergency medical personnel.

Environmental adjustments

Health impairments often weaken the body's immunological system, making children susceptible to other illnesses. Therefore, control of contagious diseases can be crucial. When students' illnesses have produced physical limitations, adaptations to equipment may be necessary to ensure their access to activities (Shiu 2004).

Curricular adjustments

With the exception of AIDS, most chronic childhood illnesses do not have a direct permanent effect on the brain's capacity to learn, although fatigue and many conditions such as low blood sugar levels (e.g. associated with Type 1 diabetes mellitus) can temporarily impair students' cognitive functioning for the duration of the episode (Cunningham & Wodrich 2006). Some medical treatments such as radiotherapy or chemotherapy can themselves cause disabilities and subtle attention, sequencing, memory and sensory integration difficulties, particularly in younger children (Shiu 2001). In addition, children who are unwell produce higher levels of the stress-related hormone, cortisol (Watamura et al. 2003). This can lead to stress reactions when they are exhausted or feel that the demands of their day exceed their capacity to cope.

Many are anxious about their ability to catch up and keep up with their work and will need a planned program for doing so (Bessell 2001; Worchel-Prevatt et al. 1998). Although you might be able to send home some learning activities during their absence, the illness can impair their ability to complete these. Once they return to school, while extra tutoring may be needed, they can still lack the energy during convalescence to add this into their day.

Upon their return, routine procedures will need adjusting – for example, to allow a classmate to accompany a student to the school office during a health crisis, or to recognise that some students will need to leave the classroom without seeking permission, so that they can attend to urgent physical care needs (Kliebenstein & Broome 2000).

Prohibitions on students' activities in an effort to keep them safe from further injury or infection not only limit their ability to learn, but also affect their self-esteem (Ashton & Bailey 2004). Therefore, encourage students to be as independent as possible and do not restrict them unless a particular activity poses a clear danger. It is important that, as far as possible, school provides a venue for them to be 'normal' and, therefore, does not emphasise their additional needs (Bessell 2001).

Emotional support

Children's misunderstandings of their condition and its treatment, their early encounters with pain and perhaps even the prospect of death can lead to anxieties and fears that surpass those of healthy children (McCarthy 1987). Unwell children may be fearful about the future and be stressed not only from their illness and its treatment but because of the observable strain on their family members. Many children will adapt to the demands of their illness and its management, whereas those with emotional difficulties may resist the imposition of routines for its management, placing them at risk for treatment non-compliance that compromises both their health status and school inclusion (Cunningham & Wodrich 2006).

Some, therefore, can benefit from opportunities to talk about their experiences. So that you do not confuse them or undermine their parents, you will need to prepare for these inevitable discussions by discovering from parents what their children have been told about their condition and what the parents would like you to say, particularly with respect to terminal illnesses (McCarthy 1987).

Social inclusion

Children's repeated absences are likely to interrupt and disrupt their peer relationships (Shiu 2001). Half of all chronically unwell children experience social dislocation, may feel very different from their peers, and suffer anxiety about their inclusion on their return to school after prolonged absences (Bessell 2001; Shiu 2004). They can fear teasing by classmates at changes in their appearance (Worchel-Prevatt et al. 1998). To prevent social anxieties, you might be able to coordinate a roster of home visits by some of their classmates during their absences so that they do not feel like outsiders when they return.

On their return, peers might need information about the reason for their absence, changed appearance or atypical needs (McCarthy 1987; Tyler & Colson 1994). On the other hand, unwell students might not want this information disclosed so that they can be treated as people rather than as patients (Shiu 2001).

Not only are unwell children's relationships with peers interrupted, but so too are their contacts with their teachers. As well as sending work home, teachers can ensure ongoing contact by making personal phone calls or emailing students during their absences. Children's relationships with adults can also be distorted by their experience of relating with medical personnel, which can cause them to direct their social interactions to adults rather than peers. Moreover, the requirements of their management can increase children's dependency on adults. To offset this tendency, you might have to assist their peer engagement. It will also be important not to make undue allowances for their behaviours, lest their peers interpret this as unfair favouritism and reject them (Norris & Closs 1999).

Support for parents

At the time of initial diagnosis, particularly of a potentially life-threatening illness, parents will be in shock, accompanied by fear and a sense of

powerlessness. During their child's chronic illness and treatment, mothers in particular are likely to have their working lives disrupted (Ashton 2004; Vickers et al. 2004). Your understanding of the competing and often overwhelming demands on them may be a considerable help (Vickers et al. 2004). The family's physical, social, emotional and financial resources may be stretched during their child's prolonged illness (Dockett 2004) – particularly if other members of the family are also ill (as with AIDS), or when the child's condition is uncertain or life-threatening (Bruder 1995).

Parents have to advocate for their child's needs. Even if their concerns seem excessive or parents seem to be too protective, trust them. Helicopter parents hover over their children not because they want to, but because they have a genuine reason to be concerned. Parents are the ones who have to live with the risk, and therefore they are the ones who have to determine how to minimise it (Sanagavarapu 2004).

Communication

Communication across the school will be necessary to support classroom teachers and those on duty at recess to be fully informed about courses of action to be taken in the event of a health incident. This communication also reduces the burden on parents to inform each and every staff member who may come into contact with their child, and reduces their anxiety about the care available for their child (Kliebenstein & Broome 2000; Norris & Closs 1999). To reduce the burden on parents of information dissemination, it will be useful to appoint a single influential person within the school who can transmit information from parents to the wider staff team.

Support for staff

Particularly when students are left with permanent disabilities or are dying, you will have to look after yourself so that you can channel your grief into making their lives at school as normal and productive as possible.

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