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# Young People with health problems - their views on how schools can help

The Government has identified school as a key setting for reducing health inequalities, but pupils with medical needs are not always supported as well as they would like. Current policies promoting inclusive education means that more children with disabilities and health problems are being educated within mainstream schools. What can teachers do to help such children cope with their condition in order to minimise any impact on their education?

Listening to children and young people who have had experience of a long term health condition can give some clues. This article describes three evidence-based examples of pupils with illness and disability in mainstream school. Their views are discussed in relation to ways in which schools and teachers can contribute to reducing health inequalities. The three examples are:

- Pupils with disabilities in mainstream schools
- School children's perceived sources of asthma support
- Website of young people talking about their experiences of cancers

### Pupils with disabilities in mainstream schools

A study of 33 children with illnesses and/or disabilities being educated within mainstream secondary schools was carried out as part of a wider research study to assess the impact on school life (Lightfoot, Wright and Sloper, 1999). Interviews carried out with the children showed that, although they had a wide variety of conditions, they had common concerns. One of the most important was absence from school, which could be due to illness, treatment or medical appointments. They were keen to keep absence to a minimum, as pointed out by a 12 year old girl:

"I miss enough of it when I'm really poorly and I just enjoy it when I'm there. So if I've got a bit of headache I don't tell anybody.... I have off days but I don't really want to come home."

Many expressed their appreciation of teachers who had helped them to keep up with their education. A variety of ways were highlighted such as sending work home, giving extra work following absence, and having time to explain parts of the curriculum they didn't understand on return to class.

Mobility problems were a cause of concern to many pupils, for example being excessively tired, or in fear of being knocked over. They felt that teachers could help by being flexible, for example, by allowing the pupil to leave class early in order to safely move around school. The vast majority found PE to be problematic, and a third didn't join in at all. If not taking part pupils liked to be given a constructive alternative activity, such as catching up with work, and were grateful to teachers who allowed them to have a friend with them. They wanted to make their own decision about whether or not to join in a particular session, and were unhappy if they felt they were pushed beyond their capabilities, as illustrated by the following quote by a 14 year old girl with a heart and lung condition:

"He had me running round the field. He had me walking, jogging, running and I said, 'Sir I can't do this, I'm going to be sick.....' 'the teachers know but they don't seem to care....'"

Bullying due to being different was highlighted by over a third, and pupils adopted a variety of coping strategies such as: ignoring, retaliating, or avoiding (staying off school, not wearing glasses or splints in school). They felt teachers could help by intervening in bullying situations, but this didn't always happen, as exemplified here by a 14 year old girl:

"I get picked on, pick, pick, pick, pick and I get called the horriblest names and when I go off crying people go and tell (the deputy head) she doesn't do anything at all. I can't really do anything."

Nearly all the pupils felt they had supportive relationships with individual teachers, usually the Special Educational Needs Teachers. Simple kindnesses, such as acknowledging a pupil's return from absence, or asking how they were feeling, were much appreciated. However, teachers in the same school could have very different approaches, some which appeared to lack any awareness of how the pupil was coping with life at school. For example, a quote from a 16 year old boy:

"The more people who know the less mistakes are made.... Ignorance is the root of all the problems I've had, it's people with a lack of knowledge that have made it difficult."

Knowledge of individual needs was

important, for example allowing those with continence problems to access the toilet as required. Essentially, pupils wanted teachers to understand enough about the condition so that appropriate arrangements could be made, "without making fuss".

### School children's perceived sources of asthma support

As the most common chronic condition of childhood, asthma provides a suitable model of how schools can support pupils in managing a long-term health problem. The impact on school life for those whose asthma is poorly controlled has been shown, for example in a survey of over 4,000 children from the charity, National Asthma Campaign (NAC, now called Asthma UK). This indicated that around one third missed a week or more of school per year, and a similar proportion missed out on sports lessons (NAC, 1999)

Asthma can, for the vast majority, be effectively controlled with appropriate inhalers. There are national guidelines for treatment, asthma clinics at GP practices, and good patient support information from Asthma UK. Despite this, some asthmatic children do not access the care they need. What can schools and teachers do to reduce this health inequality? Asthma UK has recently updated its model school asthma policy, in which basic training for all school staff is advocated ([www.asthma.org.uk](http://www.asthma.org.uk)). But, what are the views of pupils? What do they think would help them cope better with their asthma?

Several questions on asthma at school were included as part of a survey of asthmatic children aged 4-17 years, carried out in two contrasting GP populations (Gleeson C, 2005) within the same Primary Care Trust area (PCT). One practice, P1 had a long-standing asthma clinic, the other, P2 did not. A structured questionnaire was completed by 124 from P1 and 107 from P2. In response to the question "If an asthma problem occurred at school who would you ask for help?", the vast majority said they would ask a teacher, but they also felt that teachers needed more information. Respondents identified other staff, including dinner ladies, secretaries and school nurses. Although two thirds had mentioned the school nurse, few were able to say when she was available to them, and some inadvertently named other members staff

(such as secretary, lunchtime supervisor, form tutor) as a school nurse.

Children in P2 reported symptoms at a similar level to those published nationally (NAC, 1999 and 2001), whereas children who had access to the asthma clinic in P1 had less symptoms. They were asked if they would like an asthma nurse to visit their school for review and information, and over half said they would, but a few (less than 20%) would not. When asked what sources they used for asthma information, responses included parents / family, nurses, doctors and leaflets. Very few had used videos or the internet. Children at the two GP practices attended a wide variety of schools, 37 in all.

### Website of young people's experience of cancers

In contrast to asthma, children may become ill with rare but serious conditions such as cancers, and they and their families may feel very isolated. This is where a new website, called [www.youthhealth.org](http://www.youthhealth.org) can help. A charity, called DIPEX, recently added this young person's site to its adult modules which give personal accounts of health problems and illness. A major strength of DIPEX is that the patient experiences are supplemented by evidence-based information about the illnesses (which is not always the case with medical internet sites). DIPEX thus acts as a reliable resource for families, health professionals and others, such as teachers and social workers who may be supporting a young person over time.

The website, [www.youthhealth.org](http://www.youthhealth.org), has video clips and quotes from young people who have been diagnosed with cancer. They describe their feelings about their illness and treatment, including how it affects school life. These descriptions can be hugely helpful to other young people and their families who are going through similar illnesses. They can also provide insight for teachers if they have a young person with cancer in their class. A selection of aspects of school life described by contributors to the site is given below.

The experience of cancer made some determined to make the most of their education, for example:

"Now I know I'm able to do anything I want as long as I work for it."

School absence for a year or more is common for teenagers with cancer, so some disruption to their education is inevitable. Getting back to school was important as it made them feel less isolated and more 'normal', for example:

"She was determined to do well in her GCSEs and found that both schoolwork and art took her mind off her illness."

Despite wanting to do well, some found their school work difficult due to tiredness, lack of concentration or illness during treatment. At times some felt like 'giving up'. Ways in which teachers had helped included being flexible about allowing the pupil to go

home if tired, sending work home, giving extra lesson to catch up on return from absence, and being given extra time during exams.

Most found their teachers to be very supportive, but unfortunately not all experiences were positive. For example, one school had presumed that a young man's absence (due to being in hospital for several months) was due to truancy, and his family received a visit from a welfare officer. Bullying was another aspect in which schools sometimes failed to support the pupil:

"...said she was bullied at school but the headteacher denied it."

Following their cancer experience some young people changed career plans as they wanted to help others, in various capacities, such as in the health professions, in dance therapy, or with cancer charities. A few decided not to return to school at all.

### Conclusion

The three examples are from pupils with widely differing health problems. But regardless of seriousness to health, they illustrate common concerns, and common ways in which pupils feel teachers can help. Two main aspects stand out, firstly that they want to participate in school life, and secondly, that some can feel very isolated. A key factor in feeling supported was the individual teacher's knowledge of the individual pupil.

How can teachers be adequately informed so that they can support pupils with medical needs? Written information about their condition is helpful, particularly in specifying what a pupil can do (rather than only what they can't). Confidentiality is a prominent concern of young people, and Lightfoot et al, (1999) found that pupils did not have a consensus view of who should know about their condition, so an individual approach is required.

For long-term conditions like asthma, the National Service Framework gives practical guidance, using scenarios to illustrate how schools and health professionals can work in partnership to meet health needs (Department of Health, (2004a, 2004b). There is also a Model School Asthma Policy, developed by Asthma UK which can be tailored to each school's needs (Asthma UK, March 2006). Implementation of this means that, as a minimum, children should have access to inhalers, avoidable triggers are removed from school, and school staff know what to do if a child has an asthma attack.

The guidance documents highlight a key role for school nurses in several ways: participating in setting up a school health policy (including asthma); providing a link with GP practices; ensuring that school staff are trained and updated; supporting individual pupils - for example with written information, and being regularly available at school drop-ins. As a scarce workforce, the knowledge and skills of school nurses need

to be utilised as effectively as possible. Linking with GP practices is an area that needs improvement so that consistent messages are given across the whole care pathway (Richardson-Todd, 2002). The current Government policies of widening parental choice in education makes this role more challenging, with children attending schools outside local pyramids (as seen in the participants of the asthma survey, Gleeson, 2005).

For asthma, and other long-term conditions, the main aim is to empower the child (and family) to manage their condition, to know how to deal with deterioration and when to seek medical help. The internet is a resource which is currently under-used for patient education - this is perhaps where the school librarian or SENCOs could direct pupils to appropriate sites. The annual surveys of Health Related Behaviour have consistently shown that a proportion (around 10-20%) of pupils feel they have no one to talk to for health or related concerns (Balding, 2005). Accessing evidence-based, reliable internet sites can reduce feelings of being alone with their worries, as is poignantly illustrated on the [youthhealthtalk.org](http://youthhealthtalk.org) site.

At the launch of [www.youthhealth.org](http://www.youthhealth.org) it was inspiring to hear a presentation by a young lady who had recovered from cancer as a teenager. She described how, during the treatment stages of her illness, she had felt unable to express her isolation and anxieties with her family or hospital staff, but would have loved to access this kind of website.

Another speaker at the launch was the author Philip Pullman. He talked about the power of stories, saying that people's descriptions of personal experiences represented a kind of human democracy. Being able to hear what the person is going through at a time of fear and uncertainty helps others feel less alone with their illness.

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