

## Children at school with a life limiting or life threatening illness: guidance for healthcare professionals

School is about so much more than just an education, it is also a place where children and young people make friends, learn about life and hopefully feel valued as an individual. This information sheet discusses ways in which healthcare professionals can ensure that these opportunities are also provided for children and young people with a life limiting or life threatening illness (LLTI) .

### Continuing to attend whenever possible is important

For children and young people (CYP) maintaining school attendance can be crucial to their overall well-being, especially when survival to adulthood is unlikely. School offers normality and a chance to be just like everyone else. It is a welcome refuge from the world of hospitals and illness. Facilitating and supporting school attendance and involvement must therefore be viewed as an essential part of the role of any healthcare professional (HCP).

When a CYP with LLTI is starting school, moving to a new school or returning to school after a period of absence, it is essential that the HCPs work with the school and family to ensure safe and successful integration. School staff may be anxious about taking on the responsibility of supporting a pupil with complex health needs. For this reason, identifying the pupils day-to-day care needs, and anticipating and managing potential risks are key factors to ensuring success.

It will help if the HCP can arrange a school visit as early as possible to discuss a pupil's health needs. The pupil and family should be given the opportunity to attend and contribute.

### Sharing information with schools

Sharing health information with school is essential to ensure the safety and meet health needs of the CYP. Understandably, there will be occasions when the child or family may not want this to happen. A sensitive explanation from a HCP as to why sharing information is helpful may change their views. The HCP can reassure the family that not everyone needs to know everything and a discussion held with the family and the CYP as to what is shared, and how widely, may help. CYP like to be involved in decisions that affect them at school and should be aware which staff members have information about them and what information they have been given.

Staff may be anxious that a pupil will die while at school. Although the family will understandably find it hard to talk about this, it will help if the HCP can have a conversation with the family and the school in order to get a realistic perspective on how likely this is to happen. The HCP will then need to assist staff to put plans in place. Involving the family when making any plans will make certain that their wishes are taken into account.

### Informing other students

The school, together with the family and CYP, need to decide how much information is shared and with whom. It is a balance between recognising a CYP's need for privacy and the reality being that most peers will have already have some idea that something is wrong. Finding out more about a fellow pupil's illness can provide students with an opportunity to be supportive, and has the added bonus of helping to dispel any myths, rumours and untruths that may be circulating.

Not all families want the wider community to be aware of their child's illness but doing so can result in the same benefits as informing other pupils. The situation may bring to the surface difficult feelings for other families who therefore come across as not very understanding. They may need sensitive support to alleviate any fears or misplaced perceptions.

### **Individual healthcare plans**

Schools will already have protocols for supporting pupils with health needs. In addition, a pupil who has a LLLTI will require an individual plan, written jointly by family, pupil, school and HCP. It must be reviewed regularly as needs will change.

It should address;

- Transport. If a pupil needs care during travel, arrangements need to be made for this
- Activities that require extra support such as moving between classrooms, or eating, or personal hygiene. A member of the school staff should coordinate this although some support may be provided by fellow pupils if appropriate
- Purchase and restocking of any extra equipment, e.g. oxygen storage. Arrangements for maintenance of this equipment needs to be clear and the person(s) responsible identified
- Routine medical needs, including administration of and secure storage for any medication. HCPs should provide school staff with written guidelines for this and training to ensure responsibilities are clear
- Emergency situations. Members of staff need to be trained to ensure they know what to do and how to do it. Guidelines for calling emergency services and giving medication must be available. The CYPs resuscitation status must be clearly documented with plans for implementation at the school
- A name and contact number of an appropriate HCP, or team, for school to liaise with regarding any health concerns in school.

### **Legal requirements**

HCPs should be familiar with the legal regulations, particularly around the education of CYPs with complex healthcare requirements. In England, most are likely to meet the definition of disability, so schools are obliged to make reasonable adjustments to ensure that their pupils' needs are met. Plans must aim to allow full access to the curriculum, including any play or social activities. The school should identify any concerns with regard to the CYP accessing all levels of the curriculum and the HCP can help the school identify reasonable solutions.

### **The Curriculum**

HCPs should try to ensure special considerations are given to the timetable. If the CYP is unlikely to complete full days, or weeks, in consultation with the school, the timetable will need to be adapted. To provide as rich an experience as possible for the CYP, the focus may not need to be on academic learning. Leaving a lesson early to attend to care needs may be preferable rather than missing out on social interaction at break times.

### **Emotional support**

Most CYPs with a LLLTI want to fit in with their peer group without being identified as different, yet will need allowances made for some aspects of school life. HCPs can assist school to make appropriate adjustments e.g. longer time to complete homework or being allowed to leave classroom early without having to explain why. The school must ensure that all staff are aware of these allowances.

Any siblings attending school will need consideration. They will be coping with their own emotions, a disrupted life and possibly fielding questions about their brother or sister. If the school has a counselling service, the HCP should remind the siblings this is available should they wish to use it.

### **When death is close**

When approaching death, many CYPs are anxious to complete coursework or important projects. Teaching staff need to be aware and, where possible, make arrangements to facilitate this as well as being encouraged to mark work early and return promptly.

Even when too ill to attend school and unlikely to return, continued inclusion in school life may still be very welcome. Home visits from staff and/or pupils can give structure to the day and help give a sense of purpose. If visits are not possible, letters, cards, texts and e mails may be welcomed. While staff may be apprehensive of intruding, families often feel that contact from school indicates that their child is still a valued member of the school community. The HCP can liaise with the CYP and their family with regard to what ongoing contact, if any, they would like from staff and friends. Families vary, some really value the continuing relationship with school but others do not.

### **Support for school staff**

Support for staff is essential and HCPs should assist the school to identify resources for this. Anxieties often stem from fear of saying or doing the wrong thing and the emotional burden of caring for a student who is likely to die. Staff will value support from an HCP and regular opportunities for groups or individuals to voice concerns or share feelings will help. HCPs can also remind staff that they can contact Child Bereavement UK 01494 568900 for support and guidance.

### **Summary**

In schools, HCPs can help set a positive attitude with the focus on living rather than dying by acknowledging the vital role of a school in the life of a CYP, however ill they are, and the role of the CYP in the life of the school. Schools and the resources at their disposal vary enormously. All are under pressure to meet targets and cope with constant change. A pupil with LLLTI will add to this and the school response may not always be as accommodating as a HCP would like. However, with sensitive support, timely explanation, and most of all practical help, the majority of schools will respond with compassion and humanity. Indeed, many will go far beyond what is being asked.

For further guidance call the CBUK Support and Information Line 01494 568900 or visit [www.childbereavementuk.org](http://www.childbereavementuk.org).

### **Resources**

#### **Child Bereavement UK Schools Information Pack**

A series of 22 fact sheets offering guidance, information and details of relevant resources. Topics covered include: Pupils with a Life Threatening Illness, When a Family Member is Terminally Ill and Age Related Booklists. Only available from Child Bereavement UK. Cost £10.00 <http://www.childbereavementuk.org/shop>

#### **Child Bereavement UK Information Sheets:**

When A Sibling Is Terminally Ill: supporting children

[www.childbereavement.org.uk/Portals/0/Support%20and%20Information/When%20a%20sibling%20is%20terminally%20ill%20%20JA%20format.pdf](http://www.childbereavement.org.uk/Portals/0/Support%20and%20Information/When%20a%20sibling%20is%20terminally%20ill%20%20JA%20format.pdf)

A Guide For Parents of Terminally Ill Children

[www.childbereavement.org.uk/Portals/0/Support%20and%20Information/Guide%20for%20Parents%20Terminally%20Ill%20Children%20%20JA%20format.pdf](http://www.childbereavement.org.uk/Portals/0/Support%20and%20Information/Guide%20for%20Parents%20Terminally%20Ill%20Children%20%20JA%20format.pdf)

#### **CLIC Sargent. [www.clicsargent.org.uk](http://www.clicsargent.org.uk)**

Returning to School: Primary school children with cancer

Talking to primary school children about cancer

**Supporting children with medical needs in school.** Department of Health (DoH) and Department for Education and Skills (DfES). Circular 14/96. London:DoH/DfES 1996

**Supporting children with medical needs – a good practice guide.** Department of Health (DoH) and Department for Education and Skills (DfES). London: DoH/DfES 1996

**Winston's Wish** Various resources and support [www.winstonswish.org.uk](http://www.winstonswish.org.uk)

**Together for Short Lives.** The UK Children's Palliative Care organisation. [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)

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