

Special report

Facts for teachers of children with cancer

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SUMMARY As the prospects of cure for children with cancer increase, the long term consequences of treatment and the quality of life experienced by survivors assume greater importance. Strategies to encourage early return to school after diagnosis are of considerable importance both educationally and socially, but teachers require information to help them facilitate the child's return. The extent to which professional contact is fostered between children's cancer centres and the education service is the subject of this short survey.

The prospects of cure for children with cancer are steadily improving. Approximately 1200–1400 children are diagnosed with cancer each year in the United Kingdom¹ yet almost 60% of children treated at institutions affiliated to the United Kingdom Children's Cancer Study Group (UKCCSG) are alive five years from diagnosis² and most of these will be long term survivors. Median survival, even among children who ultimately die of their disease, has been prolonged by modern multimodal treatment.³ These improving results bring with them concerns about the quality of life achieved by children with cancer, both during and after treatment, and physical, psychological, and social consequences are now being described in long term survivors.⁴ The consequences vary, depending on the type of malignancy, the treatment used, and the age of the child at diagnosis.

Whether a child's cancer is diagnosed before or during school life, attending school provides a common experience. School provides organisation in children's lives. It develops the child intellectually, physically and, through social contact, it encourages emotional maturity. Early return to school provides a return towards normality for the child with cancer and the effects of school absenteeism are reported by long term survivors to be among the most important consequences of having had cancer.⁵ High rates of absenteeism found among children with cancer are only partly explained by clinic visits, hospitalisation, or acute illness and previous studies have shown that the child encounters many difficulties in returning to school after diagnosis.^{6,7} Anxieties and embarrassment arising from their illness, together with the frequent development of a dependent,

protective relationship between parent and child,⁸ may reinforce absence from school.

Attempts to modify school attendance patterns have focused on school staff and surveys have shown that teachers need more information about childhood cancer and its specific implications for schooling.⁹ In our own unit, which serves as the paediatric oncology centre for the West Midlands health region, a leaflet written specifically for teachers (and parents), addressing some of the issues involved in returning the child to school, is used as the principle way of providing appropriate information for schools. This is sent, with parental consent, to the schools of all newly diagnosed children, by the hospital school, which provides a point of professional contact to which a child's teacher can refer, in addition to contact with the medical staff. The information contained provides an overview of cancer in children, a perspective on prognosis with modern treatment, and a discussion of the potential hazards of contact with infectious disease. It addresses the anxieties experienced by children on their return to school, with suggestions for helping reintegration and discusses the appropriate use of the home teaching service. The leaflet appears to be well received. We recently wrote to all paediatric oncology centres in the United Kingdom requesting information about their contact with schools in order to assess the pattern of school liaison available for children with cancer in this country.

Methods

In order to assess current strategies for liaising with the schools of children with cancer, we wrote to the

other 18 regional paediatric oncology centres in the United Kingdom asking them what contact they had with teachers and for copies of any written information they provided for schools. We analysed the contents of the documents and other services provided by centres for teachers and schools.

Results

Replies were received from 13 (72%) of the 18 centres contacted. Analysis indicated that the information provided fell into three main categories and the data included information from all the centres which responded, including our own.

GENERAL INFORMATION LEAFLETS

Six (43%) centres sent schools copies of information pamphlets written for families—such as those issued by the Leukaemia Research Fund—but did not have any specific information for distribution to teachers. One centre sent copies of booklets written for children themselves, which explained the disease, its treatment, and common emotional problems in general terms suitable for younger children. All centres emphasised the need for personal contact with teachers.

MEETINGS WITH TEACHERS

One centre held meetings with teachers of newly diagnosed children on a regular basis.

SPECIFIC INFORMATION FOR SCHOOLS

Five (36%) centres, including our own, used leaflets, written locally but specifically designed for teachers. The information they contained included the following points (number in square brackets refers to the number of booklets referring to each point):

(1) *Overview of childhood cancer*: it was noted that (a) cancer in children is relatively uncommon but chances of survival are improving with modern treatment [4]; and (b) cancer is not infectious and affected children pose no health risk to their classmates [5]; (c) the types of treatment used (for example, chemotherapy, radiotherapy) and the more obvious possible side effects (for example, hair loss, change in weight) were explained [5].

(2) *Infection risks and medical problems at school*: there was (a) emphasis on the importance of measles and chicken pox contacts [5]; (b) emphasis on the small risk of medical problems arising at school [1]; and (c) advice on the management of fever and bruising [1].

(3) *Children's knowledge of their disease*: it was

explained that children know the nature of their disease and that their questions should be answered honestly in an age appropriate way [2].

(4) *School attendance*: (a) it was explained that absence for medical reasons may be unavoidable at times but that the child's or parent's anxieties may reinforce absenteeism at other times [5]; and (b) that an early return to school is important to the psychological well being of the child [5].

(5) *Academic performance*: (a) it was emphasised that it was important to maximise the child's potential and that inappropriately reduced expectation is a common finding among both parents and teachers [5]; (b) the provisions for schooling in hospital and at home were explained [3]; and (c) an invitation for teachers to contact the oncology department to discuss details of the child's school performance was made [3].

(6) *Other points made were*: (a) advice to teachers in explaining the illness to the child's peers at school [3]; (b) an explanation that the patient's siblings may also experience emotional difficulties and that their teachers should also be informed [2]; and (c) a discussion of death and dying [1].

Discussion

Teachers faced with the diagnosis of cancer in one of their pupils have to confront several problems. First, on an emotional level, they may greet the news with the same mixture of emotions as do the family or the child's close friends. Second, they encounter rational anxieties which relate to their lack of knowledge about the situation. The child or his classmates may ask questions for which they are unprepared or they are unwilling to answer, raising concerns about how much the child has been told of his disease and prognosis. They may be concerned that the child could become seriously ill while in their care, or acquire infection from contacts with classmates, for which they would feel responsible. Finally, the teacher faces a conflict between the care of the individual—the child with cancer—and the needs of the rest of the class.

Many of these concerns can be addressed by 'educating the educators' and most children's cancer centres recognise the need to liaise with schools and to provide information for teachers as a means of facilitating their patients' return to the classroom. The results of our brief survey show that efforts to achieve this in the United Kingdom are variable. Although all centres acknowledged the importance of information for schools, and many make con-

siderable efforts to contact teachers individually on behalf of their patients, less than half of the centres which replied to the survey provided specific written guidance for teachers about schooling for children with cancer. All the written material available provided the same overview of cancer in children, its frequency and treatment, and stressed the importance to the child of an early return to school. Only a few, however, addressed issues such as an explanation that children are usually aware of their diagnosis and that acute medical problems occurring in children while at school are unlikely—both areas that would provide considerable reassurance for teachers' anxieties. The provision of teaching in hospital, the use of the home teaching service and part time attendance at school are all ways in which schooling can be continued until the child is well enough to return to a full time curriculum—points discussed by some leaflets only. It is interesting that all leaflets countered the anxiety that cancer might be infectious and emphasised that the affected child presents no risk to others—a reassurance that many might be surprised to believe is necessary.

The problems experienced by children with cancer, and their teachers, are not unique and some of the solutions might apply equally to children with other medical problems (for example, cystic fibrosis and diabetes). The relation between medical services and schools has recently been considered by the British Paediatric Association and the need for interprofession liaison was emphasised.¹⁰ The value of educational programmes, including seminars and meetings, as well as the provision of written information, in educating teachers and school medical nursing staff about the problems of school for the child with cancer has been established.¹¹ Certainly, the introduction of meetings for teachers

of recently diagnosed children in our own unit has been received with enthusiasm. Whether such efforts have appreciably improved the excessive absenteeism and educational disruption seen among this group of patients remains unproved. How such an improvement can be best achieved must be the focus of further study.

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