

## Survey of psychosocial support provided by UK paediatric oncology centres

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**Key words:** Psychosocial support, childhood cancer, paediatric oncology, family support, teenagers

**Abbreviations:** NHS – National Health Service, POONs – Paediatric Oncology Outreach Nurses, TCT – Teenage Cancer Trust, UKCCSG – United Kingdom Children's Cancer Study Group

## Abstract

**Objective:** to obtain a comprehensive overview of current patterns of psychosocial support provided by National Health Service (NHS) paediatric oncology treatment centres across the UK.

**Design and setting:** a postal questionnaire was sent to UK Children's Cancer Study Group (UKCCSG, a professional body that is responsible for the organisation of treatment and management of childhood cancer in the UK) co-ordinators in 21 treatment centres and three separate Teenage Cancer Trust (TCT) units.

**Main outcome measures:** a range of psychosocial topics were explored, including ratio of staff providing support to patients; facilities provided for children and families; psychosocial support services, such as support groups, information provision and transition support.

**Results:** results demonstrate that there were many good areas of support provided by centres but there were also few standard practices and procedures. All centres employed social workers, play specialists and paediatric oncology outreach nurses (POONs) but patient to staff ratios varied across centres. Poorest staff provision was amongst psychologists, patient to staff ratios ranged from 132:1 to 1100:1. Written information was standard practice, provision of other types of information (audiovisual, online) varied, indeed, none of the centres provided audio information specifically for children/young people.

**Conclusion:** this variability in practices amongst centres frequently occurred as centres rarely had procedures formally agreed or recorded in writing. British government policy currently seeks to develop standards and guidelines of care throughout the National Health Service. This paper demonstrates further the importance of standards and the need to agree guidelines for the provision of psychosocial support for children/young people and their families throughout the course of the illness.

## Introduction

Childhood cancer is a traumatic event for children/young people and their families. Although major treatment advances have been made with survival rates now exceeding 70 per cent,[1] evaluation of psychosocial support is less developed, with little information available about differing patterns of provision across the UK.

In the UK, psychosocial support is provided and funded by a number of different organisations. Support has developed in an ad-hoc manner and historically from a time when patterns of treatment for and survival from childhood cancer were different. Research on the experiences of children with cancer or leukaemia and their families has demonstrated the need for psychosocial support. Parents and children experience a wide range of emotions throughout their illness and uncertainty is a key cause of anxiety.[2][3][4][5] Distress can also persist for both parents and children long after treatment ends.[6][7][8][9] Families also face many changes in their everyday lives, practically, socially and emotionally. Practically, parents frequently care for their sick child whilst also trying to juggle their everyday roles and responsibilities.[9] [8] This can have important financial implications in terms of employment patterns and incurring additional expenditure.[10][11][12] Practical and financial support and advice is therefore important.

Preparing and supporting parents and patients, discussing treatment procedures throughout the course of the illness and providing “someone to talk to” has been demonstrated as advantageous.[2] [13] Clear and accessible ongoing information, in a range of formats about cancer and leukaemia for parents and children/young people is also important.[14][15][16]

For children/young people, the significance of ongoing family support, especially from mothers has been well documented.[17][18] Research also highlights the importance of well planned and coordinated re-integration programmes between hospital, school and families.[19][20][21] In order to meet the diverse needs of children/young people and their families, health and social care professionals need to work together to provide support, being sensitive to the needs of the family unit as a whole and its individual members.

This paper reports the results of a survey of psychosocial support service provision for children/young people and their families at paediatric oncology treatment centres in the UK. The survey was carried out in early 2003 as the first stage of a wider study exploring the support needs of children with cancer and leukaemia and their families.

## Methods

A questionnaire was drawn up based on key psychosocial themes identified in the existing literature and input from the project steering group, comprising representatives from the UKCCSG and key voluntary organisations. The questionnaire employed a mixture of closed and open questions and was piloted at two treatment centres. Topics covered were:

- Staffing and number of patients treated
- Facilities provided for children and families
- Psychosocial support services, including assessment, support groups and activities
- Information provision
- Transition support

The questionnaire was sent to UKCCSG coordinators in the 21 UK paediatric oncology treatment centres and three separate Teenage Cancer Trust (TCT) Units. The UKCCSG co-ordinator at each centre either nominated a member of staff or convened a group meeting of relevant staff to complete the questionnaire. Telephone reminders were made after three weeks and written reminders were sent after ten weeks.

An Access database was created and frequencies were calculated for the responses to each survey question. There was a small amount of missing data for individual questions.

Ethical approval was obtained from a Multi-Centre Research Ethics Committee.

## Results

Twenty-three of the 24 centres (96%) completed questionnaires, with one TCT unit not responding. The 23 centres varied in terms of size and patterns of working. For example, the number of new patients in an average year varied from 15 to 250 (mean=97). Only six centres delivered care on a single site. Over half of the centres (15) shared care with other hospitals. This ranged from one centre that shared care with only one other hospital to two centres that shared care with 50 to 60 hospitals.

### Staff providing psychosocial support

Twenty-two centres provided data on staff regularly employed. In order to compare the staffing of different centres, ratios of numbers of new patients per year to number of whole time equivalent posts (wte) were calculated (see table 1). All centres employed social workers, play specialists and POONs. However, the ratio of patients to staff varied across centres. The poorest area of staff provision was counselling and psychological support. Only one centre reported employing a counsellor on a regular basis (0.8 wte). Twenty centres provided data on psychologists, eleven centres employed psychologists on a regular basis, but only four on more than a half time post, and nine did not employ a psychologist. There is likely to be a considerable crossover between the roles of different groups of staff providing psychosocial support and the ratio of patients to all staff taking this role shows a narrower range of variation. A further factor to be taken into account is that the figures reported are based on staff in the main paediatric oncology centres, and it is important to recognise that staff in shared care hospitals also contributed to psychosocial care and support. The correlation between number of hospitals sharing care with the main treatment centre and ratio of patients to total numbers of psychosocial staff was significant ( $r_s=0.52$ ,  $p=0.015$ ). This

suggests that although centres which had a lot of shared care had higher patient to staff ratios, the effects of this on patient care may be mitigated by the provision available in the hospitals with which they shared children's care and treatment. Nevertheless, there were some exceptions to this. For example, a centre with no shared care had the highest ratio of patients to staff and two others above the median had few shared care hospitals.

**Table 1: Ratio of patients to staff across centres**

Type of staff	Minimum	Maximum	Median
Psychologists	132:1	1100:1	333:1
Social workers	23:1	157:1	55:1
Play specialists	18:1	220:1	43:1
POONS	15:1	97:1	33:1
All psychosocial staff	6:1	32:1	14:1

There was a considerable input from the voluntary sector in funding staff posts (table 2). All the centres providing information had psychosocial staff posts funded, at least in part, by the voluntary sector.

**Table 2: Number of centres with staff funded from statutory or voluntary sources**

Type of staff	Statutory funding only	Voluntary funding only	Mix of statutory and voluntary funding	No. of centres providing information
Psychologists	9	1	1	11
Social workers	0	13	4	17
Play specialists	11	2	7	20
POONs	12	4	3	19

### Patient facilities

All centres with child patients provided a playroom for in-patients; only one centre did not provide a playroom for day-patients and two centres did not provide this for out-patients. The majority of centres (20) also provided a teaching area/classroom for in-patients; these areas could be used by day-patients in 14 centres and out-patients in eight centres. Policies for the provision of education were agreed in 16 centres but only recorded in writing at seven centres.

Seventeen centres had some form of separate facilities for teenagers and it was largely centres with low numbers of teenage patients that had no or few separate facilities. Patients were best served at the five centres with teenage units; here teenagers had their

own space with age appropriate décor, facilities and activities. Amongst other centres, facilities ranged from separate teenage areas (three), single rooms or cubicles (four), activity rooms only (two) to partitioned areas on general wards (three).

### **Family accommodation**

All 23 centres provided family accommodation and this was largely free of charge (20 centres); 22 centres provided more than one type of accommodation (see table 3).

**Table 3: Family accommodation provided by centres**

<b>Accommodation type</b>	<b>Number of centres providing</b>
Bed on a ward	22
Self contained accommodation	18
Room within the hospital	12
Room at another hospital	1
Nurses accommodation (single room)	1
Local hotel or guesthouse	2

Everyday facilities, such as private washing/toilet amenities, telephones, laundry, self-catering, televisions, videos/DVDs and books/games, were routinely available in over three quarters of centres (19).

Family accommodation was not always provided for all family members or to all families. Accommodation was routinely available to parents (or main carers) of in-patients but provision for other family members varied. Seven centres did not provide any accommodation for siblings and eight centres did not provide for grandparents. Less than half of the centres (nine) provided accommodation for families travelling long distances to attend out-patient appointments. Parking facilities were also considered problematic by many centre staff, 12 centres reported insufficient parking spaces and 16 centres charged families to park.

### **Assessments and supportive preparations**

Formal psychosocial assessments of patients were not routinely made, with only three centres formally assessing every patient. Most centres (20) carried out an informal assessment of all new patients and only followed this with a formal assessment if a need was identified. Social workers were involved in assessments in the majority of centres (18) and at 20 centres routinely met all patients and their families. In contrast, psychologists regularly performed assessments in only three centres and did not meet all patients or families in any centre. Assessment procedures and their frequency varied, only two centres reported using the Framework for the Assessment of Children in Need. Seven centres reported carrying out regular reviews of assessments; these ranged from on each admission to every three to six months.

Involving play specialists in the preparation of children and parents for invasive treatment procedures, such as central line insertions, was reported as standard practice. Only four centres reported the input of psychologists in treatment preparations.

### **Support groups and bereavement support**

Support groups could be accessed at most centres (21); however, the number of groups offered, and for whom they were targeted, varied across centres (see Table 4).

**Table 4: Different types of support group provision**

<b>Support group type</b>	<b>Number of centres providing</b>
Parents	18
Bereaved families	17
Teenage patients	16
Siblings	16
Child patients	7
Cancer survivors	6
Grandparents	4

Most groups were organised by the centres themselves but at eight centres, local voluntary sector organisations ran specific groups. Frequency of meetings varied; some groups met regularly, others more sporadically, even annually. In addition to bereavement support groups, social workers (16 centres) and nursing staff (15 centres) reported regularly providing bereavement support, usually via home visits. At 14 centres, staff also referred families to external bereavement agencies.

### **Leisure activities**

All 23 centres provided some form of organised leisure activities for patients and their families (see figure 1).

### **Information and advice**

Written information was provided as standard practice across centres for parents, teenagers and children. Play related information was also available for children at 20 centres. The provision of other types of information varied across centres and between family members.

Provision of financial information and advice was standard practice across centres, 22 had a designated person providing this information, usually a social worker, and all 23 centres reported that help was available to families completing application forms, such as Disability Living Allowance. Most centres (18) provided families with a hospital or ward welcome pack, but specific information for children and teenagers was less frequently available (five centres). Fourteen centres reported involving families in the production of information but only six indicated that they involved children.

Seventeen centres reported taking the cultural needs of different families into account, through the services of translators (15 centres) and interpreters (13 centres). Three centres felt that they were not culturally responsive to the diverse needs of their population and six centres did not report taking any specific action, however, the latter did not have large ethnic minority populations.

### **Transition support**

#### *Hospital to home*

Twenty-two centres reported providing an outreach service for families in the community. POONs provided this service in all centres, with community paediatric nurses also being involved in nine centres and social workers in eight centres.

Outreach support was routinely provided in the form of home visits, continuing social worker support and telephone advice from a doctor or nurse. GPs (18 centres) and health visitors (17) were the two community based professionals hospital staff most frequently met. Eighteen centres had procedures laid down for the transition of care from hospital to home.

Regularly involving patients and parents in the handover decision-making process was reported as standard practice in 22 centres. However, only six reported involving siblings and one involved grandparents.

#### *Returning to school*

Twenty centres reported having a designated person responsible for assisting families with the return to school; usually a member of nursing staff (14 centres) and/or a teacher (12 centres). Liaison frequently took place in the child's school (21 centres) and family involvement usually took the form of inclusion in transition discussions with professionals (parents at 16 centres and children/teenagers at 13). Information for schools and teachers (books/leaflets, particularly Cancer Research UK's 'Welcome Back') was routinely provided by over half (13) of the centres. However, only ten centres had procedures formally recorded in writing.

#### *Transition to adult services*

There was considerable variability in when young people were transferred to adult services. For those still receiving treatment, eight centres did not transfer care to adult services, age of transfer at other centres ranged from 14 to 21 and two did not have any set ages. For young people who had completed treatment, 10 centres did not transfer follow-up care, age of transfer at other centres ranged from 14 to 23, and two did not have any set ages. None of the centres had formally agreed procedures or policies recorded in writing.

#### *Long-term survivorship*

Eleven centres, varying in terms of size and age of patients, reported providing ongoing psychosocial support for long-term survivors. Seven had a designated person responsible for support, usually a consultant oncologist (five centres). However, the 11 centres varied in terms of when support was provided, from "open door" policies to

regular check-up clinics organised on an annual to monthly basis. Formally, recorded policies and procedures were rare (three centres).

## Discussion

The results of the survey provide an overview of patterns of psychosocial support available to children/young people and their families at UK treatment centres. Such services are clearly an established part of centre provision. Positive findings include the employment of social workers, play specialists and POONs as standard practice across centres and their involvement in a range of support, such as assessments, support groups, preparation for invasive treatment and transition issues, especially hospital to home transitions; and the availability of more than one type of information, with written information as standard across centres and play information provided for children in most centres. Centres provided a range of accommodation for parents/carers of in-patients and it is heartening that many recognised the needs of teenagers, providing some form of separate facilities.

However, in many areas there were few standard practices and procedures. This is frequently the result of an informal/formal divide, where practices may be acknowledged and respected but how, when and the degree to which they are implemented can vary. Five key areas of variability were identified:

- There was no standard practice in the number or type of staff employed across centres, counselling and psychological support was particularly poor. An absence of psychological input was identified in both assessment and support. This mirrors a wider shortage of psychologists within the NHS (The Psychologist, 2003).
- Family support focused upon patients and their parents, support for other family members, such as siblings and grandparents, was less frequently provided.
- Teenage facilities varied across centres with teenagers best served at TCT units, continuing the work of the TCT is clearly important. However, centres without units also need to develop their facilities for teenagers.
- Alternative forms of information, such as audiovisual and online and information targeted at specific groups, such as children/young people, minority ethnic families and other family members (siblings and grandparents), was poorly provided.
- Transition support in all areas (hospital to home, back to school, child to adult services and long term survivorship) varied with practices rarely recorded in writing.

Results indicate a need for more targeted resources and support for specific groups, such as teenagers, siblings and other family members, especially grandparents. Indeed, recent research has indicated that grandparents are an important source of support for many families.[22] However, there is very little, if any research on the specific support

they provide for families experiencing childhood cancer. In light of treatment centres' focus upon the nuclear family, this is an important area for future research. In addition, past research has also indicated that children with a range of chronic conditions and their families can be at risk of poor psychosocial outcomes.[23] The importance of psychosocial support is noted, however, there appears to be an absence of current service provision data. Studies of psychosocial service provision similar to the survey discussed here would thus be advantageous for children with other chronic conditions.

It is clear that the voluntary sector plays a key role in the provision of psychosocial support services, funding staff posts, accommodation for families and specially designed facilities for teenagers. In their open comments at the end of the questionnaire, staff indicated some anxiety over the effects of cutbacks in such funding agencies, particularly in relation to social worker posts. However, the recent merging (first quarter, 2005) of two key voluntary sector childhood cancer organisations providing psychosocial support (Cancer and Leukaemia In Childhood and Sargent Cancer Care) may allay some of these fears. Consolidation and sharing resources may lead to a more holistic approach, which would be advantageous for treatment centres.

British government policy is currently working to establish standards in all areas of health care and such policies recognise the importance of psychosocial support. The Children's National Service Framework Hospital Standard emphasises the importance of child and family centred care [24] and the Standard for Children and Young People who are ill states that services should address children's health, social, educational and emotional needs.[25] More specifically, guidelines on the treatment and care in childhood cancer were established in 2000.[26] Within these, four basic elements were identified: diagnosis and treatment, social, psychological and reintegration. Guidance has been further developed and updated by The National Institute of Clinical Excellence who are currently finalising specific standards for childhood cancer (first consultation, Autumn 2004).[27] In particular, the guidance advocates that all families should be offered the advice and support of a social worker, access to expert psychological support, especially from those with expertise in children's cancer, and structured psychosocial assessments at key points of the illness. These guidelines are an important development, as they recognise the significance of psychosocial support for patients and their families, its complexity across the illness trajectory and also pinpoint key areas of support, including the role of social workers and the absence of psychological services, both of which were highlighted by the treatment centre survey.

Although these guidelines begin to establish greater clarity and, as this paper has demonstrated, there is much good practice in paediatric oncology centres, there is still a real need to develop more formal policies and agree standards across centres, to ensure that all children/young people with cancer and their families receive a comprehensive package of care and support, whatever treatment centre they attend.

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**Competing interests statement**

No competing interests

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### **What is already known on this topic**

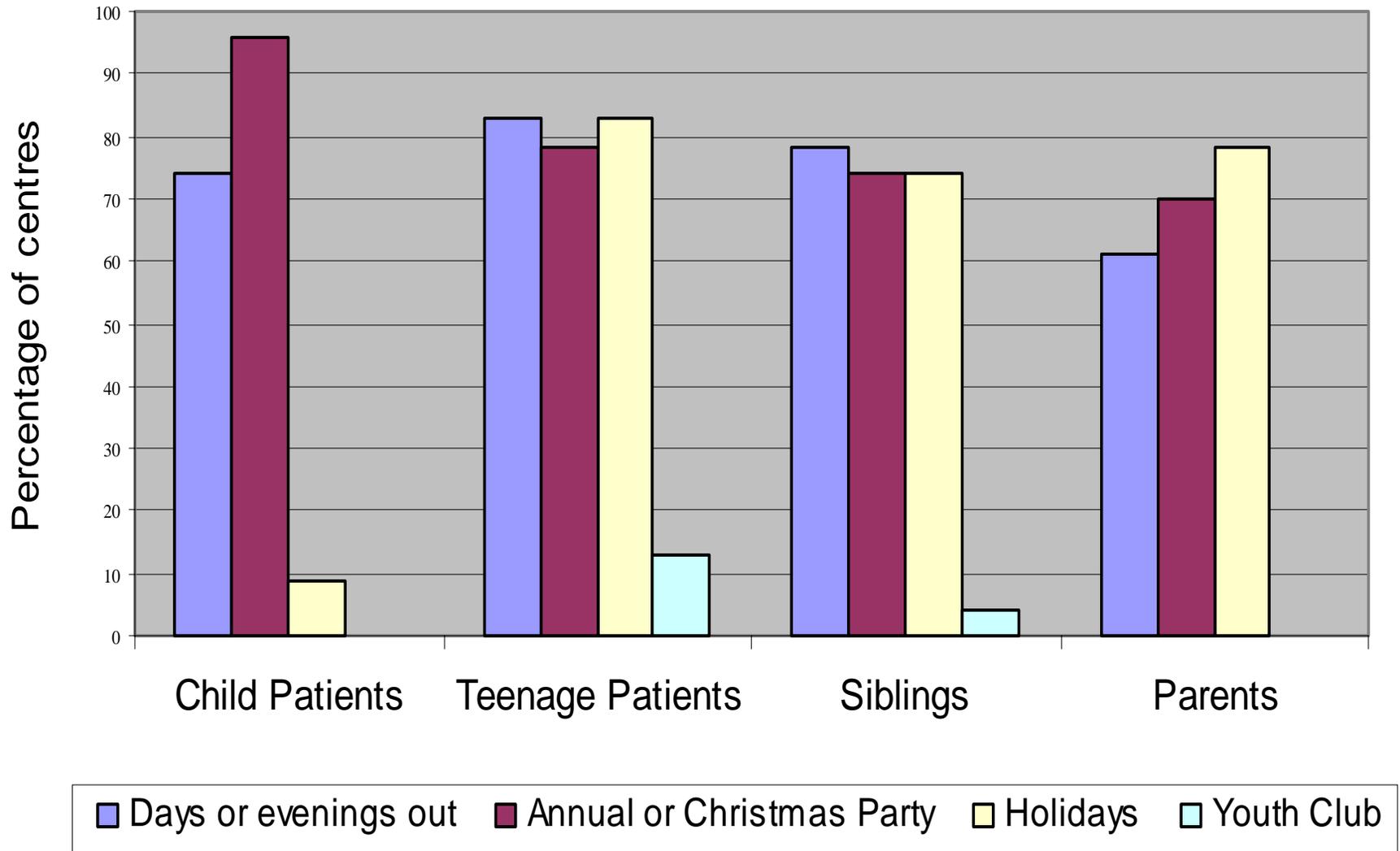
1. The importance of providing psychosocial support to patients and their families across the illness has been demonstrated in previous studies. As survival rates continue to improve, the need for ongoing support has been highlighted.
2. Past studies of regional treatment centres demonstrate that the range and type of services provided can vary but there is little research comparing service provision across centres.
3. The statutory and voluntary sector both provide psychosocial support and services, however the relationship between the two can be complex and is often unclear.

### **What this study adds**

1. It provides a comprehensive overview of current UK patterns of psychosocial services and support provided by paediatric treatment centres.
2. It examines a wide range of psychosocial services and support issues, including staffing levels, facilities provided for children and families, support groups and activities, information provision and transition support.
3. It draws upon multi-disciplinary knowledge and expertise provided by health, social and psychological professionals employed within centres.
4. It documents specific services provided for parents and children/young people, recognising that parents and children/young people can have different service and support needs.

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