

Guideline for Schooling and Other Activities for Children and Young People Receiving Immunosuppressive Cancer Treatment

Changes Between Versions 1 and 2

- References updated.
- Change of terminology from Macmillan Nurse or POSCU link nurse to Cancer Key Worker (PTC or POSCU Specialist Nurse)
- Added seeking consent from parents for Information Sharing across organisational boundaries with Education Services.
- Included liaising for key events such as GCSE exams.
- Included liaison with Hospital Schools and Home Tutors

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Date for Review	August 2015

1. Scope of the guideline

- 1.1 This document provides guidance to ensure that children and young people receiving cancer treatment have optimal opportunity for social, psychological and academic development, whilst ensuring their safety during immunosuppressive treatment.
- 1.2 This document is also links to the role of the Cancer Key Worker for school liaison in peer review measures 11-7B-207, 11-7B-308, 11-7C-407, [DH Manual for Cancer Services (2008): Children's Cancer Measures (2011)] and optimising psychosocial outcomes described on pages 76 & 134 of the N.I.C.E. (2005) Improving outcomes in children & young people with cancer. It aims to promote educational support & where possible school attendance in recognition of the vital part that education and school plays in every child's life as described in the report "More than my illness" CLIC Sargent for Children with Cancer (2008)

2. Guideline background

- 2.1 "Children with cancer are likely to have their education disrupted due to prolonged or repeated periods of hospitalisation and frequent health appointments. Learning capacity can also be impacted by certain types of cancer, for example in the case of some brain tumours. Education systems can struggle to accommodate the individual needs of these children. These factors can contribute to children with cancer achieving less than their peers in education and subsequently in employment.

There is also an important emotional component to keeping up with education. Going to nursery, school or college is a major part of a child's life and is intimately related to their social networks." CLIC Sargent (2008)

Sometimes parents, carers and even health care providers can be overcautious about encouraging school attendance due to fears about infection risk. Occasionally schools are concerned about having a child with cancer in school and place barriers in the way of successful reintegration. With support for the child / young person, parents, carers and teachers the cancer diagnosis and treatment effects need not preclude school attendance and children & young people can successfully maintain their education and social support networks.

3. Guideline statements

This guideline covers:

- Children receiving standard dose or maintenance chemotherapy, or radiotherapy, or within 6 months of completing either

This guideline does not cover:

- Children who have undergone Bone Marrow or Stem Cell Transplantation
- Children who have received High Dose Treatment with Stem Cell Rescue
- Children undergoing Treatment for Acute Myeloid Leukaemia (AML)

Children in these 3 groups will be advised by their own consultants regarding the appropriate time to return to school and other social activities.

Guidelines for Attendance at School and Other Social Groups

(NB "School" is used here to cover schools, nurseries, colleges and other social groups such as sports clubs, scouts etc. The term child is taken to mean all children of nursery and full time education age.)

- Return to school should be encouraged as soon as possible after diagnosis provided that the child is well enough. A template "Pupil Details" sheet & "checklist" for the child with cancer returning to school is available on page 96 - 99 of Pupils with Cancer: A Guide for Teachers The Royal Marsden NHS Foundation Trust and The Specialists Schools and Academies Trust.
- Cancer Key Workers undertaking liaison with schools on behalf of parents and carers should discuss information sharing policies and seek verbal consent to share the child's relevant information with school.
- Children should attend their usual school or nursery regardless of neutrophil count, taking the precautions described below, provided that they are otherwise well.
- Advice to schools should include methods of ensuring the child's physical health in school. Advice should be given to help the school accommodate changes in the child's;
 - appearance (hair loss, weight gain/loss)
 - physical capacity (reduced mobility, pain, anaemia, increased risk of bruising and bleeding, reduced vision/hearing/speech ability)
 - intellectual ability (poor concentration, missed schooling, ability to access exams, the potential for long-term cognitive deficits and consideration of post 16 options)
 - emotional capacity (anxiety, mood swings etc)

Advice on infection

- Schools should be encouraged to promote good hand and general hygiene within the class.
- Teachers should be reassured that the everyday cough and cold does not constitute a major risk to children receiving cancer treatment.

- The child on treatment should be kept apart from other children who have signs of other infections during the school day (e.g., diarrhoea, sickness, sore throat)
- **Chickenpox and shingles** Where children do not have immunity to chickenpox at diagnosis (and any child following BMT), it is advised that letters are sent out to the families of all children who share a classroom area with the child on treatment, asking their parents to inform the school if their child develops chickenpox or shingles. A template letter is available on page 95 of Pupils with Cancer: A Guide for Teachers The Royal Marsden NHS Foundation Trust and The Specialists Schools and Academies Trust.

News of such contacts will then be passed from school to the child's parents or professionals. If there has been direct indoor contact for at least 15 minutes between the patient (A) and the child with chickenpox (B) during the period from 48 hours prior to that child (B) developing spots until the vesicles have crusted over, then the patient (A) should receive prophylaxis. For shingles prophylaxis this is only required if there is direct contact with exposed lesions (as per RCPCH Best Practice Statement) <http://www.rcpch.ac.uk/>. Search publications "immunocompromised"

- **Measles** All schools, nurseries and other social groups should be aware of the need to inform parents/professionals if a child comes into direct contact with a person developing measles, in the period of 5 days before or 4 days after the rash develops. The diagnosis of measles should be confirmed clinically and preferably virologically. Prophylaxis is required regardless of antibody titres. Even though this will be less effective after 72 hours, it is still recommended that prophylaxis is given for contacts up to 14 days previously.
- Schools should be encouraged to have a low threshold for contacting parents should the child show signs of becoming unwell during the school day. For younger children particular attention should be paid to children complaining of being too hot or too cold at normal room temperature, sudden aches and pains, sleepiness and changes in behaviour.
- If school attendance is likely to be impossible for a prolonged period of time, home tuition should be considered. Where possible this should be in conjunction with occasional school visits to ensure that children remain in social contact with their peers.
- With the permission of parents and the child/young person themselves, schools and other social groups should be offered written and/or verbal advice from a member of the child's treatment team (usually the Cancer Key Worker – PTC or POSCU nurse specialist). This advice may be given verbally by telephone, at a school visit, or in writing in a booklet form. Recommended documents include the Royal Marsden Guide, CLIC Sargent leaflets and planned CCLG booklet (revision & adoption of copyright from historical CRUK booklet in progress)

- With the family's permission, schools will be invited to a Teacher's Meeting held at Birmingham Children's Hospital or a West Midlands Paediatric Oncology Shared Care Unit
- Specific advice on care of central venous lines, nasogastric tubes etc. should also be given where appropriate
- All schools should have the name and a contact number for the child's treatment centre.
- Medical evidence will be provided if there is a need for additional resources in school or for a statement of Special Educational Need, or for application by the school to the examination bodies for special consideration with exams, e.g. GCSE

Guidelines for children unable to attend school

- Where a child has significant periods of hospitalisation >2 weeks or periods at home where they are not yet well enough to attend school, e.g. > 2 weeks. The hospital school teachers must be made aware of the child and a request made for an assessment of the child's educational needs and capabilities. Ideally school teacher input should be made available from day 1 every admission.
 - **In hospital** Where possible the child should be encourage to attend the school room or undertake bedside activities appropriate to their age and physical / cognitive health at the time. This should occur daily through term time to maintain normal patterns of education. Teachers are often able to provide access to web-based learning and activities that parents can offer to their child when well enough.
 - **At home** When an assessment has been undertaken by the hospital school teachers, with the child & family (and possibly the Cancer Key Worker or Consultant) and school attendance is not achievable for periods of longer than 2 weeks at home, steps should be put in place to request home tutoring support from the Local Education Authority or Hospital School outreach. Local rules may apply on age range for home tutoring or duration of time at home before home tutoring can be offered.
 - Parents and carers often need support to understand the importance of maintaining education for the child. This is particularly difficult when the child has poor prognosis disease. Parents may focus on the futility of educational achievement or need to spend as much time with their child as they can with what time they have. This requires sensitive but open discussion to offer parents views they may not have considered about the importance of school for children in maintaining normality, connecting with peers, achieving a sense of independence when their disease may have taken away the control they had in other aspects of

their life.

Guidelines for children attending activities inside & outside school

- The CCLG booklet “Sport & Exercise for children & young people with cancer: A parent’s guide” (Nov 2011) provides excellent advice for both parents and schools. It offers really practical advice to encourage all levels of activity and suggests ways for children to maintain some level of participation (e.g. refereeing) even when they are physically very limited.

4. Monitoring of the guideline

- 4.1 Consultants, Cancer Key Workers, Social Workers and Teachers should enquire about school attendance during routine assessments and regular contact with families.
- 4.2 The Guideline will be reviewed every 3 years by the WMCCNCG and any new reports, national guidance, & reputable patient information literature will be incorporated. New evidence against any items within this guideline should be a prompt for immediate review.

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References

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- **CLIC Sargent for Children with Cancer** (May 2012) V2. Talking to schoolchildren about cancer: for primary school teachers www.clicsargent.org.uk
- **CLIC Sargent for Children with Cancer** (May 2012) V2. Children with Cancer – Information for teachers Ref: SER074_12149 www.clicsargent.org.uk
- **CLIC Sargent for Children with Cancer** (2008) More than my illness: Delivering Quality Care for Children with Cancer www.clicsargent.org.uk

- **RCPCH.** (2002) Immunisation of the immunocompromised child: Best Practice Statement
www.rcpch.ac.uk/
CCLG (2011) Sports & Exercise for children & young people with cancer: A parent's guide www.cclg.org.uk

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