Whittington Health NHS

Leukaemia - Management of the Newly Diagnosed Child/Young Person

Subject:	Leukaemia – Management of the Newly Diagnosed Child/Young Person
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Policy Executive Owner:	Dr Andrew Robins, Consultant Paediatrician
Designation of Author:	Macmillan Paediatric Oncology Nurse Consultant POSCU Lead Consultant
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Version Control Sheet

Version	Date	Author	Status	Comment
1	2010	Wendy King, Dr Heather Mackinnon Dr Agathe Pachnis	Published	Written to provide guidance to the paediatric health care team when a child/young person is newly diagnosed with Leukaemia
2	July 2013	Wendy King Dr Gopa Sen	Updated and published	Previous guideline required review. Re-wording and changes as per referral pathway from the Principle Treatment Centre

➢ Criteria for use

This document is intended to guide teams looking after a child or young person up to their 18th birthday, with a new diagnosis of suspected Leukaemia. Please use it alongside advice given by the Primary Treatment Centre (PTC) and refer to the Supportive Care Guidelines and the Clinical Management Protocol/children/leukaemia on the I: drive.

Clear documentation including times of any phone call discussions with PTC (names) is essential.

Primary Treatment Centres (PTC):

- GOSH for all children aged 12 years or under
- UCLH for children aged over 12 years
- All children less than 1 year of age must be referred to GOSH

➢ Background/ introduction

When a child has a potential new diagnosis of leukaemia, there are a number of important clinical issues that need urgent attention and careful management. The main aim is to keep the child safe prior to transfer to a PTC.

➢ Clinical management

What to do first:

During working hours inform POSCU Lead Consultant and Paediatric Oncology Nurse Consultant/Specialist Nurse. Out of hours discuss with the Attending/On call Paediatric Consultant. All suspected new malignancies must be discussed with the relevant PTC.

The Blood Film:

- This needs to be looked at locally at the Whittington Hospital Laboratory by a Consultant Haematologist.
- The PTC may ask that films are prepared and couriered over for review
- Blood films for children aged 12 years or under should be sent to the Camellia Botnar Laboratory at Great Ormond Street Hospital.
- For children being transferred to UCLH, liaise with the Haem/Onc SpR about where films should be sent.

Children who are at home when an unexpected abnormal blood result is phoned through, (suggesting the possibility of Leukaemia), should be recalled to the hospital urgently if:

- They are under a year old

- They are or have been febrile
- They are critically anaemic or thrombocytopenic (see below for levels of haemoglobin and platelets for transfusion)
- They have a high white cell count (>50x10^9/l)
- Any suggestion of other significant clinical complications

Otherwise the family should be recalled first thing the next day (including weekends).

History and Examination:

- Full physical examination including height and weight, hepatomegaly, splenomegaly, lymph node size and distribution, kidney size, infection sites

Baseline Investigations:

- FBC, differential and film (Document the highest white cell count)
- Clotting screen including fibrinogen
- U&E, LFT, Bone Profile, Urate
- CMV, VZV, Measles, HSV antibody status
- Save serum
- **Do Not Transfuse packed cells or platelets without first taking 5 mls of blood for saved serum.**
- CXR
- Test G6PD for all high risk newly diagnosed patients likely to require rasburicase (e.g. high white cell count)

Transfer Documents:

- Referral proforma for all newly suspected malignancies is in the Paediatric Oncology Folder on the I: Drive.
- Please leave the template document blank and save a new referral proforma for each patient and complete electronically.

Arranging a bed/transfer:

- It is the responsibility of the PTC to arrange a bed (or a Day case admission) usually for a bone marrow aspirate and Lumbar Puncture under general anaesthetic.
- If there are no beds in the local PTC's, they will search for a bed across the UK and advise whom to liaise with.
- Keep all senior team members regularly updated.
- Document all discussions.

The PTC will need:

- The referral proforma
- Nursing transfer documents
- The borough the family lives in so that the appropriate community nursing team can be involved
- Parent's names, occupation and contact numbers
- Details about siblings and any unusual or important aspects to the social history
- Documentation of the weight and surface area (use the UKCCSG chart)
- The highest WCC
- Documentation of all blood tests and medication given
- All imaging electronically transferred
- Outline of what the family knows and understands

A copy of the transfer proforma (electronically or hard copy) should be sent to POSCU Lead Paediatric Oncology Consultant and Paediatric Oncology Nurse Consultant. Lead Consultant or Paediatric Oncology Nurse Consultant/Specialist Nurse will then liaise with the PTC and the family as needed.

How to look after a child on the ward whilst waiting for a bed:

Actively search for and manage any oncological emergency (see below).

- **Children with an increasing mediastinal mass should be transferred urgently as they may require high dependency care**
- Febrile Neutropenia (high risk of overwhelming sepsis)
- Tumour Lysis Syndrome (can occur spontaneously and early)
- Hyperleukocytosis
- Hypertension
- Coagulopathy/Diseminated Intravascular Coagulopathy
- Superior Vena Cava obstruction
- Raised intracranial pressure

The most likely time for these to occur is around the time of diagnosis. Use the Supportive Care Guidelines (Chapter 12).

Fever:

Assume all newly diagnosed children or young people have non-functional neutrophils (regardless of the counts) and thus any febrile episode must be managed with broad spectrum antibiotics.

All newly diagnosed children (under the age of 12 years) with cancer, should be tested for the A1555G mutation as soon as possible after arrival at Great Ormond Street Hospital. Until the results of this test are known, avoid using aminoglycosides in these patients wherever possible. Patients who are febrile and immunosuppressed should be treated routinely with single agent piperacillin/tazobactam. However, if the patient has rigors or is hypotensive requiring a fluid bolus, or there is clinical suspicion of sepsis, then they should be treated with an aminoglycoside and piperacillin/tazobactam, as the benefit of aminoglycosides outweighs the potential risk or deafness.

Children and young people who are truly allergic to penicillin should be treated with Meropenem. This will provide good gram positive cover and is less likely to cause reactions than with a cephalosporin. (This should be discussed on an individual patient basis with Microbiologist or on-call Haematology Registrar at GOSH).

(See Supportive Care Guidelines Chapter 5 for doses).

Tumour Lysis Syndrome:

All children should be regarded as being at risk of Tumour Lysis Syndrome. (High risk if high presenting WCC and/or mass disease). See Supportive Care Guidelines Chapter 12.

Prevention:

- Clinical review every 4-6 hours.
- Hyperhydration - 3 litres/m²/day IV (or 125 ml/m²/hour) of 0.45% Sodium Chloride and 2.5% Dextrose. If serum potassium or phosphate continue to rise, discuss urgently with PTC.
- **Do not add potassium** (KCL) into the fluid bag – this is dangerous
- Start Allopurinol at 100mgs/m² TDS oral. Round up to the nearest 50 mg.
- If the WCC is >50x10^9/l or mass bulky disease is present, discuss with PTC. These children may need to be transferred urgently.
- Strict input and output charts with daily weights (urine volumes must be measured or nappies weighed)
- Ensure urine output is >2mls/kg/hour. If urine output less than this discuss the use of Frusomide (0.5mg/kg bd), with the PTC
- 4-6 hourly – U&E, phosphate, calcium and urate for children with a WCC >50x10^9/l or "bulky" disease
- 8-12 hourly bloods for other children
- Monitor for rising urate, phosphate and/or potassium. These can occur unexpectedly and require prompt action. **Do not assume that a high potassium result is a sampling/lab error.** To bring potassium level down, see Supportive Care Guidelines chapter 12 and start cardiac monitoring.
- Monitor for hypertension and heart failure – particularly in younger/smaller children
- Treat hypertension with Nifedipine (see Supportive Care Guidelines Chapter 10)

Children with a High White Cell Count (>50x10^9/l):

Hyperleukocytosis occurs in about 10-20% of children with leukaemia and the higher the count the higher the risk.

- The white cells are not functional, so all fevers should be treated as per febrile neutropenia protocol.
- "Hyperleukocytosis" refers to children with a WCC >100x10^9/l.
- Children with counts >50x10^9/l are also at risk of hyperleukocytosis and should be prioritised for transfer to the PTC.

These children are at risk of:

- Tumour Lysis Syndrome
- Coagulopathy
- Stroke-like and CNS events
- Respiratory decompensation.

Transfusions:

Packed Cells:

- If WCC is <50 transfuse packed red cells if symptomatic and Hb < 7g/dl
- If WCC >50 there is a risk of hyperviscosity. Please discuss with PTC.
- Prescribe 10 mls/kg.
- Ensure all baseline bloods are done first (see the first section)

Children with high count or bulky disease should be transfused very cautiously in aliquots of 5 mls/kg, following discussion with the PTC. Over transfusion in these children can precipitate complications of hyperleukocytosis.

Platelets:

- Transfuse if platelet count is <10 $x10^9$/l
- If febrile, transfuse if platelet count is <20$x10^9$/l.
- If there is a suspicion of AML – M3 (APML) or coagulopathy related to hyperleukocytosis, then platelet count should be kept above 30$x10^9$/l.
- Transfuse at any level if there is active bleeding.
- Correct coagulopathy with FFP +/or cryoprecipitate and maintain the platelet count ≥50$x10^9$/l (see Supportive care protocol for volume required).

The PTC may suggest different thresholds for transfusion according to clinical need and anticipated interventions.

Breaking Bad News:

An experienced senior member of staff – Lead Paediatric Oncology Consultant, Paediatric Oncology Nurse Consultant, Attending Consultant or Senior SpR, should undertake this.

Explain to the family that there is a suspicion of leukaemia and that in order to make a definitive diagnosis a Bone Marrow Aspirate test is needed and that this is best done at the Primary Treatment Centre.

The family should be warned that their child will be transferred to an oncology unit (even if suspicion is low, it is a huge shock to parents when they arrive at the PTC if they haven't been warned what kind of unit it is).

It is appropriate to be optimistic about prognosis as overall the survival rates for childhood leukaemia are good and improving. However, without knowing which type of leukaemia a child has, it is not possible to provide anything in more depth. Many of the questions parents ask will only be answerable after diagnostic and follow up tests are complete. Do not be tempted to do more than is possible at this stage. Explain that these questions will be answered at the PTC.

If the opportunity arises, it is appropriate to answer any questions that the family may have about what to expect over the coming days. If possible try to introduce the Shared Care Service here and mention the Lead Paediatric Oncology Consultant, Associate Specialist, Paediatric Oncology Nurse Consultant and Paediatric Oncology Specialist Nurse, if they haven't been available to meet the family.

➢ Further information

Supportive Care Guidelines; A collaborative Publication from Great Ormond Street Hospital for Children NHS Trust, The Royal Marsden NHS Trust, University College London Hospital NHS Trust; version 5.0; August 2011

North Thames Children's and Young People's Cancer Network Group; PTC Clinical Management Protocols; April 2011

North Thames Children's and Young People's Cancer Network Group; CCN Initial Referral Protocol; April 2011

- **Contacts (inside and outside the Trust including out-of-hours contacts)**

Dr Gopa Sen – Lead Paediatric Oncology Consultant – Extension 5460 or aircall/mobile via Switch

Wendy King – Macmillan Paediatric Oncology Nurse Consultant – Extension 5817 Bleep 3377 or mobile 07876492437

Sonal Patel – Paediatric Oncology Specialist Nurse – Extension 5817 Bleep 3377

Attending Paediatric Consultant – via Switch

Paediatric Registrar – via Switch or Bleep

- **References (evidence upon which the guideline is based)**

Supportive Care Protocols: Paediatric Haematology & Oncology (2011) A collaborative Publication from Great Ormond Street Hospital for Children NHS Trust, The Royal Marsden NHS Trust, University College London Hospital NHS Trust; version 5.0; August 2011

North Thames Children's and Young People's Cancer Network Group; PTC Clinical Management Protocols; April 2011

North Thames Children's and Young People's Cancer Network Group; CCN Initial Referral Protocol; April 2011

- **Compliance with this guideline (how and when the guideline will be monitored e.g. audit and which committee the results will be reported to) Please use the tool provided at the end of this template**

The Macmillan Paediatric Oncology Nurse Consultant will review this guideline every two years. Compliance with this guideline will be audited retrospectively and results reported to the Whittington Hospital Paediatric Oncology Shared Care Unit annual strategic meeting and reported in the Annual Report.

To be completed and attached to any procedural document when submitted to the appropriate committee for consideration and approval

		Yes/No	Comments
1.	**Does the procedural document affect one group less or more favourably than another on the basis of:**	No	
	• Race	No	
	• Ethnic origins (including gypsies and travellers)	No	
	• Nationality	No	
	• Gender	No	
	• Culture	No	
	• Religion or belief	No	
	• Sexual orientation including lesbian, gay and bisexual people	No	
	• Age	No	
	• Disability - learning disabilities, physical disability, sensory impairment and mental health problems	No	
2.	**Is there any evidence that some groups are affected differently?**	No	
3.	**If you have identified potential discrimination, are any exceptions valid, legal and/or justifiable?**	N/A	
4.	**Is the impact of the procedural document likely to be negative?**	No	
5.	**If so can the impact be avoided?**	N/A	
6.	**What alternatives are there to achieving the procedural document without the impact?**	N/A	
7.	**Can we reduce the impact by taking different action?**	N/A	

If you have identified a potential discriminatory impact of this procedural document, please refer it to the Director of Human Resources, together with any suggestions as to the action required to avoid/reduce this impact.

For advice in respect of answering the above questions, please contact the Director of Human Resources.

Checklist for the Review and Approval of Procedural Document

To be completed and attached to any procedural document when submitted to the relevant committee for consideration and approval.

	Title of document being reviewed:	Yes/No	Comments
1.	**Title**		
	Is the title clear and unambiguous?	Yes	
	Is it clear whether the document is a guideline, policy, protocol or standard?	Yes	
2.	**Rationale**		
	Are reasons for development of the document stated?	Yes	
3.	**Development Process**		
	Is it clear that the relevant people/groups have been involved in the development of the document?	Yes	
	Are people involved in the development?	Yes	
	Is there evidence of consultation with stakeholders and users?	Yes	
4.	**Content**		
	Is the objective of the document clear?	Yes	
	Is the target population clear and unambiguous?	Yes	
	Are the intended outcomes described?	Yes	
5.	**Evidence Base**		
	Are key references cited in full?	N/A	
	Are supporting documents referenced?	N/A	
6.	**Approval**		
	Does the document identify which committee/ group will approve it?	Yes	
7.	**Dissemination and Implementation**		
	Is there an outline/plan to identify how this will be done?	Yes	
8.	**Document Control**		
	Does the document identify where it will be held?	Yes	

	Title of document being reviewed:	Yes/No	Comments
9.	**Process to Monitor Compliance and Effectiveness**		
	Are there measurable standards or KPIs to support the monitoring of compliance with and effectiveness of the document?	Yes	
	Is there a plan to review or audit compliance with the document?	Yes	
10.	**Review Date**		
	Is the review date identified?	Yes	
	Is the frequency of review identified? If so is it acceptable?	Yes	
11.	**Overall Responsibility for the Document**		
	Is it clear who will be responsible for co-ordinating the dissemination, implementation and review of the document?	Yes	

Executive Sponsor Approval			
If you approve the document, please sign and date it and forward to the author. Procedural documents will not be forwarded for ratification without Executive Sponsor Approval			
Name		Date	
Signature			
Relevant Committee Approval			
The Director of Nursing and Patient Experience's signature below confirms that this procedural document was ratified by the appropriate Governance Committee.			
Name		Date	
Signature			
Responsible Committee Approval – only applies to reviewed procedural documents with minor changes			
The Committee Chair's signature below confirms that this procedural document was ratified by the responsible Committee			
Name		Date	
Name of Committee		Name & role of Committee Chair	
Signature			

Tool to Develop Monitoring Arrangements for Policies and guidelines

What key element(s) need(s) monitoring as per local approved policy or guidance?	Who will lead on this aspect of monitoring? Name the lead and what is the role of the multidisciplinary team or others if any.	What tool will be used to monitor/check/observe/Asses s/inspect/ authenticate that everything is working according to this key element from the approved policy?	How often is the need to monitor each element? How often is the need complete a report ? How often is the need to share the report?	What committee will the completed report go to?
Element to be monitored	**Lead**	**Tool**	**Frequency**	**Reporting arrangements**
Use of guideline by staff when a newly diagnosed patient presents	**Dr Gopa Sen**	**Staff feedback following the presentation of a newly diagnosed patient**	**Annual**	**All guidelines reviewed and presented to Paediatric Oncology Strategic meeting held annually**